

***HIV/AIDS AND HOME-BASED CARE:
EXPERIENCES OF PATIENTS AND
HOUSEHOLDS***

BY:

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Declaration

I, VUYOKAZI OCTAVIA NTSUNTSWANA, declare that the script hereby submitted by me for the Masters Socialis Scientiae in Clinical Social Work Degree at the University of Johannesburg is my own independent work and has not yet been submitted by me to any other University or Faculty. I furthermore cede the copyright of the script in favour of the University of Johannesburg.

V.Ntsuntswana



January 2006

*THIS STUDY IS DEDICATED TO MY MOTHER
AND ESPECIALLY TO MY FATHER WHO WAS
ALWAYS WITH ME IN THE MIDST OF THE
MOST DIFFICULT ACADEMIC VENTURE
AND ALSO TO MY GRANDMOTHER WHO'S
CONTINUING NURTURING HEART WILL
NEVER BE FORGOTTEN*

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ABSTRACT

The challenge of HIV/AIDS is a global issue, instead of decreasing the number of people infected with the disease the number is increasing.

Fortunately we have men and women who are volunteers to fight the increase of this pandemic. These heroes are the voluntary caregivers who are the mainstay of people with AIDS.

However the fact that the caregivers suffer from loneliness and social isolation related to stigma and discrimination cannot be ignored. Voluntary caregivers can benefit from the opportunity to express basic emotions concerning, financial, emotional and physical issues and open line of communication should be in place. Providing an avenue for emotional expression may enhance both physical and mental health to voluntary AIDS Caregivers.

The qualitative study undertaken to explore the experiences of AIDS patients and their families regarding the home based care as service delivery. An explorative and qualitative design was used to determine the experiences of the AIDS caregivers, and AIDS patients concerning the support that they receive.

AIDS patients and the families were selected from the organisations that are funded by the Department of Social Development in the Free State, Bloemfontein area. Pilot study was conducted prior to the commencement of the study comprising of ten participants in each group.

Participants were requested to give information during the interviews. Data was collected and analysed and it was followed by the literature control. The findings did not differ significantly in emotional and social aspects. The researcher drew conclusion and recommendations. Limitations were discussed.

Opsomming

MIV/VIGS is n' globale uitdaging weens die toename, eerder as die afname, van hierdie verskynsel. Vrywillige werkers bide n' welkome uitkoms in die stryd teen die pandemie. In verskeie opsigte bied hierdie groep vrywilligers n' laaste uitkoms aan pasiente.

Desnieteenstaande behoort die feit dat vrywilligers blootgestel word aan vereensaming en sosiale isolasie as gevolg van stimatisering en diskriminasie aagespreek te word. Vrywillige werkers kan baatvind by geleenthede om basiese gevoelens rondom finansies, emosies an fisiese kwessies te bespreek, en bekikbare kanale vir kommunikasie in hiedie verband behoort beskikbaar gestel te word.

'n Kwalitatiewe studie is onderneem ten einde die ervaringe van VIGS-pasiente en hulle gesinne ten opsigte van tuis-gebaseerde sorg te eksploreer. 'n Eksploratiewe en kwalitatiewe ontwerp was aangewend ten einde die ervaringe van VIGS-versorgers, asook pasiente wat hierdie diens ontvang, vas te stel.

VIGS-pasiente en hulle gesinne is geselekteer vanuit organisasies wat befonds word deur die Departement van Maatskaplike Ontwikkeling in die Bloemfontein Oranje Vrystaat area. 'n Loodsprojek is uitgervoer op 10 repondente binne elke groep alvorens die studie 'n aanvang geneem het. Inligting is verkry vanaf die deelnemers tydens onderhoude wat gevoer is. Data was ingesamel en ge-analiseer voordat dit blootgestel is aan 'n literatuur-kontrole.

Die bevindings het nie besondere verskille ten opsigte van sosiale en emosionele aspekte aangetoon nie. Laastens het die navorser 'n bespreking aangaande die beperkings van die studie aangebied, en ook gevolgtrekking en aanbevelings daargestel.

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Chapter 1.

Problem statement and background

1. INTRODUCTION

It became clear to the health and social care delivery system that volunteers who are providing HIV/AIDS services experiencing great strain in their daily work situation and seem fatigued and stressed. The problem is identified when the caregivers retire from the care giving role process because of exhaustion occasioned by demands of caring terminal ill patient without receiving ongoing support and advice from health professionals and families. Volunteers experience strain as they carry huge loads of caring bedridden patients, having also to attend to home chores, e.g. cleaning, washing, cooking and educating their young ones. Because of this load they become overwhelmed.

Volunteers take over the care of the patient for few hours, whilst the families catch up on the sleep, goes shopping, visit friends and perform private duties. A problem identified is that when volunteers are fatigued and stressed, quality health care is impaired. Ignorance is still the people's greatest enemy regarding HIV. Assistance requested from other relevant stakeholders like Non Governmental Organisation' Faith Based Organisations and Community Based Organisations to provide support programme for families infected and affected with HIV and AIDS has rendered impetus towards the control of HIV and AIDS. With the election of the new Government of National unity in April 1994, new policy guidelines were formulated about different aspects of society, including the health services delivery system.

The focus changed mostly from curative services to primary health care services. These changes influenced health and social professionals, families, and volunteers to participate in the transformation of health and social services. In this research the volunteers, patients and families are viewed holistically as individuals and as integral part of the community. Because of this holistic viewpoint it is necessary to understand the support that volunteers/caregivers provide to AIDS patients and their families and to explore and understand the experiences of AIDS patients and families regarding the nature of home based care as service delivery in their everyday lives. Home based care

is defined as care given to individuals when they are supported by their families, which include health and social services by formal and informal caregivers in the home of the HIV/AIDS directly affected family to promote individuals member level of comfort (Van Dyk, 2001:324).

1.2. MOTIVATION OF THE STUDY

The researcher is currently employed by the Department of Social Development in the Free State Province as a social worker. In order to ensure that the service towards HIV/AIDS patients and their families is rendered effectively and efficiently, the Department appointed the researcher in HIV/AIDS field. During field practice, the researcher realised that the communities are not satisfied with service delivery in care and support. The role of voluntary caregivers is confusing to the consumers or clients. This situation has been observed through meetings held with organisations funded by the Department of Social Development in the four districts in Bloemfontein, Free State Province. Though social work intervention, the researcher realised that infected and affected families are not satisfied with health and social care service delivery in their community. There are problems and frustrations experienced in practice due to lack of knowledge and guidelines for service rendering. The personal battles with an issue related to the research question, also motivate the researcher to engage in research to better understand the issue causing the subjective conflict. There is lack of support in the community concerning health and social service delivery. Patients experience great strain with health professionals. What is clear is that these families have unique social needs that could be attended to in rendering preventative services in the social work domain. Through interviewing AIDS patients and families who daily encounter lack of support facts are obtained. For the purpose of this study, it is important that the researcher understands the experiences of AIDS patients and their families regarding the nature of support they receive from their caregivers. The reason for selecting the topic is that, the researcher shows personal interest in how the infected and affected families perceive and understand the support they receive from their caregivers on care and support. Through this research, it will help the researcher to improve her skills in reviewing the existing guidelines and in the development of policy guidelines in the role of volunteers and their relationship with the

Department of Social Development. It is important for the researcher to understand and research the experiences of the research population because suffering and grief is what they felt or experience, secondly facing death, depression, fear and financial concerns are the major issues for people living with AIDS. Affected families experience more or less the same psychosocial feelings as do their HIV positive loved ones. Because there are no prevention programmes that can be successful without the support, commitment of community leaders and other role players ranging from government to private sector. Research population express disapproval that “the support is there” but not enough” and cannot cope effectively.” The researcher wants to understand whether home based care as service delivery is empowering, meaning that people can take responsibility and control over their own lives.

Community perceptions are that HIV/AIDS prevalence is high and growing and that patients lack care and support from health facilities. Clinics are overcrowded. The researcher discovered that people who have feelings of anger do not get support from health professionals. Patients feel isolated especially when they are confined to the home or bed. Many people are not ready for home based care because of ignorance and fear of being stigmatised by other members of the community. They feel that there should be more primary caregivers as clinics are not always able to provide treatment. In home-based care some form of support is always required and necessary to identify what support is needed and who needs it. For these reasons the researcher wants to understand their lived experiences on the nature of support as individuals. For the purpose of resolving conflict and for better service delivery amongst the researched population, the research will help to transform policy guidelines which are in place. The challenge for department of Social Development is to clarify roles of all stakeholders, put monitoring and evaluation in place so that a network of home based care services offering quality services to be established.

1.3. PROBLEM STATEMENT

Volunteers who are providing HIV/AIDS services may experience disruption of interpersonal relationships, social and work life, as well as financial strain associated with care giving whilst AIDS patients experience physical, health problems and

depression. If support is not well provided they may also suffer from burnout syndrome often characterised by a depressive mood, anger, anxiety and insomnia (Flaskerud, Carter & Lee, 2001:121). According Flaskerud, Carter & Lee, 2001:121 projections on HIV/AIDS indicate that the visible signs of the epidemic are only at their initial phase, with increase in deaths accompanied by poverty will be experienced from 2005, possibly reaching a peak in 2010. Furthermore there is a connection between HIV/AIDS and poverty in some of the affected countries, the living standards of the many poor people is already deteriorating before the full impact of the epidemic. In general AIDS-affected households are more likely to suffer severe poverty than non affected households. AIDS takes away the income and production capacity of family members that are sick at the same time creating extraordinary care needs and rising household expenditure on medical and other costs such as funeral expenses. AIDS care related expenses can on the average absorb one third of a household's monthly income. South Africa studies of AIDS affected households reveal that most of them are already poor that their monthly income fell by 66% because of coping with AIDS related sickness (UNAIDS,2004;8) The epidemic is significantly reducing countries agricultural workforce and family's income. This is especially damaging for people living with AIDS who need calories than uninfected individuals (UNAIDS, 2004:9)

There is a great value in maintaining the type of continuity that the product of a settled group of caregivers need. A good home care programme will decrease the need for hospitalisation, which is a major cost saving, as the cost of hospitalisation and transportation to and from a hospital can be financially crippling.

The importance of continuity in home based care is needed because; a good basic care can be successful in the homes. People who are sick or dying prefer to stay at home so that they can spend their last days in familiar surroundings. Home based care is less expensive for families to care for someone at home.

The increasing number of orphaned and vulnerable children can result in a heavy burden on the South African economic and social structure. The care supporters who function as volunteers provide care and support in an environment where resources are limited Documenting HIV/AIDS case studies in South Africa, (2003:32). From personal experience, it is also true that there are many people who are able and willing to work as volunteers, and it is also true that many projects will never get off the ground without such people.

Statistics released by the Free State Department of Health, and the Nelson Mandela Human Sciences Resource Council Study on HIV/AIDS, (2002) with regard to deaths

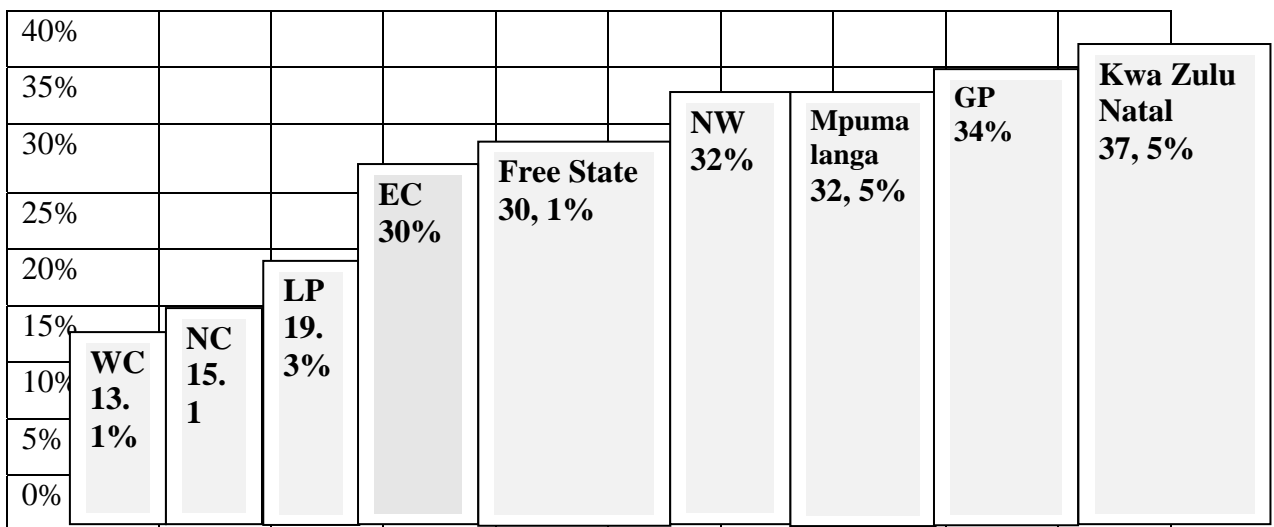
due to HIV/AIDS related conditions state that:.

- 176.4/1000, of the population (23-25.6%), is infected with HIV/AIDS. The overall HIV prevalence death rate in the Free State Province is presently 14.9%. This is the highest in South Africa. People suffering from HIV/AIDS are between ages 2-50 years:

The issue regarding volunteer support experienced by AIDS patients and their families is definitely important enough to be investigated. This study will therefore focus on AIDS patients and their families. The above statistics released by the Free State Department of Health seems to suggest that HIV prevalence is slowly stabilising, while HIV rates have not declined nationally.

According to the National HIV and Syphilis Antenatal Sero Prevalence Survey (2004), KwaZulu Natal recorded the highest number of new infections among antenatal clinic attendees last year, with 37,5% 2004 compared to 33, 5% in 2001, followed by Mpumalanga recording a 32,5% prevalence rate, and then followed by the Free State with 30,1%. The Western Cape recorded the lowest infection rate of 13, 1%. According to the above mentioned report HIV and AIDS is still an important public health problem in South Africa. The following graph illustrates the HIV/AIDS growth in the nine Provinces.

1.3.1. ANTENATAL ATTENDEES PER PROVINCE IN 2004

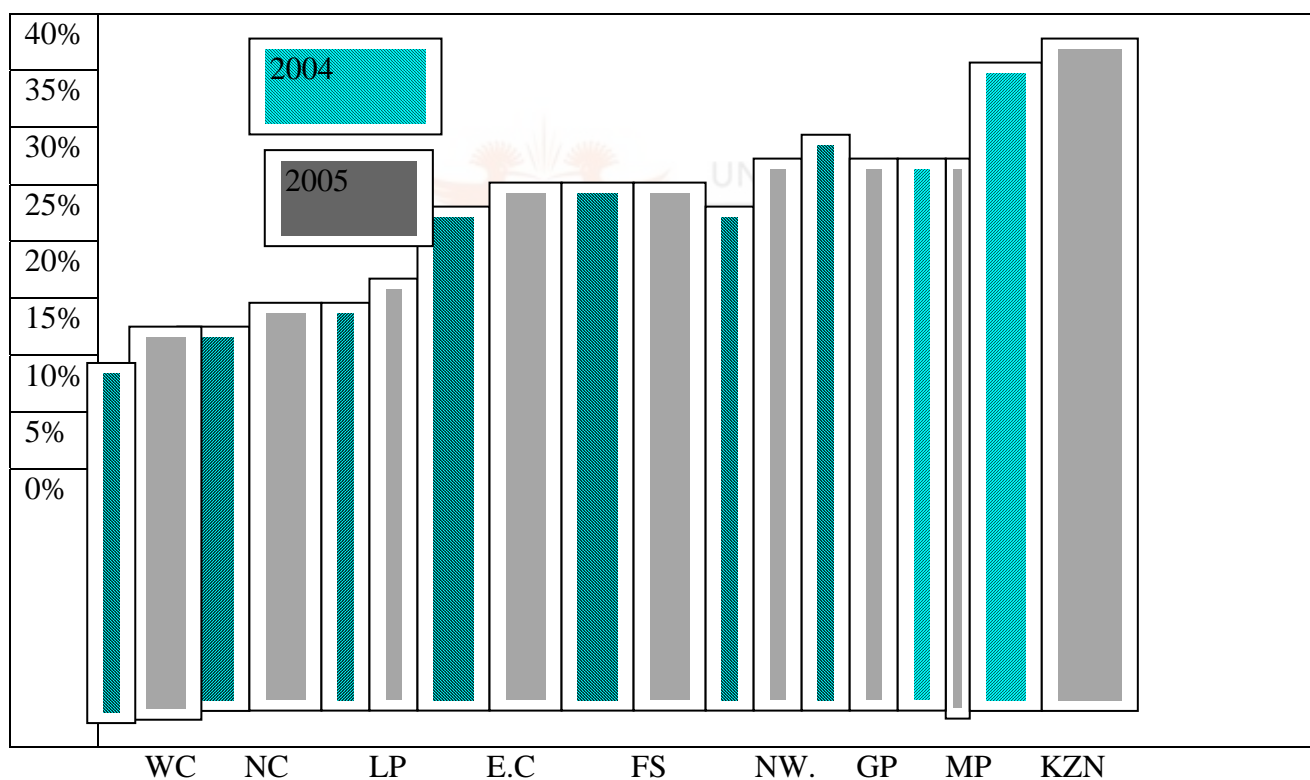


This graph shows the growth of HIV and AIDS in the nine provinces of South Africa as illustrated in National HIV and Syphilis prevalence survey, South Africa, 2005: The

epidemic is the highest in KwaZulu Natal and lowest in Western Cape. The reasons include good health practices amongst the inhabitants, early discovery of the disease, and good health facilities. It might imply sustained changes in moral behaviour among young people including engaging in safer sexual practices (National HIV and Syphilis prevalence survey, South Africa, 2005:17)

The report on the findings of the 2005 survey in comparison with the 2004 survey shows difference in figures quoted. The report provides us with valuable information to address challenges of care and support while sustaining the momentum in the prevention of the HIV/AIDS epidemic. The following graph illustrates the HIV/AIDS growth in the nine Provinces for the 2005 survey compared with the 2004 survey.

1.3.2. HIV PREVALENCE RATE ON ANTENATAL ATTENDEES PER PROVINCE IN 2005

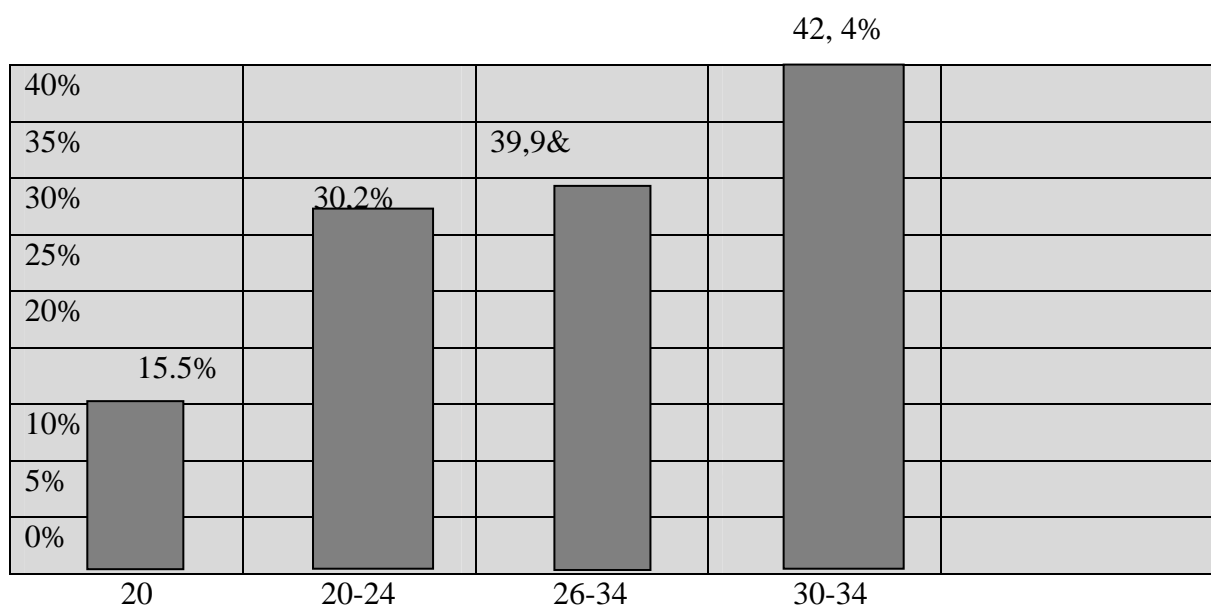


The HIV prevalence rate per province has decreased slightly in KwaZulu- Natal and Gauteng province between 2004 and 2005. There was slight increase in the seven other Provinces mostly notably in the North West Province. HIV prevalence rates between 2004 and 2005 were very similar.

The HIV prevalence per district in the Free State in 2004 as compiled for Flanders International Cooperation Agency for the Centre for Health Systems Research and

Development (2006), recorded the highest HIV antenatal prevalence rate per district, in the Free State, According to report compiled by Flanders International cooperation agency, (2004) in the Free State reported that the entire Free State Province recorded 29, 5% on HIV antenatal prevalence in 2004. The HIV prevalence by age group in the Free State in 2004 was 42, 4%, which is higher between the age group of 30-34. The age group between 26-29 reflects 32, 9%, followed by the group between the ages 20-24 reflecting 30, 2%. The age group under 20 recorded 15, 5%.

1.3.3. AGE DISTRIBUTION OF HIV/AIDS GROUP IN THE FREE STATE



In view of the above graph, it is understandable that a great deal of work needs to be done to ensure that new infections no longer take place at all in South Africa. Voluntary AIDS caregivers often fear for themselves becoming infected with the Human Immuno Virus. Stigmatisation, prejudice and discrimination surrounding HIV and its life threatening effects may compromise their ability to provide quality care (Gubb, 1998:8). Home- based care volunteers are champions in the struggle to fight the discrimination and stigma associated with HIV/AIDS.

Voluntary AIDS caregivers frequently come to the attention of psychiatric health care nurses because of their need of supportive counselling, psycho- and pharmacotherapy for the distress they experience (Given & Given, 1998:20; Turner and Catania, 1997:26). As a result of caring for patients with a stigmatising illness, voluntary AIDS caregivers may feel stigmatised and have a fear to die. Because of that, they tend to suffer from depressive moods, insomnia and anxiety.

1.4. CLARIFICATION OF CONCEPTS

1.4.1. AIDS

AIDS is the Acquired Immune Deficiency Syndrome, a viral infection caused by the virus HIV that enters the body from outside. AIDS is a syndrome of opportunistic diseases, infections and certain cancers each or all of which has the ability to kill a person in the final stages of the disease (Van Dyk, 2002:222).

1.4.2. Volunteer

According to Moroney (1998) voluntary work may be considered as formal or informal depending on the formal training received and the specific job as a volunteer. An accredited trainer in home-based care trains the caregivers accredited at for instance the Department of Health and South African CCP

1.4.3. Support

Support means to give strength, help or encouragement through physical, social, psychosocial, vocational and educational means (Gubb, 1998:6).

1.4.4. Experience

Experience refers to knowledge and skills gained through practical involvement in an activity or event (Conventry & Nixon, 1999:176).

1.4.5. Community

A community is a group of people living in the same geographical area or within a territorial boundary sharing the same norms and values and having the potential of interacting with one another (Dreyer, Hattingh & Lock, 1997:104).

1.4.6. HIV Positive Patient

An HIV positive patient is an individual in whose blood the Human Immuno deficiency Virus antibodies are detected through a specific test aimed at the identification of a particular virus (Vlok, 1996:600). According to Van Dyk, (2001:60) it means that the individual has been infected with HIV and is therefore is as a carrier of the virus for life and in a position to infect other people.

1.4.7. Home /Community based care

Community home based care is the care given to individuals, in their own home, when they are supported by their families, their extended families or those of their choice. (Van Dyk, 2001:327).

1.4.7. Home -Based Care

Home- based care is defined as the provision of comprehensive services which include health and social services by formal and informal caregivers in the home of HIV/AIDS patients and directly affected family members in order to promote, restore and maintain the individual member's maximum level of comfort, function and health, including care towards a dignified death. Home -care services focus on the family as whole and can be classified into preventative, promotive, therapeutic and long term maintenance (Mcanyana, 2004: 9).

1.4.8. Quality of care

Quality of care is the degree of goodness in providing care to people infected and affected by HIV/AIDS (Dictionary for South African school, 1988)

1.5. AIMS AND OBJECTIVES OF THE STUDY

1.5.1. The Aim

The aim of the study is to explore and understand the experiences of patients and their families with regard to the nature of home based care as local service delivery by voluntary caregivers.

1.5. 2. Objectives of the Study

- To conduct a literature study in order to establish a theoretical base for the study.
- To develop a data collection instrument for the collection of qualitative data on home -based care service delivery.
- To conduct an empirical study based on qualitative methodology.
- To formalise conclusions and recommendations for social work practice.
- To formulate policy guidelines on the role of volunteers and their relationship with the Department on service delivery

1.5.3. Research Question



The research question or problem is a concise, interrogative statement developed to direct studies that are focused on description of events and the examination of relationships during interactive processes (Burns & Grove, 1997:793). It is necessary to phrase a research question in a manner that will provide flexibility and freedom to explore a phenomenon in depth.

The following is the research question that will provide the focus for the study:

- ❖ What is the nature of home-based care as local service delivery to the HIV/AIDS patient?

1.6. RESEARCH METHODOLOGY OVERVIEW

1.6.1. Research design

The researcher will make use of qualitative methodology, specifically an exploratory design, since the purpose of the study is to explore the experiences of AIDS patients concerning provision of support. This approach will lead to the exploring the field of study to enable the researcher to gain new insight into domain phenomenon.

(Uys & Basson, 1985:38). This approach will also gather recipient's response of the service to be able to make policy guidelines on the perception and experiences regarding the support.

In this research, focus group interviews will be useful in exploratory design because they generate new ideas for items, and the interpretation of results is uniquely suited to quickly identify qualitative similarities and differences. Although focus groups can produce quantitative data, they are almost always carried out with the collection of qualitative data as their primary purpose Bickman & Rog, (1998:506) as quoted in Neuman, (1997:19).

It is referred as a process based on interpretative approach and aims mainly to understand social life and the meaning that people attach to everyday life (De Vos, 2003). The researcher is going to build and collect facts about the way the subjects experience the support rendered. The researcher conducts the study in a natural setting with detailed views of informants. This method will focus on individual experiences. It will recognise that the way people behave is determined by many factors, including what they think is expected of them. It will involve documenting of real events, recording of what people have said, gestures made, tone of voice, and observing specific behaviour.

The qualitative research is applicable to this study and chosen because,

- ❖ The researcher will try to explore the experiences of HIV/AIDS patients regarding nature of home based care as a local service delivery by means of description
- ❖ The researcher wants to understand the social life and the meanings that people give to everyday lives on HIV/AIDS and generate solutions to the problem identified.

- ❖ It will use focus group interviews to acquire an in -depth knowledge and to compare data to different data sources.

1.6.2. Collection of data

1.6.2. 1. Population

According to Powers (1985:235) as quoted by De Vos, (2003:198) population refers to as the set of entities in which all measurements of interest to the researcher are represented. The entities may be people, or things. This definition links to that of Seaberg in Grinnell (1988:240) as quoted in De Vos; (2003: 200) which describes the population as the total set from which the individuals or units of the study are chosen. The total population of the study will consist of AIDS patients, family members and voluntary caregivers as they are providing services to AIDS patients and their families. Voluntary caregivers, AIDS patients and family members of patients will be the units in the study. There are 750 volunteers trained in home-based care in the Free State province. There are +-18000 beneficiaries that are receiving services in home-based care programmes. The researcher has chosen the population because she is working with the researched population within the Bloemfontein area. The population has +_80 000 people from the black population in which the sample has been selected. The population is having more than half of the population with people living with HIV and AIDS. There are more than 205 organisations in the Free State funded by the Department of Social Development working with people living with AIDS and affected families in the population. One hundred and seventy organisations that are funded in 2005/6 in the Free State are providing home-based care and support services to the frail and their beneficiaries in the Free State, Bloemfontein area, and other organisations are providing services to orphaned and vulnerable children.

1.6.2.2. Sample

A sample is described as a part of, or fraction of, the whole or sub-set of a larger set selected by the researcher to participate in a research project (De Vos, 2003:200). The sample will be chosen from the organisations that are supported by the Department of Social Development in the Bloemfontein area Free State. AIDS voluntary caregivers, AIDS patients and their families will be chosen as the sample to represent the

population.

1.6.2.3. Sampling method

Sampling is a process of systematically selecting cases for a research project. A sampling element is the unit of analysis or case in a population. In qualitative research, the sampling method does not rely on the number of the participants but primarily on the quality of information obtained from the sample. Purposive sampling is an acceptable kind of sampling in this research because the researcher has general knowledge of the population and the researcher will pick those who meet the requirements of the study. It will select cases with a specific purpose in mind (Neuman, 1995:206). A limitation of qualitative research is that data cannot be generalized. This research method, however, enhances reliability.

1.6.2.4. Specific Method of Data Collection

The researcher will rely mainly on focus group interviews as a method of data collection to obtain the information needed to support the purpose of the study. According to Brink (1996:148) data collection denotes the gathering of information needed to address a research problem. The researcher will collect data during the focus group interviews, which will consist of ten (10) participants each. The focus group interviews will take place on two consecutive days in a pre-arranged venue. The following strategies will be used to ensure that no data will be lost:

(a) Audiotaped data

- Each group will be interviewed and audio taped. Two audiotapes will be used simultaneously to record the data so as to avoid the loss of data.
- Audiotapes will be tested prior to the commencement of interviews in order to identify technical problems that could lead to the loss of data
- The cassettes that are going to be used are of a high quality.

(b) Field notes

Observational, methodological, theoretical and personal field notes will be taken. Each participant's opinion and observed behaviour will be recorded.

1.6.2.5. The method of data interpretation

Neuman (1997:426-427) refers to data analysis in qualitative research as a search for patterns in data-recurrent behaviour, objects or a body of knowledge. It is a process that involves examining, sorting, categorising, evaluating, comparing, synthesising and contemplating the coded data as well as reviewing the raw and recorded data. In order to make sense of the process of data collection, the researcher will consider categorising the data into main categories, sub-categories and themes. The data analysis process will involve clustering together related types of narrative information into a coherent scheme. Information is often in the form of jotting down notes such as observational field notes and interview transcriptions. The researcher will systematically follow the next steps:

- ❖ Listening to the audiotapes of focus group interviews.
- ❖ Organising the new data
- ❖ Reading through the information provided
- ❖ Writing out the information on the transcripts.
- ❖ Coding the data
- ❖ Comparing categories
- ❖ Formulating the main categories and themes
- ❖ After that the researcher will formulate the results and compare it to literature.

A detailed research process will be provided in chapter 3, (research methodology)

1.7. LIMITATIONS OF THE STUDY

- Since the research is purposive in nature and sampling procedures are non-probable, results cannot be generalised beyond the scope of the study undertaken.
- Focus of research on specific participants limits the extent to which the study can be generalized.
- Validity and reliability of this research study is limited as the study is exploratory and qualitative in nature.
- No standardised instruments were used as the focus was to gain insight into the experiences of AIDS patients on home based care as service delivery.
- The research is confined to exploring issues around families' experiences of

support which cannot be generalised beyond the scope of the study as this is purposive in nature.

1.7.1. Challenges

The scope of the project is limited to the number of participants who were interviewed.

1.8. VALUE OF STUDY

Through the study, both proactive and reactive influence may probably occur with regard to implementation of policy. The knowledge framework of the social work and associated professions with regard to service delivery may be extended by this study.

This study will influence the implementation of policy on HIV/AIDS. It can contribute to a holistic approach towards service rendering to families, such as treatment action campaigns.

Findings of the study may also influence social work practice and that of associated professions because practitioners will be able, on the basis of the model in this study, to formulate and implement both effective and preventative programmes in various departments so that effective programmes are implemented in the communities and more treatment action campaigns can be initiated. This study can be used as a reference for students and practitioners.

1.9. OVERVIEW OF THE STUDY

The study will be divided into:

Chapter 1. Introduction to the study

The reason for conducting the study which includes the aims and objectives of the study, problem statement and motivation on why the study is conducted, is presented in this chapter.

Chapter 2 Literature review

The following chapter will be a literature study of on volunteers and home- based care programmes.

Chapter 3 Research methodology

It will provide the research design, approach, method of data collection, and analysis

Chapter 4 Data analysis

It will provide the analysis of data.

Chapter 5 Recommendations and conclusions

Recommendations on how support should be provided will be presented in this chapter

1.10. CONCLUSION

In this chapter the problem statement and the background was presented. An in-depth review of the literature, which follows in chapter two, will influence the reliability of the study.

CHAPTER 2

LITERATURE REVIEW

2. INTRODUCTION.

This chapter focuses on the literature study on home-based care services. It introduces the reader to the primary focus of home-based care programmes as a service delivery model as rendered by the voluntary caregivers, as well as looking at the role or relevance of volunteers in home based care. This chapter will then present:

- ❖ The nature of home- based care as service delivery to HIV/AIDS patients
- ❖ The role of volunteers in home based care programmes.
- ❖ The benefits of home-based care.
- ❖ The needs of volunteers in home- based care
- ❖ The limitations and challenges of home- based care

It is important to do the study because families and other carers find it difficult to cope on their own with the demanding care of people living with HIV/AIDS. There are no clear guidelines on how home- based care programmes for HIV/AIDS and TB can be developed, implemented and evaluated. There are now well developed home- care systems in most South African communities, which are usually provided by the family, or friend caregiver.

According to Van Dyk (2001:281), the HIV/AIDS epidemic imposes an intense strain on families, communities and health services. The burden escalates with advancing disease, when people living with AIDS may have increased requirements for medical care and social services. Home care is the only option available for many HIV/AIDS patients because hospital care is unaffordable and sometimes, in some areas, not accessible. An effective and affordable home-based care programme can relieve the load on hospitals. This is observed in practice as a good option for people living with AIDS where home based care services are provided by the voluntary caregivers in offering a range of care and support services. The purpose of the literature study is to have a theoretical framework, which will guide the researcher to form an interview schedule.

2.1. HOME -BASED CARE PROGRAMMES

2.1.1. Home- based care

For the purpose of the study community home- based care is defined as placement of informal and formal caregivers in the home to promote, restore, and maintain a patient's maximum level of comfort function and health including care towards dignified death (Uys & Cameroon 2003:22). Van Dyk (2001:327) states that Home- based care is the care given to individuals in their own homes where they are supported by their families, extended families or those of their choice. It is care provided within the home of the client. It is also an integral part of community-based care. Mathebula (2000) quoted by Lindsay, Hischeffield, Tlou, Ncube, (2003:24) states that home- based care is the care given to individuals in their own natural environment by their families and communities to meet spiritual, material and psychological needs with the individual playing a role, as it is recognised that South Africa has limited health care resources.

Rosenberg, Mabude, Hartwig, Rooholami, Tetteth & Merson (2005:30) state that in South Africa the government developed a national home-based care strategy because of:

- ❖ Inadequate numbers of health professionals are available
- ❖ People prefer to receive care in familiar environments close to their family members and friends
- ❖ Effective home- based care has been shown to improve the quality of life of patients as well as their primary caregivers, for example, families may be convenient and less expensive than transporting sick family members to the hospitals.

Home- based care programmes have been described as sharing certain characteristics, for instance, in providing services primarily in the home. It includes a focus on the family as the unit of service, and the utilization of the family system and community resources in the mobilization of services. Home-based care programmes that are sponsored by the Department of Social Development have generally addressed the following areas:

- ❖ The family's basic needs,
- ❖ Focusing on practical help for the family's economic functioning
- ❖ Household and life management problems (Minunchin 1989:206).

Home based care workers are skilful in carrying out the social and economic aspects of the mandate, mobilizing services and community help in such areas as household assistance, welfare, transportation, and medical necessities. The home- based carers are

able to support individuals emotionally and psychologically, but often lack the skills for mobilizing an extended family, or for facilitating systematic changes that can create and sustain improvement in the functioning of the family members.

Home-based care aims to provide a continuum of care for people living with HIV/AIDS from diagnoses to death. This includes care for people living with AIDS and support of people who are relatively symptom free, while placing emphasis on palliative care and terminal care. The model of home-based care is specifically aimed at developing a care system that is effective and sustainable (Uys & Cameron 2003). Van Dyk (2003: 327) states that it is to provide the organisational structures and resources that will enable the family to look after its own sick members. Community-based care is an essential element of the continuum of care and contributes to the delivery of humane, efficient and effective services. People living with AIDS and their families prefer care offered near home. The other goals as illustrated by Rosenberg, Mabude, Hartwig, Rooholami, Tetteth & Merson (2005;11), incorporate spiritual and psychosocial support, which includes care outside as well as within home and places stronger emphasis on pain control and relief.

2.2. NATURE OF HOME- BASED CARE PROGRAMMES

Home-based care programmes consist of a number of partners who collaborate to provide a continuum of services which enhances holistic care of people living with AIDS, their families and support for caregivers and increasing understanding of the families. This includes a home-based care team, hospice, clinic and a hospital. According to Uys & Cameron (2003; 273) counselling is an essential part of the care. An integral part of the integrated community home based care model is the involvement of collaboration between hospital, hospice and the primary health care clinic that, together with the community, take ownership of the programme. According to the World Health Organisation (1993) quoted by Uys, (2003: 271), home-based care draws on families and communities to provide support, hope and high quality of care to ill people in the home, including psychosocial palliative support and spiritual activities. In many African countries, home-based care is implemented by any of the non-governmental organisations and faith-based organisation (Uys, 2002:273).

Shu, Lung & Huang (2002: 262), describe the following elements of home-based care,

- ❖ Improvement of accessibility and quality of support for family members.
- ❖ Improvement of quality of care and ease with services are provided.

- ❖ Enabling the primary caregiver to continue caring for the child over the longer term is a desirable outcome and therefore efforts should be made so that the primary caregiver is under appropriate health supervision.
- ❖ A further follow- up allows a better understanding of the long term effectiveness of home based care services
- ❖ Home- based care can satisfy the needs of the child and the family members and can improve communication and build relationships between the family members and care workers.

In home- based care, family members are the main and immediate caregivers. However, trained community volunteers or caregivers participate daily in the care of patients, especially in basic care nursing, counselling and provision of medical advice to patients (Fru Nsutebi, & Walley, Mataka, Finkasa, 2001:24). A good example from the documented cases studied in South Africa is that of Thembisile Home-Based Care enter in Tshwane, where volunteers assist terminally ill patients in providing medical care with the support of trained community volunteers. Thembisile home-based care also provides educational support to children orphaned by AIDS as well as other vulnerable children. Volunteers do home visits to the terminally ill and offer counselling, nutritional support, provision of food parcels. Trained volunteers provide emotional and spiritual support, whilst friends and volunteers provide practical help for certain household duties and maintaining the referral system.

Community home- based care services follow different procedures in some settings. Community caregivers or volunteers may go to the nearest clinic where they get the names and addresses of clients from nurses. In other settings, they go from house to house looking for any sick persons who need assistance. In this way they trace people living with AIDS (Uys & Cameroon, 2003:10). Home- based care programme are directed towards healthy people, frail, older persons, to those that are recovering from illness in need of assistance and people living with HIV/AIDS or any other mental illness. An integrated home community-based care model for National Social Development and Health Department, South Africa (2005:4), illustrated common Health and Welfare functions for home based care programmes for service delivery. These include the provision for:

- ❖ Home care supplies and home visits,
- ❖ Community mobilisation,
- ❖ Provision of material assistance,

- ❖ Counselling, and monitoring
- ❖ Poverty alleviation programmes.
- ❖ Community- based care programmes for orphans and vulnerable children and affected children.

Strategies that are addressed by Uys & Cameron, (2003:213) regarding the nature of home-based care for orphans highlight, that the community should make sure that:

- ❖ Siblings remain together
- ❖ Support that benefits the entire community is preferable
- ❖ Non Governmental Organisations should work through local Community Based Organisation's.
- ❖ Programmes focusing on vulnerable children must ideally be linked to developmental programmes.
- ❖ Monitoring and evaluation of care and support for orphans and affected children is undertaken

In home-based care, some form of support is always required. It is necessary to identify what support is needed and who needs it (Uys & Cameron, 2003). The authors further indicate that home- based care is not aimed at poverty alleviation but in many countries there are no other agencies doing this work. The need for poverty relief is, however, encouraged. Russell & Schneider (2000) quoted in Uys (2002; 271) identify the community- based care roles and support for people living with AIDS that are available in South Africa as follows;

- ❖ Advocacy and community mobilisation
- ❖ Drop- in centres and support groups
- ❖ Home visiting programmes
- ❖ Comprehensive home- based care

These roles are important to the researcher's study because the AIDS patients and their families are mobilised in the community in promoting linkages between community-based care and support services. Volunteers link families with other programmes. The provision of comprehensive home-based care is important through home visits to patients from door-to-door.

In view of the above the Free State Strategic planning for 2005/6 of the Department of Social Development also addresses and supports the above activities and roles.

2.2.1. Benefits Of Home Based Care

Uys & Cameron, (2003:4) state that the benefits of home based care are as follows:

- ❖ It allows the patient and the family time to come to terms with the illness and the impending death of the patient.
- ❖ It is less expensive for the family because problems such as transport to hospital, time spent on hospital visits, and other costs are reduced.
- ❖ Care is more personalised and people living with AIDS feel less isolated from family and friends.
- ❖ Relatives can take care of their patients while attending to other chores.
- ❖ People prefer to face ill health and death in familiar surroundings rather than in a hospital ward.

Van Dyk, (2002:328) states that community home based care provides:

- ❖ Good basic care which can be successfully provided in homes
- ❖ Sick people are comforted by being in their homes and communities and with their families
- ❖ Home-based care provides a holistic approach to care.
- ❖ Families and the community are involved in the care of their own patients.
- ❖ As a family unit, each individual member is more likely to remain independent, productive and more satisfied with life.
- ❖ Family members benefit from the care-giving experience by feeling secure in a strong kinship system.
- ❖ A research report conducted on elderly people on how they benefit from the care giving role found that from the three quarters of the respondents reported, that the care-giving makes them feel useful (Bass, 1990:15). All family members feel self reliant and cohesive.
- ❖ Hoffman, Kamlet & Serick (1996) support Van Dyk (2003) in indicating that home-based care is less expensive for individuals than the care received at hospitals. Home care may appear less expensive than in-patients care due to cost shifting rather than a true reduction in economic burdens.

The researcher is of the opinion is that hospitals gain more, because people move in and out of hospital beds. Patients with HIV/AIDS are admitted daily and their medical aids become exhausted and as a result they are left out if they do not have any financial assistance to pay the hospital expense. On the other hand, people feel comfortable if

they die in their homes whilst some patients become severely distressed when they fail to recover in hospitals. Families are capacitated and encouraged to have access to a variety of resources by their caregivers in the form of love care, patience and medical supplies.

2.3. NEEDS OF VOLUNTEERS AND FAMILIES OF HIV/AIDS PATIENTS

Home- based care programmes address models of care and support that includes community involvement in which there is a general consensus that the interventions to assist orphans and affected children should be based in and owned by the community themselves (Uys & Cameron, 2003:181).

Members of the community are in the best position to know which households are the most affected and what sort of help is appropriate. They are also in a position to know who is dying or who has died or taken in by the relatives, who is living alone, and who has enough food to eat. Home- based care addresses the issue of orphans and affected children in terms of who should receive support in the form of meals on wheels, supervision, training to care for an ill parent, counselling, life skills training, income generating skills and drop in centres (Uys, & Cameron 2003:185).

Caregivers experience varying degrees of stress that can be overpowering if ignored. Therefore an aspect about care giving that care is problematic, difficult to handle and stressful should be explored. Care recipients come to the place where they cannot care for themselves independently and turn to others to help meet their basic needs (Moroney, Dockeyki & Gates, Haynes, Newbrough & Nottingham, 1998:57).

There is some mix of services necessary for a comprehensive service delivery system. Moroney, Dockeyki & Gates, Haynes, Newbrough & Nottingham (1998:57) state that there are care-giving transactions that are performed by voluntary caregivers. This involves two people, the one providing and the other receiving care giving services. According to Moroney, Dockeyki, Gates, Haynes, Newbrough & Nottingham (1994:59), caregivers in home-based care need:

- ❖ Information on how to provide care
Caregivers need information on how to provide care to frail people in the community and to be informed on the availability of services in every department
- ❖ Techniques that can be used to assist a bedridden parent to the bathroom without physically harming them.

This refers to skills in physical caring for the patients and how to treat them if they are bedridden. This task should be shared evenly amongst families and their caregivers.

- ❖ Caregivers also need to have a working knowledge of community resources specific to their needs, for instance, there might be common needs for all caregivers.
- ❖ Transportation is a basic need often taken for granted and overlooked. Care recipients often need transportation to go, not only to and from medical care centres, but also to schools, churches, day care facilities, therapy sessions and support group meetings.

When transportation is unavailable, these and other services tend not to be used, with negative results for the carer and the receiver (Moroney, Dockey & Gates, Haynes, Newbrough, Nottingham (1994; 59). While care recipients often rely on family members for transportation. They sometimes they seek out paid caregivers for help with this service.

- ❖ Community care givers must be equipped with pre-post test counselling skills which they frequently use in hospitals and in home care setting (Uys & Cameron 2003: 273).

Caregivers use the term counselling in the context of pre-test counselling in clinics. Caregivers do not consider the capability of providing counselling services to their patients and families as an ongoing process. As a researcher it is possible to provide counselling session information on HIV/AIDS as a process. Disabling conditions by HIV/AIDS frequently keep care recipients from doing regular housecleaning and preparing meals and they rely on the informal caregivers for help to perform home chores. Home- based care should address preparation for teamwork and participation in group discussion. Decision and action must be included in the learning experience.

Basic training in Home-based care should be provided to help new volunteers to understand and enjoy their jobs, learn some skills and techniques to perform those tasks, and to have an interesting and challenging experience. Moroney, Dockey, Gates, Haynes, Newbrough & Nottingham (1998) found that 42% of informal caregivers desired more information on developments in medicine and health care. Lazarus and Folkman, (1984) as quoted by Moroney Dockey, Gates, Haynes, and Newbrough & Nottingham (1994:58) state those emotional or cognitive resources is another type of service that should be provided to the care-giving relationship. The purpose of this service is to help the caregiver and the recipient to cope with the situation throughout

services such as social support groups, counselling and psychotherapy. It enables people to understand their thoughts and feelings about the care giving situation (Stephens, (1993) as quoted by Moroney, Dockecki, Gates, Haynes, Newbrough & Nottingham 1994:60).

Some health care workers feel that emotional care of the family is important and should always be provided, because most of the time the patients diagnosis keep them moving from one hospital to another. Most people living with AIDS do not want their families to know that they are HIV/positive and most health workers do not provide emotional care to the families because people living with AIDS refuse permission for their families to know about their status and it becomes the duty for health worker to provide emotional care (Uys & Cameron, 2003:277).

Uys & Cameron (2003: 279) identified a need to increase the support for home- based care in the model of choice for people living with AIDS. It is also stated the patient is surrounded by a family who often cannot afford to visit to hospitals. It is therefore important for all concerned to realize that home- based care is not the second best option for developing countries only, but that it actually improves the illness and death experience. Home-based care attempts to address emotional, professional and practical needs of caregivers, promote structure, and the increase opportunity for permanent employment in the community.

All home- based care programmes offer some form of training to caregivers. Caregiver's valued ongoing training, accreditation and skills development programmes (Rossenberg, Mabude, Hartwig, Rooholami & Tetteth (2005: 35). There seems to be a clear need to use more volunteers to support the families, especially where large numbers of clients have been identified (Uys & Cameron, 2003:279). More resources should be allocated to home-based care programmes to enhance the quality of life and death of people living with AIDS.

2.4. THE ROLE OF VOLUNTEERS IN HOME- BASED CARE PROGRAMMES IN DEALING WITH HIV/AIDS IN SOUTH AFRICA

Volunteers are important in meeting the needs of the dying patients, their families, home care team and hospital itself. Volunteer work is usually done part time or during spare time just for a few hours per month. In the proper use of volunteers, there must be a careful balance between professional and volunteer services since patients are dependent upon both. It needs to be a shared contribution amongst the formal agencies (Jone, 1994).

As volunteers in their caring work, they fulfil multiple roles. Community volunteers should be given training so as to be effective in their roles including those supporting orphans and affected children. According to Moroney, Dockecki, Gates, Haynes, Newbrough & Nottingham, and (1998:53):

- ❖ Voluntary caregivers provide assistance in dressing their patients and providing physical assistance such as helping them to walk, moving in and out of bed, or moving up the stairs or getting into a bath for washing,
 - ❖ Help with paper work regarding financial matters as well as other practical work such as to prepare meals, do shopping and undertaking household chores
 - ❖ Keep the care recipient company and administering medication
 - ❖ Formal caregivers offer skilled medical services to alleviate painful symptoms caused by a disability or a disease
 - ❖ Voluntary caregivers often provide money to help with the care recipient's bills.
- The backbone of Community-home Based Care is its volunteers. How they are selected, trained, utilised and given an ongoing support will determine whether the programme succeeds or fails (Mcananya, 2004:33).

Volunteers in this field play an important role in Community-home Based Care programmes. According to Frohlic (1999) quoted by Van Dyk, (2002:330), many of the perceived disadvantages of using volunteers can be overcome if volunteers are recognised as key workers in the programmes, if they are chosen by members of the community, and if they are properly trained in basic home care.

There is general consensus that assistance for orphans should be targeted at supporting families rather than setting up institutions (orphanages) for the children. (UNAIDS, 2000c: WHO, 2000) quoted by Van Dyk, (2003).

The volunteer caregiver's role is important because without the volunteer the programme is almost non-existent. It is for this reason that whilst the caregivers render services to infected and affected individuals and their families, should be a programme that offers services to the caregivers simultaneously. Following, are some of the services to be directed to volunteer AIDS caregivers whilst rendering a service.

- ❖ Orientation and continuous training

Volunteers need to be orientated and receive continuous training regarding services rendered. They do not understand some services or programmes, for instance, there is a need to orientate the voluntary caregivers towards the terms Orphan and Vulnerable child.' as these terms are often confused.

- ❖ Debriefing and support sessions

Caregivers need to share their experiences in care giving and support role they render to the AIDS patients and their families. Debriefing session is needed to support them in their emotional experiences and psychological care.

- ❖ Supervision and mentoring

Caregivers need to be supervised and guided in the provision of services to their communities.

- ❖ Training on life management skills such as stress management, dealing with loss, and personal management

Therefore, the role of voluntary AIDS caregivers in home-based care starts with the identification of children in need of care as well as all vulnerable groups that need help. Volunteers provide data on families and provide essential services in the identification of orphans and other children made vulnerable by HIV and AIDS. They address the emotional and social needs of the families.

- ❖ This programme may be the only source of accurate information regarding the needs of children after the death of parents. The AIDS caregivers strengthen the capacity of families by identifying children orphaned by HIV/AIDS, child headed households and children who are infected. AIDS caregivers address the special needs of child headed households. Volunteers enhance the capacity of foster parents and link or refer children who need other social work services. Volunteers promote and provide informal foster care for children without families in that they mobilise foster care in communities and obtain community agreement for volunteers to foster children (Uys & Cameron, 2003:190).

The voluntary caregivers support children at day care centres and teach children domestic work. Uys & Cameron, (2003: 185) recommended standardised forms that need to be developed for use in the identification of orphans and affected children. A register should be established and maintained (Uys & Cameron 2003:185). Assessment of orphans and affected children can include:

- ❖ How the community perceives orphans and affected children.
- ❖ Who talks or listen to children and who do children talk or listen to.
- ❖ Who do they call for assistance (Uys & Cameron, 2003:34-35)

According to Uys & Cameron (2003:187), there are a number of strategies that are required for a community- based response to orphans to succeed. These including the following:

- ❖ volunteers should raise awareness about the problem
- ❖ Assess the needs
- ❖ Find out what communities can do for themselves
- ❖ Check on progress
- ❖ Mobilise action
- ❖ Network
- ❖ Mobilise volunteers from affected families.

The voluntary AIDS caregiver's role is to provide counselling services to the affected families. (Save the children, (2000:14), and to train children in basic survival skills and life skills (Uys & Cameron, (2003). This is done by the caregivers who are able to communicate on at least a basic level with children in the language of their community of origin to foster a sense of belonging and cultural and identity of the child. Volunteers support extended families in providing basic counselling to affected and infected.

An important role of the voluntary AIDS caregivers is to link families with the resources such as food, clothing, shelter, education and health services (Van Dyk, 2001:330). According to Uys & Cameron, (2003) the kind of support that needs to be provided to child- headed households includes providing practical, nutrition, and material assistance. The volunteers also provide developmental and emotional support to ensure that educational and training needs are met.

For a home- based Care support programme to work effectively and live up its expectations, a number of support groups which are either therapeutic, self-help or educational must be established and maintained. The Strategic plan 2005/6 for the Free State, Department of

Social Development supports the literature in which the following roles that need to be performed by the volunteers in home- based care programmes are addressed;

- ❖ Establishment and strengthening of community-based services
- ❖ Establishment and maintenance of inter-sectoral structures at Provincial, District and Local level
- ❖ Linking child care forums
- ❖ Rendering care services to the frail
- ❖ Rendering holistic services to the affected families
- ❖ Identifying child-headed households and orphans (OVC)
- ❖ Support groups, volunteers and care givers that provides Home and Community Based Care
- ❖ Provide Lay Counselling to all reported

Training volunteers in childcare forums depends on the progress made by voluntary AIDS caregivers, and the number of vulnerable children identified. Voluntary caregivers are trained to identify and establish poverty relief programmes, but the government departments facilitate these programmes. The AIDS caregivers strengthen the capacity of families by providing early identification of children in need of care, as well as vulnerable children. In this field, the caregivers identify children who are in distress, assisting them in birth registration of children and obtaining death certificates. Volunteers assist children and families in obtaining resources.

According to Rossenberg, Mabude, Hartwig, Rooholami, & Tettach (2000) a rural HIV/AIDS programme in South Africa quoted in Uys, (2003:12) made the following recommendations related to a proposed model for identification of orphans and affected children:

- ❖ There should be collaboration in each identified organisation. A community childcare forum should be established in all administrative areas to ensure necessary support is provided. Therefore, volunteers do not work alone, as Community- home Based Care and support programmes are not exclusively for HIV/AIDS.

Volunteers interact with the Home Affairs Department, the Education Department and local government structures. The researcher is of the opinion is that, the volunteers in support programmes are front line staff; the core of service delivery, field workers, and highly influential in the entire generation of orphaned children. A need to appoint community coordinators should be stressed.

In view of the above, volunteers may experience problems in caring for people with AIDS, have difficulty in handling patient's demands and their inability to restore AIDS patients to health and experience feelings of ineffectiveness and of "not being a good giver" as a result of caring for patients with a stigmatising illness. Voluntary AIDS caregivers may also feel stigmatised by other hospital staff.

2.5. LIMITATIONS OF HOME BASED CARE

Shu, and Huang, (2002: 262) described the following limitations;

- ❖ inadequate training in long term care of children with special disabilities and disintegration of care,
- ❖ A lack of knowledge concerning the comprehensive care of this population by the caregivers and affected families.
- ❖ Family background and religion not taken into account when providing services.
- ❖ Inadequate resources to help care coordination

Fru Nsutebu, Walley, Mataka and Fikanso, (2001) also describe the following limitations:

- ❖ The lack of information about satisfaction of patients with the service

In the view of the above there is lack of consideration of family members about their level of satisfaction and whether their patients want their status to be revealed to their caregivers by the nurses who just refer the caregivers to the AIDS patients.

- ❖ Welfare services are not appropriate for government health facilities
- ❖ Government lacks technical expertise or motivation for developing and for implementing programmes in the field of HIV/AIDS
- ❖ Surveys are needed to assess the important indicator of service
- ❖ Integration of T.B.&HIV/AIDS services appears to be one of the factors that influence the effectiveness of community caregivers.

2.5.1. Challenges Associated With Community Home- Based Care

Van Dyk, (2002:328) identified some problems associated with home based care:

- ❖ Non-compliance with treatment often occurs because the patient or caregivers do not know how and when to administer the medication. There is a lack of knowledge about the disease, and treatment and many caregivers are afraid lest they themselves become infected with HIV.
- ❖ A caregiver may retire from the care giving process because of exhaustion and burnout occasioned by the demands of caring for terminally ill patients. It is said that it is vital for caregivers to have support systems and to know how to care for themselves.
- ❖ Community caregivers can be successful if caregivers are well trained and if ongoing support and advice is available.

Fru Nsutebi, Walley, Mataka, (2001; 246-247) describes the following challenges:

- ❖ All projects of home based care face the challenge of providing care in the context of food insecurity and household poverty of clients.
- ❖ Home -based care should consider forming partnerships with agencies
- ❖ Home- based care projects should budget for the start up of funds
- ❖ Systems are more distressing and less flexible.

Rossenberg, Mabude, Hartwig, Rooholami, & Tettach (2005.16:35) reveal other challenges for home -based care which includes the following:

- ❖ Difficulty in providing care in the context of poverty

It is difficult to provide care where there is high rate of poverty where people do not have enough resources, and do not have enough information on the availability and accessibility of resources or services. People need to be informed about basic services. Social and economic benefits must be experienced in term of income generating projects.

- ❖ The need to increase the coverage of home- based care programmes.

There is a need to increase the coverage of home-based care services in rural and semi urban areas where there are no services at all. If there are some existing social services they need to be capacitated and make sure that these services are accessible to all .An

integrated approach is not followed.

- ❖ Ensuring that these home -based care programmes are of high quality and effective
- ❖ Lack of integration of home based care into government health care provision.

In the opinion of the researcher there is still a lack of integration and collaboration of services between the other Departments, as the National Department of Health and Social Development initiated the home-based care programmes. Other Department have to integrate with the existing social services to avoid duplication of services. There is lack of coordination of programmes by the departments, churches, and community based care organisations. There is a need for the involvement of the business sector and faith -based organisations where possible and for counselling and for matters of the affected families.

- ❖ Supervisory visits are a challenge for home-based carers and records of activities. Should be maintained.
- ❖ Health workers lack knowledge on counselling
- ❖ People travel long distances to the clinic to receive palliative care services (Uys & Cameron, 2003:277).

In rural areas people travel long distances to get to the clinics for medication, as there are no mobile clinics and no social services within reach.

The central idea of home-based care is to provide home care for HIV/AIDS patients and affected families. A further focus is on integrating care plans and support into existing government and other NGO projects and strengthening the ability of families to care for their children. Home-based care should be provided in areas where there are no services at all, or to communities at risk and informal settlements.

Shifting the emphasis of care to the beneficiaries in the community and reducing unnecessary visits and admissions to health facilities should also be emphasised

2.6. SYNTHESIS

A comprehensive literature study was carried in terms of on the findings of other researchers in matters related to topic under the study. An overview of the available literature on home -based care was performed and includes a comprehensive description of the concept of home based care, the benefits of home based care, and the role of volunteers in home based care. This discussion is presented continuously through the interpretation of details from the literature that pertains to the model of home-based

care. This literature study assists the researcher to form questions for the interview schedule for focus groups.

2.7. CONCLUSION

There is a need to expand the experiences of home-based care programmes. The government effort in community care has been very limited and needs further involvement in providing some form of basic care. There are challenges to successful care and support that need to be highlighted. Chapter 3 will describes the research methodology followed.



CHAPTER 3

RESEARCH METHODOLOGY

3. Introduction

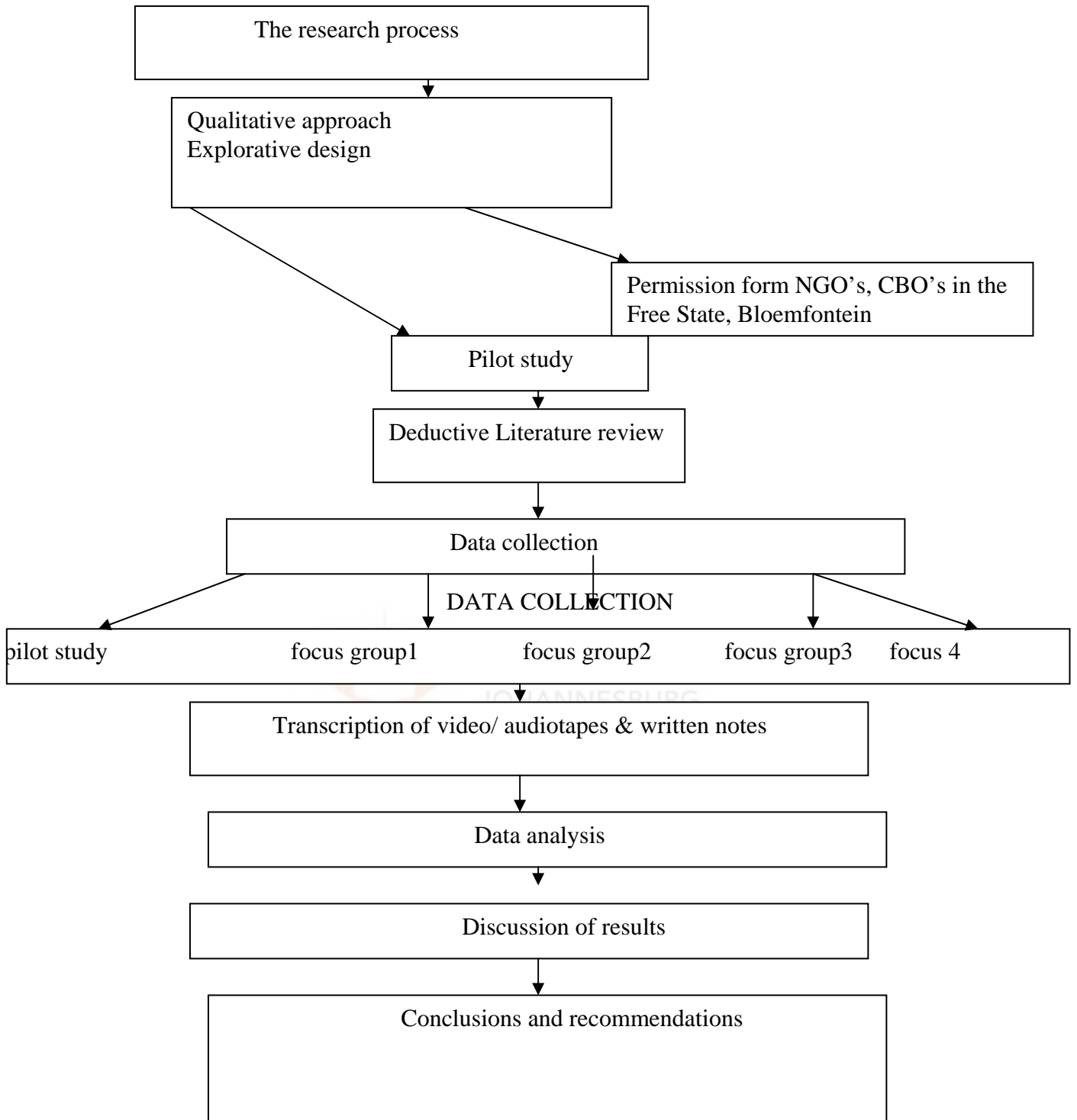
The research methodology discussed in this chapter involves a research approach, the nature of the research design, population, sampling method, data collection as well as analysis. A detailed description of the data will be discussed in this chapter. The purpose of focus group interviews was to encourage the subjects to participate and communicate their feelings related to the nature and support they receive from their caregivers.

3.1. RESEARCH PROCESS AND DESIGN

The research design is described by (Burns & Grove, 1997:225; Brink, 1996:214), as an overall planning for gathering of data in a research study. It begins with identifying and developing the problem based on theory or concepts, before examining into the project, up to the final plans for data collection. In this study the qualitative design is relevant to the study in the collection and analysis process. The researcher is exploring the experiences of patients and their families regarding the nature of support when receiving voluntary services and also interested in understanding lived experiences rather than analysing the data and information...

The qualitative design in this study is applied to explore the actual experiences of stories of support to AIDS patients and their families provided by the voluntary caregivers in care giving that includes including direct physical, emotional, social, personal relationship support as well as performance of caregivers in their lives. A Qualitative design was used to explore strategies or recommendations that could be generated in order to implement suggestions regarding the support that should be provided.

THE RESEARCH PROCESS



3.1. Diagram: Data collection process

3.1. 1. Discussion of the diagram

The diagrams illustrate a research process from a qualitative perspective.

An explorative design has been selected based on the purpose of the study and on the nature of the research question (De Vos, 2003). The researcher went directly to the phenomenon under study and observed it in order to get a deeper and fuller

understanding. The planning for the fieldwork was done where the researcher decided on how to collect the data from the subjects and the preparation on how the data will be processed. The pilot study was undertaken to test the interview schedule before the researcher conducted the main study.

The techniques that are used to collect information are by means of the interview schedule through focus group interviews. The audiotapes and written notes are for data preservation. The results were verified against the literature by relating this to larger theoretical perspectives and a narrative report will be written.

3.2. AIMS AND OBJECTIVES OF THE STUDY

3.2.1. The Aim

The aim of the study was to explore and understand the experiences of patients and their families with regard to the nature of home based care as local service delivery by voluntary caregivers.

3.2. 2. Objectives of the Study

- Conducting a literature study in order to establish a theoretical base of the study.
- Developing a data collection instrument for the collection of qualitative data on home based care service delivery.
- Conducting an empirical study based on qualitative methodology.
- Formalising conclusion and recommendation for social work practice.
- Formulating policy guidelines on the role of volunteers and their relationship with the department for local service delivery

3.2.3. Research Question

The research question/problem is a concise, interrogative statement developed to direct studies that are focused on description of events and the examination of relationships during interactive processes (Burns & Grove, 1997:793). It is necessary to phrase a research question in a manner that will provide flexibility and freedom to explore a phenomenon in depth.

The following was the research question developed for the study:

- ❖ What is the nature of home-based care as service delivery to the HIV/AIDS patient?

3.3. RESEARCH METHODOLOGY

3.3.1. A Qualitative approach

This approach focused on individual experiences and meaning and how these are described. It recognised that the way people behave is determined by many factors, including what they think is expected of them.

A qualitative approach refers to a process based on interpretation and aims mainly to understand social life and the meaning that people attach to everyday life (De Vos, 2003).

(Burns & Grove, 1997:71-72) describe the strengths of qualitative research as follows:

- ❖ Qualitative research enables the researcher to be concerned with meaning, multiple sources and concern with the nature of something, rather than investigating components that are unevenly distributed. The researcher was concerned about the meaning of experiences the AIDS patients and their families have concerning AIDS voluntary caregiver's provision of support, and tried to determine the nature of support.
- ❖ Qualitative techniques for gathering data are less wedded to a specific theory. The researcher wanted to create a set of categories and themes and become familiar with basic facts on concerns and experiences regarding the support that AIDS patients and families receive.
- ❖ It processed, collected materials analysed data and verified results by means of triangulation with a literature control. The researcher verified the results through literature asking participant's views or getting feedback from an observer or the participants.

By using this type of a research the researcher tried to gain understanding into the experiences of AIDS patients regarding caregivers support and made attempts to place into a larger whole (Neuman, 1997:71). The researcher helped participants to describe "social phenomena".

3.4. RESEARCH DESIGN

3.4.1. Explorative design

This is a design that leads to the exploration of a relatively unknown field to enable the researcher to gain new insight into the domain phenomenon. An exploratory study provides the most general information about the research problem with the aim of developing new insights regarding a situation (Neuman, 1997:253). An exploratory design was used because it creates new ideas for items. It asked questions to generate experiences rather than to gather information. For this purpose, the researcher was interested in stories of AIDS patients and their families regarding the support programmes provided by the caregivers. The researcher needs to implement an exploratory design in order to know more information on the nature of home-based care as service delivery to HIV/AIDS patients and their families. To gather recipient's response of the service to be able to make policy guidelines on the perception and experiences regarding the support. Data was collected and meanings and general descriptions of experiences were analysed within a specific context.

3.5 DATA COLLECTION

3.5. 1. Population

According to Powers (1985:235) quoted by De Vos, (2003:198) population refers to set of entities in which all measurements of interest to the researcher are represented. The entities may be people or things. This definition links to that of Seaberg in Grinnell (1988:240) quoted in De Vos, (2003) which describes the population as the total set from which the individuals or units of the study are chosen. The total population of the study consisted of

- AIDS patients
- family members of HIV&AIDS patients
- Voluntary caregivers rendering services through home based care to the above group which will be included.

The researcher has chosen the researched population because she is professionally involved with this group. There are more than 205 organisations funded by the

department of Social Development working with people living with AIDS and their families in Bloemfontein, Free State Province. One hundred and seventy organisations are providing home-based care and support services to the frail and their beneficiaries. There are +-18000 beneficiaries that are receiving services in home-based care programmes. 750 volunteers are trained in home-based care in the Free State.

3.5.2. Sample

A sample is described as a part of or fraction of the whole or sub-set of a larger set selected by the researcher to participate in a research project (De Vos, 2003:200). The sample is drawn from the AIDS caregivers and AIDS patients from the organisations that are funded by the Department of Social Development. Ten participants per group were regarded as sufficient in the exploratory design. A selection of thirty was made. (10) AIDS patients, (10) family members and inclusion of (10) voluntary AIDS caregivers that render direct services to the AIDS families. This was done to identify and to make use of participants who could best supply information relating to the conceptual requirements of the study.

3.5.2.1. Inclusion criteria for the sample

A deductive analysis from literature review as outlined in chapter 2 informed the criteria for the selection of a sample. An assumption from the literature study conducted, that one should be included to participate in the research study will be discussed below. According to Burns and Grove (1997:295) inclusion criteria are characteristics that must be present for the participants to be included in the study.

The inclusion criteria are:

For a participant to be included in this study he /she has to share certain characteristics which are essential for the study. These should be:

- ❖ Frail people that are cared for in the family or in a hospice or community based care organization situated in the Free State province.
- ❖ Being HIV/AIDS patient
- ❖ Living in or around Bloemfontein.
- ❖ Inclusion of age group 15 to 50 is based on the ages of the AIDS patients and the families cared for.
- ❖ Volunteers or community caregivers working for specific organisations or

- hospices that have received special training
- ❖ Volunteers providing direct patient services.
 - ❖ Willingness to participate and sign a written consent in which the recording of the interview is stated.
 - ❖ able to communicate in English, Xhosa or Southern SeSotho
- English, Xhosa and se-Sotho are chosen because the researcher and volunteers are proficient in these languages and used frequently in the Free State Province.

3.5.3. Sampling method

Sampling is a process of systematically selecting cases for a research project. A sampling element is the unit of analysis or case in a population. In qualitative research, the sampling method does not rely on the number of the participants but primarily on the quality of information obtained from the sample. Purposive sampling is a scientific kind of sampling in this research because the researcher has knowledge of the population and the researcher selected those who meet the requirements of the study. Purposive sampling is described by Rubin and Babbie (1993:225) as a type of non-probability sampling method in which the researcher selects participants for the study on the basis of personal judgement about which one will be the most representative or productive, and selects cases with a specific purpose in mind (Neuman, 1995:206). For this purpose, the researcher selected a purposive sampling because it cannot be generalised to larger population and it assists gaining understanding of AIDS families regarding their experiences on home- based care as service delivery.

3.6 THE METHOD OF DATA COLLECTION

3.6.1. Pilot Study /Testing Of an Instrument

A pilot study is the pre-testing of an instrument of measurement (De Vos, 2003). The relevance or the value of the pilot study in this study was to:

- ❖ Assess whether the research question is clear, unambiguous and would facilitate the type of information needed to meet the research purpose.
- ❖ Detect problems that must be solved before the major study is attempted.
- ❖ According to De Vos, (2002:316) pilot testing focus group questions are too difficult. Although pilot testing is important, it presents social problems with focus groups.

- ❖ Check the data collection method and suitability of the sampling frame. By analysing the obtained data, a researcher can obtain an indication of problems that would arise during the analysis of data.
- ❖ For evaluation of the study, in this research one can determine weak and strong points of the investigation can be determined
- ❖ The variability of the population helps to check the highest or lowest qualification in the research group
- ❖ The involvement of the researcher is also considered, for example, the researcher might realise that she is either over or under involved in the project.

The pilot test was the first focus group with the participants. The researcher tested the focus group questions using a few participants that are included in the study.

The purpose or relevance of doing the pilot study in this project was to test the questions before the main study is conducted. The interview was unstructured to gain perceptions of the particular topic. During the interview, the researcher was more aware that open-ended questions allow for richer and fuller information, as the participants are verbally expressive and co-operative.

The researcher made use of careful listening skills to transcribe the audio-taped conversation. The researcher noted the observable responses of participants such as verbal and non-verbal responses used during the interview. For example, the gestures of participant number two and three supported what they were saying. The findings will be then integrated into exploration of the phenomenon of experience of support rendered by voluntary AIDS caregivers that participated in the pilot study.

3.6.2. INSTRUMENT

The following methods were used to collect data:

1. Focus group as a data collection instrument

A focus group is an interview with a group of participants assembled to answer and discuss a question (De Vos 2002:305). Focus group research is also a scientific research method because it is a process of disciplined inquiry that is systematic and verifiable (Krueger & Casey, (2000:199) as quoted in De Vos, and (2002:306). According to De Vos, (2002:306) participants are selected because they have certain characteristics in

common that relate to the topic of the focus group. In this study, the researcher relied mainly on focus group interviews as a method of data collection to obtain the information needed and to support the purpose of the study. Focus group interviews have some advantages:

- ❖ It promotes self-disclosure among participants to know what people really think and feel.
- ❖ It saves time and it is a quick data collection instrument
- ❖ It collects information from a group of people.

Data collection used three (3) focus group interviews consisting of ten participants each. The researcher allocated ten participants to each group. (Krueger & Casey, (2000:72) quoted in De Vos, (2002:308). The group discussion guided the researcher and directed her so as to remain focused on the topic of interest. The researcher's experience in qualitative research played an important role in maintaining the interviews. The voluntary AIDS caregivers were asked to describe their experiences concerning' provision of support.

3.6.3. DATA PRESERVATION

According to De Vos, (2002:309), it is important to preserve data. Different strategies were used to ensure that no data would be lost:

□ Audio-taped data

Each group was interviewed and audio -taped. Audio-tape was used simultaneously to record the data so as to avoid the loss of data. Audio-tape was tested earlier before the commencement of interviews in order to identify technical problems that could lead to the loss of data. The cassettes used are of a high quality.

□ Field notes

Observational, methodological, theoretical and personal field notes were taken. Each participant's opinion was recorded, and observation of behaviour was done. The interviews conducted in this study focused on "live experiences" with the purpose of understanding the meaning of support the voluntary AIDS caregivers render. The verbal data was collected in a relaxed atmosphere. The focus group questions were open-ended, non-directional and formulated to restate the purpose of the study more specifically.

The researcher used phenomenological reduction by means of “bracketing” which is described as a process of identifying and setting aside any set of beliefs and opinions the researcher might have about the phenomenon under investigation. In other words, the researcher firstly identified what she expected to discover and deliberately set aside this idea (*Brink, 1996:120*).

All arrangements were discussed with the co-facilitator and dates for the interviews were also confirmed. The task of taking field notes in this study was the responsibility of the co-facilitator (*De Vos, 2002: 317*). The researcher and the co-facilitator discussed their notes as soon as possible after the focus group session.

All the data that is collected is safeguarded and the protection of participants will be taken into account by ensuring that no information will be publicly divulged. These are some principles about safeguarding and handling data, that are especially well suited to qualitative research. Precautionary measures to safeguard the data included the following. All audiotapes are labelled as “focus group 1, 2, 3 and 4”. Each group’s audiotapes and field notes are packed separately and all the data that is collected is placed in a safe place. The researcher and the co-facilitator are the only people who have access to the information. The issue of safeguarding data is closely related to the form of data collection. No data collected linked with any participant as an individual and this enhances objectivity.

3.6.4. THE PARTICIPANTS AND PHYSICAL ARRANGEMENTS

The dates for the interviews were discussed with the participants and thereafter confirmed by phoning each participant the day before to remind them of the session and confirm their intention to participate. It reminded participants who might have forgotten about the session (*Krueger & Casey, 2000:89* quoted by *De Vos (2002:318)*). Each group included ten participants. The group size was deliberately kept small so that the members did not feel intimidated but could express opinions freely (*Crombie & Davies, 1996:158*).

The researcher served as a facilitator during the focus group interviews (*Krueger & Casey, 2000:11* quoted by *De Vos, 2002*). The facilitator tried to stimulate discussion and keep participants from straying off the topic. In this way, the focus groups will produce a rich body of data expressed in the participants’ own words and context.

The researcher also kept in mind that the intent of the focus group is to produce information, not to generalize, but to determine the scope or the level, and not to make a

statement about the population but to provide insights into how AIDS patients, family members and voluntary AIDS caregivers in groups perceive or experience provision of support.

The facilitator made use of an effort to experience the phenomenon under discussion in the same way as the participants.

3.6.4.1.. *The setting*

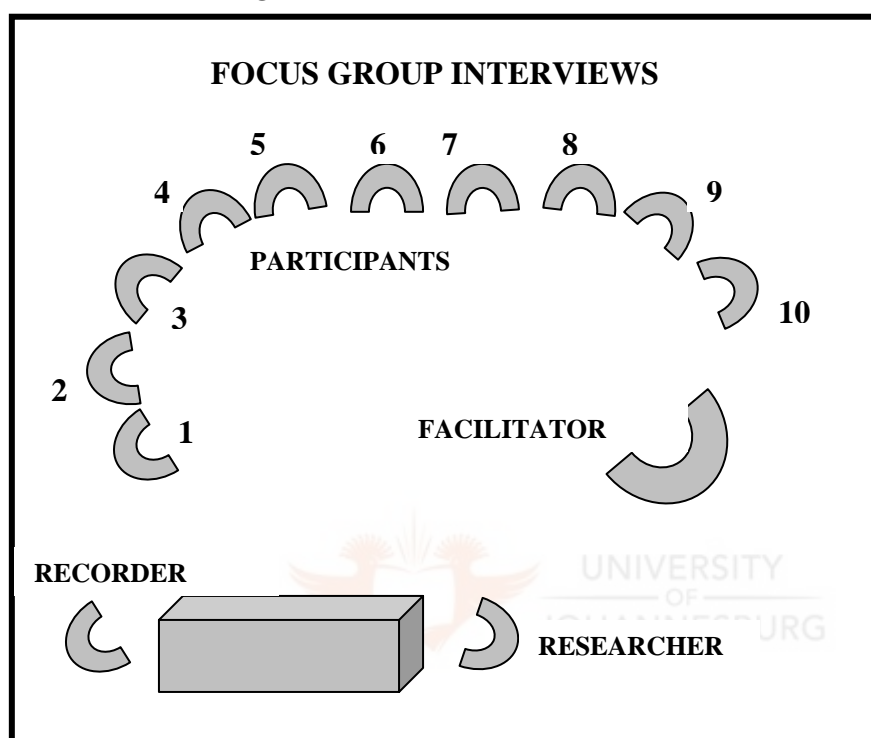


Figure (3.6.4.1): The setting of focus group interviews

The setting is the physical location and condition in which data collection takes place (Polit & Hungler, 1999:715). It could be an area that is natural to those being studied, for example, at home or at the workplace (Polit and Hungler, 1999:708). However, Bogdan and Taylor (1975:28) noted that they would *"recommend that researchers choose a setting in which the subjects are strangers and in which they have no particular professional knowledge or expertise."*

The selection of the field setting is an important decision the researcher has made. The researcher chose a setting in which the participants are strangers and they have no particular professional knowledge or expertise (Bogdan & Taylor, 1975:28 quoted in De Vos, 2003). This place was also free from visual or audible distractions. Permission to use the venue was obtained from the Department of Social Development. All the

participants were orientated towards the location, since they originate from the Bloemfontein area. Chairs were arranged before the interview started. No one seated higher than the other and the circle format was used through out. A warm friendly atmosphere was created to the participants and the introduction was done in a comprehensive manner.

3.7. THE PROCESS OF DATA ANALYSIS

Neuman (1997:426-427) refers to data analysis as a search for patterns in data. This refers to recurrent behaviour, objects or a body of knowledge. Analysis is a process that involves examining, sorting, categorising, evaluating, comparing, synthesising and contemplating the coded data as well as reviewing the raw and recorded data. The researcher used the following steps to analyse the data:

3.7.1. STEP 1. ORGANISING THE DATA

- ❖ The researcher needed to be familiar with the notes gathered and to get a sense of the data. The researcher played and listened to audiotapes from the three focus groups during the interviews. Four separate audiotapes were used and will be listened to. The researcher read through the entire interview transcript for the purpose of becoming familiar with the data and to get the sense of the whole by gaining an overview of the information gathered
- ❖ The process of refinement (sifting and sorting) of material according to key issues in order to identify the themes. After each and every session the researcher compiled written information on the discussions done and listened to the audiotapes of focus group interviews. Units of meaning relevant to the research question were identified. This involved the process of sifting and sorting material according to the key issues such as familiarizing.
- ❖ Write out the information on the transcripts and key issues were noted.

3.7.2. STEP 2. CLASSIFY CATEGORIES

According to De Vos, (2003:428) coding pertains to the naming and categorising of data. The data was coded and later combined into categories of responses and these categories will be refined and integrated into research themes.

- ❖ In formulating the main categories and themes, the researcher made a list of all topics, and shaped these topics into columns. Example of these topics were:
 - ❖ 1. The nature of support that is provided regarding the caregivers
 - ❖ 2. the nature of support that you receive
 - ❖ 3. Recommendations on the support that should be provided by voluntary caregivers

These lists of categories or subcategories will be classified

3.7.3 STEP 3. OPEN CODING

Each question was coded and later combined to form categories of responses and these categories were refined and integrated into research themes. For example, care giving roles were recorded. Open coding will be used. These are some procedures that the researcher followed in data analyses De Vos, (2003:345):

(a) Open coding

- ❖ *Labelling the phenomena*

This implies taking an observation, a sentence or paragraph and giving each idea or event a name. For example, economical support or financial support was given a name by the researcher. The researcher compared participants data provided so that similar themes were given the same names. For example, the emotional experiences like fear and isolation of family members will be grouped together. Stipends and disability grant will be labelled as financial support.

- ❖ *Identifying categories*

The researcher grouped the names identified during the labelling phase. This process is called categorising (De Vos, 2003). It is said the phenomenon will be given a conceptual name. The names are given by the researcher himself. The name was related to the data it represented for example, communication was a name for a category.

A category was analysed and patterns that exemplified the experiences of family caregivers were identified and analysed.

❖ *Writing code notes*

Initial code notes for coding were taken or written straight out of the interview notes. Categories were written as code notes where co-researcher notes were available and these notes were kept separately. This assisted the researcher to read from the code notes written for each focus group on their stories and experiences. In this manner, the training required in the care –setting was noted.

❖ *Variations in terms of doing the coding*

According to De Vos (2003:348), coding varies according to the researcher's choice and themes are analysed. Here the researcher analysed the first interview and then turn analysing similarities or differences. The narrative report of the data was presented and compared to the formulated themes within available literature.

3.8. TRUSTWORTHINESS OF THE RESULTS

Trustworthiness is the extent to which one can believe in the research findings. Polit et al., (2001:312) asserts that qualitative research is trustworthy when using the criteria for assessing it. In order to ensure the trustworthiness of the research findings of the study, the researcher made use of Guba's model as outlined by Sandelowski (1986) in Woods and Catanzaro, (1988:473) that is widely used in qualitative research. The model focus focuses on:

- *Truth-value*
- *Applicability*
- *Consistency*
- *Neutrality*

3.8.1. Truth-value (credibility)

Truth-value is about steps taken by qualitative researchers to improve and evaluate data credibility. It refers to confidence in the truth of the data (Lincoln & Guba, 1985:290; Polit et al., 2001:312; Woods & Catanzaro, 1988:473).

Flick (1999:232) outlines the following strategies to enhance the credibility of data

analysis.

- The prolonged engagement with participants in the setting is undertaken to ensure sufficient time to build a trusting relationship.
- Member checks in the sense of communication validation of data and interpretations with members.

The researcher obtained an essential description of a lived experience and developing relationships in which she intensively interviewed relatively few people. The researcher further ensured that she uncovered the truth of experiences of voluntary AIDS caregivers and AIDS patients on the experience of home-based care. This was promoted by prolonged engagement and persistent observation during interviews with each focus group. Four focus group interviews were conducted and there was a consensus discussion with co-coder. An interview environment was decided by the subjects. This was done to allow them to choose a place where they felt comfortable. The researcher did verbatim transcriptions of recorded interviews as soon as possible after the interview. Categories identified from data collected verified that the focus throughout the research project was on AIDS patients and the support that they receive from AIDS caregivers.

3.8.2. Applicability (transferability)

Applicability is described as the degree to which the findings of the study can be applied to other contexts and settings or to other groups. This fittingness of the data is a criterion for evaluating the quality of qualitative data. The researcher has chosen a purposive sampling on AIDS patients, their families, and AIDS caregivers. All sample groups participated in the focus group interviews.

3.8.3. Consistency (dependability)

Consistency in qualitative data refers to data stability over time and over conditions (Guba and Lincoln, 1998, 235). There can be no trustworthiness in the absence of dependability. Consistency is similar to reliability. The research methodology was clearly and fully described. The co/facilitator or co-coder had consensus discussion with the researcher. The researcher coded the data. The researcher identifies categories and sub-categories.

3.8.4. Neutrality (confirmability)

Neutrality is referred as “confirming ability” that depends on the existence of audit ability, which means that the systemic collection and systemic documentation of data allows the qualitative researcher to draw conclusions about the data, the truth-value and applicability. Objectivity refers to the extent to which two independent researchers would arrive at a similar judgement or conclusion (unbiased by personal values or beliefs). There was no prior meetings or arrangements entered into by the researcher and the subjects. Two study leaders subjected the study to critical evaluation from beginning to end and an expert researcher did the audit.

3.9. Conclusions and recommendations

The researcher came to conclusions on the basis of the findings and the literature review. The researcher made recommendations based on these conclusions.

3.10. CONCLUSION

In this chapter, the research methodology and method of data analysis was described. The aim of the study is implemented by focus group to gather qualitative data. Focus groups are including three groups of participants. In this chapter the analyses and development of themes was described. The analyses and interpretation of data collection of results will follow in chapter 5 with regard to the literature control



CHAPTER 4

3. DATA ANALYSIS AND FORMULATION OF RESULTS

INTRODUCTION

The research methodology was extensively discussed in chapter 3. The focus in this chapter will be on the analysis and literature control of the results of focus group interviews conducted with participants.

The researcher has mentioned the process of a transformation and change that has occurred in 1994 with the inception of government of National Unity, highlighting many problem areas that need to be addressed with regards to health service delivery systems. The approach has shown little ability to perceive the needs of curative services to primary health care services and to the larger unique environments of the family and the community of which they are part. The researcher has observed from her practice setting that approaches which stress the use of resources and strengths in people and their environments achieve positive and desirable results with volunteers and AIDS families.

An in-depth intensity of the analysis was determined by the purpose of the study, which was to explore the experiences of home -based care as service delivery. Focuses was placed on the nature and kind of support the HIV/AIDS patient and families receive, and to find out whether there is any recommendations on how support should be provided by voluntary care givers.

4.1. Qualitative analysis

Qualitative analyses is a process of fitting data together, of making the invisible obvious and of linking and attributing consequences to antecedents. It is a process of bringing order, structure and meaning to the mass of collected data (De Vos, 2003:339). This description is well supported by Neuman (1997:426-427) who refers to data analysis as a search for patterns in data-recurrent behaviour, objects or a body of knowledge. A process that involves examining, sorting, categorising, evaluating, comparing, synthesising and contemplating the coded data, as well as reviewing the raw and recorded data, also complemented the above and indicates that data analysis is the systematic organisation and synthesis of research data, and the testing of research hypotheses using this data

4.2. COMPOSITION

The focus group usually includes six to ten participants. This size allows everyone to participate while still eliciting a range of responses (De Vos, 2002:311).

The composition of focus group members composed of ten volunteers, ten HIV/AIDS patients and ten of their family members who are homogenous in nature and had something in common. The sample is taken from Bloemfontein, Free State Province which opens up the possibility of conducting group interviews with groups of similar individuals. Specific reference to age, gender, cultural background and educational levels was not considered for stratification in this study

4.3. THE PROCESS OF DATA ANALYSIS

The actual data analysis process is an intensive, creative and time-consuming activity that involves clustering together related types of narrative information into a coherent scheme and is typically an active process. It is a search for general statements about relationship among categories of data and it builds grounded theory (Marshall&Rossman 1995:111 quoted by De Vos, (2003:340). The researcher applied the following strategies in data analysis phase:

- Field notes were gathered.
- The audiotapes of focus group interviews were scrutinized.
- Transcription of the information on the transcripts.

The researcher and the co- facilitator working in the Department of Social Development agreed on the categories, the sub-categories and the themes. In the pilot study, the first main category was divided into four categories, which included economical, physical, emotional and spiritual support, and data from the three focus group interviews was grouped into these main categories. This was followed by reading the participants 'entire descriptions from the transcripts. Preliminary grouping of descriptive expressions was agreed upon by the supervisor and the co-facilitator.

The researcher reduced the experiences to a few concepts by grouping according to similarities and differences. In the study, the data is in the form of words that is relatively unclear, diffused and context-based, with possibly more than one meaning (Neuman, 1997:420).

Therefore the researcher reads narrative data over and over in search of meaning and deeper understanding.

The reason for reading transcripts repeatedly, was to develop a sense of the whole. In conclusion, the process of data analysis in qualitative research is less theoretical than that of quantitative research.

Codes and coding

The core of qualitative analysis is a twofold task, namely to select a portion and assign it to a category. Codes are legal statutes arranged to avoid inconsistency and overlapping of data while coding is a term used for analysing data resulting from where structured responses can be assigned to pre-defined categories. The codes and categories were sorted, compared and contracted.

RESULTS

During the focus group interviews the researcher noticed the following about each group

- *Pilot study*

The group was concerned about general issues that were not part of the study.

- *Focus group 1*

The second focus group was more homogeneous as all members participated well during the interview. Their feedback with regard to the research question was also applicable. Unfortunately, as with the first focus group interview, there was redundancy of information

- *Focus group 2*

Arrangements were made with the ten (10) participants of families. The group was homogenous

- *Focus group 3*

Following the inclusion guidelines, more participants were selected from those who indicated that they were willing to participate as patients.

Focus groups 2, 3 and 4 possess the same characteristics. Both groups had ten members and are homogeneous with regard to inclusion criteria.

In qualitative research, sample size should be determined on the basis of informational needs. The statements were classified into many categories, and then classified into themes

4.4. MAIN THEMES AND CATEGORIES

4.4.1. THEMES AND SUBCATEGORIES

4.4.1.1. FINANCIAL SUPPORT

4.4.1.1.1. The stipend is not enough and the stipend is unsatisfactory.’’

All the volunteers of focus groups 1, reported that the stipend is insufficient, not enough, delayed and unsatisfactory. Families experience lack of support in getting pension whilst patients experience lack of support in terms of grants, Stipend, which does not come in time for voluntary AIDS caregivers, results in families struggling to maintain their health condition and patients not getting their sick pensions or disability grants.

Volunteer’s Response:

‘‘If you render a service you do it from your heart, we don’t receive enough stipends from the department they give us R300 per month at least we need R500-R700 per month. The support we receive is ‘‘unsatisfactorily at all ‘‘you’ll find the other month we don’t get money the other month, we get R300 only.’’

Volunteer’s Response

‘‘The stipend does not come every month, we have to wait for so many months and we work hard Informal’’.

‘‘Caregivers do not receive payment that designate to compensate them for their duty.’’

‘‘We get the stipend late’’, ‘

‘‘Volunteers must be paid every month,’’

Patient’s response

‘‘We need social grants’’

4.4.1.1.2. Economic Responsibility is great

With regard to socio-economical problems, the families and patients reported that the economic responsibility is great. Hospitals are reported to make profit and a good name for themselves. Some participants are complaining that they are taken to the private hospitals to pay higher prices for medication that they can buy cheaper elsewhere.

Volunteer's Response:

'There is no allowance that we receive, ' we need ARV, s''

'Hospitals put our patients in separate rooms''

Family response:

'We pay a lot in the private hospital''

'We don't get pension''

4.4.1.1.3. No benefits



Volunteers have human rights and should not be exploited because of their poor income and lack of opportunity. Volunteers often hope that volunteering will lead to remuneration that will enable them to improve their own and their families' lives.

Feelings of having no benefits appear explicitly in focus group 1, which was verbalised by the voluntary AIDS caregivers. Health insurances including fees for separate room and medical certificate were a source of dissatisfaction to volunteers, families and their patients.

Volunteer's Response:

'We are not covered by Health insurances''

'We don't have any benefits'

'We don't get any allowances''

4.4.1.2. SOCIAL AND PHYSICAL SUPPORT

Caring for terminally ill and dying patients involve aspects of four dimensions namely, psychological, physical, spiritual and emotional. “It is absolutely vital to have support systems and to know how to care for themselves as well if they want to prevent themselves from being overwhelmed by burnout.” Physical support is the most basic of all human needs because it concerns survival, food and rest.

4.4.1.2.1. Psycho –social support experienced by families and patients concerning the volunteers

The families and caregivers reported that they don't receive support from the formal system that is at hospital and at the Department. It seems there is lack of available support systems and family members are not present at time of death. It is also clear that families depend on their caregivers and nursing staff. Families report that they receive proper social support from the caregivers.

Patient's response:

“We are not getting any support from the department”,

“we don't receive any support from the clinics”.”

“The nurses don't take care of us”, *“the support is there but not enough”*

Volunteer's response:

‘My family does not understand my commitment to my work’,

‘my husband says the other day’ these people will infect you, if I get infected it will be your fault you will see what will happen’

Patients' responses:

‘We are shouted by the nurses’

‘We receive home help services by our caregivers,’ but few are receiving meals on wheels and less are using step down facilities.

4.4.1.3. EMOTIONAL UNDERSTANDING OF PATIENTS, FAMILIES & VOLUNTEERS

Caregivers often feel the same stresses. In general, people with HIV infection and their caretakers, face greater emotional strain than most people ever do. Those affected by the disease are shocked, angry, depressed, and afraid, confused or have number of these emotions at once. They worry about dying.

4.4.1.3.1. Focus groups participants' emotional experience of AIDS

Participants from all focus groups express strong emotions such as negativity, pressure, uncertainty about the future, confusion, dissatisfaction, and feelings of hatred and demoralisation. There is no emotional understanding and support given to caregivers, families and patients. Most of the families view the professionals as not providing emotional care to their patients and the patients describe a sense of loneliness and isolation. The volunteers feel tired and sad because they have additional burdens of having to deal with multiple deaths of families. Caregivers experience depression and personal neglect. Every participant in this study reported stress.

Volunteer's Response:

'I was told to stay with the patient 24 hours to avoid patient going to the hospital''

''We are kicked from this hospital to the other''

''I need someone to talk to''

''There is a feeling of tiredness, exhaustion, depression and often neglect of our own health.

'I feel isolated because I have to care for my patient,

'' I sometimes cannot got to church, I have to be with him at all the time''

'' I feel sad when my client passed away'' I am depressed''

Patient's response

''The doctor gave me news, that I am positive''

''I feel stressed and think I am going to die now''

Family's response

'My daughter was diagnosed o AIDS, I felt sad'

4.4.1.4. EXPERIENCE OF HIV/AIDS PATIENTS ON CARE-GIVING BY VOLUNTEERS

Care giving is a human service transaction that is built on a relationship between caregivers and care-recipients.

4.4.1.4.1. Experiences of HIV/AIDS patients regarding care by volunteers

Some participants reported that the quality of care given from the medical staff in the context of nursing is not good. They prefer their caregivers in psycho-social support.

Patients 'response:

'The staff just told us, we will not give you the medication because you will not get well'

4.4.1.4.2. Psychological care inadequate

Many patients and caregivers are experiencing stress that threatens their relationship with their families. Patients are disappointed, depressed and frustrated with psychological care in the context of nursing, and there is a need for interpersonal communication and shared confidentiality.

Patient's response:

'There is no confidentiality at the clinics, the clinic sister simply refer the volunteer to you without knowing''

' We are not cared for''

'We are just told that, you are HIV positive''.

'Nurse should have given emotional support to my child not only injection''

' she was crying''

'My daughter was lying in pains and slept at the chairs of the clinic without any sympathy''

4.4.1.4.3. Differences in quality of care

Some participants reported that care giving varies among professionals some participants reported that informal caregivers rather than the health professionals are very helpful in psychological and physical care. Volunteers report that they are not treated well and with respect and dignity. Patients and their families report that they are not treated well and with respect by the hospitals.

Patients' response:

“The medical staff do not support us and we never recover in hospitals.

“ instead we get worse and worse. “Nurses are always in a hurry to explain everything for us,”

“ Caregivers help us in explaining about the treatment and in household chores because I cannot walk”

Volunteer's response:

’Yes, we are the volunteers but we must be treated equally.

” I love my work,”

“ This kind of job is hard “

“As a wife, my children and my husband are complaining because I am working for nothing”.

Patient's response

“Medical professionals do not pay attention to us, as we are sick”

“ It is better to stay at home rather than going to a hospital because in hospital when someone died we knew it immediately as a dead person is carried of”

” I don't know whether this is an intention to show us to prepare for death”

“We are not treated with dignity at the hospitals and sometimes we don't trust our caregivers because they would talk about our status”

4.4.1.4.4 Differences in quantity of care

The quantity of information differs. Participants reported that there is no information received on how to care, and that is not clear. The quantity of information from caregivers and nurses at

clinics is not sufficient; some reported that there is a lack of caring in the hospitals. Some of the HIV/AIDS patient's family members are dissatisfied with the medical treatment that is provided to them.

Patient's response:

'We have received counselling but I am not sure if it had any meaning,

'' everything to me sounds irrelevant and did not help''

'I believe that I will be healed and never recover but the staff nurses told me that they will not give me a treatment because I will never get well, ''

'We were told doctors would provide no medical treatment, only pain medication''

4.4.1.4.5. Patient's perception on the use of volunteers in caring

Some HIV/AIDS patients reported that there is lack of care in the hospitals. They do not care about how they feel as patients. There seems to be a clear need to use more volunteers to support the families, especially where large numbers of people have been identified. Half of the participants have accepted involvement of volunteers in home -based care and the health professionals only in the provision of respite care.

Participants were asked what type of care they would prefer in different circumstances. Over half of them prefer to receive care from their families, friend. One half of the respondents prefer professionals and this need is higher in the case of personal care services, such as bathing, and dressing

Patient's response:

'We are not respected by the sisters at the clinics''

'We are exhausted and hope that we will recover when we are in hospitals but we are not given attention''

'We are forced out of hospitals or only stay for a week and kicked to the next hospital. It's better to stay at home to be nursed by my caregivers;''

4.4.1.5. FAMILY’S FEELINGS ON ISSUE OF CONFIDENTIALITY ABOUT CAREGIVERS

Confidentiality in the HIV/AIDS field is difficult and complex. It is ones responsibility to the client, their partners or the community at large.

4.4.1.5.1. Secrecy and fear of disclosure

It is clear that there is lack of confidentiality form the caregivers regarding the family’s status regarding those who want to know or do not want to know about their status.

Family’s response:

“We are not considered by the clinics, they just refer the caregiver to our homes and not being told that there is somebody coming to visit. “We don’t trust even these volunteers they would talk about our status.”



Patient’s response

“Volunteers just come without knowing”

“Clinic refer these people to us

4.4.1.6. STIGMATISATION

Social isolation of the family often results from secrets kept regarding the cause and the death of the loved one. Families of HIV/AIDS are more withdrawn. Because people are victims of stigmatisation in peer groups, this leads to aggressive behaviour and further isolation.

4.4.1.6.1. Stigma associated with HIV/AIDS in the families and community

There is still stigma in communities and feelings of guilt due to the suitability of people caring. The study indicates that other people still take AIDS as not being the disease of the people, and there is still “blame” in their communities.

Stigma continues to be an important reason for reluctance of using social services by the families. Family members living with their patients experienced stigma.

Family's response:

'We are afraid to go to the community other will laugh about us ''

'I don't want join even the support groups that sister at the clinic said I must join''

'I have never received any break from my work''

'We experienced a stigma even in our community,

'There is discomfort about the discussion''

Patient's response:

'I am afraid to go the social workers and afraid to talk to my friend about my status, although I don't trust volunteers. But since they come for help, I am used to them and I prefer them to talk and rather than going to the social workers, I feel embarrassed''

Volunteers Response:

'My husband says one of those people is going to infect you and it will be your fault if I am infected and have AIDS''

'No there was not turning point, but I was thinking of my family relationship which was becoming bad because I am not paid by the Department every month and I was still continuing with my work as it is call from God. I only receive R500 or less the amount I am supposed to get. The support is unsatisfactory. At least I wanted to be relieved from all the burden of caring.'''

4.4.1.7. COMMUNICATION OF INFOMATION TO THE FAMILIES BY CAREGIVER

Caring requires being legitimate, sincere and clear. Lack of cooperation among service providers and fragmented service delivery systems creates a number of serious problems for caregivers to provide social health care services to the families.

4.4.1.7.1. Lack of communication of information by volunteers and other stakeholders

There is duplication of services and shortages of social service. People travel long distances to health care facilities and it is difficult to find out about the availability of services. There is no partnership amongst the volunteers and other stakeholders and lack of clear communication in government.

Some participants reported that they are shouted at government facilities and nurses do not cooperate with them.

Family' & patient's response

“ When you get to the clinics late, nurses shout at you and found out there is no medical treatment given to you’

Patients' Response

‘Clinics don't talk to us nicely’

‘We are shouted’

‘We are not given medication and treatment’

‘We don't have information on how to take care of ourselves’

4.4.1.8. EXPERIENCES OF VOLUNTEERS IN CARING FOR HIV/INFECTED&AFFECTED INDIVIDUALS

Some caregivers are infected themselves. They observe at first hand while caring for people with AIDS how they will too become sick and die. Caregivers often experience stress because they are unable to be there for their clients when they need to be Most of the family members enjoy shopping. Whilst others enjoy sleep

4.5.1.8.1. Experience of volunteers in caring AIDS patients and their families

Participants in focus group1 experienced varying periods of depression, anger and fear towards family members of HIV/AIDS patients

Volunteers Response:

'I am stressed when my patient dies''

'We are not treated well at the homes of HIV/AIDS patients'

'Families do not listen to us, and goes shopping when we are there''

4.4.1.9. NATURE OF HOME-BASED CARE FOR FAMILIES, PATIENTS AND VOLUNTEERS

Participants in focus groups 3 and 4 reported that there is a good nursing care service at their homes that is provided by their caregivers. They maintain that caregivers promote and maintain their hygiene, assist them in taking medication and teaching the family in caring for their patients.

Because of the patients' disability, many care recipients have difficulty performing routine tasks such as walking, feeding, bathing and dressing.

4.4.1.9.1. Experiences of patients and their families on the nature of home- based care as local service delivery

Participants in focus groups 2 and 3 reported that caregivers promote and assist them in transportation to and from the clinics. Participants from focus group 4 reported that there is a lot that is done by their caregivers in maintaining their health status, and they indicated that they receive assistance from their caregivers rather than from health professionals.

It is said that care recipients require transportation to go not only to the clinics, but also to church, day care facilities, therapy sessions and support groups. Both the caregivers and recipients tend to suffer. While patients rely on their families for transport, they must sometimes seek out paid caregivers for help with this service.

Family's response:

“Caregivers are encouraging ourselves to talk about our status, and feel strong that we are positive”

“I really feel strong about my status and ever since I met them I don't have any fear of talking about myself even in public”

Patient's response;

‘Hospital does not take care we want to stay at home’

“Volunteers provide good assistance in their care like bathing us and give medication”

“We are not supported at the clinics on hope to recover’ they rather say you are going to die

‘The carers come three times a week’

“They take us to the clinics for treatment”

4.4.1.10. EDUCATION AND TRAINING

Education is a basic infection control and prevention practice. Caregivers, family members or outsiders can be exposed to infection because of ignorance or because they have not been taught correctly. Caregivers should make the education of the patient and family members a basic element of their routine, starting with basic care -giving, personal hygiene. Being informed about the disease and care is an essential part of care giving, especially where the family is responsible for a portion of the patient's daily care.

4.4.1.10.1. Experiences of families and patients regarding educational and training programmes done by voluntary caregivers

Some participants in focus group 2, 3 and 4 reported that there is a need for educational support such as workshops on information regarding HIV/AIDS and how to care for patients. It is clear that patients continue to suffer due to the lack of information in a range of medical and social services. There is lack of assistance of the families to manage home-based health care. The focus

group of volunteers reported that they need training, as they do not want to remain volunteers. The family should get as much information as possible.

Patients & Families maintain that they receive information on educational programmes such as door to door campaigns, awareness campaigns regarding their health status

Volunteer's response:

'We need educational support, ' they call us volunteers, 'we are human beings''

'Workshops and trainings on how to take care of us '

'I don't know what to do with my patient''

Families & Patients' response

'We get more information on HIV/AIDS by our carers. '

'We receive educational programmes when they come to visit''

4.4.1.11. COUNSELLING SERVICES BY LAY COUNSELLORS AS VOLUNTEERS

Counselling should be available at all stages of the illness, from pre-test counselling to bereavement support. There is no cure for HIV/AIDS and there is no alternative but to focus caring on the physical as well as the psychological welfare of the HIV infected individual.

4.4.1.11.1. Lack of counselling services provided by voluntary caregivers and clinics

From half of the caregivers and patients' responses, it became clear that respondents do not receive any counselling in the form of pre-post test counselling from their caregivers and do not understand what is even said in a counselling process that is provided by their caregivers.

Patient's response:

'I mean there is nobody helping us in terms of accepting our status except caregivers.' At clinics, there are no nurses or doctors available''.

'We also receive counselling from the caregivers, more than the sisters in the clinics''

'But the counselling is not enough ', we need somebody to talk to''

'At home they get tired especially when you are sick'

'I need counselling everyday, social workers do not come everyday in the house at least I could have somebody to talk''

4.4.1.12. LACK OF AVAILABILITY OF SERVICES

There are still shortages and these are continually to be felt by informal caregivers and patients. Home-based care should allow for financial incentives, medical kits, transportation, and provision of accessible caregivers and families in order to boost their morale.

4.4.1.12.1. Lack of resources experienced by volunteers & patients

HIV/AIDS patients and caregivers reported concerns about receiving adequate care and there is insufficient numbers of nurses especially at night and on Sundays, and sick people have difficult time during the night. Their caregivers are not there at night to support them.

Patient's response:

'We rely on the caregivers support to take us at the clinics''

''There is no sufficient number of staff at the clinics''

''They come three time a day''

Volunteer's response

'Equipment insufficient, ''

''We have no computers at the offices and no protective clothing.''

''We need gloves''

Family's response:

''We waited here since morning, nurses seems in a hurry and could not have time to talk to me''

''We kept waiting and we had to wait until the next morning''

''We don't know where to go if we had a problem in clinics''

4.5. OBSERVATIONAL, PERSONAL AND THEORETICAL NOTES

4.5.1. PURPOSE

4.5.1.1. Observational notes

Observational notes are descriptions about the observed events and conversations. It is important to observe research respondents for gaining an understanding of the physical, social and cultural contexts. Observational notes help the researcher to make sense of the data. These are experienced through watching and listening.

4.5.1.2 Personal notes

Personal notes are important to the researcher as they record what the researcher has observed and experienced. Personal notes include an account of events on how people behaved and reacted, what was said in conversation and where people were positioned. Personal notes are the written comments about the researcher's own feelings during the research process. These notes help the researcher to remember and explore the process of an interview. The researcher hears, sees, experiences and thinks about in the course of interviewing. The researcher constantly identified support as the most important need for the patients, families and volunteers. This study encourages the provision of integrated systems to provide support in order to assist voluntary caregivers, patients and their families.

4.5.1.3. Theoretical notes

Theoretical notes are interpretive attempts to attach meaning to observations. Observational notes and theoretical notes were categorised under the headings reflected in table 4.4.

Table 4.4.

FOCUS GROUP 1	HOMOGENEITY	ATTENTION	GESTURES
Observations	<i>Participants were selected based on the inclusion criteria</i>		
	<i>It gives the researcher an opportunity to interview them and the group has similar characteristics with open ideas</i>	<i>Some of the members were not participating much</i>	<i>The other members were crying concerning the support that they receive from the clinic sisters</i>
Theoretical	<i>They support each other concerning the support they receive from the caregivers They used short responses They expressed emotional feelings They respect each other.</i>	<i>The members first were embarrassed to talk at first</i>	<i>The group was nodding their heads and hesitating to talk about the support they receive from caregivers</i>

FOCUS GROUP 2	HOMOGENEITY	ATTENTION	GESTURES
Observations	<i>Participants were selected based on the inclusion criteria</i>		
	<i>It gives the researcher an opportunity to interview them. the group has similar characteristics with open ideas</i>	<i>Some of the members were not participating much</i>	<i>The other members were crying concerning the support that they receive from the clinic sisters</i>
Theoretical	<i>They support each other concerning the support they receive from the caregivers They used short responses They expressed emotional feelings They respect each other</i>	<i>The members were embarrassed to talk at first</i>	<i>The group was nodding their heads and hesitating to talk about the support they receive from caregivers</i>

FOCUS GROUP 3	HOMOGENEITY	ATTENTION	GESTURES
Observations	<i>Participants were selected based on the inclusion criteria</i>		
	<i>It gives the researcher an opportunity to interview. the group has similar characteristics with open ideas</i>	<i>Some of the members were not participating much</i>	<i>The other members were crying concerning the support that they receive from the clinic sisters</i>
Theoretical	<i>They support each other concerning the support they receive from the caregivers They used short responses. They expressed emotional feelings. They respect each other.</i>	<i>The members were embarrassed to talk at first</i>	<i>The group was nodding their heads and hesitating to talk about the support they receive from caregivers</i>



4.6. ETHICAL CONSIDERATIONS

4.6.1. The quality of the study

“Qualitative researchers strive for understanding that deep structure of knowledge that comes from visiting personally with informants, spending extensive time in the field and probing to obtain detailed meanings”

Participants who were willing to participate in the study signed an informed consent form. The research was pilot- tested to ensure that the questions were unambiguous and well understood.

Focus group interviews were one of the strategies used to define “quality,” test monitoring procedures and generally understanding issues relating to quality (*cf* Krueger & Casey, 2000: 17 quoted in De Vos, 2003).

A researcher who was appropriate for the situation because of her training, background and sensitivity conducted the interviews. The co-facilitator listened carefully to participants, observed how they answered and sought clarification on areas of ambiguity.

Confidentiality was maintained throughout the study. No information was linked to any participants. The researcher also applied the four aspects of trustworthiness during the research process.

The data analysis was followed up by a literature control in order to indicate the similarities and the differences.

4.6.2. Competence of the researcher and facilitator

The researcher is anonymous in qualitative research. During focus group interviews, the researcher acted as a facilitator and documented the placement of participants, the interaction between them and their non-verbal behaviour. The co-facilitator jotted down field notes.

A researcher and co-facilitator facilitated the focus group interviews with extensive experience in interviewing, and the utilisation of various communication

techniques. Her expertise added to the high quality of the study because of the rich data that she obtained from participants.

4.6.3. Permission to conduct the study

The research commenced after formal written permission was granted. The researcher followed Began and Taylor's advice (1975:30) of gaining access to an organisational setting.

The gatekeepers of the setting where the interviews were conducted were notified ahead of time that permission had been granted. After building a relationship of trust with the participants, the researcher also obtained their permission to participate in the study,

4.6.4. Informed consent by participants

Informed consent is an ethical principle that requires the researcher to obtain the voluntary participation of the participants after informing them of possible risks and benefits (*De Vos* 2003).

The researcher informed the potential participants about the intended study including the following factors:

4.6.5. A brief description of the purpose and procedure of the study.

The researcher made sure that each prospective participant was well informed before signing in as a voluntary informant because the voluntary consent of the human subject is essential for the conduct of ethical research (*De Vos* 2003). A copy of their signed consent was given to the participants to ensure that the conditions of the agreement were always available to them.

4.6.6. Assurance of confidentiality

(*De Vos* 2003) asserts that participants' privacy must be maintained throughout the study. In this study the researcher safeguarded the right of privacy of the participants by assuring them that: (a) they would not be linked to the information provided during the data collection phase.

(b) Information provided would not be made accessible to parties other than those involved in the research.

4.6.7. Protection from harm and discomfort

(*De Vos* 2003) cautions researchers that the psychological consequences of participating in a study are generally little and thus require close attention and sensitivity. Researchers should strive to avoid inflicting psychological harm by tactfully phrasing questions and by providing debriefing sessions after completing the data collection to permit participants to ask questions. The researcher considered this as one of the most important techniques for establishing the credibility of qualitative data, and took precautions to safeguard participants from harm.

In conclusion, in this form of research, the quality of the study is not dependent on the size of the sample. In focus group research, the rule of thumb has been to conduct three or four focus groups with a particular audience and then to decide if additional groups should be added to the study (Krueger & Casey, 2000:206 quoted in *De Vos* 2003). The researcher tried to apply most of the underlying principles throughout the research process.

4.7. LITERATURE CONTROL

Introduction

A comprehensive literature study was carried out on the findings of other researcher's in matters related to the topic under the study. This was done upon the completion of the interviews and transcription thereof to avoid any bias by the researcher. Phenomenologist believe that the literature should be revealed after data collection and analysis so that the information in the literature will not influence the researcher' objectivity.

4.7.1. STIPEND

All volunteers reported that the stipend is insufficient, not enough and irregular. Stipend is described as a generous monetary incentive offered to encourage the participation of economically disadvantaged groups to compensate for time and expenses.

There are shortages, and these shortages are continually to be felt by informal caregivers who are carrying the major responsibility of the care of so many family members, relatives and friends (Moroney, et al, 1998:72).

In South Africa as elsewhere, donor agencies play an important role in the fight against HIV/AIDS, not only the way of supporting, advising and funding projects but also in funding and managing HIV/AIDS projects via NGO's CBO's and FBO's (Van Pelsler, Steyn, Boysen, Andendorf, Rensburg, Friedman, & Ngwenya, (2002:113)

4.7.2. BENEFITS

Home -based care should allow for financial incentives, transportation, medical kits and their re-supply, and make provision accessible caregiver support mechanisms in order to boost the morale of caregivers and staff that often face difficult physical and emotional work conditions (Rossenberg, 2005:35).

The 1985 report on social welfare recommended improvements in financial support, including the payment of the prescribed carer's allowance to the carer rather than the person being cared for (Timenon&McMenamin 2002:21).

Volunteers have human rights and should not be exploited because of their poor income and lack of opportunity. Such volunteers often hope that volunteering will lead to remuneration that will enable them to improve their own and their families' lots (Uys & Cameroon, 2003:12).

Carers should be involved in the planning process and be treated as full and equal partners. Both carers and cared for persons should have a choice and adequate information on which to base that choice. Carers should be obliged to take on the caring role, but should be able to say no if they wish. Carers should have adequate income and should not be penalised financially for taking on the caring task (Keathley: 144 quoted by Davidson & Hunter 1994)

The community care legislation offers specific support for adopting existing services for the benefits of carers. Carers are expected to take greater responsibility and provide huge amounts of care. Carers need information about the services available in the area and about the benefits to which they are entitled to about the changes in legislation and about the conditions of the person for whom they are caring. Most carers receive no services at all (Keathley: 144 quoted by Davidson & Hunter 1994).

4.7.3. EMOTIONAL UNDERSTANDING

“Emotional’ is described in terms of mental well-being or more specifically by symptoms of anxiety and depression. Stress is lodged as being central to the construct of care giving (Grant &Whittel, 2000 as quoted by Servick, Kamlet, Mark &Hoffman, 1996:763). Fixed debriefing time needs to be rescheduled with a suitably experienced and qualified professional in order to give psychosocial support (Uys&Cameroon, 2003:28). Emotional or cognitive resources help define perception of care -giving transactions through services such as social support groups, counselling and support coping efforts (Moroney, Dockecki, Gates, Haynes, Newbrough, 1998).

Caregivers often feel the same stresses. In general, people with HIV- infection and their caretakers face greater emotional strain than most people ever do. Those affected by the disease are shocked, angry, depressed, afraid and confused or have a number of these emotions at once. They worry about dying (Bartlett& finkbeiner 1994:4).

4.7.4. PSYCHOLOGICAL& SOCIAL SUPPORT

Caring for terminally ill and dying patients involves aspects of all the four dimensions of psychological, physical, spiritual and emotional aspects. It is absolutely vital to have support systems and to know how to care for themselves as well if they want to prevent themselves from being overwhelmed by burnout. Physical support is the most basic of all human needs, because it concern survival, food and rest.

The nature of AIDS, an incurable and highly stigmatised disease, means that the need for psychological support for people infected and affected by the virus is great. Infected people need support in coming to terms with their diagnosis and coping with range of emotions such as anger, fear and self stigmatisation that is evoked by the issues of disclosure. Those affected especially carers’ children who

may be orphaned and other close relatives need support in understanding and coping with their own complex feelings, including bereavement. Psychological needs vary enormously from one person to the other with different stages of diseases (UNAIDS: 1).

4.7.5. FEELINGS OF FAMILY ON CONFIDENTIALITY ISSUES

According to Uys & Cameroon, (2003:57) confidentiality in a counselling context is non-negotiable. A counsellor may under no circumstances disclose HIV status or any information to anybody without the express permission of the client. Confidentiality in the HIV/AIDS field is difficult and complex. It is one's responsibility to the client, their partners or the community at large.

Caregivers often experience stress because they are unable to be there for their clients when they are needed because they are unable to meet needs such as food and have feelings of guilt and anxiety about the family members (Van Dyk, 2003).

4.7.6. NEEDS AND RESOURCES

The bulk of mental resources are found in hospitals and serve the needs of in-patients, while most people with mental health problems who require care are in the community at any given time (Renshaw: 83, quoted in Davidson & Hunter, 1994). The balance of resource has to shift towards the community in order to match the needs.

No services can run without resources. People living with AIDS and their families often live in poverty. It is said that it is impossible to be involved in home-based care without getting involved in poverty relief. Food parcels, clothes, and assistance with other urgent economic needs, make it essential that the home care service links up with a social service to deal with this aspect. Resources also include human and service resources. The management should ensure that caregivers have access to social worker, counsellor and consultant for medical

issues. Without such network home based care could be of poor quality leading to disenchantment of patients and their families (Uys & Cameron, 2003:10).

4.7.7. COMMUNICATION AND CO-OPERATION

It is essential that the community caregivers receive proper training in providing a high standard of care. If caregivers are not equipped with the knowledge and skills they need, they will not be able to function as part of the health care team and the home based care programme will not succeed (Uys & Cameron, 2003:33). The South African Qualification Authority Act (SAQA) of 1995; 58) has created a new framework for education and training.

Home-based care programmes should consider forming partnerships with agencies that are able to offer economic development possibilities to households in need. Home-based care needs stronger government coordination, integration and monitoring and evaluation in order to increase quality coverage. Integration of home-based care programmes into government health programmes is important as the government begin to roll out ARV's (Rossenberg, Mabude, Hertwig: 2005:35). Communication problems often arise between health-care facilities and undertakers, a situation resulting in families not being notified of a death or not knowing what has happened to the body of the deceased (Van Rensburg, Friedman, Ngwenya, Pelser, Steyn, Booysen & Adendorff, 2002:149).

4.7.8. COUNSELLING SERVICES

Counselling refers to a structured conversation aimed at facilitating a client's quality of life in the face of adversity (Van Dyk, 2001:200). Counselling should be available at all stages of the illness, from pre-test counselling to bereavement support. There is no cure for HIV/AIDS and therefore no alternative but to focus our caring for the physical as well as psychological welfare of the HIV infected individual.

The task most performed by the caregivers is counselling, information giving, psychological and emotional support (Uys & Cameron, 2003:7). Counselling is amongst the most important skills caregivers have to have. The objectives of counselling and teaching task are to promote a positive acceptance of the diagnoses, to promote disclosure and to enhance understanding of the illness and a healthy life style. Counselling includes pre-post test counselling helping people with HIV/AIDS and their family to live with the diagnosis, dealing with loss, and preparing for death (Uys&Cameoon, 2003:8).

Communication and cooperation between statutory and voluntary services on the one hand and between health and social services on the other hand is inadequate, communication problems often arise between health care facilities and undertakers, a situation resulting in families not being notified of death or not knowing what has happened to their body of a deceased (Rensburg, Fredman, 2002:149)



4.7.9. NATURE OF SUPPORT

More support services are needed in facilitating and supporting carers to a much greater extent. Most patients and families enjoy the caring from the caregiver's presence for longer than the five days while others stated that those cared for in a hospital settings are complaining, because they do not see their caregivers. Family members provide a basic element of their routine starting with basic care- giving, personal hygiene, information about the disease and care is an essential part of care giving especially where the family is responsible for a portion of the patients' daily care (Uys & Cameron, 2003).

4.7.10. PSYCHOLOGICAL CARE

Mullan 1993, quoted by Moroney, Dockecki, Gates, Haynes, Newbrough & Nottingham described psychological strains as manifested in feelings of anxiety, anger and depression. Without support, this leads, to burnout. When burnout occurs, people become despondent and lose their capacity to give care.

4.7.11. EDUCATION AND TRAINING

Education is a basic infection- control and prevention practice, as caregivers, family members or outsiders can be exposed to infection because of ignorance or because they have not been taught correctly. Caregivers should make education of the patient and family members a basic element of their routine starting with basic care giving, and personal hygiene, and information about the disease and care. This is an essential part of care giving especially where the family is responsible for a portion of the patient's daily care (Uys & Cameron, 2003:11). It is essential for a community caregiver to receive training to provide a high standard of care.

Training is a learning process that involves the acquisition of skills, concepts, or attitudes to increase the performance of employees. It is said that a great deal is invested in home care volunteers. This gives them additional skills and confidence and, in some instances, makes them employable (Uys & Cameroon, 2003:12).

4.7.12. AVAILABILITY OF SERVICES

The bulk of resources are channelled to institutions rather than informal and community care (McMenamien & Teirmon, 2002 31). There are still shortages and these are continually to be felt by informal caregivers and patients. Home-based care should allow for financial incentives, medical kits, and transportation, and provide accessible caregiver and families in order to boost their morale.

4.7.13. ACCESSIBILITY

According to the White Paper on Social Welfare of 1997: page 34, legislation will be made accessible to the public by ensuring that the source of information is effective, clearly understood and readily available. An example is of a home based care programme in kwaZulu Natal where people living with HIV&AIDS, who attend a hospital or primary heal health care clinic, are given information regarding the availability of home care and criteria for admission to the programme.

4.8. CONCLUSION

In this chapter the literature control has been undertaken based on the transcriptions of the interviews. The conclusion and recommendations will follow in chapter 5



CHAPTER 5

5. FORMULATION OF CONCLUSION AND RECOMMENDATION

INTRODUCTION

For the purpose of this study, a literature study was initially undertaken in which voluntary AIDS caregiver's role and the nature of home based care regarding support was explored. An empirical investigation was undertaken. For the purpose of the empirical investigation qualitative interviewing through the use of semi structured interviewing schedules was used, and is attached as appendix. Through the literature study an attempt was made to explore home based care as service delivery to AIDS patients and their families.

Focus group interviews were analysed and integrated into a discussion of the literature control in chapter four. Recommendations, conclusions and limitations of the study are presented in this chapter.

5.1. AIMS AND OBJECTIVES OF THE STUDY

5.1.1. The Aim

The aim of the research was to explore the experiences of AIDS patients and their families concerning the home based care as service delivery.

5.1.2. Objectives of the Study

- Conducted literature study in order to establish a theoretical base of the study.
- Developed a data collection instrument for the collection of qualitative data on home based care service delivery.
- Conducted an empirical study based on qualitative methodology.
- Formalised conclusions and recommendations for social work practice.
- Formulated policy guidelines on the role of volunteers in their relationship to the Department of Social Development

5.1. 3. Research Question

The research question/problem is a concise, interrogative statement developed to direct studies that are focused on description of events and the examination of relationships during interactive processes (Burns & Grove, 1997:793). It is necessary to phrase a research question in a manner that will provide flexibility and freedom to explore a phenomenon in depth.

The following was the research question provided for the study:

- What is the nature of home-based care as service delivery to the HIV/AIDS patient?

5.2. CONCLUSIONS

A number of conclusions are formulated to establish whether the aim of the study has been achieved. The researcher used the same categories and themes indicated in chapter 4. The economical category in terms of stipend features in all categories and the stipend was considered insufficient and not enough.

5.2.1. Financial support

Voluntary caregivers seem not to be clear on the issue of getting a R500 stipend per month. Pay dates of the stipend by the department increases conflict among themselves and their work performance. The caregivers are not clear on the issue of benefits.

5.2.2. Experience on Emotional support

The three focus groups did not differ significantly regarding emotional support. In each and every group, the emotions of distress were significantly related to each other, and not being considered by hospital staff. Patients felt angry and demoralised when on visits at hospitals because they are not given the respect they

expect from such professional health members. Most of the time, they are ignored, and disrespected.

- The strong emotions expressed by the three focus groups indicate the extent to which the three groups experience deprivation, loneliness and isolation
- There is a feeling of tiredness, exhaustion, depression and often neglect of volunteer's own health.

5.2.3. Social and physical support

Volunteers were concerned about their physical problems that affect their mental health if they continue to provide the bulk of services in caring without physical support and social support.

- ❖ The risk of becoming infected is high in volunteer and the family groups.

5.2.4. Nature of home based care support

Caregivers were the source of support for each daily living activity. They provide many other services including shopping and coordinating home care services to their patients and their families.

- Most patients and families enjoy the caring from the caregiver's presence for a period longer than five days

5.2.5. Psychological care inadequate

Lack of supports systems from the professionals make it difficult for the caregivers and families to provide quality care to patients.

5.2.6. Difference in quality of care

Dissatisfaction of AIDS patients, families and caregivers concerning the quality of care makes them feel difficult to cooperate with service rendering.

- The preference by the two focus groups is for home- based care

- Hospitals do not render services effectively and seems to make profit by admitting the patients for one day, only to discharge them again the following day.

5.2.7. Difference in quantity of care

There is a lack of information from caregivers on how to take care of patients, and there is a high rate of HIV- infection despite the training offered to them.

5.2.8. Availability of resources

All focus groups do not have a working knowledge of community resources specific to the need. No home-based care can provide a quality of care if there is poverty in such homes.

Patients and families do not have information regarding the availability of other services and where to receive help except from the voluntary caregivers when on visits.



5.2.9. AIDS patients, families and AIDS caregiver's experiences on care giving by volunteers

All focus groups were satisfied with informal care such as home-based care because people are looked well after at home, with reasonable financial expenses. Patients relate hospitals with death and are deeply distressed if admitted.

5.2.10. Home based care as local service delivery for AIDS patents and families

Home-care is seen as the best option for the families and patients and it needs to be further implemented in contrast to hospital care.

Caregivers were the source of support for each other's daily living activities. they provide many other services including shopping, washing and bathing the patients, identifying children in need of care and coordinating home -care

services to their patients and their families. Patients are identified being cared for and by their caregivers

5.2.11. Families' feelings on the issue of confidentiality by caregivers and clinics

Volunteers are not trusted by the families in terms of secrecy.

5.2.12. Stigmatization

Stigma was experienced by two focus groups, families and the patients. It shows that there is still discomfort about the discussion of the epidemic around the families, and AIDS patients. Stigma prevents people to obtain or access services because of the secrecy around the diagnoses.

5.2.13. Education and training programme

.Most of the volunteers and families wished to be trained in skills of counselling, basic management of the terminally ill and self-knowledge. Families and patients continue to suffer from a lack of information in a medical context. Caregivers do not have working knowledge. Patients do not believe the diagnoses because of fear of rejection from their families or fear of disgrace. Caregivers do not consider the possibility of providing counselling although the policy of the Department of Health specifies that lay counselling is compulsory before testing. Counselling is done in a wrong way and, if done there is no confidentiality.

5.2.14. Communication and cooperation (Informed about issues)

Communication and cooperation among all partners should be effective and efficient. Lack of communication and information had negative effect on productivity

5. 3. RECOMMENDATIONS

The following recommendations of the study were generated based on the conclusions

5.3.1. Policy Co-Ordination and Development

- Government should assess the implication of the remuneration policy for caregivers
- Voluntary caregivers should sign a memorandum of agreement that stipulates all the rules and regulations and should be read in front of the whole organisation.
- Management should establish policies for the functioning of the service to prevent problems as far as possible. These should include a job description, conditions of service, and financial policy.
- A Private Public Partnership sub- directorate should communicate delayed payment in time.
- A Private Public Partnership sub- directorate should communicate delayed payment in time.
- A policy on volunteering must always state the issue of benefits. The policy on health insurance should be drawn and clearly state the issue of benefits of insurance to volunteers and families receiving the service. A hierarchical policy on relationship on the role volunteers as well as NGO's must be developed.

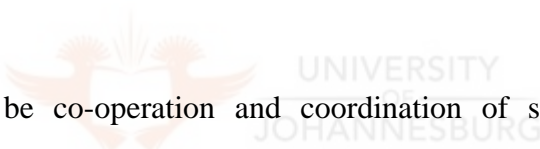
5.3.2. Financial issues

Volunteers working in the field of HIV/AIDS care and support should receive some form of compensation or incentive while the content and procedures of training and mentoring provided to the caregivers need to be standardised. Sponsors should be involved in funding.

5.3.3. Capacity Building

- Strategies to relieve these burdens such as encouraging more volunteers in caring for patients, and financial support from the community and companies should be considered.
- Support programmes for volunteers and families are needed to support them and boost their morale through giving praise as they experience distressful emotions.
- The needs of voluntary caregivers should be met through a negotiation process
- Psychological support should be provided to the voluntary caregivers providing services to AIDS patients.

5.4.4. Integrated Planning and Collaboration at Local Level

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- There should be co-operation and coordination of services amongst service providers emphasised and integrated into a local plan, coordination is essential to address poverty and HIV & AIDS.
 - Home -based care need to be implemented in all areas and more caregivers are needed for the implementation of this service.
 - Information centres or sessions in the community should be made available.
 - Professionals should be motivated to be friendly, respectful and available to information.
 - The Departments should make sure that there is cooperation and open communication especially between the Department of Social Development and the Department of Health Department in order to avoid duplication of services in terms of home based care services
 - An integrated framework within ongoing programmes and coordinated services is essential.

5.4.5. Support Programmes for Prevention and Accessibility

- Community home- based care programs should be established for patients and families who do not want to go to the hospitals.
- The government should make services accessible to all. There should be more educational programmes in the community on the availability of services.
- There is a need for more trained volunteers in the community on HIV/AIDS related matters or services. These volunteers should be capacitated in terms of training and education.

5.4.6. Code of Conduct

- A code of conduct may be the best option for community-based organisations that are developing and it should be reinforced to all service providers.
- A home-based care code of conduct should be drawn, assured and signed. This should include the confidentiality of volunteers.
- Conflict management and behaviour modification must be enforced to the AIDS caregivers.

5.3.7. Provision of Resources

- Provision of services should be made available to the community-based organisations.
- The department should make sure that care kits are distributed via the organisation to the voluntary caregivers to avoid the level of infection.
- There should be an encouraging working environment. Suppliers should support volunteers with equipment, uniforms and name- tags to avoid confusion
- The government should make sure that clinics and hospitals are accessible to all. Reliance on private hospital is problematic because it places a considerable financial burden on people and their families.

- More step-down facility programmes and meals on wheels should be implemented for AIDS patients and their families.
- Resource allocation criteria are to be applied to ensure that an area with high burdens of poverty and HIV/AIDS receives an equitable share of available resources.
- An income-generating project for the families infected and affected should be started appropriate training for empowerment provided.

5.3.8. Training & Education

- Training and education on HIV/AIDS related matters and care giving. is the best source for the families and voluntary caregivers? Communication improves through education and training.
- Workshops on HIV/AIDS programmes should be implemented and more training sessions should be identified for health care workers, volunteer's patients and their families.
- Implementation of counselling before HIV/AIDS testing is essential to develop HIV/AIDS counselling courses to address the issue of living with AIDS.
- Good counselling programmes on HIV/AIDS should be implemented and social workers should be trained for HIV/AIDS pre -post test counselling.
- Meetings and trainings for volunteers and families should be encouraged

5. 4. LIMITATIONS OF THE STUDY

- Participants were limited to discontented volunteers with regard to the issue of stipends by the service providers. The volunteers are not aware of the service provider's service delivery methods, and ended up criticizing the departments, without considering that there is an integrated collaboration of service.

- Some of patients and families were also dissatisfied with the practical and economic burden and care received by themselves from the clinics and even from their carers.
- There was also a selection bias as participants were recruited from the families who agreed to participate.
- Lack of appropriate information about patients dissatisfaction with the services in particular, and whether services reflect their needs.
- The response was higher from the volunteers than from the AIDS patients and affected families. The AIDS patients and their families could not verbalise more about their experiences on support that volunteers provide.
- Volunteers were more focused on the issue of stipends rather than on the lived experiences of the support provided by them to AIDS patients
- Research is purposive in nature and sampling procedures are non probable. Results cannot be generalised beyond the scope of the study undertaken.
- Focus of research on specific participants limits the extent to which the study cannot be generalized, and the participants of the focus groups did not statistically represent any meaningful population
- Validity and reliability of this research study is limited as the study is exploratory and qualitative in nature.
- No standardised instruments were used as the focus was to gain insight in experiences of AIDS patients and their families on home based care as service delivery.
- The research is confined to exploring issues around family's experiences of support which cannot be generalised beyond the scope of the study as it is purposive in nature
- Findings may not apply to participants and setting that differ widely.
- Surveys are needed to assess the quality of home-based care programmes
- Research is limited to the number of participants who were interviewed

5.5. CONCLUSION REMARKS OF THE STUDY

5.5.1. RESEARCH FINDINGS

Findings support the existing theories but cannot be generalised as participants and settings differ widely. The researcher did not get enough responses from the families regarding their experiences on the nature of support they receive from their caregivers. The caregivers were dominating in the study as they gave more information on the issue of stipends and lack of support they receive from the Department. The data presented here may be biased in that half of the members of patient's focus group were not experiencing any problems concerning the volunteers. The participants of the focus groups did not statistically represent any meaningful population. The researcher did not get a sense of the whole as two focus groups did not explore more on their experiences and understanding of support.



5.5.2. IMPLICATIONS OF RESEARCH FINDINGS TO STAKEHOLDERS

The need for integration of home- based care into government health programmes is particularly important. Effective home based care cannot be delivered without focusing on poverty alleviation for both patients and their caregivers. While volunteers offer their time despite the lack of regular incentive, government and policy makers should consider the ethics of not compensating people who accept heavy responsibilities of care giving for the terminal ill.

5.5.3 SUGGESTION ON THE RESEARCH STUDY

Further research is required in this theme or field of study. The study is demarcated by the researcher to three focus groups especially to patients and their affected families. Additional research would for example be required on other affected families. Various cultural groupings, and to persons who have AIDS, only.

5.6. CONCLUSION OF THE STUDY

Establishing, supporting and maintaining a continuum of care for people living with AIDS and their families through out the period of illness, is a challenging enterprise. The characteristics also tend to overwhelm practitioners, so that the exploration of quality of care issues is neglected. Nevertheless, the thousands of South Africans who are infected and can be expected to die over the next decades have a right to quality health care. Health -care providers cannot change the fact of death, but they can change the experiences of death. These thousands of people must be assisted to die with dignity. The effect of this illness on communities will be worse than it is already. Improvement of accessibility and quality of support for family members is needed. Enabling the primary caregiver to continue caring for the child over the longer term, is a desired outcome, and therefore efforts should be made that the primary caregiver is under appropriate health supervision. Home-based care can satisfy the needs of the child and the family members and can improve communication, while assisting in the formation of better relationships between family members and care workers.

CHAPTER 6

6. REFERENCE LIST

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ANNEXURE A

Table1. Categories, sub-categories and themes

ANNEXURE 1

FOCUS GROUP 1 PILOT STUDY

CATEGORY	SUBCATEGORY	THEMES
PERSONAL SUPPORT	Economic problems for families and caregivers	<ul style="list-style-type: none"> ❖ <i>Unsatisfactory support, stipends not enough,</i> ❖ <i>Earn R500 a month which is very little, no medical protection for us,</i> ❖ <i>Others in other department earn more money than us, delayed stipends,</i> ❖ <i>Patients helped by us when they do not have food.</i> ❖ <i>The family also helped by us when there is nothing to eat at home</i> ❖ <i>Caregivers need insurances (funeral cover) others get R1000 per month</i> ❖ <i>Pensions have been cut off whereas we are sick.</i> ❖ <i>We need food grocery,</i> ❖ <i>We need treatment like ARV</i>
	Spiritual and religious interpretation	<ul style="list-style-type: none"> ❖ <i>We need support to lift our support</i> ❖ <i>We need psychosocial support</i> ❖ <i>We need care and support</i> ❖ <i>We are called to do the work</i>

	Emotional and understanding	<ul style="list-style-type: none"> ❖ <i>We are considered as volunteers not as full time workers we feel, as we are not part of social development staff although we do the work,</i> ❖ <i>The department does not fulfil the needs,</i> ❖ <i>Nurses do not do anything. Social development must stop saying that we are volunteering.</i> ❖ <i>Professional people do not take care of caregivers,</i> ❖ <i>The department is fighting with the volunteers</i> ❖ <i>We should taken as human beings</i> ❖ <i>Families do not care about their patients.</i> ❖ <i>We are angry at their family members because they misuse the pensions</i> ❖ <i>Community has not yet accepted us</i> ❖ <i>We are having problems with their families as they do not tell the truth about their families, we don't know where to cry, this causes negative attitude, and the department don't fulfil their promises. It is unfair to promise at the end there is no fulfilment</i>
	Physical and social	<ul style="list-style-type: none"> ❖ <i>Cant wash without soap, have to</i>

	support	<p><i>buy food</i></p> <ul style="list-style-type: none"> ❖ <i>The washing is done by the carer whilst the family doesn't do anything</i> ❖ <i>No protective clothing</i> ❖ <i>We experience physical distresses specially when the patient dies</i> ❖ <i>We do job like professionals, we are misused here we need to be reconsidered and put in better position</i>
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MAIN CATEGORY	SUB-CATEGORY	THEMES
QUALITY OF CARE/EXPERIENCE IN CAREGIVING	Psychological care	<ul style="list-style-type: none"> ❖ <i>Psychological care inadequate</i> ❖ <i>No support given</i> ❖ <i>We feel a pain</i> ❖ <i>We are cursed by the clinics</i> ❖ <i>Better our caregivers and staying at home</i>
	Differences in quality of care	<ul style="list-style-type: none"> ❖ <i>Dissatisfied with care form the clinics</i> ❖ <i>Patients are not recovering when in hospital or clinics</i>
	Quantity of information	<ul style="list-style-type: none"> ❖ <i>No other alternatives of care given</i> ❖ <i>Not enough information on care</i> ❖ <i>Do not know where to receive help</i> ❖ <i>Nurses are not there</i> ❖
	Family caregivers and patients perception on	<ul style="list-style-type: none"> ❖ <i>Palliative care is the last place of dying for our patients</i> ❖ <i>Insufficient information about the</i>

	care	<i>availability of care</i> ❖ <i>Not present at the patients death in hospital</i> ❖ <i>Carers are needed</i> ❖ <i>Hospital a place where you'll never come back</i> ❖ <i>Lack of accurate information</i>
	Consideration of family	❖ <i>Not considered in time of death</i> ❖ <i>Not even informed about the cause of death</i> ❖ <i>Status is known to the community</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
STIGMA	Stigmatisation Personal relationships and family dynamics	<i>One of the people going to infect you and you'll give me the virus</i> ❖ <i>You let these people come everyday</i> ❖ <i>It will be your fault when I am infected</i> ❖ <i>Don't listen to me</i> ❖ <i>We are fighting</i> ❖ <i>Don't understand my situation</i> ❖ <i>Its not a disease</i>

MAIN CATEGORY	SUB-CATEGORY	THEMES
SERVICE SUPPORT	Resources and remuneration	❖ <i>No protective clothing, the registered nurses are given an injection when contracted a virus but we are not taken into consideration</i>

		<ul style="list-style-type: none"> ❖ <i>Offices not well equipped</i> ❖ <i>Equipment insufficient</i> ❖ <i>Nurses not involved in patient care</i> ❖ <i>We need uniform, we need name tags,</i> ❖ <i>We need step down facility</i> ❖ <i>We do not have gloves to wash those patients they have bad sores.</i> ❖ <i>We need transport</i> ❖ <i>Not receiving money as promised</i> ❖ <i>Need permanent job</i>
	Education and training	<ul style="list-style-type: none"> ❖ <i>We need training in</i> ❖ <i>We need support</i> ❖ <i>Our qualification are not recognised</i> ❖ <i>Caregivers need counselling services and support</i> ❖ <i>"We need a social worker to counsel us"</i> ❖ <i>"We need somebody who will facilitate the process of children in home affairs"</i> ❖ <i>Workshops are needed to the families for awareness programme</i>

MAIN CATEGORY	SUB-CATEGORY	THEMES
COMMUNICATION AND COOPERATION	Lack of Communication	<ul style="list-style-type: none"> ❖ <i>"We are not given time to talk to children at school"</i> ❖ <i>Nurses don't communicate with us properly at the clinics,</i> ❖ <i>"We work together with social development and there is problem with health departmen"t</i> ❖ <i>Health services and social services</i>

		<i>inadequate</i> ❖ <i>Duplication of services</i> ❖ <i>Difficult to find about availability of services</i>
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MAIN CATEGORY	SUB CATEGORY	THEMES
ACCESSIBILITY	Availability of services	❖ <i>Most admitted immediately</i> ❖ <i>Long waiting periods at the clinics</i> ❖ <i>nurses or doctors not present</i>

ANNEXURE 2. Table2: main categories, sub-categories and themes

FOCUS GROUP 2 VOLUNTEER -CAREGIVERS

CATEGORY	SUB-CATEGORY	THEMES
PERSONAL SUPPORT	Economic problems for families and caregivers	❖ <i>Organisations getting money from the government or the department</i> ❖ <i>R500 is not enough</i> ❖ <i>Stipend never given in time</i> ❖ <i>We share the money for stipends</i> ❖ <i>We don't have enough money for transport,</i> ❖ <i>"The stipends is irregular and insufficient"</i> ❖ <i>Department of social development must at least add R500 to R700 to make living</i> ❖ <i>"We need R 1000 just like</i>

		<p><i>Department of Health volunteers"</i></p> <ul style="list-style-type: none"> ❖ <i>Family burden heavy"</i>
	<p>Physical and social issues</p>	<ul style="list-style-type: none"> ❖ <i>"The department should at least give food parcels for the patients and to us because when we get to the house we find that there is no food to eat"</i> ❖ <i>Grants are stopped so we have to buy food for the families</i> ❖ <i>Care giving is dangerous we need protective clothing</i> ❖ <i>"We need uniform, and name tags working environment is not good"</i> ❖ <i>"We afraid to be infected, we take risk on ourselves, "</i> ❖ <i>"We don't have offices and equipments"</i>

	Emotional and understanding	<ul style="list-style-type: none"> ❖ <i>No support from the department our needs are unfulfilled.</i> ❖ <i>Doing the work of the community just like social workers do</i> ❖ <i>Its painful when the patient died</i> ❖ <i>The clinics discriminate the us</i> ❖ <i>Poor working relationship between the clinic sisters</i> ❖ <i>No support from the managers they should come and see the good work that we are doing</i> ❖ <i>The clinic sisters don't talk nice to us</i> ❖ <i>'We are angry with the department''</i>
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QUALITYOF CARE/EXPERIENCE IN CAREGIVING	Psychological care	<ul style="list-style-type: none"> ❖ <i>Feel disappointed with psychological care in the context of nursing</i> ❖ <i>Patients are not treated with dignity and well</i> ❖ <i>Family care burden is heavy</i> ❖ <i>Not taken as human beings</i> ❖ <i>"We are undermined"</i>
	Differences in quality of care	<ul style="list-style-type: none"> ❖ <i>Our patients not treated well in the clinics</i> ❖ <i>Some families don't take of us</i>
	Differences in Quantity of care	<ul style="list-style-type: none"> ❖ <i>No information received on How to care or other alternatives</i>

		<ul style="list-style-type: none"> ❖ <i>Lack information about the service</i> ❖ <i>No training received</i> ❖ <i>Receive basic training</i>
	Volunteers perception on care	<ul style="list-style-type: none"> ❖ <i>Not seen as good helpers</i> ❖ <i>Nursing staff not taking care of us</i> ❖ <i>Not treated well in the clinics</i> ❖ <i>Department don't consider the good work we do</i> ❖ <i>Families & patients appreciate what we are doing for them</i> ❖ <i>No supervision</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
STIGMA	Stigmatisation Personal relationships and family dynamics	<ul style="list-style-type: none"> ❖ <i>One of the people is going to infect you and you'll give me the virus</i> ❖ <i>It will be your fault when I am infected</i> ❖ <i>I will be angry with you</i> ❖ <i>"We are fighting with my husband"</i> ❖ <i>Changes in our life</i>

MAIN CATEGORY	SUB-CATEGORY	THEMES
SERVICE SUPPORT	Resources and remuneration	<ul style="list-style-type: none"> ❖ <i>No protective clothing, and no medication for the patients</i> ❖ <i>Not receiving money after training</i> ❖ <i>Office equipment</i> ❖ <i>No financial support from the department</i> ❖ <i>transport for visits</i> ❖ <i>"We need offices to operate"</i>

		<ul style="list-style-type: none"> ❖ <i>Need permanent job</i> ❖ <i>Insurances and benefits</i>
	Education and training	<ul style="list-style-type: none"> ❖ <i>"We need training on home based care for 59 days"</i> ❖ <i>"We need support programmes such as basic counselling training and education"</i> ❖ <i>"We need a social worker to train on home based care training"</i>

MAIN CATEGORY	SUB- CATEGORY	THEMES
COMMUNICATION & COOPERATION	Lack of Communication	<ul style="list-style-type: none"> ❖ <i>Not given time</i> ❖ <i>Nurses don't communicate with us properly at the clinics,</i> ❖ <i>"We work together well with social development and there is problem with Health department"</i> ❖ <i>Duplication of services</i> ❖ <i>No partnership in government</i> ❖ <i>Nurses always in a hurry</i> ❖ <i>Discrimination at the clinics</i> ❖ <i>Families don't understand the reason for the visits</i>
	Psychosocial Needs	<ul style="list-style-type: none"> ❖ <i>Need counselling sessions to explore what is about care giving that is problematic</i> ❖ <i>"We need sources to do the job"</i> ❖ <i>"We need contact with formal service"</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
ACCESSIBILITY	Availability of services	<ul style="list-style-type: none"> ❖ <i>Most patients admitted immediately</i> ❖ <i>Long waiting periods at the clinics</i> ❖ <i>nurses or doctors not present</i>

TABLE 3.

ANNEXURE 3. (FOCUS GROUP 3 WITH THE FAMILIES)

CATEGORY	SUB-CATEGORY	THEMES
PERSONAL SUPPORT	Financial issues for families and caregivers	<ul style="list-style-type: none"> ❖ <i>The department needs to pay the volunteers stipends every month</i> ❖ <i>Receive grants</i> ❖ <i>Will be happy if you can help them (volunteers) with the transport money</i> ❖ <i>Social grants or pensions for sick patients</i> ❖ <i>Money for transport to and from the hospital</i> ❖ <i>Economic burden heavy</i> ❖ <i>Spend my money in going to hospital</i>

	Emotional and understanding	<ul style="list-style-type: none"> ❖ <i>The patients are not cared for in the hospitals and clinics</i> ❖ <i>The clinics are unfair</i> ❖ <i>Our sick people are discriminated and we are also discriminated by our communities where we live, and</i> ❖ <i>"We feel very much unhappy"</i> ❖ <i>We are feeling a pain when we get to the hospitals or clinics.</i> ❖ <i>"We are shouted by the clinic sisters"</i>
	❖	
	Physical and social support	<ul style="list-style-type: none"> ❖ <i>Supported by caregivers</i> ❖ <i>Done the washing, help to bath the patient</i> ❖ <i>Need protective clothing</i> ❖ <i>Taking of the sick to the hospital</i> ❖ <i>Check the medication taken</i>

QUALITY OF CARE/EXPERIENCE IN CAREGIVING	Psychological care	<ul style="list-style-type: none"> ❖ <i>Psychological care not enough</i> ❖ <i>Individuality of patient not respected</i> ❖ <i>No information about other alternatives</i> ❖ <i>Lack of consideration of families who did not want other people to know about our status</i>
	Differences in quality of care	<ul style="list-style-type: none"> ❖ <i>Dissatisfied with care from the clinics</i>

		❖ <i>Patients are not recovering when in hospital or clinics</i>
	Difference in Quantity of care	❖ <i>No other alternatives of care given</i>
	Family perception on care regarding home based care as service delivery	<ul style="list-style-type: none"> ❖ <i>Hospital care is the last place of dying for our patients</i> ❖ <i>Insufficient information about the availability of care or services</i> ❖ <i>Not present at the patients death in hospital</i> ❖ <i>Carers are the best helpers at home</i> ❖ <i>Hospital a place where you'll never come back</i> ❖ <i>Lack of accurate information form the clinics</i>
	Issue of confidentiality	❖ <i>Family not considered if you don't want other peoples to know about the patients status</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
STIGMA	Stigmatisation Personal relationships and family dynamics	<ul style="list-style-type: none"> ❖ <i>Afraid to be infected</i> ❖ <i>Community does not accept them</i> ❖ <i>Its your fault I am infected</i> ❖ <i>Fight as a family</i> ❖ <i>Poor relationship with my family</i>

MAIN CATEGORY	SUB-CATEGORY	THEMES
SERVICE SUPPORT	Resources and remuneration	<ul style="list-style-type: none"> ❖ <i>We need food parcels every month</i> ❖ <i>Houses</i> ❖ <i>Insufficient number of carers</i> ❖ <i>Pension funds to support the patients</i>
	Education and training	<ul style="list-style-type: none"> ❖ <i>"We need information on caring the sick person"</i> ❖ <i>"We receive training from the caregivers on how to take care of patient "</i> ❖ <i>"We don't have enough education about the disease"</i> ❖ <i>Need other alternatives of care</i> ❖ <i>Education on availability of services</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
COMMUNICATION AND COOPERATION	Lack of Communication	<ul style="list-style-type: none"> ❖ <i>Patients prefer to talk to the caregivers than us as their families</i> ❖ <i>Volunteers tell us about the real sickness</i> ❖ <i>Disclose information of our patients</i> ❖ <i>No communication between the house,</i> ❖ <i>family imbalance</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
ACCESSIBILITY	Availability of services	<ul style="list-style-type: none"> ❖ <i>Patients not admitted immediately</i> ❖ <i>Long waiting periods or procedures in hospital better receive help at home</i> ❖ <i>nurses or doctors not present</i> ❖ <i>Good home based care at home</i>

TABLE 4

ANNEXURE 4. FOCUS GROUP 4 PATIENTS

CATEGORY	SUBCATEGORY	THEMES
PERSONAL SUPPORT	Financial issues	<ul style="list-style-type: none"> ❖ <i>Unsatisfactory support, no medical protection and treatment</i> ❖ <i>Pensions have been cut off whereas we are sick</i> ❖ <i>Not given ARVs treatment at the clinics</i> ❖ <i>"We in need of disability grants"</i> ❖ <i>Food parcels</i> ❖ <i>Volunteers provide us with transport money to go to hospital</i> ❖ <i>The volunteers provide food</i>
	Spiritual and self esteem	<ul style="list-style-type: none"> ❖ <i>"We need spiritual support to lift our support"</i> ❖ <i>I need a pastor to pray for me everyday</i> ❖ <i>I know I will die</i>

	Emotional and understanding	<ul style="list-style-type: none"> ❖ <i>"We are not considered as patient's"</i> ❖ <i>'We should be taken as human beings just like other people"</i> ❖ <i>Family members do not take care of me</i> ❖ <i>Community has not yet accepted us</i> ❖ <i>Nurses don't care about us</i> ❖ <i>Nurses discloses our status when they talk to us at the clinics</i> ❖ <i>Feel very said when you are told that you are positive</i> ❖ <i>I feel lonely, my friends do not visit me</i> ❖ <i>I am secured when the carer comes</i> ❖ <i>We don't trust the volunteer</i>
	Physical & Social support	<ul style="list-style-type: none"> ❖ <i>"We experience physical distresses specially when we are at the clinics"</i> ❖ <i>I can't work because of the sickness</i> ❖ <i>No social support from my family</i> ❖ <i>The caregivers help us in washing ourselves and give us medical treatment, food when they visit us.</i>

		<ul style="list-style-type: none"> ❖ <i>"We receive basic counselling support from the volunteers not enough counselling"</i>
<p>QUALITY OF CARE/EXPERIENCE IN CAREGIVING</p>	<p>Psychological care</p>	<ul style="list-style-type: none"> ❖ <i>"We sleep at the same rooms in the hospitals"</i> ❖ <i>Families not considered if you don't want other people know about the status</i> ❖ <i>Individuality of patients not respected</i> ❖ <i>Patients not treated with dignity</i> ❖ <i>Affect us when somebody is dead at hospital</i> ❖ <i>Receive support from the carers</i>
	<p>Differences in quality of care</p>	<ul style="list-style-type: none"> ❖ <i>Dissatisfied with quality of care</i> ❖ <i>Do not get medication ARVs</i> ❖ <i>Quality of care varies among nurses and caregivers</i> ❖ <i>Receive small counselling from the caregivers</i>
	<p>Difference in quantity of care</p>	<ul style="list-style-type: none"> ❖ <i>Insufficient information from our caregivers</i> ❖ <i>Don't know whether I have understand them</i> ❖ <i>Nurses do not sit down with us</i> ❖ <i>Lacking information on how to care</i>

	Patients perception on care	<ul style="list-style-type: none"> ❖ <i>Availability of care not enough</i> ❖ <i>Insufficient information on other alternatives of care</i> ❖ <i>"We are left in separate rooms in hospitals"</i> ❖ <i>Taken as dead people in the hospitals</i> ❖ <i>There is frightening way of showing us that we will die</i> ❖ <i>See a person dying in front of yourself</i> ❖ <i>"We are not care for"</i> ❖ <i>Caregivers are better off than the nurses</i> ❖ <i>Care given at home is much better</i>
	Issue of confidentiality	<ul style="list-style-type: none"> ❖ <i>Not considered on our views whether you want your family know about your status</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
STIGMA IN A FAMILY	Stigmatisation	<ul style="list-style-type: none"> ❖ <i>Reluctant to use different social services</i> ❖ <i>Feel embarrassed to go for counselling</i> ❖ <i>It her fault I'm sick</i> ❖ <i>Mother not talk to me</i> ❖ <i>Said I must leave the house</i> ❖ <i>Referred to the step down</i>

		<ul style="list-style-type: none"> ❖ <i>Caregivers assist us</i> ❖ <i>Fight</i>
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MAIN CATEGORY	SUB-CATEGORY	THEMES
SERVICE SUPPORT	Resources and remuneration	<ul style="list-style-type: none"> ❖ <i>There is no medical treatment for us</i> ❖ <i>We need step down facility</i> ❖ <i>Centres for stress relief</i> ❖ <i>We need food parcels every month</i> ❖ <i>Need jobs to support us</i>
	Education and training	<ul style="list-style-type: none"> ❖ <i>We experience lack of support from the social workers because they don't come and see us,</i> ❖ <i>Volunteers talk to us on how to stay healthy</i> ❖ <i>There is lack of education in our families concerning the disease</i> ❖ <i>Ignore me</i> ❖ <i>Workshops are needed to our families to educate them in HIV/AIDS and how to take care of ourselves</i> ❖ <i>"We don't have any information regarding HIV/AIDS"</i> ❖ <i>In families we live they tend to ignore what sisters at the clinics told them</i>

MAIN CATEGORY	SUB-CATEGORY	THEMES
COMMUNICATION	Lack of Communication	<ul style="list-style-type: none"> ❖ <i>Nurses don't communicate with us properly at the clinics,</i> ❖ <i>Our families don't talk to us and have understanding about HIV/AIDS</i> ❖ <i>"My mother do not want to talk to me "</i> ❖ <i>The caregivers are only people that understand my situation</i> ❖ <i>Nurses just refer a volunteer at home without any notification and without knowing the person</i>

MAIN CATEGORY	SUB CATEGORY	THEMES
ACCESSIBILITY	Availability of services	<ul style="list-style-type: none"> ❖ <i>Not admitted immediately</i> ❖ <i>Long waiting periods</i> ❖ <i>Nurses or doctors not present</i>

ANNEXURE B

Coding of the Main categories, themes and sub- categories

1. Personal Support

1.1. Financial issues for families and caregivers

- Unsatisfactory support
- Earn R500 a month
- No medical protection
- Delayed stipends
- Economic burden heavy
- pensions are cut off
- hospitals make money about our patient

1.3. Emotional and understanding

- no care by our families at home
- We are angry about the
- Community not accept us
- There is a negative attitude
- Physical distress

1.4. Physical and social support

- care giving is dangerous
- We need protective clothing
- No social support from the
- We are discriminated at the clinics, Poor working relationship

2. Experience of patients and families regarding care giving support

2.1. Experience In Care giving

- Psychological care in inadequate in the context of nursing
- Patients are not treated with dignity
- No confidentiality
- Quantity of information on the availability of services insufficient
- No support systems for the families
- Medical profession do not pay attention to families and the
- No medical treatment provided to the patients
- Families not considered if they want other people to know about their status

2.2. Difference in quality of care

- Care is different from the nurses
- Care changes among the care facilities
- No information received on how to care

2.3. Family perception on care

- insufficient information about the availability of services

3. Stigmatization

3.1. Stigma

- one of those people going to infect you
- And you will give me the v
- It will be your fault when I am infected

4. Service support

4.1. Resources and remuneration

- No protective clothing
- Offices do not have furniture
- Equipment insufficient
- We need uniform
- Step down facility
- Transport means
- Insurances and medical benefit
- We need a social worker for counselling

4.2. Education and training

- ▶ we need training on home based care
- ▶ We need support programmes such as basic counselling
- ▶ Poor qualification not recognised
- ▶ Caregivers need counselling services
- ▶ We need to be educated in terms of

4.3. Communication and cooperation

- ▶ No time to talk to children at school
- ▶ Nurse do not communicate with us at the clinics
- ▶ Always in a hurry
- ▶ Have no time to sit and talk
- ▶ Nurses not always there at times
- ▶ Volunteers always available
- ▶ Duplication of services
- ▶ We work together with Social Development
- ▶ No partnership

4.4. Psychosocial needs

- ▶ we need counselling sessions as volunteers
- ▶ To explore what is about care giving that is problematic
- ▶ We need sources to do the job
- ▶ A social worker is needed

5. ACCESSIBILITY

5.1. Availability of services

- ▶ we are not admitted immediately
- ▶ Long queues at the clinic
- ▶ Nurses not present
- ▶ We need information on HIV/AIDS

CATEGORIES AND SUB CATEGORIES REGARDING SUGGESTION ABOUT SUPPORT THAT SHOULD BE PROVIDED MADE BY PARTICIPANTS ARE REFLECTED

Suggestions regarding the support made only covered only in the categories mentioned below in table 1.1.

FOCUS GROUP 2 VOLUNTEERS

CATEGORY	SUB-CATEGORY	THEMES
Economical Support	“Stipend not enough, irregular, No protective clothing, “the registered nurses are given an injection when contracted a virus but we are not taken into consideration” “Offices not well equipped” “Equipment insufficient”	“The department must pay us in time” “We need step down facility” “Nurses must be involved in patients care” “Uniform and name tags should be provided”
	“No benefits” “Need permanent job”	“The department must provide us with insurances We need medical benefits”
	“Protective clothing” “Transport “	“The department should provide us with gloves and care kits “We should be provided with transport money to the clinics
social and physical support	“Social support” “Social workers “Food grocery” Pensions”	“There should be social worker for counselling”
Emotional support	“Emotional understanding”	“We need counselling services”

<p>QUALITY OF CARE/EXPERIENCE IN CAREGIVING</p>	<p>“Psychological care inadequate”</p>	<p>“We should be treated with dignity”</p>
<p>Education & training</p>	<p>“Our qualifications are not recognised” There is nobody who facilitate the process of children in home affairs” “Workshops are needed to the families for awareness programme”</p>	<p>“There should educational workshops, we need counselling services, training in HIV/AIDS should be provided” “Caregivers need counselling services and support” We need a social worker to counsel us” “We need training on home based care for 59 days”</p>
<p>Communication</p>	<p>“Lack of communication amongst service providers” “We are not given time to talk to children at school” “Nurses do not communicate with us properly at the clinics,” “we work together with social development and there is problem with health department” “Duplication of services” “no partnership in government”</p>	<p>“Department should communicate with us when issuing of stipends Clinic sisters must talk to us nicely”</p>
<p>Resources</p>	<p>“We don’t have protective clothing No offices” No equipments”</p>	<p>The department should provide us with care kits “we need offices” Stipends must be paid every month”</p>

	No stipends or they are not enough'' We share the stipends''	
Accessibility	Nurses don't communicate with us Clinics are at a distance	Communication must be clear We want counselling as caregivers

FOCUS GROUP 3 FAMILIES

Economical Support	The department is not paying the volunteers stipends every month Social grants or pensions for sick people Money for transport to and from the hospitals	The department needs to pay the volunteers stipends every month Receiving grants Will be happy if you can help them (volunteers) with the <i>transport money</i> We need Social grants or pensions time
	We need benefits	We need pensions We need social grants
	We need transport	We should be provided with transport money to the clinics
Social and physical support	We cannot wash ourselves and our patients without soap we have nothing in our homes The caregivers help us on how to bath our patients and help us to take the sick to the hospital	There should be social worker for counselling The department must not cut our pensions we are sick We should be provided with houses and food parcels every month We also need protective clothing because our patients have sores and they bleed

Emotional support	<p>The patients are not cared for in the hospitals and clinics</p> <p>Our sick people are discriminated and we are also discriminated by our communities where we live,</p> <p>We feel very much unhappy about that</p> <p>We are feeling a pain when we get to the hospitals or clinics.</p> <p>We are shouted by the clinic sisters</p>	<p>Community must accept us</p> <p>And understand our situation</p> <p>Clinics must care for us</p>
QUALITY OF CARE/EXPERIENCE IN CAREGIVING	<p>Psychological care not enough</p> <p>Individuality of patient not respected</p>	<p>Individuality of patient to be respected</p> <p>Information about other alternatives must be explained to us by the caregivers</p> <p>We need to be consideration about our status</p>
	<p>Differences in quality of care</p> <p>Patients are not recovering when in hospital or clinics</p>	<p>We need more caregivers</p> <p>Our patients must stay at home and be given medical assistance</p>
	<p>Family perception on care</p>	<p>Hospital care is seen as the last place of dying for our patients home is the best option</p> <p>More caregivers are needed</p> <p>They should be paid monthly</p>
Communication	<p>Lack of communication amongst service providers</p>	<p>Department of Health should not shout at us</p> <p>Clinic sisters must talk to us properly</p> <p>We need social workers to talk to us</p>
Resources	<p>Food parcels are not provided</p>	<p>Pensions should not be cut</p>

	Our pension are being cut	Food parcel to be provided monthly We need more caregivers to help us
Accessibility	Nurses don't communicate with us Clinics at a distance Patients not admitted immediately There are long queues	Attendance of patients at the clinic should be good

FOCUS GROUP 3 PATIENTS

Social Support	Pensions have been cut off whereas we are sick We are not given ARVs treatment at the clinics We are not given food parcels We experience problems when you want to get to the clinics and hospitals Volunteers provide us with transport money to go to hospital	We plead the department to pay our volunteers enough money so that they come to us everyday ARVs to be provided to everybody We need disability grants Food parcels to be provided because we cant take medication without food
	No benefits	We need sick pensions We need disability grants ARV's
	Transport	We should be provided with transport money to the clinics we cannot walk long distances
Social and Physical support	Social support Social workers Food grocery	There should be social worker for counselling The department must not cut our pensions we are sick

	<p>Pensions</p> <p>No medical protection and treatment</p>	<p>We should be provided with food parcels every month</p>
Emotional support	<p>We are not considered as patient's</p> <p>Family members who do not take care of us</p> <p>Community has not yet accepted us</p> <p>Nurses don't care about us</p> <p>Nurses disclose our status when they talk to us at the clinics</p> <p>Feel very sad when you are told that you are positive</p> <p>I feel lonely, my friends do not visit me</p> <p>I am secured when I am with my carer</p> <p>We sometimes do not trust the volunteers</p>	<p>We need counselling services</p> <p>Clinics must not shout at us</p> <p>We should be taken as human beings just like other people</p> <p>Community must accept us as people</p> <p>We need at least social workers</p> <p>Volunteers are needed</p>
QUALITY OF CARE/EXPERIENCE IN CAREGIVING	<p>Psychological care inadequate</p>	<p>Patients must be respected</p>
	<p>Differences in quality of care</p>	<p>Dissatisfied with quality of care</p>
	<p>Quality of information</p>	<p>Insufficient information from our caregivers</p>
	<p>Patients perception on care</p>	<p>Availability of care not enough</p> <p>Insufficient information on other alternatives of</p>

		care We should be treated with respect Going to die we need special rooms
Consideration of views	Not considered on our views whether you want your family to know about your status	We should be considered
Communication	Lack of communication amongst service providers	Clinic sisters must talk to us nicely We need social worker to talk to us except the caregivers
Resources	We need a social worker	Stipends must be paid every month to our caregivers
Accessibility	Nurses don't communicate with us Clinics at a distance	We want counselling or somebody to talk to
Education and training	Workshops, HIV/AIDS counselling Families do not obeying doctors orders	There should be educational workshops, we need counselling services, training in HIV/AIDS should be provided

ANNEXURE C

Box 5053
Botshabelo
9781
01 March 2005

The Manager
Naledi Hospice
118 Andries Pretoria's
Bloemfontein
9300

Dear Sir /Madam

**APPLICATION TO BE GRANTED AUTHORITY TO CONDUCT A RESEARCH
PROJECT AMONGST THE VOLUNTEER AIDS CAREGIVERS**

I am pursuing a Masters degree in Social work with the University of Johannesburg and hereby to submit a formal request to conduct a study in your organisation following our conversation at the end of 2004. The study is on the voluntary AIDS caregivers with AIDS families.

A researcher would like to commence with the pilot study in which few participants will be involved. The main study will be conducted on May 2005 at 10 am to 11 am. Confidentiality will be assured; the names of three participants will not be mentioned in the study. Participants will share their knowledge, skills and experiences thus enhancing the study

I hope my application will receive your favourable consideration.

Yours faithfully

Vuyo Ntsunswana (miss)
Study Leader: A VERMUELEN

ANNEXURE D

Box 5053
Botshabelo
9781
01 March
2005

The Manager
Department of Social Development
P/Bag x 26160
Bloemfontein
9300

Dear Sir /Madam

**APPLICATION TO BE GRANTED AUTHORITY TO CONDUCT A
RESEARCH PROJECT AMONGST THE VOLUNTEER AIDS
CAREGIVERS**

I am pursuing a Masters degree in Social work with the University of Johannesburg and hereby to submit a formal request to conduct a study in organisation that has been funded by the department of social development, the study is on the voluntary AIDS caregivers with AIDS families.

A researcher would like to commence with the pilot study in which few participants will be involved. The main study will be conducted on May 2005 at 10 am to 11 am. Confidentiality will be assured; the names of three participants will not be mentioned in the study. Participants will share their knowledge, skills and experiences thus enhancing the study

I hope my application will receive your favourable consideration.

Yours faithfully

Vuyo Ntsunswana (miss)
Study Leader: A VERMUELEN

ANNEXURE E.

Box 5053
Botshabelo
9781
01 March 2005

Dear Sir /Madam

PARTICIPATION CONSENT

**THE VOLUNTARY AIDS CAREGIVERS WITH AIDS FAMILIES
RESEARCHER: VUYO NTSUNTSWANA**

I the above mentioned researcher; currently pursuing a Masters degree in Social work with the University of Johannesburg and hereby to submit a formal request to conduct a study in organisation that has been funded by the department of Social Development, The study is on the voluntary AIDS caregivers with AIDS families.

A researcher would like to commence with the pilot study in which few participants will be involved. The main study will be conducted on May 2005 at 10 am to 11 am. Confidentiality will be assured; the names of three participants will not be mentioned in the study. Participants will share their knowledge, skills and experiences thus enhancing the study. The interview will take +-1:30. Ten participants will participate at a time. An audiotape will be used to ensure no data will be lost.

Your name will not appear any where in the report. The information will be treated as confidential as possible. Please note that your participation is voluntary, you have the right to withdraw your consent to participate any time without being discriminated against.

PARTICIPANTS SIGNATURE -----DATE

RESEARCHERS SIGNATURE -----DATE

ANNEXURE F.

TRANSCRIPTION OF FOCUS GROUP INTERVIEWS.

ANNEXURE 1

Research Questions

INTERVIEWS: VOLUNTEERS

Researcher: V.NTSUNTSWANA
Co -Facilitator: SEGALO ITUMELENG
Recorder: MOTSIRI
Participants: 4
Venue: BOTSHABELO BOARDROOM
Date: JULY 10
Time: 10:00 - 11:00

RESEARCHER



Good morning my name is Vuyo. I am doing the interview for research pilot study. Please feel free to speak and say whatever. I am not going to ask your names. So there is no mentioning of names in the tape. You can answer in Sotho, Xhosa, and English.

Okay the question is I would like you to talk about the experiences regarding support provided by AIDS families to you in you caring for the patients.

The 3 focus group questions will be the same to the 3 groups that direct the study:

-“What is the nature of support that you experience regarding caregivers in their caring for AIDS patients?”

-Tell me about the kind of support that you receive?

-What recommendations do you have regarding the support that should be provided?

Researcher

Tell me about the support that you receive as you are caring your AIDS patients?

Participant

“The support we get “is there but not enough” the department is not taking care of us, as we are the caregivers, we are not paid in time”; we don’t get our stipends in time.

Researcher

How do you perceive support regarding the family members and your family?

Participant

My family does not understand my commitment to my work. My husband says to me the other day “these people will infect you then you’ll give me the virus, if I ever get infected it will be your fault, you’ll see what will happen.

Researcher

How do you feel as you are caring the members?

Participant

There is a feeling of tiredness, exhausted, depression and often neglect of our own health. ‘I feel isolated because I have to care for my patient, I sometimes cannot got to church, I have to be with him at all the time”

Researcher

What do also experience as you are caring the family members?

Participant

Some) we experienced a stigma even in our communities, because some members voice out that there is discomfort about the discussion even in the family.

Participant

Family burden is heavy because nurse is forcing me to stay with my patient." At her home I was told to stay with my patient to avoid the patient getting sick".

Researcher

What support do you need or experienced as home-based carers?

Participant

(All) yes we need stipends every month

Participant

We all need support services, systems centralised and controlled by government well. Our Mental and our physical health need to be supported.

Participant

We need counselling services for patients and for us as volunteers, because our clients continue to suffer from lack of information in a range of medical context, they do not know when to receive the ARVs.

Researcher

Tell me why or how did you involve in caring?

Participant.

I am interested in working with the sick as I was caring my family I tell myself that I want to help others at their homes and I get trained for doing this.

Researcher

How does your care work influence your relationship at home?

Participant

“My family does not understand my commitment to my work. My husband says to me the other day “these people will infect you then you’ll give me the virus, if I ever get infected it will be your fault, you’ll see what will happen.

Researcher

Was there a turning point in this?

Participant

No there was not turning point but I was thinking of my family relationship which was becoming to be bad because I am not paid by the department every month and I was still continuing with my work as it is call from God, I only receive R500 or less the amount I’m supposed to get. The support is unsatisfactorily At least I wanted to be relieved from all the burden of caring.

Researcher



What support do you receive and encouragement and in which ways?

Participant

We don’t receive care and support from the clinics and encouragement from the staff, we don’t receive any equipment, and there is always insufficient number of doctors in hospitals and nurses not available at night and on Saturdays.

Participant

There is wide variation of care amongst hospitals and even in the family homes other do care for their patients and others do not, they only told that carers are there for their family burden, there are some nice nurses. And we got experiences of only one or two nurse in the clinics others are not available at night.

Researcher

Can you tell me a story of someone in whose life your care work really made a difference?

Participant

Researcher

Tiredness, bothersome depression and discouragement seems to be bothersome in your work, how do you cope with that?

Participant

I'm not going to give up my work regardless of circumstances

"Yes, we become tired of the department that does not take of us and not getting paid in time , we become tired of that"

Researcher

'Would you mind to tell more about "not enough" Tell me what you mean when you say it is unsatisfactorily'

Participant

"If you render a service you do it from your heart, we don't receive enough stipends from the department they give us R300 per month at least we need R500-R700 per month. The support we receive is "unsatisfactorily at all "you'll find the other month we don't get money the other month, we get R300 only."

"I mean that we work as volunteers and we don't receive our money in time we need our money every month"

Researcher

So you are saying you don't get the money every month or in time?

Participant

"The other thing we work as volunteers we don't get any equipment as the support like protective clothing we need the gloves from time we are told by the department that we are volunteers

Researcher

So are you saying that you are not volunteers?

Participant

“Yes we are the volunteers but we must be treated equally” I love it,” I wake up every morning, this kind of job is hard with as a wife my children are complaining working for nothing.”

Gloves are needed because some of our patients have bad sores, we are afraid that we will be infected

Participant

“We need counselling “

Researcher

What kind of counselling and why do you say you need counselling?

Participant

“We need counselling because when you get into the family and you find out the person has died you feel stressed. The patient will report to you that her husband want to have sex with her whilst is very sick and when I ask the husband he will say “ Are you going to give me what my wife will give it to me she is my wife. Nurses do not do anything; we do everything for the patients. We don’t get any support from the families. “The social worker is needed to give counselling the families because the families want to kill themselves when they came from the clinic.”

Participant

“Social development does not appreciate the work of volunteers the department should stop playing with us” “I have separated with husband because of this kind of job I am doing, this voluntary work for nothing, if the care giving can be suspended HIV/AIDS will be no use.”

Researcher

Are you saying that social development doesn't give you support?

Participant

"Yes it does not support us at all, the Health department discourages us by saying home based care is for health, professional people do not take care or undermines us. We need to be taken as professional because we do job like professionals. "Teachers at school do not accept, if we want to do Information Education and awareness programme at school we are not given a chance to talk to the children.

Researcher

Okay let's talk about your experiences in your caring and the kind of support you receive from the families?

Participant

"Families get tired of us and even with the patient; families do not care about their patients

We don't get support form the families if you want to do the washing for them the family say "no don't touch the tap"

Participant

"We wash the patients; we feed them and give them medication but the families appreciate that.

Researcher

What else do you do you what kind support do you provide?

Participant

“We take them to the clinics for medication and even to the hospitals and sometimes we provide basic counselling. We identify orphaned and vulnerable children from the families. ”

Participant

“We apply for them for social grants that is food parcels”

Researcher

What recommendation do you have in mind regarding the support that should be provided?

Participant

“Firstly health department should work with us well, hey should not treat like badly. We are human beings. We need counselling support services to share like support groups because we feel stressed when we care about the clients”

Participant

“Community involvement and volunteering is a problem we need to be trained as counsellors all of us. The department should not discriminate us.”

Participant

“We need a social worker specifically for HIV/AIDS counselling because if you come to the office to any one we will be told that this one is not supposed to do counselling”

“Again we want the medical fund and step down facility to work as soon as possible.”

Researcher

‘So are you saying you want the medical insurance or incentives?’

Participant

Yes (all)

“The material that exists should be given to us, many volunteers are trained but it is inadequate there is no follow up of training done by the two departments”

Participant

“We also need transport money because when it is raining we can't go to their homes,

Researcher

Are you not receiving or getting transport money?

Participant

“Yes, before but now it has been stopped. We need funding from the departments, we need to be trained and be supported and monitored by the department. The department does not take care of us.

Researcher

Anything else that you would like us to say

Participant

“Another thing I would like to say is that if the department can have workshops to the family for awareness programmes but they happen but do not happen in the families, community is not also aware and accepted the HIV/AIDS, they need to be work shopped.”

Researcher

Okay other sorts of suggestions

Participant

“We are expecting to be someone in future it is very nice to work for your family and to be permanent, we call ourselves that we are working but we don’t get anything R500 is just nothing, we are just wasting our time, so we need more money government should take care of us. The government is not thankful of what we are doing. Health and social development must work well and we need better coordination form the two departments”

Okay if there is nothing else I would like to thank you participating in the study and for your experiences and recommendations you have made.



ANNEXURE 2

FOCUS GROUP 2 (WITH FAMILIES)

TRANSCRIPTION

INTERVIEWS:

Researcher: V.NTSUNTSWANA
Co -Facilitator: SEGALO ITUMELENG
Recorder: MOTSIRI
Participants: 10
Venue: BOTSHABELO BOARDROOM
Date: JULY 21
Time: 10:00 - 11:00

RESEARCHER

Good morning my name is Vuyo. I am doing the interview for research. Please feel free to speak and say whatever. I am not going to ask your names. So there is no mentioning

“Oh, they ask us about the I.D. if we have them, except washing the patient, they help me in the registration of birth certificate I have my daughter’s son whom she left long I don’t know where he is, the caregiver helped me with my grandsons birth registration.”

Participant

“At my home the caregivers came and identify an orphan and help me with the application of foster grant. The child do not have a parent, the child was left by my relative long the caregivers as they visit in they come with the social worker to talk about the child and ask me if I want the child they will place the child under my name and said I must wait for the grant from Social Development to be approved, and the application was done by the caregivers”

Researcher

You are saying the caregivers help you with the birth registration social grants; do you just wait for them to do everything for you?

Participants

“They just kept quiet (Mhhh) not waiting for them but I am old to make a long queue in home affairs

Researcher

What other support do you experience or receive?

Participant

“Patients and volunteers should be given emotional support not only the injection, nurses seem in a hurry they never tried to sit down to talk with us, informal caregivers are helpful rather than care professionals”

Participant

“The other thing caregivers identify the children who have no parents in our homes and check if these children have I.D. or birth certificate, you know “ngwanaka,” I am old to go around by myself, home affairs sometimes is full, you have to queue on the line so they come to help us”.

Researcher

Okay you are saying they come and identify children, who do not have birth certificate, do you let them go alone “you are saying you are old” to follow the queues in home affairs

Participant

“Volunteers sometimes get tired of families; sometimes they will come to the house and sometimes do not come, they will say “ department is paying a little

amount only R500 per month sometimes they don't receive the money, I don't know what should happen if they come to help us really I live with one child who has no parents, this child was brought by somebody to stay with me and I only depend on my pension, I am old to stay with the child, I don't receive anything, The caregiver came and say she will refer the child to the social workers so as to receive social grants, but I am still waiting till now.

Participant

"My child is sick and I am also sick,"Ke eena ke na le eena "(look this is my child) we don't receive anything from government, when we go to social security for food parcels they will say the doctor say we are not sick, we must go and find job. "Ke kula ke le Jena" (being sick like this) how can I look for job. Oh we really thank these caregivers for their job, because even when you go to the clinics or hospitals, the nurses shout at you. " (Bana ba rethusa hahulu) " the caregivers help us very much even when I don't have food in the house they come with something to cook or vegetables".

Researcher

You are saying that the caregivers identify orphans and children who don't have certificate, what else do you think they support you with, some of you are saying they are old enough to stay with their children and cannot go or wait longer in the queues in home affairs.

Participant

"They take the sick people to the clinics for medication and even to the hospitals and sometimes they provide basic counselling, such they teach us how to care of the sick one at home, bath and cleaning, I did not know if my child when sick with this AIDS what she must eat, Now I know that I must cook " Moroho" vegetables such spinach and now my child is better now."

Participant

"They help us with the application for social grants that is food parcels and foster care grant, some times they will invite us as families to HIV/AIDS awareness

campaigns done by them to talk about AIDS. I did not know that my child is having this sick I thought she is just coughing and has flue and my child didn't tell me, I knew when the clinic sister told me and I started to see the volunteers coming to my house to see /visit the child and she was not talking anything to me but prefers the volunteers when they are in the house."

Researcher

What do you think should be done /what recommendation do you have in mind regarding support?

Participant

"The community should be made aware of HIV/AIDS. Where I live people always discriminate my house because as "my child and myself, we are sick" they say you all live with virus "Mme le moradi WA hae". Oh my heart is painful" (crying)."

Researcher



Okay, what else do you think should be done?

Participant

"The clinic sisters should treat us well, they should not shout at us, when we brought our children.

Participant

"The caregivers must be paid every month because they are the ones that help us.

Participant

"We need food parcels or sick pension and improvement on the treatment, health department should work well with us, and we plead them not to shout at us."

Researcher

Do you want to receive sick pensions?

Participant

“All responded) no some of us are receiving social grants and some the doctors say we are not sick, we must go to work and our pensions have been cut by the social security.”

Researcher

“The government should stop playing with us; we cannot work whilst we are sick, and we don't have food. Community nutrition is needed. Volunteering should be encouraged because they help us very much (the caregivers)”

Researcher

What else you would like to recommend?



Participants

“ (Batho ba-batla) training, the community need to be trained because they don't accept people who are HIV/AIDS. AIDS councils should stop taking sides when it comes to government things especially food parcels.”

Researcher

Okay if there is nothing else I would like to thank you participating in the study and for your experiences and recommendations you have made. Please keep it up with the good work that you are doing.

ANNEXURE 3.

FOCUS GROUP 3 (WITH PATIENTS)

TRANSCRIPTION

INTERVIEWS:

Researcher: V.NTSUNTSWANA
Co -Facilitator: SEGALO ITUMELENG
Recorder: MOTSIRI
Participants: 10
Venue: BOTSHABELO BOARDROOM
Date: 28 JULY 2005
Time: 10:00 - 11:00

RESEARCHER

Good morning my name is Vuyo. I am doing the interview for research. Please feel free to speak and say whatever. I am not going to ask your names. So there is no mentioning of names in the tape. You can answer in Sotho, Xhosa, and English.

Okay the question is I would like to talk about the experiences regarding support that is provided by the caregivers.

The research questions will be:

- “What is the nature of support that you experience regarding caregivers in their caring*
- Tell me about the kind of support that you receive?*
- What recommendations do you have regarding the support that should be provided?*

Researcher

Tell me about nature of support that you receive from caregivers in their caring?

Participant

“ They are supporting me by washing myself, clean because I cant wash myself, I have scars in body all over my body.”

Researcher

What type of care do you receive?

Participant

“Psychological care is inadequate; I am disappointed with the care that we receive in the context of daily nursing care by caregivers and nurses. There is no confidentiality when you go to the clinics; sisters reveal our status in front of our patients, even I don't trust the caregivers so much”

Participant

“I am HIV/positive; the caregivers do not care about me ”

Researcher

How do you know that they do not care about yourself?

Participant

“We are not satisfied about the information given to us by the volunteers and nurse including the test results they just say you're HIV positive.”

Researcher

Are the volunteers giving you the test results?

Participant

“Yes because the nurses refer the caregiver to me and I was given test result by them when they visit they told me I have AIDS and I cried ”

Researcher

What support do you receive and encouragement and in which ways?

Participant

“We do not receive the good counselling from caregivers and they do not know on how to do counselling and at hospitals there is a shortage of nurses and social workers are not there when we are at the clinics, so we don’t receive enough counselling, nurses shout at us”

Participant



‘The caregivers help me to walk to the clinics and I was coughing “

Researcher

When you say that there is a shortage of nurses in counselling, what do you mean?

Participant

“I mean there is nobody helping us in terms of accepting our status except the caregivers at home when you come at clinics at night there are no nurses or doctors available.”

Researcher

Okay can you please tell me more about the support and encouragement you receive?

Participant

“The caregivers help me to wash myself, when they enter in the house they clean the house, I met my caregiver in January there was no food in the house they give us food, I can’t work because of the illness so there is nothing at home. The kind of work they are doing is too much; they also help us with T.B. medication and take us to the clinic for treatment.”

Participant

“In the hospital we pay almost everyday when you visit.”

Researcher

Tell me the personal experience of care and lack of it?

Participant



“We believe that a miracle will happen when you to hospital but the staff simply say” we will not give you a treatment” you will not get well”. We are dissatisfied about the care provided in hospitals because there is no medical treatment provided except pain medication, its better the care that we receive at home by the volunteers.”

Participant

“Medical professionals do not pay attention to us, as we are sick It is better to stay at home rather than going to a hospital because in hospital when someone died we knew it immediately as a dead person is carried off, I don’t know whether this is an intention to show us to prepare for death. We are not treated with dignity at the clinics ad sometimes we don’t trust our caregivers because they would talk about our status.”

Participant

“I never wanted to go to the hospital but actually I have no place to go because my family does not care much for me, there are caregivers that feed us, bathe and give us medication. It’s a distressing experience that medical professionals viewed the patient’s death as duty work.”

Participant

“My family get tired soon in caring me; the caregivers help me in applying for grants washing myself always check if I have something to eat”.

Participant

“Also in the clinic I was not treated well the nurse was saying to me” you are HIV/Positive”. I was very hurt because the nurses do not n care how we feel.”

Participant

“We travel long distances to the clinics, we don’t have money for transport, the volunteers are the only people that they care much about us sometimes they help us with the money to go for treatment.”

Researcher

So you are saying that the nurses do not care about your status and what quality of care do you receive?

Participant

“There is no confidentiality amongst carers themselves and professionals like nurses

The nurse do give us emotional support, they are always in a hurry they never try to_sit_down.” My mother has to lie down on a very small bed in the waiting room; her condition was so bad shouted by the nursing staff.”

Participants

“There is no care in the clinics; it is better at home than going to hospital, there, you don’t recover”

Researcher

Did you receive any counselling sessions before the clinic sister can give you the results?

Participant

“No, I was just told that I should go to Social Development for the application of grant and they just refer me to the caregivers in the clinics. There is insufficient information about the availability of care services we are receiving.”

Researcher

Does AIDS find easy or difficult to enter your community and why are saying that if yes?

Participant

“No there are still personal relationship problems between my families and me because at home there is still the stigma that I am going to infect them, they don’t use my spoons and I sleep alone in the room especially when I am coughing”

Participant

“We as patients we still do not believe to the diagnoses because of fear of rejection from the family and also fear of disgrace to the community.”

Researcher

What strategies do you use to resist the effects of AIDS in your life?
In which areas of your life are you winning?

Participant

“The basic management of my health and self-knowledge in carers”

Participant

“I also talk to my friend although sometimes I find it difficult to manage alone especially when I am alone I become frustrated and think that I am going to die and fear of the people.”

Participant

“We as a patients we don't return for test results so that we can receive further counselling services because most of the time these caregivers are the only people that attend to us we only come back when we are very ill”

Participant



To add “there we also don't understand what is said at the clinics about the test results that's why we come back when you are ill”

Researcher

Okay what gives AIDS strength in your life?

Participants

(All) say Prayer gives me more strength and the caregivers more that clinic staff helped me to wake up and walk”

Researcher

Tell me about the kind of support you have received so far? I could hear from all of you that the caregivers are working well with you except the treatment that you receive from the clinics?

Participant

“The caregivers teach about HIV/AIDS, how to keep ourselves healthy. They provide with counselling, they always advise us to keep ourselves healthy eat balanced diet especially the vegetables.”

Participant

“We also receive counselling from them more than the sisters in the clinics.”
But the counselling is not enough we need somebody to talk to you everyday at home they get tired especially when you are sick.”

Researcher

What do you mean when you are saying that counselling is not enough? Tell me more about the counselling that should be provided?

Participant

“I need counselling everyday, social workers do not come everyday in the house at least I could have somebody to talk to, I need someone to share with.”

Researcher

Are you saying you need support group where you can share your feelings?

Participant

“The caregivers refer myself to the support group; there is a support group that is available, caregivers conduct the support groups or refer us to the organisation that has support groups. ”

Researcher

Are caregivers providing enough counselling sessions or in the support groups or do they help you in giving information on HIV/AIDS?

Participant

“The caregivers also conduct some workshops on HIV/AIDS information and also involve us in poverty alleviation programmes where they taught us about food gardens even at homes, life skills are also provided by the caregivers”

Researcher

What kind of life skills is provided?

Participant

“Caregivers are capacitating us in encouraging ourselves to talk about our status, and feel strong that we are positive” I really feel strong about my status and ever since I met them I don’t have any fear of talking about myself even in public.”

Researcher

What do you think should be done or what recommendation do you have in mind regarding the support that should be provided? /received from the caregivers?

Participant

“The community should accept and even at the clinics they should not shout at us

Researcher

Okay, what else do you think should be done? Except about the professional staff

Participant

“The volunteers must receive their money every month “

Participant

“We need support group’s everyday, caregivers should be given a special place where we can get them everyday.”

Participant

“We need food gardens to be provided to us”“we should receive sick pensions”

Participant

“Promotion of home based care and to be strengthened and others should benefit”

Participants “

“The doctors should stop playing with us; we cannot work whilst we are sick more support services are needed and to support the carers”

Researcher

Is there anything else that you would like recommend about the support that you receive from your caregivers?



Participants

“Educational and counselling programmes for patients and their families because clients continue to suffer from the lack of information in range of medical context.”

Participants

“Volunteers working in the field of HIV/AIDS should receive some form of compensation and training need to there at all times. Patients must be treated with dignity, and counselling should have meaning because when we receive it does not help us. And family members must be considered if they don’t want their status to be known”

Researcher

Okay if there is nothing else I would like to thank you participating in the study and for your experiences and recommendations you have made. Please keep it up with the good work that you are doing.

ANNEXURE G

BUDGET

EXPENDITURE	Amount
Travelling expenditure	R1500
Typing cartridge	R700
Duplication and binding	R800
Other expenses such as beverages	R400
Editing	R100
TOTAL	R2.500



ANNEXURE H

Work schedule on the qualitative research

ACTIVITIES	DATE
Proposal and chapter 1 planning of research	28 th February 2005
Establish rapport with supervisor and prospective participants	February 2005
Methodology	February and March 2005
Data collection instrument	March 2005
Collection of data	April to June 2005
Analyses of data and formulation of results	June to July 2005
Literature control	August 2006
Formulation of conclusions and recommendation	September 2006
Final editing	December 2006
Submitted to the supervisor	15 th January 2007

