An empowerment programme for social work students regarding HIV and AIDS: Adapted REds programme

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An empowerment programme for social work students regarding HIV and AIDS: Adapted REds programme

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ABSTRACT

According to Lerole (1994:9), practitioners in the health care and social services find themselves in the frontline regarding their attempt to prevent the spread of HIV as well as deal with its consequences. Having well-trained, knowledgeable and highly motivated professionals working in service delivery at all levels is crucial for effective management of the HIV epidemic. HIV and Aids present a significant problem at both societal and professional levels for social workers. Individuals who are affected by HIV or Aids have needs that may require a multitude of services including counselling, social services (Wexler, 1989), advocacy, community outreach and case management (Wiener & Siegel, 1990). At a broader level, there is a need for preventive programming, education and policy making. Social work has a significant role to fulfil in meeting the needs of individuals affected by HIV or Aids. The skills social workers perform in integrating people with larger systems, their focus on context and environment evolving from work with historically marginalised groups, and their commitment to human rights and fairness are critical in addressing the issues surrounding HIV and Aids.

The overall aim of this research was to determine whether the evaluated Resilient Educators (REds) support programme can be adapted to become an effective empowerment programme for social work students in supporting people infected with and affected by the HIV and Aids pandemic. Attention was given to the following aims of the study as discussed in each chapter.

Chapter 1 contains the problem statement, research objectives and a discussion on the strengths perspective as well as the procedures followed. Furthermore, the limitations of this study were discussed, the definitions of key words were given and an exposition of the composition of the research report was also given. Chapter 2 gives an overview of the research methodology and includes a discussion of the intervention research model applied. The concurrent embedded strategy was used in this study and was implemented with a mixed method design model. The single system design and interviewing procedures were used to collect quantitative and qualitative data simultaneously.

In Chapter 3 the nature and content of the REds programme for educators are discussed. REds was conceptualised as a potentially supportive, participatory group intervention for educators affected by the HIV and Aids pandemic to ensure educators excellence and sustainability. Group work as a research process was simultaneously offered, enabling intervention or leading to positive social change. An overview of the REds programme was provided by stating the aim of each session and documenting the process of each session as it occurred. This chapter provided a background for the next chapter that reported on the effectiveness of the REds programme.

Chapter 4 reports on the effectiveness of REds. REds was presented to affected educators from two schools in the Matlosana district in the North West Province. The results of this study are based on a comparison of pre-test data and post-test data within both the qualitative and quantitative paradigm. The quantitative data was gained by using the Professional Quality of Life Screening questionnaire (Stamm, 2005). The qualitative data was gathered by way of in-depth interviewing where symbolic drawings, open-ended questions and participants' comments on each session, were integrated. The REds programme was evaluated as being successful for this group. However, a need for services from other health care professionals, such as nurses or social workers, was established.

Chapter 5 focuses on the role of the social worker in providing empowerment to those infected with and affected by HIV and Aids and a literature study was conducted on the role of the social worker within an HIV and Aids reality.

Chapter 6 focused on the development of an empowerment programme for fourth-year social work students regarding HIV and Aids, adapted from the REds programme. The HIV and Aids empowerment programme was developed to educate the social work student with the necessary knowledge and skills to ensure that they are well-trained to deliver an effective service to those people infected with and affected by HIV and Aids, when they enter the social work practice. The programme consists of a detailed workbook designed as a practical toolkit to address the issue of HIV and Aids through the use of multi-media training methods.

Chapter 7 evaluated the effectiveness of an empowerment programme regarding HIV and Aids – the adapted REds programme. Eleven fourth-year social work students at the Department of Social Work, North-West University, Potchefstroom Campus, participated in this research. Pre- and post-assessment were done and both qualitative and quantitative approaches were used. However, the main focus in this study was on the qualitative data. The efficacy of the empowerment programme was evaluated, and implications for future educational preparation for students to work effectively in their roles as social workers regarding HIV and Aids were discussed. Chapter 8 provided a summary of the findings and conclusions of the research report, and some recommendations were made.

OPSOMMING

Volgens Lerole (1994:9) bevind praktisyns in die gesondheidsorg- en maatskaplike dienste hulle in die voorste linie met betrekking tot hul pogings om die verspreiding van MIV te voorkom asook om gevolge daarvan te hanteer. Dit is van kritieke belang om goed opgeleide, deskundige en hoogs gemotiveerde professionele persone te hê wat op alle gebiede in dienslewering werk sodat die MIV-epidemie doeltreffend bestuur kan word. MIV en Vigs bring vir maatskaplike werkers op beide sosiale en professionele vlak 'n aansienlike probleem mee. Mense wat deur MIV of Vigs geaffekteer is, het behoeftes wat 'n menigte dienste kan vereis, insluitend voorligting, maatskaplike dienste (Wexler, 1989), voorspraak, gemeenskapsuitreiking en gevallebestuur (Wiener & Siegel, 1990). Op 'n breër vlak is daar die behoefte aan voorkomingsprogramme, onderrig en beleidmaking. Maatskaplike werk het 'n betekenisvolle rol om te vervul met betrekking tot die voorsiening in die behoeftes van individue wat deur MIV of Vigs geaffekteer is. Die vaardighede wat maatskaplike werkers beoefen in hulle pogings om mense met groter sisteme te integreer, hul fokus op konteks en omgewing wat voortspruit uit hul werk met histories gemarginaliseerde groepe en hul toewyding aan menseregte en regverdigheid is van die allergrootste belang om vraagstukke rakende MIV en Vigs onder die loep te kan neem.

Die oorkoepelende doel van hierdie studie was om vas te stel of die geëvalueerde "Resilient Educators (REds)" ondersteuningsprogram aangepas kan word om 'n doeltreffende bemagtigingsprogram vir maatskaplikewerk-studente te word ter ondersteuning van mense wat deur die MIV- en Vigs-pandemie geaffekteer en daarmee geïnfekteer is. Aandag is geskenk aan die volgende doelwitte van die studie, soos in die onderskeie hoofstukke bespreek:

Hoofstuk 1 bevat die probleemstelling, navorsingsdoelwitte en 'n bespreking van die sterkteperspektief asook die prosedures wat gevolg is. Verder is die beperkinge van hierdie studie bespreek, die definisies van sleutelwoorde is gegee en ook 'n uiteensetting van die samestelling van die navorsingsverslag. Hoofstuk 2 gee 'n oorsig van die navorsingsmetodologie en sluit in 'n bespreking van die intervensienavorsingsmodel wat toegepas is. Die gelyktydig geïntegreerde strategie is in hierdie studie aangewend en is met 'n gemengdemetode-ontwerp geïmplementeer. Die enkelstelsel en onderhoudvoeringsprosedure is benut om kwantitatiewe en kwalitatiewe data gelyktydig in te samel.

In Hoofstuk 3 is die aard en inhoud van die REds-program vir die onderwysers bespreek. REds is ontwerp as 'n potensieel ondersteunende, deelnemende groepintervensie vir onderwysers wat deur die MIV- en Vigs-pandemie geaffekteer is om voortreflikheid en volhoubaarheid aan die onderwysers te verseker. Groepwerk as 'n navorsingsproses is

benut om gelyktydige intervensie in staat te stel of tot positiewe sosiale verandering te lei. 'n Oorsig van die REds-program is voorsien deur die doel van elke sessie te stel en ook die proses van elke sessie namate dit voorgekom het, te dokumenteer. Hierdie hoofstuk het die agtergrond vir die volgende hoofstuk voorsien wat verslag gelewer het oor die doeltreffendheid van die REds-program.

Hoofstuk 4 lewer verslag oor die doeltreffendheid van die REds-program. REds is vir onderwysers uit twee skole in die Matlosana-distrik in die Noordwes-Provinsie aangebied. Die resultate van hierdie studie is gebaseer op die vergelyking van voortoets-data met natoets-data binne beide die kwalitatiewe en kwantitatiewe paradigma. Die kwantitatiewe data is bekom deur die "Professional Quality of Life Screening questionnaire" (Stamm, 2005). Die kwalitatiewe data is deur middel van indiepte-onderhoudvoering bekom waar simboliese tekeninge, oop-eindevrae en deelnemers se kommentare op elke sessie geïntegreer is. Die REds-program is geëvalueer as geslaagd vir hierdie groep. Die behoefte aan dienste van ander gesondheidsorgkundiges, soos verpleegsters of maatskaplike werkers is egter bepaal.

Hoofstuk 5 fokus op die rol wat die maatskaplike werker vervul in die verskaffing van bemagtiging aan diegene wat deur MIV en Vigs geaffekteer en daarmee geïnfekteer is, en 'n literatuurstudie is uitgevoer ten opsigte van die rol van die maatskaplike werker binne 'n MIV- en Vigs-realiteit.

Hoofstuk 6 fokus op die ontwikkeling van 'n bemagtigingsprogram vir vierdejaarstudente rakende MIV en Vigs, soos aangepas uit die REds-program. Die MIV- en Vigs-bemagtigingsprogram is ontwikkel om die maatskaplikewerk-student toe te rus met die nodige kennis en vaardighede om te verseker dat hulle goed opgelei is om 'n doeltreffende diens te lewer aan dié persone wat deur MIV en Vigs geaffekteer en daarmee geïnfekteer is, wanneer hulle die maatskaplikewerk-praktyk betree. Die program bestaan uit 'n gedetailleerde werkboek wat ontwerp is as 'n praktiese instrument om die vraagstukke rakende MIV en Vigs te hanteer deur multimedia-opleidingsmetodes toe te pas.

Hoofstuk 7 het die doeltreffendheid van 'n bemagtigingsprogram rakende MIV en Vigs geëvalueer – die aangepaste REds-program. Elf vierdejaar- maatskaplikewerk-studente van die Departement Maatskaplike Werk, aan die Noordwes-Universiteit, Potchefstroomkampus, het aan hierdie navorsing deelgeneem. Voor- en na-assessering is gedoen en beide kwalitatiewe en kwantitatiewe benaderings is toegepas. Die hoofklem in hierdie studie het egter op die kwalitatiewe data geval. Die doeltreffendheid van die bemagtigingsprogram is geëvalueer, en implikasies vir toekomstige opleidingsvoorbereiding vir studente om doeltreffend in hul rolle as maatskaplike werkers met betrekking tot MIV en Vigs te werk, is bespreek. Hoofstuk 8 voorsien 'n opsomming van die bevindinge en ook gevolgtrekkings waartoe die navorsingsverslag geraak het. Enkele aanbevelings is ook aan die hand gedoen.

"As in life, people facing death have a right to do it their own way. Do not pry or force patients to feel feelings or 'face' death. It's a disservice to force patients to give up their denial or to give cheery false hopes. Sometimes I just want someone to listen. Sometimes I do not want to talk about my medical treatments. Sometimes I do not want to talk at all. If you stay in the moment, contribute what you can, and permit the patient to do the same, you cannot fail. I thank you for your commitment to helping all sick people".

Palermino, 1988

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CHAPTER 8

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

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CHAPTER 1
GENERAL INTRODUCTION

1. PROBLEM STATEMENT

HIV and Aids affect every walk of life and not only those who are infected. It has a profound influence on everything one does – in one's relationships, at work, at home and at school/college/university. Just as the virus infects the body and every cell in the body, it also affects every person on earth. Despite world-wide attention and multiple efforts, the HIV and Aids pandemic continues to impact calamitously on the infected and affected.

It is estimated that approximately 42 million people world-wide are HIV positive and roughly 22 million deaths on account of Aids have been recorded. The reality is especially grim in Sub-Saharan Africa. It is estimated that 29.4 million of the 42 million infected persons reside in Sub-Saharan Africa (United Nations Department of Economic and Social Affairs, 2003; World Bank, 2002). Quinn (2003) suggests that more than 1 in every 10 South Africans are HIV positive. According to the Pretoria News (2003), the projected number of daily deaths in SA resulting from Aids is approximately 1000.

It is predicted that by 2010, South Africa will have lost five million people due to HIV and Aids-related deaths. According to Coombe (2000:3), it is estimated that 50%-65% of South African 15-year olds will die of HIV and Aids-related illnesses within the next 30 years. Aids is also exacting a heavy toll on South Africa's children. By 2015, when the pandemic is expected to reach its peak, about four million children will be orphans due to parents dying from HIV and Aids-related causes and will probably not seek education, or will not be in a position to seek it.

In South Africa there are many children who have lost both parents due to Aids, whether or not they themselves are infected. Many of these children have been abandoned by the

community due to the stigma of the disease, resulting in the older children heading the household or living totally alone. Households headed by orphans are becoming common (UNAIDS, 2000:27).

Children still living with their families are likely to suffer a multitude of other deprivations, especially if the parents are intravenous drug users who have to resort to other antisocial activities such as petty crime or prostitution, to support their habits. The quality of life for these children seems unlikely to be anything other than grim. Apart from the physical and psychological problems, these children often experience a variety of social problems. An infected mother may not be well enough herself to care for the child and it is always difficult to place a child with chronic disease or a handicap with foster parents.

Caring for an Aids patient at home places a tremendous physical and emotional burden on health care professionals, relatives, friends and loved ones. Caring for an individual with Aids-related diseases is usually time consuming, burdensome and unpredictable and may place an unbearable strain on the family or marital system (Ross, 2001:22). Psycho-social consequences occur as a result of diagnosis of HIV-status and are exacerbated as the disease progresses. Stress and depression can compromise function and well-being in all areas of the family life, including school and work performance, family relationships, and capacity for child care. At the same time, stigmatisation of HIV and Aids often causes social rejection and alienation, and can compromise employment, housing, schooling and child-care responsibilities (Love Life, 2001:9).

The statistics leave one with the unnerving reality of an epidemic with enormous implications. Urgent action is needed from all professionals in addressing HIV throughout the African Continent – action such as leadership, supervision, training, resources, drugs, motivation, community support and empowerment.

The South African education sector is thought to be particularly affected by this harsh reality, in part because learners affected by HIV and Aids are leaving school and in part

because infected education stakeholders are dying (Shisana, Peltzer, Zungu-Dirwayi & Louw, 2005: xiv). According to a 2005 report prepared for the Education Labour Relations Council (Hall, Altman, Nkomo, Peltzer & Zuma, 2005), South African educators are viewed as a high risk group in terms of HIV and Aids. This is assumed because the typical person living with HIV and Aids is a female African between the ages of 15-35 years (Vass, 2005). Thus educators are more likely to be affected, because most educators are Africans, females and in the age group 25-35 years.

The HIV and Aids pandemic impacts the affected educators in various ways. According to Hall *et al.* (2005:23) and Theron (2005:59), the educators are firstly emotionally impacted. The educators report experiences of depression and sadness. Educators also report high levels of fear, stress, tension and suicidal ideation. The educators are also professionally impacted. Affected educators report lower levels of professional morale. Affected educators also testify to greater workloads and overcrowded classes with concomitant stress when colleagues are either ill or absent as a result of the pandemic. Educators are also burdened by Aids orphans and vulnerable children in their classes.

The professional demands on affected educators are described as generally taxing (Bhana, Morrell, Epstein & Moletsane, 2006; Coombe, 2003; Theron, 2007a; Theron, 2008). What emerges strongly from the literature on professional demands is that affected teachers are severely challenged by caregiver demands. In 2005, 14.4% of all children between the ages of 2 and 18 were identified as orphans (Shisana, Rehle, Simbayi, Parker, Zuma, Bhana, Connolly, Jooste & Pillay, 2005:112) and, therefore, educators are increasingly distressed by the large numbers of learners made vulnerable by HIV and Aids and Aids-orphans in their classes (Bhana *et al.*, 2006; Boler, 2003). Many of these vulnerable learners need more than didactic lessons – most have additional needs such as grief counselling, hunger, accommodation, school fees; most need support to cope with discrimination, abuse, rejection and lost childhoods (Bhana *et al.*, 2006; Coombe, 2003; Ebersöhn & Eloff, 2002). At many schools there is an absence of professionally trained staff to respond to the HIV-related needs of learners and teachers have to fill this gap (Bhana *et al.*, 2006; Coombe, 2003; Hoadley, 2007; Theron, 2007a). Many educators

represent the lone source of hope, information and/or comfort for learners of community members affected or infected by the pandemic. According to Govender (2008), provincial departments of education often lack the human resources to provide counselling or under-spend funds earmarked for support and care of HIV-affected learners. Many learners only have teachers to turn to as they have no access to mental health service providers (Theron, 2007b).

Effective teaching is being thwarted due to care-work related to multi-teacher roles (Bhana *et al.*, 2006; Hoadley, 2007; Theron, 2007a) and this creates time-management problems for teachers (Theron, 2007a). Education authorities erroneously presupposed that educators could play caregiver roles, but in effect educators bemoan inadequate preparation and support in this regard (Bhana *et al.*, 2006; Coombe, 2003).

Teachers are often overwhelmed by the professional and personal impacts of living and teaching in a HIV-altered milieu. Many are engulfed by emotional and spiritual distress (Theron, 2007a) and progressively floundering professional morale and performance (Hall *et al.*, 2005). Significantly, affected educators are more likely to consider leaving teaching than those who are not (Hall *et al.*, 2005:23). The pandemic affects not only individuals; it attacks systems, and it is attacking the education system in this country.

According to Dawson, Chunis, Smith and Carboni (2001), research reconfirmed the need for more HIV and Aids-related training for teachers. A similar South African study (Peltzer & Promtussananon, 2003) found that sampled high school teachers felt only moderately comfortable teaching about HIV and Aids and at least 25% held misconceptions about HIV and Aids which suggested inadequate HIV and Aids-related knowledge. The same study noted that teachers reported scant material resources and community support from religious groups and parents with regard to prevention education.

The South African educators need comprehensive support to cope with the challenges of a professional role that has been escalated to encompass HIV-prevention, counselling and

social work. An interactive, participatory support programme, entitled Resilient Educators (REds) was compiled (Theron, Geyer, Strydom & Delport, 2008:77-88).

REds has the express aim of supporting affected educators to cope resiliently with the challenges of the pandemic by supporting educators to respond adaptively to a teaching context that demands responses more typical of medical personnel trained to prevent HIV, counsellors and social workers. With this in mind, the content of REds includes the biomedical facts, guidelines on HIV prevention, guidelines on nursing people with Aids-related illnesses, tips on using social networks, government grants and non-governmental structures to give and gain psychosocial and socioeconomic support, grief-counselling skills, guidelines for coping with and minimizing HIV-related discrimination, information on HIV-related education policy, stress management skills and resilience training. These contents are grouped into eight modules (Theron *et al.*, 2008:77-88).

REds was conceptualised as a group support programme which relies on active participation of participants and one that can be implemented flexibly according to participant time restraints (e.g. over a weekend, weekly, bi-weekly). According to research initiatives to empower teachers to cope better with the HIV-beleaguered context, the use of participatory approaches seemed intrinsic to participant empowerment (De Lange, Mitchell, Moletsane, Stuart & Buthelezi, 2006; Ferreira, 2007; Mitchell, De Lange, Moletsane, Stuart & Buthelezi, 2005), taking educators moral (Hall *et al.*, 2005), the social isolation of many affected educators (Theron, 2007a) and limited educator time into consideration (Schulze & Steyn, 2007; Theron, 2007a).

REds was piloted in four South African Provinces with small groups of volunteer educator-participants, during 2006 and 2007. The researcher was trained as a facilitator to facilitate the content and participatory process of REds. The researcher presented REds during 2007 to two schools in the North West Province as part of her research.

After the REds programme was presented the educators from the two schools in the North West Province identified that they were stressed and exhausted by the demands of

basic social support, the responsibility for providing basic counselling support and for providing safe and secure learning environments, which included caring for those affected by HIV and Aids. Although they felt better empowered to deal with the demands in the classroom, they identified the need for a multidisciplinary approach, and felt that professionals in every sector in this country are necessary to make a difference, especially social workers and/or health care workers. According to Lerole (1994:9), practitioners in the health care and social services find themselves in the frontline regarding both preventing the spread of HIV and dealing with its consequences.

Having well-trained, knowledgeable and highly motivated professionals working in service delivery at all levels is crucial for effective management of the HIV epidemic. Families living with HIV and Aids desperately need access to reliable, accessible and affordable treatment and care. This treatment includes resources to emotional, financial and social aspects. Given that HIV and Aids impact on every aspect of human existence it, therefore, demands the involvement of professionals such as social workers to provide care for the infected and affected. Aids is a social problem that potentially affects all; unless one can help society in general to come to terms with the real plight and moral dilemma facing HIV patients, then all are at risk. One must develop and provide a continuum of care and support to those infected and affected by the pandemic.

Social workers have had a long experience working in the delivery of social health care services, working with ill people and their families. Social workers who work with people suffering from acute, chronic and life-threatening illnesses and with their families could be of assistance in serving the HIV and Aids population. HIV and Aids shares many of the characteristics of other life-threatening conditions. However, HIV and Aids are also very different, thus calling for the development of new knowledge, skills and strategies.

HIV and Aids present a significant problem on both societal and professional levels for social workers. Individuals who are affected by HIV or Aids have needs that may require a multitude of services including counselling, social services (Wexler, 1989), advocacy,

community outreach and case management (Wiener & Siegel, 1990). On a broader level, there is a need for preventative programming, education and policy making. Social work, a profession that is recognised for supporting the socially disadvantaged and those who are discriminated against by the larger society, has a significant role to perform in meeting the needs of individuals affected by HIV or Aids. The skills that social workers perform in integrating people with larger systems, their focus on context and environment evolving from work with historically marginalised groups, and their commitment to human rights and fairness are critical to addressing the issues surrounding HIV and Aids.

The advances in medical treatment of HIV and Aids also means that individuals who are sero-positive will live longer lives, increasing the need for the development of appropriate resources, provision of services such as counselling, treatment and support and enhancing the quality of life. The shift in incidence of the disease requires that all social workers possess knowledge and appropriate beliefs that promote the well-being of individuals affected by HIV and Aids, regardless of their chosen area of practice (Podolsky-Scarth, 1999:3).

Research in the social work profession has already been done on various HIV and Aids awareness and prevention programmes, as well as educational programmes for peer groups and support programmes for educators. The following research was done: Guidelines for a peer educator programme for HIV and Aids: A social work perspective (Basupeng, 2002), Evaluation of an HIV and Aids programme for students at a tertiary institution with emphasis on peer group involvement (Strydom, 2002) and, Life Maps as Technique in a social group work programme for young adults with HIV and Aids (Herbst, 2002). However, in the research done by Olivier (2009:230), she found that less that 20% children in the research received bereavement counselling after the death of their parent and in two thirds of these cases the counselling was done by a pastor/minister or a neighbour. A serious lack of bereavement counselling was discovered and support after the death of a parent was minimal. A study done by Modise (2005) shows that social work, as a profession, is essential in the lives of communities, especially in rural areas. Social work is also an essential profession in addressing the needs of children. Due to the

severity of the HIV and Aids pandemic, social workers, as professionals, cannot act indifferently towards service delivery in communities. The study, however, shows either a shortage of social workers or an absence of social work service delivery.

The above leaves one with the reality of an epidemic with enormous implications. The question that arises from this is, whether the social work student is well-trained, knowledgeable and professionally motivated enough to manage the HIV epidemic effectively and provide care and support to those living with HIV and Aids. Little research could be found on the equipment of the social work student who will enter practice with accurate and the most vital information as well as with a practical toolkit programme to empower those people living with HIV and Aids and to face an epidemic this enormous.

The researcher came to the conclusion that support programmes for educators, such as the REds programme and a social work empowerment programme can contribute and provide a vital resource for the fight against HIV and Aids. This study will focus on the development of an empowerment programme for fourth year social work students, adapted from the REds programme, to provide them with knowledge and skills to support those people living with HIV and Aids adequately. REds was named a support programme, while the social work programme was an empowerment programme. This can be attributed to the fact that REds was started by educationists, while the social work empowerment programme by social workers. Whenever mention is made of social work students, in this specific group, fourth year social work students are meant.

Taking the above-mentioned into consideration, the following questions arise:

- What is the nature and content of the REds (Resilient Educators) support programme for educators?
- What is the effectiveness of the REds (Resilient Educators) support programme on educators affected by HIV and Aids?

- What is the role of the social worker in providing empowerment to persons infected with and affected by HIV and Aids?
- Can the REds programme be adapted in order to formulate an empowerment programme for fourth year social work students?
- What is the effectiveness of the newly adapted and developed empowerment programme for fourth year social work students?

On the basis of the questions formulated above, the aim of this study is given in the following section.

2. AIM AND OBJECTIVES OF THE STUDY

The aim of this research project is to explain the nature and content of REds, to evaluate REds and to determine whether the evaluated HIV and Aids support programme for educators (REds) can be adapted and evaluated to become an effective empowerment programme for fourth year social work students in supporting people infected with and affected by the HIV and Aids pandemic.

From this the following objectives arise:

- To explain the nature and content of the REds (Resilient Educators) support programme for educators.
- To determine the effectiveness of REds as an effective programme in supporting educators affected by the HIV and Aids pandemic.
- To investigate the role of the social worker in providing empowerment to persons infected with and affected by HIV and Aids.
- To develop an empowerment programme for fourth year social work students by adapting the REds programme for those infected with and affected by HIV and Aids.
- To evaluate the effectiveness of the newly adapted and developed empowerment programme for fourth year social work students.

3. CENTRAL THEORETICAL ARGUMENT

If the existing REds programme can be adapted for social workers, it can be used as an empowerment programme for fourth year social work students in supporting people infected with and affected by the HIV and Aids pandemic.

4. STRENGTHS PERSPECTIVE

This section was included to indicate that the study was undertaken from a strengths perspective. HIV can affect clients, families, and communities in numerous and complex ways. Although most social workers may have some knowledge about HIV, many lack adequate understanding of the contexts and processes of HIV, particularly in light of treatment advances. Unfortunately, this misunderstanding can result in inappropriate care and increased distress for the person with HIV and his or her support system. In response to breakthroughs in HIV treatment that greatly enhance the quality of life for people with HIV, this study provides multiple contexts for understanding HIV: the historical context; a consideration of the human behaviour contexts of the person who is infected with HIV; the biomedical context; and the social environment. These contexts and the related social work principles are derived from existing approaches that are re-examined and re-applied to address anew the needs of people infected with and affected by HIV and Aids, who may now live longer, healthier lives.

Although effective antiretroviral medications represent promising developments in the fight against HIV and Aids, they also pose new challenges to understanding the impact of HIV on individuals, families, and groups affected by the disease. As a result, new models or the reapplication of existing models for understanding HIV and conceptualising social work practice in HIV are needed and must take a holistic approach in assessing, understanding and intervening with HIV-infected clients. In recent years social work has come to use the strengths perspective as one of its theoretical approaches. The strengths perspective has been applied in a wide variety of client populations: mentally ill persons and their families, child welfare clients, homeless woman, the elderly, addicted drug

users, working with those infected with and affective by HIV and Aids and farm dwellers (Ryke, 2004).

Strengths-based social work is largely associated with the work of David Saleebey. Saleebey (2002) often speaks of empowerment as a goal of social work, while proponents of the empowerment approach almost always advocate a reinforcing of client strengths. The proponents of empowerment theory tend to emphasise the political realities of coping, while proponents of the strengths perspective focus more on helping clients build on their own resources. Saleebey stated that his approach considers the notion of strengths as an essential component of empowerment theory and practice. The empowerment approach can effectively incorporate strengths into each phase of the helping process.

Strengths perspective assumed that strengths are inherent in humanity itself. Saleebey (2002:1-11) states that the human spirit has innate wisdom, people have the inherent capacity for transforming an inborn facility of body and mind to regenerate and resist, the capacity for health and healing and the capacity to know what is right. Saleebey (2002:11) refers to it as a natural state of affairs. The strengths perspective facilitates this normative human process that directs people toward a healthy development fulfilling their potential. This perspective provides structure and content as it assesses attainable goals, mobilises resources to promote change and self-esteem, and instills hope in the future. Further, resiliency theory and the strengths perspective share a common faith in human beings that characterises a possibility-focused paradigm.

The strengths perspective emphasises that in the midst of human pain and suffering, there are locked up strengths, potential and possibilities. Humanity has strengths with which it can survive problems and disease, even rising above them. The strengths perspective believes that the world in which we live can be transformed. Transformation is possible because human beings can generate their inherent goals and vision for a better quality of life (Saleebey, 2002:1-7). Both strengths and weakness are inherent in humanity.

Weakness, according to Saleebey, is anything or anybody that causes alienation, marginalization and oppression of human beings.

According to the strengths perspective, strengths are also found within the environment. The environment can be seen as the person's experience of his world. Healing requires a beneficent relationship between the individual and the larger social and physical environment. An environment is strong when there is community and membership that provide protection against alienation, marginalisation and oppression. The strengths approach declines individualism and regards humankind as a relational being. Relationships are based in mutuality and connection of a network of institutional and interpersonal relationships in which a person is entangled that contribute to, sustain and shape a person's misery, struggle and mistakes (Saleebey, 2002:5-11). Humanity is regarded as context-bound in comparison with the individualistic perspective that places the individual above society (the environment) (Ryke, 2004:19).

From a strengths perspective, Smit (1999:1-29) stated unlimited equal encounters between people and groups dedicated to healing and empowerment are the ultimate value for all. According to Saleebey (2002:6), reflected knowledge is profounded with the emphasis on relevance of a client to making meaning and making sense in a situation. People need to be directed not only to their own innate strengths, but also to those in their environment.

This perspective is utilised in working with those dealing with HIV and Aids. When a practitioner works from the strengths perspective, a different view of the client and their environment is adopted. The focus of practice turns towards potential and possibility. The client and the environment are mined as the source of empowerment, knowledge and strength. "It is an approach honoring the innate wisdom of the human spirit, the inherent capacity for transformation of even the most humbled and abused" (Saleebey, 2002:1-7). Working in HIV and Aids has brought about recognition of the incredible strength of the human spirit when faced with unbelievable obstacles and the complications of daily living. This has and continues to be a source of inspiration to practitioners. Therefore,

working from this theoretical orientation can be a progressive approach to practice for those touched by HIV and Aids. This study will highlight the salient issues and techniques involved in utilising the strengths perspective. In doing so, it will deal with such issues as supporting strengths, while also allowing for the complex spectrum of feelings and grief responses typical of those with HIV and Aids. Material from individual cases and groups will be used to illustrate these concepts.

The conclusion is drawn that the strengths perspective is based on the assumption that a strong environment is based on human beings that are connected with their innate strengths and who contribute to building a strong environment (Ryke, 2004:18). Social workers should examine their perspectives on person/environment and the surrounding strengths and entrapments. Intervention will have no effect without a perspective based on a belief in strengths on the potential of empowerment. Social work education should emphasise using perspectives such as the strengths perspective as a basis for developing personal practice approaches.

5. RESEARCH METHODOLOGY

The methods used for investigation were a literature study and an empirical investigation.

5.1 LITERATURE STUDY

A literature study was conducted on various aspects of the study. Delport (2005:171) states that, in order to undertake meaningful research, the researcher should have made a thorough study on the subject under review.

The research comprises two sections. Section A focused on the problem formulation, research methodology, description of the nature and content of the Resilient Educators (REds) programme and the evaluation of REds, as effective in supporting educators from the North West Province affected by the HIV and Aids pandemic, in order that educator excellence and sustainability be secured. The aim of the literature study in this section

was to place the research problem in theoretical perspective by studying the available literature related to the problem.

The second section, section B, of this research focused on the role of the social worker when working with people infected and affected by HIV and Aids, developing an empowerment programme for social work students regarding HIV and Aids and the evaluation of the effectiveness of the empowerment programme. A literature study was utilised to gather more information on the subject and to analyse the problem statement. The literature study will focus on the role of the social worker in developing and providing appropriate means of support and care when working with people infected with and affected by HIV and Aids, to realise their psychosocial strengths in order to cope with the impact of the pandemic. The literature study was also utilised to develop an empowerment programme for social work students regarding HIV and Aids.

5.2 EMPIRICAL INVESTIGATION

The empirical research was conducted to evaluate the efficacy of the REds support programme, to assess the role of the social worker in providing empowerment to those infected and affected with HIV and Aids, the development of an effective HIV and Aids empowerment programme for fourth year social work students adapted from REds, and to evaluate the effectiveness of the newly developed social work empowerment programme.

5.2.1 Intervention research model

In this study the intervention research model was utilised. Intervention research is defined as studies carried out for the purpose of conceiving, creating and testing innovative human service approaches to prevent problems or to maintain quality of life (De Vos, 2005a:394). The intervention research model is a six phase model, consisting of problem analysis and project planning; information gathering and synthesis; design; early development and pilot testing; evaluation and advanced development and dissemination.

Each phase comprises a series of steps. All the steps of the phases were utilised in this research and will be discussed in detail in Chapter Two.

5.2.2 Research design

A research design is the total plan used to aid the researcher in answering the research question. As part of the plan, it must be decided what the research question should be, what data would be required to answer it, from whom the data would be obtained and exactly what the best way would be to gather the data. The chosen research design directed the entire research process, including which research methods and procedures would be followed (Grinnell & Unrau, 2008:330). In this study a mixed methods research design was used. Mixed methods research is an approach to inquiry that combines or associates both qualitative and quantitative forms and involves the use of qualitative and quantitative approaches and the mixing of both approaches in a study (Creswell, 2009:4).

This study consisted of two sections. In Section A, the problem formulation, research methodology, description of the nature and content of the REds programme and the evaluation of REds, as effective in supporting programme for educators from the North West Province affected by the HIV and Aids pandemic, were described. In Section B of the research the focus was on the role of the social worker when working with people infected and affected by HIV and Aids, developing an empowerment programme for social work students regarding HIV and Aids and the evaluation of the effectiveness of the empowerment programme.

Because the aims of this study varied, more than one research design was needed. The researcher use the exploratory research design, the descriptive research design and the explanatory design was also used in the two sections of this study. These three research designs will be discussed in Chapter Two.

5.2.3 Participants

In both the two sections of this study non-probability sampling was used.

In the first part of this study the REds programme, a support programme for educators, was implemented in 2 township schools in the North West Province during 2007. The educators that participated in this research were 10 educators from one school and 14 educators from a second school that volunteered to be part of the study. The participants were both male and female educators in the North West Province, who were affected by the HIV and Aids pandemic.

The second part of this study was the evaluation of a newly developed empowerment programme, adapted from REds, for social work students. This programme was presented to 11 fourth-year volunteering social work students from the North-West University, Potchefstroom Campus, after completing their block placements for the study year 2008. The students chosen for this study were the first 11 students (from a class of 27) who volunteered to be part of this study. The participants were both male and female. The participants completed pre-post assessments before and after completion of the programme.

5.2.4 Measuring instruments

Data collecting methods can be of a qualitative and quantitative nature. A combined-method study was utilised and can be described as one in which the researcher uses multiple methods of data collection and analysis. Alternatively it involved mixing between methods drawing on both qualitative ad quantitative data-collection procedures (De Vos, 2005b:357). The effectiveness of the REds programme was measured by conducting a pre-test and post-test with both quantitative and qualitative measuring instruments.

The effectiveness of the social work empowerment programme for fourth year social work students was also measured by conducting quantitative instruments, as well as qualitative measuring instruments.

5.2.5 Procedure

This research consisted of two sections. In Section A, the implementation of the REds support programme for educators, permission was first obtained from the Department of Education in the North West Province and the principals of the participating schools in the North West Province. Permission was also obtained from the voluntary participants of two schools. The participants gave their permission that all information collected might be used for research and publication purposes, in both South Africa and other countries. The REds programme was presented to the first group of participating educators from May 2007 until June 2007. As each module was implemented, participating educators were asked to comment on the efficacy of each module so that the programme could be improved. At the close of the first round, the programme was rewritten partly to accommodate the suggestions of the participants. The improved programme was implemented in round 2 from August 2007 until October 2007, with a second group of participating educators, followed by a second revision.

In Section B, a new empowerment programme was developed after adaptations were made from the evaluated REds programme. Permission was obtained from the Social Work Department of the North-West University to research the effectiveness of an empowerment programme. Permission was also obtained from the voluntarily participating fourth-year social work students. The participants gave their permission that all information collected could be used for research and publication purposes, in both South Africa and other countries. The participating fourth-year social work students decided that the implementation of the programme should consist of 9 sessions, and was presented during a 3 day workshop. Each session lasted for approximately 2 hours. The effectiveness of the programme was measured by the knowledge, attitudes and skills that the students obtained concerning HIV and Aids and related matters before and after the

implementation of the programme. The single system design and interviewing of the group were utilised to collect the data to evaluate the participants' outcome in both the studies. Single system and interviewing will be discussed fully in Chapter Two.

5.2.6 Ethical aspects

Ethics is a set of moral principles which are suggested by an individual or group, are subsequently widely accepted and offer rules and behavioural expectations concerning the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students (Mitchell & Jolley, 2007:512-513; Monette, Sullivan & De Jong, 2008:48-56; Strydom, 2005a:57-67). Informed consent was obtained from each member involved in the research. Throughout the study it was important that conditions of privacy, anonymity and confidentiality were maintained.

5.2.7 Data analysis

De Vos (2005c:334-337) explains that data analysis is a process through which order and structure are brought to the mass of collected data. The purpose of data analysis is to reduce data to an intelligible and interpretable form so that the relations of research problems can be studied and tested and conclusions can be drawn (Kruger, De Vos, Fouché & Venter, 2005:218). Data of the standardised measuring instruments were analysed and transformed into statistically accessible form by counting procedures designed by the Department of Statistical Consultation Services of the North-West University (Potchefstroom Campus). The qualitative data that were collected were analysed thematically according to Tesch's approach (Poggenpoel, 1998:343-344).

6. LIMITATIONS OF THE STUDY

This study is of a scientific nature and, therefore, it is important to mention the following limitations of the research:

- According to Strydom (1999:14) objectivity is a prerequisite for scientific research and, therefore, the researcher must make his/her observations in such a way that other people will be able to control and confirm the results. In this study it was not always possible to be completely objective, because of the researcher's personal interest with regards to Aids. The researcher was determined that the programme be successful at all costs and expected the users to feel the same way. This might have influenced the researcher to become subjective to a certain extent.

- The report of this research is comprehensive and can be considered a limitation. To be thorough it had to be done and the reason for this is the fact that the implementation of the REds programme had to be discussed, the evaluation had to be done with many measuring instruments giving much empirical data, the literature study on the role of the social worker regarding HIV and Aids and the development of the empowerment programme for social work students, as well as the evaluation thereof, had to be done.

- A non-probability sampling procedure (Strydom, 2005b:202) was used instead of a probability procedure, which could perhaps have given better results. For the purpose of this sample a non-probability procedure was the best, seeing that it was not possible to select participants on a probability procedure.

- Prospective participants were recruited by announcements in school staffrooms. The participants who volunteered first may well have experienced the impact of the pandemic more keenly and were, therefore, eager to participate in REds and eager to be empowered. This sampling bias could imply that participants in this study may not be truly representative of all affected educators - this must be borne in mind when conclusions are drawn from the data. For the group work to be effective only a limited number of participants could be involved in this study. This limitation makes it difficult to generalise conclusions to the larger population.

- In spite of the assurance to the participants that the questionnaires were anonymous and confidential, it was possible that the participants were not completely truthful when they answered some of the intimate questions.

7. TERMINOLOGY

To clarify certain concepts, it is necessary to define a few key terms which were used extensively in this research.

7.1 HIV

HIV is the abbreviation for the **Human Immune-Deficiency Virus** (Whiteside & Sunter, 2000:2). The Human Immuno Deficiency Virus reproduces in the white blood cells of humans. White blood cells are very important to the immune system of human beings. When an individual is infected with HIV, the virus multiplies until there are millions of viruses present (UNESCO & UNAIDS, 2006:8). According to Evian (2000:7), the HI-virus ..."enters the body and destroys important cells which control and support the immune system". This was found to be the cause of AIDS and various other immune system diseases and opportunistic infections.

7.2 AIDS

AIDS is the acronym for **Acquired Immunodeficiency Syndrome**. The following explanation of the acronym is given according to Van Dyk (2005:3):

- The disease is **acquired** as it is not inherited, but is caused by a virus entering the body from the outside.
- **Immunity** refers to the body's natural defense system against infection and disease.
- **Deficiency** indicates that the defense system is inadequate.

- **Syndrome** implies a group of specific signs and symptoms characteristic of a particular pathological condition.

AIDS may, therefore, be defined as a syndrome of opportunistic diseases and infections, caused by the human immunodeficiency virus which eventually leads to death (Whiteside & Sunter, 2000:1).

7.3 SOCIAL WORK

In this study the term social work is used in its familiar context. The definition for social work according to the International Federation of Social Workers (2000) is that the "social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments". Principles of human rights and social justice are fundamental to social work. "Social work in its various forms addresses the multiple, complex transactions between people and their environments. Its mission is to enable all people to develop their full potential, enrich their lives, and prevent dysfunction." Professional social work focuses on problem solving and change. As such, social workers are change agents in society and in the lives of the individuals, families and communities they serve. "Social work is an interrelated system of values, theory and practice" (Adopted by the IFSW General Meeting in Montréal, Canada, July 2000).

According to Du Bois and Miley (2005:4), "social work activities empower client systems to enhance their competence and enable social structures to relieve human suffering and remedy problems". Social work as a profession is, therefore, concerned with promoting positive social functioning by helping people cope more effectively with problems such as HIV and Aids and by working to create systems which are more humane and responsive to the needs of the people. Social workers, according to Du Bois and Miley (2005:5), are people who wish to work with people, who want to do something that counts who want to have a career that makes a difference. The term social worker in

this study can be seen as the same as a counsellor, mental health care provider or clinician.

7.4 EDUCATOR

An educator is a person who educates people. It is someone who is specialised in the theories and methods of education. Education involves teaching people various subjects, usually at a school or college, or being taught. An educator is a person who systematically works to improve another person's understanding of a topic (Genetics Encyclopedia, 2003). In this case educator refers to teachers from primary or secondary schools.

7.5 RESILIENCE

Resilience is the ability to overcome, steer through and bounce back when adversity strikes (Jenson & Fraser, 2006:8; McAdam-Crisp, Aptekar & Kironyo, 2005:72; Reivich & Shatté, 2002:3; Schoon, 2006:1, 6; Sternberg, 2004:325-338; Ungar, 2005:xvi-xviii). Resilience is defined as relatively positive functioning despite being faced with taxing circumstances that might generally connote risk for positive psychological outcomes. Positive functioning is promoted by a dynamic interaction between the individual's protective resources and protective resources within the individual's context (Ungar, 2005:xvi-xviii).

7.6 PROGRAMME

According to the Terminology Committee for Social Work (1995:49), the term programme is defined as the process between a group and a social worker where a systematic pattern of activities is followed to achieve group goals. Programmes for social work have the broad goal of enhancing individual and social change by providing services that meet individual and community needs. In this research, the empowerment programme provided the researcher the opportunity to influence the participants while at

the same time utilising the programme to reach the goals of the research. According to Geyer (2006:15) a social group work empowerment programme suggests a series of group meetings where the collective needs and challenges of the group members are being met in a group context. This occurs through the application of an empowerment process in the social group work from a strengths perspective.

The term support programme can be seen as the same as an empowerment programme for the purpose of this study. The REds was named a support programme for educators while the social work programme was called an empowerment programme. It can be attributed to the difference in semantics between education and social work as sciences.

7.7 EMPOWERMENT

Turner (1996:24) defines "empower" as: to give power or authority; to give ability to; enable; permit. Empowerment means embarking on a process that leads people to discover competences, create new competences and find new ways to apply these competences in all encounters in their lives (Kinlaw, 1995:7). This is a process whereby individuals feel increasingly in control of their own affairs (Arnold & Underman-Bogg, 2003:145; Hitchcock, Schubert & Thomas, 1999:218). Compton, Galaway and Cournoyer (2005:238) describe empowerment as an active process through which individuals become strong enough to participate in, take control of and influence institutions and events that affect their lives. Empowerment is also exercising psychological control over personal affairs as well as exerting influence over the course of events in a social political arena (Du Bois & Miley, 1996:26) According to Turner (1996:219), the empowerment approach is a unifying framework that presents an integrative approach to meeting the need of members of certain groups.

Individuals can be helped to mobilise power with the following intervention methods identified by Compton *et al.* (2005:238), namely, enhancing self-awareness, accessing information, securing resources, strengthening of social skills, facilitating decision making and finding meaning.

Empowerment is, therefore, the process of increasing the capacity and spiritual, political, social and economic strength of individuals and communities to make choices and to transform those choices into desired actions and outcomes.

7.8 AFFECTED

For the purpose of this study all educators who have loved ones, colleagues and learners who are HIV-positive, or who have loved ones, colleagues or learners who have died of Aids-related diseases or have Aids orphans and vulnerable children in their classes (Hall *et al.,* 2005; Theron, 2006:4) are considered affected.

7.9 INFECTED

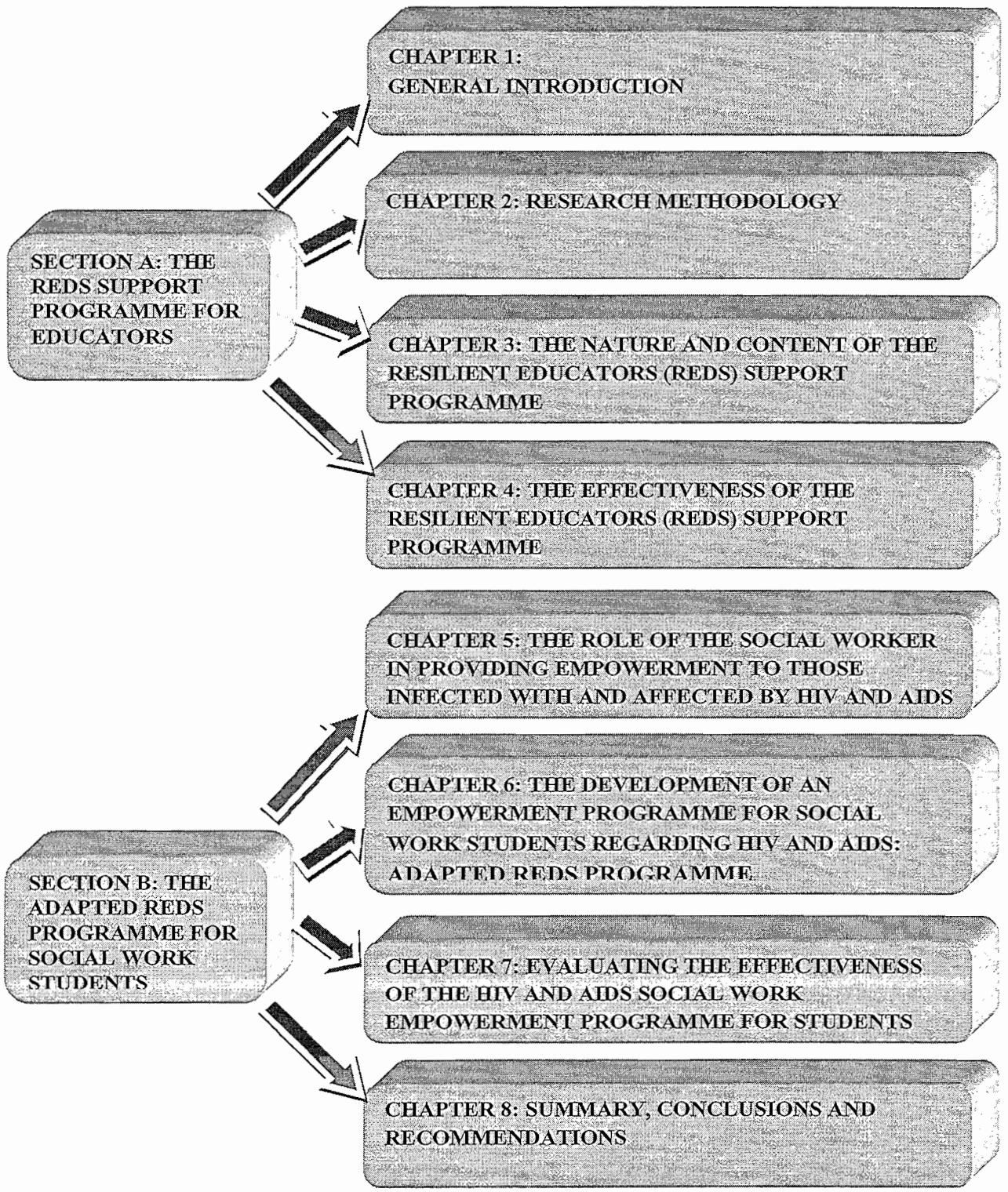
According to Hornby (2001:614), a person is infected when a disease or illness consisting of harmful bacteria is spread to him or her. In other words, people who fall ill due to a virus (in this study, the Human Immuno Deficiency Virus) are infected.

8. PRESENTATION OF THE RESEARCH REPORT

The research report can be seen as the final product of the research process and is a combined effort of integrating theory and practice (Strydom, 2005c:247). Throughout the report theoretical and practical aspects supplement each other.

The research report was divided in two sections and consisted of eight chapters. Figure 1.1 gives an overview of the format of the research report, including the chapters which follow.

FIGURE 1.1: FORMAT OF THE RESEARCH REPORT



8.1 CHAPTER 1: GENERAL INTRODUCTION

The first chapter serves as a general introduction and gives an overview of the research that allows the reader to understand the fundamental principles of the study. These include aspects such as the problem statement and motivation for the research. Other aspects included are aims and objectives, theoretical argument as well as research methodology, the research design, the research procedures, the measuring instruments, the methods of data analysis, the limitations of the study and the definitions of key concepts.

8.2 CHAPTER 2: RESEARCH METHODOLOGY

Chapter Two supplies detail on the research methodology that has been followed in this study. The research design and procedures are described.

8.3 CHAPTER 3: THE NATURE AND CONTENT OF THE RESILIENT EDUCATORS (REDS) SUPPORT PROGRAMME

This chapter will provide an overview of the content and activities of the presented Resilient Educators (REds) support programme for infected and affected educators and serves as a background for the empirical study.

8.4 CHAPTER 4: THE EFFECTIVENESS OF THE RESILIENT EDUCATORS (REDS) SUPPORT PROGRAMME

This chapter discusses the results of the REds intervention programme for educators affected by HIV and Aids. This chapter will also report on the recommendations made by the participants and serves as the foundation for further study as discuss in chapter five.

8.5 CHAPTER 5: THE ROLE OF THE SOCIAL WORKER IN PROVIDING EMPOWERMENT TO THOSE INFECTED WITH AND AFFECTED BY HIV AND AIDS

In this chapter attention is given to the role of the social worker in providing empowerment to those people infected with and affected by HIV and Aids.

8.6 CHAPTER 6: THE DEVELOPMENT OF AN EMPOWERMENT PROGRAMME FOR SOCIAL WORK STUDENTS REGARDING HIV AND AIDS: ADAPTED REDS PROGRAMME

Chapter Six is concerned with the development of a HIV and Aids empowerment programme for fourth-year social work students working with those infected and affected by HIV and Aids. This programme was adapted from the REds programme and could be applied to individuals and groups in general. This programme could also be applied by complementary disciplines, including nursing and psychology.

8.7 CHAPTER 7: EVALUATING THE EFFECTIVENESS OF THE HIV AND AIDS SOCIAL WORK EMPOWERMENT PROGRAMME FOR STUDENTS

Chapter Seven reports on the implementation and evaluation of the effectiveness of the HIV and Aids empowerment programme for fourth-year social work students by presenting the data collected from the experimental group.

8.8 CHAPTER 8: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Chapter Eight is the last chapter, consisting of a comprehensive summary, conclusions and recommendations regarding this study.

CHAPTER 2
RESEARCH METHODOLOGY

1. INTRODUCTION

The aim of this chapter is to define the research methodology that has been applied in this study. The study was divided into two sections and in each phase the same research designs were applied. The research conducted in this first section was to determine whether the REds programme is effective in supporting educators affected by the HIV and Aids pandemic, in order to secure educator excellence and sustainability. In the second section an empowerment programme regarding HIV and Aids for fourth-year social work students was developed and evaluated.

In this chapter the intervention research model will receive attention, as it is this model that was utilised in the study. The history, definition and phase of the research model will be discussed. The researcher will indicate in what way the different phases were applicable to this research. The participants of both the sections of this study will be described. Thereafter the procedure of the research study will receive attention. This comprises of the use of the single system and interviewing. There will also be a discussion on the measuring instruments used, methods of assessment, ethical aspects and data analysis. The chapter will conclude with a summary of the content.

Leedy and Ormrod (2005:1) stated that in virtually every subject area, knowledge is incomplete and problems are waiting to be solved. By asking relevant questions and then seeking answers through systematic research one can address the gaps in one's knowledge and those unresolved problems.

2. LITERATURE STUDY

The literature review places the research problem in theoretical perspective and is aimed at contributing towards a clearer understanding of the nature and meaning of the problem that has been identified (Fouché & Delport, 2005:123). A literature study equips the investigator with a complete and thorough justification for the subsequent steps, as well as with a sense of the importance of the undertaking. A careful review of the literature can save much unnecessary work and prevent the researcher from wasting time studying a problem that has already been investigated (Royse, 2004:20). All stages in the research process are important, although a logical and systematic review of the literature provides a framework within which one can answer the important questions that one poses. The aim of the literature study was to place the research problem in theoretical perspective by studying the available literature related to the problem. The literature study was also utilised to develop an empowerment programme for social work students regarding HIV and Aids.

The researcher mainly used literature from the North-West University library, handouts and newsletters from the Government Gazette, newspapers as well as Internet Sources. Manuals, journals, current and completed research sources were also studied. There are a considerable number of books, journals and publications on HIV and Aids available, both nationally and internationally. Because HIV and Aids is seen as a global epidemic and a multidisciplinary problem, publications from social work, medicine, nursing, sociology and psychology were consulted. In the specific fields of teaching and social work, however, few updated publications are available.

To ensure a purposeful search, the EBSCO Host: Academic Search Premier, Nexus, ERIC, Repertoire of South African Journals, Social Work Abstracts, PsycINFO, Social Sciences Index and SA Media databank were used.

3. EMPIRICAL RESEARCH

3.1 INTERVENTION RESEARCH MODEL

3.1.1 Background information on intervention research

Thomas developed the developmental research and utilisation model during 1981 and an updated design and development model during 1984. During 1980 Rothman developed a social research and development model. During a later publication in Rothman and Thomas (1994) the developmental research models were integrated into intervention research. Intervention research is targeted to address the practice application of research.

Rothman and Thomas (1994) argued that to develop technology in the human service professional fields requires a special type of research, related to the development research undertaken in the fields of engineering and business and adapted to the needs of the human professions such as social work. They viewed design and development as an aspect of intervention research, to extend knowledge of human behaviour and to relate such knowledge to human service intervention or intervention knowledge development, and they linked and utilised the findings from intervention knowledge development research in practical application (De Vos, 2005a:393).

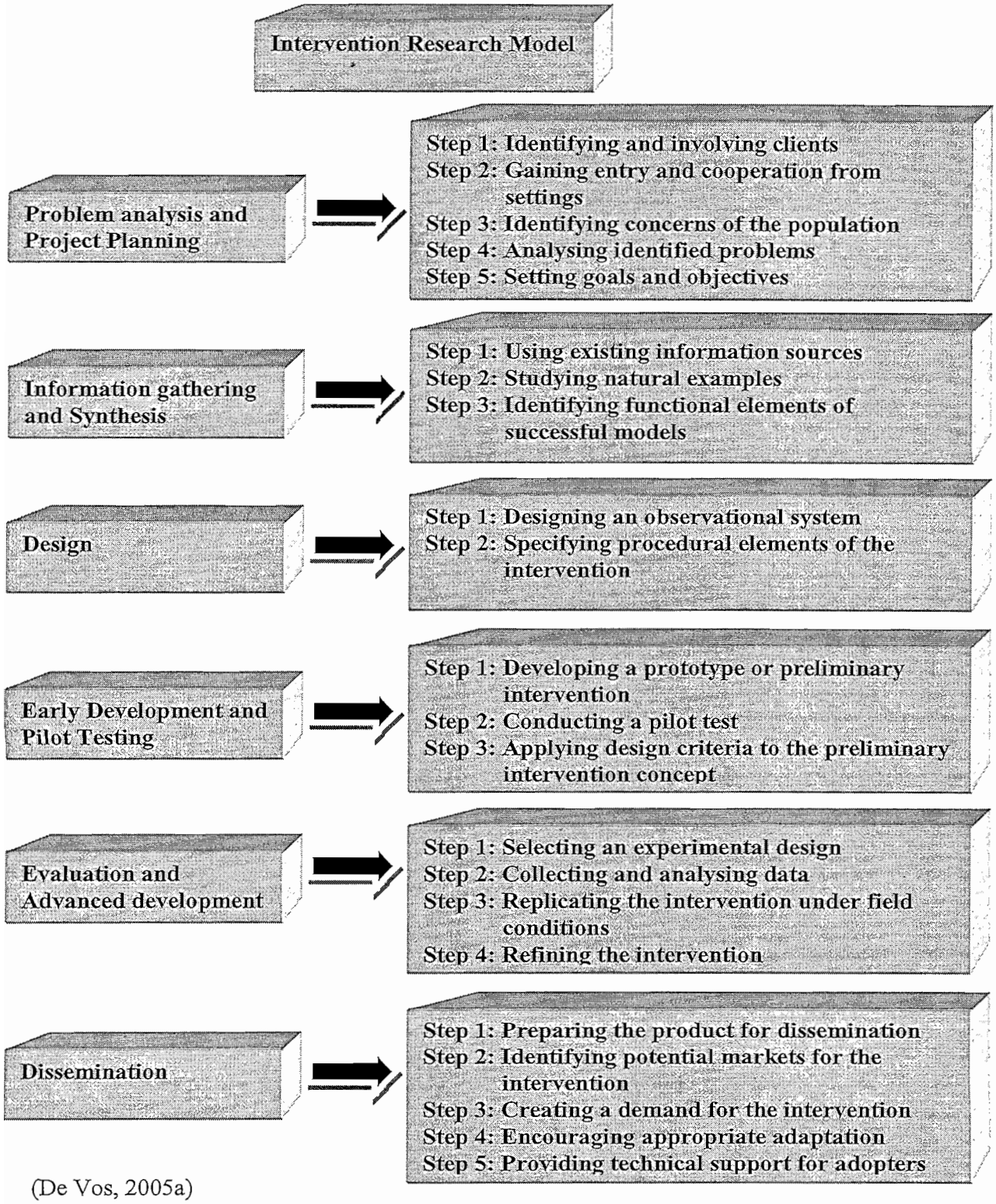
3.1.2 The definition of intervention research

Intervention research is defined as studies carried out for the purpose of conceiving, creating and testing innovative human service approaches to prevent or improve problems or the maintaining of quality of life. In general, social work interventions include strategies that draw on and seek to strengthen the social ties between the individual and the social environment (De Vos, 2005a:394).

3.1.3 The phases of intervention research

Intervention research was untilised as a framework for the implementation and evaluation of the REds support programme. It was also used in discussing the role of the social worker regarding HIV and Aids as well as the development of an empowerment programme regarding HIV and Aids for social work students and the evaluation and dissemination of the empowerment programme, adapted REds. The intervention research model is a six phase model, consisting of problem analysis, information gathering, design, early development, evaluation and dissemination. Each of the phases in turn comprises a series of steps (De Vos, 2005a:395). The researcher will describe the phases of the model in theory and then indicate how the theory was applied in practice during each phase in this study. Figure 2.1 summarises the intervention research model.

FIGURE 2.1: INTERVENTION RESEARCH MODEL



(De Vos, 2005a)

The following is a discussion of the six phases of the intervention research model and the steps of each phase will be discussed in the following chapters as they were applied.

Phase 1: Problem analysis and project planning

Social problems are conditions of society which have negative effects on large numbers of people. A social problem is a condition that has been defined by significant groups as a deviation from some social standard, or a breakdown of social organisation, about which it is felt something could be done through collective action (De Vos, 2005a:395). HIV and Aids are a social problem affecting every sector in our country, especially the education system. REds aims at supporting educators to be resilient in the face of this pandemic and that educator excellence and sustainability be secured. The researcher provides an overview of the nature and the content of REds in Chapter 3. An overview of the aim and the process of each session as it occurred were documented. This phase consists of several operations and was formulated as the following series of steps to be executed during this phase (De Vos, 2005a:398-400):

- Identifying and involving clients.
- Gaining entry and cooperation from settings.
- Identifying concerns of the population.
- Analysing identified problems.
- Setting goals and objectives.

Phase 2: Information gathering and synthesis

According to Fawcett, Suarez-Balcazar, Balcazar, White, Paine, Blanchard & Embree (1994:31-32), it is essential to discover existing information sources, study natural examples and identify functional elements of successful models. According to De Vos (2005a:399), knowledge acquisition involves identifying and electing relevant types of knowledge and using and integrating appropriate sources of information. Particularly useful sources are existing forms of archival information and natural examples of

successful practices of individuals or organisations. The existing REds was evaluated as an effective and affordable support programme for educators affected by the HIV and Aids pandemic. The researcher received training on the successful implementation of REds. Functional elements were identified before REds was implemented. As a result of the evaluation done on the REds programme, a need for social workers, with their necessary skills and training, was identified when working with the HIV and Aids-infected and affected learners, families and community members. The steps of this phase are as follows:

- Using existing information sources.
- Studying natural examples.
- Identifying functional elements of successful models.

Phase 3: Design

Designing an observational system is of crucial importance in the design phase. Researchers must design a way of observing the problem and studying naturally occurring innovations and other prototypes. In so doing, they can identify procedural elements for use in the intervention. Prinsloo (2001:17) used existing programmes and the process of social group work to determine procedural elements in intervention. The researcher studied the need for social work interventions when presenting the existing REds programme. The researcher also studied the role of the social worker related to the HIV and Aids pandemic. The researcher identified certain elements for use in the intervention. The following steps are an indication as to what must be done in this phase:

- Designing an observational system.
- Specifying procedural elements of the intervention.

Phase 4: Early development and pilot testing

De Vos (2005a:401) describes development as the process by which an innovative intervention is implemented and used on a trial basis, developmentally tested for its adequacy, and refined and redesigned as deemed necessary.

Certain adaptations from the existing REds for those infected and affected by HIV and Aids were made as part of the development of the empowerment programme for fourth-year social work students working with those infected and affected by HIV and Aids. The steps included in this phase are as follows:

- Developing a prototype or preliminary intervention.
- Conducting a pilot test.
- Applying design criteria to the preliminary intervention concept.

Phase 5: Evaluation and advanced development

This phase of the intervention research model comprises selecting an experimental design, collecting and analysing data, replicating the intervention under field conditions and refining the intervention.

The newly developed empowerment programme for social work students was evaluated as an effective social work empowerment tool by presenting the programme to 11 volunteering fourth-year social work students. The effectiveness was measured and data was collected through conducting a pre-post assessment. The data on both a quantitative and qualitative basis were analysed. Conclusions were drawn, recommendations and certain adaptations made as part of advanced development of the programme. This phase comprises the following steps:

- Selecting an experimental design.
- Collecting and analysing data.
- Replicating the intervention under field conditions.
- Refining the intervention.

Phase 6: Dissemination

Commenting on the last phase of the new model, namely dissemination, Fawcett *et al.*, (1994:39-43) stated that once the community intervention has been field tested and evaluated, it is ready to be disseminated among community members. The information from this study is being prepared to be disseminated through publishing articles in accredited journals. The empowerment programme is available to potential markets. The following steps help to make the process of dissemination more successful:

- Preparing the product for dissemination.
- Identifying potential markets for the intervention.
- Creating a demand for the intervention.
- Encouraging appropriate adaptation.
- Providing technical support for adopters.

3.2 RESEARCH DESIGN

According to Strydom (1999:77), the research design implies the plan, structure and strategies to find answers to the research problem at the level of collecting information and knowledge. The chosen research design directed the entire research process including which research methods and procedures would be followed. According to Babbie and Mouton (2001:55), the research design can be defined as a blueprint of how the researcher intends to conduct research.

In this study a mixed methods research design was used. Mixed methods research is an approach to inquiry that combines or associates both qualitative and quantitative forms and involves the use of qualitative and quantitative approaches and the mixing of both approaches in a study (Creswell, 2009:4). The collecting and analysing of both quantitative and qualitative data in various parts of the study can be seen as the reason why the researcher employed a mixed methodology design. The concurrent embedded strategy was used in both the phases of this study. Creswell (2009:214) explains that the

concurrent embedded strategy of mixed methods is identified by its use of one data collection phase during which both quantitative and qualitative data are collected simultaneously. According to McKendrick (1989:34), a researcher should use more than one measuring instrument because it enhances the data.

This study consisted of two sections. In section A, the problem formulation, research methodology, description of the nature and content of the REds programme and the evaluation of REds, as effective in supporting programme for educators from the North West Province affected by the HIV and Aids pandemic were described. In section B of the research the focus was on the role of the social worker in working with people infected and affected by HIV and Aids, developing an empowerment programme for social work students regarding HIV and Aids and the evaluation of the effectiveness of the empowerment programme. Because the aims of this study varied, more than one research design was needed. The researcher used the exploratory research design, descriptive research design as well as the explanatory design in both the phases of this study.

3.2.1 Exploratory design

The aim of this design is to gather data in an area of inquiry where little is known and to build a foundation of general ideas and tentative theories which can be explored more rigorously later on (Grinnell & Unrau, 2008:192; Neuman, 2006:33). Although much research has been done on Aids in general, for the South African educational sector this is a fairly new field and needs comprehensive support to cope with the challenges of a professional role that has been escalated to encompass HIV-prevention, counselling and social work. An interactive, participatory support programme, REds was compiled and explored whether it could provide support to infected and affected educators. Having well-trained, knowledgeable and highly motivated professionals working in service delivery at all levels is crucial for effective management of the HIV epidemic. This study further explored the role of the social worker in the face of this pandemic as well as whether the social work students were empowered enough when working with and

supporting those infected and affected by HIV and Aids. According to Babbie (2010: 92), much of social research is conducted to explore a topic. Exploratory studies are appropriate for more persistent phenomena. This approach occurs when a researcher examines a new interest and tests the feasibility of undertaking a more extensive study.

3.2.2 Descriptive design

The purpose of many social science studies is to describe situations and events. The researcher observes and then describes what was observed, evaluates and then documents the findings (Babbie, 2010:93). Ginsberg (2001:157-158) is of the opinion that descriptive designs are useful when the intention of a study is to gain an accurate description of programme activities. These designs examine association or correlation between a programme and its outcomes. In both the sections of this research, the study focuses on the incorporation of knowledge, empowerment, increasing awareness, effecting positive changes in the school environment, improving the lives of those involved, creating a support network and finding solutions to a specific problem in a community. The research on the newly adapted and developed empowerment programme, as well as the training of a group of social work students, was documented in an objective and precise manner to present a complete picture.

3.3.3 Explanatory design

Explanatory research design was applied as it was aimed to give explanations of certain phenomena. Explanatory design may involve groups or social experiments which are applicable in this study. These could help social workers to develop new treatment approaches (Royse, 2004:25). According to Grinnell (2001:255), the explanatory design was also applied in this study as it tested whether or not the independent variable in phase one (the REds support programme) had an influence on the dependent variable (the infected and affected educators) as well as whether the independent variable in the second phase of his study (the empowerment programme) had an influence on the dependent variable (the social work students).

3.3 PARTICIPANTS

Before a study can be undertaken, careful consideration should be given to the population that will be studied. Salkind (2000:86) defines a population as a group of potential participants to whom you want to generalise the results of the study. The population for the two sections in this study consisted of the following:

In the first part of this study, the REds programme was implemented in two Township schools in the Matlosana district, North West Province during 2007. The population in this part of the study was, therefore, all the teachers at these two schools.

The participants included both male and female educators who were affected by the HIV and Aids pandemic (i.e. loved ones, colleagues or learners who are HIV positive; or loved ones, colleagues or learners who have died from Aids-related diseases; or Aids orphans and vulnerable children in their classes), and who were willing to volunteer as REds participants after school hours. However, this study was localised due to logistics. The educators that participated in this research were the first 10 educators from the one school and 14 educators from the second school that volunteered to be part of the study. The 10 participating educators from the first school came from a primary school in the Alabama Township in Klerksdorp. The participants from the second school came from a secondary school in the Kanana Township in Orkney, Matlosana district. Fourteen participating educators were present when the second round started but only 13 were able to complete the programme.

The second part of this study was the evaluation of a newly developed empowerment programme, adapted from REds, for social work students. This programme was presented to 11 fourth-year volunteering social work students from the North-West University, Potchefstroom Campus, after completing their block placements for the study year 2008. The students chosen for this study were the first 11 students from a class of 27, which can be regarded as the population that volunteered to be part of this study. The participants

included both male and female students. The participants completed assessment forms before and after completion of the programme.

A purposive sample with a maximum of 15 participants and a minimum of 8 participants was recruited. A sample of 10 participants was considered ideal because REds was implemented in a group setting. According to Corey and Corey (2002:107) and Toseland and Rivas (2009:167), a group of this size is adequate to give sufficient time for interaction and small enough for every participant to be actively involved, to feel accepted and part of the group.

3.4 MEASURING INSTRUMENTS

In order to be accountable and show progress, precise measurements must be taken (Royse, Thyer & Padgett, 2010:271). Instruments form the basis of measurements. Well-developed instruments help one to understand why some clients benefitted from an intervention and others did not. They also allow one to examine more closely those clients whose progress was meager or moderate – interventions do not always have the same effect on every person. According to Neuman (2006:41), gathering data for the research is divided into two categories, namely qualitative and quantitative.

3.4.1 Measuring instruments used to measure the REds support programme

The effectiveness of the REds support programme was measured by conducting the following:

- **Quantitative instruments**

  - A standardised measuring instrument, the Professional Quality of Life Screening (ProQol) (Stamm, 2005) was used in the pre-testing and post-testing.

- **Qualitative measures**

  - Qualitative measures used were pre-post open-ended questionnaires that reflected the participant's opinions on how the HIV and Aids pandemic affected them.
  - Symbolic drawings to pre-post assess the impact of the pandemic on the participants.
  - Semi-structured interviews afforded the participants the opportunity to express their pre-post views on the issues being investigated.
  - Post-reflections and feedback of participants on each session of the REds programme.
  - Post-interviews with the participants and principal(s)/head of department regarding perceived efficacy of REds.
  - Facilitator's feedback, observations and process notes regarding the REds programme.

3.4.2 Measuring instruments used to measure the social work empowerment programme

The effectiveness of the social work empowerment programme for fourth year social work students was measured by conducting the following:

- **Quantitative instruments**

  - A standardised measuring instrument, the Professional Quality of Life Screening (ProQOL) (Stamm, 2005) was used in the pre-testing and post-testing.
  - The short form Affectometer 2 Questionnaire (AFM) (Kammann & Flett, 1983) was used in the pre-testing and post-testing. To measure the sustainability of this empowerment programme, the participating students were asked to complete the post-testing of this instrument 3 months after completion of the programme.

- **Qualitative measures**

  - Participant reflections and feedback on each session of the programme regarding perceived efficacy of the programme as an empowering tool.
  - Symbolic drawings to pre-post assess the impact of the pandemic on the participants.
  - Self formulated questionnaire pre-test and post-test issues being investigated.
  - Semi-structured interviews post-test the participants' views on facets to improve the programme.
  - Facilitator's reflections, observations and process notes.

3.5 PROCEDURE

This research comprised two sections.
In Section A, the procedure for evaluating REds was as follows:
Permission was obtained from the Department of Education in the North West Province (Addendum 2.1) and the principals of the participating schools in the North West Province. Permission was also obtained from the voluntary participants of the two schools. The participants gave their permission that all information collected might be used for research and publication purposes in both South Africa and other countries (Addendum 2.2).

REds consists of 9 sessions and was presented to the first group of participating educators from May 2007 until June 2007. As each module was implemented, participating educators were asked to comment on the efficacy of each module so that the programme could be improved. At the close of the first round the programme was partly rewritten to accommodate the suggestions of the participants. The improved programme was implemented in round 2 from August 2007 until October 2007 with a second group of participating educators, followed by a second revision. The participating educators decided that the implementation should occur over 9 consecutive weeks. Each session took approximately 2 hours in the afternoon after school (a time slot convenient to the

educators involved). The sessions were held at the staff room at each of the two schools. Refreshments were given because the group sessions started directly after the school day ended. The effectiveness of the programme was measured by multiple pre-test and post-test measurements.

Section B was developed after adaptations were made from the evaluated REds programme. The procedure followed in evaluating the newly developed empowerment programme for fourth-year social work students was as follows: Permission was obtained from the Social Work Department of the North-West University to research the effectiveness of an empowerment programme. Permission was also obtained from the voluntarily participating students (Addendum 2.3) as well as that all information collected could be used for research and publication purposes in both South Africa and other countries. The participating students decided that the implementation of the programme should consist of 9 sessions, and was presented over a 3 day workshop. Each session lasted for approximately 2 hours. The effectiveness of the programme was measured by the knowledge, attitudes and skills that the students obtained concerning HIV and Aids and related matters before and after the implementation of the programme.

The procedures used to collect data were through the single system design and interviewing procedure. The researcher used the single system to monitor and evaluate the participants' outcome in the intervention. The single system was used in both sections of this study and can be described as the study of a single subject on a repetitive basis. The single system establishes that the cause comes before the effect by manipulating the treatment variable before presenting the dependent measure task. The single system is a direct form of research and results are immediately available. The evaluation of the effectiveness of the intervention programme in respect of every client becomes possible. Modifications in intervention are possible and practitioner and client can, when feasible, move over to a more appropriate intervention programme. Hypotheses can be tested about the relationship between a specific intervention procedure and changes occurring in the client.

Interviewing was also one of the procedures used to collect data from the participants in this study. The researcher used an interview schedule with specific instructions for the interviewer, specifically formulated questions and transition phrases (Monette, *et al.*, 2008:172) that were read to the respondent. Interviewing was chosen because it heightens the reliability and complex issues could be clarified. In this study face-to-face interviewing took place. Interviewing was done in an overall interviewing context where part of the interview was the completion of the standardized measuring instrument as well as the open-ended questionnaires and the symbolic drawings done by the participants. The rest of the interview was focused on interviewing the group as a whole where the focus was on evaluating the success of the programme according to a number of questions. The researcher and co-therapist/observer were present throughout the total interviewing situation and made observations. These observations were also reported on in the form of process notes.

3.5.1 The single system

The single system can be described as the study of a single subject on a repetitive basis. The single subject can be an individual, a group, an organisation or a community (Grinnell, 2001:457; Strydom, 2005d:145). The single system establishes that the cause comes before the effect by manipulating the treatment variable before presenting the dependent measure task. The procedure strives to keep non-treatment factors constant (Mitchell & Jolley, 2007:433). The single system is a set of empirical procedures used to observe changes in an identified target that are measured repeatedly over time. With the single system one manipulates independent variables to observe their effects on dependent variables. The power of these various forms and ways in which single systems can be implemented are implied. In the single system designs, multiple measures are taken from a single participant over time, both before and after a manipulation. The basic comparison is between the same participant's pre-treatment and post-treatment scores (Strydom 2005d:146). Social workers use single systems to monitor and evaluate clients' outcome in the intervention with which they address client target problems. It can be used for clinical and programme evaluation purposes (Royse *et al.*, 2010:141).

In this research, the researcher chose the single system because of its advantages and it was regarded as suitable to measure the efficacy of the REds support programme for educators as well as the newly developed empowerment programme for social work students, seeing that there was no control/comparison group available. The researcher utilised the single system design in the implementation of REds with the first group of volunteering educators. Before and after the REds was presented it was evaluated. Modifications were made to the REds programme to accommodate the recommendations of the participants. The modified REds programme was again implemented, using a second group of volunteering educators. The single system design was again used in the second phase of this study. The researcher used single systems to monitor and evaluate clients' outcome in the intervention with which they address clients' target problems. Thus the single system was regarded as suitable to measure the effect of the newly developed empowerment programme on the fourth-year social work students.

3.5.1.1 Steps of the single system design

The single system has certain steps which are common to both research and practice. These steps run a logical course and make the linkage between theory and practice possible. Strydom (2005d:148) identified the following steps in the single system design:

- **Formulate the problem**

The researcher reviews relevant problem areas within the client system. It is then arranged in order of priority, one problem is selected and focused on and it is then clearly and specifically defined. In this research the group members and the researcher specified the problem of the group as a lack of knowledge and support regarding HIV and Aids. Questionnaires were designed to measure the extent of the problem.

- **Review the literature**

The review of relevant literature helps the researcher find the most effective methods of intervention that are available. The researcher made a study of the available literature on

HIV and Aids to see how other researchers had addressed the phenomenon of HIV and Aids.

- **Develop goals and objectives**

In order to give direction to the research, certain aims and objectives should be formulated. Aims and objectives were developed for both the sections of this research.

- **Development of hypothesis**

The researcher developed a hypothesis about the ways in which certain variables might be affecting the problem and how best to go about changing those variables or the relationship between them. It is a statement of expected results of a research study.

- **Develop the design**

Design refers to the researcher's plan for collecting and analysing data. This includes who will collect the data, how, from whom, where and when. Depending on the objectives of the research, the researcher decides on the most suitable design (Strydom, 2005d:148). There are a number of single system designs that can be used, for instance: the basic single-system design (A-B); the basic experimental designs (A-B-A; A-B-A-B; B-A-B); multiple baseline designs and multi target designs; changing intensity design and successive intervention design; alternating intervention programmes and interaction design (Strydom, 2005d:152). For this research, the basic experimental design (A-B-A) was chosen. When using this design, a baseline is first established. This means that for a period of time nothing is done and the level of the group's problem as it presently exists is measured. This is phase A. During the first session of the group the members were subjected to measurement. After the baseline was obtained, the intervention, in this case the REds programme for educators and the empowerment programme for social work students, regarding HIV and Aids, took place. This is phase B. The second A was

obtained after termination of the programmes. This design may be illustrated as follows in Figure 2.2:

FIGURE 2.2: EXPERIMENTAL DESIGN (A-B-A)

A	B	A
Baseline	Intervention (programme)	Baseline
Before-test		After-test
Preparation phase	Beginning, exploration and utilisation phase	Termination phase

(Strydom, 2002:57)

- **Define the dependent variable**

A dependent variable represents the outcome of the research in measurable and precise terms. This allows the researcher to keep track of how well the intervention programme, the REds support programme for educators and the empowerment programme for social work students, is proceeding and to evaluate its success. The dependant variable for the REds was to support educators to cope resiliently with the challenges of the pandemic in order that educator excellence and sustainability be secured. The dependant variable in the study of the empowerment programme for social work students that had to be addressed was the lack of knowledge and skills when working with people infected with and affected by HIV and Aids.

- **Define the independent variable**

The independent variable is the intervention programme, the strategy and specific techniques and procedures the researcher will use to change the client or client system. The researcher must be specific in defining the dependent variables and the specific outcomes in measurable and precise terms. This allows the researcher to keep track of how well the intervention programme is proceeding and to evaluate the success (Strydom, 2005d: 148). In this research the independent variable was the REds

programme and the empowerment programme regarding HIV and Aids for social work students in the second section of this research.

- **Determine obstacles**

During this stage the researcher tries to determine whether there may be any obstacles that could stand in the way of completing the study or intervention and plans to avoid them (Strydom, 2005d:149). The obstacles that the researcher determined were the motivation of the participants to attend all the sessions of the programme. The researcher kept the participants motivated by preparing well for the group sessions and kept them interested by providing them with practical aids they could use after completion of the programme.

- **Baseline phase**

The baseline is a precise record of the frequency of the behaviour before any treatment methods are implemented. After the preparation phase and before the commencement of the prevention programme, the participants of this research were required to complete questionnaires. The baseline can also be repeated at a later stage, as it was in the case of this research. After the second baseline, questionnaires were again completed (Strydom, 2002:58). The researcher made use of quantitative measuring and qualitative measuring such as self-formulated questionnaires, with open-ended questions, to give the participants the opportunity to give their views on the REds and the empowerment programme for students regarding HIV and Aids. The participants' behaviour was also observed as it occurred naturally.

- **Intervention phase**

The intervention phase is the phase in which the independent variable is applied. The researcher performs certain actions with regard to the participants in order to achieve specific objectives. In this study the group sessions of the intervention phase (REds and

the empowerment programme, regarding HIV and Aids) occurred between session two (the beginning phase) and session nine (before the termination phase).

- **Analyse the data**

As soon as the programme is completed, the researcher analyses the data to see whether there have been changes in the dependent variable, to look for relationships between variables and to try to determine whether it was the independent variable that affected the dependent variable (Strydom, 2005d:149). In this research different measurements were compared regarding both quantitative and qualitative data and the results showed that there were changes in both the sections, the REds support programme for educators and the empowerment for social work students regarding HIV and Aids. According to Strydom (2005d:149), it is important to establish whether it was definitely the independent variable that caused the changes in the dependent variable. In order to make sure that there were no external factors present which could influence the dependent variable in this research, all the groups were homogeneous, the prevention programme was presented on a regular and consequent base, group members did not participate in other similar programmes and care was taken that the questionnaires were completed under the same circumstances every time.

- **Report the findings**

A critical phase of the research process is the writing up and disseminating the research findings. After the analysed results have been interpreted and conclusions drawn, the entire research effort should be described in a report, so that information can be published to communicate the findings to colleagues. This research was documented in a thesis, so that other social workers would be able to use this research as a knowledge base. Articles are also being prepared for publication in accredited journals. It would also enable other practitioners to use successful intervention approaches to enhance the effectiveness of their own practice.

3.5.1.2 Advantages and disadvantages of the single system

The use of the single system design is popular with social workers for several reasons. The following advantages as listed by Strydom (2005d:154-155) and Royse (2004:89-90) were the reason why the researcher chose this design:

- Single systems design readily lends itself to clinical practice situations. This approach allows for all the participants to be treated and evaluated, a control group is not necessary to test the success of an intervention, and it also avoids the ethical issue of not treating those participants in the control group.
- The single system is basically a do it-yourself procedure, which keeps costs down.
- It is a direct form of research and the results are immediately available and it gives valid and reliable information about a single individual.
- This design is easy to use and to understand and is not disruptive to the treatment process. It enhances goal-directedness in both therapists and clients and it gives a continuous report of the total intervention effort.
- Modifications in intervention are possible and the practitioner and client can, when feasible, move over to a more appropriate intervention programme. The hypotheses can be tested about the relationship between a specific intervention procedure and changes occurring in the client.
- The single system design attempts to work in an explanatory manner and thus collects qualitative information.

The disadvantages the researcher encounters as suggested by Strydom (2005d:156) and Royse (2004:89-90) were:

- Implementation of the single system was very time-consuming.
- Generalisation cannot be drawn from single systems, because they suffer from the lack of comparisons. This also applied to this study, because the numbers of participants were too small and scattered so that generalisations could not be made.

3.5.2 Face-to-face interviewing

Face-to-face interviews are the most flexible form of data collection method (Alasuutari, Bickman & Brannen, 2009:317). The interview is an alternative method of collecting survey data. Rather than asking respondents to read questionnaires and enter their own answers, researchers send interviewers to ask questions orally and record respondents' answers. Interviewing is typically done in a face-to-face encounter, but telephonic interviewing follows most of the same guidelines (Babbie 2010:274). In this study face-to-face interviewing took place. Interviewing was done in an overall interviewing context where part of the interview was the completion of the standardized measuring instrument as well as the open-ended questionnaires and the symbolic drawings done by the participants. The rest of the interview focused on interviewing the group as a whole where the focus was on evaluating the success of the programme according to a number of questions. The researcher and co-therapist/observer were present throughout the total interviewing situation and made observations. These observations were also reported on in process notes.

3.5.2.1 General guidelines for interviewing

The manner in which interviews ought to be conducted will vary somewhat by survey population and survey content. Babbie (2010:275-277) stated some general guidelines that apply to most interviewing situations:

- **Appearance and demeanor**

Dress and grooming are typically regarded as signs of a person's attitudes and orientations. Impressions could bias responses or affect the willingness of people to be interviewed. Good interviewers will be relaxed and friendly and make the respondent feel comfortable. The interviewer must be able to read the questions fluently. The interviewer must also be familiar with the specifications prepared in conjunction with the questionnaire. Some questions will not exactly fit a given respondent's situation and the

interviewer must determine how the question should be interpreted in that situation. The researcher must prepare herself before the interviewing takes place. The researcher uses an interview schedule with specific instructions for the interviewer, specific formulated questions and transition phrases that are read to the respondent.

- **Familiarity with the schedule**

If the interviewer is unfamiliar with the schedule, the study suffers and the respondent faces an unfair burden. The interview is likely to take more time than necessary and be unpleasant. The interviewer cannot acquire familiarity by skimming through the schedule. It must be carefully studied, question by question. The question must be read without error. The researcher familiarised herself properly with the specifications prepared in conjunction with the schedule. The specifications gave guidance if a question did not fit in a given situation.

- **Following question wording exactly**

The interviewer must be instructed to follow the wording of schedule exactly, if not, the careful phrasing of questions to obtain the information needed and to ensure that the respondents interpret items precisely as intended, will be wasted. A slight change in wording may lead to an opposite answer. Allowing the interviewer to intervene does increase the possibility that the interviewer will impact the data collected. The questions were read according to the schedule specifications given.

- **Recording responses exactly**

The interviewer must record the answers to the schedule containing open-ended questions exactly as given. No attempt should be made to summarise, paraphrase or correct bad grammar. This exactness is especially important because the interviewer will not know how the responses are to be coded. The researcher will do the coding when all the data

has been read. The responses of the participants were recorded with their permission and process notes were written after implementation of each session of the programme.

- **Probing for responses**

In an interview respondents may give an inappropriate or incomplete answer. In such cases, a probe, or request for an elaboration can be useful. Probes are more frequently required in eliciting responses to open-ended than close-ended questions. Sometimes the best probe is silence. If the interviewer sits quietly the respondent will probably fill the pause with additional comments. Appropriate verbal probes might be "how is that?" or "in what ways?" The most useful probe is "anything else?". Sometimes interviewers need to probe for answers that will be sufficiently informative for analytical purposes. In every case such probes must be completely neutral and must not affect the nature of the subsequent response. When one anticipates that a given question may require probing for appropriate responses, one should provide one or more useful probes next to the question in the questionnaire. This will ensure the best neutral probes and all the interviewers will use the same probes, when needed. The researcher asked for explanations of answers given by the participants.

3.5.2.2 Advantages and disadvantages of interviewing

The researcher chose face-to-face interviewing because of the following advantages as listed by Alasuutari *et al.*, (2009:317-318), Babbie (2010:275), and Grinnell and Unrau (2008:338):

- The researcher could establish rapport with respondents and the interviewing ensured high response and completion rates which heightens the reliability.
- Interviewing allowed greater depth than a questionnaire and it allowed clarification of misunderstanding of questions.
- It allowed for observation of nonverbal gestures and spontaneous answers that were recorded in the process notes.

- The researcher had control over the environment in which the schedule was completed and more complex questions could be used.

The disadvantages in this study as suggested by Alasuutari *et al.*, (2009:317-318), Babbie (2010:275) and Grinnell and Unrau (2008:338) were:

- Interviewing required much time and high cost and a limited number of people could be included.
- The interview response could be affected by social norms, potential invasiveness with personal questions and the fact of no anonymity.
- The analysing of data is time-consuming.

3.6 ETHICAL ASPECTS

For researchers in the social sciences, the ethical issues are pervasive and complex, since data should never be obtained at the expense of human beings (Mertens & Ginsberg, 2009:152). Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted and offers rules and behavioural expectations concerning the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students (Mitchell & Jolley, 2007:512-513; Monette *et al.*, 2008:48-56; Strydom, 2005a:57-67). The University of the North-West gave ethical clarification, NWU-00013-07-A3, for the research of the REds programme. For this research, the following aspects were adhered to:

- Permission was obtained from the Department of Education in the North West Province and the principals of the participating schools in the North West Province.
- Informed consent was obtained from the participants, in both the phases of the research, after all the aspects of this particular research had been explained to them (Cozby, 2009:42; Strydom, 2005a:59).

- The participants were informed that the information would be utilized for a research document (Strydom, 2005a:65) and that it could help in making a useful contribution to their community and society in general.
- The subjects voluntarily participated in this programme, therefore without coercion. Nobody should ever be coerced into participating in a research project, because participation must always be voluntary (Neuman, 2006:135). Babbie (2010:64-65) and Thomas and Smith (2003:21) call informed consent "voluntary participation".
- All participants were afforded the right to expect that the information they provided would be treated confidentially, especially with regard to Aids-related matters (Etemad, 1995:824; Kartell & Chabilall, 2005:215; Motepe, 2005:45).
- The respondents were informed as to what would happen during the course of the research and of the purpose of the research.
- Before completing the questionnaire, participants involved were assured of their anonymity.
- It was ensured that the findings of this research would not have a negative impact on the participants.
- The findings were reported as accurately and objectively as possible.
- In order to assist participants and minimise harm, participants should receive the opportunity to express their emotions and feelings following the intervention (Mertens & Ginsberg, 2009:152). In this study, debriefing of participants was done by providing them with the opportunity to record their feelings and emotions directly after each session by completing a reflection sheet. They were also provided with possible local contacts and resources for further debriefing, if necessary.

3.7 DATA ANALYSIS

Data of the standardised measuring instruments, in both the phases, were analysed and transformed into statistically accessible form by counting procedures designed by the Department of Statistical Consultation Services of the North-West University (Potchefstroom Campus). De Vos (2005c:334-337) explains that data analysis is a process through which order and structure are brought to the mass of collected data. The

purpose of data analysis is to reduce data to an intelligible and interpretable form so that the relations of research problems can be studied and tested and conclusions can be drawn (Kruger, *et al.*, 2005:218).

The qualitative data that was collected, in both phases, were analysed thematically according to Tesch's approach. According to Poggenpoel (1998:343-344), Tesch proposes eight steps to consider in data analysis. Firstly the researcher ought to review all the collected data by reading through it and jotting ideas down at random. The researcher then selects one interview and goes through it while writing down ideas that emerged while asking questions like *"What is the importance of the information gathered or what is it about?"* The same procedure should be repeated for several respondents. Similar topics are clustered together and formed into columns that might be arranged into major topics, unique topics and leftovers. The topics are abbreviated as codes and reverted to the text. This preliminary organizing scheme identified new categories and codes. The researcher then selected descriptive wording for different topics and drew lines between the categories to show interrelationship. A final decision was then made on the abbreviation of each category and codes were arranged in alphabetical order. Similar data material was assembled and a preliminary analysis was performed. The researcher then recoded existing data when necessary for categories and sub-categories.

4. CONCLUSION

In this chapter the emphasis was on the research methodology, namely research design, participants, measuring instruments used and the procedure that was followed in this study. The intervention research model was described theoretically and the process was applied to this study. The procedure to collect data was briefly described, focusing on the single system and face-to-face interviewing. The advantages and disadvantages of the different procedures were also discussed. The ethical procedures and data analysis for this study were also discussed. In the next chapter, the nature and content of the presented REds support programme for educators affected by the HIV and Aids pandemic will be discussed. The group work process will also be discussed.

CHAPTER 3
THE NATURE AND CONTENT OF THE RESILIENT EDUCATORS (REDS) SUPPORT PROGRAMME

1. INTRODUCTION

Teachers are often overwhelmed by the professional and personal impacts of living and teaching in a HIV-altered milieu. Many are engulfed by emotional and spiritual distress (Theron, 2007a) and progressively floundering professional morale and performance (Hall *et al.*, 2005). Significantly, affected educators are more likely to consider leaving teaching than those who are not (Hall *et al.*, 2005:23).

The South African educators need comprehensive support to cope with the challenges of a professional role that has been escalated to encompass HIV-prevention, counselling and social work. An interactive, participatory support programme, entitled REds was compiled (Theron *et al.*, 2008:77-88). This chapter provides an overview of the nature and the content of the Resilient Educators (REds) support programme for educators affected by the HIV and Aids pandemic, in order that educators' excellence and sustainability be secured. The aim of each session was stated and the process of each session was documented as it occurred.

2. PROBLEM STATEMENT

The South African education sector is thought to be particularly affected by this harsh reality, in part because learners affected by HIV and Aids are leaving school and in part because infected education stakeholders are dying (Shisana *et al.*, 2005: xiv). According to a 2005 report prepared for the Education Labour Relations Council (Hall *et al.*, 2005), South African educators are viewed as a high risk group in terms of HIV and Aids. The professional demands on affected educators are described as generally taxing (Bhana *et al.*, 2006; Coombe, 2003; Theron, 2007a; Theron, 2008). What emerges strongly from the

literature on professional demands is that affected teachers are severely challenged by caregiver demands.

Educators are increasingly distressed by the large numbers of learners made vulnerable by HIV and Aids and Aids-orphans in their classes (Bhana *et al.*, 2006; Boler, 2003). Teachers are often overwhelmed by the professional and personal impacts of living and teaching in a HIV-altered milieu. Many are engulfed by emotional and spiritual distress (Theron, 2007a) and progressively floundering professional morale and performance (Hall *et al.*, 2005). The pandemic affects not only individuals; it attacks systems, and it is attacking the education system in this country. According to Dawson *et al.*, (2001), research reconfirmed the need for more HIV and Aids-related training for teachers. A similar South African study (Peltzer & Promtussananon, 2003) found that sampled high school teachers felt only moderately comfortable teaching about HIV and Aids and at least 25% held misconceptions about HIV and Aids, which suggested inadequate HIV and Aids-related knowledge. The same study noted that teachers reported scant material resources and community support from religious groups and parents with regard to prevention education.

REds has the express aim of empowering affected educators to cope resiliently with the challenges of the pandemic by supporting educators to respond adaptively to a teaching context that demands responses more typical of medical personnel trained to prevent HIV, counsellors and social workers. With this in mind, the content of REds includes the biomedical facts, guidelines on HIV prevention, guidelines on nursing people with Aids-related illnesses, tips on using social networks and non-governmental structures to give and gain psychosocial and socioeconomic support, grief-counselling skills, guidelines for coping with and minimizing HIV-related discrimination, information on HIV-related education policy, stress management skills and resilience training. These contents are grouped into nine modules (Theron *et al.,* 2008:77-88).

REds was piloted in four South African provinces with small groups of volunteer educator-participants during 2006 and 2007. The researcher was trained as a facilitator to

facilitate the content and participatory process of REds. The researcher presented REds during 2007 at two township schools in the Matlosana district in the North West Province as part of her research.

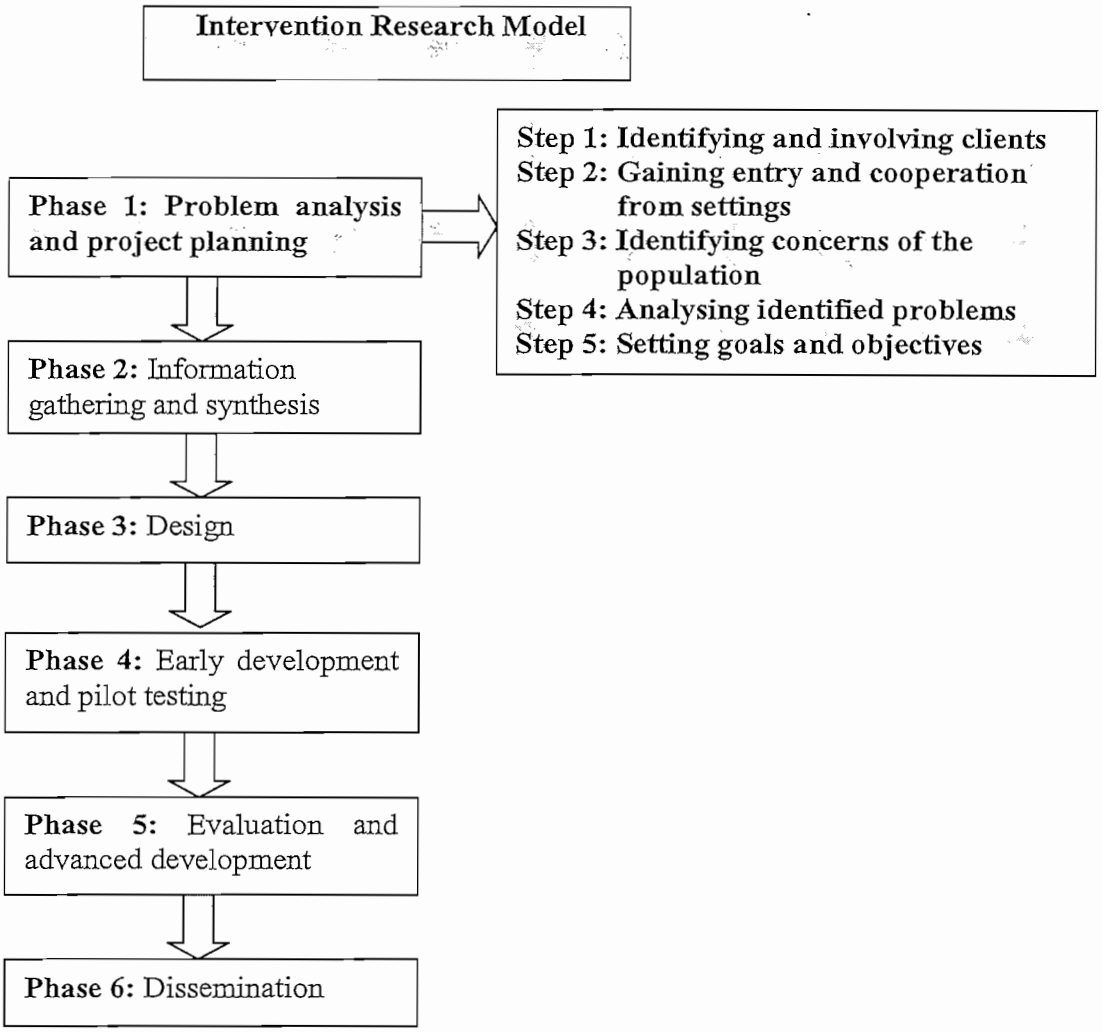
3. AIM

The aim of this chapter is to explain the nature and content of the REds (Resilient Educators) support programme for educators.

4. RESEARCH MODEL

In this chapter the intervention research model was utilised. The intervention research model, Figure 3.1, is a phase model consisting of six phases (De Vos, 2005a:394). The first phase was conducted during this part of the research.

FIGURE 3.1: INTERVENTION RESEARCH MODEL



The researcher will describe Phase 1 of the intervention research model in theory and how it was applied in practice in this chapter.

Phase 1: Problem analysis and project planning

This phase consists of several operations and was formulated as the following series of steps to be performed (De Vos, 2005a:395-398):

- **Step 1: Identifying and involving clients**

In this phase the researcher chooses a population with whom to collaborate. A population is selected whose issues are of current or emerging interest to the society. The researcher, together with the population, identifies the specific targets and goals of the intervention. The population included educators who were directly affected by the HIV and Aids pandemic. The participants, both male and female (ages range from early thirties to mid-fifties), were educators in the North West Province who were affected by the HIV and Aids.

- **Step 2: Gaining entry and cooperation from settings**

Conversations with key informants help the researcher understand what they have to offer and how to articulate the benefits for potential participants. Successful intervention researchers form a collaborative relationship with representatives of the setting by involving them in the identifying of problems, and in planning and implementation of selected interventions. The researcher informed the North West Department of Education as well as the headmasters of the two identified schools of the intended research and a letter of permission was granted. During a teachers meeting the educators from the two schools were informed of the proposed research.

- **Step 3: Identifying concerns of the population**

Once the setting has been accessed, the researcher attempts to understand the issues of importance to the population. The researcher becomes involved with the educators by using informal contact and attending meetings were concerns regarding HIV and Aids and work stress are raised.

- **Step 4: Analysing identified problems**

The researcher analyses the problems the educators identified in their school and community regarding HIV and Aids. The behaviour that needs to be changed to address the problems was also analysed.

- **Step 5: Setting goals and objectives**

Goals refer to the outcomes that are desired by the community of interest, in this research the participating educators, while objectives refer to those specific changes in programmes, policy or practices that are believed to contribute to the broader goal. In the REds programme objectives for each session were specified so that attaining those objectives would result in the achieving of the broader goal.

5. GROUP WORK AS METHOD IN SOCIAL WORK

The REds programme was presented in the form of group sessions. Toseland and Rivas (2009:12) define a group as a "goal-directed activity with small treatment and task groups aimed at meeting social-emotional needs and accomplishing tasks. This activity is directed at individual members of a group and to the group as a whole within a system of service delivery". A group process can be defined as a number of people or things that are together in the same place or that are commonly connected in some ways to one another (Hornby, 2001:524). According to Toseland and Rivas (2009:163), the principle of homogeneity suggests that members should have a similar purpose for being in the group. The participants were all connected to one another, because they were all educators affected by HIV and Aids and had all volunteered to participate in the implementation of REds. Some of them had infected loved ones, while others had infected colleagues or learners.

5.1 TYPES OF GROUPS

Toseland and Rivas (2009:14) classify groups as either treatment or task groups. Task groups are used when the purpose is to accomplish a goal that is neither intrinsically nor immediately linked to the needs of the members of the group. Treatment groups are those whose major purpose is to meet members' socio-emotional needs (Toseland & Rivas, 2009:14). In this study the focus is more on treatment groups. The five primary purposes for treatment groups are support, education, growth, therapy and socialisation (Toseland & Rivas, 2000:20).

The researcher used the following in the group sessions:

5.1.1 Support groups

The primary goal of support groups is to help members cope with stressful life events and to revitalize and enhance members' coping abilities so they can function effectively. Support can help the educators to cope with the effects of HIV and Aids. This type of group can help to empower the educators to be more resilient to adapt effectively to and cope with future stressful events caused by the HIV and Aids pandemic.

5.1.2 Educational groups

Education and information can help the educators to learn more about HIV and Aids. Education is aimed at increasing members' information or skills. According to Zastrow (2001:5), educational groups "usually have a classroom atmosphere, involving considerable group interaction…".

5.1.3 Growth-orientated groups

Growth-orientated groups offer the opportunities for members to become aware of, and change their thoughts, feelings and behaviors regarding themselves and others. The group

is used as a vehicle to develop members' capabilities to the fullest. It focuses on promoting social-emotional health and providing a supportive atmosphere in which individuals can gain insights, experiment with new behaviour, get feedback and grow as human beings.

5.1.4 Social groups

Socialisation helps the group members to learn social skills and socially acceptable behaviour patterns so they can function effectively in the community. These groups use activities such as ice-breakers, role-play and games to help members. The group workers may assume responsibility for the group's activities or seek to encourage members to offer suggestions and to contribute their own resources and skills for the benefit of other members.

5.1.5 Therapy groups

Therapy groups help educators affected by HIV and Aids to cope with problems and trauma that they have to face in the classroom as well when loved ones are infected. Therapy groups focus on remediation and rehabilitation (Toseland & Rivas, 2009:25-26).

5.2 GROUP DYNAMICS

According to Toseland and Rivas (2009:64), "an important task of the group worker is to help groups develop dynamics that promote the satisfaction of members' socio-emotional needs while facilitating the accomplishment of group tasks". Those infected and affected with HIV and Aids are very sensitive due to stigma. The worker must, therefore, ensure that group dynamics such as communication, cohesion, social control mechanisms and group culture are developed.

Each member of a group is influenced by the other members, which in turn influences them in the direction of her or his goals and the group goal. A member's influence over a

member is derived from the meaning that group membership holds for them. It depends on the group's goals, norms, cohesiveness, communication and interpersonal interactions. The emotional climate of the group may affect the degree of control or influence exerted. The group's influence has a positive impact on providing open communication among members, sharing of emotions and gaining support.

5.3 STAGES OF GROUP DEVELOPMENT

Models of group development provide a framework to describe worker roles and appropriate interventions during each stage of a group. They also help workers organize and systematize strategies of intervention. For example, in the beginning stage, a worker's interventions are directed at helping the group define its purpose and helping members feel comfortable with one another. Models of group development can also prepare the leader for what to expect from different types of groups during each stage of development.

The model of group development includes four broad stages: (1) planning, (2) beginning, (3) middle, and (4) ending.

Toseland and Rivas (2009:86), discuss that a stage is a differentiable period or a discernible degree in the process of growth and development. A group's entire social structure, its communication and interaction patterns, cohesion, social controls, and culture evolve as it develops. Therefore, an in-depth understanding of group development is essential for the effective practice of group work.

The **beginning stage** of groups is concerned with **planning, organising and convening**. The beginnings of groups are characterized by an emergence of group feeling. As the beginning stage progresses and norms and roles are differentiated, members explore and test the roles they are beginning to assume in the group.

The **middle stage** is where most work is accomplished. A deepening of interpersonal relationships and greater group cohesion begin to appear. After this occurs, groups concern themselves with the work necessary to accomplish the specific tasks and goals that have been agreed on. This stage includes **problem solving, performing, maintenance, intimacy, work and maturity.** Task accomplishment is preceded by a differentiation of roles and accompanied by the development of feedback and evaluation mechanisms.

The **ending stage** of a group is characterised by the completion and evaluation of the group's efforts. During this stage, task groups make decisions, finish their business and produce the results of their efforts. In treatment groups, which have emphasised socio-emotional functioning as well as task accomplishment, a process of separation begins, during which group feeling and cohesion decline. Often members mark termination by summarising the accomplishments of the group and celebrating together.

5.4 PRINCIPLES OF GROUP DEVELOPMENT

The following practice principles (Toseland & Rivas, 2009:89-90) are derived from an understanding of group development:

- Closed-membership groups develop in discernible and predictable stages. The worker should use systematic methods of observing and assessing the development of the group and should teach group members about the predictable stages of group development.
- Groups generally begin with members exploring the purpose of the group and the roles of the worker and each member. The worker should provide a safe and positive group environment so that members can fully explore the group's purpose and the resources available to accomplish the group's goals.
- After the initial stage of development, groups often experience a period of norm development, role testing, and status awareness that results in expressions of difference among members and the leader. The worker should help members

understand that these expressions of difference are a normal part of group development.

- Structure has been demonstrated to increase member satisfaction, increase feelings of safety and reduce conflict in early group meetings. A lack of structure can lead to feelings of anxiety, insecurity, and can lead to acting out and projection. Therefore, the worker should provide sufficient structure for group interaction, particularly in early group meetings.
- Tension or conflict sometimes develops from differences among members. The worker should help the group resolve the conflict by helping the group develop norms emphasising the importance of respect and tolerance and by mediating the differences and finding a common ground for productive work together.
- Groups enter a middle stage characterized by increased group cohesion and a focus on task accomplishment. To encourage movement toward this stage, the worker should help members stay focused on the purpose of the group, challenge members to develop an appropriate culture for work, and help the group overcome obstacles to goal achievement.
- In the ending stage, the group finishes its work. The worker should help members review and evaluate their work together by highlighting accomplishments and pointing out areas that need further work.
- Groups sometimes experience strong feelings about endings. The worker should help members recognize these feelings, review what they accomplished in the group, and help members plan for termination.

5.5 PROGRAMME ACTIVITIES

Programme activities are the resources used within the group context to assist individual group members and the group as a whole to achieve their objectives (Modise, 2005:62). According to Toseland and Rivas (2009:227), programme activities "provide a medium through which the functioning of members can be assessed in areas such as interpersonal skills, ability to perform daily living activities, motor coordination, attention span and ability to work supportively". Skidmore, Thacheray and Farley (1994:85) regard

programming as the means of goal attainment and if appropriately developed, the programme will stimulate and free individuals to behave and release their feelings in acceptable ways. According to Roux (2002:184), programme activities include verbal programme activities such as group discussions, socio-drama as well as non-verbal programme activities such as art, music and games.

According to Toseland and Rivas (2009:255), the selection of programme activities should be made on the basis of:

- The objectives of the programme activity.
- The purpose and goals of the group.
- The facilities, resources and time available for the activity.
- The characteristics of the group members.
- The characteristics of particular programme activities.

According to Masisi (2002:60), different programme activities can be utilised in order to achieve the objectives and goals formulated. Activities that could be utilised are ice-breakers, group discussions, posters, drama, relaxation exercises, speakers and evaluation questionnaires. In this study the activities mentioned were used to present the REds programme in order to support educators effectively to be resilient in the face of the pandemic.

5.6 THE ROLE OF THE FACILITATOR

The REds support programme was presented in a group format, where the researcher acted as facilitator. A facilitator can be defined as an individual who mediates a process and who supports and assists another individual or group. Facilitation can be explained as holistic and flexible teamwork where strengths are shared and members are empowered, while different personalities are used for different team roles (Ebersöhn & Eloff, 2006:28).

Group work may be understood as a series of activities carried out by the group worker, in this case the facilitator, during the life of a group. It entails the deliberate use of intervention strategies and group processes to accomplish individual, group, and community goals using the value base and ethical practice principles of the social work profession. Therefore, the group worker's intentions, according to Toseland and Rivas (2009:4-5), should be guided by the developmental needs of individual members and the group as a whole.

In this study, the theme was to determine the efficacy of REds, a support programme, on educators affected by HIV and Aids. The facilitator strove to create an atmosphere of trust, safety and acceptance in which participants could engage in dynamic interchange (Corey & Corey, 2002:35).

The role of the facilitator was to support participants and to create opportunities to empower the group members regarding the impact of HIV and Aids on affected educators, affected colleagues and affected loved ones. The activities of the REds support programme were created in such a way that participants were motivated to share, discover, develop and learn. The facilitator also encouraged members to participate in the group interaction in order to empower the members and to make members feel that they have some influence, control and stake in the group situation (Corey & Corey, 2002:35).

5.7 THE ROLE OF THE OBSERVER

An observer is a person involved in introspection rather than active verbal interaction. The role of the observer or co-therapist is to understand and reveal the words and expressions used by participants in specific situations (Strydom, 2005e: 277). Therefore, participant observation can be explained as a qualitative research procedure (Strydom, 2005e: 277). Participant observation is usually unstructured, because the researcher can gain information from unforeseen data sources as they emerge and are recorded by the observer (Leedy & Ormrod, 2005:144).

For this study, the observer made use of field notes (Strydom, 2005e: 277) while observing the reaction and comments of the participants. Process notes including the observer's field notes were written down in more detail by the researcher after the group session to assist the researcher in processing the information. The observer also used a tape recorder to record discussions and conversations in order to help the researcher make detailed interpretations after the group session.

5.8 ADVANTAGES OF GROUP WORK

For the purpose of this study a group support programme was used because group discussions offer the following advantages (Corey & Corey, 2002:113).

- Groups enhance self-esteem because group members realise that other people experience the same emotions as they do.
- Group members learn to know, accept, support and understand one- another better, therefore social skills are improved.
- For the researcher, group work is easily understood and the results seem credible.
- Results do not have to be presented on complicated statistical charts, but can be shared, using everyday language with quotes from group members, which could be an advantage to the researcher.
- Group discussions have the potential to explore topics and generate hypotheses.

6. DESCRIPTION OF THE REDS PROGRAMME

The following table, Table 3.1 provides a schematic description of the content of the REds programme. A more detailed discussion of the programme will follow.

6.1 SCHEMATIC DESCRIPTION OF REDS

TABLE 3.1: DESCRIPTION OF THE REDS PROGRAMME

SESSION	TABLE OF CONTENT	PROGRAMME ACTIVITIES
1.	Introduction	• Ice breaker • Explore impact of pandemic • Explore concept of infected and affected • Define affected and support • Discuss purpose of *REds and expectations • Ethical clarification • Conclude session and reflect on session
2.	HIV/AIDS Manual for Educators (Part 1): Facts about HIV/AIDS	• Discuss facts about HIV/AIDS (HIV transmission) • Discuss myths surrounding HIV • Preventing HIV transmission at home • Phases of HIV infection • Reflection on session
3.	How to give and gain support	• Ice breaker (illustrate importance of support) • Knowledge of support for ill loved ones • Knowledge of support for *OVCs • Provide grief and bereavement skills to support grieving learners/colleagues

		• Provision of some activities for grieving learners and guidelines to cope with grieving learners in classroom • Being comfortable with death to assist others who are grieving • Conclusion and reflection on session
4.	HIV/AIDS manual for Educators (Part 2-4): Health Care	• Care of the sick at home • Care for the dying • Management of AIDS related problems at home • Reflection on session
5.	How to cope with stigma	• Ice breaker (Role-play stigma situation) • Understanding concept stigma • Knowledge of steps of stigma • Discuss values that prevent school/community from stigma • Discuss ideas for combating stigma • Provide knowledge of strategies for coping with stigma • Conclusion and reflection on session
6.	Workplace policies	• Ice breaker (Introduce notion of rights) • Rights with regard to discrimination • Rights with regard to absenteeism and leave

		• Rights with regard to protection against HIV at schools • Understand concept of a supportive school environment • Conclusion and reflection on session
7.	How to cope with stress	• Ice breaker (Introduce notion of stress) • Steps to manage stress: ➢ Stress identification ➢ Stress management • Combat work stress • Conclusion and reflection on session
8.	Resilient in a pandemic	• Ice breaker (Resilience in face of HIV pandemic) • Participants experience of resilience • Steps to be resilient • Debriefing • Reflection on session
9.	Conclusion	• Concluding reflections • Debriefing • Hand out attendance certificates • Schedule post-test

*** REds – Resilient Educators**

*** OVCs – Orphans and vulnerable children/learners**

6.2 DETAILED DISCUSSION OF THE CONTENT OF THE REDS PROGRAMME

6.2.1 Session 1: Introduction

6.2.1.1 Aim

Session one was primarily an introductory session. The aim of the research and the course of the programme were explained to the participants. The objectives included:

- Completion of the pre-test.
- Get to know each other.
- Explore the concepts related to REds.
- Determine expectations for this group with regard to REds.
- Determine group rules for REds.

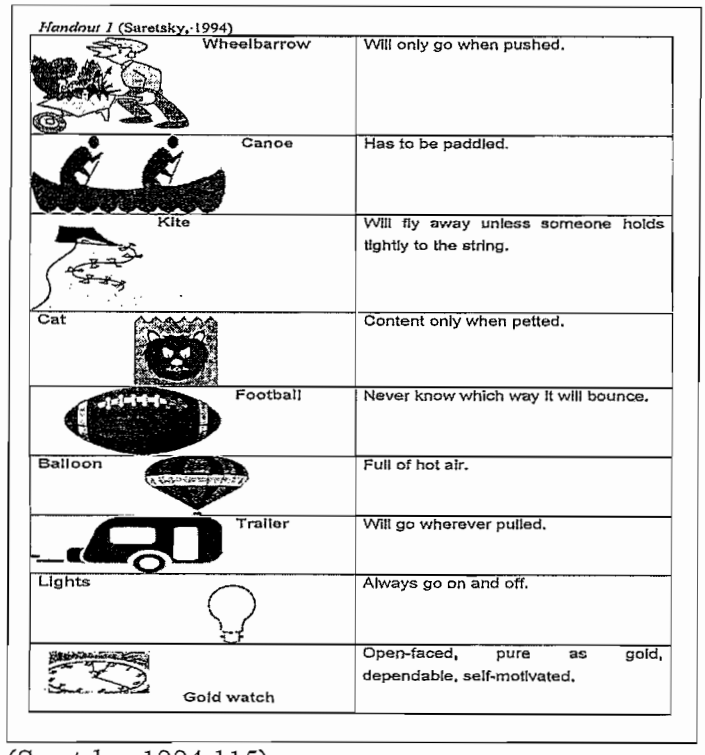
6.2.1.2 Overview on the programme activities

- Ice breaker - Explore impact of pandemic.
- Explore the concept of infected and affected.
- Define affected and support.
- Discuss purpose of REds and expectations.
- Ethical clarification.
- Conclude session and reflect on session.

6.2.1.3 Content

The researcher used an ice breaker to start this session. The participants were asked to complete a symbolic work sheet from Saretsky as used for REds (Theron, 2006) (Figure 3.2). The participants chose a symbol that would describe them the best. This was used as a means for the participants to introduce themselves.

FIGURE 3.2: SYMBOL WHICH DESCRIBES THE PARTICIPANT



Handout 1 (Saretsky, 1994)

Wheelbarrow	Will only go when pushed.
Canoe	Has to be paddled.
Kite	Will fly away unless someone holds tightly to the string.
Cat	Content only when petted.
Football	Never know which way it will bounce.
Balloon	Full of hot air.
Trailer	Will go wherever pulled.
Lights	Always go on and off.
Gold watch	Open-faced, pure as gold, dependable, self-motivated.

(Saretsky, 1994:115)

The concepts of REds (Resilient Educators) were explored as well as what the participants understanding of the term infected and affected are. The facilitator used the example given in her facilitator's training manual to explain the concept resilient. A green, young twig that can bend without breaking when putting pressure on is compared to a resilient educator that is flexible and would not break under pressure. In opposing to this a brown, dead twig breaks when one puts pressure on it and is therefore not resilient. A definition of infected and affected is given to clarify the fact that all of us are actually affected by this pandemic.

The facilitator explained to the participants that REds is a support programme for educators who are affected by the HIV and Aids pandemic and that it forms part of ongoing research. The expectations of the group for the REds were discussed and recorded, to review again at the end of REds, to determine if all the expectations were met. The ethical issues governing the study were carefully explained to the participants.

A suitable time for all the group members to commence with the REds programme was determined. Due to the fact that the meetings would take place in a group form, the group discussed and agreed on certain group rules applicable to them. Some of the group rules were: participation from all group members, confidentiality and respect for each other. In conclusion of Session 1 a poem "I walk down the street" written by Portia Nelson, was read to the participants. This was given as handout 2 in the REds Facilitator Manual (Addendum 3.1).

The participants completed a reflection worksheet to evaluate session one, according to three aspects: what was the most helpful about today's module; what was the least helpful; and what would you change before the module is presented again (Addendum3.2). This reflection worksheet was used after the completion of each session.

6.2.2 Session 2: HIV and Aids Manual for Educators (Part 1): Facts about HIV and Aids

6.2.2.1 Aim

The aim of this session, HIV and Aids Manual for Educators, was to enable the participants to:

- Be knowledgeable about the correct facts about HIV and Aids.
- Be less afraid of HIV and Aids regarding the myths about the transmission of HIV.
- To feel more confident and comfortable because the participants will be able to help themselves and their family members.

6.2.2.2 Overview on the programme activities

- Discuss facts about HIV and Aids (HIV transmission).
- Discuss myths surrounding HIV.
- Preventing HIV transmission at home.
- Phases of HIV infection.

- Reflection on session.

6.2.2.3 Content

In the introduction to this session it was important to explain that many educators have heard the facts surrounding HIV transmission and prevention, but do not know/ understand these facts. The story of Mukasa and Yulia (AIDS Support Organisation, 1993) was read to the participants to illustrate how HIV can be transmitted. The story was of Mukasa who contracted HIV in 1984 when he had to do business in the city. He was unaware of his status when he married Yulia in 1985. Without either of them knowing, Mukasa had passed the HI-virus to Yulia. They were blessed with two children of whom the youngest was born HIV-positive. The story is an effective way of explaining the key issues surrounding HIV and Aids and the participants could relate to this story.
Most people find that information about HIV transmission and Aids is very difficult to teach to others and the technical details are hard to grasp, thus people in the community have problems understanding the important points. The session was presented by an expert on HIV and Aids from Life Line. Audio-visual material was also used to explain the facts about HIV and Aids (HIV transmission); the myths surrounding HIV were discussed; as well as the prevention of HIV transmission at home and the phases of HIV infection. The facilitator also handed out booklets from Soul City regarding the above topics.

The participants completed a reflection worksheet (the same form as in Session 1) to evaluate Session 2 to help improve REds.

6.2.3 Session 3: How to give and gain support

6.2.3.1 Aim

Session 3 was aimed at illustrating the importance of support to cope with the HIV pandemic. It is important to have knowledge about support resources in order to educate others on how to give and gain support.

6.2.3.2 Overview on the programme activities

The following activities were included in Session 3:

- Ice breaker (illustrate importance of support).
- Knowledge of support for ill loved ones.
- Knowledge of support for OVCs.
- Provide grief and bereavement skills to support grieving learners/colleagues.
- Provision of some activities for grieving learners and guidelines to cope with grieving learners in classroom.
- Being comfortable with death to assist others who are grieving.
- Conclusion and reflection on session.

6.2.3.3 Content

An ice breaker was used to open Session 3. The group members had to stand in a circle while the facilitator stood in the middle, blindfolded. The group members were asked to push the blindfolded facilitator backwards and forwards, while the group members were responsible for not letting the facilitator fall. Everyone in the group had a turn to be blindfolded. The one being blindfolded had to learn to trust the group members.

A group activity was used to share knowledge of important support avenues in the community. The group compiled a list of local supportive resources and every participant received a copy. The facilitator gave a small book-marker to all the participants, with important telephone numbers and contact details of supportive resources (Addendum 3.3). This is a helpful tool that they can carry around and also give to others.

The facilitator provided grief and bereavement skills to the participants to enable them to support grieving learners/colleagues. Activities were provided to help grieving learners and guidelines to cope with grieving learners in classroom. To teach grief and bereavement skills the facilitator used posters and showed examples of activities, such as scrapbooking, memory work and memory boxes. The facilitator also handed copies of a

book, "Growing through grief" (Davis, Marcus & Friedland, 2003), that the participants could use as a tool in their class room. The skills and activities, as well as the tools provided gave confidence to the participants when assisting others who are grieving.

The participants completed the same reflection worksheet as in Session 1, to evaluate Session 3 to help improve REds.

6.2.4 Session 4: HIV and Aids Manual for Educators (Part 2-4): Health Care

6.2.4.1 Aim

In Session 4 the focus was on caring for the ill. The objectives of this session are:

- To ensure that the participant be less afraid of HIV Aids regarding the care of the sick at home, infection control at home and the use of medicine.
- Learn to do things which will help the infected and affected to stay healthy.
- Learn how to care for the dying.
- Know how to identify and manage common Aids-related health problems in their homes.
- Learn to recognise danger signs and learn when and how to seek more help.
- Feel more confident and comfortable to help themselves and family members.

6.2.4.2 Overview on the programme activities

The following activities were included in Session 4:

- Care of the sick at home.
- Care for the dying.
- Management of AIDS related problems at home.
- Reflection on session.

6.2.4.3 Content

This session consisted of three sections. The first section "care of the sick at home" as well as the section on "management of Aids related problems at home" was presented by a nurse with knowledge on how to care for a person with HIV and Aids. Posters with body-building foods, energy giving foods and foods that protect the body from infection were shown to the participants and the benefits were discussed. The importance of general hygiene (personal, as well as environmental) was discussed. Emphasis was placed on the following: making water safe to drink; how to keep food safe to eat; infection control at home; universal precaution to discard body fluids and guide to use medicine correctly. Posters were used to convey the information to the participants.

The group participated actively in the discussion on management of common Aids-related health problems in the home, like anxiety, coughing, constipation, fever, fatigue, night sweats and weight loss. This section gave guidelines on how to care for a sick person at home.

The facilitator presented the section on "care for the dying" last. At some point in the disease process of Aids, there is nothing more that can be done to treat the opportunistic infections. The infections or illnesses have progressed beyond what medicines can cure. At this point, the goal of care (medical, nursing, pastoral and psychological) is to keep the person as comfortable as possible and to maintain their dignity. The facilitator used additional information handouts, posters, and discussions to meet the goal of this very sensitive issue of palliative care. The grieving process was also explained to the group. The information focused on: how to give comfort; allow the sick person independence; how to prepare for death. Information in the manual is not enough and does not convey the importance of palliative care to the participants sufficiently. Extra material should be included in this section.

The participants completed the same reflection worksheet as in previous sessions to evaluate Session 4 to improve REds.

6.2.5 Session 5: How to cope with stigma

6.2.5.1 Aim

The aim of Session 5 was empowerment of participants with knowledge and skills to combat and cope with stigma surrounding the pandemic. In the end of this session the participants must understand stigma, identify steps involved in combating stigma and strategies to cope with stigma.

6.2.5.2 Overview on the programme activities

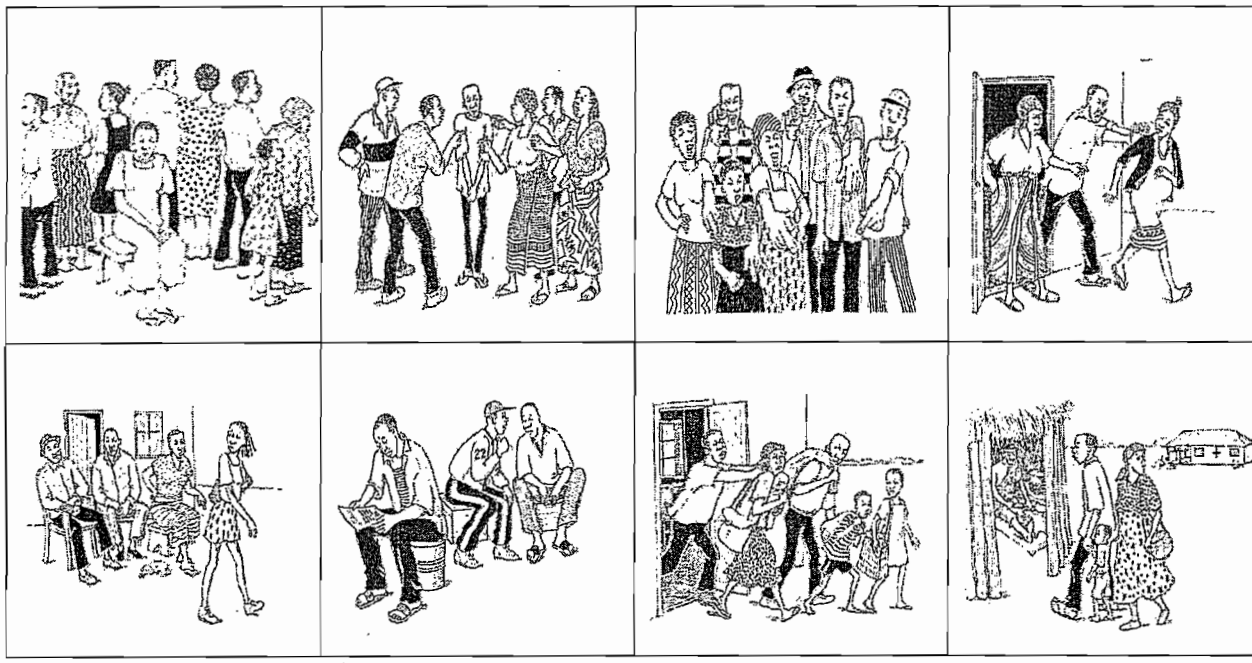
The following activities were included in Session 5 to reach the above goals:

- Ice breaker (role-play stigma situation).
- Understanding concept stigma.
- Knowledge of steps of stigma.
- Discuss values that prevent school/community from stigma.
- Discuss ideas for combating stigma.
- Provide knowledge of strategies for coping with stigma.
- Conclusion and reflection on the session.

6.2.5.3 Content

This section started with an ice breaker activity. The participants divided into 2 groups. Different pictures as illustrated in Figure 3.3 (Change Project, 2005), were provided as handouts. The participants chose a picture and discussed the effect of stigma on an individual and on family members that those pictures represent.

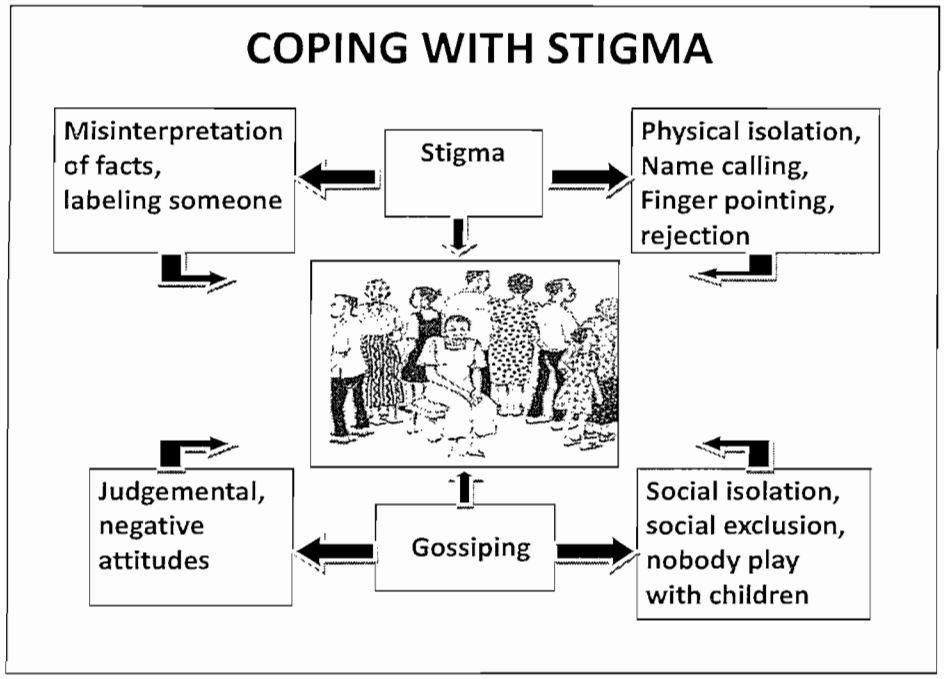
FIGURE 3.3: PICTURES WHICH REPRESENT STIGMA



(Change Project, 2005)

The pictures were also used to explain the concept stigma. Stigma is identified as misinterpretation of facts or to label someone, physical isolation, rejection, social isolation, gossip, judgemental and negative attitudes. Figure 3.4 summarises the interpretation of stigma surrounding HIV and Aids (Change Project, 2005).

FIGURE 3.4: A DEFINITION OF STIGMA



(Change Project, 2005)

To assist participants in combating stigma and gaining knowledge of the different steps to minimise stigma, the participants had to identify and share their ideas on how to combat stigma in schools and in their community.

The following steps to address stigma were discussed:

- Recognise stigma.
- Provide in-depth knowledge about HIV and Aids to prevent misconceptions and myths.
- Avoid language with stigmatisation (verbal and non-verbal).
- Involve people with HIV and Aids in community.
- Discuss values that underlie stigma.

The participants completed a reflection worksheet to evaluate Session 5, the same as in Session 1, to help improve REds.

6.2.6 Session 6: Workplace policies

6.2.6.1 Aim

The main aim of Session 6 was to make educators aware of their rights regarding discrimination, absenteeism, leave and protection against HIV at school. They were also introduced to the concept of a supportive school environment.

6.2.6.2 Overview on the programme activities

The following activities were included in Session 6:

- Ice breaker (Introduce notion of rights).
- Rights with regard to discrimination.
- Rights with regard to absenteeism and leave.
- Rights with regard to protection against HIV at schools.
- Understand concept of a supportive school environment.
- Conclusion and reflection on session.

6.2.6.3 Content

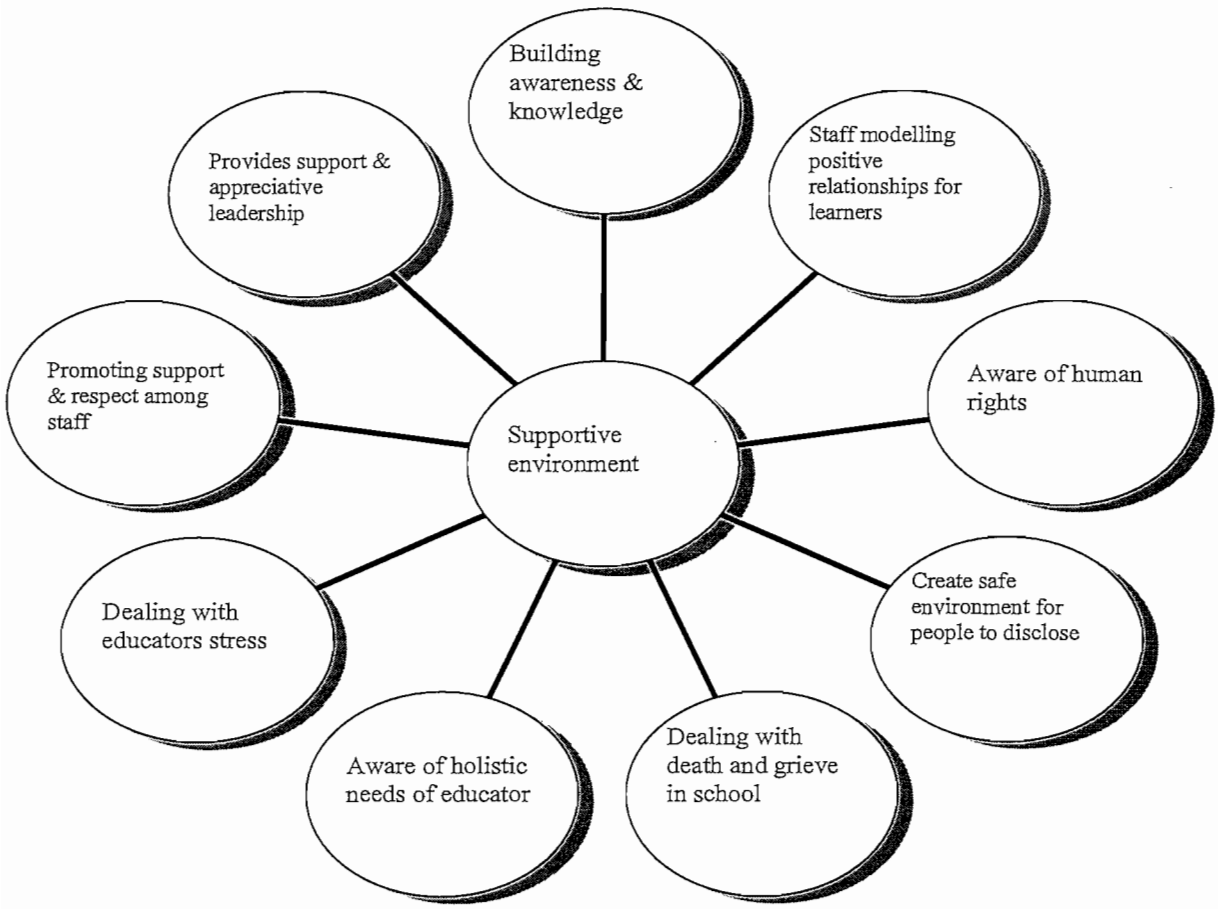
As an ice breaker and a way of introducing the idea of the "rights" to the participants, they had to hold a cup of water in the air for an indefinite time. The group did as they were told without questioning and after a while became tired. This illustrated that the participants did not think about their rights, they did everything as they were told. They did not use their right to question or their right to decide for themselves. The facilitator gave a set of questions, handout 12 in the REds manual (Addendum 3.4) to the participants and divided them into 2 groups. The groups then had to debate these questions about their rights with regard to discrimination. Different sections of the South Africa Employment Equity Act (55/1998), the South Africa Labour Relations Act (66/1995) and the South Africa Department of Education's National Policy on HIV and

Aids for Learners and Educators (1999) were discussed to make sure that the participants knew their rights.

To ensure that the educators understood the concept of a supportive school environment, they had to explain what they understood under a supportive environment and why it was important to work in a supportive environment. A supportive working environment could motivate educators who were working under difficult circumstances and it could reduce depression and burnout among educators. Figure 3.5 was used to explain what a supportive school environment entails.

The participants indicated that this session was very educative and informative. They agreed that a supportive environment motivates individuals to work under difficult circumstances and that support can also fight depression, stress and burnout. Figure 3.5 illustrates a supportive school environment for employees within a school system.

FIGURE 3.5: SUPPORTIVE SCHOOL ENVIRONMENT FOR EMPLOYEES



(Esterhuizen, 2007:131)

Each participant was given a copy of the universal precautions as it should be implemented at all schools to minimise the risk of transmission of all blood borne pathogens and HIV.

The participants completed the same reflection worksheet as in the previous sessions to evaluate Session 6 to help improve REds, as in Session 1.

6.2.7 Session 7: How to cope with stress

6.2.7.1 Aim

The aim of Session 7 was to provide participants with skills to be able to cope with stress and fatigue in their personal lives, as well as in their work environment. In order to combat stress, it is important to understand and recognise the stressors.

6.2.7.2 Overview on the programme activities

The following activities were included in Session 7:

- Ice breaker (Introduce notion of stress).
- Steps to manage stress:
  - stress identification,
  - stress management.
- Combat work stress.
- Conclusion and reflection on the session.

6.2.7.3 Content

This session started with an ice breaker. Each participant received a ball of clay with which they had to model any figure which symbolises stress to them and then had to explain what they had made. This activity has a secondary goal: a good way of reducing stress is to play with clay. Examples of three of the participants' symbols of stress can be seen in Figure 3.6.

FIGURE 3.6: SYMBOLS OF STRESS

		
A gun represented stress, the violence in our country caused stress	A virus, bacteria represented stress, because people were sick	This purple monster of stress was consuming the body and was taking it over

In the section on "steps to manage stress" the facilitator explained the definition of stress and used a worksheet with 3 columns to help the participants to manage their stress. In the first column the participants had to identify everything that is causing them to stress. In the second column the participants had to list the irrational beliefs, causing the corresponding stress. In the third column the participants had to list the modified response to the stress.

In the section on "work stress" the participants discussed in a group what could cause stress at work. The facilitator suggested that the participants could make a "to-do-list", which helped them to prioritise, which would reduce stress, because poor time management can also cause stress. They had to divide their list into "must, should and want to do". The facilitator used a poster with pictures and the participants had to identify and discuss the time wasters. This helped the participants identify their work stress and also how to control it.

To end this session the participants had to make a "joy list". The facilitator reminded them that the things that they enjoy were probably the things that would help them to reduce stress if they took the time to do it.

In conclusion the participants learned a relaxation exercise and while soft music was playing they had some time to close their eyes and relax. The goal of this session was also for the participants to debrief. The participants completed the same reflection worksheet as in the previous sessions to evaluate session seven to help improve REds.

6.2.8 Session 8: Resilient in a pandemic

6.2.8.1 Aim

The aim of Session 8 was mainly to help affected educators identify whether they are resilient and strong in the face of the pandemic. The pandemic is causing stress and burnout due to an excessive workload, the nursing and caring of HIV-infected loved ones and coping with orphans and vulnerable children in their classes. The aim was to summarise the REds and to provide closure for the participants participating in this programme.

6.2.8.2 Overview on the programme activities

The following activities were included in Session 8:

- Ice breaker (Illustrate resilience in face of HIV pandemic).
- Participants experience of resilience.
- Steps to be resilient.
- Debriefing.
- Reflection on session.

6.2.8.3 Content

The facilitator read from Mr. N. Mandela's autobiography, "Long walk to freedom". The story displayed how Mr. N. Mandela stayed resilient, although he went through rough

times. The participants were asked to define resilience and to identify certain forms of resilience that they may have learned as a result of REds. The facilitator again used the example of Mr. Mandela's life story to identify the steps toward becoming resilient in the face of a difficult situation. The facilitator used posters as visual media to make sure that the participants understood the six steps toward becoming resilient. The steps were:

- Accept that the pandemic is a reality.
- Focus on the parts that can be managed.
- Connect with others to give support.
- Use the pandemic for self-growth.
- Stay hopeful and visualise an alternative to the present reality.
- Take care of yourself.

The facilitator explained the A-Z list of resilience (Addendum 3.5). In the last part of this session the participants were debriefed, in order to adhere to ethical guidelines (Strydom, 2005a:66). The participants also completed the same reflection worksheet to evaluate Session 8 to help improve REds, as in the previous sessions. The facilitator invited the participants to contact her if necessary.

6.2.9 Session 9: Conclusion

6.2.9.1 Aim

The aim of Session 9 was mainly to hand out the REds certificates, to confirm the participation of this group of educators in the REds programme.

6.2.9.2 Overview on the programme activities

The following activities were included in Session 9:

- Concluding reflections
- Debriefing.

- Hand out attendance certificates.
- Schedule post-test.

6.2.9.3 Content

The facilitator encouraged the participants to share any other reflections they might have on the REds programme. The facilitator again gave them the opportunity to debrief any feelings they might experience.

Before the REds certificates (Addendum 3.6) were handed out, the participants completed the post-test on the REds programme. According the ethical guidelines (De Lange, Mitchell & Stuart, 2007:36) the participants did give their permission to be photographed during the Certificate Ceremony (Addendum 3.7). They were very honoured to be part of the research process and asked that an article be put in the local newspaper to congratulate them on completing this course. A small celebration followed to end this session.

7. DISCUSSION

Group work as a process was studied and taken into consideration in the planning process of the group. The planning and compiling of a group is an intense process and consists of different aspects. In order to ensure that people are served effectively, sound preparation is essential for the initiation and subsequent development of a group. The researcher performed a number of tasks before the first group meeting to ensure that the group was likely to succeed. In preparing for the first meeting, the worker reviewed the plan for the group and made a preliminary assessment of the members. Knowing who the members were their knowledge about the particular subject of research, needs and the situations of members, literature and other resources were used to increase their knowledge.

The programme activities should be considered carefully as it plays an important role in the presentation of the programme. Different aspects were considered in the actual

planning of the group work. These aspects include the structure, nature and aims of the group, the preparation of the researcher and facilitator of the REds programme, the needs to be addressed by the group, relationship between the group members and the facilitator, as well as the procedure of the group. In preparation of the group members, their level of motivation and the aim of the different group work sessions were discussed, as well as the methods and procedures that were utilised during the programme were introduced.

REds was conceptualised as a potentially supportive, participatory and empowering group intervention for educators affected by the HIV and Aids pandemic. Group work as a research process was used simultaneously to enable interventions and to lead to positive social change. Individuals gained certain skills through the group work process. Functional helping aids such as posters, pictures, activities and music were utilised during the group work programme to assist, stimulate, explore and assess the group work process.

8. CONCLUSION

The purpose of this chapter was to provide an overview of the process of the implementation of the REds programme. The activities and the content of each session were described. In this chapter the group work process was also described because the REds programme was presented in group sessions. Through the group process the participants gained certain skills and the group intervention led to positive social change. The data collected from the group sessions served as a starting point for evaluating the REds support programme for educators affected by the HIV and Aids pandemic, as affective, in order that educators' excellence and sustainability be secured.

The empirical study will be discussed in Chapter 4. It will entail data analysis of the pre-assessment and post-assessment of the quantitative and qualitative data of both groups. The recommendations for the adaptation of the REds programme made by the participants will also be discussed in Chapter 4.

CHAPTER 4

THE EFECTIVENESS OF THE RESILIENT EDUCATORS (REDS) SUPPORT PROGRAMME

1. INTRODUCTION

Educators and practitioners in health care and social services find themselves in the frontline regarding both preventing the spread of HIV and dealing with its consequences (Lerole, 1994:9). South African educators are considered to be a high risk group in terms of HIV and Aids (Hall *et al.*, 2005). According to Dawson *et al.*, (2001), research reconfirmed the need for more HIV and Aids-related training for teachers. A similar South African study (Peltzer & Promtussananon, 2003), found that sampled high school teachers felt only moderately comfortable teaching about HIV and Aids and at least 25% held misconceptions about HIV and Aids which suggested inadequate HIV and Aids-related knowledge. The same study noted that teachers reported scant material resources and community support from religious groups and parents with regard to prevention education. The South African educators need comprehensive support to cope with the challenges of a professional role that has been escalated to encompass HIV-prevention, counselling and social work. REds was designed by Theron (2006), to support the educators with the challenges of a professional role. To determine whether REds is effective in supporting educators affected by the HIV and Aids pandemic in order that educator excellence and sustainability be secured in the North West Province, the programme was implemented and evaluated in two schools in the Matlosana district, North West Province.

2. PROBLEM STATEMENT

It is well documented that the HIV and Aids pandemic is impacting adversely on education and educators and disempowering the system (Coombe, 2000). The educators affected by HIV and Aids are vulnerable and struggle to cope in the face of the pandemic.

Urgent support for affected educators who become involved and go beyond the call of duty in the fight against HIV and Aids, is of the utmost importance (Coombe, 2003; Hall *et al.*, 2005; Simbayi, Skinner, Letlape & Zuma, 2005; Theron, 2005:59). These educators need to be taught skills in order to cope with HIV and Aids. Affected educators necessitate being psychosocially and emotionally strong while facing this ravaging pandemic. In other words, educators need to become resilient.

Resilience is the ability to persevere and adapt successfully when things go amiss and cope with life's unexpected challenges and setbacks (Jenson & Fraser, 2006:8; Reivich & Shatté, 2002:1). Schoon (2006:6) defines resilience as a dynamic process where individuals positively adapt despite difficult circumstances. Resilience is all about the way an individual responds in an adverse or difficult situation. Reinforcing educators' resilience plays an important role in the well-being of every individual. It is clear that educators affected by HIV and Aids are vulnerable and struggle to cope in the face of the pandemic. Support for affected educators who become involved in the fight against HIV and Aids, is of utmost importance.

For this reason it is necessary to provide educators with a programme such as REds, which purposefully aims to buffer educators against the impact of HIV and Aids. To determine whether REds is effective in supporting North West educators affected by the HIV and Aids pandemic in order that educator excellence and sustainability be secured, the programme was implemented in two township schools in the Matlosana district in the North West Province during 2007.

REds consists of 9 sessions conducted over 9 weeks covering topics such as the giving and gaining of support, health care, coping with stigma and resiliency in a pandemic. REds was presented to the first group of participating educators from May 2007 until June 2007. As each module was implemented, participating educators were asked to comment on the efficacy of each module so that the programme could be improved. At the close of the first round, the programme was partly rewritten to accommodate the suggestions of the participants. The improved programme was implemented in round 2

from August 2007 until October 2007, with a second group of participating educators, followed by a second revision.

In order to support and teach educators to become resilient in the face of the pandemic, the following question arise:

- What is the effectiveness of the REds (Resilient Educators) support programme on educators affected by HIV and Aids?

3. AIM AND OBJECTIVES

The aim of this research is to determine whether REds, designed by Theron (2006), is effective in supporting educators from the North West Province affected by the HIV and Aids pandemic in order that educator excellence and sustainability be secured. The research conducted in this study will form part of the piloted study of the REds programme in four South African provinces.

In order to achieve this, the following objectives are proposed:

- Evaluation of the implemented support programme (REds) efficacy in supporting affected educators.
- Modification of the programme, to accommodate the suggestions of the participants.
- Implementation of the modified support programme, using a second group of volunteering educators.
- Revision of the modified support programme.
- Recommendations regarding increased effectiveness of the intervention programme.

4. RESEARCH METHODOLOGY

The methods used for investigation were a literature study and an empirical investigation.

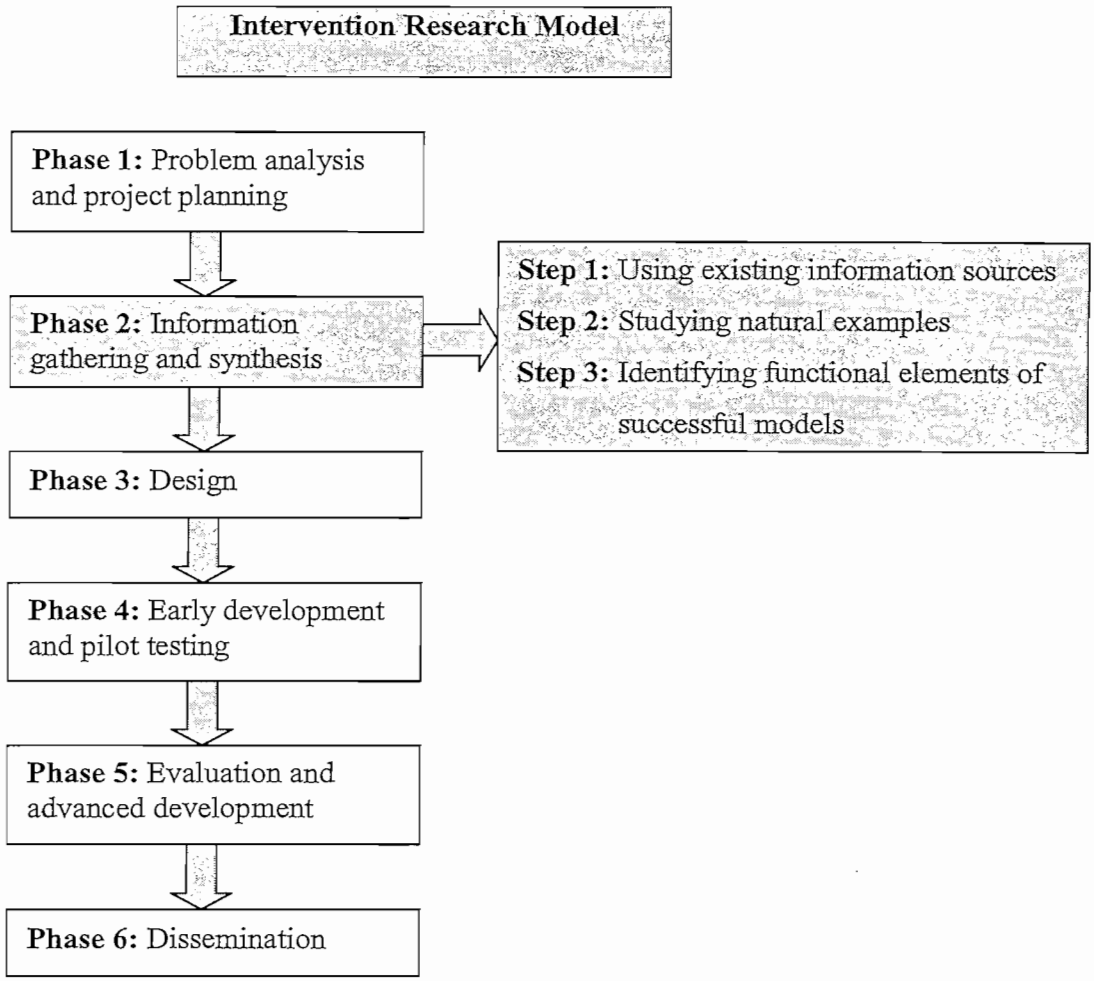
4.1 LITERATURE STUDY

The express aim of this study was to evaluate REds, a support programme for educators affected by HIV and Aids to cope resiliently and respond adaptively to the challenges of a professional role that has been escalating due to the HIV and Aids pandemic. The aim of the literature study in this phase of the research was to place the research problem in theoretical perspective by studying the available literature related to the problem. The literature study was also utilised to study the empirical research used in the evaluation of the REds programme.

4.2 EMPIRICAL INVESTIGATION

The empirical research was conducted to evaluate the efficacy of the REds intervention programme. The model used for this study is the intervention research model, a phase model consisting of six phases (De Vos, 2005a:394). Figure 4.1 gives an outline of the phases and the steps used in this chapter.

FIGURE 4.1: INTERVENTION RESEARCH MODEL



The intervention research model is the background and Creswell's Mixed Methods strategy (Creswell, 2009:213-214) of combining both quantitative and qualitative data was followed in the same study. This part of the empirical study focused on Phase 2 of the intervention research model.

Phase 2: Information gathering and Synthesis

Phase 2 consists of several operations and was formulated as the following series of steps to be performed (De Vos, 2005a:398-400).

- **Step 1: Using existing information sources**

According to Prinsloo (2001:14-15), a literature review usually consists of an examination of selected empirical research, reported practice and identified innovations relevant to the particular concern under study. Intervention researchers must look beyond the literature of their particular fields. They must contribute to both the generation of new knowledge about behaviour-environment relations and establish new linkages between concepts and methods of various disciplines. Because HIV and Aids is a universal concern, it was easy to establish links between the concepts and methods of the various disciplines. Resources, including books and articles, from different disciplines were also consulted.

- **Step 2: Studying natural examples**

A particularly useful source of information is observing how community members faced with the problem under study have attempted to address it. Interviews with people who have actually experienced the problem, or those with knowledge about it, can provide insights into which interventions might succeed and the variables that may affect success (De Vos, 2005a:399).

- **Step 3: Identifying functional elements of successful models**

Researchers analyse the critical features of the programme and practices that have previously addressed the problem of interest. By studying successful and unsuccessful models or programmes, researchers identify potential useful elements of an intervention. They can ask themselves what made a programme effective or what caused it to fail (De Vos, 2005a:400). The researcher received training on the implementation of the REds programme. Some advice was given on the implementation of the programme, using resources and previous successful implementations of the REds programme in the Vaal Triangle Region of Gauteng Province to make this programme a success. The researcher

presented REds during 2007 at two township schools in the Matlosana district in the North West Province as part of her research.

5. RESULTS OF THE EMPIRICAL STUDY

The effectiveness of the programme was measured by multiple pre-assessment and post-assessment of the quantitative and qualitative measurements. The researcher also collected data from the participants' feedback after each session was implemented as well as interviews with the participants on the efficacy of REds as a support programme. The researcher utilised the single system design as well as face-to-face interviewing to collect the data. The single system was utilised because this method can determine the effectiveness of the programme by comparing the before and after measurements (Strydom, 2005d:156). In this research, the single system was regarded as suitable to measure the effect of the REds support programme on the educators' excellence and sustainability and to monitor and evaluate clients' outcome in the intervention.

The following is a discussion of the impact of REds on the participants (educators affected by HIV and Aids) in order to comment on the efficacy of REds. According to Neuman (2006:41), collecting data for the study is divided into two categories, namely qualitative and quantitative. The results will be discussed according to the pre-test and post-test data analysis, consisting of quantitative as well as qualitative data.

5.1 QUANTITATIVE INSTRUMENT: ProQOL QUESTIONNAIRE

Before the programme started the participants completed the Professional Quality of Life Screening questionnaire (ProQOL) (Stamm, 2005) (this was considered as the pre-test) and after the 9 consecutive weekly sessions, after completion of the programme, the participants completed the same test (considered as the post-test).

5.1.1 Background of the ProQOL

The ProQOL is an instrument which measures the professional quality of life among staff of organisations such as state's social workers, general health workers or educators (Stamm, 2005:9). The ProQOL (Addendum 4.1) consists of 30 questions/items which the respondents had to answer by making use of a Lickert Scale according to the following categories:

- Never.
- Not often.
- Quite often.
- Often.
- Very often.

The ProQOL consists of three subscales (Stamm, 2005:4), namely:

- Compassion Satisfaction (CS).
- Burnout (BO).
- Compassion Fatigue or Secondary Trauma (T).

Compassion satisfaction entails the pleasure one obtains from being able to do one's work successfully (Stamm, 2005:5). When one finds delight in one's work and experience positive feelings towards one's colleagues, one will have a high score in this section. The items in this sub-scale: 3, 6, 12, 16, 18, 20, 22, 24, 27, 30.
Burnout is associated with feelings of hopelessness and complications when performing work (Stamm, 2005:5). Aspects such as an ever increasing workload or non-supportive work environment can cause burnout. The items in this sub-scale: 1, 4, 8, 10, 15, 17, 19, 21, 26, 29.

Compassion fatigue or secondary trauma entails exposure to work-related stressful situations (Stamm, 2005:5). When experiencing sleeplessness or fear regarding work, one might be exposed to compassion fatigue. The items in this sub-scale: 2, 5, 7, 9, 11, 13, 14, 23, 25, 28.

When scoring the ProQOL, the scores of some items need to be reversed. These 5 items are: 1, 4, 15, 17 and 29. The quantitative data generated were analysed by means of descriptive data analysis, according to the specifications of the ProQOL.

5.1.2 Reliability and Validity

The reliability of a test refers to the consistency of scores obtained by the same persons when they are re-examined with the same test on different occasions, or with different sets of equivalent items, or under other variable examining conditions. The validity of a test concerns what the test measures and how well it does so (Anastasi & Urbina, 1997: 84, 113). Reliability and validity could not be assured statistically in this study population, as a result of the fact that there were only 10 participants from the first group and 13 participants from the second group, but the literature reported reliability.

Stamm (2005:7) reported the following on reliability. The alpha reliabilities for the sub-scales are as follows: Compassion satisfaction is about the pleasure derived from being able to do work well. For example, one may feel like it is a pleasure to help others through work. One may feel positively about colleagues or ability to contribute to the work setting or even the greater good of society. Higher scores on this scale represent a greater satisfaction related to ability to be an effective caregiver in one's job. Reliability for compassion satisfaction alpha was 0.87. Burnout from a research perspective is associated with feelings of hopelessness and difficulties in dealing with work or in doing the job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that efforts make no difference, or they can be associated with a very high workload or a non-supportive work environment. Higher scores on this scale mean that one is at higher risk for burnout. Reliability for burnout alpha was 0.72. Compassion fatigue (CF), also called secondary trauma (STS) is work-related and secondary exposure

to extremely stressful events. If exposed to other's traumatic events as a result of work, such as in an emergency room or working with child protective services, this is secondary exposure. Reliability for compassion fatigue alpha was 0.80.

5.1.3 Statistical procedures

The statistical significance of results in research is not only important when results are reported but to comment on the practical significance of a statistically significant result (Ellis and Steyn, 2003:51-54). Ellis and Steyn (2003:51-53) further explain that statistical inference draws conclusions concerning the population from which a sample was drawn by using descriptive measures that have been calculated. Instead of only reporting descriptive statistics, effect sizes can be determined. Practical significance can be understood as a large enough difference to have an effect in practice. It is important to remember that the effect size is independent of the sample size used in the study and is a measure of practical significance. As a result of the fact that in this study no random sampling was done, interpretation of the results was done by calculating effect sizes. Pre-test results for each participant were subtracted from the post-test results for each participant to test if the mean of the differences was zero. Cohen's effect size for differences between means of dependant groups was calculated according to the following formula: $d = \frac{\text{mean of difference}}{\text{Standard deviance of difference}}$

According to Cohen (1988:567) guidelines of effect sizes for differences between means are as follows:

- d = 0.2 a small effect
- d = 0.5 a medium effect
- d $\geq$0.8 a large effect and also practical significant.

5.1.4 Results of the ProQOL

- **Results of the ProQOL questionnaire for Group 1**

The following are the results of the pre-post assessment done on REds that was implemented from May 2007 until June 2007. The results are given in Table 4.1.

TABLE 4.1: RESULTS OF THE ProQOL FOR GROUP 1

Subscales	N	Mean difference	Standard difference	Mean before	Standard before	Mean after	Standard after	d-value
Compassion Satisfaction	10	-1.80	6.69	29.50	5.33	27.70	4.60	0.26
Burnout	10	2.44	5.33	13.20	5.25	15.64	3.31	0.45*
Compassion Fatigue/ Trauma	10	2.74	5.42	14.20	5.39	16.94	6.26	0.50*

* Practically significant

- **Interpretation of the results**

Non-practical significance difference was found between the pre-test and post-test scores with regard to the **subscale: compassion satisfaction** for Group 1. As a result of the fact that the effect size was lower than 0.5 (medium effect) the programme did not have an effect on the participants' compassion satisfaction. The participants in this study were more positively disposed to their profession than the average educator. The REds programme did not succeed in elevating compassion satisfaction beyond the original above average levels measured in this sample. However, a medium significance difference was found for the **subscales: burnout and compassion fatigue/trauma.** The results illustrated an effect size of 0.45 for burnout, the approximate *d*-value 0.5, which

means that the REds programme had a medium effect and did lower the degree of burnout in this sample.

The results illustrated an effect size of 0.5 for the **subscale: compassion fatigue or secondary trauma.** The exposure to stressful situations which are work-related, such as exposure to other people's trauma (being affected by HIV and Aids or witnessing learners being orphaned and left vulnerable due to HIV and Aids) could cause secondary trauma or compassion fatigue. The result indicates that REds impacted positively on the trauma which affected the participants with regard to the HIV and Aids.

- **Results of the ProQOL Questionnaire for group 2**

The following are the results of the pre-post assessment done on REds that was implemented from August 2007 till October 2007. The results are given in Table 4.2.

TABLE 4.2: RESULTS OF THE ProQOL FOR GROUP 2

Subscales	N	Mean difference	Standard difference	Mean before	Standard before	Mean after	Standard after	d-value
Compassion Satisfaction	13	-1.15	3.82	33.30	4.11	32.15	5.25	0.30
Burnout	13	-0.01	5.31	15.55	4.62	15.53	5.66	0.00
Compassion Fatigue/ Trauma	13	-0.25	7.84	18.25	8.79	18.00	9.47	0.03

- **Interpretation of the results**

As a result of the fact that all the effect sizes were lower than 0.5 (medium effect) the programme did not have an effect on the participants' **compassion satisfaction, burnout**

and compassion fatigue for group 2. This non-significant difference means that the participants probably derive a good level of professional satisfaction regarding participants' teaching career, despite adverse circumstances. The REds programme did not succeed in elevating compassion satisfaction beyond the original above average levels measured in this sample. The REds programme also had no effect on the levels of burnout or secondary trauma experienced by the participants from this study before the implementation of the programme. A possible explanation can be that the participants from this sample group are from an area with considerable available resources, thus information and support regarding HIV and Aids are available. The researcher reasons that in a rural setting or community with less available resources, the REds programme may have a practical significant difference on the compassion satisfaction, burnout and compassion fatigue for affected educators from such an area as in group 1.

5.2 QUALITATIVE MEASURING

Qualitative measuring that were used were the pre-post open-ended questionnaires that reflected the participant's opinions on how the HIV and Aids pandemic affected them; symbolic drawings to pre-post assess the impact of the pandemic on the participants; semi-structured interviews conducted before and after the REds programme was implemented to determine the impact of the epidemic on the educators' physical, emotional, social, spiritual and professional health; the participants' reflection and feedback on session 1 to 9 were recorded; interviews with the participants and management regarding the perceived efficacy of the REds programme was conducted and the facilitator made observations and wrote process notes. Table 4.3 summarises the qualitative instruments used in this chapter.

TABLE 4.3: SUMMARY OF QUALITATVE INSTRUMENTS

Qualitative instruments					
Open-ended questions	**Symbolic drawings**	**Semi-structured interviews**	**Participants' reflection and feedback on each session**	**Interviews - participants and management**	**Facilitator's observation and Process notes**
• **Pre-test** • **Post-test**	• **Pre-test** • **Post-test**	• **Pre-test** • **Post-test**	• **Test per session**	• **Post-test**	• **Post-test**

5.2.1 Open-ended questions

The researcher made use of a non-standardised open-ended questionnaire consisting of 5 questions which focused on determining how the educators felt emotionally about the pandemic (Addendum 4.2). The participants completed the questionnaire in writing. The open-ended questionnaire was repeated during the post-test assessment. During analysis of the pre-test and post-test data, similar opinions of the participants in both group 1 and group 2 were identified and the results of common themes are reported by the researcher as follows:

5.2.1.1 When thinking of the future...

Three themes were identified in the **pre-test** open-ended questionnaire for both group 1 and group 2. The participants experienced mixed feelings of negativity and hopelessness and they were scared and worried when thinking of the future. They were:

- "*scared and worried about the children's future because of the rising percentage of people infected and affected every day, with no cure*".
- "*felt negative about young people that tend to be careless about life*".

- *"feeling hopeless because of difficulties and challenges they had to face because of the disease with no cure and most children left without parents"*.

In both groups some participants still felt positive when thinking of the future, despite the pandemic. They were still hopeful and put their trust in God.

The last theme that was identified in the question, when thinking of the future, was that some participants wanted to help particularly the affected learners and also to prevent discrimination.

In the **post-assessment** most of the participants from group 1 and 2 still felt negative when thinking of the future, and replied as followed:

- *"scared and doubtful when thinking of the future"*.
- *"worried about the pandemic spreading every day, with no cure in sight and children left orphans"*.
- *"youth, today, got too much power without knowing how to use it"*, they became *"uncontrollable without thinking of the consequences"*.

After REds was presented, some of the participants truly understood the enormous implications of the pandemic for the first time and that caused negative feelings. Some participants were more positive in the post-test results about the future, because they *"gained knowledge"* on how to give support to those living with HIV and Aids.

5.2.1.2 Giving up…

In both the groups the participants felt in the **pre-assessment** that giving up or quitting was not an option. Giving up would not solve any problems and would not help the world. They felt that:

- they were *"called to make a difference in other people's life"*.
- that *"people must pray about the situation"*.

After REds was presented, the participants indicated in the **post-assessment** that giving up was still no option, they felt:

- *"no option and no solution to any problem"*.

- "*empowered by the knowledge obtained through the REds programme*".
- "*more resilient*".
- "*could support others and dealt with stigma*".

These aspects would help them cope with any difficult situations and see a purpose in life. They felt that they would also rather keep on believing and keep their faith.

5.2.1.3 I hope that…

The themes the participants identified in this open-ended question in the **pre-assessment** of the two groups were:

- "*in future they hoped for a better life*".
- "*to achieve their personal goals and accomplish their dreams*".
- "*help others to overcome the problems they were facing, all live a happy life*".

The participants hoped to get more knowledge, to help their fellowman:

- "*get proper training and education in helping the affected ones*" and "*through that help change the society*".
- *"hoped to make a difference and support those who could not help themselves", "hope people take responsible decisions, avoid carrying the scars of their wrong decisions throughout life and that one day, there would be a cure for HIV and Aids*".
- "*hope and prayed to God that the world be a better place to live in and that God would give more strength in future*".

They also hoped that the leaders would open their eyes to the problems the ordinary citizens saw.

In the **post-assessment**, after REds was presented, the overall theme identified was still one of helping their fellowman and to make a difference in somebody's life. They wanted:

- "*to make a difference and leave a good mark where they've been*".
- "*live life to the full extent*".
- "*to serve those who cross their path and need help and support*".

For most participants death became a reality and they wanted to be remembered for the good that they had done. Some participants hoped for improvement in their work situation. They hoped that the government would do more about the pandemic, take responsibility for the pandemic and stop wasting time and money.

5.2.1.4 When things go wrong…

In the **pre-assessment** the participants reported that when things went wrong they would handle the situation as follows:

- "*get upset*".
- "*cry*".
- "*tried to remember their goals*".
- "*make some changes and work through it*".

Most of the participants would use positive coping skills when confronted with problems. They would do some introspection, tried to relax and then tackle the problem with more objectivity, they would think of their goals and that motivates them to persevere, they would try much harder and turn the negative into positives.

When things went wrong they reported that they would keep on:

- "*praying*".
- "*try not to lose hope*".
- "*try much harder and turn the negative into positives*".
- "*keep on supporting others*".

The participants also reported that one must not look for excuses or do blame shifting, they must rather try to make a difference themselves.

One participant mentioned that she "*trusted her medical doctor*" and would discuss her problems with him.

In the **post-assessment** only two participants from group 2 still felt negative, sad and de-motivated and tended to lose hope and trust. The other participants from the 2 groups felt more empowered and positive even when things went wrong. They knew that they could get help when needed and used a support system, and they were not alone.

The participants would again draw from their religion and spiritual strength. They indicated that prayer would become very important when seeking for solutions and they would:

- "*ask for strength from God*".
- "*pray for wisdom for the leaders*".

5.2.1.5 I can…

The participants from the two groups were very positive that if they put their mind to something they would succeed and they responded as follows in the **pre-assessment**:

- "*could face any situation and succeed if they were determined and believe in themselves*".
- "*could make a difference towards this pandemic if they got the knowledge and training*".
- "*could grow more as a helper to help those infected by HIV and Aids, give hope, motivate those who were affected and could be part of saving our nation regarding the pandemic*".
- "*trust in religion to give strength to make a difference*".

After the REds programme was presented the participants felt positive in the **post-assessment** that they could make a difference in other people's life, with the knowledge they gained through REds:

- "*they could make a difference and positive change to peoples' life*".
- "*by sharing the material and information they received from the REds they felt confident that they can make a difference, no matter how small*".
- they could "*form support groups*".
- one participant indicated that she "*could cope better with her own status and felt confident to motivate other people to accept it*".

The participants felt that they could do anything because "*God gave them the strength to overcome any obstacles in their life*". The overall feeling was one of empowerment.

5.2.1.6 Conclusion

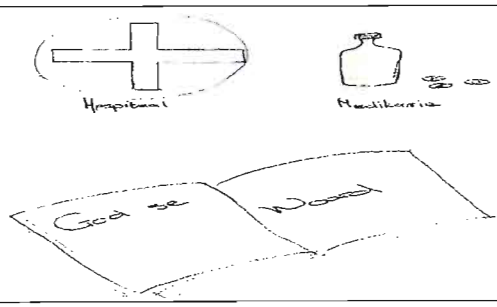
In conclusion the data gained from the five open-ended questionnaires were: When thinking of the future the respondents felt contradictory feelings. Some felt negative because the pandemic is spreading every day, with no cure in sight and children are left as orphans. Some felt positive that they gained knowledge on how to give support to others. Giving up was not an option and no solution to any problem for them. They hope for different things but mostly to make a difference in somebody's life. The participants felt more empowered with knowledge and they would use a support system and draw on spiritual strength when things go wrong. The participants felt that they could cope better with their status and felt confident to motivate other people due to knowledge gained through the REds programme and with the strength of God.

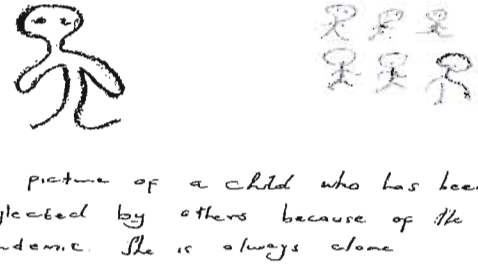
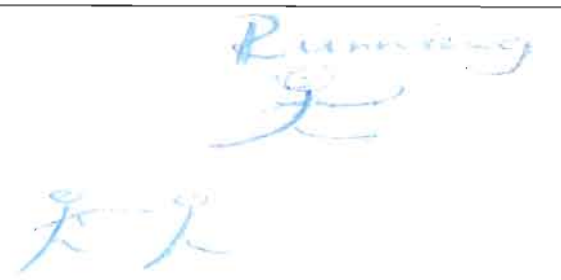
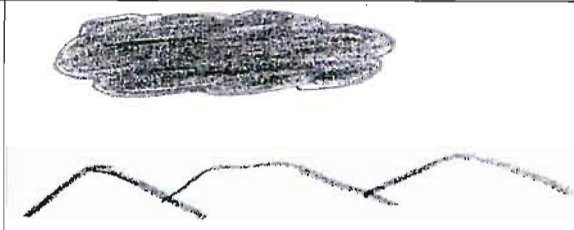
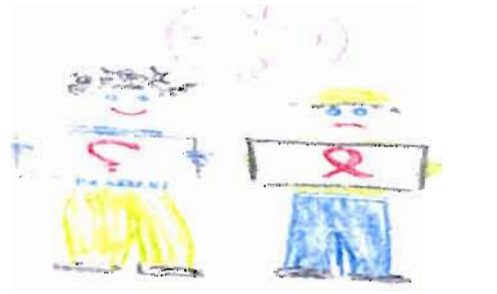
5.2.2 Symbolic drawings

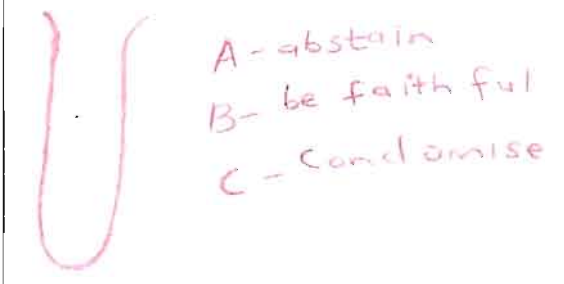
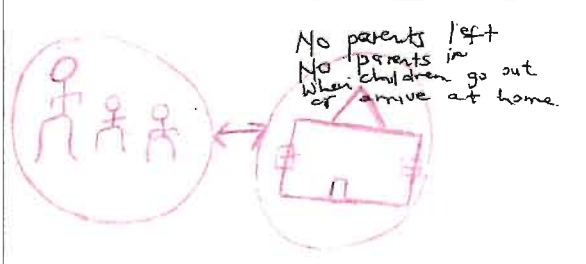
The participants were asked to draw a symbol of what they associated with the pandemic and its impact on them as teachers and to explain their symbol either verbally or in writing. The purpose of this was to gain a deeper understanding of educator's experience and appraisal of the impact of the HIV and Aids pandemic (Leedy & Ormrod, 2005). Symbolic drawings are a form of projection which allows the individual to project perception of an event onto a self chosen symbol. The symbol is used as a metaphor for the individual's perception of the event. According to Reber and Reber (2001:624), symbolic drawings are representations or expressions of the unconscious mind of a person. The participants drew any symbol that came to mind when thinking how the pandemic had affected them. The pre-test instruction was repeated during the post-test assessment. To determine whether participants perceived the pandemic to be less threatening following their participation in the REds programme, the content of their symbolic drawing was thematically analysed. During analysis of the pre-test and post-test data, similar symbolic drawing contents were grouped and various themes were identified. Figure 4.2 contains the similar themes of the participants' symbolic drawings,

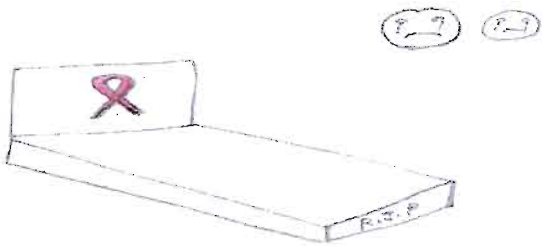
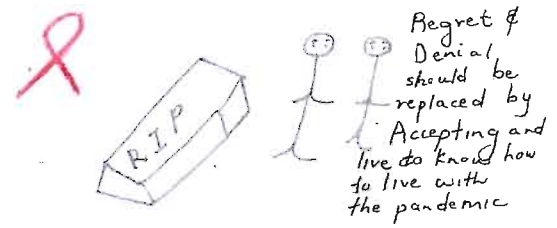
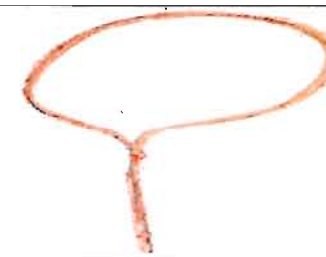
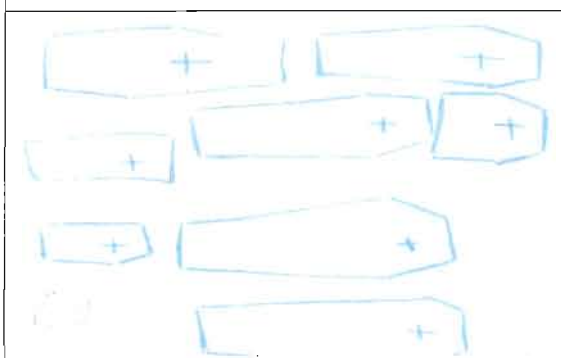
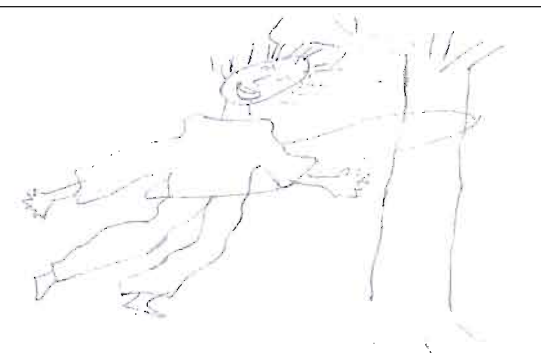
explanation of the participants of the drawing and the researcher's interpretation of the symbols, of both the groups.

FIGURE 4.2: SYMBOLIC DRAWINGS AND INTERPRETATIONS TO ILLUSTRATE THE PANDEMIC

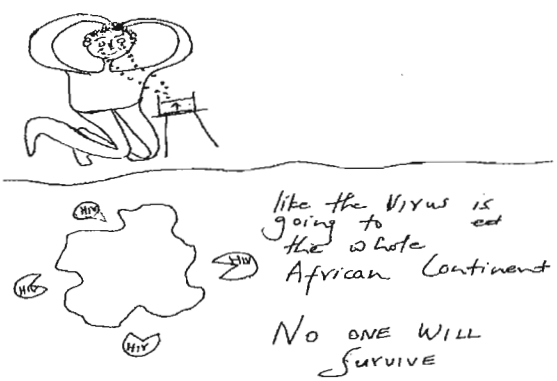
Pre-test	Post-test
	
One participant drew a red heart and star and described it as a representation of her sore heart. The theme identified is of grief.	In the post-test drawing she drew a big heart with the words "love heart" inside it and the words "love always wins" as an accompanying description. After the REds the participant felt that with support and love one could live with this disease positively. The researcher identified a theme of hope.
	
When thinking of how the pandemic affected one participant she drew a hospital sign, medication and a Bible. The hospital sign and medication represent the illness and the Bible the death at the end.	In the post-test the participant drew a Bible with the words "information" on it and the words "hope" as a description. When thinking of the pandemic, the information gained from REds spelled hope for her.

	
One participant drew a picture in a black colour, it's of a child alone and separated from other children playing. She described it as, a picture of a child who has been discriminated by others because of the pandemic, she is always alone. The use of black colours may mirror feelings of sadness, depression.	In the post-test the participant drew a picture of a child running and playing with others. She drew this picture in the colour blue. For her the REds programme helped to overcome stigma, isolation and discrimination.
	
One participant drew the aids ribbon, because it symbolised to her the fight against Aids.	Two participants drew dark clouds, which symbolised the unpredictable nature of the pandemic.
	
A few participants drew a crying face, because that was how the pandemic was	This participant explained that life after getting to know your status is better,

affecting them, they experienced feelings of sadness, hopelessness.	because you can then get treated. The picture also expressed hope and empowerment, due to the information and knowledge gained regarding HIV and Aids. However the watch reminded her that time was running out and she must get tested, without delay.
	
One participant drew a cross on a grave and wrote the words "HIV, AIDS and CRIME" as a description. The pandemic represents death and crime (such as rape) for this participant. The participant also used a black colour to mirror feelings of fear, depression and sadness.	In the post-test the participant drew an aids ribbon and a heart. The participant also wrote the words "In love condomise" as a description. The drawing symbolised that when people are in love they should use a condom for safe sex and also to have one partner and then the fight against Aids could be won. The participant used the colour red to mirror feelings of love.
	
In the pre-test the participant drew a condom, for her the only ways to fight HIV and Aids were by abstaining, being	In the post-test the participant drew a figure of a child alone and a house. The accompanying descriptions stated "alone in

faithful and to condomise.	a house – orphan". This pandemic is devastating and left children alone to care for themselves. Compassionate sadness was identified.
	
A few participants drew graves with Aids ribbons on them relating to their experiences that the pandemic causes death and loss.	One participant drew a grave and aids ribbon with the descriptions: "Regret and denial should be replaced by accepting and live positively and empowerment, know how to live with the pandemic".
	
Two participants drew a burning candle relating to their experiences that the pandemic causes death, loss and grieving.	The candles drawn in the post-test symbolised memory of a person's life. The flying balloon symbolised the letting go of the grieving emotions.
	
One participant drew many coffins to	The participant drew a figure that hung

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relate to the high statistics of death caused by the pandemic. The emotion that he wanted to convey was a sense of grief, loss, sadness and gloom.	from a tree. This pandemic left him feeling hanging and disempowered.
	
A few participants drew aids ribbons, because it symbolised the fight against Aids.	In the post-test a participant drew an aids ribbon but with an accompanying description, support. After REds was implemented the symbol that came to mind when thinking of Aids was one of support.
	
One participant drew a figure crying and a little Aids virus eating away on the whole of the African continent. The description accompanying the drawing was, "no one will survive". The drawing symbolised a very negative and unpredictable picture and this pandemic cause the participant to cry. The emotion experienced was one of anxiety.	In the post-test, the symbol that came to mind was a boat on sea swamped by a big wave, to symbolise the aids virus is a "danger" just like a big wave. The red drops symbolised the fast growing HIV statistics spreading faster than grass growing. The end of the picture is a little figure running, as the participant described it felt like he was running out of time.

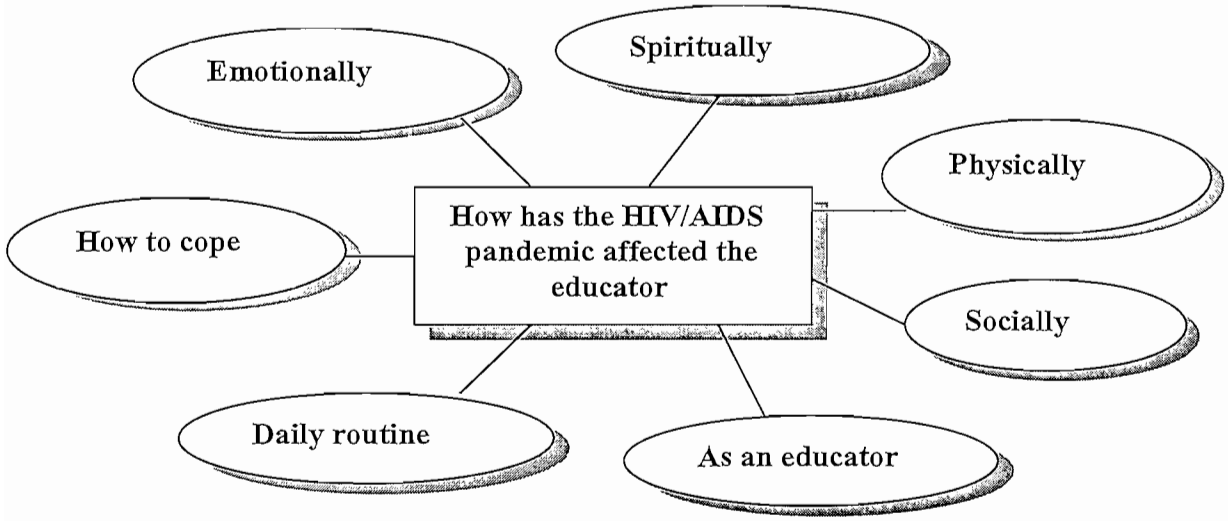
5.2.2.1 Conclusion

All the participants agreed that the impact of the pandemic influenced them negatively. This was clear from their symbolic drawings. When the participants told the group about their drawings, all of them could relate to the various symbols they had drawn. The symbolic drawings in the post-test moved from negative to more positive feelings. Their explanations illustrated that REds empowered them with knowledge regarding the pandemic and that they were more hopeful towards the future. Explanations such as "*with support and love one could live with this disease positively*", "*information spelled hope*", "*children running and playing with others, no more stigma*", "*it's better to get to know your status*" and "*comdomise*" prove a more positive change after REds.

5.2.3 Semi-structured interviews

The impact of the pandemic requires understanding within the context of the educator in totality, and that health must be understood multi-dimensionally. The participants were interviewed before and after the REds programme was implemented, using a schedule with semi-structured questions (Addendum 4.3) to determine how the pandemic affected the educators emotionally, spiritually, physically, socially, professionally, any change in their daily routine as an educator and how they coped. Although semi-structured interviews follow standard questions, the opportunity exists to ask one or more personalised questions to clarify a person's reasoning, beliefs and perception of a certain topic (Greeff, 2005:297; Leedy & Ormrod, 2005:184). These interviews were audio taped with the permission of the participants and the data transcribed by the researcher. The transcripts were analysed for similar responses to the questions. The results are delineated according to common themes that were identified and contradictory results. Figure 4.3 represents the different ways the pandemic affects the educator.

FIGURE 4.3: WAYS THAT THE PANDEMIC AFFECTS THE EDUCATOR



5.2.3.1 The emotional effect of the HIV and Aids pandemic

In the **pre-test interviews** the participants from both group 1 and 2 responded that the pandemic affected them emotionally very much. Most of the participants referred to negative emotions experienced in response to the impact of the HIV pandemic. These emotions included feelings of sadness, sorrow, depression, fear and stress. They responded that it affected them negatively when:

- "*seeing innocent children who had lost both parents, through Aids, to notice the devastation and desperation on their faces, nowhere to go, hungry and to end up as a street child or orphan*".
- "*seeing people discriminated against infected people and learners*".
- "*felt fear, because the reality is that every person is vulnerable to this pandemic*".
- the visualisation of "*a person that was sick, laying in bed and being powerless, was a very emotional picture*", as described by one participant.
- "*it was also very emotional to think of loved ones they had lost*" and "*saddened by the pain family members were going through*".
- it was stressful to think: "*more people depending on them due to the pandemic*" and was saddened by the pain family members were going through.

To interact with HIV infected people affected three participants emotionally positively because of the way that "*they were still brave under the circumstances*". One participant felt it was best to accept the situation and look at it as a challenge. The participants mentioned that they valued people more because of the pandemic.

The post-test interviews revealed that more than half of the participants still experienced negative emotions, they felt stress, emotionally disturbed, very negative, felt helpless and sympathetic towards those who were affected.
One remarked that at first she was "*angry towards people living an irresponsible sex life, setting negative examples and not putting the welfare of their partners, family or children first*". After the REds programme was presented she felt that she would be more supportive towards those living with Aids.

5.2.3.2 Spiritual experience

The participants from both groups responded as follows in the **pre-assessment**:
Most of the participants referred to negative spiritual experience as a consequence of the pandemic. The negative spiritual experience included a sense of hopelessness, spiritual disillusionment and punishment asking

- "*why God allowed this*"?
- "*couldn't provide a cure*"?
- "*God had no mercy when she saw people dying*".

It affected another participant greatly because as a Christian she prayed that this killer disease must go away. One participant felt very disappointed about how people could let themselves into this disease's claws.
Some felt spiritually stronger and more hopeful through prayer:

- "*prayed for those affected by HIV and Aids*".
- most of them prayed for "*God's protection*".
- placed their hope in their faith that "*one day there would be a cure for Aids*".
- Some felt a sense of duty that "*they would not give up on those who needed their help*".

- *"they would interact with people infected and affected with HIV and Aids and encourage them that there could be a better life"*.

Two participants felt that they could do more to set and teach the right moral values.

In the **post-testing interviews** the participants responded that they realised that they have a huge responsibility as a parent and as an educator to *"teach, support and bring hope to the people and children with whom they made contact"*. They also realised there are few values in the community. All the participants felt stronger through prayer and prayed more to God for help.

5.2.3.3 The physically effect of the pandemic

In the **pre-assessment** the participants from both groups indicated that they were physically affected by the pandemic. They responded as follows:

- *"sometimes worried"*.
- *"lost of appetite when seeing people suffered"*.
- *"when visiting or seeing HIV infected people she felt that she could be infected too and many negative thoughts came to her mind"*.
- *"not sleeping well and were constantly thinking of death especially when someone passed away"*.

Most participants were not physically affected because when they were thinking of Aids, they knew that there was anti-retroviral medication to help the infected ones, but reported that they stress when thinking of the extra work due to the pandemic.

Two participants felt that it helped to accept that the disease was there, and through accepting the situation it helped to overcome many things and it also helped to deal with the situation by being strong for those who needed her help. One participant was worried about her own children, young adults, and wondered if they were infected or not.

The post-test assessment indicated that 6 participants felt that they were not physically affected by the pandemic. Some participants still reported that they couldn't sleep when they had been to a funeral of one of the school children, or if they saw the children

became ill when they came to school. One teacher felt burnout. One participant was not physically affected by the pandemic, she reported

- "*didn't feel overwhelmed*", she realised that
- "*if she could make a difference to one persons' life, she felt that she had succeeded*".

5.2.3.4 Social interaction experience

The participants from group 1 and 2 reported in the **pre-test data** unpleasant social experience with regard to the pandemic. This experience included social isolation:

- "*afraid to have a personal relationship with the opposite gender because they didn't know whether a person was ill, only a test can tell*".
- "*social clubs did not exist anymore because of HIV and Aids*".
- "*scared because there is still no cure for this pandemic*".
- "*didn't feel like socialising with other people because they didn't want to share anything with anyone*". They felt unsafe to socialise with infected people and their social life was not the same anymore.

One participant reported that the pandemic changed the way she was living as she took better care of herself now. Another reported that in her spare time she always helped a friend that was infected and another had to cut time from her social life to visit a sick sister. One participant was being very careful with herself, her children and her learners to prevent infection and to accept those infected. An infected participant indicated that he felt socially neglected and subjected by others because of his status. Some participants felt that the pandemic had not affected their social interaction at all. Their reasons were that life goes on and they interact with everyone regardless of their status. HIV and Aids did not change how they felt about their infected friends.

The **post-test data** shown the participants felt overall socially more positive. Their reasons were:

- they realised that they could become more involved in a support group or even started a support group themselves.

- they felt more aware of HIV and STD's, they would avoid certain social places and take more care of hygiene (washing of hands) at places such as doctor's rooms, dentists, hospitals, hotels and other public places.
- that because of stigma they were still afraid to disclose their status.

5.2.3.5 Impact on an educator as a professional

The participants reported in the **pre-test** that the HIV and Aids pandemic affected them professionally as educators. All the participants accept one, commented that this pandemic affected them negatively. They reported:

- "*deteriorating morale*".
- "*higher levels of professional stress*".
- "*escalating workloads*".

Three participants mentioned that losing some of their learners and colleagues affected their work performance. It affected them negatively:

- "*seeing their colleagues die like ants – with no help*".

Their work was also affected due to a high percentage of learners being absent from school. They felt that an educator worked hard but the end of the year results showed that the learners were not up to standard. The participants mentioned that the following affected them:

- "*to see learners who had lost parents because of the pandemic and not getting the care and the love they needed*".
- "*some children did not have anything at home to eat, to wear and when parents of the learners died, their performances tended to drop due to sickness and lack of proper care*".
- "*it was disturbing to some to learn that some learners were infected with HIV, they didn't know but their faces show the reality of the pandemic*".
- some participants found it "*difficult to give information about HIV and Aids in the presence of learners who were infected and it was also difficult when learners*

disclosed their status and explained how they felt about the disease", and they did not have the knowledge or skills to handle the situation.

Five participants reported that as educators they were more alert and sensitive to the children in their class. They had more patience especially when the children were not feeling well. The participants felt more willing to help and they also comforted the children more thus the children knew there was someone who cared. Some participants were depressed because learners who lost their parents didn't cope most of the time in the class. They also felt that the workload was more, due to situations they must handle because of this pandemic. The participant who mentioned that the pandemic did not affected him professionally, said that being an educator was a calling and he would be able to handle infected learners.

In the interviews **after REds was presented** the data shown that the participants felt that they had an "*eye opening*" experience. They realised that there was a need and that educators must be prepared to know how to deal with any situation, due to the pandemic. After REds was presented they felt:

- "*more confident to talk to the learners about HIV and Aids*".
- some felt that it was not an educators' responsibility to be involved with this problem, but realised and accepted that "*the school was often the best place to start HIV education programme*".
- they also felt that the "*school must employ, a nurse and social worker as part of the personnel, it will be much more effective and worth the money spent, as millions were wasted on all the wrong things*".
- felt more "*confident to get help if necessary*".

5.2.3.6 A change in the daily routine

The participants mentioned in the **pre-test** that the pandemic affected their daily routine drastically:

- It made them more cautious and sensitive to treat all the children in their class the same despite their HIV status, not to discourage or discriminate.
- Some felt that they were putting more "*effort, time and allowed more space*" to reach the one child that might need them. The participants reported that children absent from school due to health status caused a "*disruption in their daily routine*" and they could not accomplish the work for that day. They felt that the teachers' work performance deteriorated. One educator mentioned that it changed her role and she turned to be a counsellor and talked to those who were affected.
- Some participants were involved with HIV children after school. They monitored the food learners had and gave food where possible and they made plans when there was no food. They always tried to take care and supported those who were infected and affected. One had to go the extra mile and meet with family members of learners and help find practical ways of supporting them.

Five participants mentioned that their daily routine did not change and one participant mentioned that there was not an ill child in her class.

After REds was implemented the **post-test data** showed that the participants were more attentive to the needs of the children in their classroom and they felt more confident to talk about HIV and Aids:

- "*more alert and aware of the children's emotional behaviour (poor concentration, hurt, anger) in a class, due to illness or illnesses at home*".
- the participants indicated that they would "*try and find the reason when a child was absent due to illness or an illness in the family*".
- some felt "*more confident after the programme to talk about HIV and Aids and share information*".

5.2.3.7 Ways educators cope with the pandemic

In the **pre-test** the participants reported the following coping skills:

- they would "*normalize*" the situation as a way of coping,
- they carried on with their work as if nothing had happened,

- they treated learners equally with no discrimination,
- their relationship with "*God helped them to cope*".
- some felt they cope through the "*strength and support of others*".
- through "*workshops, HIV education, Aids programmes and the support from social workers*" helped them to cope with the pandemic.
- knowledge and information such as the use of regular medication and with healthy food people can keep strong, helped them to understand and gave hope.

Two educators felt they got recognition when helping learners who needed help and felt inspired when seeing infected learners being brave.

The **post-test data interviews** indicated that the participants coped better after the REds programme was presented, because of practical, useful information the participants gained and because of the available knowledge of support groups and support systems in the community.

5.2.3.8 Conclusion

In the **pre-test interviews** the participants from both group 1 and 2 responded that the pandemic affected them emotionally very much. The pandemic also affected them physically, spiritually as well as socially negatively. The pandemic had an affect on them professionally and their daily routine as an educator. **The post-test data interviews** indicated that the participants gained knowledge on HIV and Aids and of support groups and support systems in the community and they coped better after the REds programme was presented because of practical, useful information they gained.

5.2.4 Participants' reflection and feedback after each session

The reflections and feedback were completed after each session of the REds programme was implemented. To be optimally effective the REds programme needed to be refined by a process of participatory reflection. After each session the participants were asked to reflect on possible improvements or amendments that would heighten the efficacy of that

session and REds as a whole. The participants completed a reflection worksheet regarding elements of the session that the participants found particularly helpful, elements participants experienced as not helpful at all and components the participants would like to change or add to the session. In Table 4.4 the information gained was analysed and suggestions for further research were made.

TABLE 4.4: EVALUATION OF EACH SESSION OF REDS PROGRAMME

Session 1: Introduction of REds
In this session the focus was on the importance of the educators' role in this pandemic and how the HIV and Aids affected the quality of education. The educators identified with the problem and a need was established to attend the REds programme. The educators felt that the completion of the ProQOL resulted into introspection on how they really felt towards HIV and Aids. The questionnaires were too long and time-consuming. The story of Yulia and Mukasa helped them to understand how HIV and Aids could affect communities. Extra information was added on the effect of HIV and Aids on the education system and the role of the educator in this pandemic was emphasised.

Session 2: HIV and Aids Manual for Educators
The participants evaluated the following as helpful in this session: This session was presented by Life Line. The HIV and Aids information presented was helpful to get the real facts about this disease. The participants believed that they knew the facts about HIV and Aids, but after the programme was presented they realised that they did not know the facts. Information new to them was information on sex and sexuality, understanding the human body and the reproductive system, the human immune deficiency virus, the effect on the immune system, transmission of HIV, different HIV testing, CD 4 counts and anti-retroviral medication. The participants identified a need to have knowledge and the necessary skills to explain sex and sexuality to children (in different ages). They found it difficult to talk about sex and preventing HIV and Aids, because they did not grow up in a culture where sex was discussed. They evaluated a need for information and practical aids on how to explain to

children how the human body and reproductive system work.

They knew the importance of talking to their children and learners, but lacked the necessary skills and confidence to do so. The participants also identified the need to get more information on teenage pregnancies, because it is a huge problem in their school. Teenage pregnancies are a result of unsafe sex.

The facilitator handed out extra information and booklets on the topic of sexuality education. All the information in this session was important and helpful to them.

Session 3: How to gain and give support

The participants evaluated the following as helpful in this session:

The ice breaker that was used demonstrated support and trust. All the information regarding supportive resources for educators and how to assist vulnerable children was appreciated as well as the information on how to explain death to a child and how to support a child who had lost both parents. The participants advised that more information on available social grants is needed to assist children and families. The group felt that the group participation was very helpful in this session.

Session 4: Care for the sick and dying

The participants found the following information very helpful:

The information on how a parent could talk to his/her child about their HIV status; the information on death and dying and bereavement; as well as how to prepare for death (writing of a will and planning for children's future) were helpful. This session was presented in a practical manner to teach the participants the skills of counselling and to be confident when they supported affected learners. The facilitator handed out extra information and booklets and practical tools on the topic of bereavement at different ages. This extra information was not part of the REds, but it would be helpful if included. The practical information given to assist a child with the grieving process, particular the young, was helpful. The group participation brought new insights. The participants advised that more time be given on this module when it is presented again. It is also advised that a social worker present this session to teach counselling skills regarding grief and bereavement.

Session 5: How to cope with stigma
The following were the comments of the participants: The participants felt that this was a very important session because stigma is a reality and the reason why people did not disclose their status. This session gave practical advice on how to handle this problem. The participants found the inspirational thoughts and handouts helpful. The participants felt it helped them to share their feelings with the group because they were without hope and then realised that there were others that felt the same.

Session 6: Workplace Policies
The participants responded as follows on this session: The participants found the information gained on workplace policies very informative and educative. They identified a need for a social worker, or health nurse, or aids counsellors at schools to give support concerning the pandemic, because they felt already overwhelmed with all that they must do. They also identified a need for ongoing support groups for educators at schools.

Session 7: How to cope with stress
The feedback of the participants on this session was the following: The group felt that this session was helpful to identify the stressors in their work but also the stressors about the pandemic. The measures to relieve stress and manage time effectively were helpful to most of the participants as well as the skills learned to cope with stress. It was clear that the group enjoyed this session. They advised that in future this session must be presented with enough time to practice all the activities.

Session 8: Resiliency
The following were the participants' evaluation on this session: The participants evaluated this session as a good closure for the REds programme. The participants realised that a resilient person is strong and could support others in coping with difficult situations, no matter how difficult. The group process was positive because

the members could share information and emotions with others. The participants felt strong and empowered and not alone.

Session 9: Conclusion
The participants' feedback on this session was as follows: The participants appreciated the debriefing of this session. The certificates were appreciated. It was important to them to have proof and to show the other teachers what they have learned and achieved.

5.2.4.1 Conclusion

The overall feedback on the presented REds was very positive. At the closure of each session the participants reflected on improvements or amendments that would heighten the efficacy of that session and REds as a whole. The participants completed a reflection worksheet regarding elements of the session that the participants found particularly helpful, elements participants experienced as not helpful at all and components the participants would like to change or add to the session.

5.2.5 Post-test interviews

5.2.5.1 Post-test interviews with the participants

The researcher interviewed the participants after REds was implemented. Semi-structured interviews were used with both group 1 and group 2 to identify needs for the future REds interventions. The researcher used Questionnaire 4 as interviewing schedule (Addendum 4.4). These interviews were audio taped with the permission of the participants and the data transcribed by the researcher. The transcripts were analysed for similar responses to the questions and the results delineated according to the same suggestions to improve the REds programme. The following are the suggestions of the participants:

- **Facets to be included in future REds**

The participants suggested that the following be included in the future REds programme: It would be helpful if the programme included a video/DVD – it could be more effective and could save time. The participants wanted more statistics about the pandemic, more booklets for children to explain HIV and Aids and information on death and the grieving process. Some educators felt the need that sexuality education and the preventing of teenage pregnancy be included in this programme, because of high incidents of teenage pregnancies in the particular school, thus teenagers have unsafe sex. Some of the participants needed more information on treatment of stress and medication. The participants suggested that more teachers and more schools should be included to participate in the REds programme, to educate more educators regarding the pandemic. Three participants felt that the learners should also be included in this programme and that more time must be given to this important programme. Two participants felt it would be helpful to invite infected people to address the educators. Most of the teachers felt that the Department of Education must appoint Aids counsellors at schools, social workers and nurses for emergencies, and a properly supplied first aid kit.

- **Facets to be retained**

The total group felt that nothing could be left out of the REds programme and that everything was important. They felt that this was an outstanding course and that it definitely "*opened their eyes*".

- **Facets about the presentation**

The participants reported that they liked the following about the presentation:
The presenter was well prepared, friendly and helpful and the presentation was informative, lively and the examples read were interesting. They reported that the presenter used many illustrations, visual material, posters and flip charts and that it was easier to focus on that than to work through a 160 page programme in book form. They

gained much information and knowledge from the speakers (specialists) included in the programme that gave talks. The discussions and openness of the presentation were "*informative, motivational and courageous*".

- **Facets to be changed**

The participants agreed that nothing about the way REds was presented should change. It was very informative and presented well. The group felt that more time should be allowed for this programme because it has much to offer. The participants would like more small groups where the participants could practice role play. They also wanted more time for questions, ideas and discussions from the participants.

- **Facets most helpful**

All the participants indicated that the extra booklets handed out by the presenter were helpful. Five participants felt that the session on how to support people living with HIV and Aids especially the telephone numbers and where to get support in the community were helpful as well as how to take care of the infected and affected ones. The training on the grieving process, talking about death, information on how to take care of the sick, how to cope with death and information on the pandemic were important and helpful. The discussions on the different topics were helpful to gain more knowledge. It was helpful to learn the correct facts on HIV and Aids, how to help prevent HIV and Aids, how one become infected, why it was important to get tested. Three participants felt that the session in dealing with stress and the stress release exercises were very helpful to them. Two felt that the session on stigma and how to deal with that were helpful. The session on workplace policies were helpful to most of the group members.

- **Facets the least helpful**

The participants reported that all the information was helpful. Everything was good, including the presentation, the pictures and the information. One felt that it would be

helpful if there was an ongoing support group, similar to the REds programme, for teachers.

- **Material that should change**

Some of the participants felt that the book could be compiled as a more practical toolkit, more consumers friendly and easier to use. Not everybody has the time to read or work through a thick book– it is easier in a group session or to listen to a CD or watch a DVD. The participants felt that the content of the manual was important and should not be changed and they felt they received enough handouts to help them after the workshop. One group member wanted files to put the handouts in.

- **The impact of the REds personally**

All the participants agreed that the REds programme helped them personally and felt more equipped to handle any situation successfully. The participants contributed this to more knowledge that they acquired. They felt well informed about how to give support to people infected with HIV and to go for testing and talk about the pandemic freely to anyone. The information gained on anti-retroviral medication and the working of the immune system was personally helpful to some. One educator felt that with the knowledge gained she would be able to help those who live with HIV and took precautions not to get infected. One participant looked differently at the HIV and Aids pandemic after REds was presented. Some participants felt educated enough to cope with the pandemic and started different support groups as well as gained confidence to talk about it to the community. They also felt more informed and they reported that the handouts about death were very helpful.

- **Impact of REds professionally**

All the participants reported that the REds programme helped them professionally and they indicated that they now knew how to handle difficult situations better. They learned

new information that empowered them to feel more in control and less stressed. The participants reported that the following were helpful to them professionally: they learned how to deal with HIV in the workplace and adapt to the situation; they learned how to support colleagues if infected and how to disclose; and they felt with the knowledge gained that they would be able to help and support learners, colleagues and even the community. The participants felt that with the correct facts they would be able to give relevant information to others. The participants felt empowered to deal with orphans, colleagues and those infected and now know how to help and support them. They felt they could face the reality of the pandemic in the school and at home and they also realised there are policies that protect them that they did not take into consideration before.

- **Other Comments**

All the participants felt that this programme was very successful and fruitful. The participants gained better insight into this pandemic. The participants reported that they felt it was time for key role players in the government to stop talking and be more pro-active in doing something about the pandemic. They felt that much time and money were being wasted and they suggested that silly advertisements should stop and that the television could be used to educate people because more people watch television rather than to listen to educators. They suggested that the government should employ nurses and social workers at every school to help with the pandemic and that more support groups were needed. They also felt that more teachers should attend this course. This course must also be presented in the community. They also would like to have other similar courses. Most of the participants felt that the Department of Education should provide each school with a school nurse, aids counsellors, fully equipped medical kits that were checked every 3 months and that every school must have specialists like social workers, who work directly with the learners and have regularly contact with them.

They suggested that information on teenage pregnancies must be included in the programme because there was a high incidence rate and learners did not practice safer

sex. They felt that communities needed knowledge and awareness because most people still lack information and did not know what to do when they were infected and affected. People should be motivated to disclose so that they could be treated before it became worse.

- **Conclusion**

During interviewing all the educators felt that REds gave them hope and perspective. The information gained changed their attitude towards the pandemic and infected and affected adults, colleagues, learners, loved ones and orphans. They now knew how to care for and deal with the infected and affected, especially the learners in their classes. REds empowered them to treat the infected and affected as normal people. REds also informed participants on how to care for the sick. Personally and professionally they felt stronger in the face of this pandemic. They suggested that the future REds programme should include age appropriate information on sexuality and grief and bereavement. The programme should also be changed into a more practical toolkit. They suggested that the Department of Education should employ nurses or social workers to deal with the impact of this pandemic at schools.

5.2.5.2 Post-test interviews with management

The researcher interviewed the principals of both schools from which staff members attended the REds programme. Both the principals were very positive towards the REds programme. They experienced that the educators who attended the REds programme influenced the other staff members and the learners positively as well as a change of attitude towards the pandemic. The principals reported that the educators were very enthusiastic about the information and knowledge that they gained through this programme and mentioned that they felt that they could implement the information in the classroom.

- **Conclusion**

The principals from both the schools where REds was presented reacted positively towards the presented programme and felt that the REds programme should continue and that the information they had gained should be shared with other educators and schools.

5.2.6 Facilitator's reflections, observations and process notes

During the critical reflection phase the researcher reflected on the participation of the participants during the REds programme. Process notes were used to record how REds was implemented and how participants responded to each module of the programme. The process notes evaluated and recorded information observed and gathered by the facilitator and observer on the goals of each session, as well as the participant reactions and emotions. Directly after each session the researcher wrote the process notes. Each session was processed separately. In human science, process generally refers to a series of steps or progression towards a goal. Often this process implies change (Reber & Reber, 2001:567). Process notes record the step-by-step progression towards a goal. During the processing of notes, the researcher considered answers, comments, specificity of comments, as well as the context which occurred during each session (Greeff, 2005:298). According to Reber and Reber (2001:479), observation is an informal recording and interpretation of what has been observed. Reactions and emotions of participants were recorded by collecting information and data for the evaluation of the REds programme. The following are the suggestions of the facilitator after the reflection:

5.2.6.1 Schedule time sessions

The sessions were held on a Tuesday, every week, directly after school. The participants had no other school activities on that day. The participants did not want to attend sessions on a weekend because that was their family time. The facilitator provided snacks before the session started that was appreciated very much seeing that they were hungry after a school day and there was not time to go home for lunch. The session started directly after

school. It is recommended that sessions must be held on a weekday, directly after school to assure attendance.

5.2.6.2 Audio-visual aids

The researcher made use of a number of large, colourful visual aids such as posters and flip charts. The speaker from Life Line did a power-point presentation on a computer laptop and projector she brought with her. The schools where the REds was implemented were not equipped to use other visual aids. The researcher recommends the use of visual aids, such as a computer and proxima where photos and pictures could be presented more easily, or that the facilitator uses posters or a flipchart in cases where there is no audio visual equipment at the school. The REds manual gives information but it is not practical due to the fact that it is a workbook and not a practical guide and did not have aids, such as posters, pamphlets and a tool kit that would make it more user friendly. Visual aids make the information more user friendly. The participants commented throughout the programme that the posters used made the presentation more practical and visual.

5.2.6.3 Involve HIV-positive speakers

The participants recommended that an HIV infected person be used as a speaker because they could learn from their other experiences. They could convey information on how they experience HIV and Aids and what support they needed.

5.2.6.4 Extra materials

The facilitator used handouts, pamphlets, colouring-in books, practical materials and a first aid box to make the presentation of the programme practical. Especially the books for pre-school and primary school children, explaining HIV and the prevention of HIV and Aids, were helpful for educators to convey sensitive information to learners. Practical information regarding the grief and bereavement process for children at different ages must also be included.

5.2.6.5 Content to be included

The participants identified the need for information on sexuality education for different age groups as well as the prevention of teenage pregnancies. There was a need for information on how to talk to children about HIV and Aids in different age groups as well as how to prevent them from being infected. This information should be included in this programme to empower educators to support learners effectively.

5.2.6.6 The use of a social worker as facilitator of group

The facilitator recommended that a social worker or a skilled counsellor present the REds programme in future. The participants disclosed many emotions that needed to be dealt with by a trained professional, especially those infected with HIV or the participants that had a family member with Aids. The facilitator needed knowledge on grief and bereavement before the session on how to support a child who had lost a parent and how to care for the sick and dying. The facilitator must also have the necessary knowledge on debriefing to debrief the participants at the closure of the programme.

6. INTERPRETATION AND DISCUSSION

In order to determine the efficacy of REds it was implemented over a nine-week period with 10 volunteering participants from a primary school in Alabama, Klerksdorp. After the revision, the modified programme was presented to a second group of 13 volunteer participants from a high school in Kanana township, at Orkney in the Matlosana district, North West Province. After the implementation of the programme, evaluation regarding the effectiveness of the intervention programme was made. A Mixed Methods Research design was used where both the quantitative and qualitative data were gathered concurrently.

6.1 INTREPRETATION OF THE RESULTS OF THE QUANTITATIVE MEASURING INSTRUMENT

According to the results of the pre-tests and post-tests provided in Chapter 4, the educators that participated in this research were indeed affected by the HIV and Aids pandemic. The quantitative measures done through the ProQOL questionnaire did not show a significant difference between the pre-assessment and post assessment with regard to the subscale: Compassion satisfaction, for group 1. It did show a medium effect between the pre-assessment and post-assessment with regard to the 2 subscales: burnout and compassion fatigue/trauma, for group 1. However the quantitative measures done through the ProQOL questionnaire did not show a significant difference between the pre-assessment and post-assessment with regard to the subscales: Compassion satisfaction, burnout and compassion fatigue/trauma, for group 2. The qualitative measurements reflected that the participants benefited from the REds programme. The information gained from the qualitative measures was analysed and the following is reported:

6.2 INTERPRETATION OF THE RESULTS OF THE OPEN-ENDED QUESTIONS

The researcher interpreted that teachers are in a helping profession and the participants all have the same aim that they wanted to help people who are less fortunate. Before the REds programme was presented the participants reported that they were more overwhelmed by the amount of work they had to deal with in face of this pandemic. They had mixed feelings and experienced fear and uncertainty throughout, and depression, disturbance, fatigue and concern with regard to their future, as well as that of their loved ones and learners. They wanted to get knowledge to help make the world a better place. After REds was presented they truly understood the enormous implications of the pandemic. From the post-test data it seems that there was an improvement in the participants' feelings as they were less worried about persons they helped, the participants felt more satisfied because they were able to help others successfully and they felt that they could make a difference. With the information and knowledge obtained

through REds they felt empowered and gained confidence to share information with others, to support others and they felt confident that they could do anything they set their mind to and could succeed.

6.3 INTREPRETATION OF THE RESULTS OF THE SYMBOLIC DRAWINGS

All the participants agreed that the impact of the pandemic influenced them negatively. This was clear from their symbolic drawings in the pre-test. When the participants individually told the group about their drawings, all of them could relate to the various symbols they had drawn. During analysis of the pre-test data the themes that were identified were: grief, loss, unpredictability, disempowerment and anxiety.

All the participants agreed that they experienced feelings of relief, hope and excitement after completing the REds programme. In the post-test drawing the themes identified were: hope, empowerment, mastery, compassionate sadness and unpredictability. In the explanations the participants related to having increased strength to cope with the impact of the pandemic and that this strength was experienced as empowering. In the symbolic drawings unpredictability was still a theme and the participants explained that they were realistic when looking at the fast growing HIV statistics and felt that we were running out of time unless more was done to empower people. According to the colourful drawings in the post-test, it is clear that most of the participants felt empowered and resilient.

6.4 INTERPRETATION OF THE RESULTS OF THE SEMI-STRUCTURED INTERVIEWS

The educators' responses suggested that the impacts of the pandemic potentially undermine their healthy functioning on all levels. This can be summarised as follows:

Poor emotional health – The educators reported negative emotions experienced in response to the impact of the HIV pandemic. These emotions included feelings of sadness, sympathy, sorrow and depression. The educators felt negative spiritual experience which included a sense of hopelessness, spiritual disillusionment and

punishment. Some participants experienced comfort in their spirituality when they were confronted with the pandemic. Affected educators reported physical health problems such as that they could not sleep and were constantly thinking of death especially when "*someone passed away*". They indicated unpleasant social experience with regard to the pandemic. This experience included social isolation, "*because of stigma they were still afraid to disclose their status*". They reported deteriorating morale, higher levels of professional stress and escalating workloads. Three participants mentioned that losing some of their learners and colleagues affected their work performance; it affected them "*seeing their colleagues die like ants – with no help*". Their work was also affected due to a high percentage of learners being absent from school.

The educators' responses suggest that the impacts of the pandemic potentially undermine their healthy functioning thereby confirming the general understanding in current literature the HIV-affected educators are professionally and personally debilitated by the pandemic (Coombe, 2000 and 2003; Kelly, 2000; Fredriksson & Kanabus, 2002; World Bank, 2002; United Nations, 2004; Hall et al., 2005; Kinghorn & Kelly, 2005; Shisana *et al.*, 2005; Theron, 2005).

After the REds was presented all the participants felt that the REds programme helped them personally. They felt more equipped to handle any situation successfully. The participants gave the following reasons: they acquired more knowledge; they felt well informed about how to give support to people infected; and they learned new information that empowered them to feel more in control and less stressed. The participants reported that the following were helpful to them professionally: they learned how to deal with HIV in the workplace and adapt to the situation; they learned how to support infected colleagues that disclosed to them; and they felt with the knowledge gained they would be able to help and support learners, colleagues and even the community.

The educators reported that their work performance deteriorated and their role changed to that of a counsellor. They suggested that the school must employ a nurse and social worker as part of the personnel, and that this will be much more effective in dealing with

the problem. Some educators reported that could cope with the pandemic through workshops, like the REds programme, HIV education and the support from social workers.

6.5 INTERPRETATION OF THE INTERVIEWS WITH PARTICIPANTS AND MANAGEMENT

During the individual interviews the educators suggested the following for future REds interventions:

In the REds programme all the content is important and nothing should be left out of the programme. The REds equipped them with the correct facts on HIV and Aids and the necessary skills to fight the disease. It gave them a realistic view on the pandemic and the affect of it on their and other peoples' lives. The information in the sessions had changed their attitude towards the pandemic and infected and affected adults, colleagues, learners, loved ones and orphans. The REds empowered them to treat the infected and affected as normal people. REds also informed participants on how to care for the sick. Two participants felt it would be helpful to invite infected people to address the educators.

Some educators felt the need that sexuality education and the preventing of teenage pregnancy be included to this programme because of high incidents of teenage pregnancies in the particular school with teenagers having unsafe sex. Practical information regarding the grief and bereavement process for children at different ages must also be included. Some participants felt that the session in dealing with stress and the stress release exercises were very helpful and more time should be spent on exercising the relaxation techniques. The educators proposed the REds manual could be compiled as a more practical toolkit, with visual material, posters and pictures.

The participants suggested that more teachers and more schools should be included to participate in the REds programme to educate more educators regarding the pandemic. Some felt that the learners should also be included in this programme. They felt that this course must also be presented in the community. They would also like to have other

similar courses. In both groups the participants suggested that the Department of Education should provide each school with a school nurse, aids counsellors, fully equipped medical kits that were checked every 3 months, and specialists like social workers, who could work directly with the learners and have contact with them regularly.

In the interview with the management, the principals of the two particular schools felt that the REds programme should continue and the information gained should be shared with other educators and schools. The REds programme should be implemented at every school and become part of the curriculum and they suggested that the programme should be altered for the learners.

7. RECOMMENDATIONS

The researcher based the overall recommendations for the efficacy and adaptation of REds on all data collected from participants, such as reflection worksheets, regarding elements of the sessions that the participants found particularly helpful, elements participants experienced as not helpful at all and the components the participants would like to change or add to the session, drawings of participants and interviews with participants and management.

- It is recommended that the scheduled time for group sessions should be on a weekly basis, directly after a school day to ensure attendance.
- It is recommended that the contents of the REds programme be retained.
- It is recommended that information on sexuality education for different age groups as well as teenage pregnancies, information on how to talk to children about HIV and Aids in different age groups and how to prevent them from being infected, be included.
- It is recommended that grief and bereavement information for children and the dying person be included. Information on how to support a child who had lost their parents should also be included.

- Extra practical programme materials, for example posters, handouts, pamphlets, colouring-in books and the toolkits were much appreciated and made the information more practical and user friendly. Especially books for pre-school and primary school children, explaining HIV and the prevention of HIV and Aids, were helpful for educators to convey sensitive information to learners. Practical information regarding the grief and bereavement process for children at different ages must also be included.

- The researcher recommends the use of electronic aids, such as a computer and proxima where photos and pictures could be presented more easily, or that the facilitator used posters or a flipchart in cases where there is no audio-visual equipment at the school. The REds manual gives information but it is not practical, due to the fact that it is a workbook and not a practical guide. Visual aids make the information more users friendly. The participants commented throughout the programme that the posters used made the presentation more practical and visual.

- It seems to be important to involve HIV-positive speakers to convey information from their own experiences.

- The REds programme should be implemented at every school and become part of the curriculum.

- It is recommended that the REds programme should be altered and presented to learners. It is also recommended that this cause be presented in the community to reach more people.

- Educators should also form partnerships with other stakeholders such as health care workers and social workers and it is recommended that social workers or nurses be implemented at schools to deal with this pandemic effectively.

- The facilitator must also have the necessary knowledge on debriefing to debrief the participants at the closure of the programme. The facilitator must also have the necessary counselling skills to deal with the emotions of the participants if they disclose their status.

8. CONCLUSION

This particular study involves the investigation and improvement of the impact of an intervention programme, REds, on educators affected by HIV and Aids. After the REds programme was presented the educators from the two schools in the North West Province identified that they were stressed and exhausted by the demands of basic social support, the responsibility for providing basic counselling support and for providing safe and secure learning environments which included caring for those affected by HIV and Aids. The collected data reflected that the participant's felt more satisfied with their work, they also felt more positive and empowered after the REds programme was implemented. Prior to the implementation of REds they viewed themselves as passive victims. The information gained by this programme gave them knowledge, confidence and empowered them to help those infected and affected by HIV and Aids. From the feedback on the sessions and interviews they felt that they gained much information to make a difference and felt confident that they could do something about the pandemic and to help others.

Although they felt better empowered to deal with the demands in the classroom, they identified the need for a multidisciplinary approach and suggested that the Department of Education consider employing school nurses or social workers to provide support and counselling regarding this problem. They also suggested that the visual aids, the handouts, practical materials and toolkits provided must be included in the programme in order for the programme to be even more effective and user friendly. Information that must be presented practically for instance is information on grief and bereavement. Information on sexuality education, preventing of teenage pregnancy and how to talk to a child about HIV and Aids in different age groups should also be included in this programme.

It would seem from the results of the pre-test and post-tests provided in Chapter 3 that the educators affected by the HIV and Aids pandemic reacted positively to the REds programme and benefitted from the programme. Hope and a more positive attitude were noted in the post-test. It is also clear that the REds programme needs to be modified in

terms of the recommendations made, in order to be even more effective. The results of the presented REds programme substantiate a need for social work services to help and care for the individuals who have been affected by the disease effectively. The need for this study is further supported by the shift in incidence of the disease. The shift in incidence of the disease requires that all social workers possess knowledge and appropriate beliefs that promote the well-being of individuals affected with HIV and Aids. The advances in medical treatment of HIV and Aids also means that individuals who are sero-positive will live longer lives, increasing the need for the development of appropriate resources in the community, the provision of services such as counselling, treatment and support, and enhancing the quality of life.

Chapter 5 will focus on the role of the social worker in providing empowerment to those infected and affected by HIV and Aids.

CHAPTER 5
THE ROLE OF THE SOCIAL WORKER IN PROVIDING EMPOWERMENT TO PERSONS INFECTED WITH AND AFFECTED BY HIV AND AIDS

1. INTRODUCTION

Since Aids was first recognised as a new health problem in the USA in 1981, counsellors and other professionals have been at the forefront of care-giving to people infected with or affected by HIV. Alongside the rapid advances over the decade in the fields of epidemiology, virology, immunology, clinical management, nursing care, clinical therapy and prohylaxis, there has been a supreme effort to understand more about the psychosocial sequelae of the HIV disease and to translate that comprehension into counselling.

Social workers have had long experience working in the delivery of health social care services, working with ill people and their families. Social workers who work with people suffering from acute, chronic and life-threatening illnesses and with their families could be of assistance in serving the HIV and Aids population. HIV and Aids shares many of the characteristics of other life-threatening conditions. However, HIV and Aids are also very different, thus calling for the development of new knowledge, skills and strategies.

A second epidemic developed from HIV and Aids, an epidemic of stigma, fear, ignorance and discrimination. The people infected and affected by HIV face social isolation, disruption of social and sexual relationships, lack of needed services, loss of jobs and alienation from family and friends (Aronstein & Thompson, 1998:xxi). The quality of life of an infected person depends on the healing of the social side, the availability of needed treatment and services, the reduction of stress and the existence of a supportive and caring network.

Social workers have much to bring to this field of practice. The traditional broad psychosocial perspective encourages social workers to be sensitive to all of the factors that impact the life of a person with HIV. Social workers have the expertise to work with individuals, couples, families, groups and communities. They call upon multiple roles depending on the situation: counsellor, psychotherapist, social broker, organiser, advocate, programme and policy developer, and social change agent. These are the flexibility, creativity, the breadth of vision, and the multiple service roles that responding to HIV and Aids requires (Aronstein & Thompson, 1998:xxii).

This chapter focuses on the role of the social worker in providing empowerment to those infected with and affected by HIV and Aids. The role of the social worker was discussed according to the 9 sessions of REds as well as adaptations made according to the recommendations from the evaluated REds programme for educators. With this in mind the content of this chapter includes the role that the social worker has regarding the biomedical facts, guidelines on HIV prevention, HIV-testing and antiretroviral medication, guidelines on promoting wellness and stress management skills, guidelines on nursing people with Aids-related illnesses, tips on using social networks, caring for children in the face of the pandemic, government grants and non-governmental structures to give and gain psychosocial and socio-economic support, care for the dying and grief-counselling skills, and information on the rights of an HIV positive person in the workplace. These contents are grouped into seven sections. The role of the social worker as a multifaceted professional, utilises different methods and techniques, is discussed in these seven sections and forms the basis of the development of the empowerment programme regarding HIV and Aids for social work students.

2. PROBLEM STATEMENT

Since its identification, HIV and Aids has grown to epidemic proportions. It is estimated that approximately 42 million people world-wide are HIV positive and roughly 22 million deaths on account of Aids have been recorded (United Nations Department of Economic and Social Affairs, 2003; World Bank, 2002). The reality is especially grim in

Sub-Saharan Africa. It is estimated that 29.4 million of the 42 million infected persons, reside in Sub-Saharan Africa. Quinn (2003) suggests that more than 1 in every 10 South Africans is HIV positive. It is predicted that by 2010, South Africa would have lost five million people due to HIV and Aids-related deaths. By 2015, when the pandemic is expected to reach its peak, about four million children will be orphans, due to parents dying from HIV and Aids-related causes. These statistics substantiate a need for social work services and for awareness, education and professional preparation to help and care for the individuals effectively who have been affected by the disease.

Caring for an Aids patient at home places a tremendous physical and emotional burden on health care professionals, relatives, friends and loved ones. Caring for an individual with Aids-related diseases is usually time consuming, burdensome and unpredictable and may place an unbearable strain on the family or marital system (Ross, 2001:22). Psycho-social consequences occur as a result of diagnosis of HIV-status and are exacerbated as the disease progresses. Stress and depression can compromise function and well-being in all areas of the family life, including school and work performance, family relationships, and capacity for child care. At the same time, stigmatisation of HIV and Aids often causes discrimination, social rejection and alienation, and can compromise employment, housing, schooling and child-care responsibilities (Love Life, 2001:9). The fact that the HIV disease results in death and its chronic, progressive nature substantiates it further as a complex problem.

HIV and Aids present a significant problem on both societal and professional levels for social workers. Individuals who are affected by HIV disease or Aids have needs that may require a multitude of services including counselling, social services (Wexler, 1989), advocacy, community outreach and case management (Wiener & Siegel, 1990). On a broader level, there is a need for preventative programming, education and policy making. Social work, a profession that is recognised for supporting the socially disadvantaged and those who are discriminated against by the larger society, has a significant role to perform in meeting the needs of individuals affected by HIV disease or Aids. The skills that social workers perform in integrating people with larger systems,

their focus on context and environment evolving from work with historically marginalised groups, and their commitment to human rights and fairness are critical to addressing the issues surrounding HIV disease and Aids. According to Smale, Tuson and Statham (2000:5) "social work is about the interventions made to change social situations so that people who need support or are at risk can have their needs met more appropriately than if no interventions were made".

The shift in incidence of the disease requires that all social workers possess specialised skills, knowledge and appropriate beliefs that promote the well-being of individuals affected with HIV and Aids, regardless of their chosen area of practice (Podolsky-Scarth, 1999:3), to intervene effectively with clients, their families and the community. The advances in medical treatment of HIV and Aids also means that individuals who are sero-positive will live longer lives, increasing the need for the development of appropriate resources, provision of services such as counselling, treatment and support and enhancing the quality of life.

The question that arises from this is whether the social work student is well-trained, knowledgeable and professionally motivated enough to manage the HIV epidemic effectively and provide care and support to those living with HIV and Aids. This chapter aims at establishing the role of the social worker in empowering those infected with and affected by HIV and Aids.

Taking the above-mentioned into consideration, the following question arises:

- What is the role of the social worker in providing empowerment to persons infected with and affected by HIV and Aids?

3. AIM

The aim of this chapter is to investigate the role of the social worker in providing empowerment to persons infected with and affected by HIV and Aids.

4. RESEARCH METHODOLOGY

The method used for this investigation was a literature study.

4.1 LITERATURE STUDY

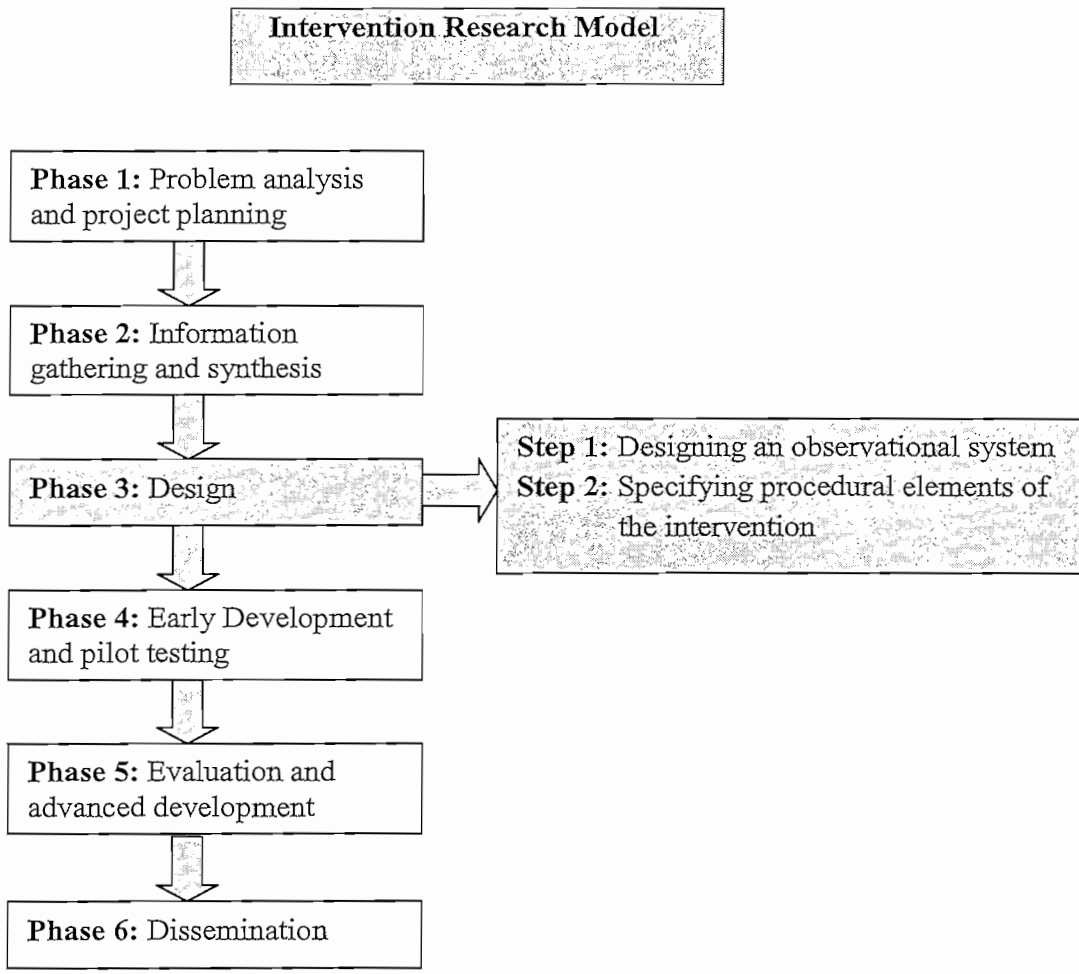
A literature study equips the investigator with a complete and thorough justification for the subsequent steps, as well as with a sense of the importance of the undertaking (Fouché & Delport, 2005:123). A literature study was conducted on various aspects of this chapter. Delport (2005:171) states that, to undertake meaningful research, the researcher should have made a thorough study of the subject under review. The focus of this study was on the role of the social worker in providing empowerment to persons infected and affected by HIV and Aids according to the biomedical facts of HIV and Aids, guidelines on HIV prevention, HIV-testing and antiretroviral medication, guidelines on promoting wellness and stress management skills, guidelines on nursing people with Aids-related illnesses, tips on using social networks, caring for children in the face of the pandemic, government grants and non-governmental structures to give and gain psychosocial and socioeconomic support, care for the dying and grief-counselling skills, and information on the rights of an HIV positive person in the workplace.

A wide range of literature was identified and studied, including books, academic studies, government and informal publications and scientific magazines. To ensure a purposeful search, the EBSCO Host: Academic Search Premier, Nexus, ERIC, Repertoire of South African Journals, Social Work Abstracts, PsycINFO, Social Sciences Index and SA Media databank were used.

4.2 RESEARCH MODEL

In this study the intervention research model, a six phase model was utilised (De Vos, 2005a:394). The empirical study in this chapter focused on Phase 3 of the intervention research model, as seen in Figure 5.1.

FIGURE 5.1: THE INTERVENTION RESEARCH MODEL



The researcher will describe Phase 3 of the model in theory and how it was applied in practice in this part of the research.

Phase 3: Design

- **Step 1: Designing an observational system**

A researcher must design a way of naturalistically observing events related to the phenomenon, as well as a method system for discovering the extent of the problem and detecting effects following the intervention (De Vos, 2005a:400-401). The observational

system is closely linked to the process of designing an intervention and it serves as a feedback system for refining early prototypes. The relevant behaviours, roles and environmental conditions of the social worker working with those infected and affected by HIV and Aids was observed.

- **Step 2: Specifying procedural elements of the intervention**

By observing the problem and studying naturally occurring innovations and other prototypes, researchers can identify procedural elements for use in the intervention (De Vos, 2005a:400-401). These procedural elements, including the use of information, skills and training for their acquisition, environmental change strategies, policy change or enforcement strategies, should be specified in sufficient detail to be able to be replicated by other typically trained change agents. In designing the intervention the researcher studied the literature as well as other prototypes to identify elements that could be used in the newly developed programme.

5. HIV AND AIDS: A NEW CHALLENGE FOR THE SOCIAL WORKER

Shernoff (1998:28) discussed that mental health care providers are increasingly instrumental in efforts to control the Aids epidemic. Aids is as much a behavioural as an infectious disease problem. This is evident by the manner of its transmission, its effects on the central nervous system, its stigmatic nature and its often lethal outcome. Specialists in mental health care and behavioural change are indispensable in controlling the epidemic through education, prevention, treatment and research. Mental health caregivers can help people overcome the biases that impede rational responses to the disease and fears that characterise the Aids epidemic by providing compassionate care by suggesting innovative methods of prevention and research (Shernoff, 1998:28). There are different methods and techniques that social workers can utilise to assist. Social work is a multi-faceted profession and the practitioners in social work have assumed responsibility for the interaction between people and their environments. According to Pincus and Minahan (1983), the purpose of social work is to:

- Enhance the problem solving and coping capacities of people.
- Link people with systems that provide them with resources, services and opportunities.
- Promote the effective and humane operation of these systems.
- Contribute to the development and improvement of social policy.

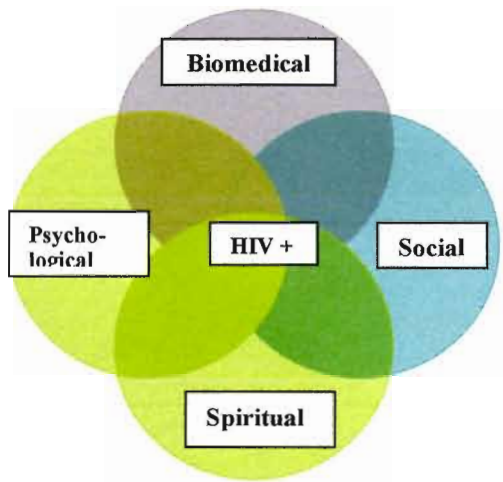
According to Podolsky-Scarth (1999:21), the literature also defines the social work role as one which assumes a proactive part in initiating change and meeting client's needs, in providing empowerment to persons with Aids, and ensuring that services are equitable. The unique role of social work stems from its value base which is seen as central to the identity of the profession and defines professional social work practice. Social work is a profession dealing with different people of different cultures and diversity. It is, therefore, important for a profession of that nature to have values that embrace the profession. Thompson (2000:104) defines social work values as: "a set of fundamental moral and ethical principles to which social workers are/should be committed". Social work values are founded on the precepts of humanitarianism. They include values such as respect for individuality, enhancing of individual worth and dignity of all persons, social justice, human rights and self-determination (CASW, 1994; King-Pike, 1996). The specific set of values that characterises the social work value base is deemed critical to shaping professionally appropriate beliefs, behaviours, decision making processes and ultimately, practice with clients.

A major challenge in doing Aids work, according to Wright, Blackburn and Taylor-Brown (1999:59), is how to communicate across cultures about medicines, illness, sickness and death, and how to communicate new information in a way that is understandable and believable. Cultural factors have a powerful role in the development of health care perspectives, beliefs, attitude and practices. The effectiveness of health care providers in reaching and working with multicultural populations rest heavily upon the sensitivity, respect and understanding paid to ethnic diversity. The barriers to providing appropriate services to ethnic populations are a lack of appropriate informational materials concerning resources, rights, and responsibilities for multi-ethnic

groups, compounded by a shortage of trained, bilingual, multi-culturally educated personnel. The subsequent lack of culturally responsive service affects client behaviour, access and outcome (Julia, 1996:4). Because cultural forces affect so many of our daily routines (for example, what and when one eats, how one dresses) and extraordinary life events such as celebrations and holidays, one sometimes become blind to the effect of one's own cultural perspectives on others. The power of culture is a force acted out in almost all human interactions. The skills associated with developing multicultural competence are no less important than the skills developed in professional pursuits. Developing a conscious awareness of diverse cultural perspectives is only one step in the process. Competency is about the knowledge and the skills that are needed to deal successfully with human differences – racial, ethnic, and socio-cultural. The ethical, social, political, and professional reasons for implementing multicultural training in health care settings are compelling.

Serving the affected individuals and populations would require an integrated multi-disciplinary approach within the paradigm of a bio-psychosocial spiritual and information model (Soreff, 2007; Van Wormer & Davis, 2008). According to Soreff (2007), the bio-psychosocial information formula is now becoming the new medical paradigm. Figure 5.2 explains the bio-psychosocial spiritual model.

FIGURE 5.2: BIO-PSYCHOSOCIAL SPIRITUAL MODEL



(Winiarski, 2004: 23)

Treatment of people with HIV necessitates a multi-dimensional assessment and also a multi-dimensional intervention strategy. Attention to medical, social, political and psychological issues is critical. Social workers are in a unique position to be able to deliver this service, because of their tradition to explore all the dimensions. The role of the social worker will be discussed under the headings which follow. The sections will not necessarily be mutually exclusive, seeing that HIV and Aids are multi-faceted diseases affecting every part of the community, family life and the individual.

5.1 INFORMATION ABOUT HIV AND AIDS

In the battle against HIV and Aids, social workers have been on the front line since the beginning. Today, social workers help clients cope with HIV and Aids in a wide variety of settings, including explaining information on HIV and Aids and myths surrounding HIV and Aids, the transmission and prevention of HIV and Aids, support systems such as health agencies, hospitals, infectious disease clinics, and Aids service organisations.

While the doctor's relationship with the patient seldom extends beyond the clinic or hospital doors, the social worker's concern reaches into every area of the client's daily life, confronting the challenges the client faces every day.

As medical understanding of the disease has evolved and treatment plans have become more complex and varied, social workers are one of the strongest sources of social support associated with high levels of medication and complicated treatment plans compliance in patients with HIV and Aids.

5.1.1 The facts about HIV and Aids

A few decades ago, this terrible disease previously unknown to the human race, began to kill people in the most alarming and terrifying circumstances. HIV and Aids is known to be a virus, but it is unlike any virus previously known. Its deadly effects are felt all over the world, but nowhere more tragically than in Sub-Saharan Africa. Aids is the leading cause of death of adults between ages of twenty five and forty four (Cadwell, 1998:269). HIV is part of one's life and is bound to be a part of a social worker's profession, as they either work directly with people who are infected with HIV or affected by Aids, their loved ones, or people who are sexually active and need to be educated about HIV prevention.

Most people find that information about HIV transmission and Aids is difficult to teach to others. The technical details are hard to grasp even for doctors, and most people in the community have problems understanding the important points and acting on this information in ways that are helpful. Education and knowledge are the keys to reducing the rate at which this disease is spreading, as is the reduction of stigma. As long as it is not possible to talk openly about the disease one will not win the fight. According to NASW News (1995:15), all social workers need to be better informed about all aspects of HIV infection and Aids and they must have the resources and motivation to keep up with developments. No matter what a social worker's function is, he or she will always be asked very basic questions about HIV and Aids, the history of the pandemic, explanations

on the unique characteristics of the HIV virus and how it affects the human immune system, as well as exploring the latest development in the search for a vaccine. Knowledge needed by the social worker is how the virus is transmitted via sexual intercourse and contaminated blood and how it may be transmitted from mother to baby. It is also important to explore issues such as why it is difficult for disempowered women to avoid HIV infection and how poverty and other social problems contribute to the spread of HIV, as well as to recognise and treat the symptoms of other sexually transmitted infections. The social worker also needs to discuss the symptoms of HIV infection, Aids and Aids-related illnesses. The important relationship between the CD4 cell count, the viral load and disease progression is also important information needed.

The social worker needs to be prepared to deliver services, both preventative education to the uninfected and service to the infected. The most vital issues of a social worker's time converge in HIV work: sex, addiction, distribution of care and resources, cultural diversity, poverty, religious beliefs and moral values. Social workers deal with the core human experiences of hope and dread, love and loss, isolation and community, courage and anxiety, shame and pride, and life and death. The social worker can be a vital source of accurate information and provide a supportive relationship that helps the client determine what safer sex will mean to him or her. The social worker can provide a safe relationship in which the client's concerns and anxiety about HIV can be expressed, clarified and dealt with.

5.1.2 The effect of HIV on the immune system

For any treatment of HIV and Aids to be effective the client needs to understand how this complex virus works. The role of the social worker is to translate the bio-medical information into understandable language to the client. Once the HIV has entered the body, usually via the thin surface of the vagina or the penis opening, it makes its way into the blood. The HIV virus favours the white blood cell called a T-helper cell, also referred to as a CD4+ cell. CD4 cells play a very important part in the body's immune system (defense system). When the virus multiplies in CD4 cells, they are damaged and die.

While the body can produce new CD4 cells at first, eventually it cannot keep up with the destruction of CD4 cells caused by the virus. When the number of CD4 cells in the blood drops, the immune system starts to fail. If a person's immune system is functioning poorly they are said to be "immune deficient". The Human Immunodeficiency virus is, therefore, a cause of immunodeficiency. Usually it takes several years for HIV to cause immunodeficiency in this way. When it happens, the person develops Aids. A person with Aids has poor defense against infections by other viruses, bacteria and fungi. These other organisms cause the symptoms of Aids such as shingles, pneumonia and thrush (Yeats, 2001:10). The social worker should use different techniques and age appropriate mediums to explain this information to the client in different developmental stages.

5.1.3 Assessing client's risks of exposure to HIV

Social workers need to be armed with the basic knowledge about assessing risk behaviour, finding local resources and develop appropriate intervention skills in order to best serve the vulnerable client. Before the development of an accurate test in 1985 to determine the presence of HIV in blood products, people who received transfusions were at risk of contracting HIV through blood they were given. Currently the vast majority of new HIV infections occurs either through sexual exposure or sharing intravenous-drug-using apparatus. In attempting to assess whether a client is at risk for Aids, a social worker must ascertain both the client's current sexual practices as well as what they were in the past. In attempting to do a risk assessment for high risk behaviour, the social worker needs to ask questions regarding drug use and sexual practices in an accepting, nonjudgmental, matter-of-fact, gentle way that does not incorporate the use of labels. Social workers need to learn how to talk to drug users honestly and completely about their drug use (Shernoff, 1998:29, 30).

5.1.3.1 Aids prevention: Sexual practices

A challenging dimension of this work includes the vital importance of the therapist in obtaining a detailed sex history and staying attuned to risks in the client's sex life (Cadwell, 1998:271). Discussing sexual issues can cause discomfort even for the most sophisticated worker. Especially when the discussion involves sexual practices that the clinician believes are immoral, distasteful, repugnant or nonconformist sexual practices or beliefs.

It is the moral and ethical responsibility of every clinical social worker to introduce the issue of sexual practices in relation to Aids prevention with each individual. Social workers who see adolescents or individuals in sexually non exclusive relationships, newly separated, divorced, or widowed adults; and any person contemplating having sex with a gay or bisexual man, current or former intravenous drug user, or transfusion recipient needs to learn about safer sexual practices. The current epidemics of all sexually transmitted diseases, has made it essential for clinical social workers to ask clients effective questions about sexual practices (Shernoff, 1998:34).

Social workers need to be aware of a variety of cultural or dynamic situations that contribute to the likelihood of heterosexually married individuals presenting as HIV positive or with symptoms of Aids. Societal homophobia powerfully influences many men of diverse ethnicities to hide their homosexual activity within a heterosexual marriage (Shernoff, 1998:31).

5.1.3.2 Aids prevention: Drug use

According to Van Dyk (2005:142), programmes should focus on the primary prevention of drug use especially among young people; on the rehabilitation of drug users and on the prevention of HIV among drug users who do not want to (or cannot) stop the habit. Shernoff (1998:32) notes that use of alcohol and illegal substances increases a person's vulnerability to HIV in the following ways:

- A person who shares hypodermic needles or other drug paraphernalia with someone infected with HIV is at risk of becoming infected.
- A person who becomes intoxicated or high may lose inhibitions against risky practices for example, neglecting the use of a condom during a drunken or stoned sexual encounter.
- A number of substances, such as alcohol, cannabis and cocaine may suppress one's immune system and can accelerate the collapse of T-cell activity.
- It is suggested in a risk reduction model, that social workers working with chemically dependent clients must not confuse the goals of providing Aids education and risk education with the goals of helping clients stop using drugs.

5.1.4 Reasons why HIV and Aids are still spreading

Factors driving the epidemic in South Africa include stigma and discrimination, gender violence against woman and children and poverty. Aids-related stigma and discrimination remain the greatest obstacles to people living with HIV infection or Aids. Stigma and discrimination increase people's vulnerability, isolate them, deprive them of care and support and worsen the impact of infection. Stigma and concerns about discrimination are the main reasons why people do not come forward to have an HIV test, to access antiretroviral drugs, to adopt safe feeding methods for their babies, or to change high-risk sexual behaviour. Stigma, discrimination and human rights violations form a vicious circle, legitimizing and spurring each other on (UNAIDS, 2002:67). The provision of treatment, care and support provides more hope and gives people the incentive to have an HIV-test to find out their status. With treatment, HIV will become more like any other chronic disease, which can be managed and lived with for long periods of time.

Both physical and socio-economic factors make women and girls more vulnerable to HIV. The genital of a woman has large areas of exposed sensitive skin, which can get cut during intercourse. This allows HIV to enter the body more easily. Semen also stays longer in the vagina after sex, increasing the risk of transmission. The socio-economic status of women places them at a higher risk of HIV infection. Many women cannot

choose to abstain, use a condom, or insist on other forms of safer sex, because this may result in violence or abandonment by their male partners. Rape contributes greatly to the spread of HIV. Poverty forces women into sex-work in order to survive and support their children. Girls living in poverty may engage in sex with older men in exchange for favours, gifts or money. Some men are reluctant to visit hospitals and clinics when they have sexually transmitted infections. Migrant workers or men who are working away from home for long periods of time, may have sex with sex workers or other partners and this places them and their partners at risk.

5.1.5 Involvement of traditional healers as vehicles of change

The community plays a very important role in traditional life in Africa. Health care professionals who work in Africa should resist the temptation to stigmatise beliefs and practices that are different from their own as ridiculous, superstitious and harmful. They should focus on those beliefs that can promote Aids education and prevention. Traditional beliefs are based on principles such as the value of the collective interest of the group, the survival of the community and the union with nature. One cannot exist alone, whatever happens to the individual happens to the whole group. The collective existence gives rise to values such as communality, group orientation, cooperation, interdependence and collective responsibility (Van Dyk, 2005:124).

No Aids prevention programme can succeed in Africa without the help of traditional healers. Traditional healers are effective agents of change because they have authority in their communities. They function as psychologists, marriage and family counsellors, physicians, priests and legal and political advisors. They are the guardians of traditional codes of morality and values. Traditional healers have greater credibility in their communities, especially with regard to social and spiritual matters (Van Dyk, 2005:125). Collaborative health programmes involving traditional healers can be used effectively in HIV/STI prevention programmes.

The involvement of the community in the planning, implementation and evaluation of Aids education programmes is also important for the success of such programmes. Aids educators should be creative and imaginative in incorporating traditional beliefs and healing methods into Aids education programmes. The tradition of social sharing, of rituals, of story telling, of drama, of singing, drumming and dancing should be used to convey the threat of HIV infection to traditional people.

5.2 HIV-TESTING

The HIV-test is different from all other tests. It has enormous emotional, psychological, practical and social implications for the client. Not many things in life could be as stressful as waiting for HIV-test results. A positive test result can be emotionally devastating, sometimes resulting in a psychiatric decomposition or a relapse into active use of alcohol or drugs. HIV-testing should, therefore, never be done without thorough pre-test counselling.

The client may come to the social worker because of questions he or she has about being tested for HIV. The social worker can help the client understand what it means to him or her to be tested (Cadwell, 1998:270). After being tested, a client may need to talk about the emotional impact of the test results. If the client is negative, he or she may have survival guilt. The client who is positive may need to talk about the meaning of his or her positive status. The social worker needs to know where anonymous and confidential HIV-testing is available in the client's community in order to make a referral when appropriate. It is also important to know about any existing Aids service organisations and other local HIV and Aids resources in the community, and which physicians, hospitals, and medical centres are most experienced in treating people with HIV and Aids. According to Shernoff (1998:36), there are a number of situations in which a social worker clearly needs to raise the issue of a client being tested for HIV.

- The client mentions that he/she has recently had a sexually transmitted disease.
- A client discovered that their spouse/partner has been sexually unfaithful.

- A client has been sexually assaulted or raped.
- A client reports high-risk sexual or drug-taking activities, such as sharing a needle.

Raising the issue of HIV-testing will raise the client's anxiety. If the client raises the issue of being tested, the social worker must explore why they want to be tested, as well as how they feel about it. The final decision of being tested must always be the client's decision.

5.2.1 Counselling before and after the HIV-Test

Each individual planning to take the HIV-test needs to receive counselling regardless of whether he or she tests negative or positive. The period of time while a person is waiting for test results is heightened with anxiety, which often includes somatic symptoms and sleeplessness.

The purpose of pre-test counselling is to give someone who is considering being tested for HIV all the necessary information and support to make an informed decision. Information on the technical, social, psychological, legal and ethical implications of being diagnosed as either HIV-positive or HIV-negative should be provided. In the pre-test counselling it is important to find out the reasons why individuals wanted to be tested, the nature and extent of their previous and present high-risk behaviour and the action required to prevent them from becoming infected or from transmitting HIV infection.

Pre-test and post-test counselling should preferably be done by the same person because the established relationship between client and counsellor provides a sense of continuity for the client. Counselling after testing will depend on the outcome of the test, which may be a negative result, a positive result or an indeterminate or inconclusive result. Post-test counselling must include information on safer sex no matter what the results are and referrals to medical and mental health services if the client tests positive.

5.2.2 Counselling when a client is HIV positive

When a client has learned that he/she has been exposed to HIV, the social worker has a number of crucial tasks to help him or her adjust to living with a life-threatening illness, as stated by Shernoff (1998:37):

- Become well educated about HIV and Aids.
- Establish a relationship with a knowledgeable medical professional who can explain various symptoms, treatments and options.

Crisis intervention is often necessary after an HIV-positive test result is given, especially if the client shows suicide tendencies. The social worker has to take a more active role in crisis intervention to help the client contain his or her anxiety or despair, to identify and evaluate any immediate threats to safety and to take active steps to increase the safety of the client. The social worker should focus on options to access immediate informal support, professional help or emergency services. According to Van Dyk (2005:211), the social worker needs to discuss the following issues when a client is HIV positive:

- Fear of pain and death are often the most serious and immediate problem for the client. Helping clients to explore their fears for the future is an important therapeutic intervention.
- Clients need information about antiretroviral medication, opportunistic infections or symptoms that they are vulnerable too and that it can be successfully treated and prevented with medication.
- Disclosure is one of the major concerns for HIV-positive people. Role-play situations in which the client can practice communicating the news to others are helpful.
- Fear of losing their jobs. The legal rights of HIV-positive people must be discussed.
- Financial problems may be a concern for some clients. Discuss welfare options including disability grants and how these are accessed.
- Concerns about children should be discussed, such as prevention of mother-to-child transmission, termination of pregnancy, family planning, guardianship of orphans and testing children.

- Discuss medical options such as follow-up test, a health care plan, available treatments and cost, alternative health options (traditional healers) and regular medical check-ups.
- Inform the client of increased risk of TB and treatment if they develop symptoms.
- Lifestyle changes such as to stop smoking and drinking alcohol, getting sufficient sleep and rest, exercise, dealing with stress, eating a balanced diet, safer sexual behaviour and infection control should be discussed.
- Refer clients to available support groups in the community.
- Help the client develop a problem management plan according to the problem solving model.
- Identify the way the client dealt successfully with problems in the past and help them develop new coping skills.

Although Aids is a terminal illness, clients need to hear that there is usually a period that increasingly lasts up to 10 years or more where people remain asymptomatic. As clients become seriously ill from Aids-related opportunistic infections and their serological tests indicate that the immune system is severely damaged with a CD4 cell count below the 200 mark, the client should be prepared for the risk of dying from a serious Aids-related complication (Shernoff, 1998:37).

Social workers must be knowledgeable about the stages of the illness and how its progression may present. Being informed about the disease is especially important in regard to the neuropsychiatric manifestations of the illness, since bizarre or non-cooperative responses from clients in the advanced stages of Aids may be misinterpreted as resistance or hostility as opposed to a symptom of disease-related organicity. It is essential to have a close working relationship with a psychiatrist who is experienced in diagnosing and treating Aids-related dementia (Shernoff, 1998:36).

5.2.3 Anti-retroviral treatment

Protease inhibitors in combination therapy carry the promise of prolonged health. This represents a major step toward transforming HIV from a life-threatening illness to a chronic illness resulting in reduced hospitalisations and enhanced quality of life. However, the protease inhibitors are very difficult drugs to take for a variety of reasons. They must be taken on exact schedules without any doses being missed. Three of them (saquinavir, ritonavir, and nelfinavir) must be taken with food, while a third (indinavir) must be taken either two hours after eating or one hour prior to eating to ensure the best level of absorption. If an individual is concurrently taking medication, which also has to be taken either two hours after eating or one hour before eating but cannot be taken at the same time as indinavir, the scheduling of drug taking becomes a nightmare. Managing prescriptions, and monitoring when and how each needs to be taken becomes a full-time job, especially a single HIV-positive parent who relies on public assistance to care for her children, has numerous realistic concerns about beginning protease inhibitor therapy (Shernoff, 1999:6).

Social workers have a prominent role to play in translating complex medical information issues into everyday language that patients can understand and incorporate into their lives. Social workers also need to have the necessary knowledge about medications the clients are considering, the limitations of medications and the implications for choosing or not choosing to use them. These concerns should be discussed with an empathetic and knowledgeable professional who will not judge the client for whatever decision she or he decides to make. Social workers are in a unique position to translate patients' concerns and reluctances to beginning this therapy to medical staff so that physicians and nurses will understand the various and complex reasons why certain patients decide inhibitory therapy is not right for them. They help the medical staff to not view patients as non compliant or self-destructive and refusing to do what is in their best interests (Shernoff, 1999:8), but are respected as persons who have made a treatment decision which appears correct to them at the present time.

Strub (1997:59-60) notes that the three factors highly relevant to successful combination therapy – compliance, absorption, and resistance – are only vaguely understood by the mass media, many people with HIV, and tragically, far too many physicians, psychologists, and social workers who work with HIV-infected clients. If a patient cannot comply with the strict and rigorous scheduling and food requirements, the therapy is destined to fail because of the growth of insufficiently suppressed viral strains. According to Surface (2007:20), there are many variables related to social support that can affect the client's ability to remain compliant such as socio-demographic variables like age, gender, education, finances, transportation, socio-economic status and ethnicity. However, social support seems to be a prime variable or indicator that is associated with higher levels of medication compliance. It is crucial when working with clients with HIV and Aids to work with the person in his or her system. In the case of people with HIV and Aids, the client's system may include any or all of the following: family, children, spouse, friends, staff of community-based Aids service organisations, and primary medical providers.

Therapists working with people with HIV and Aids should be well informed about new developments to assist clients best who are faced with the issues surrounding this new therapy. Biomedical advances underscore the rapid introduction of new medications and the emerging understanding of the effects of these drugs, are constantly being refined and updated. As professionals, "empowerment means that we strive to provide our consumers with all the information we have at our disposal so that they can make informed choices about their lives" (Wright, Blackburn, & Taylor-Brown, 1999:60). As social workers one needs to assist clients in evaluating whether to take this medication or not by developing patient education materials that help the clients to understand the medical and financial implications of the medications, help communicating concerns about whether to begin this therapy and, once begun, how to maintain such a rigorous medical regimen. Social workers must incorporate goals of health promotion, health maintenance, and a participatory relationship in the treatment process (Berkman, 1996:541-551).

5.2.4 Adapting to change

An HIV-positive test result makes a tremendous and irreversible impact on a person's life. Important decisions and changes have to be made by the client and loved ones to live within the constraints imposed by the virus.

In contrast with the early years of the epidemic when people often died within months of diagnosis, people are living longer with the disease. Combination therapies including protease inhibitors are resulting in increased health for people with Aids, who are now being presented with challenges previously unforeseen, including returning to work. Clients may seek the social worker to talk about the course of their illness with HIV. They may need to talk about their decision to go on disability, or the final stages of illness. They may need to have someone to talk to about their feelings concerning their life and death (Cadwell, 1998:270). Many clients who are on disability will now want to at least consider and discuss all the ramifications of possibly returning to work (Shernoff, 1999:29). An important factor that the social worker must keep in mind is that a client's time of change in health condition and possible readiness to return to work is exceedingly confusion for many people who are living with HIV disease, ill or well; with Aids or without Aids; able or disabled. However, these polar concepts are too limited for dealing with the new reality of HIV. There is a now a wider spectrum of illness and wellness than ever before, including dealing with issues they thought they would never again face, such as work, feeling better, socialising and even dating.

The social workers need to inquire and elicit feelings about the toll HIV disease has taken on people's lives, dreams, and expectations, even during this period of renewed vitality and optimism. Counsellors should also seek to help clients re-establish a balance between living in the present and planning for the future. This involves helping clients understand and retain what they value about living in the moment, while defining long-term needs and strategies for satisfying them (Shernoff, 1999:24). The social worker needs to employ techniques that include both problem solving and role-playing in an effort to empower the

individual with HIV who is faced with the daunting task of discussing these issues with well-meaning loved ones.

5.2.5 When drugs do not work

There are numerous patients who, after a very brief period of benefiting from the new drugs, are unable to tolerate the side effects, or are resistant to the new drugs. According to Jacobs (1997:1-13), between 10 and 30 percent of those who take Aids medication fails to respond. They are understandably disappointed and often angry that these drugs did not work for them. Social workers need to be knowledgeable about anticipated side effects the individual may be experiencing and how this is making him or her feel about this new drug regimen. In addition, patients need to be coached to request anti-nausea and anti-diarrhoea medication from their physicians. Providing clients with the information, encouraging proactive interactions with medical providers, and when necessary, advocating on their behalf are necessary interventions that must be considered in work with clients faced with the critical decision of taking antiretroviral medication (Shernoff, 1999:15).

Tragically, a growing majority of people with HIV do not have money, education, or even time to become as informed as they must be in order to survive. This is where well informed and skilled social workers can make an enormous difference in the lives of people living with HIV. All professionals must continue to advance the work with their clients to support treatment information and education, access to medication, support as clients adjust to new medication and the prospects of returning to prior levels of functioning, lifelong adherence to medication regimens and the decision to take medication that may have limited effects. The role of social workers extends beyond the delivery of biomedical information and must encompass the capacity to work with the client system to translate information into usable terms (Shernoff, 1999:16-17).

5.2.6 The influence of support in combination therapies

Support group models offer psycho-educational information regarding the use of holistic, alternative treatments that have long been considered vital in the maintenance of mind/body health for people living with Aids. Through the utilisation of a forum in which group members feel known and supported in the sharing of their triumphs, fears, such as fear of sudden and debilitating illness, and losses, support group participation often serves as the primary emotional outlet (Shernoff, 1999:32). The social worker plays an important role in starting support groups in the community for those infected by HIV. Support group meetings have served to reduce the isolation often associated with confusion and anxiety, and provide support through illness and death. Using the wellness group model, group members are able to look beyond combination therapy for treatment of their HIV and gain some control in the maintenance of their health (Shernoff, 1999:39).

5.2.7 HIV positive women and pregnancy

Women are the fastest growing group diagnosed with HIV. Becoming a mother is an important part of a woman's life. For many, nurturing children is seen as the primary role of women in our society. HIV does not diminish the desire to have children. A life-threatening disease may heighten the desire to create a new life as a continuation of oneself. From the onset of the pandemic, controversy has surrounded an infected woman's choice to bear or not to bear a child.

The decision to have a child is linked to a number of factors that extend beyond the medical facts. The decision to have a child is complicated for an HIV-infected woman by the possibility of transmitting the disease to her offspring and the likelihood of premature maternal death. No one wants to transmit HIV to a child, but this potential is a reality for women with HIV and woman will need to consider the impact of having either an infected or uninfected infant. Parents must weigh the risks of transmitting a disease with their desire to have a family. Each choice is very emotional with a lasting impact for all

members of the family. All infected women need support as they cope with the decision to have children or not. Frequently, women find out that they are infected during their pregnancy or when their baby is born, without the benefit of pre-test or post-test counselling. Psycho-socially this is one of the worst times to learn about the diagnosis (Taylor-Brown, 1998a:375-376). For some women, the decision to bear a child is not their decision. They do not have control over their sexual relationships with their partner and have no influence over the partner engaging in additional sexual relationships.

The social worker can effectively help a woman explore the meaning of creating a life by examining the role of her past reproductive experiences, her religious background, her partner's expectations and the meaning of her illness. Counselling can help them to make informed decisions whether to continue a pregnancy or not. The social worker can also supply updated information on treatment options. It is not possible to predict whether or not a woman will give birth to an infected child. If she chooses to go ahead with the pregnancy, support will help her cope with the inherent anxiety (Taylor-Brown, 1998a:378). A woman may seek counselling after she is told she is pregnant. A careful assessment of her reaction to the pregnancy is needed before exploring her options with her. For many women, abortion is not an option, and it is helpful to find this out before reviewing options. For a woman who decides to have a child, the social worker needs to provide psycho-social support throughout the pregnancy, focusing on anxiety management regarding the possibility of vertical transmission. Regular prenatal care that integrates HIV management will help her to access aggressive prophylaxis and treatment of opportunistic infections, which can adversely affect mother and child (Taylor-Brown, 1998a:381). It will be helpful to explore the long-term realities for the child ranging from being a part of a family to coping with the reality of maternal death and needing guardianship arrangements. Support should be continued regardless of a woman's decision to bear children or to defer childbearing.

Working with women regarding childbearing also requires the social worker to understand the complexities of implementing safer sex and behaviour change models. Women need to receive education regarding contraception and reproduction. Education

can clarify the noted misperception. Women need to know the facts of transmission. All social workers are ethically bound to present the contraceptive and reproductive information in a non judgmental manner (Kurth, 1995:1-4). Support groups can provide a safe place for HIV-infected women to explore the complex issue of the loss of never having a child or having a child without worrying about whether the infant will be positive or not. By sharing experiences, group members can help another member to decide what is best for her. She may also benefit to learn about available community services from other consumers (Taylor-Brown, 1998a:384).

As politicians and care providers struggle over standards of care, women's needs are frequently secondary. Women are often negatively portrayed with little concern about the medical and emotional needs of HIV-infected mothers. An infected mother needs access to quality medical care to enable her to care for herself and her children. Social workers can advocate and help women to weigh their options and then make the best decision.

5.2.8 Potential barriers to successful intervention

Unavailability or limited resources available to people with Aids, particularly in rural areas, are a major barrier to successful interventions. Many people with Aids are homeless, are inaccessible, and have limited resources and support. Finances are often a potential barrier as well as geographically, if there are no organisations or support systems in the rural areas. Psychological testing for HIV-associated dementia requires access to professional consultants with specialised training in neuropsychology. Many rural settings may not have access to professionals with expertise in neuropsychological practice. Social workers must advocate for the underserved clients who are not receiving care. The social worker can provide a list of community agencies that provide emotional and financial support that are useful. Poor and other marginalised clients are not sophisticated and demanding consumers of health care and have little experience in advocating for themselves with doctors, nurses, and health care institutions and agencies. Thus, workers need to instruct all clients on how to become self-empowered, self-advocating consumers of medical care without necessarily becoming adversarial.

Medication non-compliance also represents a barrier to successful intervention. It is known that several antiretroviral medications are effective in improving cognitive function in persons with an HIV-associated dementia (Citron, Brouillette & Beckett, 2005:38). Intervention addressing the patient's resistance and caregiver education regarding the role of antiretroviral medication in enhancing cognitive function is the best means of addressing this potential barrier. It becomes increasingly more difficult to be optimistic and hopeful when previous treatments did not work. Experiencing periods of hope, coupled with letdowns and despair, can create powerful mood swings that lead to the emotional roller coaster of living with HIV and Aids. Therapists and counsellors need to elicit each client's feelings about new treatment options and give them the opportunity to discuss and explore those feelings in depth.

5.3 LIVE A LONGER, HEALTHIER LIFE WITH HIV

Patients with HIV infection and Aids need physical, emotional, psychological and spiritual care, because of its unique feature. Any programme should be holistic, compassionate and person centred and it should always take place in a nurturing environment (Van Dyk, 2005:297). Most of the difficulties of people with HIV and Aids are familiar to health care professionals because the physical and psychological needs of people with Aids are often similar to those needs of other terminally ill patients. A much more holistic approach is required for people with HIV and Aids, because their immune systems are so depressed that they can contract virtually any disease.

5.3.1 Physical wellness

The current emphasis in the treatment and management of HIV infection and Aids is on the strengthening of the immune system so that the infected person can be kept healthy for as long as possible, preventing opportunistic diseases, treating opportunistic infections and addressing general health problems, using antiretroviral therapy and to improve the general health of the patient (Van Dyk, 2005:297). A healthy lifestyle not only improves the quality of life, it also strengthens the immune system's capacity to combat infections.

The social worker can empower their clients by giving information on positive living, nutrition, care of general health problems and opportunistic infections and the correct use of medications and stress management. The aims of health education in HIV-prevention programmes should not only be the prevention of illness, they should also focus on the promotion of physical and mental health. HIV and Aids education should, therefore, be part of a broader strategy to empower people with the necessary life skills to make the right health choices and to improve the overall quality of their lives (Van Dyk, 2005:143).

Increasing numbers of people exposed to HIV remain completely asymptomatic, leading healthy and productive lives for 10 years or more, despite their HIV status. To hear that the diagnosis is most often not an immediate death sentence is a very empowering experience and sharing this information with newly diagnosed patients and their loved ones, helps them internalise some hope in adjusting to an HIV or Aids diagnosis. Social workers with socially disadvantaged clients must teach these individuals the concept of primary medical care and urge them to seek regular contact with physicians and wellness clinics for themselves and their children. The social worker must know the resources available in the community for providing Aids support. They also need to know what people or organisation may be willing to provide assistance for example, transportation, meals, home base care and pastoral care.

5.3.2 Psycho-social wellness

An HIV-positive diagnosis creates a crisis, which often leaves people feeling anxious, overwhelmed, depressed and/or emotionally numb, all very normal responses (Giulino, 1998:165). People often describe that living with HIV is like living with a time bomb and never knowing when it will go off. No known cure exists, and one is forced to live with a high degree of uncertainty and ambiguity over an extended period of time. The illness has an unpredictable course and possibly a complicated treatment process which affects patients medically in different ways. In addition, such a diagnosis is not always met with

compassion by family members and society, which affects an individual's ability to adapt.

People with HIV and Aids may report feelings of fatigued, a loss of energy, interrupted sleep patterns, being sad and lonely, socially isolated and change in appetite. The clients may present symptoms of anxiety and depression. The social worker should consider whether this is an adjustment reaction to coping with a life-threatening illness, a major depression or an Aids dementia complex. The frequency of HIV dementia parallels the progression of systemic HIV disease. Medication is available to treat the symptoms and a referral to a psychiatrist for psychopharmacological intervention is important (Giulino, 1998:166-167).

The social worker needs to do a careful psycho-social assessment to determine what services and other interventions a client may need. The focus of the psychotherapy is to help patients stabilise and achieve some sense of control over their life. The therapy process can help people return to a previous level of coping, decrease anxiety and depression and improve interpersonal relationships (Giulino, 1998:166).The social workers' task is to obtain a primary medical provider, provide education and information about the disease and its transmission, or help the client to access other resources of care and social support. All of this enhances the developing treatment alliance. Treatment also provides a place for people to address their fears, to enhance problem solving skills and to obtain information that will give them a sense of control. With the help of therapy, people can begin to take charge of their life and accept responsibility for it. Social workers are particularly well situated to assist people with the complex psychological tasks of reconstructing their lives and also the concrete tasks of setting goals, choosing priorities and accessing resources. A significant part of the treatment is developing a sense of meaning. Gaining a sense of understanding of one's life provides cohesion, balance and a sense of mastery and control.

5.3.2.1 Skills and techniques in taking control

There is only one weapon against HIV infection and Aids and that is behaviour change. It is unfortunately the most difficult and complex weapon to use, because people find it extremely difficult to change their behaviour. One of the main educational functions of health care professionals is to encourage changes in unsafe sexual behaviour. Health care professionals should set realistic goals: although people will never stop having sex, they can be taught to practice safer sex, as well as life skills for the implementation and maintenance of safer sex practices (Van Dyk, 2005:129).

The social worker should facilitate life skills to enable young people who are not yet sexually active to learn safe habits from the start and those with acquired risky sex patterns to begin to practice safer sex. Women especially should be taught to be more assertive and self-efficient in sexual matters and learn negotiation skills to practice safer sex. Various strategies may be used to promote life skills. Role play can teach new skills which can then be practiced. Social modelling (on video) helps individuals observe and understand how to deal with interpersonal situations and the ability to handle peer pressure. People must be taught the ability to exercise control over their lives and behaviour and taking responsibility for themselves and for others in the community. Some need to be trained to communicate effectively with their sex partners if the partners are resistant, defensive or manipulative as well as conflict resolution (Van Dyk, 2005:143). Social workers must help their clients develop responsible and effective coping skills which will enable them to prevent HIV infection and also help them to enhance their lives on various levels.

5.3.2.2 Skills and techniques in reducing stress

Research has shown that many diseases are caused or aggravated by an interaction of social, psychological and biological factors. Chronic stress was found to create greater susceptibility to many diseases such as flu, dermatitis and the recurrence of herpes symptoms (Sue, Sue and Stanley Sue, 2000). Psychological factors such as stress,

emotional inhibition, a negative self concept and a lack of social support have been shown to contribute to a more rapid progression from HIV infections to Aids (Cole, Kemeny & Taylor, 1997:320). Stress has a very negative effect on the immune system and increased stress can decrease the number of CD-4 cells. Self-efficacy and an ability to cope with stressors were associated with a slower deterioration of the immune system in HIV-positive individuals. Thus HIV-positive people must learn to cope with stress. The social worker should help people develop an optimal functional plan, including change lifestyles to prevent illness and to enhance the quality of their lives. Clients should be encouraged to avoid or manage stressful situations, establish priorities and postpone low priority tasks. To reduce stress actively, clients should engage in relaxing and enjoyable activities and exercise regularly. Relaxation techniques should be taught and HIV-positive people should also be encouraged to join support groups. Treatment for stress can include medication for the physical symptoms of stress. (Van Dyk, 2005:224).

5.3.2.3 Skills and techniques in the treatment of fears related to HIV and Aids

The impact of the diagnosis on the internal organisation of the patient and the family system is significant. While each family is different, each must absorb and process the information about Aids. Blame, guilt, anger, shame, anxiety, sadness and depression must be dealt with. The social worker needs to be aware that in the context of HIV and Aids, the grief process and bereavement issues are present throughout the course of the disease, from diagnosis, with the loss of expectation of a long and healthy life, to the multitude of other losses that occur over time. These losses include the loss of ability to work, the loss of social contacts, loss of a sense of role in society, loss of self-esteem, loss of energy to do things, loss of familiar body image, and loss of eyesight from cytomegalovirus retinitis in the later stages of Aids. People respond differently to these losses, depending upon the available emotional, spiritual, financial and social resources they have to draw on. Within the context of psychotherapy, many themes as identified by Giulino (1998:176-178), become central to the treatment of fears related to HIV and Aids. These themes are loss, self blame and guilt, revelation of HIV-status, uncertainty,

fears of symptoms, despair versus hope, sex, fear of transmission, financial concerns and shame.

5.3.2.4 Skills and techniques in coping with stigma

Aids-related stigma and discrimination remains the greatest obstacle to people living with HIV infection or Aids. Stigma and discrimination increase people's vulnerability, isolate them, deprive them of care and support and worsen the impact of infection. Stigma and concerns about discrimination are the main reasons why people do not come forward to have an HIV-test, to access antiretroviral drugs, to adopt safe feeding methods for their babies, or to change high-risk sexual behaviour. Stigma, discrimination and human rights violations form a vicious circle, legitimizing and spurring each other (UNAIDS, 2002:67). Counsellors should not only advocate for universal precautions, but also for universal tolerance and knowledge about HIV and Aids (WHO, 2000:6-4). The following efforts should be implemented worldwide to fight stigma and discrimination (UNAIDS, 2002:67):

- Leaders at all levels of life should be encouraged to visibly challenge and act against the many forms of HIV-related discrimination.
- People living with HIV and Aids should be actively involved in the response to the epidemic.
- Violations of human rights should be monitored, people should be able to challenge discrimination, and institutions should be designed to safeguard human rights.
- Governments should take urgent action to protect women's property and inheritance rights, and to protect children against sexual exploitation.
- A legal environment supporting the fight against discrimination should be created.
- Prevention and treatment, care and support services should be accessible to all.

5.3.2.5 Changing negative attitudes

Health care professionals can act as role models for others in helping to combat stigma, discrimination and the isolation of people living with HIV and Aids. The basic training and values of social workers, such as respect the worth of each individual, non-judgmental acceptance and caring make a critical antidotes to shame. Social workers can become advocates for acceptance and care only if they examine their own beliefs, values, assumptions and attitudes towards HIV and Aids. Prevention strategies will become far more successful if and when HIV is treated like any other disease and when people feel safe to be open about their HIV status. Programmes should also seek to counter harmful gender norms that lead to the sexual coercion and exploitation of women and girls. Long term strategies to change harmful gender norms should be directed at underlying cultural and social structures and their aim should be to promote mutual respect between men and women and equal access to all types of resources. Social goals such as education, the empowerment of women and human rights should, therefore, be promoted (Van Dyk, 2005:102).

5.3.2.6 Disclosure of HIV-positive status

The decision whether or not to disclose being HIV-positive is difficult because disclosure (or non-disclosure) may have major and life changing consequences. Social workers should help their clients to consider carefully the benefits such as reduce stress of coping on their own and the negative consequences that disclosure may have for them as individuals. Disclosure can ease access to medical services, care and support, including access to antiretroviral therapy. It can help people protect themselves and others. It may help reduce the stigma and promote responsibility to plan for the future (Southern African AIDS Trust, 2000:220-221).

Disclosure can also be accompanied by negative consequences such as problems in relationships, with sexual partners, family, friends, community members, employer or colleagues and rejection. The social worker can support the client to think through all the

pros and cons and plan ahead before they disclose by using the following guidelines (Southern African AIDS Trust, 2000:6-7):

- Help the client to explore the implications of disclosure and consider the reaction of family, friends, and others that might be of help. Develop a plan for disclosure, including aspects such as, who will they first tell, how and where will they disclose, as well as level of disclosure.
- Before disclosing the client should feel comfortable with his or her diagnosis. The social worker can provide support to help client accept themselves.
- Identify sources of support such as groups for people living with HIV and Aids, church members and counselling organizations.
- Prepare the client for a shocked and hostile reaction from other people when they decided to disclose.
- Role play can help prepare the client for disclosure.
- Provide the client with information and support to live positively and give information on safer sex practices to protect sex partners.

5.3.2.7 The impact of HIV infection on affected significant others

The significant others play an important role in the life of a person living with HIV and Aids. The social worker can play a tremendous role in counselling the partners, friends and family of the HIV-positive person in the practicalities of physical and emotional care. According to Van Dyk (2005:219), the following prominent themes tend to emerge repeatedly in HIV and Aids counselling: uncertainty about the progress of the disease, relationship problems with significant others, issues surrounding the disclosure of HIV-positive status, dealing with the fear and stigma associated with HIV infection, pregnancy, career and financial concerns, sexual relationships, stress and anxiety, depression and suicidal thinking, spiritual and existential matters and issues about death and dying.

5.4 HOW TO CARE FOR AN ILL LOVED ONE AT HOME

More than 80% of families affected by HIV are from poor communities, many of whom are already burdened by poverty, discrimination and limited support systems. These families are usually without savings, employment, income, medical aid and social support (Wiener, 1998:315). HIV and Aids make demands on the community and society that cannot be met by hospitals alone. The importance of family and community involvement in the care and support of people cannot be denied especially in communities where resources, facilities and finances are limited, such as found in many rural clinics and homes. The only practical and humane solutions are to care for patients in their own homes and communities for as long as possible and to develop an integrated home-based care service with professional community and volunteer caregivers.

5.4.1 Sources of support

5.4.1.1 Medical providers

Aids-related illnesses can have a sudden onset (Rabkin, Remien & Wilson, 1994:17). Often HIV-positive persons and their families are ill prepared to cope with decisions that could have been discussed in depth prior to a medical emergency. It is best to raise the difficult and painful issues long before there is apparent need for them. When the client is well, he or she is more likely to have the necessary energy for planning these difficult realities (Shernoff, 1998:42).

As people develop symptoms of more advanced Aids, they increasingly lose control over their bodies and lives. The social worker needs to help people living with HIV in planning for hospitalisation and an acute medical emergency. By addressing these issues they can ensure that they will have a measure of control over what happens to them. For many clients the concept of developing relationships with medical providers and becoming an active member of the medical team is a foreign one. Social workers can

teach clients how to assert themselves more effectively. Role playing can be an useful technique in helping clients develop these skills.

5.4.1.2 Involving families in caring for persons who are ill

People are cared for at home, because it is less expensive and also comfortable for the client. Families are involved in providing home care to people with Aids. Unfortunately people with Aids often have limited families of origin. The definition of a family has broadened to include the partner and/or friends that may be the primary support system of many individuals (Babcock, 1998:101).

The client may not be able to prepare meals or take care of household chores, and as they become weaker, they need some support as they deteriorate. Involving family members in getting proper care for the client at home may prove difficult (Brennan, 1998:125). Family members might have some fears regarding transmission, medication and stigma associated with HIV and may be reluctant to provide support to someone at home. Feelings of helplessness are common among family members providing support to someone who is extremely ill, particularly when he or she is at home. They feel helpless because there are many opportunistic infections that cannot be treated curatively and, therefore, it feels as though there is nothing to be done. It is the task of the social worker to understand the family dynamics and what the family is capable of managing at home in order to prepare for the client to receive home care. This will decrease the overall feeling of helplessness (Brennan, 1998:126). Within a family meeting concerns and opinions of how to proceed with the care for a patient can be addressed. The provision of clear and accurate information is often the most valuable and effective intervention a social worker can make. It is, therefore, imperative that the worker ask the client not only about his or her understanding of HIV and its attendant opportunistic infections, but also what the family member knows about his or her loved one's medical status.

Families isolated from support systems are going to have a very difficult time in accessing home care services and will need extra support from social workers who are

aware of the available resources. These resources include various home care and hospice programmes, their specialities, their availability within certain geographical areas or within various cultural populations, community resource agencies, Aids service organisations, volunteer service agencies, meal delivery systems and financial assistance programmes. It is important to find a list of resources available to people living with Aids.

5.4.1.3 Home-based care programmes

Local community volunteers play an important role in home-based care programmes. Volunteers usually come from a variety of backgrounds and they may be trained and experienced professionals, trained community caregivers, family members or compassionate community members who wish to help those in need (Van Dyk 2005:263). Important functions of home-based care programmes are:

- To empower the community and the family to cope effectively with the physical, psychosocial and spiritual needs of those living with HIV infection and Aids.
- To educate the community about the prevention of HIV transmission.
- To support family members in their care giving roles.
- To reduce the social and personal impact that living with HIV infection and Aids makes on all those concerned.

Volunteers should never be expected to offer home-based care without a good basic training and understanding of the physical, psychosocial, emotional and spiritual conditions that they may encounter and how to deal with these. The social worker can provide training to the volunteers. The training provided will depend on the level of care required as well as the basic facts about HIV and Aids, transmission, signs and symptoms of infections and confidentiality.

5.4.1.4 Hospice care

Hospice is a type of home care service that focuses on caring for clients during the final phase of their illness. Hospice home care can provide regular psychosocial support, chaplain services, volunteer assistance and bereavement support for families after the death of a client. In certain geographical areas, they can provide an inpatient hospice facility and the social worker can refer the client if necessary. The social worker must discuss the myths surrounding hospice care with the client and family members before involving them. Social workers can, with the help of the client and family members, develop a care plan through assessment, link clients with services and monitor as well as advocacy where necessary. This action can form an integral part of intervention for people with Aids and minimise problems in the provision of services.

The main goal of hospice care programmes is to provide the organisational structures, resources and framework that will enable the family to look after its own sick members. Hospice care promotes a holistic approach to care. This means that the physical, social, cultural, psychological, emotional, religious and spiritual needs of a patient can all be fulfilled by the family and the health team (Van Dyk 2005:260).

5.4.2 Managing Aids related health problems at home

The most common Aids-related health problems that a person can experience are, coughs, pneumonia, tuberculosis, diarrhoea, constipation, fatigue, nausea, night sweats, weight loss, skin problems, stress and depression and dementia. These problems can be taken care of at home. It is also advised that the person experiencing any of these health problems be referred to a wellness clinic or a medical practitioner (Van Dyk 2005:304)

The most common neuro-psychiatric illness in persons infected with HIV is HIV-associated cognitive/motor complex or Aids dementia complex that parallels the progression of systemic HIV disease. Such dementia affects only 5% of those with asymptomatic infections and demonstrates cognitive and intellectual abnormalities

related to their sero-positivity (Buckingham, 1998:281). The cognitive impairment increases as the individual becomes increasingly immuno compromised and symptomatic. In the early stages of HIV infection, these cognitive symptoms may manifest as the following: shortness of attention span, short-term memory loss, decreased ability to concentrate and difficulty in planning complex activities. Behavioural symptoms include apathy, depressed mood, fatigue, social withdrawal and insomnia. Motor symptoms may include gait disturbance, clumsiness and changes in handwriting. As the disease progresses a client may experience seizures, difficulty with gait, mania and psychosis.

Many of the early symptoms resemble depression. According to Buckingham (1998:281), assessment of clinical depression is important in any client with HIV. The social worker must differentiate between early signs of HIV-associated dementia such as slowing, forgetfulness and concentration problems and the effects of a major depressive disorder. If the person's symptoms are suggestive of a clinical depression, referral to a psychiatrist with Aids experience in treating neuropsychiatric disturbances with psychopharmacology is necessary to explore if an antidepressant could improve his or her quality of life.

When patients experience mood disturbances, slowed thinking and memory difficulties and poor coordination due to HIV-associated dementia, clients should be taught compensatory techniques such as using note pads and reminders. This will assist the individual in dealing with the everyday aspects of coping with the disorder (Buckingham, 1998:290). Providing structure and a familiar environment will facilitate greater independence in activities of daily living. Unfamiliar environments with no one to assist with daily living activities may increase confusion in a patient with mild dementia. Family members or significant others are often frustrated by the physical and mental debilitation their loved one has experienced. The social worker can provide information and educational resources to the patient and family members. Many clients have little or no understanding of neurological functioning or the diseases that affect cognition. Psychotherapy provides an opportunity for patients to ventilate their frustration with declining capacities as well as other issues unique to HIV. Psychotherapy may assist

with problem solving in a concrete fashion, educate the patient and his/her family regarding the problems associated with this condition and set limits regarding activities that may create potential problems due to motor difficulties or slowed thinking. In addition to psychotherapy to improve the affected individual's adjustment to his or her situation, it may be helpful to inform the client that certain antiretroviral medication can improve cognitive impairment (Buckingham, 1998:289).

5.5 CARING FOR CHILDREN IN THE FACE OF HIV AND AIDS

It is important to let children know that they can talk to their parents about anything. Children need to feel comfortable talking to their parents about things that happen in their daily life, like their school, friends and sport. They also need to know that they can talk to parents about issues that they think are sensitive, such as sexuality and HIV and Aids. Cultural beliefs and traditions might make it difficult to communicate about these issues with children. The education of children on sexual matters is, therefore, often neglected or ignored. Research has shown that children are engaging in sexual activities at increasingly younger ages. This results in more young people becoming pregnant, having abortions and contracting sexually transmitted diseases, including HIV.

5.5.1 Communicate with children about HIV and Aids

HIV and Aids education should not concentrate on the dissemination of information on HIV and Aids alone. To make responsible decisions, a child must have knowledge that is based on healthy values, norms and attitudes and skills to implement these decisions. For an HIV and Aids education programme to be successful, there should be a balance between knowledge, life skills, values and attitudes.

The basic requirements for a successful HIV and Aids education should form part of a life-skills education programme that includes sexuality education as well as information on HIV and Aids. This education should begin at an early age when children's behaviour patterns have not yet been established and they are very receptive to the principles that

govern healthy behaviour. HIV and Aids education should be an ongoing process. It is important to include parents, community leaders and spiritual leaders for active input at all stages of programme development. Sexuality and HIV and Aids education should always be appropriate to a child or young person's particular developmental stage. All education programmes should be based on protecting and promoting the rights of the child, including the rights to information, education, health and health care, freedom from rape and sexual coercion and cruel and inhuman treatment. (Van Dyk, 2005:147-148).

The school has a very important role to play in empowering children with the necessary knowledge, attitudes, values and life skills to protect themselves against HIV infection and Aids. However, the responsibility for protecting children should not be left up to schools. Many children are school dropouts, orphans and others made vulnerable by HIV and Aids as well as street children that cannot be reached by the formal education system. Churches, civic organisations, youth groups, NGO's and individual volunteers should all be involved in HIV and Aids prevention and life-skills training programmes so that children who do not go to school can also be reached (Van Dyk, 2005:172).

5.5.2 HIV and Aids education for adolescents

The threat of Aids presents an enormous challenge for adolescents. The developmental stage of adolescence is a period marked by change and confusion for many teens. Adolescents are considered to be one of the high-risk groups for Aids. Many engage in behaviours that may put them at risk of acquiring HIV infections, other sexually transmitted infections or infections associated with drug injection (Sunenblick, 1998:387). In exploring their sexuality, adolescents must come to terms with the reality of Aids. The life-and-death issues of Aids cannot be separated from an understanding of the adolescent's tendency toward experimentation and risk taking.

Social work practitioners should work toward creating environments that are safe for adolescents' to talk about sex, Aids and mortality. Attention must be given to the adolescents understanding of HIV, including topics on risk factors of transmission, safe

sex practices and access to good health care that can provide adolescents with the necessary information to make safe choices about their sexual behaviour and clarify misconceptions (Sunenblick, 1998:388). Social workers need to inform the adolescent of his or her rights to give consent for a HIV-test if the adolescent is 12 years and older as well as the right to use condoms (South Africa Children's Act, 38/2005). When working with adolescents, social workers need to consider the adolescent's ability to delay gratification, to contain impulse control and to draw upon cognitive abilities to understand and change behaviour. Social workers also need to recognise the developmental stage of adolescence that involves a move toward interpersonal closeness and intimacy, which includes sexual intimacy. In their search for identity consolidation and autonomy, adolescents often experiment and take risks. A faulty self-esteem can contribute to impulsive and potentially dangerous behaviours for some adolescents (Sunenblick, 1998:389).

Social workers have a responsibility to help the adolescent assess his or her risk for infection by taking a sexual history as a routine part of a psychosocial assessment and to learn new behaviours to reduce this risk. Pipher (1994:3-20) suggests a set of criteria needs to be in place for adolescents before they are having sex. This includes thinking about circumstances, choice of partner, protection options and safe sex behaviours. Role-playing with the adolescent can be a useful exercise. Social workers can present discussions about sex and sexuality in a variety of ways in order to reach as many adolescents as possible. They can create environments that allow open discussion on sex and sexual practices, using individual and group approaches. Psychodynamic, psycho-educational, behavioural and cognitive perspectives can all be used. Intervention strategies that address the importance of low-risk sexual behaviours are also important to consider. Films such as "sex, drugs and Aids" include material to elicit affective reactions from adolescents. This type of intervention can be conducive to small group discussion to exchange information on a more personal level (Sunenblick, 1998:390). It is also helpful to spread risk-reduction literature, in languages used by clients, to incorporate this information into new behavioural practices.

5.5.3 Role of families in preventing the spread of HIV

Researchers emphasise the role that families play in healthy development. Families are considered by many to be the single most influential force in the life of children and adolescents (Szapocznik & Coatsworth, 1999). HIV prevention family programmes have typically taken the form of education about HIV and Aids and interventions aimed at developing parental competencies that can influence adolescents' behaviours. Pequegnat and Szapocznik (2000:513-531) social ecological theory considers parents as the most fundamental social context influencing children's development into adaptive or maladaptive adolescents.

Most sex education programmes are individually directed toward adolescents themselves and are provided through convenient venues such as school and community agencies. Some students may understand and use the information, but others may not be ready. One option for matching readiness of youth with availability of information is to provide parents with information and skills (including training on developmentally appropriate ways of relating and communicating about sexuality) to guide their adolescents in making responsible decisions regarding sexual behaviour. Parents play a pivotal role in guiding adolescents' sexual behaviour during transition years in which situations of "sexual possibilities" are likely to increase (McKay, Baptiste, Coleman, Madison, Paikoff & Scott, 2000:67-87). Parents communicate values, model appropriate behaviour, encourage bonding to family and school, encourage children to form a long-term view of their behaviour and monitor the behaviour of their children and their friends. Alert parents can have considerable information about what is occurring in the life of an adolescent at any time and they can adapt their interventions to the life conditions and the potential risks facing their adolescent. These efforts are aimed at fostering family involvement in the sexual health of adolescents, including delay of sexual intercourse.

5.5.4 Disclosure of a parent's HIV positive status to a child

Disclosing an HIV-positive status to a child is possibly one of the greatest struggles that a parent could have. However hard it is for parents to disclose to children, evidence suggests that children may suffer more from the silence around HIV. Children who were informed of their parents' terminal illness showed significantly less anxiety than children who were not told. To be kept in the dark made them feel guilty, anxious, depressed, isolated and lonely. Children need to be supported through, rather than protected from emotional pain, including illness and death (Stein, 2004:19). Silence and secrecy deprive children of the opportunity to share feelings and ask questions.

The issue of disclosure initially brings most parents to seek clinical social work services. Talking to children about a parent's HIV disease takes preparation and is a process that takes place over time. A child cannot understand all aspects of a parents' illness after one discussion. The full impact of the diagnosis will take time to absorb and will depend on several factors such as how the illness is explained and the parent's health at the time the child learns about the diagnosis. Children may begin to struggle with fears associated with a parent's progressive illness and death. Separation anxiety is not uncommon for the school-age or preadolescent child. Older children who fear the loss of a parent may become withdrawn, isolated, resentful, and angry, or they may begin manifesting acting-out behaviours (Wiener, 1998:316). Assessing a parent's readiness to disclose is an essential step prior to the actual disclosure. Social work interventions must be based on a developmental understanding of children's needs, emotional development and cognitive abilities. Guidelines in preparing a parent for this difficult task include the following:

- Help parents identify a place where they would like to tell their children the diagnosis and who they would like to be present.
- Assist parents in thinking what the most important message is that they want to convey to their child.
- Prepare parents for the child's potential reactions.

- Children need constant reassurance that they did not cause the illness. A child needs assurance that HIV is hard to get and you do not get it from hugging, kissing, sharing food, dishes or bathrooms.
- The parent should also prepare the child that he or she may look different as the disease progresses and may even be hospitalised. Prepare the child that the parent may need help around the house and include children in the care of the sick parent.
- Share plans for the child's future with him or her. The child may be concerned about who is going to care for him or her after the parent's death.
- The parent and child should talk openly about feelings such as sadness, anger, guilt as well as happy feelings and the future. Encourage the child to ask any questions and share feelings no matter how difficult the subject is.
- Encourage the family to keep life as normal as possible. Routines should be kept the same as before the parent became ill, for example, meal times, school activities.
- Suggest that the family do as many things together as possible.
- Motivate parents to provide their children with information about their own childhood such as making a memory book, writing letters or making a videotape.

Regardless of the best social work interventions, some parents will decide not to share their diagnosis with their children. This becomes problematic when the parent becomes ill and the child learns from someone other than their parent the true source of the illness.

5.5.5 Keeping children in school

Every child with a chronic illness strives to maintain as normal a lifestyle as possible. Attending school is a key source of social interaction. As medical treatment has improved more children with HIV are reaching the age to attend day care or school. A child's ability to function in the classroom depends on his or her health. A study on education for children with HIV has shown that 78-93% of children with symptomatic infection experience some developmental abnormality, which may affect classroom functioning

(Task Force on Pediatric AIDS, 1991:645-647). Many of these children will need specialised placements to function in a school setting. As the disease progresses, neuropsychological changes may occur, necessitating adaptations in the child's educational programme. When children become more ill, medical appointments and hospitalisations increase, adversely affecting school performance.

When a child with HIV is ready to enter day care or school, parents are apt to ask for assistance regarding whether or not to notify the school about the infection. The social worker may facilitate meetings between the parents and the school to develop a viable plan for the child. There may be a need for additional meetings as the child's illness progresses (Taylor-Brown, 1998b:370). The social worker can explore possible reactions to the disclosure in order to help parents consider their options. Advantages and disadvantages of disclosure should be explored. By engaging parents in this process, the social worker strengthens their sense of control as a parent. The social worker's task is to provide guidance to families about how to negotiate with the school system. Social workers need to familiarise themselves with the national laws on education and school policies on HIV and Aids and the rights to obtain an education for their child while the school may need to be reminded about its responsibility to provide this care. They need to empower families in accessing legal counsel when necessary.

Affected and infected children need supportive services that emphasise normative development and coping. There also needs to be greater effort to help children adjust to and survive the illness. Schools may play a crucial role in helping children adjust to the major challenges they are facing with HIV disease and provide support structures. When the school is uninformed, the possibility of supplemental services does not exist (Taylor-Brown, 1998b:363). While many day care centre and schools successfully integrate children with HIV, some are not as receptive. Fears of getting the virus casually can affect the child's integration into the classroom. The social worker needs to educate staff, students and parents regarding HIV disease and universal precautions to ensure that all children and staff are protected and address misconceptions regarding HIV.

5.5.6 Caring for children who are HIV positive

Although there is no cure for Aids, the symptoms of Aids can be treated. After receiving a diagnosis of HIV, many adolescents seek more information in an attempt to make sense of their health status. Denial and acceptance alternate throughout this information-gathering process. Information becomes for some a mechanism to regulate fear and uncertainty for both child and family. Social workers can direct clients to appropriate journals and books, since information about the latest treatment and research can readily enhance coping. Some adolescents that are denying their HIV- status do not want to know about treatment or the status of their illness. Their denial behaviours may include a lack of cooperation regarding medical involvement, non compliance with medication, problematic lifestyle habits and a disinterest to monitor T-cell counts. Social workers can discuss ways of managing their disease and a means of developing the semblance of a normal life issues related to relationships, secrecy, stigma, sexual practices and fears associated with rejection in both individual counselling and support groups (Sunenblick, 1998:398).

An essential component to providing psychosocial support to HIV-infected children, adolescents and families is a comprehensive assessment that identifies each family's strengths and vulnerabilities. Clinical support services are often a significant resource to children with HIV and their families. These services can take on many modalities, individual, family or group and often complement one another. For the child, play therapy can provide a safe haven to work through feelings of isolation, separation and abandonment or to learn to cope with medical procedures. Displacement activities, such as storytelling and art are other important interventions that often help school-age children begin to address their worries. Drawing a picture or writing a story can be used to explore feelings within a safe modality. This often leads to direct communication of the child's thoughts, feelings, fears and anxieties. Support groups are effective in reducing emotional isolation and providing a safe therapeutic environment to explore issues (Wiener, 1998:322).

Community action is a powerful weapon. The strongest educational and prevention efforts are those that involve all parts of the community, businesses, schools, civic groups, volunteer groups, religious organisations and individuals. Social workers and other members of the helping profession must start educating policy makers. Policy makers should strive to develop public information campaigns that include many youth-oriented materials. Policies should aim toward developing community-based, regional and national prevention programmes. Not all youth can be reached through the schools. Educational efforts should include street outreach, clinic-based education, counselling, testing, referral programmes and programmes that address the specific needs of runaways, migrants, homeless and other youth at risk.

5.5.7 Support for orphans and other vulnerable children

Neither words nor statistics can adequately capture the human tragedy of children grieving for dying or dead parents, stigmatised by society through association with HIV and Aids, plunged into economic crisis and insecurity by their parents' death, and struggling without services or support systems in impoverished communities (UNICEF, 1999:8).

The Aids epidemic has left behind millions of orphans and other children made vulnerable by HIV and Aids in Africa, and the conditions in which these children live are often appalling. The extended family system in communities most affected with Aids is greatly overextended and can often no longer take care of its orphaned children. Stigma associated with Aids deaths in communities, results in many families that do not want to look after Aids orphans (UNAIDS, 2000, 2004). As the number of adults dying of Aids rises, increasing numbers of orphans will grow up without parental care and love and be deprived of basic rights to the family land or house. Because children usually no longer have access to education and lack of family support of any kind, they often end up living on the streets.

It is extremely important to identify orphans and other children made vulnerable by HIV and Aids in communities and provide support for them. Community-based approaches to caring for orphans and other vulnerable children are the best way of meeting the child's physical, psychological, emotional, educational, spiritual and social needs in a synergistic way. A circle of support approach can be implemented. The family and community-based caregivers will require support such as health, food, education and social services by government and NGO'S to remain viable. They need access to health, education, social and counselling services. Caregivers should contact the Department of Social Development to enquire about current social security provisions for children in the form of child support grants and foster child care grants as described in the South Africa Child Care Act (74/1983). Religious organisations can play an important role in providing them with necessary support. Only through an enormous commitment of resources can the world hope to contain the HIV and Aids pandemic and care for those who are ill (WHO, 1993).

The following models of care and support for orphans and other vulnerable children exist in South Africa as identified by the South African Law Commission (Van Dyk, 2005:276).

- Independent living of orphans (including child-headed families).
- Independent living of orphans with external support and supervision (including child-headed families).
- Foster care including traditional family, cluster care of multiple children and collective care of individuals or multiple children.
- Adoption.
- Institutional care including places of safety, shelters, short-term infant homes and traditional children's homes or orphanages.
- State or NGO-sponsored community-based support structures including feeding schemes and day-care facilities.

5.6 CARE FOR THE DYING

Death touches every individual and family and society. It is during the period immediately after the diagnosis of life-threatening illness such as Aids until shortly before death that individuals and families can greatly benefit from skilled mental health interventions. These interventions may help all concerned to express the feelings and fears they are experiencing, balancing hope with the realities of having a life-threatening illness, preparing for the end of life, ensuring that the dying person will be in as much control of his or her life as possible during the final part of life and saying good-bye to those people who are closest.

Social workers need to prepare clients and their families for the end of life issues, especially when the client is a single parent and has not made any provisions for who will care for his or her children when they become too ill to parent actively or who will have custody of the children following death (Shernoff, 1998:43).

5.6.1 End of life issues

When an individual has a life-threatening illness such as cancer or Aids, it is often difficult for all concerned to determine when the person has made a transition from living with this illness to starting to die from it. It is often even more difficult to tell when the people around the individual should acknowledge that dying has entered the relationship. At a certain point, different for each individual, one must all let go of living well and begin to consider the concept of "dying well."

People with Aids who have become debilitated after going through extensive treatment often speak of being ready to die since they no longer have a meaningful quality of life (Rabkin, Remien & Wilson, 1994:147). It is imperative for the therapist not to judge this feeling and to elicit how the client feels about approaching the end of his or her life. One of the most important functions of the social worker will be as liaison between the client and his or her family, between the client and physician or other health care providers or

home care agencies and between the client and social service agencies. Assisting people who are dying and their significant others is founded upon the professional's ability to be comfortable with helping people directly confront some of life's most painful issues and decisions. If the mental health professional has not examined personal beliefs surrounding death, he or she will not be able to initiate discussions about this with patients.

5.6.1.1 Preparing for serious illness

As people develop symptoms of advanced Aids, they increasingly lose control over their bodies and lives. One task of counselling is to help people living with HIV and Aids to recognise what they can control.

Family therapy can be a valuable tool to help family members adjust to the changes that the progression of a loved one's illness has on the family structure and dynamics. Clients living with a progressive disease such as Aids require help in planning for debilitating illnesses. It is best for the social worker to raise the difficult and painful issues discussed long before any associated problems arise. This ensures that the client is still well and is, therefore, more likely to have the necessary physical and psychic energy to plan for the ensuing difficult realities. Social workers need to question clients' unwillingness to discuss concrete plans or desires for a living will or treatment options. Therapists should emphasise the importance of addressing these difficult issues while the client can ensure that they will have a measure of control over what happens to them later. This is certainly true if the client is a single parent and has not made provisions for child care, if the client becomes too ill to parent actively, or for child custody following death. Crucial points according to Shernoff (1998:43) to discuss with clients are:

- The client needs to know if he/she wants to be taken to a hospital in the event of an emergency and who in their support system knows this.

- If clients live alone or with small children, who is the contact person, even in the middle of the night, to provide transportation to the hospital and/or the care for children during a crisis.
- Clients need to maintain a list of all prescribed medication and dosages that can be brought to the hospital during an emergency admission.
- Clients need to discuss advanced medical directives that include whether they wish to be kept alive or not to be resuscitated if there is no reasonable hope for recovery or for a good quality of life. Clients need to be reminded that they can always revise these instructions if any of their feelings change over the course of their illness.
- A living will should be prepared. These directives need to be written down and given to the physician and brought to the hospital to be placed in the chart at the start of each hospitalisation.

5.6.1.2 Categories of dying

During the end stage of living with HIV, it is common for people to reminisce about their life. They often know they are living on borrowed time and may want to complete unfinished business. Social workers or caregivers need to inquire if there are final conversations they wish to have with family members and friends. In this final stage of life, the patient usually turns inward. This withdrawal is normal and expectable behaviour. As patients are preparing to lose everyone and everything, they begin to disengage and distance themselves. Families need to respect this behaviour and need to give them permission to die (Giulino, 1998:175).

Follansbee (1996:5) describes four categories of dying, two of which are primarily psychological and two of which are primarily physical. For social workers to intervene effectively with people living with or dying from HIV or Aids, an understanding of these categories is very helpful, especially when helping a client conceptualise where he or she is on the continuum of the process of dying. The categories are:

- Psychic, the process of accepting death.
- Sociologic dying, withdrawal from people and activities.

- Biological dying, the loss of human characteristics.
- Physiologic dying represents the failure of the body's organs, the state that most recognise as death.

By introducing the above-mentioned categories of dying, social workers can help patients to recognise the difference between living with a terminal disease and dying from it. It is the role of the social worker to explore in psychotherapy with the client their feelings about whether or not to cease treatment or to continue for extra time and to help the patient evaluate whether he or she is depressed.

5.6.1.3 Pain management

Many associate the dying process with all the worst things, from pain to mental deterioration. A skilled social worker can help the client explore what it would mean to die well, and what steps need to be taken in order to promote such an outcome. The worker should ask the client questions that will offer him or her options and some control over the process.

According to Rabkin, Remien and Wilson (1994:73), most people fear that they will be in excruciating pain as they near death from a terminal illness. People need to be taught to describe explicitly how much pain they are experiencing and to communicate this clearly to the physician. Pain can be effectively controlled even if the client decides to die at home. In addition, therapists can help clients who experience pain by teaching them the techniques of visualisation.

5.6.1.4 Preparation for death

One of the issues dying people have is that they will have no control over what happens. Social workers can empower clients at the end of their lives by discussions about where they want to die. It can be enormously helpful if the therapist raises the issue and explains the concept of hospice care. One useful intervention is to suggest that an intake

worker from hospice visits the client and his or her family to describe the process in detail.

Working with people with Aids who are dying and their loved ones requires the ability to engage in conversations about quality of life, spirituality, dying and death. Dying patients want to do some intra-psychic exploration, the content of sessions usually focuses increasingly on practical issues related to death, unfinished business with important loved ones, and feelings accompanying the knowledge that their lives are ending. The professional needs to inquire about the patient's spiritual beliefs and the comfort he or she may derive from traditional religious beliefs and institutions. Religion may be comforting and important to a client.

Health care professionals must do everything in their power to ensure that the needs of dying clients are met, for example, aggressive control of pain and anxiety. As Follansbee (1996:6) states, "the dignity of a peaceful death, without pain, fear or futile therapy can be realised only if time is spent in its preparation". Most people fear dying alone. Thus, all therapists can be of enormous assistance by ensuring that clients are not alone at the time of their deaths.

5.6.1.5 Funerals and memorial services

A way of empowering dying clients is by urging them to discuss what they wish done with their bodies after they have died. Confronting these details may be too stressful for some individuals who cannot face making those plans. For those who have been able to discuss these issues during counselling, the next step is to encourage the client to discuss them with family members. If the family or loved ones refuse to discuss these issues, the social worker should encourage them to work through their feelings of denial, sadness and discomfort in counselling. These family sessions can help families to carry out the client's wishes after they have passed away. It is a useful intervention to restructure the reality from one of morbid preoccupation with the unpleasant inevitability to allow the person who is ill to take control over the few areas of their life that are still controllable.

Establishing post death details is one way the person who is dying is still able to take care of loved ones (Shernoff, 1998:45).

5.6.2 Grief and bereavement

Grief and bereavement are a part of every human being's experience. The effects of grief on human coping are profound. If one does not have the opportunity to express one's grief and receive support concerning grief, long term implications of mental health may ensue. The bereavement experienced by a person who has lost a loved one and the bereavement experienced by a terminally ill or dying person are very similar. Both experience a deep sense of loss, loss of a loved one, loss of future, hope, health, self-esteem and well being as well as dignity as a human being. In either case people are confronted with their own mortality and imminent death.

In the HIV and Aids scenario the social worker is confronted with a dual process of bereavement of the HIV-positive person as well as those who will be left behind when the client dies. The process of bereavement also begins for the significant others of the infected person as they are forced to witness how their loved one gradually loses all the features of normal health and active human existence. The separation or loss initiates a process of grief. Grief is a very basic biological reaction that may cause aggressive behaviour and stimulates attempts to regain the lost object. Elisabeth Kubler-Ross (1997) examined the many and varied reactions to loss and found similarities according to which she identified the various stages of grieving that someone may go through, as well as the issues they may be dealing with during the grieving process.

5.6.2.1 Multiple losses

Communities dealing with HIV and Aids are confronting multiple loss and bereavement overload. People dealing with the loss of someone to Aids have often lost more than one person to this disease. Individuals are often confused by their feelings and overwhelmed by the number of deaths they have experienced. They also experience symptoms similar

to post-traumatic stress disorder, including numbness, depression and potentially self-destructive behaviour. It is important to provide opportunities for people to feel all their emotions as part of the grieving process. Clients must have the opportunity to think about what they need as a community to move forward in their grief.

The literature on bereavement encourages people to participate in support groups because one of the key components of bereavement support is preventing isolation from others who are experiencing a similar situation. This is particularly true of people who have had a loss due to Aids because of the stigma associated with HIV. The social worker should identify if a person is interested in connecting with a group of people who are experiencing a similar loss or prefers one-on-one support.

5.6.2.2 Bereavement counselling

Counselling HIV-positive clients is often extra-ordinarily difficult, especially counselling on emotional and religious issues resulting from the disease, such as sexually transmittance. HIV-positive people are reluctant to expose their true feelings and experiences in counselling sessions because of their expectation of being condemned and judged (Van Dyk, 2005:249). Spiritual beliefs can be a source of comfort during the grieving process. Forgiveness and ways of cleansing the mind and body are basic to all religions. It should be emphasised that HIV-infection is not a condemnation or the end of the road for infected individuals. It is an opportunity for them to prepare themselves properly for the remainder of their lives and for their transition to another world. One of the most important functions of religion is to provide coping strategies for accepting the inevitability of death. A feature of spiritual and religious counselling is that, as hope for physical recovery gradually diminishes, the patient's approaching death is counteracted by an increased emphasis on eternal hope – the hope that the person will continue to enjoy a spiritual life in another world after death.

Grief is a complex and lifelong process. The assessment of the needs of people who are grieving is the most critical role that the social worker can take in supporting someone

through the grieving process. Social workers can assist their clients in various ways to actualise their loss. Although it may seem inadequate to some, talking about one's grief is still one of the most important ways of getting to grips with it. According to Van Dyk (2005:239), narrative treatment theory can be utilised in providing counselling to bereaved individuals. Grieving people need to tell their story and the story of the person who died. In the telling of this story, grieving people begin to make meaning of the loss and to adjust to a new life without the deceased person and they develop a new understanding of the process and gather new insights. It is important to give people the opportunity to reflect on their relationship with the deceased person. It is strongly encouraged to discuss both the good and the difficult parts of the relationship. It is also important for people to invest in new relationships and to make connections that allow them to move forward in their life. Practical techniques that may be used to facilitate the mourning process are objects and memorabilia, imagery, writing, drawing, role playing, cognitive restructuring and memory books.

HIV has affected many cultures and the needs and responses of these groups to death and dying and the grief process are extremely varied. Some communities are accustomed to limited discussions and feelings and in other cultures expressing grief in loud and dramatic ways is considered absolutely essential to show their feelings regarding the death. It is important to provide psychotherapeutic or emotional support for people who are grieving, but also educational support to family and friends who are grieving (Brennan, 1998:140).

Grieving people are often isolated and, therefore, social workers have to be creative about the ways in which opportunities are provided to do grief work. Bereavement programmes should include individual, group and social supports. Rituals can also be used in coping with loss. Memorial services, music concerts, memorial quilting, candle lighting and other kinds of rituals can be beneficial in helping people heal their losses. Volunteering and political action are often ways for people who are trying to heal their grief. These interventions have the added benefit of successfully decreasing isolation.

5.6.2.3 Helping children cope with death

Many societies and cultures hold myths and misconceptions about children's understanding of death (Pequegnat & Szapocknik, 2000:165). These myths tend to deny children opportunities to talk about their grief or to mourn with the help of a supportive adult. These misconceptions, in turn, are integrally tied to adults' poor understanding about what children of different ages understand about death. A child's understanding of the meaning and causes of death is closely associated with developmental stage. Young children may be unable to grasp the abstract concept of death, but they do understand and grieve a loss. However, by age 7 or 8, children generally understand that death is final, and by age 10 or 11, they can understand the causes of death (Citron *et al.*, 2005:189). Although children can understand death and do grieve, children do not mourn like adults. They may acknowledge loss of the parent in the real world but try to maintain a relationship with the dead parent in their inner world.

Research found that for most children, psychological problems after parental death are not short-term grief reactions because many children exhibit their first serious symptoms years after the loss. Pequegnat & Szapocknik (2000: 159) found that 52% of children had severe psychological disturbance 18 months after the death of a father. Given the predicted rise in the number of orphaned youth, the need for preventive interventions to address risk for psychological disturbance cannot be over emphasised. Adults need to handle a child's grief reactions and concerns in a developmentally appropriate way. However, adults may be afraid to deal directly with a child in explaining the death of a loved one, not realising that children are capable of understanding and expressing a wide range of reactions to someone's dying (Pequegnat & Szapocknik, 2000:165). Lack of communication may deprive children of the needed opportunity to express feelings of loss and anger, ask questions, and adequately process their grief reactions. The subsequent suppression of feeling can deepen depression and so delay the resolution of the bereavement process.

Disclosure of parental illness (but not necessarily HIV) to child and caregiver is necessary to prepare the child for parental death and to develop a custody plan. It is a necessary component to encourage open communication so that the child can talk about his or her feelings and fears. To avoid unnecessary pileup after maternal death, social workers should develop a viable custody plan with the mother; in particular, this will help avoid unnecessary multiple placements after death. In addition, new caregivers will need counselling on the importance of maintaining a stable, regular routine for the child, including assuring contact with friends and siblings. New resources need to be arranged after parental death by identifying financial and housing services for new caregivers. In addition, the social support systems of both the caregiver and child need to be assessed and enhanced because emotional and practical support has been shown to be related to a child's adjustment to stressors. Pequegnat & Szapocknik (2000:163) found that childhood resilience is in part determined by the presence of a caring adult, thus adaption will be enhanced by facilitating a positive relationship of caregiver and child.

5.6.2.4 Creative ways of helping the bereaved and permanency planning

All parents hope to care for their children until they are ready to establish independent lives as young adults. HIV threatens a parent's ability to accomplish this. Creating a legacy is not something that many HIV-infected parents will initiate so usually a social worker introduces the topic. It is a proactive approach that empowers parents by providing them with a medium to leave a legacy for their children, preserve family memories, family values and beliefs for the generations to come (Wiener & Taylor-Brown, 1998:344). Parents are able to tell their children in their own words what they hope for their future and to provide ways for the children to remember them.

Creating a legacy can lay the foundation for exploring the parent's painful reality of premature parental death. In the process of healthy development, children strive on both a conscious and an unconscious level to maintain psychological access to their deceased parent. They often hold on tight to whatever concrete evidence of their parent that they can find as a means of maintaining a link to him or her. The social worker can explore

different legacy options, including writing letters, collecting photographs, creating a family tree, and making audio or videotapes. Special jewellery, art work, clothing or other treasured possessions are also part of preserving a parent's heritage (Wiener & Taylor-Brown, 1998:340).

In context of creating a legacy for children, the social worker can facilitate early permanency planning by discussing this emotional topic with the parents and emphasising that it's a way to shape their children's uncertain future positively. This is a supportive approach in a future without parents. A major consequence of this pandemic is the large and growing number of Aids orphans. Extended family members, grandparents and friends are trying to care for the children who have experienced parental loss. Foster care and adoption are options when the family is unable to intervene (South Africa Child Care Act 74/1983). The social worker can explore with parents different options to pursue to ensure that their children are adequately provided for when the parent is no longer able. A concern of parents is keeping siblings together, but it is not always possible for relatives or foster care families to care for so many children. According to Taylor-Brown (1998c:350), social workers need to familiarise themselves with the options available to their clients. These include informal arrangement for children's future placement, designation of a guardian in a will, adoption and voluntary and involuntary placement in foster care. Careful monitoring of a parent's emotional state and supportive counselling may help prepare him or her to make the necessary arrangements. The social worker who works closely with parents should be prepared to intervene when the parent requests it or when the parent dies. The social worker can explore future childcare options with parents in order to help them avoid a situation in which custody is relinquished to the state after their death.

Parental death is often a symbolic ending of the child's life as he or she has known it. The reconstituted family will benefit from clinical services addressing the loss experiences and the adjustments needed as the new family begins. Losses include parental loss, loss of the family the child knew, and sometimes the loss of sibling relationships when children are placed in separate homes. Social workers are at the fore

front of efforts to help the family of origin and the reconstructed family to cope with parental loss. Bereaved children may act out their feelings of loss. The new guardians may benefit from education and guidance about the process of grieving and assistance in being supportive to the child who is trying to make sense of all that has happened (Taylor-Brown, 1998c:349,353).

5.6.2.5 Potential barriers to successful intervention

Bereavement issues that cause a barrier to successful intervention include concerns for the persons who, because of the stigma surrounding Aids are less likely to turn to their extended family, friends and churches for support. This leaves families isolated and at risk for retreating into possible feelings of shame for lying about the diagnosis or for having ambivalent feelings about the person who died, feelings they did not have time to deal with prior to the death. If family members cannot speak truthfully about the diagnosis, no one can appreciate the depth of their pain.

Bereavement services are often considered secondary and not primary care. If people do not get to grieve, they may internalise their feelings of shame and isolation. This can result in depression or other situations in which clients do not take good care of themselves, including relapse into substance use or unsafe sex. Grief work must be seen as preventative work to assist people who are struggling with overwhelming loss and struggle to move forward in their life (Brennan, 1998:142).

5.7 RIGHTS OF AN HIV PERSON IN THE WORKPLACE

South Africa is believed to have one of the highest infection rates in Africa. It has been estimated that by December 2005, approximately 6.6 million South Africans are living with HIV and Aids (Page, Louw & Pakkiri, 2006:91). According to People Management (2006:20), the age groups most infected by HIV and Aids are those between the ages of 20 and 45. These age groups account for those either entering the job market or those in the early part of their working career. These people are expected to be the breadwinner at

home and skilled labourer at the work place for many years to come. If these infected workers not have access to anti-retroviral medication, a significant reduction in skilled workers will be seen due to early mortality.

South Africa has one of the largest HIV-infected populations in the world. This will affect economic growth in future because it results in:

- A decline in the size of the working age population.
- A reduction or downturn in their productivity.
- Rising medical costs and health care and increase in retirement plans and insurance payments.

As a result, employers have a great opportunity and responsibility to educate their workforce about HIV. Many companies have active HIV educational programmes. Unfortunately, HIV education is not implemented at many work sites until an employee reveals that he or she is infected. Employees with HIV have some special needs at certain points of their disease progression. Employers have to take on the HIV-positive employee's health and work load, as well as take any adaptations the company will need to make for reasonable accommodation into consideration. A responsive HIV education plan includes a workplace policy on HIV and Aids. In a draft guideline document, the South Africa Department of Labour (2000) recommended that every organisation needs to develop a suitable HIV and Aids policy.

5.7.1 Purpose of workplace policy on HIV and Aids

The main purpose of the policy is to ensure that employees affected by HIV and Aids are not discriminated against in employment practices. A company's HIV and Aids policy should define the company's position and practices in dealing with the disease in the workplace. With such a policy, standards on how employees should behave will be set, and how communication about HIV and Aids should be handled. The policy should inform employees where they can go if they need assistance or information, and advise

supervisors and managers on how to deal with HIV and Aids in the workplace (Page, Louw & Pakkiri, 2006:110).

The HIV and Aids policy of an organisation should cover the following:

- The organisation's position on HIV and Aids.
- An outline on the HIV and Aids programme.
- Details on employment policies.
- Express standards of behaviour expected of all employers, employees and trade unions.
- Grievance procedures.
- Communication strategies.
- Employee assistance programmes.
- Roles and responsibilities of participating role players.
- Monitoring and evaluation mechanisms.

5.7.2 Services to people with HIV and Aids in the workplace

An effective HIV and Aids workplace programme encourages employees to know their HIV status. A very important aspect of such a programme is the management and support of those infected, because the main objective of encouraging employees to know their status is to ensure that they lead healthy and productive lives. Assistance that companies provide may include:

- On-site social workers. Social workers can assist the employee and his/her family to come to terms with the reality of their status.
- Employee Assistance Programmes (EAP). These are usually managed by external companies who specialise in counselling services. Employees sometimes prefer EAP services as they believe them to be more confidential than in-house social workers.
- Companies such as Sasol, De Beers and Anglo are only a few South African-based companies that provide subsidised antiretroviral medication to employees.

Provision of antiretroviral medication is normally managed by external companies and ensures that employees remain healthy until such a point as they require treatment.

- Community-based support. Companies should provide employees with a list of resources available within their community. Employees should have the choice between in-house or community-based support.
- Wellness programmes. The main objective of such a programme is healthy living on all levels – physically, mentally and spiritually. Wellness programmes encourage employees to take responsibility for their health and manage their stress constructively. Successful wellness programmes should give employees practical advice and must cater for all income groups and religions.

Management and support for HIV-positive employees will only be successful if the workplace promotes fair treatment of those infected and de-stigmatisation of the HIV and Aids virus (Van Wyk, 2007:26-27). The Constitution of South Africa Act (108/1996) and the South Africa Promotion of Equality and Prevention of Unfair Discrimination Act (4 /2000) make it illegal for anyone to discriminate unfairly against anyone who has HIV.

There are many laws protecting the employee's rights at work. The language of some of the Acts is sometimes difficult to understand. The social worker can educate people infected with HIV on their rights, or refer them to support systems in the community who can help them, like the AIDS Law Project.

6. DISCUSSION

- Aids has become woven into the fabric of our society. As social workers, one has a responsibility to help clients understand how Aids impacts their lives and how to protect themselves from this disease. Risk assessment for HIV infection must become an integral part of the clinical work as one helps the clients reach their goal of achieving healthy and satisfying lives.

- Due to the severity of the HIV and Aids pandemic, social workers, as professionals, cannot act indifferently towards service delivery in communities. It is extremely essential that social workers should make their services fully available to the communities in rural areas and especially also in the remote rural areas.
- HIV and Aids challenges all aspects of modern life and counselling must adopt a holistic approach that takes all aspects of modern life into account. Clients need information and knowledge to cope with the disease (cognitive information) and they also need to be equipped to cope emotionally and spiritually with the ravages of the disease.
- Those who are doing well on treatment find that living with HIV as a chronic manageable condition is not necessarily as simple as that the epidemic is over. People face a complex set of issues in going about the profound task of reconstructing the future. Recreating a sense of having a future is an awesome, complex task. For those who were fortunate to have a sense of purpose, did meaningful work and had positive relationships with friends and family, going back to the future is likely to be joyful. However, for the growing numbers of HIV-positive individuals who had limited job skills and opportunities, felt isolated or depressed, the future may be more fearful (Rose, 1998:68). One of the social worker's tasks is to help the client balance a realistic sense of hope with practical issues inherent in learning to live with HIV and Aids.
- The role of the social worker regarding the biomedical facts, guidelines on HIV prevention, HIV-testing and antiretroviral medication, guidelines on promoting wellness and stress management skills, guidelines on nursing people with Aids-related illnesses, tips on using social networks, caring for children in the face of the pandemic, government grants and non-governmental structures to give and gain psychosocial and socioeconomic support, care for the dying and grief-counselling skills, as well as information on the rights of an HIV-positive person in the workplace, were studied and social workers have much to bring to this field of practice. The traditional broad psychosocial perspective encourages social workers to be sensitive to all of the factors that impact the life of a person with HIV.

- Social workers have the expertise to work with individuals, couples, families, groups and communities. They call upon multiple roles depending on the situation such as counsellor, social broker, organiser, advocate, programme and policy developer, and social change agent. This is the flexibility, creativity, the breadth of vision and the multiple service roles that responding to HIV and Aids requires (Aronstein & Thompson, 1998:xxii).
- Since it is evident that social work is an essential profession in addressing the needs of those infected with and affected by HIV and Aids, it is recommended that the social work student be empowered with information on all aspects of this pandemic.

7. CONCLUSION

Social workers have been actively involved in the HIV epidemic from the beginning. They have responded with their clinical skills to help individuals, couples and families deal with the trauma of learning about the infection, with the "roller coaster" of disease progression, and frequently with confronting the final stages of disease and death. They have responded with their organisational and political skills, helping with the founding and implementation of community-based organisations to educate and advocate on behalf of people with HIV and Aids. Social workers have also responded with their research skills to help demonstrate "what works" in interventions aimed at helping people with HIV and Aids and their loved ones.

This study indicates that social work as a profession is essential in the lives of communities, especially in rural areas. Social workers have ethical principals and standards that they utilise in order to help people. They also have responsibilities towards their communities. To ensure that they deliver an effective service, there are skills and knowledge that each social worker needs to have.

Aids, a new medical, social, psychological an political phenomenon emerged in the late twentieth century at a time of maturity of the social work profession and challenges the social work profession. Aids has placed demands and expectations on the profession to

remember its core values of self-determination, the dignity and worth of the individual, justice and commitment to the poor and the vulnerable. As a result local, regional, national and international conferences and continuing education programmes on HIV and Aids for social workers have been developed. This chapter emphasises the important role the social worker plays in the face of this pandemic. The purpose of the HIV and Aids education is not only to disseminate information, but also to change attitudes and behaviour, to equip people with necessary life skills, to empower them to prevent the spread of HIV infection and to care for the people already infected.

In the next chapter an HIV and Aids empowerment programme for social work students is developed to educate the social work student with the necessary knowledge and skills to ensure that they are competent to deliver an effective service to those people infected with and affected by HIV and Aids. This next chapter contains a detailed workbook for the fourth year social work student with information on the intervention topics for each session and icebreakers and exercises to be worked on with the facilitator and tasks to be accomplished between sessions, as well as a toolkit, added as an addendum, with practical resource material, posters, booklets, colouring-in books, play cards and relaxation CD. The intent is to make the workbook as simple and user-friendly as possible while encouraging both adherence to the intervention and quality control.

CHAPTER 6

THE DEVELOPMENT OF AN EMPOWERMENT PROGRAMME FOR SOCIAL WORK STUDENTS REGARDING HIV AND AIDS: ADAPTED REDS PROGRAMME

1. INTRODUCTION

Since HIV and Aids was first recognised as a new health problem in the USA in 1981, counsellors and other professionals have been at the forefront of care-giving to people infected with or affected by HIV. Alongside the rapid advances over the decade in the fields of epidemiology, virology, immunology, clinical management, nursing care, clinical therapy and prohylaxis, there has been a supreme effort to understand more about the psychosocial sequelae of HIV disease and to translate that comprehension into counseling (Aronstein & Thompson, 1998:xxi).

This chapter is not meant to be an introduction to the basics of HIV and Aids, either medically or psychosocially. It is rather an effort in continuing to provide professionals in the field and students in training with the most current practice information about psycho-social health practice and HIV and Aids. With this in mind the content of this chapter includes the role that the social worker has regarding the biomedical facts, guidelines on HIV prevention, HIV-testing and antiretroviral medication, guidelines on promoting wellness and stress management skills, guidelines on nursing people with Aids-related illnesses, tips on using social networks, caring for children in the face of the pandemic, government grants and non-governmental structures to give and gain psychosocial and socioeconomic support, care for the dying and grief-counselling skills and information on the rights of an HIV-positive person in the workplace. This content is grouped into seven modules and presented in nine sessions.

2. PROBLEM STATEMENT

Aids emerged in the late twentieth century at a time of maturity of the social work profession, as a new medical, social, psychological and political phenomenon. It disproportionately effects members of society who have been traditionally marginalised and stigmatised and has challenged the social work profession "in its stride." Aids has placed demands and expectations on the profession to remember its core values of self-determination, the dignity and worth of the individual, justice and commitment to the poor and the vulnerable. As a result local, regional, national and international conferences and continuing education programmes on HIV and Aids for social workers have been developed. The purpose of the HIV and Aids education is not only to disseminate information, but also to change attitudes and behaviour, to equip people with necessary life skills, to empower them to prevent the spread of HIV infection and to care for the people already infected.

People from Aids-affected households have various needs. Those needs can be classified as physical needs, including physical care, health and nutrition, economic implications and maintenance of the family. When the parent(s) or caregiver(s) of children is affected by or infected with HIV and Aids, it will also affect the children. Aids-affected households tend to be poorer and consuming less food and left with smaller disposable incomes, and children from these households are usually less well-nourished (Bhana *et al.*, 2006; Coombe, 2003; Ebersöhn & Eloff, 2002). The emotional needs that were identified were love and support regarding discrimination and psychological and emotional impact. Spiritual care is also identified as a need.

Unavailability of or limited resources available to people with Aids, particularly in rural areas, are a major barrier to successful interventions. Many people with Aids are homeless, are inaccessible, have limited resources and support. Finances are often a potential barrier as well as geographically, if there is no organisation or support system in the rural areas. Medication noncompliance also represents a barrier to successful intervention (Surface, 2007:20). Intervention addressing the patient's resistance and

caregiver education regarding the role of antiretroviral medication in enhancing cognitive function is the best means of addressing this potential barrier. Frequent changes in the home and care providers, lack of consistency in providing the child's medical care and parental drug use, may lead to unfavourable psychosocial outcomes. Grieving people are often isolated and social workers have to be creative about the ways in which opportunities are provided to do grief work.

According to the White Paper for Social Welfare (SA, 1997:90), home-based, family orientated and community care strategies are the preferred options for coping with social consequences of HIV and Aids and the need for care. These strategies also ensure the provision of a continuum of care and normalisation of services for children who have become vulnerable due to HIV and Aids. Furthermore, it ensures that children who are infected have access to integrated services which address their basic needs for food, shelter, education, health care and family as alternative care and protection from abuse and maltreatment. The shift in incidence of the disease requires that all social workers possess specialised skills, knowledge and appropriate beliefs that promote the well-being of individuals affected with HIV and Aids, regardless of their chosen area of practice (Podolsky-Scarth, 1999), to intervene effectively with clients, their families and the community. The following question arises in this chapter:

- Can the REds programme be adapted in order to formulate an empowerment programme for fourth year social work students to empower those infected with and affected by HIV and Aids?

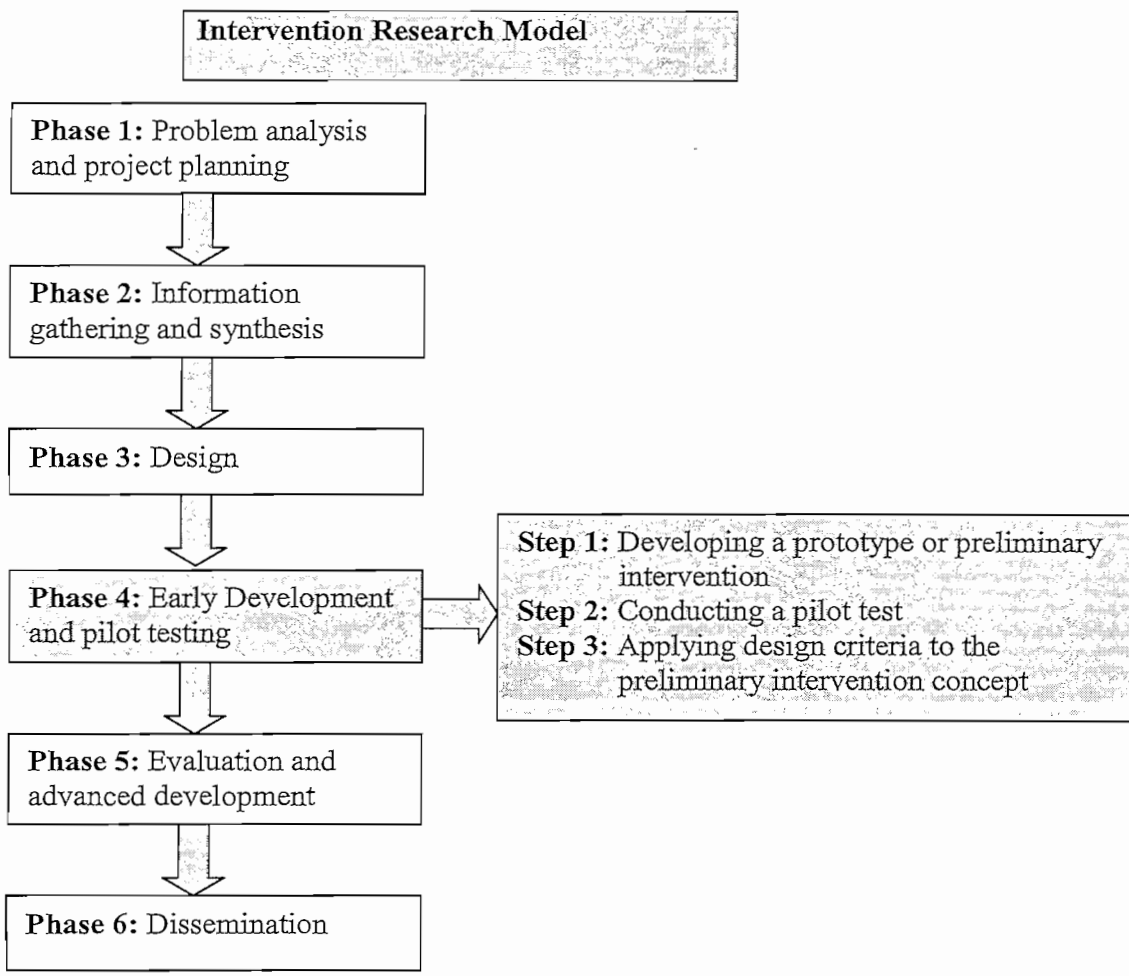
3. AIM

The aim of this chapter was to develop an empowerment programme regarding HIV and Aids for fourth year social work students by adapting the REds programme for those infected and affected by HIV and Aids.

4. RESEARCH MODEL

In this study the **intervention research model** was utilised. De Vos (2005a:394) defines it as research which is targeted to address the practice application of research. The intervention research model is a six phase model consisting, of problem analysis and project planning; information gathering and synthesis; design; early development and pilot testing; evaluation and advanced development; and dissemination. This chapter focused on phase 4, the early development and pilot testing of the newly developed empowerment programme for social work students, as seen in Figure 6.1.

FIGURE 6.1: INTERVENTION RESEARCH MODEL



The researcher will describe the steps of Phase 4 of the model and indicate how the theory was applied in practice during each step in this chapter.

Phase 4: Early development and pilot-testing

- **Step 1: Developing a prototype or preliminary intervention**

The preliminary intervention procedures are selected and specified. In order to develop a prototype for use in pilot testing, the researcher may also need to establish ways of communicating the intervention to intended users. Feedback from consumers and implementers should be obtained to help refine and simplify the prototype for the intervention (De Vos, 2005a:402; Naude, 1999:168). The researcher did a literature study on the development of an empowerment programme for social work students regarding HIV and Aids. The recommendations and comments of the educators on the REds programme were also taken into consideration to help refine the development of a new empowerment programme for students. The researcher communicated the empowerment programme to intended users through an information session at one of the fourth year social work students' classes.

- **Step 2: Conducting a pilot test**

Pilot tests are implemented in settings convenient for the researcher and are somewhat similar to ones in which the intervention will be used. These pilot tests help to determine the effectiveness of the intervention and identify which elements of the prototype may need to be revised (De Vos 2005a:402). There is always the possibility of error when collecting data. The surest protection against such errors is to test the questionnaire in full or in part by a representative sample. Adaptations made from the questionnaires used in the REds programme help to refine and determine the questionnaires to be used in the empowerment programme.

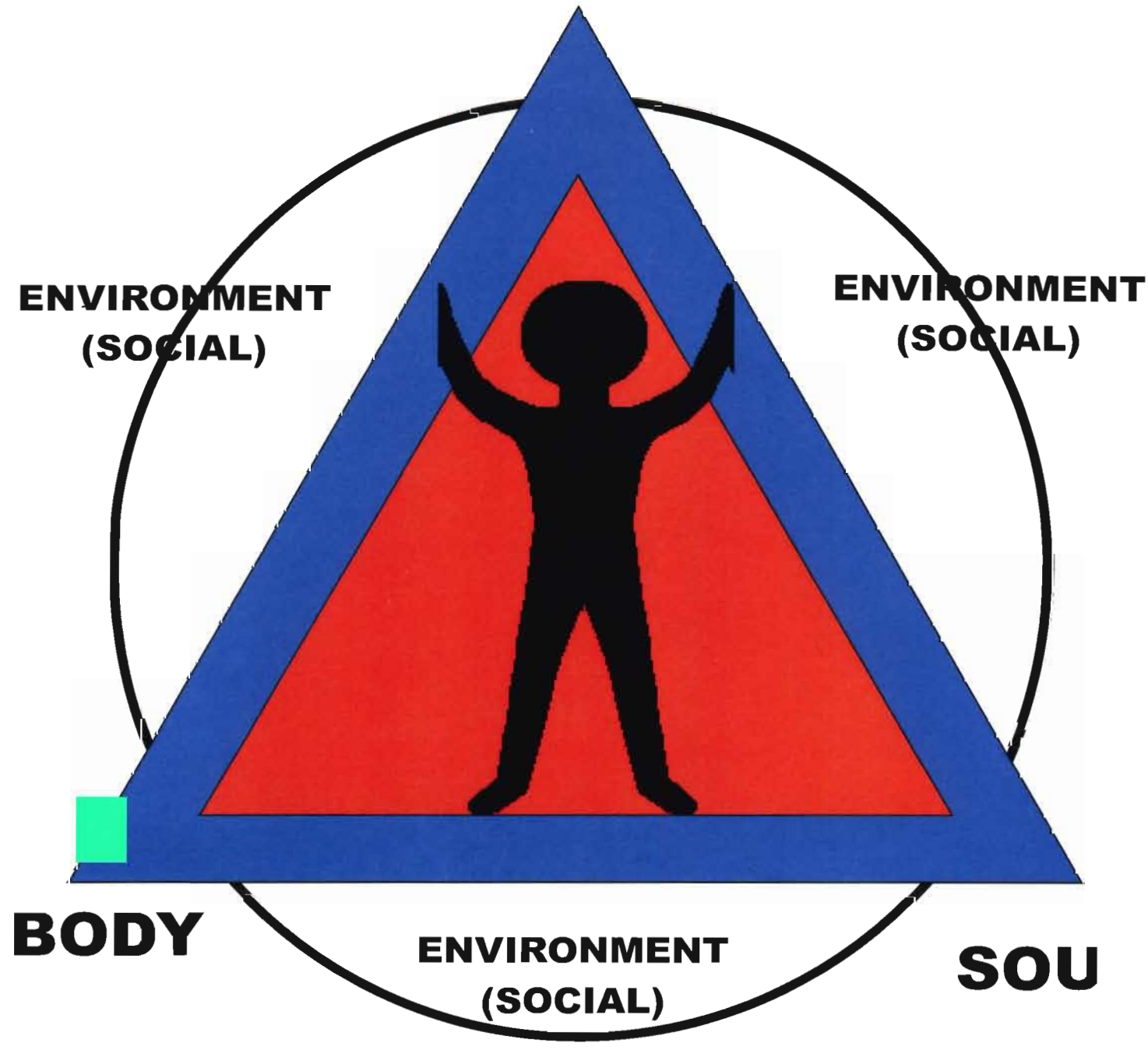
- **Step 3: Appling design criteria to the preliminary intervention concept**

By using common guidelines and values the appropriate community intervention is determined. Relevant questions include: Is the intervention effective? Is it replicable by end-users? Such criteria help to guide the design of interventions that are subjected to pilot testing and formal evaluation (De Vos, 2005a:402). It was determined that the appropriate community for this programme intervention will be the fourth year social work students. During the implementation of the empowerment programme the researcher will in collaboration with the participants make changes to the programme to make it more effective.

5. AN EMPOWERMENT PROGRAMME FOR SOCIAL WORK STUDENTS REGARDING HIV AND AIDS

The newly developed HIV and Aids empowerment programme for social work students was designed to assist the student to empower the client, those infected with and affected by HIV and Aids with accurate and vital information. A tool kit was designed to address the issue of HIV and Aids. Having well-trained, knowledgeable and highly motivated professionals working in service delivery is crucial for effective management of the HIV epidemic. The purpose of this course is to support the student to empower the HIV and Aids infected and affected individuals (reference to self, family members, friends, caregivers, community members and employers) with the correct information on HIV and Aids, the transmission and prevention. The programme also focused on the physical care and symptom management of the HIV and Aids infected individual. Later, as the person moves into the chronic and finally the terminal stages of Aids, they may become more interested in practical concerns such as making preparations for the care of children as well as in the spiritual and emotional preparation for dying. The infected and affected person and family have the main responsibility for giving care at home. The responsibility of a social worker is to provide information and counselling to enable the person infected and affected with HIV and Aids to manage their own health.

HIV AIDS EMPOWERMENT PROGRAMME FOR SOCIAL WORK STUDENTS



A HOLISTIC APPROACH

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INTRODUCTION

There can be little doubt that the same catastrophic combination of stigma, taboo and silence that continues to fuel the deadly epidemic in Sub-Saharan Africa is evident in South Africa. Educators and practitioners in health care and social services find themselves in the frontline regarding both preventing the spread of HIV and dealing with its consequences (Lerole, 1994:9).

The HIV and Aids Empowerment programme for social work students is a practical toolkit and will enable social workers to educate and counsel other people.

The overall goal of this empowerment programme is to empower people who are infected and affected by HIV and Aids. In order to cope adaptively and effectively in the midst of this pandemic, people need to have knowledge about what really causes HIV and Aids and how to prevent infections. The facts and skills in this programme will help them to understand HIV and Aids. Parents can also teach their children this knowledge and skills.

In this programme people will also learn how to care for the very sick as well as gain knowledge about resources in the community that can give support. People will also be empowered by knowledge such as dealing with death, the grief process and also how children experience the pain of loss.

There is much information and many skills to learn in this course and it will require the participant's full participation. It is a golden opportunity to express opinions and to share valuable information with fellow course-goers.

In developing this course it was endeavoured to address as many of the issues involved in an open and as educative manner as possible. Some of these issues will be sensitive or controversial – but we hope you will find it useful and feel more confident to tackle the issues raised by HIV and Aids.

This programme was compiled by Hanelie Malan and reviewed by Prof. H Strydom, North-West University, Potchefstroom.

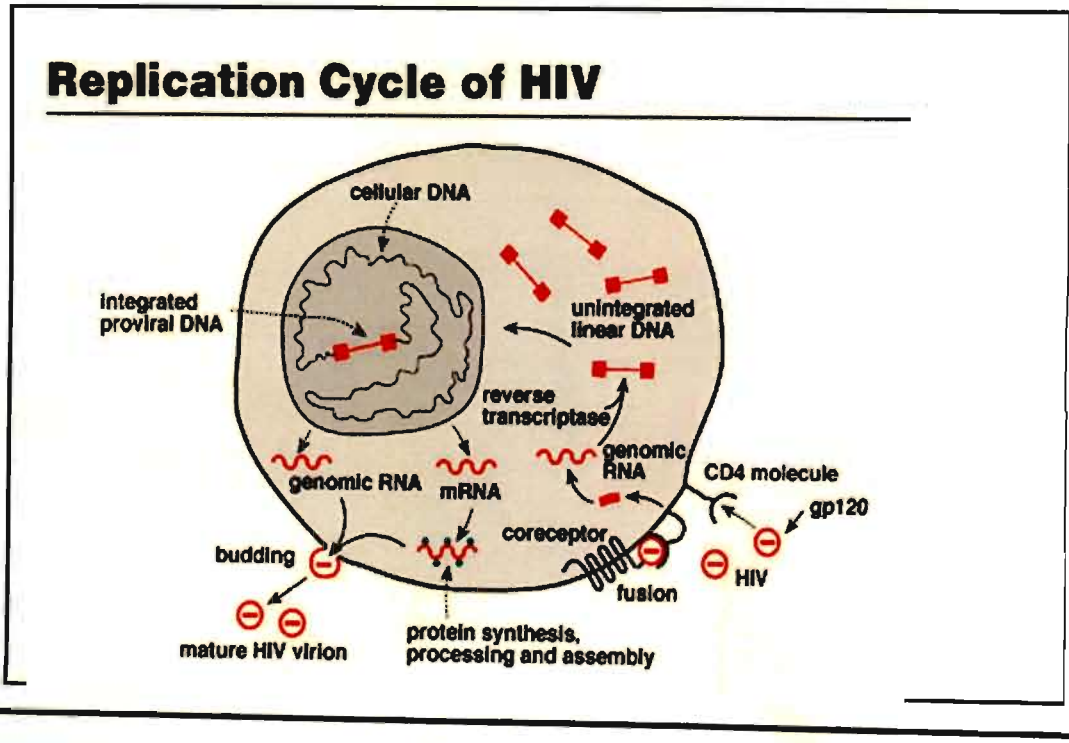
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MODULE 1:

HIV AND AIDS: A NEW CHALLENGE

1. **THE HISTORY OF HIV AND AIDS**
2. **FACTS ABOUT HIV AND AIDS**
3. **HOW DOES A PERSON GET HIV?**
4. **THE STAGES OF HIV INFECTION AND THE TIMELINE OF AIDS**
5. **HOW TO PREVENT THE SPREAD OF HIV**
6. **WHY IS HIV STILL SPREADING?**

- **Stigma/discrimination**
- **Poverty and inequality**
- **Myths about HIV**
- **Gender**



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MODULE 1: HIV AND AIDS: A NEW CHALLENGE

1. THE HISTORY OF HIV AND AIDS (Cichocki, 2006)

1980	**Dr M Gottlieb at UCLA sees a case of pneumonia and discovers that the patient's blood lacks T-helper cells (part of the immune system). 31 Deaths occur in the U.S. that are later found to be HIV-related.**
1981	**In 1981, 41 gay men in the U.S. suffered from a rare cancer – Kaposi's Sarcoma (Initial term used: gay-related immune deficiency). In U.S. 152 reported cases, 128 patients died by the end of 1981.**
1982	**The first blood transfusion recipient is identified with Aids in the U.S. Cases of Aids reported in haemophiliacs, women, infants, drug abusers – transmission of an infected agent through blood and sexual contact was suspected. 771 cases reported in U.S. and 618 deaths.**
1983	**Dr Luc Montagner and his team announce a retrovirus that probably causes Aids. Two strains of Aids are identified in Europe, one is linked to Africa. In 1983 Aids is reported in 33 countries. U.S reported 2807 new cases and 2118 deaths.**
1984	**Dr Robert Gallo and his team announce that they have found the virus HIV that causes Aids. Scientists isolate a virus that causes an Aids-like illness in monkeys. U.S. reported 7239 cases of Aids.**
1985	**Rock Hudson dies of Aids. US blood banks begin screening their blood supplies. Dr Gallo patents a test kit. Ryan White (14 year old haemophiliac) is barred from school because he is HIV positive. In Uganda and other countries in Central Africa the disease is rife.**
1987 - 1989	**The first HIV-drug (AZT) is approved by American authorities. In 1988 the health ministers around the world meet in London to discuss the HIV and Aids epidemic.**
1990	**Ronald Reagan apologises for neglecting the Aids issue during his term. The WHO estimates the number of people living with HIV and Aids worldwide at more than 1 million.**
1991 - 1992	**Magic Johnson, basketball hero, announces his HIV positive status and retirement from the game. The WHO estimates HIV infections worldwide at more than 10 million. The red ribbon becomes the Aids symbol. FDA approves the first drug to be used in combination therapy with AZT.**
2001	**South Africa, the country with the single most cases of HIV.**

*** WHO – World Health Organisation**

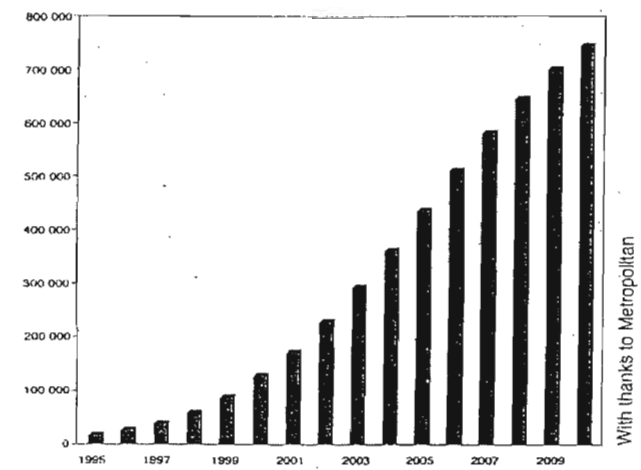
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BASIC STATISTICS

- More than 2000 people become HIV positive every day in South Africa.
- The largest percentage of people becoming HIV positive is between 19 to 35 years old.
- One out of every 5 sexually active people in South Africa are believed to be HIV positive.
- It is also reported that approximately 900 deaths per day in South Africa are due to this pandemic.
- **By comparison:**
  - Aids has killed 23.8 million people that we know of, with 3 million people dying in the year 2000 alone.
  - The flu pandemic of 1918 killed approximately 50 million people worldwide.
  - The World War II killed approximately 40 million people.

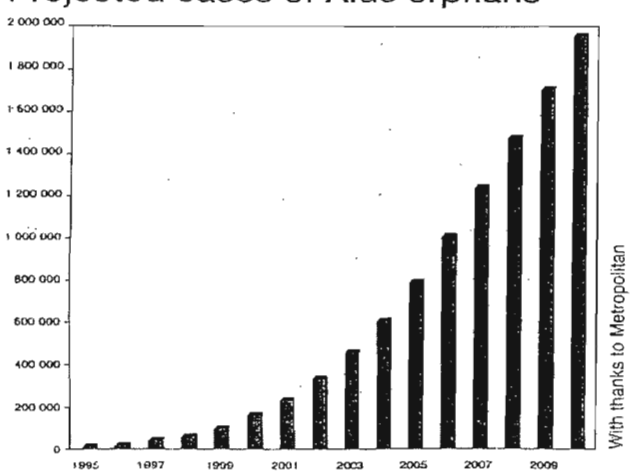
(People Management, HIV/AIDS Management Guideline Booklet, 2006:16)

Projected Aids cases in SA



- This table indicates the number of people who have progressed from the first stages of HIV to Aids.
- These people would probably already be experiencing Aids related symptoms and illnesses and therefore require medical care and need access to either private or public health services.
- In addition, the Aids related illnesses might require extended or additional periods of sick leave.

Projected cases of Aids orphans



- The additional cost to support children who have lost one or both parents to HIV and Aids will result in an increased burden upon the state to provide social welfare grants that will cover the cost of food, housing as well as education and medical care of these children.
- If children are not supported by a welfare grant they will be forced to leave the education system at an early age to seek employment.
- If employment cannot be secured, these children will be forced into a life of crime in order to survive.

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2. FACTS ABOUT HIV AND AIDS

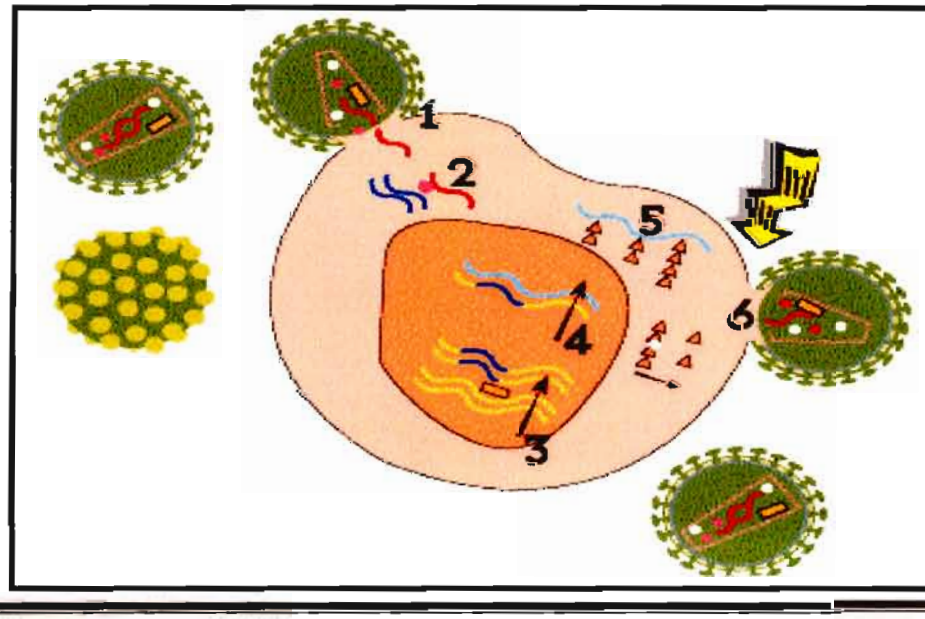
Viruses are extremely small organisms. The HIV virus is so tiny that more than 5000 of the virus can fit on the head of a pin. Viruses can only be seen with a powerful microscope called an electron microscope.

There are thousands of different types of viruses that infect the cells of plants and animals/humans, they cannot do anything for themselves outside of a plant or animal or human cell.

Viruses have to 'hijack' cells of a host plant or animal or human to become active, and to reproduce themselve. Some viruses cause diseases when they are active in plants and animal/human cells. Examples of human diseases caused by viruses are measles, chicken pox, flu and Aids (Yeats, 2001:9-11).

2.1 WHAT IS HIV?

HIV is the Human Immunodeficiency Virus. This virus needs to enter the bloodstream to do damage. The HIV enters the body, usually via the thin surface of the vagina or the penis opening and then makes its way into the blood. Once in the bloodstream the virus attaches to a host cell – in this case a CD4 cell - enters the cell, replicates inside the cell, feeds off the cell and once the cell has been destroyed, millions of viruses break out of the cell running in the bloodstream with the main aim of replicating themselves again, and in the process destroying the host CD4 cell.



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Once you become infected with the virus you sero-convert and become HIV positive. This virus mutates in your body and, therefore, changes shape. Currently in Southern Africa there are at least 5 different strains of HIV. If a HIV-positive person has unprotected sex with another HIV-positive person with a different strain of this virus, they could be re-infecting themselves. This means they now have two different HIV strains destroying the same immune system – which could lead to a shorter life expectancy.

Progression to Aids happens when the person's immune system deteriorates and they become sick. HIV enters and destroys the CD4 cells (a type of white blood cell), which control and support the immune system. The job of the CD4 cell is to instruct other disease-fighting cells to kill viruses and other foreign microbes that enter the body. When CD4 cells are infected, they cannot do their job properly. Once the immune system becomes depleted, the body does not have the ability to fight off disease and then the person gets ill. This is called the Aids phase.



2.2 THE DIFFERENCE BETWEEN HIV AND AIDS

Many people think being HIV-positive means you have Aids, but HIV infection and Aids are not the same.

- **HIV is the Human Immunodeficiency Virus**

  HIV is a **virus**. It lives in the **blood**, **sperm** and **vaginal fluids**. It is passed from one person to the other through sexual juices or blood. It can also be passed on from a pregnant woman to her unborn baby, or when a mother breastfeeds.
  When HIV is in the body, it attacks the **immune system.**

  Once in the body, the virus uses the CD4 cells of the body's immune system to replicate itself, and in the process destroys these cells. These CD4 cells are vital as they coordinate the body's immune system, protecting us from illness. As the amount of HIV in the body increases, the number of CD4 cells decreases, weakening the immune system even further.

  If a person's immune system is functioning poorly they are said to be 'immuno deficient'. The **Human Immunodeficiency Virus** is, therefore, a cause of immune deficiency.

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Usually it takes several years for HIV to cause immune deficiency in this way. When it happens, the person develops Aids.

Acquired Immune Deficiency Syndrome (Aids)

Aids is the collection of diseases that are 'acquired' from HIV once the immune system is no longer able to protect the body from illness. As HIV weakens the immune system, a person with HIV develops a number of diseases that the body would normally be able to fight off. These are known as opportunistic infections. When a person's immune system has deteriorated so much that he or she starts becoming ill with life-threatening and often unusual illnesses, he or she is said to have **Acquired Immunodeficiency Syndrome (Aids).** A person with Aids has poor defence against infections with other viruses, bacteria and fungi. These other organisms cause the symptoms of Aids such as shingles, pneumonia and thrush.

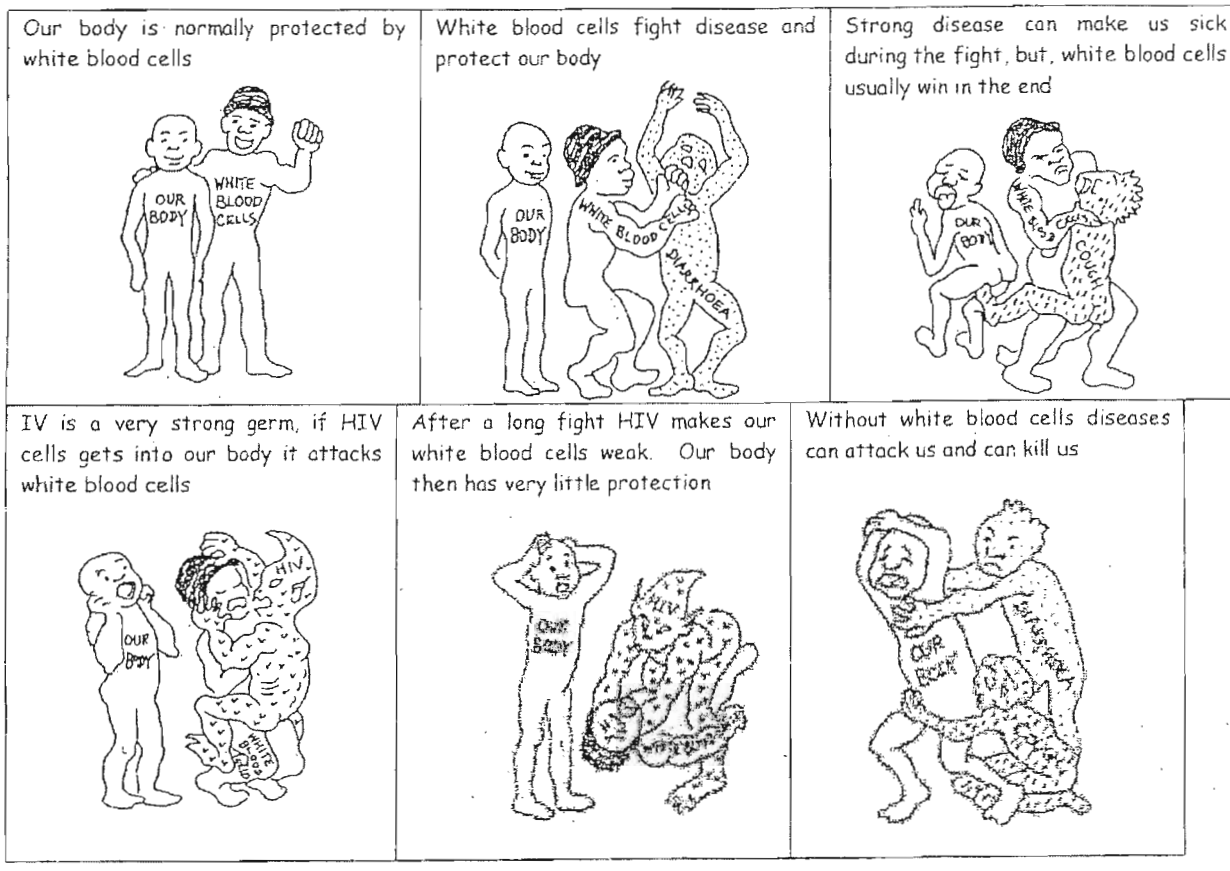
2.3 WHAT IS THE IMMUNE SYSTEM?

- The immune system protects our bodies from illnesses. It also heals the body after illness or injury.
- One way of measuring how strong your immune system is, is by doing a CD4 blood test. CD4 cells are part of our immune system. When your immune system is strong, your CD4 count is high. This means you are healthy. In a healthy person there would be approximately 1000 CD4 cells per *ml* of blood, (People Management, 2006:49).
- HIV breaks down the immune system. Then your CD4 count slowly goes down. A low CD4 count means your immune system is weak.
- When your immune system is weak, you start to get ill often. At this stage, your health worker should discuss anti-retroviral treatment (ART) with you. He or she will do a CD4 blood test to tell if you need ART. Your health worker will talk to you about the benefits and problems of ART, and how to make it work for you. A CD4 count of 250 CD4 cells per *ml* of blood means that you have full-blown Aids.
- ART will slow down the HIV. If you take the medicines properly, your CD4 count will become high again as your immune system gets stronger. Then you will feel well again.

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- ART helps you lead a longer, healthier life with HIV. After you have started taking these medicines, you need to carry on for the rest of your life. If you stop, your CD4 count will start to go down again.
- When you are on ART, you must have a CD4 count test regularly so that your health worker will know if the treatment is helping you, (Soul City, 2004:3).

This process is described in a cartoon from Uganda shown below.

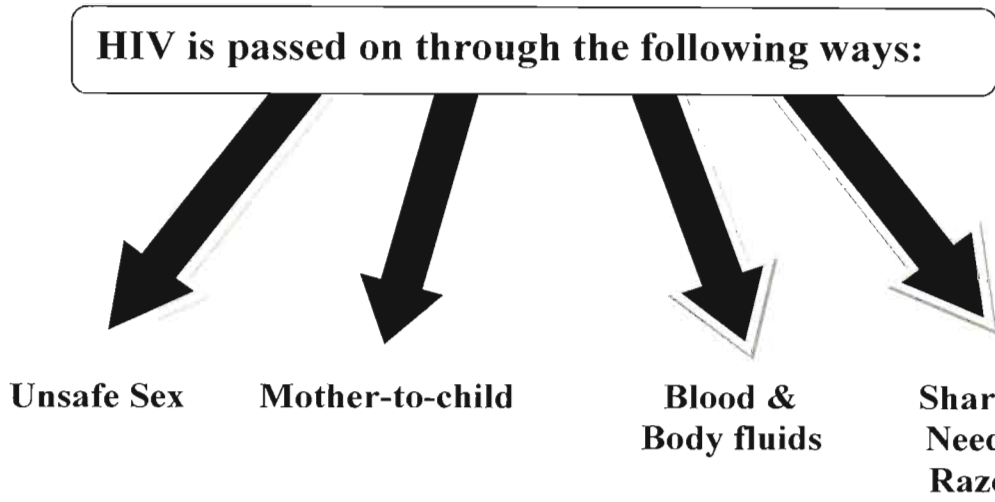


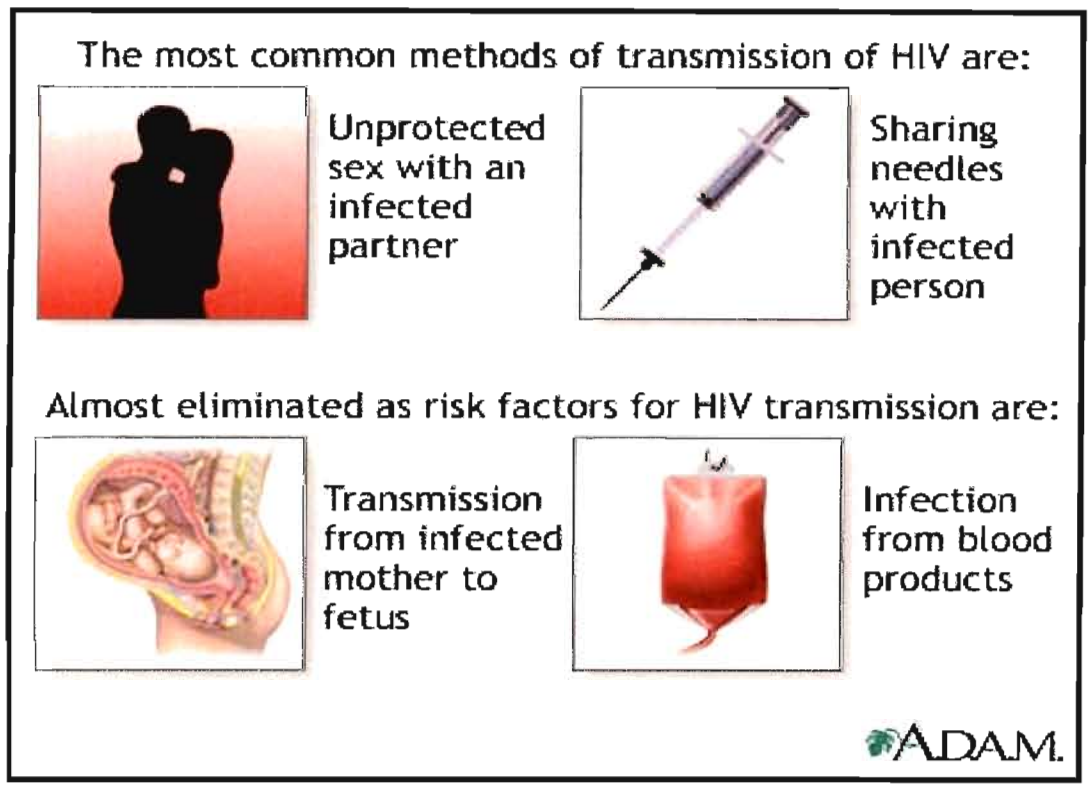
3. HOW DOES A PERSON GET HIV?

The four main body fluids that can carry the virus are:

- Blood.
- Semen.
- Vaginal fluids.
- Breast milk.

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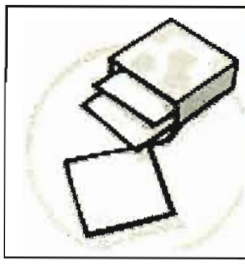
Unprotected sexual intercourse



- The most common way for a HIV virus to be passed on is when a person has **unprotected sex** (sex without a condom) with someone who already has the HIV virus. Sex, whether between men and women, or between men who have sex with men. During sex, body fluids containing HIV can come into direct contact with the thin, moist lining of the vagina or the opening of the penis. It is present in significant amounts in some body fluids such as semen (sperm) and vaginal secretions that moisten the vagina. It can be found in other body fluids such as

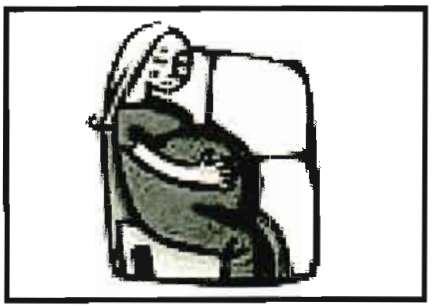
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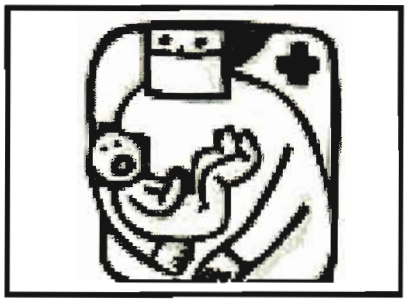
saliva or urine, but at such a low concentration that these fluids carry almost no risk of transferring the infection.



- In the case of **anal sex**, the thin, moist lining of the rectum is also vulnerable to HIV-infection.
- During **oral sex**, there is a risk to the person whose mouth comes into contact with semen or vaginal fluid.
- However, kissing mouth to mouth is a very **low-risk** activity for HIV transfer because there is so little virus present in saliva.
- It is easier for the HIV virus to be passed on if you or your partner has a **sexually transmitted infection** (STI) like syphilis, herpes or the drop. If you think you may have an STI, go to the clinic for treatment. Ask your sexual partner(s) to get treatment at the clinic. A barrier between the partners' genitals, namely a **condom**, will greatly cut down the risk of transmission during sex.
- Children can get the HIV virus from an HIV-positive adult who has sexually abused or **raped** them.

Mother–to-child transmission (Pregnancy and breast-feeding)

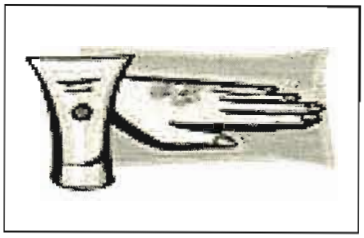






- A pregnant mother who is HIV-positive can pass the virus on to her unborn child. This can happen:
  - In the womb, when she is pregnant.
  - A great risk of infection to the child is during childbirth.
  - Through breast milk during breastfeeding.
- About 1 in every 3 babies born to HIV-positive mothers will get the HIV virus. It is estimated that in 2004, almost 550 000 children in Africa became infected with HIV, mostly through mother-to-child-transmission.
- A woman is more likely to pass on the HIV virus if she is ill with AIDS when she becomes pregnant or gets the virus while she is pregnant (Page, Louw & Pakkiri, 2006:33).

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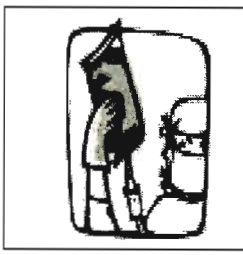


Blood & Body fluids

- In order for HIV to be **transmitted** from an infected person to an uninfected person body, fluids from an infected person, containing a **large enough quantity** of the virus, must enter the body of the uninfected person.
- **Direct contact with the blood of a person living with HIV.** Although rare, this can happen if you have a freshly open cut or wound which comes into contact with the blood of a person with HIV. The virus can also be absorbed through the mucous membrane of the body.



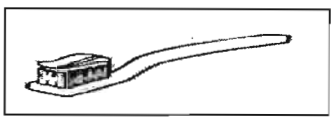
- It can also be passed on if they both have a cut or an open wound and their blood gets mixed.
- Sick people may be given extra blood through a blood transfusion. In South Africa **blood transfusions** are safe because all blood is tested for HIV before it is given to anyone.
- The uninfected person must be exposed to the virus long enough for it to enter the **bloodstream.** If you work with blood, always wear gloves



Sharing needles or instruments



- The HIV virus can pass from a person who is HIV-positive to another person if they **share needles, e.g. by drug abusers and syringes** that are not properly cleaned.
- **By sharing toothbrushes** (the virus can spread through cuts in the mouth) and **razor blades** with a person who is HIV positive.

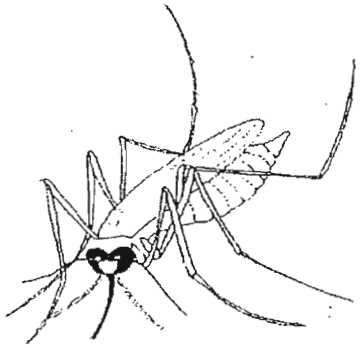
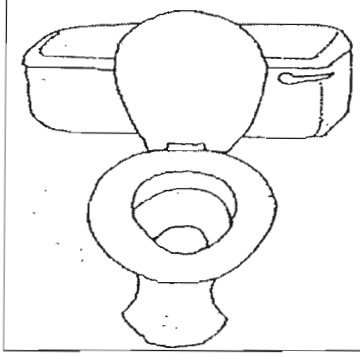
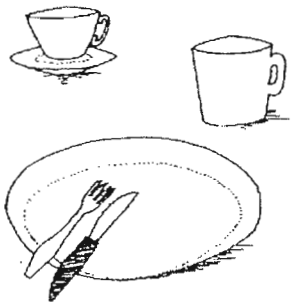


Less common ways that HIV is transmitted

- People who have medical occupations have a small risk of being infected with HIV if they injure themselves with a needle that has been used to take a blood sample from an HIV-infected person.
- People who receive a lot of blood transfusions for medical reasons have been at risk of acquiring HIV. Today, in most countries, blood donations are tested thoroughly for HIV and other infectious diseases, and it is now rare that HIV is transmitted by blood transfusion.

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HIV is not transmitted through:

INSECTS SUCH AS MOSQUITOES 	**SHAKING HANDS** 	**HUGGING AND KISSING** 
TOILET SEATS 	**SHARING FOOD, DRINK OR SAME UTENSILS** 	**COUGHING** 

4. THE STAGES OF HIV INFECTION AND THE TIMELINE OF AIDS

The way in which HIV progresses to Aids is a gradual process that moves through various phases. The World Health Organisation (WHO, 1993) divides HIV infection into four stages. These divisions should be seen as a guide only.

The first few weeks after the body first becomes infected with HIV there is a period of **acute infection**. The immune system is unprepared for the virus, and so it takes some time for the body to recognise the virus as foreign and to start preparing to fight the virus. The virus is able to invade host cells without interference by the immune system, and the host cells produce many new viruses (Sanders, 2001:18-19).

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WHO - STAGE 1: **Window Period**		HIV enters the body duplicating itself rapidly in the CD4 cells. There are few or no signs that a person is infected. Swollen lymph glands are common, but are not usually a cause for alarm. This occurs a few weeks to a few months after infection.
WHO - STAGE 2: **Asymptomatic Period**		This stage is typically characterised where one keeps getting repeated infections of the upper airways – the chest and throat as well as other symptoms like weight loss, skin problems, Herpes Zoster (shingles). It may last 6 months to 10 years that a person looks and feels good.
WHO - STAGE 3: **Symptomatic Period**		During this period, the amount of HIV in the body, or the viral load, is increasing. In this process it is destroying more and more CD4 cells, the immune system is starting to get weak. More serious problems begin to occur, and the clinical features at this stage, which one could call Aids, include: weight loss, chronic diarrhoea, fever, oral thrush, pneumonia and T.B. All this indicates that Aids will occur within a year or two.
WHO – STAGE 4 : **AIDS**		At this stage, a person is very ill. CD4 count is lower than 200 Opportunistic infections occur, meaning that the body's defence system is no longer working. Germs cause severe infections: thrush in the oesophagus, infections of the brain, severe diarrhoea, profound weight loss and cancers such as Kaposi's Sarcoma. (Average survival time is about 18 months- but varies).

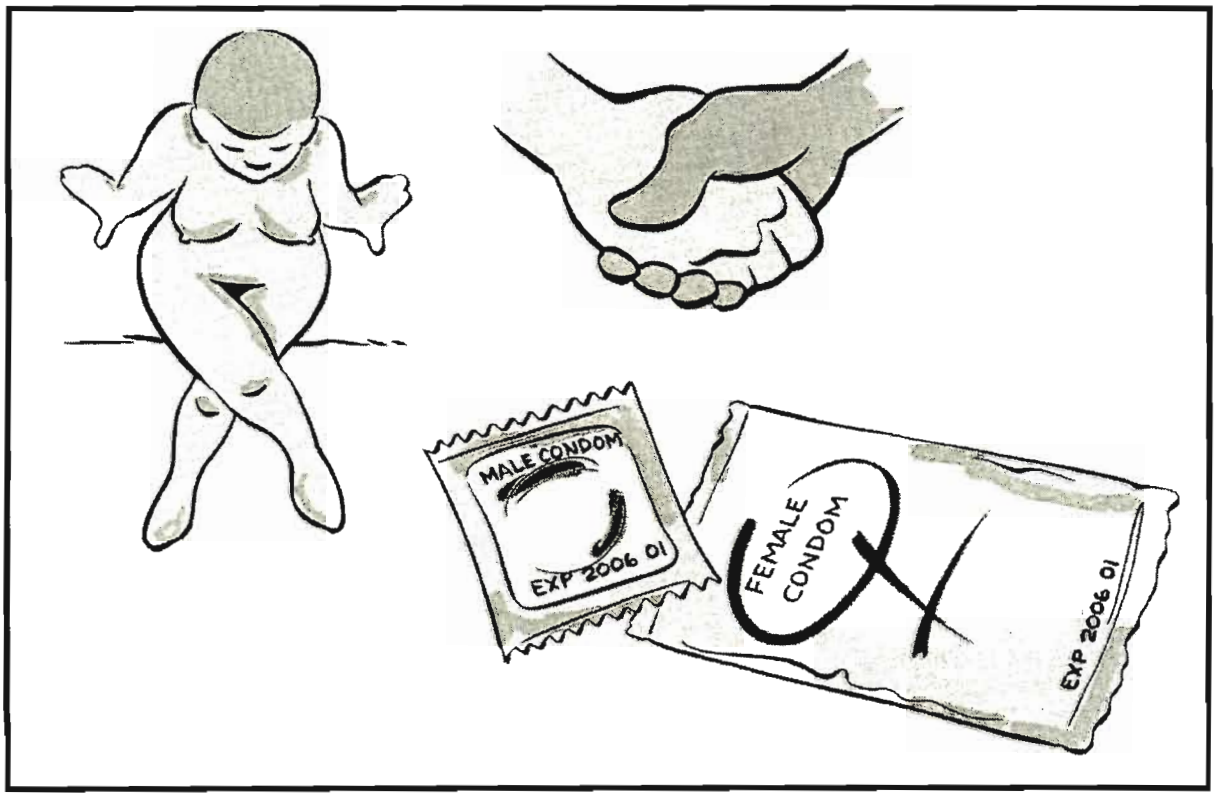
*** WHO – World Health Organisation**

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5. HOW TO PREVENT THE SPREAD OF HIV

Everyone is at risk of getting HIV. Antiretroviral medicines are now available to prolong life, but there is still no cure for HIV. Preventing infection is essential. You can protect yourself and others from getting HIV in the following ways:

The ABC of Sex



1. Abstain from sex:

HIV is mainly spread by sex. You cannot get HIV if you are not having sex. The safest way to stop the spread of HIV is to **abstain** from having sex.

Having sex is a very serious decision, especially if you are a young person. Your body may feel like it is ready for sex, but you may not be ready to deal with the responsibility of having sex at a young age. Older people or people who have had sex before may also choose to abstain from sex. You can have a relationship without sex. It is not true that sex makes a relationship stronger. There are many ways you can show another person that you love them without having sex with them (Evian, 2006).

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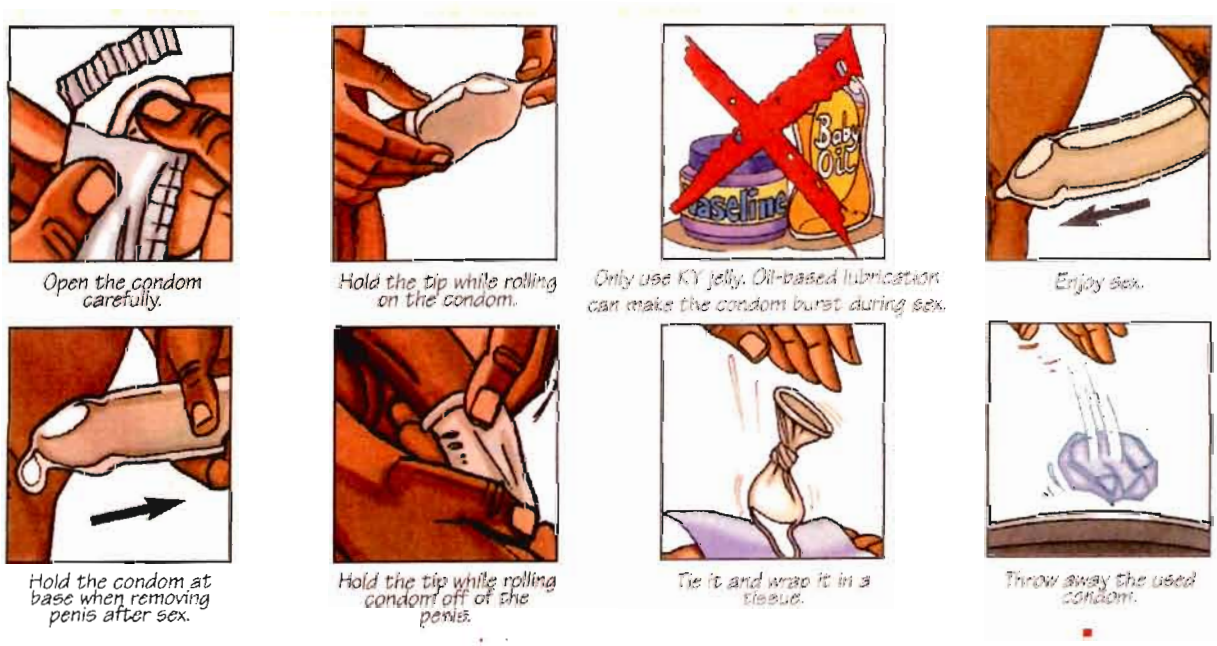
2. Be faithful:

Be faithful. Have one partner whose HIV status you know. Both partners have to be faithful to one another.
Have a mutual partner – where both partners are HIV negative. You cannot tell if someone has HIV. The only way to find out is by having a blood test. If you decide to have sex in a new relationship, it is important to use condoms until you and your partner have been tested. If you are positive, you need to continue to use condoms when you have sex. If you are both negative, and have not had unsafe sex in the last 3 months, you can assume you are HIV negative. As long as you remain faithful to each other, you may decide to stop using condoms. However, if either have sex with someone else, you need to use a condom again, and you must be retested.

3. Correct condom use:

Have safer sex. Safe sex means using a condom every time you have sex. Oral sex is less risky than vaginal or anal sex, but if you or your partner have sores in the mouth or on the penis, vagina or anus, it is possible to get HIV through oral sex (Theron, 2006:16).

How to put on a condom



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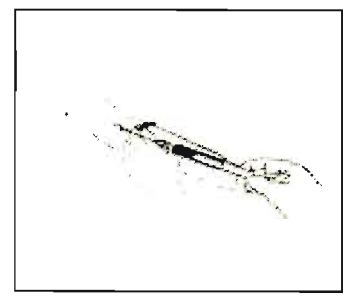
- **Treat all sexually transmitted infections (STIs)**

If you have a sexually transmitted infection, then you and your partner must both be treated as soon as possible. A STI can increase your risk of HIV infection as it allows the HIV to enter the body more easily.

- **Know your status**

Having an HIV antibody test will allow you to know whether you are HIV-negative or HIV-positive. If you are HIV-positive, you can prevent others from getting HIV, and you can get care, support and treatment for opportunistic infections. You can also get antiretroviral treatment as soon as you need it. This will prolong and improve the quality of your life. You can also make decisions about whether you want a baby or not. A pregnant woman who knows she is HIV-positive can reduce the chances of HIV being passed on to her baby by taking informed decisions about treatment and breastfeeding. She also has the right to terminate the pregnancy.

- **Never share needles.**

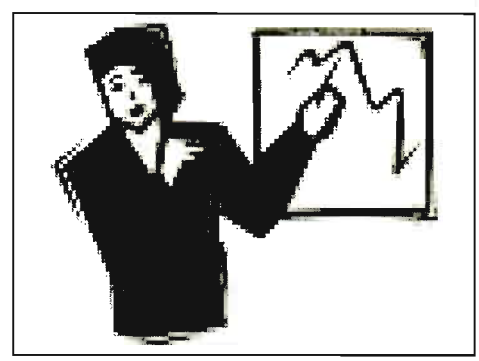


Drugs are illegal, harmful and should be avoided. A person who chooses to inject drugs can prevent HIV by using clean needles and syringes each time, and by using a condom when having sex.

- **Take precautions when handling blood.**



When helping someone who has been injured, always use latex gloves to prevent contact with the blood. Doctors, nurses, dentists and other health workers should also use gloves when treating patients to prevent themselves from getting HIV when handling sharp instruments such as injections and scalpels.



6. WHY IS HIV STILL SPREADING?

There are many reasons why HIV is still spreading. Factors driving the epidemic in South Africa include: stigma and discrimination, gender and violence against women and children, and poverty.

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6.1 STIGMA AND DISCRIMINATION

HIV is a sexually transmitted infection associated with death. This causes many fears and prejudices, collectively described as 'stigma'. Stigma is largely due to lack of knowledge. It influences the way many respond to people living with HIV, and often results in discrimination. Often, people living with HIV and Aids are treated with indignity. The direct consequence of this is that people are scared to be open about their status, forcing the disease underground. This often prevents them from seeking the help they need, and also makes it very difficult to control the further spread of HIV.

Silence and denial due to stigma is the reason why many people who are HIV-positive do not tell anybody because they are afraid that the community will blame them for being infected. Communities then think that HIV is not so serious because they do not see people living with HIV.

Many people do not use condoms because they are afraid that their partners will think that they are HIV-positive and think badly of them. Young people complain that some health workers shout at them if they come to the clinic to ask for condoms.

Some people fear being tested for HIV because they are worried that others will treat them badly.

People living with HIV do not go for treatment because they are afraid that health workers will tell others that they are HIV-positive. This is against the law. Health workers do not have the right to tell anyone.

6.2 POVERTY AND INEQUALITY

Women who are poor will sometimes have sex **in exchange** for money or special **favours.** Poverty forces many women into sex-work in order to survive and support their children.

In many societies women do not have control of their sex lives. Society tells them they have to do what their husband or boyfriend tells them. They are afraid to ask their partner to use a condom, even if they know he has had unprotected sex with other woman.

Many cultures and religions do not speak openly about sex. This means that wrong ideas about sex, HIV and Aids are spread.

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6.3 MYTHS AROUND HIV

- HIV is a punishment from God. **This is not true.**

- HIV happens to people who are homosexual, black, poor and migrants. **This is not true.**

- Some believe they can get HIV through casual contact. This myth has led to children affected by HIV being prohibited from attending school due to fears that they will pass on HIV to the other children. **This is not true.**

- Some employers believe that people with HIV are sick, unproductive and will burden their companies. Colleagues may refuse to share office facilities with someone living with HIV for fear of getting HIV. **This is not true.**

- Some communities and families believe that someone with HIV brings shame upon them. People have been banished, hidden, abandoned and even murdered because they are HIV-positive. For fear of this, many people deny or hide their HIV-positive status. **This is not true.**

6.4 GENDER

Both physical and socio-economic factors make women and girls more vulnerable to HIV.

- **Women are physically more vulnerable to HIV than men**

The vagina has large areas of exposed and sensitive skin, which can get cut during sex. This allows HIV to enter the body more easily. Semen also stays longer in the vagina after sex, increasing the risk of transmission. The penis has a small surface area, which is in contact with the vaginal fluids for a shorter time.

- **Socio-economic factors place women at risk**

The socio-economic status of women places them at a higher risk of HIV infection due to the fact that:

- Many women cannot choose to abstain, use a condom, or insist on other forms of safer sex, because this may result in violence or abandonment by their male partners.

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- Rape contributes greatly to the spread of HIV because of the risk of trauma to the vagina.
- Some men are reluctant to visit hospitals and clinics when they have sexually transmitted infections. Many also blame their woman partner for having an STI. The violence that may follow also discourages women from telling their partners they have an STI.
- The fear of violence and abandonment also prevents many women from disclosing their HIV status to their partner, and from seeking help and treatment for HIV.
- Many older men have sex with younger girls in exchange for favours, gifts or money. Girls living in poverty are often more vulnerable to this. Older men tend to have had more sexual partners, which increases their own risk of getting HIV, and consequently passing it on to younger girls.
- **Mobility and migration** across Africa seeking employment cause HIV to increase across the continent. Men who are removed from their families for long periods of time, such as truck drivers, soldiers and migrant workers, may have sex with sex workers or other partners who provide them with companionship when they are away from home (Soul City, 2005:12-16).

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MODULE 2: HIV TESTING

HOW DO YOU KNOW IF YOU ARE HIV-POSITIVE?

1. Why testing?

2. Where can I be tested for HIV?

3. What happens when you go for an HIV test?

3.1 Voluntary counselling and testing
3.2 Pre-test counselling
3.3 Post-test counselling
3.4 What if a test is negative?
3.5 What if a test is positive?
3.6 Follow-up visits

4. How is the test conducted?
- HIV antibody testing and the window period

5. Types of HIV tests
5.1 Elisa test
5.2 Oral rapid test
5.3 Blood rapid test
5.4 Other tests in connection with HIV and Aids
5.5 Anonymity and confidentiality
5.6 Testing babies for HIV

6. Starting anti-retroviral treatment

7. How to make anti-retroviral treatment work best

8. Side-effects of anti-retroviral treatment

9. HIV-positive women and pregnancy

10. Babies and HIV

11. Post-Exposure Prophylaxis

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HOW DO YOU KNOW IF YOU ARE HIV-POSITIVE?

Many people have HIV but do not know that they have it. This may be because they do not feel ill so they have not got tested or because there are no testing facilities where they live.

Having an HIV test is not an easy **decision** to make, but the only way to know if you have the HIV virus is to have a blood test. Having an HIV antibody test can help save your life. It can also be scary and life changing. Therefore, before you decide to have a test, you need to be sure you understand the implications that the result could have on your life.

1. WHY IS IT IMPORTANT TO HAVE THE HIV TEST?

If you are worried that you are HIV-positive, a test can put your mind at rest and it means you are taking responsibility for yourself

If you test negative, you will be able to adjust your sexual lifestyle so that you can avoid being infected with HIV in future.

If you test positive, you can take a number of steps to manage your health, stay healthy for longer and delay the onset of Aids

Pregnant women testing positive can make plans to avoid mother-to-child transmission

If you test positive, you can get medication and treatment to stay healthy and productive longer.

If you test positive, you can make sure you protect other people from getting the HIV virus



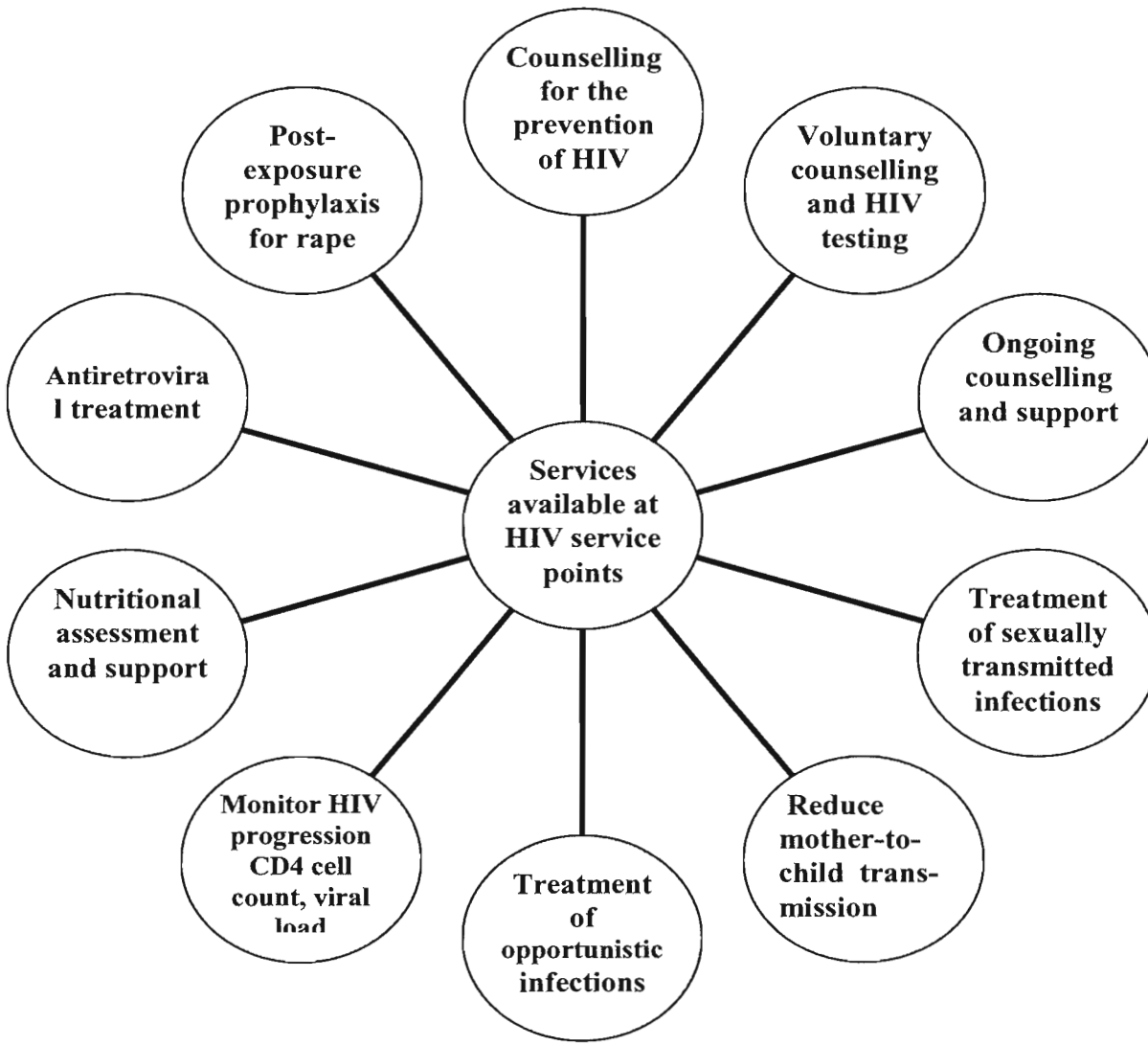
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2. WHERE CAN YOU BE TESTED FOR HIV?

You can be tested for HIV at:

- Government HIV service points, which are one-stop centres for HIV and Aids-related information and services. They are being developed in each community.
- Most private doctors, clinics, hospitals and laboratories.
- Contact the Aids Helpline on 0800 012 322, for information on your nearest service point.

2.1 WHAT SERVICES CAN I GET FROM THE HIV SERVICE POINTS?



HIV service points are information and service centres for HIV and Aids, located within one hospital or spread over a number of service providers in a given area. These service centres will ensure that people living with HIV in South Africa receive care and support from the moment they are diagnosed as HIV-positive (Soul City, 2005:26).

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2.2 WHO WILL PROVIDE THESE SERVICES?

A team of medical personnel trained in the management of patients living with HIV and Aids will provide these services. This includes medical doctors, professional nurses, pharmacists, dieticians, nutritionists, social workers and counsellors.

2.3 CAN I USE MY OWN PRIVATE DOCTOR?

If you test HIV-positive, it is best to receive care and treatment from a doctor trained in the management of HIV. If your doctor is not trained in the management of HIV, you may want to request him/her to refer you to a doctor that can provide you with the best possible care. You can also contact the Aids Helpline 0800 012 322.

2.4 WILL MY MEDICAL AID COVER MY EXPENSES IF I AM HIV-POSITIVE?

Many medical aid schemes do have programmes in place to manage patients who are HIV-positive, and make provision for antiretroviral treatment (ART) through private doctors and medical facilities.

3.WHAT HAPPENS WHEN YOU GO FOR A HIV TEST?

3.1 VOLUNTARY COUNSELLING AND TESTING

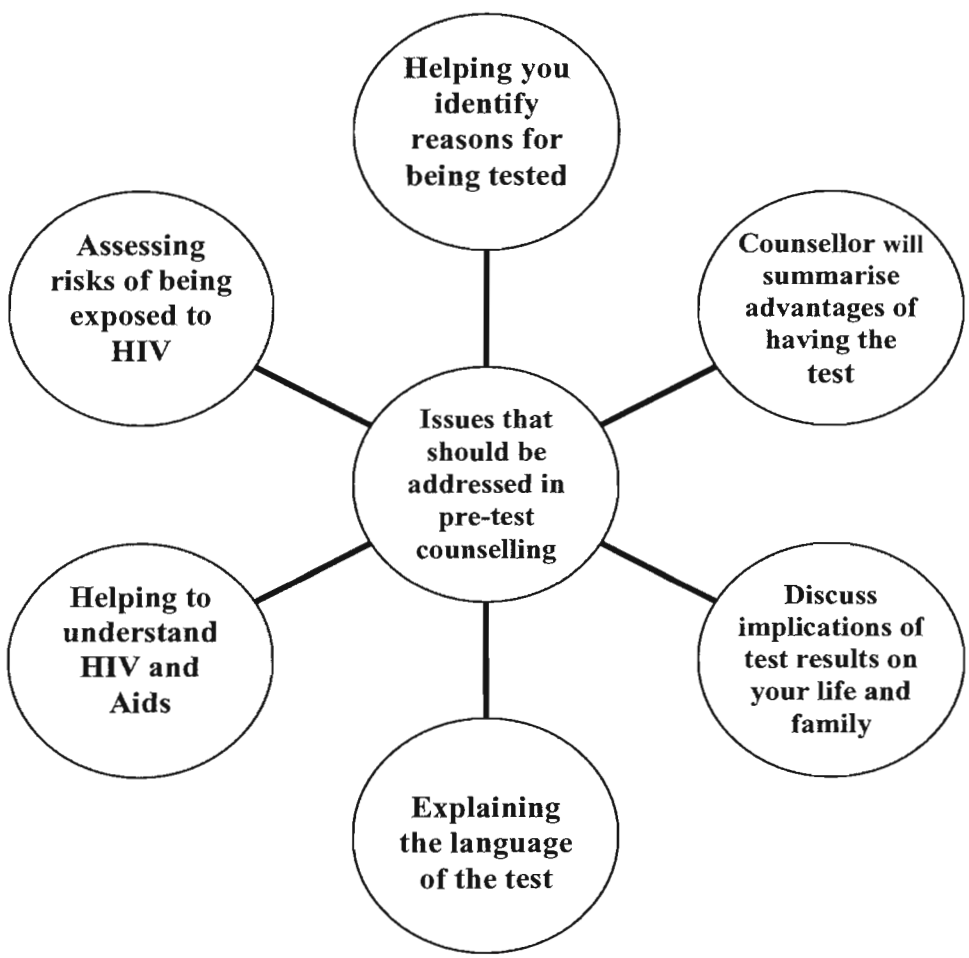
- Before HIV testing, pre-test counselling is essential which enables a person to understand the advantages of knowing their HIV status. With this knowledge, they can make an informed decision about being tested for HIV.
- After pre-test counselling, if the person chooses not to continue with the test, his/her decision must be respected.
- It is important to speak to a counsellor/health worker about having a test. They can help by answering any questions you may have about HIV and Aids, and about the test.
- The counsellor/health worker knows that you may be **afraid and worried**. They will give you **support**, and help you prepare for the results of the test. This is called pre-test counselling.
- Some people may take a friend/someone they trust with them. This person can give support and care before and after the test.

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- Voluntary counselling and testing is very important because the results of an HIV test can have enormous psychological and social implications for the person being tested.
- **NOTE: By law, an HIV test should not be given without pre-test counselling and the person should not be given his/her results without post-test counselling, even if the results of the test are negative.**

3.2 PRE-TEST COUNSELLING

Pre-test counselling provides information so that the person being tested feels more prepared for the test. It should provide information on the possible personal, medical, social, psychological and legal implications of being diagnosed, either HIV-positive or negative. Pre-test counselling reduces fear and feelings of helplessness and anger, thus helping the person being tested to cope with the results of the test (Brouard, 2001:22).



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3.2.1. Identifying the reasons for testing

The person being tested needs to be clear on why he/she is being tested. A rape survivor will need different counselling from someone who practices high-risk behaviours.

3.2.2. Assessing risks

The counsellor should assess how the testee may have been exposed to HIV by taking into account the type and frequency of behaviours, such as vaginal or anal sex without a condom, sharing needles while using drugs, or sharing a toothbrush with someone who is HIV positive.

3.2.3. Clarifying beliefs about HIV and Aids

This involves correcting all the myths and misunderstandings surrounding HIV and Aids that the testee might have.

3.2.4. Obtaining information about HIV and Aids

The testee must understand what taking the test involves and that being HIV positive is not the same as having Aids. The concept window period should also be explained, and the need for further testing if the testee is practicing behaviours that place him/her at risk.

3.2.5. Discussing the implications of the test result

An individual who is HIV-positive should feel free to discuss the personal, medical, social and psychological implications of a positive test result. He/she should also know that tests are not always 100% accurate and any positive HIV test result should be confirmed with a second test.

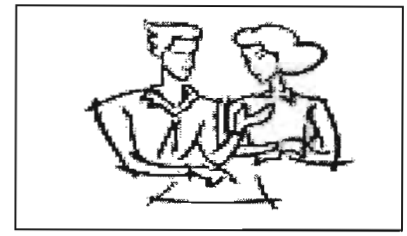
3.2.6. Explaining the language of the test

It is important that the testee understands all the words that could be used when the results are given, especially the meaning of HIV-positive (HIV+) and HIV-negative (HIV-).

3.2.7. Encouraging testee to return for results of test

Not all HIV tests give an immediate result, and the tested might be told to come back a week or so later for the result of the test. Many people who go for HIV tests do not go back for their results. The counsellor must explain the importance of returning for the test results.

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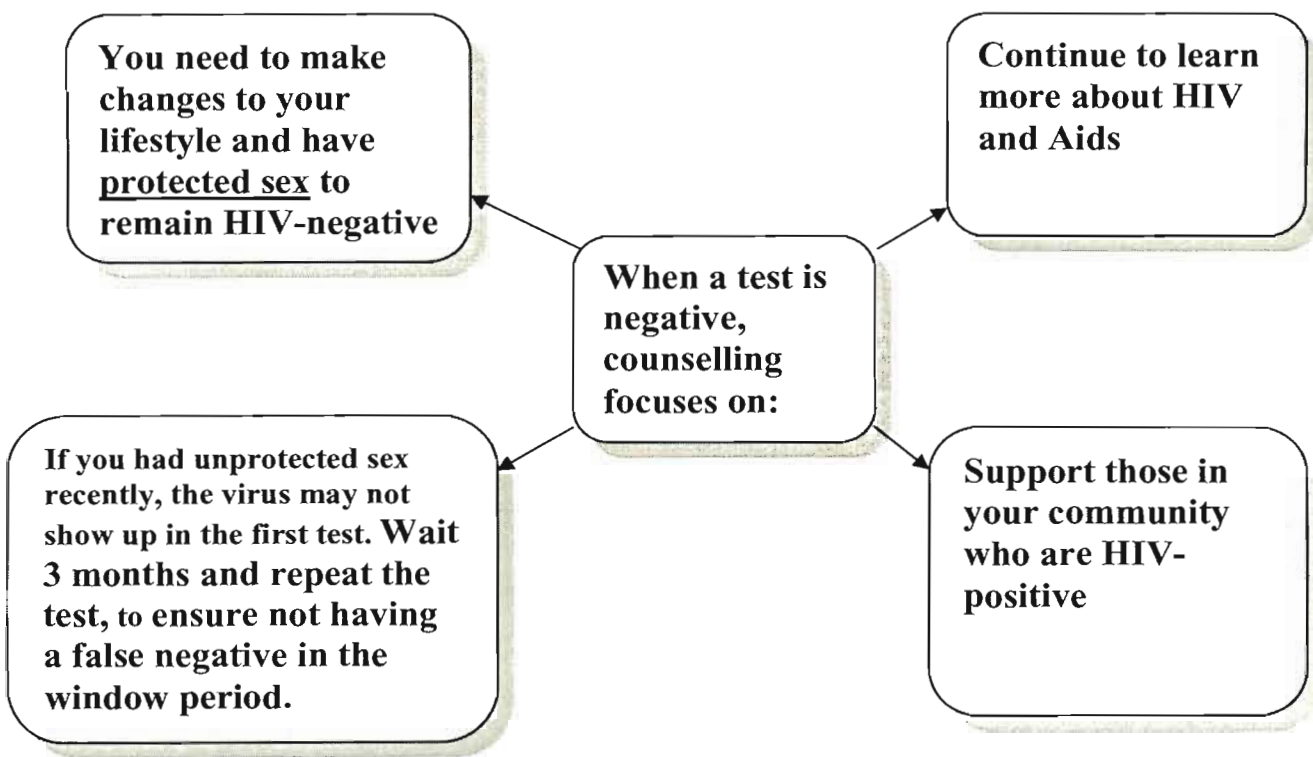


3.3 POST-TEST COUNSELLING

- You will need to talk to a counsellor/health worker when you go and get your test results. They will discuss the results with you, and what this means. This is called post-test counselling.
- When you receive your HIV test result, you have the right to post-test counselling. The discussion in the post-test session will depend on whether you have tested negative or positive.
- Although a negative result will be a relief for the testee, it may give a high-risk individual a false sense of security to continue practicing high-risk behaviour. In such cases advice on reducing risk and safer sex is very important.
- There should be open and honest communication between the counsellor and the testee. The language that is used to give the result should be straightforward and not allow any misunderstanding, neither to give false hope nor helpless scenarios.

3.4 IF THE TEST IS NEGATIVE

This means you do not have the HIV virus in your blood. You must still do these things:

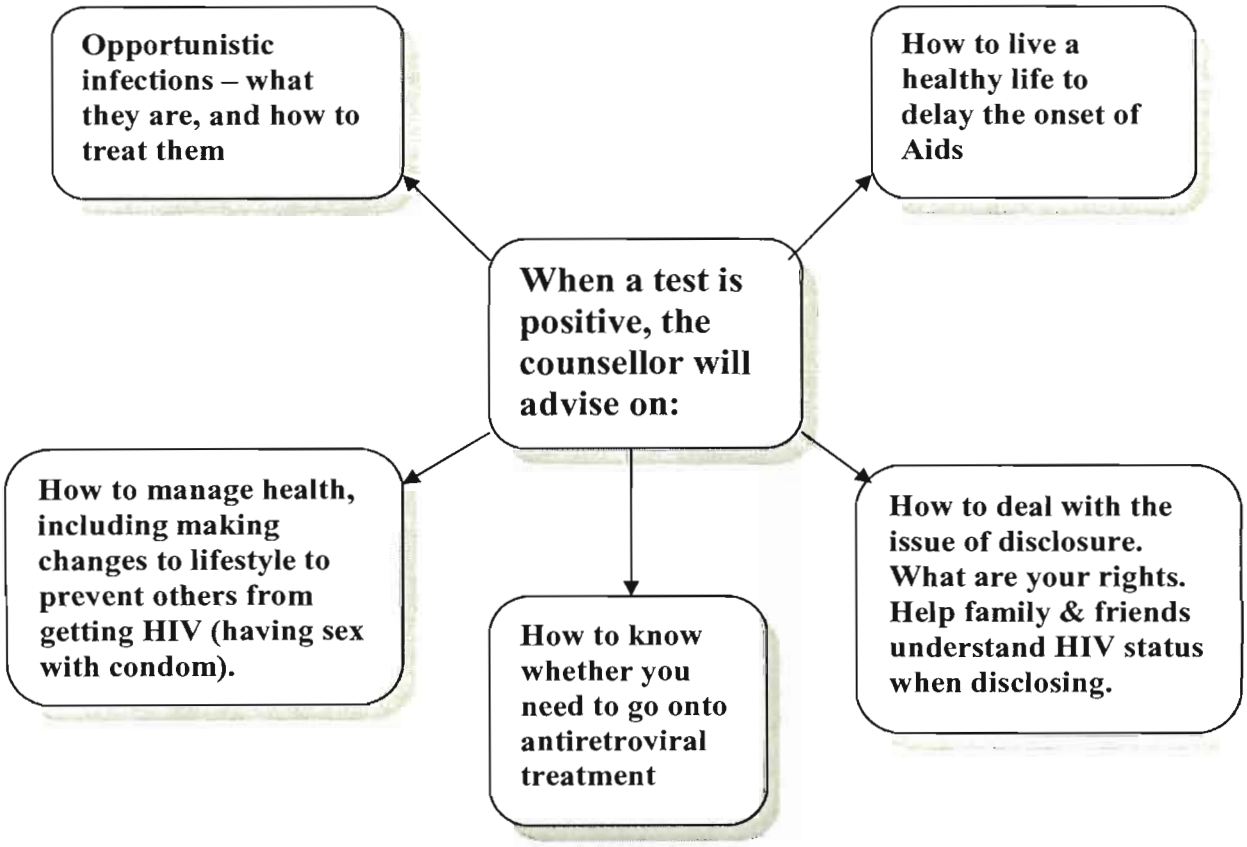


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3.5 IF THE TEST IS POSITIVE

The person's reaction may include a number of emotions, including shock, crying, agitation, fear, disbelief, guilt, refusing to communicate, anger and outrage. These feelings are normal. The counsellor should be prepared for any of these, and know how to help the tested through this difficult time (Soul City, 2005:24).

- Help the tested not to panic. Advice that a person can still live a healthy life for a long time with the virus in the body.



3.6 FOLLOW-UP VISITS SHOULD BE ARRANGED

This will help HIV-positive people deal with their fears and minimize the stress they are feeling. Follow-up visits are important so that questions can be answered as they arise. Testee can also be assisted in dealing with any problems they encounter, such as how to tell friends and family.

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3.7 WHERE TO GO FOR ADVICE AND COUNSELLING

Counselling is offered by a variety of organisations. It is important to find support systems that will advise about health and sexuality. The following organizations are very helpful (Page *et al.*, 2006:63):

1. The Aids Helpline	0800 012 322
2. Department of Health	012-3120121
3. Youth Line	0800 000 001
4. The Love Life Helpline – Thethajunction	0800 121 900
5. Treatment Action Campaign (TAC)	021-7883507



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Voluntary HIV counselling and testing procedure (Van Wyk, 2007:16-18)

Step 1: Registration

↓

- Employees who request testing or have been referred for testing approach nursing staff or medical doctor.

Step 2: Counsellor

↓

- The counselling procedure will take place in a room suitable for a confidential discussion.
- The counsellor will complete the client's basic details on a VCT record card. Other details will be completed at appropriate stages in the consultation.
- Before commencing counselling, the counsellor will confirm that they have come because they wish to discuss HIV testing.
- The counsellor will briefly explain the VCT procedure (i.e. discussion about HIV, the record card, one or more finger-prick blood tests, being informed of results, discuss options).

Step 3: Pre-test Counselling

↓

Pre-test counselling will be undertaken by the counsellor according to the guidelines set out in their training course. The counsellor's role at this stage is primarily gentle questioning and listening. The counsellor will:

- Emphasise confidentiality.
- Aim to help the client to feel as secure and relaxed as possible.
- Ascertain the client's current knowledge of HIV/Aids.
- Explore the basic facts about HIV/Aids.
- Discuss the reasons for wanting to be tested (personal risk profile).
- Discuss and probe how he or she would feel/react to a positive or negative result.
- Discuss the potential benefit of either test result – plan life, change lifestyle, live positively, look after health, not put others at risk, etc.
- Discuss who would he or she inform? Who would he/she not inform? Stress that disclosure is his/her choice but should be encouraged to approach/contact at least one person for the necessary support.
- Probe to find out what support systems the client has in place.

Please note that the pre- and post-test counselling must be conducted by the same person.

Step 4: Information giving

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This will take place in response to the client's questions or after the counsellor has identified gaps in their knowledge, and will:

- Explain the blood test procedure and when he or she can expect the result.

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- Explain that either one or two (but occasionally more) finger-pricks tests will be required and that this decision will be taken by the tester.
- Warn that, in a few people it is not possible to get a definite result from the rapid test kit, in which case the option of having a different test will be discussed.

Step 5: Informed Consent

↓

- Ask the client if he or she is ready to have the test; he/she may like to go away and think about it.
- Note that HIV testing will not be carried out without the written, informed consent of the individual.
- If he or she is unable to write, the counsellor will sign to witness that he or she has given consent. The client will be asked to make a mark or thumbprint.
- Explain that this is a formal process designed to protect the individual's interests and ensure HIV testing is not carried out improperly.
- Use the rapid HIV test consent form in their preferred language (not the laboratory test form).

Step 6 : Finger-prick test

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- The nurse tester will take the finger-prick sample and perform the screening test in the test room.
- The nurse tester will approach the client if a second sample is required.

Step 7: Communicating test result

↓

- First ascertain readiness; should the individual be unsure, counsel and consider referral for further counselling.
- The counsellor must communicate the test result in a professional, mature manner.

Step 8 : Post-test counselling

↓

- Be empathetic to positive clients. Explain that with a healthy lifestyle, it is possible to lead a long and productive life.
- If the result is negative, discuss the window period (approximately ten weeks for the rapid tests) and elicit information on how the client plans to retain this status.
- Inform him or her about leading a healthier lifestyle.
- Encourage the individual to spread the word on the benefits of VCT.
- Give pamphlets/literature to the individual to read.

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Step 9: Follow-up plan

- Make an appointment for follow-up counselling.
- Give individual telephone numbers, details as to where/how to get help.
- Refer where necessary for medical treatment and a support group.
- Offer individuals with complex counselling issues referral to social worker/ psychologist.
- Give all HIV-positive individuals information on antiretroviral medication and refer to Wellness Clinic.

If the rapid test is inconclusive

Step 8b: Post-test counselling

- Explain that the tests have not given a clear result.
- Do not be forced into guessing what the result may be.
- Strongly recommend a laboratory test on a blood sample.
- Explain the advantages (more likely than the rapid test to give a conclusive result) and the disadvantages (up to one week's delay before result available, 5 ml blood sample required).

Step 9b: Informed Consent

- Ask the client if he or she is ready to have the test. He or she may like to go away and think about it.
- If the client is unable to write, the counsellor will sign to witness that they have given consent. The client will be asked to make a mark or thumbprint.
- Use the laboratory HIV test consent form in the client's preferred language (not the rapid test form).

Step 10b: Follow-up plan

- The counsellor will make an appointment for the client to return for the result of the laboratory test.

Step 11b: Venous blood test

- The nurse tester or professional nurse will take a 5 ml blood sample.
- Occasionally a rapid test will produce an invalid (no control line/spot appears). In such a situation the same test should be repeated once. Indicate on the tick sheet that a test has been wasted.

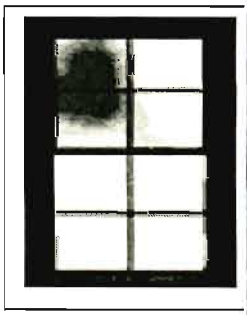
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4. HOW IS THE TEST CONDUCTED?

HIV tests can only be done by people who have been trained to administer them, to interpret the results and to provide the necessary counselling. So it is not possible to buy an over-the-counter HIV test like a pregnancy test.

Testing for HIV today is a lot simpler, faster and more effective than ever before. If a rapid test is used, the health worker will prick your finger and a drop of blood will be placed onto the test kit. A chemical agent will be added, and you will get your result within 10 – 15 minutes.

If the test is positive, a second rapid test will be done to confirm the original test. If the first test is positive and the second one is negative, a blood sample will be taken and sent to the laboratory for an ELISA test to confirm the result.



☩ HIV antibody testing and the window period

It is very important to remember that if a person becomes infected with HIV, there is a **window period** during which time the body is recognizing the foreign matter, and preparing to defend itself against the virus. It is during this time that the body has no antibodies against HIV and the test will show negative for HIV. Even when the body does begin to make antibodies against HIV, the number of antibodies may still be too low to give a positive test result. Most people have a **window period of six to twelve weeks but it can be as long as six months**. For this reason it may be recommended that if you have had unsafe sex in the three months prior to testing, you should have a second HIV test three months later to confirm the result of a negative first test (Page *et al.*, 2006:63).

NOTE: A lot of people do not return for another test or the test results, the reasons given:

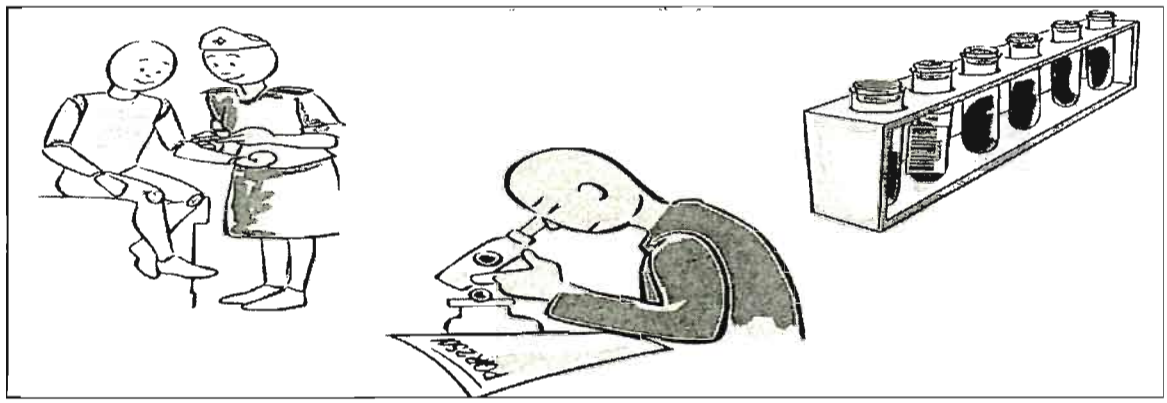
- **Fear of a positive result.**
- **Lack of transportation.**
- **Relocating to a new city.**
- **Belief that they are at low risk for HIV and, therefore, the result will be negative.**
- **Fear that their HIV status will be disclosed to someone else.**

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5. TYPES OF HIV TESTS

There are a number of different types of tests that can be used to determine if a person is HIV-positive or negative. Most of them work by **testing for the presence of HIV antibodies in the blood**. HIV anti-bodies are only made if a person has HIV, if a test shows that HIV antibodies are present, the testee has been infected with HIV.

5.1 THE ELISA TEST



The two types of tests most commonly used to detect HIV infection are the ELISA (enzyme-linked immunoassay) and Western blot tests. These tests are very accurate, but they are only able to detect HIV antibodies and not the HIV virus particle itself. The test must be performed by a Registered Nurse or a Doctor. The results can only be determined in a laboratory (People Management, 2006:77).

Procedure:
A small blood sample is taken from a vein in the arm and sent to a laboratory. Here the blood sample is tested for the presence of HIV antibodies.

The test result takes about a week. As the ELISA test is not 100% accurate, a positive result must be followed by a second test to confirm the positive result. This may be a second ELISA test or at times a different type of HIV test is performed, like the Western blot test.
The Western blot test is more accurate, though it is also more expensive and takes longer to perform. As a combination, the ELISA and Western blot tests have a very high degree of accuracy when the sample is taken outside of the window period. If both the ELISA and Western blood tests are positive, you are presumed to be HIV positive (Source: www.emedicinehealth.com).

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5.2 THE HIV ORAL RAPID TEST



These are affordable and almost 100% accurate. Most rapid tests can be done without sending a sample to a laboratory, and the results can be ready in about 20 to 30 minutes, using saliva, blood or plasma.

It is more convenient to administer rapid tests in rural areas where access to laboratories may be limited. The tests do not require specialized equipment.

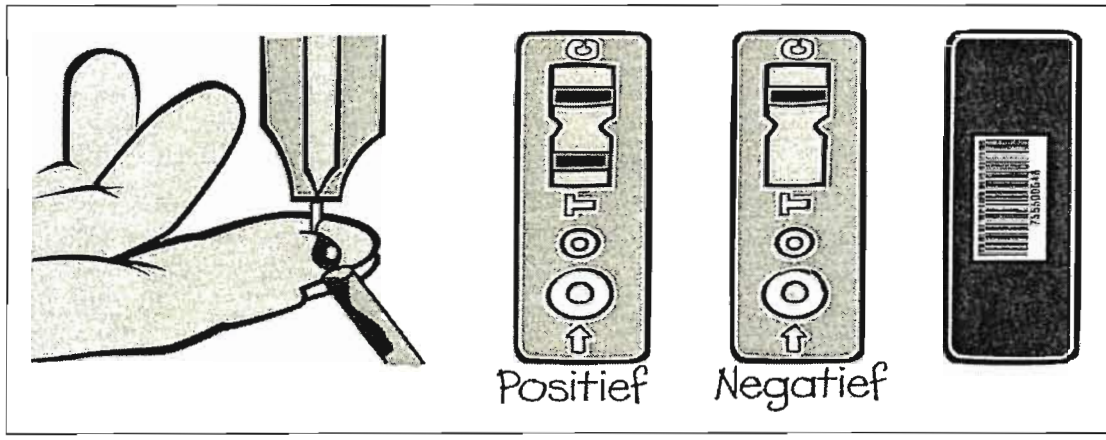
Procedure:
If the rapid test uses oral fluid the person being tested for HIV gently swabs (wipes) the device around in the mouth. The device must be wiped around the upper and lower gums and between the cheek and the teeth. The device is then inserted into a vial containing a developer solution. After 20 minutes the test device will indicate if HIV antibodies are present. Oral fluid can be stored at room temperature

Other significant benefits of the new rapid HIV tests for oral fluid include the following:

- Advantage of this test is that an anxious testee does not have to endure waiting a week or more for results. A rapid test also eliminates the problem of people not returning for their results because they are too worried or due to transport problems.
- An oral test is less dangerous to the tester. With an oral test there is no risk to a healthcare worker accidentally being pricked by a needle or being exposed to blood.
- People who do not like needles or are otherwise afraid of a blood test may decide to be tested. If people know immediately that they are positive for the HIV virus, they can begin to receive treatment sooner and take steps to prevent transmission of the virus (People Management, 2006:78).

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5.3 THE HIV BLOOD RAPID TEST



The disadvantage of sending a blood sample to a laboratory for HIV testing is that you have to wait for a few days and must return to the clinic or testing centre to get the results. For this reason, rapid tests to detect HIV antibodies have been developed.

Procedure:
These tests are simple to perform and do not require any laboratory equipment so that they can be done by a health care professional at the clinic or testing centre or at the bedside of a patient. A blood rapid HIV antibody test is a blood test, which can be done by pricking the finger with a lancet, and applying the test tube. The result is ready within approximately 15 minutes (Source: **www.emedicinehealth.com**).

- Rapid tests are very useful for the diagnosis of HIV infection in rural or isolated areas that are far removed from diagnostic laboratories and where clients often cannot afford to come back for test results.
- These tests are relatively cheap and they demonstrate a high rate of reliability if correctly used. The accuracy of rapid tests is variable but some tests are just as good as an ELISA test.

NOTE: All positive rapid HIV results should always be confirmed with a second rapid test or with a laboratory.
- **An HIV test is not a test for Aids. The test looks for the presence of antibodies or for the presence of the HIV virus.**
- **An HIV test cannot tell how or when the person became infected or where the person is in the timeline of HIV infection.**

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5.4 OTHER TESTS IN CONNECTION WITH HIV/AIDS

Other tests done in connection with HIV or Aids are the **CD4 counts** (tests the number of CD4 cells per mm^3 blood) or a **viral load test** (tests the number of viruses per ml^3 blood). It is very important when deciding whether someone is ready to be treated. These tests are not a test for diagnosing HIV, but are used rather to determine how far a person is on the HIV timeline, what condition his/her body is in. If a person is having antiretroviral treatment, then CD4 counts or viral load tests are done to determine how the body is responding to the medicines, and whether the virus has developed a resistance to any of the medicines, which then have to be changed (Page *et al.*, 2006:66).

5.5 ANONYMITY AND CONFIDENTIALITY

Many people are concerned that if they go for an HIV test, the result might not remain confidential.
When a person applies for life insurance when buying a house, for example, the insurance company may request an HIV test. By taking the test you are giving permission for the result to be released to the insurance company.
Your place of work may ask for all the employees to take an HIV test for the purpose of future planning. In this case, each person gives an **anonymous sample** of blood or oral fluid. In other words, it is not known to whom each sample belongs. For example, none of the samples have names or numbers on them and they are all placed together in a one large container.

The reason why companies do this type of testing is because they need to find out how many of their employees are HIV-positive at that time. This enables them to plan for the future, for example they might be assessing whether they can afford to offer their staff antiretroviral drugs or they are estimating how much money they will need to budget to train more workers in the future when the current ones are too sick to work. Note, in situations like this, the company will never know which of the employees are HIV-positive or not, as each test is completely anonymous and cannot be linked to any specific person.

NOTE:
It is illegal for an HIV test result to be revealed to anyone else unless the testee gives their permission.

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5.6 TESTING BABIES FOR HIV



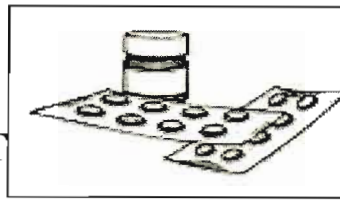
The HIV tests test for the presence of the antibodies to HIV. The presence of HIV antibodies is proof that a person has been infected with the HIV virus.
When a woman is pregnant, any of the antibodies she has in her body are able to cross the placenta into the body of the unborn baby she is carrying, and so these antibodies will also be present in the baby's blood when it is born. This does not mean that the baby has had or is infected with the disease for which he/she carries the antibodies. Slowly, over the next few months, those antibodies in the baby's body will be broken down and destroyed.

So the baby will initially test HIV-positive at birth if an ELISA test, rapid test or any other test for HIV antibodies is used.
If the baby has not been infected with HIV, he or she should test negative when approximately 16 months old. By then all the antibodies that were transferred from the mother will have broken down.

Any baby born to an HIV-positive mother, who is very sickly in the first year of life but was not tested, could be infected with HIV.
Any baby born to a mother who is HIV-positive but thrives for the first two years after birth is unlikely to have been infected with HIV during pregnancy or during birth. It is, however, possible for an HIV-positive mother to transmit HIV to a baby born HIV negative during breastfeeding.

NOTE:
All babies born to HIV-positive mothers first test positive but their test results may change over time. A newborn baby that test HIV-positive on an ELISA or rapid test should be retested every three to six months until he/she is 18 months old.

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6. STARTING ANTI-RETROVIRAL TREATMENT

6.1 WHAT IS ANTI-RETROVIRAL TREATMENT?

Anti-retroviral treatment (ART) is a combination of medicines that are given to someone who is ill with Aids. They fight HIV in the body.
Anti-retroviral medicines suppress the replication of HIV by blocking the enzymes HIV uses to replicate itself.
ART is not a cure for Aids. It helps make your immune system stronger so that you can be healthier. It also helps your body to fight off and prevent illnesses such as pneumonia, TB and diarrhoea.

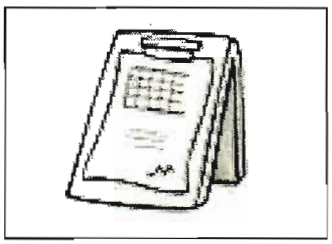
6.2 HOW DOES ART HELP?

Antiretroviral treatment (ART) prolongs and improves the quality of life of a person with HIV. It is not a cure for HIV. ART must be taken for life. Once you start taking ART, you should not stop unless indicated by a doctor, who may need to prescribe a different set of antiretroviral medicines for you.

If the person taking ART is a breadwinner or a parent, they can continue to provide and care for their family for longer.

6.3 WHERE CAN I GET ART?

Some health centre (**clinics**) will offer the treatment. ART will also be provided through all government HIV service points. Some workplaces and private practitioners also provide this treatment.



6.4 WHEN DO I START TREATMENT?

According to Government's Comprehensive HIV and Aids Care, Management and Treatment Plan for South Africa:

- People should start taking ART once their CD4 cell count falls **below 200 cells/*mm*^{3}.**
- Or if they have opportunistic infections associated with **Stages III or IV** of HIV that may be life threatening.

The CD4 cell count test (which indicates the strength of the immune system) and the viral load test (which indicates the amount of HIV in the body) will indicate when to start ART. A health worker will take a blood sample, and send it to a laboratory for testing. ART prevents the

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virus from multiplying, therefore, decreasing the amount of the virus in the blood. This allows the CD4 cells to increase and the body's immune system to recover. The CD4 test and the viral load test determine when treatment should begin and also monitor whether it is working.

If the CD4 count is higher than 200, it is not necessary to take treatment. There are a lot of things a person can do to stay healthy:

- Join a support group. A person can learn a lot about HIV, and share any of their problems with others.
- Eat healthy and exercise. This will keep the body and mind strong.
- Stop smoking and drinking.
- Go for regular check-ups. The health worker should take regular CD4 blood tests to know when to start ART. If a person takes the medicines too late, they may be too ill for the medicine to help.

The decision to begin taking ART should be taken together with a doctor (Soul City, 2004:26-27).

NOTE:
Start anti-retroviral treatment (ART) immediately when the CD4 count is less than 200.

6.5 HOW WILL I KNOW IF THE DRUGS ARE WORKING?

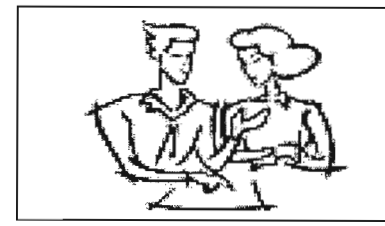
The viral load count is an important indicator as to whether the treatment is working. If the treatment is working, your viral load will reduce quite rapidly to levels that are "undetectable". Your immune system will begin to recover, and your CD4 cell count will increase. If the anti-retroviral stops working, then the viral load will increase again, and your CD4 count will decrease. This is why it is important to have regular medical check-ups to monitor CD4 cell counts and viral loads. The government HIV service points will provide these check-ups.

Most people starting ART will feel a lot better very soon. The occurrence of opportunistic infections will reduce, and you will begin to put on weight.

If your CD4 cell count is below 50 cells/mm3 and your immune system is very weak, then taking ART may initially result in symptoms

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of TB and pneumonia, and you could feel quite ill. This means that your immune system is starting to work again and reacting to the opportunistic infections. You must also receive treatment for these infections. Talk to a doctor about this, but do not stop taking the ART unless your doctor tells you to.
Where the CD4 cell count is extremely low and ART has been started late some people may not survive, even though they are on ART.
To ensure that the ART is most effective, it is important that you know your HIV status early, and regularly monitor your CD4 cell count and viral load.



7. HOW TO MAKE ART WORK BEST

7.1 HAVE A TREATMENT HELPER

Before you start taking any treatment, make sure that at least one person knows you are about to take ART. This person could be a friend or family member, a treatment buddy. A treatment buddy supports a person living with HIV by ensuring that they take their medicine as prescribed every day, they can also help with side-effects and make sure they go for regular check-ups at the HIV service point or with their doctor.

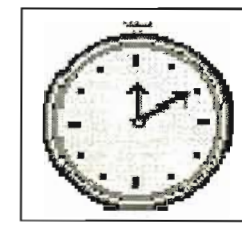
7.2 WHAT DOES AN UNDETECTABLE VIRAL LOAD MEAN?

An undetectable viral load does NOT mean that you are cured of HIV. ART does not cure HIV. There is no cure for HIV. It merely shows that the ART is effectively suppressing the HIV. HIV is still present in the body, and research suggests that it may be replicating slowly even while using treatment.



7.3 MEDICINE SHOULD NOT BE SHARED

There may be other people in your household who need treatment. If you give them some of your medicines, the ART will not work for you or for them. It makes HIV in your body stronger if you don't take the right dose. So even if you take the treatment properly the next time it will not work for you.



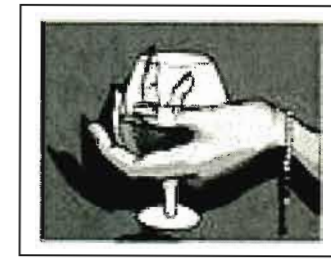
7.4 TREATMENT SHOULD BE TAKEN EVERY DAY AT THE SAME TIME

Each time a person forgets to take their medicine, the HIV virus

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becomes stronger. After a while, the treatment will not work anymore. A time-table of when to take medicines will help. A treatment helper can help to remember to take the ART medicine.

7.5 STOP DRINKING ALCOHOL BEFORE STARTING ART



Alcohol weakens the immune system. It may also make a person forget to take their medicine.

7.6 ALWAYS USE CONDOMS WHEN HAVING SEX

ART may make a person strong, but it does not cure HIV. Even when a person feels strong, the HIV is still in their body. A person can still infect a person who is HIV negative. You can also increase HIV in your body if you have unprotected sex with another HIV positive person. (Get re-infected with another strain of HIV). Then the treatment might not help you.

7.7 HAVE REGULAR CHECK-UPS

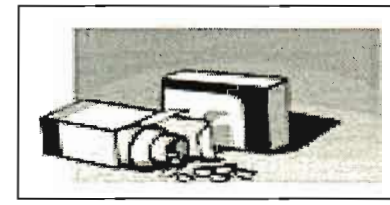


You should have regular check-ups at the clinic. The health worker will then be able to treat any new illnesses or problems. He or she will also make sure your treatment is working well (Soul City, 2004:23).

7.8 TELL THE HEALTH WORKER IF YOU ARE TAKING ANY OTHER TREATMENT

This includes vitamins, any medicines you get from a chemist and traditional medicines like the African Potato. If you take them with the ART, the treatment may not work, or make a person ill. It is important to know the correct names of the medicines you are taking. If you do not know them, take them with you to show the health worker.

8. SIDE EFFETS OF ART



8.1 WHAT DO SIDE-EFFECTS MEAN?

All medicines are chemicals. Anti-retroviral medicines are very strong and may have side-effects. Sometimes they make you feel unwell.

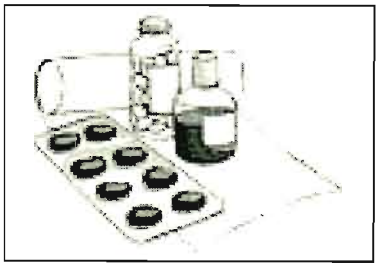
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This is called the side-effects of the medicines. Some people complain of side-effects when they start ART (Soul City, 2004:28-29).

8.2 WHAT ARE THE SIDE-EFFECTS OF ART?

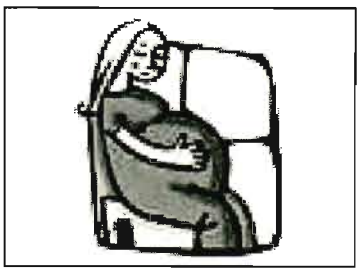
Some of the side-effects you may have when you take ART:

- Nausea and vomiting
- Painful legs
- Headaches
- Skin rash
- Not sleeping well
- Painful stomach
- Bad dreams
- Feeling very tired
- Diarrhoea



The side-effects often go away after a few weeks, you will feel better then. But you should tell your health worker immediately if you have these side-effects. Most of the side-effects can be managed, and you can get advice on how to reduce them. Do not stop the treatment without speaking to the health worker first.

9. HIV POSITIVE WOMEN AND PREGNANCY



Many people think that a woman who has the HIV virus will not be able to get pregnant. This is not true. Thousands of babies are born with the HIV virus each year.

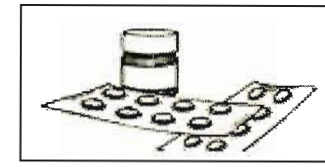
Women who are HIV-positive and pregnant can pass the HIV virus on to their babies. This can be very hard to cope with, especially if they discover that they are HIV-positive when they are already pregnant. Women who know that they are HIV-positive should think carefully before they decide to have a baby. This is because:

- About one out of every three babies born to HIV-positive mothers will also have the HIV virus if the mother and baby do not take medicine to stop this happening.
- Babies who have the HIV virus get sick often. They usually die when they are very small.
- If a woman is HIV-positive and pregnant, she may get ill with Aids quicker.

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9.1 HOW TO PREVENT PASSING HIV TO A BABY

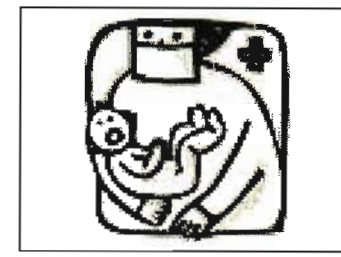
If you are HIV-positive, there are things you can do to lower the chance of passing the HIV virus to the baby. Talk to a doctor or health care worker.



- **Take nevirapine during labour**

  Nevirapine is a medicine that lowers the chance of passing the HIV virus to a baby. The baby must also be given a small amount of nevirapine within 3 days of the birth. Babies take it in syrup form so it is easy for them to swallow. The government has a legal duty to give nevirapine to the mother and baby if they are HIV-positive.

- **Caesarean Birth**



  There is a bigger chance that the HIV virus will pass from a mother to her baby in natural childbirth than in Caesarean birth.

- **Feed the baby with care**

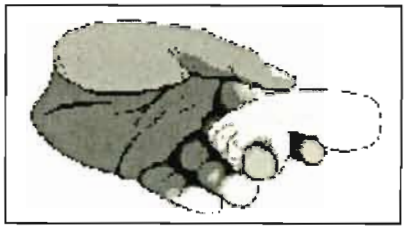
  Even if a mother has taken nevirapine, she can still pass the HIV virus on through breast-feeding. Breast milk does contain HIV. A milk formula instead of breastfeeding can be used to minimize this risk.





NOTE:
If you are HIV-positive and pregnant, you have the same right to an abortion as other women. If you choose to have an abortion, it is better to have it early in the pregnancy. An abortion can be done until a woman is 20 weeks pregnant. Ask a health worker for advice on where you can have an abortion.

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10. BABIES AND HIV

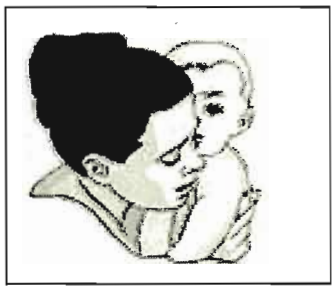
Most babies who are HIV-positive do not live for very long. Many infected babies die when they are still small. Some die before they are two years old. Almost all children who are HIV-positive die before they are 8 years old.
Most babies get the HIV virus from their mothers. This may happen during:

- Pregnancy
- Birth
- Breast-feeding

10.1 HOW DOES ONE KNOW IF A BABY HAS THE VIRUS?

- Sometimes some babies get ill more often than other babies. This may be because their mothers are HIV-positive. The baby may then also be HIV-positive.
- If a baby does not put on weight, this can sometimes be a sign that he or she is HIV-positive.

Only a blood test can tell if a baby has the HIV virus or not. If the mother is HIV-positive, the baby should be tested to see if he or she has the HIV virus. The test can only tell you this when your baby is 15 to 18 months old.



10.2 WHEN A CHILD IS HIV POSITIVE

Children who are HIV-positive need love and care.
Just like adults, children who are HIV-positive can live a healthy life. If your child is HIV-positive you must:

- Make sure that your child eats healthy food.
- Take your child for regular check-ups at the clinic. The health worker will do a CD4 blood test to check if the immune system is still strong.
- If the CD4 count is weak and is less than 200, your child should get anti-retroviral treatment (ART).



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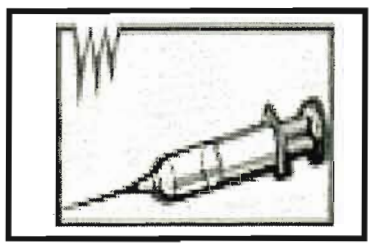
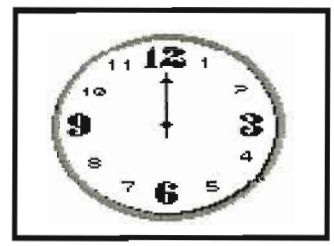
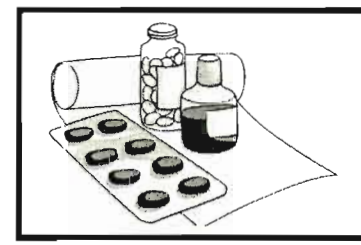
10.3 ART AND CHILDREN

- Children, like adults, can get ART when their CD4 count is less than 200.
- ART works if you take it every day at the same time.
- Children who are on ART need someone who will make sure they take their treatment properly.
- The child should also have all his/her immunizations.
- The child should attend the public health clinic regularly.

11. POST-EXPOSURE PROPHYLAXIS (PEP)

Antiretroviral medicines can lower the viral load if there has been exposure to blood through an **injury of a needle** or a person is **raped**, thereby reducing the risk of HIV transmission. This is called post-exposure prophylaxis (PEP).

INJURY OR RAPE **2-48 HOURS** **28 DAYS Treatment**

This is a short term anti-retroviral treatment, and needs to be taken within 2 – 48 hours after exposure. The reason for this is that the medication will protect the CD4 cell so that the virus cannot get inside it to replicate and multiply. If not taken before that time the medicines will not work.
The HIV virus will stay in the bloodstream for about 23 days and will either be destroyed by the body or will die because it cannot replicate itself. Therefore, this medication MUST be taken for at least **28 days** to protect the person from becoming infected.

- When a person has been raped or injured they must report to a doctor/HIV service point as soon as possible, and ask to get PEP.
- When a person goes to the clinic for PEP, they will be asked to be tested for HIV as there is no need in giving this medication if the patient is already HIV-positive. Before and after the test the

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person should receive pre-test and post-test counselling on HIV and on PEP.

- Due to the window period, if a person is exposed to HIV today the anti-body test will only show that a person is HIV-positive within 6 weeks to 3 months. This means that if they test HIV-positive just after exposure, that they have been HIV-positive for at least the past 6 weeks to 3 months.
- This medication might very likely have side effects, but the patient must be motivated to stay on the medication for the period of time.
- This medication can ONLY be prescribed by a medical doctor.
- You can also be given emergency contraception. This must be taken within 72 hours of the rape.
- You must also get treatment for sexually transmitted infections.

NOTE: Ensure that you and your family are aware of where you could access such medication in your area in case of an emergency.

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MODULE 3: LIVE A LONGER, HEALTHIER LIFE WITH HIV – "A WELLNESS PROGRAMME"

1. UNDERSTNDING WELLNESS

2. PHYSICAL WELLNESS (BODY)

2.1 Nutrition and HIV – The importance
2.2 Good nutrition can help someone with HIV
2.3 Poor nutrition weakens the immune system
2.4 Eating healthy meals / Good nutrition
2.5 Key nutritional management tips
2.6 Food must be safe as well as nutritious
2.7 Nutritional problems
2.8 Personal hygiene
2.9 Infection control at home
2.10 Environmental hygiene
2.11 Guide to use medicine

3. PSYCHOLOGICAL WELLNESS (MIND)

3.1 Emotional impact of an HIV diagnosis
3.2 Emotional reaction to HIV and Aids
3.3 Factors influencing the patient's psychological response - fears
3.4 Value of appropriate information

4. SOCIAL WELLNESS

4.1 Factors influencing the patient's psychological response – family
4.2 Factors influencing the patient's psychological response – social aspects

5. SPIRITUAL WELLNESS

6. SKILLS AND TECHNIQUES IN REDUCING STRESS

7. COPING WITH STIGMA

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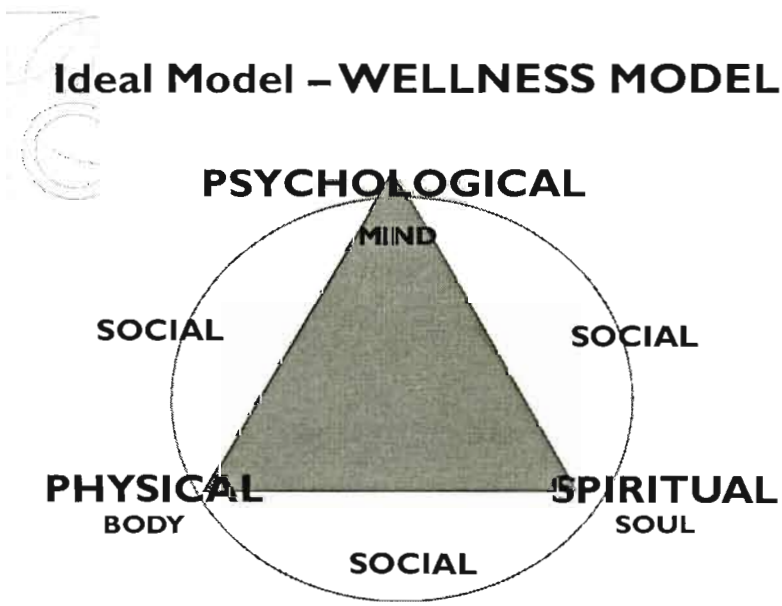
MODULE 3:

LIVE A LONGER, HEALTHIER LIFE WITH HIV – "A WELLNESS PROGRAMME"

Stress, malnutrition, poverty and loneliness are some of the factors that make people living with HIV and ill from Aids much faster. In Africa, positive living and healthy eating are now more important than ever, so that the Aids medicines can do the work in people's bodies that they are supposed to do.

1. UNDERSTANDING WELLNESS

- It is important to continually advise patients about how they can support and help their bodies to remain well as long as possible. This means that they should try to live healthy lifestyles and prevent re-infection with HIV.
- The idea behind wellness is to get patients to move beyond the point of: "HIV and Aids means I'm going to die" to, **"what can I do to look after myself, stay well and live every day".**
- Wellness will then extend life expectancy and improve **quality of life** for the individual.
- To understand total wellness is to look at the patient's **MIND, BODY, SOUL** and **SOCIAL** issues (People Management, 2006:36).



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TAKE CARE OF YOUR BODY, MIND AND SOUL

When you are HIV-positive or have Aids, you need to keep your body and mind strong. This helps you not to get sick (People Management, 2006).

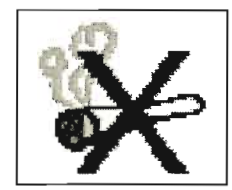
- **Eat the correct, healthy food**

Food will not cure HIV, but it can help to keep your immune system strong. Eat fresh food like fruit, vegetables, beans, chicken and fish.



- **Limit body toxins**

It is important to **stop smoking**. Smoking weakens your immune system and causes a lot of illnesses. Smoking can cause lung infection, which can be serious for someone with HIV.



- **No alcohol**

Alcohol causes many problems for people with HIV. It harms the liver and weakens the action of vitamins which prevent infections. It weakens self-control so that people might not practice safe sex. Unsafe sex (not using a condom) can pass the virus on to a partner.



- **Importance of exercise**

The cells in your body that fight infections work better when you are doing exercise. Physical exercise helps keep body temperature up, will build muscle, which keeps weight up. Exercise also makes people feel good. Do regular moderate exercise, 20 minutes a day, like walking or dancing or running slowly, do not do too much! If you are very ill, get someone to help you move your arms and legs to help you fight the infection.



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- **Get enough rest and sleep (manage fatigue and energy)**

If you are working hard you need to make sure that you get enough sleep and rest. Try not too work when you are feeling very tired – rather get some rest or sleep. Try to always use holidays or off days to get enough sleep and rest.

- **Go for regular medical check-ups**

A person with HIV should visit the clinic for a check-up every 3 to 4 months. The health worker will give advice, and will help you to deal with any problems you may have.

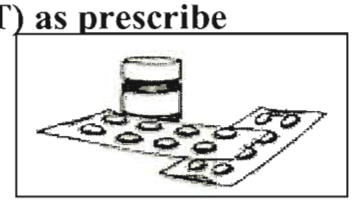


- **Treat any new diseases or problems**

People with HIV get ill very easily. It is important to go to the clinic if you are ill. This is because every illness makes the body weaker and less able to fight the HIV virus. If the clinic finds that you have any new illnesses or problems, they should treat them. If they are not treated quickly, they may get worse and make you very ill.



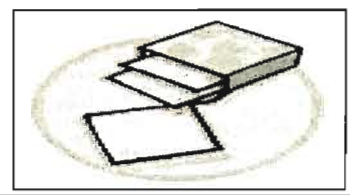
- **Take anti-retroviral medicine (ART) as prescribe**



ART is available, it is not a cure, but it will help you to live a longer and healthier life. Most people do not need ART when they find out that they are HIV-positive. They can still live for a long time before they start treatment. Talk to your health care worker when to start ART. Manage the side-effects of ART.

- **Practice safe sex**

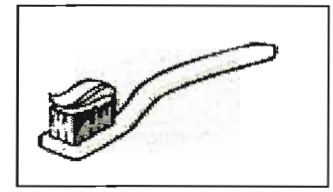
Always use a condom to protect your partner and yourself from re-infection.



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- **Building the immune system**

General personal and environmental hygiene and infection control at home to protect a sick person.



- **Lower stress levels**

People should be encouraged to be positive and live each day as calmly as they can. Worry and stress can affect sleep and weaken the immune system.

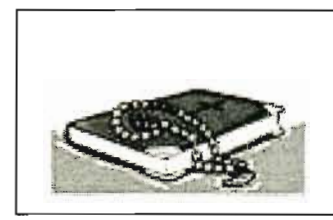


- **Develop a positive attitude**

Try to maintain a positive outlook which is known to boost the immune system. Strive to find meaning by using your positive status to help others.

- **Strengthen spiritual ties**

Faith and support from a church helps



- **Be a survivor, not a victim**

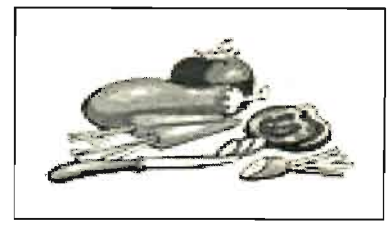
Believe in the future, take control of your destiny and create a supportive environment for yourself. HIV is a manageable condition, and people with HIV can live productive lives for many years. The use of ART can prolong life.

- **Get support from people**

Join a support group of people living with HIV and Aids. Talk to someone when you feel lonely, sad or angry.



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2. PHYSICAL WELLNESS (BODY)

2.1 NUTRITION AND HIV – THE IMPORTANCE

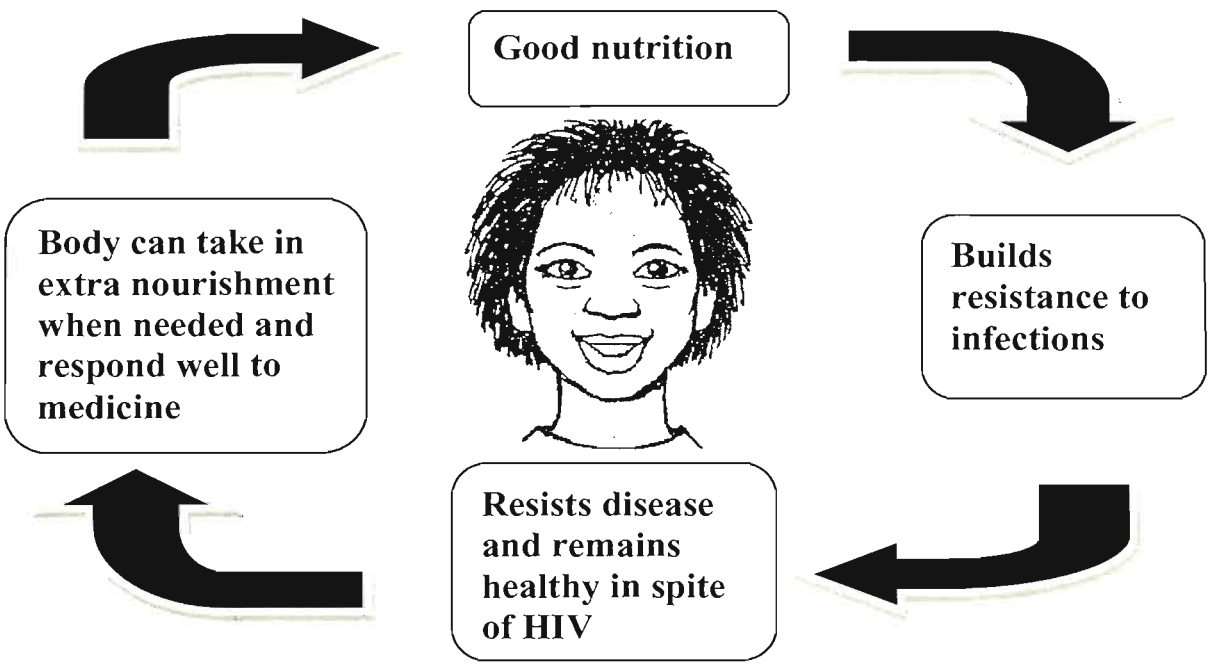
Maintaining a healthy and nutritious diet is important to all people, but particularly to people living with HIV. Good nutrition gives the body energy and special substances which strengthen the immune system. People who practice good nutrition can keep themselves healthy even when they have HIV. Also, even when HIV starts to cause health problems, good nutrition can slow down the development of diseases. Nutrition is not a substitute for treatment – eventually all persons infected with HIV will need to take anti-retroviral medicines to support their immune system. A poor diet impairs the functioning of the immune system, and hastens the progress of HIV infection to Aids.

Therefore, starting early with good nutrition is clearly very important for the person with HIV (Soul City, 2005:31).
Usually, someone needs counselling how to practice good nutrition.

2.2 GOOD NUTRITION CAN HELP SOMEONE WITH HIV

Good nutrition can **strengthen** the body's 'defence force' – the immune system.

A POSITIVE CYCLE OF NUTRITION:



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2.3 POOR NUTRITION WEAKENS THE IMMUNE SYSTEM

- The immune system is our body's 'fighting force' which resists all the different diseases we can get.
- Poor nutrition weakens this defense force so that we can't easily resist parasites, bacteria and viruses (like HIV).
- HIV and Aids also weakens the immune system so that different diseases can enter our body and take hold.
- A weak immune system then leads to poor nutrition again. The weakened body:
    - Needs more nutrients.
    - Actually loses nutrients (e.g. through diarrhoea).
    - Can not absorb food properly.
- HIV and other infections damage the lining of the gut, so that it can no longer absorb nutrients from foods properly.
- Diarrhoea results from poor absorption and the body loses nutrients and water during diarrhoea.
- Also, anxiety actually makes the immune system use up some nutrients and can thus weaken it further.

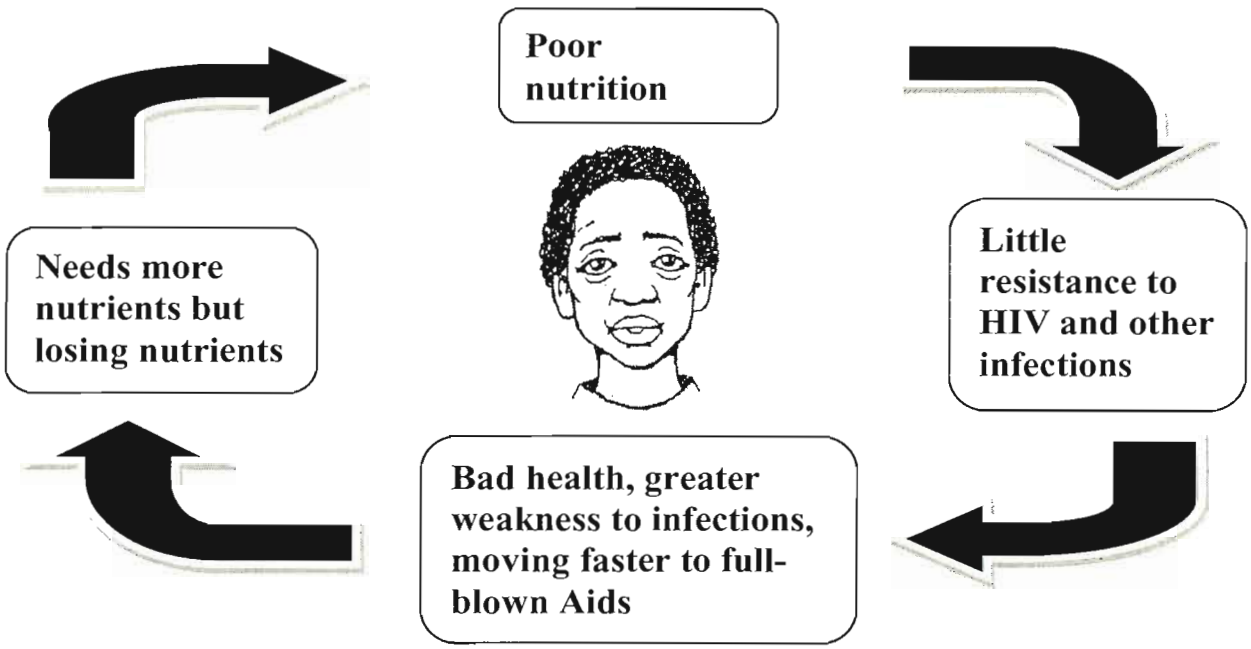
Secondly, people with HIV and Aids *eat less* because:

- During infections and illness they lose their appetite.
- Mouth and throat infections make eating difficult and unpleasant for them.
- Tuberculosis and fever.
- Some medicines reduce their sense of taste.
- Worry and depression can lead to poor appetite.
- The high cost of medicines and the loss of work can make it difficult for them to afford all the foods they need.
- Nausea/vomiting.

In this way a bad cycle starts and repeats itself without a change for the better. Thus things can get worse and worse (South Africa Department of Health, 2001).

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A NEGATIVE / "BAD CYCLE" OF POOR NUTRITION:

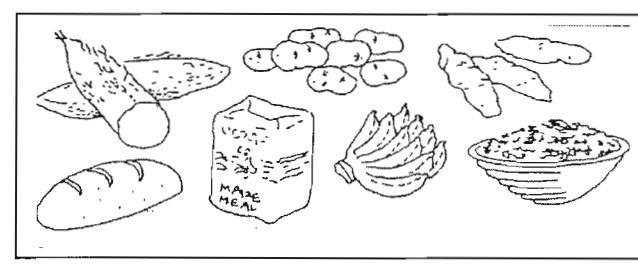


2.4 EATING HEALTHY MEALS / GOOD NUTRITION

An ill person has an even greater need for food than a healthy person. People should be encouraged to think about the foods that will help make them healthy, rather than worry about foods that are not considered to be good for them.
All of the foods you are familiar with will fall into one of the following three groups. Everyone should try to eat food from each of these groups at every meal.

★Energy-giving foods: These include:

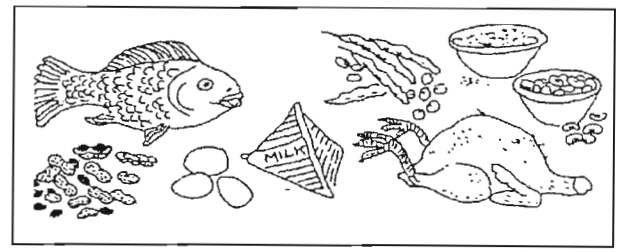
- Brown bread or traditional steamed whole wheat bread;
- Mealie meal, oats porridge or maltabella porridge;
- Potatoes, sweet potatoes, gems;
- Mealies, samp, rice, and pasta
- Sugar, wheat (Theron, 2006:41).



Make **starchy foods the basis of each meal** because they supply most of the energy, help to keep the body weight up and are cheap.

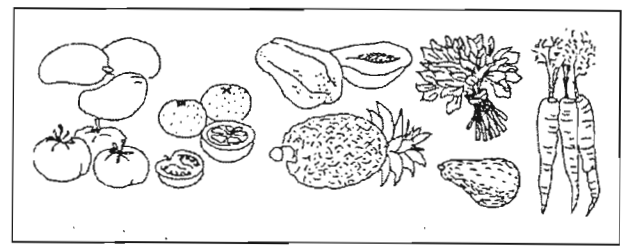
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★ **Body-building foods: These include:**



- Peas or beans, soya, nuts, eggs, meat, fish and milk, maas, cheese.
- These foods are rich in protein and contain iron and calcium. They help people to build muscles, bones and blood and keep to immune system healthy.

★ **Foods that protect the body from infection (vitamin-rich foods): These include:**



- Vitamins and minerals are in:
- All fruits and vegetables. Tomatoes, spinach, morogo, cabbage, butternut, carrots, paw-paw, banana, orange.
- Cooking for too long destroys vitamins, cook or steam lightly, and use the cooking water used as a soup or sauce.

2.5 KEY NUTRITIONAL MANAGEMENT TIPS:

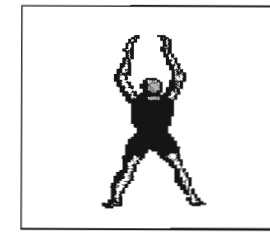
- **Start early!**
  Start taking care and eating well as soon as possible, so that you can stay healthy. If you don't eat well in the early stages of HIV infection, you may struggle to catch up later, when you start to feel ill and get infections.

- **Choose your own food!**
  Once you know what types of food you need, choose the healthy foods that you like and can afford. Choose foods that you usually have in the house and can get easily.

- **Choose a variety of foods.**
  There are lots of foods you can enjoy! Make sure that you base your meals mainly on starchy foods. Then choose from the other foods to add the different nutrients you need. You don't need to include all food groups with every meal. But choose several every day.

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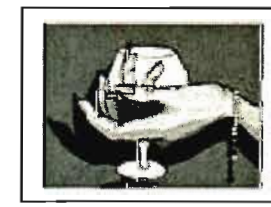
- **Use salt sparingly.**
  Eating a lot of salt can cause high blood pressure. Rather use a little salt and control your blood pressure so that you won't need medicines for it.
  You can use herbs and spices, garlic, curry, onions or ginger to give flavour to food.
  (Sometimes you may need to use more salt to replace salt you have lost when you have diarrhoea.)



- **Be as active as possible.**
  Strong muscles help to keep your weight steady. Therefore, as long as you are feeling well, keep up work around the house and walk a lot. Do any exercise you can manage without tiring yourself.



- **Drink lots of clean, safe water.**
  You need about 8 cups of water a day. You may need more if you are vomiting, sweating at night or have diarrhoea. Take cold drinks, milk, fruit juice and other drinks too. Tap water is usually safe, but if your water comes from a well, river or borehole you should take steps to clean it before you drink it.



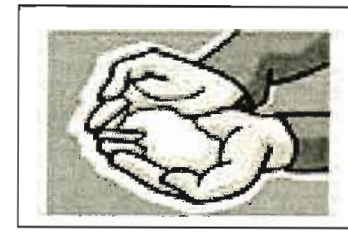
- **Don't take alcoholic drinks.**
  Such drinks include wine, beer (also traditional beer), ciders, brandy, whisky, rum, cane, vodka, gin, etc.

Alcohol harms the liver and makes people lose vitamins which support the immune system. Alcohol also combines with medicines (which many people with HIV and Aids have to take) can harm the liver.

2.6 FOOD MUST BE SAFE AS WELL AS NUTRITIOUS

When you advise people with HIV and Aids about food safety, you need to be sure that they understand that germs can enter food in different ways and in different places. Also, there are different dangers for different kinds of food (Page, Louw & Pakkiri, 2006:72-73).

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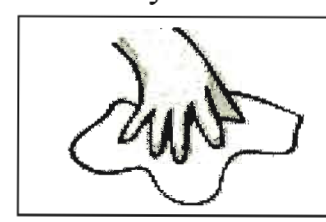
2.6.1 Personal hygiene when handling food

The most important guideline for personal hygiene is to keep your hands clean so that dirt and germs on them don't contaminate the food. Therefore:

- ***Wash your hands well*** with soap and water (preferably warm water): - Before you touch food.
  - Between touching raw food and cooked food.
  - After touching any animal at all.
  - After using the toilet.
  - After sneezing or blowing your nose.
  - Before you eat your meals.



- ***Cover all wounds when working with food.*** Use rubber gloves if possible, because plasters can get dirty on the outside even if they are keeping the wound clean.



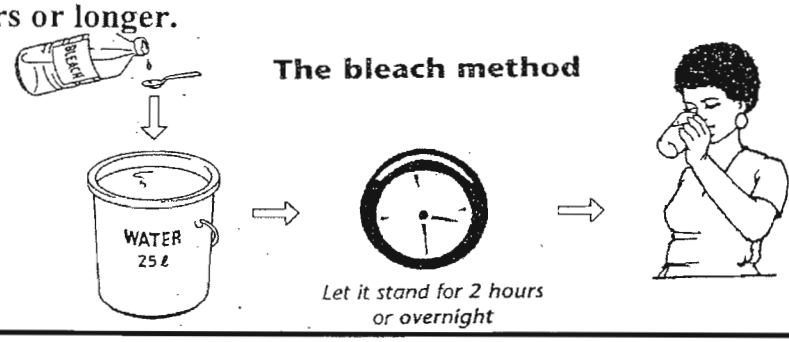
2.6.2 Guidelines for food safety

- **Keep your kitchen safe for food.** The room itself must be clean and well aired so that germs and moulds can't grow. Wash all work surfaces (sinks, shelves).
- **Keep rubbish in a covered bin** that is emptied and washed regularly.
- **Cleaning cloths, sponges and scourers should be kept clean.** They can be disinfected with bleach and dried in sunlight, which also kills germs.
- **Wash dishes in hot soapy water if you can.**
- **Don't use cracked cups or scratched plastic containers.** Germs hide easily in the cracks and scratches.
- **Use a special cutting board, not the sink, for cutting raw food.**
- **Safe vegetables and fruit.** Wash all vegetables and fruit. If you can't wash them, peel them. Throw away any vegetables that are mouldy or rotten.
- **Safe milk and dairy products.** Look for the word **'PASTEURISED'** on the milk bottle or packet.

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- **Safe meat.** Meat should not be 'off' and smelly, but it is just as important to ensure that it is fully cooked, wherever you eat it. Don't eat meat that is raw or pink inside.
- **Safe eggs.** Don't eat raw eggs in any form at all. Make sure that the white is cooked and the yellow is firm. Wash eggs before you break them and don't use cracked eggs – germs can enter the eggs through the cracks.
- **KEEP WATER CLEAN AND SAFE**
  Dirty water is a major cause of diarrhoea in South Africa. People with HIV and Aids have to be extra careful not to get infections caused by dirty water. If they get their water from a river or well, they should:
- Boil the water before they drink it, or use the bleach method.
- Store clean, safe water in a clean container and covered.

Use bleach method to make water safe when it's not possible to boil it. Add 1 teaspoon of bleach to 25 litres of water Mix well and let it stand for 2 hours or longer.



2.6.3 The danger of food poisoning for people with HIV and Aids

Healthy people who get diarrhoea, nausea, stomach cramps and vomiting often say, "It must have been something I ate". Bacteria can sometimes poison us in food that has spoiled. The food sometimes still looks good or even tastes good although it has 'gone off'.
You need to explain carefully to people with HIV and Aids that their weakened immune system can't fight off germs carried in food easily. People with HIV and Aids can get serious food poisoning from:

- Raw or undercooked chicken, meat, fish and eggs.
- Unpasteurized milk.
- Water that does not come from a tap.

People may get symptoms like stomach pain, nausea, vomiting, diarrhoea, headaches, chills, fever and muscle pain (Evian, 2006).

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2.7 NUTRITIONAL PROBLEMS

PROBLEMS PEOPLE MIGHT HAVE	WAYS TO COPE
Weight loss: Weight loss is a major problem and causes poor health and early death of people with HIV and Aids. It usually happens when the HIV positive person has an infection like pneumonia, tuberculosis and/or diarrhoea. Each time the person has an infection they may lose a lot of weight. When the person gets better, they can put one some of the weight again, but they often fail to regain all the weight. Over time their weight drops gradually and during times of weight loss the muscles weaken and reduce badly.	If a HIV-positive person does start losing weight, they should talk to a health worker about it as soon as possible. Anti-retroviral medicines could help them to keep their body weight steady and you can advise them on nutrition: • Strive to keep up their body weight from the start by eating plenty of starchy foods, sugars and fats. • Build muscles by eating energy and protein rich foods and taking suitable exercise. **Healthy eating does not have to be expensive.** • Choose vegetables and fruit that are in season as this is when they are cheapest. If fruit is too expensive, eat more vegetables. • Lentils, beans and soya mince are cheaper than meat and chicken. • Drink water and rooibos tea rather than fizzy cool drink. • Prepare your own fresh food rather than buying meals.
Poor appetite: Caused by illness or ART medicine	• Eat what you like best and when you feel like eating. • Eat smaller meals, but more often. • Try high-energy drinks like maas, milk, yoghurt or mageu.

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	• Try exercise (e.g. walking before meals) to improve appetite.
Feeling tired: Because of HIV or Aids	• Ask others for help with preparing food, and accept their offers of help. Join a support group which gives home care or even food parcels when needed. • Keep high-energy foods which are easy to eat like bananas, avocados or peanuts. Canned foods are also easier at such times. • Rest as much as you can. • Talk to a health worker if you think you may have anaemia.
Feeling nauseous: For most people with HIV, nausea is temporary. Both infections and medicines can cause it.	• Eat smaller meals more often. • Eat foods that are cold rather than hot and plain rather than spicy or sweet. • Dry toasts or biscuits/crackers help relieve nausea. Avoid greasy food. • Sip cool juices or cold drinks between meals, but no liquid with meals. • If you vomit, replace the lost fluids with different drinks, including soup. • Try medicines for nausea that health workers recommend.
Diarrhoea:	• Drink 8 or more cups of fluid to replace water that is lost. Try to use juices, soups or jelly that also replace energy and vitamins. • Replace salts by eating bananas, potatoes, tomatoes, pineapples and peaches. • ***Foods to eat:*** Simple starchy

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	foods like pap, pasta, white rice and bananas. • ***Foods to avoid:*** Dairy products, skins of fruit or vegetables, green/unripe fruit. Foods like prunes (or juice) that are laxative. Caffeine or alcohol (coffee, tea) • Eat smaller meals more often, rather than 2-3 large ones. • Avoid any fatty meats, fried foods, oil, margarine, etc. Use low-fat milk.
Sore mouth and throat Infections like thrush (candida) can cause painful sores in the mouth.	• ***Foods to choose:*** Soft and moist foods like porridge, mashed potato, soup. Soothing drinks that are not sour or gassy. • ***Foods to avoid:*** Dry, rough or hard foods like: acidic foods like tomatoes, pineapples. Spicy or salty foods (use herbs instead). Very hot or very cold foods. • Try mashing your food and using a straw for liquids. • If it is painful to brush teeth, rinse the mouth with a little bicarbonate of soda mixed with water.

(South Africa Department of Health, 2001:36-38).

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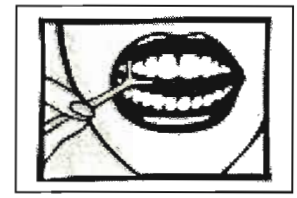


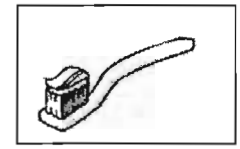
2.8 PERSONAL HYGIENE

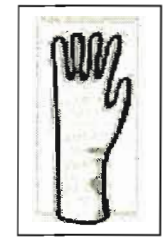
When you keep yourself, your family and environment clean, you stop germs that make people ill.



- Wash your body, hair, clothes.
- Wash hands with soap and water:
  - Before working with food.
  - Before you eat.
  - After changing a baby's nappy.
  - After going to the toilet.
- Sick people must wash every day.
- Use running water to wash.
- Wash with soap and water.
- Do not spit on the ground.
- Cover mouth and nose when sneezing.
- Never use grounds where vegetables are planted as a toilet. If there's no toilet make a hole in the ground and cover the hole.
- Keep fingernails short, germs can grow under long nails.
- Wash clothes and linen with spills of blood, urine and body fluids, separately.
- Use gloves when washing patients.
- Cover open wounds with plaster/bandage.
- Don't share toothbrushes, razors or needles.







2.9 INFECTION CONTROL AT HOME

Basic hygiene principles in infection control:

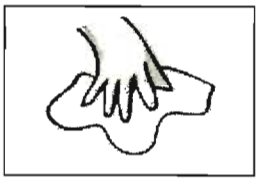
Universal precaution to protect caregiver and ill people based on risk of exposure to blood, semen, menstrual discharge, body tissue, wound secretion, abdomen- pregnancy- body fluids and breast milk.



- Wash hands with soap and water.
- Keep wounds covered with bandages or cloth.
- Remove households waste – sealed in plastic refuse bag.
- Keep bedding and clothes clean.

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- Don't share personal items like a razor, toothbrush and needles.
- Wipe fluid spills immediately – use paper towels, place them in a plastic bag and throw away.
- Store food properly.
- If someone is ill (flu), do not share cups.
- When coughing and sneezing cover your mouth.
- Wash eating utensils with soap and water.
- Wash raw fruit and vegetables and baby toys.



2.10 ENVIRONMENTAL HYGIENE

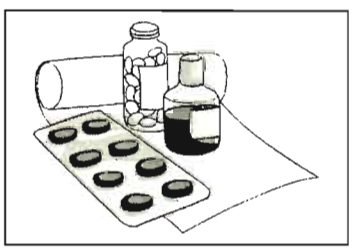


Good hygiene at home/environment prevents diarrhoea and respiratory infections:

- Plants and trees prevent rain from carrying away the soil.
- Get rid of rubbish it can cause pollution and is unhealthy.
- Proper waist disposal - put nappies, tissues, soiled objects in a container – burn or bury objects.
- Healthy houses need windows to let in light and air – germs grow in dark places.
- Keep water and food in a clean place/workspace and cover containers.
- Fireplaces/stoves need a roof opening, to let out the smoke.
- Every house needs a toilet, it can be outside.
- Keep animals away from house, they can carry diseases.
- Use water from a tap, or boil water, or add 5 drops of bleach on 1 L of water.
- Wash hands with soap before working with food.
  (Theron, 2006: 42-44).



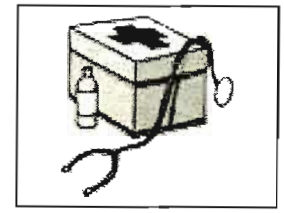
2.11 GUIDE TO USE MEDICINE



Medicine must be used according written instructions otherwise it's harmful and useless.

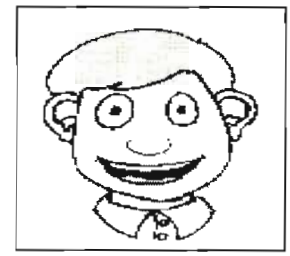
- Get instructions from a doctor or nurse on how to use medicine.

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- Know why it is prescribed.
- Know how it will help.
- Know for how long it should be taken.
- Keep medicine cool and out of sunlight.
- Take medicine every day, at the same time, as instructed (every 4, 6, 8 hours?)
- Take medicine after a meal.
- If vomiting occurs after medicine is taken, the dose should be taken again, if vomiting occurs 20 min. after taken, do not repeat dose.
- If tablets cannot be swallowed, crush them.

Know what the side-effects, if any, are and how to manage them.



3. PSYCHOLOGICAL WELLNESS (MIND)

HIV-positive. What now?

Few patients will forget the shock/disbelief

"It felt as though the doctor were talking about someone else"

Next the patient will experience mixed feelings of fear and depression

This gives raise to premonitions about the future and feelings of helplessness, eating, sleeping and concentration patterns become abnormal

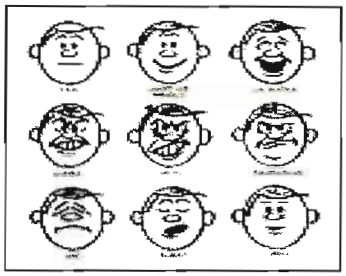
3.1 EMOTIONAL IMPACT OF AN HIV DIAGNOSIS

HIV diagnosis affects the patient, family and friends. One feels uncertain about changes that will take place. People tend to shut down when they hear the word "HIV' or "Aids". The patient experiences extreme **"distress"**.

Distress is an unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with the ability to cope with

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this illness. It extends from normal feelings of sadness, fear to problems such as depression, anxiety, panic, feeling isolated.
Guidance and support services are of the utmost importance to the patient.

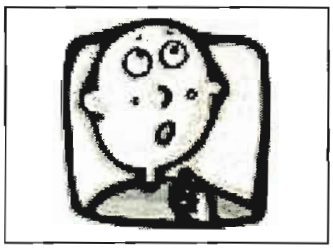


3.2 EMOTIONAL REACTION TO HIV AND AIDS

People who know that they have HIV and Aids feel many different emotions. Some feel shocked. Some feel angry. No matter how much you are prepared it is a shock to learn that you have HIV and Aids. You may feel very confused and not know what to do. It is good to be with someone you trust at this time.

The feelings of people with HIV and Aids change often. One day they may feel rejected and lonely. The next day they may feel hopeful. This is NORMAL. Some of the different feelings experienced by people with HIV and Aids:

SHOCK / DENIAL



At first some people cannot believe that they have HIV or Aids. They say: "The doctor must be wrong".
"It can't be true. I feel so strong".

ANGER

Some people get very angry when they find out that they have HIV or Aids. They blame themselves or the person they think gave them HIV. Some may even blame God.



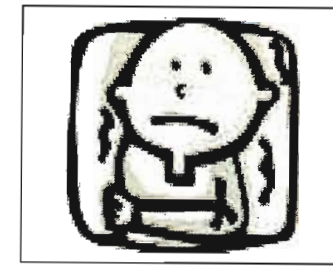
Anger is normal but it is not helpful. Talking to a counsellor or a friend can help you through the feeling of anger.

BARGAINING

Some people try to bargain. They think: "God will cure me if I stop having sex." "The ancestors will make me better if I slaughter a goat." People with HIV or Aids need to be helped to get through the feelings of bargaining.

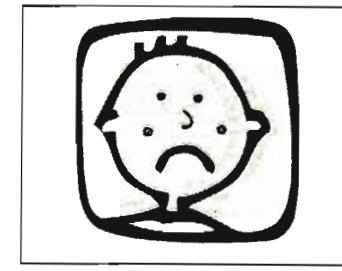
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LONELINESS



People with HIV or Aids often feel lonely.
If you have HIV and Aids, remember you are not alone. Many other people have HIV or Aids. If someone you know has HIV or Aids, give them companionship. Take away their loneliness, start a support group.

FEAR



People with HIV and Aids fear many things:

- Pain.
- Losing their job.
- Other people knowing that they are infected.
- Leaving their children.
- Death.

It is frightening to have HIV or Aids, but you may find that your fear becomes less when you talk to someone who understands. You may also find that you are worried about things that you do not need to fear. For example, you may find that when other people learn you have HIV, they can show you great love and kindness.

SELF-CONSCIOUSNESS

Some people with HIV or Aids think everyone is looking at them or talking about them. This makes them want to hide. Sometimes they feel rejected by other people, or they reject themselves. Sometimes they feel guilty.

If you have HIV or Aids, don't hide. Try not to feel discouraged if people talk about you. Stay active in your community. By staying active, you can show the world that people with HIV and Aids are valuable members of society, just like anyone else.

If you have HIV or Aids, try to think well of yourself. Be proud of yourself. You are still you. You are still important.



DEPRESSION

Some people with HIV or Aids feel there is no good reason for living. They feel useless. Sometimes they stay at home, not eating, not talking to anyone.

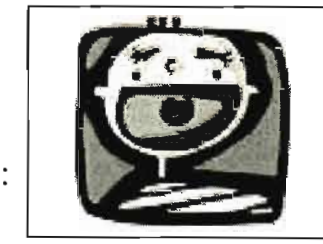
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Depression can make you weak in mind and body. So it is important to try to overcome depression. If you have HIV or Aids, don't give up. Put on your nice clothes. Visit your friends. Keep busy. Do something that helps others. If you have children, think about them, they still need you. Social workers may help if you feel very depressed. Do not hesitate to visit one if your depression is very bad or long-lasting.

ACCEPTANCE

After some time most people with HIV or Aids accept their situation. This is helpful. They often feel more serene (peaceful in mind). They often feel able to begin to think about the best way to live. They think:

"What can I do to make the best of the rest of life?"
"What foods should I eat to help me stay healthy?"
"What plans shall I make so my children are provided for in the future?"
They might also think: "Let me be grateful for every day. Let me appreciate my friends and family".



HOPE

People with HIV or Aids can have hope about many things:

- Hope that they will live a long time.
- Hope that scientists will find a cure.
- Hope that the doctor will be able to treat each illness as it comes.
- Hope because they are loved and accepted for who they are.
- Hope because of their belief in a life after death.

It is important to have hope. **Hope** lifts your spirits and gives you **strength** to face each situation. Hope can help you to fight HIV and Aids and live longer.

Remember: Even if you have hope today, it is possible to feel angry or depressed tomorrow. This is normal. The important thing is to try to regain the feelings of hope again and again.

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3.3 FACTORS INFLUENCING THE PATIENT'S PSYCHOLOGICAL RESPONSE - FEARS

Muskin (1998) outlines 7 factors of psychological stress that can have an affect on the individual or the family's psychosocial response and adaptation to terminal illness:

1. Severe illness threatens a person's existence and fear of no control over life.
2. Fear of strangers in hospital.
3. Separation anxiety when hospitalized.
4. Fear rejection by partner, family, friends, society, God.
5. Fear of physical pain and losing control of body, mind, emotions and life.
6. Fear of loss of body parts, being disabled and disfigured.
7. Fears related to death and dying.

3.4 VALUE OF APPROPRIATE INFORMATION

- KNOWLEDGE promotes wellness of the mind.
- Assists patient in being **part of decision making.**
- **Reduces anxiety** and it gives HOPE.
- Reduces side effects of therapy.
- Increases self-care behaviour.
- Increases active coping modes.
- Power and control increases motivation to deal with illness.

4. SOCIAL WELLNESS



4.1 FACTORS INFLUENCING THE PATIENT'S PSYCHOLOGICAL RESPONSE - FAMILY

Families are very important for people with HIV or Aids. The family home can be a shelter:

- Where someone can rest assured that they are loved and accepted.
- Where they don't have to be brave or hide their feelings.

If someone in your family has HIV or Aids, you can help them in many ways:

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- You can help them to rest by doing their household jobs for them.
- You can help them to eat nutritious food by going to the market and cooking for them.
- Wash their clothes and sheets.
- Nurse them.
- You can help to dispel their fear by making them feel loved.

If you have HIV or Aids, it is usually good for your family to know:

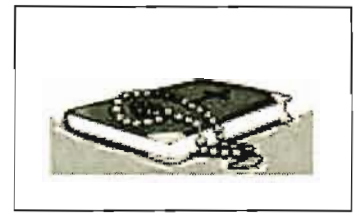
- They can give your love and support.
- You can make plans for the future.
- They can share the financial burden.
- It will be easier for you if you do not have to hide your situation.

Sometimes families argue about who is to blame for bringing HIV into a marriage. This can cause great unhappiness and lead to separation that will result in extra problems, pain and isolation.

Remember: If you have HIV or Aids, you can use the knowledge you have to help others. You can teach your family how HIV is spread, and how it is not spread. You can help them to avoid HIV. This is one of the most loving contributions you can make.

4.2 FACTORS INFLUENCING THE PATIENT'S PSYCHOLOGICAL RESPONSE - SOCIAL ASPECTS

- Absence of social support network.
- Changes in interpersonal relationships.
- Perceptions and stigmas of HIV and Aids.
- Financial stability, job security and insurability.
- Personal relationships.
- Social interaction, acceptance, belonging.
- There is an emotional relationship between family members, mutual support.
- Family members experience the diagnosis just as traumatic.
- Sexual activity.
- Concern about the financial burden.



5. SPIRITUAL WELLNESS

Many people with HIV or Aids get great strength from spiritual beliefs, counselling and care. Religious support can strengthen the

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spiritual beliefs and can help the person to accept themselves and others. It can help the person to get rid of bad feelings and live positively. They realise that in their struggle they are not alone. They find that their fears are diminished.

Reading holy books helps people to get personal messages to encourage them. Praying can be helpful to reduce fear and anxiety. Spiritual care helps people with HIV or Aids to prepare for death and **to reconcile and heal damaged relationships**. It helps one find a sense of purpose and meaning in life ("meaning in illness").

6. SKILLS & TECHNIQUES IN REDUCING STRESS

There are many stresses associated with HIV. These include discovering one's status, deciding to disclose and even deciding if and when to take ART. Stress has a very negative effect on the health of people living with HIV. You can manage the stress by participating in a support group, or by talking to a social worker or psychologist. Spend more time doing things that relax you.

6.1 ASSIST A PERSON LIVING WITH HIV OR AIDS IN DEVELOPING AND OPTIMAL FUNCTIONAL PLAN

- Specialised medical care.
- Proper information that will enable the patients to make informed decisions.
- Access to psychosocial support.
- Assist patients in developing self care skills.
- Promoting exercise.
- Good nutritional advice.
- Managing side effects and symptoms.
- Manage side-effects of treatment.
- Manage pain and discomfort.



6.2 POSITIVE THINKING/COGNITIVE RESTRUCTURING

This involves changing negative thoughts into constructive and positive ones.



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PURPOSE IN LIFE

- Perception of one's self as a helpless victim in uncontrollable events, diminishes a individual's sense of hope and purpose.
- Motivation should, therefore, rather be based on focusing on purpose and passion for life.
- HOW TO FIND PURPOSE IN LIFE:
  Explore interests, needs, values and passions.

DETERMINATION TO LIVE

What do you want from your life? What are your dreams and your goals? How will you achieve these? How determined are you not to give up?

Determination to live means, that you have a strong and positive feeling that good things can happen in your life, even if you do not know how. Some people call this **hope**. Others call it **positive motivation** or the will to live.

Your determination to live will help you deal with difficult times. You will need to have this determination when you need to make some difficult changes in the way you think, act, eat and live. You will need determination to stay healthy. To strengthen your determination is to think of things that make you happy, to dream of a future, goals that you want to achieve in your life, e.g. education and skills, career/job.

6.3 STRESS MANAGEMENT

People should be encouraged to be positive and live each day as calmly as they can. Worry and stress can affect sleep and weaken the immune system.
Stress is an emotional and physical response to a difficult situation, feelings and thoughts.



How can one manage stress?

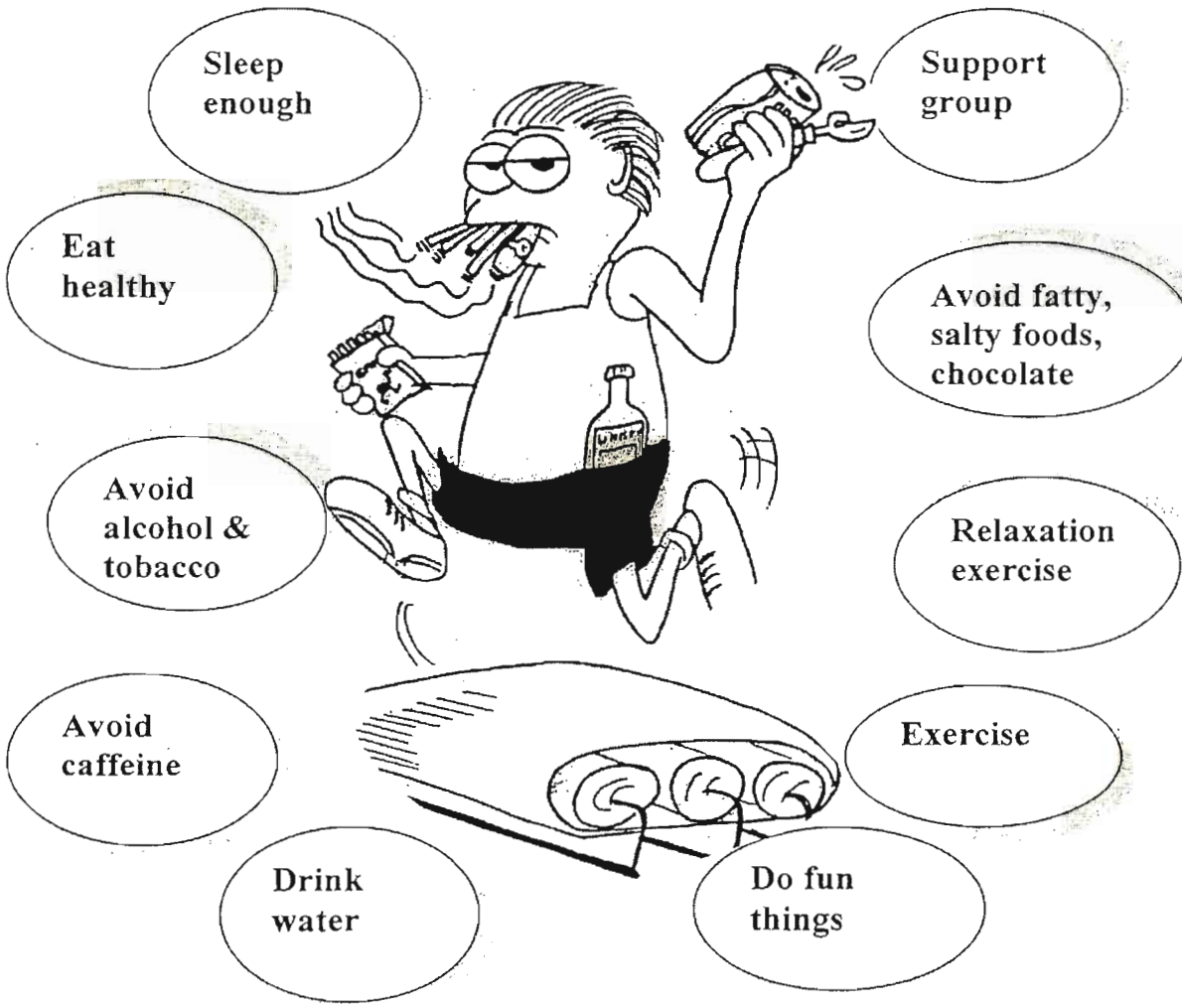
In order to manage stress, you need to identify the things that cause stress:

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1. Make a list of all the things that cause stress.
2. Ask a social worker or counsellor to help you to change irrational beliefs to a more rational response.
3. Focus on the stressors that you can change rather than on the overwhelming emotions of those you cannot change.
4. Use **relaxation exercises**, imagery therapy or meditation to get inner strength.
5. Spend time with supportive people, go to a support group.
6. Reduce stress by prioritising tasks, from important to least important. Give yourself a realistic time to do it and get people to help you with different tasks.
7. Do fun things – watch a movie, read a book, exercise, play with your children or a pet, go for a massage, sing or dance, take a long bath.
8. Look after your body: eat healthily, exercise, get enough sleep, avoid toxic foods and drink lots of clean water.



What else can you do to manage stress?



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6.4 ACKNOWLEDGE AND DEVELOP INSIGHT IN THE GRIEF PROCESS

HIV or Aids cause physical and emotional stress – this results in shock, anger, fear, guilt. Ask a social worker to help you cope with these feelings (Soul City, 2004:20).



Shocked – you may not believe what you hear.



Angry – you may be angry with yourself for having had unprotected sex.



Afraid – you may be afraid of how your family will react. You may also be afraid of dying.



Guilty – you may also feel as if it is a punishment for something you have done wrong.

7. COPING WITH STIGMA

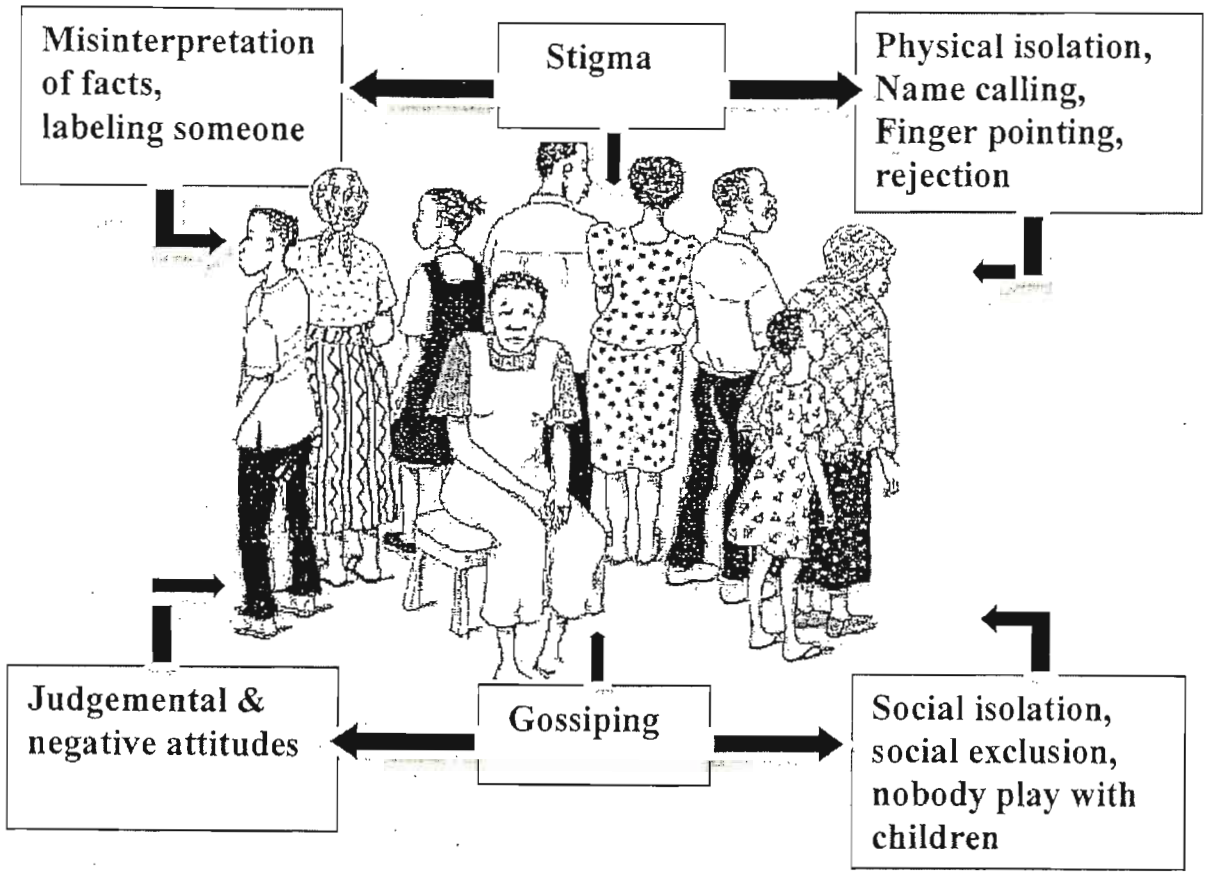
7.1 Understanding Stigma

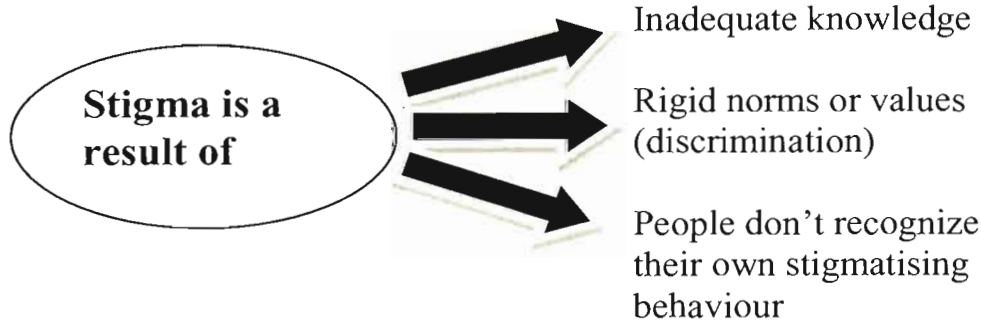
People are afraid of the stigma associated with an HIV-positive status. This is one of the reasons why people are afraid to find out whether they are infected with the virus, and why people who are infected are afraid to disclose their status. This stigma has arisen because HIV and Aids is seen as a punishment for sin, a curse from the ancestors for not obeying cultural traditions, a shame on family members.

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To combat stigma, the concept must be understood

Stigma is to label someone, to see them as inferior because of an attribute they have (Change Project, 2005:12). Secondary stigma is experienced by all people who are associated with people with HIV or Aids - family members, children, caregivers and even friends. When one member in a family has HIV, people often judge the whole family. Sometimes a result of stigma is a loss of livelihood or income and sometimes snooping people visit to see people living with HIV or Aids.





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7.2 STEPS IN ADDRESSING STIGMA IN THE COMMUNITY

7.2.1 Recognise stigma

People are often not aware that they stigmatise people living with HIV and Aids. Make people aware of the typical stigmatizing behaviours, like avoid contact with people living with HIV (not shaking hands, kissing, sharing utensils, toilets) (Van Wyk,2007:22).

7.2.2 Provide knowledge about HIV and Aids

Inadequate knowledge, especially regarding transmission of HIV, can lead to sitgmatising actions.

7.2.3 What messages do you give about HIV

The message when talking to people living with HIV is usually of fear, hopeless, helpless victims, worthless.

7.2.4 Involve people with HIV and Aids

HIV does not mean immediate death. Without medical treatment (ART), HIV usually becomes Aids within approximately ten years (depending on a healthy diet). Positive people, with treatment, live longer. To truly combat stigma, involve HIV people, to regularly talk to learners and the community. They can still work and provide for their families, if they have a job (Change Project, 2005).

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MODULE 4:

HOW TO CARE FOR AND GIVE SUPPORT TO LOVED ONES WHO ARE ILL

- ICE BREAKER: HOW TO MANAGE THE PANDEMIC?

1. SOURCES OF SUPPORT

1.1 SOMEONE TO TALK TO
1.2 ORGANISED HOME BASE CARE AND/OR SUPPORT
1.3 LEGAL INFORMATION REGARDING HIV AND AIDS
1.4 ANTI-RETROVIRAL TREATMENT CENTRE
1.5 HOSPITALS OR CLINICS OFFERING ANTI-RETROVIRAL TREATMENT (ART)

2. CARING FOR PERSONS WHO ARE ILL

2.1 WHAT CAN WE DO FOR PEOPLE WITH AIDS?

3. MANAGING AIDS RELATED HEALTH PROBLEMS AT HOME

3.1 PRECUATIONS TO TAKE IF YOU ARE CARING FOR A PERSON LIVING WITH HIV OR AIDS
3.2 OPPORTUNISTIC INFECTIONS
3.3 PREVENT OPPORTUNISTIC INFECTIONS

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MODULE 4:

HOW TO CARE FOR AND GIVE SUPPORT TO LOVED ONES WHO ARE ILL

Many South Africans face difficult circumstances that radically change their lives.

We cannot change the reality of the pandemic, but we can change how we think about it and how we respond to it, how we adapt and go on with life.

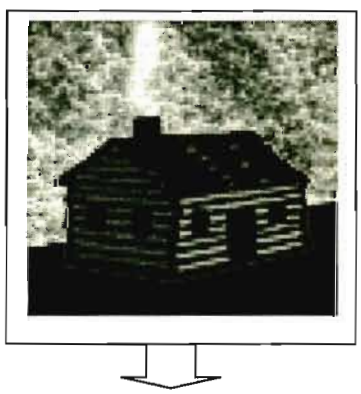
Instead of focusing on how bad the pandemic is, focus on the parts that can be managed.

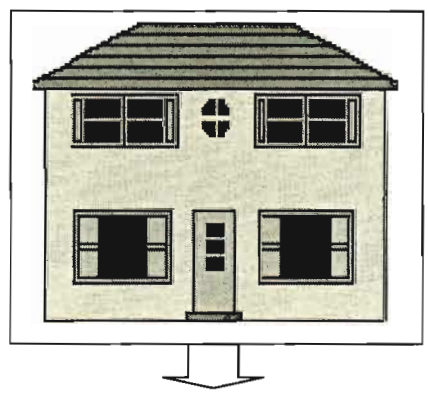
How to manage the pandemic?

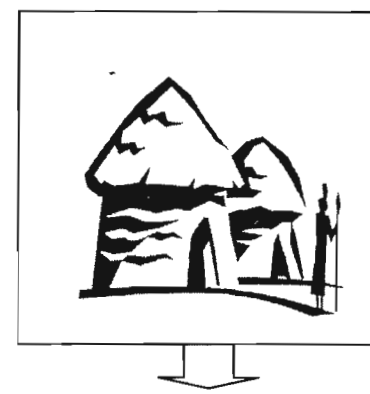
When loved ones are HIV positive and ill, you need to connect with other people/organisations. To manage the pandemic you need support. It helps to have positive relationships with family members, friends and others – who give support and assistance and listen to you.

Who do you think can help you to be strong? Make a list of people/organisations that you can connect to (Theron, 2006:24-25).

AT HOME: **AT WORK/SCHOOL:** **COMMUNITY:**

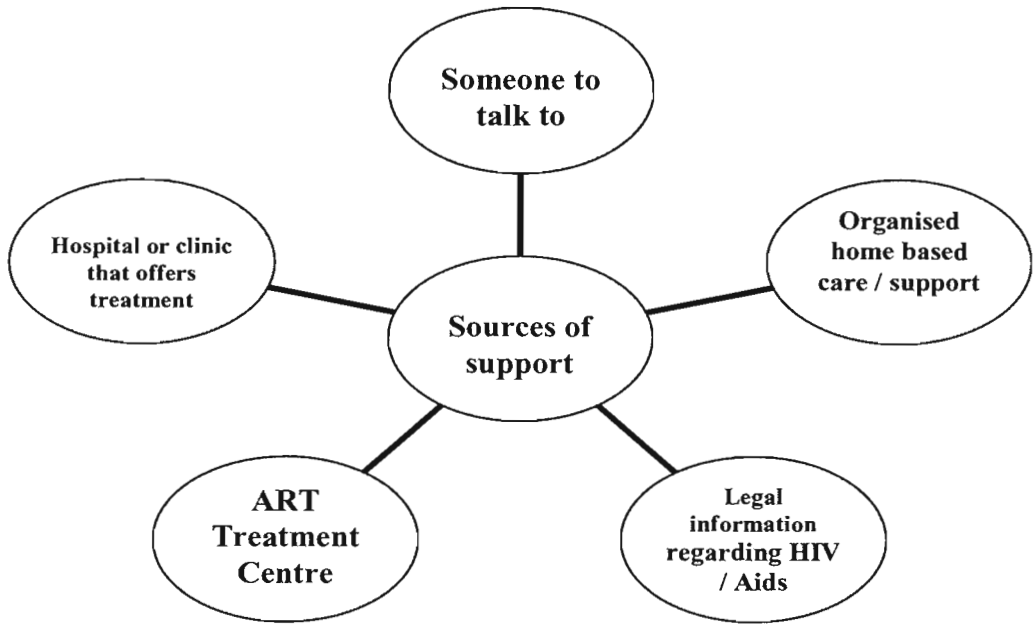






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1. SOURCES OF SUPPORT



1.1 SOMEONE T TALK TO

If you want support any time of the day (up to 22h00 at night), such support is only a phone call away at the **Aids Helpline**. You can talk to them about any Aids related issue or fear. Whatever you need to know, there is one free number to call: **0800-012-322.**
You can also contact **Life Line** in your town or the social worker working in your community, if you need someone to talk to.

1.2 ORGANISE HOME BASED CARE AND/OR SUPPORT

The local Hospice runs a home-based care and support group. Home-based care provides basic nursing and care by formal or informal caregivers to people in their very own homes. In this way ill people's mental, physical, emotional and social needs are catered for. People who qualify for this care include those who have had strokes, who are living with HIV and Aids, who are physically or mentally challenged, the weak elderly, or those who are terminally ill. Home-based care tries to re-establish and keep up optimal comfort, performance and health, including care towards a dignified death. Home-based care has advantages, including that a network of relationship is formed. This network includes people who provide medical support, but also emotional support by being there and encouraging them to stay healthy. Often such support leads to meeting people who understand what it means to be HIV- positive.

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1.3 LEGAL INFORMATION REGARDING HIV AND AIDS

If you need information regarding you or your loved one's legal rights with regard to HIV and Aids, contact the Aids law project at:



Telephone number:	(011) 717 8600
Fax number:	(011) 403 2341
Website:	www.alp.org.za
Email:	alpadm@law.wits.ac.za

1.4 ANTI-RETROVIRAL TREATMENT CENTRE

If you want to find out where the nearest ART treatment centre is, call Gauteng Health Department: (011) 355 3421

Find out if there is a wellness clinic in your community that treats HIV and Aids.

1.5 HOSPITALS OR CLINICS OFFERING ART TREATMENT

If you want to know which hospital or clinic offers ART treatment, consult the following website:

http://www.healthinsite.net/health/HealthProfile.dll/eCareCentreDetail?fh=1595

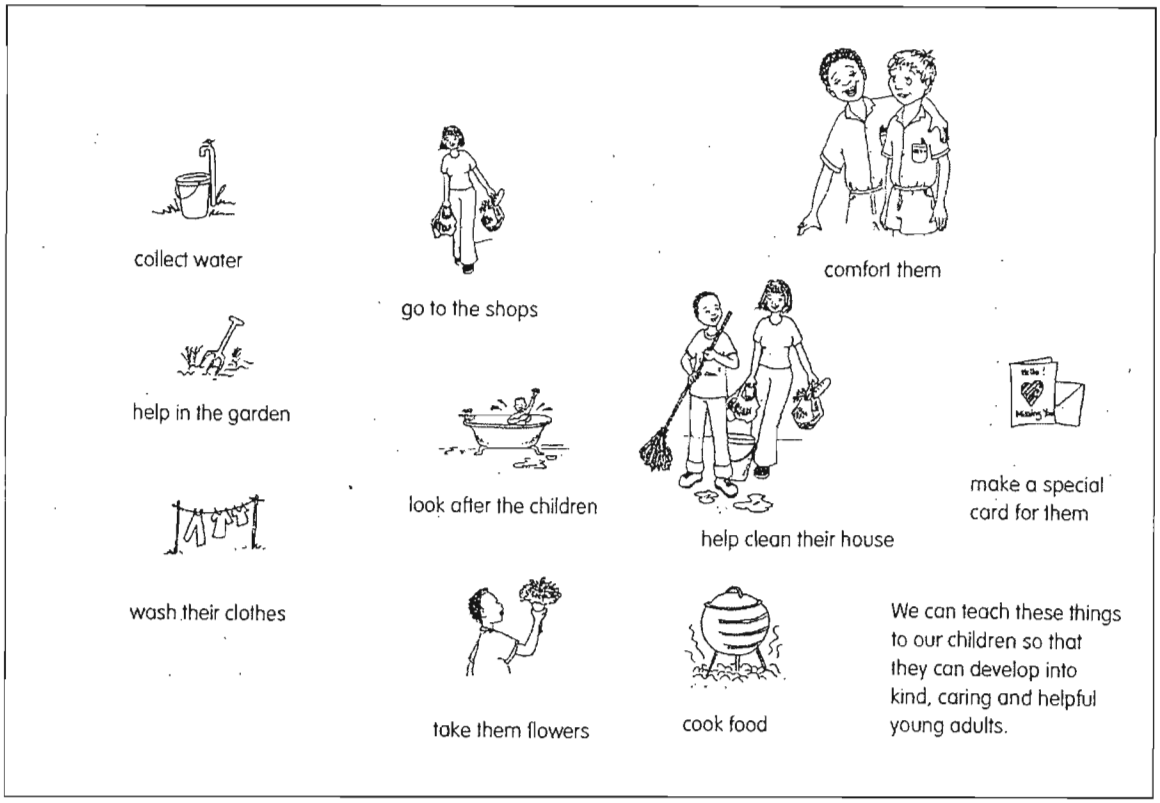
2. CARING FOR PEOPLE WHO ARE ILL:

You may already know someone who has HIV or is dying or has died of Aids. In years to come we will come into contact with more who are infected or affected by this disease in some or other way.

People who are infected need lots of love and care. They need family members, friends and neighbours. Children can also be taught that they do not have to fear someone with this disease and that they should never discriminate against someone with HIV and Aids.

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2.1 WHAT CAN WE DO FOR PEOPLE WITH AIDS?



(Edwards, 2000:30).

3. MANAGING AIDS RELATED HEALTH PROBLEMS AT HOME

3.1 PRECAUTIONS TO TAKE IF YOU CARE FOR A PERSON LIVING WITH HIV OR AIDS



- Wear latex or vinyl gloves, or plastic bags over your hand, when you wash the person, deal with blood or clean any sores.
- Wear latex or vinyl gloves, or plastic bags over your hand, when washing bedding or clothes that have, diarrhoea or any other body fluids on them.



- Keep bedding or clothes with blood, diarrhoea or any other body fluids separate from other washing.
- Use soapy water when washing bedding or clothes that have blood, diarrhoea or any other body fluids on them. Add some bleach if possible.

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- Burn any bandages or menstrual pads that are contaminated with blood.
- Keep all sores, both on the patient and all other household members, clean and covered with waterproof plasters and bandages.



- Do not share razors, needles or toothbrushes with the patient.
- Ensure that the correct procedures for cleaning any blood spills are followed.
- Always wash your hands thoroughly after caring for or cleaning the patient, and if possible, use antiseptic soap.



But above all, remember that casual contact, such as hugging, will not transmit the virus, and that the patient needs your love and emotional support.

3.2 OPPORTUNISTIC INFECTIONS



- Opportunistic infections are HIV and Aids related illnesses caused by bacteria, fungi and viruses. Due to an immune system that is weakened by HIV, most deaths associated with HIV occur as a result of opportunistic infections.
- Preventing and treating opportunistic infections quickly and effectively improves one's quality of life and delays the onset of Aids.
- It is important that the clinic or private doctor regularly assesses a person's health and determines at which stage of HIV he/she is. This will inform one of the health needs and when to start taking antiretroviral medication. The provision of antiretroviral medicines assists in preventing certain life threatening opportunistic infections from occurring as it allows for the immune system to recover.
- An HIV-positive person has a weakened immune system, so it is important to avoid all possible situations that could lead to an infection. Every infection that an HIV-positive person has weakens the immune system more. This means not getting too close to an ill person; maintaining good hygiene practices such as washing the hands frequently and prevent flies by disposing of rubbish in an hygienic way; routine visits to the doctor or clinic and treating any infections as soon as possible (Van Dyk, 2005: 304-318).

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3.3 PREVENT OPPORTUNISTIC INFECTIONS

- **Have regular check-ups** to monitor your health.

- **Learn about the symptoms** that might indicate an opportunistic infection. Be on the lookout for them to get treatment as soon as possible.

- **Drink clean water** as unpurified water may contain germs that can cause opportunistic infections. Tap water in South Africa is generally clean, but stagnant or river water must be boiled or sterilized. Avoid drinking or accidentally swallowing water directly from lakes and rivers.

- **Maintain good hygiene.**

- **Food must be kept as safe and germ free as possible**, as germs found naturally on food and in foods pose a risk to the health of people living with HIV. Always wash hands with soap and water before and after handling food and clean all equipment properly. Wash all food before preparing it and ensure that it is cooked thoroughly and served hot, as heat kills bacteria. Avoid raw foods, especially raw meat, fish and chicken. Do not use food that has passed its expiry date. Never eat food that looks rotten or moldy.

- **Avoid exposure to contagious diseases** such as flu, colds, gastroenteritis, chicken pox, cold sores or blisters.

ART will not cure Aids. It will make a person stronger so that their body can fight illnesses. But any illness must always be treated. Below are some common illnesses that affect people with HIV (Theron, 2006:54-78).

COUGHS:

There are different kinds of coughs. Some coughs may be serious.

Treatment:

Go to the clinic if:

- You have been coughing for more than two weeks.
- You cough up blood.
- You have difficulty breathing.

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If the cough stays for a long time and your chest is painful when you cough, you may have bronchitis. This will need treatment from the clinic.

Self care:
Here are some strategies that you may try to help you feel better:



- Avoid rough foods that irritate the throat.
- Use a cough mixture like *Borstol*.
- Inhale steam, using hot water with *Vicks*.
- Drink sips of hot water or warm fluids. You may add generous amounts of lemon.
- Inhale steam, using hot water with "morukudu" or "lengana".
- Drink holy water, tea ("lemon grass") or coffee.

PNEUMONIA:

Pneumonia is serious and you may need to be hospitalised.
You may have pneumonia if:

- You have a sharp pain in the chest. Your cough is dry.
- You feel short of breath.
- You have a fever – you feel very cold and very hot.

Treatment:
People who are HIV-positive may get different kinds of pneumonia call PCP. This is very serious – it means your immune system is very weak. The doctors can tell this by a blood test called a CD4 count. If your CD4 count is low, you will need ART. This makes your immune system strong so that it can fight illnesses.

Some clinics will give you medicine to prevent PCP if you are HIV-positive. This means you take these medicines even when you are not ill.

TUBERCULOSIS (TB):

TB is always serious, but when you have HIV, it can get even worse.



Treatment:
Go to the clinic if:

- You have been coughing for more than two weeks.
- You cough up blood, or yellow or green mucus.

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- You have a fever.
- You sweat at night.

Remember: Not everyone with TB has HIV or Aids.

- Make sure that you get treatment as soon as possible.
- Always finish the medicines, even if you feel better. If you do not, the next time you are ill, the medicines will not work for you.
- If the medicines make you feel bad or you get a skin rash, tell the health worker. Do not just stop the medicines.

DIARRHOEA:

When you pass more than three loose or watery stools a day you have diarrhoea. Diarrhoea is dangerous because it causes dehydration. If you body gets too dry, you can die. It is important to drink lots of fluids.

Treatment:
Go to the doctor or clinic if you have any of these signs:

- Loose and dry skin.
- Dry tongue and mouth.
- Feeling dizzy and weak.
- Little or no urine passed.

Self care:
Some strategies you may try to help you feel better:

- Eat frequent small meals.

Foods / drinks to consume:

- Oatmeal, potatoes, apples (peeled and allowed to brown), bananas, maizina porridge.
- Ten glasses of water per day, oral rehydration solution, barley water, rice water, sour milk, water mixed with custard powder or flour, energy drinks, for example *Lucozade*.

Foods / drinks to avoid:

- Caffeine, fast foods, fried foods, cold meats, hot dogs, bacon, chips, dairy products (except for yoghurt), whole grains, cornmeal, bran, granola, wheat germ, nuts, seeds.
- Caffeinated, alcoholic and carbonated beverages.

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Being prepared:

- When planning activities away from home, consider the availability of bathrooms.
- Consider taking an extra change of undergarments with you if you will be away from your home for an extended period of time and an extra roll of toilet paper. Bring along hand wipes to clean your hands.

Skin care:

- Keep your skin clean by washing with warm water after each bowel movement if you can. Dry the skin thoroughly.

CONSTIPATION:

Problem:

You may experience problems with constipation, not passing stools for a week and/or experiencing a feeling of fullness in the stomach. You may take days before passing a stool.

Treatment:

There are many ways to treat this problem. The first step is to contact your physician or nurse. If possible, the cause of the constipation should be identified. This may include prescription or non-prescription medicines or other treatments.

Self care:

Some strategies that you may try to help you feel better:

- Check with your physician or nurse (clinic / hospice) before having an enema. You may use a small teaspoon of Sunlight ™ soap (a very mild liquid soap) and lukewarm water.
- Eat fruits and vegetables and drink warm water after meals.
- Drink plenty of fluids (water, juice, non-caffeinated beverages) – at least six to eight glasses per day.
- Eat paw-paw / papaya in the morning with breakfast.
- Eat a high roughage diet.
- Eat regularly. Do not starve yourself.
- You may need to do manual removal of impacts (with a glove on). Ask your local nurse (clinic / hospice) about this procedure.
- Exercise regularly.

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LOSS OF STRENGTH (FATIGUE):

Problem:
You may feel tired, exhausted or experience a loss of concentration. Some fatigue in life is to be expected. Fatigue may be associated with stress, poor eating habits, inadequate sleep, mental strain, boredom, depression or other conditions.

HIV infection, HIV medication, drugs or other health problems, such as anemia, can cause fatigue too. If you experience a marked reduction in your energy levels which persist despite adequate rest, report it to your physician or nurse.

Treatment:
Contact you physician or nurse. If possible, the cause of the loss of strength should be identified. By working together a treatment plan can be developed for you. This plan may include prescription or non-prescription medications or other treatments.

Self care:

- Do small tasks to avoid fatigue.
- Drink energy drinks (*Lucozade*) and/or take oral rehydration solution.
- Rise slowly when waking up – sit up first.
- Make "imbita" (drinking solution) from bulbs of an African Potato and drink ¼ to a cup daily. Do not take this for more than three months.
- Drink solution from boiled beetroot.
- Chew 2 to 3 cloves of garlic three times a day.
- When cooking vegetables ensure that they are not overcooked as vitamins get destroyed.
- Add marmite to soft porridge.
- Try relaxing or stress reducing activities such as deep breathing exercises, meditation, personal "quite time", massage, listening to music or relaxation tapes, getting involved in activities (for example volunteer work), taking walks, leisure reading, taking a warm bath, Tai-Chi, etc.
- Take breaks at work, mid morning and mid afternoon.
- Go for a walk everyday at your own pace, in your home or outside. Exercise has been shown to reduce anxiety, depression and fatigue.
- Get more of the following foods: oatmeal and other whole grain cereals, fruit and raw vegetables, whole grain baked goods, yoghurt and low or non-dairy products.

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- **Limit the following foods**: sugary foods, fast foods and other high fat foods. Reduce alcohol and caffeine intake, as these tend to make you sluggish later.
- Develop a routine of going to bed in the evening and getting up each morning at the same time. A good night's sleep can help you think more clearly. Naps are okay, but keep them short and early in the day.
- Take your medication as prescribed. Report any side effects or irregularities to your doctor or nurse.
- Avoid or reduce your use of alcohol and other mood altering non-prescription drugs (for example cocaine, speed, dagga, glue).

NAUSEA:

Problem:
You may experience nausea, upset stomach, heaving. Sometimes, nausea is accompanied by vomiting. You may also experience headaches and loss of appetite (no desire for food), which may result in loss of weight.

Treatment:
Contact your physician or nurse. If possible, the cause of the nausea should be identified. A treatment plan can be developed for you. This may include prescription or non-prescription medication or other treatments.

Self care:
Some strategies you may try to help you feel better:

- Use oral rehydration solution.
- Avoid odours, sights or sounds that trigger the feeling.
- Breathe in fresh air.
- Breathe in pleasant smells such as lemon or lime peels and ginger.
- Use aromatherapy, such as extract of wild strawberry or ginger.
- Try relaxing or stress reducing activities such as deep breathing exercises, meditation, personal "quite time", massage, listening to music or relaxation tapes, getting involved in activities (for example volunteer work), taking walks, leisure reading.
- Try to focus your mind on something pleasant (imagining).
- Avoid greasy foods, fried foods and alcohol.
- Eat small portions of food when least sick.
- Try eating dry foods such as toast or crackers.
- Remain sitting for at least 30 minutes after eating.

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- Take your medication as prescribed. Report any side effects or irregularities to your doctor or nurse.
- Take frequent sips of water or suck on ice.

NIGHT SWEATS:

Problem:
You may experience sweating that is not related to exercise. Night sweats can occur during the day or night, but usually at night. You may wake up with your clothes and bed sheets soaking.

Night sweats are associated with HIV, or other conditions such as TB, and typically are not associated with fever and infection.

Treatment:
If possible, the cause of the night sweats should be identified. Prescription or non-prescription medications or other treatments, as prescribed by the doctor can be used.

Self care:
Some strategies you may try to help you feel better:

- Keep you skin warm and dry.
- Wear light cotton clothing and use fewer blankets.
- Open windows to allow ventilation and fresh air.
- Drink plenty of fluids (water, juice, non-caffeinated beverages) – at least six to eight glasses per day.
- Drink cold water.
- Sponge yourself with tepid water.
- Change your clothing and linen regularly.
- Place a towel over your pillow in cases of profuse sweating.
- Talk to your doctor or nurse about taking any medication before going to bed at night.

WEIGHT LOSS (UNPLANNED):



Problem:
You may experience a loss of 10% or more of your usual body weight, when you do not intend to lose weight. Weight loss of any amount can be dangerous and should be treated as soon as possible.
Unplanned weight loss may be due to HIV infection, HIV medications,

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depression, fatigue, an infection or other health problems.

Treatment:
Contact your physician or nurse. If possible, the cause of the weight loss should be identified.



Self care:
Some strategies you may try to help you feel better:

- Eat frequent, small meals.
- Take multivitamins.
- Drink a solution made with African Potato. Do not take this for more than three months.
- Add garlic to your food.
- Keep track of your weight by weighing yourself or by looking for changes in the way your clothes fit.
- Cook and eat with friends or family to make meals enjoyable.
- Eat high protein, high calory foods and snacks such as peanut butter and jelly sandwiches, crackers and cheese, pudding and yoghurt.
- Add instant breakfast drinks, milk shakes or other supplements to your diet and drink them any time of the day.
- Take a multivitamin with at least 100% Recommended Daily Allowance (RDA) every day.
- Keep foods that are easy to prepare on hand (for example frozen and canned foods).
- Eat fresh fruits and vegetables.
- When travelling, take high calory snack bars or powdered calory supplements along.
- Do some light exercise to boost your appetite.
- If it is difficult to chew or swallow, or if you have mouth sores – see your health care provider for possible treatment of your mouth sores.
- Drink lemon grass tea to boost your appetite.
- Eat cold foods and soft / liquid foods.



SKIN PROBLEMS (DERMATITIS)

Problem:

Skin problems are very common in people living with HIV. This problem may be due to different kinds of infection. You may experience skin rashes or

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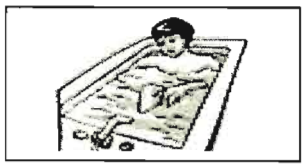
changes in skin condition that may be short or long lasting. You may experience redness, itching, swelling or pain. It does not mean that everyone who has skin problems has HIV. Anyone can get them.

Treatment:

- If you have a skin problem, go for an HIV test.
- Visit a doctor or clinic. They will know which medicine you need to take.

Self care:

- Bath with antiseptics such as Dettol (diluted with water).
- Use bandages or a clean cloth for any bleeding discharges or drainage to prevent the spread of the infection to other parts of your body or to other people.
- Wear light, non-irritating clothing.
- Wash your hands frequently.
- Do not share towels or linen.
- Try not to scratch. Keep fingernails short and clean.
- Apply hot compresses to the affected areas.
- Put two slices of onion overnight over the boil and dress with salt water.
- Place the inside part of paw-paw / papaya over the boil overnight, then wash with salty water.
- Squash the leaves of a bean tree (munawa) and apply to wound.
- Keep sheets and blankets off sensitive skin. For example, use a pillow at the foot of the bed to hold sheets off your feet.



In general:

Eat a diet high in protein and vitamin C to promote wound healing.

STRESS AND DEPRESSION:

Problem:

It is not easy living with any illness. People with HIV often go through a lot of feelings. They may feel lonely, worried or afraid. This is normal. Some people call it stress (Soul City, 2004:35).

You may have depression if you have the following signs:

- You feel down or sad most of the time.
- You lose interest in doing things. Sometimes you do not even want to

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get out of bed.

- You sleep badly at night.
- You struggle to concentrate.
- You don't feel like eating.



Treatment:

There are many ways to treat this problem. The first step is to contact your physician or nurse (clinic / hospice).

- Telling someone how you feel may make you feel better.
- Join a support group.
- Exercise also relieves stress.

If your feel like you might hurt yourself or others, seek help immediately (for example by calling your local emergency number, like 911), or going to an emergency room. If possible, the cause of the depression should be identified. Treatment can include prescription or non-prescription medications, counselling or other treatments.

Self care:

Strategies that you may try to help you feel better:

- Try relaxing, stress reducing activities such as deep breathing exercises, meditation, massage, listening to music or relaxation tapes, getting involved in activities (volunteer work), taking walks, reading, taking a warm bath.
- Get involved in activities such as community groups, support groups, church groups, social clubs or sport activities.
- Avoid or reduce your use of alcohol and other mood altering non-prescription drugs (for example cocaine, speed, dagga, glue).
- Go for a walk everyday at your own pace, in your home or outside. Exercise has been shown to reduce anxiety, depression and fatigue.
- Develop a routine of going to bed in the evening and getting up each morning at the same time. A good night's sleep can help you think more clearly.
- Get up, wash and get dressed at a regular time each day.
- Take your medication as prescribed. Report any side effects or irregularities to your doctor or nurse (at clinic / hospice).

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DEMENTIA:

Problem:
A person with dementia has some of the following signs:

- You become very forgetful.
- You cannot pay attention.
- You lose balance or even become paralysed.
- You change the way you behave.
- You are confused – you are not making sense.
- You may stop talking to people.

Treatment:
These signs can be caused by other illnesses. A nurse or a doctor should check for other illnesses before they say it is dementia. When you have dementia it may mean that HIV has affected you brain. It is a serious illness. You may need to have ART.

(Evian, 2006)

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MODULE 5:
CARING FOR CHILDREN IN THE FACE OF HIV/AIDS

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1.1 Ways to communicate with your children
1.2 Sexuality education

2. TALKING ABOUT HIV AND AIDS WITH CHILDREN

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- ❖ **Circle of support**

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MODULE 5:
CARING FOR CHILDREN IN THE FACE OF HIV/AIDS

1. COMMUNICATE WITH YOUR CHILDREN:

Sometimes the most difficult part about talking to children is beginning the conversation (Takalani Sesame, 2005)

It is important to let children know that they can talk to their parents about anything. Children need to feel comfortable talking with their parents about things that happen in their daily life – like their school, friends and sport. Then they will find it easier to talk to them about HIV and Aids.

It is important to make time for children – talk to them and listen to them. Even talking for just a few minutes each day to children can let them know that you care about them and are there for them.

1.1 WAYS TO COMMUNICATE WITH YOUR CHILDREN

- **Talk to children in a way that feels right for you.**

  It is difficult to talk to children about issues that they think are sensitive. Cultural beliefs and traditions might also make it difficult to communicate with young children about these issues. Find ways to communicate that feels comfortable to you.

- **Use language that is right for the children's ages.**

  When you talk with children, think about their level of understanding.

  Young children (3 to 6 year olds) need information that affects them and their daily lives.

  Older children (8 and older) can understand and discuss more abstract, complicated issues.

- **Use play to help discuss difficult issues with young children.**

  Young children often use actions and play to express themselves.

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Playing with your children and talking to them as you play together can help you to better understand your children's thoughts and worries.

- **Choose conversations that are about your children's daily lives.**

  Ask children specific questions about their day. Start by asking a general question, like "Did you have a good day?"

  Be aware of what children are saying through their words and their body language.

  If your children don't want to talk or have difficulty expressing feelings, ask them to draw a picture to show what they are thinking.

- **Respect your children's privacy.**

  Sometimes they need time to be alone and to think.

  Give them the chance to have their own personal space – especially older children.

- **Try to answer your child's questions.**

  Use resource material to help with discussions.

  Help children to use booklets, TV programmes and help lines to get more information about a topic. Help children choose library books, videos and games that are right for their age.

- **HIV and Aids are a very complicated issue.**

  It is okay to let your children know that you don't have all the answers - you can learn more about this topic together.

  You can have fun giving each other different facts about the topic.

- **Counsellors can help you to get more information about the topic.**

- **Be a role model to your children.**

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Children learn from your actions, as well as your words.
It is important to make sure that your actions and words are giving the right messages.

1.2 SEXUALITY EDUCATION

Through sexuality education we want our children to become responsible men and women and to have warm, caring and satisfying relationships with other people.

When we talk about sexuality education we mean that we are going to give children the correct information about sexual matters, and that we are also going to teach them skills to cope with life and especially with difficult situations. We also want to establish important values and attitudes in them.

1.2.1 Talking about sexual matters

In many cultures it is taboo to talk to children about sexual matters. Parents often do not speak to their children about sexual matters because they feel uncomfortable, embarrassed or they do not know how to talk about it.

Some parents feel that if they talk to their children about sexual matters they are giving them information on sex and permission to become involved in sexual activities.

The education of children on sexual matters is, therefore, often neglected or ignored. By not talking to our children, we allow somebody else the opportunity to do it. We need to ask ourselves the question:

If we do not talk to our children about sexual matters, where are they going to get the information? They may get it from "the street", in other words from their friends or magazines, etc. Friends may provide incorrect information and much damage can be done.

The information received from television, advertising, soap operas, music videos, movies, magazines and books is also often not correct and incomplete. The negative consequences of sexual activity are not shown, for example, do not show that this lead to a pregnancy or that a person can contract a sexually transmitted disease such as HIV.

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1.2.2 The importance of parents talking to their children about sexual matters

Research has shown that children are engaging in sexual activities at increasingly younger ages. Many of them have several partners. This results in more young people becoming pregnant, having abortions and contracting sexually transmitted diseases of which HIV is the most serious.

If our children are not prepared, they can become innocent victims of sexual abuse, forced sex and rape. It is clear that there is an urgent need for sexuality education for children by parents and others who work with young people (Edwards, 2000:12-24).

1.2.3 Sexuality education at different stages in a child's life

- **SEXUALITY EDUCATION DURING THE TODDLER STAGE:**

Talking about body awareness with young children:

You might feel that it is not right to talk with children under six about sex. But it is important to help children of all ages to feel okay about talking and asking questions about their bodies and how they work. If they do this when they are young, it creates an open and easy way to talk about more sensitive things later on, like sexuality, healthy sexual choices or sexual abuse.

Talk to your children about the ways in which their bodies work and the changes that happen as they grow up. At this stage you can help your children to understand that their bodies are special, and they must learn to look after them. When teaching toddlers to name their body parts, include the words "penis" and "vagina". If you show children that it is okay to talk about bodies and body parts, they will also feel it is okay to talk about theirs. This will help to build trust, and make it easier for them

Explain where a child come from:

A little seed grew under mummy's heart, in a special place called the womb. The womb is a soft, warm place where the seed grows into a baby. The baby can hear the mummy's heart and feel the mummy's love.

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Explain how a child get out:

You know it is so wonderful – between mummy's legs there is a special opening passage where a baby can come through and be born.

Explain how did a child get in there:

Daddy puts the seed into mummy's body when they love each other very much.

Prepare a child for school:

By the time a child goes to school, he/she should know the following:

- That she/he is unique and special, a human being worthy of respect.
- Just as a child has hands and feet he has a penis if he is a boy and a vagina if she is a girl.
- His/her **private parts are those parts covered by a bathing costume and nobody except a doctor is allowed to touch him/her there.**
- He/she may have friends of both sexes and he/she should respect them equally.

SEXUALITY EDUCATION IN THE PRIMARY SCHOOL PHASE
(6-12 years)

Children grow very fast during this phase. Children of this age tend to show a greater interest in sexual matters. They are interested in aspects such as the difference between a man and a woman.

Explain where a child come from:

Parents can reply that he/she comes from a seed (egg) that was planted in a special place in the mother's tummy called the womb. There it was kept safe and warm while it grew and became a baby. The baby grew inside the mummy's womb until it was big enough to be born (to come out) and to live with mummy (and daddy). This will make the child feel safe and secure.

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Explain how it happen, how did the egg (baby) get in:

Inside the mother are special places called ovaries where the eggs are kept safe. To make a baby an egg inside the mother has to join with a seed or sperm from the father. A mother and father who love each other will hold each other closely. The father will put his penis in the mother's vagina so that the seed (sperm) can come out of the father's penis and join with the ripe egg in the mother's womb. The baby will grow in this special place until it is ready to be born.

Do not supply too much information. It is not necessary to give particulars of sexual intercourse for this age group.

SEXUALITY EDUCATION IN THE PRE-TEENS AND ADOLESCENTS (12-18 years)

Prepare a child for changes:

It is very important to prepare children for the often quite drastic changes that take place during puberty. Pre-teens often worry about whether they are "normal", for example girls are concerned about their breast size and boy are concerned about their penis size.

Explain body parts and functions:

Boys and girls need to know the different parts of their bodies. They need to understand how their bodies develop and function. They should also know how the bodies of the opposite sex develop and function. If they do not understand certain aspects of their development, they will also not understand, for instance, how pregnancy and HIV can be prevented.

Emphasise important values and norms:

Matters such as abstinence, responsibility, respect for life, respect for their own as well as other people's bodies, self control and being able to wait for things should be continually highlighted.

Emphasise responsibility:

Tell your teenager that having a baby is a very big responsibility. Therefore, it is better to have a baby when he or she is older, has finished his/her education and has a job.

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Talk about responsibility and sex:

Teenagers who are not prepared to abstain from sex or who are already sexually active should be taught to be responsible towards themselves and others by using condoms in all sexual encounters. In doing so they can protect themselves from negative consequences such as teenage pregnancy or contracting sexually transmitted diseases.

The chances of getting a sexually transmitted disease such as syphillis, gonorrhea and HIV should also be dealt with. Teenagers should now take responsibility for their bodies and for everything that can happen to them. The best thing is to abstain from sex until they are adults with a job and are married and ready to have a committed and fulfilling relationship.

2. TALKING ABOUT HIV AND AIDS WITH CHILDREN

Silence is bad for everyone. You may be afraid to tell your children that you are HIV-positive. There are many stigmas around HIV, so there are many reasons why parents do not want to tell their children they are HIV-positive. But even if they do not feel ready or happy to tell their children they are HIV positive, it is important to let their children know they are ill. This can help their children to understand why their parents are upset or acting differently. It also helps them to prepare for the time when their loved one gets very ill or dies.

The importance of parents telling their children when they're HIV-positive

- Children need to know that anyone can get HIV, and that it is nothing to be ashamed of.
- Children need to feel they are included in decisions that are made about their parent's illness. They may also want to help take care of a parent who is ill.
- Children and parents can talk about what could happen in the future. It is important for parents to understand their children's feelings.

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- Children need help and support to deal with HIV and Aids. Ask close friends and family members for support.
- They may blame themselves for your illness.
- They may not know how to show love and support.
- Sometimes they may believe the wrong thing they hear about HIV and Aids.

These worries may affect their schoolwork and make them scared and insecure.

2.1 HOW TO TALK ABOUT HIV AND AIDS

Talking to children about issues such as HIV and Aids is a process. Young children often can only understand and remember little bits of information at a time. They need lots of chances to ask questions.

For children to fully understand an idea, they may discuss the same topic several times. When talking about HIV and Aids, use words and information that are right for your children's age and maturity.

➢ **It is okay not to have all the answers.**

Not knowing much about a subject shouldn't stop you talking to your children. It is, however, important to give then correct information.

➢ **Make sure you have the correct facts.**

Use resources to make sure your information is correct. You and your children can learn more about the disease together by using books, clinic pamphlets, TV programmes, Aids help lines, health workers and HIV/Aids counsellors.

2.2 FACTS ABOUT HIV AND AIDS

➢ **The meaning of HIV and Aids**

HIV stands for Human Immunodeficiency Virus. This is the virus that causes people to get Aids.

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AIDS stand for Acquired Immune Deficiency Syndrome, also called "slim" disease in some countries. Aids is a collection of diseases that result when the immune system is broken down after it has been invaded and weakened by HIV.

- **The effect of HIV on the body**

The body is normally protected from diseases such as colds and flu by its immune system. HIV is a very small germ called a virus. HIV invades the immune system and destroys it by killing the white blood cells that protect the body against diseases. HIV makes the body weak and less able to fight off diseases.
People with HIV in their bodies eventually become sick with Aids. They are then more likely to get illnesses such as cancer, pneumonia and tuberculosis.

1. You cannot tell if someone is HIV-positive just by looking at them.
2. Both boys and girls can be infected with HIV and Aids.
3. People of any race, ethnic group, religion, culture, gender, sexual orientation, social status, profession and age can be infected with HIV and Aids.
4. You do not have to be HIV-positive if your mother is infected. Also, if one person in a family is infected, this does not mean that other members of their family are also infected.
5. You could have a cough, a rash or other symptoms that look like Aids. This does not mean that you have HIV or Aids.
6. You can live with HIV for a long time before you get sick.
7. When a person cannot fight HIV anymore, and starts getting very ill, we say that the person has Aids.
8. People die from Aids.
9. Aids is not caused by witchcraft.

2.3 HOW HIV IS SPREAD

It is also important to let children know how the disease is not passed on. Share these facts with your children:

- The virus cannot pass through skin.
- You can hug, kiss and show affection to an HIV positive person and not get infected.

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- A child can play with an HIV person without getting infected.
- You can share a taxi, be in the same room, and use the same toilet as an HIV person, without getting infected.
- You cannot get infected with the virus from insects, like flies or mosquitoes.

2.4 HIV AND AIDS EDUCATION AT DIFFERENT AGES

3 TO 6 YEAR OLDS:

With this age group, you can discuss the following:

- HIV is a disease.
- You cannot get HIV from playing with someone with the disease.

7 TO 11 YEAR OLDS:

With this age group, you can talk about the above issues as well as:

- HIV can pass through an injection needle that has been used by a person who is living with HIV.
- It can be passed on through sex.

12 TO 18 YEAR OLDS:

With this age group include all of the above information. It is very important to have general conversations about HIV and sex. For example:

- One of the main ways that people get HIV is through unprotected sex. This means sex without a condom. It can also spread through infected blood and also mothers can pass the virus on to their babies.
- Talk about sexually transmitted infections (STI). Open discussion about this topic can help with delaying sex, encouraging safe sex and reducing HIV.
- Sometimes when discussing sex and STI, it is best to keep the conversation simple. For example, you could say, "People who don't use a condom during sex can get HIV if one person is infected".

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2.5 HELPING CHILDREN TO PROTECT THEMSELVES FROM HIV

Children need to know that there are things that they can do to lower their risks of infection. It is important to talk about this with children of all ages (Takalani Sesame, 2005).

3 TO 6 YEAR OLDS:

- Children should never touch anyone else's blood. They should call an adult to clean up if there is any blood.
- If they cut themselves, they should cover their blood with their hands and call an adult to put on a plaster.
- Don't touch sharp objects such as razors, blades or broken glass.
- Don't touch rubbish lying on the ground or in a rubbish bin.
- They should know that adults must wear gloves when treating an open cut or sore.

7 TO 11 YEAR OLDS:

Talks with this age group can also be about blood transmission. They should also include:

- Discussion about safe sex. This means how condoms can protect people from getting HIV. At this stage, children may have heard about condoms, and may start asking what condoms are. You could answer, "A condom is a plastic (latex) cover for a man's penis that he wears during sex. It helps to stop infection".

12 TO 18 YEAR OLDS:

Conversations with this age group can also be about blood transmission, safe sex and more detail on how to prevent STIs.

- Talk about condoms, how to use them and where to get them. Talk about the importance of knowing their boyfriend/girlfriend's HIV status before they have sex. Also how they should remain faithful to each other once they do have sex.

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- You can also talk about things like abstinence. For example, "It is best to wait for sex until you are older. You still have so much else to explore before you are an adult." OR "You don't have to have sex to prove you love someone".

- Often it is useful to use resources like booklets or TV programmes to help you begin these conversations. Or you may want to ask another adult you know and trust to talk to your children, if you find it difficult.

- When you have to use skin piercing instruments such as razor blades, needles and syringes, make sure they are sterilized. You should not share these instruments with other people.

- When a surface has been contaminated with body fluids or excretion, clean it with running water and household bleach (1:10 solution) and disposable cloths. The person doing the cleaning must wear rubber gloves or use plastic bags to avoid contact.

- Cover cuts and wounds with waterproof plasters. If you do not have plasters, use a piece of clean cloth to cover the wounds.

2.6 HOW CHILDREN CAN COPE WHEN THEIR PARENTS ARE HIV-POSITIVE

Children may already know someone who has HIV or is dying or has died of Aids. People who are infected need lots of love and care. They need family members, friends and neighbours who will support them and help take care of them. Children should be taught that they do not have to fear someone with this disease and should never discriminate against someone with HIV or Aids (Edwards, 2000).

- **Let children known their parent's illness might lead to changes in their daily routine.**
  This may include school routines, household routines, changes in where people sleep, and medical treatments. It may also include family members and friends helping at home.

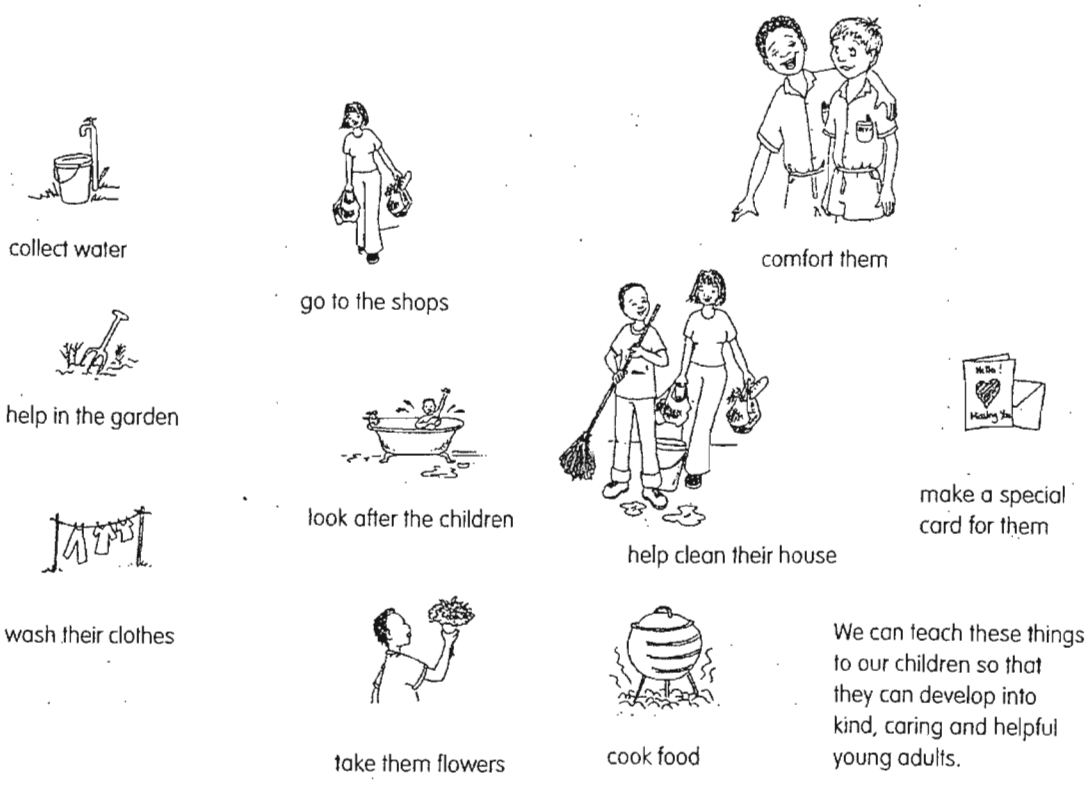
- **Let children know that it is not their fault that their parent is ill.** Sometimes children feel as if they are responsible for someone being ill – maybe because they behaved badly, maybe they didn't do what

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you asked. It is important to clearly let them know that they did not cause the person to be ill.

- **Let children know it is important for them to continue their normal activities.**
  Sometimes children might feel guilty having fun if someone they love can't. They should try to keep going to school and playing with their friends.

- **Help children to find ways they can help their loved one who is ill.**
  This will help them to feel valued, no matter how young they are.



3. CARING FOR CHILDREN IN NEED

To help children we must know what their rights and needs are. We need to know when children need help and how to help children get what they need. We want to see all our children grow into responsible, happy and caring adults. The following will help us gain the knowledge to achieve the above goals (Department of health, 2005).

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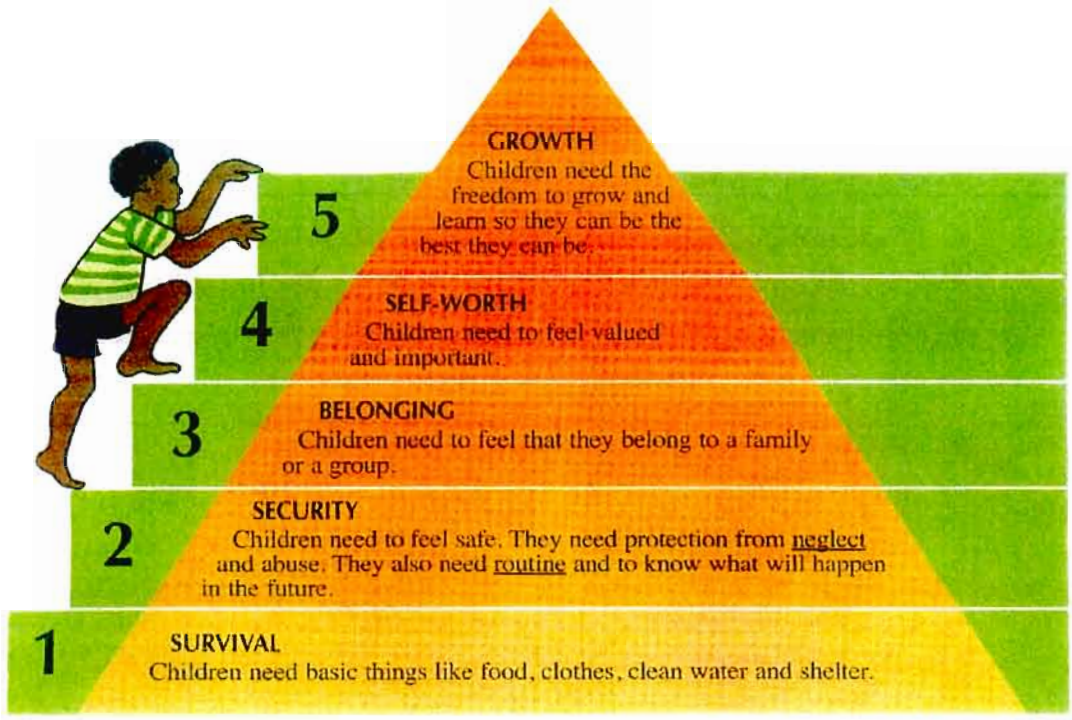
3.1 CHILDREN'S RIGHTS

All children have rights, rights to:

- Food.
- A home.
- Health care.
- The love and support of caring adults.
- Protection from abuse, discrimination and exploitation.
- Education.

3.2 CHILDREN'S NEEDS

Children need things for their body, mind and spirit. This helps them to grow to be healthy, happy adults. Some things are learnt and provided for by the family. Other things are learnt outside of the family. The 5 steps below show the order of children's needs. The most basic important need is no. 1 – survival. When children have the things in no. 1, they can move to no. 2. If a child feels safe and secure, they then move to no. 3. They need to feel they belong to a family. Then they move to no. 4 – self worth and then to no. 5 – growth (Department of health, 2005:3).



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3.3 WHEN CHILDREN NEED HELP

There are many ways that you can tell if children need help:

- They don't get enough to eat.
- They are often ill.
- Sometimes they do not have school uniforms or school fees.
- Maybe they cannot go to school.
- They have to care for sick adults or brothers and sisters.
- They have to do adults' work.
- Sometimes they do not have the love and support of caring adults.
- Maybe they have to live on the streets.
- They have to beg or sell themselves for food.
- They live with stigma, discrimination or exploitation.
- Sometimes they are treated badly by people around them.
- They are often left alone.
- Maybe they have a disability.
- They are often very poor.
- They may behave badly or differently.

People may think badly of children who live in families affected by HIV and Aids. This hurts children and it is wrong. Learn the facts about HIV and Aids. Accept and care for these families.

3.4 CARING FOR CHILDREN IN THE COMMUNITY

There are many organisations and people who can help to raise a child.

Circle of support



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3.4.1 Relatives, neighbours and friends

The first level of support around the child is made up of the people closest to the child and his or her family, like relatives, neighbours and friends. It is better for children to be cared for in families than institutions like orphanages. Helping the child by providing the following:

- They can give food and clothes, if they are able to.
- They can care for people who are ill.
- They can go shopping and cook meals.
- The group can help with food gardens or in fields.
- Looking after children or telling them stories is helpful.
- They can take a child to the clinic for immunisations or if they are ill.
- They can make sure that others do not hurt or abuse vulnerable children.
- They can show they care by listening to a person's problems.

3.4.2 The community

Community members can decide to join, or create a support group to help children in need in the community. By working together more can be done to help. It can start as just a few neighbours and friends. Community groups can ask other organisations, like Aids support groups, for help.

3.4.3 Organisations and Government Service

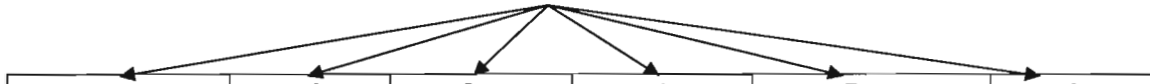
- Organisations that can help, can be youth and church groups, they can help to care for the ill, fight stigma and look after children.
- Local Aids support groups can give emotional help, care for the ill and fight stigma.
- NGOs like Hospice or the Child Welfare Society can help children cope with illness, death and abuse.
- Local business can sponsor food, clothes and school necessities.
- Men's and women's groups can help care for children or ill person, and families where there is abuse.
- Traditional leaders can protect children and help fight stigma and discrimination.
- Home-based care group can help by supporting the ill.
- The government can help may help with funds and basic services like water.
- Local clinics and hospitals can help children who have ill parents. They may also give cleaning materials and gloves.

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- Social workers can counsel children who are unhappy or behaving badly.
- Caring teachers can look out for children in need, and send them for help. They can organise a school feeding scheme and try to keep the children in school.
- The SA police can help fight abuse.
- The Department of Social Development has different government grants for children and families in need.

3.5 HOW TO CREATE A SUPPORT GROUP

If you know children in need, start a support group in your neighbourhood. Even two/three people are enough. These are the things you can do to create a support group:



1	2	3	4	5	6
Make a list of people and organisations that could help children in need	Make a list of children and families who need help	Find out what they need, for example clothes, emotional and social support, take care of children or taking them to school	Divide the tasks between group members. Each should know what to do	Make a plan how to fight stigma and discrimination in the community	Support group must meet regularly to find out what is being achieved

When you start a support group, you will all need to talk about the ways you want to help. There are many children and families who need help. You will not be able to help everyone. Never promise help you are not able to give. When you cannot help, you can tell people about other places that can. You need to tell them what you are going to do for them and for how long. This builds trust between you.

3.6 CARING FOR CHILDREN WHO ARE HIV-POSITIVE

- Children who are orphans and/or heads of households are often forced to take on the chores and responsibilities of adults, with little or no

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support. It is important for adults and for the community to be aware and supportive of them. Talk to the teachers or local community social worker.

- Children who are HIV-positive need the same love, care and compassion as other children.

- Find out if there is a home-based care organisation in your area. They will give support and advice on caring for HIV-positive or ill children. If there isn't one, talk to community members or health workers at the clinic or hospital. They will help to set up a support group for the care of children.

- Take HIV-positive children to the clinic as soon as they get ill. Make sure they take their medicine for as long as the health worker says they must. Children under 6 years old can get free health care at any government clinic or hospital.

- HIV positive children should exercise, play and also get plenty of rest. HIV positive children cannot infect other children that they play with, share food with, hug or touch.

- Children should go to school and learn and play in the same way as other children.

- Prevent direct contact with your skin when you clean up body fluids like vomit or blood from children with HIV. Use rubber or plastic gloves. If you don't have gloves, put plastic bags or thick cloths on your hands. Sometimes you can get gloves from a clinic or a home based care organisation.

- It is important that small children know they shouldn't bite others.

- Like other children, HIV-positive children must be immunized 5 times in their first year of life. This protects them from dangerous illnesses like polio, diphtheria, tetanus, mumps and measles.

3.7 KEEPING CHILDREN IN SCHOOL

Every child has the right to go to school. If someone is sick in a family, it may be difficult for a child to go to school. If you know a child who isn't at

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school, you can help. You can join with others and start a support group to keep the child in school.

3.7.1 School is important for children

At school children learn and play with other children their age. They have routine and discipline and have more opportunities when they are older.

3.7.2 Protect children's rights

- Children sometimes bully or tease children who are different from them. They may not play with them or share their toys. Sometimes teachers also discriminate against children. This is wrong!

- No school can refuse entry to children because they are infected with HIV or because anyone in their household is infected with HIV.

- Poor children and those with HIV, or family with Aids, have the same rights as other children.

3.7.3 Things that can prevent children from learning

- The children may be hungry or ill.
- They are being abused or hurt at home.
- They have an eye problem and need glasses. They can't hear properly or they may have another learning disability.
- They cannot concentrate because they are worried about ill family members at home.
- They don't get enough sleep.
- Children don't get enough time for homework.
- They are grieving the death of somebody close to them.

3.7.4 Children's needs to go to school

Needs	**Assistants from support group**
School uniforms	Collect uniforms from children that outgrow them.
Transport to get them to school	Make sure children walking to school are safe.
School fees	No school can refuse to take children that can't pay. Speak to the principal

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	to apply for a school scholarship.
Books and stationary	Ask people in the community, local businesses and charity organisations.
Encouragement	Help children with homework.
Food	Children cannot learn when they don't eat enough.
Support from parents or caregivers	Encourage parents to send children to school.
Time to go to school	Help children with households, to get time to go to school.

4. GOVERNMENT GRANTS FOR CHILDREN

The South African government wants to help poor families. They also want to help caregivers who can't support children on their own. A grant is money that is given by the government to take care of a child. A support group can help families get government grants to care for their children.

You can apply for Child Support Foster Care and Care Dependency Grant at the Department of Social Development offices or Government Welfare Offices (Soul City, 2004:46-48).

4.1 DIFFERENT GRANTS FOR CHILDREN

The Child Support Grant (R240-00 a month):
The Child Support Grant is given to any person who takes care of a child under the age of 16 years. As long as the child has not turned 16 you can receive the grant. To apply for the Child Support Grant, you and your husband or wife must together have a monthly income of: • Less than R800-00 if you live in a town or city. • Less than R1 000-00 if you live in a rural area or informal settlement. IF the child is not your own, and you are taking care of him/her, you need to make an affidavit at a police station. This is to prove that you have permission from the parents to take care of the child.
The Foster Care Grant (R680-00 a month)
For children without parents. This grant is given to the caregiver of a child who is not the caregiver's own child by birth. This person is called a foster parent. Anyone who looks after

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a child who is not their own can apply to become a legal foster parent at the Children's Court. This can be done through a social worker who is with the Department of Social Development or Child Welfare Society. This grant is given to children who are under 18 years of age. It can be extended to 21 years of age if the child is still at school.

To apply to legally foster a child, you must prove that:

- The child's parents are dead, or
- The child's parents are not able to care for their child.

Once you have applied to be a foster parent, a social worker will check everything you have said. He or she will write a report that will go to the Children's Court. If the Court decides you can foster a child, you will be given a Court Order. Once you have the Court Order, you can apply for the Foster Care Grant.

The Care Dependency Grant (R1010-00)

For children with disabilities.

This grant is paid to people who care for children who have severe disabilities and need to be cared for full-time. They can be parents, foster parents or people who have been made caregivers by the Court. When you apply, you need to have a medical report saying what is wrong with the child. The grant is given to children who are between 1 and 18 years of age.

Talk to a social worker or doctor from a Provincial hospital about this.
You can apply for a Care Dependency Grant at the Department of Social Development offices or government welfare offices.

4.2 WHAT TO TAKE WHEN YOU APPLY FOR A GRANT

Death certificate if one or both of the child's parents are dead:	**A bar-coded South African document:**	**Proof of income:**	**A birth certificate for the child (with a 13 digit identity number):**	**You marriage certificate or divorce order:**
If you need to get a death certificate: * Get a notice from the doctor	If you don't have an identity document (ID): *Phone the Home Affairs office to find out how much it	If you are employed, you need to get a salary slip or a letter from your employer to say how much you earn.	If a child in your care doesn't have a birth certificate, this is what you	If you don't have these, you can apply for them at Home Affairs. * You must take your own identity

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or health care worker who last treated the person. This is a piece of paper saying that the person has died. Take this to the Home Affairs office. They will write out a death certificate. * You will need to take the parent's death certificate as proof that you are now responsible for the child.	costs to apply for one. *Take your birth certificate, two passport photographs and the right amount of money to your nearest Home Affairs office.	*If you are unemployed, you need to make an affidavit to prove you don't have an income.	must do: *Ask for a maternity certificate at the hospital or clinic where the child was born. *Take the maternity certificate and your own ID to Home Affairs. You can apply for the child's birth certificate there.	document with you.

When you apply for a grant you will make lots of visits or phone calls to state offices, keep a record of these. This will help you with your application and with any delays or problems. Write down:

- The date.
- What office you visited or contacted.
- The name of the person you spoke to.
- What advice they gave.
- Your reference number.

Remember: It might take a long time before you get the grant money! To prevent delays have the relevant documents!

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MODULE 6: CARE FOR THE DYING

- **ICE BREAKER: How to support a dying person and grieving family?**

1. **INTRODUCTION**
2. **FEELINGS ASSOCIATED WITH A TERMINAL ILLNESS**
3. **CARE FOR SOMEONE WHO IS DYING**
4. **PREPARE FOR DEATH**
5. **THE FAMILY OF THE TERMINALLY ILL PERSON**
6. **HELPING CHILDREN COPE WITH DEATH**
7. **CREATIVE WAYS OF HELPING BEREAVED CHILDREN AND FAMILIES**
8. **CONCLUSION**

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MODULE 6: CARE FOR THE DYING

How to support a dying person and grieving family?

In order to support those who are grieving, it is necessary to think about death. Take a few minutes and ponder the following:

- What do you think death looks like?
- What emotions do you see on death's face?
- What colour is death?

Now draw what you visualised.

1. INTRODUCTION

At some point in the disease process of Aids, there is nothing more that can be done to treat the opportunistic infections, or the symptoms that they cause. The infections or illnesses have progressed beyond what medicines can cure. At this point, the goal of all care (medical, nursing, pastoral and psychological) is to keep the person as comfortable as possible and to maintain their dignity. In some places this is called palliative care.

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- When does this begin?

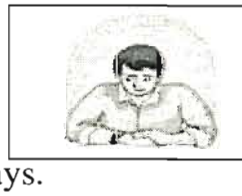
  It is often difficult to decide when the focus on medical treatment should stop and care for the dying should begin. The change in care may begin, for example:
  - When medical treatment is not available or is no longer effective.
  - When the person says he or she is ready to die and really does appear to be very sick – this is clearly different from someone who is depressed for a time and who must be encouraged not to give up.
  - When the body's vital organs begin to fail.

- Where is care provided for someone who is dying?

  Care for the dying can be provided in a hospital or in the home. Most people prefer, or are forced by circumstances, to remain at home. However, some people may not want to actually die in the home. They may want to stay at home until the last moment but either because of their own or the family's wishes they may want to go to the hospital to die. If this is the case, a plan for transporting them will need to be thought out.

2. FEELINGS ASSOCIATED WITH A TERMINAL ILLNESS

Guidance and support services are of the utmost importance to the terminally ill patient. According to Lauria *et al.* (2001: 28), the following are factors that can have an affect on the individual's or the family's psychosocial response and adaptation to terminally illness:



2.1 EMOTIONS A PATIENT EXPERIENCE DURUNG ILLNESS

People who are sick and dying will respond to their illness in different ways. No one client will go through the same feelings and emotions as another.
For a caregiver to effectively provide end-of-life care for clients, they must understand some of the feelings and emotions people experience throughout illness, particularly as they become seriously ill and acknowledge that they may be dying. Not all clients will experience each emotion, but it is important to recognise these emotions if they are to respond effectively.

Anticipatory Grief involves grieving by both persons and their families that begins once they realise he or she has an incurable illness. Feelings

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associated with anticipatory grief may include anger, fear, anxiety, sadness or blame. These feelings are normal and are part of to come to terms with a situation, and preparing for the idea that illness may threaten their own life, or the life of a loved one.

The 5 stages Kubler-Ross (1997) identified in coping with terminal illness are:

2.1.1 Denial and isolation

This stage is associated with a numb feeling of shock and an inability to discuss the diagnosis or problem, "No – it can't be true". The denial allows people time to compose themselves and to activate their defense mechanism. It therefore functions as a buffer. Withdrawal, isolation and mood swings are also associated with this stage.

The patient's wish to deny should be respected. It is also helpful to encourage the person to talk about feelings, to accept the mood swings and to be supportive. Denial can be seen as a way of anaesthetising the pain until the patient or family is ready to deal with it.

Some patients may remain in denial until they die. If this state of denial is perceived as beneficial, enabling the patient to function normally, then responses should be limited to empathetic listening.

2.1.2 Anger

Rage, anger and resentment may replace denial. A typical response may be: "Why me?" The family may react by feeling very guilty. Furthermore, it is characterised by feelings of frustration, anxiety, fear, helplessness, hopelessness and loss of confidence.

The expression of feelings must be allowed. The family and patient can develop insight towards the reasons for the anger to prevent guilt feelings and intolerance.

2.1.3 Bargaining

This stage is associated with a child-like reaction. An agreement is entered into with God to postpone the inevitable. It is, therefore, often a process of negotiation between the dying person and his or her spiritual beliefs, and is not actually put into words. It is unfortunately often detrimental to the quality of the person's remaining life. Bargaining should also be allowed.

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2.1.4 Depression

When there can no longer be denial and bargaining seems to be of no avail, depression may occur. It is a natural reaction to a sense of loss. Depression is a quiet, non-verbal sadness where the person has an ignorance of others and an expression of sorrow in attitude is noticeable. It is necessary to be with the person, to express empathy and to be very supportive, avoid false assurances. This stage prepares for acceptance and must not be blocked or interfered with.

2.1.5 Acceptance

Given enough time, a person, with help, will work through the previous stages, and having mourned his/her loss, can reach quiet expectation. He/she will be tired and probably weak. The person is able to focus upon future life goals and realistic progress and plans. We need to teach them how to set these goals and live one day at a time and that life is about making memories and learning to truly live out this divine gift until we die.

2.2 FEARS RELATED TO DEATH AND DYING

When faced with a life threatening illness, the first fear to confront is dying. People are not so much disturbed by death as they are by the possibility of dying in pain, lonely, dependant and helpless.
According to The National Cancer Association of South Africa the fears of dying of an incurable illness, includes fears related to the following:

- Process of dying.
- The effect on the body.
- Family and survivors.
- Loss of this life and this future.
- Unfinished business.
- Guilt feelings.
- Afterlife.
- General fears related to previous experiences.



Kirkpatrick (1990) associated the following fears specifically with patients dying of Aids (also Lauria *et al.* 2001:40-41):

- Fear of physical pain.
- Fear of rejection by partner, family friends, society and God.
- Fear of being disabled or disfigured.
- Fear of losing control of mind, emotions and life.

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- Pain of being part of a minority viewed with suspicion.
- Fear of exposure.

2.3 NEEDS OF A TERMINALLY ILL PERSON



Young (1999) distinguishes between four needs:

2.3.1 Physical needs

- These centre on the relief of symptoms.

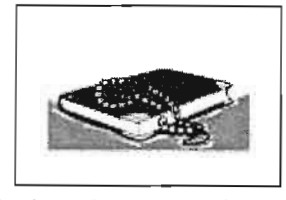
2.3.2 Psychological needs

Aspects that are important are:

- Safety (a feeling of security).
- Understanding (explanation of the disease and symptoms and to discuss the process of dying).
- Self-esteem (involvement in decision-making).

2.3.3 Social needs

- Acceptance (without discrimination).
- Belonging (need to connect with family and others).
- Disengagement (to take leave of those people and things one is attached to, to hand responsibilities to others).



2.3.4 Spiritual needs

Elements of importance are:

- **Love** (expressions of affection, human contact).
- **Reconciliation** (the opportunity to heal damaged relationships, and seek forgiveness).
- **Self-worth** (the knowledge that one is loved and valued).
- **Purpose** (a feeling that one's life still has meaning and direction).

Studies concerned with spiritual well-being, indicate that an awareness of spirituality should be fundamental in any life threatening or terminal illness.

- Active participation in a religious group could provide certain types of instrumental and cognitive support that are beneficial to the individual.
- A religious belief system may provide the individual with meaning of life and better enable them to cope with painful circumstances.

Certain religious views may actually influence the ways in which individuals perceive and handle problems (Powell, 2004).

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3. CARE FOR SOMEONE WHO IS DYING

3.1 GIVE COMFORT

Keep the person dying, comfortable and protect them from problems that can make them feel worse.

- If the person is in constant pain – make sure pain medication is available in regular doses.
- Use relaxation techniques – encourage deep breathing, give back rubs/body massages.
- Basic physical care – keep the person clean and dry to prevent skin problems and stiffness or locking of joints.
- Encourage communication within the family and community.
    - ➢ The dying person needs to feel that they are not excluded from love and life in the community.
    - ➢ Increase acceptance of the whole family.
- Provide physical contact by touching, holding hands and hugging.
- Provide counselling if desired – religious/spiritual counselling.

3.2 ALLOW ILL PERSON INDEPENDENCE

- Accept the ill person's decisions such as refusal to eat or get up.
- Show respect by allowing the patient to make decisions like having visitors or not.
- Decision making impeded by a sense of hopelessness. Being part of decision-making the patient should be motivated – feeling of self-worth.
- **DECISION MAKING Include: Daily activities, financial planning, medical treatment, living will, nursing care facilities, terminal care and even funeral planning.**
- Ask what the sick person is feeling, listen and allow the person to talk about their feelings.
- Accept that the person may have feelings – of anger, fear, grief and other emotions (Van Dyk, 2005).

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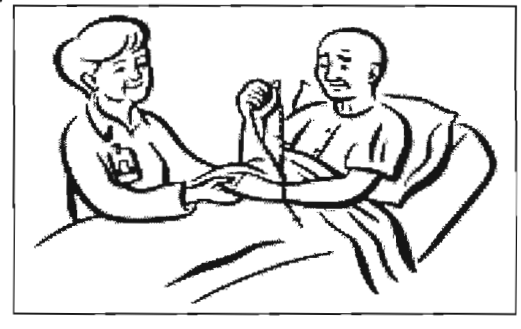
4. PREPARE FOR DEATH

ART helps the infected person to live a longer life. But it is not a cure for Aids. The infected person still needs to prepare for the future.

Things to do while the dying person is still strong

4.1 HIV-POSITIVE PARENTS AND PREPARE FOR THE FURTURE

- Talking about death if a person wants to:
  - Discuss concerns and begin planning for the future of the children.
  - To avoid talking about death is a form of denial.
- A common worry for most dying patients is the future of the family. They fear who will take care of the children, school fees, money for food etc.
- Talk to friends and relatives about who will look after the children if you are not able to do so yourself.
- Talk to your children about where they will live if you die.
- Talk to a social worker if you do not have relatives to look after your children. Tell the social worker what you want to happen to your children and your belongings when you die.
- Put all your important documents in a safe place. Tell the children where these are kept. Documents like your will, their birth certificates, identity books, school certificates, papers of the house and phone numbers of friends/relatives, name and number of your burial society.
- Make a will. This is legal document that says what should happen to your things when you die.
- Make a memory box with your children. You can keep special belongings inside that you want your family to have when you die. This will make the grief process easier.
- **Other aspects of importance**
  - Resolving unfinished business.
  - Creating memories.
  - Positive thinking.
  - Living in the present.



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4.2 DEALING WITH DEATH AND DYING

Death is not something people want to discuss, but it is important to think about it and plan for it. One way to live **positively** is to think about the future while you are still strong. Make plans so that your family will be able to cope if you get very ill or die.

4.3 WHAT HAPPENS TO CHILDREN IF THEIR PARENTS DIE

- When a father dies, his children may lose their home. A father who wants to make sure that his children stay in their home can talk to his relatives about this before he dies. He should also put his wishes into a will.
- When a mother dies, her children may be sent back to her family. When this happens, the children lose their home, their community and their friends.
- Children may have to leave their rented home when both their parents die. If there is nowhere else to go, they may have to live on the street.
- Relatives may take the children. For many families, taking in more children means even less food and clothing for everyone. Children may struggle for food and other **needs.** Government grants can be helpful.
- Brothers and sisters may be separated because they are sent to live with different relatives.

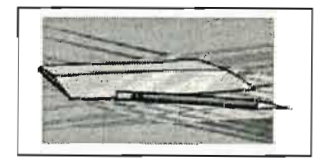
4.4 WORRIES OF BEING IN PAIN AS THEY NEAR DEATH

The fear can be lessened if they are prepared for what will happen. If the person asks, describe what might happen, such as difficulty in breathing, or passing in and out of consciousness. If pain medications are available, reassure the person that they will be used in order to prevent unnecessary pain. Provide information about:

- Pain management.
- Body changes with disease progression.
- Advice on emotional support.
- Provide additional resources.
    - Spiritual support.
    - Emotional support in dying well.

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- Provide reassurance that you (family/spouse) will be available to help the patient through the dying process.
- Encourage additional questions
    - What do you understand about your current health
    - Want to die peacefully and in privacy
    - Listen carefully – often patients want permission to talk about death.



4.5 WORRIES OF WHAT WILL HAPPEN AFTER THEY DIE

- The anxiety can be lessened by helping them to write a will, by planning details such as funeral arrangements and discussing spiritual beliefs, perhaps with a representative of the person's religion.

4.6 PRECAUTIONS THE FAMILY NEED TO TAKE WITH THE BODY OF SOMEONE WHO HAS DIED OF AIDS

- When dealing with the body of a person dying of Aids, the family needs to take the same precautions as dealing with a person through their illness:
    - Hands should be protected when cleaning the body.
    - Wash with soap and water.
    - Cover wounds with plaster or bandages.

(Shortly after the person died the virus will also die).

5. THE FAMILY OF THE TERMINALLY ILL PERSON

During the course of the illness, many changes and losses can be experienced by the patient and family, such changes may include:

- Disruptions to normal household routines and life style.
- Increased stress and demands in caring for the ill person.
- Reduced contact with friends and increase, potentially intrusive, contact with those who provide medical and nursing care.
- Limited opportunities to talk about the illness and its impact due to social "taboos" about topics such as Aids, dying and death.
- The physical deterioration and gradual loss of functioning experienced by the sick person.

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5.1 UNDERSTANDING LOSS AND GRIEF

Loss is accompanied by grief. When loved ones become ill, the loss starts, because they are no longer there for us as they were before.

Grief is a normal, dynamic process that occurs in response to any type of loss. It encompasses physical, emotional, cognitive, spiritual and social responses to the loss (Couldrick, 1997).

Depending on how it is dealt with, the grief process can last a long time and it may leave scars. Yet, it is the process by which healing occurs.

- The family needs to grieve.
- Help to arrange practical matters.
- Help arranging the funeral.
- Grieving will take place months after the death of a person.
- It helps to visit the family when possible – to help them to think of life beyond the painful time.
- If you noticed that death makes you uncomfortable or depressed, you may need to get additional support for yourself if you need to work closely with people who are grieving. For additional support, you could turn to a counselor, a priest, a telephone counselor (e.g. Lifeline 0861 322 322).

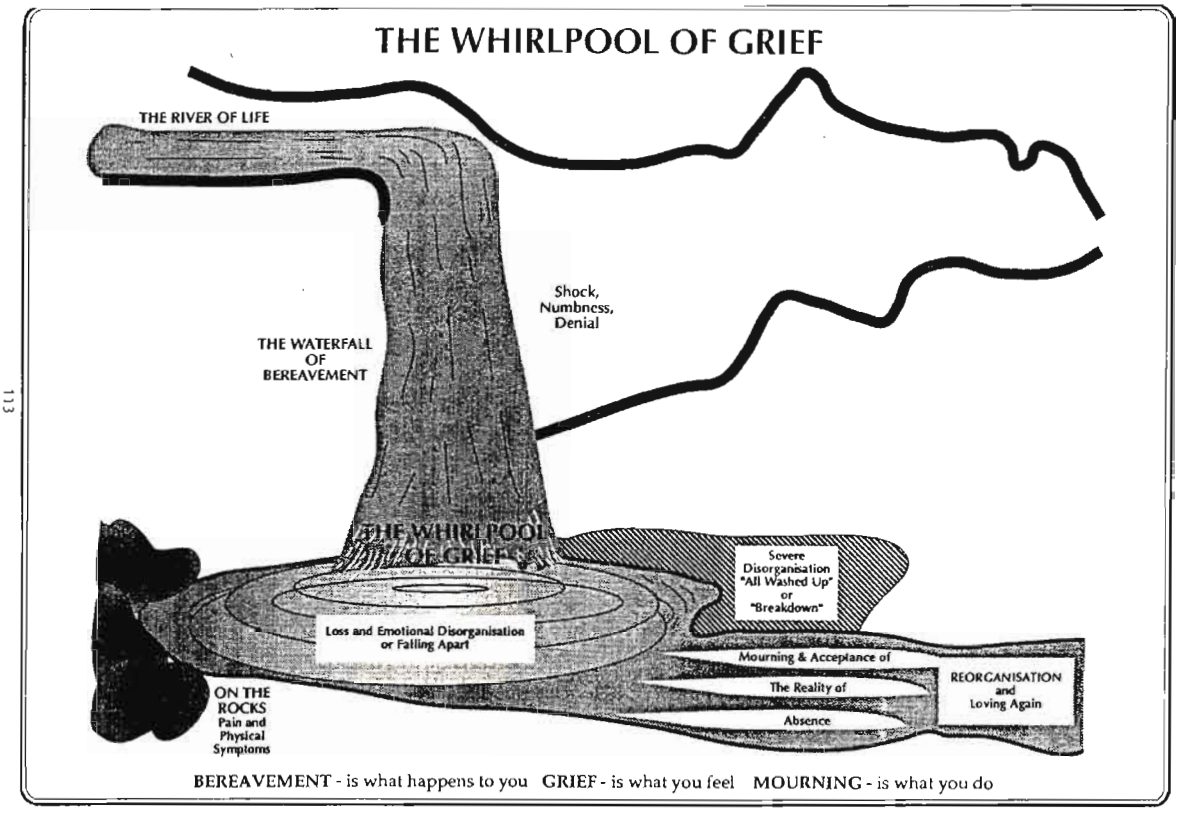
5.2 GRIEF CAN TAKE MANY FORMS, INCLUDING:

- Sadness.
- Anger.
- Withdrawal.
- Poor concentration.
- Mood swings.
- Guilt.

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5.3 THE GRIEF PROCESS – WHIRLPOOL OF GRIEF

(Thomas & Chalmers, 2007)



(www.childbereavement.org.uk)

- As the illness progresses, many emotional ups and downs can be experienced with those involved fluctuating between times of hope and despair.
- This emotional roller coaster can leave patients and carers with uncertainty about how to deal with the patient's possible death.
- People will experience "anticipatory grief", in which they acknowledge, albeit unwillingly, the possibility of death and begin to grieve and prepare for life after the loved one has passed

Please remember that grief is personal – no two people grieve in exactly the same way; it is a unique process. **The goal of the grieving process is healing.** There are some basic guidelines for the grief process:

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5.4 HELPING THE BEREAVED

Give:

- A good ear.
- Time to really listen.
- A hug where appropriate.
- Continuing contact.

5.5 SUGGESTIONS TO KEEP A GRIEVING PERSON MOVING IN THE RIGHT DIRECTION

5.5.1 Accept the grief.

Roll with the tides of it. Do not try to be brave. Take time to cry.

5.5.2 Talk about your loss.

Share your grief within the family. Do not try to protect them by silence. Also find a friend to talk to. Talk often. If the friend tells you to "snap out of it," find another friend.

5.5.3 Deal with guilt, real or imagined.

You did the best you could at the time. If you made mistakes, accept the fact that you, like everyone else, are not perfect. If you continue to blame yourself, consider professional or religious counseling. If you believe in God, a pastor can help you believe in God's forgiveness.

5.5.4 Keep busy.

Do work that has a purpose. Use your mind.

5.5.5 Eat well.

Grief stresses the body. You need good nourishment now more than ever, so get back to a good diet soon. Vitamin and mineral supplements may help.

5.5.6 Exercise regularly.

Exercise lightens the load through bio-chemical changes. It also helps you to sleep better. Return to an old programme or start a new one. An hour-long walk every day is ideal for many people.

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5.5.7 Nurture yourself.

Each day try to do something good for yourself. Think of what you might do for someone else if they were in your shoes and then do that favour for yourself.

5.5.8 Join a group of others who are mourning.

Your old circle of friends may change. Even if it does not, you will need new friends who have been through your experience. This will reduce feelings of isolation.

5.5.9 Associate with old friends also.

Some will be uneasy, but they will get over it. If and when you can, talk and act naturally, without avoiding the subject of your loss.

5.5.10 Postpone major decisions.

Wait before deciding whether or not to sell your house or to change jobs.

5.5.11 Record your thoughts in a journal.

Writing helps you get your feelings out. It also shows your progress.

5.5.12 Turn grief into creative energy

Find a way to help others – sharing someone else's load will lighten your own. Write something as a tribute to your loved one.

5.5.13 Take advantage of a religious affiliation

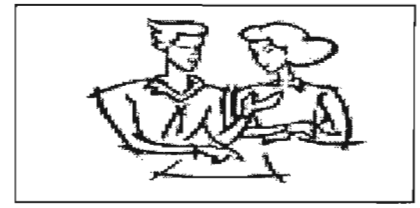
If you have been inactive, this might be the time to become involved. For some people, grief opens the door to faith. After a time, you might not be as mad at God as you once were.

5.5.14 Get professional help if needed.

Do not allow crippling grief to continue. There comes a time to stop crying and to live again. Sometimes just a few sessions with a trained counsellor will help a lot.

No matter how deep your sorrow, you are not alone. Others have been there and will help share your load if you will let them.

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5.6 THE IMPORTANCE OF COUNSELLING

Unresolved grief is life-limiting in all future relationships. If you fell down and gashed your leg and blood was pouring out, would you immediately seek medical attention? If circumstances and events conspired to break your heart, would you seek attention, or would you allow yourself to bleed to death emotionally? Unresolved grief can cause complicated grief. Emotions that are suppressed goes to an unconscious level and these emotions have an 'uncontrollable' effect (on the individual). They come to the surface when you least expect it (Van Dyk, 2005: 236-247).

5.6.1 Indications of complicated grief:

- Difficulty in mentioning the name of deceased.
- Minor events trigger intense emotions.
- Difficulty in parting with personal belongings.
- Constant themes of loss in conversation.
- Same physical symptoms as deceased.
- Radical lifestyle changes.
- Persistent guilt, lowered self-esteem, coupled with depression.
- Suicidal ideation.
- Unaccountable sadness.
- Phobias about illness and death.
- Avoids death related rituals and activities.
- Delayed, disenfranchised, chronic grief.
- Absence of grief and mourning.



6. HELPING CHILDREN COPE WITH DEATH

6.1 CHILDREN NEED TO BE PREPARED FOR DEATH

Many children in our country lose a family member at an early age. This can be very painful. To help them cope, children need to be prepared. Children who have a parent infected with HIV may also feel sad during the illness before the parent dies. Without help and counselling, young people may take unhealthy feelings into adult life. Children sometimes get hurt from the **stigma** of HIV and Aids.

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Ideally the first conversation about death should happen before they experience it personally. Children from a very young age have to confront loss in one form or another. When a child experiences loss they should be allowed to express themselves openly and freely.



6.2 WAYS TO HELP CHILDREN COPE WITH DEATH

6.3.1 Talk about death

- Communicate with the child in a loving and natural way and in a language that they understand based on their age abilities.
- Even small children can get an understanding of what death is. We are all born, and we all have to die, even animals and plants. This is the cycle of life. Death means no movement and no breathing. The left-over body needs to be buried.
- Talk about where they will live and who will look after them after the parent dies. Let children be part of decision making about their future.
- Children are prepared by talking about the illness and dying before the parent dies.
- If possible, they should be able to say goodbye to the loved one.
- Try to avoid using words such as "passed away"; "left us"; "gone on a long journey"; "is asleep."



6.3.2 Allow attendance of customs and rituals

Customs and rituals around death help children understand that it is something that is accepted and safe. Talk with the child about the ritual, funeral or burial before it happens.

When children take part in customs and rituals, they experience family tradition. It makes them feel part of a long line of family members. Religious beliefs in life after death can be a real comfort for children and adults. You could also talk about grief, and how people might show this, for example through crying and wailing.

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6.3.3 Feelings of belonging

Children get better more quickly after a death if they feel they belong in a family or group. Being together and doing things with other people make the child feel better.

Children need to feel safe and protected. Their fears and worries need sympathy so that they feel safe. They need a familiar routine. If children know what will be happening from day to day, they will be less worried.

If possible, families should try not to send children to new homes. They should try to keep brothers and sisters together. If this is not possible, help them to stay in contact with each other.

6.4 ALLOW CHILDREN TO GRIEVE

Children, like adults, often find it hard to cope with the death of a loved one. They also find it difficult to discuss what they are feeling. It is important to help them to deal with the death or serious illness of a friend or loved one. Children grief as much as adults, but expresses their grief in different ways (Thomas & Chalmers, 2007).
Help them to understand their emotions, and let them know that it is healthy to show how they feel.
A child's play is his world. Through play a child communicates his/her feelings. It enables them to express their feelings and to release anxiety, about events they have no control over.

6.4.1 Grieving is a process that takes time

- At first a child might feel **shock** and **confusion**. The child might **deny** that the person has died. The child might believe that their loved one will come back. They might pretend the person is not really dead.
  Gently tell them the truth, and be ready to offer love and comfort.

- Often children will go through a time of being afraid. They could worry about many things they were not worried about before. **Listen to their fears and reassure them.**

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- Children might feel **guilty** and believe that they have caused the loved one to die. **Let them talk about this, and keep telling them that it's not their fault.**

- Children might feel very sad, or angry at life and at everyone. **Gently help them understand that death is part of life.**

6.4.2 People that can help children

The best people to comfort and help a grieving or **orphaned** child are people who the child trusts. This could be a teacher, a relative, a caregiver or a friend.
Some people think it is better **not** to talk with children about grief and death. They hide death from children. Some adults think this will stop children being sad. This is wrong.

It is very important that children feel all their hurt feelings for however long it takes. Adults can help by allowing them to do this, and by comforting them. Grief is a natural **process** that helps children to heal after a death. But remember, every child is different.

- Contact a counsellor if a child isn't healing, or you are worried about his or her **behaviour**.
- There are no rules about how long it should take for a child to get over a death. It could take anything from a few months to a few years.

6.4.3 Show children how to grieve

- Children often copy adults, so try to be a good **role model**.
- Through watching adults, children learn these things:
  - They learn how to **mourn.**
  - They learn how to live with sorrow.
  - They learn that life goes on.
- Be open with your feelings. This lets children know they are not alone. It gives them a chance to talk about their own feelings, and to ask for help.
- Tell stories and talk with the child. Allow the child to play and demonstrate what happened, using toys or drawings. These are all

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good ways for children to understand their feelings and to deal with them.

- All children need **attention.** Listen to them so they feel important and valued.
- Children do not cope well if:
  - They are shut out of family talks and decisions.
  - They are sent away.
  - They are not told what is happening.

Some people think it is okay to do this. But it is **not** the best thing for children.

6.5 CHILDREN GRIEVE DIFFERENTLY AT DIFFERENT AGES

Babies: 0 to 3 years
• Babies can't talk about their grief. • They show it physically by crying, clinging and behaving like younger babies. **They need holding, cuddling, baby-games and songs.**
Pre-school: 2 to 5 years
• Children at this age have difficulty understanding the permanence of death. They tend to see death as the same as sleep from which one will awaken or a long journey from which one will return. • They may feel insecure as they try to make sense of the lost person or thing – they may be weepy and cling more than before, they may search for the missing person and repeat the same questions over and over. • The child's grief may be expressed in anger, tantrums, screaming or fighting and destructive behaviour. Just knowing that the child is expressing his/her grief in this way may help you to be more patient and consoling. **They need a lot of <u>patience</u>, hugs and cuddles. It helps them to tell their story by <u>play-acting.</u>**
Primary school: 5 to 12 years
• Children at this age tend to have a clearer understanding of the

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permanence of death.

- The child may have had to deal more with other people's reactions and questions. They may be more aware of adult's reactions to grief and try to protect adults from their feelings.
- They may experience guilt and unrealistic or magical thoughts about how something about them, their behaviour, thoughts may have caused the loss to occur.
- They may express a fascination and curiosity around death – they may ask interesting and challenging questions.
- They may also develop fears and have nightmares about death.
- They may experience physical symptoms as a result of their loss. They may express/feel more anger and express injustice at death. They may withdraw or isolate themselves.
- They may also be more likely to deny loss in a similar way to an adult.

Primary school children need to talk about their feelings and the death. They need someone to be a new "parent". They feel valued and important if they help others.

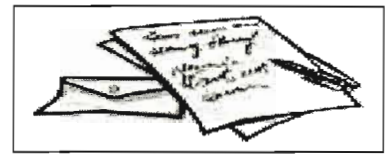
Adolescents: 13 to 18 years

- Adolescents may feel lonely and isolated and as a result may withdraw socially.
- We should try to include them in what is going on. Give them an opportunity to take part in services. Let them choose and keep a memento if they want.
- Expect mood swings and be sympathetic to them if you can. Reassure them that such reactions are normal.
- Be there for them and create opportunities for them to share their feelings and express their grief. Accept that they may prefer to confide in close friends or another adult who is not so involved in their loss.
- Show your feelings, so that they know they are acceptable. Explain about the kinds of feelings that they may experience and especially the range of conflicting emotions common in grief.

Adolescents may show grief as anger and by being <u>rebellious.</u> They need good friends, and to build trust with a caring adult. A job or a sport will give them hope.

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7. CREATIVE WAYS OF HELPING BEREAVED CHILDREN AND FAMILIES



7.1 MEMORY WORK

It is the deliberate setting of a safe space in which to contain the telling of a life story. This space might be a room, the shade under a tree, a drawing or a map, or a memory box, basket or book. In therapeutic context, the scope of memory work is not necessary restricted to the past, its purpose is often to deal with difficulties in the present, and its main orientation often tends towards planning the future (Morgan, 2004).

Ways to do memory work:

- **MEMORY BOOKS**: "a written record of family and individual history, important facts, memories, hopes and messages" (Ward, 2006).

- **MEMORY ALBUMS**: scrap booking or any other form.

- **MEMORY BOXES**: a container of memories. "A memory box is a metaphor, but the term also designates a physical object: a box which can be decorated with photos or drawings and contains the story of the deceased person as well as various objects pertaining to the history of the family" (Denis, 2003).

  It is important to help children who may struggle to remember their loved ones. If they have real things around, it will help them. For example, a photograph or something that belonged to the person who died.

  A good thing to do is to help the child make a memory box. This is any small box filled with things that help to remember the loved one. **It's best if this is made with the parent or caregiver before the parent dies.** But you can help the child to make one even after the parent has died.

  - A memory box helps children to talk about death.
  - It helps children to cope with the loss.
  - It will help them to remember their parent.

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Help the child to choose a box and the things he or she wants to put in it. These could be:



- Photographs.
- Music tapes.
- Children's drawings.
- Letters.
- Voice tapes.
- Special things.
- Small things that belonged to the loved one-like a scarf.

7.4.2 Legacy

LEGACY is about knowing that, our voice, our stories and our connections can remain with those who love us. What we don't realise is that everyday we live is part of our legacy. It is to know that I will continue to exist within my community of significant others, long after I am no longer alive in body. The thought is precious, knowing that I matter and that my life will continue to influence those I cherish, after my death. We are alive daily in our children and loved ones lives, even in our physical absence – and that will continue.

7.4.3 Rituals

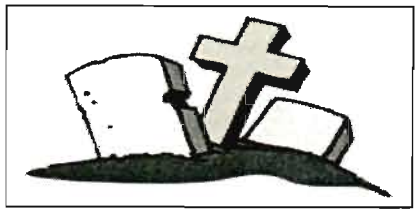
Sometimes experiential activities are more helpful than words. Rituals give a safe place to talk about and mention a loved one who passed away.

7.4.4 Life story work or life maps

Life story work or life maps are tools for self-discovery, and guides to various aspects of your life as you experience it (Herbst, 2002).

- **It focuses on seven questions:**
  1. Who am I?
  2. Where have I come from?
  3. Where am I going?
  4. What is stopping me?
  5. How will I get there?
  6. What help do I need?
  7. What will it be like when I get there?

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8. CONCLUSION

If grief is dealt with in a respectful way and the person feels he/she can experience and express their feelings freely, the process of healing can start and hopefully we can also experience the gift that goes with it.
Love, life and death are the greatest gifts given to us, but mostly they are passed on, unopened!

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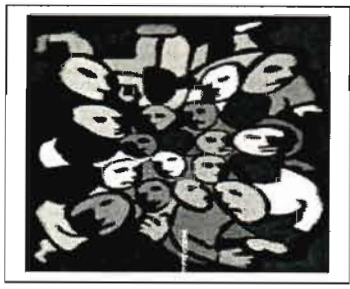
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MODULE 7: RIGHTS OF AN HIV PERSON AND WORKPLACE POLICIES ON HIV AND AIDS

1. HIV AND AIDS IN THE WORKPLACE
2. PRINCIPLES
3. WORKPLACE POLICIES ON HIV AND AIDS
4. RESPONSIBILITIES
5. HIV/AIDS AND THE LAW

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MODULE 7

RIGHTS OF AN HIV PERSON AND WORKPLACE POLICIES ON HIV AND AIDS

1. HIV AND AIDS IN THE WORKPLACE

HIV and Aids affects million of South Africans from all walks of life, including people in the workplace. Therefore, it is important for organisations to take an active role in trying to combat the pandemic.

Page *et al.*, (2006) stated that employers and employees can take the following steps to deal with the HIV and Aids epidemic by:

- Developing a workplace policy on HIV and Aids.
- Negotiating benefits such as medical aid, insurance, retirement benefits and disability cover in the interests of all employees.
- Developing a workplace programme that includes awareness campaigns, condom distribution, treatment of sexually transmitted infections and care for HIV-positive employees.

The Department of Labour suggests that workplace HIV and Aids prevention and wellness programmes should include the following:

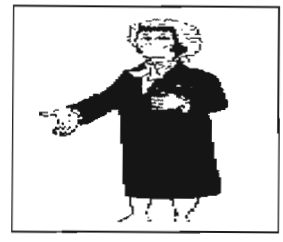
- Raise awareness of the Human Immunodeficiency virus (HIV) and the Acquired Immunodeficiency Syndrome (Aids) and Sexually Transmitted Diseases (STDs).
- Ensure a better understanding of HIV and Aids in the workplace.
- Seek to minimize the socio-economic and developmental effect HIV and Aids has on the Department, its employees, and their next of kin.
- Prohibit unfair discrimination on the basis of HIV and Aids status;
- Provide a comprehensive programme to improve health and safety at work and not deal with HIV and Aids as isolated issues for employees living with HIV and Aids.
- Provide voluntary counselling and testing programmes either as an on-site service or as a referral to a service in the community.
- Ensure the provision of free condoms and health education lessons on HIV and Aids and STDs.
- Minimum standards for the departmental HIV and Aids programme will be developed as an addendum to the policy.

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- Promote gender sensitive programmes that empower employees to be able to protect themselves from HIV and Aids.

2. PRINCIPLES

There are a number of laws and guidelines relating to people who have HIV/Aids in the workplace. The most important of these is that employees or prospective employees with HIV and Aids shall have the same rights and obligations as all other employees or prospective employees. Employees and prospective employees with HIV and Aids shall be treated in a just, humane and life-affirming manner. They cannot be treated differently to other employees by employers or by co-workers.



3. WORKPLACE POLICIES ON HIV AND AIDS

3.1 DISCLOSURE AND CONFIDENTIALITY

- Employees and prospective employees have the right to confidentiality with regard to their HIV and Aids status.
- If an employee informs an employer of his or her HIV and Aids status, this information shall not be disclosed to any other employee without that employee's written and express consent.
- A breach of confidentiality in this respect will be subject to disciplinary measures, which may include dismissal.

3.2 RECRUITMENT AND EMPLOYMENT

- A prospective employee is under no obligation to inform the workplace of his or her HIV and Aids status.
- The same legislation, regulations, codes, and policies shall govern all employees or prospective employees with HIV and Aids.
- Pre-employment testing for HIV and Aids is prohibited and will not be conducted.
- HIV and Aids status shall not be a criterion for refusing to promote, train and develop an employee.
- HIV and Aids status shall not deny an employee full participation in all the activities of a workplace.
- Employees who wish to be tested for HIV and Aids shall have access to counselling and referral to appropriate facilities.

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3.3 INJURIES ON DUTY

- All employees and in particular those employed within laboratories shall be provided with a protocol with regards to work place injuries.
- All employees injured on duty must report the incident immediately to their supervisor and must make themselves available for testing in order to be eligible to claim for compensation as a result thereof.
- All employees who are injured on duty must ensure that they are provided with the necessary documentation which must be completed as soon as possible after the incident. The completion of the documentation is to ensure that correct records are maintained of the incident, in the event of an Injury on Duty (I.O.D.) claim at a later stage.
- All employees will be provided with pre and post counselling and prophylactic treatment at the workplace's expense.
- All personnel who are injured on duty, who refuse to make them self available for testing forfeit their right to compensation.

3.4 TERMINATION OF EMPLOYMENT

- No employee shall be dismissed or have his or her employment terminated based solely on his or her HIV and Aids status.
- Should an individual be unable to continue to perform the duties for which she or he is employed, suitable alternative employment, with the relevant reduction in salary and status, if necessary, will be considered.
- The policies and procedures pertaining to termination of services on grounds of ill health that apply to all employees will also apply to employees who have HIV and Aids.
- HIV and Aids status of an employee shall not be used as a criterion to identify or influence the selection of employees for retrenchment.
- Refusal to work with an employee that has HIV and Aids shall be regarded as a breach of the employment contract.

3.5 SICK LEAVE

- Existing sick leave procedures must also apply to employees with HIV and Aids.

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3.6 RECORD KEEPING

- No flags, symbols or any other means of identification will be used on an employee's personnel or other records to indicate HIV and Aids status.
- An employee's HIV and Aids status shall not be required on any medical or personnel report.

3.7 INFORMATION

- All employees will be supplied from time to time with education and information about the modes of transmission of HIV, the means of preventing such transmission, the need for counseling and care, and the social impact of infection on those who are infected by HIV and Aids, and those who are affected by HIV and Aids.

3.8 DISPUTE RESOLUTION

- Any dispute between the workplace and an employee in relation to or arising from the interpretation of this policy shall be subject to a process of conciliation.
- Where the alleged dispute remains unresolved, it will be referred for arbitration.

4. RESPONSIBILITIES

- All employees shall be held responsible and accountable for complying with this policy.
- All managers must ensure that all members of staff are aware of and understand the content of the Workplace Policy on HIV and Aids.
- All managers are responsible for implementing this policy, ensuring compliance with and knowledge of its terms, and for taking immediate and appropriate corrective action where necessary.
- All managers must ensure that every new employee receives a copy of this policy.
- All managers must open and maintain communication channels to raise awareness concerning HIV and Aids.

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5. HIV/AIDS AND LAW

HIV and Aids affects millions of South Africans from all walks of life, including the workplace where of life, including the workplace where it is estimated that about 30% of the country's workforce will be HIV-positive. For this reason, there are a number of laws to protect people with HIV/Aids, the most important being that a HIV positive employee has the same rights and duties as other employees. The following Labour laws ensure that HIV-positive workers in all sectors are protected against discrimination in the workplace (Aids Law Project, 2005).

- **The Employment Equity Act, No. 55 of 1998** states that you cannot be asked to take a HIV test at work or when applying for a job unless specific permission has been granted to your employer by the Labour Court. This Act was the first law to state that employers may not unfairly discriminate against employees because of their HIV status. The unfair discrimination may involve using HIV status to demote or not promote the employee; block the employee from access to training and development; make an unfair distribution of employee benefits to the employee.

- **The Labour Relations Act, No. 66 of 1995** states that you cannot be dismissed because of HIV infection. The Act specifies the fair procedures to be followed when people living with HIV and Aids can no longer do their work, including changing the nature of their work.

- **The Occupational Health and Safety Act, No. 85 of 1993** and the **Mine Health and Safety Act 29 of 1996** both specify that employers must reduce the risk of being infected with HIV at work, especially in health care situations, in occupations where injury is common and in laboratory workers.

- **The Compensation of Occupational Injuries and Diseases Act, No. 130 of 1993** allows employees to claim compensation if they become infected with HIV because of a work-related accident.

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- **The Basic Conditions of Employment Act, No. 75 of 1997** entitles you to basic working conditions as all other employees are, including sick leave.

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CONCLUSION

HIV and Aids is a major threat to all people and businesses across the globe. Those who are not infected will be affected in some way by this pandemic. No areas of health care and counselling are emotionally easy. However HIV and Aids are especially difficult. The client's situations are complicated and often can not be fixed, but only changed a little. Social workers witness the suffering, orphaning and deaths of children. They accompany adults on a long and difficult biomedical, emotional, social and spiritual journey. The social worker's compassion and competence face repeated challenges. It is difficult not to be touched by HIV and Aids and the social worker can also become stressed and emotionally traumatised and this may result in burnout over time until the social worker is no longer able to cope.

During the termination phase of the empowerment programme the group members must be helped to become less dependent on the group and to help them to rely on their own skills and resources as well as on sources of support outside the group. The participants must also receive a chance to reflect on the aim and importance of the programme and to allow time for the expression of feelings about the programme and how this pandemic affects their own lives. The importance of self care and debriefing must also be discussed to prevent burnout.

Self care involves the mental and physical well-being of people who provide care in the community and help to relieve stress and lead a healthy lifestyle. Burnout is the result of feeling stress over a period of time. If not dealt with, this stress can combine to impact negatively on a social worker's mental or physical health; damage his or her relationships; and ultimately, his or her ability to care for people living with HIV and Aids. Social workers can take care of themselves by paying attention to them self. Self care strategies for preventing and reducing burnout are:

- If you are feeling stressed and unable to cope seek professional help.
- Talk to Life Line or Aids Line (Life Line 0861 322 322 or Aids Helpline 0800-012-322).

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- Educate yourself (understanding HIV and AIDS).
- Getting self-help by reading books on coping.
- Keep a daily journal.
- Discuss problems and feelings with a friend or join a support group.
- Debrief by discussing care-related problems with a supervisor or other colleagues as they occur.
- Make use of your spiritual support system.
- Engage in recreational activities outside of work.
- Learn relaxation techniques.
- Maintain for good health.
- Get rest or go for a walk to clear your head or read a good book.

Now that the participating social work students are equipped with strategies for self care, it is important that they share these strategies with the primary caregivers of their clients and clients themselves. By assisting clients and families to reduce stress, social workers may find that the level of stress they experience from caring activities also reduces.

To close the programme a brief ceremony with the hand out of certificates and refreshments are an important reward to appreciate and recognise the enormous willingness and important service the participants provides in the community.

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6. DISCUSSION

TABLE 6.1: DISCUSSION ON THE DIFFERENCES BETWEEN REDS AND THE HIV AND AIDS EMPOWERMENT PROGRAMME

REDS PROGRAMME	HIV AND AIDS EMPOWERMENT PROGRAMME
SESSION 1: INTRODUCTION	**SESSION 1: INTRODUCTION**
During the introduction session the purpose and expectations of REds were discussed. The impact of the pandemic was explored. The concepts infected and affected were explored and the key word support was defined. The ethical clarification of the study was done, as well as the pre-test, before the programme was presented. To conclude the session the participants reflected on the improvement of the session.	During the introduction session the facilitator discussed the purpose of the research and explained the course of the programme. The pre-assessment was completed and the participants' expectations of this programme were clarified. The group rules of the workshop were determined and the ethical clarification of this study was done. The participants were introduced to the HIV and Aids empowerment programme and toolkit. To conclude the session the participants gave feedback on how to improve this session.
SESSION 2: HIV/AIDS MANUAL FOR EDUCATORS (Part 1): Facts about HIV and Aids	**SESSION 2: HIV/AIDS : A NEW CHALLENGE**
During Session 2 the facts on HIV and Aids (HIV transmission) were discussed, as well as myths surrounding HIV, preventing HIV transmission at home and the phases of HIV infection. The session was concluded with an evaluation to improve this session. The participants advised that information on HIV-testing is important and must be included. This	The empowerment programme focused on the enhancement of knowledge of the participants. During Session 2 the correct facts on HIV and Aids were explored, the following information was included: • The history of HIV and Aids. • The facts of HIV and Aids. • The transmission of HIV.

information was added as session 3 in the empowerment programme. The participants also evaluated a lack of information on how to communicate sexuality to children, at different developmental stages, and how to explain the transmission of HIV. This aspect was added as Session 6 in the empowerment programme.	• The stages of HIV infection and the timeline of Aids. • The prevention of the spreading of HIV and reasons why it is still spreading, such as stigma, discrimination, poverty, inequality, myths and gender. The session was concluded with an evaluation to improve this session.
SESSION 3: HOW TO GIVE AND GAIN SUPPORT	**SESSION 3: HIV-TESTING**
Session 3 focused on the importance of support, the information on where to get support for ill loved ones, for orphans and vulnerable children. Grief and bereavement skills to support grieving learners/colleagues were also given to the educators that participated in this study. Information was also given on some activities for grieving learners and guidelines to cope with grieving learners in classroom. Death was explored to improve the participant's skills to assist others who are grieving. The participants evaluated that more time must be spent on learning grief and bereavement skills, as well as aids and practical information to explain to children the concept of death and to assist them in the grieving process. The educators also advised that a social worker assists learners with grief and bereavement, because of their specialised training.	Session 3 of the empowerment programme focused on providing knowledge on HIV-testing, different types of HIV-tests, pre-post-test counselling and starting anti-retroviral treatment. The addition of this information was necessary to complete the information on HIV and Aids and make sure that people understand the importance of being tested and to start with medication. One of the roles of a social worker is to support people when being tested and to explain the complicated medication regime to ensure successful medication compliance. The session was concluded with an evaluation to improve this session.

SESSION 4: HIV/AIDS MANUAL FOR EDUCATORS (Part 2-4): Health Care	SESSION 4: LIVE A LONGER, HEALTHIER LIFE WITH HIV-"A Wellness Programme"
This session focused on how to care for the sick at home, how to care for the dying and managing Aids-related problems at home. The participants evaluated a lack of information on how to communicate to children, at different developmental stages, the process of dying as well as disclosure of HIV-positive status to their children. These aspects were also included in the empowerment programme in Session 5 and 6.	The advances in medical treatment of HIV and Aids result in individuals who live longer. The shift in incidence of the disease requires that all social workers possess specialised skills, knowledge and appropriate beliefs that promote the well-being of individuals affected with HIV and Aids. Session 4 was included in the empowerment programme and focused on a wellness programme to enhance the immune system of the person living with HIV and Aids. This programme included information on physical wellness - health and nutrition-, psychological wellness, social wellness, spiritual wellness skills and techniques in stress reduction and coping with stigma. This session was not presented as a wellness programme in REds, but the holistic approached was evaluated as necessary information and was presented as such in the empowerment programme. The session was concluded with an evaluation by the participants to improve this session.
SESSION 5: HOW TO COPE WITH STIGMA	**SESSION 5: HOW TO CARE FOR AND GIVE SUPPORT TO LOVED ONES WHO ARE ILL**
Session 5 focuses on the concept stigma. Information on the values that can prevent stigma in a school/community, ideas for	Session 5 focuses on identifying different sources of support in the community and the importance of support to manage the pandemic

combating stigma and strategies for coping with stigma were discussed. The session was concluded with an evaluation to improve this session. Information in this session was adapted and forms part of Session 4 of the wellness programme of the empowerment programme.	effectively. Information on how to care for a person who is ill, what family members can do in managing health problems at home and prevention of opportunistic infections at home, were discussed. The session was adopted from REds. This session concluded with an evaluation by the participants to improve this session.
SESSION 6: WORKPLACE POLICIES	**SESSION 6: CARING FOR CHILDREN IN THE FACE OF HIV/AIDS**
Session 6 discussed the rights of educators with regard to discrimination, absenteeism and leave. Information on protection against HIV at schools and understanding the concept of a supportive school environment were also discussed as part of this session. The session was concluded with an evaluation to improve this session. The information on this session was adapted to include the rights of any person within a working environment, regarding HIV and Aids in the empowerment programme.	Session 6 was included in the empowerment programme to empower parents and those caring for vulnerable children with information to care for children in the face of HIV and Aids. The information included is ways to communicate with children at different developmental stages about sexuality education, about HIV and Aids, the prevention of the spreading of HIV and coping when parents are HIV-positive. Caring for children "in need" was also discussed with the focus on children's rights, children's needs, the circle of support model, caring for children who are HIV-positive and keeping children in school as well as different government grants for children. This session included aids, such as posters, pamphlets and colouring-in books to explain the different topics in a language understandable to a child. The session was concluded with an evaluation by the participants to improve this session.

SESSION 7: HOW TO COPE WITH STRESS	SESSION 7: CARE FOR THE DYING
Session 7 focused on steps to manage stress, including stress identification and stress management. Information on how to combat work stress was also explained. The session was concluded with an evaluation to improve this session. The information from this session forms part of the wellness programme discussed as Session 4 of the empowerment programme.	Session 7 was included in the empowerment programme to empower parents, family members and children on how to care for people dying. Information included is discussions on feelings associated with a terminal illness, discussions on how a person can prepare for death, the grieving process of the family of the terminally ill person, grief and bereavement skills when helping children cope with death. This session included aids such as posters, pamphlets and colouring-in books and working through grief books, to explain the different topics in a language understandable for a child. Although REds provides information on grief and bereavement, it was evaluated as not sufficient. Session 7 of the empowerment programme included more information as well as aids that are age appropriate. The session was concluded with an evaluation by the participants to improve this session.
SESSION 8: RESILIENT IN A PANDEMIC	**SESSION 8: RIGHTS OF AN HIV-INFECTED PERSON AND WORKPLACE POLICIES ON HIV AND AIDS**
Session 8 served as a summary of REds. The steps to be resilience in the face of the HIV pandemic were discussed as well as the participants' experience of resilience. This session also served as a debriefing for the	The empowerment programme in Session 8 focused on the role the social worker has to play in providing information on workplace policies to any person infected with HIV and Aids. REds focused only on the educator and

participants with the conclusion of this programme. The session was concluded with an evaluation to improve this session.	workplace policies of an educator. The session was concluded with an evaluation to improve this session.
SESSION 9: CONCLUSION	**SESSION 9: CONCLUSION**
During the concluding session, attendance certificates were handed out and the post-test was scheduled. The session was concluded with an evaluation by the participants, to improve this session.	Session 9 focused on closure and debriefing after completion of the empowerment programme. The post-test was also completed and the participants received attendance certificates. The session was concluded with an evaluation by the participants, to improve this session.

6.1 CONCLUSION OF THE PROGRAMME

The two programmes in this study are different. REds focuses on the affected educator. The aim of the information in REds was to support the educator to become more resilient in the face of the pandemic and to learn coping skills to cope with the pandemic within the classroom. The focus of the empowerment programme is to provide the social work student with information to empower people infected with HIV and those affected by Aids with knowledge and skills to cope with the pandemic. The information in the empowerment programme was presented as a practical toolkit that can be presented to any individual, group or community in different developmental stages. Extra information included in the empowerment programme that was not in REds was the history of HIV and Aids, myths about HIV and why the pandemic is still spreading, information in HIV-testing and the use of antiretroviral medication, the introduction of a wellness programme and how to communicate to children about sexuality, HIV and Aids, death and grief and bereavement. The session on 'care for the dying' was discussed in detail, to prepare family members and children on this drastic phase of this pandemic and to make permanency planning for the children left vulnerable by this disease. The circle of support model was introduced as well as different government grants available to care for children.

7. CONCLUSION

This chapter provided the newly developed and adapted empowerment programme for the fourth year social work students regarding HIV and Aids. Each session was discussed as well as the activities of each session.

The following chapter provides an overview of the process of the implementation and evaluation of the empowerment programme. As such it contained the research model and different phases of the research process. The results will be discussed according to the pre-test data analysis, as well as the post-test data analysis, consisting of qualitative and quantitative data. Recommendations for the adaptation of the empowerment programme made by participants will also be discussed.

CHAPTER 7

EVALUATING THE EFFECTIVENESS OF THE HIV AND AIDS SOCIAL WORK EMPOWERMENT PROGRAMME FOR STUDENTS

1. INTRODUCTION

HIV and Aids present a significant problem on both societal and professional levels for social workers. Individuals who are affected by HIV or Aids have needs that may require a multitude of services including counselling, social services (Wexler, 1989) and, according to Wiener & Siegel (1990), advocacy, community outreach and case management. On a broader level, there is a need for preventative programming, empowerment, education and policy making. Social work, a profession that is recognised for supporting disadvantaged and those who are discriminated against by the larger society, has a significant role to perform in meeting the needs of individuals affected by HIV or Aids. The skills that social workers perform in integrating people with larger systems, their focus on context and environment evolving from work with historically marginalised groups and their commitment to human rights and fairness are critical to addressing the issues surrounding HIV and Aids.

Having well-trained, knowledgeable and highly motivated professionals working in service delivery at all levels is crucial for effective management of the HIV epidemic. Families living with HIV and Aids desperately need access to reliable, accessible and affordable treatment and care. This treatment includes resources for emotional, financial and social aspects. Given that HIV and Aids impact on every aspect of human existence it, therefore, demands the involvement of professionals such as social workers to provide care for the infected and affected. Aids is a social problem that potentially affects everyone; unless one can help society in general to come to terms with the real plight and moral dilemma facing HIV patients, then all are at risk. A continuum of care and support must be developed and provided to those infected and affected by the pandemic.

An empowerment programme was designed to increase understanding of how to prepare students best for their professional roles in dealing with a multi-faceted problem such as HIV and Aids. In order to assist the social work student with accurate and vital information, an empowerment tool kit was designed to address the issue of HIV and Aids. This empowerment programme focuses on various angles: political, economical, health, social and community consequences, family and personal prevention or treatment. The programme comprises of an HIV and Aids informative manual, posters, booklets, different resource instruments suitable for children's developmental stages, a workbook for grieving children and stress relaxation aids. This programme was developed to assist the social work student to empower any individual or group infected with HIV and affected by Aids. The newly developed and adapted HIV and Aids empowerment programme for social work students was presented to 11 fourth year social work students. The single-system and face-to-face interviewing were used to measure the effect of the HIV and Aids empowerment programme on the students' knowledge, beliefs and attitudes.

2. PROBLEM STATEMENT

In a study done by Wexler (1989:147) it was found that social work students, respondents in the study, held appropriate beliefs and attitudes towards HIV and Aids, however, they lacked specific knowledge of the disease that was weakly and positively correlated with students' attitudes toward the disease. Deficits in knowledge of the disease consisted of how the disease has impacted minorities and drug populations. Wexler concluded that social work curricula regarding Aids should focus on instilling the knowledge and techniques that will allow students to act in ways consistent with the profession's values. Peterson's (1992) study assessed the knowledge of the National Association of Social Workers (NASW) members, which identified specific areas of understanding and deficits in knowledge of the disease. The social workers in this sample were knowledgeable about transmission of the virus and were less knowledgeable about how the epidemic has impacted specific sub-populations. Peterson identified the lack of difference in knowledge on minority issues between the respondents who had either personal or

professional reasons for being informed about the disease and those who did not, as a concern. Shi, Samuels, Richter, Stoskopf, Baker and Sy (1993) also reported in their study that specific understanding of the disease was needed for the ethnic and cultural differences among people with the disease. They concluded that greater understanding of counselling terminally ill patients, women, children, intra-venous drug users and gay clients and the resources available to these clients were needed.

The literature on HIV and Aids reveals that it is a disease surrounded by stigmatisation and discrimination on social, political, personal and professional levels. Although much has been discovered and learned about this disease, deficits in knowledge and preparation to work with these clients exist. HIV and Aids requires specialised skills, knowledge and awareness on the part of professionals to intervene effectively with clients, their families and the community. The advances in medical treatment of HIV and Aids also means that individuals who are sero-positive will live longer lives, increasing the need for the development of appropriate resources in the community, the provision of services such as counselling, treatment and support, and enhancing the quality of life. This leaves one with the reality of an epidemic with enormous implications. The question that arises from this is, is the newly developed empowerment programme effective enough to increase the knowledge and skills of the of the social work students to prepare them best for their professional roles in dealing with a multi-faceted problem such as HIV and Aids.

Taking the above-mentioned into consideration, the following question arises:

- Is the newly adapted and developed empowerment programme for fourth year social work students effective?

3. AIM AND OBJECTIVES

The aim of this chapter is to determine whether the evaluated HIV and Aids support programme for educators (REds) can be adapted to become an effective empowerment programme for fourth year social work students in supporting people infected/affected by the HIV and Aids pandemic.

In order to achieve this aim, the following objectives are proposed:

- To implement the newly developed and adapted empowerment programme for fourth year social work students regarding HIV and Aids.
- To evaluate the effectiveness of the newly developed and adapted social work empowerment programme for fourth year social work students, using a volunteering group of fourth year social work students.
- To make recommendations regarding the effectiveness of the empowerment programme and how it can still be improved.

4. RESEARCH METHODOLOGY

The methods used for this investigation were a literature study and an empirical investigation.

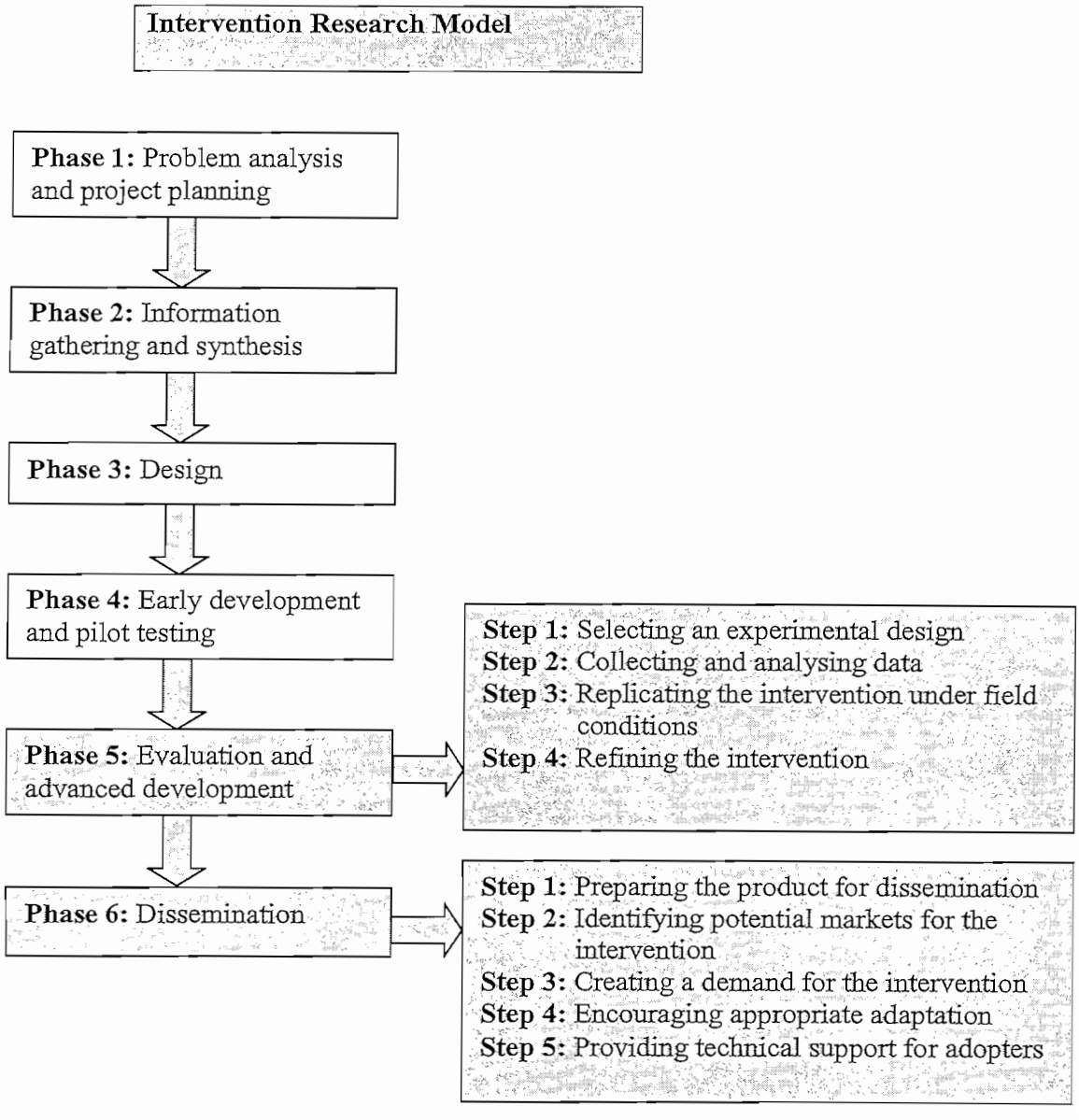
4.1 LITERATURE STUDY

The central focus of this study was to evaluate the effectiveness of a newly developed HIV and Aids empowerment programme for fourth year social work students, adapted from the REds programme. A literature study was utilised to gather more information on the subject of HIV and Aids and to analyse the problem statement. Delport (2005:171) states that, to undertake a meaningful research, the researcher should have made a thorough study of the subject under review.

4.2 EMPIRICAL INVESTIGATION

In this study the intervention research model was utilised. De Vos (2005a:394) defines it as research which is targeted to address the practice application of research. This model is a six phase model, consisting of the following phases. This chapter focuses on phases 5 and 6, the evaluation and advanced development and the dissemination of the newly developed empowerment programme for social work students, as seen in Figure 7.1.

FIGURE 7.1: INTERVENTION RESEARCH MODEL



Phase 5: Evaluation and Advanced Development

The researcher will describe the steps of Phases 5 and 6 of the model and indicate how the theory was applied in practice during each step in this research.

- **Step 1: Selecting an experimental design**

These designs help demonstrate casual relationships between the intervention and the behaviours and related conditions targeted for change. According to De Vos (2005a:403), factors such as the goals and magnitude of change sought by the target group, the types of behaviours, the desired immediacy of change and the goals of the research affect the choice of design. For this research the single system and interviewing were chosen to determine the effectiveness of the intervention. During the first and last sessions of the programme the group members were subjected to measuring by the single system and interviewing.

- **Step 2: Collecting and analysing data**

During the testing and evaluation of an intervention, data are continuously collected and analysed (De Vos, 2005a:403). Ongoing graphing of the behaviour and related outcomes helps to determine when initial interventions should be implemented and whether supplemental procedures are necessary. The effectiveness of the programme could be determined by measuring the different aspects discussed in the various sessions. Measurements were taken at the first and last sessions.

- **Step 3: Replicating the intervention under field conditions**

A primary goal of intervention research is to develop interventions that are effective in a variety of real-life contexts with those who actually experience the problem. Replication under various field conditions helps to assess the generability of the effects of the intervention. The programme was presented to a group of fourth year social work students from the North-West University, Potchefstroom campus.

- **Step 4: Refining the intervention**

Errors are instructive: the results of full field testing are used to resolve problems with the measurement system and intervention (De Vos, 2005a:404). Adaptations to the language, content and intervention methods may produce desired behaviour changes and outcomes for the full range of intended beneficiaries. The recommendations and feedback from the social work students that participated in this programme were recorded to make the necessary adaptations to refine the programme.

Phase 6: Dissemination

- **Step 1: Preparing the product for dissemination**

A brand name helps differentiate a certain intervention from other similar ones at the point of adoption and while in use. Adopters come to recognise brand names from community interventions; they associate the name with certain values such as effectiveness, dependability or efficiency. By establishing guidelines for using community interventions correctly, researchers provide the basis for maintaining the integrity of the product (De Vos, 2005a:405). The programme is ready for dissemination. The standards for use of the programme will be maintained by insisting that users be trained before the programme can be implemented. Programme material such as the manual, posters and aids in the toolkit will only be issued to users that receive training.

- **Step 2: Identifying potential markets for the intervention**

In defining a market of potential adopters for a community intervention, researchers should ask certain questions, such as: Which people could benefit from the intervention? Which media approach would be most suitable? Which market segment would most likely adopt the intervention? (Fawcett *et al.*, 1994:41). The empowerment programme can be used by other social work practitioners and social support structures or it can be used for the educational preparation of social work students.

- **Step 3: Creating a demand for the intervention**

Disseminators must convince potential purchasers that they will benefit from the intervention (De Vos, 2005a:406). This programme has been tested thus it can be used in practice. The participants in this research received training as well as a manual and programme material after the completion of the presentation. The participants were encouraged to use this programme when they start working as social workers.

- **Step 4: Encouraging appropriate adaptation**

Certain elements of interventions, such as content and format of an educational programme, may be modified or deleted and new elements may be added. Adopters may modify the original intervention to fit local conditions and the specific target group.

- **Step 5: Providing technical support for adopters**

Adopters of the programme may require support from the researcher to assist with troubleshooting or adapting the intervention to meet their specific needs (De Vos, 2005a:406). Technical support may be critical in implementing to maintain long-term client satisfaction. The researcher will be available to assist in providing technical support if there are other adopters of the programme. The social work students were trained in the use of the empowerment programme and practical aids provided in the toolkit.

5. EVALUATION OF THE EMPOWERMENT PROGRAMME

Evaluation is a collection of activities designed to determine the value or worth of a specific programme, intervention or project. That means being able to link a particular outcome directly to a particular intervention. Evaluation is the observation of objects or events according to certain rules. The observations are being recorded in numerals and complex facts are being transferred into manageable simplicity. The evaluation or

measuring process involves the assessment of the programme content, scope or coverage, together with the quality and integrity of implementation. Outcome evaluation is benefits of changes for individuals or populations during or after participating in programme activities. Outcomes may relate to behaviour, skills, knowledge, attitudes, values or other attributes. These are different ways in which the participants know, think, act or behave, or their different condition following the programme (Ginsberg, 2001:222).

The HIV and Aids empowerment programme was presented to 11 fourth-year volunteering social work students from the North-West University, Potchefstroom Campus, after completing their block placements for the study year 2008. The participants were both male and female students who will be working with people infected and affected with HIV and Aids. The programme consisted of 9 sessions and was presented in a workshop course over 3 days. The aim of these group work sessions was to evaluate this programme as an effective HIV and Aids empowerment tool for fourth-year social work students using both quantitative and qualitative measuring instruments, however, the main focus in this research was on the qualitative data.

6. RESULTS OF THE QUANTITATIVE MEASURES

The quantitative measures, the Professional Quality of Life screening (ProQOL) and the short form Affectometer 2 questionnaire (AFM) were used to investigate the effectiveness of the empowerment programme regarding HIV and Aids.

6.1. PROFESSIONAL QUALITY OF LIFE SCREENING (ProQOL)

One of the quantitative measuring instruments used for the pre-assessment and post-assessment for this study was The Professional Quality of Life Screening (ProQOL) Questionnaire, (Stamm, 2005) (Addendum 4.1), as used in Chapter 4. The ProQOL is a standardised scale that can be used when helping people. Helping people puts you in direct contact with those people's lives. The compassion for those you help has positive and negatives aspects. This instrument measures the professional quality of life among

staff of organisations such as government social workers, general health workers or educators (Stamm, 2005:9). The questionnaire consists of 30 questions/items and is composed of three sub-scales which determine the following:

- Compassion satisfaction (CS).
- Burnout (BO).
- Compassion fatigue or Secondary Trauma (T).

Compassion satisfaction entails the pleasure one obtains from being able to do one's work successfully (Stamm, 2005:5). When one finds delight in one's work and experience positive feelings towards colleagues, one will have a high score in this section. The items in this sub-scale: 3, 6, 12, 16, 18, 20, 22, 24, 27, 30.

Burnout is associated with feelings of hopelessness and complications when performing work (Stamm, 2005:5). Aspects such as an ever increasing workload or non-supportive work environment can cause burnout. The items in this sub-scale: 1, 4, 8, 10, 15, 17, 19, 21, 26, 29.

Compassion fatigue or secondary trauma entails exposure to work-related stressful situations (Stamm, 2005:5). When one experiences sleeplessness or fear regarding one's work, one might be exposed to compassion fatigue. The items in this sub-scale: 2, 5, 7, 9, 11, 13, 14, 23, 25, 28.

The questionnaire consists of 30 items which the respondents had to answer by making use of a scale according to the following categories:

- Never.
- Not often.
- Quite often.
- Often.
- Very often.

When scoring the ProQOL, the scores of some items need to be reversed. These 5 items are: 1, 4, 15, 17 and 29. The quantitative data generated were analysed by means of descriptive data analysis, according to the specifications of the ProQOL.

6.1.1 Reliability and validity

The reliability of a test refers to the consistency of scores obtained by the same persons when they are re-examined with the same test on different occasions, or with different sets of equivalent items, or under other variable examining conditions. The validity of a test concerns what the test measures and how well it does so (Anastasi & Urbina, 1997: 84, 113).

Reliability and validity could not have been assured statistically in this study population, as a result of the fact that there were only 11 participants, but the literature reported reliability. Stamm (2005:7) reported the following on alpha reliability for the subscales: The alpha reliability for Compassion satisfaction is 0.87. Compassion satisfaction is about the pleasure one derives from being able to do one's work well. For example, one may feel like it is a pleasure to help others through one's work. One may feel positive about colleagues or ability to contribute to the work setting or even the greater good of society. Higher scores on this scale represent a greater satisfaction relating to ability to be an effective caregiver in the job. The alpha reliability for Burnout is 0.72. Burnout from a research perspective is associated with feelings of hopelessness and difficulties in dealing with work or in doing a job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that one's efforts make no difference, or they can be associated with a very high workload or a non-supportive work environment. Higher scores on this scale mean that one is at higher risk for burnout. The alpha reliability for Compassion fatigue (CF), also called secondary trauma (STS) is 0.80. Compassion fatigue is work-related, secondary exposure to extremely stressful events. If one is exposed to others traumatic events as a result of one's work, such as in an emergency room or working with child protective services, this is secondary exposure.

6.1.2 Statistical procedures

The statistical significance of results in research is not only important when results are reported but to comment on the practical significance of a statistically significant result (Ellis & Steyn, 2003:51-54). Ellis and Steyn (2003:51-53) further explain that statistical inference draws conclusions concerning the population from which a sample was drawn by using descriptive measures that have been calculated. Instead of only reporting descriptive statistics, effect sizes can be determined. Practical significance can be understood as a large enough difference to have an effect in practice. It is important to remember that the effect size is independent of the sample size used in the study and is a measure of practical significance. As a result of the fact that in this study no random sampling was done, interpretation of the results was done by calculating effect sizes. Pre-test results for each participant were subtracted from the post-test results for each participant to test if the mean of the differences were zero. Cohen's effect size for differences between means of dependent groups was calculated according to the following formula:

$$d = \frac{\text{mean of difference}}{\text{Standard deviance of difference}}$$

According to Cohen (1988:567), guidelines of effect sizes for differences between means are as follows:

- d = 0.2 a small effect
- d = 0.5 a medium effect
- d $\geq$0.8 a large effect and also practical significant.

6.1.3 Results of the ProQOL Questionnaire

The following are the results of the pre-post assessment done on the HIV and Aids empowerment programme for social work students that was implemented during October 2008. The results are given in Table 7.1.

TABLE 7.1: RESULTS OF THE ProQOL

Subscales	N	Mean difference	Standard difference	Mean before	Standard before	Mean after	Standard after	d-value
Compassion Satisfaction	11	0.54	2.94	35.36	3.95	35.90	4.80	0.18
Burnout	11	-1.23	1.37	9.36	3.44	8.13	4.23	0.81*
Compassion Fatigue/ Trauma	11	-1.18	3.57	12.81	3.68	11.63	4.45	0.33

* Practically significant

- **Subscale: Compassion satisfaction**

Non-practical significant difference was found between the pre-test and post-test scores for this group. Thus the programme did not have an effect on the participant's compassion satisfaction subscale, which means that participants experienced job satisfaction. The participants in this study were more positively disposed to their profession and the empowerment programme did not succeed in elevating compassion satisfaction beyond the original average levels measured.

- **Subscale: Burnout**

A practical significant difference was found between the pre-test and post-test scores for this group. Thus the programme did reduce burnout that the participants experienced before the programme was presented. After the programme was presented the participants felt more empowered to deal with the problems regarding the HIV and Aids pandemic. They also experienced more positive feelings about their effectiveness in the work environment.

- **Subscale: compassion fatigue/trauma**

The exposure to stressful situations which are work-related, such as exposure to other people's trauma (being affected by HIV and Aids or witnessing children orphaned and left vulnerable due to HIV and Aids) could cause secondary trauma or compassion fatigue. Non-practical significant difference was found between the pre-test and post-test scores for this group with regard to the subscale compassion fatigue. Thus the programme did not have an effect on the participants' compassion fatigue/trauma. The researcher reasoned that the participants were students and not yet exposed to the compassion fatigue/trauma that is sometimes synonym with social work in practice.

6.2 THE SHORT FORM AFFECTOMETER 2 QUESTIONNAIRE (AFM)

6.2.1 Rationale

The short form Affectometer 2 questionnaire (AFM) (Addendum 7.1) is an inventory designed to measure general happiness or a general sense of well-being based on measuring the balance of positive and negative feelings experienced recently. Psychological well-being is measured on an affective or emotional level. The overall level of well-being is conceptualized as the extent to which positive feelings predominate over negative feelings (Kammann & Flett, 1983).

6.2.2 Nature, administration and interpretation

Two equivalent editions of the AFM exist: the 20-sentence item scale and the 20-adjective item scale edition (Kammann & Flett, 1983). In this investigation the 20-sentence item scale edition will be used. The AFM can be utilized on individuals or on groups. The instructions are easily understood and the scale takes approximately five minutes to complete. The scale is composed of sentences to which the respondent must indicate on a five point scale how often he/she has experienced the indicated experience over the past few weeks:

1. Not at all.
2. Occasionally.
3. Some of the time.
4. Often.
5. All the time.

This time frame reflects a compromise between measuring the sense of well-being in its most global meaning and the choice of a time period amendable to reasonably accurate recall (Kammann & Flett, 1983).

Ten items measure positive affect (PA) and ten items measure negative affect (NA). To score the scale, the total scores are computed for the sub-scales (PA & NA) as well as the score for the positive-negative affect balance (PA-NA=PNB). A high total score indicates positive affective well-being and a low total or negative total score indicates a predominated negative affective well-being.

6.2.3 Reliability and validity

Reliability and validity could not been assured statistically in this research as a result of the fact that there were only 11 participants in this study, but other research studies done in South Africa did report reliability.

Kammann and Flett (1983) report high reliability and validity indices for the AFM. According to these researchers, a Cronbach alpha index of 0.95 is obtained. In an investigation done on a South African population, Wissing and Van Eeden (1994) report the following Cronbach alpha indices for the different sub-scales PA: 0.86, NA: 0.90, and PNB: 0.92.

6.2.4 Motivation for the selection of the AFM

Affect balance is one of the main constructs in the conceptualisation of the affective component of psychological well-being. It was selected because it measures affect balance reliably and validly. According to Wissing and Van Eeden (1994), the positive

and negative affect are important indicators of a person's general life orientation and psychological well-being.

6.2.5 Statistical procedures

The statistical significance of results in research is not only important when results are reported but also to comment on the practical significance of a statistically significant result (Ellis & Steyn, 2003:51-54). Practical significance can be understood as a large enough difference to have an effect in practice. As a result of the fact that in this study no random sampling was done, interpretation of the results was done by calculating effect sizes. Pre-test results for each participant were subtracted from the post-test results for each participant to test if the mean of the differences were zero. According to Cohen (1988:567), guidelines of effect sizes for differences between means are as follows:

- d = 0.2 a small effect
- d = 0.5 a medium effect
- d $\geq$0.8 a large effect and also practical significant.

The following are the results of the pre-post assessment of the Affectometer done on the HIV and Aids empowerment programme for social work students implemented during October 2008. To measure the sustainability of this empowerment programme, the participating students were asked to complete the Short Form Affectometer 2 (AFM) (Kammann & Flett, 1983) Questionnaire, 3 months after the programme was presented. Only 10 participants completed the Affectometer questionnaire after 3 months, one participant did not complete the questionnaire. The results are given in Table 7.2.

TABLE 7.2: RESULTS OF THE AFFECTOMETER

Subscales	N	Mean difference	Standard difference	Mean before	Standard before	Mean after	Standard after	d-value
Affect positive	10	0.10	2.80	42.36	3.41	42.40	2.98	0.03
Affect negative	10	-0.50	2.01	14.90	3.80	14.20	3.88	0.24
Affect balance	10	0.60	3.77	27.45	6.68	28.20	6.51	0.15

6.2.6 Interpretation of the results

For this group the quantitative results show non-practical significant difference between the pre-test and post-test scores. Thus the programme did not have an effect on the participants' psychological well-being. Reasons for non-practical significant difference can be that the participants have no work experience in this professional field with the emotional and psychological issues related to living with HIV and Aids and affecting their emotional well-being. Participants indicated that the empowerment programme raised their interest to read and learn more about HIV and Aids. Furthermore, the participants possess values that are founded on the precepts of humanitarianism.

Rosenthal, Rosnow and Rubin (2000:5) came to the conclusion that when "we are confronted with a 'non-significant' *p* and a 'large' effect size, we were to conclude on the basis of the significance level that 'nothing happened', we might be making a serious mistake. A small sample size may have led to failure to detect the true effect, in which case, we should continue this line of investigation with a larger sample size".

6.3 CONCLUSION

The ProQOL questionnaire showed a non-practical significant difference between the pre-test and post-test scores for the subscales compassion satisfaction and compassion fatigue for this group. However, a practical significant difference was found between the pre-test and post-test scores for the subscale burnout. Thus the programme did reduce burnout that the participants experienced before the programme was presented. After the programme was presented the participants felt more empowered to deal with the problems regarding the HIV and Aids pandemic. The quantitative results of the Affectometer show a non-practical significant difference between the pre-test and post-test scores. Thus the programme did not have an effect on the participants' psychological well-being. Reasons for non-practical significant difference can be that the participants have no work experience in this professional field with the emotional and psychological issues related to living with HIV and Aids and affecting their emotional well-being.

7. RESULTS OF THE QUALITATIVE MEASURING INSTRUMENTS

Qualitative measuring was used to evaluate the effectiveness of the empowerment programme. The measuring instruments used were the participant reflections and feedback on each session of the programme regarding the knowledge, attitudes and skills that the students gained; the efficacy of the programme as an empowering tool; the pre-post symbolic drawings that assessed the impact of the pandemic on the participants; completion of a self-formulated questionnaire in the pre-test and post-test that afforded the participants the opportunity to express their views on the issues being investigated; and semi-structured interviews post-test gave the participants the opportunity to express their views on the perceived efficacy of the programme as an empowering tool; as well as the facilitator's reflections, observations and process notes concerning HIV and Aids and related matters before and after the implementation of the programme.

7.1 PARTICIPANT'S FEEDBACK AFTER EACH SESSION OF THE EMPOWERMENT PROGRAMME

The HIV and Aids empowerment programme consists of 9 sessions and was presented in a 3 day workshop. To be optimally effective as a resource, the empowerment programme needed to be refined by the process of participatory reflection. After each module was implemented, the participating fourth-year social work students were asked to comment on the efficacy of each module so that the programme could be improved.

The participants completed a reflection worksheet regarding elements of each session that the participants found particularly helpful, elements participants experienced as not helpful at all and components the participants would like to change or add to the session. The information gained was analysed and suggestions for further research were made as in Table 7.3.

TABLE 7.3: EVALUATION OF EACH SESSION OF THE EMPOWERMENT PROGRAMME

SESSION 1: INTRODUCTION OF THE EMPOWERMENT PROGRAMME
• Session 1 was primarily an introductory session where the purpose of the research and course of the programme were explained to the participants, the group rules of the workshop were established as well as the ethical clarification. In this session the focus was on discussing the importance of the social workers' role in this pandemic. Having well-trained, knowledgeable and highly motivated professionals working in service delivery is crucial for effective management of the HIV epidemic. The social work students could identify with this and a need was established to attend this workshop. In this session the students completed the ProQOL and Affectometer as well as the qualitative measuring instrument as pre-assessment and this resulted in introspection on how they really felt towards HIV and Aids.
• The participants were introduced to the newly developed empowerment programme. The programme was designed to provide information, to empower and to counsel to empower the HIV and Aids infected and affected to manage their own health.

Everyone is in charge of their own body and, therefore, responsible for their own health – body, mind, soul. The sick person and the family have to maintain responsibility for giving care at home. Today there is a wealth of information about HIV and Aids and the subject can be discussed from various angles: political, economical, health, social and community consequences, family and personal prevention or treatment. In order to assist the social work student to empower their clients with accurate and vital information, a practical toolkit was designed and presented to address the issue of HIV and Aids.

- All the participants completed the consent form (Addendum 2.3), as used in Chapter 2. Everyone understood the importance of the role of the social worker and the need for well-trained, knowledgeable and highly motivated professionals. Some participants did their block placements for the study year 2008 at organisations and worked with HIV infected and affected people. They reported that they did not have hands on skills or experience. Each participant received a toolkit (Addendum 7.2) that comprises of an HIV and Aids manual, posters, Soul City booklets, resource information for children (different ages), colouring-in books, play cards and pamphlets, a workbook for grieving children and a relaxation exercise CD. All the participants remarked positively on the toolkit and practical material they received and could use when presenting a preventative group or counselling session to an individual, family or group.

SESSION 2: HIV AND AIDS: A NEW CHALLENGE

Session 2 was presented by Life Line and the aim was to enable the participants to gain the correct information on HIV and Aids and to empower the participants regarding the different facets of the HIV infection and on reasons why the disease is still spreading. This session explored the facts of HIV and Aids and the participants gained information on how to explain to other people the history and facts of HIV and Aids, the transmission, stages, the prevention and myths about HIV. The participants also received information on how to prevent HIV and how to explain to community members the correct use of a condom. This information can be very sensitive and social workers sometimes avoid

talking about this preventative measure when they did not feel confident enough.

The HIV and Aids information presented was helpful to obtain the correct facts about this disease. Information new to the participants was information on sex and sexuality, understanding the human body and the reproductive system, the human immune deficiency virus, the effect on the immune system, transmission of HIV and why HIV is still spreading.

In the pre-test questionnaire the participants reported that they had enough knowledge concerning the HIV and Aids virus, only 2 responded that they had little knowledge and one participant felt that a person could always learn something new. In the post-test questionnaire all the participants agreed that the empowerment programme equipped them professionally enough to render a service they reported the following:

- They learned facts and gained information on how the virus works (the knowledge they previously had was a lot of assumptions).
- They gained more information through good programme media, knowledge about resources and practical information.
- Felt more empowered with techniques, information and facts to approach the community, to talk to people about HIV and Aids and also how to protect themselves.
- One participant mentioned that before the programme was presented she would not share utensils, but after the programme she realised that one cannot get HIV by sharing utensils.
- All the participants agreed that the information in this session was important and helped them personally. The material (especially the detailed manual) was also very helpful.
- They understood aspects of Aids that were previously unclear and another indicated that she gained enough confidence to have an HIV blood test.

SESSION 3: HIV-TESTING

The aim in Session 3 was to provide the participants with information on HIV testing. This session was very important because the information about different HIV tests and

when and how to use anti-retroviral medication is very complicated and sometimes difficult for clients to understand, especially if the clients are illiterate. The social worker's responsibility is to explain why it is important to go for an HIV test, where a person can be tested, what happens when a person is tested, types of HIV tests and the correct use of anti-retroviral treatment, how to manage side-effects of anti-retrovirals, testing babies for HIV, HIV and pregnancy and when Post-Exposure Prohylaxis is important.

The participants reported that this session was very informative and important, especially information on different tests, when to use medication, how to counsel a pregnant mother and the information on post-exposure prohylaxis was personally important to them. For most of the participants this information was new, informative and very important if they have to counsel a client. The participants reported that all the information in this module was important and nothing could be left out.

SESSION 4: LIVE A LONGER, HEALTHIER LIFE WITH HIV – A WELLNESS PROGRAMME

The aim of Session 4, live a longer, healthier life with HIV, was to enable participants to understand and explain the following information to other people regarding: Understanding wellness. This was explained according to a holistic approach, using the wellness model, the focus on physical wellness, psychological wellness, social wellness and spiritual wellness. After completion of this session the participants should also be knowledgeable on skills and techniques in reducing stress and coping with stigma of HIV and Aids.

The participants reported that they gained information on total care and not just physical care. The participants felt that this was a very important session, especially infection control at home. It was also important for them to know how to discard of body fluids and using universal precautions. The participants received a handmade box (a first aid kit) with cloves, condoms, a plastic bag to discard any material with body fluids, hand liquid soap, a bandage and plaster to cover open wounds, a guide on correct hand washing techniques and an information book on basic health information. The participants also received play cards for toddlers to convey the importance of washing

hands, not to touch blood and other basic information. The participants found these tools very helpful practical information.

Another important section of this session was the information given on how to cope with stigma. Stigma is a reality and the reason why people did not disclose their status. Pictures and exercises were used to explain stigma to the participants. This session gave practical advice on how to handle this problem. The participants felt it helped them to share their feelings with the group, because they felt hopeless and then realised that there were others that felt the same. Nine of the participants found that the part on coping with stress very helpful, how to identify your stressors, relaxation techniques, and how to cope with the grieving process. Only two participants felt that this part could be left out of the programme. The quantitative measurement reported a significant difference between the reduction in stress levels before the programme and after this programme was implemented.

SESSION 5: HOW TO CARE FOR AND GIVE SUPPORT TO LOVED ONES WHO ARE ILL

Session 5 focused on how to care and give support to ill loved ones. The objectives of this session were to identify different sources of support in the community, how family members can care for people that are ill, managing Aids-related health problems at home and prevention of opportunistic infections.

This session started with an ice breaker. The participants were divided into 3 groups (with 2, 3, 6 participants in the different groups). One person in the group had to be lifted and carried around for a few minutes. The group with 6 participants could easily carry one member around for a very long time. This demonstrated that when there were more people in an ill person's support system, a better service could be delivered to take care of that person and family with less strain on the support system.

Secondly, different sources of support in the community were explored. Thirdly, a nursing sister presented the section on caring for ill persons using case studies. The participants were asked to identify the needs of an infected and affected family and solutions were discussed. Information on managing Aids-related health problems at home were also discussed including precaution measures if one is caring for a person living

with HIV and Aids as well as the prevention of opportunistic infections.

The participants evaluated the following as helpful in this session:

- The ice breaker that was used helped to understand support and trust.
- All the information regarding supportive resources, how to assist and care for persons who were ill, was helpful.
- Information on caring for HIV-positive persons was helpful and they felt empowered with the practical advice for the infected and affected.
- The participants agreed that this session taught them different ways to support people suffering from this virus.

SESSION 6: CARING FOR CHILDREN IN THE FACE OF HIV AND AIDS

Session 6 aimed at giving the participants information on caring for children in the face of HIV and Aids. With this information the participants should be able to empower their clients on: how to communicate with children at different ages, sexuality education at different ages, how to talk to children about HIV and Aids, how the whole community can care for children in need and vulnerable children, and government grants that can provide in the needs of children. The facilitator used the circles of support concept, as well as Maslow's need triangle to explain the different topics. Resources such as posters, play cards, pamphlets for teenagers and colouring-in books for pre-school children were included (Addendum 7.3) to help educate parents and the community to take care of the children.

The participants found this session very helpful. They felt empowered with knowledge and gained the necessary skills to explain sex and sexuality to children, to explain HIV and Aids at different age groups, also how children can protect themselves from getting infected. The practical information and tools received were very helpful.

SESSION 7: CARE FOR THE DYING

Session 7 focused on the care for the dying. At some point in the disease process of Aids there is nothing more that can be done to treat the opportunistic infections. At this point the goal of care (medical, nursing, pastoral and psychosocial) is to keep the person as

comfortable as possible and to maintain their dignity. The facilitator researched additional information and added handouts on palliative care in the empowerment programme. To reach the aim of this session the following were discussed:

An icebreaker was used to start this session. The participants were asked to visualise death and then illustrate a picture of how they visualised death. The aim of the icebreaker was to explore death in order to know how to support those who are grieving. The participants were asked to think about what death looks like, what emotions they saw on death's face and what colour death was. This exercise was necessary in order for the participants to become comfortable talking about death. In the figure below some results of the pictures that the participants visualise of death and the interpretation are given. The following topics were also discussed to reach the aim of this session: feelings associated with a terminal illness, care for someone who is dying, prepare for death and helping children cope with death.

The participants found the following information in this session very helpful:

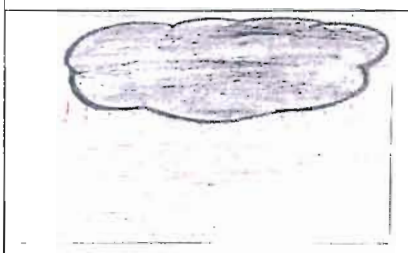
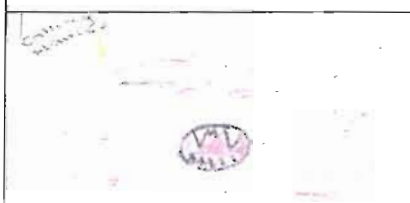
- The ice breaker used opened communications about a very sensitive subject.
- The information on how a parent could talk to his/her child about their HIV status, the information on death and dying and bereavement, as well as how to prepare for death (writing of a will and planning for children's future) were helpful.
- The section on helping children cope with death with emphasis on how to explain death to a child and how to support a child who had lost both his parents, was extremely helpful to the participants. They welcomed the practical information, a book: "Growing through Grief" (Addendum 7.4), given to assist a child with the grieving process, and the information on creative ways of helping the bereaved children and families.

The group felt that the group participation was very helpful in this session and they could learn how to talk about death from each other. The group participation brought new insights. The participants advised that more time should be given to this session when it is presented again.

The following Figure 7.2 explains the results of the participants' visualisation of death:

FIGURE 7.2: RESULTS OF PARTICIPANTS' VISUALISATION OF DEATH

PARTICIPANTS' PICTURES	DESCRIPTION OF DRAWINGS
	This participant symbolised death with a black square. Inside the square a white square was drawn with a white hart.
	Death for this participant was symbolised by a door with a question mark. No one knows what lies behind the door of death, it is a mystery.
	Death was symbolised by a cross with the spirit leaving the grave.
	This participant gave a description of the drawing. The black clouds symbolised the pain and grief of children being left behind (orphans) or the pain or grief of parents that lost a child. The yellow clouds represented joy and relief one could experience when dead. The participant also drew two figures. The figure of a person on the left of the cross was sad and crying, the figure on right was joyful about the deliverance. The earth was drawn in a black colour and symbolised pain.

	This participant's perception of death was as follows: Life after death was symbolised by a beautiful and colourful palace with a garden full of flowers and a tree. The figure of a person in the after-life had a happy face. The participant drew an earth globe, to symbolise earth. On earth a coffin represented death. A sad, crying figure represented the emotions of the people on earth. The participant drew this in a black colour, a contrast to the colour of life after death.
	Three participants drew black clouds which symbolised death for them. The black colour symbolised mourning.
	Death was symbolised by this participant as a monster with an aggressive mouth and sharp teeth that was "calling names" of people whose time it was to die. Death scared this participant.
	This participant's perception of death was a sad, crying face on earth, described as "this world". The participant used black colours for this. Life after death were symbolised by colourful music notes, a heart, flowers and a happy face. The words joy and victory explain the feelings of life after death.
	To illustrate death this participant drew an abstract picture of an object that was going upwards, a bit of a mystery. The picture was in bright yellow and blue colours.

SESSION 8: RIGHTS OF AN HIV INFECTED PERSON AND WORKPLACE POLICIES ON HIV AND AIDS

The aim of Session 8 was to make the social work students aware of workplace policies and the rights that people have regarding disclosure and confidentiality, discrimination, recruitment and employment, injuries on duty, absenteeism, sick leave and termination of employment.

This session started with a quiz. Questions were asked and the participants had to answer true or false. This was a practical exercise to discuss information on different policies and acts related to this matter (Employment Equity Act, Labour Relations Act, The Occupational Health and Safety Act, The Compensation of Occupational Injuries and Disease Act).

The participants found the information gained on workplace policies informative and they felt that they would be able to advise infected and affected people on this matter.

SESSION 9: CLOSURE

The aim of this session was to assist the participants to obtain closure and debriefing after participating in the empowerment programme.

- Debriefing sessions during which subjects felt the opportunity, after the study, to work through their experience and its aftermath, are one possible way in which the researcher can assist subjects and minimize harm (Strydom, 2005a:66).

- Through debriefing, problems generated by the research experience can be corrected (Babbie, 2010:70). The easiest way to debrief participants is to discuss their feelings about the project immediately after the session. After completion of the project, the researcher has to rectify any misperceptions that may have arisen in the minds of participants. A research project must always be a learning experience for both participants and researchers.

- Termination and withdrawal of the therapy must be handled with the utmost sensitivity in cases were subjects benefited from the therapeutic aspect of the research.

The quantitative and qualitative post-test were completed and the symbols on how the pandemic affected the participants after the implemented of the programme were redrawn. Arrangements were also made for the Affectometer to be completed 3 months after completion of this programme to measure the sustainability of the intervention.

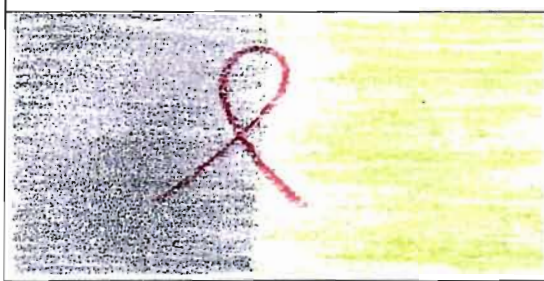
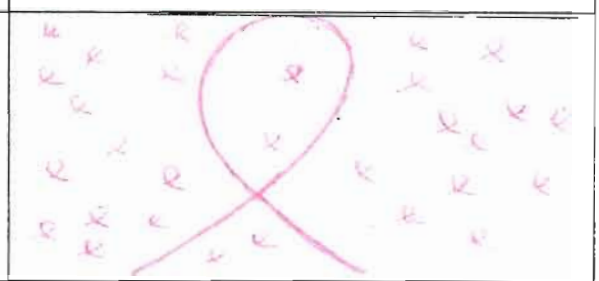
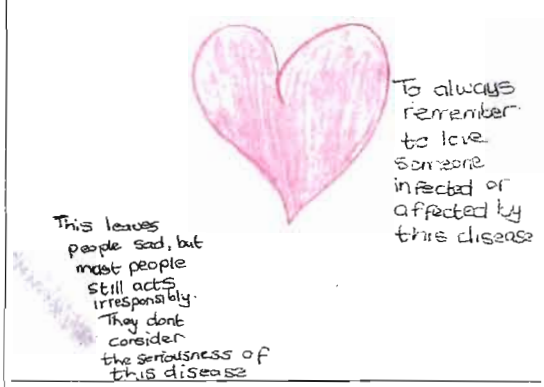
A Certificate Ceremony was held and all participants received certificates (Addendum 7.5) as proof of their participation.

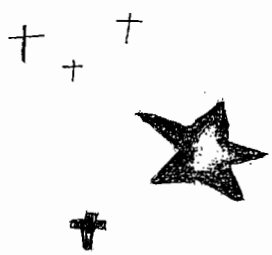
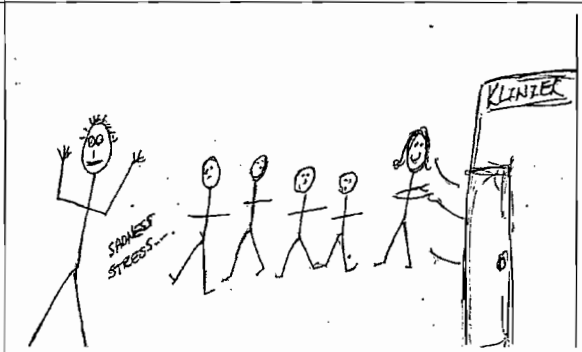
The participants appreciated the debriefing of this session. The certificates were appreciated. It was important to prove that they completed the course for the purpose of their curriculum vitae.

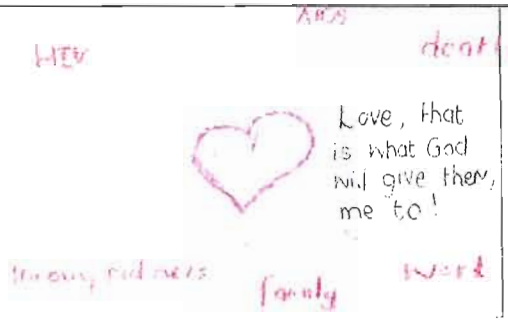
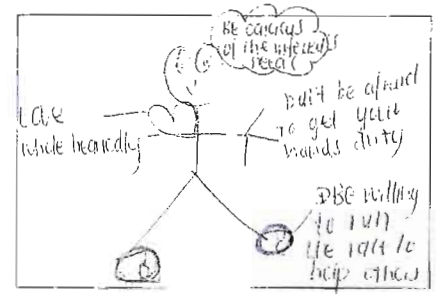
7.2 SYMBOLIC DRAWINGS

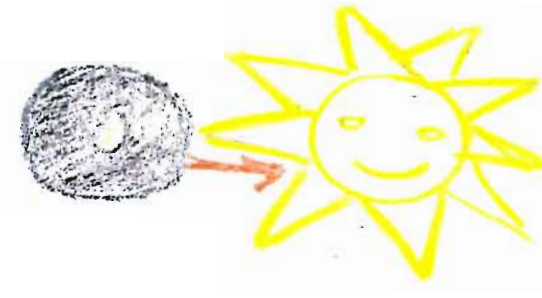
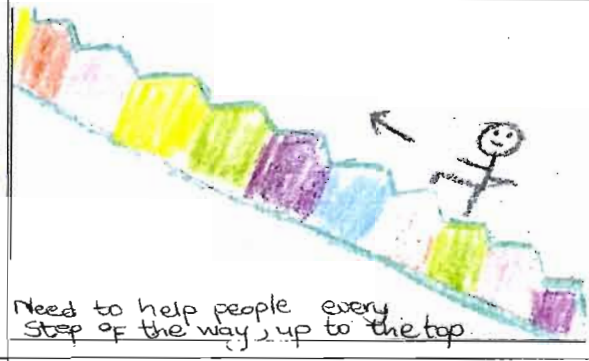
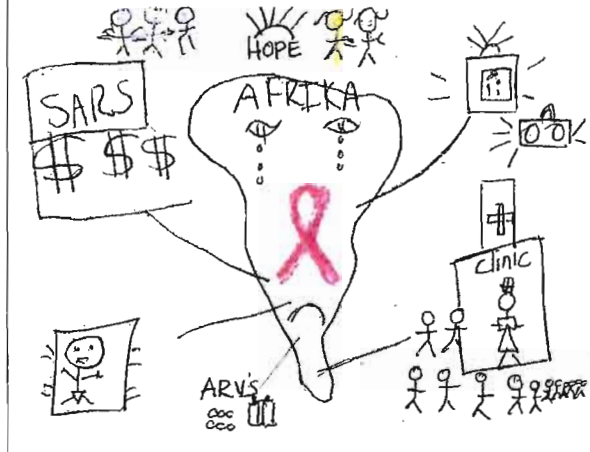
The participants were asked to draw any symbol that come to mind when thinking of how the pandemic had affected them and explain their symbol either verbally or in writing. The purpose was to gain a deeper understanding of the impact of the HIV and Aids pandemic on the participants. Symbolic drawings are a form of projection which allows the individual to project perception of an event onto a self chosen symbol (Theron, 2008:33). Symbolic drawings are representations or expressions of the unconscious mind of a person (Reber & Reber, 2001:624). The pre-test instruction was repeated during the post-test assessment. To determine whether participants perceived the pandemic to be less threatening following their participation in the empowerment programme, the content of their symbolic drawings was thematically analysed. During analysis of the pre-test and post-test data, similar symbolic drawing contents were grouped and various themes were identified. Figure 7.3 contains the similar themes of the participants' symbolic drawings, their explanation of the drawing and the researcher's interpretation of the symbols.

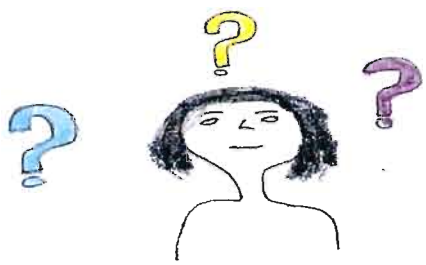
FIGURE 7.3: SYMBOLIC DRAWINGS AND INTERPRETATIONS: PRE- AND POST-TEST

PRE –TEST	POST-TEST
	
One participant drew the Aids ribbon, because it symbolised to her the fight against Aids.	In the post-test one big Aids ribbon was drawn with small Aids symbols to symbolise the escalation of this pandemic.
	
In the pre-test this participant drew the South African flag with a crying face on it. To him this symbolised a country in mourning due to this pandemic.	In the post-test the participant again drew a map of South Africa on a globe with a crying face. After the programme was presented the participant felt more or less the same, that it was a nation and a whole world in mourning.
	

The participant drew a big red heart with an accompanying description. The participant described the pandemic as follows: "This leaves people sad, but most people still act irresponsible. They don't consider the seriousness of this disease." The participant also wrote: "Always remember to love someone infected or affected by this disease." The heart symbolised that people infected and affected still needs love.	After the completion of the empowerment programme the participant symbolised the pandemic as people holding hands and to be strong by being "a supportive community".
	
The pandemic was illustrated by a black star and crosses. It symbolized death to the participant.	After the empowerment programme was implemented the participant illustrated figures representing a family that was going to the clinic. Describing words that were accompanying the illustration were "sadness" and "stress". For this participant the pandemic was still causing sadness and stress, the clinic was seen as a support system in this pandemic.

	
In the pre-test the participant drew a heart as a diagram with accompanying descriptions connecting the heart: HIV, Aids, death, work, family, sadness that symbolised the pandemic. The participant described that God gave love and through love everything was connected.	In the post-test the pandemic symbolised love and care to this participant, illustrated by a heart with accompanying words.
	
This participant drew a tree with fruit of the spirit that represented the qualities, love, joy, patience, kindness, self control and gentleness that a social worker should have to work with people infected and affected with HIV.	In the post-test the participant drew a figure with descriptions of the attributes needed to fight this pandemic, love whole heartedly, without discrimination, be conscious of the infected ones needs, do not be afraid to do physical and willingness to help.

	
This participant drew a red heart with a cross through it. This symbolised a broken heart, sadness and grief to her.	In the post-test the participant drew a colourful flower and hearts that symbolised to her to 'make a difference, make their lives blossom'.
	
In the pre-test a participant drew a yellow sun that symbolised life and a black round shape that was threatening life.	In the post-test this participant drew a figure climbing steps; it symbolised that the pandemic could be won if people were helped every step of the way, up to the top.
	
In the pre-test the participant drew a	A crying face was drawn on a map of

wellness clinic when she thought of the pandemic.	Africa. The crying was because of Aids as symbolised by the aids ribbon on the face. Other pictures on the drawing that symbolised and described the pandemic, were: dead people if they did not use antiretroviral medication, government money spent on medication, by holding hands and by supporting each other people have hope, television and radio must be used to informed people of HIV and by visiting clinics people can be treated.
	
Before the programme the pandemic was symbolised by medication to cure Aids.	After the programme the pandemic was symbolised by a red heart with the description 'hope'.
	
This participant drew a face with a few question marks, the pandemic was not well known and unpredictable to her.	In the post-test an Aids ribbon symbolised the fight against Aids.

7.2.1 Conclusion

The contents of the pre-test and post-test drawings reflect a change in participant perception of the HIV and Aids pandemic from a phenomenon that provoked vulnerability to one that could be managed. During analysis of the pre-test data the themes that were identified were: grief; loss; mourning; sadness; unpredictability and life threatening and a need for love and support. In the post-test data some participants still felt negative and explained their drawings as a "*world in mourning*" and "*an escalating pandemic that causes stress and sadness*". The majority felt more positive and hopeful and symbolised that the pandemic can be won through "*holding hands*" and "*a supportive community*", "*providing medication, support and clinics*", "*without discrimination*" and "*with support they can make a difference*".

7.3 SELF-FORMULATED QUESTIONNAIRE (PRE-TEST AND POST-TEST)

The participants' understanding of the impact of the pandemic within the multi-dimensionally context were explored. The data were gathered through a self-formulated questionnaire (Addendum 7.6), to determine how the pandemic affected them emotionally, spiritually, physically, socially, their sexual activity and professionally, as well as how they coped as social work students. The questions gave the respondents the opportunity to express their views on the issues being investigated before and after the implementation of the empowerment programme. The responses were delineated according to common themes that were identified to give meaning and structure to an enormous amount of information. The following information was analysed:

7.3.1 Feelings experience toward someone with HIV or Aids

When asked to comment on the feelings experienced towards a person with HIV and Aids, the participants generally interpreted their feelings in the pre-test as sorrow, empathy and concern because people were "*suffering*" and have a "*limited lifespan*"; the participants wanted to support and educate the infected to live healthily and responsibly.

There was also concern for the infected person's "*negative emotions*" they might experience and wanted to urge them to regain "*hope and joy*". It is reported that they should be treated in the same way as other people, without rejection. Feelings of hurt and nervousness were reported when it became clear that a friend had Aids. They also reported anger towards the infected people for "*sleeping around*" and for the system that was failing them.

In the post-test the participants reported that they still felt the same towards the persons infected with HIV. As social workers they have certain values and ethics to accept people as they are and not to reject them, irrespective of their HIV status. However, they reported that they gained knowledge and skills on how to support people infected with HIV.

7.3.2 The emotional effect of the HIV and Aids pandemic

No single response suggested positive emotional experience. All the participants referred to negative emotions experienced in response to the impacts of the HIV epidemic. These emotions included sadness, anger and emotional pain, and the participants also felt scared and stressed. Participants experienced emotional distress as a result of the pandemic and responded that they "*felt sad because of a country dying*", "*children being orphaned*", "*victims becoming infected unknowingly*" and "*because it portrayed death*". Participants referred to feelings of anger and stress "*because it affected the whole world*" and it was "*stressful working with those people who are infected*". The participants felt that working with the infected and supporting them more than was expected resulted in unfavourable consequences.

In the post-test results the participants indicated that they still felt emotionally negative because they were realistic about the devastating effect of the pandemic. However, they felt more hopeful that they could mobilise more support to make a difference with the knowledge gained.

7.3.3 Spiritual effect of the HIV and Aids pandemic

Some participants perceived the pandemic as a spiritual scourge or punishment and experienced it as the "*reason for HIV and Aids happening to humans*". Some participants used their spirituality to comfort them and pray for the infected, "*pray for healing*", "*pray for a cure*". For some participants their spirituality encouraged their humanitarian side to work with the infected and shared positive experiences as a Christian with those feeling hopeless. Three participants experienced spiritual disillusionment, they pray but received no answer, they question the "*ways God was working*" and one felt that churches did not respond to stop this pandemic. One participant responded and said she would feel hopeless if she got infected.

After the programme was presented the participants felt more positive and spiritually inspired that they could do more to support the infected.

7.3.4 The physical effect of the pandemic

Some participants reported that the pandemic did not affect them physically due to the fact that they did not have much experience of working directly with infected people. Some reported that they were more careful and preventative, "*not having unprotected sex*", "*maintain a healthy lifestyle*", be "*careful when working with people*". The participants who worked with infected people during their block placements felt "*physically tired*" and also reported that they experienced physical symptoms, such as "*feeling sick*" when seeing ill people, "*experiencing headaches*" and "*stomach cramps*".

The participants reported in the post-test that they gained information on how to take care of their health as well as how to prevent stress and burnout through exercises and relaxation techniques.

7.3.5 Effect on social interaction

Some participants responded that the HIV and Aids pandemic had no affect on their social interaction. There were responses that before the programme was presented the participants would not share utensils, but after the programme they realised that one cannot get HIV by sharing utensils. Most participants indicated that the pandemic did affect their social interaction negatively as well as their sexual activity. They were "*more cautious with their sex life*" and "*more careful with social contact with other people because not all people are responsible*". There were also participants who were worried about their friends' social activities.

The participants reported in the post-test that they were more tactful in their interaction with infected people, and tried to be more sensitive and sincere in their contact, without discrimination.

7.3.6 Effect of HIV and Aids pandemic on sexual activity

In both the pre-test and post–test some participants indicated that they were never sexually active. The participants that were sexually active indicated that the pandemic made them more "*careful, more responsible*" and be "*more faithful and abstain from sex*". They believed in safety by *using protection such as concoms*. They would also advise their "*partners to go for HIV-tests*".

7.3.7 Responses suggestive of coping

Coping responses that the social work students, as participants of this study, identified in the pre-test when working with HIV and Aids people were:
Suggestive responses were that their social work training, their social work values and meaningfulness of a social worker's role as well as their knowledge about HIV and Aids, maintaining a healthy lifestyle and how to be careful not to get HIV, helped them to cope.

The participants indicated that through their spirituality and Christian principals, to love, to hope, to have faith and acceptance of all people, helped them to cope.

In the post-test the participants reported that the knowledge gained as well as the practical aids received through this programme gave them certain coping skills to help them when working with those infected by HIV or affected by Aids. One participant acknowledged in the post-test that to have someone close being infected with HIV encouraged her to want to make a difference in that person's life. The positive attitudes of the infected people and the way they cope emotionally with their infection serves as an encouragement and inspiration to the participants.

7.3.8 Conclusion

In the responses in the self-formulated questionnaire a shift from a negative to a more positive attitude toward the effect of the pandemic on the participants' emotional, spiritual, physical, social and sexual were observed. Post-test results indicated that they still felt emotionally negative because they were realistic about the devastating effect of the pandemic. However, they felt more hopeful that they could mobilise more support to make a difference with the knowledge gained.

7.4 SEMI-STRUCTURED INTERVIEWS (POST-TEST)

The researcher interviewed the participants, using semi-structured schedule (Addendum 7.7), after the empowerment programme was implemented to evaluate whether the programme equipped the participants' enough when working with people infected and affected with the HIV and Aids pandemic in future. Although semi-structured interviews follows standard questions, the opportunity exists to ask more questions to clarify a person's reasoning, beliefs and perception of a certain topic (Greeff, 2005:297; Leedy & Ormrod, 2005:184). The questions gave the respondents the opportunity to express their views on the issues being investigated. The questions also identified whether the programme was helpful or not, what material must be included or excluded in the future

interventions and programme. The responses from the interviews were analysed for similar responses to the questions. The results are delineated according to common themes that were identified. The information was analysed as follows:

7.4.1 Knowledge concerning HIV and Aids virus, prior to this workshop

The participants assumed that they had enough knowledge concerning HIV and Aids prior to the presentation of this empowerment programme. Only a few acknowledged that they had little knowledge about the subject and only one participant felt that a person could always learn something new.

7.4.2 The impact of the HIV and Aids empowerment programme to equip the social work student to render a professional service

All the participants agreed that the empowerment programme equipped them enough professionally to render a service. Their reasons were as follows:

- They gained information on total care, psychological, social, spiritual and not just physical care.
- The information they gained on how to advise family members on caring for a person living with Aids was informative and practical.
- They were taught different ways on how to support people suffering from this virus.
- They learned the correct facts about HIV and Aids and how the virus works. They also received practical aid materials on how to convey this to children and adults who are illiterate. The participants assumed that the information they had was correct, but after the presentation acknowledged that the information they received during the presentation was valuable training.

- The information gained through a good programme medium, knowledge about resources, a toolkit with practical information equipped them as social work students to render a professional service.
- The material (especially the detailed manual) was very helpful.
- They were empowered with techniques and information to approach the community, to tell people the correct facts on HIV and Aids and also how to protect themselves.

7.4.3 Personal impact of the empowerment programme

All the participants agreed that the programme helped them personally. They gained information to understand the aspects of Aids. They felt more equipped to handle any situation successful. They even gained confidence to be tested for HIV.

7.4.4 Material that should be included in the programme in future

- All the participants agreed that there was not anything else they would include in this programme. They agreed that the way the programme was presented was perfect, including the use of different multi-media and speakers.
- One participant asked for more practical activities although every session contains practical activities.
- The participants advised that a person infected with HIV must be involved as a speaker to get first hand experience and advice from that person.

7.4.5 Facets to be excluded from the programme in future

- The participants felt that nothing could be left out of the programme and that everything was beneficial.
- Only two participants felt that the session on personal stress management and burnout could be left out. On the contrary, the quantitative measurement, the ProQOL

reported that a practical significance was found between the pre-test and post-test scores for this group. Thus the programme did reduce burnout that the participants experienced before the programme was presented.

7.4.6 Facets to be changed about the presentation of the programme

- The participants agreed that nothing of the way the programme was presented must be changed. One participant commented as follows: "*it was perfect*". They comment positively on the expert speakers that presented certain sessions and that the programme was very "*informative and they gained knowledge*".

7.4.7 Facets most helpful in this programme

The participants reported the following as helpful:

- The information on stress management and relaxation techniques.
- The information on how to take care of the infected person, their nutrition as well as their hygiene.
- The programme material given, the manual and the toolkit, with posters and other aids given to the participants to present this programme in the community were helpful.
- The bio-medical explanations of the virus and how 'crabs", a sexually transmitted infection, are transmitted.
- Everything was helpful, the new information gained and the practical presentation how to convey this information to the client.

7.4.8 Facets the least helpful of this programme

- The participants agreed that everything was helpful and important. Two participants felt that the part on stress management was the least helpful to them.

7.4.9 Facets to be changed about the practical tools (handouts)

- The participants reported the following on the practical tools: the handouts were excellent and they summarise and explain the information of the manual perfectly. The pictures on the posters are helpful, effective and beneficial to give to clients who are illiterate.

- The participants advised that nothing should change about the handouts, but one asked for more statistics of specific provinces in South Africa and predictions on them.

- One participant advised to use pictures of other ethnic groups, because black people think other ethnic groups do not get Aids, although the researcher made sure that there were pictures of all racial groups in the handouts.

7.4.10 Conclusion

The participants responded positively on the empowerment programme. They replied that through the programme they gained knowledge on HIV and Aids. The programme also equipped them personally and professionally with skills to render a professional service. There are no facets that they wanted to exclude from the programme and felt that the programme should be retained as it is.

7.5 FACILITATOR'S REFLECTIONS, OBSERVATIONS AND PROCESS NOTES OF THE PROGRAMME

The evaluation was conducted during and after the presentation of the programme and represents the viewpoints of the researcher (the programme facilitator) and a co-therapist (observer) on various aspects of the programme. Process notes were used to record how the empowerment programme was implemented and how the participants responded to each session of the programme. The researcher wrote process notes after each session. The process notes evaluated and recorded the goals of each session, the participant

reactions, emotions and information observed and gathered by the facilitator and observer. According to Strydom (2005e:277) and Reber and Reber (2001:479), observation is an informal recording and interpretation of what has been observed. Reactions and emotions of participants were recorded to collect information and data for the evaluation of this programme.

Through the feedback it was identified that fourth-year social work students did gain from this newly developed HIV and Aids empowerment programme. Prior to the workshop the participants reported that they thought they were knowledgeable enough to work with those infected and affected by the HIV and Aids pandemic. After the programme was presented, all the participants agreed that the empowerment programme equipped them professionally enough to render a service. The focus of this chapter is on whether the social work student's knowledge and skills of the pandemic was altered following voluntary participation in the HIV and Aids empowerment programme.

The results suggested that social work students are in need of interventions such as behavioural, cognitive and affective interventions to empower infected and affected people towards resilient functioning. The facilitation of the acquisition of cognitive knowledge and skills include: to obtain the correct facts on HIV and Aids, life skills programmes and practical material to empower the client, family and community on physical, emotional, spiritual, social and professional health, including stress management skills.

Skills acquisition which empower include: skills empowering social work students to cope with the anticipated adjustments by providing developmental programmes and cognitive-behavioural workshops, focusing on coping skills, providing the students with projected statistics and morbidity of the situation and personal and professional adjustments to cope with this pandemic and prevent burnout. The participants that worked with the infected and affected during their block placements reported work overload, stress and the overwhelming physical and emotional effect when working with those infected and affected. Occupational stressors could heighten the professional stress experienced as a result of the pandemic, resulting in burnout and poorer quality of work.

A positive psychological perception to cope with the workload of the pandemic and forming a coalition between all stakeholders, clients, community leaders, government and other support systems should be facilitated. Of importance is awareness of support systems in the community and creating support groups for affected people to provide a safe space for venting and talking about issues relating to stigma and social support in a time of a crisis.

The contents of the programme were evaluated as being sufficient. The group work method in social work was evaluated as having been positive. The group work sessions gave the participants the opportunity to learn from one another and to communicate solutions to certain identified problems. The group also provided support to the members to be less stressed and to enhance group cohesion.

7.5.1 Conclusion

Through the facilitator's reflections, observations and process notes it was concluded that the participants gained from the empowerment programme. The results suggested that social work students are in need of behavioural, cognitive and affective interventions to empower infected and affected people towards resilient functioning. There is a need for the facilitation of skills acquisition which empower and a need to facilitate a positive psychological perception to cope with the workload of the pandemic and form a coalition between support systems. The contents of the programme were evaluated as being sufficient. The use of the group work method was successful in enhancing the group cohesion of this group.

8. FUTURE OF THE PROGRAMME

The intervention research model was utilised during the empirical investigation of this study. One of the steps of this six phase model is to disseminate the programme to possible users. This research report is being prepared into various articles to be sent to different professional journals for publication for a wider audience of readers. These

journals include the *Social Work/Maatskaplike Werk* as well as the international journals, namely *International Social Work* and *Practice Social Work in Action.* This programme can have implications for future coursework and educational preparation for students to work effectively in their roles as social workers regarding HIV and Aids. This programme can be used by students in their professional roles in dealing with a multi-faceted problem such as HIV and Aids, or in future research studies. Eleven fourth-year social work students participated in this research study and were trained in the future presentation of this programme. They also received a manual and a tool kit with practical aids to use when working with those people and communities infected with HIV and affected by Aids. This programme has copyrights but can be bought by other health care professionals. The estimated costs to present the programme are illustrated in Table 7.4.

TABLE 7.4 COSTS OF THE PROGRAMME

ITEMS	**COSTS PER SESSION**	**TOTAL**
Venue	R 200-00 per session x 9 sessions	R 1800-00
Transport	R 30 per person (11 persons) x 9 sessions	R 2970-00
Food, snack and drinks	R 25 per person (11 persons) x 9 sessions	R 2475-00
Programme materials	11 persons @ R 200 per person (manual and tool kit)	R 2200-00
TOTAL		R 9445-00

The estimated cost per person for inclusion in the programme is R 860-00 which makes external funding essential for future presentation of the programme. The cost of the programme can be reduced if volunteering stakeholders such as schools or churches can provide a venue within the community and also exclude transport fees.

9. DISCUSSION

The purpose of this study was to evaluate the effectiveness of a newly developed empowerment programme for social work students regarding HIV and Aids adapted REds programme. A mixed methods research approach was followed with both

quantitative and qualitative measuring instruments. Eleven fourth-year social work students participated voluntarily in this study. The single system design was utilised and the pre-test post-test results were compared. The following are an interpretation of the quantitative and qualitative results.

9.1 Interpretation of the quantitative measures

The quantitative measures utilised in this study was the Professional Quality of Life Screening (ProQol) questionnaire and the Affectometer 2 questionnaire, an inventory designed to measure general happiness or a general sense of well-being. The ProQOL measured non-practical significant difference between the pre-test and post-test scores for the subscale compassion satisfaction. Thus the programme did not have an effect on the participant's compassion satisfaction subscale, which means that participants experienced job satisfaction. The participants in this study were more positively disposed to their profession and the empowerment programme did not succeed in elevating compassion satisfaction beyond the original average levels measured. A practical significant difference was found between the pre-test and post-test scores for the subscale burnout. Thus the programme reduced burnout that the participants experienced before the programme was presented. After the programme was presented the participants felt more empowered to deal with the problems regarding the HIV and Aids pandemic. They also experienced more positive feelings about their effectiveness in the work environment. Non-practical significant difference was found with regard to the subscale compassion fatigue. Thus the programme did not have an effect on the participants' compassion fatigue/trauma. The quantitative results on the Affectometer show a non-practical significant difference between the pre-test and post-test scores. Thus the programme did not have an effect on the participants' psychological well-being.

Reasons for non-practical significant difference can be that the participants have no work experience in this professional field with the emotional and psychological issues related to living with HIV and Aids and affecting their emotional well-being. Participants indicated that the empowerment programme raised their interest to read and learn more

about HIV and Aids. Furthermore, the participants possess values that are founded on the precepts of humanitarianism. The specific set of values that characterises the social work value base is deemed critical to shaping professionally appropriate beliefs, behaviours, decision making processes and ultimately, practice with clients (Podolsky-Scarth, 1999). These values help cope with the well-being of the social work students.

9.2 Interpretation of symbolic drawings

The contents of the pre-test and post-test drawings reflect a metamorphosis in participant perception of the HIV and Aids pandemic from a phenomenon that provoked vulnerability to one that could be managed. During analysis of the pre-test data the themes that were identified were: grief, loss, mourning, sadness, unpredictability and life threatening circumstances and a need for love and support.

The participants agreed that they experienced feelings of relief, hope and empowerment after the programme was completed. In the post-test drawings the following themes were identified to help fight the pandemic: a supportive community, clinic can provide help, love/support is needed to fight this disease, love and support without discrimination, a willingness to help, conscious of the infected one's needs, and hopefulness to make their lives blossom. In the explanations the participants related to having increased strength to cope with the impact of the pandemic. In the post-test drawings there were still two symbolic drawings that represented unpredictability and grief. The participants explained that they were realistic that this pandemic would cause much grief and sadness if people were not empowered to prevent the spread.

9.3 Interpretation of the responses on the self-formulated questionnaire

The responses interpreted the effect of the pandemic on the participant's emotions, on spiritual, physical, social, sexuality and professionally aspects, as well as on how they cope. The participants reported experiencing the following feelings towards HIV or Aids:

The participants' responses varied from feeling sorry and angry to feeling concerned and had empathy towards those infected. They wanted to support and educate them to live healthy and responsible lives. They felt that they should be treated without rejection and stigma.

From the above it was clear that all the participants were emotionally affected by the pandemic. No single response suggested positive emotional experience. All the participants referred to negative emotions experienced in response to the impact of the HIV epidemic. These emotions included sadness, anger, participants felt scared and stressed. The participants' spiritual experiences vary from HIV and Aids as the spiritual scourge for humans, spirituality as the comfort in traumatizing circumstances, spirituality encouraged their humanitarian side to work with the infected and they also experienced spiritual disillusionment, they pray but received no answer and they would feel hopeless if they became infected. The pandemic did affect the participants physically. They reported that they were more careful and preventive, physically tired and stressed when working with HIV persons. Other physical symptoms they reported were feeling sick when seeing ill people, experiencing headaches and stomach cramps. The participants indicated that the pandemic did affect their social interaction also, as well as their sexual activity. They were more careful with their sex life and more careful with social contact with other people.

Responses suggestive of coping were to be well-informed, the counselling skills they acquired, increased faith, meaningfulness when someone close suffers and positive attitudes and hopefulness of infected ones. The participants reported their social work training, knowledge about HIV and Aids and values as a social worker helped them to cope. Their spirituality and Christian principals, to love, to hope, to have faith and acceptance of people, helped them to cope as a social work student while working with HIV and Aids and affected people. Someone also reported to have someone close being infected, served as an encouragement to help others. The positive attitudes of the infected people were also an inspiration to some.

10. RECOMMENDATIONS

The researcher based the overall recommendations for the effectiveness of the HIV and Aids empowerment programme for fourth-year social work students on all the data collected from the participants, such as the reflection worksheet and feedback regarding the sessions that the participants found particularly helpful, elements the participants experienced as not helpful at all and the components the participants would like to change or add to the session. The recommendations were also based on drawings by the participants and completing a self-formulated questionnaire before and after the programme was implemented.

- The participants remarked positively on the toolkit and practical material, (manual, posters, pamphlets, booklets, play cards, etc.) they received and could use when presenting a preventative group or counseling session to an individual, family or group. They reported that they did not have hands-on skills or experience. They recommended that this programme be retained as it is.

- The HIV and Aids information presented was helpful to gain the correct facts about this disease. The participants reported that they learned facts and obtained more information on how the virus works (the knowledge they previously had was only assumptions). They felt more empowered with techniques, information and facts to approach the community, to talk to people about HIV and Aids and also how to protect themselves. The participants agreed that the presentation (using different multi-media and speakers) was perfect and commented positively on the expert speakers that presented certain sessions and that the programme was very "knowledgeable". They recommended that nothing of the presentation must change.

- The participants reported that the information on HIV-testing was very important, especially information on different tests, pre-test and post-test counselling, how to counsel a pregnant mother, the information on post-exposure prohylaxis and information on how and when to use medication and recommended that it must be included to prepare when counselling a client.

- The participants reported that they gained information on total care, infection control at home, how to discard of body fluids and the use of universal precautions. The participants received a hand made box (a first aid kit) with cloves, condoms, a plastic bag to discard any material with body fluids, hand liquid soap, a bandage and plaster to cover open wounds, a guide on correct hand washing techniques and an information book on basic health information. The participants also received play cards for toddlers to convey the importance of washing hands, not to touch blood and other basic information. The participants recommended that the practical aids should be included in this programme.
- The information on how to identify your stressors, relaxation techniques, and how to cope with the grieving process was helpful. The information on how a parent could talk to his/her child about their HIV status, the information on death and dying and bereavement, as well as how to prepare for death (writing of a will and planning for children's future) was helpful and should be retained in the programme.
- One participant recommended that a person living with HIV and Aids must be involved in this programme to give advice and share their experience of this disease.
- It is recommended that this programme should be evaluated using larger and more groups, so that the quantitative results of this research can be confirmed or refuted. It would also be advised to include a questionnaire to evaluate the participants' knowledge and values of certain aspects of HIV and Aids.
- It is recommended that this programme should be presented in 9 sessions over a period of time and it is not advisable to give too much information per session, because an overload of information can lead to confusion. The success of the on-site programme will depend on the ability of a social worker to create a safe, transparent, informative and non-discriminatory atmosphere. It is also advisable to utilize different programme activities in order to empower the client.
- The programme can be presented individually or in group session and it can also be presented to different ages groups.
- All human service and health care providers face the challenge of coping with stress and burnout. A challenging fact is that in spite of the best efforts, many patients will become progressively ill and some will die. A potential challenge that arises from this

is that health care providers often become vulnerable. The programme should include a session with information on understanding and minimising the stresses of HIV caring and caring for oneself as a professional.

11. CONCLUSION

The purpose of this chapter was to evaluate and determine the effectiveness of the newly developed empowerment programme for social work students, adapted from REds. From the data collected and the results of the pre-assessment and post-assessment provided in Chapter 7, the empowerment programme can be evaluated as having been successful. The fourth-year social work students reacted positively to the HIV and Aids empowerment programme and benefited from the programme. The aim of this research to determine whether the evaluated HIV and Aids support programme for educators (REds) can be adapted to become an effective empowerment programme for fourth-year social work students in supporting people infected/affected by the HIV and Aids pandemic was reached.

The findings of this study can be applied usefully by all health care providers and by the social support structures. The programme was developed and tested to become an empowerment tool in service delivery to the social work students and as a result assisted them to empower people infected and affected by HIV and Aids with accurate and vital information. This empowerment programme, as a toolkit, was designed to be presented to individuals, groups and community in different developmental stages, so that they can benefit from this intervention. The empowerment programme can be presented to other social work students on the campus of other universities. The dissemination of the programme forms an important part of the research project. This research report is being prepared into various articles to be sent to different accredited journals for publication for a wider audience of readers and copies of the PhD are also available at the North-West University library.

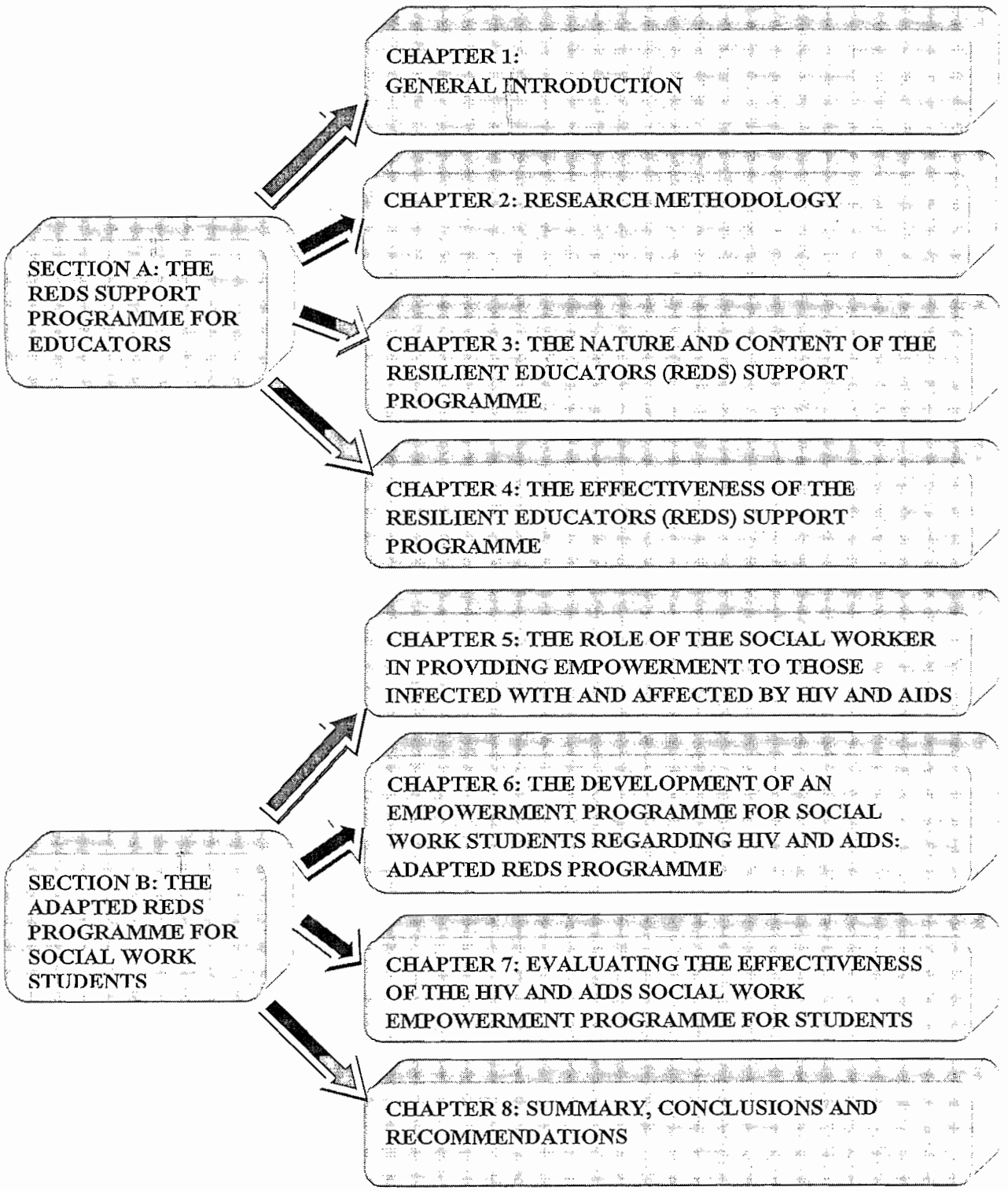
The following chapter, Chapter 8, consists of a summary of the research report with conclusions and recommendations for future endeavours.

CHAPTER 8
SUMMARY, CONCLUSION AND RECOMMENDATIONS

1. INTRODUCTION

This research project comprises of two phases. The first phase, section A is the Resilient Educators (REds) support programme for educators and focuses on: the general introduction, in Chapter 1, research methodology in Chapter 2, the description of the nature and content of REds and the evaluation of REds, as effective in supporting educators from the North West Province affected by the HIV and Aids pandemic in order that educator excellence and sustainability be secured, as discussed in Chapters 3 and 4. The second phase, section B focused on determining the role of the social worker in the face of HIV and Aids, as discussed in Chapter 5. Chapters 6 and 7 focus on the development and evaluation of an empowerment programme, adapted from REds, for fourth-year social work students regarding HIV and Aids. Chapter 8 comprises of a summary, conclusion and recommendations of this study. The following figure, Figure 8.1, is an overview of the composition of the research report.

FIGURE 8.1: FORMAT OF THE RESEARCH REPORT



2. SUMMARY AND CONCLUSIONS

The most important findings and conclusions of this study are summarised in this final chapter and each chapter will be discussed separately.

2.1 SECTION A: THE REDS SUPPORT PROGRAMME FOR EDUCATORS

2.1.1 CHAPTER 1: GENERAL INTRODUCTION

HIV and Aids affects every walk of life and not only those who are infected. It has a profound influence on everything one does – in relationships, at work, at home, and at school/college/university. Just as the virus infects the body and every cell in the body, it also affects every person on earth. Despite world-wide attention and multiple efforts, the HIV and Aids pandemic continues to impact calamitously on the infected and affected. The statistics leave one with the unnerving reality of an epidemic with enormous implications. Urgent action is needed from all professionals in addressing HIV throughout the African Continent – action such as leadership, supervision, training, resources, drugs, motivation, community support and empowerment. Having well-trained, knowledgeable and highly motivated professionals working in service delivery at all levels is crucial for effective management of the HIV epidemic.

The South African education sector is thought to be particularly affected by this harsh reality, in part because learners affected by HIV and Aids are leaving school and in part because infected education stakeholders are dying (Shisana *et al.*, 2005: xiv). The South African educators need comprehensive support to cope with the challenges of a professional role that has been escalated to encompass HIV-prevention, counselling and social work. An interactive, participatory support programme, entitled Resilient Educators (Reds), was compiled (Theron *et al.*, 2008:77-88).

Individuals who are affected by HIV or Aids have needs that may require a multitude of services including counselling, social services (Wexler, 1989), advocacy, community

outreach and case management (Wiener & Siegel, 1990). On a broader level, there is a need for preventative programming, education and policy making. Social work, a profession that is recognised for supporting the socially disadvantaged and those who are discriminated against by the larger society, has a significant role to perform in meeting the needs of individuals affected by HIV or Aids. The question that arises from this is: is the social work student well-trained, knowledgeable and professionally motivated to manage the HIV epidemic effectively and provide care and support to those living with HIV and Aids? The researcher came to the conclusion that a social work empowerment programme regarding HIV and Aids can equip the social work student, who will enter practice with accurate, vital information and a practical toolkit to empower those people living with HIV and Aids and to face an epidemic this enormous.

This study was undertaken from a strengths perspective. Strengths perspective, as described by Saleebey (2002), assumes that strengths are inherent in humanity itself. The strengths perspective emphasises that in the midst of human pain and suffering, there are locked up strengths, potential and possibilities. Humanity has strengths with which it can survive problems and disease, even rising above them. The strengths perspective believes that the world in which one lives can be transformed. Transformation is possible because human beings can generate their inherent goals and vision for a better quality of life. Working in HIV and Aids has brought about recognition of the incredible strength of the human spirit when faced with unbelievable obstacles and the complications of daily living.

Taking the above-mentioned into consideration, the following questions arose:

- What is the nature and content of the REds (Resilient Educators) support programme for educators?
- What is the effectiveness of the REds (Resilient Educators) support programme on educators affected by HIV and Aids?
- What is the role of the social worker in providing empowerment to persons infected with and affected by HIV and Aids?

- Can the REds programme be adapted in order to formulate an empowerment programme for fourth-year social work students?
- What is the effectiveness of the newly adapted and developed empowerment programme for fourth year social work students?

On the basis of the questions formulated above, the aim of this study is as follows:

The aim of this research project is to explain the nature and content of REds, to evaluate REds and to determine whether the evaluated REds can be adapted and evaluated to become an effective empowerment programme for fourth-year social work students in supporting people infected and affected by the HIV and Aids pandemic.

2.1.2 CHAPTER 2: RESEARCH METHODOLOGY

The goals were reached by studying the literature and by means of an empirical study.

2.1.2.1 Literature study

A literature study equips the investigator with a complete and thorough justification for the subsequent steps, as well as with a sense of the importance of the undertaking (Fouché & Delport, 2005:123-124). To conduct the literature study a wide range of sources was identified and studied, including books, academic studies, government and informal publications and scientific magazines on HIV and Aids, both nationally and internationally. A literature study was conducted on various aspects of this study, and it was utilised to gather more information on the subject and to analyse the problem statement. The literature study was also utilised to study the empirical research used in the evaluation of REds for affected educators as well as the development and evaluation of an empowerment programme regarding HIV and Aids for social work students. A literature study was also done to determine the role of the social worker in the face of the pandemic.

2.1.2.2 Empirical research

- **Intervention research model**

The model used for this study is the intervention research model (De Vos, 2005a:394). The intervention research model is a phase model consisting of six phases. These phases are: Phase 1 - Problem analysis and project planning, Phase 2 - Information gathering and synthesis, Phase 3 - Design, Phase 4 - Early development and pilot testing, Phase 5 - Evaluation and advanced development, Phase 6 – Dissemination. Each phase comprises a series of steps. The intervention research is a practical and useful structure for social work research, supplying new and innovative programmes.

- **Research design**

Mixed methods research is an approach to inquiry that combines or associates both qualitative and quantitative forms and involves the use of qualitative and quantitative approaches and the mixing of both approaches in a study (Creswell, 2009:4). The concurrent embedded strategy was used in this study. Creswell (2009:214) explains that the concurrent embedded strategy of mixed methods is identified by its use of one data collection during which qualitative and quantitative data are collected simultaneously. This approach has a primary method that guides the project and secondary database that provides a supporting role in the procedures. According to Creswell (2009:213), the secondary method (qualitative or quantitative) is embedded within the predominant qualitative and quantitative method. In this research the two methods were integrated embedded throughout the study. This study takes all three the research designs: exploratory, descriptive and explanatory designs into consideration.

- **Participants**

The first part of this study, the REds programme for affected educators, was evaluated. REds was implemented at 2 township schools in the Matlosana district, North West

Province, in 2007. The participants were both male and female educators who were affected by the HIV and Aids pandemic (i.e. loved ones, colleagues or learners who are HIV positive; or loved ones, colleagues or learners who have died from Aids-related diseases; or Aids orphans and vulnerable children in their classes), and were willing to volunteer as REds participants after school hours. Ten educators from a primary school participated in the first group. After the programme was adapted according to recommendations of the participants, the programme was implemented again and 13 educators from a secondary school participated in the second round.

In the second phase of this research a newly developed empowerment programme regarding HIV and Aids, adapted from REds, for fourth-year social work students was evaluated. This programme was presented to 11 fourth-year volunteering social work students from the North-West University, Potchefstroom Campus. The students chosen for this study were the first 11 students (from a class of 27) that volunteered to be part of this study. Both male and female participants took part in the study.

- **Procedure**

The single system design and face-to-face interviewing were used in both the phases in this study. The single system can be described as the study of a single subject on a repetitive basis. The single subject can be an individual, a group, an organisation or a community (Strydom, 2005d:146). The single system was utilised because this method can determine the effectiveness of the programme by comparing the before and after measurements. Social workers use single systems to monitor and evaluate clients' outcome in the intervention with which they address client target problems. In this research, the single system was regarded as suitable to measure the effect of the REds support programme on the educators' excellence and sustainability as well as the efficacy of the empowerment programme regarding HIV and Aids for social work students.

Interviewing was done in an overall interviewing context where part of the interview was the completion of the standardised measuring instrument as well as the open-ended

questions and the symbolic drawings done by participants. The rest of the interview was focused on interviewing the group as a whole where the focus was on evaluating the success of the programme according to a number of questions. The researcher and co-therapist were present throughout the total interviewing situation and made observations. These observations were also reported in process notes.

- **Measuring Instruments**

Different measuring instruments were utilised in the process of the evaluation of the effectiveness of REds. Quantitative and qualitative measures were used in the pre-assessment and post-assessment of the programme. The quantitative measurement includes the Professional Quality of Life Screening (ProQol) (Stamm, 2005). The qualitative measures include symbolic drawings to pre-post assess the participants' attitude towards the pandemic; an open-ended questionnaire to express pre-post views on the issues being investigated; semi-structured interviews regarding perceived efficacy of REds; post-reflections and feedback of participants on each session of the REds; post-interviews with the principal(s)/head of department and the facilitator's feedback, observations and process notes regarding the REds.

The effectiveness of the social work empowerment programme for fourth-year social work students was measured by conducting pre-assessment and post assessment using quantitative and qualitative instruments. The quantitative instruments utilised were the Professional Quality of Life Screening (ProQOL) (Stamm, 2005), and the short form Affectometer 2 Questionnaire (AFM) (Kammann & Flett, 1983). The qualitative measuring instruments used were: feedback on each session of the programme regarding perceived efficacy of the programme; symbolic drawings to pre-post assess the impact of the pandemic on the participants; the completion of a self-formulated questionnaire in the pre-test and post-test on issues being investigated; semi-structured interviews in the post-test gave the participants the opportunity to express their views to improve the programme and the facilitator's reflections, observations and process notes.

- **Data analysis**

Data of the quantitative instruments were analysed and transformed into statistically accessible form by counting procedures designed by the Department of Statistical Consultation Services of the North-West University (Potchefstroom Campus). In research, the practical significance of results is not only important when results of the population data are reported but also for commenting on the practical significance of a statistically significant result (Ellis & Steyn, 2003:51-53).The Qualitative data that were collected during this study was thematically analysed according to Tesch's approach (Poggenpoel, 1998:343-344).

2.1.3 CHAPTER 3: THE NATURE AND CONTENT OF THE RESILIENT EDUCATORS (REDS) SUPPORT PROGRAMME

REds was conceptualised as a potentially supportive, participatory group intervention for educators affected by the HIV and Aids pandemic. Teachers are often overwhelmed by the professional and personal impact of living and teaching in a HIV-altered milieu. Many are engulfed by emotional and spiritual distress (Theron, 2007a) and with progressively floundering professional morale and performance (Hall *et al.*, 2005). Significantly, affected educators are more likely to consider leaving teaching than those who are not (Hall *et al.*, 2005:23). The pandemic affects not only individuals; it attacks systems, and it is attacking the education system in this country. REds was piloted in four South African provinces with small groups of volunteer educator-participants, by other students, during 2006 and 2007. REds was implemented in two township schools in the Matlosana district in the North West Province as part of the researcher's study.

The objective of this part of the study was to explain the nature and content of the REds support programme for educators affected by the HIV and Aids pandemic, in order that educators' excellence and sustainability be secured. REds is a 9 session interactive programme, and was presented in 9 sessions. The ninth session took the form of a certificate ceremony. Each module took approximately 2 hours and was presented

weekly. An overview of the REds was provided in this chapter by stating the aim of each session and documenting the process of implementation of each session as it occurred. The activities and the content of each session were described.

Group work as a research process was used to offer simultaneously enabling intervention or lead to positive social change. Group work as a process was studied and taken into consideration in the planning process. The researcher considered different aspects before the first group meeting to ensure that the group was to succeed. These aspects included the structure, nature and aims of the group, the preparation of the researcher and facilitator, a needs assessment of the group members, relationship between the group members and the facilitator, as well as the procedure of the group.

Through the group process the participants gained certain skills and the group intervention led to positive social change. The data collected from the group sessions served as a starting point for evaluating REds as effective in order that educators' excellence and sustainability be secured.

2.1.4 CHAPTER 4: THE EFFECTIVENESS OF THE RESILIENT EDUCATORS (REDS) SUPPORT PROGRAMME

The objective of this part of the study was to investigate the efficacy of REds, a group intervention programme, designed to support educators affected by the HIV and Aids pandemic. REds was presented to 10 voluntarily affected educators at Alabama Primary School in Klerksdorp, from May 2007 until June 2007 at a time suitable for all participants. As each module was implemented, participating educators were asked to comment on the efficacy of each module so that the programme could be improved. At the close of the first round, the programme was adapted to accommodate the suggestions of the participants. The improved programme was implemented from August 2007 till October 2007, in round 2, with a second group of 13 affected educators from a secondary school in Kanana, in the Matlosana district, followed by a second revision. The single system design was again used in the second group in this study. The single system can be

described as the study of a single subject on a repetitive basis. The single subject can be an individual, a group, an organisation or a community (Grinnell, 2001:457; Strydom, 2005d:145). The single system was utilised because this method can determine the effectiveness of the programme by comparing the before and after measurements.

The results of this study are based on comparing pre-test data with post-test data within both the qualitative and quantitative paradigm. A mixed methods research design was used and it involves the use of qualitative and quantitative approaches and the mixing of both approaches in a study (Creswell, 2009:4). The quantitative data was gained by using the Professional Quality of Life Screening questionnaire (Stamm, 2005). A medium significance difference was found for the subscales, burnout and compassion fatigue or secondary trauma for the first sample group. The second sample group showed a non-significant difference result for the subscales: compassion fatigue, burnout and secondary trauma.

The qualitative measuring used was open-ended questionnaires, symbolic drawings, semi-structured interviews, feedback on sessions 1 to 9, interviews with the participants and management regarding the perceived efficacy of the REds and the observation and process notes of the facilitator. During the pre-test, all the participants agreed that the pandemic influenced them negatively. They experienced negative emotions of fear and uncertainty, depression, disturbance, fatigue and concern with regard to their future. Overall, participants felt doomed, ignorant, hopeless and desperate because the pandemic is spreading every day, with no cure in sight and children are left orphans. Prior to the implementation of REds they viewed themselves as passive victims. The participants in the post-test felt more empowered with knowledge on HIV and Aids and how to give support to others. From the above-mentioned, REds apparently made a difference in the lives of the participants. Although participants generally reported in the post-test to experience feelings of enthusiasm, hope, perseverance, motivation, strength, comfort, faith and freedom, they were realistic about the remaining challenges regarding the pandemic. The results of the presented REds also substantiated a need for a multi-

disciplinary approach, including social work services to help and care for the individuals effectively who have been affected by the disease.

2.2 SECTION B: THE ADAPTED REDS PROGRAMME FOR SOCIAL WORK STUDENTS

2.2.1 CHAPTER 5: THE ROLE OF THE SOCIAL WORKER IN PROVIDING EMPOWERMENT TO THOSE INFECTED WITH AND AFFECTED BY HIV AND AIDS

The objective of this chapter was to investigate the role of the social worker in providing empowerment to persons infected with and affected by HIV and Aids. A literature study equips the investigator with a complete and thorough justification for the subsequent steps, as well as with a sense of the importance of the undertaking (Fouché & Delport, 2005:123-124). A literature study was conducted on various aspects of this study. Delport (2005:171) states that, to undertake meaningful research, the researcher should have made a thorough study of the subject under review. The focus of this study was on the role of the social worker in providing empowerment to persons infected and affected by HIV and Aids according to the biomedical facts of HIV and Aids, guidelines on HIV prevention, HIV-testing and antiretroviral medication, guidelines on promoting wellness and stress management skills, guidelines on nursing people with Aids-related illnesses, tips on using social networks, caring for children in the face of the pandemic, government grants and non-governmental structures to give and gain psychosocial and socioeconomic support, care for the dying and grief-counselling skills, and information on the rights of an HIV positive person in the workplace. This chapter incorporates several issues that reflect the challenges to the profession of social work.

The need for this study is further supported by the shift in incidence of the disease. The shift in incidence of the disease requires that all social workers possess knowledge and appropriate beliefs that promote the well-being of individuals affected with HIV and Aids. The advances in medical treatment of HIV and Aids also means that individuals

who are sero-positive will live longer lives, increasing the need for the development of appropriate resources in the community, the provision of services such as counselling, treatment and support, and enhancing the quality of life.

Social work, a profession that is recognised for supporting the socially disadvantaged and those who are discriminated against by the larger society, has a significant role to perform in meeting the needs of individuals affected by HIV disease or Aids. The skills that social workers perform in integrating people with larger systems, their focus on context and environment evolving from work with historically marginalised groups, and their commitment to human rights and fairness are critical to addressing the issues surrounding HIV disease and Aids. According to Smale, Tuson and Statham (2000:5), "social work is about the interventions made to change social situations so that people who need support or are at risk can have their needs met more appropriately than if no interventions were made". Social workers have much to bring to this field of practice. The traditional broad psychosocial perspective encourages social workers to be sensitive to all of the factors that impact the life of a person with HIV. Social workers have the expertise to work with individuals, couples, families, groups and communities. They call upon multiple roles depending on the situation: counsellor, psychotherapist, social broker, organiser, advocate, programme and policy developer, and social change agent. This is the flexibility, creativity, the breadth of vision, and the multiple service roles that responding to HIV and Aids requires (Aronstein & Thompson, 1998:xxii).

2.2.2 CHAPTER 6: THE DEVELOPMENT OF AN EMPOWERMENT PROGRAMME FOR SOCIAL WORK STUDENTS REGARDING HIV AND AIDS: ADAPTED REDS PROGRAMME

The objective of this chapter was to develop an empowerment programme regarding HIV and Aids for fourth-year social work students by adapting the REds programme. The newly developed HIV and Aids empowerment programme was designed to educate the social work student with the necessary knowledge and skills to ensure that they are well-trained to deliver an effective service and to empower people infected with and affected

by HIV and Aids when they enter social work practice. Having well-trained, knowledgeable and highly motivated professionals working in service delivery is crucial for effective management of the HIV epidemic. The purpose of this workshop is to support the student to empower the HIV and Aids infected and affected individuals (reference to self, family members, friends, caregivers, community members and employers) with the accurate and vital information on HIV and Aids, the transmission and prevention. The programme also focused on HIV-testing, physical care and symptom management of the HIV and Aids infected individual. Later, as the person moves into the chronic and finally the terminal stages of Aids, they may become more interested in practical concerns such as making preparations for the care of children as well as in the spiritual and emotional preparation for dying. The infected and affected person and family have the main responsibility for giving care at home. The responsibility of a social worker is to provide information and counselling to enable the person infected with and affected by HIV and Aids to manage their own health.

The programme consists of a detailed workbook designed as a toolkit to address the issue of HIV and Aids through the use of multi-media training methods. The nine sessions in this programme are also discussed, according the facts about HIV and Aids, HIV-testing, a wellness programme, how to support and care for ill loved ones, caring for children in the face of the pandemic, care for the dying and grief and bereavement counselling and workplace policies. Practical resource material is included as an addendum, consisting of posters, booklets, colouring-in books, play cards and a relaxation CD. The intent is to make the workbook as simple and user-friendly as possible while encouraging both adherence to the intervention and quality control of the programme.

Each session of this programme had its own aims and objectives and by meeting these aims and objectives, the goals of the programme could be accomplished. It is important for every session to be included in the programme, so that the students can receive information and training on the various aspects that are vital to equip them to empower those people infected with and affected by HIV and Aids.

2.2.3 CHAPTER 7: EVALUATING THE EFFECTIVENESS OF THE HIV AND AIDS SOCIAL WORK EMPOWERMENT PROGRAMME FOR STUDENTS

The objective of this section of the study was to evaluate the effectiveness of a newly developed empowerment programme for social work students regarding HIV and Aids, adapted REds programme.

The empowerment programme was developed and tested to become a tool in service delivery to the social work students and as a result to assist them to empower people infected and affected by HIV and Aids with accurate and vital information. This empowerment programme, as a toolkit, was designed to be presented to individuals, groups, in different developmental stages or a community. The literature on HIV and Aids reveals that it is a disease that affects all levels of human existence such as social, economical, political, personal and professional aspects. Although much has been discovered and learned about this disease, deficits in knowledge and preparation to work with these clients exist. This chapter evaluated the effectiveness of an empowerment programme regarding HIV and Aids, designed to equip the fourth-year social work student at the School of Psychosocial Behavioural Sciences, Social Work section, North-West University, Potchefstroom, with knowledge and skills to prepare themselves best as social workers to empower those people infected with and affected by the HIV and Aids pandemic. Eleven participants, male and female fourth-year social work students were involved. In this study a mixed methods research design was used. Pre-assessment and post-assessment were done and both qualitative and quantitative approaches were used, however, the main focus in this study was on the qualitative data. The single system design was utilised and the pre-test and post-test results were compared. The following are interpretations of the quantitative results and the qualitative results.

A practical significance difference was found between the pre-test and post-test scores for the subscale burnout of the ProQOL. Thus the programme did reduce burnout that the participants experienced before the programme was presented. After the programme was presented the participants felt more empowered to deal with the problems regarding the HIV and Aids pandemic. They also experienced more positive feelings about their

effectiveness in the work environment. Non-practical significant difference was found between the pre-test and post-test scores with regard to the subscale compassion satisfaction and compassion fatigue. Thus the programme did not have an effect on the participants' compassion satisfaction subscale and the compassion fatigue subscale, which means that participants experienced job satisfaction. The participants in this study were more positively disposed to their profession. The quantitative results on the Affectometer show a non-practical significant difference between the pre-test and post-test scores. Thus the programme did not have an effect on the participants' psychological well-being. The researcher came to the conclusion that the social work students were not yet confronted with the unnerving reality and the enormous implications of this pandemic and the effect on the social worker's well-being due to working with this social problem in practice.

The qualitative measuring instruments used were: the participant reflections and feedback on each session of the programme regarding the knowledge, attitudes and skills that the students gained to perceive the efficacy of the programme as an empowering tool; the pre-and post-test symbolic drawings assessed the impact of the pandemic on the participants; completion of a self formulated pre-test questionnaire afforded the participants the opportunity to express their views on the issues being investigated; and a post-test questionnaire gave the opportunity to perceive the efficacy of the programme as an empowering tool as well as the facilitator's reflections, observations and process notes concerning HIV and Aids and related matters before and after the implementation of the programme.

The results of the qualitative measures were the following: during analysis of the pre-test data the themes that were identified were: grief, loss, mourning, sadness, unpredictability and life threatening diseases and a need for love and support. The participants' responses varied from feeling sorry and angry, and they also felt concerned and had empathy towards those infected. All the participants were emotionally affected by the pandemic. No single response suggested positive emotional experience. The pandemic also affected the participants physically. They reported that they were more careful and preventive,

physically tired and stressed when working with HIV persons. In the post-test results all the participants agreed that they experienced feelings of relief, hope and empowerment after the programme was completed. They wanted to support and educate people infected and affected by HIV and Aids to live healthily and responsibly.

All the participants agreed that the impact of the pandemic influenced them negatively. In the pre-test data the themes that were identified were: grief, loss, unpredictability, disempowerment and anxiety. In the post-test drawings the following themes were identified to help fight the pandemic: "*a supportive community*", "*clinic can provide help*", "*love/support is needed to fight this disease*", "*love and support without discrimination*", "*a willingness to help*", "*conscious of the infected one's needs*" and "*hopefulness to make their lives blossom*". In the explanations the participants related to having increased strength to cope with the impact of the pandemic. The participants suggested responses for coping were being well-informed, counselling skills they acquired, increased faith, meaningfulness when someone close suffers and the positive attitudes and hopefulness of infected ones in spite of their circumstances. The participants reported that their training, knowledge about HIV and Aids, such as living a healthy lifestyle and how prevent transmission as well as their values as a social worker helped them to cope. Their spirituality and Christian principals, to love, to hope, to have faith and acceptance of people, helped them to cope as a social work student while working with HIV and Aids and affected people. The HIV and Aids information presented was helpful to obtain the correct facts about this disease. The participants commented that they learned facts and obtained more information on how the virus works (the knowledge they previously had, were many assumptions). They felt more empowered with techniques, information and facts to approach the community, to talk to people about HIV and Aids and also how to protect themselves.

From the data collected and the results of the pre-assessment and post-assessment provided in Chapter 7, the empowerment programme can be evaluated as being successful. The fourth-year social work students reacted positively to the HIV and Aids empowerment programme and benefited from the programme. The findings of this study

can be usefully applied by mental health practitioners, social support structures and future educational preparation of students to work effectively in their roles as social workers. The empowerment programme can be presented to other social work students at other universities. The dissemination of the programme forms an important part of the research project. The media approach could be in the form of an article in a newspaper or scientific publications, a presentation at a conference or seminar and copies of the PhD made available at the libraries.

The overall aim of this research to determine whether the evaluated REds can be adapted to become an effective empowerment programme for fourth-year social work students in supporting people infected/affected by the HIV and Aids pandemic was reached.

3. TESTING THE CENTRAL THEORETICAL ARGUMENT

This research was based on the following theoretical argument:

The existing REds programme can be adapted for social workers and it can be used as an empowerment programme for fourth-year social work students in supporting people infected with and affected by the HIV and Aids pandemic.

Based on the findings and conclusions of this research, as discussed previously, the central theoretical argument was proven based on qualitative and quantitative research.

4. AIM AND OBJECTIVES OF THE STUDY

4.1 GENERAL AIM

The aim of this research project was to explain the nature and content of REds, to evaluate REds and to determine whether the evaluated REds can be adapted to become an effective empowerment programme for fourth-year social work students in supporting people infected and affected by the HIV and Aids pandemic.

4.2 OBJECTIVES

The above-mentioned aim was reached by achieving the following objectives:

4.2.1 To explain the nature and content of the REds (Resilient Educators) support programme for educators.

- This objective was reached in Chapter 3, problem analysis and project planning, phase 1 of the intervention research model. The participants were identified, goals and objectives were set and the nature and content of the sessions of REds were described as it was implemented at two schools in the North West Province.

4.2.2 To determine the effectiveness of REds, as an effective programme in supporting educators infected and affected with the HIV and Aids pandemic.

- This objective was reached in Chapter 4 by using information gathered, studying the information and evaluating REds as an effective support programme.

4.2.3 To investigate the role of the social worker in providing empowerment to people infected with and affected by HIV and Aids.

- This objective was reached in Chapter 5 by exploring the role and need of the social worker in working with those infected with and affected by HIV and Aids.

4.2.4 To develop a social work empowerment programme for fourth year social work students by adapting the REds programme for those infected with and affected by HIV and Aids.

- This objective was reached in Chapter 6 where the development and compilation of an empowering programme for social work students was achieved.

4.2.5 To evaluate the effectiveness of the newly adapted and developed social work empowerment programme for social work students.

- This objective was reached in Chapter 7, by implementing and evaluating the designed empowerment programme for fourth-year social work students and preparing the product for further dissemination by submitting articles for publication in accredited journals.

5. RECOMMENDATIONS

- Having well-trained, knowledgeable and highly motivated professionals working in service delivery at all levels is crucial for effective management of the HIV epidemic.

- The South African educators need comprehensive support to cope with the challenges of a professional role that has been escalated to encompass HIV-prevention, counselling and social work.

- A Resilient Educators (REds) support programme was implemented in two township schools in the North West Province. The participating educators evaluated REds as successful in providing support and felt better empowered professionally to deal with the demands in the classroom. Based on recommendations from REds, the participants identified a need for a multidisciplinary approach and recommended that the Department of Education consider employing school nurses and/or social workers, with the expertise to work with individuals, couples, families, groups and communities, to provide support and counselling.

- It was also recommended that the extra visual aids, the handouts, practical materials and toolkit provided during the presentation of REds must be included in the programme, as well as information on grief and bereavement. Information on sexuality education, preventing of teenage pregnancy and how to talk to your child about HIV and Aids in different age groups should also be included in this programme.

- An empowerment programme regarding HIV and Aids for fourth-year social work students was developed to become an effective tool in service delivery to the social work students and as a result assisted them to empower people infected and affected by HIV and Aids with accurate and vital information. Based on quantitative and qualitative data the empowerment programme was evaluated as successful and it was recommended as an empowering intervention to be presented to individuals, groups, communities, in different developmental stages.

- The participants remarked positively on the empowerment programme as an effective toolkit, consisting of a manual and practical material, such as posters, pamphlets, booklets, play cards and colouring-in books, for people at different developmental stages, and recommended that it be used when presenting a preventative group or counselling session to an individual, family or group.

- The researcher made use of a convenience sample which means that all participants came from the same geographical region, therefore, the findings cannot be generalised to all populations. It is recommended that the empowerment programme for social work students be tested on social work students of other universities.

- It is recommended that an instrument that measures knowledge on certain aspects of HIV and Aids be used before and after the implementation of the programme. This will give an indication what the knowledge of the participants is before the programme and if the programme indeed enhances knowledge on HIV and Aids after implementation.

- The findings of this study can be usefully applied by social workers, mental health practitioners, social support structures and future educational preparation for students to work effectively in their roles as social workers regarding HIV and Aids.

- All human service and health care providers face the challenge of coping with stress and burnout due to working with an increasingly complex client in an era of diminishing resources. It is recommended that information on understanding and

minimising the stresses of HIV caring and caring for oneself should also be researched in further studies.

6. CONTRIBUTION

The following contributions were made by this study.
The researcher presented and evaluated the efficacy of REds during 2007 to two schools in the North West Province as part of an ongoing piloted study in four South African provinces. The participating educators gained important information regarding HIV and Aids, which could assist them personally and professionally. The study provided the educators with information regarding various types of support. This study made a number of recommendations for the improvement of REds. By suggesting improvements, this study provides a potentially better support tool for future implementations with educators who are affected by the pandemic.

From the recommendations of the evaluated REds, a need for social work service regarding HIV and Aids developed. The role of the social worker from current literature is categorised and summarised into 7 modules focusing on the bio-medical information, guidelines on HIV prevention, HIV-testing and antiretroviral medication, guidelines on promoting wellness and stress management skills, guidelines on caring for people with Aids-related illnesses, tips on using social networks, caring for children in the face of the pandemic, government grants and non-governmental structures to give and gain psychosocial and socioeconomic support, care for the dying and grief-counselling skills, and information on the rights of an HIV positive person in the workplace.

An empowerment programme regarding HIV and Aids for social work students was developed from an adapted REds programme. The programme was also tested on fourth-year social work students and evaluated. The researcher equipped 11 social work students with knowledge and skills working as professionals in service delivery at all levels which is crucial for effective management of the HIV epidemic. They were also supplied with a HIV and Aids empowerment workbook and a tool kit with practical aids. One of the aims

of this study is to disseminate the programme to possible users. This programme is also made available for future educational preparation for students to work effectively in their roles as social workers with HIV and Aids. The research report is also being prepared into various articles to be sent to different professional journals for publication.

7. CONCLUSION

In conclusion, the aims that were highlighted for this research were accomplished in explaining the nature and content of REds, evaluating REds and determining whether the evaluated REds can be adapted to become an effective empowerment programme for fourth-year social work students in supporting people infected and affected by the HIV and Aids pandemic.

The statistics on HIV and Aids in South Africa indicate a need for social work preventative and support programmes for those people infected with and affected by HIV and Aids. Having well-trained, knowledgeable and highly motivated professionals working in service delivery at all levels is crucial for effective management of the HIV epidemic. Thus a need arose for a social work empowerment programme regarding HIV and Aids to equip the social work student, who will enter practice, with accurate, vital information and a practical toolkit to empower those people living with HIV and Aids and to face an epidemic this enormous.

The importance of self-efficacy in Aids programmes must not be underestimated by Aids educators. People's self-efficacy should be increased and reinforced by making sure people possess the required communication, negotiation and problem solving skills to carry out the desired actions. The purpose of HIV and Aids empowerment is not only to disseminate information, but also to change attitudes and behaviour, to equip people with necessary life skills, to educate them to prevent the spread of HIV infection and to care for the people who are infected. The shift in incidence of the disease requires that all social workers possess knowledge and appropriate beliefs that promote the well-being of individuals affected with HIV and Aids. The advances in medical treatment of HIV and

Aids also means that individuals who are sero-positive will live longer lives, increasing the need for the development of appropriate resources in the community, the provision of services such as counselling, treatment and support, and enhancing the quality of life.

HIV and Aids is a major threat to all people and businesses across the globe. Those who are not infected will be affected in some way or other by this pandemic. It is, therefore, crucial that we join hands in the fight against HIV and Aids - together we can tackle this disease, as Mandela (2000) said: "We have to rise above our differences and combine our efforts to save our people. History will judge us harshly if we fail to do so now, and right now. The time to act is now!"

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ADDENDUMS

ADDENDUM 2.1
CONSENT FROM THE DISTRICT MANAGER

Department of Education
Lefapha la Thuto
Departement van Onderwys

KLERKSDORP AREA PROJECT OFFICE

SECOND FLOOR DE WINTER BUILDING, PRIVATE BAG A23, KLERKSDORP, 2570.
TEL. (018) 4627523 FAX. (018) 4643103

TO: HANNELIE MALAN

FROM: AREA PROJECT OFFICE MANAGER

DATE: 02 MAY 2007

SUBJECT: PERMISSION TO CONDUCT RESEARCH IN MATLOSANE APO AT KANANA SECONDARY AND ALABAMA PRIMARY SCHOOLS

This memo serves to acknowledge your letter dated 26 April 2007 regarding the above stated matter.

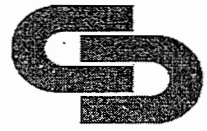
Kindly be informed that permission is granted and the following must be observed:

i. Contact time with learners must not be compromised
ii. The research participants must be well informed of what the study entails
iii. All research ethics must be observed.

I take this opportunity to wish you well in your studies.

.....
M.A. MOTAUNG (MRS.)
AREA PROJECT OFFICE MANAGER

ADDENDUM 2.2
CONSENT FROM THE EDUCATORS



NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

Informed consent

I _____ agree to voluntarily participate in REds. I understand that the purpose of REds is to empower me as an educator who is affected by the HIV/AIDS pandemic. I understand that REds consists of _____ sessions and that each session should take approximately _____ hours.

I understand that all information which is collected from me will be kept confidential. I give permission that any information which is collected from me may be used for research and publication purposes, both in South Africa and other countries.

I understand that if something troubles me while participating, the researcher will be prepared to provide me with information about community resources that can help me.

I understand that participating in REds does not mean that I can present REds to other affected educators without being trained as a REds facilitator.

If I have any concerns about this study or my participation in it I am free to contact the local researcher _____ at _____ or Linda Theron (email: Linda.theron@nwu.ac.za or 016 910 3076 / 016 910 3082 or P.O. Box 1174, Vanderbijlpark, 1900).

Signature: _____

ADDENDUM 2.3
CONSENT FROM THE SOCIAL WORK STUDENTS



NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOMKAMPUS

Informed consent

I _____ agree to voluntarily participate in the HIV and Aids empowerment programme for social work students. The purpose of this programme is to educate me to empower those infected and affected by the HIV and Aids pandemic. I understand that this programme consist of 8 modules and will be presented over three days.

In order to improve this programme the following questionnaires must be completed: Affectometer (AFM), ProQol, open-ended questions and symbolic drawings. The questionnaires and drawings will determine this. It will be required of me to complete the same questionnaires at the termination of the programme and the Affectometet again 1 month later.

I understand that all information which is collected from me will be kept confidential. I give permission that any information which is collected from me may be used for research and publication purposes.

I understand that if something troubles me while participating, the researcher will be prepared to provide me with information about community resources that can help me.

If I have any concerns about this study or my participation in it I am free to contact the researcher, Hanelie Malan at Tel: 078 2579 912 or Prof. H. Strydom Tel: 018-299 1677.

Signature: _____

ADDENDUM 3.1
POEM

I walk down the street.

There is a deep hole in the sidewalk.
I fall in.
I am lost . . . I am helpless.
It isn't my fault.

It takes forever to find a way out.

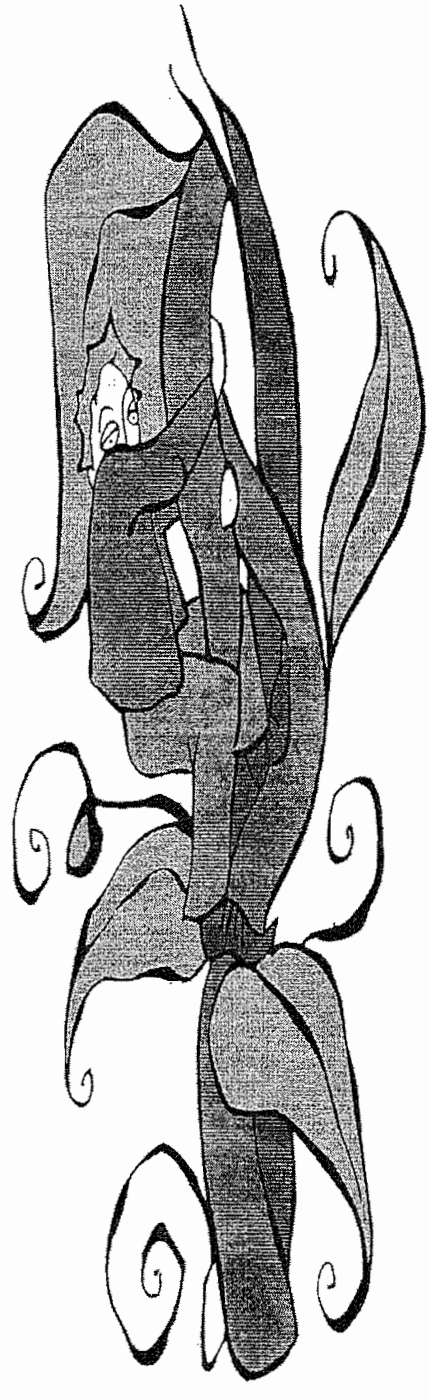
I walk down the same street.
There is a deep hole in the sidewalk.
I pretend I don't see it.
I fall in again.

I can't believe I am in the same place.
But, it isn't my fault.
It still takes a long time to get out.

I walk down the same street.
There is a deep hole in the sidewalk.
I see it is there.
I still fall in. It's a habit.
My eyes are open.
I know where I am.

It is my fault. I get out immediately.
I walk down the same street.
There is a deep hole in the sidewalk.
I walk around it.

I walk down another street.



Portia Nelson
in Covey's *The 7 Habits of Highly Effective Teens* (1998: 62).

ADDENDUM 3.2
REFLECTION WORKSHEET

Help to improve
REds



ADDENDUM 3.3
BOOK MARK



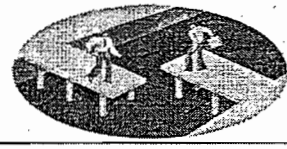
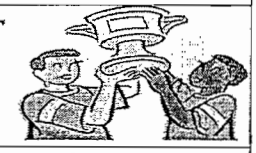
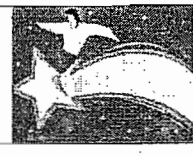
RESOURCES

Clinic:	
Klerksdorp	**Tel: 018-4622151**
Parkstreet	
Jouberton	**Tel: 018-4653157**
Alabama	**Tel: 018-4675009**
Orkney	**Tel: 018-4739501**
c/Kingsley/Shakespeare	
Kanana	**Tel: 018-4762125**
	Tel: 018-4761141
Stilfontein	**Tel: 018-4841471**
Khuma	**Tel: 018-4891141**
Tigane	**Tel: 018-4310306**
Hospice:	
Klerksdorp Offices	**Tel: 018-4623916**
Home Base Care	
Hendrik Potgieterroad	
Hospice Pre-School	**Tel: 018-4623916**
Kaia Tshepo Pre-School	
Hendrik Potgieterroad	
Klerksdorp	
Hospice In-Patient Unit	**Tel: 018-4652113**
4196 Ext. 7	
Jouberton	
Life Line:	
Klerksdorp	**Tel: 018-4621234**
13 Viljoenstreet	
Pienaarsdorp	
AIDS helpline:	
AIDS Support	**Tel: 0800-012-322**
AIDS Law	
Aids Law Project	**Tel: 011-7178600**

ADDENDUM 3.4
SET OF QUESTIONS

Statement	True	False
1. LEARNERS AND EDUCATORS WITH HIV/AIDS ARE PROTECTED FROM UNFAIR DISCRIMINATION.		
2. AN EDUCATOR CAN BE DENIED A POST OR FIRED BECAUSE OF HIS OR HER HIV/AIDS STATUS.		
3. AN EDUCATOR CAN BE COMPELLED TO DISCLOSE HIS/HER HIV STATUS.		
4. THE SGB OR PRINCIPAL CAN FORCE AN EDUCATOR TO TAKE AN HIV TEST.		
5. A LEARNER CAN REFUSE TO BE TAUGHT BY AN EDUCATOR WITH HIV/AIDS.		
6. AN EDUCATOR CAN REFUSE TO WORK WITH AN EDUCATOR WITH HIV/AIDS.		

ADDENDUM 3.5
A-Z LIST OF RESILIENCE

A	Avoid negative sources, people, places, things and habits.	N	Never lie, cheat or steal; always strike a fair deal.
B	Believe in yourself.	O	Open your eyes and see things as they really are.
C	Consider things from every angle. 	P	Practice makes perfect.
D	Don't give up and don't give in.	Q	Quitters never win, and winners never quit. 
E	 Enjoy life today—yesterday is gone, tomorrow may never come.	R	Read, study and learn about everything important in your life. 
F	Family and friends are hidden treasures, seek them and enjoy their riches.	S	Stop procrastinating.
G	Give more than you planned to.	T	Take control of your own destiny.
H	Hang on to your dreams. 	U	Understand yourself to better understand others.
I	Ignore those who try to discourage you.	V	Visualize it! 
J	Just do it!	W	Want it more than anything.
K	Keep trying no matter how hard it seems—it will get easier.	X	Xcellerate your efforts.
L	 Love yourself first and most.	Y	 You are unique of all God's creations, nothing can replace you.
M	Make it happen.	Z	Zero in on your target and go for it!

ADDENDUM 3.6
REds CERTIFICATE

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

School of Educational Sciences

Honours are hereby awarded

to

SIMANGELE VICTORIA MATHUNJWA

for

successful completion of

REds

September 2007
DATE

Hanelie Malan
PROGRAMME FACILITATOR

Dr LC Theron
PROJECT LEADER

Vaal Triangle Campus

ADDENDUM 3.7
CERTIFICATE CEREMONY

EDUCATORS FROM GROUP 1 PARTICIPATING IN THE REds PROGRAMME



EDUCATORS FROM GROUP 2 PARTICIPATING IN THE REds PROGRAMME



ADDEMDUM 4.1
EXAMPLE OF PROQOL QUESTIONNARE

As a teacher, you help many people. Mark the block that honestly shows how often you felt like this *in the last 30 days.*	Never	Rarely	Quite often	Often	Very often
1. I am happy.	1	2	3	4	5
2. I am worried about more than one person I help.	1	2	3	4	5
3. I get satisfaction from being able to help.	1	2	3	4	5
4. I feel connected to others.	1	2	3	4	5
5. I jump or am nervous when hearing unexpected sounds.	1	2	3	4	5
6. I feel re-energized after working with those I help.	1	2	3	4	5
7. I find it difficult to separate my personal life from my life as a helper.	1	2	3	4	5
8. I am losing sleep over experiences of people I help.	1	2	3	4	5
9. I am affected by the disturbing experiences of those I help.	1	2	3	4	5
10. I feel trapped by my work as a helper.	1	2	3	4	5
11. Because of my helping, I feel nervous about various things.	1	2	3	4	5
12. I like my work.	1	2	3	4	5
13. I feel depressed as a result of my work as a helper.	1	2	3	4	5
14. I feel as if I am experiencing the trauma of those I help.	1	2	3	4	5
15. I have beliefs that support me.	1	2	3	4	5
16. I know how to use different helping techniques.	1	2	3	4	5
17. I am the person I always wanted to be.	1	2	3	4	5
18. My work makes me feel satisfied.	1	2	3	4	5
19. Because of my work, I feel exhausted.	1	2	3	4	5
20. I have happy thoughts and feelings about those I help.	1	2	3	4	5
21. I feel overwhelmed by the amount of work I have to deal with.	1	2	3	4	5
22. I believe I can make a difference through my work.	1	2	3	4	5
23. I avoid some situations because they remind me of disturbing experiences of people I've helped.	1	2	3	4	5
24. I plan to be a helper for a long time.	1	2	3	4	5
25. As a result of my helping, I have disturbing thoughts.	1	2	3	4	5
26. I feel frustrated by the system.	1	2	3	4	5
27. I think I am a success as a helper.	1	2	3	4	5
28. I can't remember important parts of when I've helped others.	1	2	3	4	5
29. I am a very sensitive person.	1	2	3	4	5
30. I am happy that I chose to do this work.	1	2	3	4	5

ADDENDUM 4.2
OPEN-ENDED QUESTIONS

Please complete / finish the following sentences honestly:

1. When I think of the future

2. Giving up

3. I hope that

4. When things go wrong

5. I can

ADDENDUM 4.3
INTERVIEW SCHEDULE

1. How has the HIV/Aids pandemic affected you emotionally, if at all?

2. How has the HIV/Aids pandemic affected you spiritually, if at all?

3. How has the HIV/Aids pandemic affected you physically (e.g. do you sleep badly/ decrease appetite, etc.) if at all?

4. How has the HIV/Aids pandemic affected your social interaction, if at all?

5. How has the HIV/ Aids pandemic affected you professionally/ impacted on you as an educator?

6. How has the HIV/Aids pandemic changed your daily routine as an educator, if at all?

7. What has helped you to cope with teaching whilst the HIV/Aids pandemic rages?

ADDENDUM 4.4
POST-TEST INTERVIEWS

Questionnaire 4 **Please tell us what you think:**



What do you think REds must include in future?

What do you think we can leave out of REds in future?

What did you like about the way REds was presented?

What would you change about the way REds was presented?

What was the most helpful/best part of REds for you?

What was the least helpful part of REds for you?

What would you change about the material (handouts)?

Did REds help you personally? If yes, how?

Did REds help you professionally? If yes, how?

Any other comments?

ADDENDUM 7.1
AFFECTOMETER (AFM)

AFFECTOMETER (AFM)
(Kammann, & Flett, 1983)

This inventory consists of 20 sentence items. Read each sentence and decide how often the feeling was present over the past few weeks, according to the following graded response scale:

1 Not at all
2 Occasionally
3 Some of the time
4 Often
5 All the time

You are to mark your answer next to each statement as it applies to you. Please answer every statement

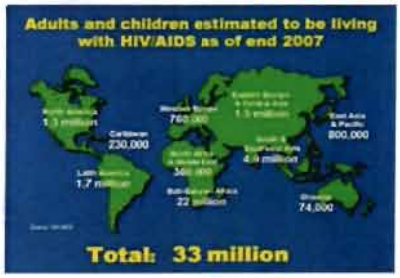
1	My life is on the right track.	1	2	3	4	5
2	I wish I could change some part of my life.	1	2	3	4	5
3	My future looks good.	1	2	3	4	5
4	I feel as though the best years of my life are over.	1	2	3	4	5
5	I like myself.	1	2	3	4	5
6	I feel there must be something wrong with me.	1	2	3	4	5
7	I can handle any problems that come up.	1	2	3	4	5
8	I feel like a failure.	1	2	3	4	5
9	I feel loved and trusted.	1	2	3	4	5
10	I seem to be left alone when I don't want to be.	1	2	3	4	5
11	I feel close to people around me.	1	2	3	4	5
12	I have lost interest in other people and don't care about them.	1	2	3	4	5
13	I feel I can do whatever I want to.	1	2	3	4	5
14	My life seems stuck in a rut.	1	2	3	4	5
15	I have energy to spare.	1	2	3	4	5
16	I can't be bothered doing anything.	1	2	3	4	5
17	I smile and laugh a lot.	1	2	3	4	5
18	Nothing seems very much fun anymore.	1	2	3	4	5
19	I think clearly and creatively.	1	2	3	4	5
20	My thoughts go around in useless circles.	1	2	3	4	5

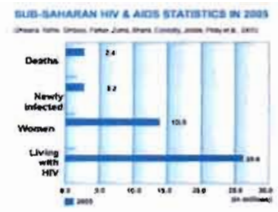
ADDENDUM 7.2
EMPOWERMENT TOOLKIT



ADDENDUM 7.3
RESOURCE MATERIALS
POSTERS

STATISTICS of HIV & AIDS





Aids is like an iceberg: most of it is hidden below the surface



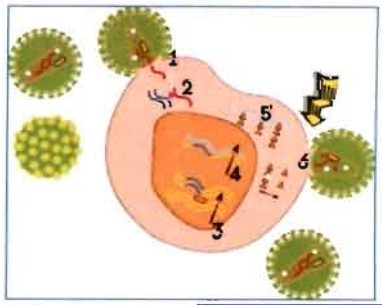
1. Persons with Aids we know about (sick)
2. Persons with the HIV virus that we know (not sick)
3. Healthy people who has the HIV virus in their blood that do not know that

Orphans	• 2 531 8100 (14% of all children between the ages of 2 and 18)
Infected Woman	• More than 1 in 3 women (25 - 34 years)
Infected Men	• 23.3% of men meaning almost 1 in 4 (30 - 39 years)

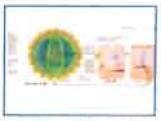
The pandemic in South Africa is not showing signs of abating (Shisana et al, 2005)

HIV AIDS Empowerment programme

How the VIRUS works



Step 1:
Free Virus-bind and penetrates cell
Step 2:
Reverse Transcription: makes a DNA copy of the virus's RNA
Step 3:
Integration Viral DNA is combined with the cell's own DNA
Step 4:
Transcription - HIV's genetic material is inside the cell's nucleus, it directs the cell to produce new HIV.
Step 5:
Translation mRNA strand has been transformed into new viral proteins needed to make a new virus
Step 6:
Viral Assembly and Maturation-the virus is able to infect new cells.



- HIV attacks the body's CD4 cells, which build the immune system.
- The virus climbs into the cell and makes new viruses.
- The new viruses enter the blood stream and destroy more CD4 cells.
- CD4 cells help protect the body they fight off bacteria and viruses, and clear away some harmful cells.

How to PREVENT the SPREAD of HIV



The CORRECT use of a CONDOM



How does a PERSON get HIV?

HIV is passed on through the following

Unsafe Sex | Mother-to-child | Sharing Needles/Razors | Blood Body fluids

The most common methods of transmission of HIV are:



Unprotected sex with an infected partner



Sharing needles with infected person

Almost eliminated as risk factors for HIV transmission are:

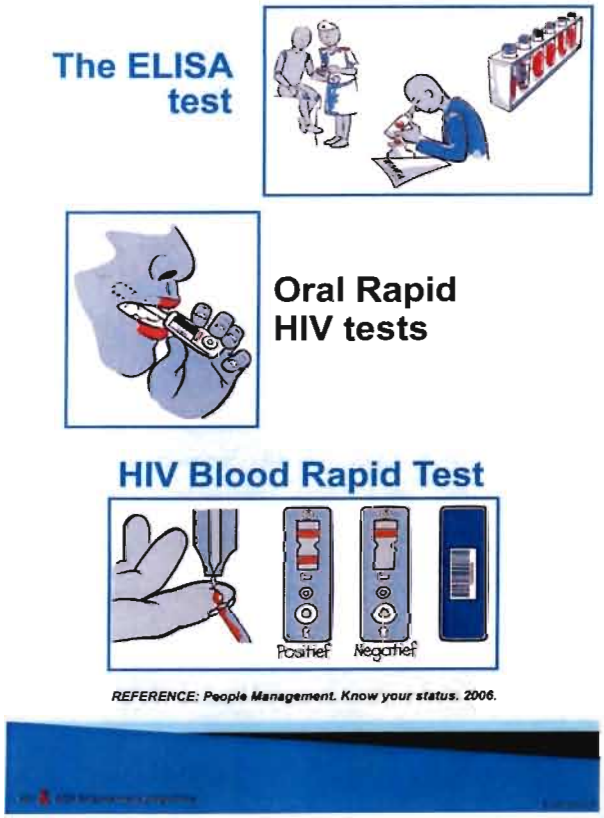


Transmission from infected mother to fetus

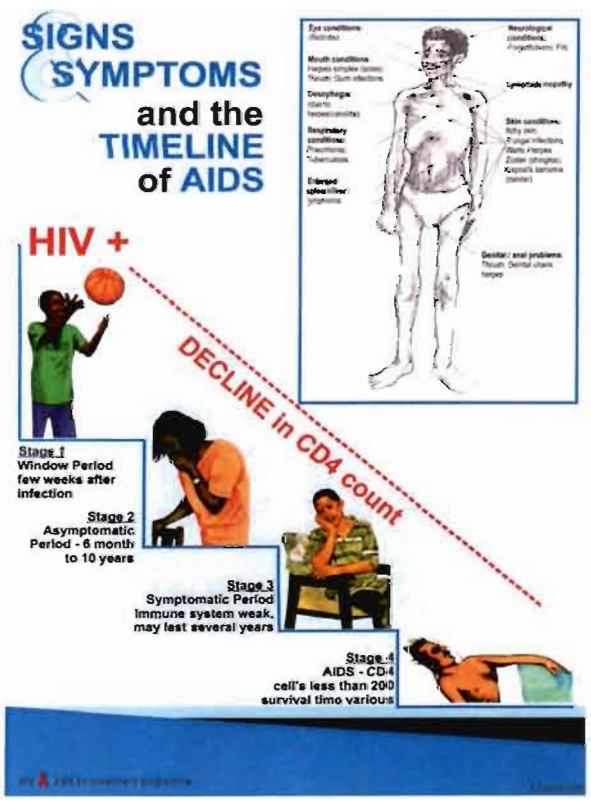


Infection from blood products

POSTERS


The ELISA test
Oral Rapid HIV tests
HIV Blood Rapid Test
Positief
Negatief
REFERENCE: People Management. Know your status. 2006.


Starting ANTI-RETROVIRAL Treatment (ART)
Your CD4 count is less than 200. You must start on anti-retroviral treatment (ART)
HOW DOES ART HELP?
The patient can live a healthier and longer life.
If the person taking ART is a bread-winner or a parent, they can continue to provide and care for their family.
WHERE CAN I GET ART?
Health centres, clinic's and private doctors offer the treatment.
Health workers need to be properly trained to be able to know how to help people who need ART.
Have a treatment helper
Take treatment at the same time every day
Do not share your medicines
Stop drinking alcohol before starting ART
Always use condoms when having sex
Have regular check-ups


SIGNS SYMPTOMS and the TIMELINE of AIDS
HIV +
DECLINE in CD4 count
Stage 1
Window Period
few weeks after infection
Stage 2
Asymptomatic Period - 6 month to 10 years
Stage 3
Symptomatic Period
Immune system weak, may last several years
Stage 4
AIDS - CD4 cell's less than 200
survival time various


MAIN FOODS & HELPER FOODS
Body-building foods:
Are rich in protein and contain iron and calcium. They help people to build muscles, bones and blood and keep the immune system healthy.
Energy-giving foods:
Make starchy foods the basis of each meal they supply energy; keep the body weight up and are cheap.
Foods that protect the body from infection (vitamin-rich foods)
Keep water CLEAN & SAFE
Make water safe when it's not possible to boil it. Add 1 teaspoon of bleach to 25 litres of water Mix well and let it stand for 2 hours or longer
Wash hands before preparing food
Basic hygiene infection control at home
Cook meat properly
Limit body toxins
stop smoking
& limit alcohol
HIV AIDS Empowerment programme

POSTERS

WELLNESS PROGRAMME

Live a longer, healthier Life with HIV

When you are HIV positive or have Aids, you need to take care of your mind, body & soul, this will help you not to get sick.



MAIN FOODS & HELPER FOODS

Body-building foods:
Are rich in protein and contain iron and calcium. They help people to build muscles, bones and blood and keep the immune system healthy.



Energy-giving foods:
Make starchy foods the basis of each meal they supply energy; keep the body weight up and are cheap.



Foods that protect
the body from infection (vitamin-rich foods)



Keep water CLEAN & SAFE

Make water safe when it's not possible to boil it. Add 1 teaspoon of bleach to 25 litres of water Mix well and let it stand for 2 hours or longer





Cook meat properly

Wash hands before preparing food
Basic hygiene infection control at home

Limit body toxins stop smoking & limit alcohol



HIV AIDS Empowerment programme

PSYCHOLOGICAL WELLNESS

HIV/Aids cause physical & emotional stresses WORK THROUGH THE EMOTIONS



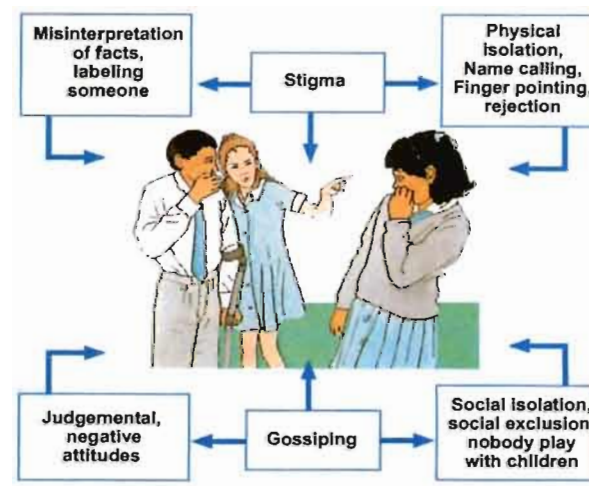
RECOMMENDATIONS to COPE with HIV/AIDS

- BE A SURVIVOR NOT A VICTIM
- GET A PURPOSE IN LIFE
- TAKE CONTROL MANAGE HIV
- LOWER STRESS LEVELS
- JOIN A SUPPORT GROUP
- STRENGTHEN SPIRITUAL TIES



UNDERSTANDING STIGMA

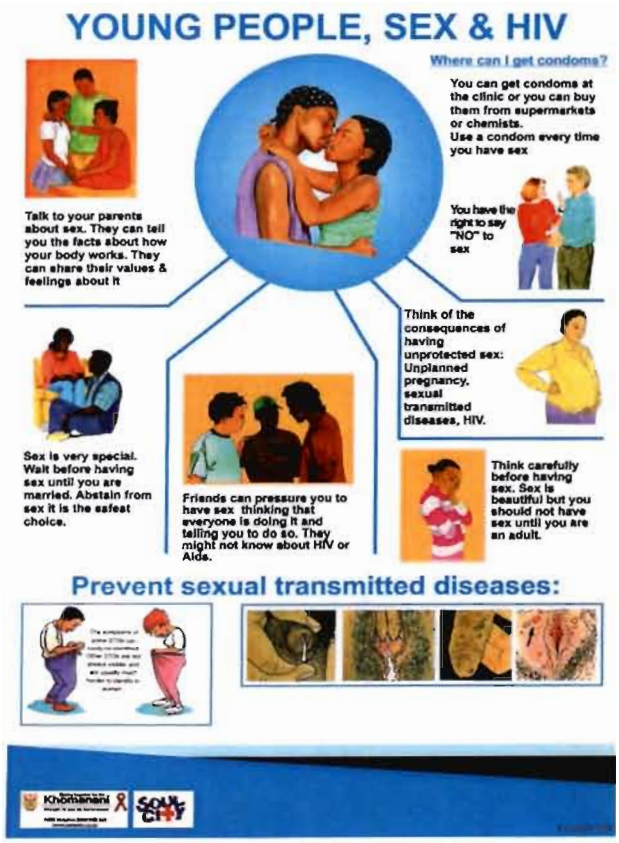
To combat HIV & AIDS - Stigma & Discrimination must be fight

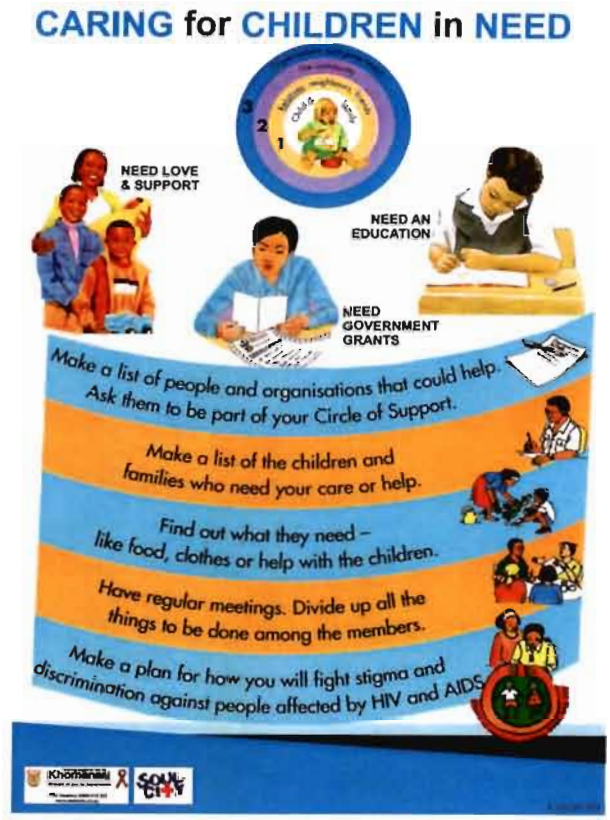


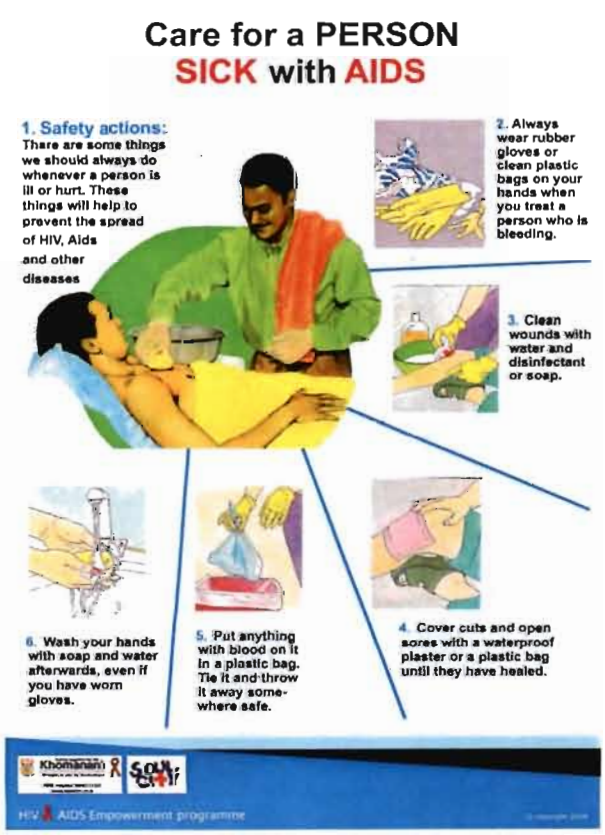
Stigma is a result of

- Inadequate knowledge & myths
- Rigid norms or values - Discrimination
- People don't recognize stigmatizing behaviour

POSTERS


YOUNG PEOPLE, SEX & HIV
Where can I get condoms?
You can get condoms at the clinic or you can buy them from supermarkets or chemists.
Use a condom every time you have sex
Talk to your parents about sex. They can tell you the facts about how your body works. They can share their values & feelings about it
You have the right to say "NO" to sex
Think of the consequences of having unprotected sex: Unplanned pregnancy, sexual transmitted diseases, HIV.
Sex is very special. Wait before having sex until you are married. Abstain from sex it is the safest choice.
Friends can pressure you to have sex thinking that everyone is doing it and telling you to do so. They might not know about HIV or Aids.
Think carefully before having sex. Sex is beautiful but you should not have sex until you are an adult.
Prevent sexual transmitted diseases:


CARING for CHILDREN in NEED
NEED LOVE & SUPPORT
NEED AN EDUCATION
NEED GOVERNMENT GRANTS
Make a list of people and organisations that could help. Ask them to be part of your Circle of Support.
Make a list of the children and families who need your care or help.
Find out what they need – like food, clothes or help with the children.
Have regular meetings. Divide up all the things to be done among the members.
Make a plan for how you will fight stigma and discrimination against people affected by HIV and AIDS


Care for a PERSON SICK with AIDS
1. Safety actions:
There are some things we should always do whenever a person is ill or hurt. These things will help to prevent the spread of HIV, Aids and other diseases
2. Always wear rubber gloves or clean plastic bags on your hands when you treat a person who is bleeding.
3. Clean wounds with water and disinfectant or soap.
4. Cover cuts and open sores with a waterproof plaster or a plastic bag until they have healed.
5. Put anything with blood on it in a plastic bag. Tie it and throw it away somewhere safe.
6. Wash your hands with soap and water afterwards, even if you have worn gloves.
HIV AIDS Empowerment programme


HOW TO PREPARE FOR DEATH
Prepare children for death. Get counselling for young people to help them cope with the loss.
Make a will, this is a legal document that says what should happen to your things if you die. Put all your important papers in a safe place. Tell your children where they are kept.
Write letters to each child & family. Tell them that you love them. You can share your thoughts & feelings with the family.
Making a memory box is:
It is a box with special things inside that you want your family to remember you by, after you died. The box can contain photos, tapes, poems, letters, special personal things, tie, shirt... This will help the family to cope with the loss.
Talk to your children about where they will live if you die. Talk to your relatives & tell the social worker what you want to happen to your children & belongings if you die.

PLAY CARDS FOR CHILDREN



You cannot be infected with HIV by sharing food.



You cannot be infected with HIV by playing together.



You cannot tell by looking at a person if he/she is infected with HIV, only a blood test can tell.



Children have the Right to go to school and to be educated.



You can get AIDS by sharing needles for self-injection of drugs.



You can get AIDS if you touch blood when having an open cut on your hand. Don't touch blood, always wear gloves, when attending to someone who is bleeding and cover wounds with a plaster.



No one is allowed to touch your private parts (it is parts of your body that is covered with your swimwear). You can say "NO" and tell an adult if it happens to you.

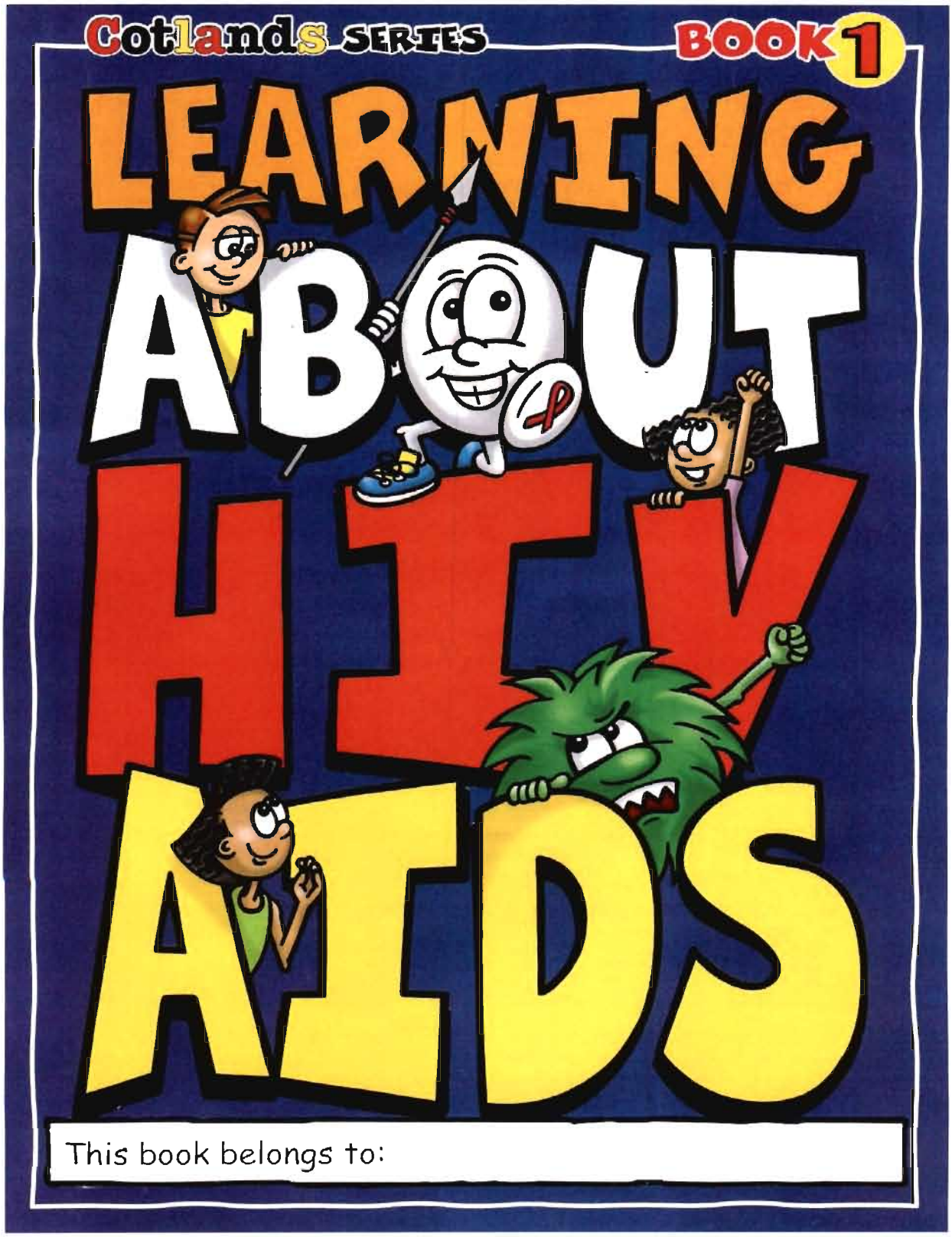


AIDS is cause by a germ (virus) living in the body's fluids. The virus weakens the body, so that people who have AIDS die because the body can no longer fight off other serious illnesses.



Wash hands before eating and after using a toilet to prevent germs from making you sick. Always wash your hands and wrists with soap & water for one minute.

COLOURING-IN BOOK FOR CHILDREN



INFORMATION PAMPHLET



Want to know more ?

How can you protect yourself against AIDS?

✚ Think carefully before you decide to have sex. You have the right to say NO. It's "cool" to be responsible.



✚ Always practise safer sex. Safer sex means using a condom correctly everytime you have sex.

✚ You can only be sure that you and your sex partner are uninfected with the AIDS virus by having a blood test before starting a sexual relationship. You and your boyfriend/girlfriend can remain uninfected by staying faithful to one another.

What can you do?

Knowing how you can get the AIDS virus and how to prevent it can, undoubtedly, save your life. But you must also learn how to cope with the demands made by boyfriends, girlfriends or friends in general.

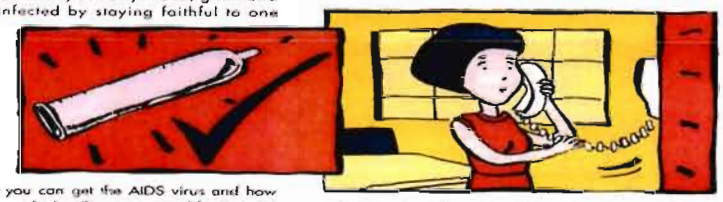
Talk freely about issues such as AIDS, sex and condoms, not only with your boyfriend/girlfriend, but also with your friends, parents, teachers, doctors and nurses.



Remember ANYONE can become infected with the AIDS virus. Try to understand, support and help people with AIDS in any way you can.

Find out all you can about AIDS! For more information:

- visit your nearest AIDS Training and Information Centre (ATIC), or
- visit your nearest clinic, or
- phone Lifeline AIDS Line tollfree at 0800 012 322



All enquiries will be handled in absolute confidence.



AIDS. Don't let it happen.



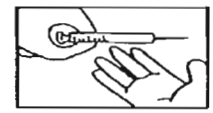
Shaking hands



Crying

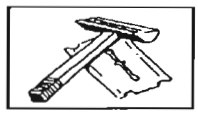


Sex with condom

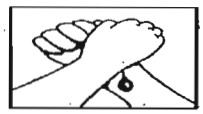


Sharing needles and syringes

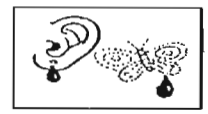
HOW YOU CAN/CAN'T BE INFECTED WITH THE HIV??



Sharing blades and razors



Mixing blood as blood brothers



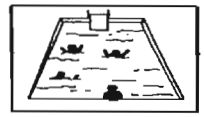
Tattooing and ear-piercing



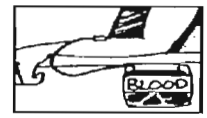
Sharing a telephone



Mosquito bites



Swimming



Donating blood



Hugging

ADDENDUM 7.4
GROWING THROUGH GRIEF JOURNAL



GROWING
Through Grief

A workbook for the grieving child.

Created by Adene Davis, Carin Marcus and Trudy Friedland

This Journal belongs to

_____

My special person who died

_____

_____ Passed away _____

ADDENDUM 7.5
HIV/AIDS EMPOWERMENT PROGRAMME CERTIFICATE

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

School of Psychosocial Behavioural Sciences: Social Work

Honours are hereby awarded

to

for successful completion

of

HIV/AIDS Empowerment programme for social work students

8 - 10 October 2008

Hanelie Malan
Programme Presenter

Prof H Strydom
Programme Supervisor

ADDENDUM 7.6
SELF-FORMULATED QUESTIONNAIRE

Complete the following questions to evaluate if the pandemic affects you and to determine your coping meganisms.

1. How do you feel about someone who has HIV or Aids?

   _____

   _____

2. How has the HIV/Aids pandemic affected you emotionally, If at all?_____

   _____

3. How has the HIV/Aids pandemic affected you spiritually, if at all?_____

   _____

4. How has the HIV/Aids pandemic affected you physically (e.g. do you sleep badly/ decrease appetite, etc.) if at all?

   _____

   _____

5. How has the HIV/Aids pandemic affected your social interaction, if at all? _____

   _____

6. How has the HIV and Aids pandemic affected your sexual activity? _____

   _____

7. What has helped you to cope as a social work student while working with HIV and Aids infected and affected people?

   _____

   _____

ADDENDUM 7.7
SEMI-STRUCTURED INTERVIEW SCHEDULE

Please tell us what you think:

1. Did you have any knowledge concerning HIV and Aids virus: prior to you attending this workshop?

2. Do you feel that this HIV and Aids empowerment programme equipped you enough, professionally to render a service to the HIV and Aids infected and affected? If yes, how?

3. Did this programme help you personally?

4. What do you think this programme must include in future?

5. What do you think we can leave out of this programme in future?

6. What would you change about the way this programme was presented?

7. What was the most helpful of this programme for you?

8. What was the least helpful part of this programme for you?

9. What would you change about the practical tools (handouts)?