LIFE MAPS AS TECHNIQUE IN A SOCIAL GROUP WORK PROGRAMME FOR YOUNG ADULTS WITH HIV/AIDS

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Dedicated to Boithetelo, who taught me about positive living and who died in a tragic shooting accident. I learned that HIV is not only for Human Immunodeficiency Virus, but also for **H**ope **I**s **V**ital!

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"HOPE

IS CRITICAL.

IT MEANS LOOKING

FORWARD

TO LIVING TODAY,

AND

TO HAVE A POTENTIAL PLAN

FOR TOMORROW

AND THREE MONTHS

FROM NOW."

Erik Peper

OPSOMMING

Suid-Afrika is een van die lande in die wêreld met die vinnigste groeiende voorkoms van HIV/VIGS. Die infeksie koers is die hoogste onder seksueel aktiewe adolessente en jong volwassenes en toekomstige projeksies is dat een uit elke vier adolessente teen 2005 geïnfekteer sal wees.

Suid-Afrika se HIV/VIGS strategieë is oorhoofs op voorkoming gemik, wat absoluut noodsaaklik is. In die tussentyd is daar egter 'n geskatte 4.2 miljoen mense reeds geïnfekteer en hulle het 'n behoefte aan ondersteuning en berading. Die meeste van hierdie mense is jonger as 45 jaar wat veroorsaak dat die mees produktiewe burgers van ons land met 'n epidemie moet saamleef waarvoor daar tans geen kuur is nie. Beperkte maatskaplike ondersteuningsprogramme is beskikbaar om die psigo-sosiale behoeftes van jong volwassenes met HIV/VIGS te bedien.

Hierdie navorsingstudie is onderneem met die oorhoofse doel om 'n intervensieprogram daar te stel wat 'n bydrae kon lewer tot die behoefte aan maatskaplike ondersteunings-programme vir mense met HIV/VIGS. Die studie het uit twee fases bestaan: die behoeftebepalingsfase en die programontwikkeling- en evalueringsfase. Die volgende twee doelstellings is vir die studie gestel:

- Om die psigo-sosiale behoeftes van jong volwassenes met HIV/VIGS te bepaal
- Om 'n maatskaplike groepwerkprogram, waar lewenskaarte as tegniek gebruik word, vir jong volwassenes met HIV/VIGS te ontwikkel

Die eerste doelstelling is bereik deur 'n ondersoekprosedure om die psigo-sosiale behoeftes van die jong volwassene met die siekte te bepaal. Die populasie het bestaan uit 'n groep van 45 jong volwassenes met HIV/VIGS in die Koppies en Bloemfontein geografiese gebiede. Die behoeftebepaling is gedoen deur middel van 'n vraelys en 'n gestandardiseerde meetinstrument, Hudson se Algemene Lewenstevredenheid Indeks.

Met verwysing na die tweede doelstelling, is 'n maatskaplike groepwerkprogram ontwikkel waar lewenskaarte as tegniek benut is. Hierdie tegniek is redelik onbekend in maatskaplikewerk praktyk, maar het die potensiaal om 'n bruikbare terapeutiese hulpmiddel te wees. Die lewenskaarte tegniek bestaan uit sewe eksistensiële vrae, wat voortspruit uit die volgende teorieë: die selfaktualiseringsteorie van Maslow, die eksistensiële teorie van Frankl, die realiteitsteorie van Glasser en die gestaltteorie van Perls. Lewenskaarte toon ooreenkomste met ander tegnieke, insluitend lewensstories en tydskrif foto collages.

Die voorgestelde groepwerkprogram is ontwikkel deur dit aan 'n groep jong volwassenes met HIV/VIGS voor te hou. Die klassieke eksperiment is benut om die program te evalueer. Die Algemene Lewenstevredenheid Indeks is as meetinstrument in die voor- en natoets gebruik. Data wat ingesamel is, was meerendeels kwalitatief van aard en is verwerk aan die hand van Tesch se benadering.

Een van die gevolgtrekking wat vanuit die studie gemaak kon word is dat jong volwassenes met HIV/VIGS 'n behoefte aan 'n sinvolle lewe het. Ander gevolgtrekkings sluit in: die sewe vrae wat in die lewenskaarte gevra is, het antwoorde op sekere eksistensiële vrae gebied en die lewenskaarte tegniek kan sinvol in maatskaplike groepwerk aangewend word. Die algemene lewenstevredenheid van die eksperimentele groep het toegeneem nadat hulle aan die program blootgestel was, terwyl die algemene lewenstevredenheid van die kontrole groep feitlik dieselfde gebly het. Laasgenoemde was dan die belangrikste gevolgtrekking: die maatskaplike groepwerkprogram, het 'n posititiewe invloed gehad op die algemene lewenstevredenheid van jong volwassenes met HIV/VIGS.

SUMMARY

South Africa is one of the countries with the fastest growing incidences of HIV/AIDS in the world. The infection rate is worst among sexually active adolescents and young adults and a situation is faced where one out of every four adolescents will be infected by 2005.

The emphasis in South Africa's HIV/AIDS strategies is on prevention, which is absolutely essential. In the meanwhile, an estimated 4.2 million people are already infected and are in need of support and counseling. Most of these people are younger than 45 years, leaving our country with our most productive members of society living with an epidemic for which there is no cure at the moment. Limited social work support programmes are available to address the psycho-social needs of young adults living with HIV/AIDS.

This research study was undertaken with the purpose of developing an intervention programme to supply in the need for social support programmes for persons living with HIV/AIDS. The study was undertaken in two phases, the needs assessment phase and the programme development and evaluation phase and included the following two aims:

- To determine the psycho-social needs of young adults living with HIV/AIDS
- To develop and evaluate a social group work programme for young adults living with HIV/AIDS where life maps are used as technique.

The first aim was achieved by the survey procedure to determine the psycho-social needs of young adults living with the disease. The population consisted of a group of 45 young adults living with HIV/AIDS in the Koppies and Bloemfontein geographical areas. The needs assessment was done by means of a questionnaire and a standardized measuring instrument, Hudson's General Contentment Scale (GCS).

As far as the second aim was concerned, a social group work programme was developed where life maps as technique was applied. This technique is fairly unknown in social work and has the potential to be a helpful tool in social work practice. The life maps technique consists of seven existential questions, including theoretical principles that originate from the self actualization theory of Maslow, the existential theory of Frankl, the reality theory of Glasser and the gestalt theory of Perls. Life maps could be linked to similar techniques, including life stories, life scripts and magazine photo collages.

The suggested group work programme was developed and implemented to a group of young adults living with HIV/AIDS. The true experiment was used to evaluate the effectiveness of the programme. The General Contentment Scale was used for pre and post testing. The data collected from this study was mainly qualitative and was processed by following Tesch's approach.

The most important conclusions that could be drawn from this study included a need among young adults living with HIV/AIDS to have a meaningful life; the seven questions asked by the life map technique supplied answers to some existential questions of the young adult living with HIV/AIDS; the life map technique could be applied effectively in social group work; and the general contentment of the experimental group increased after application of the programme, while the control group's general contentment stayed more or less the same. The latter indicated that the social group work programme that was developed, had an influence on the general contentment of a group of young adults living with HIV/AIDS.

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CHAPTER 8

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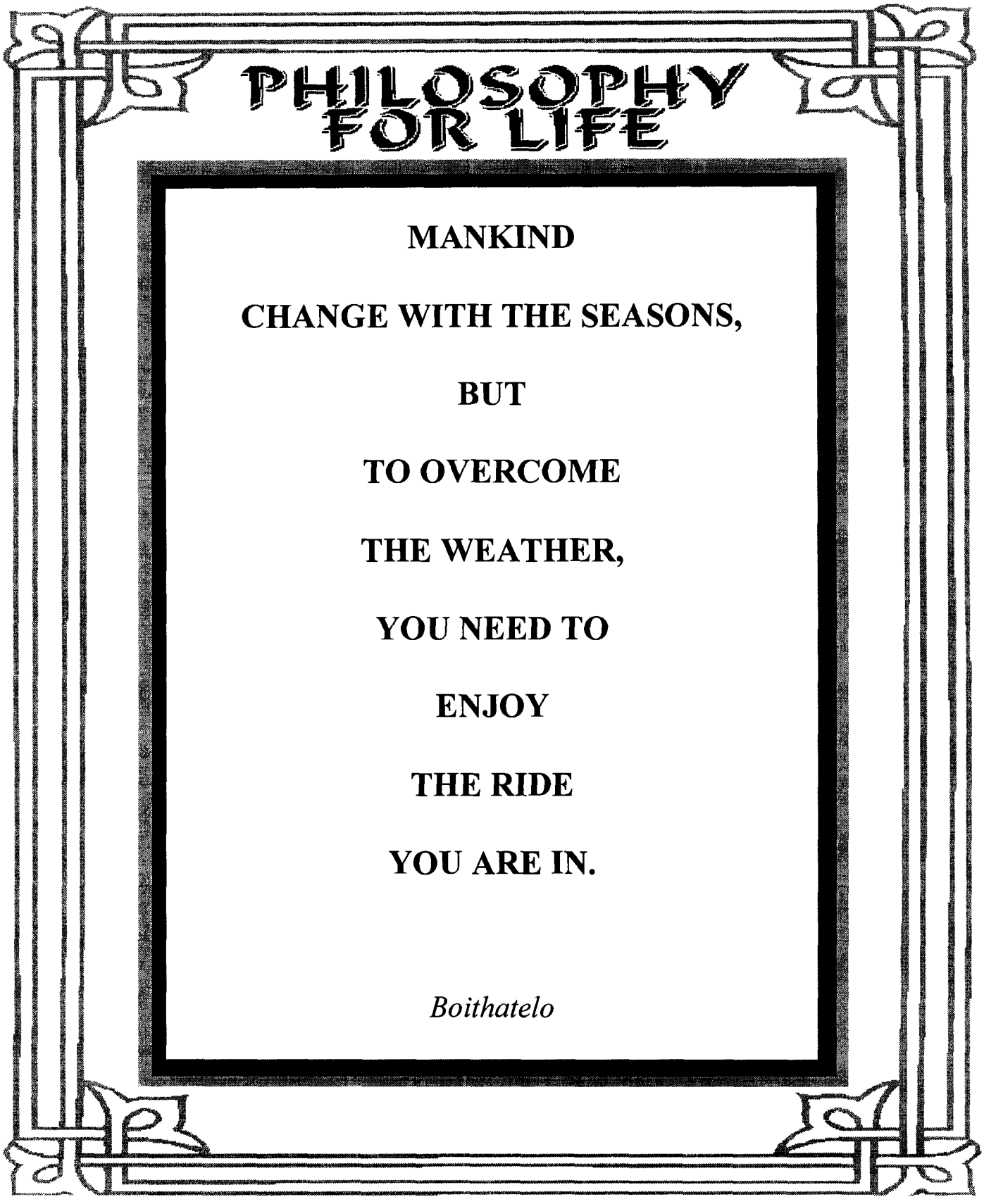
LIST OF ABBREVIATIONS

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
PLWA	Person(s) living with Aids
ARC	Aids related conditions
ATICC	Aids Training Information and Counseling Centre
GCS	General Contentment Scale of Walter Hudson
STD	Sexually transmitted disease


PHILOSOPHY
FOR LIFE
MANKIND
CHANGE WITH THE SEASONS,
BUT
TO OVERCOME
THE WEATHER,
YOU NEED TO
ENJOY
THE RIDE
YOU ARE IN.
Boithatelo

CHAPTER 1

INTRODUCTION, PROBLEM FORMULATION AND OBJECTIVES

1. PROBLEM STATEMENT

HIV/AIDS is probably the biggest international problem of the twenty first century. South Africa is one of the countries with the fastest growing incidence of HIV/AIDS in the world (Skweyiya, 2000: 2). The following facts regarding the incidence of HIV/AIDS are given by Asmal (1999: i): "There is good evidence that well over 3 million people in South Africa have HIV right now" and "If the current rate of infection does not slow down, by the year 2010 one in every four people in the country will have HIV". Gresak and Patient (1999: i) indicate that the HIV/AIDS epidemic is worst among adolescents and young adults as the 1998 statistics reflect a situation where HIV increased by 65% from 1997-1998 among this age group. According to these authors, the future prediction could be 1 out of every 4 adolescents in South Africa suffering from HIV/AIDS within the next five years. Beaver (1999: 85) confirms this situation: "... the latest statistics tell us that the HI-infection rate is worst among sexually active teenagers". The latest statistics supplied through a survey by The Department of Health (2000: 7) show the following reality:

- A 16.1% HIV prevalence rate in persons younger than 20
- A 29.1% HIV prevalence rate in persons between the ages of 20-24 years
- A 30.6% HIV prevalence rate in persons between the ages of 25-29 years.

These statistics leave us with the reality of an epidemic with enormous implications. Various authors focus on the implications on the South African labour market, economy, health budget, the delivery of government services and infrastructure (ANON., 1999: 6; Boshoff, 1999: 23; Cowlin, 1999: 33-34). The social impact of the HIV/AIDS crisis is summarized by the Minister of Education: "The idea of one in four South Africans becoming sick with a fatal illness is too awful for us to grasp. We cannot imagine what this rising wave of illness and death will do to our families, our schools and other workplaces, and our communities. While our country is struggling

to create jobs and overcome poverty, the epidemic is destroying the most productive members of our society" (Asmal, 1999: i).

The need for welfare programmes, providing support and care for people living with HIV/AIDS, was included in the ten priorities of the National Youth Commission in a submission to the National Consultative Process (Mulaudzi, 2000: 3). At the third African Population Conference in Durban in December 1999, it was agreed that HIV/AIDS is South Africa's single biggest population and development challenge and that HIV/AIDS care and support should be integrated into national and provincial programmes (Van Zuydam, 2000: 9). According to Gresak and Patient (1999: ii), existing information and counseling programmes are insufficient.

The problem can be summarized as follow:

- HIV/AIDS statistics predict a future with enormous socio-economical dilemmas
- Adolescents and young adults are directly influenced by HIV/AIDS and are a target group for new group work programmes in order to establish a future with more productive members of society
- Existing HIV/AIDS programmes are insufficient

The assumption can be made that the social functioning of young persons will be negatively influenced by the psycho-social implications of HIV/AIDS. Van Rooyen & Combrink (1980: 54) describe social functioning as all activities of the individual on all the levels of his existence, in interaction with others in his environment. The psycho-social impact of HIV/AIDS could influence the individual's general contentment.

In addition, Du Preez (1989: 110) emphasizes that man's social functioning can be positively influenced by group interaction. Social group work could be an effective method to use in this research project as it also has the advantages of time and cost effectiveness.

The researcher came to the conclusion that dealing with HIV/AIDS is a topic that could not be researched enough, neither could new, innovative programmes be of any use. That was the starting point which initiated this research project and brought the researcher to the following question: Can a young adult experience contentment while living with a killer-disease such as HIV/AIDS?

2. CHOICE OF RESEARCH TOPIC AND MOTIVATION FOR THE STUDY

Life mapping is a technique that has been used by the researcher for the past ten years in general social work practice. It was found to be an effective tool for assessment and to help people gain self-knowledge and insight into their problems, but is has never been properly described or researched. This led to the primary motivation for this study: to describe this technique by doing proper research on its origin, theoretical foundation, applicability and what the outcome would be when it was applied to a specific group.

The seriousness of the HIV/AIDS crisis in our country is something that no one can deny any more and the researcher was interested in the existing programmes to support people living with HIV/AIDS. It seems as if various programmes have been developed by government and non-government organizations to prevent the spreading of HIV/AIDS. Although these programmes are of the utmost importance, the question arises what is being done for all the persons who have already contracted the disease and have to live with it from day to day. It was discovered that very few programmes of this kind exist and it is also very difficult to get funding for projects like these. The researcher works as a medical social worker and the support of people with chronic or terminal diseases has always been a field of interest. The survival, both physical and emotional, of people living with HIV/AIDS was something "unknown" and caused an intense interest with the researcher to conduct this study.

In the third place, the researcher would like to formally publish information on life maps as technique, as it was personally found to be an effective technique in social work practice. Such publication will, however, not be possible without proper research, both theoretical and empirical. This study could be the foundation of such a publication.

3. RESEARCH GOALS AND OBJECTIVES

This study consists of two primary aims, which are divided into more practical objectives.

3.1 GOAL 1: TO DETERMINE THE NEEDS OF ABOUT 50 YOUNG ADULTS WITH HIV/AIDS AND TO MEASURE THEIR GENERAL CONTENTMENT

3.2 OBJECTIVES THAT FOLLOW THIS GOAL INCLUDE:

- To identify the psycho-social needs of young adults living with HIV/AIDS by using a structured needs assessment questionnaire.

- To measure the general contentment of young adults living with HIV/AIDS by using Hudson's Generalized Contentment Scale (GCS) (Bloom, Fischer & Orme, 1999: 220).

3.3 GOAL 2: TO DEVELOP AND EVALUATE A SOCIAL GROUP WORK PROGRAMME FOR YOUNG ADULTS LIVING WITH HIV/AIDS WHERE LIFE MAPS ARE USED AS TECHNIQUE

3.4 OBJECTIVES THAT FOLLOW THIS GOAL INCLUDE:

- To develop a social group work programme for young adults living with HIV/AIDS from the results of the needs assessment.

- To implement and apply the social group work programme where life maps are used as technique

- To evaluate the social group work programme with special reference to the general contentment of young adults living with HIV/AIDS.

- To utilize an experimental design in order to prove the efficiency of the programme

4. CENTRAL THEORETICAL ARGUMENT

If young adults living with HIV/AIDS are involved in a social group work programme where life maps are used as technique, certain of their needs will be satisfied and their general contentment will increase.

5. PILOT STUDY

The pilot study can be seen as the researcher's orientation towards the planned research and from a theoretical point of view it should consist of the following four components (Strydom, 1998(a): 179-182; Strydom, 2000: 48-53).

- Study of the literature
- The experience of experts
- Preliminary exploratory studies
- Intensive study of strategic units

These four aspects will be described as they were applied in this study.

5.1 STUDY OF THE LITERATURE

The aim of the literature review was to place the research problem in theoretical perspective by studying the available literature related to the problem.

By making use of the infrastructure of the local University Library, it was possible to conduct a thorough literature study. Various databases were consulted, including The Eric Nexus Database, Dissertation Abstracts and the Internet. The National Research Foundation was consulted to determine if other similar studies were conducted or were in progress.

After consulting the applicable databases and other resources, the study of applicable literature commenced. In this process the researcher realized that information on HIV/AIDS was easily obtainable, but that very little or no literature could be found on life maps as technique. There was also limited literature regarding counseling and support programmes for people living with HIV/AIDS. Most of the programmes were aimed at prevention. The researcher was convinced that this study should be conducted in a field were there is insufficient information available and was motivated to go ahead with the planned study.

5.2 THE EXPERIENCE OF EXPERTS

The researcher made use of formal and informal consultation with experts in the field of HIV/AIDS counseling. The following experts were consulted to guide the researcher:

- The matron of the local community health centre and other nursing staff
- The local general practitioners
- A minister involved with a Christian programme in dealing with HIV/AIDS among young persons
- The Aids Training and Information and Counseling Centre (ATICC) in Bloemfontein
- The Leratong Support Group for people living with HIV/AIDS in Mangaung

Each of these groups of experts gave valuable information to the researcher, but the most important information was gathered during a meeting of the Leratong Support Group. In this meeting, information was supplied by the real experts: the people living with HIV/AIDS (PLWA). It was during this meeting that the researcher came into direct contact with the daily problems, fears, hopes, dreams and difficulties of PLWA. After this meeting the researcher came to the most important realization: people with HIV/AIDS are just people! They have the same dreams, hopes, fears and problems as any other human being, adding to it the psycho-social impact of a deadly, incurable disease. The following important aspects, learned from this group, need to be highlighted:

- There was an increased need to live openly with the disease by disclosure to family and friends
- A need for acceptance was verbalized by most of the group members
- They sought independence, but obstacles such as poor health, the inability to obtain a job, poverty and social isolation caused them to be constantly dependent on the support of a primary family and health care services.
- The need to be among other PLWA were verbalized and with that the need for support programmes.
- Two of their biggest problems were stigmatization and rejection, even by their own parents.
- A need to discuss issues regarding death and dying was verbalized.

- Many of the support group members were voluntarily involved in HIV/AIDS projects, including lay counseling, day care of HIV/AIDS orphans and home based care. They mentioned a need to feel valued and to use their HIV/AIDS status to help others.

These aspects were taken into consideration throughout the study and when the questionnaire was compiled.

5.3 PRELIMINARY EXPLORATORY STUDIES

According to Strydom (2002: 10) at this stage of the pilot study, the researcher should address the following aspects:

- The goals of the research project
- The resources available
- The research population
- Data gathering procedures
- Field workers

Various organizations and institutions were consulted during the preliminary exploratory study, including the local health care centers and Bloemfontein ATICC. The assurance was given that potential respondents were available and they offered their assistance to the researcher in identifying the potential respondents. The necessary consent was asked from local and provincial authorities and meetings were held with staff of the Kganya Health Care Centre and Bloemfontein ATICC.

Attending a meeting of the Leratong Support Group also formed part of the preliminary exploratory study. The research project was introduced to the group members and their participation was sought.

The researcher learned that it could be difficult to find enough respondents in a certain age group, especially adolescents. Although adolescents are statistically a large group of the persons living with HIV/AIDS in South Africa, they often are not aware of their status. When their status is known they are scared to disclose their HIV/AIDS status openly due to fear of stigmatization and social isolation.

There was, however, a large group of persons younger than thirty years who voluntarily asked to participate in the research project.

This research project was estimated to be very costly, due to the distance travelled to meet respondents in the Bloemfontein area, which caused high travelling expenses.

All these aspects were taken into consideration when the research project was planned, and so the researcher was prepared for possible obstacles.

5.4 INTENSIVE STUDY OF STRATEGIC UNITS

The measuring instruments, a structured interview questionnaire (**See Annexure 1**) and the Hudson Generalized Contentment Scale (GCS) (Bloom *et al.* 1999: 220) (**See Annexure 2**), were pre tested by a group of four persons living with HIV/AIDS who were selected by a convenience sample. These respondents did not participate any further in the research project.

During this study the researcher learned that completing the GCS could be difficult for some respondents and that it would be very difficult to complete the questionnaires without a structured interview and sometimes without the help of an interpreter. Changes were made to the questionnaire in order to overcome some of the problems identified by the group.

6. THE RESEARCH DESIGN

According to Strydom (2000: 76), the research design implies the plan, structure and strategies to find answers to the research problem on the level of collecting information and knowledge. The chosen research design directed the whole research process, including which research methods and procedures would be followed.

This study consisted of two phases, first the phase of needs assessment and secondly the phase where the group work programme was developed and evaluated. In phase one the exploratory research design was used and in the second phase it moved to the explanatory research design.

6.1 EXPLORATORY RESEARCH

Although HIV/AIDS is a well researched topic and an existing phenomenon, certain aspects, including support programmes and the psycho-social needs of PLWA, need further exploration and description (Bailey, 1982: 38). According to Fouche and De Vos (1998(b): 124), explanatory studies could include the following aims:

- to gain new insights into the phenomenon
- to undertake a preliminary investigation prior to a more structured study of the phenomenon
- to explicate the central concepts and constructs
- to determine priorities for future research
- to develop new hypotheses about an existing phenomenon

Some of the above mentioned aims could be linked to this study, including gaining new insights into the psycho-social implications of HIV/AIDS, the needs of PLWA and existing support programmes for PLWA. In some way it could also be seen as a preliminary investigation for the second phase of this study, where an innovative support programme was developed, evaluated and introduced.

6.2 EXPLANATORY RESEARCH

When trying to explain a phenomenon, it is important that facts, insights and theories should be compared and causalities be explained. The first aim should be to better understand the phenomenon and to supply answers to the questions: *why?* and *how?*. Secondly theorizing should take place in order to answer the *why?* and the *how?* questions and should consist of the process of providing explanations for a specific phenomenon (Bailey, 1994: 40; Strydom, 2000: 78).

In this study the *why?* and *how?* questions were being answered in the second phase of the study. Information gathered in this phase was evaluated and applied to theory in order to give an explanation for the researched phenomenon. A theoretical basis for life maps as techniques could therefore be supplied and a foundation could be laid for the formulation of an group work programme for PLWA.

Components of both exploratory and explanatory research designs were applied in this study.

7. RESEARCH PROCEDURES

7.1 STUDY OF THE LITERATURE

A wide range of literature was identified and studied, including books, academic studies, government and informal publications and scientific magazines. Literature regarding HIV/AIDS in social work is limited and most literature was obtained from related professions including psychology, medicine, nursing and sociology. Literature on life maps was extremely limited and only two books and a few articles could be found on this topic. This study could be seen as a contribution to literature on this technique.

The study of the literature was a time consuming effort, but was an essential part of the study as it supplied the necessary background for the research topic and placed it in a theoretical framework. Fouche and De Vos (1998 (a): 64) emphasize that the literature study aims to clarify the nature and meaning of the problem.

7.2 EMPIRICAL STUDY

The intervention research model (Fouche & De Vos, 1998(a): 67-71) was applied, as the aim of this study was to develop an innovative intervention strategy. This research model consists of the following phases:

- Problem analysis and project planning
- Information gathering and synthesis
- Design
- Early development and pilot testing
- Evaluation and advanced development
- Dissemination

With the intervention research model as background and following Creswell's two-phase model of combining quantitative and qualitative research (De Vos 1998: 360), the empirical study was divided into two phases: the needs assessment phase and the programme development and evaluation phase. It was necessary to divide it into these two phases as the research process consisted of combined quantitative-qualitative research methods. The first phase included more data with a numerical content (quantitative) and the second phase contained data that were principally verbal (qualitative) (De Vos, Schurink & Strydom, 1998: 15). The two phases will be described briefly in figure 1.

The following research procedures were used in this study:

- A survey (structured questionnaires and standardized measuring instrument)
- An experiment

(Bailey, 1994: 192 & Strydom, 2000: 79.)

The group work programme, as it was presented to the experimental group, will be discussed in full in Chapter 6. Evaluation of the group work programme is summarized in Chapter 7.

FIGURE 1: THE TWO PHASES OF THE EMPIRICAL STUDY

PHASE 1: NEEDS ASSESSMENT	PHASE 2: PROGRAMME DEVELOPMENT AND EVALUATION
DESIGN: The exploratory research design	**DESIGN:** The explanatory research design
RESPONDENTS: Fifty young persons living with HIV/AIDS selected by a convenience sample to complete structured interview needs assessment questionnaires	**RESPONDENTS:** An experimental and a control group of 10 young persons living with HIV/AIDS selected by purposive sampling to participate in the social group work programme
MEASURING INSTRUMENTS AND PROCEDURES: A survey, including a structured needs assessment questionnaire and a standardized measuring scale, Hudson's Generalized Contentment Scale (GCS) (Survey procedure) **ETHICAL ISSUES:** As confidential information was obtained, all respondents gave written informed consent to participate in the research project and all information was treated confidentially at all times	**MEASURING INSTRUMENTS AND PROCEDURES:** Experimental research with a experimental and control group. Life maps and the standardized GCS were used as measuring instruments **ETHICAL ISSUES:** A large percentage of the original respondents were excluded from the experimental group and could be denied the opportunity to gain from the suggested programme. To overcome this, it was agreed that the programme would be made available to ATICC Bloemfontein after this study was completed for possible application to other groups. The issue of publication of group members' personal information was discussed and they gave written informed consent to participate. All information was treated confidentially. Debriefing sessions after termination of the group sessions were scheduled to reduce the possibility of leaving respondents with unfinished personal issues.
DATA ANALYSIS: The information gathered in this phase was processed by hand and by computer	**DATA ANALYSIS:** The steps of Tesch's approach to data processing were followed

8. THE UNIT OF ANALYSIS

The unit of analysis for this study was individuals – the needs of young persons living with HIV/AIDS (Bailey, 1994: 35-36; Fouche & De Vos, 1998(a): 68). The study was executed in two Free State areas, Koppies and Bloemfontein. Information on possible respondents was obtained from the local and provincial health care centers. No biographic information was

supplied without the consent of individuals. Information was obtained from the following organizations:

- Kganya Health Care Centre – Kwakwatsi
- ATICC Bloemfontein
- The Leratong Support Group

All information supplied to the researcher was evaluated. Only persons younger than 30 years, of both sexes, could be included in the research project. The most prominent criterion was that a respondent had to be a person positively diagnosed with HIV/AIDS.

9. POPULATION, SAMPLING AND SAMPLING METHODS

9.1 POPULATION

The population of this study consisted of persons living with HIV/AIDS and who were younger than 30 years. Potential respondents were approached at the local health care center and the Leratong Support group meeting. Information on the research project was supplied and persons were motivated to participate. Individuals who wanted to participate were asked to complete the structured interview needs assessment questionnaire.

9.2 SAMPLING AND SAMPLING METHODS

In the first phase a convenience sample (Bailey, 1994: 94) was used to identify the first respondent, followed by snowball sampling (Bailey, 1994; 96), where identified respondents brought the researcher in contact with other potential respondents.

In the second phase purposive sampling (Bailey, 1994: 96) was used to select respondents for the experimental and the control groups. Firstly those who indicated a further interest to participate in the research were listed. The researcher then divided them in two groups, trying to match their sex and age Each group consisted of 10 members. The following figure supplies further information on the composition of the groups.

FIGURE 2: COMPOSITION OF THE EXPERIMENTAL AND CONTROL GROUPS

EXPERIMENTAL GROUP			CONTROL GROUP		
NUMBER OF GROUP MEMBERS: 10*			NUMBER OF GROUP MEMBERS: 10		
SEX OF MEMBERS: MALE 2 FEMALE 8			SEX OF GROUP MEMBERS: MALE 3 FEMALE 7		
AGE OF GROUP MEMBERS			AGE OF GROUP MEMBERS		
18-21 YRS	22-25 YRS	26-30 YRS	18-21 YRS	22-25 YRS	26-30 YRS
4	**3**	**3**	**2**	**4**	**4**

*The number of experimental group members changed to 9 after the first group session when one member withdrew from the group.

10. ANALYSIS OF EMPIRICAL INFORMATION

The data analysis in the first phase was done by hand and by computer. In the second phase Tesch's approach to qualitative data processing (Poggenpoel, 1998: 343-344) was followed.

11. ETHICAL ISSUES

The ethical dilemmas that were experienced in this study are briefly described in Figure 1. With reference to ethics, anonymity, confidentiality, professionalism, respect and ethical decision-making seem to be the key concepts (Corey, Corey & Callanan, 1993: 4 & 229; Grasso & Epstein, 1992: 18-119; Strydom, 2002: 16-17; Strydom 1998 (b): 23-25). According to Cameron (1993: 6-8), ethical problems surrounding HIV/AIDS usually consist of the following categories:

- Alcohol and drugs

- Chronic illness
- Death
- Discrimination
- Finance and business
- Health care
- Personhood
- Relationships
- Service
- Sexuality

These aspects need to be considered throughout this study and form an important part of the psycho-social problems of PLWA.

The following figure by Cameron (1993: 9) serves as an excellent example of the basic nature of ethical problems involving HIV/AIDS.

FIGURE 3: THE BASIC NATURE OF ETHICAL PROBLEMS INVOLVING AIDS

WHAT IS THE RIGHT WAY TO LIVE AND DIE IN RELATION TO OTHER PEOPLE?
CONFLICT of values about what to believe, who to be, and what to do (Descriptive ethics and metaethics)
RESOLUTION based on intuitive beliefs, desire to be a good person, and rational choice (Normative ethics and metaethics)
RATIONALE revolving around a desire for meaning (seeing one's life as part of a bigger, purposeful picture) and integrity (living in harmony with one's values) (Normative ethics and metaethics)

The ethical issues mentioned in this figure, show definite links with the themes of the life maps that will be described in Chapters 5 and 6.

12. LIMITATIONS OF THE STUDY

12.1 LITERATURE

Due to limited literature on HIV/AIDS in social work, literature was obtained from medical and psychological sources, which could lead to an impression that it was not a social work survey in general. This imbalance was overcome by using a wide range of literature on social group work and the theoretical foundations of life maps.

Literature on life maps was the other limitation as only a few sources could be obtained. This led to using the same sources over and again, with more or less the same viewpoints and very little to compare it to.

12.2 SURVEY PROCEDURE

The use of structured interview questionnaires was essential because often respondents were illiterate, had limited writing skills or could not understand Afrikaans or English. This type of interview also had the advantage that all questions were answered and a high response rate was established. Using this procedure, however, had the disadvantages of making it very costly and time consuming (Bailey, 1994: 190).

Respondents also found completing the GCS very difficult. Some complained that they could not understand what certain items meant and that the similarity of certain items confused them. These items included:

- Item 2: "I feel blue"
- Item 7: "I get very depressed"
- Item 10: "I feel downhearted"

Only a few of the respondents were able to complete this scale independently.

The above-mentioned problems led to the question if the conclusions drawn from this measuring instrument were always valid and reliable. There was concern that some respondents completed the scales at random because they did not always understand the meaning of items.

12.3 THE POPULATION

It was very difficult to identify potential respondents due to the following obstacles:

- Persons living with HIV/AIDS were reluctant to get involved, fearing possible stigmatization if they disclose their HIV status
- All information on persons' HIV status is strictly confidential, making it impossible to obtain a "list" of potential respondents
- Very often people were suspected of having HIV/AIDS, but the tests to confirm it could not be done due to lack of funds in the provincial health budget at that time. No one could be included in this study unless a positive diagnoses of HIV/AIDS had been made
- Potential respondents were not all willing to participate in the planned experimental group
- Some of the originally identified respondents died before they could participate any further in the study
- A very sad obstacle was the death of one of the field workers, who also was one of the experimental group members and a young living ambassador. She did not die of HIV/AIDS, but in a shooting incident. She was in possession of at least 20 completed questionnaires, which could not be found after her death.

One of the biggest problems was the fact that certain respondents who were willing to participate further in the research, were not willing to participate in a group situation. This problem caused that the experimental and control groups could not be handled exactly the same. The control group was followed up telephonically while the experimental group was followed up in a group session. This was the only way to respect respondents' right to confidentiality.

These problems caused the study to have a slow start and resulted in a very costly and time-consuming investigation. The results of the experiment could be affected by the fact that the experimental group was not involved in a group situation.

Taking into consideration the difficulty to obtain potential respondents, it was almost impossible to rely on probability sampling. Most respondents were selected by convenience or snowball sampling.

13. DEFINITIONS OF KEY CONCEPTS

13.1 AIDS

According to Van Dyk (1992: 5), AIDS is the acronym for Acquired Immunodeficiency Syndrome and she defines it by explaining each word in the acronym:

- 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

Further, AIDS is strictly spoken of not as a disease, but a as a collection of various conditions damaging the immune system. This leads to the concept HIV, which will be defined next.

13.2 HIV

HIV is the abbreviation for ***the human immune-deficiency virus*** (Whiteside & Sunter, 2000:2). According to Evian (2000: 7), the HI-virus " ...enters the body and destroys important cells which control and support the immune system". This virus was found to be the cause of AIDS and various other immune system diseases and opportunistic infections.

13.3 SOCIAL GROUP WORK

Social group work is defined by the Terminology Committee for Social Work (1995: 48) as a "method in social work whereby the individual and group objectives are realized within the group

context by purposefully applying the group work process". Barker (1991: 218) adds to this definition that social group work also involves activities designed to achieve certain common goals in the group.

These goals are further defined by Fatout (1992: 3), stating that social group work " uses the group approach to accomplish the goals common to all social work activities: (1) to prevent members from developing dysfunctional ways of coping with their situations; (2) to enhance members' engagement in and use of artistic, social, intellectual, and other endeavors; and (3) to rehabilitate members who have developed handicaps in their social and personal functioning".

Gestalt group therapy has partly been used in this study and involves individual therapy in the presence of others (the group) where the central task is the facilitation of the person's awareness of self, including feelings, behaviours, experiences and unfinished business (Fatout, 1991: 86 & 92).

A group can be presented as a marathon group where the participants remain together for extended periods of 18 to 24 hours or more (Barker, 1991: 139; Rose, 1998: 51).

In this research project the gestalt group workshop was applied in a marathon way.

13.4 GENERAL CONTENTMENT

Contentment can be defined as "a satisfied state" or "tranquil happiness" (The Oxford Encyclopedic English Dictionary, 1991: 314) and "freedom from worry" and "rest of mind" (Webster Comprehensive Dictionary, 1998: 282).

On the instructions of the GCS, contentment is described as the way one feels about one's life and surroundings.

For purposes of this study, general contentment is defined as positive feelings of the individual towards himself, his environment and life situations.

13.5 LIFE MAPS

"Life maps are tools for self-discovery, and guides to various aspects of your life as you experience it. They are a way of outlining the territory, signposting the terrain and becoming familiar with the landscape of your life. Maps can help you connect up the various aspects of your life by

establishing links between your past, present and future, and the different levels of your being, for example, your mind, body, emotions and spirit. They can help you focus on the detail of specific areas of your life" (Mulligan, 1988: 12).

According to Yochanan (1991: 91), life maps are a tool to meet various aims of an group work programme including: defining the problem; determining goals; collecting information; developing alternatives; and evaluation of outcome.

According to Barker (1991: 132), life review is a process where the individual takes an overview of his life, tries to assess it and searches for the meaning of life, as it is an important part of existential social work. *(The concept of existential social work will be described in chapter5 under the theoretical foundations of life maps).*

The previous definitions were summarized and integrated by the researcher to formulate the following definition:

Life maps are therapeutic tools for assessment and counseling where individuals or groups review their lives in terms of the past, present and future by focusing on their views of themselves, others, the world, their problems and coping skills.

In this study, life maps refer to the technique applied in the group work programme to enable group members to discover themselves, come to terms with their past, identify their problems, finding possible solutions for these problems and to set a direction for the future.

13.6 SOCIAL GROUP WORK PROGRAMME

According to the Terminology Committee for Social Work (1995: 49) defines the term programme as the process between a social worker and a group where a systematic pattern is followed to achieve group goals. For purposes of this study the concept social group work programme refers to the suggested self-developed group work programme applied to the experimental group.

13.7 EXPERIMENTAL RESEARCH

Experimental research can be seen as highly scientific and one of the best ways to measure causality between a program treatment and expected outcome. It consists of the following characteristics: A manipulated independent variable; at least one dependent variable; the random assignments of subjects; and the process of pretesting and posttesting (Babbie, 2001: 216; Grinnell & Williams, 1990: 167; Powers, Meenaghan & Toomey, 1985: 206 – 207).

14. FORMAT OF THE RESEARCH REPORT

The research report can be seen as the final product of the research process (Strydom, 1998(c): 419) and is a combined effort of integrating theory and practice. Throughout the report theoretical and practical aspects supplement each other. The findings of this study cannot be interpreted without bearing this integrative process in mind.

The report was divided in two sections and consisted of eight chapters. Figure 4 gives an overview of the format of the research report, including the following chapters:

In **Chapter 1,** a general introduction gives an overview on the problem statement and the motivation for the research. Other aspects include the research aims and objectives; the central theoretical argument; the preliminary investigation; the research design; the research procedures; the unit of analysis; the universe; the sampling methods; the methods of data analysis; the limitations of the study; and the definitions of key concepts.

Chapter 2 supplies detail on the research methodology that has been followed in this study. The research design and procedures are described in full.

In **Chapter 3** attention is given to background information on HIV/AIDS and the psycho-social implications it has on the young individual within his social system. This social system includes family, friends, intimate relationships, career and general social circumstances, including poverty.

Chapter 4 consists of the data gathered from the needs assessment questionnaire and serves as the empirical foundation of the suggested group work programme.

Chapter 5. focuses on social group work as method of intervention and the nature of life maps as technique. In order to give a theoretical foundation to life maps, various existential theories are described.

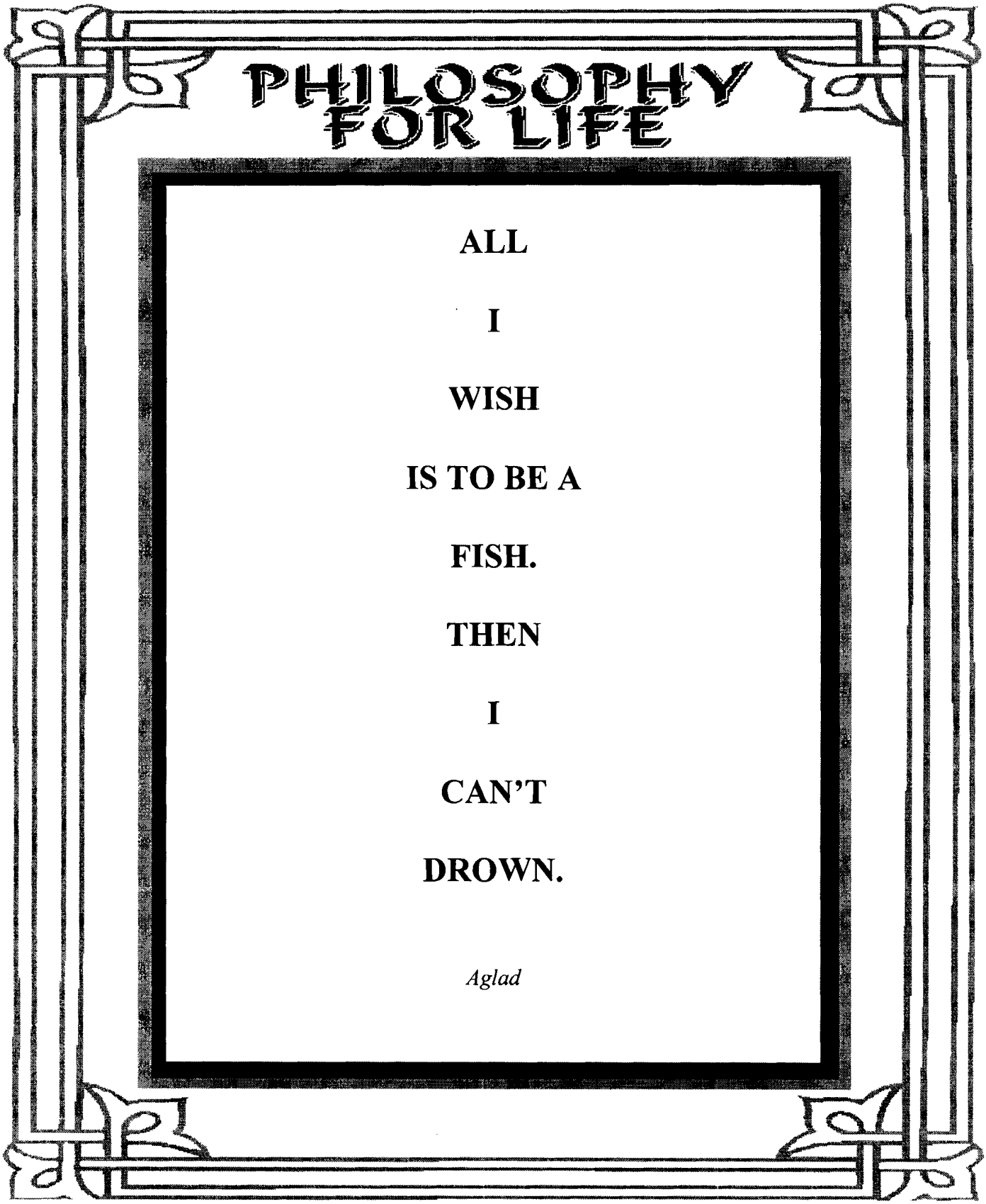
Chapter 6 presents the suggested group work programme. Although, for purposes of this study, it was applied to young persons living with HIV/AIDS, it could be applied to individuals and groups in general. The programme could also be applied by complementary disciplines, including nursing and psychology.

In **Chapter 7** the group work programme is being evaluated by presenting the data collected from the experimental and control groups.

Chapter 8 is the last chapter, consisting of a summary, conclusions and recommendations.

FIGURE 4: THE FORMAT OF THE RESEARCH REPORT

SECTION 1 : NEEDS ASSESSMENT PHASE			
CHAPTER 1	**CHAPTER 2**	**CHAPTER 3**	**CHAPTER 4**
Introduction, problem formulation and objectives	Research methodology	The psycho-social implications of HIV/AIDS on young adults	Empirical data collected from the needs assessment
SECTION 2 : PROGRAMME DEVELOPMENT AND EVALUATION			
CHAPTER 5	**CHAPTER 6**	**CHAPTER 7**	**CHAPTER 8**
Life maps as technique in a social group work programme	The suggested group work programme	Research findings and evaluation of the programme	Summary, conclusions and recommendations


PHILOSOPHY FOR LIFE
ALL
I
WISH
IS TO BE A
FISH.
THEN
I
CAN'T
DROWN.
Aglad

CHAPTER 2

RESEARCH METHODOLOGY

1. INTRODUCTION

The first objective of this chapter is to define the research design that has been applied in this study. The study was divided in two phases and in each phase a different research design was applied.

In the first phase, where a needs assessment was done, the exploratory research design was applied. This design was chosen because an existing phenomenon was further explored and described in order to identify the needs and to supply answers on how young adults' general contentment was affected by HIV/AIDS.

In the second phase where the group work programme was developed and evaluated, the explanatory research design was applied. This design is especially applicable where limited information is available on a subject and it may involve comparison groups or social experiments that could assist social workers to develop new treatment approaches (Royse, 1995: 28). Life maps as technique is fairly unknown in social work practice and in this study experimental research was applied to compare a group where the life maps were applied and another group where life maps were not applied.

The second objective of this chapter is to describe the type of research, the research model and the different research procedures applied in this study.

As the aim of this study was to develop an innovative intervention strategy, the intervention research model was applied. Both qualitative and quantitative methods were used.

Every phase of the research involved different research procedures, measuring instruments and data processing. All of these aspects will be discussed in this chapter. The following figure summarizes the research methodology that was followed in this study. .

FIGURE 5: THE RESEARCH METHODOLOGY

THEORETICAL	AS APPLIED IN THIS STUDY
TYPE OF RESEARCH	Applied research
RESEARCH PERSPECTIVE	Qualitative-quantitative combined
RESEARCH DESIGN	Exploratory and explanatory designs
RESEARCH PROCEDURES	Survey, experimental design, intervention research, experimental group
DATA COLLECTION PROCEDURES	Standardized measuring instrument (GCS), Needs assessment questionnaires, Life maps

2. THE RESEARCH DESIGN

Selecting a research design is probably the starting point of all research as it will determine the research methods and procedures to be applied. The concept research design is described by Royse (1995: 27) and Strydom (2000: 76) in the words of Grinell as: "logical strategies for planning research procedures and providing evidence for the development of knowledge" and "a blueprint or detailed plan for how a research study is to be conducted – operationalizing variables so they can be measured, selecting a sample of interest to study, collecting data to be used as a basis for testing hypotheses, and analyzing the results". A summarized definition of research design is supplied by De Vos & Fouche (1998 (a): 99) where they described it as " the roadmap or blueprint according to which we intend achieving our research goals and objectives". When describing the research design, the following information should be included:

- *who* will be studied
- *what* will be observed or measured
- *when* the observations and/or measurements will occur
- *how* these data will be collected.

It seems impossible to conduct research without a proper research design as it provides the researcher with a certain structure and strategies to follow through the research process (Smit, 1985: 25). It also involves the level on which information is collected.

In this study both the exploratory and explanatory research designs were used. Each of these designs will be described briefly.

2.1 THE EXPLORATORY RESEARCH DESIGN

The exploratory research design is recommended for studies where little or no information is available on a certain topic (Dane, 1990: 5) but also when certain concepts of a topic need to be better described and defined (Hofmeyr, 1989: 3). According to Dane (1990: 234), explanatory research has intrinsic value as it stimulates persons to do research.

Taking these viewpoints into consideration, the researcher applied the explanatory research design for the first phase of the research. HIV/AIDS is not unknown territory in the field of social work, but during the literature study it was clear that insufficient information is available on the psycho-social needs of young adults living with HIV/AIDS. There is especially a lack of emotional support programmes for PLWA.

During the literature overview, it was found that information on HIV/AIDS in general is easily obtainable and available, but limited information is available on the psycho-social aspects of HIV/AIDS and support programmes from a social work point of view. Information on life maps as technique is almost non-existing, which confirmed that the research topic of this study needed further exploration.

2.2 THE EXPLANATORY RESEARCH DESIGN

In the second phase of this study, the explanatory research design was applied as it was aimed to give explanations for certain phenomena. Explanatory research may also involve groups or social experiments, which are applicable in this study. These could help social workers to develop new treatment approaches (Royse, 1995: 28). Facts, theory and the results of measuring were compared in order to supply possible explanations (Bailey, 1994: 40-41; Strydom, 2000: 78). Using this design also enabled the researcher to gain new insights into the psycho-social needs of PLWA. In the last place the explanatory research design was important as it could test whether or not the independent variable (life maps) had an influence on the dependent variable (the general contentment of young PLWA) (Dane, 1990: 245).

3. TYPE OF RESEARCH AND RESEARCH PERSPECTIVE

The main objective in any research is to gather information to broaden knowledge on a specific topic or phenomenon. A researcher has to determine what the purpose of his research should be by viewing the two main types of research: basic (pure) research and applied research. Basic research refers to the gathering of abstract information about human behavior, mainly on an intellectual level, but without real practical applicability. Applied research, on the other hand, is research designed with the purpose of practical application and problem-solving and is often used in human sciences (Bailey, 1994: 24-25; Monette, Sullivan & De Jong, 1998: 5). A third type of research is described by Strydom (2000: 10) as action research. In this type of research the aim is to improve existing services. An exciting, new view of applied research, intervention research, is introduced by De Vos, Schurink & Strydom (1998: 9). This type of developmental research enables the researcher to evaluate, develop and create new technology (Botes, 1997: 27). Intervention research was applied in this study and will be described in full later in this chapter.

Another form of research that has been applied in this study is needs assessment research. This type of research could be viewed as one of the oldest forms of social research and is defined by Schuerman (1983: 86) as: " research aimed at documenting the needs of people living within a

particular community or other geographical region or the needs of a particular subgroup within a region". This type of research usually involves interviews or questionnaires and the aim is to determine what the need for a potential program is (Grinnell & Williams, 1990: 251). It is the researcher's opinion that without thorough needs assessment research it would be very difficult, if not impossible, to do intervention research. Needs assessment research will not be described to the same extent as intervention research, as it is a well-known form of research in social work. The questionnaire that was used as needs assessment instrument will, however, be fully described in this chapter.

It is also important to refer to *qualitative* and *quantitative* research. These two aspects can be seen as the perspective one takes on the planned research. In quantitative research, objective facts are measured and data can be analyzed statistically. Qualitative research, on the other hand, deals with data that are more verbal, based on personal values and experiences and tries to describe situations in a narrative and holistic way (De Vos, Schurink & Strydom: 1998: 15; Neuman, 2000: 16-17; Strydom, 2000: 74-75). A qualitative-quantitative-combined method can also be used.

Whatever type of research is chosen, the following four basic principles of research should be considered:

- it should add to the broadening of knowledge;
- it should have a scientific character;
- it should keep to scientific regulations and principles; and
- it should maintain objectivity

(Strydom, 1999: 10-13.)

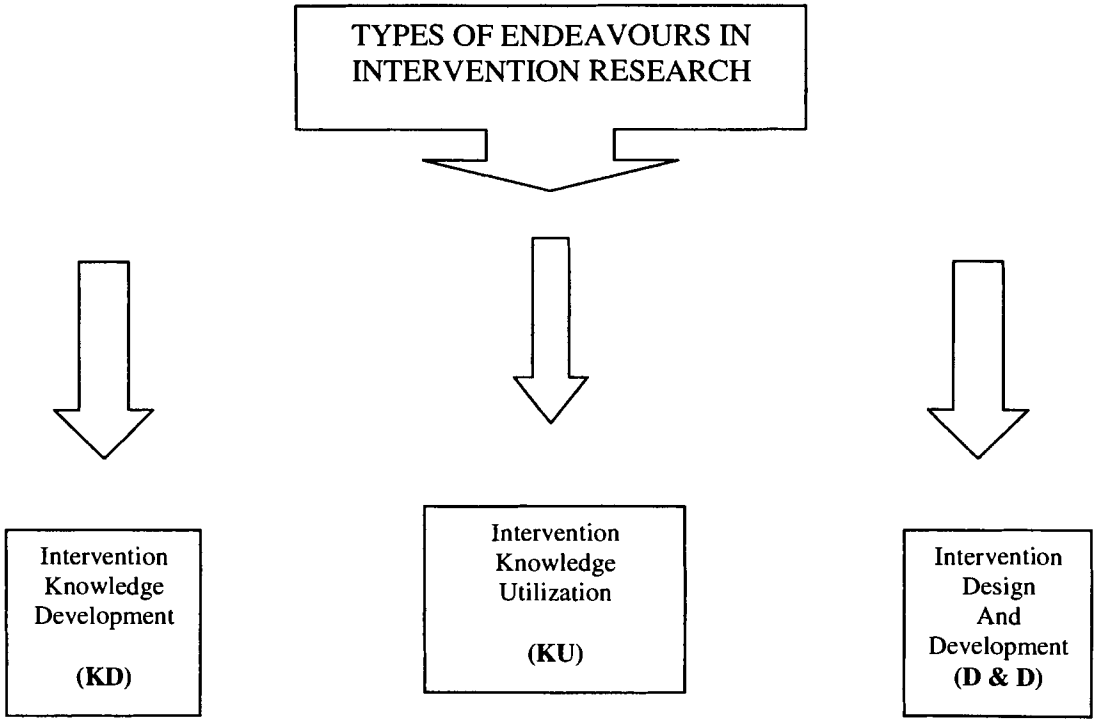
4. THE INTERVENTION RESEARCH MODEL

4.1 AN OVERVIEW

Intervention research is described as applied research with a specific intervention mission (Thomas & Rothman, 1994: 3). Thomas & Rothman can be seen as the pioneers in the field of

developmental research with their model of developmental research and utilization, also termed DR & U (De Vos, Schurink & Strydom, 1998: 9). When referring to intervention research, it seems as if there are three types of endeavours to consider. These endeavours are summarized in the following figure:

FIGURE 6: THE THREE TYPES OF ENDEAVOURS IN INTERVENTION RESEARCH



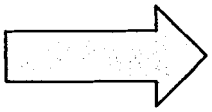
(Thomas & Rothman, 1994: 3.)

In this study intervention research in general was applied. The six phases involved in intervention research will now be described.

4.2 PHASES OF THE INTERVENTION RESEARCH PROCESS

According to De Vos (1998 (b): 385) and Thomas & Rothman (1994:10) the process of intervention research consist of six phases with certain operations. These phases are summarized in figure 7.

FIGURE 7: PHASES AND OPERATIONS OF INTERVENTION RESEARCH



PROBLEM ANALYSIS AND PROJECT PLANNING

1. Identifying and involving clients
2. Gaining entry and cooperation from settings
3. Identifying concerns of the population
4. Analyzing identified concerns
5. Setting goals and objectives

INFORMATION GATHERING AND SYNTHESIS

1. Using existing information sources
2. Studying natural examples
3. Identifying functional elements of successful models

DESIGN

1. Designing an observational system
2. Specifying procedural elements of the intervention

EARLY DEVELOPMENT AND PILOT TESTING

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

EVALUATION AND ADVANCED DEVELOPMENT

1. Selecting an experimental design
2. Collecting and analyzing data
3. Replicating the intervention under field conditions
4. Refining the intervention

Preparing the product for dissemination

DISSEMINATION

1. Identifying potential markets for the intervention
2. Creating a demand for the intervention
3. Encouraging appropriate adaption
4. Providing technical support for adopters

4.2.1 PROBLEM ANALYSIS AND PROJECT PLANNING

In this phase five steps should be followed:

- Identifying and involving clients
- Gaining entry and cooperation from settings
- Identifying concerns from settings
- Analyzing identified concerns
- Setting goals and objectives

(De Vos, 1998 (b): 385.)

These five steps were followed in this study in the following ways:

*The **first step** was followed in this study by identifying a sub group for the planned research. The aim of the study was to identify the needs of young adults living with HIV/AIDS and to involve them in a programme where life maps were applied. At first it was planned to involve clients from the Kwakwatsi community, but due to certain problems mentioned in chapter 1, it was impractical. Another community was then identified in the Bloemfontein area.*

*The **second step** was to involve relevant organizations and persons. The ATICC in Bloemfontein was the starting point and allowed the researcher to introduce the project to various stakeholders, including the Bloemfontein Hospice, Leratong support group and the Young Positive Living Ambassadors Project. After introducing the project to members of the Leratong support group, respondents could be selected to complete the needs assessment questionnaires and to participate in the experimental group.*

*The **third step** was intertwined with the second. While introducing the project, concerns were raised by support group members, that they were tired of researchers writing reports from their points of view and making decisions without consulting the real experts: every PLWA. Some of them were really "questionnaire sick", complaining about completing questionnaires, without ever getting feedback on the outcome of the research. These concerns were taken into consideration and the*

contents of the group sessions were discussed, emphasizing that the focus would be on their own personal views, experience and input. The nature of qualitative research was briefly described, introducing it as research with a human focus rather than on statistics and numbers. The Bloemfontein ATICC requested a copy of this study to possibly introduce the suggested group work programme on a larger scale once the research is completed.

*During the **fourth step** the researcher had to take the potential respondents' concerns in serious consideration. The whole study was then planned with active involvement of the different stakeholders, bearing in mind the humanity and vulnerability of the respondents. Respondents were treated throughout this study as colleagues and experts, rather than research objects. Feedback on the results of this study will be given to ATICC Bloemfontein for further feedback through newsletters and applicable meetings with PLWA.*

*The **fifth step** involved the setting of goals and objectives and mainly focused on the improvement of PLWA's general contentment through applying an group work programme where life maps were being used.*

4.2.2 INFORMATION GATHERING AND SYNTHESIS

During this phase it is important to determine what similar programmes were available and what were the outcomes thereof. The following three steps should be followed:

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

(Fawcett, Suarez-Balcazar, White, Paine, Blanchard & Embree, 1994: 32-33.)

These steps were followed by an intensive literature study and consultation with Bloemfontein ATICC on existing programmes. Although various HIV/AIDS programmes existed, very few were aimed at supporting PLWA and none used life maps as technique. Programmes were mainly focused on prevention.

4.2.3 DESIGN

This phase consists of the following two steps:

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

(Strydom, 2000: 147.)

These steps were followed when the researcher attended meetings of the Leratong Support group. PLWA's real concerns, problems, fears and lifestyle could be observed in a relatively naturalistic way, giving the researcher the opportunity to identify issues that should be addressed in an group work programme. Various issues/topics were identified during this process and were summarized by the researcher under the following three headings:

- *Dealing with personal issues, including independence, spirituality, a fear to disclose HIV status and negative self-image*
- *Relationship problems, including the opposite sex and unresolved family conflicts*
- *Social problems, including poverty (poor living standards), stigmatization, isolation, rejection, and ignorance by the broader community*

4.2.4 EARLY DEVELOPMENT AND PILOT TESTING

During this phase the planned intervention should be tested by including the following three operations:

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

(Fawcett *et al.*,1994: 36-37.)

In this study, this phase consisted of three basic operations: pilot testing of the structured interview needs assessment questionnaire; a preliminary presentation of the suggested programme to staff of

ATICC, Bloemfontein; and presenting a workshop on life maps as technique to a group of social workers and psychologists at the Child Guidance Clinic in Kroonstad. The aim of this workshop was to help the researcher to evaluate the planned group work programme by answering the following relevant questions, identified by Fawcett et al. (1994: 37):

- Is the intervention effective?
- Is it replicable by typical end-users?
- Is it simple to use?
- Is it practical?
- Is the intervention adaptable to various contexts?
- Is it compatible with local customs and values?

This phase was very time consuming, but of the utmost importance in developing the group work programme that was applied in this study.

4.2.5 EVALUATION AND ADVANCED DEVELOPMENT

According to De Vos (1998: 397), four major aspects should be considered in this phase:

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

The classic experimental design with a pretest-posttest control group was selected to indicate causality between the intervention and PLWA's general contentment. The classical experimental design will be described in paragraph 5. Data were collected and analyzed on a continual basis.

4.2.6 DISSEMINATION

This phase deals with the end result of the group work programme, making it ready for use in practise and consists of five steps:

- **Preparing the product for dissemination**, including the following issues:
  - Choosing a brand name
  - Establishing a price
  - Setting standards for use
- **Identifying potential markets for the intervention**
- **Creating a demand for the intervention**
  - Modeling
  - Sampling
  - Advertising
- **Encouraging appropriate adaptation**
- **Providing technical support for adopters**

(Fawcett *et al.*,1994: 39-43.)

The way these steps were applied in this study will be described in Chapter 8 under suggestions and recommendations.

The research procedures utilized will be described subsequently.

5. THE RESEARCH PROCEDURES

5.1 THE SURVEY

According to Strydom (2000: 80-81), the survey is a well-known procedure in social research. He mentions the following aspects to be considered when the survey procedure is to be utilized:

- The goals of the research
- The necessity of the research
- The suitability of a survey to obtain the necessary information
- Determine what information and knowledge are available
- Which concepts should be defined
- Who is the target population
- With whom will interviews be held
- The personnel required and cost of the study
- The duration of the study
- The feasibility of the study

5.1.1 INTRODUCTION TO SURVEYS

Various types of questionnaires can be utilized in research, including mailed questionnaires, telephonic questionnaires, personal questionnaires, questionnaires delivered by hand, personal interviews and group-administered questionnaires (Botes, 1997: 41; Fouche, 1998: 152-155; Strydom, 2000: 119-123). The different kinds of surveys will be discussed in 5.1.7

5.1.2 BASIC PRINCIPLES IN QUESTIONNAIRE CONSTRUCTION

A few basic principles regarding questionnaire construction should be considered before starting to construct a questionnaire. Some of these principles were identified by Bailey (1994: 107-108), Fouche (1998: 157-158) and Strydom (2000: 118-119) and can be summarized as follows:

- The quality of the questionnaire will determine the quality of the data to be collected
- Double-barreled questions will lead to answers without comparison
- Leading questions will cause biased answers
- Vague or abstract questions will result in vague answers
- The level of wording should be brief, clear and understandable to the respondents
- The sequence in which questions are presented will help dealing with sensitive and threatening questions
- Questions must be relevant to the study and the respondents
- Every question must contain only one thought

- Researchers must not take for granted that respondents will have knowledge of a certain subject
- It is an art to gather maximum information through as few questions as possible. It is important to keep questionnaires as concise as possible
- Keep to the objectives of the study when compiling a questionnaire

Another outstanding aspect regarding the preparation of questionnaires is doing a pilot study to determine the efficiency of the questionnaire. By doing the pilot study, the researcher is able to determine whether the respondents will understand the questions properly and whether the information that will be gathered is relevant to the study. The main value of the pilot study is that modifications can be made to the questionnaire prior to the main investigation (Strydom, 1998 (a): 183). According to Hadley & Mitchell (1995: 313), the pilot study serves three purposes:

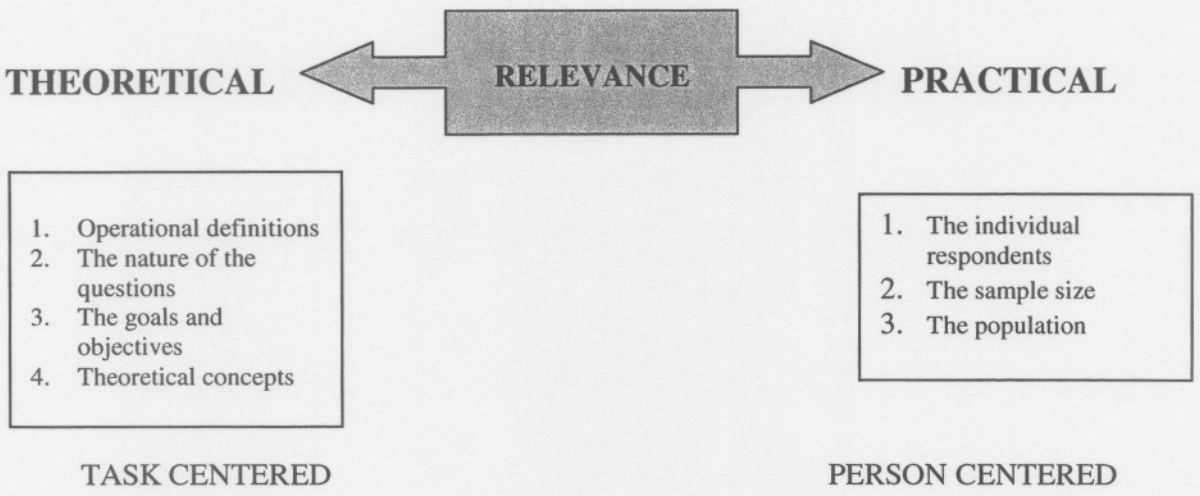
- it identifies ambiguous, overly demanding, or redundant items
- it allows an estimate of time required to respond
- it establishes a format that makes the questionnaire as easy as possible to answer and the answers easy to analyze

During the pilot study of this research project, it was determined that respondents had difficulty in completing the GCS; it would take approximately 40 minutes to complete the questionnaire; some of the respondents were illiterate and would not be able to complete a questionnaire without help; and sometimes respondents had difficulty identifying with emotions. These obstacles were overcome by including the following possible solutions:

- *Group administered questionnaires were applied where possible*
- *An interpreter assisted respondents with terms regarding emotions*
- *An interview schedule was followed*

The most important aspect to consider when constructing a questionnaire seems to be relevance (Bailey, 1994: 109-110; Strydom, 2000: 119). It is of the utmost importance that a research project must be relevant, worthwhile and legitimate. The essence of relevance is summarized in the following figure.

FIGURE 8: RELEVANCE IN QUESTIONNAIRES



5.1.3 THE FORMAT OF THE QUESTIONNAIRE

The format of the questionnaire will be determined by the type of questionnaire used. One of the most important aspects regarding the format of the questionnaire, is, however, the covering letter, which should be seen as an integral part of the questionnaire. The covering letter should include the following important information:

- Identification of the person or organization undertaking the research
- A brief description of the purpose of the study to motivate respondents to cooperate
- An indication of the importance and relevance of the study
- The anonymity of respondents must be guaranteed
- The confidential treatment of information must be guaranteed
- Personal details of the researcher for further enquiries
- Clear instructions on completing the questions

(Fouche, 1998: 157.)

Besides the covering letter, some general rules on questionnaire formatting are listed by Powers *et al.* (1985: 121):

- Group questions of the same type and subject matter together
- Do not crowd questions; leave white space
- Put only one question on a line
- Use boxes or parentheses to mark responses; open blanks are more likely to result in messy and uninterpretable answers
- Put answers consistently to one side of the form, if possible
- Mark contingency questions about how many choices to make in each question
- Precode questionnaire for data processing, if possible

5.1.4 14 POINTS TO REMEMBER WHEN COMPILING A QUESTIONNAIRE

The following aspects were taken into consideration when the questionnaire was compiled:

- Before beginning to compile a questionnaire, have clearly in mind the project's mission and the questionnaire's role in fulfilling that mission
- While writing a questionnaire, keep its purposes clearly in mind and its content focused
- Never adopt an existing questionnaire without first determining that it is as well suited to the project at hand as a newly written one would be
- Bear issues of privacy and confidentiality clearly in mind while writing the questionnaire and accompanying instructions
- Keep the questionnaire as short and simple as is consistent with its role in the project
- For the questionnaire as a whole and its component items, use the least demanding format consistent with the project's mission
- Ensure that every respondent knows what to do with every item
- Use precise, objective and efficient language
- While compiling a questionnaire, bear in mind the way answers will be analyzed, and write them in such a manner that they will elicit answers amenable to the planned analyses
- Arrange the material within the questionnaire to maximize response rate
- Include an appropriate introduction
- Keep instructions brief and clear, and devise a simple way to return completed questionnaires
- Questionnaire and accompanying instructions should be consistent with a plan for following up non-respondents

- Test a draft form of the questionnaire, including instructions, in a pilot study before it is reproduces in final form for the main study

(Hadley & Mitchell, 1995: 308-309.)

An example of the questionnaire that was used in this study can be found in ***Annexure I.***

5.1.5 TYPES OF QUESTIONS (RESPONSE CATEGORIES)

Response categories can either be open or closed-ended. Open-ended questions do not have specific response categories, while closed-ended questions direct respondents to select one or more of the specific categories (Bailey, 1994: 118-123; Mitchell & Jolley, 2001: 484-489). The different response categories that were used in this study, will be presented, followed by the advantages and disadvantages of the two types of response categories.

- **CLOSED-ENDED QUESTIONS**

  - Dichotomous questions with only two response possibilities
  - Matrix-type questions where a variety of interrelated questions are handled in a single question
  - Statements are being used to collect data of a subjective nature

- **OPEN-ENDED QUESTIONS**

  - Completion questions can be used where too many response options exist to classify them meaningfully
  - Incomplete sentences
  - Follow-up questions are being used to obtain more information about a response in a previous question

(Bailey, 1994: 118-123; Strydom, 2000: 124.)

Both types of questions were used in the questionnaire that were used in this study. Due to the qualitative nature of the study, more open-ended questions were used in the form of incomplete sentences. The incomplete sentences could include sensitive information and were placed towards the end of the questionnaire. These types of questions made data-analysis more difficult and required good writing and verbal skills, but on the other hand it allowed more freedom of expression to respondents, resulting in data without bias and a clear picture of the needs, dreams and problems of young PLWA.

5.1.6 THE ADVANTAGES AND DISADVANTAGES OF OPEN- AND CLOSED-ENDED RESPONSE CATEGORIES

The following figure was compiled from Bailey (1994: 118-123) to point out the advantages and disadvantages of open and closed-ended questions.

FIGURE 9: THE ADVANTAGES AND DISADVANTAGES OF OPEN- AND CLOSED-ENDED RESPONSE CATEGORIES

ADVANTAGES		DISADVANTAGES	
OPEN-ENDED	**CLOSED-ENDED**	**OPEN-ENDED**	**CLOSED-ENDED**
Can be used when all the possible answer categories are not known	Answers are standard and can be compared from person to person	May lead to collection of worthless and irrelevant information	Guessing of answers or answering randomly is possible
Allows the respondent to answer adequately, in detail and to clarify and qualify his answer.	Answers can be easily coded and analyzed	Data are not standardized, making comparison or statistical analysis difficult	The respondent may get frustrated if the categories do not supply a suitable option for him
Can be used when too many possible answer categories exist	The meaning of questions are clearer to the respondent	Coding is difficult and subjective, leading to low intercoder reliability	There may be too many categories to print on a questionnaire
They are preferable for complex issues	Relevant and complete answers are possible	Superior writing skills and generally a higher educational level are required	Differences in interpretation may occur
Allow opportunity for creativity and self-expression	Can deal with sensitive topics	Is time and effort consuming	Forced-choice responses may eliminate variations in answers artificially
	Easy for the respondent to complete by only choosing from categories	Requires more paper and makes the questionnaire look longer	More likelihood of clerical errors when respondents indicate another option than they really meant

(Bailey, 1994 : 118-123.)

5.1.7 KINDS OF SURVEYS

5.1.7.1 MAILED QUESTIONNAIRES

These types of questionnaires are cost effective and could be used in a large geographical area. The idea is to mail the questionnaire with a postage paid envelope for return, which allows the

respondent to complete the questionnaire in his own time. The disadvantages on the other hand are the following:

- Only literate respondents can complete the questionnaire
- Low response rate
- Non-verbal behavior cannot be evaluated

(Fouche, 1998: 153; Strydom, 2000: 119.)

5.1.7.2 TELEPHONIC QUESTIONNAIRES

A high response rate and quick data collection are made possible with telephonic interviews, but certain disadvantages cause this procedure only to be used for exploratory studies rather than in-depth research:

- No observation of non-verbal behaviour is possible
- Only persons with telephones can be included as respondents
- If telephonic questionnaires are utilized outside the geographic boundaries of the researcher, it could be very costly
- Sensitive matters cannot be discussed telephonically

(Fouche, 1998: 154; Strydom, 2000: 122.)

5.1.7.3 GROUP INTERVIEWING

Group interviewing can be seen as a combination of the personal interview and the mailed questionnaire. It is also defined as group-administered questionnaires, where the number of persons who are present in a group will complete the questionnaires. The field worker will be available to clarify information, but it is important that respondents should receive the same stimulus and complete their own questionnaires without discussion.

The biggest advantages of this procedure are that it is time and cost effective and that the researcher can combine the best parts of the personal interview and the mailed questionnaire. On the other hand it has the following disadvantages:

- Mutual influence may occur within the group
- In the group situation, individuals may be uncomfortable to ask for assistance and may answer questions arbitrarily
- Finding a suitable venue and time slot might be difficult

(Fouche, 1998: 155-156; Strydom, 2000: 123-124.)

In this study it was necessary to also use this type of survey because of the difficulty to find respondents who were HIV+. During meetings of the Leratong Support Group, it was possible to utilize this procedure as a time and cost effective method within an existing group where group members knew each other and felt comfortable with their HIV-status. The control group consisted of respondents who were not willing to participate in a group situation, but were willing to participate individually and telephonically.

5.1.7.4 THE HAND DELIVERED QUESTIONNAIRE

Questionnaires can be delivered by hand, allowing the respondent to complete the questionnaire in his own time. It is preferable to collect the completed questionnaires within 48 hours. Some of the advantages of this procedure are: high response rates due to personal contact; time effectiveness; and clarification of uncertainties when the researcher goes back to collect completed questionnaires. The disadvantages on the other hand include: a smaller geographic area can be covered; questionnaires could be lost or left uncompleted; and issues of literacy, visual competence and writing competences could influence response rate.

(Fouche, 1998: 155; Strydom, 2000: 122-123.)

5.1.7.5 PERSONAL INTERVIEWING

Although the interview can also be termed under the generic name of "questionnaire", it is the researcher's aim to clearly define it in this study, as this it the procedure that was followed to collect data for the first phase of the study.

An interview schedule is defined by Bailey (1982: 111) as: "An instrument that is not given directly to the respondent but is filled in by an interviewer who reads the questions to the respondent". This type of interview contains specific instructions for the interviewer, specific questions in a fixed order, and transition phrases for the interviewer to use (Monette *et al.*, 1998: 171). Three types of interviews are described by Strydom (2000: 120):

- Non-directive or unstructured interviews
- The directive or focus interviews
- The formally structured interview

The following figure highlights the advantages and disadvantages of this procedure.

FIGURE 10: THE ADVANTAGES AND DISADVANTAGES OF INTERVIEWS

ADVANTAGES	DISADVANTAGES
Heightens reliability	High cost
Flexibility	Interview bias is possible
High response rate	Time consuming
Observation of nonverbal behavior and demeanor of the subject is possible	Less anonymity
Control over the environment in which the questionnaire is completed	Respondents may experience inconvenience (no control over where and when he wants to complete the questionnaire)
Control over the question order	Less standardized question wording
Spontaneous answers can be recorded	No opportunity to consult records
Complete answering is possible	Lack of accessibility to respondents

Recording of time is possible	Interview response can be affected by social norms
More complex questionnaires can be used	Subject to more demanding characteristics
Can be used for complex topics which demand open-ended questions and clarification	Personality conflicts may arise
Only the respondent's answers are used (no help from friends or family	

(Bailey, 1994: 174-176; Hadley & Mitchell, 1995: 322; Powers *et al.*, 1985: 127.)

In this study the use of personal interviews was motivated by the following factors:

- *The complexity of the topic*
- *Many respondents were illiterate*
- *Due to the qualitative nature of the study, open-ended questions were used, demanding clarification of answers*
- *During the pilot study, it was realized that respondents might find completing the GCS difficult*

5.2 EXPERIMENTS

Experimental research can be seen as highly scientific and one of the best ways to measure causality between a program treatment and expected outcome (Powers; Meenaghan & Toomey, 1985: 206), is regularly applied in explanatory research (Grinnell & Williams, 1990: 167) and can be successful in the study of small group interaction (Babbie, 2001: 217). *This matches the basic aim of this study to determine whether or not the application of life maps in an group work programme will change the general contentment of a small group of young PLWA.*

5.2.1 THE CHARACTERISTICS OF EXPERIMENTAL DESIGNS

The samples for the experimental and control groups are drawn from the same population (Mitchell & Jolley, 2001: 203) and most experimental designs have four common characteristics, giving it strong internal validity. These characteristics include:

- A manipulated independent variable
- At least one dependent variable
- The random assignment of subjects
- The process of pretesting and posttesting

In this study, the experimental and control groups were drawn from the same population (young adults living with HIV/AIDS) but due to the control group members' reluctance to participate in a group, they were not included in a group situation as the experimental group, but were followed up individually and telephonically.
(Powers *et al.*, 1985: 207).

Figure 11 was compiled by the researcher to point out the characteristics and the process of true experimental research by including views of Bailey (1994: 225); Grinnell & Williams (1990: 169); Monette *et al.* (1998: 265).

5.2.2 THE ADVANTAGES AND DISADVANTAGES OF EXPERIMENTS

According to Bailey (1994: 220-221) and Strydom (2000: 112-114), experiments have the following advantages and disadvantages:

5.2.2.1 ADVANTAGES

- The influence of certain experimental variables can be established
- Control is allowed
- Clear objectives will avoid focusing on irrelevant matters and data
- The researcher has the freedom to formulate his own experimental designs if existing ones are not applicable
- Valid and reliable information can be gathered
- High scientific spirit

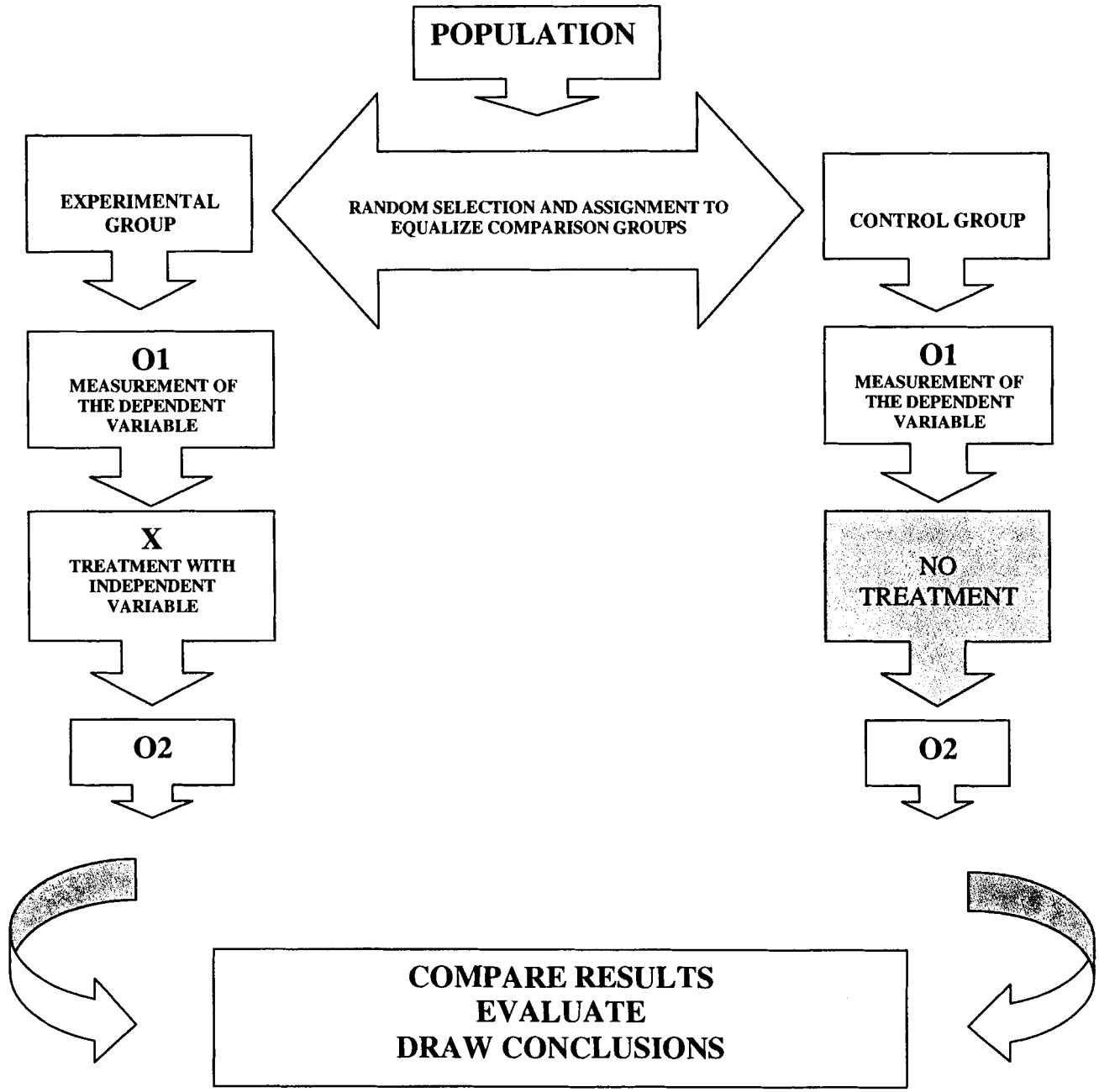
- Causality can be established
- Longitudinal analysis is possible

5.2.2.2 DISADVANTAGES

- Measuring criteria are determined before the research starts and could influence the objectivity of the researcher
- Ethical questions exist regarding withholding therapy from persons with problems
- Experimental contamination can take place where respondents are involved in other programs or media information
- There is no absolute certainty that changes that might take place in respondents result only from the independent variable, as normal growth or other inputs may also play a role
- Generalization is difficult because only small groups are involved
- Strict application of planning to ensure the same procedures causes less flexibility
- Experiments are time and money consuming

Although experimental designs have considerable disadvantages and limitations, in this study it was important to establish a causal link between the general contentment of young adults living with HIV/AIDS and the application of life maps as technique. According to Bailey (1994: 221), the experiment is the best method in social science for establishing causal links.

FIGURE 11: THE TRUE EXPERIMENT



(Grinnell & Williams, 1990: 164.)

5.2.3 KINDS OF EXPERIMENTS

There are three kinds of experiments, namely the classical experiment, the pretest-posttest experiment and the Solomon-four-group. Each of these types of experiments will be briefly discussed, with more attention to the classical experiment, which was applied in this study.

5.2.3.1 THE CLASSICAL EXPERIMENT

This design includes two groups, the experimental group and the control group. Assignment to the groups is done randomly. Measurement of the dependent variable *(general contentment of young PLWA)* takes place in both groups. The independent variable *(group work programme where life maps are applied)* is then introduced to the experimental group only. A posttest then takes place when measurement of the dependent variable is repeated (Grinnell & Williams, 1990: 168).

The classical experiment can be written as follows:

Experimental group:	**R**	**01**	**X**	**02**
Control group	**R**	**01**		**02**

Where:

R = Random selection and assignment to the group
01 = First measurement of the dependent variable
X = Independent variable
02 = Second measurement of the dependent variable

(Grinnell & Williams, 1990: 167 ; Monette *et al.*, 1998: 265; Powers *et al.*, 1985: 208.)

5.2.3.2 RANDOMISED POSTTEST-ONLY CONTROL GROUP DESIGN

With this type of experiment there are again two groups present, with the only difference from the classical experiment - there is no pretest. Random assignment to the experimental and control groups is essential. This kind of experiment can be described as follows:

Experimental group:	**R**	**X**	**01**
Control group:	**R**		**01**

This design can be applied in situations where it is impossible to conduct a pretest and/or where the pretest can strongly influence the results of the posttest (Fouche & De Vos, 1998 (b): 134-136; Strydom, 2000: 110-111).

5.2.3.3 RANDOMISED SOLOMON FOUR-GROUP DESIGN

This kind of experiment consists of four randomly assigned groups, two experimental and two control groups and can be written in the following way:

Experimental group 1:	**R**	**01**	**X**	**O2**
Control group 3:	**R**	**O3**		**04**
Experimental group 2:	**R**		**X**	**O5**
Control group 4:	**R**			***06***

The first experimental group takes a pretest, receives the independent variable and takes a posttest. Group two also receives the independent variable, but no pretest is being done. The first control group takes both the pre and posttests, but the second control group only takes the posttest.

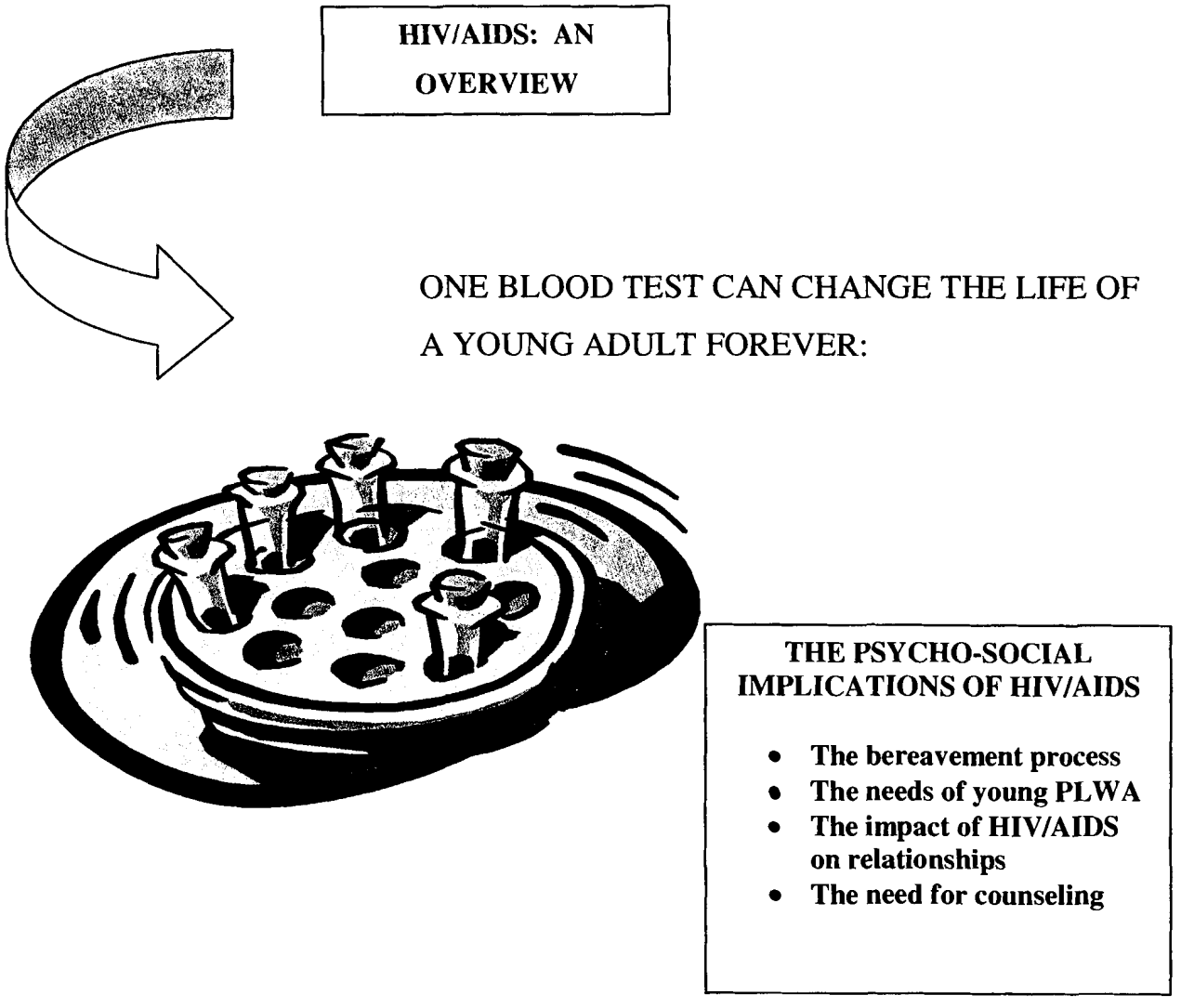
This design has elements of both the classical and post-test only experiments and the biggest advantage is that the effect of the pretest situation can be controlled. On the other hand, it has the disadvantage that twice as many respondents will be needed, making it a time and money consuming method (Fouche & De Vos, 1998 (b): 135-136; Strydom, 2000: 111).

6. SUMMARY

In this chapter the emphasis was on the research design and procedures that were followed in this study. The intervention research model was described theoretically and the process was applied to this study. The survey and experimental procedures were briefly described, focusing on the advantages and disadvantages of the different procedures and why they were chosen for this study.

In the next chapter, attention will be given to the psycho-social implications of HIV/AIDS on young PLWA. The following figure supplies a summary of what is to be expected in the next chapter.

FIGURE 12: SUMMARY OF CONTENTS OF CHAPTER 3



PHILOSOPHY FOR LIFE

THE STEP FORWARD:

**I MYSELF, GREW UP IN A BIG FAMILY,
WHERE THERE IS A LOT OF RESPECT AND MORALS.
WE WERE THE MEMBERS OF ZCC
AND MY FAMILY AND ME TRULY BELIEVE
IN THE LORD.
I GREW UP WITH LOTS OF MIRACLES HAPPENING
IN FRONT OF MY VERY EYES.
I HAVE MY UP'S AND DOWN'S WITH MY FAMILY.
AND ALL I CAN SAY IS THAT I AM VERY
LUCKY TO HAVE THE FAMILY I HAVE NOW.
I STAYED AT RUSTENBURG AND BORN THERE TILL
THE AGE OF 15.
I MOVED TO WELKOM,
NEVER SETTLING DOWN WITH MY FAMILY.
SO MANY THINGS HAPPENED, THINGS
THAT I COULD'T SHARE WITH ANYONE,
UNTIL I DECIDED TO BREAK THE SILENCE AND
TOLD MY SISTER.
I GOT VERY SICK LAT YEAR 2000 AND THEN
I WAS DIAGNOSED.
I WAS HURT FOR A LONG TIME,
FEELING ALONE AND DEPRESSED.
BUT NOW I CAN SEE THAT I SHOULD BE
THANKFUL THAT I WAS DIAGNOSED,
BECAUSE BY DIFFICULTIES
HELPED ME GROW AND NOW I WANT TO GO
FURTHER WITH WORKING WITH HIV PEOPLE,
INCLUDING MYSELF.**

Debrah

CHAPTER 3

THE PSYCHO-SOCIAL IMPLICATIONS OF HIV/AIDS ON YOUNG ADULTS

1. INTRODUCTION

Since the first reported cases of HIV/AIDS in the early 1980s, a challenge started for the medical and associated professions which were the first to deal with this international epidemic for which no cure exists at this time. While medical researchers are still working on a cure, the epidemic spreads rapidly, leaving a track of death, poverty, orphans, panic and a rising quest for health care.

Although HIV/AIDS is primarily a health issue, it is even more a social disease, as people are involved, leaving the social sciences to investigate " the interrelated patterns of behavior, beliefs and circumstances" (Joubert, 1991: 22). The HIV/AIDS questions for the human sciences are: *What is the impact of this dreadful disease on mankind? What is the meaning of an illness without cure, affecting one out of five of our population?* Louw (1997: 126), as a logotherapist, is searching for the meaning of AIDS, mentioning that "AIDS has become a national and systemic problem influencing the quality of social relations and the character of our Christian love. It is affecting every individual in our country."

In this chapter scant attention will be given to the medical aspects of HIV/AIDS. There is sufficient literature available on this aspect and the focus of this chapter will be on identifying and discussing the psycho-social implications of HIV/AIDS on young adults and their families. This will include the social and emotional needs, emotional reactions, behavioural patterns, implications on the family system and the impact on society in general.

The basic needs of young adults will be discussed, followed by some key aspects regarding HIV/AIDS, as well as an overview on demographic issues and statistics. This chapter will be concluded by some therapeutic goals in HIV/AIDS counseling, giving consideration to important aspects and principles that should be included in a counseling programme.

2. YOUNG ADULTHOOD AS DEVELOPMENTAL STAGE

2.1 DEFINING YOUNG ADULTHOOD

Young adulthood is defined differently by different authors. Everatt & Milner (1994: 6) define young adulthood as "youth", including persons between the ages 16 and 30. Okun (1984: 5-6) emphasizes that adulthood cannot be defined only by considering chronological age, but that maturity is of the utmost importance. This argument led to a working definition of adulthood that includes biological, psychological and philosophical dimensions with the following goals:

- The ability to be a self-differentiated individual with meaning and purpose in life
- The ability to maintain intimate relationships and to care for oneself and for others
- The ability to take responsibility for one's choices and their consequences, to renounce unattainable choices and to recognize that some variables influencing choices are beyond one's control
- The ability to deal with the disappointments and frustrations of adult life
- The ability to balance continuously individual, work and family roles

Finally young adulthood can be defined as the developmental phase which lasts from the mid-twenties to the mid-thirties and is characterized by exploration of adult roles, membership, relationships, responsibilities, commitments and the establishment of adult lifestyle, a career and a family (Okun, 1984: 72).

For purposes of this study, young adulthood is defined as persons from 18 to 30 years of age and identity formation, role clarification and fulfillment are considered very important at this stage of life.

2.2 PHASES OF THE YOUNG ADULTHOOD DEVELOPMENTAL STAGE

According to Papalia & Olds (1986: 467), this developmental stage actually includes three phases:

- The early adult transition (17 to 21 years)
- Entering the adult world (22 to 28 years)
- The age-30 transition (28-34 years)

Each of these developmental stages has certain characteristics which will be briefly listed in the following figure.

FIGURE 13: CHARACTERISTICS OF THE DEVELOPMENTAL STAGES OF YOUNG ADULTHOOD

THE EARLY ADULT TRANSITION (17-22 YEARS)	ENTERING THE ADULT WORLD (22-28 YEARS)	THE AGE-30 TRANSITION (28-34 YEARS)
In this phase the individual achieves independence from the family, experiences a greater sense of autonomy and feels that real adulthood is just around the corner	The individual feels like an adult, manages to establish a lifestyle, gains independence from the primary family and sets personal goals	In this stage the individual questions the sense of living and starts to reassess work and family patterns

(Papalia & Olds, 1986: 467.)

2.3 YOUNG ADULTHOOD AS DEVELOPMENTAL STAGE

The term developmental stage or life stage can be seen as the framework in which to consider developmental tasks and issues. The following aspects regarding developmental stages are pointed out by Okun (1984: 11):

- Developmental change is a continuous process

- Change is sequential, and therefore it is necessary to view each stage of life in relation to the developmental changes that precede and follow it
- Changes in individuals must be considered in the context both of the prevailing norms of the day and of the historical time within which one lives

The last aspect is very important to the researcher: it is impossible to consider young adulthood without looking back at adolescence and without focusing on the future. It is especially important when life maps are administered because life maps can be used to bridge the past, present and future.

2.4 DEVELOPMENTAL TASKS OF YOUNG ADULTS

According to Louw, Van Ede & Louw (1998: 474), the developmental tasks of early adulthood can be divided in four categories. These categories include the following:

- Tasks relating to the self
- Tasks relating to interpersonal relationships
- Tasks relating to work and leisure-time activities
- Tasks relating to the community

Each category of tasks will be described briefly according to the above-mentioned authors.

2.4.1 TASKS RELATING TO THE SELF

- To achieve independence and responsibility
- To stabilize one's identity
- To define one's values
- To develop intimacy and commitment

2.4.2 TASKS RELATING TO INTERPERSONAL RELATIONSHIPS

- To choose a partner
- To establish a satisfying and meaningful relationship with your partner
- To become a parent and raise children

2.4.3 TASKS RELATING TO WORK AND LEISURE-TIME ACTIVITIES

- To become established in a career
- To develop a pattern of recreation

2.4.4 TASKS RELATING TO THE COMMUNITY

- To find a place in the community and to contribute towards it

In summary it seems as if this developmental stage can be seen as the foundation of adulthood, where the individual experiences real independence, establishes important interpersonal relationships, finds a career and becomes productive members of society.

2.5 DEVELOPMENTAL ISSUES IN LATE ADOLESCENCE AND EARLY ADULTHOOD

The following figure gives an indication of the developmental tasks, general issues, requisite skills and significant others associated with late adolescence and early adulthood.

FIGURE 14: DEVELOPMENTAL ISSUES

DEVELOPMENTAL TASKS	GENERAL ISSUES	REQUISITE SKILLS	*SIGNIFICANT OTHERS*
Identity formation Make provisional career, living and educational decisions	Individuation Separation from family Internalized morality Self-sufficiency Sex-role clarification	Abstract thinking Problem solving Initial decision making Educational and career skills	Peers Family of origin School/work personnel Community members
Initial intimacy Develop and maintain new heterosexual and same-sex relationships Let go of outdated relationships Renegotiate existing relationships	Relationships Sexuality Substance abuse	Social skills Interpersonal skills Beginning conflict-resolution skills	Family of origin Old peers New peers – varied ages School/work personnel Community members
Development of intimacy Clarify sex role Develop mutual sexuality Develop mutuality in relationships Balance individuation, family and career demands Reassess relationships Withstand conflicts and disappointments within relationships	Commitment to mature relationships Discrimination among relationships Ability to share with others	Decision making Juggling of time, energy and boundaries Interpersonal skills Sophisticated conflict-resolution skills Sharing	Lover(s) Spouse Children Extended family Friends
Development of career Enter the career path Develop mentor relationships Develop competencies and skills Reassess and redirect	Balance of career context needs with individual needs Job reality variables	Interpersonal skills Time and energy management Pressure management Conflict resolution Assessment skills	Colleagues Supervisors Supervisees Mentor(s)

(Okun, 1984: 63 & 79.)

2.6 IDENTITY FORMATION AND YOUNG ADULTHOOD

Identity formation can be seen as one of the fundamental aspects in adolescence and young adulthood, but the process of identity formation continues throughout the life cycle (Okun, 1984:

58-59). Newman and Newman (1999: 372) refer to two basic criteria of Erikson's theory on identity formation: crisis and commitment. ***Crisis*** involves constant role experimentation and decision-making among choices. ***Commitment*** involves personal involvement in all decisions and actions. This is supplemented by Okun (1984: 60) who refers to the four types of identity statuses, of which only the first one can be considered postive:

- Identity achieving (Where the identity crisis is resolved and commitments can be made to occupation and ideology)
- Foreclosure (Confrontation is avoided, parental views are introjected and young adults tend to be very self-critical)
- Moratoriums (Preoccupation with identity issues, but unable to make commitments)
- Identity diffuse (Chronic indecision and lack of interest)

Identity formation is one of the key issues in life maps and is an aspect that could be rudely influenced by a HIV/AIDS diagnoses. In the researcher's opinion, support programmes for young PLWA need to address identity issues.

2.7 YOUNG ADULTS AND ILLNESS

The identifiedee developmental tasks could be threatened by illness. Louw *et al.* (1998: 483-485) state that adults younger than 45 years usually enjoy excellent health, but that two diseases particularly may affect them. These illnesses are tuberculosis and HIV/AIDS. According to Sourkes (1992: 25-26), the young adult confronted with a life-threatening illness "experiences the sense of being stopped short" and "Just as the individual is planning and fulfilling life goals, the open horizons of the future are sharply delimited". The young adult's developmental tasks will be influenced by a HIV/AIDS diagnosis and include aspects that could be negative towards identity formation (Klein, 1998: 20).

The physical, social and emotional impact of HIV/AIDS on the young adult, will be described later in this chapter.

3. STATISTICS AND DEMOGRAPHIC PREDICTIONS REGARDING HIV/AIDS

The implications of HIV/AIDS for demography in Southern Africa and the world necessitate regular updates of the statistics of the disease and its spread and making projections for the future. Statistics and projections are necessary for efforts to do social, economical and labour planning. The following statistics and predictions give an indication of the current impact of HIV/AIDS and what more to expect.

3.1 STATISTICS

- There are approximately 30 million people infected by HIV worldwide of which nine out of ten do not know that they are infected;
- There are 16 000 new HIV infections per day, 90% of which are in the developing world;
- Over 50 % of new infections in non-infants are among young people aged 15-25;
- 590 000 children under the age of 15 were infected with HIV in 1997;
- Every day, at least 7 000 young people aged 10 to 24 become infected with HIV/AIDS – that's five young people every minute;
- Young adults have the highest levels of infection (20% of HIV infected persons are aged between 20 and 24);
- 1.7 Million young people in Africa become infected with HIV every year, leaving sub-Saharan Africa with 14 million persons, or 63% of the total population with HIV/AIDS;
- Nearly a half of the 2,7 million HIV infections in 1996 occurred in women;
- In 2000 the figure on women contracting the disease remained almost the same;
- 17 % of South African pregnant women, almost 1 in 5, were HIV infected by late 1997;
- The infection rate amongst first time mothers who attended antenatal care services in the Free State was 27,9% for the year 2000;
- The infection rate seemed to have stabilized in 2000, leaving the Free State to drop from the second highest infection rate nationally in 1999 to the fourth position in 2000;

- In KwaZulu Natal, Mpumalanga and the Free State, between 1 in 4 and 1 in 5 pregnant women are HIV positive; and
- 20 % of the South African workforce were infected by HIV in the year 2000.

(Department of Health, 1998: 1; Department of Health, 2000: 1; Fransen, 1998: 1; Kinghorn & Steinberg, 1998: 9-11; UNAIDS, 1999: 3.)

3.2 PROJECTIONS FOR THE FUTURE

Although projections for the worldwide spread of HIV/AIDS are available, the focus will be on sub-Saharan Africa and South Africa. The following projections are important to mention:

- Projections for 13 countries in Africa for the year 2010 predict a total population of 303 to 331 million without AIDS and 276 to 310 million with AIDS, or a difference of about 30 million (Fransen, 1998: 3)
- About 6 million South Africans could be HIV infected by 2005 (Kinghorn & Steinberg, 1998: 11)

4. THE NATURE OF HIV/AIDS

When addressing the nature of HIV/AIDS, it is not only to define a disease, but to respond to the actual impact on mankind, social transformation, economical and community development.

The following key characteristics of HIV/AIDS are formulated by Fransen (1998: 14):

- AIDS is a new epidemic, first recognized as a specific condition in 1981, and a cause and test to detect it have only been identified in 1984.
- It has a long incubation period, leaving people who are infected many years of normal productive life, although they can infect others during this period.
- The prognosis for people infected with HIV is currently bleak.
- The scale of the epidemic is different from most other diseases.

- The disease is found mainly in two specific age groups: infants and adults between 20 –40 years.
- In the developing world, slightly more females than males are infected, and women are infected and develop the disease at a younger age than men.
- HIV interacts with other diseases (e.g sexually-transmitted diseases and tuberculosis), both in terms of causing HIV/AIDS to spread and to arise from HIV infection.
- HIV is not only a public health burden in itself, but is directly linked to the burden of other significant public health problems.
- In general the epidemic is still spreading, having peaked in certain urban centers, but continues to spread in the rural areas.

To summarize the above-mentioned, it seems as if HIV/AIDS is a rapidly spreading epidemic, infecting mostly infants and young adults, with more significant implications than any other disease. What is especially important for this study is the long incubation period of the disease, leaving people with many productive years. The question is, however, if they are sufficiently skilled and have enough support to lead a productive life.

5. THE BIOPSYCHO-SOCIAL STAGES ASSOCIATED WITH THE MEDICAL COURSE OF AIDS

When referring to the stages associated with HIV/AIDS, it is important to focus not only on the medical or physical process, but to take into consideration the physical, emotional and social course of the illness. The concept "biopsycho-social" summarizes these 3 aspects.

Various authors have different stages for the course of HIV/AIDS, starting with an asymptomatic phase, working through increasingly more difficult medical, social and emotional problems caused by AIDS related conditions (ARC), towards an end stage with death as the only outcome (Lachman, 1990: 61; Evian, 2000: 26; Van Dyk, 1992: 9-11).

According to Tiblier; Walker & Rolland (1989: 105-111) there are four broad stages through which the HIV/AIDS patient goes. These stages include the following:

- **The "worried well"**, which includes persons who fear that their past experiences could have exposed them to the HI-virus
- **Seropositivity**, which initiates the crisis phase of the illness and when the individual starts to experience the sick role and stigmatization
- **ARC diagnosis**, when the individual moves to a world of chronic illness with symptoms
- **AIDS diagnosis,** which is the terminal phase and is life-threatening

Each of these phases has unique stressors and psycho-social demands. These were summarized by the researcher and are presented in the following figure.

FIGURE 15: IMPORTANT ISSUES DURING THE BIOPSYCHO-SOCIAL STAGES OF AIDS

THE PRE CHRONIC STAGES

THE "WORRIED WELL"	SEROPOSITIVITY
Fear of exposure to the HI-virus	Dividing line between normal life and life at risk of fatal illness
Risk to become obsessed with anxiety	Crisis phase of the illness

THE CHRONIC AND TERMINAL STAGES

ARC DIAGNOSIS	AIDS DIAGNOSIS
Chronic illness with symptoms, including extreme fatigue	Life-threatening episodes may begin
Financial stability is threatened	Progressive illness with minimal asymptomatic periods
Fear of loss of employment	Continual adaptation and role change
Decisions whether to inform friends and relatives and the fear of disclosure	Increasing strain on family caretakers
Inability to yield previous roles	Uncertainty about illness, relative good health and death
Possible loss of family support	Dealing with the social stigma associated with AIDS
Fear of dying	Dealing with chronic illness and death

6. THE NEEDS OF PERSONS LIVING WITH HIV/AIDS

The basic needs of PLWA will be linked to the two main phases mentioned in figure 15.

6.1 NEEDS IN THE PRE CHRONIC STAGES

In these phases, many uncertainties may exist in the individual suspecting that he has contracted HIV. These uncertainties revolve around the following aspects (Steyn, 2000: 1):

- When he became infected
- When he will develop symptoms of diseases and what these diseases might be
- How and if he would respond to treatment
- How long he will be able to lead a normal life

Taking these uncertainties into consideration, the individual in the "worried-well phase" or the phase of seropositivity, may experience the following (Evian, 2000: 275-279):

- The need for medical advice, including HIV testing, pre and post counseling and HIV care options
- A need for supportive relationships
- A fear of discrimination and rejection

A newly diagnosed PLWA may experience the following emotional reactions, feelings, losses and fears (Van Dyk, 1992: 81; Van der Westhuizen & Thompson, 1994: 18-21):

- Shock
- Anger
- Negotiation
- Isolation
- Fear, uncertainty and anxiety (Fears can include the fear for isolations, stigmatization and rejection; uncertainty about the future and worries about a career, family and friends)
- Depression
- Suicidal thoughts
- Obsessiveness
- Denial
- Feelings of guilt, self-blame and self-consciousness
- Acceptance

- Hope

It seems as if the person, suspecting that he has contracted HIV, may feel vulnerable because of the possibility of having an incurable disease with wide spread personal and social implications. This may lead to a loss of identity and control over one's life. The focus on hope is essential for this study, as the aim is to improve the general contentment of young PLWA.

6.2 NEEDS IN THE CHRONIC AND TERMINAL STAGES

The following sources of distress in these stages were identified by PLWA (Orr, 1994: 45):

- Social hostility and stigmatization
- The use of health-care services
- Possible job discrimination
- Harassment
- An uncertain future
- Profound implications for relationships –including sex and intimacy
- Social isolation and loneliness
- Depression
- Morbid preoccupation and fatalism
- Possible dependency on others
- The development of physical symptoms that could cause chronic distress
- Mortality

A personal view of the needs and experiences of a PLWA were shared by a disclosed PLWA during a training session of HIV/AIDS counselors and can be found in ANNEXURE 3. This personal and open talk included various aspects that were mentioned in the previous paragraphs and included some of the following:

- The need for medical advice and emotional assistance when going for a HIV test
- The need for family support and counseling
- Feelings of depression and uncertainty
- Suicidal thoughts
- Feelings of anger

- A fear of rejection
- Loneliness
- Feelings of loss
- A need to get applicable information on HIV/AIDS

Many more emotional reactions could be described, but for purposes of this study the needs mentioned are sufficient. The most commonly expressed psycho-social themes and the bereavement process of PLWA will be described briefly.

6.3 FIFTEEN COMMON PSYCHO-SOCIAL THEMES EXPRESSED BY PLWA

According to Winiarski (1991: 57-68), the following 15 themes are commonly expressed by PLWA:

- Why me? (Feelings of anger, frustration and coming to terms with a HIV diagnosis)
- It's not me! (Denial)
- Shame and guilt
- Abandonment
- Betrayal
- Loss of control and independence
- Fear of dying
- Loss of the future
- A life of unknowing
- Questions regarding living fully
- Dealing with family issues
- Financial concerns
- Envy of the healthy
- Relationships with medical professionals
- Issues regarding disclosure

Taking these themes and psycho-social experiences into consideration, the researcher found it necessary to compile a framework to focus on the bereavement process of PLWA.

6.4 THE BEREAVEMENT PROCESS OF PLWA

The following figure on the typical grief reactions of PLWA and their families was compiled by Klein (1998: 20) and includes the losses experienced by PLWA of which the most common losses include: loss of identity; loss of control; loss of autonomy; and loss of health.

FIGURE 16: TYPICAL GRIEF REACTIONS OF PLWA

COMMON GRIEF FEELINGS		
Depression	**Fear**	**Anxiety**
Irritability	**Apathy**	**Feelings of unreality**
Self-reproach	**Guilt**	**Confusion**
Numbness	**Anger**	**Shock**
Self-doubt	**Panic**	**Deep sorrow**

COMMON GRIEF REACTIONS		
Difficulty accepting loss	**Re-experiencing feelings related to previous deaths**	**Lack of meaning in life**
Constant tearfulness		**Inability to concentrate**
Sense of losing one's mind	**Dreams/Nightmares**	**Blaming others**
Insomnia	**Restlessness**	**Social withdrawal**
Denial and disbelief	**Change in sexual desire**	**Wanting to run away**

PHYSICAL REACTIONS		
		Weight loss
Sighing	**Loss of appetite**	**Exhaustion**
Trouble catching one's breath	**Heaviness in the chest**	
	Tightness in the throat	

7. THE EMOTIONAL IMPACT OF HIV/AIDS ON THE INDIVIDUAL

7.1 IDENTITY

Identity is defined by Saari (1991: 5) as the " content of the individual's meaning system".
For purposes of this study, the concept "identity" will include aspects such as self-esteem, sexuality, body-image, self-actualization, spirituality and socialization.

Sourkes (1992: 35) includes loss of identity as one of the losses experienced by patients with life-threatening illnesses. She points out that the person will initially see the illness as something external, but later on it will be incorporated in the individual's identity. This identity includes adaptation to altered body image, physical abilities and sexuality. The feeling of the disease as an external matter, could be linked to the first emotional reactions to any loss: shock and denial (Van der Westhuizen & Thompson, 1994: 16).

Creating one's own identity is one of the key tasks of adolescence, the developmental stage initiating young adulthood. The concept of identity formation was first described by Erikson, who defined this developmental stage as the phase of achieving identity versus identity diffusion, where identity formation is a lifelong process which " emerges as an evolving configuration gradually established by successive ego synthesis and resynthesis throughout childhood" (Rice, 1990: 86-87).

This ego synthesis can be interrupted by HIV/AIDS as a life-threatening illness as such an illness "throws an assumed sequence out of order" (Sourkes, 1992: 27). The normal development of the young adult is therefore disrupted by a HIV/AIDS diagnosis, leaving the individual with uncertainties, unfinished business and questions regarding his own being.

During adolescence and young adulthood, sexual identity is formed. HIV/AIDS threatens this identity in every sense of the word (Rice, 1990: 428; Kirkpatrick, 1988: 278-279).

Aspects regarding identity that is influenced by HIV/AIDS diagnosis can be summarized as follows:

- The self concept
- Body image and sexuality
- Questions regarding the meaning of life
- Disruption of normal human development

7.2 LIFE-VIEW ISSUES

In logotherapy (one of the theoretical perspectives that will be described in Chapter 5) it is assumed that it is in the nature of mankind to search for meaning in life and life matters. This can be applied to persons suffering from HIV/AIDS. If one looks at the HIV/AIDS crisis, one can easily assume that there is no meaning in this epidemic, causing physical, emotional, social and economical suffering. This leads to the next question: is there any meaning at all in suffering and illness?

Louw (1997: 131) emphasizes that the person living with HIV/AIDS not only has to deal with the matters of life and living, but also with issues such as facing a terminal situation and death. This causes the person, not only to face issues of life and death, but also questions within himself such as: Who am I? Am I still the person I used to be? These two questions are directly related to identity, as described in 7.1

These internal issues that have to be dealt with can therefore force the individual to take an overview of his life, focusing on the past, present and future.

7.3 DEPRESSION

Depression in PLWA can often be linked to negative perceptions from society and the destructive process of labeling. The person living with HIV/AIDS faces feelings of helplessness and " becomes a captive in his own mind and sick body without any hope for the future" (Louw, 1997: 132-133). According to Orr (1994: 46), the following factors can contribute towards depression:

- Loneliness and lack of social support
- Affiliative loss
- Dealing with the possibility of death
- Dealing with the absence of a medical cure

The importance of maintaining hope need to be emphasized because a feeling of hope can prevent depression, increase coping skills, help with problem solving and enhance physical and mental health (Orr, 1994: 47).

It is the researcher's opinion that depression should be seen as part of the normal bereavement process and should not always be evaluated as clinical depression. This opinion is supported by Sourkes (1992: 49-51) who spells out that certain "normal" feelings may be mistaken for depression. These feelings may include the following:

- Physical draining due to illness and/or medical treatment may cause the individual to emotionally withdraw while using energy for physical survival
- A kind of weariness that constantly leads to unpleasant feelings
- Sadness for all the losses incurred by the diagnosis
- A need for time to adjust to the diagnosis
- Existence is stripped to the essence

Depression should therefore not be confused with feelings of sadness and withdrawal while the individual is trying to adapt to an illness, absorbing almost all his physical, mental and emotional energy.

7.4 GUILT

Guilt and self-reproach for contracting HIV are commonly expressed. The feeling of guilt is worsened by the idea that one could also have infected others. According to Van Dyk (1992: 81) and Kirkpatrick (1988: 279), these feelings are often associated with the person's unresolved conflicts about sexuality.

According to Louw (1997: 133), guilt is caused by the knowledge that a value or norm was transgressed and it is important to distinguish between guilt and feelings of guilt. Feelings of guilt are associated with the individual's negative attitudes, emotional turmoil and low self-esteem. These aspects can lead to several questions that could torture the PLWA:

- What am I going to leave behind?
- Did I fail in life?
- Is AIDS God's punishment for previous sinful behavior?

The PLWA may also feel guilty for the emotional, financial and practical burden he places on family members (Sourkes, 1992: 95).

It seems very likely that PLWA will experience guilt and feelings of guilt. Guilt originates in the individual's perception of the illness, how he contracted it, how his HIV/AIDS status affects others and how he placed his own life in jeopardy. In the researcher's opinion the feelings of guilt may hide an underlying anger – especially anger towards oneself for making choices that could have lead to contracting the disease. According to Louw (1997: 133), unresolved guilt may lead to the following:

- A state of being with destructive consequences for mental and spiritual health
- A barrier to finding meaningful purposes in life
- The quest for meaning may remain unsolved

8. THE IMPACT OF HIV/AIDS ON RELATIONSHIPS

According to Evian (2000: 275), HIV/AIDS can cause various relationship problems, including a fear for rejection and feelings of guilt and shame. Relationships on all levels are influenced by a HIV/AIDS diagnosis. These include primary family relationships, intimate relationships with partners and social relationships (e.g. friends, colleagues and the broader community). Attention will be given to each of these relationships.

8.1 PRIMARY FAMILY RELATIONSHIPS

8.1.1 DISCLOSING ONE'S HIV/AIDS STATUS TO THE PRIMARY FAMILY

According to Busse (2000: 55), informing one's family regarding one's HIV/AIDS status is one of the biggest obstacles a PLWA has to overcome as it is a "much more emotionally loaded issues to talk to a family member because I think one's worry is what is their reaction going to be" and "when disclosing to family, their reaction is critical".

During a meeting of the Leratong support group for PLWA (27 January 2001), a few members dislclosed that they were indeed rejected by family and friends when they revealed their HIV/AIDS status. One lady (32) told the group that she was forbidden by her father to ever come near their house again. The same reaction of parents was described by a 22 year old man.

The following important aspects regarding disclosure are pointed out by Vinassa (1999: 86):

- Remember that the news was a shock to you, so it will be a shock to the family too
- The family needs time to get used to the news
- PLWA should expect tears and anger when disclosing the news to the family
- Do not take the family's (normal) reaction to heart and experience it all as rejection

8.1.2 THE PLWA'S NEED FOR FAMILY SUPPORT

Family support and understanding, under normal circumstances, are of the utmost importance to any human being. It is even more important during the developmental stages of adolescence and young adulthood. This group needs their parents to be interested in them; helping them as needed; listening to them; loving and accepting them; trusting them; and accepting their autonomy (Rice, 1990: 434-437). Young adults living with HIV/AIDS have these same basic needs, involving their parents. They might need it even more as they are facing a fatal illness which influence both parent- and childhood prevailing a "tragic absurdity where time is shortened and order is shattered" (Sourkes, 1992: 27).

8.1.3 THE FAMILY'S REACTIONS AND FEARS FOLLOWING A HIV/AIDS DIAGNOSIS

Getting informed that an immediate family member is diagnosed with HIV/AIDS places tremendous stress on the family system (Seibert, Garcia, Kaplan & Septimus, 1989: 47). The family of a PLWA may often need help to themselves in coming to terms with their own fears, prejudices, their loved one's illness and the possibility of death (Van Dyk, 1992: 81).

The following list contains emotional and social themes that are often expressed by the families of PLWA:

- The existence of a life-threatening disease represents a premature separation from the family by possible death, leaving family members with grief, mourning, shock, fears and a sense of helplessness
- Family members, especially if they have to care for a person with full-blown AIDS, may fear getting infected, experience financial problems, have to deal with a disturbed routine and may become extremely exhausted
- They may experience depression and anxiety
- Disappointment and a lost of trust, but still love for the family member
- A feeling of obligation to help the infected family member
- Feelings of guilt and shame and a fear for stigmatization, discrimination and social isolation
- Anger towards the person with HIV/AIDS for contracting a disease connected with low moral standards and values
- Loneliness and a lack of social and emotional support
- Over protectiveness

(Harvey, 1988: 16-17; Moreland-Smith & Moreland-Smith, 1990: 145-146; Kirkpatrick, 1988: 279; Sourkes, 1992: 27; Seibert *et al.*, 1989: 49-51.)

LoveLife (2001: 8-10) also refers to the practical implications of HIV/AIDS on the family system:

- Disability that can lead to unemployment
- There is the possibility that more than one household member could be infected
- Poor financial situation (poverty)
- The possibility of orphans in the family

8.2 INTIMATE RELATIONSHIPS

Intimate relationships refer to any relationships involving a sexual partner. The following issues in intimate relationships may be disturbed by a HIV/AIDS diagnosis:

- Emotional support
- Communication
- Trust
- Guilt

- Anger
- Blame
- Sexuality
- Decisions regarding reproduction, with reference to the following aspects:
    - Whether to have children or not
    - The possibility of adopting a child
    - The choice to terminate a pregnancy
    - The possibility to care for a sick and/or dying infant
    - Future birth control options
    - If having a child, the possibility that the child may be orphaned

(Evian, 2000: 207 & 275; Gresak & Patient, 1999: 3; Seibert *et al.*, 1989: 48.)

When referring to intimate relationships, both partners' emotions and needs must be considered. Kirkpatrick (1988: 279) supplies a summary of these needs and emotions which are reflected in the following figure.

FIGURE 17: THE EMOTIONS AND NEEDS OF PARTNERS IN AN INTIMATE RELATIONSHIP, WHERE ONE PARTNER IS HIV INFECTED

EMOTIONS OF THE NON-INFECTED PARTNER	EMOTIONS OF THE INFECTED PARTNER
GRIEF AND SHOCK	ANXIETY ABOUT THE VIRUS
A SENSE OF HELPLESSNESS	DEPRESSION ABOUT THE INEVITABILITY OF THE DISEASE
A FEAR THAT THE PARTNER MIGHT DIE	A MORBID OBSESSION WITH THE DISEASE
A FEAR OF BEING INFECTED	GUILT ABOUT OWN SEXUALITY AND INFECTING A PARTNER
REDUCED SEXUAL FUNCTIONING	SOCIAL, DOMESTIC AND OCCUPATIONAL DISRUPTION
UNCERTAINTY ABOUT WHAT TO DO NEXT	
CLINICAL ANXIETY AND DEPRESSION	

In summary it seems as if the basic components of an intimate relationship, passion, commitment and intimacy (Evian, 2000: 207; Gresak & Patient, 1999: 3; Louw *et al.*, 1998: 546) may be affected by a HIV/AIDS diagnosis.

8.3 SOCIAL RELATIONSHIPS

Social relationships include for purposes of this study all relationships outside the family context like professional or career relationships, friends and being part of a community (church, sport and recreation).

In general, society has some misconceptions regarding HIV/AIDS. Some of these myths may include:

- Only homosexual men can get AIDS
- AIDS is only a disease of white or black people
- Some traditional healers claim that they have a cure for AIDS
- AIDS can be spread in food and water, from toilets, showers, baths, pools, mosquitoes or by touching a person with HIV/AIDS
- Some people say that condoms do not give much protection against AIDS
- AIDS is a punishment by God for sinful behavior
- Having sex with a virgin will get rid of the virus in an infected person

(Gresak & Patient, 1999: 33-34; Louw, 1997: 134 .)

These myths may contribute to a society condemning PLWA, by unnecessary prejudice, isolation and stigmatization. In this process, PLWA are denied some of their basic human rights. Although many human rights exist, the researcher's opinion is that the human right that is mostly affected by HIV/AIDS is probably dignity. The PLWA loses his dignity due to self-blame and rejection by the community.

It seems as if the PLWA has mainly the following two problems when referring to social relationships:

- Stigmatization
- Isolation

Due to these two factors, the PLWA may experience difficulty in achieving social goals with reference to obtaining a work, getting involved in community activities and making acquaintances.

9. THE IMPACT OF THE PSYCHO-SOCIAL IMPLICATIONS OF HIV/AIDS ON THE DEVELOPMENTAL TASKS OF THE YOUNG ADULT

With reference to the developmental tasks of the young adult mentioned in paragraph 2.3, the researcher compiled the following summary to show how the young adult's developmental tasks are affected by a HIV/AIDS diagnosis.

FIGURE 18: THE IMPACT OF HIV/AIDS ON THE DEVELOPMENTAL TASKS OF THE YOUNG ADULT

DEVELOPMENTAL TASKS	IMPLICATIONS OF HIV/AIDS
Obtaining independence and taking responsibility for oneself	Possibility of losing independence and becoming dependent on others
Stabilizing own identity	Disruption of identity formation
Defining own value systems	Values are being questioned by oneself as well as by society in general
Developing intimacy and commitment Choosing a partner Establishing a meaningful relationship with a partner	Issues arise regarding existing intimate commitments and HIV/AIDS may influence the possibility of choosing a partner and making future commitments
Becoming a parent and raising children	The risks of having a HIV infected child have to be considered and there is the possibility that existing children may become orphaned
Establishing a career	Career opportunities still exist, but may be influenced by one's medical condition
Developing a recreational pattern Contributing to the community	Could be influenced by poor health, stigmatization and isolation from the community

This summary may give a very negative picture of the psycho-social circumstances of the PLWA. It is indeed so that PLWA suffer on the physical, emotional and social level, but the researcher wants to point out that it is possible to lead a meaningful life with HIV/AIDS. This opinion is supported by Green & Miller (1986: 124) who state that "the issue for many AIDS patients is not so much the problem of dying as the problem of living. A large part of that is the way that society reacts to them". The researcher experienced this during the study, whenever talking to PLWA. Some of them took on the living part of HIV/AIDS and tried very hard to do it properly. One of the projects that support this view is The Young Positive Living Ambassadors Project. Some of the Ambassadors taught the researcher that the abbreviation HIV does not only stand for "Human Immunodeficiency Virus", but also for **HOPE IS VITAL**. This is a positive outlook on HIV/AIDS and is essential for assisting young PLWA who are busy with the living part of the disease.

Decisions regarding medical treatment are another matter that needs further exploration and will be described in the next paragraph.

10. DEALING WITH THE PHYSICAL CONSEQUENCES OF HIV/AIDS

With reference to the three aspects surrounding HIV/AIDS being addressed in this chapter, the last one to cover is the physical part, including medical treatment and dealing with the possibility of death. Discussions about medical treatment will mainly be focused on the PLWA's decisions in this regard and the emotional impact it may have on the individual and his family.

Various opinions can be shared in this regard, but a comprehensive outlook on matters related to medical treatment is supplied by Evian (2000: 55-119). This viewpoint was summarized by the researcher for purposes of this study in Figures 19 and 20.

FIGURE 19: MEDICAL CARE FOR EARLY (ASYMPTOMATIC) HIV INFECTION

CLINICAL FEATURES INDICATING OPPORTUNISTIC INFECTIONS	MEDICAL MANAGEMENT PROCESS	INFORMATION TO THE PATIENT
Weight loss/loss of appetite Fever Respiratory problems Skin problems Swellings Mouth/lips/gastro-intestinal problems Central nervous system problems Mood changes Pins and needles Visual disturbances Psychological disturbances Sexual problems Lack of energy	Confirm the diagnosis of HIV Encourage regular physical check-ups Monitor HIV and immune status Give anti-HIV therapy Prevent opportunistic infections Give advice on self-care, wellness and safer sexual practices Give support and counseling	**Results of the HIV test** **Information on symptoms, treatment and lifestyle** **Information on the side-effects of medication** **Information regarding support services in the community**

FIGURE 20: MEDICAL CARE FOR ADVANCED (SYMPTOMATIC) HIV DISEASE AND AIDS

CLINICAL FEATURES INDICATING HIV DISEASE AND AIDS	MEDICAL MANAGEMENT PROCESS
Recurrent or persistent candida infections (thrush) Hairy leukoplakia (white plaque) on the tongue Herpes zoster Skin rashes Weight loss Fever and night sweats Diarrhoea Dyspnoea and cough Peri-anal conditions Tuberculosis Genital ulcers Neurological problems Anaemia Karposi's sarcoma	Assessing the immune status and stage of HIV disease Assessing the HIV viral load ARVT Preventing opportunistic infections and other ARC Support, counseling and referral Home-care, day-care, hospitalization or hospice

These two figures give a summarized view on the physical and medical issues of the PLWA. They were included by the researcher to show what intense physical problems the PLWA and his family have to deal with.

11. HIV/AIDS COUNSELING

11.1 MODELS FOR HIV/AIDS CARE

According to Louw (1997: 139), there are five possible models for HIV/AIDS care and counseling. The following models are suggested:

- **The isolation model,** an impractical and immoral model suggesting that all people infected with HIV/AIDS be removed from their immediate social environment
- **The selection model,** a model that would combat AIDS through testing and mandatory screening
- **The medical model,** where it is believed that by giving information about AIDS, people will change their lifestyles
- **The educational model,** focusing on using the facts of AIDS to frighten people into following safe sexual practices
- **The ethical model,** indicating that the only effective long term solution is to change people's attitudes and value systems, starting with the church and accompanying stakeholders, reaching out to people at grass roots level where all human values are moulded

Although HIV/AIDS counseling contains elements of the medical and educational models, it is the researcher's opinion that the ethical model is the most suitable for application in social work.

11.2 THERAPEUTIC GOALS IN HIV/AIDS COUNSELING

The following therapeutic goals are set for HIV/AIDS counseling by Winiarski (1991: 55-57). These goals include:

- Coming to terms with the HIV diagnosis and its implications

- Connection and reconnection – including self-acceptance and willingness to rejoin and feel part of the community
- Planning for the future
- Other goals

11.2.1 COMING TO TERMS WITH THE HIV DIAGNOSIS AND ITS IMPLICATIONS

The heading for the first therapeutic goal is short and simple, but implies a series of physical, emotional and social aspects the PLWA has to face. The following is a list of possible themes that could be important when counseling a newly diagnosed PLWA:

- Discussing the results of a HIV test
- Dealing with initial emotions of shock, denial, fear, guilt, depression, shame and anger
- Adjusting to safer sexual practices
- Dealing with the fact of having acquired a life-threatening disease
- Making decisions about costly ARVT and other medical options
- Coping with the many uncertainties about AIDS

(Steyn, 2000: 1.)

11.2.2 CONNECTION AND RECONNECTION

This part of the counseling goals should include active therapeutic input, dealing with the four major aspects described earlier in this chapter:

- Identity
- Life-view issues
- Depression
- Guilt

11.2.3 PLANNING FOR THE FUTURE

The following aspects with regard to the future need to be addressed in counseling:

- Maintain a positive attitude, enhancing hope
- Start with the living part of HIV/AIDS
- Follow a balanced, focused treatment program, including:
    - Behavioral and life style changes
    - A nutritional program
    - Following appropriate alternative therapies
    - Repairing emotional fences through love, self-acceptance, forgiveness and letting go of bitterness and hatred
    - Getting rid of a victim attitude of "poor me" and "why me?"
    - Conquering fear
    - Focusing on changing attitude (Chaitow & Strohecker, 1994: 141-144.)

- Focus on family-related issues, including:
    - Reconstructing of disturbed relationships
    - Making decisions regarding children (to have any; dealing with a HIV-infected baby; the possibility that children may be orphaned)
    - Coping with financial matters
    - Dealing with sexual problems
    - Coping with the future loss of a family member (Steyn, 2000: 1.)

11.2.4 OTHER GOALS

- Utilize community support opportunities (support groups, health services, family and friends)
- Make decisions on medical treatment and wishes once in the terminal phase of the disease

(Vinassa, 1999: 86.)

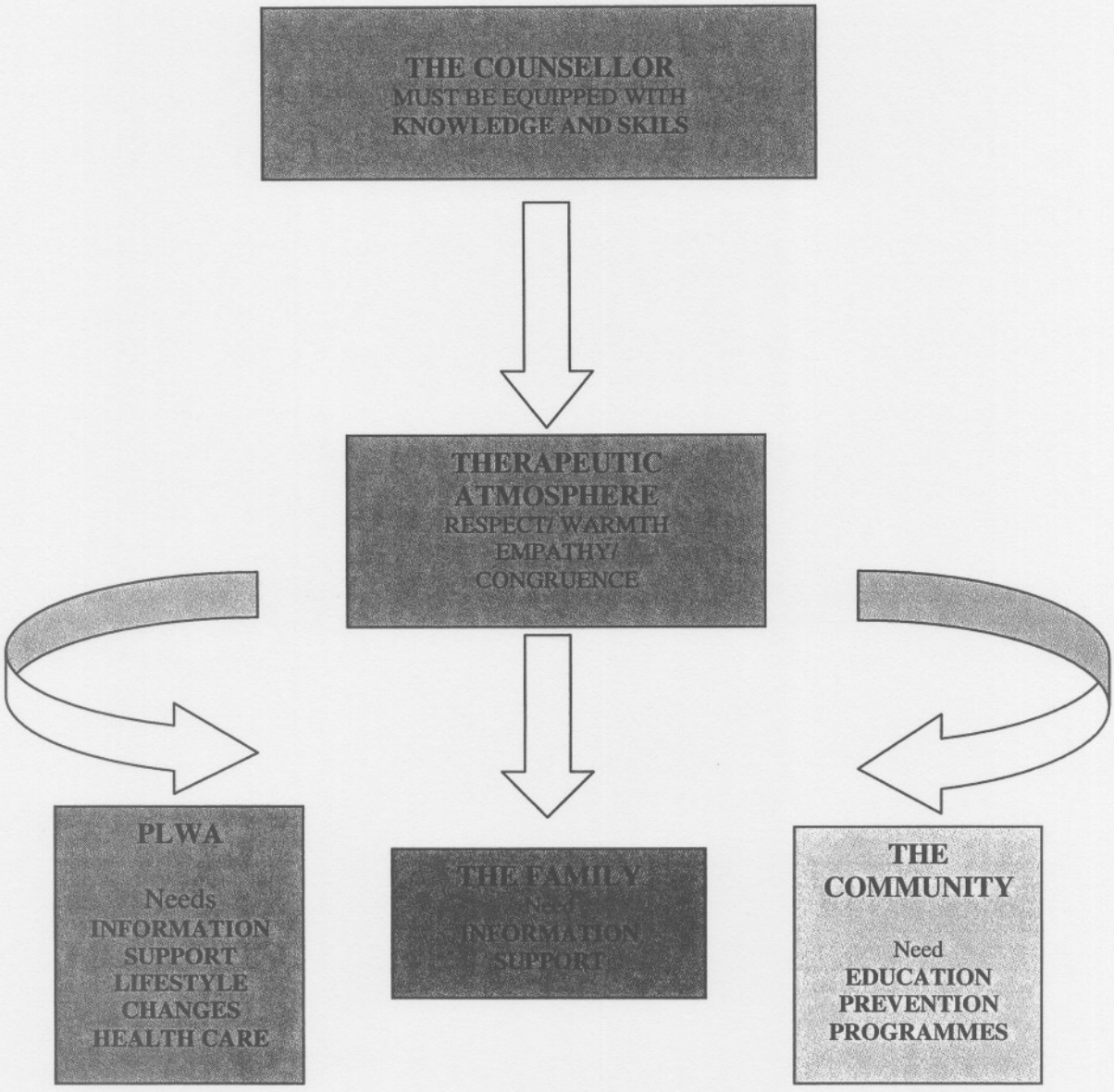
11.3 REASONS WHY COUNSELING IS IMPORTANT

Taking the previously mentioned goals into consideration, the researcher summarized the reasons why counseling is necessary as follows:

- HIV/AIDS is a life-threatening disease, currently without medical cure, causing intense emotional reactions and practical problems
- HIV/AIDS can be transmitted to other people, placing many lives in jeopardy
- Young adulthood is a very important developmental stage, delivering a large part of the productive force of society
- PLWA may have many years of good health. The need support, lifestyle counseling and motivation to keep them busy with the living part of HIV/AIDS.

The following figure illustrates the researcher's opinion on how these goals can be achieved.

FIGURE 21: THERAPEUTIC INPUTS REGARDING HIV/AIDS COUNSELING



12. EXISTING HIV/AIDS SUPPORT PROGRAMMES

During this study the researcher came to the realization that very few official support programmes for PLWA exist. Programmes are mainly focused on prevention. A comprehensive list of these

programmes can be obtained from any ATICC. The following supportive programmes can be mentioned:

- Support groups in various communities
- The Soul City programs on SABC 1 and radio stations, in co-operation with Jacana Education
- The Beyond Awareness Campaign of the Department of Health
- The Young Positive Living Ambassadors Project, initiated by the National Youth Commission
- Various individual support programmes presented by churches, community institutions and professionals

Although many HIV/AIDS programmes exist, the researcher came to the conclusion that there is still a need for more supportive and therapeutic programmes for PLWA.

13. SUMMARY

In this chapter the focus was on the nature of HIV/AIDS; the statistics and demographic predictions; and the biopsycho-social implications on the PLWA, the family and the community. Aspects regarding HIV/AIDS counseling were described, emphasizing the need for counseling and typical themes that should be attended to. Young adulthood as developmental stage was described, focusing on how a HIV/AIDS diagnosis can influence the developmental tasks of this stage.

The researcher came to the conclusion that a HIV/AIDS diagnosis has a definite influence on the young adult, his family and the community. A lack of official support programmes could prevent young adults with HIV/AIDS to concentrate on the living part of the disease, leaving them hopeless, isolated and vulnerable.

In the next chapter attention will be given to defining and describing life maps as technique in a social group work programme for young PLWA. The life maps technique consists of seven maps with the following themes:

- ***WHO AM I?***
- ***WHERE HAVE I COME FROM?***
- ***WHERE AM I GOING?***
- ***WHAT IS STOPPING ME?***
- ***HOW WILL I GET THERE?***
- ***WHAT HELP DO I NEED?***
- ***WHAT WILL IT BE LIKE WHEN I GET THERE?***

The background, theoretical foundations and the application of life maps in social group work will be described thoroughly in chapter 5.

PHILOSOPHY FOR LIFE

COMMITMENT

DISCIPLINE

EXCELLENCE

Ntsetsi Gladys

CHAPTER 4

RESEARCH FINDINGS: THE NEEDS ASSESSMENT

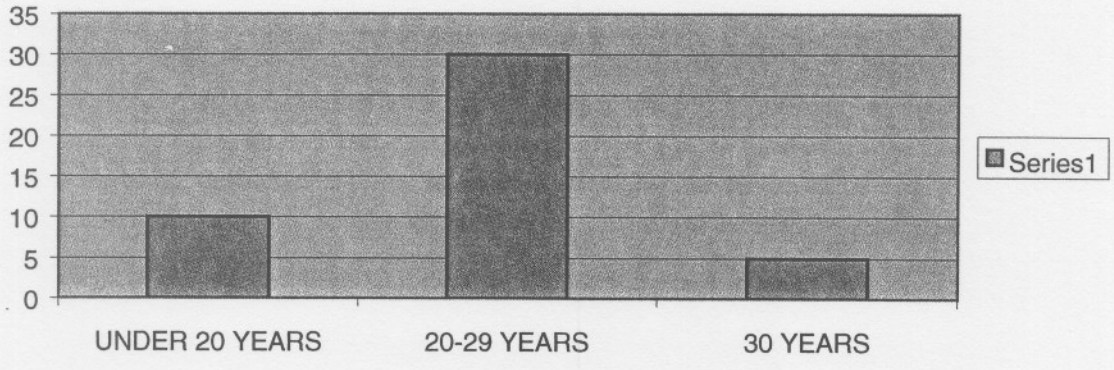
1. INTRODUCTION

In this chapter the empirical findings of the needs assessment will be presented. These can be seen as the foundation of the group work programme that has been developed for this research project. The population, sampling methods and measuring instruments will be briefly described.

2. POPULATION AND SAMPLING

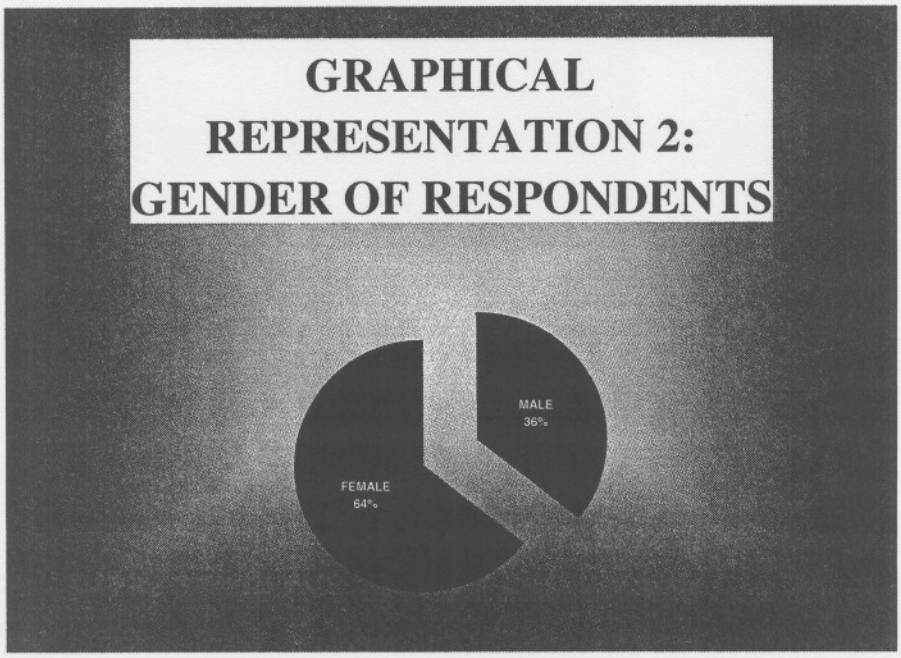
The population consisted of 45 young adults living with HIV/AIDS. They completed the needs assessment questionnaire and the General Contentment Scale (GCS) (Annexures 1 and 2). The following graphical representation give a description of the age and gender of the respondents.

GRAPHICAL REPRESENTATION 1: AGE OF RESPONDENTS



Respondents were all between the ages of 18 and 30 years, with most of them in the age group 20-29 years.

The following graphical representation gives a description of the gender distribution of the respondents.



Most of the respondents (64%) were female. This correlates with the national statistics of HIV/AIDS infection among women being the worst (Department of Health, 2000: 1).

3. RESPONSE RATE

The response rate was 100% because questionnaires were completed mainly in a structured interview situation. A 100% response rate could not be established for all questions due to the following reasons:

- Six respondents found it very difficult to complete the GCS
- Open questions in the questionnaire were not answered in detail

4. MEASURING INSTRUMENTS

The needs assessment questionnaire (Annexure 1) and the GCS (Annexure 2) (Bloom, *et al.*, 1990: 220) were used as measuring instruments. The aim of the questionnaire was to

determine the needs of young adults living with HIV/AIDS and the GCS was applied to measure their general contentment with life in the first place, and secondly, it was used as measuring instrument (pre and post test) in the experiment.

5. THE DESIGN

The exploratory research design is recommended when research is conducted on an existing phenomenon that needs further or more specific research on certain aspects of the phenomenon. In this study the focus was on the psycho-social needs of young adults living with HIV/AIDS, where ***HIV/AIDS*** can be seen as the existing phenomenon and the ***psycho-social needs of young adults*** are the specific research focus.

6. THE RESULTS OF THE NEEDS ASSESSMENT QUESTIONNAIRE (ANNEXURE 1)

The aim of the questionnaire was to determine the psycho-social needs of young adults living with HIV/AIDS and to use the collected data to develop a group work programme. The data will be presented in the question order of the questionnaire (Annexure 1) which includes the following three main themes:

- Biographic information
- The psycho-social implications of HIV/AIDS
- The future planning of young adults living with HIV/AIDS

6.1 BIOGRAPHIC INFORMATION

In this section the current diagnosis of respondents, the meaning of the HIV/AIDS diagnosis, the time of the diagnosis, their current health status, highest educational qualification, main daily activity and marital status will be represented.

6.1.1 CURRENT DIAGNOSIS OF THE RESPONDENTS

This question was asked to determine how many respondents were HIV+ at the time of the research and how many already had full-blown AIDS. The following table demonstrates the respondents' current diagnosis.

TABLE 1: RESPONDENTS' CURRENT DIAGNOSIS

HIV+	*AIDS*
40	5
88.9%	11.1%

From this table it can be seen that most of the respondents were HIV+ when the research was conducted.

6.1.2 THE MEANING OF THE HIV/AIDS DIAGNOSIS

The aim of this question was to establish whether respondents understood the meaning of the different diagnoses by answering YES or NO. This question was followed up by an open-ended question which gave the respondents the opportunity to briefly describe their interpretation of the diagnoses.

Thirty-six of the respondents (80%) answered YES to the question, while 9 respondents (20%) said NO. The following table is a summary of the responses on the follow-up open-ended question.

TABLE 2: REPONDENTS' INTERPRETATION OF THE MEANING OF A HIV/AIDS DIAGNOSIS

INTEPRETATION	NUMBER OF RESPONDENTS	%
AIDS is a virus	10	22.2
HIV/AIDS is a life-threatening disease	8	17.8
No knowledge or denial of the diagnosis	7	15.6
Correct information and good insight in the diagnosis	6	13.3
Limited knowledge based mainly on media obtained information	5	11.1
No response	5	11.1
HIV/AIDS is a STD	4	8.9
TOTAL	**45**	**100%**

The respondents' interpretation of the HIV/AIDS diagnosis centred around the topic of HIV/AIDS as a viral disease, which is life-threatening and their information on the topic seemed to be obtained mainly from the media. An alarming 15.5% of the respondents had no knowledge about the disease or denied the facts.

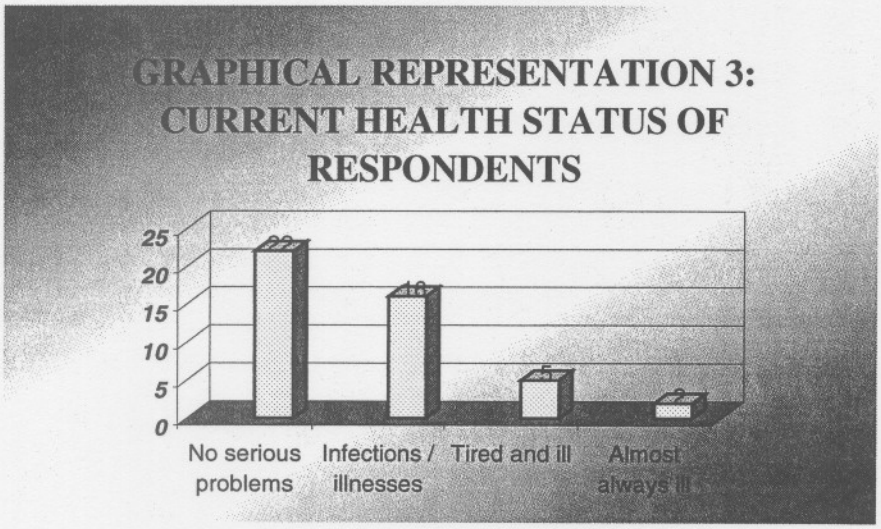
6.1.3 TIME OF DIAGNOSIS

The aim of this question was to determine how long ago respondents were diagnosed as HIV+. Of the 40 respondents who were HIV+, 15 (37.5%) were diagnosed within the past 6 months, 15 (37.5%) a year ago and 10 (25%) more than 2 years ago. Concerning to the 5

who already had full-blown AIDS, 3 (60%) were diagnosed within the past 6 months and 2 (40%) during the past 2 years.

6.1.4 CURRENT HEALTH STATUS

The following chart represents the respondents' health status at the time of this study.



Most of the respondents (48.8%) experienced no serious health problems at the time of the study, while 35.5% suffered from recurring infections and illnesses. Only 4.4% described their health as poor and themselves being almost always ill and in bed.

6.1.5 HIGHEST EDUCATIONAL QUALIFICATION

The following table summarizes the educational qualifications of the respondents.

TABLE 3: EDUCATIONAL QUALIFICATIONS

EDUCATIONAL QUALIFICATION	NUMBER OF RESPONDENTS	%
Tertiary qualification	11	25%
Standard 10	10	22.7%
Standard 8	12	27.3%
Standard 6	9	20.5%
Lower than Standard 6	2	4.5%
TOTAL	**44***	**100%**

***One respondent did not answer the question.**

The tertiary qualifications included the following:

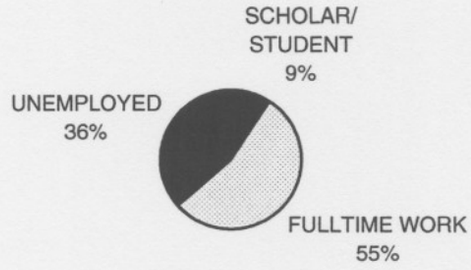
- BSc Mining Engineering (2)
- HED (2)
- B Com Hons
- B Com
- BA
- Diploma in Human Resource Management
- Diploma in Project Management
- Diploma in Hospitality Services
- Diploma in Hair dressing

From these data it was established that 75% of respondents had Standard 8 education or higher.

6.1.6 MAIN DAILY ACTIVITY

With this question the researcher tried to determine respondents' school and/or employment status. The following pie chart represents the respondents' main daily activities.

GRAPHICAL REPRESENTATION 4: MAIN DAILY ACTIVITY OF RESPONDENTS



Most of the respondents' main daily activity was a fulltime work for a salary, but a □isconcerting high percentage (36%) were unemployed.

6.1.7 MARITAL STATUS OF RESPONDENTS

In the following table, the marital status of respondents is presented.

TABLE 4: MARITAL STATUS OF RESPONDENTS

MARITAL STATUS	NUMBER OF RESPONDENTS	%
Married	8	18.2
Divorced	4	9.1
Never been married	17	38.6
Long-term intimate relationship	12	27.3
Several short-term relationships	3	6.8
TOTAL	**44***	**100%**

*One respondent did not answer this question. Many of the respondents (38.6%) had never been married, while 18.2% were married and 27.3% were involved in a long-term intimate relationship.

6.2 THE PSYCHO-SOCIAL IMPLICATIONS OF HIV/AIDS

Questions in this section were formulated from the information obtained from the literature study as described in Chapter 3. In this section of the report the influence of HIV/AIDS on normal daily activity, the direct results of HIV/AIDS, the most outstanding feeling regarding HIV/AIDS, feelings regarding HIV/AIDS status, the HIV status of immediate family members and disclosing one's HIV status will be reflected.

6.2.1 INFLUENCE OF HIV/AIDS ON NORMAL DAILY ACTIVITY

This question was an introduction to the psycho-social implications of HIV/AIDS and the aim was to determine whether respondents experienced their HIV/AIDS status as a barrier in conducting their normal daily activities.

- Twenty of the respondents (44.5%) indicated that HIV/AIDS has an influence on their daily activities.
- Twenty-four respondents (53.3%) answered NO to this question.
- One respondent (2.2%) did not answer the question.

This question was followed up by an open-ended question to motivate their answers. The following table is a summary on how respondents perceived the influence of HIV/AIDS on their normal daily activities.

TABLE 5: INFLUENCE OF HIV/AIDS ON NORMAL DAILY ACTIVITIES

PERCEIVED IMPACT ON NORMAL DAILY ACTIVITIES	NUMBER OF RESPONDENTS
Determined to manage the illness and try to live a normal life	13
Poor health and limited physical and emotional energy	9
Denying any impact	8
No response	6
Difficulty to find employment	4
Social isolation	3
Experience of closer family relationships	2
	TOTAL 45

Many respondents (28.9%) indicated that they tried to live their lives as normally as possible by managing the disease and its implications. 20% of the respondents found that poor health limited their physical and emotional energy. This correlates with commonly expressed concerns of PLWA as described by Winiarski (1991: 57-68) where questions regarding living fully seem to be a major concern. Two respondents' (4.4%) response was that their HIV/AIDS diagnosis had a positive influence on family relationships.

6.2.2 DIRECT RESULTS OF HIV/AIDS

The aim of this question was to investigate the respondents' view on how HIV/AIDS directly influenced their lives and whether or not their difficulties could be related to the HIV/AIDS diagnosis. The following frequency table indicates what respondents experienced as direct results of HIV/AIDS. Respondents could mark more than one possibility and therefore the total for this is indicated for every response.

TABLE 6: DIRECT RESULTS OF HIV/AIDS

	FREQUENCY			
RESULTS OF HIV/AIDS	**YES**	**NO**	**TOTAL**	**%**
Insufficient information on HIV/AIDS	**25 (58.1%)**	**18 (41.9%)**	**43**	**100**
Poor general health	**23(53.5%)**	**20 (46.5%)**	**43**	**100**
Financial need	**22 (51.2%)**	**21 (48.8%)**	**43**	**100**
Lack of energy	**17 (39.6%)**	**26 (60.4%)**	**43**	**100**
No sexual relationships	**16 (37.2%)**	**27 (62.8%)**	**43**	**100**
Rejection by the community	**16 (37.2%)**	**27 (62.8%)**	**43**	**100**
Unable to obtain a job/attend school	**13 (30.2%)**	**30 (69.8%)**	**43**	**100**
Isolation from the broader community	**13 (30.2%)**	**30 (69.8%)**	**43**	**100**
Few or no friends	**12 (28%)**	**31 (72%)**	**43**	**100**
Unable to keep a job	**10 (23.3%)**	**33 (76.7%)**	**43**	**100**
N=	**43***	**43***	**43***	**100**

*Two respondents did not answer this question.

More than 50% of the respondents lacked enough information on HIV/AIDS. The same number experienced poor general health as a direct result of their diagnosis. More than 30% of the respondents indicated financial need, lack of energy, no sexual relationships and rejection by the community as direct results of HIV/AIDS. The following six main problem areas or needs could thus be identified:

- Insufficient information on HIV/AIDS
- Poor general health
- Financial need
- Lack of energy
- No sexual relationships
- Rejection by the community

6.2.3 MOST OUTSTANDING FEELING REGARDING HIV/AIDS

This was an open-ended question, giving respondents the opportunity to describe in their own words what they experienced as their most outstanding feeling towards HIV/AIDS. The following is a summary of their responses.

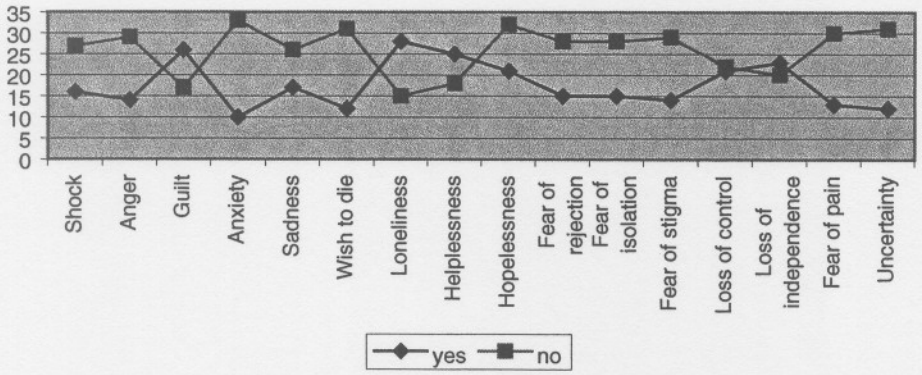
- Uncertainty, fears and anxiety – **13 (28.9%)**
- Numbness – **6 (13.3%)**
- No response – **6 (13.3%)**
- Denial – **5 (11.1%)**
- Hope for a cure – **5 (11.5%)**
- Isolation – **4 (8.9%)**
- Anger, guilt and severe sadness – **4 (8.9%)**
- Tiredness – **2 (4.4%)**

One can come to the conclusion that uncertainty, fears and anxiety were the most outstanding feelings of the respondents. This correlates with the literature in this regard, as described in paragraphs 6.1 and 6.2 of chapter 3 (Orr, 1994: 45; Van Dyk, 1992: 81; Van der Westhuizen & Thompson, 1994: 18-21).

6.2.4 FEELINGS REGARDING HIV/AIDS STATUS

This question followed the previous one with two response categories, focusing on more specific emotions. Respondents had to answer YES or NO to every question. The feelings that were incorporated in this question, were described in the literature. The aim of the question was to determine whether respondents also experienced the emotions described in the literature. The following graphical representation summarizes their responses.

GRAPHICAL REPRESENTATION 5:
FEELINGS REGARDING HIV/AIDS



More than 45% of respondents indicated the following as their most outstanding feelings: loneliness, feelings of guilt, helplessness, hopelessness and loss of independence.

6.2.5 IMMEDIATE FAMILY MEMBERS' HIV STATUS

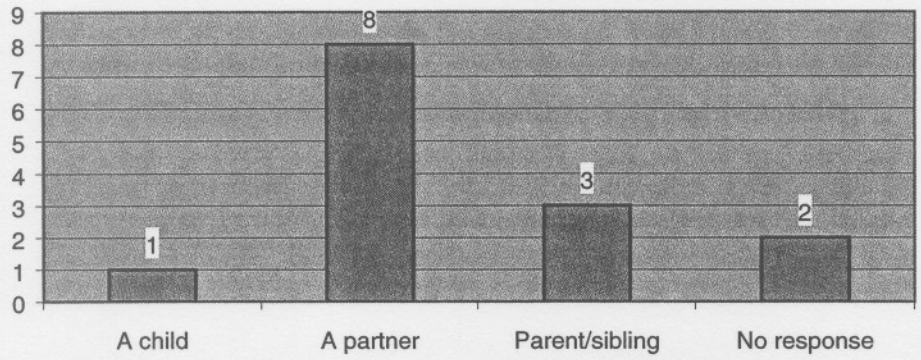
With this question the researcher tried to establish how many of the respondents' immediate family members were also infected with HIV.

- Fourteen respondents (31.1%) indicated that their immediate family members had HIV/AIDS
- Thirty respondents (66.7%) answered NO to this question
- One respondent (2.2%) did not answer the question

These data correlates with the statistics on HIV/AIDS in South Africa as presented in Chapter 3 (Department of Health, 2000: 1; UNAIDS, 1999: 3).

The follow-up question was answered only by those respondents who answered YES to the previous question and was aimed at determining the relationship to the respondents. The following chart represents the infected family members' relationship to the respondents.

GRAPHICAL REPRESENTATION 6:
HIV INFECTED FAMILY MEMBERS



In 57.1% of the cases where respondents' immediate family members were HIV+, it was their partners. This situation is also reflected in the global statistics of the HIV/AIDS infection rate being highest among sexually active persons (The Department of Health, 2000: 7).

6.2.4 DISCLOSING OF HIV STATUS

The following questions were focused on the issue of disclosing one's HIV status and included the following 8 questions:

- Are any of your immediate family members also HIV+ or diagnosed with AIDS?
- Information on how many and which family members
- Do your primary family members (parents/brothers/sisters) know that you are HIV+/have AIDS?
- Motivation for answers
- Do your friend know that you are HIV+ /have AIDS?

- Motivation for answers
- Does your headmaster/employer know that you are HIV+ /have AIDS?
- Motivation for answers
- Do you think that it is unnecessary that others know about your diagnosis?
- Motivation for answers

Disclosing one's HIV status is a sensitive matter (Busse, 1991: 67 & Winiarski, 1991: 67) and the aim of the question was to determine how respondents felt about disclosure and to whom they would disclose their status.

Most of the respondents (73.3%) disclosed their HIV status to their immediate family members, motivating this choice by explaining that they needed their support or that they also had HIV/AIDS.

Respondents were more reluctant to disclose their status to friends. Only 35.6% were willing to disclose their HIV status to friends. The other 64.4% did not want to disclose their status, mainly for the following reasons:

- Fear of stigmatisation
- Fear of isolation

Only 17.8% of respondents disclosed their HIV status to their headmaster or employer, claiming that it was a private matter, which did not influence their schoolwork or employment. Another reason for not disclosing their HIV status to their employers was the fact that 22.2% of the respondents were unemployed.

In summary, 71.1% of the respondents felt that it was unnecessary for others to know their HIV status, giving the following reasons for their answers:

- Having HIV is a personal problem and others can do nothing about it
- A fear of stigmatisation
- Only close family members need to know

Those who valued disclosure of HIV status as important, motivated their choice by emphasizing their need of family and social support.

These data confirms that PLWA are in need of social and family support on the one hand, but on the other hand fear stigmatisation and isolation. This correlates with the literature that PLWA need their families to love them, to accept them and to support them, but the realization that a family member has HIV/AIDS places tremendous stress on the family system (Seibert; Garcia; Kaplan & Septimus, 1989: 47; Sourkes, 1982: 27).

6.3 THE FUTURE PLANNING OF YOUNG ADULTS LIVING WITH HIV/AIDS

This section of the questionnaire consisted of 15 incomplete sentences. These type of questions were used because the anticipated information gathered from every individual's future planning would result in too many response options to classify it meaningfully (Fouche, 1998: 162). Analysing the data resulting from these sentences was very difficult, but the researcher included these questions to contribute towards the qualitative component of this study. Using incomplete sentences also allowed the respondents to express their feelings, thoughts and ideas more freely. This section will be presented by firstly repeating the incomplete sentence, followed by a summary of responses. Finally the central themes will be identified and summarized.

6.3.1 THE FUTURE OF HIV/AIDS MEMBERS OF SOCIETY IS ...

- Ruled by the implications of the disease – **16 (35.6%)**
- Positive and challenging – **15 (33.3%)**
- Meaningless and resulting in death – **6 (13.4%)**
- Uncertain – **4 (8.9%)**
- Full of fears – **2 (4.4%)**
- No response – **2 (4.4%)**

6.3.2 THE ONLY WORK THAT YOUNG ADULTS WITH HIV/AIDS CAN DO IS ...

- Any work that they can get – **18 (40%)**
- The same work that they are currently doing – **11 (25%)**
- Getting involved in HIV/AIDS projects – **7 (15.6%)**
- No work – **5 (11.1%)**
- Starting an own business – **2 (4.4%)**
- No response – **2 (4.4%)**

6.3.3 THE SEXUAL NEEDS OF YOUNG ADULTS LIVING WITH HIV/AIDS ARE ...

- To always practice safe sex – **19 (42.2%)**
- Normal, like anybody else's – **9 (20%)**
- Negative, because those needs were the cause of HIV/AIDS – **9 (20%)**
- To rather stick to abstinence – **5 (11.1%)**
- No response – **2 (4.4%)**
- To practice masturbation – **1 (2.2%)**

6.3.4 MY DREAM FOR THE FUTURE IS ...

- To find a suitable job and establish financial security – **9 (20%)**
- To manage my health and to hope for a cure for HIV – **9 (20%)**
- To obtain further education – **8 (17.8%)**
- To have my own family and children who will be HIV – **8 (17.8%)**
- To live my life in a meaningful way – **8 (17.8%)**
- No response - **3(6.6%)**

6.3.5 I PLAN TO ...

- Manage my health situation and support HIV projects – **12 (26.7%)**
- Accomplish certain personal goals – **10 (22.2%)**
- Obtain a job or further education – **9 (20%)**
- Establish financial and social independence – **8 (17.8%)**
- Establish a comforting family environment – **4 (8.9%)**
- No response – **2 (4.4%)**

6.3.6 IF I COULD, I WOULD ...

- Have prevented contracting HIV and valued my health – **13 (28.9%)**
- Overcome financial difficulties – **12 (26.7%)**
- Become involved in HIV projects – **10 (22.2%)**
- Obtain further education – **7 (15.6%)**
- No response – **2 (4.4%)**
- Re-evaluate religion – **1 (2.2%)**

6.3.7 IF I COULD HAVE CHILDREN ONE DAY ...

- They will also have HIV/AIDS, so it is better not to have any children – **14 (31.1%)**
- I hope that a cure or medical procedure can be developed to prevent them from having HIV/AIDS – **10 (22.2%)**
- I already have children – **8 (17.8%)**
- I want to be an efficient and caring parent – **6 (13.3%)**
- I would give them a good education, including information on HIV/AIDS – **5 (11.1%)**
- No response – **2 (4.4%)**

6.3.8 I DO NOT CARE ...

- About the future – **16 (35.6%)**

- About the opinions of doctors or researchers – **11 (24.4%)**
- What others do or say – **8 (17.8%)**
- About the person(s) responsible for spreading HIV/AIDS to me – **7 (15.6%)**
- No response – **2 (4.5%)**
- About myself – **1 (2.2%)**

6.3.9 HIV/AIDS CAN BE PREVENTED ...

- By using condoms and practicing safe sex – **26 (57.8%)**
- By being faithful to one sexual partner – **5 (11.1%)**
- I don't know – **5 (11.1%)**
- By correct information – **4 (8.9%)**
- By abstinence – **3 (6.7%)**
- No response – **2 (4.4%)**

6.3.10 I THINK I AM GOING TO ...

- Get sicker and die – **12 (26.7%)**
- Achieve personal goals – **10 (22.2%)**
- Adapt to HIV status and live positively – **9 (20%)**
- Get cured and survive – **7 (15.6%)**
- Become involved in HIV/AIDS projects – **5 (11.1%)**
- No response – **2 (4.4%)**

6.3.11 THE PEOPLE AROUND ME ...

- Are supportive and caring – **24 (53.3%)**
- Do not understand – **7 (15.6%)**
- Must take HIV/AIDS seriously – **6 (13.3%)**
- Are angry and reject me – **4 (9%)**
- Are very poor – **2 (4.4%)**
- No response – **2 (4.4%)**

6.3.12 THE BIGGEST PROBLEM IS ...

- Obtaining education, a job and financial security – **12 (26.7%)**
- The controvercy about HIV treatment – **12 (26.7%)**
- Overcoming personal and family issues – **11 (24.4%)**
- Getting social support – **5 (11.1%)**
- Rejection and isolation – **3 (6.7%)**
- No response – **2 (4.4%)**

6.3.13 IF ONLY I ...

- Can achieve personal goals and become financially secure – **17 (37.8%)**
- Can maintain health and energy – **15 (33.3%)**
- Can experience spiritual growth and obtain emotional support – **5 (11.1%)**
- Can change the past – **4 (9%)**
- Make a difference – **2 (4.4%)**
- No response – **2 (4.4%)**

6.3.14 IF ONLY OTHERS COULD ...

- Be more supportive – **18 (40%)**
- Show more understanding and compassion – **12 (26.7%)**
- Prevent the spread of HIV/AIDS – **6 (13.3%)**
- Show respect – **4 (9%)**
- Take responsibility – **3 (6.7%)**
- No response – **2 (4.4%)**

6.3.15 I AM ...

- Positive towards the future – **19 (42.2%)**
- Fulfilling my roles as child, husband/wife or parent – **10 (22.2%)**
- Ill, tired and HIV infected – **6 (22.2%)**
- Guilty, negative and sad – **4 (9%)**
- No response – **2 (4.4%)**

6.3.16 CENTRAL THEMES FROM THE INCOMPLETE SENTENCES

The following central themes could be identified from the incomplete sentences by analysing the frequency of these themes in the responses. It seemed as if these themes were not only HIV/AIDS related, but also included general life issues such as education, poverty and employment.

- A search for meaning and maintaining a positive attitude
- Dealing with the implications of HIV/AIDS and maintaining health and energy
- Financial difficulties and/or poverty
- The need for education
- Social isolation and stigmatisation
- The need for emotional, family and social support
- Employment
- Practising safe sex
- Managing health and support HIV/AIDS projects
- The controversy regarding HIV/AIDS treatment

7. THE GENERAL CONTENTMENT SCALE (GCS)

7.1 INTERPRETATION OF GCS SCORES

In this section the interpretation of the GCS scores of respondents will be presented

According to Bloom; Fischer & Orme (1999:220), the GCS (Annexure 2) scores should be interpreted as follows:

- Scores can range from 0-100%
- A score of more than 35% shows a need for improvement
- A score between 25 and 35% indicates a warning that an area needs attention
- A score below 25% is in the recommended range

Firstly all the respondents' GCS will be represented, followed by the average score of the group.

7.2 THE GCS SCORE OF RESPONDENTS

The following table is a representation of every respondent's GCS score.

TABLE 7: THE GCS SCORES OF RESPONDENTS

RESPONDENT NUMBER	GCS SCORE	RESPONDENT NUMBER	GCS SCORE
1	70 %	24	56 %
2	28 %	25	59 %
3	33 %	26	62 %
4	35 %	27	48 %
5	48 %	28	26 %
6	59 %	29	16%
7	62 %	30	42%
8	41 %	31	8 %
9	56 %	32	48 %
10	54 %	33	23 %
11	44 %	34	49 %
12	27 %	35	16 %
13	34 %	36	70 %
14	60 %	37	58 %
15	62 %	38	20 %
16	62 %	39	44 %
17	52 %	40	30 %
18	82 %	41	43 %
19	39 %		
20	74 %	TOTAL = 41*	
21	71 %		
22	55 %		
23	39 %		

*** Four respondents did not complete the GCS.**

The GCS score of respondents varied between a low 8% and scores as high as 74% and 82%. Most of the respondents' scores were higher than the recommended range of 25% and lower. The average score was:

46.5%

This score was in the range above 35%, indicating a below average general contentment and a need for improvement. The conclusion can be drawn that the respondents of this study experienced a lack of general contentment in their lives.

8. SUMMARY

The comprehensive needs assessment described in this chapter focussed on three main areas of the young adult living with HIV/AIDS: biographic information; psycho-social implications of HIV/AIDS; and their future planning. The needs assessment was concluded with the measurement of respondents general contentment with life, using a standardized scale, Hudson's GCS.

The data collected from the needs assessment indicated that young adults living with HIV/AIDS encountered various HIV/AIDS related problems, but also reflected a need for solutions to general life problems like education, financial independence, employment, interpersonal relationships and self-knowledge. Some of these needs can also be related to young adulthood as a life stage.

One of the most outstanding **needs** identified, is the need for family and social support. A large number of respondents expressed a need for respect, understanding and support from society and a fear of stigmatisation and social isolation.

The most encountered **emotions** regarding HIV/AIDS were feelings of guilt, loneliness, helplessness, hopelessness and loss of control and independence. With reference to the

direct impact of HIV/AIDS on the lives of young adults living with the disease, insufficient information, lack of energy, poor general health, strain on sexual relationships, financial need and rejection by the community were identified as the most important.

With regard to **future planning**, two main themes could be identified: efforts to adapt to the diagnosis of HIV/AIDS and living positively with it on the one hand, and on the other hand, attempts to deal with the fears, implications and psycho-social implications of a controversial and life-threatening disease. Respondents' future planning also included many general dreams, ideals and wishes of the average young adult. These dreams and ideals could often be related to interpersonal relationships, achievement of personal goals, education, career development, identity formation, involvement in HIV/AIDS projects and living a meaningful life. These aspects were taken into consideration when the suggested group work programme was planned.

The following chapter is the first part of section two of this report and focuses on the theoretical background of life maps. Attention will be given on how the technique can be applied in social group work.

PHILOSOPHY FOR LIFE

A PRAYER FOR HIV/AIDS PATIENTS

ALMIGHTY FATHER,
KEEP OUR BROTHERS AND SISTERS
FROM SPREADING THIS VIRUS TO OTHER PEOPLE.

BY SAYING THEY WERE BORN FREE FROM THIS DISEASE,
BUT HEY DO NOT KNOW WHERE AND BY WHOM,
WHO GAVE THEM THIS DISEASE,
BY CONDEMNING THEM ALIVE.

SAVE THEM FROM MAKING FOOLS OF THEMSELVES
IN CAFÉ'S, SHEBEENS AND NIGHT CLUBS
BY HUNTING INNOCENT MEN AND WOMEN
WITH THE CONCEPT
OF SPREADING THIS MONSTER DISEASE
TO OUR NATION.
LEAD THEM NOT INTO TEMPTATION,
BUT SAVE THEIR SOULS
BEDAUSE THEY DO NOT KNOW WHAT THEY ARE DOING.

AMEN

ELLEN

CHAPTER 5

LIFE MAPS AS TECHNIQUE IN A SOCIAL GROUP WORK PROGRAMME

1. INTRODUCTION

In this chapter, social group work will be described briefly. Social group work is a well described method in social work and will not be discussed in detail, as the focus of this chapter and the study is to introduce life maps as technique for application in social sciences. Social group work was selected for this study, as it was recommended in various studies with young PLWA (Gambe, 1991: 108; Gunther, Crandles, Williams & Swain, 1988: 354; Henry, 1992: 2), emphasizing the importance of identity formation in young adulthood. Aspects surrounding identity (described in chapter 3) and emotional disclosure are important aspects in identity formation and counseling PLWA. Emotional disclosure through writing or speaking is advised by Esterling, Antoni, Fletcher; Margulies & Schneiderman (1994: 130).

According to Getzel (1994: 185-186) " the mutual aid function in small groups continues to be the lifeline to so many persons affected by the pandemic". Expressive emotional disclosure is the foundation of life maps as technique, which will be the main theme of this chapter.

The technique of life maps as technique is fairly unknown in social work practice. The fundamental background for this technique is, however, not new or unknown, but is often described as life review, life scripts or life stories. In this chapter, life maps as technique will be described in detail by giving attention to the following important aspects:

- historic background
- comparison with other similar techniques
- theoretical foundations
- application of the technique in social work practice

- specific application in social group work
- advantages and disadvantages of the technique

Before life maps are discussed in detail, the following aspects regarding social group work need to be outlined:

- the objectives of social group work
- the advantages of social group work
- the disadvantages of social group work
- the types of groups
- practical considerations when deciding to use social group work
- the phases of the group process
- suggested themes for group work with PLWA

2. THE OBJECTIVES OF SOCIAL GROUP WORK

Social group work offers, by its very nature, unique opportunities for growth, learning and healing. Reid (1991: 7) refers to Klein's eight specific objectives that are part of group work and integrate social workers' historical mission of assistance to individuals regarding interpersonal relations and their encounters with their environment.

2.1 Rehabilitation. This involves restoring functioning, overcoming emotional or mental or behavioural difficulties and changing attitudes and values.

2.2 Habilitation. The focus is on growth and development rather than on treatment.

2.3 Correction. The emphasis is to help people overcome difficulties with social laws and mores.

2.4 Socialization. Individuals are being taught what is socially expected from them and how to get involved with others.

2.5 Prevention. Anticipated problems are being prevented before they can occur in a group where deterioration of social or personal functioning is a possibility.

2.6 Social action. People are taught to change their environment by active involvement in the group through leadership, participation and decision-making.

2.7 Problem solving. Group members should be helped to achieve tasks, to make decisions and to solve social problems.

2.8 Social values. Individuals should be helped to develop viable social values that are relevant to living.

(Reid, 1991: 7-8.)

3. THE ADVANTAGES OF SOCIAL GROUP WORK

In general all social work activities include three main goals (Fatout, 1992: 3):

- Prevention of dysfunctional coping
- Enhancing of artistic, social, intellectual and other endeavours in individuals
- Rehabilitation of handicaps in social and personal functioning

Taking these goals into consideration, social group work provides various positive forces to achieve them, resulting in the following advantages:

- Offers room for *mutual support, symbiotic striving and social interaction*
- a sense of *belonging, participation and cohesiveness* can be achieved
- *universalization* takes place, simulating real life, reinforcing acceptance of own problems, pain and disfigurement
- *relationships* can be supported and *caring* is made manifest
- *hope* can be installed;
- *knowledge* and *skills* are gained and shared, leading to the establishment of *values and norms*
- groups offer opportunities for *identity development* and *altruism* by taking an *overview* of one's life and making *adaptations and changes*
- *behaviour rehearsal and reinforcement* can take place
- opportunities for *growth* and *change*
- *reality testing* can take place as the focus is on *the here and now*
- *catharsis* and *corrective emotional experiences* are supplied

(Corey & Corey, 1987: 301-302; Fatout, 1992: 4; Getzel, 1994: 188; Henry, 1992: 2; Linesch, 1988: 134; Rose, 1998: 16-19.)

The following advantages were especially valuable in this study:

- *The opportunity to "belong" somewhere and to share experiences, could limit social isolation associated with HIV/AIDS*
- *The positive value of installing hope in PLWA and to acquire coping and life skills*

4. THE DISADVANTAGES OF SOCIAL GROUP WORK

The following disadvantages were identified by Rose (1998: 19):

- The group may *reinforce negative behavior and attitudes*
- *Individualization* of each member could be difficult
- *Confidentiality* is more difficult to maintain
- The group worker requires *various skills* to do effective group work

5. TYPES OF GROUPS

Various types of social groups exist, where the most basic distinction is between formed groups and natural groups. In social group work groups are usually formed and the type of group that will be applied is determined by the purpose and objectives of the group, the needs of the potential members and the available resources (Reid, 1991: 8). The following types of groups were identified and described by various authors:

- Closed groups
- Limited open groups
- Unlimited open groups
- Didactic/educational groups

- Task groups /self-help groups/ mutual-sharing groups/support groups
- Growth groups
- T-groups (laboratory-training groups)
- Therapeutic/remedial groups
- Encounter groups/counseling groups
- Marathon groups
- Long term groups
- Short term groups/structured groups
- Support groups/mutual-sharing groups
- Socialization groups

(Corey & Corey, 1987: 10-13; Du Preez, 1989: 129-130; Reid, 1991:8-10.)

The type of group that was applied in this study included elements of closed, counseling, personal-growth; mutual-sharing and marathon groups. The group was established with an existential theoretical foundation as a gestalt workshop. (These two concepts will be described in paragraph 5.3 and 5.4). The choice of group was made for the following reasons:

- *A closed group supplies the necessary confidentiality and opportunity for cohesiveness*
- *The personal growth group supports the issue of hope, the gaining of knowledge and skills and room for identity development*
- *Because of the existential approach and the utilization of the gestalt theory, it is also a counseling or therapeutic group*
- *A mutual-sharing or support group could supply PLWA with a support system without stigmatization*
- *The marathon group is selected purely for practical reasons - gathering a group of young PLWA for the minimum period of time with the maximum input. The marathon nature caused a problem with post testing which could not take place immediately after the group series because a measurement only three days after the pre test would be of little use. Follow up and post testing were done 6 weeks later.*

Aspects of these types of groups will be described briefly.

5.1 PERSONAL-GROWTH GROUPS

The focus of this type of group is to facilitate the individual's everyday needs, without real pathology and could include topics like interpersonal relationships, values, problem-solving and emotions. Examples of growth groups include:

- Marathon encounter groups
- Consciousness-raising groups
- Socialization groups

(Reid, 1991: 10.)

5.2 MUTUAL-SHARING GROUPS

This type of group is described by Getzel (1994: 185) as an integral aspect of people's survival response to HIV/AIDS, providing the following to group members:

- Co-operative activities
- Mutual support
- Socialization
- A lifeline in the AIDS pandemic
- Existential issues surrounding HIV/AIDS can be addressed

According to Reid (1991: 10), a sense of universality takes place in this type of group when group members share their feelings and personal experiences. This could supply the individual with a feeling of belonging and group members should be encouraged to share, to take risks and to mutually resolve problems and formulate life strategies. *This statement can be seen as the foundation of the existential approach to groups that was followed by the researcher and will be described briefly.*

5.3 THE EXISTENTIAL APPROACH TO GROUPS

Although existential groups were not described as a specific type of group, the researcher used an existential viewpoint when planning the group work programme and the following basic elements of this group approach were incorporated:

- Emphasis was on the individual's freedom to choose
- The four ultimate concerns of human existence were considered, including:
  - Death
  - Freedom
  - Isolation
  - Meaninglessness
- Taking responsibility for choices and circumstances
- Challenging group members to discover alternatives and to explore options to create meaning in life
- Exploring the meaning of living
- Guiding individuals to consider who they are so they can pursue a direction in life
- Empowering the individual to make well-informed choices about his life

(Corey, 1995: 236.)

5.4 THE GESTALT THERAPY WORKSHOP

Like the existential approach to groups, the gestalt therapy workshops were not identified by previous authors as a type of group, but the researcher needed to categorize it as a type of group for purposes of this report.

Following the existential approach in groups as described in 4.3, gestalt therapy workshops can be seen as an existential-experiential type of group, incorporating many aspects of the types of groups that were described earlier (Schaffer & Galinsky, 1989: 118-119). The word *gestalt* means *whole* and implicates the combination of aspects in the different types of groups.

The gestalt theory will be described later in this chapter, but the following aspects regarding gestalt groups are important when referring to the types of groups:

- The word *gestalt therapy workshop* is used rather than the concept group work
- The group meets in a non-continuous time framework (e.g meeting intensively for a month, a week, several days, or several hours) *(This reminds of the marathon type of group that was mentioned earlier)*
- Group members are guided to become aware
- Awareness can be seen as the instigator of problem-solving or dealing with 'problems of living'
- Group exercises are aimed at awareness, experience and resolving unfinished business

(Schaffer & Galinsky, 1989: 119-121.)

6. PRACTICAL CONSIDERATIONS WHEN DECIDING TO USE SOCIAL GROUP WORK

The following important aspects should be taken into consideration when planning to apply social group work (Corey & Corey, 1987: 7-8; Whitbourne, 1986: 6-18):

- Know the basic nature of human beings and the population with which one intends to work
- Identify the potential benefits one hopes to procure for potential group members and how one's own philosophy can be incorporated to enrich group members' lives
- Determine the goals and practical implications
- Clarify the role of the group worker and decide whether a co-worker will be used
- Work out a basic structure and character for the group
- Assess the costs and benefits of the planned group
- Plan in detail the change that is desirable and which techniques will be used
- Determine criteria for measuring and ways to monitor and assess the group effort
- Find a means for supporting oneself in one's group work efforts
- Commitment of self to the group work process
- Identify potential group members and engage in preparation interviews
- Decide how to initiate the group

7. THE PHASES IN THE GROUP WORK PROCESS

Social group work consists of a process with different phases or stages. From the different types of groups that were identified earlier in this chapter, the researcher decided to apply the existential approach to group work as theoretical foundation for the gestalt therapy workshop. This choice was made for the following reasons:

- The researcher is familiar with the gestalt theory and views it as a valuable theory to apply in general social work
- The nature of life maps are directly connected to existential social work
- Life maps include many components of existential social work
- The way the suggested group work programme was planned could be effectively applied in a gestalt therapy workshop

Both the social group work process and the process in the gestalt therapy workshop will be described in more detail.

7.1 THE SOCIAL GROUP WORK PROCESS

The social group process consists of six phases from the preparation phase to the post group phase. Each phase involves certain objectives and actions. In this study it was difficult to distinguish between the different stages due to the marathon nature of the group series and it was divided in three phases: the beginning phase; the middle phase; and the ending phase. A brief description of each of the six original phases of the group work process seems to be necessary.

7.1.1 THE BEGINNING/PRE-GROUP PHASE

This phase involves the identification and motivation of group members to participate in a certain group. It serves as an orientation for both the group worker and the group members. In this stage it is important to establish commitment.

7.1.2 THE INITIAL PHASE

The primary focus of this stage is to initiate group cohesion by making observations, overcoming uncertainties, building relationships and motivating group members to take responsibility for the objections of the group.

7.1.3 THE TRANSITION PHASE

This stage, as it's name describes, involve the transition between the initial uncertainties and actual involvement. At this stage, group members start to take responsibility for the group.

7.1.4 THE WORKING STAGE

In this stage cohesion, intimacy, participation, interaction and commitment are the main focus areas. The setting of a climate that will support the above-mentioned focus areas, are of the utmost importance in this phase. This is a very important stage in which growth will take place.

7.1.5 THE FINAL STAGE

This stage is a critical part of the group process, involving group members' separation from the group and reintegration into their normal daily activities. Usually evaluation of the group will also take place during this stage.

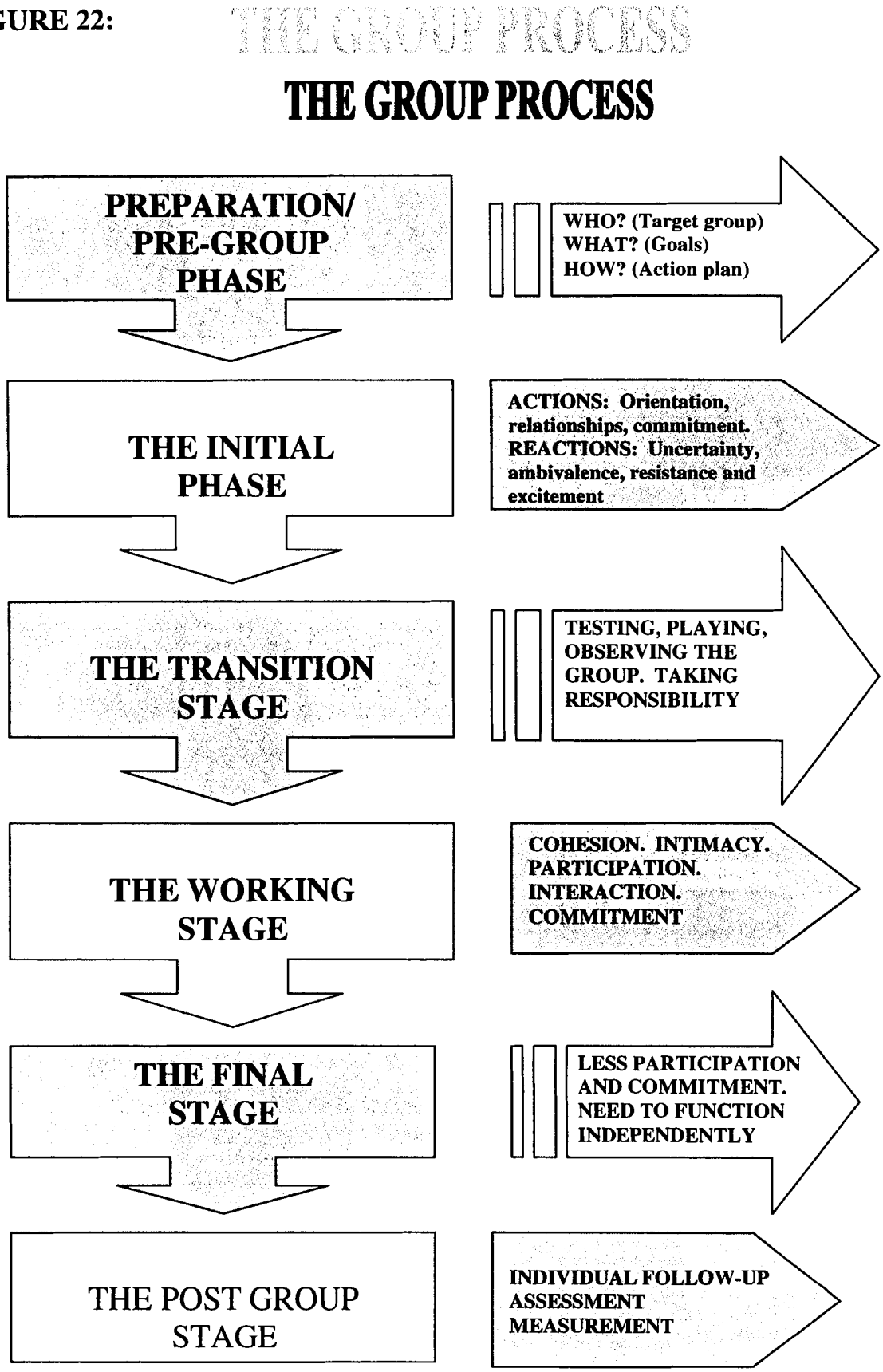
7.1.6 THE POST GROUP PHASE

Activities of this group stage include assessment, measurement, evaluation and individual follow-up where necessary.

(Corey & Corey, 1987: 228-237; Du Preez, 1989: 142-147; Toseland & Rivas, 1998: 147-180.)

The following figure was compiled to summarize the social group work process. This summary was used for the composition of the suggested group work programme.

FIGURE 22: THE GROUP PROCESS



7.2 THE GESTALT GROUP PROCESS

The gestalt group process is described by Shaffer & Galinsky (1989: 118) as the gestalt therapy workshop and consists of three stages with a total of six actions. The gestalt therapy workshop is usually implemented as a marathon group session. According to Fatout (1992: 98-102) and Shaffer & Galinksy (1989: 120-123) a framework for the gestalt group process was developed according to the following three categories of needs:

- The need to belong
- The need for autonomy
- The need for affection

The three stages that resulted from the categories of needs will be briefly introduced, followed by a schematic illustration of the six actions of the gestalt group process. Some of the gestalt concepts may seem undefined at this stage, but will be described under the theoretical foundations later in this chapter.

7.2.1 STAGE 1: IDENTITY AND DEPENDENCE

This stage can be described as the superficial contact and exploration stage. It displays a lack of contact and trust and the most important activities are contracting and boundary setting. Other activities include role clarification, exploration of resources available in the group and the sharing of mutual expectations. Group members will test the system and the here and now are important.

7.2.2 STAGE 2: INFLUENCE AND COUNTERDEPENDENCE

This stage is characterized by conflict and the search for identity. Interpersonal contact emerges during discussion. The primary interpersonal issues during this stage include the following:

- Power
- Influence
- Authority

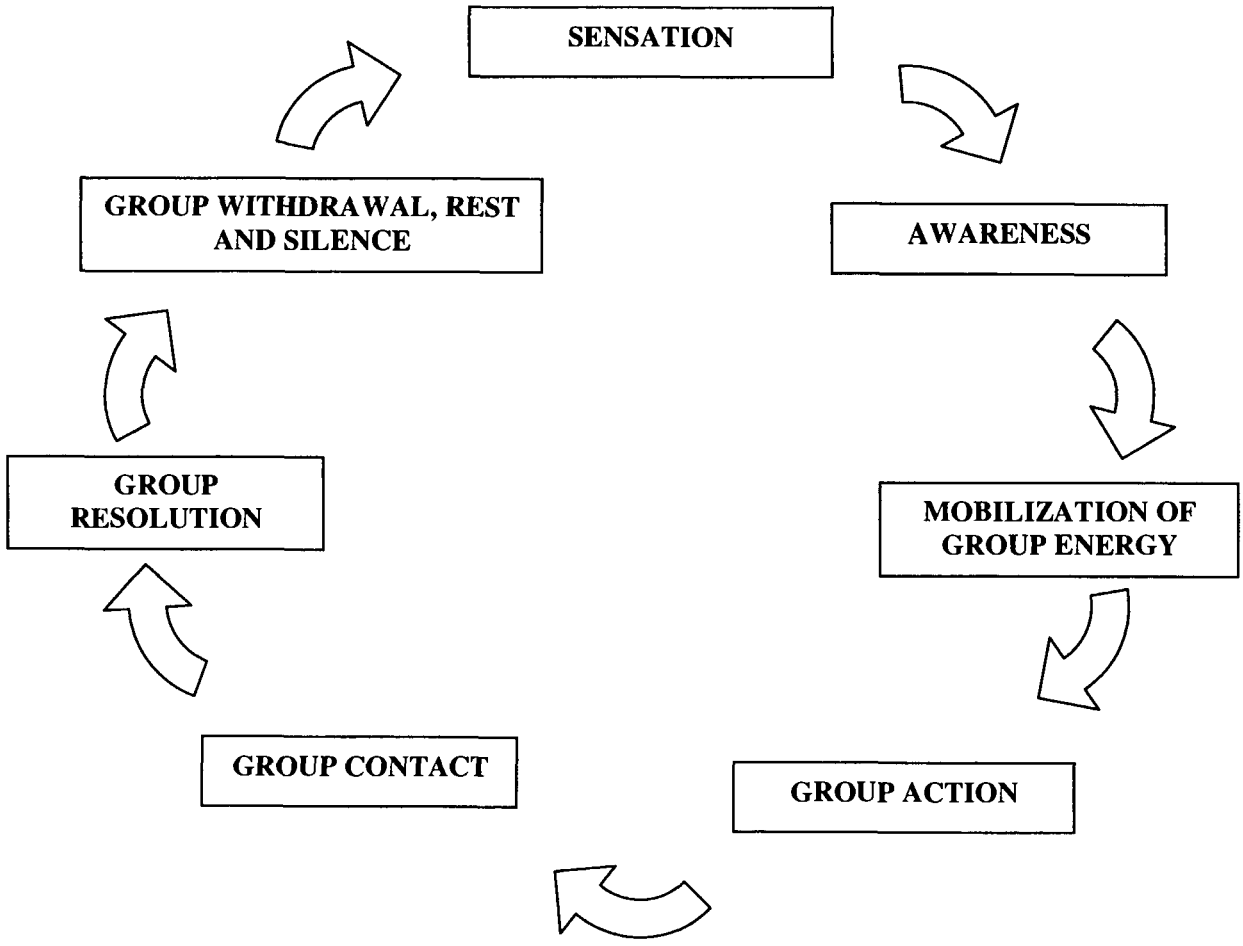
- Control

The group leader should encourage the challenges of an open discussion and emotional disclosure.

7.2.3 STAGE 3: CONFLUENCE AND ISOLATION

Interaction improves and subgroup forming may occur. At this stage the constant movement and change in the group will result in the following cycle:

FIGURE 23: ACTIONS THE GESTALT GROUP PROCESS



(Fatout, 1992:100.)

8. SUGGESTED THEMES FOR GROUP WORK WITH PLWA

The following themes for group discussions with PLWA were identified by Getzer (1994: 189-199):

- Aspects and emotions surrounding HIV/AIDS diagnosis
- Anxiety
- Support systems
- Formal help opportunities, e.g. counseling
- Confidentiality
- Relationship problems

Taking the above-mentioned into consideration, Getzel (1994: 191-195) connects the group themes to the phase of the group process. This connection is illustrated in figure 24.

FIGURE 24: SUGGESTED GROUP THEMES IN THE DIFFERENT PHASES OF THE GROUP WORK PROCESS

PHASE OF THE GROUP WORK PROCESS	SUGGESTED GROUP THEMES
Beginning phase	• Role clarification • Disclosing your HIV/AIDS status • Telling your personal narrative • Sexual orientation/substance abuse
Middle phase	• Personal issues and feelings, including rage, depression, guilt • Exploring the roles of family members and friends • Exploring coping skills for anxiety about death and dying • Finding practical ways to live hopefully day-by-day • Finding ways to give and accept support • Exploring quality-of-life options • Finding ways to affirm the meaning of lives • Constructing a personal belief system • Problem solving activities • Conflict management skills • Taking responsibility for one's own life and health
End phase	• Issues of separation and loss • Individual coping (without the group)

Group work has been found to be very useful in this study for the following reasons:

- *Every individual, but especially young PLWA, needed to relate to others*
- *Identity formation was a key issue in this programme and was enhanced by the group process*
- *Using a marathon group was time and money effective*

9. HISTORIC BACKGROUND OF LIFE MAPS

The first literature regarding life maps that could be found originated in a philosophy textbook dated 1909. The focus of this book was the individual's life (the map of life) and the correlation with happiness and contentment throughout one's life span. When studying the contents of this book, many links could be found with life maps as described in this study. The following interesting topics are worth mentioning:

- happiness is a condition of the mind
- life is full of work
- contentment and the desire for progress and self-growth should be balanced
- life actions should be guided
- there is an ending to life – named death

(Lecky, 1909: v-xiv)

There is a definite link between this book's focus on happiness and contentment and the aim of this study to evaluate the application of life maps to respondents and how general contentment is influenced by it.

The map of life could describe man's being from birth to death, emphasizing different events, people, attitudes, choices, problems/difficulties and biological processes.

Life maps, as they are applied in this study, were first described by John Heron (Mulligan, 1988: 12) as a tool for self-discovery, taking the individual through his life from birth to death, dealing with the self, significant others, obstacles, choices, beliefs and the future. More detailed information on life maps will be given in the following definitions.

10. OVERVIEW OF LIFE MAPS

10.1 MULLIGAN'S DESCRIPTION OF LIFE MAPS

"Life maps are tools for self-discovery, and guides to various aspects of your life as you experience it. They are a way of outlining the territory, signposting the terrain and becoming familiar with the landscape of your life. Maps can help you connect up the various aspects of your life by establishing links between your past, present and future, and the different levels of your being, for example your mind, body, emotions and spirit. They can help you focus on the detail of specific areas of your life" (Mulligan, 1988:12).

10.2 YOCHANAN'S DESCRIPTION OF LIFE MAPS

According to Yochanan (1991: 91), life maps can meet various aims of a group work programme including: defining the problem; determining goals; collecting information; developing alternatives; and evaluating of outcome.

10.3 LIFE REVIEW

According to Barker (1991: 132), life review is a process by which the individual takes an overview of his life, tries to assess it and searches for the meaning of life, as it is an important part of existential social work.*(The concept existential social work will be described under the theoretical foundations of life maps.)*

10.4 SUMMARY OF DESCRIPTIONS

The previous two authors' descriptions were summarized and integrated by the researcher to formulate the following description:

Life maps are an assessment and therapeutic technique to guide individuals or groups to review their lives in terms of the past, present and future by focusing on their own views of themselves, others, their problems and coping skills.

11. COMPARISON WITH SIMILAR TECHNIQUES

11.1 LIFE STORIES AS TECHNIQUE

The technique of writing one's life story is described by Mc Cormick (1996: 169-172) as a way by which the individual can write out how life has been and how one has coped in one's own way. The following aspects should be attended to when writing one's life story:

- The individual's life and development
- Important experiences and facts
- Fears and other feelings
- The changes one would like to make and ways to achieve them

One's life story could be written in prose form, with sketches, drawings, cartoons or paintings. No instructions are given to the individual on what should or should not be written.

According to McCormick (1996: 172), this is a powerful experience by which the individual, for the first time, describes how life has been for him and how attitudes towards ourselves and others contributed to present difficulties.

11.2 WRITING ONE'S OWN LIFE SCRIPT

Another viewpoint on describing one's own life is that of Retief (1999: 73-75) where she refers to this process of writing the script of one's life as if for a movie.

With transactional analysis as theoretical foundation, the starting point when writing one's own life script is the following philosophical question: "What is a person like me doing with people like you in a place like this?" (Retief, 1999: 73). The aim of this question is to guide the individual to make decisions on the following:

- Who am I?
- What are other people like?
- What is the world like?

Once again this could be a very powerful experience for the individual as there is the possibility to clarify how events and people have influenced his life and what changes or adaptations can be made.

For the researcher, these questions are important in order to establish self-awareness, which is ad integral part of gestalt therapy, the theoretical background of this study and life maps as technique.

11.3 MAGAZINE PHOTO COLLAGES

Collages are a well-known technique in social work, where the individual creates an image of his life by using magazine photos. Magazine photo collages are described as a multicultural assessment and treatment technique through which the individual can represent his own life (Landgarten, 1993: 1). When applying this technique, all tasks have a thematic orientation, leading the individual to express his life.

This technique could be applied to persons from any group, since it is not culturally biased and allows the individual to experience control. The aim is to focus on specific aspects of life and to guide the individual to experience control. The aim is to focus on specific aspects of life and to guide the individual to experience contentment.

11.4 LIFE MAPPING

This technique differs from life maps as described in this study, but includes the listing of important people or events on pieces of paper. After listing them, the client arranges them on a large piece of paper in a way that is meaningful to him. Important connections and influences can then be illustrated and used for discussion (Heppner; O'Brien; Hinkelman & Humphrey 1994: 85).

11.5 LIFE MAPS

According to Mulligan (1988: 12), life maps stretch backward into the individual's past and forward into the future by linking important events and aspects of life to the potential that may be realized in the future.

This technique guides the individual on a journey through his life by focusing on the following seven questions:

- **WHO AM I?**
- **WHERE HAVE I COME FROM?**
- **WHERE AM I GOING?**
- **WHAT IS STOPPING ME?**
- **HOW WILL I GET THERE?**
- **WHAT HELP DO I NEED?**
- **WHAT WILL IT BE LIKE WHEN I GET THERE?**

From the researcher's point of view, the most important aspect of this technique is that it does not stop in the past. It guides the individual to link the past to the present, but most importantly, urge the individual to focus on the future. (Every theme and the relevant important aspects will be addressed later on in this chapter.)

The following table was compiled by the researcher, integrating her own opinions with those of the mentioned authors to summarize the differences and similarities of the different techniques related to life maps.

FIGURE 25: SUMMARY OF TECHNIQUES RELATED TO LIFE MAPS

LIFE STORIES	LIFE SCRIPTS	COLLAGES	LIFE MAPS
Technique for assessment and self-expression	Technique for assessment and self-expression	Technique for assessment and self-expression	Technique for assessment and self-expression
Mainly unstructured	Semi-structured	Structured	Structured, but flexible
Focus on the past	Focus on the past	Focus on the past, present and future	Focus on the past, present and future
Clearly defined emotional impact	More philosophical impact	The impact is determined by the individual's own perceptions	The impact is both emotional and practical, allowing the individual to develop life skills
The individual needs to be literate to utilize this technique	The individual needs to be literate to utilize this technique	Can be administered to persons from any group	Can be administered to persons from any group

12. THEORETICAL FOUNDATIONS

Life maps refer to life review, which is defined by Barker (1991: 132) as "The process of looking back over one's life, analyzing it, uncovering the hidden themes, and understanding the meaning of life" and "Life review therapy has been an important part of existential social work".

In addition to the above mentioned, Barker (1991: 78) also defines existential social work as:

"A philosophical perspective in social work that accepts and emphasizes the individual's fundamental autonomy, freedom of choice, disillusionment with prevailing social mores, a sense of meaning derived from suffering, the need for dialogue and the social worker's commitment to the concept of client self-determination."

Existential social work is considered the ***basic theoretical framework*** *of this study, including the following theories:*

- *The self-actualization theory of Abraham Maslow*
- *The existential theory of Viktor Frankl (Logo therapy)*
- *The reality theory of William Glasser*
- *The gestalt theory of Fritz Perls*

12.1 THE SELF ACTUALIZATION THEORY OF ABRAHAM MASLOW

12.1.1 DEFINITION

The self-actualization theory of Abraham Maslow is defined by Gouws, *et al.* (1988: 318) as a theory where the individual's optimal use of talents, abilities and potential is explored and utilized.

12.1.2 KEY ASPECTS OF THE THEORY

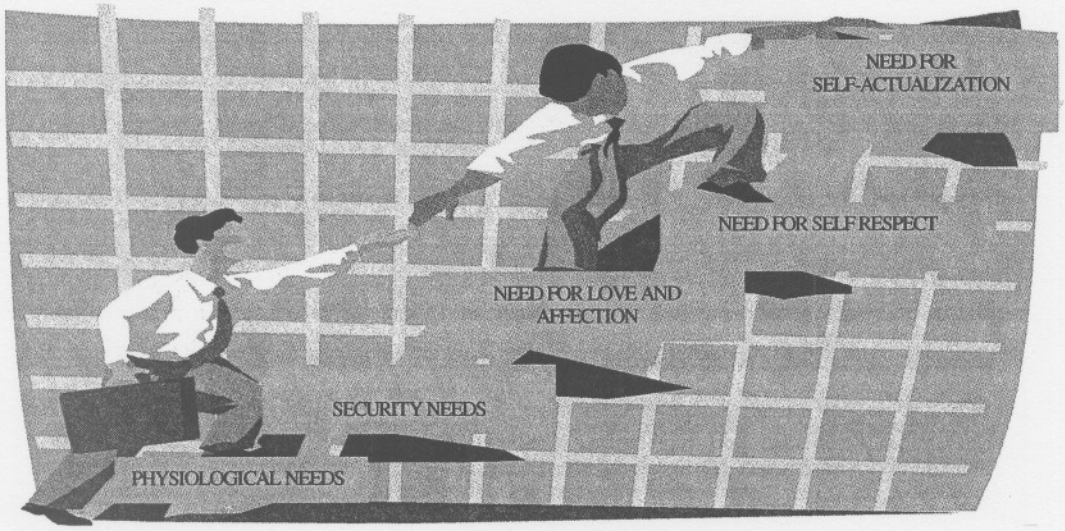
The following aspects are fundamental to this theory:

- The individual is recognized as a positive and worthy being, with an active will to grow and with an integrated functioning
- The human's need to self actualization is the basic motive of all human functioning
- The individual does not need to change his basic nature, but has to explore and utilize existing potential
- Needs fulfillment is the basis for human functioning, starting with physiological needs, peaking to the ultimate strive for self actualization
- The environment plays an important role in needs fulfillment, causing humans often not to reach the ideal of self actualization
- A holistic view of the human being is emphasized

(Moore, 1988: 376.)

The process of needs fulfillment can be illustrated in the well known hierarchy of needs as illustrated by Moore (1988: 368) and which has been adapted for this study.

FIGURE 26: THE HIERARCHY OF HUMAN NEEDS



12.2 THE EXISTENTIAL THEORY OF VIKTOR FRANKL (LOGO THERAPY)

12.2.1 DEFINITION

According to Barker (1991: 134), logo therapy can be defined as:

"The meaning-orientated philosophy and treatment application developed by Viktor Frankl and others and used by members of many disciplines to help people search for the humanistic and spiritual significance of their lives."

12.2.2 KEY ASPECTS OF THE THEORY

- Viktor Frankl's view of human kind includes three basic principles:

    - Man has freedom of will

- Man's basic motive in life is a search for meaning
- Life is meaningful

- Basically man is interested in making sense of his life and to live for meaningful things in life (ideals and values)
- Man needs to know more about being human – everything is not just about fulfilling of needs
- Man has a need for emotional and spiritual growth
- Man's need for meaning often appears under difficult circumstances or in situations where all other needs are fulfilled
- Fulfillment of physiological needs is not man's ultimate goal, but is the way to meet spiritual needs
- The meaning of life can not be created, it has to be found. It can be found in the following values:

  - Creative values – the things man can give to life by finding meaning in his work or involvement with others
  - Values of awareness – the values man receives from life, like experiencing what is good and real and beautiful. This includes love and commitment
  - Values of attitude – the way man looks at life and his attitude towards suffering

- Frankl refers to ***'The tragic triad':*** pain; guilt and death, which are crucial aspects man has to deal with in life, and emphasizes that man's attitude towards these aspects will determine man's experience of meaning in life
- For optimal development, man needs the following:

  - Self-determined behavior
  - Realistic observation
  - Humor
  - Self-transcendence
  - An active futuristic attitude
  - Seeing work as a calling

- Appreciation of the good, the truth and aesthetics
- Respect for others' uniqueness
- Finding meaning in suffering and pain

(Shantall, 1988: 447-458.)

12.2.3 USING LOGO THERAPY IN GROUPS

According to Corey (1995: 238), existential group work enables individuals to undertake a lifelong journey of self-exploration with three goals:

- Becoming honest with oneself
- Obtaining new perspectives on the self and the world around the self
- Defining meaning in the present and future

12.3 THE REALITY THEORY OF WILLIAM GLASSER

12.3.1 DEFINITION

According to Gouws *et al.*(1988: 303), the reality theory focuses on the individual's responsibility for his own behavior and for satisfactory functioning, the individual needs fulfillment of the two most important human needs: the need to feel valued and loved by self and others; and the need to show love and respect to others.

12.3.2 KEY ASPECTS OF THE THEORY

- Problems in man's life result from one factor: an inability to fulfill one's basic needs and as a result man denies the reality of the world around him
- Basic human needs include the need to love and be loved and to feel valued by oneself and others
- Successful attainment of these needs leads to a success identity and healthy self-esteem

- The concept of mental illness is discarded by this theory in favor of the concept of responsibility
- The moral issue of right and wrong is a key focus area of the theory
- The past is largely ignored and focus is on the present and future
- The unconscious is largely ignored and the focus is on ***what*** rather than on ***why.***
- The reality theory consists of teaching or learning, rather than on healing

(Thompson & Rudolph, 1992: 62-64.)

12.4 THE GESTALT THEORY OF FRITZ PERLS

12.4.1 DEFINITIONS

The word *gestalt* is a German word meaning *whole* or *configuration* and the theory is based on existential principles, focusing on *experience* rather than *intellect* (Gilliand; James; Roberts & Bowman, 1984: 95). The gestalt theory can be defined as a counseling approach where the main goal is self-awareness, including knowledge of the environment, taking responsibility for choices, self-knowledge, self-acceptance and the ability to make contact (Biggs, 1994: 108).

12.4.2 KEY ASPECTS OF THE THEORY

- *Holism* consist of two interdependent relationships:

    - **Body and soul, which are inseparable**
    - **Man and environment, which form an organismic unit**

- The *here* and *now* are very important – what the client experiences at the moment and how he behaves currently, emphasizing that the past and future are continuously linked to the present
- The person is seen as *a total organism,* not just as a brain
- The main goal of the organism is a constant *quest for equilibrium*

- The equilibrium/balance can be disturbed by *unfulfilled needs*
- Focus is on the fulfillment of one need *(the figure)* at a time until the gestalt is completed
- *Awareness* is very important, implicating the individual's ability to be in touch with his whole perceptual field within the self and the environment, including:

    - **The self**
    - **Emotions**
    - **Behavior**
    - **Experiences**
    - **Incompleteness within the self**

- Awareness can only take place through *sensation/sensoric impressions*
- The concept of defense mechanisms is rejected and Perl refers to the individual's inability to take care of his needs as neurotic mechanisms in the following six categories:

    - Lacking contact with the environment due to rigidity
    - Confluence, where the environment takes control over the individual
    - Unfinished business, causing unfulfilled needs
    - Fragmentation where needs are denied
    - The *topdog* (what people think they *should do*) versus the *underdog* (what people *want to do)*
    - Man's floundering between the polarities in life, including the following:

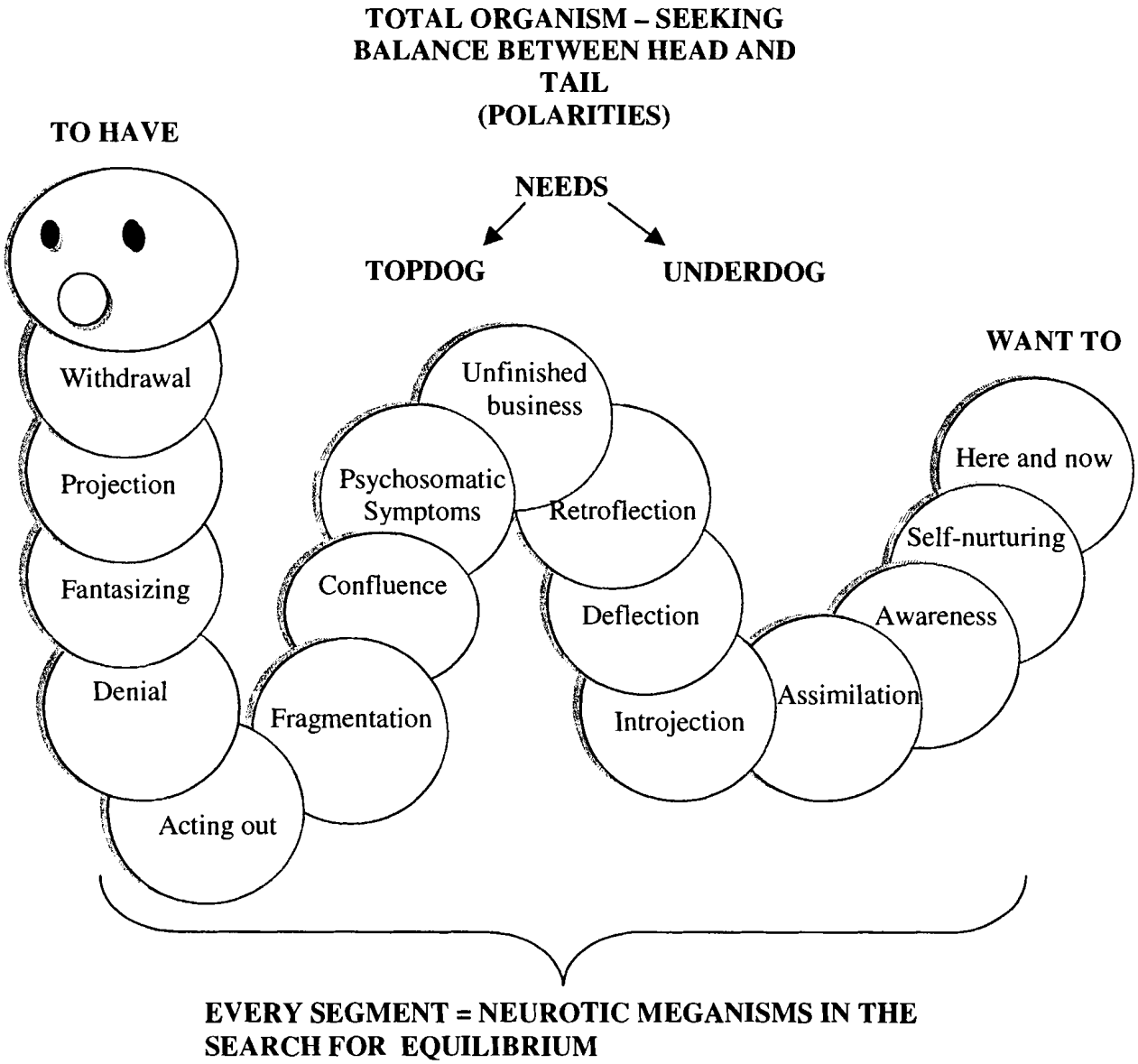
        - ***Physical polarities*** *(masculinity/femininity)*
        - ***Emotional polarities*** *(pleasure/pain; love/hate)*
        - ***Mental polarities*** *(topdog/underdog)*
        - ***Spiritual polarities*** *(intellectual doubt/dogmatism)*
        - ***Interindividual*** *(man/woman; black/white)*

(Clarkson & Mackewn, 1993: 44-46; Thompson & Rudolph, 1992: 110-112.)

12.4.3 THE RESEARCHER'S VIEW OF THE GESTALT THEORY

For the researcher, the gestalt theory is not only a theory, but a way of living. Turner (1979: 279) refers to students' remarks regarding the gestalt theory being formulated so difficult that students have to really struggle to digest is to enhance their learning and not to only study for an exam and then forget about it. This was also the experience of the researcher, but when the gestalt theory is finally *digested* and becomes part of one's *system,* theory becomes reality. In order to understand this theory better, the researcher designed the following figure, summarizing the gestalt theory.

FIGURE 27: SUMMARY OF THE GESTALT THEORY



The following notes can be added to describe figure 27.

The total organism ("worm") is in search of balance or homeostasis between the "topdog" (the head) and the "underdog" (tail). The *topdog* represents what the individual should do, while the *underdog* represents what the individual wants to do. There is constant conflict between the *topdog* and the *underdog*. This process of conflict is known as polarities. The different segments of the worm refer to the individual's coping mechanisms in the constant search for balance. The individual's needs are channeled between the *topdog* and *underdog*.

13. ASPECTS THAT CAN BE HIGHLIGHTED THROUGH THE APPLICATION OF LIFE MAPS AS TECHNIQUE

13.1 IDENTITY FORMATION

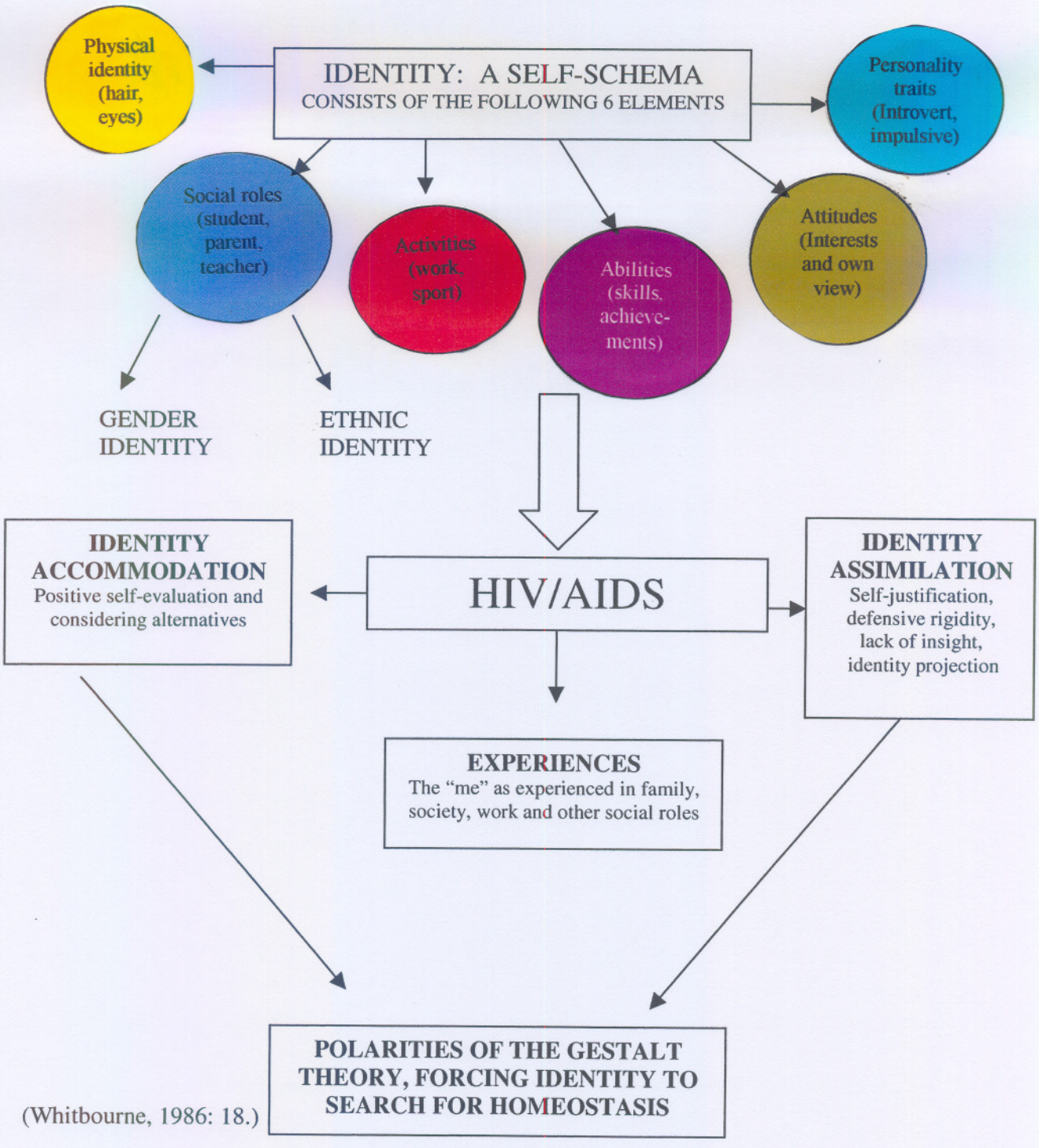
"*Who am I*" is the question being asked in map 1. This question focuses on the concept of identity, which was described briefly in chapter 3 and is the only aspect that requires a detailed discussion for the following reasons:

- Identity formation is one of the most important developmental tasks of the young adult
- Living with HIV/AIDS has a definite influence on the identity of young adults

According to Whitbourne (1986: 18), the process of identity assimilation and identity accommodation is crucial to achieve a state of equilibrium, as described in the gestalt theory. Self-knowledge and self-awareness is the essence of existentialism and the basis for finding meaning and purpose in life. Awareness is also important according to the gestalt theory. Identity is described by Johnson (1990: 63) as "a consistent set of attitudes that defines *who you are*". Without identity the individual will be anxious and depressed and there will be a lack of contentment. It was previously described that HIV/AIDS will have an influence on the identity of the PLWA. The following figure by Whitbourne (1986: 18) was adapted by the researcher to include a HIV/AIDS diagnosis and the formation of a self-schema as described by Johnson (1990: 63). The figure also includes the six

components of identity, the assimilation and accommodation of identity and the struggle of the identity to find homeostasis, as described in the gestalt theory.

FIGURE 28: HIV/AIDS AND IDENTITY



(Whitbourne, 1986: 18.)

It is preferable that the PLWA is guided to identity accommodation after HIV/AIDS diagnosis, leaving the individual to search for alternatives and a changed identity. Whitbourne (1986: 18) describes the changed identity as *"sadder but wiser"*, implying that adaptation to HIV/AIDS status is difficult, but can lead the individual to personal growth. The latter is one of the goals of life maps.

For the researcher, the question "Who am I", is crucial. Without this question no inner process in mankind has a starting point. The PLWA needs to search for himself and his abilities, come to terms with new experiences and changes caused by HIV/AIDS and start to reconstruct identity.

13.2 OTHER ASPECTS

The following are typical themes and aspects that can be linked to the application of life maps:

- Self-determination
- Personal responsibility
- Overcoming fears, feelings, obstacles, confusion and existential anxiety. Redefining the past and one's background
- Resolutions for conflicting relationships
- Utilization of personal, social and community resources
- Exploration and development of skills
- Emotional disclosure
- Problem solving
- Dealing with losses
- Gaining control
- Giving a clear vision of how things are and how they have been
- Determining the changes one would like to make and how one could begin to achieve them

(Corey, 1995: 236-248; Johnson, 1990: 65; McCormick, 1996: 172; Shaffer & Galinsky, 1989: 120.)

14. THE ADVANTAGES AND DISADVANTAGES OF LIFE MAPS

14.1 ADVANTAGES

- The individual's past, present and future can be integrated
- The individual experiences control over his own life
- The individual gains access to his own life story, while giving answers and straightening out misconceptions and confusion
- Life maps give a clear vision of how things are and how they have been
- They provide continuity and assist the individual to develop an intact sense of identity
- The individual's expression through this medium becomes the document that gains access to conscious as well as unconscious material
- It is a flexible instrument that can be used with illiterate people from any culture
- Due to specific themes, the technique is task orientated
- Life and coping skills can be explored and learned
- The individual can make alterations and adjustments in his life
- Life maps can generate interest and create enthusiasm for life
- Life maps allow freedom of expression and can guide the individual to overcome emotional blockages like anger and guilt

(Backhaus, 1984: 552; Landgarten, 1993: 2-3; McCormick, 1996: 172; Mulligan, 1988: 26.)

14.2 THE DISADVANTAGES OF LIFE MAPS

- The fixed themes could limit the individual's self-expression
- Adults may show resistance to drawing life maps
- Life maps could be time consuming
- Individuals may find it difficult to draw life maps unless a comfortable therapeutic relationship exists
- Painful memories may be revived and this process needs efficient therapeutic input

(Backhaus, 1984: 553; Mulligan, 1988: 26.)

15. SUMMARY

In this chapter the technique of life maps was placed in theoretical perspective. It was described as a tool in social group work within four existential theories. By putting the technique in theoretical perspective it can be seen as a therapeutic tool for utilization in social work practice and related professions. The themes of the life maps that have been described can guide the individual to explore and achieve life skills, including:

- Conflict management
- Problem solving
- Planning
- Relationships with the self, the environment and others

In the next chapter the theory will be put into action. The suggested group work programme, called *Thsepang Workshops,* will be introduced. The programme consists of a group worker's manual, with instructions and theoretical background and a workbook for group members, where the actual life maps can be drawn and described. It includes homework activities and explanations of why specific themes should be discussed and what the main themes could be.

PHILOSOPHY FOR LIFE

I WISH MY LIFE TO BE SOMETHING.
A WANT TO SUCCESSES AT SCHOOL.
FINISH MY MATRIC.
THEREAFTER I GO TO UNIVERSITY.

AFTER I FINISH AT UNIVERSITY,
I WANT TO TEACH OTHER YOUNG CHILDREN ABOUT HIV.
AND I WANT TO HELP MY MOTHER TO BUILD A HOUSE AND BUY A CAR FOR MY MOTHER.

THIS IS MY DREAM WHEN I SLEEP.

Anonymous

CHAPTER 6

THE SUGGESTED GROUP WORK PROGRAMME

1. INTRODUCTION

In this chapter the theoretical background that has been described in the previous chapters will be put into action. The group work programme, where life maps are applied as technique, was compiled from the opinions of various authors, integrated with the data collected from the needs assessment and the opinions of the researcher. The programme is called ***Thsepang Workshop.*** The Sotho word *Thsepang* means *to have hope/faith* and the word *workshop* was suggested as terminology for gestalt group work. This programme does not focus on HIV/AIDS only, but on the various developmental tasks at the young adult

The programme can be presented in a total of nine group sessions, consisting of the schedule in the following table.

TABLE 8: SCHEDULE OF GROUP SESSIONS

SESSION	*APPLICABLE LIFE MAP*	*THEME*
1	*NONE*	INTRODUCTION AND MEASUREMENT
2	MAP1	WHO AM I?
3	MAP 2	WHERE HAVE I COME FROM?
4	MAP 3	WHERE AM I GOING?
5	MAP 4	WHAT IS STOPPING ME?
6	MAP 5	HOW WILL IT BE LIKE WHEN I GET THERE?
7	MAP 6	WHAT HELP DO I NEED?
8	MAP 7	HOW WILL IT BE WHEN I GET THERE?
9	NONE	EVALUATION AND CLOSURE

Each map will be presented in the following format:

- Introduction to the life map
- Aims and objectives
- Materials and equipment
- Time schedule
- Instructions to the group
- Sharing of personal life maps
- Suggested discussion topics
- Summary
- Action/Homework

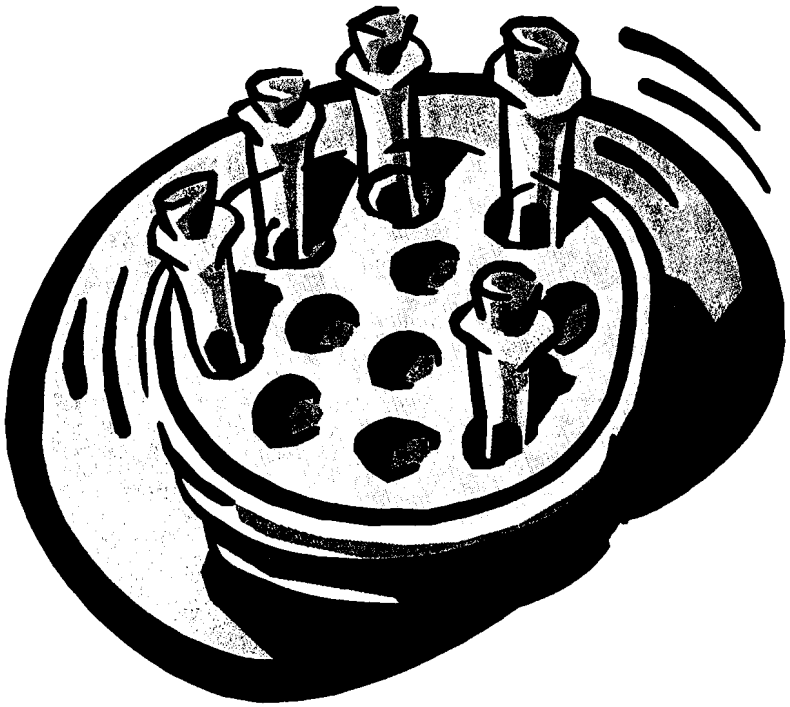
For research purposes, a follow-up session was held six weeks after completion of the programme to repeat measurement of group members' general contentment.

Please note that the format of this chapter differs slightly from the rest of this report in an effort to make the programme more presentable for application in practice.
Worksheets for each group session are attached and numbered in alphabetical order from A1 – G2 to accompany each of the seven life maps

THSEPANG

WORKSHOP

A SOCIAL GROUP WORK PROGRAMME
FOR
YOUNG ADULTS
LIVING
WITH
HIV/AIDS



"The greatest disease is to be nobody to anybody"
- *Mother Theresa*

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1. INTRODUCTION

Implementation of the programme was guided by the group work process described in chapter 5. Although HIV/AIDS is the background for this programme, the aim of the group sessions was not to continuously refer to the illness, but to give young PLWA the opportunity to incorporate two main transitions in their lives and express these in their life maps. The transitions include:

- The life stage of young adulthood
- Learning to positively live with HIV/AIDS

The following table was compiled to link the life maps to the group work process.

FIGURE 26: LIFE MAPS AND THE GROUP WORK PROCESS

PHASE OF THE GROUP WORK PROCESS	Determine WHAT is to be done, to WHOM and HOW it will be done	Needs assessment questionnaire GCS Motivational session to introduce the programme Individual preparation of group members
PREPARATION/PRE-GROUP PHASE	Orientation Build relationships Establish commitment	Breaking the ice Share expectations Declaration of participation (Annexure 4)
THE INITIAL PHASE	Initial observation, overcoming uncertainties and taking responsibility	Maps 1-3 Personal label worksheet Your lifeline worksheet Philosophy for life worksheet
THE TRANSITION PHASE	Cohesion, intimacy, participation, interaction and commitment	Maps 4-6 Problem solving worksheet Personal goals worksheet Resource application worksheet
THE WORKING STAGE		

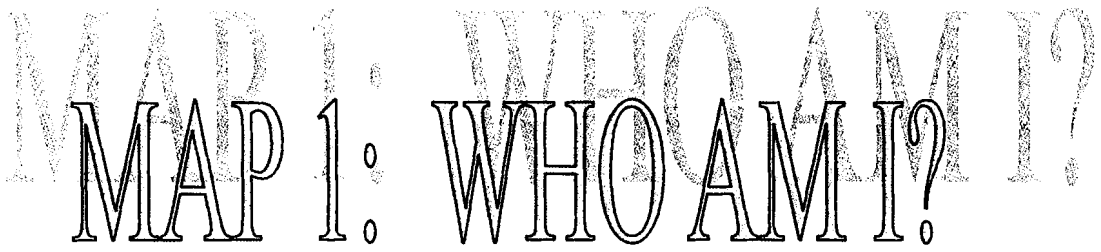
(Continue on next page)

THE FINAL STAGE	More independence and less commitment to the group	Map 7 Imaginary tombstone worksheet Candle lit ceremony HIV/AIDS quilt making exercises Evaluation
THE POST GROUP PHASE	Individual follow up Assessment and evaluation Measurement	Personal quilts for group members GCS Self-developed evaluation questionnaire

2. SESSION 1: INTRODUCTION, MEASUREMENT AND PREPARATION

In this session, group members are required to complete the GCS (Annexure 2) and to sign a declaration of participation (Annexure 4). The last component of this session is to share mutual expectations. An example of the form that was used for sharing expectations in this study can be viewed as Annexure 5.

3. SESSION 2



3.1 INTRODUCING THE MAP

This map deals with the individual's self-awareness, self-expression, perceptions of self and the development of identity or identity formation. It is not only an introduction to the self by sharing names and demographic information, but actually to illustrate one's unique personality traits and life space. Being HIV+ can influence one's identity and self-awareness. Due to society's stigmatization of PLWA, self-disclosure opportunities are limited. In this map you are allowed to describe yourself as an individual; how you perceive yourself; who you are; and what you are like.

3.2 AIM AND OBJECTIVES

3.2.1 AIM

To supply the individual with the opportunity to explore and express the self and to establish identity

3.2.2 OBJECTIVES

- To place the individual in his world (e.g. nationality, social position, work and achievements)

- To explore internal sources of identity (e.g. beliefs, values, interests, worries and ambitions)
- To guide the individual to experience his own being
- To promote self-awareness and self-image
- To give the individual an identity tag

3.3 MATERIALS AND EQUIPMENT

- Worksheets A1-A3
- Drawing materials
- Selection of magazines
- Scissors
- Glue
- A room with enough working space
- Background music (optional)

3.4 TIME SCHEDULE

Introduction to the session:	10 minutes
Instructions:	5 minutes
Drawing of map:	30 minutes
Sharing of drawings:	30 minutes
Discussion:	30 minutes
Homework:	15 minutes
TOTAL:	**2 HOURS**

3.5 INSTRUCTIONS TO THE GROUP

I would like you to make a drawing on the theme indicated at the top of the following worksheet (Hand out worksheet A1). This needs not be a drawing of a human, but should illustrate you as a person with certain abilities, problems, skills, dreams, possessions and responsibilities. If you find it too difficult to draw, you could choose pictures from

magazines or simply write down a few key words. Remember that I am not interested in how good or bad you can draw.

3.6 SHARING OF LIFE MAPS

Each group member is requested to come forward and share his map with the group in any way he wants to. During the group member's presentation of his map, no questions or comments are allowed. Afterwards questions may be asked, but the group member has the right not to answer questions if he experiences it as too personal. The focus is rather on the individual to discover himself and to gradually grow to self-expression. Follow this procedure until all group members have had the opportunity to share their maps.

3.7 DISCUSSION

The group leader now initiates and facilitates a group discussion with themes and topics gathered from the group members' presentations of their maps. The following themes can be included:

- Interests and hobbies
- Work/school activities
- Friendships and relationships
- Talents
- Values and beliefs
- Dreams and desires
- One's purpose in life
- Health, including the impact of HIV/AIDS
- Family
- Knowledge and skills
- Opportunities and constraints
- Social commitments
- Responsibilities
- One's view of oneself

3.8 SUMMARY

This life map session deals with individuality, uniqueness and basic human needs – both physical and emotional. It is important to keep a balance when referring to HIV/AIDS. One should remember, on the one hand, that PLWA are just human beings with human needs and desires, but on the other hand, HIV/AIDS has influenced their lives. It is advisable that the psycho-social impact of the disease should be discussed, but the topic should not be forced upon group members. Members are allowed to share their own beliefs and dreams and to discover more about themselves and others.

3.9 ACTION /HOMEWORK

Group members are now allowed to complete worksheet A2, by listing their strengths and weaknesses.

Hand each group member a copy of worksheet A3 for completion at home

Worksheet A1

WHO AM I?

This session deals with how you see yourself with your strengths and weaknesses; likes and dislikes; needs; dreams and expectations.

"There is inside you all of the potential to be whatever you want to be. There is a hero inside of you!"

- Mariah Carey

Worksheet A2

ME, MYSELF AND I

Use the following table to list your strengths and weaknesses

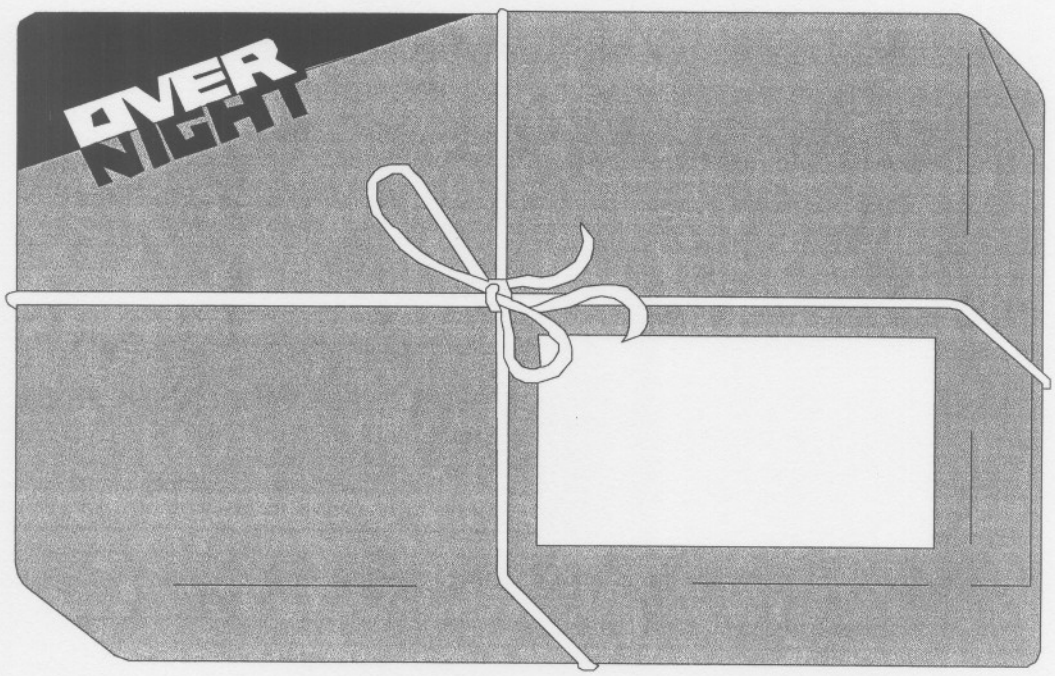
STRENGTHS	***WEAKNESSES***

4 GOOD REASONS WHY I AM A WINNER

Worksheet A3

MY PERSONAL LABEL

Imagine yourself being packed for life's journey. In order for others to identify your unique parcel and destination, you need a label. Complete the following label for yourself.



4. SESSION 3

4.1 INTRODUCTION TO THE MAP

This map focuses on the individual's background and past. In the processes of self-discovery and self-knowledge, is it necessary to become familiar and aware of one's history and roots. One has to discover what has happened to oneself up till now and how the past has influenced the present and will influence the future. It is also an opportunity to take responsibility for one's own actions.

4.2 AIM AND OBJECTIVES

4.2.1 AIM

To determine every individual's background and past

4.2.2 OBJECTIVES

- To guide the individual to take an overview of his life
- To determine the influence of one's background
- To help one understand one's legacy from the past
- To identify personal strengths, handicaps, joys and sorrows

- To motivate the individual to take responsibility, instead of shifting the blame
- To enable the individual to take charge of the future

4.3 MATERIALS AND EQUIPMENT

- Worksheets B1-B3
- Drawing materials
- Pen/pencil/scissors/glue
- Magazines

4.4 TIME SCHEDULE

The same time schedule as described for Map 1 can be followed until all 7 the life maps have been completed.

4.5 INSTRUCTIONS TO THE GROUP

Today we are going to illustrate our background or personal history. This could include your upbringing, your childhood, your parents and family, positive or negative events that influenced your life and values and beliefs. I would like you to close your eyes and *look* back into your life and then start to illustrate it by drawings, words or magazine pictures. Hand each group member the worksheet for Map 2.

4.6 SHARING OF THE LIFE MAPS

The same procedure that was described in 2.6 will be followed throughout the sessions on life maps.

4.7 DISCUSSION

Further group discussion can now be initiated by including some of the following aspects or themes:

- A lesson that I will never forget
- Geographical location
- Something that I cannot forgive
- Family
- Relationships with the opposite sex and sexuality
- Upbringing and parents
- Other important people
- Education
- Religion
- Achievements and awards
- Favorite activities
- Major events
- Where and when HIV/AIDS was contracted
- Painful experiences
- Childhood dreams and desires
- Values and beliefs

4.8 SUMMARY

Discuss the fact that it is impossible to change the past, but that nobody's life has to end in the past. The past should be the foundation of today and tomorrow. Help members to identify the most positive and most negative events in their lives. The contraction of HIV/AIDS cannot be changed, but it can be managed.

4.9 ACTION/HOMEWORK

Hand each group member a copy of Worksheet B2 and instruct them to complete Worksheet B3 at home.

Worksheet B1

Where have I come from?

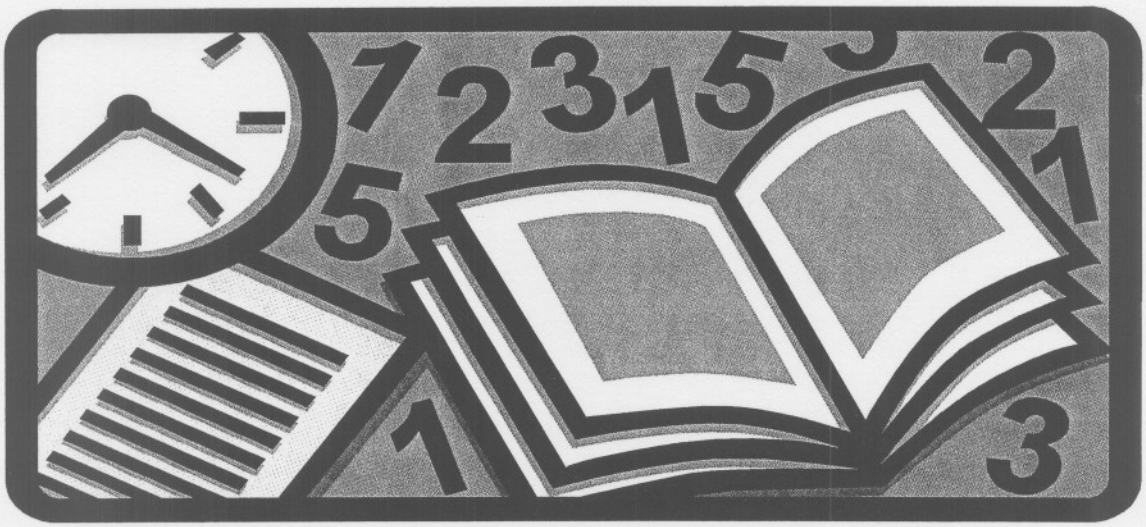
This map deals with your past. One needs to know one's background and roots in order to understand oneself better. Maybe you can discover links between your past and how it influenced your present and may affect your future.

"You can't change the past, but you can ruin a pretty good present and future by constantly living in the past."
- Barbara Johnson

- Barbara Johnson

Worksheet B2

PAST TENSE



We all take our upbringing, the people around us and past experiences with us for life. If our lives stop in the past, due to painful events, we are unable to move forward.

If I could change the past, I would ....

I know that the following aspects of my past are unchangeable and I have to accept them:

Worksheet B3

My lifeline

The horizontal line represents your life from birth to death. Above the line you can draw all the positive events and feelings and below the line, all the negative events and feelings. Map out all significant events chronologically and try to remember how each one made you feel.

(Adapted from Mulligan, 1988: 16.)

+

MY LIFE

-

5. SESSION 4

Map 3: Where am I going?

Map 3: Where am I going?

5.1 INTRODUCTION TO THE MAP

Making decisions is probably one of life's most difficult tasks. We are afraid of the unknown, which often results in stagnation, frustration and questioning the meaning of life. It could be even more difficult to find meaning in life when suffering from a life-threatening disease like HIV/AIDS. We cannot let go of the known and therefore we are unable to move on. It is important to have a vision and to find a direction for one's life.

5.2 AIM AND OBJECTIVES

5.2.1 AIM

To help the PLWA find a vision and a direction for his life.

5.2.2 OBJECTIVES

- To initiate decision-making regarding life in general, personal choices, health, career options and family obligations
- To clarify values
- To set priorities
- To determine one's point of embankment
- To clarify the present state of one's affairs
- To make the necessary changes

5.3 MATERIALS AND EQUIPMENT

- Worksheets C1-C2
- Drawing materials
- Pen/pencil/scissors/glue
- Magazines

5.4 TIME SCHEDULE

Follow the same time schedule as in the previous sessions.

5.5 INSTRUCTIONS TO THE GROUP

The aim of today's session is to help you find a direction for your life. We are going to illustrate our personal vision or plan for the future. You should actually try to describe how you would like your life to be from now on, until your death.

5.6 SHARING IN THE GROUP

Follow the same procedure described in the previous sessions.

5.7 DISCUSSION TOPICS

- Childhood dreams and ambitions
- "Favorites" in life (e.g. favorite book/movie)
- Delights
- Unfulfilled dreams
- Talents
- Own qualities
- Energy and health

- Availability of health care options and facilities
- The use of anti-retroviral medicine
- Career situation and future opportunities
- Mortality
- Values
- Opportunities
- Stress and discomfort
- Current dreams and fantasies
- Family life

5.8 SUMMARY

Now that we have described our direction in life, we have a better understanding of our own dreams, ambitions and vision. Although HIV/AIDS may have an effect on one's future, we realize that life is a journey of discovery, fear, adaptation, sacrifices, perseverance and learning. Despite all of these, we have to focus on the present and future, using past learning experiences to direct us.

5.9 ACTION/HOMEWORK

Motivate group members to write their own philosophies for life by explaining that *philosophy* could imply one's own bill of rights; one's own values and beliefs; one's view of life; and one's personal opinion on how to achieve personal goals. Hand out worksheet C2.

Worksheet C1

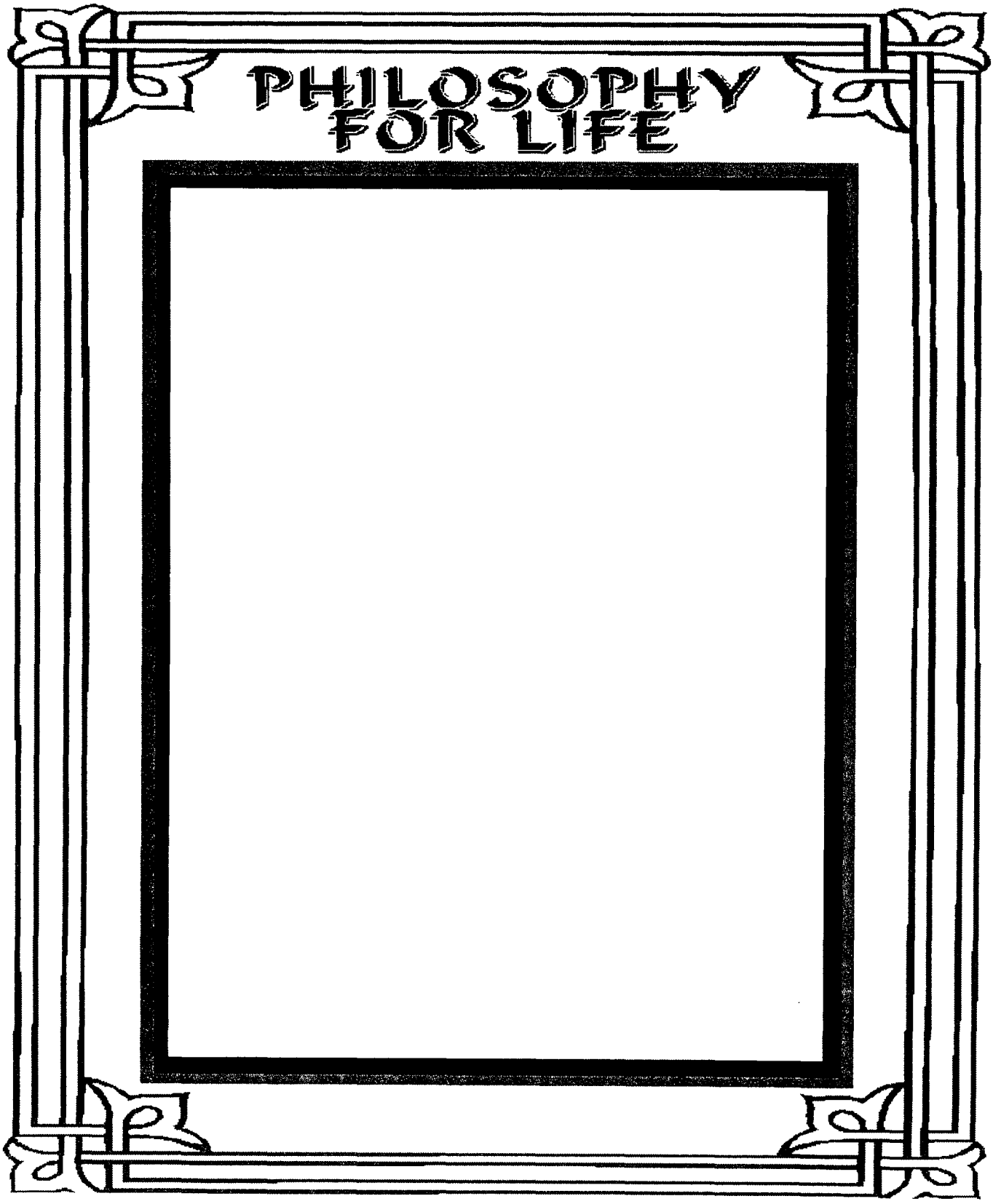
Where am I going?

This map will guide you to make decisions on the future. Usually we are afraid of the unknown or we have a lack of vision because of reluctance to change and move on. It is important to search for a vision and find direction in your life

"To become fully human, you have to make your choice to journey and commit yourself to this choice."

- Kobus Neethling

Worksheet C2



6. SESSION 5

6.1 INTRODUCTION

This session focuses on the internal and external obstacles that could limit the individual's personal and social growth. We have to identify the obstacles in our own lives which hold us back from becoming what we want to be and wish to achieve.

6.2 AIM AND OBJECTIVES

6.2.1 AIM

To identify the internal and external obstacles which limit the individual's personal and social growth.

6.2.2 OBJECTIVES

- To identify physical, social and emotional obstacles
- To make decisions on dealing with obstacles
- To motivate group members to learn new coping skills in dealing with circumstances
- To define the effect of HIV/AIDS on the individual
- To deal with important life events, circumstances and problems
- To teach group members problem solving skills

6.3 MATERIALS AND EQUIPMENT

- Worksheets D1-D3
- Drawing materials
- Pen/pencil/scissors/glue
- Magazines

6.4 TIME SCHEDULE

Use the same time schedule as in the previous sessions.

6.5 INSTRUCTIONS TO THE GROUP

Ask the group members to illustrate the aspects preventing them from achieving their dreams, hopes and ambitions for the future by using drawings, magazine pictures or words.

6.6 SHARING OF LIFE MAPS

Use the same procedure as in the previous sessions.

6.7 DISCUSSION TOPICS

The following discussion topics can be used to direct the group discussion:

- Poor problem-solving activity
- Lack of motivation
- Guilt
- Fear
- Hopelessness
- Need for security, both physical and emotional

- Poor health and the physical effects of HIV/AIDS
- Lack of energy
- Expectations of self and others
- A belief of *"I can't"*
- Destructive habits
- Responsibilities
- Poor communication
- Limited opportunities
- Lack of resources
- Lack of skills
- Uncertainty
- Physical or mental handicaps
- Self-criticism
- Absence of hope, dreams or ambitions

6.8 SUMMARY

We all experience set backs in life, preventing us to accomplish what we really want from life. It is, however, important that we take control over these obstacles by taking responsibility for our problems, our circumstances and our dreams and goals. It is necessary that we learn to actively try and solve our problems, rather than allowing our problems to dissolve and destroy us. PLWA can either allow the disease to physically, socially and emotionally control them, or they can take control and start to manage the disease as effectively as possible.

6.9 ACTION/HOMEWORK

Ask members to list all the problems they have identified in their map on Worksheet D2 and then to prioretize them. Hand out Worksheet D3 with the problem-solving cycle and instruct them to complete the cycle with their number one problem. For homework they can complete the cycle for each identified problem.

Worksheet D1

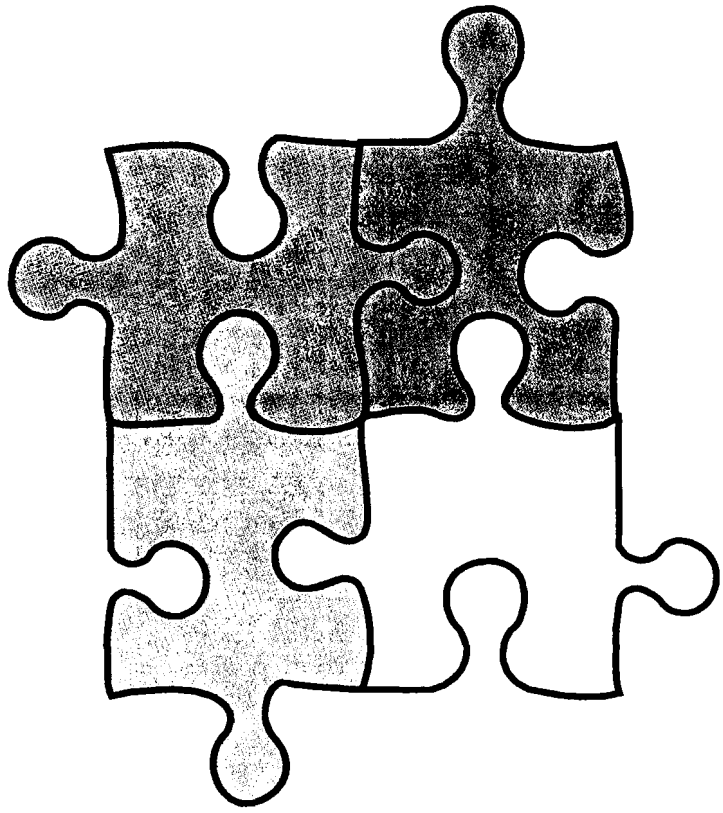
What is stopping me?

We all have to overcome certain obstacles in our lives. Some obstacles are caused by others or significant events and circumstances, while other obstacles are in ourselves. Try to identify YOUR obstacles and illustrate them here.

"It's not what happens to you, it's what you do about it!"
W. Mitchell

Worksheet D2

My problem list

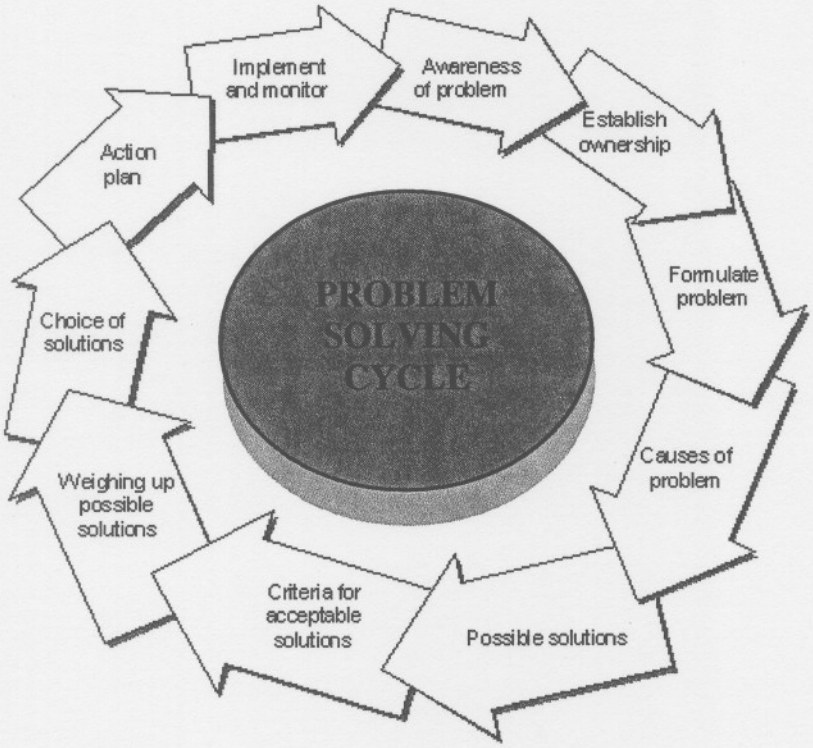


List the problems causing the puzzle of your life to stay incomplete:

Prioretize your problems by numbering them from 1 onwards.

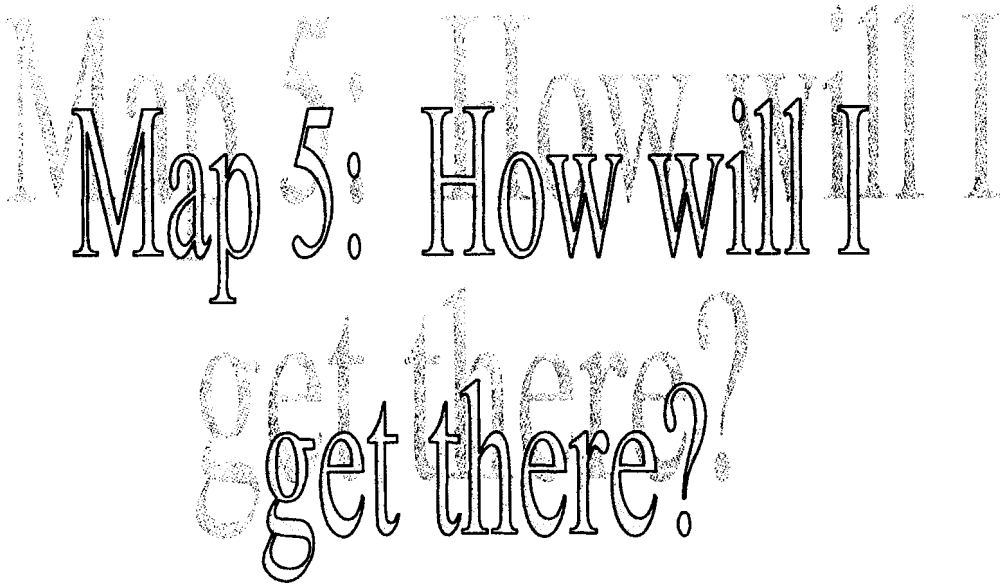
Worksheet D3

The problem-solving-cycle



(Mulligan, 1988 : 78.)

7. SESSION 6



7.1 INTRODUCTION

At this stage of the workshop we were able to set out goals and to identify our obstacles. This leads us to the next step: to put our decisions into action. This session deals with an action plan for the future.

7.2 AIM AND OBJECTIVES

7.2.1 AIM

To guide group members to put their plans and decisions into action.

7.2.2 OBJECTIVES

- To motivate individuals to take action
- To do effective planning

- To actively take control over decisions, choices and actions regarding one's own health management
- To design practical steps by which decisions can be implemented
- To organize action steps into a chronological proses

7.3 MATERIALS AND EQUIPMENT

- Worksheets E1-E4
- Drawing materials
- Pen/pencil/scissors/glue
- Magazines

7.4 TIME SCHEDULE

Use the same time schedule as in the previous sessions.

7.5 INSTRUCTIONS TO THE GROUP

Ask group members to design an action plan for their own lives by using drawings, magazine pictures or words.

7.6 SHARING OF LIFE MAPS

Follow the same procedure as in the previous sessions.

7.7 DISCUSSION TOPICS

The following themes could be included in the discussion:

- Training and education
- Job changes

- Career counseling
- Financial choices and planning
- Lifestyle changes
- Utilization of health care facilities
- Choices in interpersonal relationships
- Exploring social support systems
- Development of skills
- Clarification of values
- Making choices
- Self-motivation
- Identification of future problems/challenges
- Leisure activities and relaxation
- Effective time management

7.8 SUMMARY

By now we have increased our self-knowledge as PLWA, identified our obstacles and formulated an action plan. This action plan must become everyone's own directory guide for the future.

7.9 ACTION/HOMEWORK

Hand out the Worksheets E2-E4. The first two could serve as examples if group members need to apply for a job or need to do personal budgeting. Instruct members to complete Worksheet E4, emphasizing the importance of regular checks to monitor achievement of goals.

Worksheet E1

How will I get there?

This map will help you develop a personal plan of action.

"If it's going to be, it's up to me."
Robert Schuler

Worksheet E2

Writing my Curriculum Vitae (CV)

1. PERSONAL DETAILS

- ❑ **Surname**
- ❑ **Name**
- ❑ **Address (Residential and postal)**
- ❑ **Telephone numbers**
- ❑ **Identity number**
- ❑ **Age**
- ❑ **Highest educational qualification**
- ❑ **Language proficiency**
- ❑ **Drivers license**
- ❑ **Marital status and dependants**

2. ACADEMIC HISTORY

- ❑ **Last school attended**
- ❑ **Highest school qualification**
- ❑ **Subjects and symbols**
- ❑ **Tertiary education**
- ❑ **Name of institution**
- ❑ **Subjects and marks/symbols**
- ❑ **Informal/ in-service training**

3. WORK HISTORY

- ❑ **List all previous periods of employment, including dates, experience, key tasks and reasons for leaving**
- ❑ **Current position**
- ❑ **Current income**
- ❑ **Special skills**

4. LEADERSHIP POSITIONS

- ❑ **At school**
- ❑ **At university/technicon/college**
- ❑ **Community level**

5. SPECIAL ACHIEVEMENTS

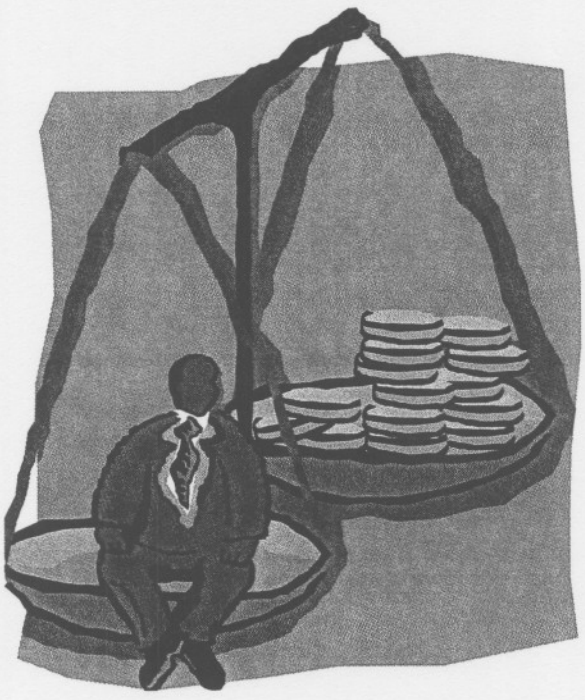
6. HOBBIES AND INTERESTS

7. REFERENCES

- ❑ **Names and contact details of at least 3 references**

Worksheet E3

Personal Budget

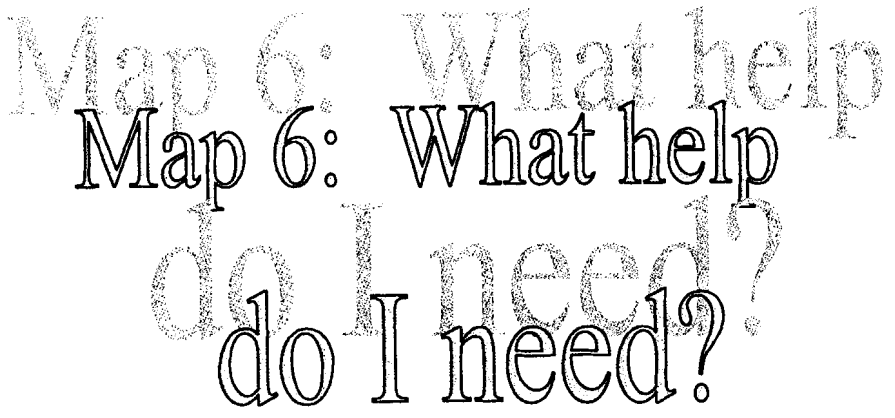


Worksheet E4

Goal sheet

PERSONAL GOALS	SOCIAL GOALS	CAREER GOALS	EDUCATIONAL GOALS
FOLLOWING 3 MONTHS	FOLLOWING 3 MONTHS	FOLLOWING 3 MONTHS	FOLLOWING 3 MONTHS
THE NEXT YEAR	THE NEXT YEAR	THE NEXT YEAR	THE NEXT YEAR
IN 5 YEARS' TIME	IN 5 YEARS' TIME	IN 5 YEARS' TIME	IN 5 YEARS' TIME

8. SESSION 7



8.1 INTRODUCTION

In the previous session we focused on taking action. It is impossible to achieve every goal on our own and it is necessary to get to know available resources as agents in our planning for life. Resources can be divided under three headings: personal, people and materials. Personal resources could include personal qualities, knowledge, skills, attitudes and beliefs. People, as resources, could mean your family, friends, colleagues, educators and other professionals. Materials as resource, indicate time, money and equipment.

8.2 AIM AND OBJECTIVES

8.2.1 AIM

To facilitate the group to identify and utilize available resources.

8.2.2 OBJECTIVES

- To establish a list of necessary resources
- To identify available resources
- To learn how to acquire available resources

- To learn how to utilize available resources

8.3 MATERIALS AND EQUIPMENT

- Worksheets F1-F2
- Drawing materials
- Pen/pencil/scissors/glue
- Magazines

8.4 TIME SCHEDULE

Follow the same time schedule as in the previous sessions.

8.5 INSTRUCTIONS TO THE GROUP

Ask group members to describe the resources they need to live positively with HIV/AIDS and to accomplish their goal(s) by using drawings, magazine pictures or words.

8.6 SHARING OF LIFE MAPS

Follow the same procedure as in the previous sessions.

8.7 DISCUSSION TOPICS

Some of the following themes can be included in the discussion:

- Money
- Imagination
- Libraries/Books
- Computers

- A supportive environment
- Communication skills
- Health care facilities
- Medication and dietary supplements
- Counseling
- A mentor
- Friends
- Willpower
- Time
- Persistence
- Support
- Guidance
- Materials
- Family
- Education

8.8 SUMMARY

Nobody can go through life without the help of others. It is a basic human need to share one's life, dreams and ideas with others. If one is not revealing one's HIV status it is very difficult to obtain family and community support and understanding. It is important that we use the available resources within ourselves, in our families and in our communities. If the necessary resources are not available, it is our responsibility to find out where we can find the resources of what we can do to help develop new resources.

8.9 ACTION/HOMEWORK

Hand out Worksheet F2. Instruct group members to write a letter to the person/institution whose help they need most.

Worksheet F1

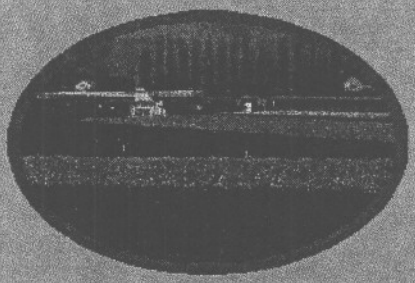
What help do I need?

This map allows you to identify the necessary resources to put your goals into action. Draw the resources you need. Resources include personal resources, people, facilities and material/equipment.

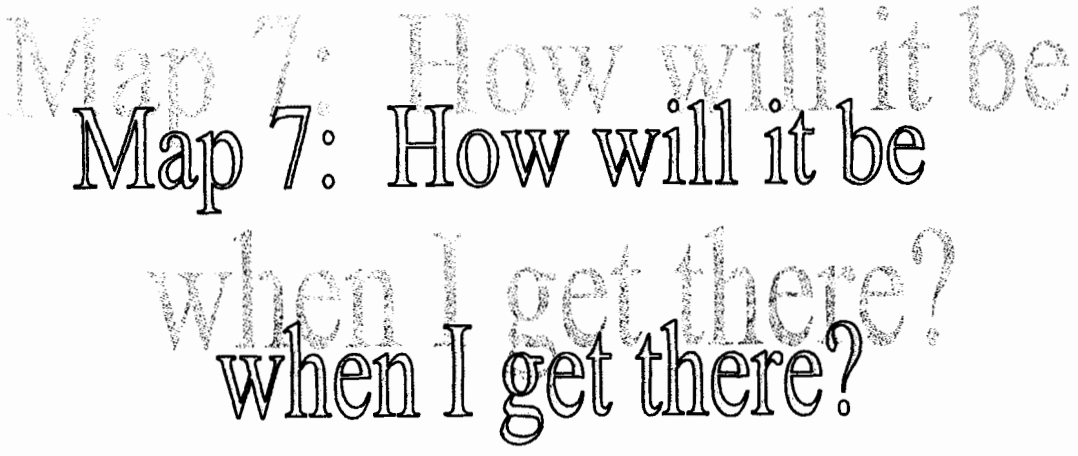
"Courage is a word without boundaries."
- Kobus Neethling

Worksheet F2

Resource application letter



9. SESSION 8



9.1 INTRODUCTION

In the previous sessions we have learned to understand ourselves better, to know our personal history, to determine our goals in life, to identify the obstacles and to learn how to utilize the available resources. In this last life map, we have to create an image of our ultimate vision for the future. Without this, our life maps will be incomplete and we will not have hope for the future!

9.2 AIMS AND OBJECTIVES

9.2.1 AIM

To help the individual to get a clear image of what he is aiming at.

9.2.2 OBJECTIVES

- To put the necessary energy into utilizing one's plan of action

- To create a vision and a future in spite of a life threatening disease
- To get a structured picture of one's "life projects" and evaluate its meaningfulness
- To make a model of the outcome with the following sub-objectives:
  - To make alterations and adjustments
  - To create enthusiasm for and interest in life

9.3 MATERIALS AND EQUIPMENT

- Worksheets G1-G2
- Drawing materials
- Pen/pencil/scissors/glue
- Magazines

9.4 TIME SCHEDULE

Follow the same time schedule as in the previous sessions.

9.5 INSTRUCTIONS TO THE GROUP

Hand out worksheet G1 and ask the group members to describe their idea or dream of the outcome of their goal(s) and action plan by using drawings, magazine pictures or words.

9.6 SHARING OF LIFE MAPS

Use the same procedure as in the previous sessions.

9.7 DISCUSSION TOPICS

The final map's discussion is very important and the following themes may be included:

- Marriage and children
- Peace and tranquility
- Relationships
- The meaning of life
- Financial independence
- Less frustration and stress
- Relaxation, hobbies and recreational activities
- Making choices
- Decision–making
- Managing health
- Dealing with the long term effects of HIV/AIDS
- Sufficient housing
- Less conflict
- Vitality
- Spiritual well-being
- Recognition
- Mortality
- Fewer fears and uncertainties
- More security
- More freedom
- Meaningful work
- Better education

9.8 SUMMARY

By mapping our lives, we have learned about ourselves, our needs, our dreams, our obstacles and our past. We have also explored the impact of HIV/AIDS on our lives. We have formulated action plans to improve our daily living. At the end of this process we should say to each other how our lives have changed and if we have more hope for the future. We also have to motivate each other to focus on our plans and dreams. Death is an inevitable part of life and should not be seen as a senseless and negative end of a human being , but as the final stage of a life full of meaning and purpose. We have to focus on living our lives to the utmost until the end of our days – with or without HIV/AIDS.

9.9 ACTION/HOMEWORK

Complete the inscriptive on Worksheet G2, focusing on how you would like others to remember your life.

Worksheet G1

What will it be like when I get there?

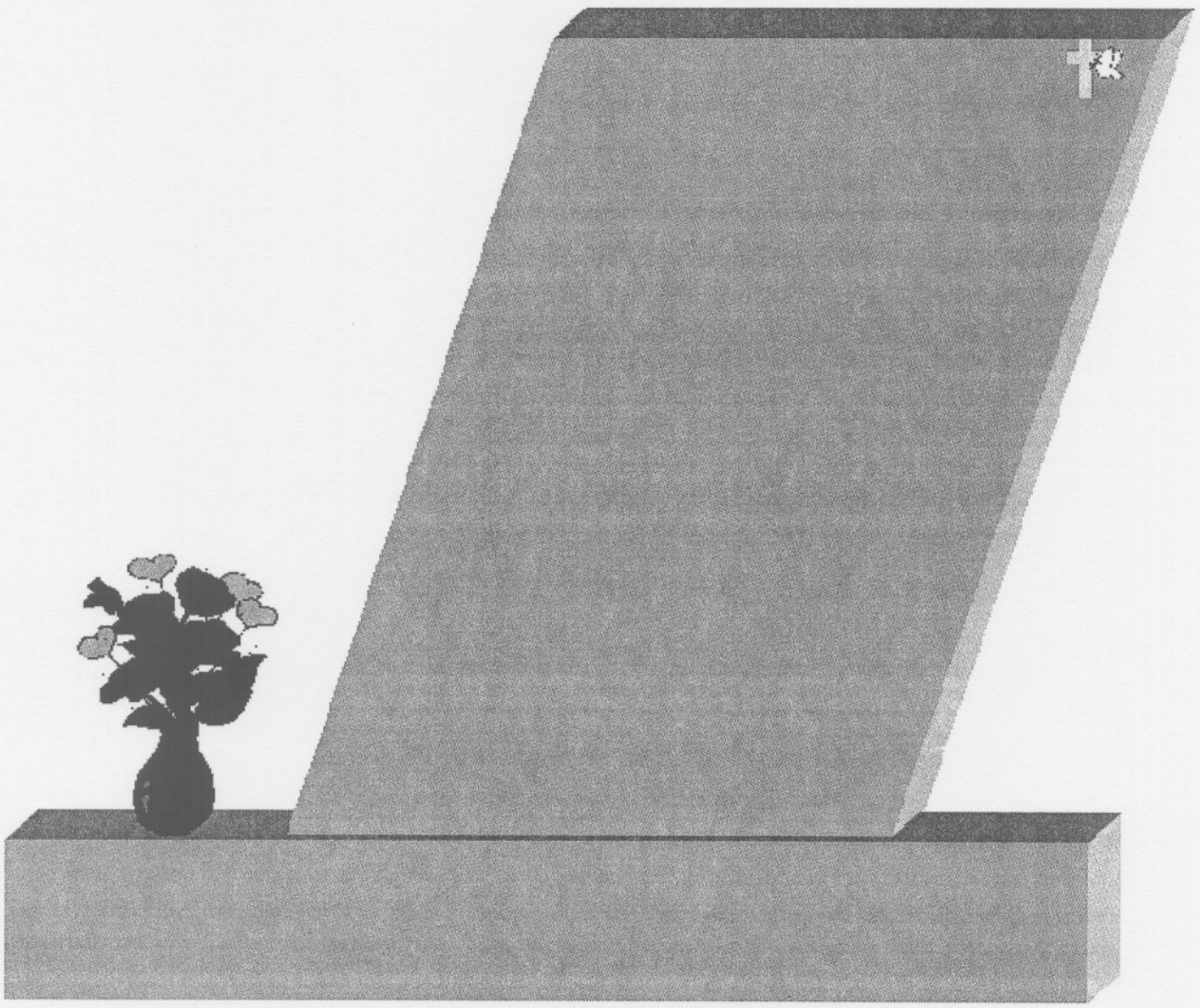
Think about your life, when everything you have mapped in this programme come together and end in you, achieving your ultimate goal in life. Draw this vision.

"Imagination is more important than knowledge."

- Albert Einstein

Worksheet G2

When others remember me and my life



10. SESSION 9: SUMMARY, EVALUATION AND CLOSURE

10.1 COMPONENTS OF THE CLOSING SESSION

This final session of 6 hours consisted of the following components:

- Formal evaluation of the workshop by means of a questionnaire (Annexure 6)
- Summary of the group series by painting a quilt
- Informal socialization by sharing a meal together
- Closure by means of a candle lithting ceremony

10.2 QUILT MAKING

Quilt making is a recognized technique in HIV/AIDS counseling and was presented in this programme as follows:

Group members were divided into two smaller groups and were issued with a large piece of material, fabric paint and paintbrushes. They were instructed to paint a collage of their experiences and impressions during the workshop. The aim of this exercise was to allow group members to summarize the group work experience in a creative way. *One of the quilts was framed and presented to ATICC Bloemfontein, while the other one was kept by the researcher to incorporate in the report as a photo.*

10.3 CANDLE LIGHTING CEREMONY

Although no formal literature could be found on candle lighting ceremonies, it is a well-known ceremony in our country to symbolically remember PLWA and those who have died of the disease. This is a very special and almost sacred ceremony for PLWA and

was therefore chosen to end the Thsepang Workshop. *The candle lighting ceremony was really a special event and made an intense impression on the researcher. It felt as if everyone in the room was connected in some way and respect was shown to every PLWA and those who have lost their lives through this disease, teaching the researcher how important it is to treat PLWA with dignity.*

In the next chapter the group work programme will be evaluated.

PHILOSOPHY FOR LIFE

MY FAMILY AND FRIENDS KNOWS ABOUT THIS HIV/AIDS.

THEY TREAT ME LIKE A NORMAL PERSON.

MY PROBLEM IS THAT MANY POOR PROJECTS DO NOT HELP ME.

I WAS SO IN LOVE WITH THE WORKSHOP.

I WAS SO HAPPY TO BE A PERSON THAT ENJOYED THIS PROJECT.

George

CHAPTER 7

RESEARCH FINDINGS: EVALUATION OF THE GROUP WORK PROGRAMME

1. INTRODUCTION

In this chapter the group work programme will be evaluated. The mainly qualitative data of phase two will be presented with emphasis on the experiment, the results of the measuring instrument that was used, the GCS, as well as the data from a self-developed evaluation questionnaire for the experimental group. If respondents' names are used in this report, it is with their permission. Firstly the population will be introduced, followed by information on the measuring instrument and the pre test results of both groups. This will be followed by the qualitative data collected from the group work programme and the evaluation by the experimental group members. The chapter will be concluded with the GCS scores of both groups.

2. POPULUTION AND SAMPLING

The population consisted of the 20 young adults living with HIV/AIDS who completed the needs assessment questionnaire. They were selected by target sampling to participate as the experimental and control groups. Target sampling is defined by Strydom & De Vos (1998: 1999) as " a purposeful, systematic method by which controlled lists of specified populations within geographical districts are developed and detailed plans are designed to recruit adequate numbers of cases within each of the targets". For the purpose of this study, the following targets were set to identify respondents to include in the experiment:

- Respondents who indicated a willingness to further participate in the needs assessment
- Respondents living in the Bloemfontein geographical area

- An equal age and gender distribution for both the experimental and the control groups

3. INTRODUCTION TO THE GROUPS

Initially the experimental group consisted of 10 young adults living with HIV/AIDS and who indicated a willingness to participate in a group situation. This group was exposed to pre testing, the group work programme and post testing. The control group also consisted of 10 young adults living with HIV/AIDS, but they were only exposed to pre and post testing. The groups were cut down to 9 respondents each after one member of the experimental group withdrew on the first day of the programme. The control group consisted of members who were willing to contribute towards the study, but were not willing and available for a group situation because they were not comfortable with disclosing their HIV status or lived outside the Bloemfontein geographical area. This ethical issue was taken in consideration, as well as the difficulty to obtain respondents who were HIV+, when the decision was made to do the pre and post testing individually and follow-up telephonically for the control group while the experimental group did pre and post testing in a group session. This was not the ideal situation for an experiment, but it was the only practical way to respect respondents' right to confidentiality and to conduct the study. The following figure is a summary of the composition of the two groups.

FIGURE 27: THE COMPOSITION OF THE EXPERIMENTAL AND CONTROL GROUPS

EXPERIMENTAL GROUP	CONTROL GROUP
NUMBER OF GROUP MEMBERS 9	NUMBER OF GROUP MEMBERS 9
SEX OF GROUP MEMBERS Male 2 Female 7 AGE OF RESPONDENTS 16-18 years: 2 19-22 years: 2 23-25 years: 1 26-30 years: 4 MARITAL STATUS OF RESPONDENTS Married: 1 Divorced: 1 Long term intimate relationship: 3 Never been married: 4	SEX OF GROUP MEMBERS Male 2 Female 7 AGE OF RESPONDENTS 16-18 years: 1 19-22 years: 3 23-25 years: 1 26-30 years: 4 MARITAL STATUS OF RESPONDENTS Married: 3 Divorced: 2 Long term intimate relationship: 1 Never been married: 3

4. MEASURING INSTRUMENT

The General Contentment Scale of Hudson (Annexure 2) (Bloom *et al.*, 1999: 220) was administered in pre and post testing. The GCS is a standardized scale that can be used in social work and according to the introduction on the answering sheet of the scale, it is designed to measure the way one feels about one's life and surroundings. This scale can only be obtained from Perspective Training College (www.perspektief.com) who administers all

the Hudson Indexes for copyright purposes and who supplies training and computer soft ware for analysis and interpretation. In this study the aim in administering the GCS was to determine respondents' general contentment with life and to use the data for pre and post testing purposes. Ultimately the data were used to determine a link between respondents' general contentment and the application of life maps as technique. The experimental group was also exposed to a self-developed evaluation questionnaire. Completion of these questionnaires formed part of measuring and post testing. The GCS scores range from 0-100% and the following values are used to interpret the GCS scores:

- A score of more than **35%** shows need for improvement
- A score between **25% and 35%** indicates a warning that an area needs attention
- A score below **25%** is in the recommended range

5. THE EXPERIMENTAL DESIGN

The true experiment (See figure 11 in chapter 2) was applied in this study, following the following formula (Grinnell & Williams, 1990: 167):

Experimental group:	**R**	**01**	**X**	**02**
Control group:	**R**	**01**		**02**

Where:

R	=	Random selection and assignment to the group
01	=	First measurement of the dependent variable (General contentment)
X	=	Independent variable (Group work programme)
02	=	Second measurement of the dependent variable (General contentment)

The aim of the experiment was to determine whether the application of a group work programme, where life maps were used as technique, had any influence on the general contentment of young adults living with HIV/AIDS.

Respondents were exposed to pre testing at the start of the group work programme and post testing took place six weeks after the group series. Measuring could not take place immediately after the programme because it was a marathon situation and post testing only four days after the pre test would be of little use.

6. PRE TESTING

The pre test was conducted by requesting both the experimental and control groups to complete the GCS before the Thsepang Programme (name of the group work programme) was presented. The following table represents the individual and group pre test scores.

TABLE 9: PRE TEST SCORES

EXPERIMENTAL GROUP		**CONTROL GROUP**	
RESPONDENT	GCS SCORE	**RESPONDENT**	**GCS SCORE**
1	59%	**1**	**49%**
2	62%	**2**	**16%**
3	48%	**3**	**70%**
4	26%	**4**	**58%**
5	16%	**5**	**20%**
6	42%	**6**	**44%**
7	8%	**7**	**30%**
8	48%	**8**	**43%**
9	23%	**9**	**25%**
AVERAGE SCORE OF GROUP	**36.9%**	**AVERAGE SCORE OF GROUP**	**39.4%**

The scores were interpreted according to the score ranges described in paragraph 4, indicating that both groups' GCS scores were above the recommended range of 25% and showed need for improvement. The experimental group's scores were slightly (2.5%) lower than those of

the control group. In the group summary profile that was compiled by using Perspective Training College Software (Paswin 2000), the following areas needed attention in both groups:

- Powerlessness to do anything about their lives
- Feelings of sadness and crying spells
- Depression
- Difficulty to get started with the things they had to do

7. PRE TESTING

The experimental group was involved in a marathon group that stretched over a period of three days from 22-24 April 2000. The group was called *Thsepang Workshop* and the contents included the seven life maps that were described in chapter 6. The control group was not exposed to the group work programme and continued with their normal daily activities during this period. The group work programme was structured, following the schedule described in Table 23 in chapter 6.

8. DATA ANALYSIS

The data collected in this phase of the research process were mainly qualitative and were analysed by following Tesch's approach as described by Poggenpoel (1998: 343-344). Qualitative data processing includes aspects of record observations, filing, organizing records, rewriting notes, creating files and using computers (Rubin & Babbie, 2001: 411-413). The process that was followed, according to Tesch's approach is summarized in the following figure.

FIGURE 28: TESCH'S APPROACH TO THE ANALYSIS OF QAULITATIVE DATA

THE EIGHT STEPS OF TESCH'S APPROACH

1. Review all collected data by reading through them carefully and jot down ideas at random.

2. Select one respondent's data that are of particular interest or are the shortest, etc. and ask the following question: *What is this all about?* The researcher then writes down his own thoughts about the underlying meaning of the information.

3. The same procedure should be followed for several respondents. The researcher then starts to combine similar themes and makes a list of topics. These topics are then clustered into columns and might be arranged into major topics, unique topics and leftovers.

4. Topics should be abbreviated as codes and reverted to the text. This needs to be done to see whether new categories and codes emerge.

5. Descriptive wording must be selected for the different topics and lines are drawn between the categories to show interrelationships.

6. A final decision is made on the abbreviation of each category and codes are arranged in alphabetical order.

7. Similar data material is assembled and a preliminary analysis is performed.

8. Recode existing data if necessary.

These steps were followed to analyse the data collected from the life maps that were used in the group work programme. The data will now be presented, following the schedule of the group work programme described in Table 8 of chapter 6. The data analysis will serve as evaluation of the programme.

9. EVALUATION OF THE PROGRAMME

9.1 SESSION 1: INTRODUCTION, MEASUREMENT AND PREPARATION

9.1.1 AIMS

The aims of this session were orientation, building relationships, establishing commitment and measuring (pre testing). Group members were requested to complete the GCS (Annnexure1) and to sign a declaration of participation (Annexure 4). During this session, sharing mutual expectations was important. An example of the form that was used to determine the mutual expectations can be viewed in Annexure 5.

9.1.2 CONTENTS OF THE GROUP SESSION

During this session, the researcher described the contents of the programme and the way it would be presented. The researcher and group members were introduced to each other, mutual expectations were shared and the rules of the group were set. The rules were very much connected to confidentiality and respect for each other. The group members were requested to complete the GCS. Two of the group members found it difficult to complete the scale and needed assistance.

The name of the group, *Thsepang Workshop,* was discussed as initial topic, resulting in interesting comments. There was a remarkably positive attitude among group members towards their HIV status. They expressed a wish to make the most of their lives, notwithstanding the fact that they were living with a life-threatening disease. Most of the group members were interested in the approach of not receiving lectures, but to actually focus on self-disclosure and self-development in a supportive environment.

9.1.3 EVALUATION OF THE SESSION

The respondents seemed excited and were looking forward to the actual contents of the programme. Communication was quite free, probably due to the fact that six of the members

knew each other from the *Leratong Support Group.* Bonding took place and commitment was established.

9.2 SESSION 2: LIFE MAP 1 – WHO AM I?

9.2.1 AIM

The aim of this session was to supply the individual with the opportunity to explore and express the self and to establish identity.

9.2.2 CONTENTS OF THE SESSION

The group members were introduced to life map 1 as a tool to promote self-awareness, self-expression and identity. The appropriate worksheets A1-A3 (described in chapter 6) were supplied and group members were reassured that they needed not be artistic to make drawings, but that it was more important that they tried to express themselves. Initially it took a while for them to settle down and start working, but once they started working, they showed great enthusiasm.

Each group member was then allowed to describe his/her life map to the group, sharing only what he/she felt comfortable with. The sharing of life maps was followed by a group discussion, including themes like personal beliefs, work situation, position in the family, personality traits, educational position and personal dreams.

In summary, group members were requested to complete Worksheets A2 and A3. In Worksheet A2 they listed their strengths and weaknesses and summarized it with four good reasons why they could see themselves as winners. Most of the group members perceived their positive living with HIV/AIDS as a real win situation. Most group members found it difficult to complete worksheet A3. Those who completed their personal labels, expressed their destination as being in life in their roles as man/woman, a parent, a family member or an employee.

9.2.3 EVALUATION OF THE GROUP SESSION

The group members enjoyed drawing or making magazine photo collages and their participation was good. At first they found sharing their life maps difficult, but it became easier after the researcher shared her life map, giving the group members an idea of how to do it. Communication became more free as uncertainties were overcome and cohesion grew. Worksheet A3 was evaluated as difficult and too abstract.

9.2.4 DATA COLLECTED FROM LIFE MAP 1

The group members' life maps were analysed and the following three main themes could be identified:

- Family and sex role related descriptions **(FSRD)**
- Health, energy and HIV status **(HEHIV)**
- Identity and personal desires **(IPD)**

The following table represents the data collected from this map by categorizing the main topics, indicating the typical themes expressed under each of them. The number of respondents who expressed similar themes are indicated in brackets after each theme. *Please note that every member could include more than one theme.*

TABLE 10: RESPONDENTS'DESCRIPTIONS OF OWN IDENTITY (MAP 1)

FSRD	HEHIV	IPD
Getting married (4)	Living positively with HIV/AIDS (5)	Living a meaningful life (7)
The need of family support (4)	Being a PLWA (3)	Obtaining an education and starting a career (5)
Being a good parent (3)	Ignoring/denying own HIV status (3)	Living with HIV/AIDS and improving health (5)
Not being able to become a parent (2)		Obtaining financial independence (4)
Family conflict (2)		Trying to become a fulfilled human being (4)
Lack of family support (1)		Likes and dislikes (4)
		Severe poverty (3)
		Loneliness and isolation (2)

An example of one of the group member's life map is attached as Annexure 7. From these data it seemed that the overall identity of respondents focused on the role of HIV/AIDS, their primary roles, education and a meaningful life.

9.3 SESSION 3: LIFE MAP 2 – WHERE HAVE I COME FROM?

9.3.1 AIM

The aim of this session was to take an overview of group members' individual background and past and determine the influence of their background on their current life situation.

9.3.2 CONTENTS OF THE GROUP SESSION

Life map two was introduced to the group members by emphasizing the role of personal history and roots on the life of mankind. Worksheets B1-B3 were handed out and group members were allowed to illustrate their live maps by using drawings or magazine photo collages. Group members were more familiar with the technique and completed their tasks with enthusiasm. During the description of their life maps, several group members became very emotional. Two of them described the loss of primary family members to HIV/AIDS, one relived the burning down of their house and another described his intense loneliness and isolation. The latter group member described that his whole social system consisted of his mother and his dog. Group members really supported each other in a very compassionate way and group cohesion, intimacy and interaction increased drastically. This session lasted for more than two hours, but served as a very necessary catharsis. Various group members expressed the positive value of being in a group of people with similar experiences and problems, where they had the opportunity to express their feelings freely.

Following the discussion, group members were requested to complete Worksheet B2: *Past Tense*. In this exercise group members were allowed to indicate what they would have liked to change about their lives. Most of them wanted their lives just the way they were, but two wished they could change the past. One wished her husband and child, who had died of AIDS were still alive and the other, a prostitute, wanted to change her lifestyle.

The last part of this session consisted of the drawing of the lifeline (Worksheet B3) and the aim was to empower group members to take an overview of their lives. The following summary is a reflection of the themes expressed in this exercise:

- Birth, childhood, education and the HIV diagnosis
- Life after the HIV diagnosis
- Career situations
- The lifelines ended in one of two ways:
  - A destination of death, preferably surrounded by family and friends
  - The day the HIV diagnosis was made.

The discussion of the lifelines resulted in another session of mutual support and encouragement. Some of the following phrases were used to give encouragement and are used in this report with the permission of the group members.

- *"I am still healthy, six years after I was diagnosed with HIV" and "HIV is not only for Human Immune deficiency Virus, but also for* ***Hope Is Vital.*** *"* – Mathilda
- *"Life is still surprisingly beautiful"* – Debrah
- *"My body is carrying the HI-virus, but I am spiritually healed."* –Boithetelo
- *"I am not dying of AIDS, I am living with it."* - George

9.3.3 EVALUATION OF THE GROUP SESSION

This was a very emotional session, resulting in increased cohesion, intimacy and mutual support. The opportunity for emotional catharsis was very important and group members gained a lot in sharing in one another's pain and suffering of the past. They were guided to acknowledge the impact of the past, work through unresolved issues and to accept the things they could not change. For many group members this was a first opportunity to share their pain and sorrow and it seemed to be a relief to them.

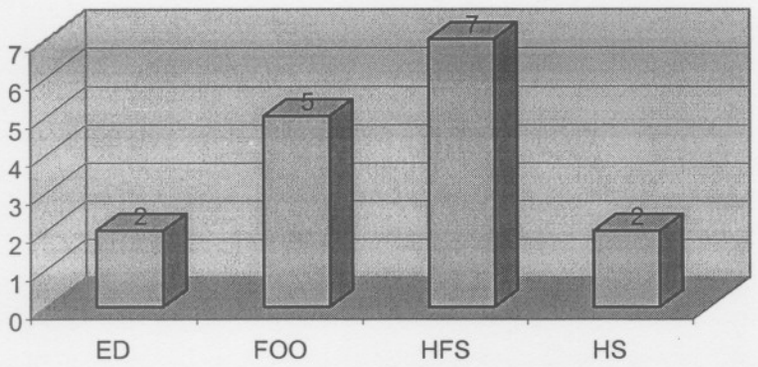
9.3.4 DATA COLLECTED FROM LIFE MAP 2

Four central themes could be identified from life map 2:

- Education **(ED)**
- Family of origin **(FOO)**
- Housing and financial situation **(HFS)**
- Health status **(HS)**

The following chart is an indication of the frequency of themes in group members' life maps.

GRAPHICAL REPRESENTATION 7:
CENTRAL THEMES OF LIFE MAP 2



An example of one of the respondents' life map is enclosed as Annexure 8. This is the map of the respondent who told the group about her family's home that was destroyed in a fire.

The researcher made notes during the group discussion that support the collected data and include the following:

- One group member lost a husband and a child to AIDS since 1998
- Early pregnancies occurred, resulting in 3 group members having children before they contracted HIV. These children were very precious to them, because they were saved from the burden of having HIV/AIDS since birth.

- The discussion on having children was upsetting for group members who had no children. Many of them expressed the painful thought of not having children or expressed the hope that a cure or future medical procedure would enable them to have children free from the HI-virus.
- The importance of family support was emphasized and they focused mainly on the role of their parents.
- Discussion themes did not only include the impact of HIV/AIDS on their past, but also focused on trauma of daily living, including the divorce of parents, poverty, prostitution and rape.

9.4 SESSION 4: LIFE MAP 3 – WHERE AM I GOING?

9.4.1 AIM

The aim of this session was to enable group members to find a vision and direction for their lives by determining their personal beliefs and values.

9.4.2 CONTENTS OF THE SESSION

Group members were requested to draw their third life map on Worksheet C1. None of them made a drawing, but preferred to illustrate the vision for their lives with magazine photo collages. They enjoyed visualizing their future dreams and goals – some realistic and some probably bound to be dreams forever.

The discussion that followed was much more positive and energetic than the discussion of life map 2, which was very emotional. Their future dreams and goals consisted mainly of obtaining education, establishing a family, living positively with HIV/AIDS, spiritual growth and financial security.

To conclude the session, group members were requested to write their personal philosophy for their lives (Worksheet C2). The concept *philosophy* was explained to them as their own bill of rights; their own values and beliefs; their own view of life; and their personal opinion on how to achieve their personal goals. One group member found it very difficult to understand, but with the assistance of another group member, managed to write a simple, but

honest philosophy. These philosophies were incorporated in this report as dividers between chapters and were used with the permission of the group members. Some of the group members requested that their philosophies be used anonymously.

9.4.3 EVALUATION OF THE GROUP SESSION

This session was full of energy, optimism and hope for the future. Group members participated enthusiastically and started to take personal responsibility for their lives. They enjoyed writing their philosophies and experienced it very positively when the researcher had each typed and formally presented to them as something they could frame and hang on the wall. The goal of giving them a vision for the future was definitely achieved.

9.4.4 DATA COLLECTED FROM LIFE MAP 3

The central themes that could be identified from this life map included:

- Education and career possibilities **(ECP)**
- Financial security **(FS)**
- Living positively with HIV/AIDS **(LHIV)**
- Marriage and family life **(MFL)**
- Spiritual growth and contentment **(SGC)**

These themes were further analysed and are presented in the following frequency table. The actual topics of discussion are presented, followed by the code presenting the central themes.

TABLE 11: THEMES FROM LIFE MAP 3

TOPICS DISCUSSED	FREQUENCY	PERCENTAGE
Getting married/ settling into a permanent intimate relationship (MFL)	5	18.5%
Being a good parent (MFL)	3	11.1%
Completing further education (ECP)	3	11.1%
Buying a car and/or house (FS)	5	18.5%
Spiritual growth and happiness (SGC)	3	11.1%
Starting an own business (ECP)	2	7.4%
Obtaining a job (ECP)	2	7.4%
Managing HIV, improving health and energy levels (LHIV)	4	14.9%
N=	**27***	100%

*Respondents could express more than one theme, therefore N= 27.

From this table, the summary can be made that most group members' vision for the future focused on education and career possibilities, followed by marriage and family life and obtaining financial independence.

9.5 SESSION 5: LIFE MAP 4 – WHAT IS STOPPING ME?

9.5.1 AIMS

The first aim of this session was to identify the internal and external obstacles that limited the group members' personal and social growth and prevented them from achieving their personal goals. The second aim was to teach group members some problem solving skills.

9.5.2 CONTENTS OF THE GROUP SESSION

The session started with the drawing of life map 4 (Worksheet D1). Being familiar with the technique, the group members completed the activity independently. The discussion that followed was spontaneous and honest. Group members did introspection and were able to identify certain obstacles in their lives that were very individual in nature. Some of the obstacles included limited time, lack of resources and the impact of HIV/AIDS. The life map drawn by Boithetelo, the group member who died in a shooting incident, included the following words that are used in this report to illustrate the irony of her death (See Annexure 9 for a copy of her life map):

"I need only time power to make all the things to fulfil my dreams. I need time. Only time will allow me! Yesterday I said I think too much within a limited space of time. Definitely going to fulfil my dreams. Energy is wanted."

Group members also expressed their temperaments and personality traits that limited their achievement of certain goals. One group member mentioned impatience and anger as two limitations in her life. Another felt that poverty and limited opportunities were his biggest obstacles.

Group members were then guided to prioritize their obstacles/problems (Worksheet D2) and to utilize the problem-solving cycle (Worksheet D3) to try and overcome certain obstacles. It was discussed that certain problems cannot be solved and that some problems were created by themselves. Little toy dustbins were handed out to each group member. They were instructed to literally throw away problems that wasted their time and energy. The group members enjoyed this activity tremendously and their feedback was that the action of throwing away certain problems brought emotional relief and perspective. Increased responsibility was observed and group members were committed to actively work on their problems. They were really interested in the problem-solving cycle as a tool to practically implement in their lives.

9.5.3 EVALUATION OF THE GROUP WORK SESSION

It was observed that group members were empowered by seeing their problems in a *black and white* situation. They mentioned that they felt in control of their lives by actually *seeing* their problems and the problem-solving cycle provided them with a tool to try and solve their problems. The high sense of responsibility was positive, because nobody can take responsibility for one's own mistakes and problems, but oneself.

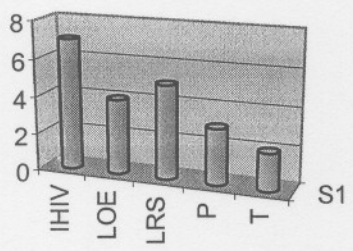
9.5.4 DATA COLLECTED FROM LIFE MAP 4

Data that were collected from this life map were analysed and they resulted in the following categories of obstacles:

- Implications of HIV/AIDS **(IHIV)**
- Lack of education **(LOE)**
- Limited resources and support **(LRS)**
- Poverty **(P)**
- Time **(T)**

The following chart represents the respondents' experience of obstacles in achieving their life goals. *Please note that group members could express more than one theme, causing N = 21.*

GRAPHICAL REPRESENTATION 8:
THEMES OF LIFE MAP 4



	IHIV	LOE	LRS	P	T
Series1	7	4	5	3	2

N=21

Obstacles in the lives of the group members were mainly associated with HIV/AIDS, followed by limited resources and support and lack of education. The following table summarizes the more specific topics related to the main themes.

FIGURE 29: SPECIFIC TOPICS RELATED TO LIFE MAP 4

IHIV	LOE	LRS	P	T
Implications of ARC's, e.g. TB and pneumonia	Obtaining bursaries for further education	Difficulty to obtain financial support for own businesses	Lack of proper income	Impulsiveness
The Government's indecisiveness regarding HIV/AIDS and treatment	Negative attitude towards education	Family demands	Ineffective budgeting	Not spending enough time on religious activity
Fear for stigmatisation	Did not complete school education	Friends having insufficient time and insight into the situation of a PLWA	Unemployment	Limited life time due to life-threatening disease
The cost of supplementary medication to improve the immune system		Lack of friends		Ineffective planning

9.6 SESSION 6: LIFE MAP 5 – HOW WILL I GET THERE?

9.6.1 AIM

The aim of this session was to actively involve group members in planning and working out strategies to achieve their life goals.

9.6.2 CONTENTS OF THE GROUP SESSION

This group session started with group members making a drawing or magazine photo collage to illustrate Life map 5 (Worksheet E1). Drawing this life map seemed to be a challenge to the group members and they worked independently on describing their personal plans of action. Two of the group members found it difficult to do future planning and explained their reluctance by claiming that they felt so helpless and sometimes hopeless, that they could not think of anything to do or plan. The other group members were very much involved in the activity and their non-verbal reactions reflected concentration and personal commitment. They tried to positively influence the two reluctant group members. Sharing of the maps was done with excitement. During the discussion, group members proudly presented their suggestions and plans to make their future dreams become a reality. Most of their plans were illustrated in the form of steps or ladders. Some of the group members' plans of action will be incorporated here to acknowledge their input.

FIGURE 30 : THE GOALS LADDER OF MATHILDA

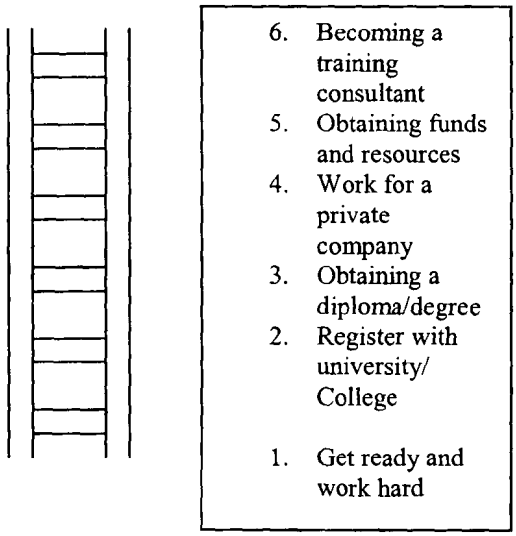


FIGURE 31 : ELLEN'S STEPS TOWARDS THE FUTURE

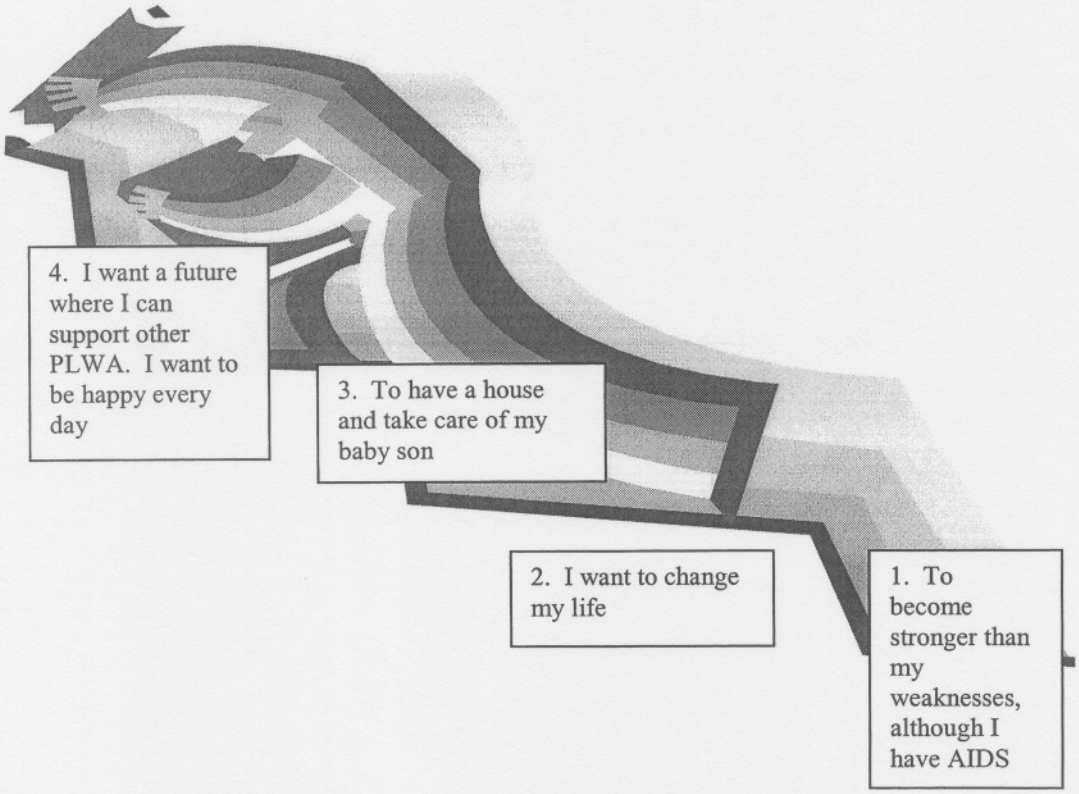


FIGURE 32 : DEBRAH'S PLAN OF ACTION

- STEP 1: Start preparing
- STEP 2: Register at the University of the Free State
- STEP 3: Complete degree
- STEP 4: Start working
- STEP 5: Buy a house
- STEP 6: Have a family
- STEP 7: Enjoy my life
- STEP 8: Live life to the fullest and leave AIDS out of the future!
- STEP 9: A happy ending

After this interesting and positive discussion, Worksheets E2-E4 were handed out and the instructions were given to group members. The aim of the worksheets was to supply group members with practical tools to assist them in implementing their plans.

9.6.3 EVALUATION OF THE GROUP SESSION

The practical impact of this session was evaluated positively and members' active participation confirmed that they were able to take responsibility for their lives and that they were inspired to do something with their lives. From their life maps and the group discussion, it was shown that they had gained insight into their strengths and weaknesses and were able to set realistic goals.

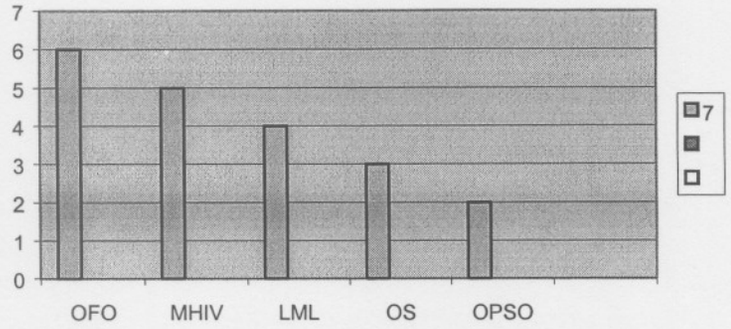
9.6.4 DATA COLLECTED FROM LIFE MAP 5

Although the data collected from this map represented a more personal and individual view, it was possible to identify certain central themes. These themes included the following:

- Further education **(FE)**
- Living a meaningful life **(LML)**
- Managing HIV **(MHIV)**
- Overcoming financial obstacles **(OFO)**
- Overcoming psycho-social obstacles **(OPSO)**
- Obtaining support **(OS)**

Living with HIV/AIDS was part of the central themes, but themes mainly focused on *normal* goals of young adults, including education, financial independence and living a meaningful life. The graphical representation on the next page reflects the central themes from life map 5.

GRAPHICAL REPRESENTATION 8: THEMES FROM LIFE MAP 5



9.7 SESSION 7: LIFE MAP 6 – WHAT HELP DO I NEED?

9.7.1 AIM

The aim of this session was to facilitate the group to identify and utilize available resources to put their plans into action.

9.7.2 CONTENTS OF THE GROUP SESSION

The group session started with drawing life map 6 (Worksheet F1). Group members completed it rather quickly and the descriptions on their life maps had both emotional and practical components. (See Annexure 10 for an example of one of the group members' life maps.) During the group discussion the main themes included access to the following resources:

- Schools and tertiary institutions
- Health care facilities
- Social support systems
- Religious institutions
- Financial institutions

Group members were assisted in completing Worksheet F2, *Resource application letter.* The aim was to teach them how to write a business letter to specific institutions which help they needed. The group members wrote letters to Landbank, universities, colleges, Hospices or their families. They read their letters to the group and group members evaluated them and made recommendations. Group members were motivated to actually send their letters to the institutions they identified as resources. In addition, group members were assisted in using use the telephone directory to obtain the telephone numbers of appropriate institutions.

One of the resources the group members expressed a need for was HIV/AIDS associated health care facilities. Bloemfontein ATICC supplied each group member with a comprehensive guide on HIV/AIDS related resources. This resource guide included private practitioners who specialized in HIV treatment, traditional healers, dieticians who supplied diet supplements and immune system boosters, support groups and counselling services. Using this guide would enable them to choose the HIV/AIDS services they needed, but also to identify organizations where they could become involved as volunteers. Some of these organizations like *The Young Living Ambassadors Project* actually employ young adults living with HIV/AIDS. Group members showed real gratitude for this guide and mentioned that they felt positive that their future goals could be achieved.

The group discussion also included a very emotional component where one group member told the group how much she needed her family as a resource. She was rejected by almost everybody in the family due to her life as a prostitute. Group members motivated her to write a letter to her parents to describe her emotions and needs and to tell them that she had decided to change her life. She asked for their forgiveness and wanted them to be reconciled.[1]

9.7.3 EVALUATION OF THE GROUP SESSION

The aim of the session was to enable group members to identify and utilize available resources. This aim was achieved by allowing group members to firstly identify the necessary resources. This was followed by teaching them how to approach identified resources. Their letters confirmed their need and willingness to put their personal plans into

[1] The researcher still has contact with this group member. She changed her lifestyle, which caused her to experience severe financial difficulties, but she was reconciled with her family. During the last telephonic contact in August 2002, she was in hospital with pneumonia. She mentioned that she was very ill and feared that she was going into the terminal phase of the disease.

action and to take responsibility for their lives. The group members supported each other very positively and group cohesion and intimacy were still very high. Although group members expressed mainly a need for practical help, there was still an emotional component involved, emphasizing the role of family and friends as resource in the lives of young PLWA.

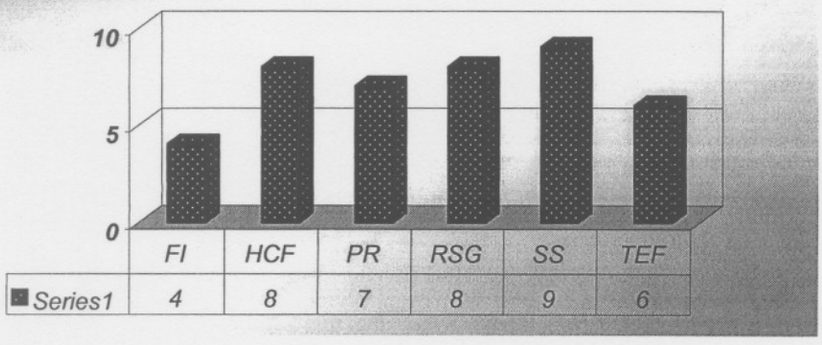
9.7.4 DATA COLLECTED FROM LIFE MAP 6

The following categories of resources could be identified from this map:

- Financial institutions **(FI)**
- Health care facilities **(HCF)**
- Personal resources **(PR)**
- Religion and spiritual guidance **(RSG)**
- Social support from family, friends and the community **(SS)**
- Training and education facilities **(TEF)**

The following graphical representation gives an indication of the focus group members' perceptions on how much they need the different resources. Group members could have more than one perception on the resources they need, causing N = 42.

GRAPHICAL REPRESENTATION 9: RESOURCES NEEDED BY GROUP MEMBERS



N=42

These data indicated that group members most needed social support, health care facilities, religion and spiritual support.

9.8 SESSION 8: LIFE MAP 7 – HOW WILL IT BE LIKE WHEN I GET THERE?

9.8.1 AIM

The aim of this session was to guide group members to get a clear image of what they were aiming at in their lives. The drawing of life map 7 also served as a summary of the previous life maps.

9.8.2 CONTENTS OF THE GROUP SESSION

Group members were supplied with Worksheet G1 to draw their final life map. They drew optimistic pictures of the pieces of their lives coming together to form a total picture (see Annexure 11 for an example). The discussion that followed was a mixture of optimism and realism. They expressed their hopes for the future on the one hand, wishing their dreams and plans to become reality, but were still aware of obstacles and the realities of their lives. One group member expressed her opinion that others should consider PLWA as *normal* people, with the same needs, dreams, abilities and emotions as anybody else. She emphasized that realizing this could be the best support anyone can give a PLWA. Most of the group members supported her opinion and an intriguing discussion took place. Family life, sexual relationships and mortality were some of the main themes of the discussion.

This session was concluded by the completion of Worksheet G2. Group members were requested to write an imaginary inscription for their tombstones. This exercise may seem morbid for a group of people who live with a life threatening disease, but the aim was that they take an overview of their lives, expressing how they would like others to remember their lives. The concept of mortality needed to be addressed and it allowed group members to evaluate the meaningfulness of their lives. Some of the group members' "tombstone inscriptions" are included with their permission (Annexure 12-18). Annexure 12 is Boithetelo's worksheet, the group member who died in a shooting incident. This worksheet

is followed by a letter from her mother to the researcher, which serves as a memorial from her family (Annexure 13).

9.8.3 EVALUATION OF THE SESSION

This session was full of emotion and realism. Group members expressed their hopes for the future, but were also realistic about their lives and their HIV status. The fact that emphasis was not on HIV/AIDS alone, but on being human, was experienced positively. The life maps were summarized and group members were guided into the final stage of the group work series.

9.8.4 DATA COLLECTED FROM LIFE MAP 7

The central themes that could be identified from this map included:

- The outcome of HIV/AIDS could be death
- Family life was a valuable asset and need
- Safe sex should be practiced
- A message of hope in dealing with HIV/AIDS was important
- A positive attitude towards living with HIV/AIDS was essential

It was remarkable that group members took responsibility for their lives, admitted the influence of HIV/AIDS, but still expressed hope for the future.

9.9 SESSION 9: SUMMARY, CLOSURE AND EVALUATION

9.9.1 AIMS

The aims of this session were to summarize, evaluate and close the group series.

9.9.2 CONTENTS OF THE GROUP SESSION

This group session of almost six hours, consisted of evaluation by means of an evaluation questionnaire, painting a quilt to summarize the group series, having a meal together and closure with a candle lighting ceremony.

The group members completed the self-developed evaluation questionnaires and the results will be discussed in 9.9.4. Quilt making is a recognized technique in HIV/AIDS counselling and was presented in this programme as follows:

Group members were divided into two smaller groups and each group received a large piece of material, fabric paint and paintbrushes. They were requested to paint a collage of their experiences and impressions during the workshop. They were allowed to summarize the group series in a creative way and enjoyed it very much. The completed quilts were framed and one was presented to the Bloemfontein ATICC and the other one was kept by the researcher. A photo of this quilt is incorporated in this report.

PHOTO 1: QUILT PAINTED BY GROUP MEMBERS

These quilts reflected the group's awareness of the impact of HIV/AIDS on their lives, but it clearly included a message of hope.

After the quilt making, the researcher and group members had a special meal together. This was done to thank the group members for their contribution towards this study and to informally socialize as part of the closing of the group series. All the group members enjoyed the meal, but the one who told the group that his only support systems were his mother and dog, came to the researcher to tell that it was the first time in his life that he had eaten in a restaurant. He expressed his gratitude for the opportunity the group series had given him to feel part of a group and to feel accepted in society. He claimed that he felt that his life had been meaningful for the past few days.

After the meal, the group series were closed by a candle lighting ceremony (see photo 2). This ceremony was really a special event and made an intense impression on the researcher. It was almost sacred and it felt as if everyone in the room was connected in some way and respect was shown to every PLWA and those who had lost their lives through this disease. The candle lighting ceremony taught the researcher again how important it was to treat PLWA with dignity and respect.

PHOTO 2: THE CANDLE LIGHTING CEREMONY

This photo is used with the permission of the group members

After arrangements had been made for the follow-up session six weeks later, the group dispersed.

9.9.3 EVALUATION OF THE SESSION

The activities included in the final session involved creativity, fun, socialization and respect and can be evaluated as an important part of the group work programme. It gave group members the opportunity to summarize their experiences and to conclude the process in an appropriate way. Formal evaluation enabled the researcher to obtain valuable feedback.

9.9.4 GROUP MEMBERS' EVALUATION OF THE THSEPANG WORKSHOP

The group members completed the short self-developed evaluation questionnaire (Annexure 6) to evaluate the Thsepang Workshop (group work programme). The following is a summary of their evaluation.

9.9.4.1 Question: Did you learn anything from the programme?

All the group members answered YES to this question. Their motivations to this answer included the following:

- Decisions to make changes in life styles – **2**
- The opportunity to disclose their HIV status in a safe environment – **2**
- Acquiring hope – **3**
- The positive impact of being with other PLWA – **3**
- Enjoying the activities of the programme – **4**
- Gaining self-knowledge – **4**

9.9.4.2 Question: Which part of the programme (map) did you find the most interesting?

The following table represents group members' evaluation of each map, by indicating how many group members evaluated each map as the most interesting part of the programme.

TABLE 12: GROUP MEMBERS' EVALUATION OF THE DIFFERENT MAPS

MAP 1	MAP 2	MAP 3	MAP 4	MAP 5	MAP 6	MAP 7
1	2	1	3	1		1

It seemed as if map 4 was rated the most interesting part of the programme.

9.9.4.3 Question: Please tell if there was anything in the programme that you did not like and why?

- There was nothing that they did not like **(6)**
- Did not like certain co-group members **(2)**
- Found it difficult to disclose personal information **(1)**

9.9.4.4 Question: Do you think other persons living with HIV/AIDS can gain from the programme?

The *YES* response to this question was 100% and they supplied the following motivations for their answers:

- Other PLWA could learn important coping mechanisms – **2**
- The positive impact of support in the group situation – **3**
- Experienced empowerment towards positively living with HIV/AIDS – **4**

10. POST TESTING

Post testing and follow up were done six weeks after the group work programme was presented. The follow up was necessary and can be seen as the last phase of the group work process described in Table 8 of Chapter 6. Both the experimental and control groups completed another GCS. The experimental group completed a structured group interview schedule while control group members were interviewed telephonically.

10.1 THE STRUCTURED GROUP INTERVIEW SCHEDULE FOR THE EXPERIMENTAL GROUP

The following four questions were asked to the experimental group:

- What do you remember from the Thsepang Workshop?
- What did you learn?
- Was there any change in your life since the programme?
- Do you have any suggestions on improving the contents or format of the programme?

The following is a representation of the responses to each of the questions in the group members' own words.

10.1.1 QUESTION: WHAT DO YOU REMEMBER FROM THE THSEPANG WORKSHOP?

- *I learned to deal better with life in general*
- *I will never forget how map 4 taught me the real obstacles in my life*
- *I learned to value my family and realized how important relationships are*
- *The importance of self-disclosure cannot be emphasized enough*
- *I found some direction for my life*
- *I was motivated to positively live with HIV/AIDS, simply by being with other PLWA*
- *I learned that nothing can be done about HIV/AIDS: one will die*

10.1.2 QUESTION: WHAT DID YOU LEARN?

- *I learned how important it is to help others and to appreciate my family*
- *I learned that I am strong although my body is frail*
- *I learned that sharing problems makes one's own problems look smaller*
- *I realized how important God is in living – with or without HIV/AIDS*
- *I learned that expressing oneself is a good way of disclosure*
- *I learned a lot about drawing*
- *I learned that I might die*
- *I learned to take responsibility for my life*

10.1.3 QUESTION: WAS THERE ANY CHANGE IN YOUR LIFE SINCE THE THSEPANG WORKSHOP?

- *My boyfriend and I decided to get married after a long term relationship*
- *I obtained information on registration for the diploma in computer studies and plan to start soon*
- *I finally disclosed my HIV status to my mother. She accepted it and supports me very positively*
- *I can change nothing about my life*
- *It is difficult to change anything without money and good nutrition*
- *I finally forgave the man who gave me HIV. He got married to another woman and it was very difficult for me*
- *I feel more comfortable with myself and my HIV status*
- *The change in my life is bad because I moved into Hospice and experience racism among the residents which upsets me very much*

10.1.4 QUESTION: DO YOU HAVE ANY SUGGESTIONS ON THE CONTENTS OR FORMAT OF THE PROGRAMME?

- *It will be good to present the programme to other PLWA to teach them about discovering themselves and living with HIV/AIDS*
- *I wish the programme can continue for a long time*
- *I want the programme for everyone living with HIV/AIDS*
- *I loved the Thsepang Programme and thank you*
- *I would like the programme to help PLWA on how to disclose their status to their family and friends. It is difficult to do and I needed help on that*
- *The programme must give more information on the resources available for PLWA*
- *I would have liked to rather paint all the time than to make drawings*
- *I don't want to change anything*

The overall evaluation of the programme was positive and group members agreed that they gained something from the programme. They made some suggestions and recommendations that will be incorporated in the final chapter of this report. Two of the group members were

referred for individual follow-up at Bloemfontein ATICC to help them deal with unresolved personal matters.

10.2 TELEPHONIC INTERVIEWS FOR CONTROL GROUP MEMBERS

For practical reasons, the control group could not attend a formal group session. The GCS was mailed to them for post testing and it was followed up with a telephonic interview. This was quite expensive because most of the group members had cellular phones, but it was more cost and time effective than to gather them into a group situation. The telephonic interview was necessary for follow up and to deal with the ethical dilemma of excluding the control group from a programme with the potential to enrich their lives. The following aspects were included in the interview:

- Thanking them for participating in the research project
- Motivating them to complete the GCS
- Evaluating their personal situation and need for counselling

Only one of the control group members expressed a need for counselling. Appropriate information was supplied to her. Another respondent was already referred to Bloemfontein ATICC and received counselling and support.

10.3 POST TEST RESULTS

The following table summarizes the post test results of both groups.

TABLE 13: POST TEST SCORES

EXPERIMENTAL GROUP		CONTROL GROUP	
Respondent	**GCS Score**	**Respondent**	**GCS Score**
1	58%	1	49%
2	28%	2	19%
3	25%	3	69%
4	18%	4	54%
5	16%	5	23%
6	34%	6	44%
7	5%	7	34%
8	38%	8	48%
9	14%	9	26%
Average score of group	**25.7%**	**Average score of group**	**40.7%**

From this table the conclusion can be drawn that after the group work programme, the experimental group's general contentment measured almost within the recommended range, (below 25%) while the control group's general contentment score of more than 35% showed a need for improvement.

10.4 COMPARISON BETWEEN PRE AND POST TEST RESULTS

The following table is a representation of both groups' pre and post test general contentment scores.

TABLE 14 : COMPARISON BETWEEN PRE AND POST TEST RESULTS

EXPERIMENTAL GROUP			CONTROL GROUP		
Respondent	**Pre Test**	**Post Test**	**Respondent**	**Pre Test**	**Post Test**
1	59%	58%	1	49%	49%
2	62%	28%	2	16%	19%
3	48%	25%	3	70%	69%
4	26%	18%	4	58%	54%
5	16%	16%	5	20%	23%
6	42%	34%	6	44%	44%
7	8%	5%	7	30%	34%
8	48%	38%	8	43%	48%
9	23%	14%	9	25%	26%
Average score of group	**36.9%**	**26.2%**	**Average score of group**	**39.4%**	**40.7%**

When the pre and post test results are compared it is clear that the general contentment of experimental group members increased with 10.7% after the group work programme. The control group's general contentment score rose with 1.3%, indicating as core that needs attention.

11. SUMMARY

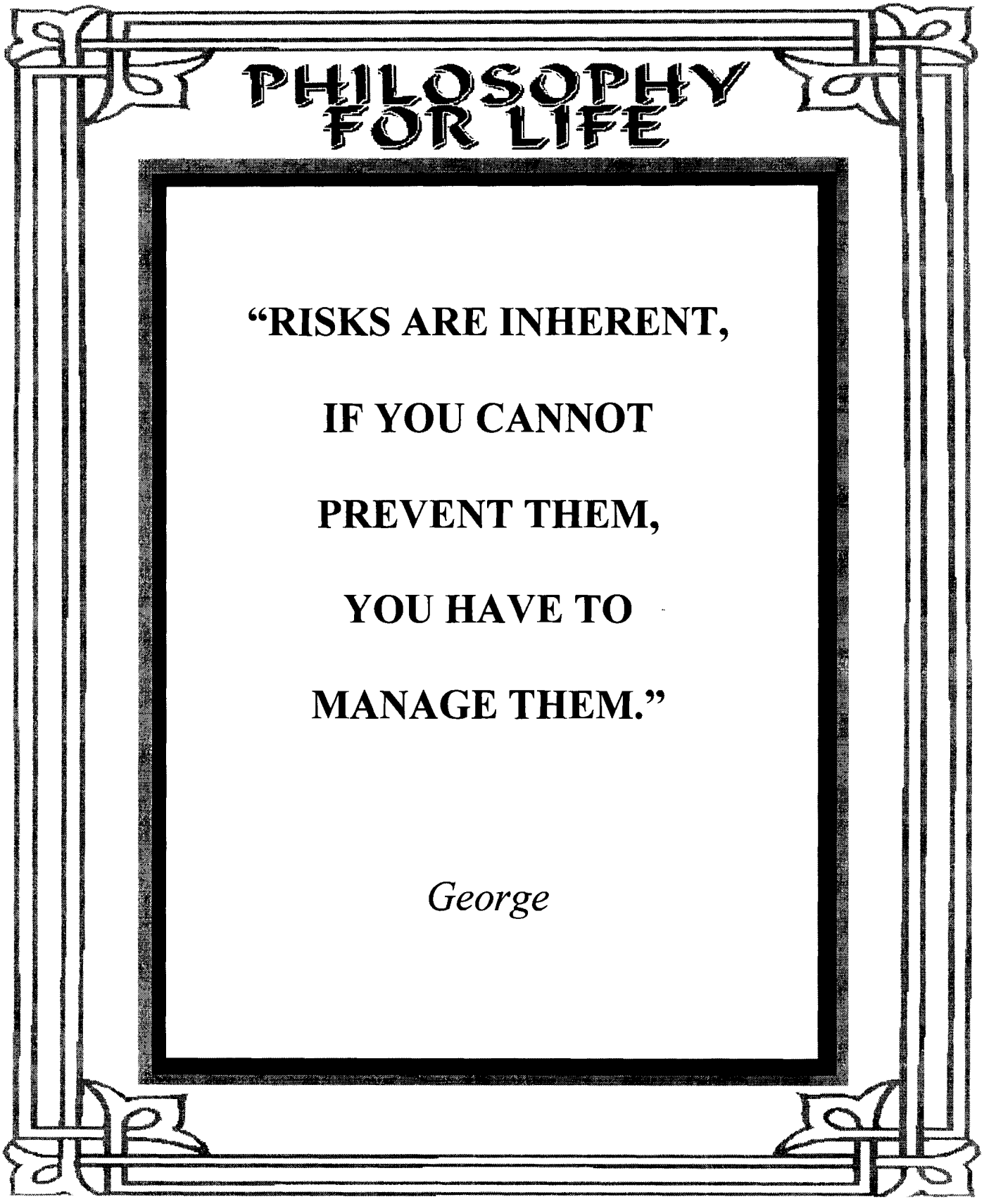
From the data collected, the group work programme can be evaluated as having been successful. It was determined that the general contentment of the experimental group members increased after application of the programme, while the general contentment of the control group, who were not exposed to the programme, stayed more or less the same. With reference to the experimental group, individual personal growth was observed and feedback from the group confirmed the observation.

The contents of the programme were evaluated as having been sufficient, but it was recommended that painting of life maps could be applied and more information on resources for PLWA should be supplied. Two of the life maps made a remarkable impression on the respondents: *Map 2 – Where have I come from?* and *Map 4 – What is stopping me?* The feedback reflected that these two maps were effective tools for personal growth and overcoming unfinished personal business. The *personal label exercise* (Worksheet A3) was too abstract and group members found it difficult to complete.

Group work as method in social work was evaluated as having been positive. The group situation provided respondents with the opportunity to be with other PLWA, making them feel part of a social system. The structured and supportive environment that was provided in the group enabled respondents to communicate their needs, problems and emotions freely. Being with other PLWA was valued important for resolving issues directly linked to living with HIV/AIDS.

Some respondents found it difficult to complete the GCS and needed assistance.

The following chapter consists of a summary of the research report with conclusions and recommendations about the research project.


PHILOSOPHY
FOR LIFE
"RISKS ARE INHERENT,
IF YOU CANNOT
PREVENT THEM,
YOU HAVE TO
MANAGE THEM."
George

CHAPTER 8

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

1. INTRODUCTION

This research project was executed in two phases. **Phase one** focused on needs assessment and was described in chapters 1-5. **Phase two** concentrated on the development and evaluation of a social group work programme and was incorporated in chapters 6-8. The following is an overview of the composition of the research report.

- **CHAPTER 1: INTRODUCTION, PROBLEM FORMULATION AND OBJECTIVE**
- **CHAPTER 2: RESEARCH METHODOLOGY**
- **CHAPTER 3: THE PSYCHOSOCIAL IMPLICATIONS OF HIV/AIDS ON YOUNG ADULTS**
- **CHAPTER 4: EMPIRICAL DATA COLLECTED FROM THE NEEDS ASSESSMENT**
- **CHAPTER 5: LIFE MAPS AS TECHNIQUE IN A SOCIAL GROUP WORK PROGRAMME**
- **CHAPTER 6: THE SUGGESTED GROUP WORK PROGRAMME**
- **CHAPTER 7: EVALUATION OF THE GROUP WORK PROGRAMME**
- **CHAPTER 8: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

In this final chapter, each chapter will be discussed separately in terms of a summary, conclusions and recommendations.

2. CHAPTER 1: INTRODUCTION, PROBLEM FORMULATION AND OBJECTIVES

2.1 SUMMARY

HIV/AIDS is probably the biggest international problem of the twenty first century. South Africa is one of the countries with the fastest growing incidence of HIV/AIDS in the world, with statistics reflecting a situation of more than 3 million people being infected. The infection rate seems to be the worst among sexually active teenagers, predicting a future where 1 out of every 4 adolescents will be infected within the next five years. Statistics show that the HIV prevalence rate in persons between 20 and 29 years is between 16.1% and 30.6%.

These statistics leave us with the reality of an epidemic with enormous implications for the labour market, economy, health budget and social infrastructure. The epidemic is destroying the most productive members of our society at a time where our country, as a growing entity, is struggling to create jobs and overcome poverty. The need for welfare programmes and providing support and care for PLWA, was rated one of the priorities of the National Youth Commission, and national and international strategies are continuously developed to deal with the crisis. Although various HIV/AIDS prevention programmes exist, there is an increasing need for support programmes for people who have already contracted the disease.

The assumption was made that the social functioning of young adults living with HIV/AIDS will be negatively influenced by the psychosocial implications of the disease. Social functioning includes activities on all the levels of an individual's existence and could influence general contentment with life. Group interaction is rated a positive influence on the social functioning of mankind.

This brought the researcher to the following question: *Can young adults experience contentment while living with a killer-disease like HIV/AIDS?* This question was the foundation of this research project.

Life maps have been used as technique by the researcher for more than ten years in social work practice. It was found to be an effective tool for assessment and to guide clients to self-knowledge and insight into their problems, but has never been properly described or researched. The researcher is at present working as medical social worker and the psychosocial impact of any disease has always been a field of interest. Taking into consideration the potential value of the group situation on individual's social functioning, the researcher found the research topic for this study to include three important aspects:

- Life maps as technique
- Social group work
- Young adults living with HIV/AIDS

After defining the research topic, the research aims and objectives could be formulated. The research project had two aims:

- To determine the needs of about 50 young persons living with HIV/AIDS and to measure their general contentment with life
- To develop a social group work programme for young adults living with HIV/AIDS where life maps are used as technique and to evaluate the programme by means of an experimental design

These aims lead to the central theoretical argument of the research project:

If young adults living with HIV/AIDS are involved in a social group work programme where life maps are used as technique, certain of their needs will be satisfied and their general contentment will be increased.

The pilot study consisted of a literature study, consultation with experts, a preliminary exploratory study and the intensive study of strategic units.

The research design included aspects of both exploratory research in phase 1 and explanatory research in phase 2 of the study. The intervention research model was applied in the empirical study with the survey and the experiment as procedures.

The universe consisted of persons living with HIV/AIDS, between the ages of 16 and 30 years and living in the Koppies and Bloemfontein geographical areas. In the first phase non-probability sampling was utilized, including a convenience sample to identify the first respondent, followed by snowball sampling to identify approximately 50 respondents. This was a difficult and time-consuming effort, leading to a sample that was not necessarily representative of the average young PLWA. In the second phase, target sampling was utilized to identify respondents for the experimental and control groups.

2.2 CONCLUSIONS

- The HIV/AIDS statistics in South Africa indicate a need for social work programmes with prevention as first priority, but also a need for support programmes for the millions of people who have to live with the disease
- Young adults are directly influenced by the HIV/AIDS epidemic, leaving our country to lose the most productive members of our society
- HIV/AIDS affects the total social functioning of young adults living with the disease
- Both aims of the study were met and will be described in the summary of the appropriate chapters
- The pilot study was the basis of the study, supplying the necessary theoretical background and research strategy
- The universe was not necessarily representative, but identifying PLWA was a difficult process due to the fact that HIV/AIDS is a sensitive issue and most persons living with HIV/AIDS are reluctant to disclose their HIV status

2.3 RECOMMENDATIONS

- More social growth and support programmes should be developed for PLWA
- Projects to motivate PLWA to disclose their HIV status should be encouraged. This could enable resources to more actively support PLWA

3. CHAPTER 2: RESEARCH METHODOLOGY

3.1 SUMMARY

This study consisted of intervention research and included a quantitative-qualitative-combined research perspective. The exploratory research design was utilized in the first phase, where new information was gathered on an existing social phenomenon, while the explanatory research design was applied in the second phase as an attempt to explain aspects of the psychosocial needs of young PLWA.

Data gathering procedures included the survey and the experimental design. The survey consisted of a needs-assessment questionnaire compiled by the researcher and a standardized measuring instrument, Hudson's GCS. The needs-assessment questionnaire consisted of closed and open-ended question. The latter supplied important qualitative data, but was more difficult to analyse. A high response rate was established by utilizing a structured interview for completion of the questionnaires. This method was, however, very time consuming. Some respondents found it difficult to complete the GCS without assistance.

Utilizing the experimental design increased the scientificalness of the research project and was a good way to measure causality between the treatment (the group work programme) and the expected outcome (general contentment of respondents). The classical experiment was used to determine whether the suggested group work programme had any influence on the general contentment of the respondents. This design had the limitation and ethical dilemma of excluding the control group from a programme which had the potential of enriching their lives.

The intervention research model was described in detail in this chapter, as it was the research model applied in this study. Intervention research has a specific intervention mission and the six phases of the intervention research process was the strategy for conducting this research project.

3.2 CONCLUSIONS

- The experimental design increased the scientificalness of the research project but created the ethical dilemma of excluding certain respondents from the group work programme
- The intervention research model was experienced as an effective structure to direct the research towards the development of an intervention programme (the suggested group work programme)

3.3 RECOMMENDATIONS

- It is suggested that more standardized measuring instruments for social work be developed
- The intervention research model will enable researchers to develop new, innovative programmes that can be utilized in social work practice and should be used more often to structure research projects

4. CHAPTER 3: THE PSYCHOSOCIAL IMPLICATIONS OF HIV/AIDS ON YOUNG ADULTS

4.1 SUMMARY

Although HIV/AIDS is primarily a health issue, it is even more a social disease, as people are involved, urging the social sciences to investigate behaviour patterns, beliefs and circumstances associated with the disease.

In this research project little attention was given to the medical aspects of the disease, as there is sufficient literature available on the topic. The focus was on identifying and discussing the psychosocial implications of HIV/AIDS on the young adult and his family. Psychosocial aspects included emotional needs, emotional reactions, behavioural patterns, impact on the family system and the impact on society in general.

Young adulthood, as a developmental stage, was discussed. Young adulthood was defined as the ages between 16 and 30 years and included three phases: the early adult transition; entering the adult world; and the age-30 transition. This developmental stage required the completion of certain developmental tasks and was divided into the following four categories:

- Tasks relating to the self
- Tasks relating to interpersonal relationships
- Tasks relating to work and leisure-time activities
- Tasks relating to the community

The developmental tasks introduced the developmental issues unique to young adulthood. These issues included identity formation, establishing interpersonal relationships, clarification of sex roles, education and entering the career path. Great emphasis was put on identity formation and the impact of HIV/AIDS on the identity of the young adult.

Statistics and predictions about HIV/AIDS were briefly discussed, followed by the four biopsychosocial stages associated with the medical course of AIDS. Each of these stages has unique stressors and psychosocial demands. The emotional reactions and needs of the PLWA were discussed, leading to the identification of the main themes for emotional support to PLWA. These themes included:

- Identity
- Life-view issues
- Depression
- Guilt
- Interpersonal relationships

Young adulthood, as developmental stage, was considered throughout the discussion, focusing on the implications of the disease and the impact it might have on the effective completion of the developmental tasks.

The chapter was concluded by focusing on HIV/AIDS counselling, giving attention to the models for HIV/AIDS care, the therapeutic goals of HIV/AIDS counselling, the importance of counselling and existing HIV/AIDS support programmes.

4.2 CONCLUSIONS

- Statistics confirm that young adults are one of the groups worst affected by HIV/AIDS
- Young adulthood, as developmental stage, has unique and important tasks and issues
- The developmental tasks and issues of the young adult are directly influenced by the psychosocial implications of HIV/AIDS
- Identity could be seen as the developmental issue worst affected by HIV/AIDS
- Counselling is a necessary and needed component of the treatment of HIV/AIDS

4.3 RECOMMENDATIONS

- Taking into consideration the psychosocial implications of HIV/AIDS, more therapeutic social work programmes should be developed to support persons living with the disease
- Young adults living with HIV/AIDS have first hand experience of the implications of HIV/AIDS and should be motivated to become involved in HIV/AIDS projects

5. CHAPTER 4: EMPIRICAL DATA COLLECTED FROM THE NEEDS ASSESSMENT

5.1 SUMMARY

This chapter consisted of the empirical findings of the needs assessment. The universe consisted of 45 persons between the ages of 16 and 30 years living with HIV/AIDS and representing both sexes. Most of the respondents were females in the age group 20-29 years. Information obtained from the needs assessment questionnaire was divided into the following

three categories: biographic information, psychosocial implications and future planning. The data will be summarized according to these categories,

- **Biographic information**
  - Only 11.1% of the respondents had full-blown AIDS
  - Their perception of the meaning of the HIV/AIDS diagnosis included information that it was a virus, which was life-threatening. A alarming 15.5% had no knowledge of the meaning of the diagnosis.
  - Most respondents did not experience any serious health problems, while 35.5% indicated that they suffered from recurring infections and illnesses
  - Most of the respondents (75%) had an education higher than Standard 8, of which 25% had tertiary qualifications
  - When describing their main daily activities, 36% indicated that they were unemployed
  - Many respondents (38.6%) had never been married, while 27.3% of the respondents were involved in a long term intimate relationship

- **Psychosocial implications of HIV/AIDS**
  - Most respondents (44.5%) indicated that HIV had an influence on their daily activities, but their responses reflected a positive attitude towards managing their health and personal lives, notwithstanding their HIV status
  - Respondents identified a need for more information on HIV/AIDS. They suffered poor health, had financial needs, lacked energy and had no sexual relationships as the direct results HIV/AIDS
  - The most outstanding feelings associated with their HIV status included uncertainty, fears, anxiety, guilt, loneliness, hopelessness and loss of independence
  - Many of the respondents (31.1%) confirmed that their primary family members were also infected by HIV/AIDS, mainly their sexual partners
  - Disclosing one's HIV status seemed to be a very sensitive matter, but 73.3% disclosed their status to their immediate family members, claiming that they disclosed it because they needed their support. They were more reluctant to disclose their status to friends, employers and headmasters, for fear of stigmatisation and isolation.

- **Future planning**
  - With reference to respondents' view of the future, it seemed as if they perceived the future ruled by their HIV/AIDS diagnosis and its implications
  - A positive attitude towards the future was expressed and respondents mentioned their attempts to face the challenges of HIV/AIDS and to live a meaningful life
  - Practising safe sex was emphasized with reference to their sexual needs
  - Respondents' dreams included obtaining further education and financial security
  - Their future planning consisted of managing their health and achieving personal goals
  - If they could change their lives, they would have tried to prevent the contraction of HIV/AIDS
  - The issue of having children had three main responses: never to have children; already had children; or hoping for a cure or medical procedure that would enable them to have healthy children
  - Recommendations for the prevention of HIV/AIDS included the use of condoms, practicing safe sex and staying true to one sexual partner
  - Most respondents' view of the future was coloured with the black picture of illness and death, while 20% expressed a positive attitude of adapting to the situation and trying to live positively with the disease.
  - Most respondents (51.1%) indicated that the people around them were supportive and caring, while 8.9% perceived the people around them as hostile and disapproving
  - Their biggest problems for the future included obtaining an education, finding a job, establishing financial security and resolving personal and family issues

The average score of the measuring of respondents' general contentment with life on the GCS was 42%. Respondents found it difficult to complete the GCS, claiming that they could not differentiate between some of the items on the scale.

5.2 CONCLUSIONS

- Six central themes could be identified from the needs assessment questionnaire:
  - **A search for meaning and a positive attitude towards managing the disease**
  - **Dealing with the implications of the disease by maintaining health and energy**
  - **Overcoming poverty and establishing financial security**
  - **A need for education**
  - **Overcoming social isolation and stigmatisation**
  - **A need for emotional, family and social support**

- The above mentioned themes needed to be considered in the planning of the group work programme
- The most outstanding needs were obtaining more information on HIV/AIDS, and a need for respect, understanding and support
- They expressed a need for more information, and called on organizations and national strategies to actively become involved in support programmes for PLWA and not only to focus on prevention programmes
- Ambivalence was identified between the respondents' fear and their anxiety resulting from their HIV status and their hopes and dreams for the future
- Many respondents had HIV infected family members
- Respondents' daily activities were influenced by their HIV status, but they also had to deal with general life issues like poverty, unemployment and obtaining an education
- Respondents' general contentment score on the GCS was above the recommended range, indicating a need for improvement and a lack of contentment with their lives

5.3 RECOMMENDATIONS

- Attempts should be made to employ PLWA in HIV/AIDS prevention and support programmes. A PLWA could make a contribution to such projects, because of his own experience, and the high incidence of unemployment among PLWA could be overcome
- The need for projects to promote training and education and overcoming poverty cannot be emphasized enough and should enjoy an even higher priority in our country

- More support programmes for PLWA should be developed and implemented

6. CHAPTER 5: LIFE MAPS AS A TECHNIQUE IN A SOCIAL GROUP WORK PROGRAMME

6.1 SUMMARY

This chapter consisted of life maps as technique utilized in group work as one of the methods in social work. These maps form the basis of the suggested group work programme. Life maps as technique is fairly unknown in social work practice, although the fundamental background is not unknown.

Social group work was described in terms of objectives, advantages and disadvantages, the types of groups, practical considerations when deciding to use social group work and the phases of the group work process. The application of group work in HIV/AIDS counselling was investigated and themes for group work with PLWA were suggested.

The historic background of life maps was found to be directly linked to the concept of contentment and aimed at prompting the individual to take an overview of his life from birth to death. Correlations between life maps and other techniques, including life stories, life scripts and magazine photo collages could be identified.

The life map technique consists of seven questions that can be presented in the form of drawings. The seven questions include:

- Who am I?
- Where have I come from?
- Where am I going?
- What is stopping me?
- What is my plan of action?
- What help do I need?
- What will it be like when I get there?

The theoretical foundation of life maps originated from life review therapy as an important part of existential social work. Existential social work was considered the basic theoretical framework of this study and included the following theories:

- The self-actualization theory of Abraham Maslow
- The existential theory of Victor Frankl (also known as logo therapy)
- The reality theory of William Glasser
- The gestalt theory of Fritz Perls

Aspects that could be addressed through the application of life maps as technique included identity formation, self-determination, personal responsibility, overcoming fears, obstacles and confusion, utilizing resources, emotional disclosure, gaining control, problem-solving and obtaining a vision for life.

6.2 CONCLUSIONS

- Social group work could be effectively applied in HIV/AIDS support programmes
- The seven questions asked by the life map technique include some of the basic existential questions described in theory
- Although life maps have certain limitations, they were presented as a useful technique in social sciences
- The application of life maps in a social group work programme for PLWA could assist them to deal with certain obstacles and concerns
- Life maps are a useful tool where identity issues need to be addressed and can be applied to overcome fears, dealing with loss, adapting to change and learning social skills

6.3 RECOMMENDATIONS

- Because life maps as a technique in social work is fairly unknown, further research on the application of the technique needs to be conducted

- The life map technique could be applied broader in social sciences, including career counselling and reconstructing the past (e.g. adoption and divorce)
- More HIV/AIDS programmes with an existential component should be developed to address the numerous existential questions arising from the HIV/AIDS crisis

7. CHAPTER 6: THE SUGGESTED GROUP WORK PROGRAMME

7.1 SUMMARY

This chapter involved putting the theoretical background that was described in this study into action by compiling a group work programme that could address certain of the identified needs of young adults living with HIV/AIDS. The suggested programme was called *Thsepang Workshop*, incorporating the Sotho word for hope/faith and the gestalt terminology for group work.

The programme consisted of a marathon group series of nine group sessions, involving the themes of the life maps. The group series was followed up with an evaluation session, six weeks later. This session also had the purpose of post testing.

A detailed discussion of the programme was incorporated in this chapter, linking the themes of each session to the group work process. The programme was presented in the format of a group work manual, including an introduction to the different maps, the aims and objectives of each session, the materials and equipment needed, a time schedule, instructions, discussion topics and applicable worksheets. One worksheet (Worksheet A3) proved to be too abstract and difficult to complete.

The first session was used for measuring (pre testing) and to orientate the group by introducing the programme, sharing expectations and building relationships.

Session two consisted of the completion of life map 1 and the appropriate worksheets, focusing on the question: *Who am I?* The aim of the session was to supply the individual with the opportunity to explore and express the self and to establish identity.

The third session dealt with the question: *Where have I come from?* The aim of the session was to determine every individual's background and past. Group members were guided to determine the influence of their past on their current situation and were allowed to express unresolved issues from the past.

In the fourth session, group members drew their third life map with the theme: W*here am I going?* The aim of this session was to help group members to find a vision and direction for their lives. They were allowed to formulate their vision, hopes and beliefs in the format of a philosophy for life.

The fifth session dealt with the obstacles group members experienced in their lives by completing life map 4: *What is stopping me?* The aim was to identify internal and external obstacles that limit the individual's personal and social growth. Group members were also taught problem-solving as a life skill.

Designing a personal plan of action was the theme of the sixth session, where life map 5 was completed. The question of this map was: *How will I get there?* The aim was to guide group members to put a plan into action to overcome their obstacles and start planning for the future. Additional information that was supplied included instructions on compiling a curriculum vitae, how to do personal budgeting and how to set achievable goals.

During the seventh session, group members were guided to identify the resources they needed by completing life map 6: *What help do I need?* They were taught the skill to write business/formal letters.

The eighth session consisted of the completion of the final life map with the theme: *What will it be like when I get there?* The aim of this session was to help the individual to get a clear image of his goals and objectives and was concluded with an imaginary tombstone inscription on how they would like others to remember their lives.

The ninth session was a summary of the group series and included formal evaluation and closure by means of painting a quilt, sharing a meal and a candle lighting ceremony.

The effectiveness of the programme was evaluated in chapter 7 and conclusions and recommendations will be made when this chapter is summarized.

7.2 CONCLUSIONS

- Utilizing the life map technique could be useful in social group work
- The programme was presented in a comprehensive, yet handy and practical format
- Worksheet A3 was not very useful
- Rituals like quilt making and candle lighting ceremonies are important in HIV/AIDS counselling
- The programme was developed to give attention to the identified needs of young adults living with HIV/AIDS, but also included components to deal with other life issues not related to HIV/AIDS (e.g. problem-solving, self-disclosure and identity formation)

7.3 RECOMMENDATIONS

- The group work programme could be incorporated in existing support programmes for PLWA
- Compiling a programme from a specific theoretical point of view, made the programme more scientific and structured
- Worksheet A3 could be excluded from the programme
- A comprehensive guide to resources for persons with HIV/AIDS should be included in the programme and should be accessible to PLWA in general
- The group work programme can be utilized in groups with social problems other than HIV/AIDS
- The life maps technique can be incorporated in quilt making as technique in HIV/AIDS counselling

8. CHAPTER 7: EVALUATION OF THE GROUP WORK PROGRAMME

8.1 SUMMARY

The focus of this chapter was to evaluate the Thsepang Workshop (group work programme) and to determine whether the application of life maps as technique in a social group work programme for young persons living with HIV/AIDS had any influence on their general contentment with life.

In this chapter the contents, results and evaluation of the group work programme were discussed and the effect of the programme on their general contentment with life was determined.

The most important question to be answered was whether the group work programme achieved its goals and objectives. This question was being answered by the application of the experimental design and by requesting control group members to do a formal evaluation of the programme by means of completing an evaluation questionnaire and a structured group interview, six weeks after completion of the programme. Measuring with the GCS was repeated and served as post testing. There was a 10% increase in the general contentment of the experimental group members, while the general contentment of the control group members stayed the same, confirming the valuable contribution the programme has made to the lives of nine young adults living with HIV/AIDS.

Information gathered from the life maps supplied valuable data on the needs, emotions, dreams and hopes of young adults living with HIV/AIDS. Although the central themes often included HIV/AIDS related issues, other issues in the lives of young adults were discussed and group members were guided to learn life skills and coping mechanisms.

Group members' evaluation of the programme was positive and they particularly identified the group situation as valuable. One of the group members mentioned that the intense and continuous emotional disclosure in the group was difficult to deal with, while two others

mentioned that they found it difficult to accept certain group members. The structured group interview, six weeks later, confirmed again that the group members learned from the group, utilized their newly acquired skills and overall felt more empowered to take responsibility for their lives.

8.2 CONCLUSIONS

- The programme was evaluated by both quantitative and qualitative measurements, to determine the effectiveness of the programme
- The general contentment of group members was increased by the group work programme
- The life map technique supplied group members with tools to self-discovery, identity formation, problem-solving, self-disclosure and resolving personal issues
- One group member experienced the openness and self-disclosure of the group negatively
- Conflicting relationships existed in the group, but can be seen against the background of normal human relationships
- Group members' overall evaluation of the group work programme was that it was a positive growth and learning opportunity

8.3 RECOMMENDATIONS

- The evaluation of this programme comprised mainly the qualitative data gathered from a small group and cannot be generalized
- The intense self-disclosure involved in this group work programme might be too revealing for some individuals

9. RECOMMENDATIONS FOR FURTHER RESEARCH

- The life map technique can be further researched for application to other social and psychological issues, including application in career counselling, the management of

change, reconstructing the past (e.g. adoption and divorce) and technique in counselling adolescents

- Research on the application of life maps in play therapy could be useful
- Research can be done to determine the value of each individual life map
- Life map themes could be investigated for use in the quilt making technique applied in HIV/AIDS counselling
- Research on life maps as possible measuring instrument can contribute to the need for assessment tools and measuring instruments in social work
- Research can be conducted to determine the actual need for support programmes for PLWA
- Existing support programmes for PLWA can be evaluated
- Research on the existential impact of HIV/AIDS on the individual and society can be undertaken
- Research to develop HIV/AIDS programmes with an existential nature could be a valuable contribution

10. FINAL CONCLUSION

The most important recommendations resulting from this study include the following:

- There is a need for support programmes for PLWA
- Emotional disclosure and disclosure of one's HIV status are important aspects of HIV/AIDS counselling
- The intervention research model is a practical and useful structure for social work research, supplying new and innovative programmes
- Involving young PLWA in HIV/AIDS projects could make a contribution to the lives of many PLWA
- The seven questions incorporated in the life map technique include important existential questions
- The life maps technique could be applied broader in the social sciences
- Further research on life maps as technique should be conducted

This research project brought statistics and predictions to the people behind the statistics, discovering their needs, emotions, dreams, fears and hopes. Although the national and international HIV/AIDS picture is dark with realities of death and economic consequences, there are people living with this disease, trying to adapt, trying to find meaning and struggling to survive.

The following *political cartoon* was drawn for a newspaper by artist Louw Henning[2]. It is incorporated in this report to emphasize that HIV/AIDS programmes should not focus only on the distribution of condoms and red ribbons. Although prevention programmes are important, millions of people have already contracted the disease and are in need of support programmes to help them deal with the psychosocial implications of the disease. Those who are HIV positive have to face the possibility of death, but in the meanwhile need assistance with the living part of the disease. A new support programme was developed during the course of this study, but the need for new programmes cannot be emphasized enough.

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[2] This picture was translated from Afrikaans and is used with the permission of the artist.

PICTURE 1: POLITICAL CARTOON – DEALING WITH THE HIV/AIDS CRISIS

PHILOSOPHY FOR LIFE

I BELIEVE LIFE IS A GAME – PLAY IT,
BUT BE CAREFUL AND WISE:
IF YOU DON'T PLAY IT RIGHT –
IT COULD TURN YOUR LIFE
AND YOU WILL REGRET IT
FOR THE REST OF YOUR LIFE.

BELIEVE IN YOURSELF
SO THAT OTHERS
CAN BELIEVE IN YOU.

LIFE IS PRECIOUS – DO NOT DESTROY IT,
CARE FOR IT.
LIFE IS A STRUGGLE:
ACCEPT IT AND NEVER GIVE UP.
HAVE POSITIVE THOUGHTS,
BECAUSE YOUR THOUGHTS BECOME YOUR WORDS.

BELIEVE IN GOD,
BECAUSE HE IS ALWAYS THERE
FOR YOU.

MK. Molahloe

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JANUARY 2000

RESEARCH PROJECT

NEEDS ASSESSMENT OF YOUNG ADULTS WITH HIV/AIDS

This letter is addressed to anybody between the ages 16 & 30, who is HIV+ or has AIDS.

I am a Ph.D-student at the University of Potchefstroom and intend to develop a support programme for young adults living with HIV/AIDS. I can, however, do no research without respondents! That is people like you and you and you: a young adult with HIV/AIDS.

Attached are two questionnaires:

- A needs assessment questionnaire, which is divided into the following sections:
  - Biographic information
  - The psycho-social implications of HIV/AIDS
  - Future planning
- The Hudson scale of general contentment.

The questionnaire is completed anonymously. If, at the end of the questionnaire you give an indication that you want to participate further in this research project, I will need to take down certain information on you. Please be ensured that this information will be treated confidentially.

Please answer all questions as honest as possible by following the instructions of each question. If you experience difficulty to understand a question or are uncertain what to do, please ask for help or the assistance of an interpreter.

Thank you very much for your co-operation.

ALIDA HERBST
SOCIAL WORKER

Annexure 1

RESPONDENT NUMBER: | | | |

1. BIOGRAPHIC INFORMATION

FOR OFFICE USE
1.1
1.2
1.3
1.4
1.5

13 – 15 yrs	
16 – 18 yrs	
19 – 25 yrs	
26 – 30 yrs	

1.1 AGE:

Male	
Female	

1.2 SEX:

HIV+	
AIDS	

1.3 WHAT IS YOUR CURRENT DIAGNOSIS?

1.4 DO YOU KNOW THE MEANING OF THIS DIAGNOSIS?

Yes	
No	

1.5 PLEASE EXPLAIN YOUR ANSWER BRIEFLY.

_____

1.6 **IF YOUR ARE HIV+ ONLY**, PLEASE COMPLETE THIS QUESTION.

HOW LONG AGO HAVE YOU BEEN DIAGNOSED AS HIV+?

The past 6 months	
A year ago	
More than 2 years ago	

1.6

1.7 COMPLETE THIS QUESTION **ONLY IF YOU ALREADY HAVE AIDS.**

HOW LONG AGO HAVE YOU BEEN DIAGNOSED WITH AIDS?

The past 6 months	
A year ago	
The past 2 years	
More than 5 years ago	

1.7

1.8 HOW WILL YOU DESCRIBE YOUR HEALTH AT THE MOMENT?

(Please mark the most appropriate)

No serious problems	
Recurring infections and illnesses	
Very tired and ill	
Almost always ill and in bed	

1.8

1.9 WHAT IS YOUR HIGHEST EDUCATIONAL QUALIFICATION? 1.9

Tertiary education	
Standard 10	
Standard 8	
Standard 6	
Lower than Standard 6	

1.10 IF YOU HAD ANY TERTIARY EDUCATION, PLEASE SUPPLY FULL INFORMATION 1.10

_____

_____

_____

1.11 WHAT IS YOUR MAIN DAILY ACTIVITY? 1.11

Scholar / student	
Fulltime work for a salary	
Unemployed	

1.12 WHAT IS YOUR MARITAL STATUS? 1.12

Married	
Divorced	
Never been married	
Long-term intimate relationship	
Several short-term relationships	

2. PSYCHO-SOCIAL IMPLICATIONS OF HIV/AIDS

2.1 DOES HIV/AIDS HAVE AN INFLUENCE ON YOUR NORMAL DAILY ACTIVITIES?

Yes	
No	

2.1

2.2 PLEASE MOTIVATE YOUR ANSWER:

_____

_____

_____

2.2

2.3 WHAT DO YOU EXPERIENCE AS A DIRECT RESULT OF HIV/AIDS? (Please mark "Yes" or "No" at every response)

	Yes	No
Insufficient information on HIV/AIDS		
Lack of energy		
Poor general health		
Unable to obtain a job/attend school		
Unable to keep a job		
Little or no friends		
No sexual relationships		
Financial need		
Rejection by the community		
Isolation from the broader community		

2.3

2.4 PLEASE DESCRIBE THE MOST OUTSTANDING FEELING THAT YOU ENCOUNTER REGARDING HIV/AIDS?

_____

_____

2.4

2.5

2.5 WHICH OF THE FOLLOWING FEELINGS DO YOU HAVE REGARDING YOUR HIV/AIDS DIAGNOSIS?

(Please mark "Yes" or "No" at every response)

	Yes	No
A feeling of shock and disbelief		
Anger		
Feelings of guilt		
Anxiety and other fears		
A feeling of extreme sadness		
A wish to die		
Loneliness		
Helpless		
Hopeless		
A fear to be rejected		
A fear to be isolated (left alone)		
A fear for the stigma of HIV/AIDS		
Loss of control over your life		
Loss of independence		
A fear for pain		
A fear to die		
Uncertainty		

2.6 ARE ANY OF YOUR IMMEDIATE FAMILY MEMBERS ALSO HIV+ OR DIAGNOSED WITH AIDS?

Yes	
No	

2.5	

2.6

2.7 IF "YES", PLEASE SUPPLY INFORMATION REGARDING HOW MANY AND WHICH FAMILY MEMBERS? 2.7

_____

_____

_____

_____

2.8 DO YOUR PRIMARY FAMILY MEMBERS (PARENTS/BROTHERS/ SISTERS) KNOW THAT YOU ARE HIV+/HAVE AIDS? 2.8

Yes	
No	

2.9 PLEASE MOTIVATE YOUR ANSWER IN 2.8. 2.9

_____

_____

_____

2.10 DO YOUR FRIENDS KNOW THAT YOU ARE HIV+ / HAVE AIDS? 2.10

Yes	
No	

2.11 PLEASE MOTIVATE YOUR ANSWER IN 2.10. 2.11

_____

_____

_____

2.12 DOES YOUR EMPLOYER / HEADMASTER KNOW THAT YOU ARE HIV+ / HAVE AIDS? 2.12

Yes	
No	

2.13 PLEASE MOTIVATE YOUR ANSWER IN 2.12. 2.13

_____

_____

_____

2.14 DO YOU THINK IT IS UNNECESSARY THAT OTHERS KNOW ABOUT YOUR DIAGNOSIS? 2.14

Yes	
No	

2.15 PLEASE MOTIVATE YOUR ANSWER IN 2.14. 2.15

_____

_____

_____

3. FUTURE PLANNING:

The following questions focus on your personal views of the future. There are no right or wrong answers. Please try to answer them as honestly as possible by completing the sentences with the first thought crossing your mind.

3.1 THE FUTURE OF HIV+ / AIDS MEMBERS OF THE SOCIETY IS

_____

_____

_____

3.2 THE ONLY WORK THAT YOUNGSTERS WITH HIV+/AIDS CAN DO

_____

_____

_____

3.3 THE SEXUAL NEEDS OF YOUNGSTERS WITH HIV+/AIDS

_____

_____

_____

3.4 MY DREAM FOR THE FUTURE IS

_____

_____

_____

3.5 I PLAN TO

_____

_____

_____

3.6 IF I COULD, I SHOULD

3.7 IF I COULD HAVE CHILDREN ONE DAY

3.8 I DO NOT CARE

3.9 HIV+/AIDS CAN BE PREVENTED

3.10 I THINK I AM GOING TO

3.11 THE PEOPLE AROUND ME

3.12 THE BIGGEST PROBLEM IS

3.13 IF ONLY I

3.14 IF ONLY OTHERS COULD

3.15 I AM

1. HUDSON INDEX 1 : GENERAL CONTENTMENT SCALE

Please complete the attached scale by following the instructions as mentioned at the beginning of the page.

2. GENERAL:

2.1 WOULD YOU LIKE TO PARTICIPATE ANY FURTHER IN THIS RESEARCH?

YES	
NO	

2.2 RESEARCHER'S COMMENTS

Annexure 2

GENERALIZED CONTENTMENT SCALE (GCS)

Naam / Name: ..... Datum / Date: .....

This questionnaire is designed to measure the way you feel about your life and surroundings. It is not a test, so there are no right or wrong answers. Answer each item as carefully and as accurately as you can by using the following scale:

Hierdie vraelys is ontwerp om jou gevoel oor jou lewe en omstandighede te meet. Dit is nie 'n toets nie, dus is daar nie regte of verkeerde antwoorde nie. Beantwoord asseblief elke item so noukeurig en akkuraat moontlik deur die bostaande skaal te gebruik:

I feel powerless to do anything about my life.	1.____	Ek voel magteloos om iets aan my omstandighede te doen.
I feel blue.	2.____	Ek voel bedruk.
I think about ending my life.	3.____	Ek dink daaraan om 'n einde aan my lewe te maak.
I have crying spells.	4.____	Ek kry huilbuie.
It is easy for me to enjoy myself.	5.____	Dit is vir my maklik om myself te geniet.
I have a hard time getting started on things that I need to do.	6.____	Dit is vir my moeilik om 'n begin te maak met die dinge wat ek moet doen.
I get very depressed.	7.____	Ek raak baie depressief.
I feel there is always someone I can depend on when things get tough.	8.____	Ek voel daar is altyd iemand op wie ek kan staatmaak.
I feel that the future looks bright for me.	9.____	Ek voel my toekoms lyk rooskleurig.
I feel downhearted.	10.____	Ek voel terneergedruk.
I feel that I am needed.	11.____	Ek voel ander het my nodig.
I feel that I am appreciated by others.	12.____	Ek voel ander waardeer my.
I enjoy being active and busy.	13.____	Ek geniet dit om aktief en besig te wees.
I feel that others would be better off without me.	14.____	Ek voel andere sal beter af wees sonder my.
I enjoy being with other people.	15.____	Ek geniet dit om by andere te wees.
I feel that it is easy for me to make decisions.	16.____	Ek voel dis vir my maklik om besluite te neem.
I feel downtrodden.	17.____	Ek voel vertrap.
I feel terribly lonely.	18.____	Ek voel vreeslik eensaam.
I get upset easily.	19.____	Ek voel maklik ontsteld.
I feel that nobody really cares about me.	20.____	Ek voel niemand gee meer om vir my nie.
I have a full life.	21.____	Ek het 'n vol lewe.
I feel that people really care about me.	22.____	Ek voel ander gee om vir my.
I have a great deal of fun.	23.____	Ek het baie pret.
I feel great in the morning.	24.____	Ek voel soggens wonderlik.
I feel that my situation is hopeless.	25.____	Ek voel my situasie is hopeloos.

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5, 8, 9, 11, 12, 13, 15, 16, 21, 22, 23, 24

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Annexure 3

THE DILEMMA OF LIVING WITH HIV/AIDS

A personal view of the needs and experiences of a PLWA were shared by a disclosed PLWA during a public training session of HIV/AIDS counselors.

1. INTRODUCTION

I would like to thank the organizers for the opportunity to talk to you today, and to everybody present for listening to what I have to say. I am going to talk to you about the dilemma of living with HIV/AIDS. Firstly I would like to read the following words spoken by Paddy Nhlapo:

"I waited log to disclose as I didn't have any information about HIV and I didn't receive any counseling. I was just diagnosed and told to go. I went to the clinic for a STD and my blood was taken so they could find out what I had. When I went back the nurse just said ... It's bad news, you have HIV. And that was it ... no counseling. I went for the results of a STD and it was a shock. I didn't tell anyone, I just kept quiet. During those four years, I was collecting lots of information. I didn't miss anything and was reading a lot. I started becoming more confident. I confided in a friend of mine. She was the first person to know. That was two and a half years after I was diagnosed. We kept quiet about it, both of us. After people started to come out and tell others publicly, I talked to quite a few people that came out. I started undergoing counseling, then I decided – I'm coming out to."

2. CONTENT

This was the story of another person living with HIV. I would like to tell you about myself. I was a regular blood donor since I was 16 years old. Five months ago, at the age of 22 I received a letter from the blood bank requesting me to visit a doctor for some blood tests. As I am self-employed, I do not have a medical aid and I went to National Hospital with the letter.

At National Hospital I was seen by Sr Rautenbach. She gave me some information about HIV and I had to sign a consent form for HIV testing. I left the hospital feeling scared and uncertain. What if I really had AIDS? I never told anybody about the HIV tests and kept all

my feelings for myself. A week after Sr Rautenbach drew my blood, I returned to the hospital for my test results. I asked my mother to accompany me because I was scared.

My mother never knew what tests I went for. When Sr Rautenbach called me to give me my results, she asked me if I would like to receive my results alone – or would I like my mother to accompany me? I asked my mother to go with me. Sr Rautenbach gave me my test results immediately. It was a tremendous shock to me to hear that I am HIV positive. My mother asked me to keep quiet about the fact that I am HIV positive. At that stage, I was referred to a lady at National Hospital for counseling. At the moment I am receiving counseling at Bloemfontein ATICC.

Since I heard I am HIV positive, I have been struggling with depression. Depression play's a big role in the lives of HIV positive people. HIV positive people think a lot about committing suicide. I get so depressed that it feels as if I can run away – but I cannot run away from a virus that is living inside of my body. Depression hangs over my head like a big sword. Sometimes I think that if I make an end to my life, I will also end all the emotional and physical pain. Maybe then I will not be bound to a bed due to illness one day. Sometimes the depression hunts me for days. The dilemma is that I am not allowed to give in to the depression – because then I allow HIV to win.

Another feeling I had when I heard I was HIV positive was that I was very angry with myself for allowing this to happen to me. I knew HIV is transmitted through blood contact and sex, and I still allowed it to happen to me. Besides feeling angry with myself, I am also angry with my so-called friends that left me when they heard I was HIV positive. Even my mother made me angry when she told people I was HIV positive without my consent – and that after she told me to keep quiet about it! I seem to get angry very quickly these days.

I am also scared of rejection. I have suffered enough rejection in my life to last me a lifetime. Rejection hurts, and I don't want to be rejected anymore. That makes me scared to love and trust people. What would happen to me if I get rejected by the people around me? Friends and family seem to disappear when you are HIV positive. Only real friends stay.

The fear of rejection causes me to be very lonely. My old friends left, and I struggle to make new friends because I fiend it hard to trust people. As my immune system is not so strong as it used to be, I cannot socialize as I used to. I cannot do what I did before. I cannot "party" the whole night through anymore as I get very tired and it I am tired I get ill

very easily. I cannot live out my life goals. As I love children, I wanted to have a lot of my own children before, but now I will not be able to fulfill that dream. I would never forgive myself it my child is born with HIV and I am not prepared to take that risk.

Not being able to live out my life goals fills me with sadness. I am sad that my friends left. I do not know may young people that are in the same circumstances as I am. Other young people do not really understand what I am going through. I am sad that I became HIV positive at such a young age. I am sad that I cannot practice all my hobbies as I did before. I cannot take part in motor racing anymore, as I cannot risk being injured. Injuries can get infected easier that before and can cause my death. I am sad that it takes my body such a long time to recover from illness. Two years ago it would have taken me a day to get back on my feet if I get bronchitis. Now it takes me a week.

Although there are a lot of negative things that come out of my being diagnosed as HIV positive there are also a few positive things that I can mention. After my HIV positive diagnosis I become a lot closer to God, and that is the most important positive thing that happened. My spiritual life is important to me now. I try to put my life entirely into the hands of God – and sometimes it is even difficult to trust God.

After my HIV diagnosis I had the opportunity to learn more about HIV and AIDS. At first HIV and AIDS was the same to me. Now I know there is a difference and that I am HIV positive – I do not have AIDS. My diagnosis also gave me the opportunity to get to know real and better friends.

3. CONCLUSION

There is definitely a dilemma in living with HIV every day. I need to have a positive attitude towards life in order for me to stay healthy. I know that, but still I cannot ignore all the negative feelings that I have. At least I have a God that carries me through difficult times, and I have friends that I know will stand by me through whatever will come on my way.

Pierre Trollip

THE DILEMMA OF LIVING WITH HIV/AIDS

Speaker: Pierre Trollip

SUMMARY

Living with HIV/AIDS causes a few dilemmas in life. After hearing you are HIV positive you experience a lot of different negative emotions. The dilemma is that you cannot give in to these emotions because then your immune system becomes weak and you get ill. You need to force yourself to live with a positive attitude. As HIVE diagnosis changes your life dramatically. These are however positive things that come from an HIV diagnoses as well.

DECLARATION OF PARTICIPATION

I, ... declare that I voluntarily joined the Thsepang Programme and I want to participate in it by being honest and by sharing my experiences with co-group members.

I understand that this programme is part of a research project and that my personal information will be published anonymously for research purposes only.

I know that all information will be treated confidentially and I will also treat the information of others in the group with sensitivity and confidentiality.

I agree to attend the whole programme and will complete another questionnaire six weeks after completion of this programme.

Signed at ..... on this ..... day of 2001.

Signature: .....

Annexure 5

EXPECTATIONS

Why did you decide to join the Thsapang programme?

_____

_____

_____

_____

What do you want to gain from this programme?

_____

_____

_____

_____

Any other expectations, comments or questions?

_____

_____

_____

_____

THANK YOU FOR JOINING THIS PROGRAMME. I HOPE THAT IT WILL ENCOURAGE YOU IN YOUR STRIVE TO LIVE WITH HIV/AIDS.

"The natural force within each one of us, is the greatest healer of disease."

- *Hippocrates*

SUMMARY, CONCLUSION AND EVALUATION

At he end of this programme your HIV/AIDS status did not change, but hopefully your attitude and feelings towards life in general, have changed.

Please complete the following to help me evaluate the programme:

1. Did you learn anything from this programme? YES / NO Please motivate your answer

   _____

   _____

2. Which part of the programme did you find most interesting? Map 1 2 3 4 5 6 7

3. Please tell if there was anything in the programme you did not like and why?

   _____

   _____

4. Do you think other persons living HIV/AIDS can gain from this programme? Please motivate your answer.

   _____

   _____

THANK YOU for your co-operation and contribution to the Thsepang Programme and my research. I hope that in some way, how big or small it may be, the programme have helped you discovering your own potential and directed you in new ways to enjoy life's journey.

Remember the words of an unknown author:
"The greatest enemy is not disease, but despair."

CELEBRATE LIFE! THSEPANG! PLUK DIE DAG!

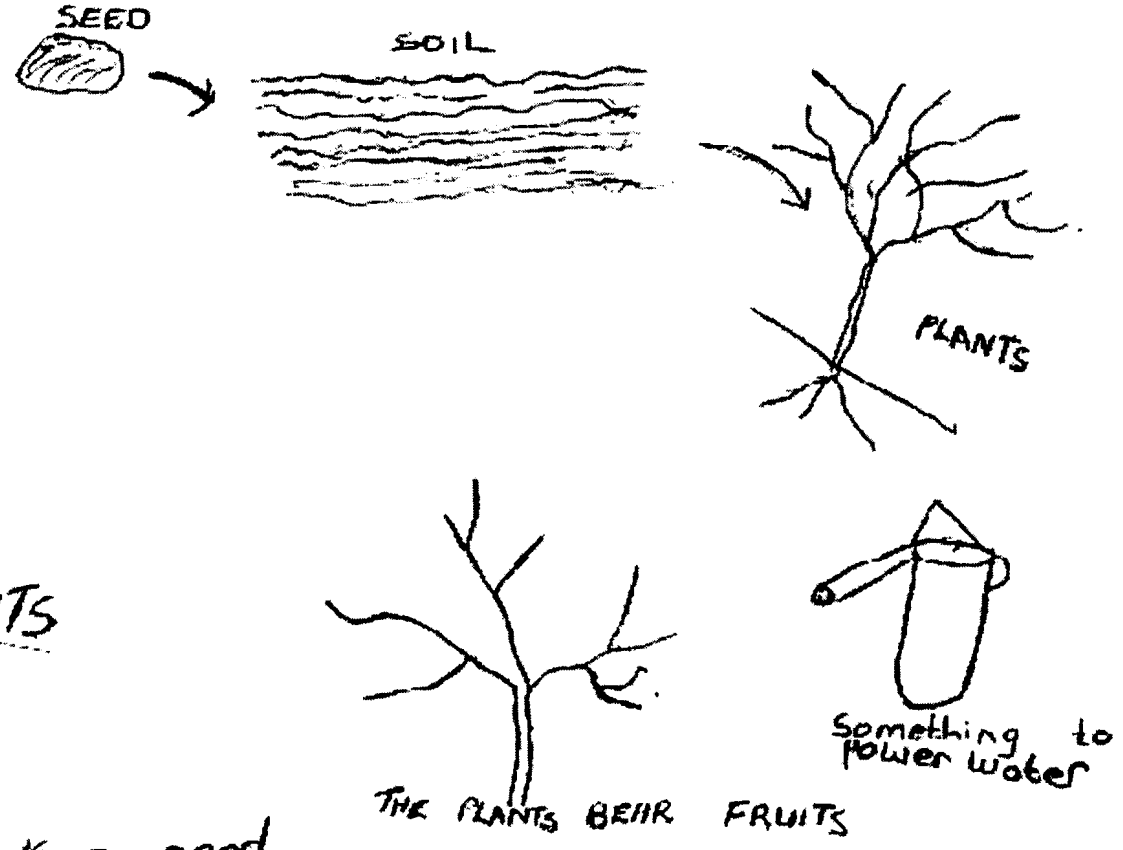
Regards

ALIDA HERBST

Annexure 7

MAP 1: WHO AM I ?

This session deals with how you see yourself with your strengths and weaknesses, likes and dislikes; needs dreams and expectations



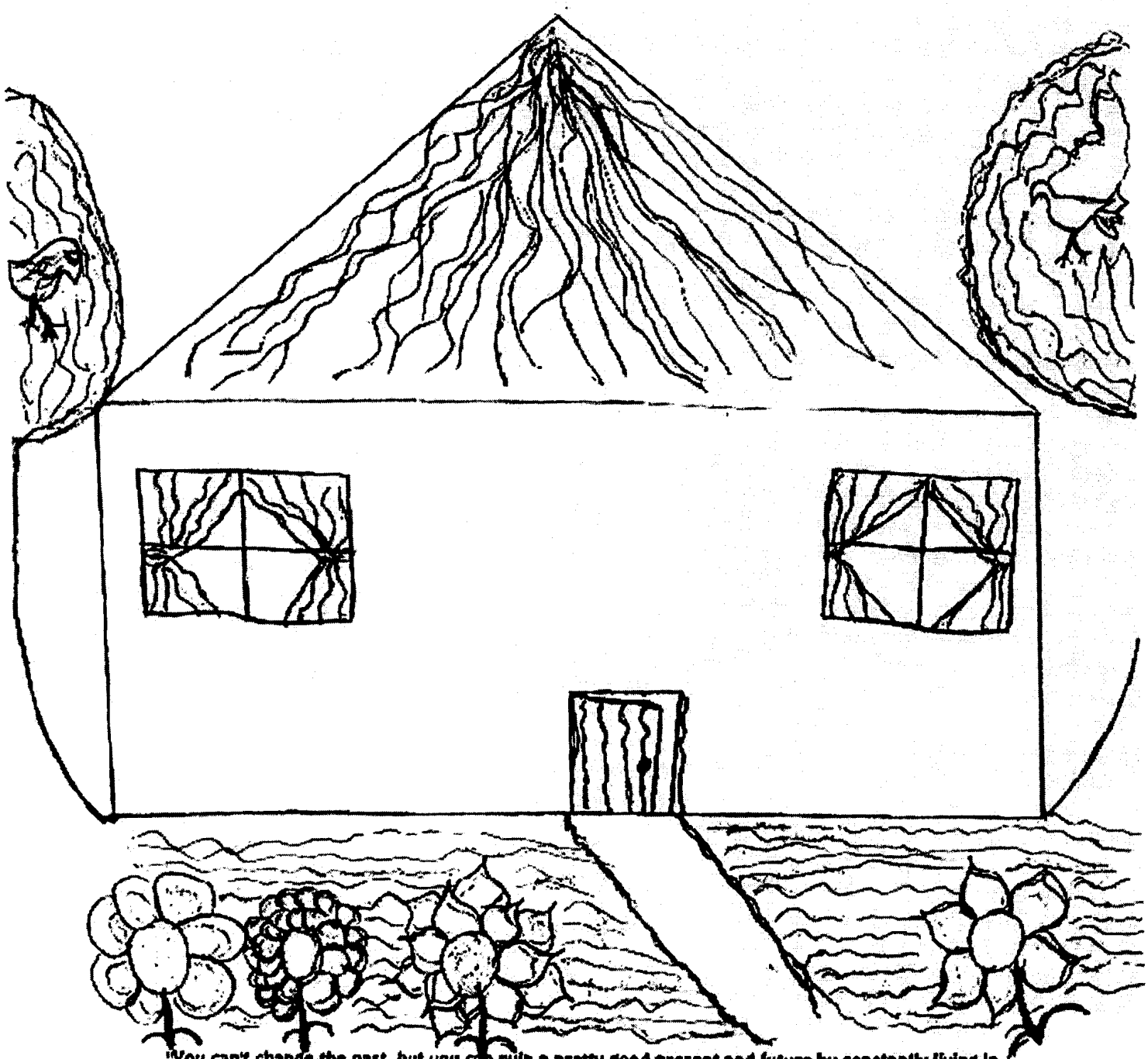
It is a good
I want to be I good person, educated, have love for me
and for others, so that when when people hello me I
can get use of that that help so that I can
help my self by doing what I suppose of by do that
it will be easy for me to get what I want in my life eg
a good life, money so that I can handle my life
this means that I will rip good fruits at I good
time

"There is inside you all of the potential to be whatever you want to be. There is a hero inside of you!" - Anon.

Annexure 8

MAP 2: WHERE HAVE I COME FROM?

This map deals with your past One needs to know your background and roots in order to understand yourself better Maybe you can discover links between your past and how it influenced your present and may affect your future



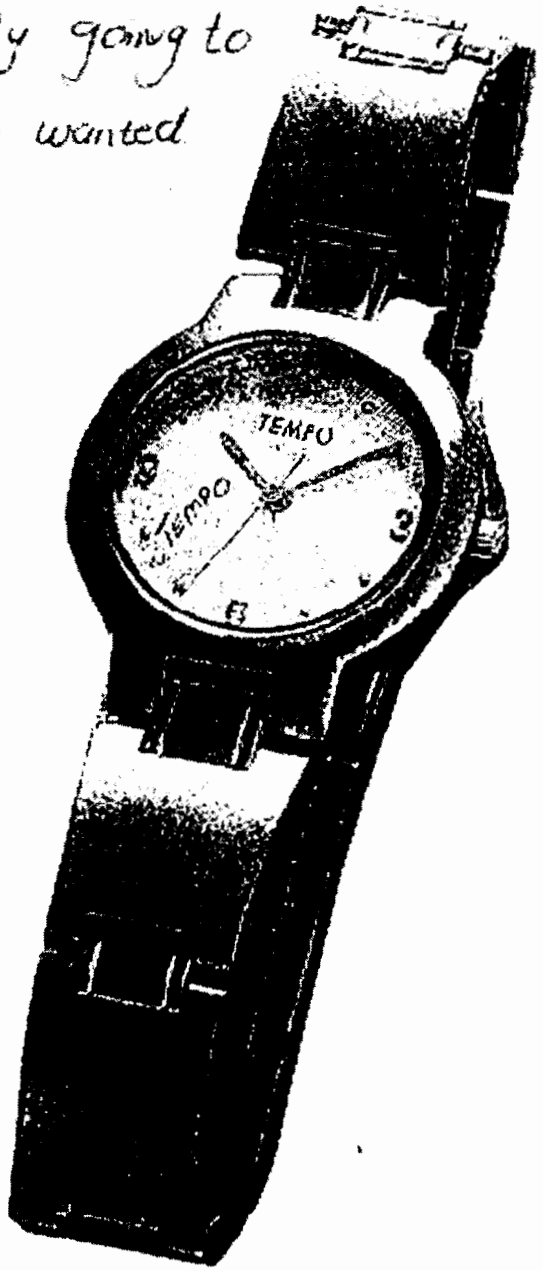
"You can't change the past, but you can ruin a pretty good present and future by constantly living in the past" - Barbara Johnson.

Annexure 9

MAP 4: WHAT IS STOPPING ME?

We all have to overcome certain obstacles in our lives. Some obstacles are caused by others or significant events and circumstances, while other obstacles are in ourselves. Try to draw these obstacles.

I need Only time (power) to make all the things To make my dreams & need true Only time will allows me Yesterday I said I think too much with a limited ... at time Definetely going to fulfil my dreams Energy is wanted



"It's not what happens to you, it's what you do about it!" - W. Mitchell

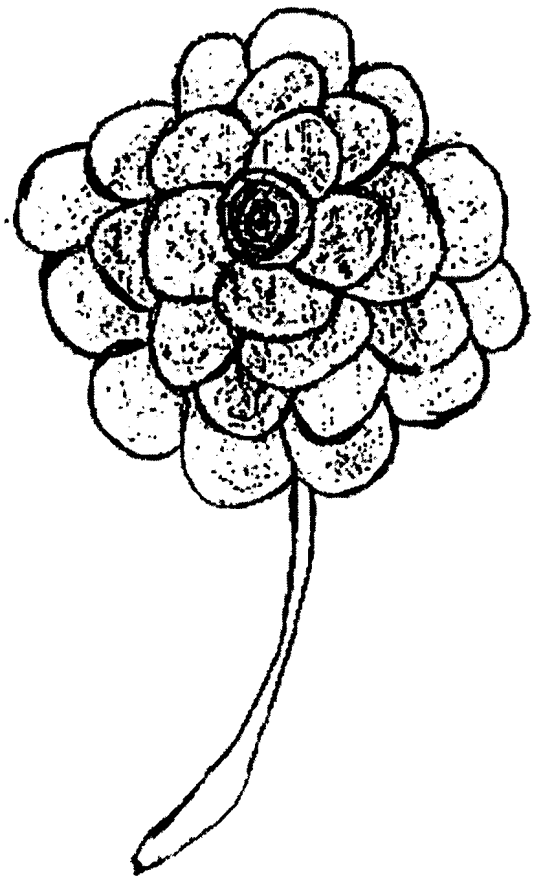
Annexure 10

MAP 6: WHAT HELP DO I NEED?

This map allows you to identify the necessary resources to put your goals into action. Draw the resources you need. (Resources include personal resources, people, facilities and material.)

I need my Mother
my brother
Uncle

I went to go to school
I went to buy book and money
to puy School

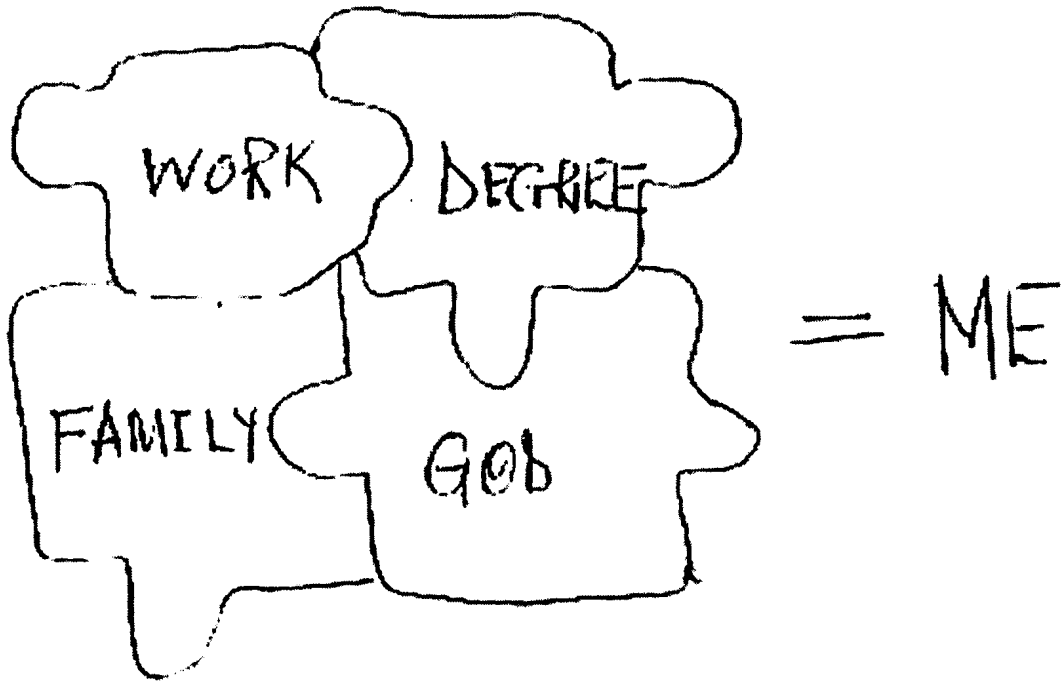


"Courage is a word without boundaries" - Kobus Neethling

Annexure 11

MAP 7: HOW WILL IT BE WHEN I GET THERE?

Think about your life when everything you have mapped in this programme come together and end in achieving your ultimate goal in life



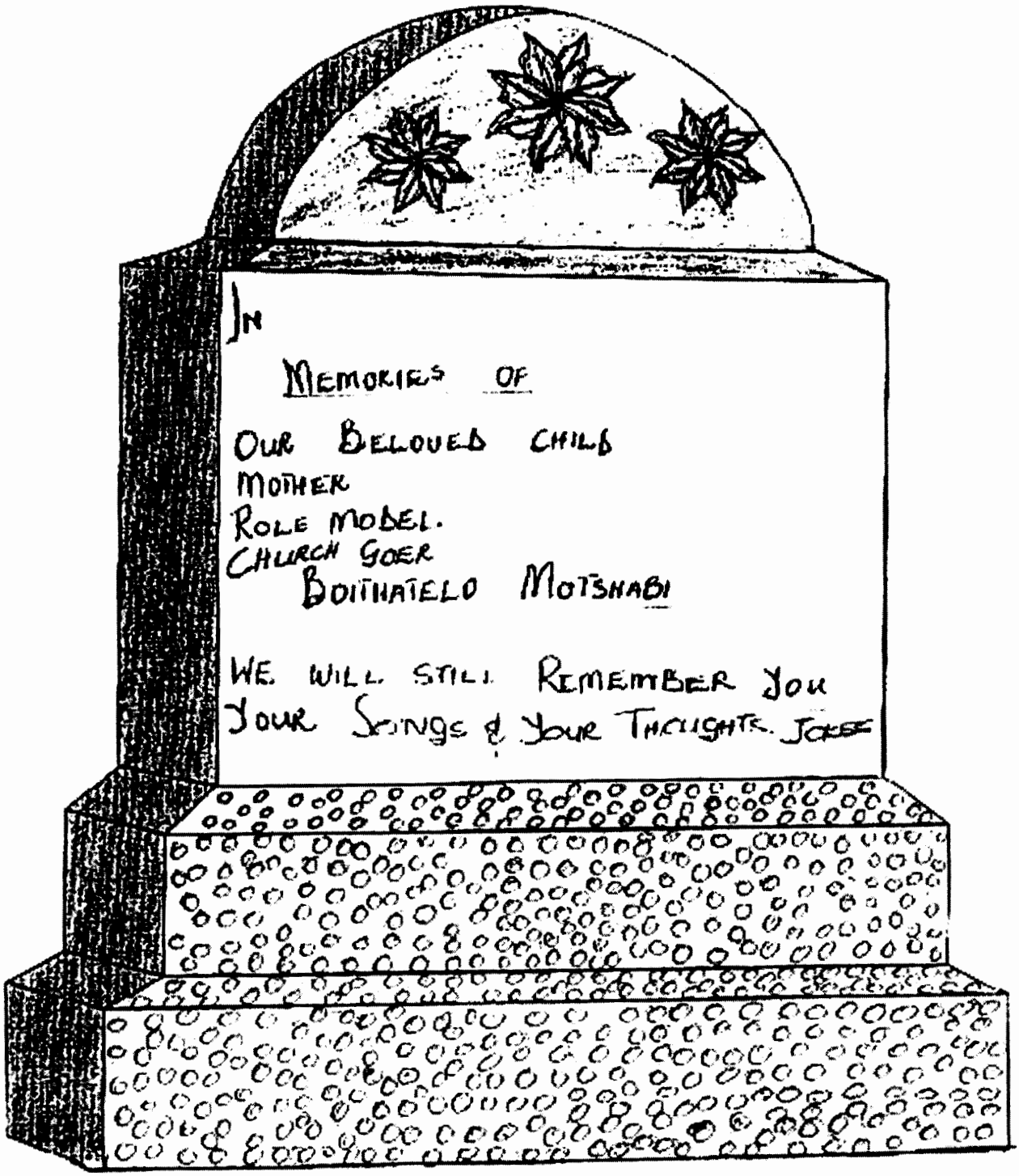
"Imagination is more important than knowledge." - Albert Einstein

Annexure 12

MAP 7: ACTION!

How would you like others to remember your life?

Imagine this as your tombstone. What inscription would you like on it?

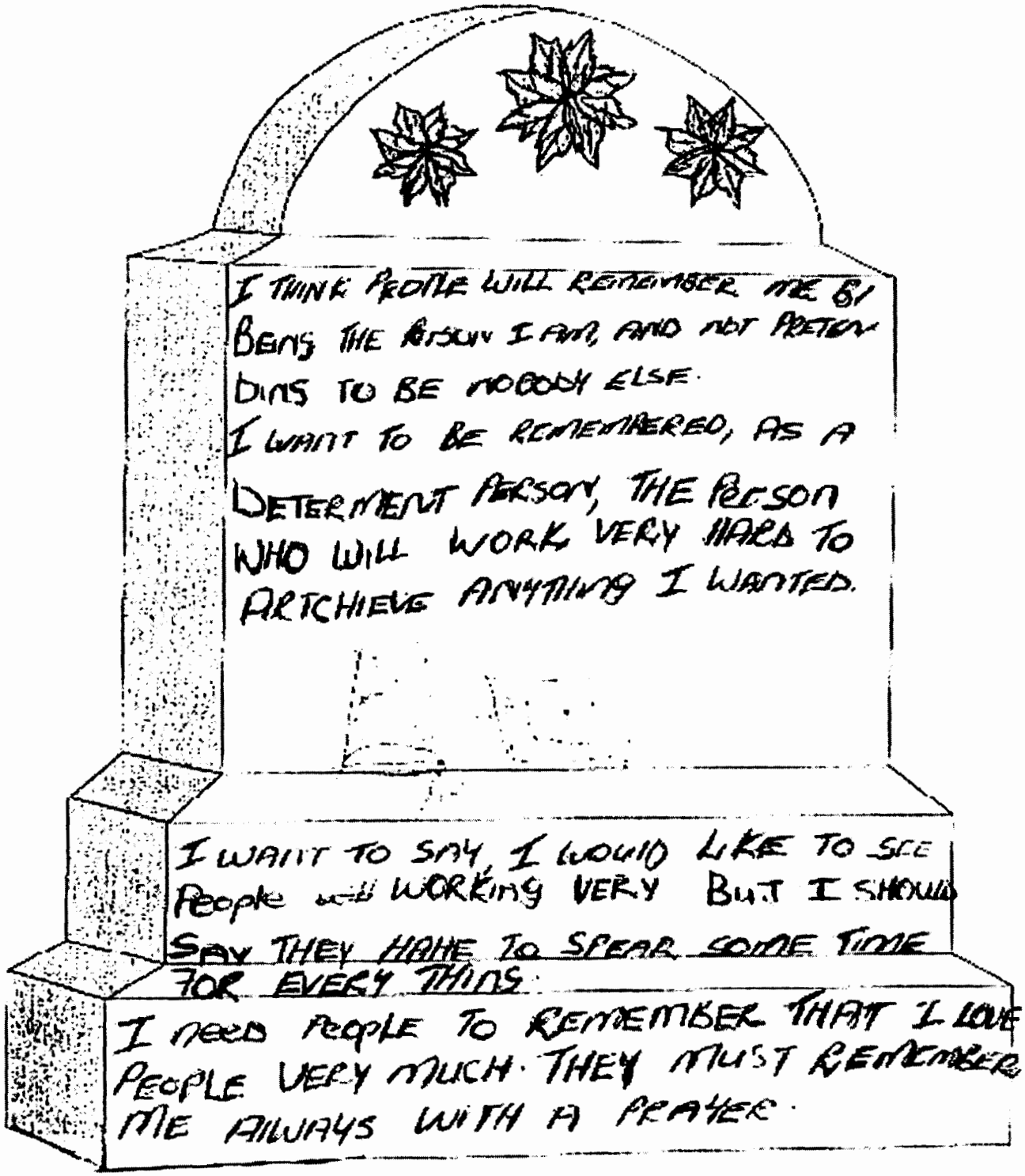


Annexure 13

MAP 7: ACTION!

How would you like others to remember your life?

Imagine this as your tombstone. What inscription would you like on it?

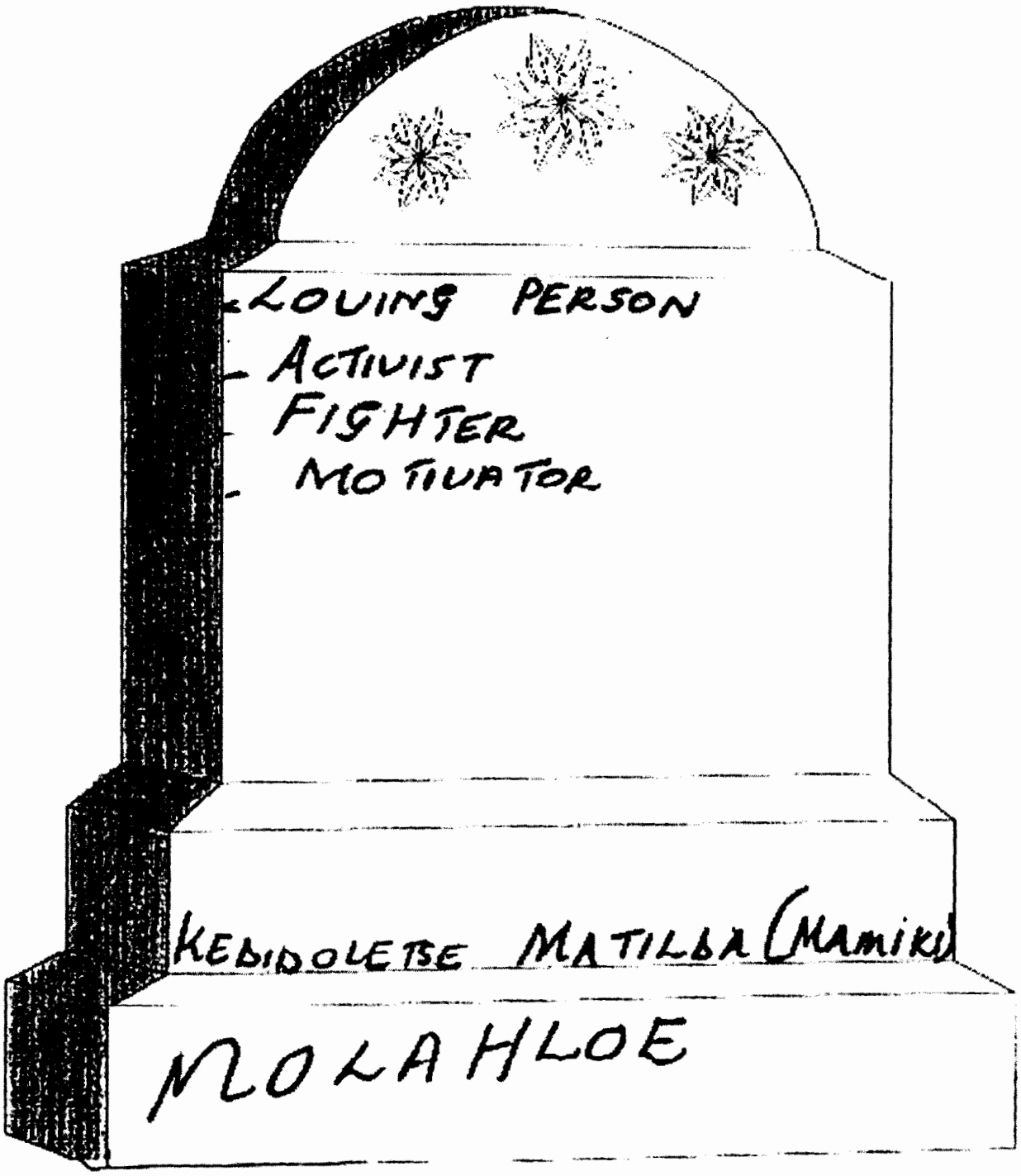


Annexure 14

MAP 7: ACTION!

How would you like others to remember your life?

Imagine this as your tombstone. What inscription would you like on it?

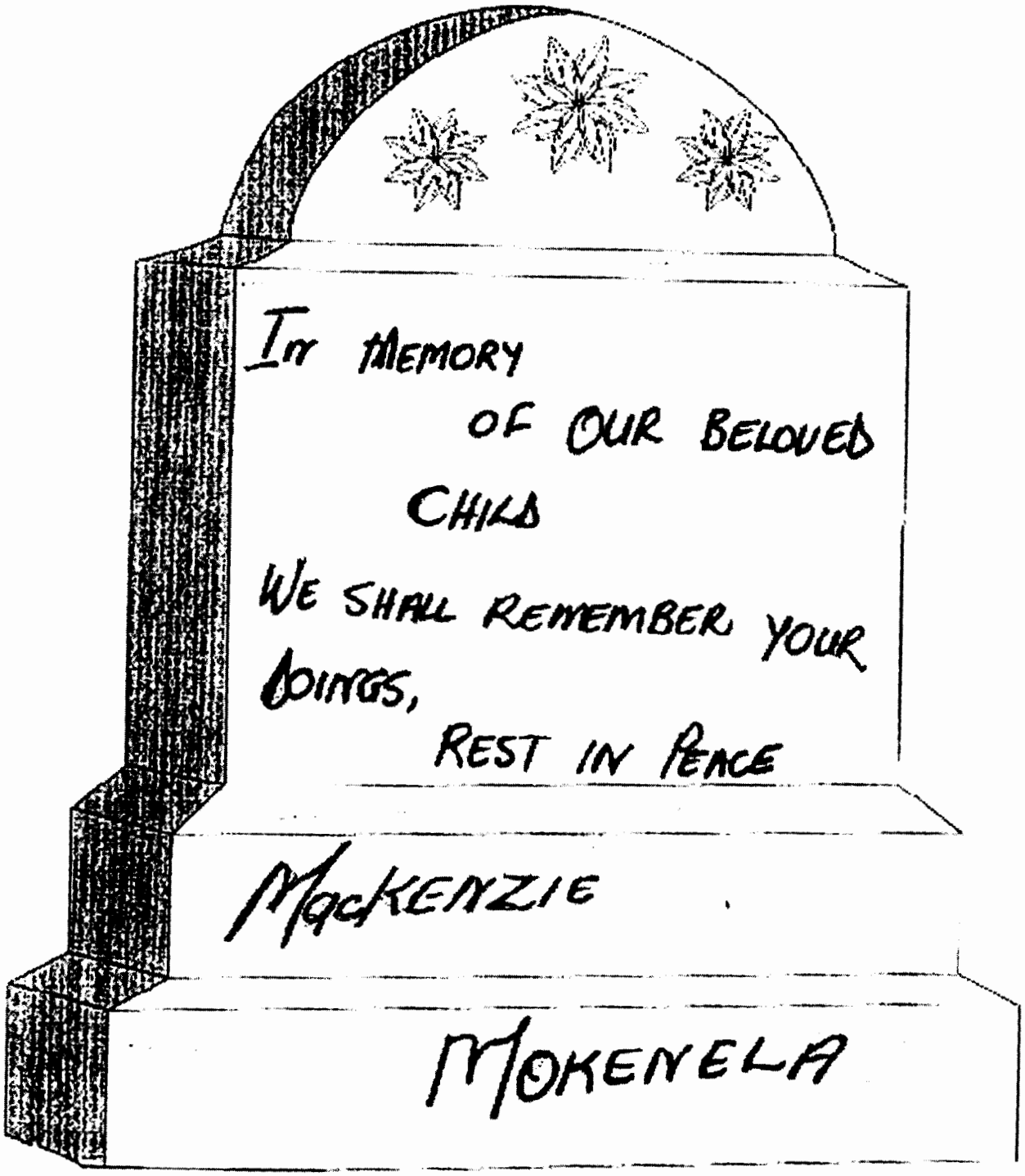


Annexure 15

MAP 7· ACTION!

How would you like others to remember your life?

Imagine this as your tombstone. What inscription would you like on it?

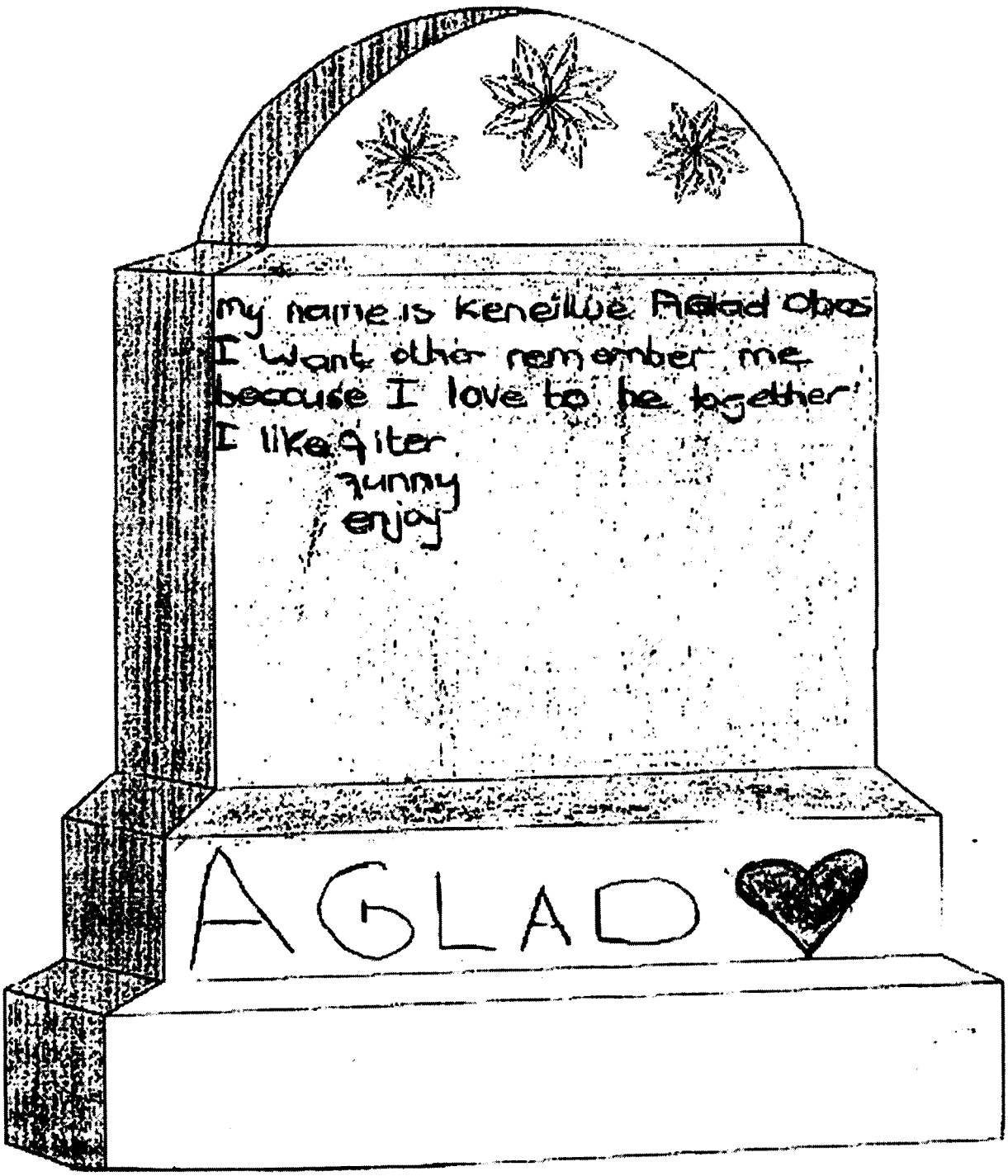


Annexure 16

MAP 7: ACTION!

How would you like others to remember your life?

Imagine this as your tombstone. What inscription would you like on it?

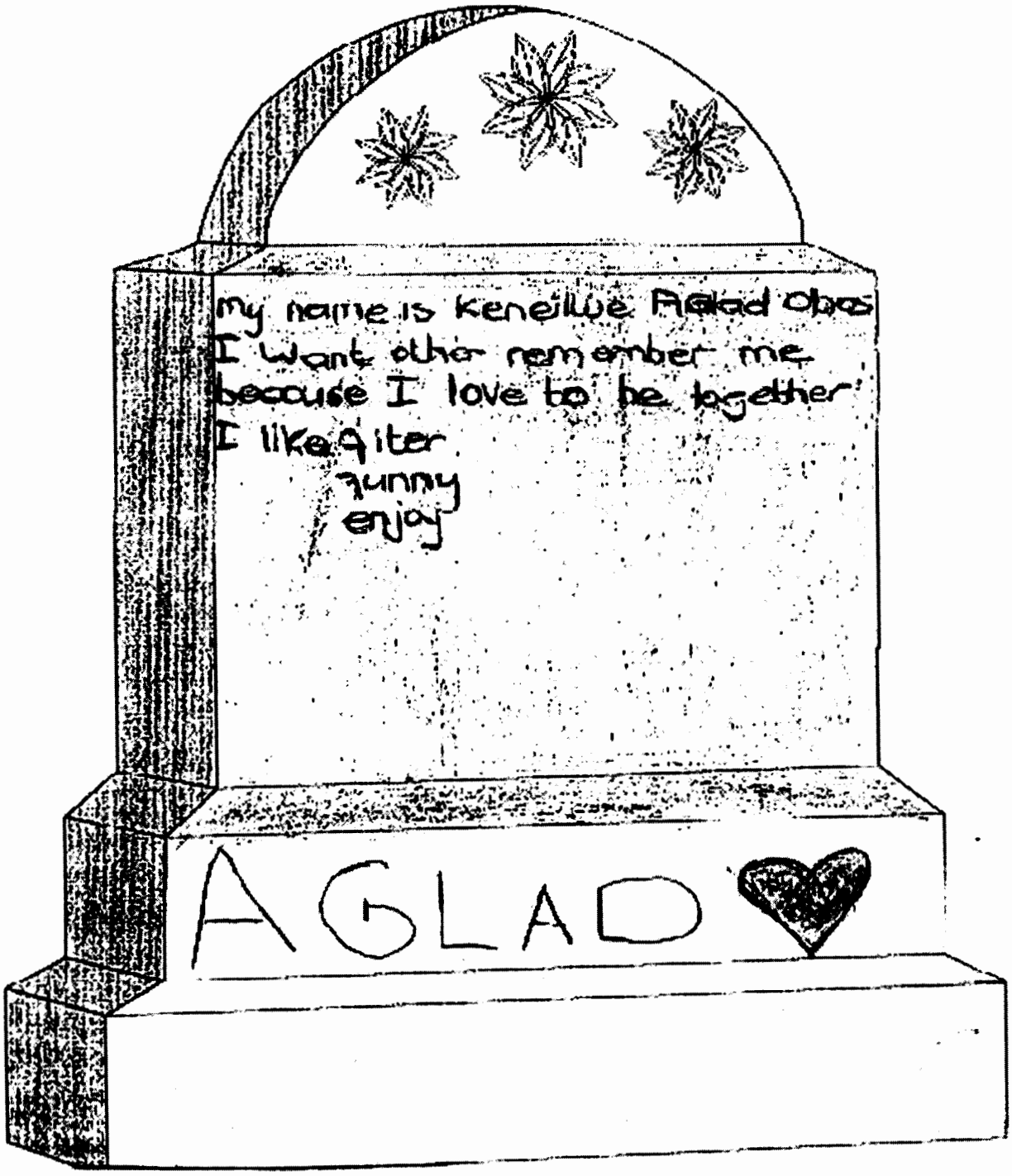


Annexure 17

MAP 7: ACTION!

How would you like others to remember your life?

Imagine this as your tombstone. What inscription would you like on it?

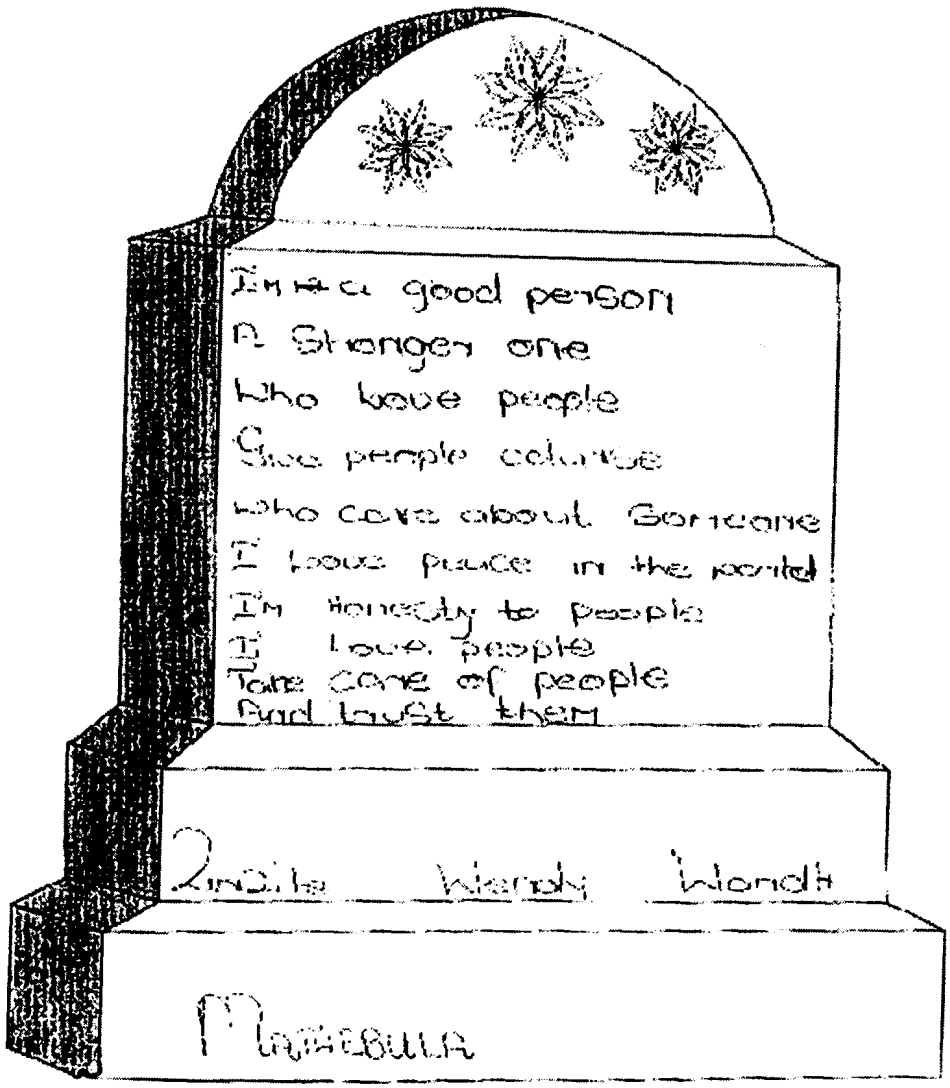


Annexure 18

MAP 7: ACTION!

How would you like others to remember your life?

Imagine this as your tombstone. What inscription would you like on it?



Annexure 19

179 Shabumeng
Bultfontein
9676
14 January 2002

From Boithatelo's Parents and Bebogang
also the Family

ALBA HERBST

We say thank you for being so
sorry forcours. But what can we
say, our silver cup so broken
Our beloved daughter we cry.
God shall grace us Alida.

Thank you

Mrs Annie Madue