

**THE EXPERIENCES OF VOLUNTEERS REGARDING THE IMPLEMENTATION
OF THE TRAINING PROGRAMME ON HIV AND AIDS COMMUNITY BASED
CARE**

BY

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SUMMARY

THE EXPERIENCES OF VOLUNTEERS REGARDING THE IMPLEMENTATION OF THE TRAINING PROGRAMME ON HIV AND AIDS COMMUNITY BASED CARE.

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The incidence of HIV and AIDS is rising rapidly and has become a serious concern in South Africa. In order to address the HIV and AIDS problem, Community Based Care was introduced to render an effective service to the HIV and AIDS patient.

The volunteers receive training to equip them to render a holistic service to the HIV and AIDS patient. The researcher's concern is that despite the training programme offered, there are still problems regarding the service delivery by the volunteers. Volunteers focus on the physical needs of the HIV and AIDS patient only and do not attend to their psychosocial

needs, despite the fact that they are trained to take care of the needs of the HIV and AIDS patient from a holistic approach.

Due to this problem, the researcher decided to explore the experiences of the volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to find answers as to why they do not attend to the psychosocial needs of the HIV and AIDS patient, although they were holistically trained. The research question was formulated as follows:

What is the experience of volunteers in the Potchefstroom Municipality regarding the implementation of the training programme on HIV and AIDS Community Based Care?

The researcher used a quantitative approach to explore the research question. Twenty (20) volunteers from the two Community Based Care programmes, namely Baptist Children's Centre and Bambanani Youth Project, were randomly selected for inclusion in the study. The data collection method used was a group questionnaire. Three themes were explored, namely, the content of the training programme, presentation of the training programme and empowerment of the volunteers to render an effective service to the HIV and AIDS patient. The findings showed that volunteers experienced limitations regarding the content and the presentation of the training programme, and much so in the area of attending to the psychosocial needs of the HIV and AIDS patient. They recommended changes to the training programme, based on their experiences in practice.

The following are key concepts used in this study:

- HIV (Human Immune Deficiency Virus)
- AIDS (Acquired Immune Deficiency Syndrome)
- Community Based Care
- Volunteer
- Psychosocial needs
- Physical needs
- Training programme
- Training curriculum
- Presentation
- Empowerment

OPSOMMING

DIE BELEWENISSE VAN VRYWILLIGERS RAKENDE DIE IMPLIMENTERING VAN DIE OPLEIDINGSPROGRAM VIR MIV EN VIGS GEMEENSKAPS GEBASEERDESORG

deur

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Die voorkoms van MIV en Vigs is besig om merkwaardig te verhoog en is 'n ernstige bron tot kommer in Suid Afrika. Gemeenskapsgebaseerdesorg is ingestel om 'n effektiewe diens aan die MIV en Vigs pasient te lewer.

Die vrywilligers van die Gemeenskapsgebaseerdesorgprogramme ontvang opleiding om hulle met die nodige vaardighede toe te rus ten einde 'n holistiese diens aan die MIV en Vigs pasient te lewer. Vir die navorser was dit kommerwekkend dat ten spyte van die opleidingsprogram wat aangebied word, daar steeds probleme is rakende die dienslewering van vrywilligers aan die MIV en Vigs pasient. Vrywilligers fokus slegs op die fisiese

behoefte van die MIV en Vigs pasient en gee nie sodanig aandag aan hul psigososiale behoeftes nie, ten spyte van die feit dat hulle opgelei is om in hierdie behoeftes van die pasient te voorsien vanuit 'n holistiese benadering.

Op grond van hierdie probleem het die navorser besluit om vrywilligers se belewenisse rakende die implimentering van die opleidingsprogram vir MIV en Vigs Gemeenskapsgebaseerde sorg te eksploreer ten einde antwoorde te vind vir die vraag waarom daar nie ook aandag aan die psigososiale behoeftes van die MIV en Vigs pasient gegee word nie, ten spyte van die feit dat hulle as sodanig daarvoor opgelei is. Die navorsingsvraag wat hierdie studie gerig het was die volgende:

Wat is die belewenisse van vrywilligers in die Potchefstroom Munisipaliteit rakende die implimentering van die opleidingsprogram vir MIV en Vigs Gemeenskapsgebaseerde sorg?

Die navorser het 'n kwantitatiewe benadering gebruik ten einde die navorsingsvraag te eksploreer. Twintig (20) vrywilligers van die twee Gemeenskapsgebaseerde sorgprogramme, naamlik die Baptist Kindersentrum en Bambanani Jeugprojek, was ewekansig geselekteer vir insluiting in die studie. Die groepvraelys is as data-insamelingsmetode gebruik. Drie temas was geëksploreer, naamlik gemeenskapsgebaseerde sorg aan die MIV en Vigs pasient, die aanbieding van die opleidingsprogram en die opleiding van vrywilligers om 'n effektiewe diens aan die MIV en Vigs pasient te lewer. Die bevindings het aangedui dat vrywilligers leemtes ten opsigte van die inhoud en aanbieding van die opleidingsprogram ondervind ten einde volledige aandag aan die psigososiale behoeftes van

die MIV en Vigs pasient te gee. Op grond van hul praktiese ervaring het hulle aanbevelings gemaak ten opsigte van veranderings aan die opleidingsprogram.

Die volgende is sleutelsterme wat gebruik is in die studie:

- MIV (Menslike Immuniteitgebrek Virus)
- Vigs (Verwonge Immuniteitsgebrek Sindroom)
- Gemeenskapsgebaseerde sorg
- Vrywilliger
- Psigososiale behoeftes
- Fisiese behoeftes
- Opleidingsprogram
- Opleidingskurikulum
- Aanbieding
- Bemagtiging

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CHAPTER 1: GENERAL ORIENTATION

1. INTRODUCTION

According to UNAIDS (2006:17), South Africa has a high number of people suffering from HIV and AIDS. The incidence of HIV and AIDS is rising rapidly, resulting in thousands of people becoming ill and dying. More and more children are being orphaned. This problem has become a serious concern to the South African government.

Van Dyk (2001:4), explains AIDS as the acronym for Acquired Immune Deficiency Syndrome. It is caused by a virus (the human immunodeficiency virus or HIV), which enters the body from outside. Immunity refers to the body's natural ability to defend itself against infection and disease while deficiency refers to the fact that the body's immune system has been weakened so that it can no longer defend itself against passing infections. A syndrome is a medical term, which refers to a set or collection of specific signs and symptoms that occur simultaneously and that are characteristic of a particular pathological condition.

According to statistics revealed by UNAIDS (2006:17), an estimated 5.5 million people in South Africa were living with HIV. The statistics also revealed that 18.8% of adults between the ages 15-49 years were living with HIV in 2005. The 2005 national household HIV survey found high levels of HIV infection levels among young people (aged 15-24 years), which were about the same as those found in a national young people survey during 2004. According to the study conducted in 2004 by the Reproductive Health Research Unit of the Medical Research Council, the HIV prevalence sharply increases once people reach

their twenties. The study showed a prevalence rate of 4.8% for the age group 15-19 years and 16.5% for the age group 20-24 years. In this age group, HIV infections were massively concentrated among women (UNAIDS, 2004:24). The 2005 survey also revealed high HIV infection levels among men aged 50 years and older: 14% among those 50-54 years of age and 8% for those 55-59 years of age (UNAIDS, 2006:17).

The above statistics indicate that services to the HIV and AIDS patients became vital and must override all considerations. These statistics have forced the government to put in place services in the form of Community Based Care in an effort to combat this serious problem. Community Based Care is a relatively new concept. The document on the Expanded Public Works programme of the Department of Social Development (2004), defines Community Based Care as the provision of comprehensive services including health and social services, by formal and informal caregivers (volunteers) in the home. Van Dyk (2001:326) and Brennan (1998:123) are of the opinion that because of the HIV and AIDS crisis, both the family and the community have to become involved in care programmes. Hospitals are overflowing with the sick and dying AIDS patients, while people with curable diseases are turned away. Many health care professionals are unable to cope with the demands of the pandemic and suffer from burnout because they can no longer actualize the healing and alleviation of suffering to which they are professionally committed (Melkote, Muppidi & Goswami, 2000:17-18; Van Dyk, 2001:327-334 & Uys, 2003:3).

Research done by Russell and Schneider (2001), Melkote *et al.* (2000), Brouard (2005) and Campbel (2005), stress the importance of Community Based Care and the role of the volunteer in Community Based Care programmes. Van Dyk (2001:326) and Uys (2003:3-5) specifically state that the important functions of a Community Based Care programme is to

empower the community and the family to cope effectively with the physical, psychological and spiritual needs of those living with HIV and AIDS. They focus further on the education of the community, the support of family members in their care giving roles and the reduction of the social and the personal discomfort that living with HIV and AIDS, creates for them. Several authors (Corey & Corey, 2002:358; Roux, 2002:240-242; Van Dyk, 2001:330; Cameron, 2003:33) agree that as the HIV and AIDS pandemic continues to expand, volunteers need to support people living with HIV and AIDS. They therefore need the necessary knowledge and skills to work effectively with these people which can be addressed through an effective training programme.

The researcher is a social worker employed by the Department of Social Development, Potchefstroom and works with volunteers rendering services to the HIV and AIDS patients. As coordinator of the HIV and AIDS programme in Potchefstroom, the researcher monitors services of the volunteers in the Community Based Care programme. These volunteers undergo training to equip them to render a holistic service to the HIV and AIDS patient. The training programme content includes the role of the volunteer, sexually transmitted infections and HIV and AIDS, tuberculosis, spiritual, religious and cultural issues, palliative care and basic nursing skills, social support, communication and counselling skills, nutrition and care of the caregiver (volunteer).

The training programme offered by the Department of Health has been developed specifically to equip Community Based Care volunteers with knowledge and skills in all the areas, so that they can work as members of an integrated team to educate and support patients. The training course focuses on holistic training for holistic care. This training takes place over a period of 59 days, but depends on the prior knowledge of the learners and the

needs of the care programme for which the learners are being trained, as well as the size of the group.

The researcher regards the training programme as an important strategy for reducing the extent and the severity of HIV and AIDS. Corey and Corey (2002:358), Roux (2002:240-240) and Cameron (2003:33) mention that it is important to train all volunteers who will be involved in Community Based Care to provide a high standard of care. If volunteers are not equipped with the knowledge and skills they need, they will not be able to function as part of the Community Based Care team, and the programme will not achieve its goal. The training needs to provide a wide range of knowledge and skills which volunteers will need in order to provide a high standard of holistic care and support.

However, despite the training programme offered, there are still problems regarding service delivery by the volunteers. The researcher realized that volunteers do not necessarily focus on the psychosocial needs of the HIV and AIDS patient, but only on the physical needs of the patient, which will influence service delivery to these people. This fact is illustrated through their day-to-day reporting to the programme managers regarding certain activities in the programme. The focus is primarily on the health or physical needs of these patients, despite the fact that the current training programme for these volunteers includes also the psychosocial care of the patients.

The researcher regards the training of these volunteers as vital, as there is not enough manpower to render the necessary services to the HIV and AIDS patient. The researcher is concerned about whether the volunteers experience the implementation of the training programme on HIV and AIDS Community Based Care as appropriate to empower them to

address the psychosocial needs of the HIV and AIDS patient? The question is whether they experience the content of the training programme as well structured to meet their educational needs as well as whether presentations are meaningful enough, to empower the volunteers to render an effective and holistic service to the HIV and AIDS patient? The question is also whether the volunteers experience the training as meaningful to empower them to implement the skills and knowledge acquired from the training programme in practice?

The above motivated the researcher to explore through this study the experiences of volunteers to find out whether the training programme on HIV and AIDS Community Based Care by the Department of Health is sufficiently implemented to empower the volunteers to attend to the psychosocial needs of the HIV and AIDS patient. The researcher hoped that the research will give an answer as to why the volunteers do not address the psychosocial needs of the HIV and AIDS patient although they were holistically trained.

Sister Kolby, (2006) the manager of HIV and AIDS programmes at the Potchefstroom Municipality indicated that more focus should be placed on the psychosocial care of HIV and AIDS patients. She is also of the opinion that volunteers must be well trained to attend to the psychosocial care of HIV and AIDS patients as they are an important manpower to support the patient living with HIV and AIDS.

Mpolokeng, (2006) a social worker at the Department of Social Development, is of the opinion that research needs to be done to explore the reasons that contribute to the fact that volunteers focus mostly on the physical needs of the HIV and AIDS patient despite the fact

that they were holistically trained, as well as to seek for solutions to ensure, that these patients' psychosocial needs will also be attended to in future.

2. PROBLEM FORMULATION

A research problem must demand an interpretation of the data leading to a discovery of facts. There are three factors determining the manner in which research problems are formulated, namely the unit of analysis, the research goal, and the research approach (Fouchè & De Vos, 1998:54, 68).

De Vos (1998:40) describes problem formulation as raising special kinds of questions to which there are no answers, or where answers exist, but where disputes arise as to their validity. This is fertile soil for the discovery of a research problem. That is, if there is no problem, there is no research.

According to Van Dyk (2001:330), volunteers play a significant role in service delivery to the HIV and AIDS patient in the HIV and AIDS Community Based Care Programme. The role of these volunteers is to give emotional and physical support to the patient infected with HIV and AIDS. Corey and Corey (2002:358), and Roux (2002:240-242), emphasise the importance of physical and emotional support to the HIV and AIDS patients to help them cope with anxieties concerning the illness.

These volunteers are trained according to an existing training programme to render a service to the HIV and AIDS patient. The content of the training programme is based on a holistic approach, which means that volunteers must be able to attend to the physical and

psychosocial needs of the HIV and AIDS patient. According to the feedback from the managers of the HIV and AIDS programmes, volunteers primarily focus on the physical needs of these patients. The emotional needs of the patient are not attended to although these volunteers received the necessary training to render a service from a holistic approach.

The researcher regards this as a serious problem in the rendering of services to the HIV and AIDS patient, because the patient certainly experiences other needs too. Kotze, Roux and Wessels (2001:73-75), Roux (2002:297) and Roux, Venter and Wessels (2001:34), specifically state that everything should be done to increase the life span of people infected with the HIV virus. This implies that one cannot only focus on the possibility to increase the duration of their lives but also the quality of their lives. This motivated the researcher to explore through this study the experiences of the volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care by the Department of Health.

In other words, do these volunteers experience the implementation of the training programme as appropriate enough to empower them to address the psychosocial needs of the HIV and AIDS patient? Do they feel that they are empowered enough to implement the acquired knowledge and skills in practice?

The researcher is of the opinion that if we explore the experiences of the volunteers regarding the implementation of the training on HIV and AIDS Community Based Care, we will be able to attend to their needs and empower them to attend to the psychosocial needs of the HIV and AIDS patient.

In this study, the researcher explored the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care by the Department of Health in order to find answers as to why they do not address the psychosocial needs of the HIV and AIDS patient, although they were holistically trained.

The problem in this study can be formulated as follows:

Despite the fact that the volunteers in the HIV and AIDS Community Based Care Programme are trained to take care of the needs of the HIV and AIDS patient from a holistic approach, it is clear through the feedback from the managers that the psychosocial needs of the patients are not being addressed in practice.

3. PURPOSE, GOAL AND OBJECTIVES OF THE RESEARCH STUDY

3.1. Purpose of the research

De Vos, Schurink and Strydom (1998:5) identified three functions of research for the social work profession. Research provides a framework for practice activities, helps to build knowledge for practice, and provides situation-specific data to inform action. Any fully scientific endeavour in social work should have at least one of the three primary objectives: to explore, to describe, or to explain.

The focus of the study is on explorative research. Bless and Higson-Smith (1995:42) defines the purpose of exploratory studies as 'to gain insight into a situation, community or person. According to Rubin and Babbie (2001:123) the purpose of exploratory studies is typical when:

- A researcher is examining a new interest
- The subject of study is relatively new and unstudied
- A researcher seeks to test the feasibility of undertaking a more careful study
- A researcher wants to develop the methods to be used in a more careful study

The researcher explored the volunteers' experiences regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to find out the reasons why they do not attend to the psychosocial needs of the HIV and AIDS patient, despite the fact that they were holistically trained.

Through this study, the researcher obtained data on the volunteers' experiences regarding the implementation of the training programme on HIV and AIDS Community Based Care by the Department of Health. The information gained can be helpful to empower the volunteers to render an effective and holistic service to the HIV and AIDS patient.

3.2. Goal of the research

Fouchè (2002:107) refers to the term 'goal' or 'aim' as the 'dream' towards which effort or ambition is directed.

De Vos *et al.* (1998:7) define a goal as a dream. It is an end towards which an effort or ambition is directed. After receiving feedback from the volunteers on their experiences regarding the implementation of the training programme on HIV and AIDS Community Based Care, the researcher hopes to find the reasons why they do not attend to the psychosocial needs of the HIV and AIDS patient, in order to attend to the problem so that

they can be empowered more to render an effective and holistic service to the HIV and AIDS patient.

The goal of this study is to explore the experiences of volunteers in the Potchefstroom Municipality regarding the implementation of the training programme on HIV and AIDS Community Based Care by the Department of Health in order to find out the reasons why they do not attend to the psychosocial needs of the HIV and AIDS patient despite the fact that they were holistically trained.

3.3. Objectives of the research

De Vos *et al.* (1998:7) state that research objectives are the steps to be taken, one by one, realistically at grass root level, within a certain time span in order to achieve one's overall aim.

According to Fouchè (2002:107) the term 'objectives' implies the more concrete, measurable and more speedily attainable conception of end toward which effort or ambition is directed. For this study the objectives may be described as follows:

- To review literature on the extent and nature of HIV and AIDS in South Africa, Community Based Care and the 59 days training programme offered by the Department of Health for volunteers.
- To conduct an empirical investigation to explore the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based

Care in order to understand the reasons why they do not attend to the psychosocial needs of the HIV and AIDS patient although they were holistically trained.

- To construct conclusions and make recommendations based on the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care and to contribute to their empowerment to attend effectively to the psychosocial needs of the HIV and AIDS patient.

4. RESEARCH QUESTION

According to De Vos (1998:115), research always commences with one or more questions or hypotheses. Questions are posed about the nature of real situations.

Trochim (2001:24) describes a research question as: Some difficulty, which the researcher experiences in the context of either a theoretical or practical solution and to which the researcher wants to obtain a solution. It is the central issue being addressed in the study, which is typically phrased in the language of theory.

This study is explorative in nature and follows a quantitative approach. A research question was more appropriate to explore the volunteers' experiences regarding their training in HIV and AIDS Community Based Care in order to find out why they do not attend to the psychosocial needs of the HIV and AIDS patient although they were holistically trained.

The research question for this study can be formulated as follows:

What is the experience of volunteers in the Potchefstroom Municipality regarding the implementation of the training programme on HIV and AIDS Community Based Care by the Department of Health?

5. RESEARCH APPROACH

The aim and objectives of the study determine the research approaches to be followed. Robson (1995:27) states that there are two types of research approaches, a quantitative and qualitative approach. Creswell (1998:15) defines qualitative research as an enquiry process of understanding, based on a distinct methodological tradition of enquiry that explores a social or human problem. The researcher builds up a complex holistic picture, analyses words, reports the views of informants in detail and conducts a study in a natural setting.

According to Fouchè and Delport (2002:77) a qualitative approach refers to research that elicits participant accounts of meaning, experiences or perceptions.

This study is quantitative in nature. Quantitative research is associated with numbers and testing of theories. According to Roestenburg (2005:31) quantitative research is used to confirm people's ideas, perceptions, attitudes and behaviours about a particular situation or event. The researcher collected data on the volunteers' experiences regarding the implementation of the training programme on HIV and AIDS Community Based Care to understand the reasons why they do not address the psychosocial needs of the HIV and AIDS patient.

6. TYPE OF RESEARCH

According to De Vos *et al.* (1998:8), there are two types of research, namely basic and applied research. The goal of basic research is to develop theory and expand the social work knowledge base. The goal of applied studies is to develop solutions for problems and applications in practice.

Fouchè and De Vos (1998:69) state that applied research is directed towards shedding light on or providing possible solutions to practical problems. Applied research seeks to develop principles that enable people to resolve problems, or to achieve desired objectives.

For this study, the focus is on applied research. This study explored the volunteers' experiences regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to find out why they do not address the psychosocial needs of the HIV and AIDS patient.

7. RESEARCH DESIGN AND METHODOLOGY

7.1. Design

Babbie and Mouton (2001:74) state that a research design is a blue print or plan of how one intends to conduct a study. Since this study will be an explorative study, the quantitative-descriptive design or survey will be used. Fouchè and De Vos (2002:143) state that the purpose of quantitative-descriptive designs is to observe or measure the net changes in the dependent variable followed by the introduction of the independent variable. In this study,

the dependent variable is the experiences of volunteers. The independent variable is the implementation of the training programme by the Department of Health. The researcher explored the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to find out why volunteers do not attend to the psychosocial needs of the HIV and AIDS patient although they were holistically trained.

7.2. Methodology

7.2.1. Data collection

The data collection procedure best suited for the information required for the purposes of achieving the aims and objectives of this study is a questionnaire. According to De Vos and Fouchè (1998:89), a questionnaire is an instrument with open and closed questions or statements to which a respondent must react. The objective of the questionnaire is to obtain facts and opinions about a phenomenon from people who are informed on a particular issue. The researcher administered a group questionnaire. The respondents present in a group, completed a questionnaire on their own, as explained in De Vos and Fouchè (2002:174). The researcher was present for clarification purposes and each respondent completed his or her own questionnaire without discussing it with other members of the group.

7.2.2. Data analysis

The data were analysed quantitatively according to the steps as set out by Roestenburg (2005: 42):

- The researcher managed the data collected by developing a filing system whereby all the questions of each respondent were labelled and filed alphabetically, so that the researcher would be able to identify and manage the information.
- The researcher read through all the answers thoroughly to get a holistic picture of the data. Some notes were made for interpretation purposes.
- Univariate analysis was used, which means that one variable were analysed at a time mainly with a view to describing that variable.
- The researcher clustered together and described all the identified information using the simple frequency distribution. Basically, this means that all the data gathered for one variable were summarized for easy comprehension and utilization. Differences and similarities will be identified. The information was interpreted to enable the researcher to gain insight into the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care.
- The information obtained from the literature was used to verify the interpretations.
- The researcher documented the findings, which is the basis for the conclusions and recommendations.

8. PILOT STUDY

According to Bless and Higson–Smith (1995:50), one of the uses of a pilot study is to allow the evaluator to investigate the accuracy and appropriateness of any instrument that has been developed.

Strydom (2002:211) defines a pilot study as: A small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate.

The New Dictionary of Social Work (1995:45) defines a pilot study as a process whereby the research design for a prospective survey is tested.

The pilot study entailed the following:

8.1. Pilot test of measuring instrument

The measuring instrument for this study is the questionnaire. Fouchè (1998:158) is of the opinion that in all cases it is essential that newly constructed measuring instruments be thoroughly pilot-tested before utilized in the main investigation. This ensures that any errors can be rectified immediately at little cost. The questionnaire was pilot tested on three volunteers. This allowed for the necessary alterations prior to the commencement of the actual study. These volunteers were not included in the main study.

8.2. Feasibility of the study

According to Barret (1998:23), the researcher needs to check whether it will be possible to conduct research in the chosen area. There are certain aspects that the researcher needs to look into, namely the availability of the subjects, the subjects' permission, manageable costs, and available time.

Permission and availability of subjects: The researcher's written requests to conduct research at the two Community Based Care programmes, Baptist Children's centre and Bambanani Youth project, were approved by the boards of management. A copy of such a permission letter is attached to this document as Annexure A. A meeting was held with the volunteers where they were informed of the purpose of the research. The volunteers provided their voluntarily consent for their participation in the study.

Cost: The cost for the study were kept to a minimum, involving only the computer costs, travelling costs, costs for phone calls, printing and copying expenses. The researcher covered all the costs herself.

Time: The researcher conducted and completed this study within four years.

9. RESEARCH POPULATION, SAMPLE AND SAMPLING METHOD

9.1. Description of research universe and population

According to Strydom and De Vos (1998:190), a universe refers to all potential subjects who possess the attributes in which the researcher is interested. In this study, the universe will be all volunteers in the HIV and AIDS Community Based Care programmes in the North West Province.

According to Trochim (2001:349), a population can be defined as the group you want to generalize to and the group you sample from in a study. For this study the population is all the volunteers at the two Community Based Care programmes in Potchefstroom

Municipality. There are only two Community Based Care programmes in the Potchefstroom Municipality, namely Baptist Children's centre and the Bambanani Youth project. There are 60 volunteers involved in the two programmes. The researcher chose those volunteers, because they attended the training programme presented by the Department of Health.

9.2. Sampling

According to Strydom and De Vos (1998:191), a sample is the element of the population considered for actual inclusion in the study, or it can be viewed as a subset of measurements drawn from a population in which we are interested. Thus a sample is a small proportion of the total set of objects, events or persons which together comprise the subject of the study.

The sample consisted of twenty volunteers from the two HIV and AIDS Community Based Care programmes by means of simple random sampling. According to Trochim (2001:352) random sampling can be defined as: A sampling method that involves drawing a sample from a population so that every possible sample has an equal probability of being selected.

The researchers placed all the possible respondent's names in a bag and draw the names until the required number was drawn. Strydom and De Vos (1998:195) categorise this method of sampling as one of probability sampling procedure. This implies that each individual in the population has an equal chance of being included and the selection of persons from the population is based on some form of random procedure attributes, representative of the population.

10. ETHICAL ASPECTS

According to Strydom (1998:24-34) a researcher needs to pay attention to certain aspects in order to ensure that his or her study is in fact ethical.

The New Dictionary of Social Work (1995:81) defines ethics as follows:

Principles, standards and expectations resulting from accepted values and norms, which determine the researcher's professional actions with or in the interest of the subjects.

The researcher attended to several aspects, listed below, in order to ensure that the study was done in an ethical manner:

10.1. Potential harm to participants

According to Strydom (1998:25), the researcher has an ethical obligation to protect subjects against any form of physical discomfort. Subjects can be harmed in a physical and/or emotional manner. It is a researcher's ethical obligation to protect subjects against any form of physical discomfort and/or emotional harm that may emerge within reasonable limits, from the researcher's project.

Strydom (2002:64) also confirmed that harm can be done in a physical and/or emotional manner. There was no medical harm or discomfort involved in this study. The researcher made sure that the respondents completed the questionnaire in a safe environment. The

researcher also discussed any possible implications concerning physical harm beforehand with the participants.

Emotional harm was more difficult to predict. Roestenburg (2005:16) states that problematic situations occur when respondents have to recall traumatic events, which may cause them harm. The researcher's commitment was to refer any of the respondents who were in need of emotional intervention, to a professional who can assist.

10.2. Informed consent

According to Fouchè and De Vos (2002:65) obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, possible advantages, disadvantages and dangers to which respondents may be exposed as well as the credibility of the researcher, be rendered to potential respondents.

The respondents were not forced to take part in the study. The researcher obtained written permission from each volunteer for inclusion in the study. Permission for inclusion in the study was asked after the researcher had explained the purpose of the study to the respondents. The researcher included accurate and complete information such as activities and disclosure of confidential information in the consent form in order to allow participants to make a voluntarily and reasoned decision about their participation in the study. The researcher also made the respondents aware of the fact that they can withdraw from the investigation at any time.

10.3. Violation of privacy/Anonymity/Confidentiality

Strydom (1998:28) describes the right to privacy of the respondents as follows:

The individual's right to decide when, where, to whom and to what extent his or her attitudes, beliefs and behaviour will be reviewed.

Strydom (2002:67) regards violation of privacy, the right to self-determination and confidentiality as synonymous.

The researcher respected the respondents' right to privacy or confidentiality at all times during the research study. The researcher discussed with the respondents their right to privacy or confidentiality before the research study and it was also mentioned in the consent form for the respondents.

In order for confidentiality or privacy to be maintained, the respondents participated anonymously. Their questionnaires were assigned letters in the alphabet.

The information that the researcher received from the respondents was also treated as confidential. The results of the study will be released with the consent of the respondents.

10.4. Deception of participants

According to Strydom (2002:66), deception involves withholding information or offering incorrect information in order to ensure the participation of subjects when they would otherwise refused it.

The researcher ensured that the respondents were aware of the real goal of the study. The researcher explained the purpose of the study, its objectives and her expectations beforehand with the respondents to ensure that their right to self-determination is respected. The respondents were given the opportunity to ask questions after the goal of the study had been explained so that the researcher can provide clarity. Unforeseen developments regarding the study were discussed with the respondents.

10.5. Actions and competence of researcher

Strydom (2002:70) said that:

Ethically correct actions, attitudes and clothing for every specific research project should be considered under all circumstances and should be part and parcel of the competent researcher's equipment.

The researcher conducted the research in a professional manner. The researcher was also honest to the respondents regarding the study.

The researcher is competent to do the study. The researcher has a degree in social work and is a qualified social worker. The researcher also has extended experience in working with volunteers in the HIV and AIDS Community Based Care programmes. This experience and knowledge contributed to the successful completion of the research study.

10.6. Release or publication of the findings

According to Strydom (2002:72), the findings of the study must be introduced to the public in written form.

Strydom (2002:72) added that shortcomings and errors should be admitted and all due recognition should be given to sources consulted.

The researcher will release information as obtained from the respondents and it will be made available to them on request. The respondents were also informed that the empirical results of the study will be made available to other professionals without disclosing their identity. The researcher undertakes to release findings in such a manner that utilization by others will be encouraged, since that would be the ultimate goal of the research project. The dissertation on the study will be made available to be read by other professionals and interested parties.

11. DEFINITIONS OF KEY CONCEPTS

11.1. HOME BASED CARE/ COMMUNITY BASED CARE

According to Russel and Schneider (2001:4), Home Care is defined as the provision of comprehensive services, which include health and social services by formal and informal caregivers/volunteers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventative, therapeutic, rehabilitative, long-term maintenance and palliative care categories. It is an integral part of Community Based Care. Community Based Care is the care that the consumer can access nearest to home which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities.

The document on the Expanded Public Works Programme of the Department of Social Development (2004), defines Home Community Based Care as the provision of comprehensive services including health and social services by formal and informal caregivers in the home. It encourages participation by people, responds to needs of people, encourages traditional community life and strengthens mutual aid opportunities and social responsibility in order to promote, restore and maintain a person's maximal level of comfort, function and health including care towards a dignified death.

Since the researcher's interest lies in the volunteer in Community Based Care, she can define Community Based Care as the services that the volunteer renders to the HIV and AIDS patient in his/her community, to address the needs of these patients in a holistic way.

11.2 HIV and AIDS

Russel and Schneider (2001:9) and the Education Training Unit (ETU) training manual (2002:52) define HIV as follows:

HIV- The virus involved in AIDS is called the Human Immune Deficiency Virus or HIV.

AIDS- According to Van Dyk (2001:4), AIDS is the acronym for Acquired Immune Deficiency Syndrome. It is caused by a virus (the human immunodeficiency virus or HIV) which enters the body from outside. Immunity refers to the body's natural ability to defend itself against infection and disease. Deficiency refers to the fact that the body's immune system has been weakened to such an extent that it can no longer defend itself against passing infections. A syndrome is a medical term, which refers to a set or collection of specific signs and symptoms that occur together and that are characteristic of a particular pathological condition.

According to the researcher, HIV and AIDS can be defined as follows:

HIV- A virus called Human Immunodeficiency Virus (HIV), which weakens the body of an affected person to such an extent that the victim becomes vulnerable to other opportunistic diseases.

AIDS- AIDS is the acronym for Acquired Immune Deficiency Syndrome. It is caused by HIV.

11.3. VOLUNTEER

A volunteer is seen as a person who offers his or her services or who is recruited to render a service at a welfare agency, usually without remuneration (SAVF Handleiding vir Vrywilligers, 1997:51)

The New Dictionary of Social Work (1995:66), defines a volunteer as a person who offers services or who is recruited to render a service at a Welfare Agency, usually without remuneration.

For the purpose of this study, volunteer refers specifically to a person who renders his/her services free to the HIV and AIDS patient through Community Based Care and who has undergone the training under the auspices of the Department of Health.

11.4. PSYCHOSOCIAL NEEDS

New Dictionary of Social Work (1995:50) defines psychosocial needs as:

A state of tension or dissatisfaction resulting from a discrepancy in interadaptation between clients and others with whom they are associated, or between clients or families and the social resources which usually permit them to function comfortably and satisfactorily to a reasonable degree.

According to the researcher, psychosocial needs refer to the psychological and social needs of the HIV and AIDS patient in order to function comfortably.

12. CONTENTS OF RESEARCH REPORT

The research report consists of the following chapters:

Chapter one

The introduction, problem formulation, objectives, and research methods are discussed in this chapter

Chapter two

Chapter two of the report will focus on a literature study regarding the extent and nature of HIV and AIDS in South Africa –focusing on the: physical, emotional, religious, psychosocial needs of the HIV and AIDS patient.

Chapter three

Chapter three of the report will focus on a literature study of Community Based Care, the role of volunteers and the 59 day training programme on HIV and AIDS Community Based Care for volunteers offered by the Department of Health.

Chapter four

Chapter four will focus on the empirical study and its findings.

Chapter five

Chapter five will focus on the conclusions and recommendations based on the outcomes of the study.

CHAPTER 2

THE EXTENT AND NATURE OF HIV AND AIDS IN SOUTH AFRICA.

1. INTRODUCTION

According to UNAIDS (2004:23), HIV and AIDS is one of the biggest challenges South Africans have to face. The incidence of HIV and AIDS is rising rapidly, resulting in thousands of people becoming sick and dying and more children being orphaned. As more people become ill, the impact of AIDS will be felt in all communities.

According to Van Dyk (2001:4), AIDS is the acronym for Acquired Immune Deficiency Syndrome. It is caused by a virus (the human immunodeficiency virus or HIV) which enters the body from the outside. Immunity refers to the body's natural ability to defend itself against infection and disease. Deficiency refers to the fact that the body's immune system has been weakened so that it can no longer defend itself against passing infections. A syndrome is a medical term that refers to a set or collection of specific signs and symptoms that occur together and that are characteristic of a particular pathological condition.

Shernoff (1998:29) and Gant (1998:6) explain that HIV and AIDS is usually spread through three main modes of transmission, unprotected sex, blood of the HIV and AIDS patient entering another's body in some way and from mother to the unborn child. In the course of the illness, four phases are identified, namely the primary infection phase, the HIV asymptomatic phase, the HIV symptomatic phase and the AIDS phase. Presently the most vulnerable groups are young women between fifteen and thirty years old, sexually active men with more than one partner, migrant and mine workers, transport workers, commercial

sex workers and drug users who share needles.

Bernstein and Van Rooyen (1994:375) state that the impact of AIDS on the society is, and will continue to be, more than merely medical in nature. That HIV and AIDS is a medical disease is a well-known fact; that it has profound psychological and sociological implications is less acknowledged. Bernstein and van Rooyen (1994:375) also state that the profession of social work generally accepts AIDS as a disease with more than mere medical implications.

Practical experience has taught the researcher that the impact of HIV and AIDS on the individual, the family, household and communities is posing a challenge for the helping profession to address. Professionals of the helping professions have to give the necessary guidance and support to the infected and the affected families and friends. The helper should be sensitive to all the factors that have an influence on the life of a person with HIV and AIDS.

In order to gain insight into the extent and nature of HIV and AIDS in South Africa, it is imperative that those concerned develop a thorough understanding of the impact of the disease. The researcher wants to explore the rapidity of the spread of the HIV and AIDS pandemic in South Africa and also aims to focus on the impact on the individual, families and the community. In this chapter the focus will be on these aspects.

2. STATISTICS ON THE PREVALENCE OF HIV AND AIDS IN SOUTH AFRICA.

2.1. Geography of the global pandemic.

Knowledge about the geography of the global pandemic will shed light on the situation in South Africa. It is especially important to compare statistics, in the first place, and secondly to predict the impact of the disease on the country. Therefore the researcher will first focus on global statistics, with specific focus on Sub-Saharan Africa.

According to UNAIDS (2004:19), the number of people who suffer from HIV continues to rise, despite the fact that effective prevention strategies exist. Sub Saharan Africa is one of the regions with extremely high HIV prevalence. This area has just over 10% of the world's population, but has 25 million people living with HIV and AIDS.

Statistics from UNAIDS (2004:20) shows that in Sub-Saharan Africa, the number of people living with HIV and AIDS has risen sharply by the end of 2004. It can be indicated as follows:

- There are 25.4 million adults and children living with HIV.
- There are 13.3 million women living with HIV.
- The adults and children newly infected are 3.1 million.
- The adult prevalence is 7.4 million.
- Adult and child deaths due to AIDS amount to 2.3 million.
- In 2004, an estimated 3.1 million people in the region became newly infected.
- In 2004, 2.3 million people died of AIDS.

- An estimated 6.9% young people between the age of fifteen and twenty four are women and 2.2% of men were living with HIV at the end of 2004.

From the global statistics one can conclude that HIV and AIDS is already a problematic issue for Sub-Saharan Africa. The number of people living with HIV and AIDS is increasing rapidly, and especially women and children are badly affected.

2.2. The HIV and AIDS pandemic in South Africa.

In comparison with the rest of Sub-Saharan Africa, South Africa remains the worst affected sub-region in the world and continues to have a high number of people living with HIV. Statistics on the incidence of AIDS and HIV in South Africa indicates that at the end of 2003 the estimated total number of people infected with HIV was 5.3 million and there is no sign of a decline in the epidemic (UNAIDS:2004:19). According to UNAIDS (2006:17), the number of people living with HIV and AIDS has risen to 5.5 million.

UNAIDS (2004:24) also indicated that throughout South Africa, HIV prevalence sharply increases once people reach their twenties. This was found in the study of the Reproductive Health Research Unit and Medical Council on HIV and sexual behaviour amongst young South Africans (UNAIDS: 2004:24). The study shows HIV prevalence to be low among 15-19 year olds (4.8%) and the highest prevalence is for the age group 20-24 years old (16.5%). HIV infections are highly concentrated among young women and about one in four (24.5%) women surveyed was HIV positive, compared to one in thirteen (7.6%) men. According to the researcher, the picture painted by this study indicates that South Africa will rapidly become a population with fewer young people, especially young women, as a

proportion of the population.

Research done by the Reproductive Health Research Unit of the Medical Research Council (2004), also indicates that prevalence levels amongst pregnant women aged 15-24 years have continued to rise from 23.1% in 2001 to 24.3% in 2003. The survey reveals significant regional variation. Prevalence among pregnant women exceeded 30% in three provinces, namely Free State, Mpumalanga and Kwazulu-Natal. In the Western Cape, Limpopo and Northern Cape, the prevalence rates were between 13% and 17.5%. Since 2001, HIV prevalence has risen in all but two provinces, namely Free State and Gauteng (UNAIDS 2004:23).

The researcher agrees with Shell (2002:14), who is of the opinion that the concentration of HIV and AIDS for pregnant women has significant consequences. The author states that HIV positive pregnant women might infect their newborn children during delivery or through breast-feeding, and that would increase infant and child mortality rates, since most of these HIV positive infants would quickly develop AIDS and, almost without exception, die within five years of birth. Recent statistics indicate that children are a high risk category.

UNAIDS (2004:20) states the following regarding children and HIV and AIDS in South Africa:

- It is believed that the total number of children living with HIV and AIDS in 2004 was 2.9 million.
- AIDS deaths in children aged under 15 years now run more than 500 000 a year.
- Children are being newly infected at the rate of 800 000 a year.

- Diagnosis is critical even before children become symptomatic, since mortality is so high.
- The majority of infected children become symptomatic by their first birthday and between 88 % and 90% will be so before the age of five.
- Children orphaned by AIDS are increasing.

The above statistics indeed shows an increase in the number of people affected by HIV and AIDS. Especially women and children are the hardest hit by the pandemic. The researcher therefore supports the view of Shell (2002:16) namely, that life expectancy is particularly sensitive to AIDS because deaths occurring among young adults, young children and infants result in a large number of years of life lost. This will result in a decline in the number of people in specific age groups, like children between 0-4 years old, as well as the age group 15-34 years.

Bradshaw (2004:12) states that analysis of South Africa's death registration data shows a rise in the total number of adult deaths in the past six years, an increase of more than 40%, and in the case of women aged 20-49 years, an increase of more than 150%. The life expectancy in 2004 was 48.5 years for males and 52.7 years for females and the infant mortality rate is 55 per 1000 births. The statistics also indicates that there is a total number of 1.1 million maternal orphans under the age of 18 years and 250 000 were newly orphaned in 2004.

According to UNAIDS (2004:25), different surveys provide evidence of a rise in mortality. One survey, conducted in a rural area of Kwazulu-Natal province, which has high prevalence among pregnant women, has confirmed a sudden and massive rise in adult

mortality starting in the late 1990's, with AIDS the leading cause of death by 2000 (48%). The risk of dying from AIDS for women peaks among women aged 25-39 years and among men aged 30-44 years.

The statistics paint a picture of a rapid rise in the number of people living with HIV and AIDS in South Africa. It therefore appears that this situation is already affecting the Health and Welfare sector in their service rendering to people affected and infected by HIV and AIDS. As the pandemic grows, the impact on the individual, family, household and the community will increase. The researcher therefore predicts that the pandemic will result in high demands on the welfare sector in future. The following divisions will thus focus on the impact of HIV and AIDS on the individual, families, households and communities.

3. THE IMPACT OF HIV AND AIDS ON THE HIV INFECTED INDIVIDUAL

Barbee, Derlega, Shertburne and Grimshaw (1998:83) state that learning that one is HIV-positive, can create many stressors. Shell (2002:19) states that the emotional reaction to HIV infection is more severe than the diagnosis of any other fatal illness. Guilino (1998:165) adds that an HIV-positive diagnosis creates a time of crisis, which often leaves people feeling anxious, overwhelmed, depressed and or emotionally numb. No known cure exists, and one is forced to live with a great deal of uncertainty and ambiguity.

Corey & Corey (2002:253) echo that the infected individual needs to find ways to cope with a crisis- generating event such as HIV and AIDS, in a more effective way. The researcher is therefore of the opinion that professionals of the helping professions can contribute to the alleviation of stress and the preparation of the patient for the re-occurrence of acute levels

of stress during the progress of HIV and AIDS.

Both Guilino (1998:165) and Shell (2002:16) agree that a diagnosis of HIV, is most of the time not met with compassion by family members and society, which affects an individual's ability to adapt. Derlega and Barbee (1998:2) said that, although it was stressful enough to have a life-threatening disease like cancer or heart disease, individuals with the HIV infection also have to face challenges that are based on other people's and society's reactions to the disease.

Shell (2002:20) mentioned that a patient who needed to come to terms with HIV infection would have to go through three psychological phases that are broadly parallel to the physiological phases the patient would experience, namely:

- The initial shock phase.
- Secondly the adaptive phase of denial, depression and aggression, sublimation and acceptance. Part of the adaptive phase is bargaining and acceptance.
- The last phase, namely the exhaustion phase, which coincides with full-blown AIDS. Individuals with HIV and AIDS experience different feelings and their feelings will keep changing.

According to the researcher, psychosocial implications refer to the way HIV and AIDS exercises an impact on the social and psychological level of an individual who has been diagnosed with the illness. This refers to the process from the infection phase until the AIDS develops. Every individual diagnosed with HIV faces the reality of death. How the disease has been contracted will contribute to the effect on the self perception with regard to

the disease. The patient's emotions will be in turmoil and anxiety about an unknown and unpredictable future, might set in. The patient diagnosed with HIV, will most probably experience the following emotions and could display the following behavioural patterns characteristic to the condition:

3.1. Shock

In spite of being prepared for possibilities, it is always a *shock* to learn that one has HIV infection or AIDS. A person might feel quite confused and incapable of taking the next step. According to Shell (2002:20), the shock phase is a critical time in the patient's life, characterised by some or all of the following: numbness, blankness, automatism, panic attacks, disordered thoughts and grandiose altruistic expressions. The researcher is of the opinion that support services must be introduced as soon as the person has been tested HIV positive to support the patient in dealing with his/her emotions.

3.2. Denial

Shell (2002:20) informs us that most HIV-positive people go through a phase of *denial*. At first they might not be able to believe that they really have HIV and AIDS. Patients will for example try to consult other doctors as a form of denial. Guilino (1998:165) believes that denial is an important and protective defense mechanism because it temporarily reduces emotional stress.

The researcher supports the view of Guilino (1998:165), that infected patients should be allowed to cling to their denial if they are not yet ready to accept their diagnosis, because

denial often gives them a breathing space in which to rest and gather their strength.

3.3. Anger

Guilino (1998:165) further explains that HIV-infected people are often very *angry* with themselves and others and this anger is sometimes directed at the people who are closest to them. They are angry because of their hopelessness, as there is no cure for AIDS and because of the uncertainty about their future. They are often also angry with those who infected them and with society's reaction of hostility and indifference.

Van Dyk (2001:258,259,278) draws our attention to the fact that anger can also manifest in suicidal behaviour. The author mentions that inwardly directed anger may manifest as self-blame, self-destructive behaviour or suicidal impulses or intentions. Suicide may be construed as a way of avoiding pain and discomfort, of lessening the shame and grief of loved ones and of trying to obtain a measure of control over one's illness. Suicide may be either active (deliberate self-injury resulting in death) or passive (concealing or disregarding the onset of the possibly fatal complications of HIV infection or disease). The helping professional should be aware of the fact that there is a significantly higher risk of suicide amongst HIV-infected individuals. Some studies reported the risk of suicide as being 36 times higher in HIV-infected individuals and it seems that suicidal thoughts and acts in association with HIV and AIDS tend to concentrate around the time of diagnosis and again at the end stage of the disease.

Van Dyk (2001:271) indicated that the reasons for suicide may differ for the two 'peak periods' in the life of the HIV- infected individual. Suicide ideation (fantasising about

suicide) or suicidal acts at the time of diagnosis may be triggered by factors such as the way in which testing was carried out, a lack of social support at the time, the individual's inability to cope and inadequate emotional resources. Suicide at a later phase of AIDS is usually associated with deterioration in health, physical illness associated with pain, disability or disfigurement, a decrease in the quality of life and a feeling that people at least want to control the way they die. Those whose loved ones die as a result of suicide are particularly vulnerable to committing suicide themselves, especially if they themselves are HIV-positive. The researcher agrees with the author that the importance of proper, conscientious and thorough counselling can therefore not be sufficiently emphasised.

3.4. Fear

Giulino (1998:176) informs us that HIV infected people have many *fears*. They are particularly fearful about being isolated, stigmatised and rejected. Because of the highly stigmatised nature of the illness, individuals struggle with things such as with whom to share their diagnosis and fear of possible retaliation or rejection. Individuals fear being rejected, isolated and abandoned by those they need most. These fears also surface as individuals attempt to negotiate friendships and intimate relationships.

Leary and Schreindorfer (1998:12) state that HIV-infected individuals may be healthy and asymptomatic for many years following their HIV-positive diagnosis, however, they fear the uncertainty about the future: when will they become symptomatic, will there be pain or disfigurement and who will look after them. To many patients who have witnessed someone who has died of AIDS, the fear of symptoms becomes all the more real. They are afraid of dying, and particularly of dying alone. Giulino (1998:176) and Van Dyk (2001:256)

confirm that many HIV-infected individuals have experienced the pain and death of loved ones and friends who have already died of AIDS, and they know and fear what awaits them. Fear may also be caused by a lack of knowledge regarding the nature of HIV-infection and how it can be dealt with.

3.5. Low self-esteem

According to van Dyk (2001:257), many individuals with HIV and AIDS suffer from a *low self-esteem*, as it is often severely threatened. Rejection by colleagues, friends and loved ones can cause one to lose confidence and a sense of one's social identity, which may contribute to the reduction of self-worth. The inability to continue in a career or to participate in social, sexual and loving relationships also diminishes the client's self-esteem. The physical consequences of HIV infection such as physical wasting and loss of strength and bodily control contribute even more to a lowering of self-esteem and financial independence.

Rose (1998:57) claims that HIV-positive people often search for meaning in their experience, they desire to regain mastery over their life and have a desire to enhance their self-esteem despite the setback. Roux (2002:24-27) is of the opinion that attention should be paid to improve the self-esteem of patients. It is important to empower them with enough skills to believe in themselves and to make them aware of their correct strengths at that point of time.

3.6. Depression

Guilino (1998:20) states that HIV-infected individuals often experience *depression* because they feel they have lost so much in life and blame themselves for it. The fact that there is no cure, serves to increase feelings of depression. People with HIV and AIDS also feel powerless about their situation, because of the uncertain future.

Derlege and Barbee (1998:7) emphasise that individuals who are HIV-positive may become depressed as they experience physical symptoms associated with advanced stages of HIV. The onset of physical symptoms may evoke stress about what will happen next. They are dependent on other family members or friends to care of them and the loss of personal control over their lives also contributes to feelings of depression. As mentioned previously, people with HIV and AIDS experience self-blame and feelings of guilt about the way in which the disease was contracted. They also experience guilt about their lifestyle and blame themselves or others for their situation. According to the researcher, it is important for the helper to recognise signs of depression at an early stage for successful intervention. The helper also needs to have a thorough knowledge of HIV and AIDS in order give effective support in this regard.

3.7. Loss

According to Knott (2003:71) and Babcock (1998:20), people with HIV and AIDS experience many *losses*. These losses are present throughout the course of the disease, from diagnosis, with the loss of expectation of “a long and healthy life, to the multitude of other losses that occur over time. Knott (2003:71), Van Dyk (2001:256) and Brouard (2005:69)

specifically state that HIV- infected people often feel that they have lost everything that is very important in their personnel lives. They experience loss of control, loss of autonomy, loss of their ambitions, their physical attractiveness, sexual relationships, status and respect in the community, financial stability and independence. They also fear the loss of their ability to care for themselves and their families and the loss of their jobs, their friends and family.

Babcock (1998:114) makes it clear that the loss of the ability to work can lead to multiple other losses, for example, dramatic changes in the standard of living, often necessitating moving to subsidised housing, loss of social contact with fellow workers; loss of a sense of purpose in society, which can, in turn, cause loss of self-esteem. They mourn the loss of their life itself. HIV-infected people also feel that they have lost their privacy and control over their lives once they begin to need constant care and with that, they fear the loss of their familiar body image.

Knott (2003:71) mentions that the most commonly experienced loss is the loss of confidence and self-worth occasioned by the rejection of people who are important to them, the people who were once friends but who now reject them because of the physical impact of HIV-related diseases.

3.8. Grief

Van Dyk (2001:257) reminds us that people with HIV infection often have profound feelings of *grief* about the losses they have experienced or are anticipating. These feelings of grief include the following: anger, abandonment, jealousy, relief, joy, deep pain and deep

sorrow. They grieve for their friends who die from AIDS and they grieve with and for those who must stay behind and try to cope with life without them.

Brennan (1998:135) elaborates and states that it is necessary to grieve not only for those who have died, but also for shattered dreams, missed opportunities and lost hopes. That is the only thing that will make it possible to recover resilience, faith and a full-hearted commitment to life. The researcher agrees with the author's view that if people do not have the opportunity to express grief and receive support concerning their grief, it can create long-term implications for their mental health. Unfortunately in our society grieving people, especially the HIV-infected individuals, are frequently isolated and do not have an opportunity to talk or be open about their pain as those around them, have a difficult time to understand them. Due to the turmoil of their emotions and their grief they have to hide their feelings. As a result of the stigma associated with the illness, people may refer to the death of a family member as resulting from cancer or some other terminal illness.

3.9. Guilt

According to Collins (1998:50), *guilt* for having contracted HIV and for having also possibly infected others, is frequently expressed by HIV-infected individuals. They often feel guilty about the behaviour that may have caused the infection or may have caused infection in others. Feelings of guilt may be associated with a person's unresolved conflicts about homosexuality, or about sexuality in general. Having to tell family members and friends that they are HIV-positive often means that they have to share for the first time their sexual preferences or sexual behaviour. There is also guilt about the sadness that the illness will inflict on loved ones and families, especially children. Previous events that may have

caused others pain or sadness and which still remain unresolved, will often now be remembered, which contributes to feelings of guilt and anguish.

3.10. Anxiety

Van Dyk (2001:257) indicated that the chronic uncertainty associated with the progress of HIV infection often aggravates feelings of *anxiety*. HIV-infected people often experience the following anxieties because of the prognosis of the illness:

- The risk of infection with other diseases.
- The risk of infecting loved ones with HIV.
- Social, occupational, domestic and sexual hostility and rejection.
- Abandonment, isolation and physical pain.
- Fear of dying in pain or without dignity.
- Inability to alter circumstances and consequences of HIV infection.
- Uncertainty about how to keep as healthy as possible in the future.
- Fear about the ability of loved ones and family to cope.
- Worries about the availability (or unavailability) of appropriate medical treatment.
- A loss of privacy and concerns about confidentiality.
- Future social and sexual unacceptability.
- The ability to function efficiently.
- The loss of physical and financial independence.

This anxiety is often manifested through obsessive conditions and hypochondria. Some HIV-infected people become so preoccupied with their health that even the smallest

physical changes or sensations can cause obsessive behaviour or hypochondria. This may be temporary and limited to the time immediately after diagnosis, or it may persist in people who find it difficult to adjust to or accept the disease. Anxiety also manifests through spiritual concerns. HIV-infected people who are confronted with death, loneliness and loss of control often ask questions about spiritual matters in their search for religious support. They may want to discuss the concept of sin, guilt, forgiveness, reconciliation and acceptance and the burden of socio-economical issues contributes to feelings of anxiety.

Guilino (1998:165) is of the opinion that socio-economic and environmental problems, such as loss of an occupation and income, discrimination, social stigma, relationship changes and changing requirements for sexual expression may contribute to psychosocial problems after the diagnosis of HIV infection. Many HIV-infected people also have to cope with financial problems. The client's perception of the level and adequacy of social support is also a very important factor because it may become a source of pressure or frustration when it is most needed. Frey, Query, Flint and Adelman (1998:129) are in agreement that people living with HIV and AIDS need social support to restore self-esteem, to create meaning out of the crisis, and to gain control over their lives.

The researcher concludes therefore that the helper needs to recognise the signs of psychosocial consequences of HIV and AIDS in order to intervene more effectively. Psychosocial support should be offered to the patient. This support can be in the form of one-to-one counselling, support groups and community interventions in the form of preventative work. A challenge for the helper is to work within the framework of the patient and to respect health, belief systems and problem management.

4. THE IMPACT OF HIV INFECTION OF A PERSON ON AFFECTED SIGNIFICANT OTHERS

According to Van Dyk (2001:260), significant others play an important role in the person's physical and psychological care. These people often need support to come to terms with their own fears and prejudices and the implications and consequences of their loved one's illness and ultimate death.

Babcock (1998:101) and Van Dyk (2001:260) are of the view that family members may include families of choice, lovers and friends, especially in the case when the infected person is gay or lesbian, as well as families that are related by birth or marriage. Sometimes the real family of an infected person will reject him or her completely. In such circumstances it is often only the family of choice, the lover and friends, who will care for the loved one until the end and beyond. It is important for the counsellor to respect these extra-legal relationships and to broaden their understanding of and appreciation for the reasons why people with HIV and AIDS may not want to disclose their diagnosis to their family of origin.

Greene and Serovich (1998:218) mention that family members might search to derive meaning from having an HIV-infected family member. Affected significant others experience more or less the same psychosocial feelings as their HIV-positive loved ones do, the same feelings of depression, loneliness, fear, uncertainty, anxiety, anger, emotional numbness and at times also hope. Sometimes family members or significant others will become more depressed as the disease progresses.

Van Dyk (2001:260) states that affected others often experience fear and anxiety about their own risk of infection as a function of their relationship with the HIV-positive person. They scrutinise the relationship or contact for possible risk situations in the past and this places a huge strain on the relationship. Corey and Corey (2002:358) indicate that infected people as well as their families and friends, are influenced by a variety of myths and misconceptions about HIV and AIDS. Families have a need for accurate and comprehensive information regarding the progress of the illness.

Research done by Roux (2002:84-92), indicates that peoples knowledge about HIV and AIDS is inadequate. The researcher is of the opinion that the helper must contribute to the development of the knowledge of families concerning HIV and AIDS.

Moore, Saul, Van Deventer, Kennedy, Lesendack and O'Brien (1998:165) are of the opinion that affected others, especially the partner of the HIV-infected person, are often angry with the infected person. They blame their partners for infecting them with the virus. This often contributes to the reason why HIV-positive people find it difficult to disclose their sickness. Marcenko and Samost (1999:39) state that the HIV and AIDS person should be helped to communicate the nature of his/her disease, because it is often too difficult for him/her to tell other people, family, friends and even a marital or cohabital partner, that he/she is HIV positive.

Derlege, Lovejoy and Winstead (1998:148) make it clear that the disclosure of a loved one's positive status is always a shock, and no two people react in the same way to the news. Affected others' responses can range from involvement, caring and support on the one hand, to abandonment, indifference and antagonism on the other hand. HIV-infected

people are often rejected by their significant others because of the stigma that still surrounds this disease in many societies. According to Roux *et al.* (2001:11) families need to be empowered with knowledge and skills in order to enhance their life satisfaction and quality of life. Families must be informed regarding the progress of HIV and AIDS, the consequences thereof and the necessity of counselling and bereavement counselling. The author proposes the method of story telling by using a character who tells his/her story. This will help families to gain knowledge and skills in a more creative manner. Roux *et al.* quote Carlson (2001:213) and state that the therapeutic value of storytelling lies in the fact that people remember more in this way. Roux *et al.* also quote Freeman (1991:208) and state that by means of storytelling people are confronted with the facts of HIV and AIDS in a more easily accepted way. The researcher is of the opinion that the helper must empower patients to communicate their status to reduce stress for themselves and their families.

Van Dyk (2001:260) reminds us that affected others begin to anticipate the loss of the HIV-infected person and issues of loss, bereavement and uncertainty are introduced into the relationship at a time when this may not be appropriate. Affected others, especially if they are very close to the infected person often feel unable to cope with the new demands that this infection place on them. They feel incompetent, unqualified and powerless in their interaction with the HIV- positive person. These feelings contribute to a need to distance themselves from the disease process as well as the person. Denial of the illness becomes a negation of the person, accounting for much of the isolation experienced by the HIV-positive person. The HIV-positive status of a significant other sadly often acquires a certain relational currency. This means that friends, relatives and colleagues tend to 'use' the infected person's HIV-positive status as an issue in their ongoing relationship with each other. Old scores are settled, new ones are initiated, and relationships are defined around the

issue of the HIV-positive person's illness. Interactions often take place around, rather than with, the HIV-infected person.

Greene and Serovich (1998:229) argue that it might be that family members lack knowledge and skills concerning HIV and AIDS and do not know how to assist the HIV-positive member. The researcher is of the opinion that families need to be educated about the progress of the disease, how to cope and how to react towards the HIV-positive individual. They need to be equipped with coping strategies, knowledge and skills.

Smart (2003:176) explains that affected others suffer in many ways as a result of untimely deaths. People who die of AIDS are usually young (between 20 and 35 years), and this leads to the 'unnatural' situation where parents outlive their children. Grandparents who are preparing themselves for a quiet old age now often find themselves forced to care for the sick and the dying children as well as grandchildren. Kistner (2003:22) and Greene and Serovich (1998:231) say that children suffer tremendously when their parents are infected, and the needs of children with infected parents are often neglected. Some parents may be unable to attend to the needs of their children due to being overwhelmed and /or depressed.

Van Dyk (2001:260) elaborates and states that in many African societies there is no tradition of talking to children as equals on an intimate basis, and caregivers often report seeing the suffering of children who are too often hovering in the shadows of a sick room, seeing and hearing everything, but never addressed directly. Children are largely excluded from the counselling process, because some caregivers often simply do not know how to talk to children. The researcher is of the opinion that the helper must be aware of the needs of these children and make sure that they are emotionally and physically cared for.

Corey and Corey (2002:358) and Roux (2002:240-242) are of the view that it is essential that people living with HIV and AIDS receive physical and emotional help to adapt to stress, because significant others often have to fulfil a role for which they have not been trained, namely that of caregiver. They have to look after seriously ill loved ones, which can be an arduous and all-consuming task that drains all the caregiver's physical, emotional and often financial resources. Neurological complications and deterioration in mental functioning in the patient can be extremely disturbing to significant others. They may feel that they are already losing their loved ones and this can precipitate an early grieving process.

As already mentioned, support is important for both the individual and significant others. Support must be given for personal grieving and the opportunity to develop effective helping skills. The researcher is of the view that this support can be in the form of counselling and support groups. The following division will now focus on the impact of HIV and AIDS on households and communities.

5. THE IMPACT OF HIV AND AIDS ON HOUSEHOLDS AND COMMUNITIES

HIV and AIDS has a significant influence on the socio-economic status of households and communities. Different studies and literature focus on the influence of HIV and AIDS on households and the community. The following areas were identified as crucial areas of influence on households and communities as a result of the pandemic:

5.1. Burden of illness and death

According to Brennan (1998:141), in communities most affected by HIV and AIDS people are dealing with an overwhelming number of deaths and therefore have to deal with multiple loss and bereavement issues. According to a study conducted by the Centre for Health Systems Research & Development at the University of the Free State (2002), households affected by HIV and AIDS carry a higher burden of morbidity and death. People in affected households were four times as likely to have been ill in the previous month and to have had an infectious disease. Affected households on average included two more ill persons than unaffected households. People in affected households experienced more severe illnesses. This fact is indicated by the number of hospital admissions, people not recovering from their sickness, and their inability to perform daily tasks. This situation places an enormous burden on the family. Families rather keep their grief secret out of fear of stigma and shame. The researcher is of the opinion that the helper has a significant role in assisting the families with dealing with their grief, by using his/her skills and knowledge to address the situation. Assistance can be in the form of bereavement counselling, individual or group work in the form of support groups.

Blom and Bremridge (2003:82) describe support groups as structures where people living with HIV and AIDS meet on a regular basis to talk about their difficulties or simply to relax and enjoy each other's company. These support groups create an environment that is safe, confidential, blame-free, non-discriminating, respectful, understanding and relevant.

5.2. Healthcare

Defilippi (2003:162) emphasises that lack of basic services results in conditions of poor hygiene that further exacerbate the vulnerability to infection of HIV. Life-threatening diseases other than AIDS, such as tuberculosis are on the rise because of this situation.

Shell (2002:17) is of the opinion that the cost of health care for affected households is also on the rise. The author states that this situation will not influence the family alone, but will have an impact on the budget of the Department of Health for treatment. From a social work perspective this situation leads to poverty and other social problems. Most households with ill or dying members carry a burden of caring, because it is impossible for the health team to attend to all the demands placed on them. The researcher strongly recommends that the helper mobilise the community to get more involve in community based care by using volunteers to address the HIV and AIDS problem in their community. Community based care will be discussed in detail in chapter three.

5.3. Poverty

Defilippi (2003:162) states that AIDS in general is associated with poverty and a definite link exists between poverty and AIDS. Whiteside & Sunter, as quoted by Kotze, Roux & Wessels, (2001:72-82), define it as follows:

“The link between poverty and health is increasingly recognised and understood. It is not clear that AIDS is simply a disease of poverty, although poverty undoubtedly helps drive the epidemic. In the early stages AIDS appears to infect the relatively well off: they have

the disposable incomes that allow them to travel and, in the case of men, purchase sex. Of course more poor people are infected because they are poorer but it is likely that, as the epidemic evolves, they may be proportionally worse affected. What is clear is that AIDS increases poverty.”

According to UNAIDS (2004:22), the impact of HIV and AIDS on households is catastrophic. At a national level the epidemic's economic and demographic effects have received substantial media and academic attention. However the epidemic's impact on HIV-affected households deserves greater analysis and policy effort. In some of the worst affected countries, like South Africa, the living standards of the poor deteriorated markedly before the epidemic even started having negative impact on households.

UNAIDS (2004:22) states that the impact of AIDS has the following devastating effects on households:

- AIDS causes the loss of income and production of a household member. If the infected individual is the sole breadwinner, the impact is especially severe. Where workers who are too ill to work are retrenched or medically boarded, they lose most of their benefits. Ultimately, they have to rely on the state or their families.
- AIDS creates extraordinary care needs that must be met (usually by withdrawing other household members from school or work to care for the sick).
- It is recognised that state hospitals are not the appropriate location nor can they provide care for people with AIDS. These patients are discharged to be cared for at home, which places an extra financial burden on the households.
- AIDS causes household's expenditure to rise as a result of medical and related costs.

Defilippi (2003:166-168) suggests certain strategies for dealing with poverty:

- ***Increasing access to social grants***

Defilippi (2003:166) is of the opinion that poor people are sometimes unaware of social grants that are available. For example, the availability of the child grant has been identified as a major problem in South Africa. The researcher is of the opinion that people need to be more educated about the different kinds of grants that are available to them and the procedures to access these grants. Access to these grants will definitely improve people's living conditions in providing the necessary resources for the household. However, Brouard (2004:69) states that difficulties obtaining social grants and high levels of poverty have led to reports that disability grants are being given to people who are HIV-positive while they are still well enough. This grant is needed so that HIV-positive persons can maintain a higher nutrition level. It is also reported that people want to be tested HIV-positive simply to get the grant.

- ***Increasing self-reliance with regard to food***

The researcher agrees with Defilippi (2003:167) that a holistic approach is the more appropriate answer to solve the problem. A holistic approach should include information about nutrition, food storage and preparation, and motivation about growing vegetables. For the researcher it is essential to include the person living with HIV and AIDS and the family in these programs. The researcher is also of the opinion that people of the social service professions, like community development practitioners should play the leading role in mobilising the community.

- ***Linking HIV and AIDS services and job creation.***

Deffilippi (2003:167) states that the idea of linking HIV and AIDS service provision to job creation is inevitable in reducing poverty in affected communities. This will contribute to a self-reliant community. The researcher is of the opinion that the helper should also play a leading role in facilitating job creation projects for affected communities. Networking with other organisations is important for the successful programme implementation of the job creation programme.

5.4. Labour supply and household finances

Shell (2002:18) said that the impact of HIV infection increased certain kinds of long-term expenditure for the household. If positive persons supported the family financially, their illness and certain death would reduce the household income. Special medical treatment, nutrition and funeral costs can be considered major financial burdens on the AIDS household budget as formerly productive members would suddenly have become dependants.

Poor households are particularly in danger of losing their economic and social viability and also of eventually being forced to dissolve. Research done by Booysen, Van Rensburg, Bachmann, Engelbrecht and Steyn of the Centre for Health Systems Research & Development of the University of the Free State, (2002:11-13) found that AIDS-affected households also appear more likely to suffer poverty than non-affected households. The study found that households affected by HIV and AIDS had a smaller supply of labour than non-affected households, with a larger proportion of children and elderly persons. Illness

and death also occurred mainly among economically active members (aged 15-49). Affected households were more dependent on government grants. They also allocated more of their resources to food, health care and rent and less to education, clothing, personal items and durables.

Kotze *et al.* (2001:72-82) of the Department Social Work of the North West University, conducted a study about the socio-economic position of HIV and AIDS patients in the North West Province, and found that the average income of HIV and AIDS-affected households were less than R100-R1500 per month. Most of the patients were financially cared for by other family members. The average monthly expenses per household were R1045.71, which proved to be more than the average income. When possible, families thus liquidate savings, borrow money or seek family support. Often though, these households have limited savings and a lack of credit or insurance options. The money borrowed was mostly used to pay for funerals and medical expenses or to pay creditors

The previously mentioned studies indicate an increase of financial expenditures for HIV and AIDS-affected households. To the researcher it is evident that a lack of finances will create more burden on family's income, and this will lead to poverty. The sole breadwinner will ultimately be responsible for the care of the patient and orphans, and the situation will create more problematic issues since the breadwinner will not be able to work for an income. This is one of the major problems that the helper together with the government needs to address in the near future.

5.5. Malnutrition

According to UNAIDS (2004), Sub-Saharan Africa accounts for 11% of the world's population. It is also stated that 24% of the world's undernourished people are from this area. This means the epidemic is unfolding in a setting dominated by chronic malnutrition and unstable food security. In fact, AIDS is intensifying chronic food shortages. It causes farm labour losses and depletes family income that would in general purchase food. In high-prevalence countries, like South Africa, a vicious cycle exists between food shortages, malnutrition and AIDS.

Roux (2002:210) points out that food insecurity is especially damaging for people living with HIV, as they need more calories than uninfected individuals. Furthermore, malnourished HIV-infected people progress more quickly to AIDS. Roux (2002:210) therefore emphasises the essential role of nutrition for people living with HIV and AIDS. The correct nutrition is important for improving their physical condition, as well for improving their immune system. As already mentioned, a helper needs to mobilise the community in providing food for themselves. This may be realised through the establishment of food gardens by affected families.

5.6. Burden of HIV and AIDS on women

According to UNAIDS (2004:24), the impact of AIDS on women is severe, particularly in areas of the world where heterosexual sex is the dominant mode of HIV. In Sub-Saharan Africa, women are 30% more likely to be HIV positive than men. Marriage and other long-term monogamous relationships do not protect women from HIV, because HIV-infected

women are often infected by their husbands. Malherbe (2002:340) states that other socio-cultural beliefs increase women's vulnerability to sexual behaviour and gender roles. Many societies value female virginity at marriage, but grant sexual freedom to unmarried men.

Malherbe (2002:338), supported by Kistner (2003:18), also states that women are more likely to be poor and uneducated than men, and are thus dependent on men for the survival of their children. Women may be afraid to risk angering or losing their partners by mentioning the issue of monogamy.

Shell (2002:19), Defilippi (2003:164) and Malherbe (2002:341) are in agreement that women are the carers, producers and guardians of family life. They bear the largest AIDS burden. Young girls may drop out of school to attend to ailing parents, look after household duties or care for younger siblings. After a spouse's death, a mother is more likely than a father to continue caring for his/her children, and a woman is more willing to take in orphans. Older women often shoulder the burden of care when their adult children fall ill. Later they may have to become surrogate parents to their bereaved grandchildren. The stigma and discrimination often leads to the social isolation of older women who cares for orphans and ill children but who are denied psychosocial and economic support.

When the male head of a household becomes ill, women have to take on additional care duties (UNAIDS, 2004:24). Providing care for an AIDS patient is arduous and time-consuming, even more so when it is done on top of other household duties. When their partners or fathers die of AIDS, women may be left without land, housing or other assets. It is common in most rural areas in South Africa that a woman may also be prevented from using her property or inheritance for her family's benefit, which in turn, hurts her ability to

qualify for loans or agricultural grants.

UNAIDS (2004:24) is also of the view that stigma has concrete repercussions for people living with HIV. Family support and solidarity cannot be assumed. A woman who discloses her HIV status may be stigmatised and rejected by her family. In most cases women are the first in the family to be diagnosed with HIV, and may be accused of being the source of it in the family.

5.7. Burden of HIV and AIDS on the extended family

According to Smart (2003:176), the extended family system has to meet most of the basic needs of children, and provides a protective social environment, in which the children can grow and develop. Smart (2003:164) also states that much of the burden generated when an adult woman dies, shifts to other, usually older women, who step in to foster the children, the very segment of society that must receive protection and care. For the extended family, additional children would increase financial hardship and pressure on relationships, weakening the capacity of the family to cope. The constraint to care for additional children is on the extended family, especially the grandparents. Grandparents attempt to stretch their pensions to enable them to provide food and schooling for their orphaned grandchildren. The question is also whether these grandparents have the ability to provide proper care for these children. According to the researcher's practical experience, many of the grandparents are too old and are very often not in a position to care for young children. Sometimes they have to care for more than one set of grandchildren whose mothers have died as a result of AIDS. This situation also demands of the helper to give guidance to the families and to arrange foster care placements and the provision of food and other necessities. According to

Kistner (2003:22), it is clear that at a time when the family is most needed as a support system for orphans and affected children, the stigma associated with HIV and AIDS is further affecting the willingness of families to care for and support these children. This creates an increase in child mobility and the exploitation and neglect of children.

5.8. Orphans and child-headed households

According to the statistics of UNAIDS (2004:19), South Africa has a total number of 29 million children living with HIV and AIDS. When parents die, the grandparents are responsible for fostering the children. Often the new foster mother has limited employment options and depends on low-paid informal activities to generate income for the newly expanded household. In most instances the grandparent is not in a position to care adequately for the children due to lack of finances and other resources. Grandparents thus have to rely on grants from government. In most instances the family does not have access to grants, thus struggle without any income.

Kistner (2003:22) believes that orphans and affected children are even more vulnerable than adults as they face the possibility of a stigma relating to their own status if they are infected, as well as a stigma flowing from their parents or caregiver's status. The stigma often continues even after death has set in. They do indeed stand a chance of being rejected by the extended family and the community. According to Kistner (2003:22), research has also shown that stigma and discrimination lead to orphans and affected children being denied or discouraged from accessing basic services, such as health care and welfare services.

Smart (2003:176), Shell (2002:19) and Kistner (2003:22) are in agreement that the reality of HIV and AIDS in the family is that children are caring for the sick and assuming adult responsibilities before they are ready to do so. Smart (2003:176) uses the term 'parentification' when she refers to the process of creating a parent out of a child in order to care for a parent or siblings. This is associated with social isolation. Younger children not only assume responsibility for more complex household chores, but are also deprived of the nurturing previously received from their now ill parents.

According to UNAIDS (2004:19), an international study found that an estimated one in five children in AIDS-affected families reported they were forced to start working in the previous six months to support their families. They had to provide care and take on major household work. Many had to leave school, forego necessities such as food and clothes, or were sent away from their home.

Smart (2003:177) identified the following devastating affects of HIV and AIDS on children:

- HIV and AIDS produces younger orphans and these young children are especially at risk.
- They tend to be nutritionally deprived.
- In many communities, children whose parents have died of AIDS are at greater risk of dying of preventable diseases, because their illnesses tend to be attributed to AIDS and thus go untreated.
- Orphans are also more likely than other children to be immunized and to have their health care needs adequately met.

Smart's (2001:177) view is that unless suitable arrangements are made for children before their parents die, the trauma, guilt and grief so common among these children, are compounded by uncertainty regarding their future.

When the extended family either does not exist or simply cannot cope, the alternative is often for siblings to live together, frequently with no adult supervision. Thus more and more children who are themselves traumatised and grieving, are heading up orphan households.

Smart (2003:177) also reminds us that a child who must head a household without parents is a common sight in South Africa. The author identified the following problems for child-headed households:

- Children with no parents and no one to care for them suffer tremendous poverty, which could lead to stunting and hunger.
- They are also exposed to abuse, problematic behaviour and sometimes child-labour due to a lack of supervision and care.
- Children in child-headed households normally have to terminate their school-going, and that leads to educational failure.
- They experience a lack of adequate medical care since there is no adult to care for them.
- The death of parents, together with the suffering experienced normally, leads to psychological problems.
- These children have to fulfill the role of adults by looking after their siblings, which means a disruption of normal childhood and adolescence.
- They are sometimes forced into early marriage as a means to improve their

circumstances.

- Discrimination is still a reality in our communities and these children are at high risk for being discriminated against due to the fact that their parents died of AIDS.

5.9. Violence and HIV and AIDS

Defilippi (2003:163) and Malherbe (2002:38) state that often sex is the only means by which a poverty-stricken woman can procure money or food and other services in order to survive. This is frequently associated with violence and exploitation. Kistner (2003:48) mentions that vulnerability to AIDS is frequently accompanied by a lack of respect for the rights of women and children. Domestic violence also increases women's exposure to HIV and AIDS. This deprives women of the opportunity to negotiate for safer sex.

Kistner (2003:23,49) is also of the opinion that HIV-transmission increases during violent or forced sex situations. This is especially true in the case of adolescent girls. Sexual abuse of young girls may lead to risky sexual relationships as adolescents. This could be connected to a lower self-esteem, which would make it harder for them to be assertive in sexual negotiations in later life. More women report sexual violence by an intimate partner. Women may hesitate to seek HIV testing or fail to return for their results because they are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home, or social discrimination. Women are furthermore afraid that they will not receive understanding and support from their partners if they disclose their diagnosis.

A study was conducted by the Reproductive Health Research Unit and Medical Research Council on HIV and sexual behaviour among young South Africans and it was found that

young women were found to be at high risk for HIV infection. Sexual aggression is common, with more than one quarter (28%) of the women reporting that their first sexual experience was unwanted, and one in ten (10%) saying that they had been forced to have sex. Almost half (49%) of the young women who said that they had been pregnant at some point, said that condom use was not the norm (UNAIDS: 2004:24)

This situation points a negative picture of the situation in South Africa. According to the researcher, it indicates that prevention practices fail in some way. Also, violence against women in the form of rape, is still practised in general.

5.10. Mobility

Kistner (2003:25) and Shell (2002:13) state that human mobility has always been a major driving force in epidemics of infectious diseases. The association between men's mobility and HIV is related to risky sexual behaviour. The statistical results remained significant after controlling for other measurable variables. Across South Africa the phenomenon of men migrating to urban centres in search of work and leaving their partners and children at home in rural areas, is widespread and has complex historical roots. A high proportion of workers in South African in the field of mining, are domiciled in other HIV devastated countries in Sub-Saharan Africa. The migrant labour system with its single sex hostels creates an environment for the spread of HIV.

According to UNAIDS (2004:19), researchers interested in the role that migration plays in spreading HIV in South Africa, studied the pattern of infection in couples in Hlabisa, a rural district of Kwazulu-Natal in which nearly two-thirds of adult men spent most nights away

from home. The study confirmed that migration does play an important role in spreading HIV, but revealed a more complex picture than had been expected. The study also found that in nearly 30% of cases the infected person was the female partner who stayed home in the rural area, while her migrant partner was HIV-negative. In other words, migration may create vulnerability to HIV exposure at both ends of the trail, and the virus may be spread in both directions. Other cultural beliefs also contribute to this scenario.

Shell (2002:14) mentions that South Africa has been urbanising at an increasing rate. Rapid urbanisation is creating a pool of unemployed poor who search for new sexual partners for security, which also creates the spread of HIV.

5.11. The impact of HIV and AIDS on population and family structure

According to UNAIDS (2004:19), South Africa has one of the world's highest HIV prevalence and faces the greatest demographic impact. The probability of a 15-year-old dying before reaching age 60 has risen dramatically. HIV's impact on adult mortality is greatest on people in their twenties and thirties, and is proportionately larger for women than men. In South Africa, the mortality rate for 15-49- year- olds living with HIV, is now up to 20 times greater than death rates for people living without HIV. It primarily affects young adults, particularly women. This means the epidemic is heavily affecting household. Shell (2002:15-16) adds that if South Africa's epidemic remains the same, its population structure will become distorted. There will be fewer people in mid-adult years, and fewer women than men aged 30-50 years.

Shell (2002:15-16) rightly states that the people who are now falling ill and dying are the parents and leaders in society, which means that a generation of children will grow up without the role models they would normally have had.

5.12. Education

Shell (2002:21) points out that the epidemic's impact on education would inevitably have far-reaching implications for long-term development. Access to primary education is by law available, but AIDS affects children's lives and therefore their ability to utilise the facilities. This would leave fewer people to benefit from such further schooling/university education as are offered. AIDS adversely affects socio-economic prosperity and growth (compare 'child-headed households' and the number of orphans) and therefore also opportunities of normal education-related growth and development.

The study conducted by Booysen *et al.* of the Centre for Health Systems Research & Development at the University of the Free State (2002:11-14), found that a large number of children of school-going age from HIV and AIDS affected households did not attend school. A larger proportion of these children were female and between the ages of 14-18 years. According to the researchers the results indicated that a death in the household appears to be directly related to AIDS. This may result in older children being forced to interrupt their attendance of school to take over the household responsibilities.

5.13. Community support

The study of Booyesen *et al.* (2002:11-14) found that AIDS-affected households rely heavily on relatives and community support. Community support structures include savings clubs, burial societies, savings schemes, loan clubs and labour exchange schemes. However, family and community support systems are sometimes not available to poor households that lack the means and time to invest sufficiently in reciprocal arrangements.

The United Nations Development Programme (2002:3) focused on strategies for communities facing the challenge of HIV and AIDS. The main approach would be to link HIV and AIDS work to sustainable development. The development would include partnerships among all community structures, and the enhancement of interrelationships and interaction.

Throughout this chapter the impact of HIV and AIDS on the individual, families and households and communities has been debated. The researcher agrees that stronger emphasis must be placed on development of the individual, families and the community as proposed. This can be accomplished through the implementation of proper counselling, group work and community development programmes.

6. CONCLUSION

Chapter two focused on the impact of HIV and AIDS on the infected individual, the significant others, households and communities. It is evident that HIV and AIDS has an enormous effect on the infected individual, leaving him/her anxious, overwhelmed and depressed, and the individual's ability to adapt is also affected. Both the HIV-infected and their families are confronted with issues to deal with regarding grief, loss and other practical and psychological problems. The impact of HIV and AIDS on households and the community is especially severe. HIV and AIDS has an impact on households as they face severe financial and resource constraints that also usually result in increased reliance on welfare grants.

Studies found that the impact of HIV and AIDS on children is increasing. A high number of children of school-going age are not attending school and it appears to be directly linked to AIDS. The number of orphans and child-headed households is also increasing. The responsibility of caring for these children usually falls on a grandmother who would lack financial means. In the next chapter the focus will be on the training of volunteers for their role in Community Based Care as a response to HIV and AIDS.

CHAPTER 3

THE TRAINING OF VOLUNTEERS FOR COMMUNITY BASED CARE

1. INTRODUCTION

According to UNAIDS (2004:19), South Africa has a high number of people living with HIV and AIDS. The United Nations Development Programme (2002:9) states: While for several years HIV and AIDS was seen as strictly a health issue, a recent shift acknowledging the importance of communities as described in the United Nations General Assembly Special Session (UNIGASS) Declaration of Commitment on HIV and AIDS. According to this declaration, communities play a key role in the response to HIV and AIDS.

Van Dyk (2001:326) and Brennan (1998:123) are of the opinion that because of the HIV and AIDS crisis, both the family and the community had to become involved in care programmes as hospitals are overflowed with the very sick and dying AIDS patients while people with curable diseases, are turned away. Many health care professionals are unable to cope with the demands of the pandemic and suffer from burnout as they can no longer actualise the healing and alleviation of suffering to which they are professionally committed.

Uys (2003:3) views Community Based Care for people living with HIV and AIDS as the answer to this crisis and states that this form of care is likely to become the dominant form of AIDS care in South Africa.

The researcher agrees with the opinion of Van Dyk (2001:326) that South Africa is a society in crisis and our only hope is to look beyond the crisis and to use the rich resources and strengths that have always resided in our communities and to respond to HIV and AIDS. The researcher's view is also that HIV and AIDS is a challenge and people in the helping professions need to guide the volunteers of the Community Based Care programmes in their service rendering to the HIV and AIDS patients.

In chapter one the researcher quoted authors like Corey & Corey (2002:358) and Roux (2002:240-242), who are of the opinion that the HIV and AIDS pandemic continues to expand and volunteers therefore need to support people living with HIV and AIDS. Cameron (2003:33) views volunteers as a key part of Community Based Care and states that they need to be supported in their service rendering. Research done by Russell and Schneider (2001), Melkote *et al.* (2000), Brouard (2005) and Campbel (2005) stresses the importance of Community Based Care and the role of the volunteer in Community Based Care programmes.

The training of volunteers is also an important strategy for reducing the extent and the severity of HIV and AIDS. Corey and Corey (2002:358), Roux (2002:240-240) and Cameron (2003:33) mention that it is important to train all volunteers who will be involved in Community Based Care to provide a high standard of care. If volunteers are not equipped with the knowledge and skills they need, they will not be able to function as part of the Community Based Care team, and the programme will therefore not achieve its goal. The training needs to provide a wide range of knowledge and skills, which volunteers will need in order to provide a high standard of holistic care and support.

Chapter three will focus on Community Based Care in South Africa, the importance of the volunteer in these programmes and the current training that is provided to them.

2. COMMUNITY BASED CARE

2.1 Definition of Community Based Care

Uys (2003:1) mentions that as early as 1986, the Committee on a National Strategy for AIDS (CNSA) for the USA, described the system of AIDS care in terms of three components, namely hospital care, out-patient care, and community based care. Through the literature study, the researcher found that different terms are used, for example, home/community based care, community based care services and community based care. For the purpose of this research, the researcher will refer to Community Based Care.

Uys (2003:3) defines Community Based Care as care occurring at a patient's residence to supplement or replace hospital-based care. This includes medication management, palliative care and social support.

Van Dyk (2001:330) describes Community Based Care as the care given to individuals in their own homes when their families, their extended families or those of their choice support them. A multi-disciplinary team support these Community Based Care givers. The team consists of all the people who are involved in care and support and may include a medical practitioner, nursing supervisor, social worker, health educator, physiotherapist, AIDS health promotion workers, volunteers, traditional healers, religious healers as well as religious leaders.

Uys (2003:3) reminds us that, if the care of the HIV and AIDS patients is to be both comprehensive and cost-effective, it must be conducted as much as possible in the community, with hospitalisation only when necessary.

2.2. The goals and objectives of Community Based Care

Van Dyk (2001:327) states that the main goal of Community Based Care is to provide the structures, resources and framework that will enable the family or community to look after its own sick members. The important functions of Community Based Care programmes are to empower the community and the family to cope effectively with the physical, psychosocial and spiritual needs of those living with HIV and AIDS, to educate the community about the prevention of HIV transmission, to support family members in their care giving roles, and to reduce the social and personal impact that living with HIV infection and AIDS, makes on all those concerned. A very important function of Community Based Care programmes is to establish a well-functioning referral system to hospitals, clinics, hospices and other health care facilities in the community.

The researcher views the role of the volunteer as important in Community Based Care and is of the opinion that the volunteer must realign himself/herself with the ultimate goal of Community Based Care for people living with HIV and AIDS. How successful the people living with HIV and AIDS will function, will depend on how well the volunteer performs his or her task as to empower and educate the HIV and AIDS patient and the community through the Community Based Care services.

2.3. Advantages of Community Based Care

Van Dyk (2001:330) highlights a few advantages of Community Based Care. The author states that good basic care can be successfully provided in the home. People who are very sick or dying often prefer to stay at home so that they can spend their last days in familiar surroundings, especially when they know that they cannot be cured in hospital. Sick people are comforted by being in their own homes and communities with family and friends all around them. The care at home prevents the patient from feeling isolated and rejected. Community based care promotes a holistic approach to care.

This means that the physical, social, cultural, psychological, emotional, religious and spiritual needs of a patient can all be fulfilled by the family and the multi-disciplinary team. Community Based Care can be comprehensive if it includes the rehabilitative, preventative, promotive, curative and palliative care.

Uys (2003:5) mentions that Community Based Care is usually less expensive for families who care for someone at home. The cost for transportation to and from the hospital can be financially crippling. If the sick person is at home, the family members can attend to their other responsibilities more easily. For the family member, it can become very difficult to cope with his or her own life if a loved one is in hospital and if the caregiver has to make frequent trips to a hospital. Because the pressure on hospitals is reduced by home care, doctors, nurses and other health care professionals can use their time more effectively to care for their critically ill patients in hospital.

Home care reduces the enormous pressure on provincial and national health care budgets. The network of health services available in Community Based Care enables family members to gain access to counselling as a support system for themselves. The involvement of families and communities in the care of their own patients creates general AIDS awareness in the community and this helps to break down fear, ignorance prejudice and negative attitudes toward people with AIDS.

In the opinion of the researcher the empowerment of the volunteer to care for the HIV and AIDS patient in the community is a very significant concept, to reduce the pressure on health personnel. The researcher is also of the opinion that family members require the necessary knowledge and skills in the process, since they have to be part of the process of caring for their own family members

Van Dyk (2001:328) mentions that Community Based Care is sensitive to the culture and value systems of the local community. The intervention in Community Based Care is proactive rather than reactive and it puts AIDS care providers in touch with potential orphans and people who desperately need help. Community Based Care is empowering of nature, which means that people take responsibility for and control of their own lives and communities.

According to Campbell, Nair, Maimane and Sibuya (2005:22) of the Centre for HIV networking at the University of Kwazulu- Natal, the roll- out of Antiretroviral Treatment (ART) provides hope for people living with HIV and AIDS. Discussions of the human resources necessary for effective roll-out tend to focus on medically trained personnel, such as doctors and nurses. Less attention is given to the role that grassroots community

representatives will need to play in ensuring the success of successful treatment. According to the researchers, Community Based Care workers will need to play an important role in the ART roll-out plan. The shortage of staff being faced by hospitals will have implications for the implementation of a full-scale antiretroviral programme. AIDS patients rely heavily on the support of Community Based Caregivers and they could play a crucial role in the monitoring and adherence of Antiretroviral Treatment.

2.4.Problems with Community Based Care

Van Dyk (2001:329) indicates that the following problems associated with Community Based Care, should be considered:

- Patients often feel isolated, especially when they are confined to the home or bed.
- Many people in communities are not ready for Community Based Care because of ignorance, superstition and mainly of fear of being stigmatised by other members of the community. For these reasons people might reject the concept of Community Based Care.
- This situation further contributes to the feelings of anguish, desperation and loneliness that often characterises AIDS.
- Non-compliance with treatment often occurs because the patient or caregivers do not know when or how to administer medication.
- A lack of knowledge about the disease, treatment, emergency situations and community resources often hampers Community Based Care, and mainly caregivers are afraid that they themselves could become infected with HIV.

- One of the greatest dangers of Community Based Care is that the caregiver might sometimes retire from the care giving process because of exhaustion and burnout occasioned by the extreme demands of caring for a terminally ill patient. Therefore it is vital for caregivers to have support systems.

The researcher agrees with Van Dyk (2001:329) regarding the problems of Community Based Care. The researcher's practical experience is that there is still much stigma attached to HIV and AIDS in communities. Presently caregivers are also overloaded and it might happen that they will leave the HIV and AIDS programme because of burnout.

2.5.Models of Community Based Care

According to Van Dyk (2005:262), there are three different models for Community Based Care, namely: Integrated home community based care, single service home based care and informal home based care. Uys (2003:5) also makes a distinction between the three different models of community based care as mentioned by Van Dyk (2005:262).

- ***Integrated home community based care***

Van Dyk (2005:262) states that the integrated community home based care model works by linking all the service providers with patients and their families in a continuum of care. The patient and family are supported by a network of services, such as community care givers (volunteers), clinics, hospitals, support groups, non-governmental organisations and community based organisations, as well as by the larger community. This integrated model

allows for referral between all partners as trust is built, and it ensures that community caregivers are trained, supported and supervised.

Uys (2003:6) states that this form of care is given based on palliative care standards and is ultimately aimed at preventing the illness by increasing openness and understanding and thereby changing behaviour. Figure 3.1 illustrates the Integrated Community Based Care model

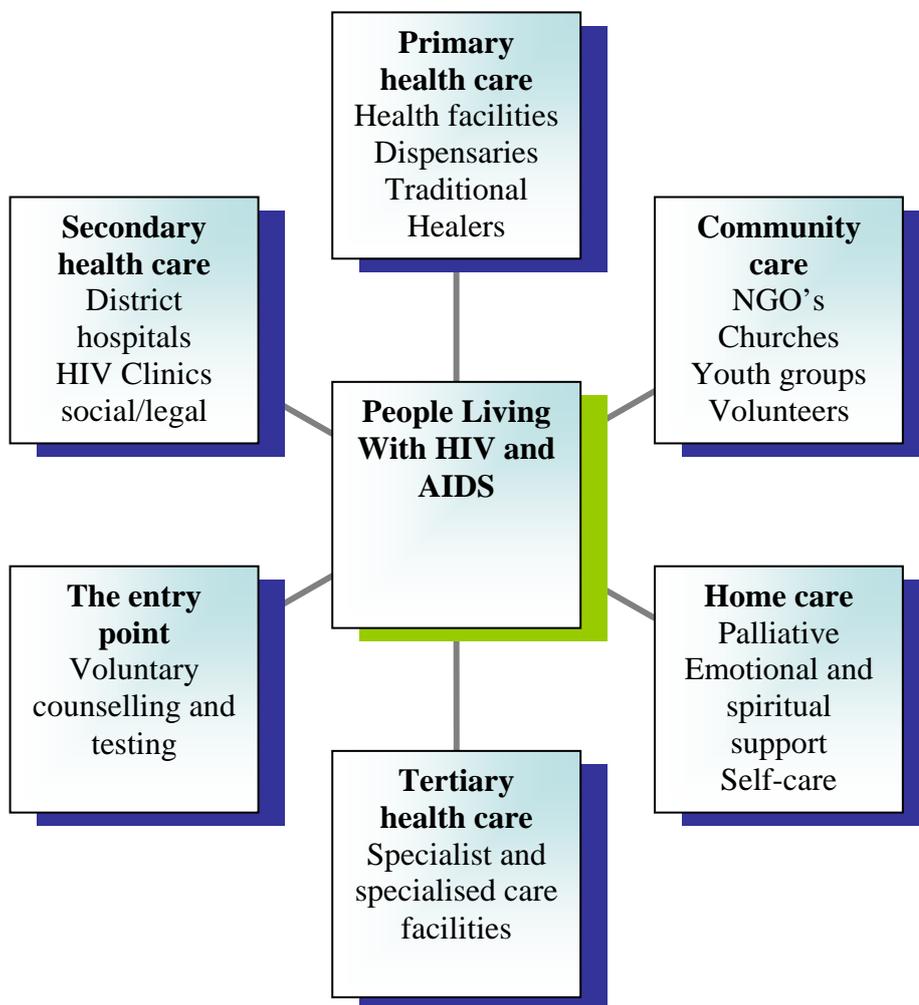


Figure 3.1

An integrated community based care model

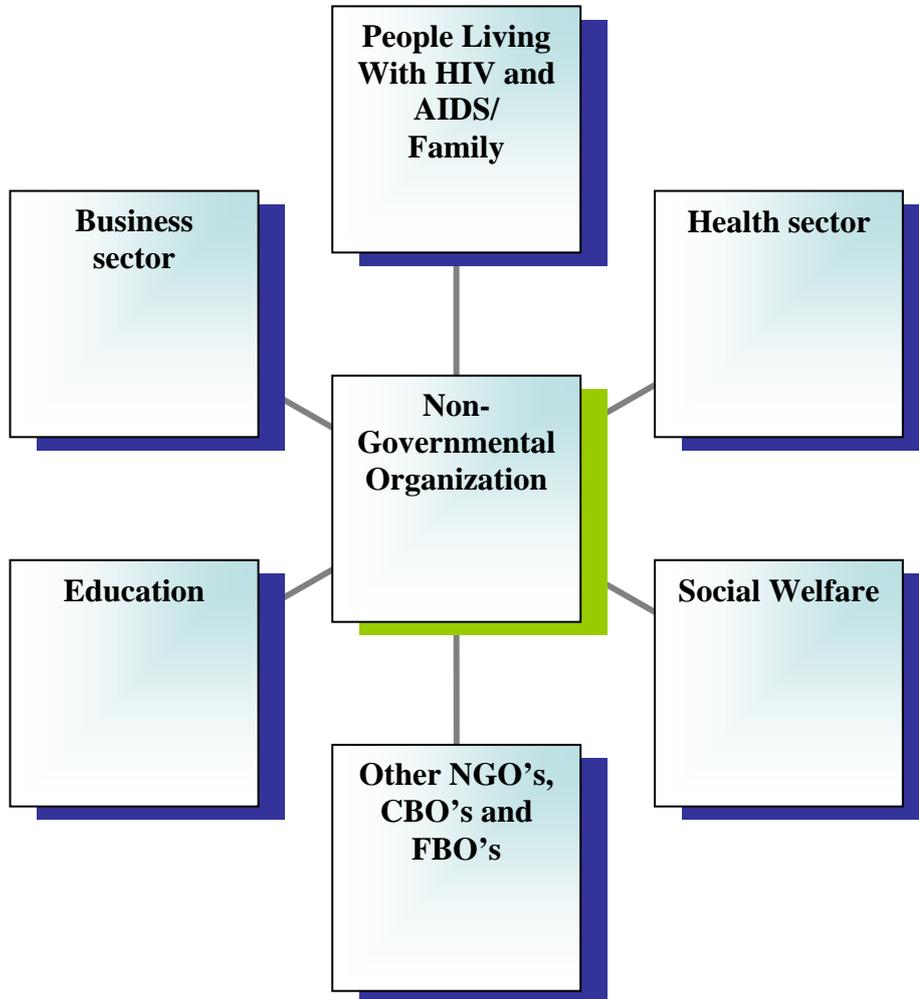
(Source: Van Dyk, 2005: 263)

- *Single service home-based care*

Uys (2003:7) states that in the single service home-based care setting, one service component (a hospital, a clinic, a non-governmental organisation or church) organises home-based care by recruiting volunteers, training them, and linking them with patients and their families at home. Van Dyk (2005:262) mentions that many home-based care programmes started this way and built their way up to offer integrated care as they recruited other partners. This model is based on the following principles:

- The responsibility of providing community based care services are given to a non-governmental organisation.
- This organisation is responsible for identifying the needs of the People Living With HIV and AIDS and his/her family. Services that are needed by the patient and his/her family are provided by this organisation
- This organisation acts as co-coordinating structure for services to the patient and his/her family and also network with other organisations in the community
- The entire community based care programme is initiated by this organisation
- In order to ensure quality services to the patient, funding is made available to the organisation for administration, running costs, transport, salaries, stipends for volunteers, training, etc
- The services at the organisation will be provided by a team which consists of a professional nurse, social worker, project-coordinator and volunteers/community caregivers, based at the organisation

Figure 3.2 is an example of a Single Service Home Community Based Care model



- *Informal home-based care*

Van Dyk (2005:262) states that in the informal home-based care setting, families care for their members at home with the informal assistance of their own social network. Nobody has any specific training or external support and there is no organisation to structure or supervise this system. People are rendering this service according to what they assume will be best for the patient. The researcher is of the opinion that the above-mentioned model is not practical, since the patient as well as the family member who acts as caregiver, will be isolated and will function without guidance from other role-players. This could lead to different psychosocial problems as discussed in chapter two, for the patient and for the family member.

According to the researcher the integrated model and the single service home based care models can be successfully implemented in the community. However, Uys (2003:5) is of the opinion that it would be the ideal if all home based care could be delivered through an integrated model. This approach ensures that the patient and family get all the help they need, from the day the diagnosis is made, through all the phases to terminal care. The family also gets support after the death of the patient. It also ensures that the quality of care is optimal since there is supervision and support for volunteers and community care workers and different services assist each other in the improvement of care.

The researcher supports the overall view of Deffilipi (2003:19), that interventions to assist patients, should be based in and owned by the affected communities themselves. Members of the community are in the best position to know which households are most severely affected and what kind of help would be appropriate. They know who is dying, who has

died, who has been taken in by relatives, who is living alone and who has resources to stay alive. The researcher is of the opinion that volunteers from within the community are more likely to visit households regularly to offer supportive help. This supportive service is best done in a structured Community Based Care programme. Van Dyk (2001:330) indicates that there must be a well functioning network and referral system between the Community Home Based Care team and the hospitals, hospices, clinics and other community based health care institutions.

3. THE ROLE OF THE VOLUNTEER IN THE IMPLEMENTATION OF THE COMMUNITY BASED CARE PROGRAMME

3.1. Definition of Volunteer

From the literature study, the researcher finds that most authors refer to the volunteers in the Community Based Care programmes as community caregivers, community health workers or volunteers. For the purpose of this study the researcher will use the term volunteer. Volunteer is defined as a person who offers his or her services or who is recruited to render a service at a welfare agency, usually without remuneration (SAVF Handleiding vir vrywilligers 1997:51).

3.2. The importance of volunteers in the Community Based Care Programme

The White Paper for Social Welfare (1997:5) views volunteers as a significant human resource to extend welfare services. The paradigm shift is towards the utilisation of volunteers in social welfare programmes, which is in line with the vision and the mission of

the National Developmental Social Welfare Strategy. Clarke (1996:23) states that the history and development of social work is inextricably linked with working with volunteers. Social workers have developed many programmes for recruiting, training and supervising volunteers.

According to the researcher, volunteerism is not a new phenomenon in South Africa, but the implementation of Community Based Care for the HIV and AIDS infected and affected, utilising volunteers, is basically a recent phenomenon. Volunteers play a significant role in Community Based Care Programmes in the service delivery to the HIV and AIDS patient as there is not enough manpower to specifically address the psychosocial needs of these patients.

The researcher is also of the opinion that the volunteer must realign himself/herself with the ultimate goal of Community Based Care for people living with HIV and AIDS. How successful the people living with HIV and AIDS will function will depend on how successful the programme is implemented.

Since the focus of the research is on the volunteer in the Community Based Care programmes, the researcher wants to focus specifically on the role of the volunteer in the Community Based Care programmes.

Marston (2003:116) states that volunteers in Community Based Care programmes come from a variety of backgrounds. They may be trained and experienced professionals, family, or members in the community who want to reach out to those in need. Before volunteers can begin with their tasks, they need to be exposed to basic training in the caring of HIV

and AIDS patients. At a community level, volunteer organisations made up of ‘everyday people’ have taken the lead in educating the public about HIV and AIDS and offering support to persons affected and infected by HIV and AIDS. The researcher’s experience in practice is that volunteers in the Community Based Care programmes are from the community. They are mostly unemployed youths or adults in the community.

According to Van Dyk (2001:330), volunteers should be recognised as key workers in the programme. They must be elected by the community and they must be properly trained in Community Based Care. Uys (2003:12) draws our attention to the fact that the concern regarding ongoing sustainability of community based care programmes, results in prioritising the use of volunteers as a cost-saving measure. Omoto, Gunn and Crain (1998:107) mention that the financial cost of caring for people living with HIV and AIDS drop markedly when volunteers provide services that would otherwise be paid for by government and other institutions.

The researcher’s experience in practice regarding the Community Based Care programmes is that volunteers are presently paid for their services rendered. Van Dyk (2005:264) mentions that the issue of payment for volunteers is a complex one. Many home based care organisations realise that volunteers are often poor themselves, and remain active and function best if they are given incentives in the form of transportation, reimbursement, food and stipends. Some organisations offer volunteers some skills development programmes that may generate some work opportunities for them.

Van Dyk (2001:330), also explains that volunteers can help alleviate some of the psychological toll that HIV disease exacts from people living with HIV and AIDS and their

social networks. Volunteers are the medium to support people living with HIV and AIDS in terms of stress they are experiencing because of the illness. Volunteers can also help people living with HIV and AIDS and their social networks to find new meaning in their lives and to surmount challenges posed by living with HIV, including changed capabilities and stigmatisation by others.

3.3. Selection of volunteers for the HIV and AIDS Community Based Care Programme

Van Dyk (2005:264) states that some of the factors to be considered when selecting volunteers are age, gender, accessibility (do they live near the patient), willingness, commitment, dedication, time (are they full-time employed), understanding of the problems involved, reliability, honesty, the ability to relate well to people and the integrity to respect confidentiality and people's basic rights. The author does not elaborate on the selecting criteria.

According to the researcher's experience, it is best to use volunteers above the age of 18 years. Volunteers above the age of 25 are the most reliable group. Gender is not really a problem, but normally caregivers are female, however, male patients prefer to be cared for by a male volunteer. Volunteers also prefer to work in the area where they stay, since they do not have access to transport. They are not in full time employment and this is the only work that they rely on. Most volunteers are dependent on the stipend that they receive from the community based care organisation. The non-payment of stipends therefore creates a problem and influences the commitment of volunteers in their service delivery to the HIV and AIDS patient. Volunteers respect the rights of the patient and treat all information received with confidentiality.

Van Dyk (2001:330) elaborates and states that, volunteers should be used wherever they fit best in terms of their personalities, qualities, expertise and interest. Volunteers directly involved in patient care should be able to speak the language of the patient and his or her family in order to communicate effectively. They must be able to write, read and calculate, since they are involved in nursing care and record keeping where the skills are necessary. They must have an interest and preferably previous experience in basic nursing care. They must also have good interpersonal skills and good communication skills. Cameron (2003:46) also supports the view of Van Dyk (2001:330) and mentions the same qualities, especially as a pre-requisite for selection for the training programme.

The researcher is of the opinion that although some volunteers do not have all the qualities as mentioned by Van Dyk (2001:330), they must be trained to acquire these qualities and skills. Training will improve their chances of meeting the demands, which, in turn, could lead to both the patient and the volunteer to experience more confidence, satisfaction and a sense of achievement in the battle against the disease.

4. THE IMPLEMENTATION OF THE COMMUNITY BASED CARE PROGRAMME

4.1. The Community Based Care team

Uys (2003:6) and van Dyk (2001:330) indicated that the Community Based Care team providing services to the HIV and AIDS patients need to consist of the following people:

- The individual with HIV and AIDS, the family and /or significant others in the home.
- The programme coordinator who is usually a professional person such as a nurse or a social worker.
- Professionals like nurses, community health or TB workers, professionals of helping professions, medical doctors, psychologists, pharmacists, physiotherapists and occupational therapists.
- Volunteers and others who offer supportive services such as residential care, respite services, pastoral care, legal aid and advice, transport services.
- Traditional healers and herbalist, community leaders, traditional leaders, village committees, religious and spiritual leaders, teachers and youth groups.

4.2. The tasks of the volunteer and team in the Community Based Care Programme

Marston, (2003:115-116) and Defilippi (2003:22) indicate that the volunteers and team should perform the following tasks in the Community Based Care programmes:

- To make a holistic assessment of the patient and his family
- To plan care and support, involving the patient and his/her family in all the stages of the care planning
- To evaluate the educational and training needs of the patient and family
- To evaluate the need for human, material and social resources
- To identify actual and potential problems and to develop a realistic plan to alleviate those problems
- To assess whether or when the patient and his/her family may need to be referred to other organisations
- To manage pain and other symptoms
- To identify children in distress and plan for their care and support
- To identify actual and potential bereavement issues and to assist with bereavement issues after the death of the patient
- To provide counselling for the patient and family and to help them come to terms with death and dying
- To provide the best possible quality of life for the patient
- To empower the patient and family to become as independent as possible in aspects of care and self-care

Table 3.1 Core functions of the volunteer in the integrated home community based care model

Core common functions	Child/family care	Home care
Identifying community needs and resources and mobilization of the community	Establish and support child care committees	Conduct home visits to assess care needs (nutrition, physical care, emotional needs)
Networking	Identify vulnerable children/families Identify other service organizations to avoid duplication of services	Provide information, education and communication materials on prevention of HIV and AIDS including other STD's Provide training for family members on care of the sick
Referral to and from other services	Refer cases to Social services for future planning and support with regard to placement of infected and affected children	Dots supervision Referrals and liaison with clinics and hospitals Referrals to service providers for ongoing services
Identifying eligibility and helping to access benefits	Refer cases for alternative care arrangements eg. Residential Foster Adoption	Provision of information on grants and points of access
Material assistance Nutrition Clothing Shelter Financial	Placement of children in care options Provision of hospice care day care facilities	Provision of food parcels Organizing collection of and distribution of clothes, blankets etc
Poverty alleviation	Development of income generating projects	Linking households with poverty alleviation projects
Emotional support of families including counselling	Link with faith based organizations and specialist Ngo services	Providing emotional and spiritual services

4.3. The first assessment of the patient and family

Brennan (1998:128) and Van Dyk (2001:332) emphasise that, before the team can provide a comprehensive service that meets the physical, spiritual, psychosocial, emotional and cultural needs of those living with HIV and AIDS, it is necessary to find out what the needs of the patient are.

Marston (2003:116) mentions that before making home visits, all members of the Community Based Care team must receive training, including training in the principles of palliative care. Volunteers must have the basic training and understand the physical, spiritual, psychosocial and emotional conditions that they may encounter. When visiting the patient for the first time, the volunteer must be able to do a thorough assessment of the patient and family. The assessment of the patient and family should be holistic with a focus on the physical, spiritual, psychosocial and emotional issues. All the following factors need to be taken into account:

- ***Medical or nursing needs:*** Does the client have any medical or nursing problems that need to be attended to by a nurse or does he or she need to be referred to a hospital or clinic? Are there functional impairments, infections or diseases of the cardiovascular, respiratory, neurological, digestive or genitor-urinary systems? What is the general nutritional state of the patient? Are there skin infections? How is his or her general hygiene? Does the patient have pain? Is the patient co-infected with tuberculosis and is it necessary for the community caregiver to supervise directly observed treatment (DOTS) as part of the home visit?

- **Basic needs:** Does the client have food, shelter, clothes, blankets, electricity, water and sanitation? If the patient lacks these basic requirements, the volunteer and other team workers must refer the case for assistance. The researcher's experience in practice is that food parcels are available for the patient and family. These food parcels are given out on a monthly basis.
- **Activities of daily living:** Is the client mobile, or is he or she confined to bed or is he/she house-bound. Does the client need somebody to assist him or her to eat? Is the client incontinent, or is he or she able to use the toilet. Who performs the task of bathing, cooking, washing clothes, shopping for the client? Van Dyk (2005:266) is of the opinion that volunteers make a valuable contribution in executing these tasks for the patient. The researcher is of the opinion that volunteers need to guide and train family members to do these tasks.
- **Social needs:** Who is the primary caregiver? How many people live in the house? Do friends and neighbours offer their support? The researcher is of the opinion that the patient needs to be linked with support systems as from the first contact or home visit. If the patient does not have a support system, the church can assist in that regard.
- **Financial needs:** Does the household have any income? Does the client receive a disability grant or any pension? According to the researcher the volunteer must also assess whether the patient has knowledge about the criteria and the knowledge regarding the different types of grants available. What other sources of income are there? Is there any assistance from welfare departments, non-governmental organisations and churches?

- ***Spiritual needs:*** To what religious group does the client belong? Does the client have any spiritual needs that are not being attended to? Is there any minister/pastor visiting the person? The researcher regards the spiritual needs of the patient as important especially when the patient is terminally ill. The experience in practice is that the spiritual needs of the patient are sometimes neglected.
- ***Psychosocial needs:*** Are relationships in the house affected by the patients HIV infection? Does it cause much tension? Does the patient or family show any psychosocial problems such as denial, guilt, fear, suicidal thoughts, altered sleep patterns, anxiety, coping with multiple losses, etc? Is the patient worried about the future of his/her children when he/she is dead?
- ***Needs of the primary caregiver:*** The primary caregiver, who is usually the mother or grandmother of the family, carries the burden of taking care of the patient. The volunteer and team must assess the situation for possible solutions.

4.4. Follow-up intervention services

According to Marston (2003:123), with each visit a holistic assessment will have to be carried out to evaluate the following aspects:

- The progress of the disease
- The effectiveness of the training
- The effectiveness of counselling
- The effectiveness of pain and symptoms management and medication counselling

- The impact on family members
- The ability of the patient to carry out the activities of living
- Special needs to be met
- Referrals to be made to other organisations
- Nutritional needs
- The impact of the disease on the patient
- New symptoms, infections

The volunteer should know when to refer the patient or family member to the professional nurse or social worker. The family should be included in the education and training within the home.

Complete and accurate records should be kept of each visit. An example of record keeping is illustrated in table 3.2. These records should be confidential and should be kept in a safe place.

Table 3.2

Assessment form

Patient assessment:	Date:
Surname:	Date of birth:
First Name:	Id no:
Religion:	Minister:
Address:	
Tel no:	Ethnic origin:
Next of kin:	Address:
Surname:	Tel no:
First name:	Tel no (w):
Address:	
Primary caregiver:	Age:
Relationship to patient:	
Hospital:	Current medicine:
OPD number:	Clinic:
CBO's involved:	
Organisation:	
Allergies:	
Referred by hospital clinic:	
Contact person:	Tel no:
Other hospice/organization involved:	

Presenting symptoms

Thrush	Pneumonia	TB
Dysphagia	Vomiting	Wounds
Skin rashes	Nausea	Diarrhoea
Sweating	Drowsiness	
Weight Loss	Confusion	Malignancy
Coughing	Mental status	
Dry mouth	Dyspnoea	
Weakness	Anorexia	
Sleeping		
What health education was given?		
Is the family aware of client's status?		
Relationship to client:		
Mobility:		
General comments:		
Children:		
Age:		
Relationship to patient:		
School:		
Future plans for children:		

Assessor:

Date:

Marston (2003:116) is also of the opinion that most patients with AIDS wish to be taken care of at home until they die. It is the ideal that they should be cared for and supported by a professional and a volunteer. The home visits to a dying patient should become more frequent for the following reasons:

- Pain and symptoms management are essential for the comfort of the patient.
- The patient and family will require additional support at this time to deal with the emotions associated with loss and their fear of the unknown.
- All involved have to be prepared for the death. Information should be shared with all involved, including children. The volunteer should at least make one bereavement visit after the death of the patient.

4.5. Implementation of the Integrated Community Based Care model

Defilippi (2003:22-28) indicated that a holistic comprehensive care package should be available for the person living with HIV and AIDS along a continuum that extends from pre-diagnosis to bereavement follow-up. Defilippi (2003:22-28) gives an example of the implementation of the integrated Community Based Care model. This model was developed to address the holistic needs of the person living with HIV and AIDS. The volunteers provide voluntarily counselling and testing and trained caregivers provide pre-and post-test counselling. The medical personnel at hospitals take the primary responsibility for the prevention and clinical management of opportunistic infections with the assistance of professional nurses from primary health care clinics and hospices as well as the caregivers and volunteers. The hospice interdisciplinary team provides expertise in the management and prevention of pain and other symptoms.

Van Dyk (2001:330) and Defilippi (2003:22-28) also state that a Non Governmental Organisation or Hospice can coordinate the community care programme. The provision of quality nursing care will rest with the professional nursing supervisors. Community care workers supported by volunteers provide the bulk of care. Social workers are supposed to render psychosocial care with assistance of the volunteers. Volunteers refer the patients and their families in need of welfare services to the social worker.

5. THE TRAINING OF VOLUNTEERS OF THE COMMUNITY BASED CARE PROGRAMMES.

5.1 The importance of training for volunteers of the Community Based Care programmes

The researcher is of the opinion that training is important for all volunteers. Since HIV and AIDS is a specialised programme, the volunteers in the Community Based Care Programmes need effective and ongoing training.

Corey and Corey (2002:358), Roux (2002:240-240) and Cameron (2003:33) mention that it is important to train all caregivers who will be involved in community based care to provide a high standard of care. If caregivers are not equipped with the essential knowledge and skills they need to render an effective service, they will not be able to function as part of the team. As a result of this, the programme will not be so successful. One would like to expect the training to provide a wide range of knowledge and skills for volunteers and caregivers in order to provide a high standard of holistic care and support to the HIV and AIDS patient.

5.2. The training providers

In the Municipality of Potchefstroom, training is given by mainly three Non-Governmental Organizations, namely Ragoga (the organisation offers the training curriculum on the behalf of the Department of Health to volunteers), Soul City, which is also a Non-Governmental Organisation and the Nursing Department of the North-West University (Potchefstroom Campus).

The training presented by the Department of Health and the mentioned training institutions, is based on the same curriculum as set out by Cameron (2003:37-47). The goal of the training is to equip volunteers to render a holistic service to the HIV and AIDS patient. For the purpose of this study, the focus will be on the 59-day training programme of the Department of Health. The 59-day training course in Community Based Care basically equips volunteers with knowledge and skills in all the areas, so that they can work as members of an integrated team to educate and support patients. The training course focuses on holistic training for holistic care. This training takes place over a period of 59 days, but depends on the prior knowledge of the learners and the needs of the care programme for which the learners are being trained, as well as the size of the group.

Through an in-depth study and literature research regarding the training of volunteers, the researcher also found that Duma and Cameron (2002:46-51) and Cameron (2003:33-47) did extensive research and published some of this information. For the purpose of this study, the researcher will therefore discuss the curriculum as set out by Cameron (2003:33-47) regarding the training of volunteers for the Community Based Care programme.

5.3.Design of a training curriculum

Cameron (2003:37) states that the Community Based Care course needs to provide training in the wide range of knowledge and skills that volunteers will need in order to provide a high standard of holistic care and support. Inadequate training will result in poor care. The course needs to combine theory and practice and make provision for formative evaluation, reflective learning and self-evaluation.

The curriculum also needs to take into account the needs and resources of the home-care programme for which it is equipping volunteers. The curriculum below was developed to cater for the many different areas of Community Based Care. The content of it has been divided into different modules that can be presented over a period of twelve months. Some modules can also be presented on its own.

The components of a community caregiver curriculum as set out in table 3.3 are as follows:

Table 3.3 Components of a community caregiver curriculum

Community Caregiver Holistic training Head knowledge Empowerment skills Heart knowledge	Health systems Hospital, clinic, hospice Principles and practice of palliative care Continuum of care
Person in need of care and family Holistic needs-physical, social, emotional and spiritual Response to illness Other problems	Community Resources Language, Culture, religion and beliefs

5.3.1. The Learning outcomes

Cameron (2003:38-43) and the training manual of the Department of Health outline the learning outcomes for the training course as follows:

Module 1 –Orientation

The volunteers are demonstrated an awareness of the requirements of the course. The focus is also on an in-depth understanding of oneself and one's attitude towards people infected with HIV and AIDS. The volunteers are expected to understand their role and responsibility in providing care

The learners will be able to:

- Demonstrate an awareness of the requirements of the course.
- Develop an understanding of themselves.

Module 2- Community based home care

Volunteers are trained on the concept of Community Based Care, the different models of Community Based Care in their communities and their role to the HIV and AIDS patient, and explore their own feelings and fears associated with their role. They are also trained about recording techniques and the different styles of reporting.

The learners will be able to:

- Identify the different health care and community structures in their area.
- Understand their role and responsibilities in the provision of care.
- Explore their feelings and fears associated with their role.
- Record, report, and refer in an appropriate manner.
- Demonstrate an awareness of the relevant ethical/legal issues.

Module 3-Teaching skills

A key aspect of the volunteer is to equip the community with the training that they receive through the course in order to empower families and the community on HIV and AIDS. Volunteers learn to understand their role as teacher during the course presentation and receive guidance on the different methods to teach people in the community.

The learner will be able to:

- Understand their role as teachers.
- Use relevant teaching methods and media to teach the person living with HIV and AIDS and families.
- Identify ‘teachable moments’ and know how to use them.

Module 4-Sexually transmitted infections including HIV and AIDS

According to Evian (2003:261) there is a close relationship and association between common sexually transmitted infection (STI) and HIV and AIDS. The care and the

prevention of STI is one of the most important and effective strategies for the control of HIV and AIDS.

This model is therefore important as volunteers focus on the definitions of STI and HIV and AIDS and the signs and symptoms and progression of HIV and AIDS, the modes of transmission, the problems associated with HIV and AIDS and the importance of safe sex practices.

The learner will be able to cope with the following aspects:

- Identify the signs and symptoms of STI.
- Define STI including HIV and AIDS.
- Take a history from an STI client.
- Explain the complications of common STI.
- Explain the progression of HIV and AIDS.
- Discuss the causes and problems associated with STI.
- Counsel STI clients on safer sexual practices.
- Explain how condoms work and demonstrate their use to a client.

Module 5-Tuberculosis

Evian (2003:243) is also of the opinion that Tuberculosis (TB) is the most common, serious and life-threatening opportunistic infection in people with HIV and AIDS. There is a higher risk of developing Tuberculosis if a person is HIV positive.

Through model 5, volunteers learn about the TB and the DOTS programme. The focus is on the spread of TB, the signs and symptoms of TB, the risk factors and the treatment of TB. The focus is also on the relation between TB and HIV and AIDS and the role of the volunteer in the community treatment process.

The learner will be able to incorporate the following:

- Identify the signs and symptoms of TB.
- Understand how TB is spread.
- Understand directly observed treatment (DOT).
- Understand TB treatment.
- Understand the interaction between TB and HIV and AIDS.

Module 6-Communication

The focus of model 6 is to create an understanding of the importance of communication at all levels by different categories of caregivers. The importance of communicating and the different communication methods are highlighted.

The learner will be able to:

- Understand what communication means.
- Identify different types of communication.
- Use different types of communication.
- Understand the role of communication in community entry.

Module 7-Spiritual, religious and cultural issues

The learner's learnt abilities will include the following:

- Describe several behaviour patterns in the community that place a person at risk of getting HIV and AIDS, STI or TB.
- Discuss various barriers in the community that may prevent individuals from changing those behaviour patterns that place them at risk.
- Discuss the role of religion, culture and tradition in the prevention, control and care of HIV and AIDS, STI' or TB.
- Explain the strategies for overcoming various barriers and their implications for the prevention and control of HIV and AIDS, STI or TB.

Module 8-Infection control

Van Dyk (2005:279) states that the fear for infection should never prevent us from caring for people with HIV and AIDS. This module is therefore important for volunteers to acquire the necessary knowledge and skills to prevent and control the spread of infection both in the home and in the community.

The learner will be able to:

- Define infection control.
- Discuss various ways infection can be spread in health care settings and communities.
- Describe various realistic ways and methods of preventing the spread of infections in health care settings and communities.

- Describe various ways of monitoring compliance and standards of practice in the prevention and control of HIV and AIDS, STI or TB in health care/social/school/ settings, according to national policies.
- Discuss cultural practices/traditions in the community that may promote the spread of infection.
- Explain strategies that can be considered in the community for the prevention of HIV and AIDS, STI or TB transmission.

Module 9-Incorporating palliative care principles into basic nursing care in the home

Volunteers acquire the necessary knowledge and skills on palliative care and basic nursing skills, basic skills such as first aid training.

The learner's will have gained knowledge on the following:

- Identify the core elements of palliative care.
- Share basic knowledge of disease and disability.
- Discuss the importance of providing a continuum of care.
- Link signs and symptoms to the relevant body systems.
- Demonstrate efficient use of body mechanisms so as to diminish the risk of injury during the process of care.
- Describe appropriate interventions for common symptoms.
- Discuss the measures that should be taken to ensure client safety in the home.
- Discuss maintenance of health status for the child and adult client as well as the family.
- Discuss the use of “teachable moments’ in linking care to prevention.
- Explain when, why and how to initiate referral.

- Asses an emergency situation and provide basic life support and first aid in order to stabilise a client prior to transfer or referral.
- Render a wide range of basic first aid services even if the required resources have to be improvised.
- Maintain accurate statistics and PLHA care records.
- Discuss the value of evaluation and audit.
- Apply and adapt their knowledge in order to render education to the community.

Module 10-Social support

Through this training module, volunteers need to know the different types of grants that are available, eg. disability grants, child support grants, care dependency grants and foster care grants, the procedures for application and the criteria needed to qualify for a grant. Social support also includes housing/shelter, legal services and nutritional supplies. Volunteers learn how to offer psychosocial support, to do an assessment on the type of counselling needed by the patient and family and how to conduct bereavement support. They also learn how to establish support groups for people living with HIV and AIDS.

Van Dyk (2005:174) defines counselling as a facilitative process in which the counsellor, working within the framework of a special helping relationship, uses specific skills to assist clients to develop self-knowledge, emotional acceptance, emotional growth and personal resources.

Knott (2003:51) and Evian (2003:275) are of the opinion that counselling is necessary for the psychosocial support of the patient with HIV and AIDS. The volunteer therefore needs the skills and must be trained to do counselling.

The researcher views counselling as the most important aspect in the training programme to address the needs of the HIV and AIDS patient.

The learner will be able to:

- Define social support.
- Identify the beneficiaries of social support.
- Identify the skills needed to provide social support.
- Identify community support and referral possibilities.
- Describe various ways of monitoring social support services.

The researcher found that this area is mostly neglected in practice although the volunteers receive the necessary training. This forms the core of the study as formulated in the problem formulation (p6). The researcher wants to find out why the volunteers neglect this area of service delivery although they were trained.

Module 11-Nutrition

According to the researcher, nutrition is one of the biggest needs in poor communities. It is often the case that HIV and AIDS sufferers are indeed poor as a result of the inability to work and it is generally known that HIV and AIDS patients do indeed benefit by proper nutrition.

Van Dyk (2005:301) emphasises, that a healthy diet may enhance the immune response to HIV-infection, and enhance resistance to opportunistic infections.

Through model 11, volunteers are trained to identify and manage problems related to nutrition. They also need to teach the patient and families on how to use available resources or to grow food.

The learner will be able to:

- Identify food groups and plan suitable meals.
- Identify and manage problems related to nutrition.
- Identify dehydration and prepare an oral dehydration solution.
- Teach PLHA and families how to use the available resources to grow food.
- Discuss the advantages and disadvantages of breast and bottle feeding.

Model 12-Care of the caregiver

Module 12 focuses on the care of the caregiver. Deffilipi (2003:28) mentions that it is only natural to feel sad and tired when one is constantly exposed to suffering and loss when working with the HIV and AIDS patient. Without support, this can lead to burnout. It is therefore vital that care for the caregiver be incorporated in the training programme.

Outcomes for learners will include the following abilities:

- Describe how they respond to their own feelings.
- Describe their own emotional coping mechanisms.
- Outline methods for measuring personal stress.

- List behaviours that enhance working relationships within the team.
- Explain situations that may cause anxiety for health care providers in the HIV and AIDS, STI or TB settings.
- Describe ways of coping with situations that cause stress and anxiety for health care providers in the HIV and AIDS, STI or TB health care settings.

5.3.2. Practical procedure

Van Dyk (2005:265) and Cameron (2003:42) mention that volunteers attending the course are expected to complete practical sessions at organisations, hospitals and clinics. The list of practical work is illustrated in table 3.4. The goal is to assess the standard of care at each institution and the limitations in the provision of care. Volunteers also do practicals in basic nursing care.

Table 3.4 Practical work

Practical work of volunteers for the Community Based Care training programme	
Wound dressing	Bathing of patient
Feeding patient	Taking temperature, pulse and respiration
Mouth care	Putting the patient in the recovery position
Measuring intake/output	Using a wheelchair
Breathing exercises	Pressure care
Helping a patient that is coughing, having oxygen therapy	Hand and foot care
Assistance with choking	Giving a bed pan
Stopping of bleeding	Catheter care
	Giving medicines

Each learner needs to be given a booklet listing all the practical procedures in which he or she is expected to demonstrate competence. It should also have a space for learners to list visits to hospitals, clinics or other organisations. It is the learner's responsibility to ensure that each practical procedure is assessed and signed by a supervisor, as proof that the learner has demonstrated competence in that procedure during the training course.

5.3.3. Length of the course

The time of each model will depend on the prior knowledge of the learners, the needs of the care programme for which the learners are being trained and the size of the group. More time needs to be allocated to the evaluation of practical work for a larger group.

5.3.4 Schedule for training

Table 3.4 Schedule for training

Module	Number of days required
1. Orientation	1 day
2. Community based home caregivers	4 days
3. Teaching skills	2 days
4. Sexually transmitted infections	3 days including HIV and Aids
5. Tuberculosis	5 days
6. Communication	2 days
7. Spiritual, cultural and religious issues	3 days
8. Infection control	2 days

9. Palliative care	10-15 days
10. Social support	1 day
11. Nutrition	3 days
12. Care of the caregiver	2 days
13. Practical work at hospital clinic and other organisations, like old age homes.	This needs to be integrated with module 9. Learners should spend an initial 1 day at each, followed by 5 days at the hospital later in the course and ongoing clinic visits. This will depend on visits that can be arranged.

5.3.5 Teaching methods

Cameron (2003:39) mentions that the teaching methods should be as varied as possible and should be designed in such a way that it will be suitable for adult learners. They could include lectures, discussions, group work, role play, case studies, micro-lectures, questionnaires and stories or songs.

5.3.6 Assessment

Van Dyk (2005:262) and Cameron (2003:39) state that during any training course, provision needs to be made for on-going formative assessment of theory and practice. This is seen as positive feedback and as a change to rectify problems. Time should be allocated for guidance, support and evaluation of each learner individually. Where possible,

summative evaluation at the end of the course could take the form of a two-hour written examination, but for learners who have a lower level of literacy, oral examination should be offered. It is recommended that the pass mark for the written or oral examination be 50%, and that if a learner achieves between 40% and 49%, a supplementary oral examination can be given. If a learner achieves less than 40%, extra guidance and support should be given before re-admission to the course is considered. Assessment of practical work is done on an ongoing basis throughout the course as the various procedures are covered. Each learner must be able to demonstrate competence in the practical procedures and the supervisor must indicate that the learner has been assessed and found to be competent.

5.3.7 Selection criteria for caregivers/volunteers

Deffilipi (2003:21) and Cameron (2003:43) point out that the success of a community care programme depends largely on those who are providing the day-to-day care and support, and it is therefore essential to have a selection criteria to select potential learners for caregiver training. As a basic guideline, caregivers/volunteers should display the following skills/characteristics:

- Have the ability to read, write and do simple calculations.
- Be fluent in the language of the patient and his/her family.
- Show evidence of prior involvement with care programmes in the community or have a recommendation from community leaders.
- Be enthusiastic about working with people in need.
- Respect others and be committed to maintaining confidentiality.
- Show an interest in basic nursing care.

- Have good interpersonal and communication skills.
- Show commitment for their own learning.

5.3.8 Course agreement

Cameron (2003:43) strongly recommends that learners who are selected to be trained, sign an agreement with the training provider or organisers of the training programme. This needs to cover the following areas:

- The nature of the training course (it does not provide nursing training or guarantee entry into any nursing training course).
- Whether or not the learners will be expected to pay course fees and who will be responsible for transport costs, including transport to hospitals, clinics and other organisations in the community.
- Course attendance requirements and assessment criteria.
- Whether or not employment will be offered to learners on successful completion of the training course.

5.3.9 Pre-course questionnaire and interview

It is useful to ask each applicant to complete a questionnaire that will give the selectors an idea of any form of training in the past and the reasons why the applicant is keen to do the course. In South Africa the National Skills Development Strategy acknowledges that prior learning needs to be recognised and taken into consideration.

Figure 3.3 is an example of questionnaire that could be used. Each applicant should also be given a personal interview so that verbal communication and attitude can be assessed.

Figure 3.3 Community volunteer candidate questionnaire

Name Male/Female.....

ID number..... Age.....

Address..... Telno.....

What is the highest school standard you have passed?.....

What is your home language?.....

What is the language spoken in your community?.....

Have you done any training courses in patient care?.....

Where did you do the course?.....

How long was the course?.....

When did you do the course?.....

Have you ever taken care of a person who was very ill?.....

What was your relationship to the person ?.....

What did you do for the person?.....

How long did you care for him/her?.....

What would you like to learn from the course?.....

6. CONCLUSION

In chapter three, the focus was on the importance of Community Based Care, the role of the volunteer in this programmes and the training provided. It is evident that Community Based Care will be of much importance presently and in future. Community base care addresses the needs of the patient with HIV and AIDS in the community. In this chapter, the advantages and disadvantages were discussed. Different models for Community Based Care are available to address the needs of the patient with HIV and AIDS and the affected family. The researcher is of the opinion that Community based care can be successfully implemented and there is a need for more such services in our communities.

According to the researcher, the role of the volunteers is important in the Community Based Care programmes. Volunteers are seen as key workers in the HIV and AIDS Community Based Care programmes. In this chapter, different areas were identified in which the volunteer can contribute in a much significant way to render an effective service to the HIV and AIDS patient.

The selection of volunteers for the programme is also an important factor. Volunteers are expected to work closely with other team members and need the necessary skills and knowledge for the successful implementation of a Community Based Care programme.

In order for the volunteers to fulfil their tasks, they must undergo training. In this chapter it was stressed that if volunteers do not receive training, they will not be able to provide a high standard of care to the HIV and AIDS patient. The curriculum of the programme was discussed. The researcher also focused on aspects such as the schedule of the training, teaching methods and the assessment methods.

Chapter four will focus on the empirical study, to explore the experiences of volunteers regarding their training on HIV and AIDS Community Based Care.

CHAPTER 4

ANALYSIS OF THE FINDINGS

1. INTRODUCTION

The previous two chapters focused broadly on the impact of HIV and AIDS and the importance of Community Based Care, the role of the volunteer and the existing training programme of the Department of Health as a response to the pandemic. In chapter two the impact of HIV and AIDS on the individual, the family and significant others as well as the impact on households and communities was discussed. In chapter three insights were given on Community Based Care and the role of the volunteer in these programmes.

The rationale for this research study was that the volunteers receive training to equip them to render a holistic service to the HIV and AIDS patient. However, despite the training programme offered, there are still problems regarding the service delivery by the volunteers. Volunteers focus on the physical needs of the HIV and AIDS patients only and do not attend to their psychosocial needs, despite the fact that they are trained to take care of the needs of the HIV and AIDS patient from a holistic approach.

The question was whether the volunteers experienced the implementation of the training programme as appropriate enough to empower them to address the psychosocial needs of the HIV and AIDS patient in practice.

2. GOAL AND OBJECTIVES OF THE STUDY

The goal of this study was to explore the experiences of volunteers in the Potchefstroom Municipality regarding the implementation of the training programme on HIV and AIDS Community Based Care by the Department of Health in order to find out the reasons why they do not attend to the psychosocial needs of the HIV and AIDS patient despite the fact that their training embraces a holistic approach. For this study the objectives were the following:

- To review literature on the extent and nature of HIV and AIDS in South Africa, Community Based Care and the 59 days training programme offered by the Department of Health for volunteers.
- To conduct an empirical investigation to explore the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to understand the reasons why they do not attend to the psychosocial needs of the HIV and AIDS patient although their training touches on both the physiological and psychosocial.
- To construct conclusions and make recommendations based on the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care, to contribute to their empowerment to attend effectively to the psychosocial needs of the HIV and AIDS patient.

3. METHODOLOGY

This study was quantitative in nature. Quantitative research is associated with numbers and testing of theories. According to Roestenburg (2005:31), quantitative research is used to confirm people's ideas, perceptions, attitudes and behaviours about a particular situation or event. The researcher collected data on the volunteers' experiences regarding the implementation of the training programme on HIV and AIDS Community Based Care to understand the reasons why they fail to address the psychosocial needs of the HIV and AIDS patient to a satisfactory level.

Applied research was conducted. This study explored the volunteers' experiences regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to identify reasons for not addressing the psychosocial needs of the HIV and AIDS patient.

The empirical study was conducted by collecting data from 20 volunteers from the two Community Based Care Programmes, namely Baptist Children's Centre and Bambanani Youth Project. The researcher administered a group questionnaire. The respondents completed the questionnaire on their own, as explained in De Vos and Fouchè (2002:174). The researcher was present for clarification purposes and each respondent completed his or her own questionnaire without discussing it with other members of the group.

The information was interpreted to enable the researcher to gain insight into the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care. The information obtained from the literature was used to verify the

interpretations.

In this chapter, the researcher will present the empirical data obtained during the empirical study through the questionnaires. The findings focus on the central themes namely, the content of the training programme, the presentation of the training programme, and the empowerment of the volunteers on Community Based Care to the HIV and AIDS patient.

4. CENTRAL THEMES

4.1. Content of the training programme

This section focuses on experiences of the volunteers regarding the content of the training programme. The responses regarding this theme are discussed below in relation to the questions asked in respect of this theme. A similar pattern is followed for the remaining themes.

4.1.1. *How did you experience the content of the training programme?*

Table 4.1. Experience of the content of the training programme

Experience of the content of the training programme	Frequency	Percentage
Poor	3	15
Average	9	45
Good	6	30
Excellent	2	10
Total	20	100

From the information reflected in table 4.1, the majority of volunteers were not satisfied with the content of the training programme. A majority of 45% rated the content as average. Of the respondents, 15% rated the content as poor. They stated that there were challenges regarding the content of the training programme. They felt that the content was not in depth and focused on general issues only, which influenced their abilities to implement their knowledge in practice. The programme was of short duration, and there were time limits to the presentations. They were aware of the fact that the role of the community volunteer would be limited in the provision of medication, however, they would have valued more information on the different types of medication, antiretroviral treatment and where to find these treatments. They were of the opinion that they were dealing with patients that were HIV positive and that it was important for them to have some information regarding medication and treatment. They also felt that more emphasis should be placed on the social and psychological care of the patient.

Another 30% of the volunteers rated the content of the training programme as good. They did receive the training as set out in the manual and the training curriculum. They knew how to take care of the patient with HIV and AIDS. They felt that the training programme empowered them with knowledge on HIV and AIDS that they lacked before. The training programme content includes the role of the volunteer, sexually transmitted infections and HIV and AIDS, tuberculosis, spiritual, religious and cultural issues, palliative care and basic nursing skills, social support, communication and counselling skills, nutrition and care of the caregiver (volunteer).

Of the respondents, 10% rated their knowledge as excellent. They felt that the information was not only of value for them, but also empowered them to teach the community about HIV and AIDS and Community Based Care.

With regard to the volunteers' experience of the content of the training programme, the majority rated the content as average. The content was not in depth and only focused on general issues. Due to the short time schedule the presentation of the training programme was limited and did not empower them with enough knowledge for implementation in practice. Corey and Corey (2002:358), Roux (2002:240) and Cameron (2003:33) state that volunteers should be provided with a wide range of knowledge and skills through the training programme to equip them to provide a high standard of holistic care to the HIV and AIDS patient. According to the responses of the volunteers, the conclusion can thus be drawn that the information did not meet the standard of the training programme as mentioned by these authors.

4.1.2 Do you think the information presented to you needs to be changed?

Table 4.2: Information change

Information change	Frequency	Percentage
Yes	11	55
No	9	45
Total	20	100

From the information presented in table 4.2 the majority of volunteers, namely 55% recommended changes to the information presented. They felt that the information presented was not enough. They felt that the information was not in depth and the focus was on background information only. They also recommended that information regarding medication and treatment, social and psychological issues related to HIV and AIDS such as abuse, needed to be included in the content of the training programme.

Of the respondents, 45% did not recommend any changes to the information presented during the training programme. They felt that the information presented was relevant and sufficient. They were able to learn more about aspects of TB, Community Based Care of which they did not know before. They also felt that the training empowered them to share the information with their communities to eradicate stigma and discrimination against people living with HIV and AIDS.

4.1.3 Please indicate what other aspects you would like to be included in the content of the training programme.

The full 100% of the volunteers felt that the content of the training programme needed to be expanded. They suggested that it should include other topics such as domestic violence, abuse, antiretroviral treatment, psychosocial support to children and families as well as a structured and in depth course on counselling. Volunteers felt that they had to deal with these problems on a daily basis and it should be included in the training programme. In this regard it seems to the researcher that the identified topics that volunteers proposed to be included in the training programme, would express a desire to gain more knowledge on psychosocial, social and medical issues. The topics for inclusion are the following:

Psychosocial support to children: Volunteers stated that they needed more information regarding psychosocial support to children, since they lack knowledge and skills to offer psychosocial support to children in practice. This fact supports the view of Kistner (2003:22) and Greene and Serovich (1998:231), who state that children suffer tremendously when their parents are infected and the needs of children with infected parents are often neglected. Children are largely excluded from the counselling process, as some caregivers often do not know how to talk to children and even more so when it comes to such a specialized problem.

Support groups: Volunteers stated that they lacked knowledge regarding support groups and would like to continue training regarding support groups. This fact supports the view of Blom and Bremridge (2003:82), who state that support groups are important for people living with HIV and need to meet on a regular basis to talk about their difficulties.

Information on medication: Volunteers indicated that they needed information regarding antiretroviral treatment and it should be part of the training course. Van Dyk (2001:239), mentions that non-compliance with treatment often occurs because the patient or caregivers do not know when or how to administer medication. A lack of knowledge about the disease, treatment, emergency situations and community resources often hampers Community Based Care. This fact supports the view of Campbell, Nair, Maimane and Sibiya (2005:22) of the Centre for HIV networking, University of Kwazulu- Natal, who state that volunteers need to play an important role in the roll- out of Antiretroviral Treatment (ART). Discussions of the human resources necessary for effective roll-out, tend to focus on medically trained personnel, such as doctors and nurses. Less attention is given to the role that grassroots community representatives will need to play in ensuring the success of proper and effective

treatment. The researchers mentioned in chapter two that Community Based Care workers will need to play an important role in the ART roll-out plan. The shortage of staff being faced by hospitals will have implications for the implementation of a full-scale antiretroviral programme. AIDS patients rely heavily on the support of Community Based Caregivers and they could play a crucial role in the monitoring and adherence of Antiretroviral Treatment. The responses of the volunteers regarding training on antiretroviral treatment, confirmed this fact.

Psychosocial support to significant others: Volunteers indicated that they lacked skills to attend to the psychosocial needs of the HIV and AIDS patient's family. Derlege *et al.* (1998:148), make it clear that the disclosure of a loved one's positive status is always a shock and no two people react in the same way to the disclosure. Affected others' responses can range from involvement, caring and support on the one hand, to abandonment, indifference and antagonism on the other hand. HIV-infected people are often rejected by their significant others because of the stigma that still surrounds this disease in many societies. The volunteers stated that they identified these problems in their community and felt that they needed ongoing training to address the problem.

Information on domestic violence: Volunteers revealed a desire to be better equipped to support women who are victims of abuse by males. Malherbe (2002:338), supported by Kistner (2003:18), points out that women are more likely to be poor and uneducated than men, and are thus dependent on men for the survival of their children. To aggravate the situation, woman often ended up being HIV and AIDS infected because of abuse by a male domestic partner. Since the problems are increasing, volunteers propose training in this area.

4. 2 Presentation of the Training Programme

4.2.1. How did you experience the presentation of the training programme?

The volunteers' experiences regarding the quality of the presentation of the training programme, can be illustrated as follows:

Table 4.3. Experience of the presentation of the training programme

Experience of presentation of training programme	Frequency	Percentage
Poor	4	20
Average	8	40
Good	5	25
Excellent	3	15
Total	20	100

The table illustrates that the majority of volunteers, namely 40%, experienced the presentation of the training programme as average. Of the respondents, 20% indicated that they experienced the presentation as poor. They felt that the trainers needed to give them all the information, but instead they have to give all the answers in group discussions. This gave them the impression that the trainers expected them to know everything regarding HIV and AIDS, although some of them did not have prior knowledge regarding HIV and AIDS.

Of the respondents, 25% stated that the presentation was good. Another 15% were of the opinion that the presentations were excellent. They were of the opinion that the trainers gave individual attention to all of them. They also stated that the trainers took time to explain everything, could be understood and had given practical examples. Two volunteers for example, stated that the training was good because there were many aspects that they did not know before, which they understood afterwards.

With regard to the above information, the researcher comes to the conclusion that in terms of the responses, the majority of volunteers felt that the trainers did not fulfil their roles adequately as mentioned by Cameron (2003:35), which is the following: Helping the learners to develop self-awareness as well as insight into their role as caregivers, helping learners to gain knowledge, showing learners the skills they will need, helping learners to practise their skills, providing opportunities for problem-solving approaches.

4.2.2 What methods were used during the presentations?

All 100% of volunteers indicated that the presenters used group discussions, flip charts and posters. They were of the opinion that group discussions gave them the opportunity to ask questions for clarity so that they could understand better.

However, they indicated that the discussions were only for a short duration of time (30 minutes) and the groups did not have time to round off the discussions. They recommended that more time be allocated for discussions. They also recommended the use of videos and story telling to make the presentations more meaningful.

Based on the responses made, the overall conclusion can be drawn that the majority of the volunteers were not satisfied with the methods of presentation. The majority regarded the method as ineffective and they strongly recommended the use of videos, storytelling and other educational equipment to increase their level of understanding. Roux *et al.* (2001:213) state that the value of storytelling lies in the fact that it helps people to remember better.

4.2.3. How long was the presentation of the training programme?

Table 4.4 Length of training programme

Time schedule for training programme	Frequency	Percentage
1 week	11	55
2 weeks	9	45
Total	20	100

From the information presented in table 4.4, it is clear that 55% of the respondents stated that the training programme took place over a period of one week. Of the remaining respondents, 45% stated that the training took part over a period of 2 weeks.

The information shows that there were different opinions from the respondents regarding the time schedule for the training programme. Cameron (2003:42) gives an indication of the schedule for the training. In relation to the above information, the majority of volunteers stated that the training was only one week. They also indicated that the training course was only of a short duration, namely five days. Two modules were presented within one day and

the practical integration of it took place over a period of one month at an old age home. They further indicated that they would prefer the training sessions to take place over a longer period of time. This information is contrasting when compared to the schedule for training modules, which outlined the specific number of days allocated for a module. Depending on the responses of the volunteers, the conclusion can therefore be made that the proposed schedule for the presentation of the programme, was not followed.

4.3 Empowerment on community based care to the HIV and AIDS patient

4.3.1. *Do you feel empowered to attend to the physical needs of the HIV and AIDS patient?*

To the question of whether they felt empowered to attend to the physical needs of the HIV and AIDS patient, they responded as follows:

Table 4.5 Empowered to attend to the physical needs of the HIV and AIDS patient

Empowered to attend to the physical needs of the HIV and AIDS patient	Frequency	Percentage
Yes	16	80
No	4	20
Total	20	100

Table 4.5 illustrates clearly that 80% of the volunteers felt that they were empowered to attend to the physical needs of the HIV and AIDS patient after the presentation of the training programme. They stated that most of the presentation focused on the physical care of the patient. They felt that after the presentation of the programme, they understood the physical needs of the HIV and AIDS patient.

However, the 20% who felt that they were not empowered to deliver an effective service, stated that they had too many patients to look after. Marston (2003:116) strongly recommends that volunteers should receive proper training on the principles of palliative care. The question can thus be asked whether they feel empowered to implement the knowledge and skills regarding palliative care, as one has to also take into consideration that they mentioned that they needed more training on palliative care and that the practical part of the training should be over a longer period of time.

4.3.2 Do you feel empowered to counsel the HIV and AIDS patient?

The respondents were further questioned whether they feel empowered to counsel the HIV and AIDS patient. They responded as follows:

Table 4.6 Empowered to counsel the HIV and AIDS patient

Empowered to counsel the HIV and AIDS patient	Frequency	Percentage
Yes	7	35
No	11	55
Not answered	2	10
Total	20	100

Table 4.6 illustrates that only 35% of the volunteers felt that they were better equipped to counsel the HIV and AIDS patient, which is less than half of the volunteers. The majority, namely 55% of the respondents, were of the opinion that they still lacked the necessary skills when it came to the counselling of patients. They felt that in some instances they needed the assistance of a professional social worker. Among the respondents were those who realised that some of the problems experienced by patients, were quite complicated of nature, in fact, too complicated for them to approach with the little knowledge they had.

According to the feedback, volunteers view counselling as they stated ‘the answering of the patient’s questions’. This illustrates that volunteers have a different view regarding counselling. In this regard, Evian (2003:279) states that counselling does not involve merely giving advice. It also does not mean you take over the client’s problem. Knott (2003:51) is of the opinion that counselling is necessary for the psychosocial support of the patient with HIV and AIDS. Given the responses of the volunteers, the conclusion can also be drawn that they do not receive enough training to counsel the patients.

4.3.3 *Do you feel empowered to attend to the social needs of the HIV and AIDS patient?*

Table 4.7 Empowered to attend to the social needs of the HIV and AIDS patient

Empowered to attend to the social needs of the HIV and AIDS patient	Frequency	Percentage
Yes	7	35
No	13	65
Total	20	100

Table 4.7 shows that 65% (13) of the volunteers felt that they were not empowered to attend to the social needs of the HIV and AIDS patient. They stated that they lacked the knowledge regarding support groups. They also felt that they needed more training on counselling to assist patients with their problems referring to abuse, violence and their ability to accept their illness. They also indicated that they felt that some problems of the patients were of such a nature that it affected their ability to assist them in an effective way. Some clients were not in possession of identity documents and could not apply for grants and to assist such a client to apply for the necessary documents was time consuming.

Seven (35%) of the volunteers were of the opinion that they were empowered through the training course to attend to the social needs of the HIV and AIDS patient. They were of the opinion that they were more aware of the resources to which they could refer the patients for further assistance.

In chapter two, the researcher quoted Barbee *et al.* (1998:83), Shell (2002:20) and Guilino (1998:165) who indicated that learning that one is HIV positive, creates many stressors for that person. Frey *et al.* (1998:129) stated that people living with HIV and AIDS, need social support to restore self-esteem, to create meaning out of the crisis and to gain control over their lives.

With regard to the above information given by the volunteers, the conclusion can be drawn that volunteers do not feel empowered to counsel the patients and to attend specifically to the social needs of the HIV and AIDS patient. They are therefore not in a position to give the support as mentioned by the authors, as referred to above. In essence, this confirms the fact that volunteers do not have all the skills and abilities to attend to the psychosocial needs of the HIV and AIDS patient.

The volunteers' abilities regarding their tasks in the Community Based Care programme as set out by Marston 2005 (115-116) and Deffilipi (2003:22) can also be questioned if they lack knowledge and skills especially with regard to social support and counselling. The question is whether they are able to make a holistic assessment of the needs of the HIV and AIDS patient and to render services accordingly.

4.3.4 Do you feel empowered to attend to the religious needs of the HIV and AIDS patient?

The respondents were questioned whether they felt empowered to attend to the religious needs of the HIV and AIDS patient. The responses were as follows:

Table 4.8 Empowered to attend to the religious needs of the HIV and AIDS patient

Empowered to attend to the religious needs of the HIV and AIDS patient	Frequency	Percentage
Yes	8	40
No	12	60
Total	20	100

From the information reflected in table 4.8, the majority of the volunteers, namely 60% (12) were of the opinion that they did not feel empowered to attend to the religious needs of the HIV and AIDS patient and the circumstances in practice make it even more difficult to do so. One volunteer clearly stated that some patients refused to take medication because of their religion and the volunteer did not have the means to change that. Another volunteer was of the opinion that it was best to never discuss religious issues with some patients.

Of the respondents, 40% (8) stated that they were empowered to attend to the religious needs of the HIV and AIDS patient. They stated that they gained enough knowledge through the training programme to do so and they were aware of the ethical aspects regarding the patients' religion and how to communicate to them about it.

4.3.5. *How often do you think the training programmes should take place?*

Table 4.9 Frequency of training programme

Frequency of programme	Frequency	Percentage
Once a week	3	15
Once a month	3	15
Once a year	2	10
Twice a year	5	25
Three times a year	7	35
Total	20	100

Table 4.9 confirms the fact that volunteers might have a need for ongoing training sessions at certain intervals to increase their knowledge and skills. Three (3) volunteers (15%) prefer the training to take place once a week, three (15%) would prefer it once a month, two (10%) once a year, five (25%) twice a year and seven (35%) three times a year. Their reasons are based on the fact that they need more training regarding the dynamics of HIV and AIDS, and more specifically the wide spectrum of needs or problems displayed by an HIV and AIDS patient and which they would prefer to be able to address.

4.3.6. *Is there anything that you think must change regarding the training programme?*

Table 4.10 Changes for training programme

Changes for training programme	Frequency	Percentage
Yes	11	55
No	9	45
Total	20	100

Table 4.10 reflects that 55% of the volunteers recommended that the training programme should be presented twice a year. They also revealed a need for more knowledge regarding the phenomenon as well as more opportunities to integrate this knowledge into practice. Another volunteer said that the trainers should be more active during the presentations and should preferably not read the information from the manuals. Some suggested that there should be limited discussions and the focus should be on visual material for effective learning.

Volunteers indicated that more focus should be placed on debriefing during the training process. In this regard, Deffilipi (2003:28) states that volunteers are constantly exposed to suffering and loss when working with the HIV and AIDS patient. Without support, this can lead to burnout. It is therefore vital that care for the caregiver be incorporated in the training programme.

The remaining 45% of the respondents did not recommend any changes to the training programme. They stated that the training programme was effective and they enjoyed it. It was meaningful and well structured.

4.3.7 *Would you motivate other volunteers to attend the training programme?*

Table 4.11 Recommendation of training course to other volunteers

Recommendation of the training course to other volunteers	Frequency	Percentage
Yes	13	65
No	7	35
Total	20	100

Table 4.11 shows that the majority of volunteers, namely 65% felt that they would recommend the course to other volunteers, who were doing Community Based Care. They indicated that although there were limitations regarding the programme, they were able to gain more information regarding HIV and AIDS. They mentioned that it was important for community members to become involved in Community Based Care. This fact is confirmed by Van Dyk (2001:326) and Brennan (1998:123) who are of the opinion that because of the HIV and AIDS crisis, both the family and the community have to become involved in care programmes.

Volunteers stated that they needed to educate the community regarding HIV and AIDS. Van Dyk (2001:326) and Uys (2003:3-5) specifically state that the important functions of a Community Based Care Programme is to empower the community and the family to cope effectively with the physical, psychological and spiritual needs of those living with HIV and AIDS.

Volunteers also indicated that through the training programme, they were able to educate the community. In this regard, Van Dyk (2001:326) and Uys (2003:3-5) stress the importance of educating the community. Some of the volunteers argued that the training that they had been exposed to, empowered them to attend to problems and situations that they otherwise would never have been able to address before. The volunteers were also of the opinion that the training course empowered them not only for working with patients in the community, but also to be of assistance to their own family members.

5. CONCLUSION

This chapter focused on the exploration of the experiences of volunteers of the Community Based Care training course. The findings suggest that volunteers experienced limitations with regard to the content and presentation of the course, especially with regard to attending to the psychosocial needs of the HIV and AIDS patient.

From the results the conclusion is drawn that the training programme places more emphasis on the physical care of the patients compared to the psychological needs of such patients. The volunteers recommended some changes to the training programme. In the next chapter, conclusions and recommendations will be presented in this regard.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

1. INTRODUCTION

HIV and AIDS is a major challenge to our communities. Community Based Care was introduced as a measure to address the problem of rendering an effective service to the HIV and AIDS patient in the community. Volunteers are holistically trained through the 59 day training programme of the Department of Health to address the specific needs of the HIV and AIDS patient. The goal of this study was to explore the experiences of volunteers in the Potchefstroom Municipality in the North West Province regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to find out the reasons why they do not attend to the psychosocial needs of the HIV and AIDS patient, despite the fact that they were holistically trained. Through this study, the researcher obtained data from the volunteers who attended the training courses. In this chapter, conclusions are drawn, based on the literature review and data analysis, followed by recommendations based on the conclusions.

2. CONCLUSIONS

The following conclusions were drawn from the results of the research with reference to the central themes:

2.1. Content of the training programme

- HIV and AIDS is a serious problem threatening the welfare of people in our communities. According to the results of the literature review and the empirical study, Community Based Care to the HIV and AIDS patient is necessary to uplift the quality of life of people living with HIV and AIDS. Volunteers therefore need the necessary knowledge and skills to work effectively with these people, a need that can be addressed through an effective training programme.
- The majority of volunteers who participated in this study, namely 60%, were not satisfied with the content of the training programme and recommended some changes. They indicated that the content of the training programme focused more on general issues and background information. The period over which the programme was presented was not sufficient to internalise all the information. This influenced their ability to implement their knowledge in practice.
- The volunteers recommended that the content of the training programme needed to be expanded. They suggested that it should include more topics that would focus on the social and psychosocial needs of the patients. Volunteers felt that they had to deal with these needs on a daily basis and that such problem areas should be included in the training programme.

2.2 Presentation of the programme

- The study indicated that 60% of the volunteers believed that the presentation of the training programme showed some limitations with regard to the length of the course and the schedule which limited their learning experiences. They indicated that the training course was not presented according to the schedule proposed by Cameron (2003:22). The course was presented only for a short duration of five days and two modules were presented within one day. The timeframe to integrate the knowledge obtained through the training programme was not long enough. They proposed that the duration of the training should be longer and that the course needed to be presented three times a year.
- The results further indicated that the volunteers were not satisfied with the methods that were followed for presenting the programme. Volunteer's felt that for effective learning to take place, they needed to be exposed to other mediums of presentations like drama, videos and storytelling. Roux *et al.* (2001:213) state that the value of storytelling lies in the fact that people remember the content better.

3. Empowerment of the volunteers to attend to the psychosocial needs of the patient with HIV and AIDS.

- According to the results of the empirical study the majority of the volunteers did not feel empowered enough to render social support and counselling to the HIV and AIDS patient. They indicated that they often needed to make use of other professionals to assist them in this regard. In other instances they did not feel equipped enough to counsel the patient, because some problems were too difficult to attend to. These responses confirm

the view of Roux *et al* (2001:30) that volunteers in general are not able to attend to the psychosocial needs of the HIV and AIDS patient. This means that they are not in a position to fulfil all the tasks as set out for volunteers as indicated by Marston (2003:115-116) and Deffilippi (2003:22). Based on the findings of the empirical study, it was clear that volunteers working in the Community Based Care programmes lacked the necessary knowledge and skills regarding social support and counselling to the HIV and AIDS patient and therefore could not effectively address the psychosocial needs of the HIV and AIDS patient.

- The study has shown that 80% of the volunteers felt that they were equipped to attend to the physical needs of the HIV and AIDS patient. They stated that the training course did focus on the physical care of the HIV and AIDS patient. A minority highlighted aspects like the high number of patients and other problematic issues like other illnesses that can make their tasks too difficult and in which they need the assistance of a professional nurse.
- Most of the volunteers who participated in the study agreed that the training sessions should be presented on a regular basis and recommended that it should take place at least three times a year. This indicates that there is a need for ongoing training at regular intervals.
- According to the results of the empirical study, the training programme needs to be changed to attend to the needs of the volunteers. More time needs to be spent on practical integration of the theory the volunteers receive. More attention needs to be given to the

debriefing of the volunteers. Deffilipi (2003:28) indicates correctly that working with the HIV and AIDS patient without support, can lead to burnout of the volunteers.

3. RECOMMENDATIONS

Based on the above-mentioned conclusions a number of recommendations can be made.

- During training sessions more focus should be placed on addressing the psychosocial needs of the patients. The holistic approach should be emphasised and promoted.
- Volunteers need more exposure during their practical training to enhance their skills to address the psychosocial needs of the patients. Better structured and more frequently practical sessions are needed as well as an improvement of the skills of the trainers to give appropriate guidance during practical sessions. The length of the practical sessions also needs to be extended.
- The researcher recommends that training institutions and universities be approached to assist with the re-evaluation of the theoretical part of the current training programme to increase its effectiveness.
- Continuous training in this field is a necessity to enhance the skills of the volunteers to enable them to render an effective service to the HIV and AIDS patient, and to secure consistency in doing so.

- The researcher recommends that techniques and aids such as drama, videos and storytelling be utilised during the presentation of the training programme to improve and establish the skills of the volunteers.

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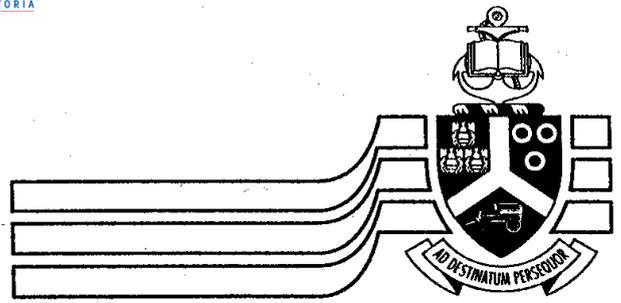
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ANNEXURE A:

Permission letter to conduct research from Community Based Care Programmes

ANNEXURE B:

Informed consent form



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INFORMED CONSENT-VOLUNTEERS

Participant's name:

Date:

Principal investigator:

Name: R.M. Carelse

Informed consent

The title of the study:

The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care.

Purpose of the study:

The purpose of the study is to explore the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care in order to find out the reasons why they do not address the psychosocial needs of the HIV and AIDS patient although they were holistically trained.

Procedures:

I will ask questions of clarity related to the study before giving any written consent for the study. I will only share information I feel comfortable with. If I feel pressured or intimidated about the process of the study, I will inform the researcher about it so that I can not be pressurized to proceed with the study against my will.

Risks and Discomfort:

There is no medical, physical or emotional risks associated with the study.

Benefits:

I understand that there are no direct benefits to be derived from my participation in the study. However, the researcher may gain more information on the experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care.

Participant's rights:

I may withdraw from participating in the study at any given time.

Confidentiality:

My identity shall be kept anonymous by the researcher. The information shared shall be kept confidential and the results thereof may be released with my consent and may be published in a professional journal or presented in a professional conference.

If I have any questions or concerns, I can call 073 137 4991/079522 6879 or (018) 297 0133.

.....
Subjects signature

.....
Date

.....
Signature of investigator

.....
Date

ANNEXURE C:

Questionnaire

Questionnaire

The experiences of volunteers regarding the implementation of the training programme on HIV and AIDS Community Based Care

Case number

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- Please answer all questions
- Make a cross in the block where applicable OR give your answer on the dotted line
- All questionnaires will be dealt with anonymously
- Thank you for your co-operation

SECTION A. Experiences regarding the content of the training programme

1. How did you experience the content of the training programme?

Poor	1	Average	2	Good	3	Excellent	4
------	---	---------	---	------	---	-----------	---

Give reasons for your answer

2. Do you think the information presented to you needs to be changed?

Yes	1	No	2
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Give reasons for your answer

3. Please indicate what other aspects you would like to be included in the content of the training programme

SECTION B Experiences regarding the presentation of the training programme

1. How did you experience the presentation of the training programme?

Poor	1	Average	2	Good	3	Excellent	4
------	---	---------	---	------	---	-----------	---

Give reasons for your answer

2. What methods were used during the presentations?

3. How long was the presentation of the training programme?

SECTION C. Empowerment on Community Based Care to the HIV and AIDS patient

1. Do you feel empowered to attend to the physical needs of the HIV and AIDS patient?

Yes	1	No	2
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Give reasons for your answer

2. Do you feel you are empowered to counsel the HIV and AIDS patient?

Yes	1	No	2
------------	---	-----------	---

Give reasons for your answer

3. Do you feel empowered to attend to the social needs of the HIV and AIDS patient?

Yes	1	No	2
------------	---	-----------	---

Give reasons for your answer

4. Do you feel empowered to attend to the religious needs of the HIV and AIDS patient?

Yes	1	No	2
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Give reasons for your answer

5. How often do you think these training programmes should take place?

6. Is there anything that you think must change regarding the training programme?

Yes	1	No	2
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Give reasons for your answer

7. Would you motivate other volunteers to attend the training programme?

Yes	1	No	2
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Give reasons for your answer

Thank you for your time