THE PERCEPTIONS OF VOLUNTARY AIDS CAREGIVERS CONCERNING HOSPICE MANAGERS' PROVISION OF SUPPORT

BY

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I, **Rosina Nomathamsanqa Gxabuza,** declare that the dissertation submitted by me for the Masters Societatis (Nursing) Degree at the University of the Free State is my own independent work and has not previously submitted by me at another University. I further cede copy right of the script in favour of the University of the Free State.

R Gxabuza

R.N. Gxabuza

DEDICATION

This book is dedicated to my late parents Nelson Thandani and Mimmie Nontsikelelo Gxabuza, who said while I was still at secondary school that I should grow and not be tired of growing because after growth is death.

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I wish to acknowledge my heroes and mentors for whom I have all respect and admiration. I speak of the people who have enriched and bettered my life, those who have made an impact on my academic journey.

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SUMMARY

The challenge of HIV/AIDS is a global issue. Instead of decreasing the number of people infected with the disease is increasing. Fortunately we have men and women who volunteer to fight the increase of this pandemic. These heroes and heroines are voluntary AIDS caregivers who are the mainstay of care of people with AIDS.

However, the fact that caregivers suffer from loneliness and social isolation related to stigma and discrimination cannot be ignored (*cf*Flaskerud & Tabora, 1998:21). Voluntary caregivers could benefit from the opportunity to express basic emotions concerning financial, emotional, physical issues and an 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.

This is a qualitative study undertaken to explore the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support. An explorative, descriptive, contextual and qualitative design was used to determine the perceptions of AIDS caregivers concerning hospice managers.

Voluntary AIDS caregivers were selected from hospices of the Motheo District. A pilot study was conducted prior to the commencement of the main study. This resulted in paraphrasing the central question as in the "grand tour" (Spradley, 1980:49), Marrow and Smith (1995:42) who ask question such as; "Tell me about your self."

Initially two focus groups were selected, comprising of ten participants in each group. Participants were requested without leading them to give detailed information during interviews. Saturation principle was not reached with the two focus groups, as there was no redundancy of information. Subsequently two more focus groups were selected in an endeavor to reach the required saturation point. Eventually four focus groups participated in the study.

Data collected was analysed according to Tesch [1990] in Creswell (1994:155) and also by making use of the N VIVO program, a design for qualitative research used to ensure that the complex data was correctly and systematically analysed.

The data analysis was followed by a literature control. The findings with regard to the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support did not differ significantly in personal and vocational support that were identified as main categories.

The researcher made recommendations and suggestions were made by voluntary AIDS caregivers are easy to follow and implement. Limitations encountered are discussed.

OPSOMMING

Die uitdaging van HIV/VIGS is 'n wêreldwye kwessie. In plaas van 'n verwagte ' n afname is daar 'n toename in getalle te bespeur. Gelukkig is daar mans en vroue wat bereid is om as vrywilligers op te tree ten einde hierdie pandemie te beveg. Hierdie helde en heldinne is vrywillige versorgers wat die ruggraat in die versorging van mense met VIGS is.

Die feit dat vrywillige versorgers aan alleenheid en sosiale isolasie lei, wat met stimatisering en diskriminering verband hou, kan nie geïgnoreer word nie (*cf*Flaskerud & Tabora, 1998:21). Vrywillige versorgers kan by die geleentheid om hulle emosies rakende finansiële, emosionele en fisieke aspekte baatvind en oop kommunikasie kanale moet in plek wees. Deur 'n roete te verskaf waardeur emosies uitgedruk kan word, kan beide die fisieke en geestelike welvaart van vrywillige VIGS versorgers verbeter.

Hierdie is 'n kwalitatiewe studie wat onderneem is om die persepsies van vrywillige VIGS versorgers rakende hospies bestuurders se voorsiening van ondersteuning te ondersoek. 'n Ondersoekende, beskrywende, kontekstuele en kwalitatiewe ontwerp was gebruik om die persepsies van vrywillige VIGS versorgers te bepaal.

Vrywillige VIGS versorgers van die Motheo Distrik is geselekteer. 'n Loots studie is voor die aanvang van die hoof studie uitgevoer. Dit het tot die herformulering van die navorsingsvraag gelei soos in die "grand tour"

(Spradley, 1980:49) and Marrow en Smith (1995:121) wat vrae soos "Tell me about yourself" gevra het.

Twee fokusgroepe is aanvanklik geselekteer wat uit tien deelnemers in elke groep bestaan het. Deelnemers is versoek om spesifieke inligting gedurende onderhoude te verskaf sonder dat leiding verskaf is. Die versadigingspunt is nie met die twee fokusgroepe bereik nie aangesien daar geen oorbodige inligting was nie. Daar is dus twee meer fokusgroepe geselekteer ten einde die vereiste saturasiepunt te bereik. Uiteindelik het vier fokusgroepe aan die studie deelgeneem en saturasie is bereik.

Data wat ingesamel is, is volgens Tesch [1990] in Creswell (1994:155) geanaliseer asook deur gebruik te maak van N VIVO, 'n program ontwerp vir kwalitatiewe navorsing. Dit is gebruik om komplekse data korrek en sistematies te analiseer.

Die data analise is gevolg deur 'n literatuur kontrole. Die bevindinge ten opsigte van die persepsies van vrywillige HIV versorgers ten opsigte van hospies bestuurders se voorsiening van ondersteuning het die beduidend verskil in persoonlike en beroepsondersteuning wat as hoof kategorieë geïdentifiseer is.

Aanbevelings en voorstelle wat maklik gevolg en ge ïmplimenteer kan word is deur vrywillige HIV versorgers geformuleer en is as volg:

Toelaag (stipend); emosionele ondersteuning; fisieke ondersteuning;
Voorrade en toerusting; onderrig en opleiding; kommunikasie

CHAPTER 1

THE PERCEPTIONS OF VOLUNTARY AIDS CAREGIVERS CONCERNING HOSPICE MANAGERS' PROVISION OF SUPPORT

1.1 INTRODUCTION

Voluntary caregivers may experience physical health problems, depression, disruption of interpersonal relationships, social and work life, as well as financial strain associated with care giving. They may feel reluctant to talk about the problems they are facing and fear being judged an inadequate caretaker (Flaskerud, Carter & Lee, 2001:121). It is suggested that if support is not provided they may also suffer from burnout syndrome often characterised by a depressive mood, anger, anxiety and insomnia.

1.1.1 Problem statement

In South Africa AIDS[1] is currently not a notifiable disease and due to voluntary reporting, the number of people living with AIDS may be seriously underestimated (Joint United Nations Programme on HIV/AIDS (UNAIDS), 1998:12; World Health Organization (WHO), 1998:6-63). However, UNAIDS (1998:12) indicated that in 1998 approximately 165,000 people in South Africa were living with AIDS and that 120,000 deaths occurred due to this life-threatening condition. Their projections

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[1] AIDS: Acquired Immuno-Deficiency Syndrome

2 HIV: Human Immune Virus

also indicate that by 2000 a quarter of a million South Africans will die of AIDS annually, and that this figure will rise to more than a million by 2008. Furthermore, they stated that the average life expectancy is expected to fall from approximately 60 years to 40 years between 1998 and 2008.

In view of the above it is understandable that voluntary AIDS caregivers often fear becoming infected with the Human Immune Virus (HIV). Stigmatisation, prejudice and discrimination surrounding HIV and its life-threatening effects may compromise their ability to provide quality care (Gubb, 1998:7; Carter, 1999:8).

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). They may experience severe stress in caring for people with AIDS; have difficulty in handling patients' demands and their inability to restore AIDS patients to health; and experience feelings of ineffectiveness of "not being a good giver" (Kelly & Lawrence, 1989:149). As a result of caring for patients with a stigmatising illness, voluntary AIDS caregivers may feel stigmatised by other hospital staff. Because of that they tend to suffer from depressive mood, insomnia and anxiety. Some voluntary caregivers of people with AIDS reported spending every waking hour in care giving (Kelly & Lawrence, 1989:150; Nash, 1989:33).

In order to investigate the issue regarding support rendered to voluntary AIDS caregivers the researcher carried out an extensive literature search.

No studies concerning voluntary AIDS caregivers' perception of support rendered to them by hospice managers were found.

Research conducted cover issues such as: The knowledge and practices of primary caregivers regarding home-based care of HIV/AIDS children in Blantyre (McIneryney, 2001:83-91); Active client participation: An examination of self-empowerment in HIV/AIDS case management with women (Flynn & McKeever, 2000:59-69); The experience of HIV reactive patients in rural Malawi (Sliep, Poggenpoel and Gmeiner, 2000); Quality of life among persons with AIDS in a hospice setting: A qualitative study (Amos-EA, 2000:134); Stress and relevant responses of AIDS family caregivers in a medical center in Taiwan: An exploratory descriptive study (Su-YL & Chen-YY, 1998:43-53); Poor women living with AIDS: self identified needs (Bunting, Bevier & Baker, 1999-2000:4) and distressing emotions in female caregivers of people with AIDS, age-related dementias and advanced-stage cancers (Flaskerud, Carter & Lee, (2000:121-130). Home-based care needs of AIDS patients in Lesotho (Motaung, 2001).

The researcher realized the need of exploring voluntary AIDS caregivers ' perception of support rendered by hospice managers and to identify the support needed. A lack of support will have a detrimental effect on the quality of care they are able to provide.

1.2 PURPOSE OF THE STUDY

The purpose of the study was to explore and to describe the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support. Based on the findings of the study, recommendations on how support should be provided were made.

1.3 CLARIFICATION OF CONCEPTS

1.3.1 AIDS

AIDS stands for Acquired Immune Deficiency Syndrome, a viral infection caused by the RNA retrovirus known as immuno-deficiency virus. It is a condition characterized by multifaceted symptoms as a result of the individual's failing immune system due to HIV invasion. The individual suffers from diverse life-threatening cancers and opportunistic infections such as herpes zoster skin rashes, recurrent herpes simplex infection and karposi-sarcoma to mention but a few (Davis, Scheider, Rapholo & Everatt, 1998: 14).

1.3.2 Caregiver

According to Gubb (1998:7) an informal caregiver is any person who has undergone training for caring for a sick person.
In this study a caregiver refers to a voluntary worker at a hospice who cares for people with AIDS.

1.3.3 Hospice

The contemporary meaning of hospice refers to "a way of caring for people nearing the end of their journey through life, faced with dying and in need of refuge" (Vines and Hartzell, 1981:3; Stanhope & Lancaster, 1988:821).

The researcher defines a hospice as a co-ordinating, non-governmental organisation for home based care for people with AIDS and a step-down facility in the community.

The study was conducted at hospices in the Free State, South Africa.

1.3.4 Hospice managers

Hospice managers are persons who control a hospice (Mellish, 1995; 158).

1.3.5 Perception

Perception is a mental process by which data intellectual, sensory and emotional are organized meaningfully (Harber, Hoskins, Leach & Sidelean, 1987:1020).

1.3.6 Reflecting

Reflecting is the communication technique that conveys expressed thoughts and related feelings. The purpose of using reflection is to acknowledge to the *voluntary AIDS caregiver* that a message has been understood (*cf* Uys & Middleton, 1997:192).

1.3.7 Support

Support is to give strength, help or encouragement through physical, social, psychosocial, vocational and educational means (Gubb, 1998:6). The researcher would also like to add spiritual support to the definition. *In this study support rendered to voluntary AIDS caregivers by hospice managers was investigated.*

1.3.8 Volunteer

A volunteer according to Williams (2001:1) is someone whom willingly and without receiving payment performs a specific task for a non-profit organization such as a hospice.

1.4 RESEARCH DESIGN

The researcher used a qualitative method with a descriptive, exploratory and contextual design since the purpose of the study was to describe the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support.

1.4.1 Qualitative research

Qualitative research is an inquiry process of understanding based on methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex holistic picture, analyses words, reports, and detailed views of informants, and conducts the study in a natural setting (Creswell, 1998:15). According to Mason (1997:4) qualitative research aims to produce understanding on the basis of rich contextual and detailed data. It is intrigued with the complexity of social interaction as expressed in daily life and in the phenomenological approach (Marshall & Rossman, 1999:2).

1.4.1.1 Phenomenological approach

In this study, the researcher sought to explore new insights into the perceptions of support by caregivers of people with AIDS and made use of the phenomenological approach to qualitative research, which are both a philosophy and a research method.

To obtain useful information the researcher utilized communication techniques that aided in the listening process, such as paraphrasing, clarifying and perceiving, to promote free communication by the participants. Due to the fact that no studies have been done in this regard an exploratory, descriptive and contextual approach were followed.

1.4.2 Explorative approach

Exploratory research was the first stage in the sequence of this study. The exploratory approach rarely yields definitive answers. It addresses the "what" question and everything about the topic that is potentially important (Neuman, 1997:19). This approach leads to the exploration of a relatively unknown field to enable the researcher to gain new insight into domain the phenomenon (Uys & Basson, 1985:38).

1.4.3 Descriptive design

In a descriptive design the search is for accurate information about the frequency with which phenomena occur. In order to obtain interactive processes of interest, the focus should be on attitudes, opinions, needs or facts (Brink, 1996:109).

Information obtained during the focus groups on the issue of support required is carefully analysed, categorized and described.

1.4.4 Contextual approach

A contextual approach refers to the research conducted in the participants' natural setting (Creswell, 1998:140). The study was carried using voluntary AIDS caregivers who are rendering care to AIDS patients in a disadvantaged socio-economic community. The geographic area from which participants were selected was part of the Free State, South Africa. The researcher considered this target group as applicable to the research purpose.

The participants' workplaces were not used to conduct the focus groups. However, feedback was recorded as if it occurred in a natural setting.

1.5 RESEARCH TECHNIQUE

The researcher relied mainly on focus group interviews to obtain the information needed to support the purpose of the study.

1.5.1 Focus groups and the focus group interview

Neuman (1997:253) defines a focus group as a special kind of interview situation that is largely non-quantitative, yet Polit et al., (2001:256). Brink (1996:159) suggested that in a focus group about 5 to 15 participants opinions and experiences are solicited simultaneously.

A nurse educator competent in both qualitative research and focus group interviews facilitated the discussions. All focus group interviews were recorded. The researcher acted as an observer and documented the placement of participants, interaction between them and non-verbal behaviour.

According to Maynard-Tucker (2000:399) the focus group facilitator must have extensive experience in interviewing and communication techniques.

To obtain the necessary data the facilitator was guided by the research questions.

1.5.2 Research question

The research question 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 questions were asked in order to facilitate the discussions regarding the support rendered to voluntary AIDS caregivers.

- *"How do you experience the support provided by hospices managers in your caring for AIDS patients?"*
- *"Hoe ervaar u die ondersteuning wat deur hospies bestuurders verskaf word in u versorging van AIDS pasiënte?"* .
- *"What suggestions do you have regarding support that should be provided?"*
- *"Watter voorstelle het u met betrekking tot die ondersteuning wat verleen moet word?"*

Communication techniques such as clarifying, checking by paraphrasing and reflecting, and probing were used to obtain information (Strauss & Corbin, 1998:41). The researcher made sure that she has understood what the participants (*cf* Uys & Middleton, 1997:193) stated.

1.6 UNIT OF ANALYSIS

Sampling is a process of systematically selecting cases for a research project (Neuman, 1997:205). 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 or non-judgmental sampling is an acceptable kind of sampling. It selects cases with a specific purpose in mind (Neuman, 1995:206).

However, a limitation of qualitative research is that data cannot be generalized. This research method, however, enhances reliability.

1.6.1 Units

The population included seventy-two (72) voluntary AIDS caregivers at two hospices in the Free State. A purposive sample of thirty-two (32) voluntary caregivers of AIDS patients' delivering a service at the hospices was obtained by using the duty register as a sampling frame with the permission of the organization's manager. The following inclusion criteria were considered in the selection process:

1.6.2 Inclusion criteria

According to Burns and Grove (1997:295) inclusion criteria are characteristics that must be present for the element to be included in the sample. For a participant to be included in the study he/she had to be a voluntary AIDS caregiver; caring for people with AIDS; between the ages of 20 and 60 years.

Inclusion of the age group 20-60 years was based on the ages of caregivers working in the specific hospices in the Free State; willing to participate and sign the written consent form (audiotaping of interview included) and able to communicate in English, Afrikaans or SeSotho. English and Afrikaans are the official languages in the Free State Province.

1.6.2.1 Allocation to focus groups

At least four groups were formed and the selection process was repeated until saturation of data was obtained. Arrangements were made with the participants. Participants who withdrew from the research were replaced by following the inclusion criteria.

1.7 PILOT STUDY

A pilot study is a small-scale study conducted before the main study on a limited number of subjects from the population but not the same ones intended for the eventual project (Brink, 1996:174).

The pilot study was conducted at one of the hospices in the Free State, with the purpose of testing the research question. Only three (3) voluntary AIDS caregivers of patients with AIDS providing a service at the hospice were included. The facilitator selected to conduct the interviews also performed the pilot interviews. The three caregivers did not form part of the final investigation.

1.8 DATA COLLECTION

According to Brink (1996:148) data collection denotes the gathering of information needed to address a research problem. Data collection is also referred to as a systematic process that entails reacting, interacting, reflecting, attaching meaning and recording data (Burns & Grove, 1997:529).

The researcher collected data regarding the two research questions during two focus group interviews consisting of ten (10) participants each. The focus group interviews took place on two consecutive days in the pre-arranged venue.

Different strategies used to ensure that no data was lost. Each focus group interview was audiotaped. Field notes, observational, theoretical, methodological and personal notes formed part of the process of data gathering. Communication techniques, for example, clarifying, checking by paraphrasing were also used to obtain information.

1.8.1 Entry to the setting

In this study entry to the hospice setting and psychiatric complex was through overt practice, which required the managers' permission. This helped to establish rapport and a relationship of trust between the researcher and participants.

1.8.1 Saturation principle

This means that the focus group interviews were conducted until "data became saturated" or until themes seemed to repeat themselves (Lincoln & Guba, 1985:201). Two focus groups were scheduled in order to obtain the necessary data. However, more sessions would be scheduled if saturation of data were not obtained.

1.9 TRUSTWORTHINESS

Trustworthiness is the term used by Lincolin and Guba (1985:290) to refer to believability of the researcher's findings. The researcher maintained a record of interview development, so as to be able to begin an "audit trial" of work, which contributed to the trustworthiness of the research outcome.

The researcher made use of four aspects of trustworthiness as referred to by Lincolin and Guba (1985:290) namely:

1.9.1 Truth-value

The truth-value of the study was ensured by making use of "member checks" whereby the researcher asked participants whether the interviewer accurately described their perception (Maykut & Morehouse, 1994: 147).

1.9.2 Applicability

Applicability means the relevance to which the findings of the study can be reflected to the participants. Applicability ensures trustworthiness, because its value is reflected in the participants' capacity to recognize the perception described in the study, its theoretical significance, its applicability to caring for people with AIDS and its influence on future research activities (Burns & Grove, 1997: 668).

1.9.3 Consistency

Consistency is another way of ensuring trustworthiness. Verifying or crosschecking observations with other participants will achieve external consistency. This will make the credibility of participants and their statements part of trustworthiness (Neuman, 1995:368).

1.9.4 Neutrality

Neutrality is the fourth aspect of ensuring trustworthiness, whereby the researcher directly observes and interacts with participants in a natural setting to get inside their perception. In this case the researcher did not see participants as a neutral medium through which social forces operate; instead she held that the participants defined the perception of support through their interaction (*cf*Neuman, 1997: 346).

As part of a socially created setting, a researcher's presence in the natural setting cannot be merely neutral data gathering. It should ensure the trustworthiness of the findings.

1.10 ETHICAL ISSUES

Ethical considerations require diligence, honesty and integrity. Informed consent, protecting participant's anonymity as well as specific situations must be available (Marshall & Rossman, 1999:90).

The researcher cannot demand access to people, situations or data for the research purpose but should obtain permission. These are necessarily linked to ethical issues (Punch, 2000:59). Ethical considerations were taken care of by way of:

1.10.1 Informed consent

The participants should have full information about the research project, including of why and how they have been chosen to participate. Participants were fully informed about what was expected of them (Brink, 1996:210).

1.10.2 Consent by participants

The researcher ensured that participation was voluntary by requiring written consent (Silverman, 2001:271). Participants were informed that if they wished to withdraw they would be allowed to do so even prior to the completion of the study.

1.10.3 Confidentiality and anonymity

Confidentiality means that although some information may be linked to participants the researcher will not at any stage of the research disclose it to the public (Neuman, 1995:452). The researcher destroyed the audiotapes after transcribing the data.

Anonymity means that the participants remain anonymous or nameless; therefore the researcher did not disclose participants' identity after information was gathered. Pseudonyms were be used to protect the anonymity of participants. Some participants may not have wanted to have their names used (Brink, 1995:205).

1.10.4 Permission to conduct the study

The researcher sought approval from the Ethics Committee of the Faculty of Health Sciences, University of the Free State, to execute the study. Permission to undertake the study was also obtained from the Free State Hospices.

1.10.5 Acknowledgement of participants

Participants received acknowledgement of the importance of their work and support if the research upset them in their care giving of people with AIDS.

1.11 DATA ANALYSIS

Strauss and Corbin [1997] in Marshall and Rossman, 1999:151) define qualitative data analysis as a search for a general statement about the relationships among the categories of data.

It builds grounded theory, yet Schatzman and Strauss, [1973] in Marshall and Rossman, (1999:150) provided classic suggestions on observational and theoretical notes. Field researches notes are outlined in Polit and Hungler, (1999:369) and were utilized by the researcher. These included observational, theoretical, methodological and personal notes.

1.11.1 The process of data analysis

The researcher made use of a procedure advocated by Tesch, [1990] in Creswell, 1998:140) for data analysis. The researcher, for example, transcribed each focus group interview very carefully; read the transcripts carefully in order to get a sense of the whole; selected the most interesting interview documents read through them and tried to find underlying meaning from the information.

The process followed by the researcher was the initial guide for categories and potential coding schemes. Computer programs available such as N VIVO provided ways of manipulating or drawing contrasts and comparisons among the codes by grouping similar issues to reduce topics. The researcher attached the final code to each category.

1.11.2 Coding of data

The researcher assigned codes to the qualitative text field notes, audiotapes and transcripts. Coding data allowed the researcher to attach codes to lines, sentences paragraphs or blocks of text. This was achieved by engaging a professional researcher who is actively involved in qualitative methodology. Both researcher and co-coder analysed the data independently using laid down guidelines.

1.11.3 Member checks

Lincolin and Guba, [1985] in Maykut and Morehouse, 1994:147) use this term to refer to the process of asking research participants to tell the researcher whether she has accurately described and stated their perception.

1.12 VALUE OF THE STUDY

The value of this study lies in the fact that the outcome will assist with recommendations of how support should be provided by hospice managers to support the health and well being of voluntary AIDS caregivers and maybe enable them to provide effective care.

1.13 CONCLUSION

Voluntary AIDS caregivers experience distressing emotions that may affect their mental and physical health. A study focused on the support they receive and the support they require was carried out by means of a qualitative research method.

1.14 OVERVIEW OF THE REST OF THE STUDY

Basic requirements to conduct a qualitative study and to enhance data collection were considered and discussed in chapter 1. This chapter contained only an outline of the research methodology. An in-depth discussion of the research process follows in chapter 2. Chapter 3 will contain the data analysis and description of the findings and in Chapter 4 conclusions, recommendations and limitations of the study will be included.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 INTRODUCTION

According to Flick (1999:9) qualitative research is a continuous process of constructive versions of reality. In Chapter 1 qualitative research methods that include the phenomenological and contextual approach, a descriptive and explorative design was mentioned and will be extensively discussed in this chapter.

2.2 RESEARCH DESIGN

The research design is described as the overall plan for gathering data in a research study. It begins with identifying and developing the problem based on theory or concepts, before plunging into the project, up to the final plans for data collection. Research designs help in setting guidelines for conducting research (Brink, 1996:214; Burns & Grove, 1997:225; Treece & Treece, 1986:41).

In this study the researcher used a qualitative, descriptive, explorative and contextual approach to explore and describe the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support. This information assisted the researcher in making suggestions about the type of support that should be rendered.

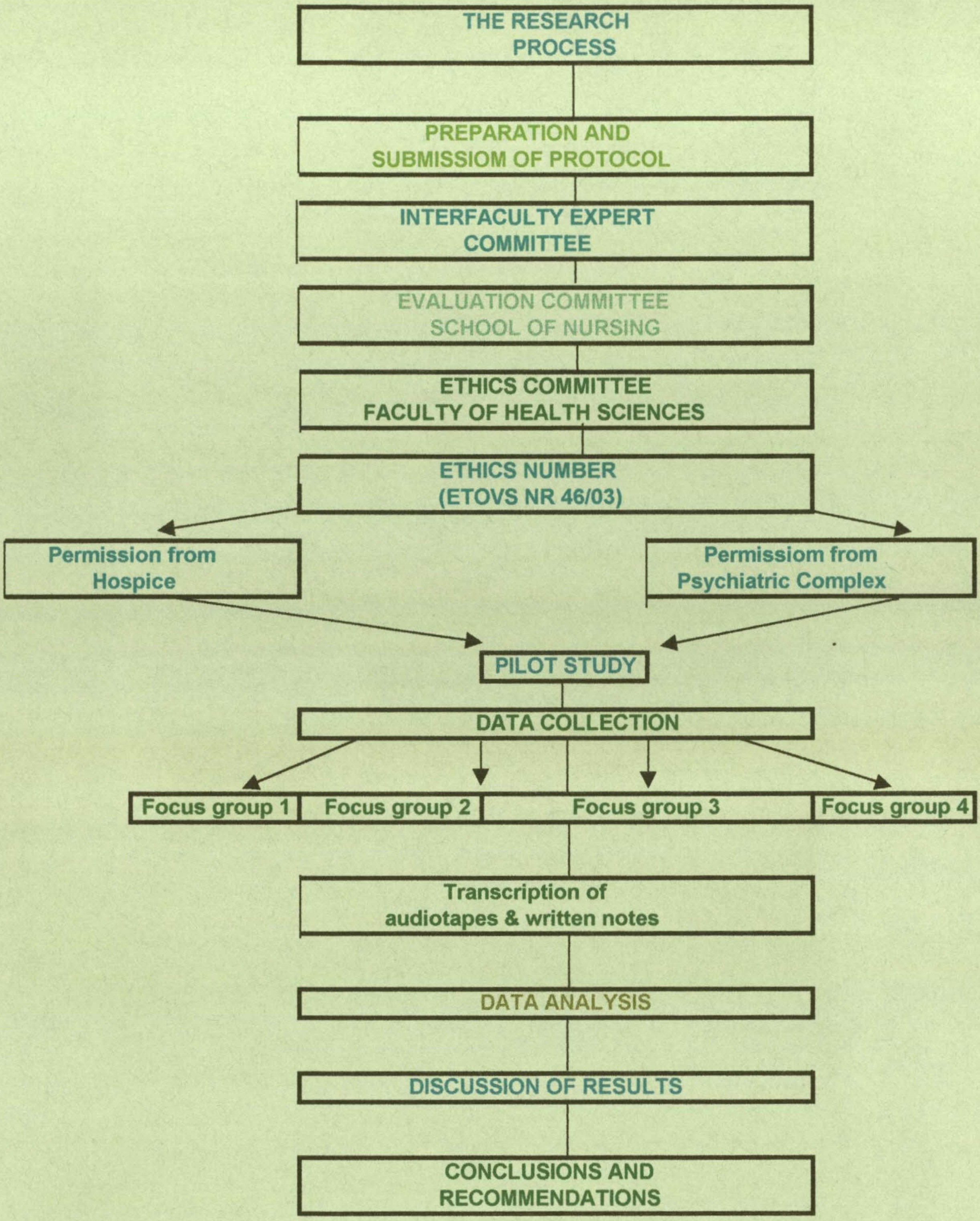

Diagram: 2.1: Data collection process

2.2.1 Qualitative design

A qualitative design refers to a process of understanding based on methodological traditions of inquiry used to explore social or human problems. This design focuses on individual perceptions and how these are described. It recognises that the way people behave is determined by many factors, including what they think is expected of them (Crombie & Davies, 1996:157).

Therefore, qualitative research involves more than looking at qualitative data. The aim is to produce understanding on the basis of rich contextual and detailed information that could, for example, be achieved by active involvement of the investigator using subjective methods like observation and interviewing (Burns & Grove, 1997:71-72; Polit et al., 2001: 15).

It involves documenting of real events, recording what people have said, gestures made and tone of voice, observing specific behaviour, studying written documents or examining visual images. It investigates components that are unevenly distributed rather than existing ones. Phenomena are studied in their natural setting (Treece & Treece, 1986:372; Neuman, 1997:328).

The researcher tried to gain new insights into the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support through the facilitation of different focus groups until saturation was reached.

2.2.1.1 Strengths of qualitative research

- Qualitative research enables researchers to be concerned with meaning, multiple sources and concern with the nature of something rather by investigating components that are unevenly distributed (Treece & Treece, 1986:327). The researcher was concerned about the perceptions of voluntary AIDS caregivers concerning hospice managers and tried to determine the nature of support through several focus group interviews.

- "It is interpretive, humanistic, or naturalistic and is concerned with understanding the meaning of social interaction by those involved" (Burns & Grove (1997: 28). Throughout the focus groups there was a social interaction between the researcher and the voluntary AIDS caregivers.

- Qualitative research evolves from the behavioural and social sciences as a method of understanding the unique, dynamic, holistic nature of the participants (Burns & Grove, 1997:28).

- It enables the researcher to make an investigation of phenomena, typical in an in-depth and holistic fashion through the collection of rich narrative materials using a flexible research design (Polit et al., 2001: 469). The facilitator used communication skills such as probing and paraphrasing in order to obtain a rich data.

2.2.1.2 Weaknesses of qualitative research

Phenomenology has its critics as noted by Leiniger (1985:106).

She noted the following limitations:

- A phenomenological approach is too subjective;
- It is difficult to replicate a descriptive study of experience;
- The language of phenomenological research is too vague;
- Researcher bias interferes with clean results;
- It may be difficult for someone learning about it for the first time to grasp (Neuman, 1997:330).

The researcher considered all the above-mentioned limitations and designed the study in such a way that the impact thereof was limited in the methodology.

Using the phenomenological approach to qualitative research, which are a philosophy and a research method, the researcher tried to gain insight into the perceptions of voluntary caregivers of AIDS patients concerning hospice managers' provision of support and made attempts to place it into a larger whole (*cf* Neuman, 1997:331). The researcher helped the participants to described "lived experiences" (*cf* Burns & Grove, 1997:71) without leading the discussion.

2.2.2 Phenomenological research

The researcher chose the phenomenological method because it investigates subjective phenomena in the belief that the essential truth about reality is grounded in peoples "lived experiences". The phenomenologist believes that these experiences give meaning to each person's perception of a particular phenomenon. (Polit et al., 200:17; Polit & Hungler, 1999:246).

In a phenomenological study, the main data source is in-depth conversation, with the researcher and informant as full co-participants (Polit et al.; 2001:215). The three aspects of lived experience that are of interest to phenomenology are:

- Lived space or spatiality

  Live space or spatiality means to conduct the study in a natural setting (Creswell, 1998:15).

- Lived body or corporeality

  Lived body or corporeality to investigate subjective phenomena in the belief that essential truths about reality are grounded in people's lived experiences (Polit & Hungler, 1999: 247).

- Lived time or temporality

  Lived time or temporality occurs when the researcher spends time with the participant during the interview process in order to collect the data (Neuman, 1997: 374).

The researcher tried to consider the above-mentioned aspects and through in-depth conversations strived to gain entrance into the participants' world and to have full access to their experiences as lived (*cf* Polit et al., 2001:215). The phenomenological approach assisted the researcher in building a complex holistic picture, analysing words, reports and a detailed view of information. The researcher believes that human existence is meaningful and interesting *(cf* Polit et al., 2001:215).

2.2.2.1 Strengths of the phenomenological method

- Reid and Smith [1981] in De Vos, Strydom, Fouche, Poggenpoel & Shrunk (1998:71) note that the phenomenological method enables the researcher to gain a first hand holistic understanding of the phenomenon of interest. It rests on the assumption that valid understanding can be gained through accumulated knowledge acquired first hand by a single researcher.

- In qualitative research the nursing knowledge base would be slim indeed, without the rich array of approaches and methods available within two paradigms methods that are often complementary in their strengths and limitations (Polit et al., 2001:16).

2.2.2.2 Limitations of the phenomenological method

The phenomenological method has few limitations as noted by Burns and Grove (1997:29-32); Polit et al., (2001:15) and Leininger (1985:106). In phenomenology the researcher considers the fact that:

- the data include the shared interpretation of the researcher and the participants;
- no attempts are made to control the interaction;
- the data are subjective and incorporate perceptions and beliefs of the participants;
- the language of phenomenological research is vague;
- researcher bias interferes with clean results;
- no procedural guidelines for conducting phenomenological research are available;
- human beings are the direct instruments through whom qualitative data is gathered, but although humans are intelligent and sensitive they are fallible tools;
- the highly personal approach that enriches analytic insights of a skilful researcher can sometimes result in petty and trivial findings amongst less competent ones;
- the subjective nature of the investigation can raise questions about the idiosyncratic nature of the conclusion;
- naturalistic studies mostly involve relatively small groups of participants, thus the generalisability of the findings from naturalistic inquiry can be challenged.

During the process of data gathering, analysis and description of findings the researcher considered the limitation of the phenomenological approach and no generalisations were made.

Due to the fact that no studies have been published in this regard the design of this study is descriptive and exploratory design with a contextual approach.

2.2.3 Descriptive design

Fawett and Downs (1992:7) supported by Polit, Beck and Hungler (2001:180) view the descriptive design as an empirically driven design that describes or classifies specific dimensions or characteristics of individuals and/or groups, situations or events by summarizing commonalities found in discrete observations, and/or the frequency with which certain phenomena occur.

This design plays an especially important role in qualitative studies because it serves to make research findings meaningful and interpretable. It further helps to stimulate research and the extension of knowledge by providing both direction and impetus (Polit et al., 2001:145).

In this study the researcher sought to obtain uninterrupted descriptions of the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support. The analysis of these perceptions helped to formulate baseline data that might assist in understanding the phenomenon. The voluntary AIDS caregivers described their perceptions during the focus groups interviews.

2.2.4 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 explorative design rarely yields definitive answers. It addresses the "what" questions and everything about the topic is potentially important (Neuman, 1997:253).

Focus group interviews are useful in exploratory research because they generate new ideas for items and the interpretation of results and are uniquely suited to quickly identifying qualitative similarities and differences. Focus group interviews are useful when rather little is known about phenomena of interest. 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; Neuman, 1997: 19, 253).

The researcher conducted several focus groups, asked indirect or open-ended questions during interviews and took advantage of serendipity because she expected to explore the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support. This assisted in making suggestions regarding therapeutic interventions and the type of support that should be rendered by hospice managers (*cf* Neuman, 1997:19).

2.2.5 Contextual approach

The contextual approach refers to research conducted in the participants' natural setting (Krueger & Casey, 2000:11). The participants in this study provided care in a disadvantaged socio-economic community and the geographic area selected was a part of the Free State, South Africa.

Although this approach involves going to the participants' workplace to conduct the interviews the researcher decided to select a venue away from the working environment that was convenient for both the researcher and participants. The fact that observations and the recording of perceptions were made in an unfamiliar setting did not influence the data provided by participants (*cf* Creswell, 1998:140). The researcher was confident that the voluntary AIDS caregivers were free to explore their feelings without any fear of discrimination by their managers.

2.2.5.1 Strengths of a contextual approach

The contextual approach commits the researcher to learn to define the world from the perspective of those studied. The researcher made use of methodological techniques that included observation, interviewing and document analysis.

Focus group interviews with voluntary AIDS caregivers were helpful in understanding their perceptions of the support rendered by hospice managers and also in identifying potential policies, or solutions and strategies. The findings were also helpful in developing quality improvement efforts (*cf* Krueger & Casey, 2000:17).

The researcher also learned while collecting and analysing data, how events vary under different conditions rather than trying to control them (*cf* Wilson, 1989:421).

2.3 UNIT OF ANALYSIS

Unit analysis is a basic unit that yields data for analysis (Polit & Hungler, 1999:216). In the following section the population and sampling methods are highlighted.

2.3.1 Population

Wilson (1989:20) defines population as the group to be studied, and to whom the findings should finally apply. This definition links to that of Brink (1996:133) and Polit and Hungler (1999: 278) who describe the population as the entire aggregation of persons or an object that is of interest to the researcher, or in other words that meets the designated set of criteria the researcher is interested in studying.

The target population of the study consisted of all voluntary AIDS caregivers in the Free State hospices particularly in the Motheo District, Bloemfontein. According to statistics obtained by the researcher this population included seventy-two (72) voluntary AIDS caregivers at the two hospices in the Free State. The voluntary AIDS caregivers' duty register was used with the permission of the organisation's supervisor as a sampling frame. Participants were selected as reflected in Chapter 1 (see Inclusion criteria 1.6.2).

2.3.2 Sampling methods and samples

2.3.2.1 Sampling methods

Probability (random) or non-probability sampling methods are available. In the first type of sampling not every element of the population has a opportunity for being included in the study. Simple random, stratified random, cluster and systematic sampling are examples in this category. In case of non-probability sampling convenience, quota, random assignment to groups, purposive and network sampling are available (Burns & Grove, 1997:298-307).

2.3.2.2 Samples

This is described as a part or fraction of the whole or a subset of a larger set selected by researchers to participate in a research project (Brink, 1996: 133; Treece & Treece, 1986:215).

In qualitative research the sampling method does not rely on the number of the participants but primarily on quality of information obtained from the sample (Neuman, 1997:206).

2.3.2.2.1 Purposive sampling

Purposive sampling is described by Polit and Hungler (1999:712) as a type of non-probability sampling method in which the researcher selects participants for the study on the bases of personal judgement about which one will be the most representative or productive; or to identify particular types of cases for in-depth investigation (Neuman, 1997:206).

According to the researcher this type of sampling best suited the purpose of the study and thirty two (32) voluntary caregivers of AIDS patients delivering a service at the hospices were initially selected based on the criteria mentioned below. The voluntary caregivers' duty register was used as a sampling frame with the permission of the organisation's supervisor and sister in charge.

2.3.2.2.2. Inclusion criteria for the sample

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 population in this study was voluntary AIDS caregivers volunteering at two hospices in the Bloemfontein area, particularly of the Motheo District, Free State Province. The voluntary caregivers who were included were those who were:

- Providing care to AIDS patients.
- Living in an urban area, that is, around Bloemfontein.

Based on findings during the pilot study the researcher included this selection criterion to ensure that groups were homogenous.

- Within the age range of 20 to 60 years.

- Inclusion of age group 20 to 60 was based on the ages of the volunteer care caregivers volunteering at the hospices in the Free State
- Working for specific hospices.
- Willing to participate and sign the written consent in which the recording of the interview was stated.
- Able to communicate in English, Afrikaans and Southern SeSotho. English, Afrikaans and SeSotho were chosen because the researcher is proficient in them and they are used frequently by voluntary AIDS caregivers of the Free State hospices.

2.3.2.2.3 Exclusion criteria

The researcher excluded voluntary AIDS caregivers who were:

- unable to read or write as the consent form was to be signed by each participant.
- never called to volunteer at hospice although their names were reflected in the register.

In the selection process the researcher kept in mind that the intent of a focus group is not to infer but to understand, not to generalize but to determine the range and not to make statements about the population but to provide insights about how people in the group perceive a situation (*cf* Krueger & Casey, 2000:83).

2.3.2.3 Sample size

The sample size in research is the key point when conducting a study and the researcher consulted several authors in this regard.

According to Treece and Treece (1985: 228) the sample size is determined by the size of the population; Sandelowski [1985] in Morse, 1991:192) recommends that six participants per group are sufficient in phenomenology directed towards discerning the essence of perceptions; and Kress (1982:213) indicates that the actual number of participants that must be contacted originally, is determined by the expected rate of response.

However, the sample size adequacy in qualitative research is more difficult to judge on the basis of reading a research report because the main criterion is redundancy of information, which is difficult for consumers to judge (Polit et al., 2001:248).

This strategy includes the fullest possible understanding of the phenomenon of interest (*cf* Polit et al., 2001:250).

Out of a population of seventy-two (72) a selection of thirty-two (32) voluntary caregivers of AIDS patients delivering a service at the hospice was initially made. This was done to identify and to make use of participants who could best supply information relating to the conceptual requirements of the study.

2.3.2.4 Sampling technique

The following steps were followed to select suitable participants:

The researcher first obtained a duty register containing a list of seventy-two (72) names of voluntary AIDS caregivers from the hospice. Thereafter she arranged to attend one of the regular meetings at the hospice. At this meeting the voluntary caregivers were given the opportunity to report back to the managers on job-related issues they had identified.

At the end of the meeting the managers were excused and the researcher as given an opportunity to introduce herself, to explain the intended study, and to invite willing voluntary AIDS caregivers to provide their names and telephone numbers.

At a later date the researcher met some of the potential participants at their day care centre and used the inclusion and exclusion criteria to perform a purposive or non-judgemental sample (*cf* Gamson, 1992:120). This means that not all potential participants who were willing to participate were included in the study.

The researcher also contacted some participants who were not available at the day care centre telephonically as their names and addresses appeared reflecting in the register in order to explain the purpose of the study. The contact was direct, personalized and occurred two weeks before the focus group session.

According to the researcher the voluntary caregivers were eager to participate in the focus group interviews, as they believed that the study was important to them.

2.3.2.4.1 Homogeneity of focus groups

The nature of the homogeneity is determined by the purpose of the study. To adhere to this principle, the researcher considered the description of Krueger and Casey (2000:71) and selected only voluntary AIDS caregivers who had something in common with what the researcher was interested in.

The advantage of homogeneous sampling is that "it opens up the possibility of conducting group interviewing with groups of similar individuals" (Patton, 1990:7).

At the end of the selection process the researcher was satisfied that the participants were more or less similar to each other in a way that was important to the researcher.

2.4 RESEARCH TECHNIQUE

2.4.1 Data collection

According to Brink (1996: 148) and Burns and Grove (1997:529) data collection denotes gathering of information needed to address the research problem, and is a systemic process that entails perceiving, interacting, reflecting, attaching meaning and recording data.

Focus group interviews provide data that are closer to emic (the data that arise in a natural or indigenous form) rather than etic (represents researcher's imposed view of the situation). Because they allowed the participants to respond in their own words using their own categorizations and perceived association (Bickman & Rog 1998:509).

Data were collected initially using three (3) focus group interviews consisting of ten (10) participants each. The researcher allocated ten participants to each group because a focus group with more than ten participants is difficult to control and tends to limit each participant's opportunity to share insights and observations (*cf* Krueger & Casey, 2000:72) (see Figure: 2.2: Seating of participants)

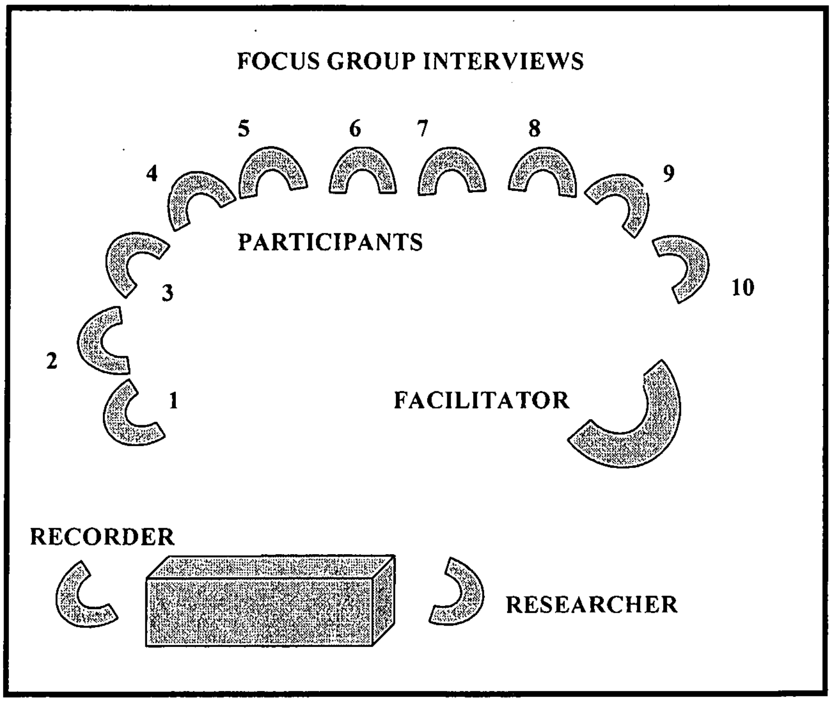

Figure 2.2: Seating of participants for data collection

The group discussion was guided and directed so as to remain focused on the topic of interest. The facilitator who has extensive experience in qualitative research played an important role in maintaining the interviews. The voluntary AIDS caregivers were asked to describe verbally their perceptions concerning hospice managers' provision of support. Different strategies were used to ensure that no data was lost:

- ☐ Audiotaped data

Each group interviewed was audiotaped. Two audiotapes were used simultaneously to record the data so as to avoid the loss of data.

Both audiotapes were tested prior to the commencement of interviews in order to identify technical problems that could lead to the loss of data

The cassettes that were used were of high quality.

- ☐ Field notes

Observational, methodological theoretical and personal field notes were taken. Polit and Hungler, (1999:369) describe observational notes as objective descriptions of, for instance, events and conversations while theoretical notes are interpretive in nature. Methodological notes are used by researcher to remind them how subsequent observations will be made.

Each participant's opinion was recorded, observation of behaviour and various forms of non-verbal communication were noted down and formed part of the data gathering process.

The verbal data was collected in a relaxed atmosphere with sufficient time to facilitate a complete description.

2.4.1.1 Phenomenological interview

Polit and Hungler (1999:705) define an interview as a method of data collection in which a facilitator asks questions of participants. In the phenomenological interviews conducted in this study the "live experiences" were investigated with the purpose of understanding the meaning of support of voluntary AIDS caregivers who function as whole beings within their background traditions (*cf* Wilson, 1989:728).

The nature of the research question is important in the phenomenological quest for knowledge. Nevertheless the question phenomenologists do not ask for an inward glance that is "precise introspection" rather they focus on understanding the meaning of life through interpretation of human experience (Morse, 1991:56; Oppenheim, 2000:46).

After the pilot study the researcher conducted phenomenological interviews with initially three (3) focus groups that consisted of ten (10) members each. However, the researcher wanted to make sure that theoretical saturation was reached after the third focus group interview. An additional fourth group was therefore selected but no new issues emerged (*cf* Flick, 1999:66).

To obtain the necessary information the proposed questions were:

"How do you experience the support provided by hospice managers in your caring for AIDS patients?"

"Hoe ervaar u die ondersteuning wat deur hospies bestuurders verskaf word in u versorging van AIDS pasiënte?"

"What suggestions do you have regarding support that should be provided?"

"Watter voorstelle het u met betrekking tot die ondersteuning wat verleen moet word?"

These questions were open-ended, evolving, non-directional and formulated to restate the purpose of the study more specifically.

The researcher made use of phenomenological reduction by means of "bracketing" which is described as a process of identifying and setting aside any preconceived 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 (*cf* Brink, 1996:120).

The facilitator who facilitated the interviews used communication skills such as probing, paraphrasing, reflecting and validating.

2.4.1.2 Focus Group Interview

A focus group interview is an interview with a group of participants assembled to answer and discuss a question (Polit et al., 2001:265). 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).

Focus group interviews are an important part of any action research project as they provide the opportunity for the researcher to investigate further, to solve problems and to gather data that could not have been obtained in other ways (Cunningham, 1993:93, Krueger, 1988:20).

Merton, Fiske and Kendall (1990:135) suggest that the focused interview with a group of people...will yield a more diversified array of responses and afford a more extended basis both for designing systematic research on the situation in hand.

In this study voluntary AIDS caregivers at two hospices participated. Preceding the focus group interviews the researcher made several arrangements:

- The focus group facilitator

To facilitate the focus group interviews an expert in the field of interviewing was identified and approached. The facilitator is a registered nurse who specializes in psychiatric nursing is a senior lecturer at a school of nursing, is employed at a university and has a PhD degree.

All arrangements were discussed with the facilitator and dates for the interviews were confirmed.

- The field notes

The task of taking field notes was the responsibility of both the researcher and the supervisor.

- The venue

As previously indicated the focus groups were not conducted in the natural setting. The researcher chose a setting in which participants were strangers and had no particular professional knowledge or expertise (*cf* Bogdan & Taylor, 1975:28).

- The participants

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. This "dentist-style" phone call served two purposes: It reinforced the importance of the group and reminded participants who had forgotten about the session (*cf* Krueger & Casey, 2000:89).

- Refreshments

Beverages were provided prior to the commencement of focus group interviews. Socialising tended to promote conversation and communication within the group.

Three subjects participated in the pilot study conducted prior to the main study (see Pilot study 2.4.1.3).

The pilot study was initially followed by three (3) focus group interviews. However a fourth (4) focus group was included to ensure saturation (see Description of focus groups) The groups consisted of participants with more or less the same characteristics as the participants in the main study.

Each group included ten participants making a total of thirty (30) participants. The group size was deliberately kept small so that its members did not feel intimidated but could express opinions freely (Crombie & Davies, 1996:158).

The focus group interviews were recorded by audiotapes and with written notes. Written notes were essential and did not interfere with the spontaneous nature of the group interview as the facilitator was conducting the interview while the researcher was jotting down notes and observing. A third person was responsible for monitoring the tape recorders and to add to the field notes.

The researcher served several functions during the focus group interviews and acted as a listener, an observer and eventually as an analyst using the inductive reasoning process. The focus groups presented a more natural environment. (Krueger & Casey, 2000:11).

During focus group interviews the researcher assumed a non-argumentative, supportive and sympathetically understanding attitude with participants (*cf* Mishler, 1986:30).

The facilitator tried to stimulate discussion and kept participants from straying off the topic. In this way the focus groups produced a very rich body of data expressed in the participants' own words and context (Bickman & Rog, 1998:507).

Researcher also kept in mind that the intent of the focus group was not to infer but to understand, not to generalize but to determine the range, and not to make a statement about the population but to provide insights into how 'voluntary AIDS caregivers in groups perceive provision of support by hospice managers.'

The facilitator made use an effort to experience the phenomenon under discussion in the same way as the participants. This was done through participation, observation and introspective reflection (*cf* Polit et al., 2001:215).

The success of each interview depended on the facilitator's use of several communication skills namely:

- Probing

Probing is a communication technique used to go deeper into interview responses (Maykut & Morehouse, 1994:95).

During interviews, the facilitator was able to probe further and learned that the participants had some stories to tell about the provision of support concerning hospice managers (*cf* Woods & Cantanzaro, 1988:30).

Probing questions such as: "Can I just ask you to elaborate a little bit on the insurance and you talk about financial support, emotional and what do you mean by physical support?" were asked. Typically, probing involve comments such as: "You want to say something else?"

During the interviews probing was used as an effective technique to elicit additional information. However, the participants were not unnecessarily interrupted and the facilitator listened while they provided more information.

Krueger and Casey (2000:110) state that in most conversations and group discussions there is a tendency for people to make vague comments that could have multiple meanings and therefore probing is an effective technique to elicit additional information.

- ☐ Reflecting

The facilitator gave feedback, in her own words, about the participants' feelings conveyed to her by responses such as: "So the affect of that is really emotional?"

In some cases the participants did not explicitly state how they felt and the facilitator had to "read between the lines" and observe the participants non-verbal messages (*cf* Uys & Middleton, 1997:191).

The facilitator was thus careful to listen to meanings as well as "what was said between the lines" and sought to formulate the implicit message and send it back to the participants, in the format of a statement: "So it seems as if you don't have a lot of certainty, you are saying that there is some sort of uncertainty of what is going to happen to you as volunteers."

☐ Validating

The facilitator validated by means of reflection of feelings during interviews (*cf* Uys & Middleton 1997:181).

This happened when the facilitator ensured that she knew what the participants were talking about. The participants' often talked about incidents and people the facilitator did not know and thought that their message was clear. The facilitator validated that she and the participants understood each other

☐ Paraphrasing

The facilitator restated the participant's basic message in similar but usually fewer words. The facilitator translated for the participants the raw data that they expressed into more precise words without adding new ideas to the message.

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

- Focus group 1

The first focus group was not homogeneous, as their perceptions of support by hospice managers was not obtained. The group was concerned about general issues that were not part of the study. They further explained that they were getting very good support from hospice managers while other members were very uncomfortable.

Theoretical saturation was not reached because a very dominant or opinionated participant biased this focus group and some group members were hesitant to talk, therefore there was no homogeneity (*cf* Bickman & Rog, 1998:509).

The above matter was discussed with the facilitator and the supervisor and it was decided that a second focus group consisting of selected participants should be included. Although the information provided by the first focus group was analysed the information was not suitable for inclusion in the study.

- Focus group 2

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 no redundancy of information and it was decided that two more focus groups should be organised.

- Focus group 3

Arrangements were made with the ten (10) participants left out of the initial selection of thirty-two (32) to form group 3.The two that (2) that were left were included in group 4.

- Focus group 4

To construct the fourth group the number of participants had to be increased. Following the inclusion guidelines eight (8+2=10) more participants were selected from those who indicated that they were willing to participate. The total number of participants was now forty (40) in an attempt to reach saturation.

Information with regard to the date, the time and the venue were provided and participation was confirmed. The contact numbers of the researcher were also provided but no participants withdrew from the study.

Focus groups 3 and 4 possessed the same characteristics as the previous groups. Both groups had ten members and were homogeneous with regard to inclusion criteria. Redundancy of information was reached with the fourth focus group.

In qualitative research, sample size should be determined on the basis of informational needs. Hence a guiding principle in sampling is data saturation (that is sampling to the point at which no new information is obtained and redundancy is achieved), (Polit et al., 2001:248).

Voluntary AIDS caregivers continued to be interviewed until theoretical saturation had occurred and no new information was obtained (Ledlie, 1999:142).

When the researcher has truly obtained saturation with a sample, informational adequacy is said to have been achieved, and the resulting description or theory is considered richly textured and complete (Lincoln & Guba, 1985: 120).

2.4.1.3 Pilot study

Treece and Treece (1986:382) define a pilot study as a small preliminary investigation of the same general character as the major study. The purpose of the pilot study is to:

- assess whether the research question was 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.

Before the research questions were piloted, two expert committees suggested that the word "perceptions" in the title should be changed to "experience" without the title of the study being changed.

The researcher conducted a pilot study using three (3) participants and the facilitator conducted interviews. The purpose was to test the research question prior to the main study and to identify the action of interviewing variables so that they can be eliminated. The members of the pilot study possessed the same characteristics as participants included in the main sample and were selected from the same group.

The facilitator made use of vignettes prior to conducting the interviews. Polit et al., (2001:274) define vignettes as brief descriptions of events or situations to which participants are asked to react. An example of such vignettes was to examine perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support.

The principal problem with vignettes concerns the validity of responses (Polit et al., 2001:225).

To promote good communication between the facilitator and the participants it was useful to question the participants in the pilot study concerning their reactions to and overall impression of the project.

The three participants were co-operative, welcoming and paid full attention as they responded well to the phenomenon in question. During pilot study interview the facilitator posed an open-ended question that allowed participants to respond in their own words. The question was:

> ***"How do you experience the support provided by hospice managers' in your caring for AIDS patients?"***
> *Hoe ervaar u die ondersteuning wat deur hospies bestuurders in u versorging van AIDS pasiente verteen word?"*

The main purpose of the pilot study interview was to assess whether the research question was clear, unambiguous and would facilitate the type of information needed to meet the research purpose. After the facilitator posed the central question, she realised that the question did not elicit free discussion and was therefore not a good example of an open-ended question.

The facilitator did not give the group total control of the discussion but posed a question on a topic that was of concern of management (Zikmund, 2000:111). To improve this study the facilitator and the researcher that the question should be formulated as in the "grand tour"of Spradley, (1980:49) and Morrow and Smith, (1995:42) which asked questions such as "Tell me about yourself" In this case the question was rephrased as:

- ***"Tell me about the support you receive from your managers in your caring for AIDS patients?"***
- *"Vertel my van die ondersteuning wat jy van jou bestuurders ontvang het in jou versorging van AIDS pasiënte."*

The recorder made use of tape-recorders to record the interview with the participants and to use the data for later transcription. The three participants of the pilot study discussed the hospice managers' provision of support until themes seemed to repeat themselves.

In the third interview the researcher was more aware that the open-ended questions allowed for richer and fuller information as the participants were verbally expressive and co-operative *(cf* Polit et al., 2001:267).

The researcher made use of careful listening skills to transcribe the audio taped conversation. Colaizzi's [1978] in Polit et al., (2001:399) method was used to analyse verbatim transcripts. The researcher noted the observable responses of participants such as verbal and non-verbal responses used during the interview, for example.the gestures participant number two and three used to support what they were saying.

After reading the transcripts, significant statements were extracted, the meaning of each statement was clarified, formulated and statements were categorised into the theme clusters. The findings were then integrated into an exhaustive description of the phenomenon of perception of support rendered to voluntary AIDS caregivers that participated in the pilot study.

2.4.1.4 The setting

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."*

In this study the natural setting was a disadvantaged socio-economic community. The target population consisted of all voluntary AIDS caregivers in two Free State hospices particularly in Motheo District, Bloemfontein.

The selection of the field setting was an important decision the researcher had to make. Three factors that were considered relevant were the unfamiliarity, richness of data and sustainability. The researcher chose a setting in which the participants were strangers and they had no particular professional knowledge or expertise (*cf* Bogdan & Taylor, 1975:28).

Therefore, the data was not collected at the hospices, the caregivers natural setting, as this setting presented barriers to communication which included small rooms where discussion would be inhibited, and the presence of the managers under discussion. A venue at a nearby psychiatric complex was available, easy to find, safe, and with adequate transport available or within walking distance. This place was also free from visual or audible distractions. Permission to use the venue was obtained from the Senior Executive Officer. All the participants were well orientated about the place since they came from the Motheo District.

An in-depth qualitative study was undertaken in that setting as the researcher was interested in studying the context of participants' perceptions of support rendered by hospice managers *(cf* Polit & Hungler 1999:159). A skilled qualitative researcher conducted the focus group interviews.

2.4.1.5 Safeguarding of data

All the data collected was safeguarded and the protection of participants was taken into account by ensuring that no information was publicity divulged (Polit & Hungler, 1999:698).

Principles about safeguarding and handling data, (Creswell (1998:157), that were especially well suited to qualitative research included the following:

- The researcher made use of the computer programs available such as N VIVO, which provided ways for manipulating or drawing contrasts and comparisons among the codes by grouping the similarities to reduce topic.

- High quality tapes were used for audio-recording data during interviews.

- The researcher developed a master list of types of information gathered from the four focus groups.

Other precautionary measures to safeguard the data included the following:

All audiotapes were labelled as “focus group 1, 2, 3 and 4”. Each group’s audiotapes and field notes were packed separately and all the data that was collected was placed in a container for safekeeping. The researcher and the co-coder were the only people who had access to the information.

The issue of safeguarding data is closely related to the form of data collection, and the basic objective of the researcher was to develop some filling and storing system for organised retrieval of information. The computer program provided an organised storage “file” system that assisted the researcher in locating material and easily keeping it safe in one place.

No data collected was linked with any participant as an individual. However responses were indicated as participant (1) or (2).

2.5 DATA ANALYSIS

To make sense of the process of data analysis the researcher considered the definitions of several authors:

Morse and Field (1995:126) explained that qualitative analysis is a "Process of fitting data together, of making the invisible obvious, of linking and attributing consequences to antecedents. It is a process of conjecture and verification of correction and modification of suggestion and defense."

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.

Polit et al., (2001:460) also complemented the above and describe data analysis as the systematic organisation and synthesis of research data, and the testing of research hypotheses using those data.

2.5.1 The process of data analysis

The actual data analysis process is an intensive and time-consuming activity that involves clustering together related types of narrative information into a coherent scheme and is typically an active process (Polit et al., 2001:382).

The purpose of data analysis, regardless of the type of data, is to organise, provide structure and elicit meaning (Polit et al., 2001:381).

The researcher commenced data analysis by going back to the intent of the study. Indeed throughout the analysis process the researcher considered and referred back to the purpose of the study. In order to guide the analysis process the researcher analysed the data independently of the co-coder.

In operationalizing the field research, the focus group interviews involved mutual sharing of experiences. The facilitator shared her background to build trust prior to the commencement of the interviews and encouraged the participants to open up, but did not force answers or use leading questions. The voluntary AIDS caregivers expressed themselves in the forms in which they normally speak, think and organise reality (cf Neuman, 1997:372).

The initial focus group interviews were conducted using open-ended questions and lasted more or less 60-90 minutes per group. Interviews were audiotaped, transcribed verbatim, and checked for accuracy by the researcher before data was entered into a computerised qualitative data management system called N VIVO.

The researcher made use of a procedure advocated by Tesch [1990] in Creswell (1994:155) in the N VIVO programme for data analysis.

Several variations are available for the analysis of phenomenological data. To perform a qualitative analysis Morse and Field [1995] in Polit et al., (2001:383) identified four intellectual processes:

- **Comprehending** is an analytic process whereby the researcher strives to make sense of data and learn what is going on.

- **Synthesising** involves a 'sifting' of data and putting pieces together.

- **Theorising** is a sorting of data. The theorising process continues to evolve until the best explanation is obtained.

- **Recontextualising.** The process involves the further development of the theory such that its applicability to other settings or groups may be explored in order to continue well after the fieldwork has been completed.

However, Bogdan and Biklen (1992) Miles and Huberman (1994) and Wolcott [1994] in Creswell (1998:140) recommend a general review of all information often in the form of jotting down notes in the margins of text such as observational field notes and interview transcriptions.

The researcher decided to make use of the method of Van Kaam [1966] Giorgi [1970] and Colaizzi [1978] for data analysis (in Burns & Grove, 1997:543). This method entails the following strategies:

- Listening to the audiotapes of focus group interviews.

- Transcribing the information on the transcripts.

- Reading all the participants' descriptions from the transcripts.

- Preliminary grouping of descriptive expressions to be agreed upon by supervisor and the co-coder.

The researcher reduced the perceptions of support to few concepts by grouping according to their similarities. Each significant statement concerning perception of support was spelt out, such as: "The support is there, but not satisfactory." Or "The support is poor."

The researcher also dealt with her own bias by "bracketing out" the preconceived ideas about the perception of voluntary AIDS caregivers so as to obtain clear meaning of phenomena. However, experimental analysis suggests that the researchers' own experience is an important source of phenomenological data and guide analysis (Morse, 1991:174).

In the study the data were in the form of words that were relatively imprecise diffused and context-based with possibly more than one meaning (*cf*Neuman, 1997:420) and therefore the researcher read narrative data over and over in search of meaning and deeper understanding (*cf* Polit et al., 2001:382).

The reason for reading transcripts time and again, word by word was to get a sense of the whole. The researcher listed and grouped similar descriptive expressions, looked closely at the words used by participants and translated ideas into metaphors.

In conclusion it may be stated that the process of data analysis in qualitative research is less abstract than that of quantitative research.

2.5.1.1 Data management

The computer program N VIVO made provision for data reduction by manipulating and drawing contrasts and comparisons among the codes of similar topics. N VIVO opens the doors for analysis possibilities that are not possible with other strategies. It allows researchers to "nest" codes. This means that researchers might have a shorter quote with a longer quote and each one could be coded differently (Krueger & Casey, 2000:137).

The N VIVO program designed for qualitative research was specifically used to ensure that the complex data was correctly and systematically analysed (Russell & Gregory, 2003:8).

Utilising N VIVO opened doors for analysis possibilities that are not comparable with other strategies. The advantage of these specially developed computer programs is that they help to manage large sets of data (Krueger & Casey, 2000:137).

The researcher found a large body of relevant issues from the transcriptions of the focus group interviews because of the type of questions and communication skills used by the facilitator. The topics that were related were grouped together in categories and subcategories (Creswell, 1994:155). The categories and subcategories were further developed into a framework to display their interconnectedness.

2.5.1.2 Data reduction

Woods and Catanzaro (1988:439) describe data reduction as a process of selecting, focusing, simplifying, abstracting and transforming raw data to simplify problems of analysis, storage and dissemination. The researcher and the co-coder made use of Polit and Hungler's (1999:576) reductionist activity of converting data to smaller, manageable and manipulated units that can be easily retrieved and reviewed.

Procedure for developing categorisation schemes and coding the data according to the categories was used. The researcher read the data carefully in order to identify underlying and clusters of concepts. Related concepts were often grouped together to facilitate the coding process.

2.5.1.3 Codes and coding

Dey (1993:57) describes the core of qualitative analysis as a twofold task, namely to select a bit of data and assign it to a category. Codes are legal statute 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 (Dey, 1993:58). The codes and categories were sorted, compared and contrasted until analysis no new codes or categories.

2.6 MEASURES TO ENSURE TRUSTWORTHINESS OF THE RESULTS

Woods and Catanzaro (1988:473) describe trustworthiness as the extent to which one can believe in the research findings. Polit et al., (2001:312) assert that qualitative research is trustworthy when it is assessed by using the criteria of:

♦ Credibility

Credibility refers to confidence in the truth of data. Lincolin and Guba (1985:281) note that the credibility of an inquiry involves two aspects that is carrying out the investigation and in a way that believability is enhanced.

♦ Transferability

In Lincolin and Guba's (1985:280) framework, transferability refers to the extent to which the findings from the data can be transferred to other settings or groups and is thus similar to the concept generalizablity.

♦ Dependability

The dependability of qualitative data refers to data stability over time and over conditions. The technique relating to dependability is the inquiry audit that involves a scrutiny of the data and the relevant supporting documents by an external reviewer (Polit et al., 2001:315).

♦ Confirmability

Confirmability refers to the objectivity or neutrality of the data, such that two or more independent people would agree about the data's relevance or meaning. In qualitative studies the issue of confirmability does not focus on the characteristics of the data (Polit et al., 2001:312).

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 Cantanzaro, (1988:473) that is widely used in qualitative study that is:

2.6.1 Truth-value

2.6.2 Applicability

2.6.3 Consistency

2.6.4 Neutrality

2.6.1. 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 (Lincolin & 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 to ensure sufficient time to build a trusting relationship.

- Persistent observation to provide depth to the findings.

- Reading them time and again.

- Analysing negative cases in the sense of analytic induction.

- Member checks in the sense of communication validation of data and interpretations with members.

The researcher increased credibility by making use of "member checks" in the sense of communicative validation of data and interpretation with participants (Flick, 1999:232).

Additional evidence was to address unresolved issues that appeared in the research. By phenomenological analysis, the researcher obtained an essential description of a lived experience and developing relationships in which she intensively interviewed relatively few people (*cf* Morse, 1991:74).

The researcher further ensured that she uncovered the truth of perception of voluntary AIDS caregivers' provision of support by hospice managers. This was promoted by prolonged engagement and persistent observation during interviews with each focus group.

2.6.2 Applicability (transferability)

Woods and Catanzaro (1988:474) describe applicability 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 provided sufficient descriptive data in the research report to assist consumers to evaluate the applicability and transferability of the data (*cf* Polit et al., 2001:316).

2.6.3 Consistency (dependability)

Consistency in qualitative data refers to data stability over time and over condition. There can be no trustworthiness in the absence of dependability. Consistency is similar to reliability. The researcher made use of "inquiry audit" as a criterion for trustworthiness, which involved the scrutiny of data *cf* Polit, & Hungler, 1999:430).

The researcher met this criterion by conducting interviews with focus groups until data saturation was reached or data redundancy was attained.

2.6.4 Neutrality (Confirmability)

Lincolin and Guba (1985:300) and Woods and Cantanzaro (1988:474) both refer to neutrality as "confirmability" that depends on the existence of auditability, which means that the systemic collection and systemic documentation of data allows qualitative researcher to draw conclusions about the data, the truth-value and applicability.

Woods and Catanzaro (1988:474) further describe confirmability as an attempt to parallel the positvist-empirists concepts of objectivity where objectivity refers to the extent to which two independent researchers would arrive at a similar judgement or conclusion (unbiased by personal values or beliefs), (Polit & Hungler, 1999:709).

In qualitative studies, the focus should not be on the characteristics of the researcher (is he or she objective and unbiased?) but rather on the characteristics of the data (are the data confirmable?), (Polit & Hungler, 1999:430).

2.7 ETHICAL CONSIDERATIONS

2.7.1 Competence of the researcher and facilitator

The researcher is a novice in qualitative research and was therefore assisted by a skilled qualitative researcher. During focus group interviews the researcher acted as an observer and documented the placement of participants, the interaction between them and their non-verbal behaviour. The researcher also jotted down field notes.

The focus group interviews were facilitated by a senior lecturer with extensive experience in interviewing and the utilisation of various communication techniques. Her expertise added to high quality of the study because of the rich data that she obtained from participants.

2.7.2 Permission to conduct the study

The research commenced after formal written permission was granted by the Ethics committee, Faculty of Health Sciences, University of the Free State (Ethics number 46/03), the Board of Governors of the hospices as well as the Senior Executive of the Free State Psychiatric Complex.

The researcher followed Bogdan 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 that had been granted. (see Annexure G). After building a relationship of trust with the participants the researcher also obtained their willing permission to participate in the study,

2.7.3 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 (Polit et al., 2001:413). The researcher informed the potential participants about the intended study at their workplace, including the following factors:

- 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 according to Burns and Grove (1997:197, 209).
- A copy of their signed consent was given to the participants to ensure that the conditions of the agreement were always available to them (*cf* Lincolin & Guba, 1985:225) (see Annexure C).

2.7.4 Assurance of confidentiality

Polit and Hungler (1999:139) assert 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:

- They would not be linked to the information provided during the data collection phase.
- Information provided would not be made accessible to parties other than those involved in the research.

2.7.5 Protection from harm and discomfort

Polit, Beck and Hungler (2001:75) caution researchers that the psychological consequences of participating in a study are generally subtle 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.

2.7.6 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* "(Stake, 1995:107).

The researcher obtained permission for entry to the setting from gatekeepers of the Free State Psychiatric Complex and hospice.

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).

A facilitator who was appropriate for the situation because of her training, background and sensitivity conducted the interviews. The 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.

Data was collected according to the descriptive analysis method as advocated by Tesch [1990] in Creswell, 1998:140).

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

In conclusion, in this form of research, the quality of the study is not dependent on the size of the sample. The intent is to achieve theoretical saturation, which is akin to redundancy. In focus group research, the rule of thumb has been to conduct three or four focus groups with a particular audience and then decide if additional groups should be added to the study (Krueger & Casey, 2000:206).

The researcher tried to apply most of the underlying principles throughout the research process.

CHAPTER 3

3.1 DISCUSSION OF RESULTS

3.1.1 Introduction

The research methodology was extensively discussed in Chapter 2. The focus in this chapter will be on the analysis and literature control of the results of focus group interviews conducted with participants. A key principle considered by the researcher was that the depth or intensity of the analysis was determined by the purpose of the study, as it was first to explore and to describe the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support.

The second purpose was to find out whether they had any suggestions on how support should be rendered. Focus group interview analysis in qualitative research differs from the analysis of numbers in quantitative research because it is done concurrently with data collection. Information obtained from each subsequent focus group is analysed and compared with the previous focus groups. (Krueger & Casey, 2000:130).

In operationalising the field research the researcher made use of the following methods:

3.1.2. Transcript based analysis

According to Krueger and Casey (2000:130) transcript based analysis uses unabridged transcripts of the focus group interviews as a basis for analysis. These are often supplemented with field notes taken by the researcher. A co-coder was responsible for recording the interviews.

Transcription not only facilitated further analysis, it established a permanent written record of the interviews that could be shared with other interested parties.

The literature on content analysis provided the foundation for computer-assisted approaches to the analysis of the focus group interview data (Bickman & Rog, 1998:514). According to Steward and Shamdasani (1990:201; Wolcott, 1994:85) a rather substantial body of literature exist on content analysis. These approaches to content analysis are increasingly being applied because they maintain much of the rigour of traditional content analysis while greatly reducing the time and cost required completing an analysis (Bickman & Rog, 1998:514).

3.1.3. Perceptions of support

The researcher and the co-coder, namely the facilitator, agreed on the **preliminary categories, subcategories and themes** that were identified in the transcriptions of the pilot study and the remaining three focus groups. The findings indicate the existence of two main categories, namely personal and vocational support. The main categories were further divided into six subcategories (see Table 3.1).

In the pilot study the first main category, personal support, was divided into four subcategories, which included, financial, emotional, physical and spiritual support. Data from the other three focus group interviews was grouped into two main categories, namely personal and vocational support, and only three sub categories namely financial, emotional, physical support because the subcategory spiritual support was not identified in these cases.

The second main category, vocational support, was divided into three subcategories, namely stock and equipment, education and training as well as communication. It is important to note that the categories were organised according to how the researcher perceived the priorities given them by participants.

3.1.4 Suggestions regarding support

A literature review was conducted by the researcher to verify the results regarding the second phenomenon being studied, namely, the suggestion of voluntary AIDS caregivers concerning support.

The analysis of focus group interview data required a great deal of judgement and care. The research question and the purpose of the data collected determined the nature of analysis. The amount of editing an analyst does on a transcribed interview is a matter of preference (Bickman & Rog, 1998: 514).

Table 3.1: Preliminary categories, subcategories and themes: Pilot study (to be continued)

CATEGORY	SUBCATEGORY	THEMES
A. **PERSONAL SUPPORT**	Financial	*-Unsatisfactory support, food prices are up* *-Pay dates irregular* *-Money not enough, we need to be clean* *-We earn only R500.00 which is too little* *-No medical funds for us* *-Others earn more salary* *-Hospice got funds from overseas* *-Transport allowance disappeared* *-People who earn more must work hard* *-No explanation of delayed stipend*
	Spiritual	*-We pray prior to commencing duties* *-We need support to lift up our spirit*
	Emotional	*-We need moral regeneration* *-We are not considered as volunteers* *-We feel as if we are not part of hospice* *-They don't fulfill promises*
		-No problem- solving support *-Supervisors not satisfied with our work* *-We are not treated the same* *-We must enjoy our job*
	Physical	*-If they were giving family support* *-Supposed to be clean* *-Can't wash without soap* *-We buy soap to wash -Can't work dirty* *-Have to buy food*

Table 3.1: Preliminary categories, subcategories and themes: Pilot study

CATEGORIES	SUBCATEGORIES	THEMES
B. VOCATIONAL SUPPORT	Stock and equipment	*-Not enough stock for patient care* *-Enough stock should be provided* *-We use limited number of stock* *-We must be supported with everything* *-The job is endless* *-We must enjoy our job*
	Education and training	*-We need education and training* *-Our qualifications are not recognised* *-We are doing nurses job* *-They must create jobs*
	Communication	*-We are not informed with important issues* *-No feedback of meeting discussion* *-We are not allowed to go to the meeting* *-They don't answer letter of meeting request*

Table 3.2: Preliminary categories and subcategories: Focus group 2 (to be continued)

CATEGORY	SUBCATEGORY	THEMES
A. PERSONAL SUPPORT	Financial	*-Hospice is getting funds from government* *-R500 is not enough- is transport money R250.00 is from hospice and R250.00 is-from Department of Health* *-We don't have enough money to consult the doctor when we are sick* *-Hospice must pay for our medical bills* *-Must at least add R300.00 to make R800.00* *-We are not insured* *-They say there is no money-Government to deduct funeral plan or pension fund* *-They fundraise every month* *-We are not insured* *-They use funds for them*
	Emotional	*-We are not getting any supports from hospice* *-There is no co-operation at hospice* *-We need co-operation from the Department -They don't treat us correctly* *-This causes a negative attitude* *-Hospice doesn't care for us* *-Is painful not to help the patient* *-We need equal treatment as volunteers regardless of hospices name- They don't accept us as humans* *-We are doing a good work* *-We are helping community* *-Hospice never fulfils the promises*
	Physical	*-We must be clean and wear clean clothes* *-Hospice give food parcels for patient monthly* *-They promise us injection for protection* *-We don't have a centre, doctor, supervisor and transport for patients* *-We are working in a church,we need our health care centre-We work for hospice* *-Volunteering is dangerous -caring for HIV & TB patients*

Table 3.2: Preliminary categories, subcategories and themes: Focus group 2

CATEGORY	SUBCATEGORY	THEMES
B VOCATIONAL SUPPORT	Stock and equipment	*-There is no medication for patients* *-We don't have linen and gloves* *-We are struggling to get equipment* *-Sometimes we use plastic bags* *-We asking medical kit*
	Education and training	*- We need to be trained* *- How long are we going to volunteer?*
	Communication	*-We need to be informed about important issues such a ' hospice week* *-There is lack of communication* *-Communication is poor* *- We are not informed about the meetings* *-We need meeting with the managers*

Table 3.3: Preliminary categories, subcategories and themes: Focus group 3 (to be continued)

CATEGORY	SUBCATEGORY	THEMES
A. **PERSONAL SUPPORT**	Financial	*-Stipend is too little* *-We get stipend late, -We need our stipend* *-Stipend never given in time* *-Department gave money to hospice* *-We need benefits such as:* ▪ *Policy for injury on duty* ▪ *Retirement annuity* ▪ *Pension fund* ▪ *Medical fund* *-Others quit, as we were not paid* *-We promise to pay accounts*
	Emotional	*-Hospice cause confusion -We need Emotional support* ▪ *To be treated equally* ▪ *Encouragement* ▪ *To be thanked* ▪ *To be straightened up* ▪ *Co-operation* *-Hospice likes to isolate* *-We cannot rely on them* *-The support is poor* *-They don't even know us* *-They are unfair* *-They don't care for us* *-We are: Demoralised and hopeless* ▪ *Pressurised* ▪ *Uncertainty about the future* ▪ *Confused* ▪ *Unsatisfied* ▪ *Taken for granted* *-We don't know where to cry to* *-Creates hatred* *-Not recognised at the clinics* *-Poor working relationship* *-No manner of approach from managers*

Table 3.3: Preliminary categories, subcategories and themes: Focus group 3

CATEGORY	SUBCATEGORY	THEMES
A PERSONAL SUPPORT	Physical	*-The work environment is not conducive for patients care* *-Hospice promise us uniform* *-Uniform is important for:* ▪ *Identification* *-There is lack of equipment* *-We improvise for equipment* *-We use plastic bags for gloves* *-They are functioning because of us*
B VOCATONAL SUPPORT	**Stock and equipment**	*-There is lack of stock* *-We improvise for equipment* *-We use plastic bags* *-We are lacking medication, gloves and gauze*
	Education and training	*-We would like further training* *-We are utilised as nurses* *-Education and training* *-There is shortage of nurses* *-We do nurses job for permanent nurse* *-We are not recommended training*
	Communication	*-There is lack of communication* *-No answer to our calls* *-They promised to come regularly* *-They must communicate with us* *-They insist that a volunteer will remain a volunteer* *-We got a lot of problems* *-Nobody solve our problems*

Table 3.4: Preliminary categories, subcategories and themes: Focus group 4(to be continued)

CATEGORIES	SUBCATEGORIES	THEME
A. PERSONAL SUPPORT	**Financial**	*-Stipend is irregular* *-No stipulated date for salary* *-Money unavailable for withdrawal* *-Parents provide us with transport money* *-Caregivers need insurance'* *-We don't know the original of stipend* *-We need UIF, education policy* *-Stipend can't by grocery or shirt*
	Emotional	*-They don't consider us* *-No co-operation from hospice* *-Is heartbreaking* *-They only: care for themselves* *-Don't care for us* *-We are crying* *-We do cry* *-We are still crying* *- We are misused* *-They offers us indemnity form* *-We are under pressure* *-There is discrimination at hospice* *-No manner of approach from managers*
	Physical	*We are:- Afraid to be affected with TB* ▪ *Caring for infectious patient* ▪ *Not cover for risk factors* ▪ *In need of uniform* *-If hospice can offer us uniform*

Table 3.4: Preliminary categories, subcategories and themes: Focus group 4

B. VOCATIONAL SUPPORT	**Stock and equipment**	*- There is shortage of equipment* *- We are given expiry gloves*
	Education and training	*-There is shortage of nurses* *-Nurses are going to overseas* *-We are utilised as nurses* *-Government is recruiting cleaners* *-We need training* *-What about us* *-We are doing nurses job* *-Some of us have standard ten*
	Communication	*-We are pleading managers and Government to pay attention to us* *-We take initiative to phone hospice* *-They don't talk nice to us* *-They throw words that are unpleasant* *-MEC no longer expecting any fax from us* *-We call a meeting every first week of the month* *-We are having many problems* *-No solution to our problems*

The preliminary categories, subcategories and themes were again submitted to an extensive analysis and the researcher realised that issues that were indicated under themes could again be categorised. This resulted in the re-grouping of focus group interviews into **new main categories, subcategories and themes** (see Table 3.5-3.8).

The two main categories, namely personal and vocational support, were substituted by seven new main categories, namely financial, spiritual, emotional, physical, stock and equipment, education and training and communication. The existing themes were re-grouped to form the new subcategories (see Table 3.5).

The researcher also did an in-depth analysis of the data to identify the frequencies of the issues that were mentioned by participants. To view results of this analysis (see Table 3.5).

Table 3.5: New categories, subcategories and themes: Pilot study interviews (to be continued)

CATEGORIES	SUBCATEGORIES	THEMES
1. **Financial support**	1.1	*-We earn only R500 which is too little* *-Unsatisfactory support, food prices are up* *-We earn only R500.00 which is too little* *-Money is not enough, we need to be clean*
	1.2	*-We have to buy food* *-Pay date irregular* *-No explanation of delayed stipend*
	1.3 No benefits	*-No medical funds for us*
	1.4 Management of stipend	*-Hospice got funds from overseas* *-Others earn more salary* *-People who earn more must work hard* *-Transport allowance disappear*
2. **Spiritual support**		*-We pray prior to commence duties* *-We need support to lift up our spirit*
3. **Emotional support**	3.1 Emotions and Feelings 3.2 Unfulfilled needs	*-We need moral regeneration* *-We are not considered as volunteers* *-We feel as if we are not part of hospice*
		-They don't fulfill promises *-No problem-solving*

Table 3.5: New categories, subcategories and themes: Pilot study interviews

CATEGORIES	SUBCATEGORIES	THEMES
4. Physical support	4.1 Personal hygiene	*-Can't wash without a soap* *-We buy soap to wash* *-Can't work dirty* *-We are suppose to be clean*
	4.2 Risks involved	
	4.3 Physical needs	*-We need to buy food*
	4.4 Working environment	
5. Stock and Equipment	5.1 Inadequate stock	*-Not enough stock for patient care* *-Enough stock should be provided* *-We use limited number of stock* *-We must be supported with everything*
	5.2 Unsuitable equipment	
6. Education and Training	6.1 Job allocation	*-They must create jobs* *-We are doing nurses job*
	6.2 Needs for training	*-Our qualifications are not recognised*
7. Communication	7.1 Attendance of meetings	*-We are not allowed to go to the meeting*
	7.2 Informed about issues	*-We are not highlight us about important issues*
	7.3 No communication channels	*-No feedback of meeting discussion*

Table 3.6: New categories, subcategories and themes: Focus group2 interviews (to be continued)

CATEGORIES	SUBCATEGORIES	THEMES
1. Financial support	1.1	*-R500.00 is not enough -is transport money* *-R250.00 is from hospice and R250.00 is from is from Department of Health* *-must at least add R300.00 to make R800.00*
	1.2	*-No specific date for the stipend*
	1.3 No benefits	*-We don't have enough money to consult the doctor when we are sick* *-Hospice must pay for our medical bills* *-We are not insured* *-They say there is no money* *-Government to deduct funeral plan or pension fund*
	1.4 Management of stipend	*-Hospice is getting funds from government* *-They use funds for themselves* *-They fundraises every month*
2. Emotional support	2.1 Emotions and Feelings	*-We don't get any supports from hospice* *-We need co-operation from department* *-They don't treat us correctly* *-This causes a negative attitude* *-Hospice doesn't care for us* *-Is painful not to help the patient* *-We need equal treatment as volunteers regardless of hospice name* *-They don't accept us as humans* *-We are doing a good work* *-We are helping community* *-There is no co-operation at hospice*
	2.2 Unfulfilled needs	*-Hospice never fulfils the promises*

Table 3.6: New categories, subcategories and themes: Focus group 2 interviews

CATEGORIES	SUBCATEGORIES	THEMES
3. Physical support	3.1 Personal hygiene	*-We must be clean and wear clean clothes*
	3.2 Risks involved	*-They promise us injection for protection* *-Volunteering is dangerous* *- We are caring for HIV & TB patients*
	3.3 Physical needs	*-We are breadwinners."*
	3.4 Working environment	*-We don't have a centre, doctor, supervisor and transport for patients* *-We are working in a church* *-We need our health care centre* *-We work for hospice*
4. Stock and equipment	4.1 Inadequate stock	*-There is no medication for patients* *-We don't have linen and gloves* *-We are struggling to get equipment* *-We are asking medical-kit*
5. Education and Training	5.1 Job allocation	*-We don't have a supervisor*
	5.2 Needs for training	*-We need to be trained* *-How long are we going to volunteer*
6.Communication	6.1 Attendance of meetings	*-We don't attend the meetings* *-We need meeting with managers* *-They don't answer our letters for meeting request*
	6.2 Informed about issues	*-We need to be informed about important issues such a ' hospice week'*
	6.3 No communication channels	*-There is lack of communication* *-We don't attend the meetings* *-We need meetings with managers*

Table 3.7: New categories, subcategories and themes: Focus group 3 (to be continued)

CATEGORIES	SUBCATEGORIES	THEMES
1. **Financial support**	1.1	*-Stipend is too little* *-We get stipend late*
	1.2	*-Stipend is too little,-we get stipend late*
	1.3 No benefits	*-We need benefits such as* *-Policy for injury on duty* *-Retirement annuity* *-Pension and Medical fund* *-Others quit, as we were not paid* *-We promise to pay accounts*
	1.4 Management of stipend	*-Department gave money to hospice*
2. **Emotional support**	2.1 Emotions and Feelings	*-Hospice cause confusion* *-We need emotional support* *-To be treated equally* *-Encouragement* *-To be thanked* *-To be straightened up* *-We are confused* ▪ *Demoralised and hopeless* ▪ *Unsatisfied* ▪ *Pressurised* *-Hospice likes to isolate* *-The support is poor* *-They are unfair* *-No co-operation* *-They promised to come regularly* *-Uncertainty about the future* *-We don't know where to cry* *-They don't care for us,creates hatred* *-Poor working relationship* *-We are taken for granted* *-They don't even know us* *-We are not recognised*

Table 3.7: New categories, subcategories and themes: Focus group 3

	2.2 Unfulfilled needs	*-They promised to come regularly*
3. Physical support	3.1 Personal hygiene	
	3.2 Risks involved	*-Our lives are in danger* *-We can be affected with any disease* *-One can be infected with anything* *-There is eruption of sickness*
	3.2 Physical needs	*-Hospice promise us uniform* *-Uniform is important for identification*
	3.3 Working environment	*-Working environment not conducive for patients care*
4. Stock and equipment	4.1	*-We use plastic bags for gloves*
	4.2	*-We improvise for stock* *-There is a lack of stock*
5. Education and training	5.1	*-We are utilised as nurses* *-We do job for permanent nurses*
	5.2	*-We would like further training* *-We are not recommended for train* *-There is shortage of nurses* *-They must give us those chances that we can move further*
6.Communication	6.1	*-They must communicate with us the feedback of meetings* *-Don't attend the meetings*
	6.2	*-No answer to our calls*
	6.3	*-There is lack of communication* *-Nobody solve our problems*

Table 3.8: New categories and subcategories: Focus group 4 (to be continued)

CATEGORIES	SUBCATEGORIES	THEMES
1. Financial support	1.1 Insufficient stipend	*-Stipend can't by grocery or shirt* *-Parents provide us with transport money*
	1.2 Stipend irregular	*-Stipend is irregular*
	1.3 No benefits	*-Caregivers need insurance's* *-We need UIF, education policy*
2. Emotional support	2.1 Emotions and feelings	*-We are pleading managers and government to pay attention to us* *-They don't consider us* *-No co-operation from hospice* -Is heartbreaking *-They only care for themselves* *-Don't care for us* *-No manner of approach from* *-Hospice like to isolate* *-They don't consider us* *-We are misused* *-We do cry* *-We are still crying* *-There is discrimination at hospice* *-We are under pressure*
	2.2 Unfulfilled needs	
3. Physical support	3.1 Personal hygiene	
	3.3 Physical needs	*-We need uniform* *-If hospice can offered us old shirts to change the uniform to be clean*
	3.4 Working environment	

Table 3.8: New categories and subcategories: Focus group 4

CATEGORY	SUBCATEGORY	THEMES
4. Stock and equipment	4.1 Unsuitable equipment	-They offered us expired gloves
5. Education and training	5.1 Job allocation	*-There is shortage of nurses* *-Nurses are going to overseas* *-There is shortage of equipment* *-We are utilised as nurses* *-We are doing nurses job*
5. Education and training	5.2 Needs for training	*-Government is recruiting cleaner* *-What about us* *-We need training* *-Some of us has standard ten* *-Nurses are gone to Overseas*
6.Communication	6.1 Attendance of meetings	*-We call meeting every first week of the month* *-We are having many problems* *-A volunteer can't say anything* *-No solution to our problems*
	6.3 Informed about issues	*-We were not informed when Step* *-Down was closed* *-Informed about issues*
	6.3 Communication channel	*-We take initiative to phone hospice* *-They throw words that are unpleasant* *-They don't talk nice to us* *-MEC no longer expecting any fax from us*

Indeed, there is no best or correct approach to the analysis of focus group interviews (Bickman & Rog, 1998:515). The information obtained from all the above-mentioned groups was finally clustered in one table to prove saturation (see Table 3.9).

Table 3.9: Categories, subcategories and themes of all focus groups

CATEGORY	SUBCATEGORY	THEMES
A. **PERSONAL SUPPORT**	Financial	*-Unsatisfactory support, food prices are up* *-Pay dates irregular* *-Money not enough, we need to be clean* *-We earn only R500.00 which is too little* *-No medical funds for us* *-Others earn more salary* *-Hospice got funds from overseas and government* *-Transport allowance disappeared* *-People who earn more must work hard* *-No explanation of delayed stipend* *-We don't have enough money to consult doctor* *-Hospice must pay for our medical bills* *-We are not insured* *-Thy use funds for them* *-We are not insured* *-Others quit as were not paid* *-We promise to pay the accounts* *-Money unavailable for withdrawal* *-Parents provide us with transport money* *-We don't know the original of stipend* *-Stipend can't pay grocery and shirt.*

CATEGORY	SUBCATEGORY	THEMES
	Spiritual	*-We pray prior to commencing duties* *-We need support to lift up our spirit*
A PERSONAL SUPPORT	Emotional	*-We need moral regeneration* *-We are not considered as volunteers* *-We feel as if we are not part of hospice* *-They don't fulfill promises* *-No problem- solving and support* *-Supervisors not satisfied with our work* *-We are not treated the same* *-We must enjoy our job* *-There is no co-operation at hospice* *-This causes negative attitude* *-Hospice doesn't care for us* *-Is painful not to help the patients* *-They don't accept us as humans* *-We are doing a good work* *-We are helping the community* *-Hospice cause confusion* *-We need: emotional support* • *Encouragement* • *To be thanked* • *To be straightened up* *-Hospice likes to isolate* *-We cannot rely on them* *-The don't even know us* *-They are unfair* *-We are: Demoralised and hopeless* • *Pressurised*

		• *Uncertainty about the future* • *Unsatisfied* • *Taken for granted* *-We don't know where to cry to* *-Poor working relationship* *-No manner of approach from managers* *-Is heartbreaking* *-We are misused* *-There is discrimination at hospice*

CATEGORY	**SUBCATEGORY**	**THEMES**
	Physical	*-If they were giving family support* *-Supposed to be clean* *-Can't wash without soap* *-We buy soap to wash -Can't work dirty* *-Have to buy food* *-Hospice give food parcels for patients monthly* *-They promise us injection for protection* *-Volunteering is dangerous, caring for HIV/AIDS patients* *-We need our health care centre as we work in a church* *-The work environment is not conducive for patients care* *-Hospice promise us uniform* *-Uniform is important for identification* *-We are afraid to be affected with T.B*

B. VOCATIONAL SUPPORT	Stock and equipment	*-Not enough stock for patient care* *-Enough stock should be provided* *-We use limited number of stock* *-We must be supported with everything* *-There is no medication for patients* *-We don't have linen and gloves* *-We are struggling to get equipment* *-Sometimes we used plastic bags* *-We are asking medical kit* *-We are given expiry gloves*
	Education and training	*-We need education and training* *-Our qualifications are not recognised* *-We are doing nurses job* *-They must create jobs* *-How long, are we going to volunteer?* *-We are utilised as nurses* *-There is a shortage of nurses* *-We are not recommended for training*

CATEGORY	SUBCATEGORY	THEMES
B VOCATIONAL SUPPORT	Communication	*-We are not informed with important issues such as hospice week* *-No feedback of meeting discussion* *-We are not allowed to go to the meeting* *-They don't answer letter of meeting request* *-There is lack of communication* *-No answer to our calls* *-They insist that volunteer will remain volunteer* *-Nobody solve our problems* *-We take initiative to phone hospice* *-They don't talk nice to us*

Bickman and Rog (1998:515) state that the analysis and interpretation of focus groups' data can be as rigorous as the analysis and interpretation generated by any other method. Focus group data can even be quantified and submitted to sophisticated mathematical analyses, though the purpose of the focus group interviews seldom requires this type of analysis.

Table 3.10 below shows several significant perceptions emerging from the quantification of data and revealed unsatisfactory support in terms of the perceptions of voluntary AIDS caregivers' concerning hospice managers.

The researcher would like to draw attention to the fact that the reference to frequencies with which participants made statements is not equal to quantitative research. The themes that appeared in the focus group interviews were clustered under the different subcategories to make the interpretation of data meaningful.

Table 3.10: Frequencies of responses from focus group interviews

MAIN CATEGORIES	SUBCATEGORIES	FREQUENCIES	FREQUENCIES	FREQUENCIES	FREQUENCIES
Financial support	Stipend not enough	2	3	4	5
	Stipend irregular	2	4	3	5
	No benefits	-	2	3	1
	Management of stipend	1	4	2	3
Emotional support	Emotions, feelings experienced:	1	3	8	9
	-Isolation	1	-	2	1
	-Pressurised	-	-	1	2
	Unfulfilled needs:	1	2	4	6
	-For co-operation	-	3	2	4
	-Equal treatment	2	1	1	1

	-Recognition	-	4	8	8
	-To be cared for	-	2	1	1
Physical support	-Personal hygiene	2	1	-	3
	-Risks	-	6	5	5
	-Physical needs	-	2	1	4
	-Working environment	-	4	3	1
Stock and equipment	-Inadequate stock	1	3	4	2
	-Unsuitable equipment	-	2	2	1
Education and training	-Job allocation	2	1	4	3
	-Needs for training	-	-	8	6

Communication	-Attendance of meetings	3	5	6	5
	-Informed about issues	3	4	3	5
	-No communication channels	1	3	4	5

3.2 RESULTS AND LITERATURE CONTROL: PERCEPTIONS OF SUPPORT

The purpose of data analysis, regardless of the type of data is to organise, provide structure to, and elicit meaning (Polit et al., 2001:381). Each category, subcategory and theme will be discussed and where possible substantiated by quotes and supported by research findings and or literature.

The literature control will ensure that the research meets the criteria of trustworthiness.

3.2.1 Main category: Financial support

Polit et al., (2001:78) describe a stipend as a generous monetary incentive offered to encourage the participation of an economically disadvantaged group to compensate for time and expenses. William, Werther and Davis (1989:338) state that compensation is the most important influence on a person's morale and it is the most effective of all managerial roles for controlling and motivating the workers.

3.2.1.1 Subcategory: Stipend is insufficient

Fourteen participants from all the focus groups mentioned that the stipend is inadequate. They stated that:

> *"The stipend of R500.00 is nothing, is just like peanuts because the distance that I travel from where I stay to my patients, is a distance. My shoes, my heels are finished, I don't have money to repair again, so it give us a physical problem of that and still that R500.00 is too little."*
>
> *"We are using double transport and that R500.00 hy is baie klein (is too little)."*
>
> *"In the issue of stipend you cannot buy a shoes and a shirt at the same time and transport because you have a rent to pay and everything you know."*

3.2.1.2 Subcategory: Stipend is irregular

With regard to the main category of financial support a subcategory that emerged in all the interviews was that of irregular payment. Five participants in focus group 4 and four in focus group 2 felt very strongly about this. The problem of irregular payment was mentioned several times.

> *"In case of stipend, we don't have the specific date, week, we receive our stipend."*
>
> *"We don't have specific date of salary."*
>
> *"We get the stipend late, sometimes they double them next month"*
>
> *"We receive stipend late, I mean we have to receive every month, but we don't receiver it. We struggle before we get it."*
>
> *"We are suffering from somebody who has lost pin code or whatever."*

3.2.1.3 Subcategory: No benefits

Feelings of not having any benefits because they are voluntary AIDS caregivers appear explicitly on the verbalisation of six participants in three different groups.

> *"We don't get anything for injury on duty."*
>
> *"We are not actually covered life covered."*
>
> *"As carers we need insurance, UIF."*
>
> *"We need insurance that covers us and provided children's education and family."*
>
> *"If you are injured while on duty, there is no cover up at hospice."*
>
> *"They offered us the indemnity form to sign as we are volunteers."*

3.2.1.4 Subcategory: Management of stipend

Participants also expressed their dissatisfaction with the way in which the stipend is managed. The frequency with which this issue was mention was the highest in focus group 2. In general participants indicated that:

> *"Some volunteers they get their stipend every month."*
>
> *"We submit claim forms early every month but they wait for other claims for stipend that are coming from other places before they can issue a stipend."*
>
> *"They use our stipend for their benefits."*
>
> *"Hospice receives donations from overseas."*

Considering all the above statements there seemed to be a problem with regard to financial support. The stipend is either abused by managers or not issued according to the guidelines laid down by the Department of Health.

The voluntary AIDS caregivers continue to provide care to the patients without a stipend or compensation, whereas in providing long-term health care service, voluntary AIDS caregivers incur significant expenses for which there is currently little compensation through government payments.

3.2.2 Main category: Emotional support

Nowadays stress at work causes emotional and psychological troubles and managers should through sensitive discussion and counselling protect their subordinates against stress (Cloete, 1990:215).

Stoner (1982:42) citing Fayol's principles of management on *esprit de corps* wrote: "*Promoting team spirit will give the organisation a sense of unity. To Fayol, even small factors could help to develop this spirit.*" Therefore the managers should provide the following:

- Attention to individual volunteers.
- A sense of security to boost the morale of each volunteer caregiver and his/her identification with the group should be good where the managers create.

When managers have met these requirements, the work will be done with zeal, pride and loyalty to the supervisor and thus to the managers.

3.2.2.1 Subcategory: Emotions, feelings and experiences

Fifteen participants from all focus groups expressed strong emotions such as negativity, pressurised, uncertain about the future, confused, unsatisfied and feelings of hatred and demoralisation. It seems that participants in focus group 4 and focus group 3 were the ones who really experienced many strong emotions. This observation is supported by Kurtz, (1997:23) who stated that voluntary AIDS caregivers suffer from low morale, burnout, anxiety, stress and even neglected with the inevitable stigma attached to HIV/AIDS.

Moch's stress curve tested in thousands of people indicated that burnout was the highest specific incidence in the workplace. The stress of anxiety, depression and lack of support experienced by voluntary AIDS caregivers in the work place also seemed to be higher *(BMJ 1994:309).* Six categories related to stress in the work place were mentioned and included boredom, understress, ideal, distress, burnout and breakdown Moch, (1999:30).

The researcher also noticed that this category had the highest frequency of all the responses indicated in all categories.

"This causes a negative attitude."

"We are demoralised and hopeless."

"We don't know where to cry to."

3.2.2.2 Subcategory: Unfulfilled needs

Thirteen participants reported that management made promises that they never fulfilled.

"Hospice promise us that they will come regularly, every month-end to come and look around everything but it never happen like that."

"They don't fulfil, we always suffer the promises of them."

"Is unfair to promise volunteer this and that, at the end of the day they don't fulfil the promise."

Other needs that were mentioned by group 4 and 2 included the need for moral regeneration, correct treatment, caring, encouragement, co-operation. The issue the participants felt most strongly about was being recognised. Woods (1992:225) confirms that recognition is the great motivator, especially if it follows the achievement of a specific goal.

Mayo's (Hellriegel and Slocum, 1989:56) found that if special attention is given to workers they will increase their effort

"They must pay attention to us"

"We are misused here and even if we complain about the wards, they don't pay attention."

"We need to be reconsidered and be put in a better direction."

"You feel like living this because I'm not recognised."

Fröhlich (1999:8) noted that many of the perceived disadvantages of using volunteers could be overcome if the volunteers are recognised as key workers in the program. For the sake of their morale and self-confidence, voluntary AIDS caregivers at every level need to know that their work is recognised and valued. Van Dyk (2002:330) suggested that volunteers should be used wherever they fit best in terms of their personalities, qualities, expertise and interest.

Motivation would decline as voluntary caregivers become convinced that management does not really care about getting the job done or appreciate what they have done or achieved (*cf* Cascio 1989:431).

Mayo found in the Hawthorne experiments as cited in Stoner (1982; 442), that managers could motivate workers by acknowledging their social needs and by making them feel useful and important.

Stanton, Buskirk and Spiro (1991:254) define motivation as a desire to expand effort to fulfil a need. As Frederick Herzberg once said: "*If you want people motivated to do a good job, give them a good job to do*" (Strickland, 1996:286).

Words of praise and thanks from managers are therefore considered to be important (van Dyk, 2002:287). The volunteer caregivers perceived the lowest level of provision of emotional support from their managers (*cf* Galinsky & Schopler, 1995:15).

> *"So emotional support we need so that the work moves on."*
>
> *"First of all if you render a service, you do it from your heart then thank you must be there and a thank you mustn't be quiet sometimes."*

"If you did something better I think even to say thank you have done yourself, I mean is more than anything thank you, just to be thanked. We don't get it, we don't even had it."

" They need to make a way of supporting and uplifting each and every one of us because they cannot only want us to do this work but they don't give us support."

Other statements included were:

"We are not getting any support from work and from management."
"We don't receive any support from hospice."
"There is poor support, they don't take care of us."
"The support is there but not satisfactory."

Van Dyk (2002:329) wrote: "It is absolutely vital for caregivers to have support system and to know how to care for themselves as well if they want to prevent themselves from being overwhelmed by burnout.

3.2.3 Main Category: Physical support

Kibel and Wagstaff (1993:394) explain physical support as the most basic and powerful of all human needs because they concern survival, food, elimination, rest and sex.

3.2.31 Subcategory: Personal hygiene

Hetzberg's two-way factor theory contends that hygiene factors alone cannot lead voluntary caregivers to feel satisfied with the work environment but there should be motivators as well (*cf* Woods, 1992:219).

One participant from focus group 3 tried to explain the phenomenon of physical support and related risks.

> *"When I talk about physical support like as I said, sometimes we have sickness that are appearing you know in the community, then you find that we don't have any access or the money that is not enough to get the particular medicine. And we just want them to help on that other note of having that access of medication."*

Two participants in the pilot group mentioned that they need to be clean all the time. Six participants referred to the issue of personal hygiene.

> *"You won't wash yourself without a soap."*
> *"We cannot work patient dirty."*
> *"We must wear clean clothes because we are working for the patients."*

3.2.3.2 Subcategory: Risks

In general sixteen references were made to the high risk involved in being a voluntary caregiver.

Three participants from focus groups 2, 3 and 4 respectively, pleaded that they are human beings not animals. Permanent staff' working in clinics was given Hepatitis B Vaccine for protection against the disease. The voluntary caregivers were just promised the injection but it was never administered.

"We are risking our lives."

"We are working with people who are HIV positive, TB patients."

"I must help the patient because is my job I do with risk."

If the Batho Pele eight principle of the Public Health Service is considered in this regard, all the citizens of this country should have access to medical services and treated with courtesy and dignity (Public Service Administration, 1999:15).

According to the Essential Drug Program (1996:106) all primary health care facilities should be provided with essential drugs and be controlled as outlined in Medicine and Related Substance Control Act 101 of 1965

"The registered nurses they are given an injection for not to be infected, we think we are human beings, they must just put their status aside and consider that we are human beings we still need that injection to be given not to be infected. So they must work hand in hand with us."

People at high risk should be given relevant treatment according to the standard treatment guidelines of essential drugs in order to reduce wasteful expenditure on inappropriate drugs (Mandela, 1994:51; Strauss, 1996:106; Essential Drug Program, 1998:3).

The South African Constitution Act, 1996(Act 108 of 1996) [Hereafter referred to as The Constitution] S24, enunciates a number of basic rights that everyone has a right to:

- The right not to be unfairly discriminated against, either by the state or another person.

- The right of access to health care services, including reproductive health care. The right not to be refused emergency medical treatment.

- The Free State Provincial Government Health Circular, External Circular No. 5 of 1998, states immunisation of health care workers against Hepatitis B is mandatory. The goal is to:

  - Have ninety (90) percent (%) of all health care workers immunised against Hepatitis B as from the date of the circular (30 December 1998).

  - Concurrently immunise new staff on entry into the health service.

Hepatitis as a communicable disease is prevented by vaccination. Therefore, hepatitis B vaccine is safe and effective only if a sterile needle is used for every injection External Circular No. 5 of 1998).

The circular further states that people at risk of contracting hepatitis B in the health services should receive hepatitis B immunisation. These include:

- Nursing personnel at all levels

- people working where service to clients and patients is rendered in places such as

- hospitals, clinics, old age homes and community health centres, including all non-professionals working in these institutions

According to this circular voluntary AIDS caregivers do qualify for this vaccination.

3.2.3.3 Subcategory: Physical needs

According to Maslow's (1943:375) needs hierarchy, physiological needs are primary and, of course, given first priority. He wrote that: "*Man lives by bread alone when there is no bread.*" While Flippo, (1984:375-376) wrote that: "*If the person is starving only food occupies the mind.*"

Several physical needs were mentioned. These included the need for uniforms, a conducive environment, transport of patients and a health care centre. In focus group 4 the participants responded to this issue as follows:

> *"I just want to add on what they said, we need uniform."*
>
> *"On uniform, if there is a chance, we ask them not to give us the other colour, not white, white or navy blue white, not that one, we ask the other*
>
> *"Then in the issue of uniform you know, uniform is important because we go in the township and then is a good way to identify ourselves. Because when you go in a household of someone you have to be well identified and the person cannot trust you if you don't have any uniform and then it is difficult to do your job without a uniform."*
>
> *"They want us to wear uniform."" I would like to add, is that yes, because is a good suggestion for identification you know because our shoes are getting finished completely. Now and then in the issue of stipend you cannot buy a shoes and a shirt at the same time."*

Transportation needs featured predominantly in participants of focus groups whose social circumstances were not satisfactory with regard of transporting sick patients to the clinics.

From the verbalisation of five participants it became clear that some voluntary AIDS caregivers experience problems in escorting very ill patients to health care centres: patient to the clinic.

> *"So you don't have a transport and the, the patient cannot walk and is far away."*

According to voluntary AIDS caregivers, transportation is the second most required service for the patients in the community who cannot go to the doctor because of severe illness. Transport would help caregivers to take the patients to the health care centre and continue to provide care as they walk long distances to visit the patients.

3.2.3.4 Subcategory: Working environment

In terms of Section 5 of the General Administrative Regulation to the Occupational and Safety Act, 1993 (Act 85 of 1993) [Hereafter referred to as Act 85 of 1993], employers have a duty to inform workers of the hazards and potential hazards existing in the work place (Kotze, 1997:378).

Three participants reported that the environment in which they worked was not conducive to safety.

Unhygienic environmental factors will cause voluntary AIDS caregivers to be dissatisfied with the physical environment (*cf* Stanton, Buskirk & Spiro, 1991:259).

Maldonado, Tanchel & Baker (1999:22-27) mentioned that the time spent doing one task environmental workload causes mental stress and it would be advantageous for managers to monitor the performance of their workers as well as work areas in an attempt to optimize production and safety.

Paraphrasing Mayo et al., (Hellriegel & Slocum, 1989:51) the researcher views the organisation of workers as a social system in contrast to Taylor's (Hellriegel & Slocum, 1989:56) view of that organisation as a technical economic system.

Eight participants were not satisfied with their working environment.

"Sometimes environmental conditions are unhygienic, especially if patient is having bedsores."

"For instance in our environment, the ward that are using on the weekend, there is nobody who is cleaning and is very wrong for the patient of TB because they had to be admitted on a clean environment."

"We don't have a centre, we are working at the church."

Van Dyk (2002:287) and Anstey, (1990:290) state that managers who have control over the working environment should have overall responsibility for its safety.

They should create a supportive environment for the voluntary AIDS caregivers by assuring that a good network system is in place and that the immediate environment is clean and safe (van Dyk, 2002:346).

Booyens (1999:341-342) supports these recommendations by explaining that immuno-compromised patients with low resistance to infections will be adversely affected with nosocomial (hospital-acquired) infections especially if the environment is not clean. This state of affairs will adversely affect caregivers.

Stoner (1982:48) citing Mayo found that informal work groups have a great influence on productivity in the social environment. Apparently the social environment in the workplace is the only one of several interacting factors that influences productivity.

3.2.4 Main category: Stock and equipment

3.2.4.1 Subcategory: Inadequate stock

Two issues, namely inadequate stock and unsuitable equipment seemed to be prominent. Ten participants indicated that there was a problem of shortage of stock and equipment and that since they did not have supervisors even the minimum stock was not controlled.

> *"The other thing of equipment, the situation that we are experiencing is still the same as there are no gloves."*
>
> *"You have to make a way on your own to get equipment from Department of Health."*

"About equipment, I mean like dressing equipment, gauze and all that and medication, gloves, we lack them, because somewhere we go to the clinic, they don't have gloves."

"The patients think that you are lying when you say you don't have equipment."

Cascio (1989:431) found that improperly maintained equipment might lead to delays in receiving supplies. Shortage of stock and equipment arises when managers fail to provide adequate material resources.

Van Dyk (2002:285) who states that volunteers are frustrated because there is often a lack of medication and health care material substantiates the finding.

3.2.4.2 Subcategory: Unsuitable equipment

Five participants reported that at some stage they work barehanded or with expired gloves

"I can say that they are offering us the expired gloves because while you are working with the patient the gloves are torn, so it is a cross-infection and we are not actually life covered, then it is your own risk."

" They say we must use a plastic bag, so it is not safe to use a plastic bag."

"Sometimes we use plastic bags for patients care."

Evian (1998:303) indicated that a caregiver should wear gloves when handling any blood-contaminated materials such as cotton wool, bandages and any body fluid.

Booyens (1999:276) states that items that have an expiry date must be carefully noted and special attention should be given to this matter when supplies are used. The items nearing the expiry date should be used first.

"There is no one who is taking care of stock control in the ward."

"We don't have masks and then someone has just messed him/herself and then this mess affects you, because right now my chest doesn't know what is happening. I don't know whether, maybe I am sick or something."

3.2.5 Main Category: Education and training

According to the Education Training Unit (2002:32) it is important to find ways of motivating volunteers and this may be done by:

Involvement of the Department of Health and First Aid Organisation so as to make sure that First Aid training is given and those certificates are accredited in terms of the National Qualification framework.

Making the project much more attractive to young people who have finished school and who have not found jobs as they will get a qualification, develop some work experience that will help them when they look for future jobs, and will develop self-esteem and confidence.

Issues that participants discussed were classified by the researcher as job allocation and needs for training.

3.2.5.1 Subcategory: Job allocation

Participants mentioned that in cases where there is a shortage of nurses they are allocated to do nurses' work.

Ten participants said that:

> *"We do a job that is for permanent sister or nurse."*
>
> *"We always do nurses job."*
>
> *"We don't do volunteers job."*

According to Covey (*cf* 1993:162) there must be clarity about the state of the role of a volunteer caregiver in the organisation.

3.2.5.2 Subcategory: Needs for training

Byars and Rue (1994:216) define training as a learning process that involves the acquisition of skills, concepts, rules or attitudes to increase the performance of the employees.

In the three focus groups the participants reported that they needed training and that they did not want to remain as voluntary caregivers. The following statements from their transcripts emphasise this concern. In focus groups three and four participants expressed themselves as follows:

"We need that training so that we can develop us on our work, not just knowing basically, just wash, do that. We need all the necessary training, that's one thing we need."

"They said that they offered us training like nursing assistant because I think it was two weeks back, we went to hospice and they said they are not responsible for that, they are just offering volunteer."

This feedback report is not in agreement with the MEC Issues Report (1997:14) that training of volunteer caregivers must be linked to and presented at Step-down facilities. A step-down facility is a facility that cares for patients who require low-level nursing or support. This is twenty-four hour service on the continuum of care and is positioned between hospital and home.

Other concerns raised indicated that training as voluntary AIDS caregivers is not in agreement with the Manpower Training Act, 1981(Act 56 of 1981) [Hereafter referred to as Act 56 of 1981] that reads thus:

" To provide for promotion and regulation for training of manpower and for the purpose providing for the establishment of a National Training Board, a Manpower Development Fund and a fund for the training of an unemployed person; to provide for the establishment, accreditation, functions and powers of training boards and to provide matters connected therewith."

Woods (1992:162) found that most experts agree that training should be viewed as a continuous cycle rather than as a single event, while Gerber, Nel & van Dyk (1998:452) state that all managers are responsible for training their subordinates to improve current and future performance.

Kasavana and Brooks (1991:331) state that a sure-fire way of motivating employees is to get them involved in an effective training program. Training could significantly reduce the frustration of voluntary AIDS caregivers who may feel that they do not have a clear- cut idea of what is expected of them (*cf* Kasavana & Brooks, 1991:331).

3.2.6 Main Category: Communication

Tortoriello, Blatt and DeWine (1987:16) define communication as an interactional process in which meaning is stimulated through sending and receiving of verbal and non-verbal messages from one person to another.

3.2.6.1 Subcategory: Attendance of meetings

Fayol's principles of management in Stoner, (1982:42) on *esprit de corps* suggested the use of verbal communication instead of formal or written forms. Eighteen participants of focus group interviews with a frequency of mentioned that they are not allowed to attend the meetings with the managers.

"When we arrange meeting with them they don't come."

"They don't give us feedback of what was discussed in the meeting as we don't attend any meetings with them."

" We are excluded in the meetings, they say, 'you are voluntary workers,' you don't go to the meeting."

"We call them and we want to have meeting to have meeting with them. They don't come they always postpone. Even if they come they don't answer us the way we ask them."

According to Van Dyk (2002:287) frequent meetings between caregivers and supervisors are important to discuss and to share problems. Management should involve voluntary AIDS caregivers in decisions and ask their opinions; after all they are the people who are working in the field.

3.2.6.2 Subcategory: Informed about issues

Fifteen participants said that they need to know everything that is happening at the hospice.

"Everything that happens at hospice we don't know about it."

"I want people of hospice to tell us any information they have. They must first come and address us about the post that are available."

"If somebody is asking us about hospice week we don't know because we are not informed."

3.2.6.3 Subcategory: No communication channels

Sillars (1994:23) and Griffin (1993:445) define a communication channel as a physical means by which the message is conveyed.

Thirteen participants reported that there is no effective communication between the managers and the caregivers. The following statements by participants bear testimony to this:

> *"There is lack of communication at hospice between caregivers and managers."*
> *"We volunteers we feel as if we are not part of hospice because."*
> *"They must communicate with us in the meeting for problems in the ward."*
> *"They don't like to communicate with us."*
> *"They must come talk with us."*

The participants further explained that there is lack of communication at the hospice.

> *"Why don't you pick up the phone and report to us that your stipend is going to delay because of this problem."*
> *"I faxed a letter to our MEC, she said that she is no longer expecting any fax from anyone. We faxed her because when we go to her office, she is out so fax was the easiest way to reach her."*

Van Dyk (2002:329) who explicitly confirmed that supports these findings: "*volunteers are frustrated because they don't have a voice in decisions that affect them and their work.*" Participants reported that they needed the opportunity to talk to managers who really understood their problems. Problems can for example be resolved through implementation of quality assurance that will again help in changing the culture of an organisation (Woods, 1992:225).

Quality assurance gives management confidence that tasks will be carried out the required standard (Department of Labour, 2001:20); whilst quality encourages teamwork, co-operation (which is lacking according to participants) and a sense of trust among all workers.

Woods (1992: 375) found that an environment that fosters open communication, positive confrontations and truthfulness results in normative behaviour that stresses honesty and candid communication or an ethical environment. However, creating a truthful environment is not an easy task. In most cases it is first necessary to assess the current conditions within the organisation in order to anticipate and plan what changes must be made (Woods, 1992:377).

This study definitely points out that managers should try to support caregivers through effective communication. Categories and subcategories regarding suggestions about support made by participants are reflected. No suggestions of support were made in the pilot study therefore it was excluded from this part of the analysis. Suggestions regarding support covered only the categories mentioned below (see Table 3.11).

Table 3.11 Focus group 2 suggestions

CATEGORY	SUBCATEGORY	THEMES
1. Financial support	1.1 Risk involved	*-They must pay hospital bills*
2. Communication	2.1 No Communication channel	*-They must include one of us to the management*

CATEGORY	SUBCATEGORY	THEMES
1. Financial support	1.1 No benefit	*-We need maternity leave*
		-We need benefit after death
2. Emotional support	2.1 Emotions and feelings	*-We need a policy on injury on duty*
	2.2 Unfulfilled needs	*-We want hospice to fulfilled their promises.*

Table 3.12 Focus group 3 suggestions

CATEGORY	SUBCATEGORY	THEMES
3. Financial support	3.1 Insufficient stipend	*-We don't want stipend, we want salary*
	3.2 No benefits	*-We need benefit on injury on duty*

Table 3.13 Focus group 4 suggestions (To be continued)

CATEGORY	SUBCATEGORY	THEMES
3. Financial support	3.2 No benefits	*-We need benefit after death* *-We need salary not stipend*
4. Emotional support	4.1 Emotions and feelings	*-We really need to be employed permanently* *-Hospice to consider our problems* *-They should consider our problems*
5. Physical support	5.1 Physical needs	*-We need uniform* *-We are asking a supervisor*
6.Communication	6.1 Communication channels	*-They should come and communicate with us*

Table 3.14 below shows several significant perceptions emerging from the quantification of data made by the participants of three focus groups regarding the suggestions that they would like to be forwarded to hospice managers concerning the support.

The frequency with which each theme appeared in the focus group interviews were clustered under the different subcategories to make the interpretation of data meaningful.

Table 3.14: Frequencies of suggestions from focus group interviews

MAIN CATEGORIES	SUBCATEGORIES		*FREQUENCIES*	*FREQUENCIES*	*FREQUENCIES*
Financial support	Stipend not enough		1	2	2
	No benefits		2	2	2
Emotional support	Emotions, feelings experienced:		-	2	4
	Unfulfilled needs:		1	2	2
Physical support	-Risks		2	1	2
	-Physical needs		-	2	2
	-Unsuitable equipment		2	2	1
Communication	-Attendance of meetings		1	1	1
	-No communication channels		-	1	2

3.3 RESULTS AND LITERATURE CONTROL: SUGGESTIONS FOR SUPPORT

3.3.1 Main category: Financial support

3.3.1.1 Stipend insufficient

Five responses were made regarding insufficient stipend and how management could render support.

> *"The other thing is that we don't want anymore stipend, we want salary."*
>
> *"As carers we need salary not stipend, we need insurance, UIF"*

3.3.1.2 Subcategory: No benefits

Suggestions on how the lack of benefits should be handled were made. Out of the six suggestions the following were considered:

> *"We are women, sometimes we get pregnant, how will you deal with that. So, they told us that we are not permanent workers so we can't have a leave; the only thing is that when you feel to go, go without informing them that is not their own sick."*
>
> *"So we don't get such a support and then if you die some of the parents, no one is working."*
>
> *"Like if someone is dead amongst us, we need to have that recognition."*

3.3.2. Main category: Emotional support

3.3.2.1 Subcategory: Emotions, feelings and experiences

Suggestions by focus group 3 and focus group 4 were also given concerning emotion, feelings and experiences:

> *"And the other thing is that, if they see, if there might be problem, they must tell us in time, so that we cannot get confused and get different stories, they have to contact us if they think there might be a problem, they have to tell us first."*

3.3.2.2 Subcategory: Unfulfilled needs

Suggestions made regarding unfulfilled needs included the following:

> *"They mustn't promise us and leave us without fulfilling those promises.'*
>
> *"What I'm asking from hospice is that a promise is a promise it has to be fulfilled."*

3.3.3 Main category: Physical support

3.3.3.1 Subcategory: Risks

Participants considered themselves at high risk in their working environment and suggested that the management should provide support for them:

"We asking a policy on injury on duty."

"I would like to add on that, we need a policy for injury on duty."

3.3.3.2 Subcategory: Physical needs

Five participants made suggestions about how support could be rendered with regard to their physical needs;

"I just want to add on what they said. We need uniform."

"The problem that I can raise, the same problem is that we really need to be employed to be permanent that's what we are in need of that because the problem, we are asking ourselves until when are going to volunteer until when?"

3.3.4 Main category: Stock and equipment

3.3.4.1 Subcategory: Inadequate stock

Only one participant responded to this issue:

"The other thing of equipment I think the situation that we are experiencing is still the same as we every time when we want to change the patient there is no gloves, is still the same."

3.3.5 Main category: Communication

3.3.5.1 Subcategory: No communication channel

Suggestions focus group 2 focus group 3 and focus group 4 were made regarding attendance of meetings and comments were made on communication channels:

> *"We are asking management of hospice to come and talk to us concerning problems we have."*

3.4 DISCUSSION OF FIELD NOTES

Field notes were taken during the focus group interviews and categorised according to the purpose they served during analysis and integration of information (*cf* Polit & Hungler, 1999:369).

3.4.1 Observational and theoretical notes

Observational notes are descriptions about observed events and conversations. These are experienced through watching and listening and contain aspects such as where, what, who, how, when and why (Polit et al., 2001:282).

Theoretical notes are interpretive attempts to attach meaning to observations.

The researcher recorded inferences in a separate section that was keyed to direct observation (Polit & Hungler, 1999:369; Neuman, 1997:364). Observational and theoretical notes relevant to this discussion were categorised under the headings reflected in Table 3.15:

Table 3.15: Observational and theoretical notes: Pilot study

	HOMOGENEITY	ATTENTION	GESTURES	INTERRUPTIONS
Pilot study	***Observational notes*** *The participants seemed to be familiar and at ease with each other.*	***Observational notes*** *All three participants responded.* *Number two was the first one to respond whilst number three was keen to elaborate.* *Number one got more involved at a later stage.*	***Observational notes*** *Participants used hands to support what they said.*	***Observational notes*** *No interruption during this discussion.*
	Theoretical notes *Homogeneity* *The nature of homogeneity is determined by the purpose of the study (Krueger & Casey (2000:71)* *Participants did not deviate with regard to their perceptions of support.* *No one in this group dominated the discussion.*	***Theoretical notes*** *Everybody started talking about equipment and material needed to care for patients.* *Eye contact was kept with the facilitator throughout the session.*	***Theoretical notes*** *According to Sillar (1991:92) information could be given through:* *-Tone of voice* *-Using gestures* *-Positioning of posture* *Participants became exited when talking about certain issues and gestures supported that.*	

Table 3.16: Observational and theoretical notes: Focus group 2

	HOMOGENEITY	ATTENTION	GESTURES	INTERRUPTIONS
Focus group 2	***Observational notes*** *Perceptions of support were similar to those of the previous groups.* *Number three seemed to be more dominant and often voiced an opinion.*	***Observational notes*** *Everybody paid attention and responded frequently.*	***Observational notes*** *The researcher noticed that participants number two and seven were either sitting with stretched legs or rubbing hands.* *Number nine held fingers against lips in order to pay attention.* *They were waving hands to draw attention.*	***Observational notes*** *No interruptions.*
	Theoretical notes *Other participants listened carefully while group member was talking.*	***Theoretical notes*** *The issues of the stipend made all participants raise their views without hesitating.*	***Theoretical notes*** *Participants were waving hands in order to be invited to talk.*	

Table 3.17: Observational and theoretical notes: Focus group 3

	HOMOGENEITY	ATTENTION	GESTURES	INTERRUPTIONS
Focus group 3	***Observational notes*** *The participants of focus groups were selected based on inclusion criteria.* *They expressed the same perceptions concerning support.*	***Observational notes*** *The group throughout the interviews supported responses.* *Participants sometimes moved to the edge of the chair to show interest.* *Number three speaks with confidence.*	***Observational notes*** *Gestures that were used included "cracking of knuckles", using hands to elaborate and nodding their heads in agreement.*	***Observational notes*** *No interruptions*
	Theoretical notes *The physical layout of the room could have a great influence on interviews as participants expressed their feelings freely without fear of their managers or the group members because of homogeneity.*	***Theoretical notes*** *The overall message that number three conveyed was based on the emphasis on the support that was lacking at hospice.*	***Theoretical notes*** *The gestures that were used by participants conveyed messages just as effectively as anything they might have said (Sillars, 1991:89).*	

Table 3.18: Observational and theoretical notes: Focus group 4

	HOMOGENEITY	ATTENTION	GESTURES	INTERRUPTIONS
Focus group4	***Observational notes*** *They expressed the same perceptions concerning support.* *The advantage of homogeneous groups is that "it opens up the possibility of conducting group interviewing with groups of similar individuals" (Patton, 1990:7).* ***Theoretical notes*** *The group members were homogeneous enough as they supported each other's statements.*	***Observational notes*** *It seemed that groups felt strongly about feedback provided because they paid attention by saying "yes".* *Number four was very slow to respond and did not participate a lot.* ***Theoretical notes*** *Number four was having abdominal colic prior to the commencement of interviews.*	***Observational notes*** *Everybody was nodding his or her head in support of statements made.* ***Theoretical notes*** *They express their feelings concerning support freely.* *Nodding suggested agreement to the statements made by participants.*	***Observational notes*** *Cell phone rang and number 2 left the room.* ***Theoretical notes*** *The phone did not cause interruption as interviews continued.*

3.4.2 Methodological notes

Methodological notes are instructions or reminders kept in mind about how subsequent observations will be made (Polit et al., 2001:283). The following methodological notes were considered in the process of focus group interviews:

- The facilitator avoided asking leading questions that could elicit a ‘yes’ or ‘no’ answer.
- More observations of voluntary AIDS caregivers after they completed the focus group interviews were done.
- All focus groups that participated in the study were thanked.

3.4.3 Personal notes

According to Polit et al., (2001:467) personal notes are the written comments about the researcher’s own feelings during the research process.

The researcher made a follow-up telephone call to one of the participants to clarify her statement as it had a figurative instead of a literal meaning. The researcher consistently identified support as the most important unmet need of voluntary AIDS caregivers.

This study encourages the provision of multifaceted systems of support in order to assist voluntary caregivers who care for AIDS patients. Financial, emotional and physical hardship experienced by these volunteer caregivers needs immediate attention in order to promote morale regeneration.

3.4.4 Conclusion

Based on a preliminary analysis of data from all focus group interviews with participants, it appears that voluntary AIDS caregivers definitely need financial, emotional and physical support from their managers. Notably, most focus groups experienced unsatisfactory support from their managers.

The trustworthiness of focus group interview findings was based on the purpose of the research and the circumstances that gave rise to the research. Furthermore, the issue of trustworthiness was addressed throughout the research process from data collection to analysis and interpretation.

The execution of each step of the research process has the potential to influence the trustworthiness of focus group findings, either positively or negatively. Understanding the limitations and possible sources of bias at each stage of the focus group process enabled the researcher to take appropriate measures to deal purposive fully with threats to the integrity of the research results.

Focus groups were helpful in developing and maintaining quality improvement because focus groups worked particularly well to determine the perceptions, feelings and thinking of volunteer caregivers about issues the services or opportunities.

CHAPTER 4

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS THE STUDY

4.1 INTRODUCTION

Focus group interviews were analysed and integrated with a discussion of the literature control in Chapter 3. In this chapter the conclusions, recommendations and limitations of the study will be discussed.

4.2 CONCLUSIONS AND RECOMMENDATIONS

In an attempt to ensure that all findings are considered the researcher decided to discuss the conclusions and recommendations using the same categories and subcategories as indicated in Chapter 3. (see Table 4.1)

4.2.1 Stipend

The stipend featured prominently in all focus groups. It was, for considered insufficient and irregular resulting in voluntary AIDS caregivers' needs not being met.

Table 4.1: Conclusions and recommendations (To be continued)

SUBCATEGORY	CONCLUSIONS	RECOMMENDATIONS
4.2.1.1 ***Stipend insufficient***	Voluntary AIDS caregivers are not clear on the issue of a stipend of R500.00.	The issue of the stipend should be discussed when voluntary AIDS caregivers are recruited. Voluntary caregivers should sign a contract to indicate that they accept the stated amount of the stipend. The stipend policy must be kept flexible even during periods of economic instability.
4.2.1.2 ***Stipend irregular***	The fact that the pay date of the stipend is irregular increases socio-economic problems in an already disadvantaged group.	A schedule of payment dates should be provided in advance. Delayed payments due to unforeseen circumstances should immediately be communicated to voluntary AIDS caregivers through an acceptable communication channel.
4.2.1.3 ***No benefits***	Voluntary AIDS caregivers are not clear on the issue of benefits.	The contract must state that benefits will be provided.

4.2.2 Emotional support

The focus group interviews did not differ significantly regarding emotional support. In each group distressing emotions were significantly related to each other and to not being considered as volunteer caregivers. Participants emphasised the fact that they were uncertain about the future and are demoralised because they were taken for granted by their managers.

Table 4.1: Conclusions and recommendations (To be continued)

SUBCATEGORY	CONCLUSIONS	RECOMMENDATIONS
4.2.2.1 *Emotions and feelings*	The strong emotions and feelings expressed could indicate the extent to which the voluntary AIDS caregivers experience moral deprivation.	Managers should: Consider each of the issues raised during the focus group interviews and build a support programme around these issues. Motivate the voluntary AIDS caregivers by recognising them and by boosting their morale through giving praise where the praise is due.
4.2.2.2 *Unfulfilled needs*	Voluntary caregivers need co-operation, to be treated equally and to be cared for.	The needs of voluntary caregivers should be met through a negotiation process with management.

4.2.3 Physical support

Table 4.1: Conclusions and recommendations (To be continued)

SUBCATEGORY	CONCLUSIONS	RECOMMENDATIONS
4.2.3.1 ***Personal hygiene***	The irregularities of a stipend result in the voluntary AIDS caregivers struggling to maintain personal hygiene.	Sponsors should be involved to provide monthly packages of toiletries.
4.2.3.2 ***Risks involved***	The risk of becoming infected with diseases such as tuberculosis and HIV/AIDS is very high in this particular job.	Vaccines such as hepatitis B injection should be made administered immediately employment commences. Volunteers should be issued with a referral letter to gain easy access to public health care centres.
4.2.3.3 ***Physical needs***	A sense of belonging and group cohesion is lacking.	Sponsors should be found to provide uniforms in order to create a sense of belonging and to reduce expenditure on clothes.
4.2.3.4 ***Working environment***	The working environmental is not conducive to job satisfaction and needs urgent attention.	A quality assurance plan should be implemented and everybody involved should be made aware of such a plan.

4.2.4 Stock and equipment

Table 4.1: Conclusions and recommendations (To be continued)

SUBCATEGORY	CONCLUSIONS	RECOMMENDATIONS
4.2.4.1 ***Inadequate stock***	A shortage of stock and equipment makes it difficult for caregivers to provide quality care.	Stock and equipment should be controlled by: - Maintaining an inventory on a quarterly basis. - Delegating a supervisor to take responsibility.
4.2.4.2 ***Unsuitable equipment***	Unsuitable and unsafe stock and equipment promote infections.	Sponsors could be involved to provide stock and equipment. Quality control also applies.

4.2.5 Education and training

All focus group participants wished to further their education through training as most of them had standard ten. They expressed the feeling that they would not like to end up volunteering.

Table 4.1: Conclusions and recommendations (To be continued)

SUBCATEGORY	CONCLUSIONS	RECOMMENDATIONS
4.2.5.1 ***Job allocation***	The scope of practice of voluntary AIDS caregivers seemed to be unclear and the allocation to nurses' duties could lead to medico-legal hazards.	The scope of practice of voluntary AIDS caregivers should be clear, concise and could be discussed with caregivers on recruitment and on a regular basis. Quality assurance applies.
4.2.5.2 ***Needs for training***	Voluntary caregivers seem uncertain about their future Most of the participants wished to be trained as nurses.	An in-service education and training programme based on the needs of the voluntary AIDS caregivers should be designed and implemented.

4.2.6 Communication

Participants were concerned about problems that could not be solved, as managers did not turn up for scheduled meetings managers. If they did come they promised to solve the problems but never fulfilled their promises.

Table 4.1: Conclusions and recommendations (To be continued)

SUBCATEGORY	CONCLUSIONS	RECOMMENDATIONS
4.2.6.1 ***Attendance of meetings***	The exclusion of voluntary AIDS caregivers from meetings caused unhappiness and insecurity.	A representative should be appointed to attend meetings and provide feedback to the rest.
4.2.6.2 ***Informed about issues***	A lack of communication and information had negative effect on productivity.	Communication could improve through a hospice newsletter or bulletin on a monthly basis. All achievements and victories of hospices should be reflected in this bulletin.
4.2.6.3 ***No communication channel***	Voluntary AIDS caregivers did not know what to do when they experienced problems, as communication channels were lacking.	A hierarchical policy on how problems are handled could be provided to the caregivers.

4.3 LIMITATIONS OF THE STUDY

Convenience sampling, the number of participants involved and the setting of the study limit this study. Findings may not apply to participants and settings that differ widely. This study suggests several avenues for future research. The data presented here may be biased in that only one group of volunteer caregivers were not experiencing any problems concerning hospice managers' provision of support.

The participants of the focus groups did not statistically represent any meaningful population (Babbie, 2001:294), and data can therefore not be generalised to other populations of voluntary AIDS caregivers.

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ANNEXURE A

Report of Evaluation Committee

School of Nursing

DIE UNIVERSITEIT VAN DIE ORANJE-VRYSTAAT
THE UNIVERSITY OF THE ORANGE FREE STATE

Fakulteit Gesondheidswetenskappe/Faculty of Health Science
Skool vir Verpleegkunde/School of Nursing

✉ 339 BLOEMFONTEIN 9300
REPUBLIEK VAN SUID-AFRIKA/REPUBLIC OF SOUTH AFRICA

☎ (051) 401-2246
FAKS/FAX: (051) 4480108 SA
E-pos/mail: gnvkeg@med.uovs.ac.za

7/2/2003

Dr L Roets
Voorsitter : Nagraadse komitee
Skool vir Verpleegkunde

Geagte Dr Roets

VERSLAG: EVALUERINGSKOMITEE:

TITEL:

Kandidaat: R. N. Gxabuaa
Studieleier: DR. A Joubert
Medestudieleier:

Evalueringskomitee lede:

Prof M Viljoen	Hoof van die Skool vir Verpleegkunde
✓ Dr L Roets	Nagraadse komitee
✓ Prof Y Botma	Navorsingskomitee
NA.	Biostatistisi
M de Wet (Sosiologie)	Navorsingskundige vanuit ander Fakulteit of Skool
	Enige ander lid

AANBEVELINGS:
Besluit of fokusgroepe of individuele onderhoude gebruik gaan word. Wysig protokol dienooreenkomstig. Kontroleer wysigings met Prof Botma/Dr Roets. Daarna gereed vir etiek komitee!

Vriendelike groete
Studieleier:
Afskrif:

ANNEXURE B

Hospice Board of Governors
Request for permission

P.O. BOX 2502
BLOEMFONTEIN
9300
08 APRIL 2003

The Executive Director
Naledi Hospice
118 Andries Pretorius
Bloemfontein
9301

Dear Madam

APPLICATION TO BE GRANTED AUTHORITY TO CONDUCT A RESEARCH PROJECT AMONGST VOLUNTEER AIDS CAREGIVERS. (ETOVS NR 46/03).

I am currently pursuing a Master's Degree in nursing with the University of the Free State, and hereby wish to submit a formal request to conduct a study in your department, following our conversation at the beginning of 2003.The study is on "The perception of voluntary AIDS caregivers and support". The Ethics Committee approved my study on the18 March 2003.(ETOVS number is 46/03).

A skilled facilitator from the School of Nursing of the University of the Free State will collect qualitative data.

The researcher would like to commence with the pilot study in which three participants will be involved from the 22 April 2003 at 10:00. The main study will be conducted on the 25 May 2003 at 09:00-11:00 and from11: 00-13:00. Confidentiality will be assured by coding data in such a way that, those voluntary AIDS caregivers' identities remain concealed. The names of the hospices will also not be mentioned in the study. Participants will share their knowledge, experiences and skills thus enhancing the study.

I hope that my application will receive your favourable consideration.

Yours faithfully

Rosina Nomathamsanqa Gxabuza (Miss)

Gxabuza

Study Leader: Dr A. Joubert

POSBUS 2502
BLOEMFONTEIN
9300
08 APRIL 2003

Uitvoerende Direkteur
Naledi Hospice
118 Andries Pretorius
BLOEMFONTEIN

Wie dit mag aangaan

AANSOEK VIR TOESTEMMING OM A NAVORSINGSPROJEK TE DOEN OP VRYWILLIGE VIGS VERSORGERS (ETOVS 46/03).

Ek doen tans my Meesters Graad in verpleging by die Universiteit van die Vrystaat en ek wil graag hiermee my formele versoekrig om die studie in u departement uit te voer, as'n opvolggesprek op die een in begin 2003.

Die studie is oor "Die persepsie van vrywillig VIGS versorgers en ondersteuning."
Die Etiek kommittee het alreeds die studie goedgekeur gedurende hul vergadering gehou op 18 Maart 2003. My ETOVS nommer is 46/03.a Ervare kwalitatiewe data van die Universiteit van die Vrystaat kolekteer. Die navorser wil graag die loods studie begin met drie respondente, op 22 April 2003.Die hoof studie sal gedoen word op 25 Mei 2003. Die studie sal gedoen word in die hoedanigheid van die bogenoemde graad. Verharlikheid sal verseker word deur kadering van data op so a manier dat die vrywillige versorgers se identiteit nie anthul word nie.

Die name van die hospise sal ook nie genoem word in die studie nie. Die voordeel van die studie is dat dit deelnemers toelaat om hul gedagtes met mekaar te deel en nuwe idees kan gegener eer word rakende versorging en ondersteuning.
Ek hoop my aansoek sal gunstige konsiderasie kry.

Die-uwe
Rosina Nomathamsanqa Gxabuza

Studie leier: Dr A. Joubert

ANNEXURE C

Hospice Board of Governors letter of approval

Naledi Hospice

FORMERLY BLOEMFONTEIN HOSPICE
A Member of the Hospice Association of South Africa

PO Box 28391, DANHOF, 93
Telephone: (051) 433 44
(051) 433 44
(051) 433 44
Fax: (051) 433 44
SUNFLOWER HOU
Telephone: (051) 448 38
e-mail: naledihosp@mweb.co.

11th April 2003.

University Of Orange Free State

TO WHOM IT MAY CONCERN

Dear Sir / Madam,

Re: Research – Volunteer Community Caregivers

Permission is hereby granted for a research project to be done with our Volunteer Community Caregivers.

Joan Marston.

J. Marston
Board of Governers

"For if you do it unto the least of these, you do it unto Me." - Matt. 25:40
Fund Raising No.: 07 700241 000 9 - N.P.O No. 003/863

ANNEXURE D

Participants consent forms English, Afrikaans and Southern SeSotho

PARTICIPATION CONSENT

STUDY TITLE:

THE PERCEPTION OF VOLUNTARY AIDS CAREGIVERS CONCERNING HOSPICE MANAGERS' PROVISION OF SUPPORT.

RESEARCHER: ROSINA NOMATHAMSANQA GXABUZA

I, the above-mentioned researcher, currently pursue a Master's degree in nursing (M. Soc.Sc.) with the University of Free State. The research is about the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support.

Information will be obtained during a group discussion that will be conducted by a skilled facilitator from the School of Nursing of the University of the Free State. The interview will take +_1:30 minutes and ten respondents will participate at a time. An audiotape of the discussion will be made to ensure that no data is lost or transcribed incorrectly.

Your identity i.e. your name will not appear anywhere in the transcription or in the report. The information will be treated as confidential as possible.
Please note that, your participation in the study is voluntary. You have the right to withdraw your consent to participate any stage of the research without being discriminated against.

Participants Signature:..................... Date:..............

Researcher's Signature:................... Date:.................

DEELNAME TOESTEMMING

STUDIE TITEL: PERSEPSIE VAN VRYWILLIGE HIV VERSORGERS RAKENDE HOSPIES BESTUURDERS SE VERSKAFFING VAN ONDERSTEUNING.

NAVORSER: **ROSINA NOMATHAMSANQA GXABUZA**

Ek, die bogenoemde navorser, is tans besig met my Meesters Graad in verpleegkunde (M. Soc.Sc.) aan die Universiteit van die Vrystaat. Die navorsing handel is oor die persepsie van vrywillig versorgers rakend hospies bestuurders se verskaffing van onderteuning.

Inligting sal verkry word gedurende groep besprekings wat gehou sal word deur a ervare fasilileerder, Skool vir Verpleegkunde van die Universiteit van die Vrystaat gehou sal word .Die onderhoud sal+-1:30 minute duur en tien respondente dit in elke groep ingesluit word. 'n Opname sal die bespreking gemaak word om te verseker dat daar geen data verlore gaan of verkeerd getranskribeer word nie.

Jou identiteit bv jou naam sal nerêns in die getranskribeerder dokument en ook nie in die verslag verskyn nie. Die inligting sal so vertroulik moontlik hanteer word.

Merk asb dat jou deelname in die studie vrywillig is. Jy het die reg om te aasseblief of om jou op toestemming tot doelname op enige stadium van die navorsing te onttrek, sonder dat daar teen jou gediskrimineer sal word.

Deelnemer handtekening:..................... Datum:..............

Navorser handtekening:...................... Datum:.................

MAIKUTLO A BAHLOKOMEDI BA BAITHAOPI BA AIDS MABAPI LE BOTSHEHETSI BA MOOKAMEDI WA HOSPICE

MMATLISISI: ROSINA NOMATHAMSANQA GXABUZA

Nna, ya boletsweng ka hodimo, hajwale ke etsa lengolo la Masters Degree booking (M.Soc Sc) Univesiting ya Foreistata. Dipatlisiso ke ka ha bahlokomedi ba baithaopi ba AIDS mabapi le botshehetsi ba mookamedi wa hospice.

Dintlha / lesedi le tla fumaneha nakong ya dipuisano ka dihlotshwana tse tla tsamaiswa ke setsebi sa tsamaiso ya dipotsolotso (interviewer) ho tswa sekolong sa booki Univesiting ya Foreistata.

Dipotsolotso di tla nka bonyane hora le metsotso e mashome a mararo (+1hour 30 minutes) mme ho tla nkwa batho ba leshome ho nka karolo nakong eo.
Sehatisa- mantswe se tla sebediswa nakong ya dipuisano ho etsa bonnete ba hore ha ho dintlha kapo lesedi le lahlehang.

Boitsebiso ba hao (identity), ke hore lebitso la hao le keke la hlahella kae kapa kae raporotong kapa kgatisong. Lesedi lohle le tla nkwa ele pinyane/ lekunutu ka moo ho ka kgonehang. Ela hloko hore ho nka karolo ha hao dipatlisisong tsena ke boithapo ba hao. O na le tokelo ya ho ikgula boemong bofe kapa bofe ba dipatlisiso ntle le kgethollo ya letho.

Monka-karolo:..........................

Letsatsi:.................................

Mmatlisisi:..............................

Letsatsi:................................

ANNEXURE E
Ethics Committee letter of Approval

GESONDHEID
HEALTH

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE

Direkteur: Fakulteitsadministrasie
Fakulteit Gesondheidswetenskappe
✉ 339 BLOEMFONTEIN 9300
REPUBLIEK VAN SUID-AFRIKA
☎ (051) 405 3013 / 401 2847
(051) 444 3103
gndkt@med.uovs.ac.za

Director: Faculty Administration
Faculty of Health Sciences
✉ 339 BLOEMFONTEIN 9300
REPUBLIC OF SOUTH AFRICA
☎ (051) 405 3013 / 401 2847
(051) 444 3103
gndkt@med.uovs.ac.za

Research Division
Internal Post Box G40
☎(051) 4053654

E-mail address: gndkgcn@med.uovs.ac.za

Mrs G Niemand

2003-03-20

MS RN GXABUZA
P O BOX 2502
BLOEMFONTEIN
0300

Dear Ms Gxabuza

ETOVS NR 46/03
RESEARCHER: MS RN GXABUZA
PROJECT TITLE: THE PERCEPTIONS OF AIDS CAREGIVERS CONCERNING HOSPICE MANAGERS' PROVISION OF SUPPORT.

You are hereby informed that the Ethics Committee approved the abovementioned study during their meeting held on the 18th March 2003.

Your attention is kindly drawn to the following:

- Failure to submit a progress report not later than one year after approval of the project may result in the termination of the study.
- That all extentions, amendments, serious adverse events, termination of a study etc have to be reported to the Ethics Committee
- These documents have been accepted as complying with the Ethics Standards for Clinical Research based on FDA, ICH GCP and Declaration of Helsinki guidelines
- Translations of the Subject Information Leaflet and Consent Form have to be submitted prior to commencement of a study.

Will you please quote the Etovs number as indicated above in subsequent correspondence, reports and enquiries.

Yours faithfully

For DIRECTOR: MEDICINE ADMINISTRATION

ANNEXURE F

Letter to

Senior Executive Officer

Request to permission to enter setting

Free State Psychiatric Complex
Neuro-A-East Ward
Private Bag x 20607
Bloemfontein
9301
22 April 2003

The SEO
Free State Psychiatric Complex
Private Bag X 20607
Bloemfontein
9301

Dear Sir

I hereby wish to apply for permission to conduct a research project at Free State Psychiatric Complex, Out Patients department. I am currently pursuing my Masters Degree with the University of the Free State.I have already granted the permission by the Ethics Committee of the Faculty of Health Sciences (ETOVS NR 46/03)

I would like to conduct the research project on the 25 April 2003 from 09:00-12:00.The participants of the of the study will be two focus groups of volunteer caregivers of the hospice, with ten members in each group. I have enclosed my approval of the project with relevant details.

Thanking you in advance

Yours faithfully
Rosina Nomathamsanqa Gxabuza

23/4/2003

1, CMO/HOCS
2, Acting Head of Psychiatr
→ For your attentio
+ Action re the FSPC Ethics Committee

ANNEXURE G

Senior Executive Officer letter of Approval

M–EAST   ME ROSINA GXA

FREE STATE PSYCHIATRY COMPLEX (FSPC) OFFICE OF THE SENIOR EXECUTIVE OFFICER (SEO)

From whom: ROSINA GXABUSA

Date Received: 03/4/2003 **Received by:** [illegible]

Subject: RESEARCH PROJECT

Priority: ☐ HIGH ☑ URGENT ☐ ROUTINE

ACTION:

a) Please refer to: CMO/HOCS – Dr Masitha

b) Make copies for: 1. Acting Head of Psychiatry – [illegible]
2. Dr Calitz Head of PSS

☐ Signature
☐ Revise / Comment / Suggestions
☐ Discuss with me
☐ Please approve
☑ Handle promptly, Please.
☐ Handle with FSPC - Extended Management
☐ Handle with FSPC - Executive Management
☐ Prepare draft reply for signature of: SEO / CEO / ....

☐ Send me a copy of reply
☐ Issue medical report ASAP
☐ For information
☐ Return to me
☐ Contents noted and returned to you
☐ Refer to FSPC - Mental Health Review Board
☐ Refer to or handle with Complex Hospital Board
☐ File

REMARKS / MESSAGES: (a) Please handle with the FSPC – Ethics Committee. (b) From SEO-office side approved in principle

FOLLOW - UP: ....

DEADLINE: 25/4/2003

DATE: 23/4/03 SEO'S SIGNATURE:

MR STC MOHAPI
SENIOR MANAGER / DIRECTOR
TEL: 4079260 OR 4472155
FAX: 4079391
E-MAIL ADDRESS: mohapist@doh.ofs.gov.za

ANNEXURE H

Transcriptions of focus group interviews

ANNEXURE I

Pilot study

TRANSCRIPTION

INTERVIEWS: PILOT STUDY

FACILITATOR:	Dr L. van Rhyn
RECORDER:	Dr A. Joubert
RESEARCHER:	R.N. Gxabuza
PARTICIPANTS:	Three (3)
VENUE:	Free State Psychiatric Complex
DATE:	22 APRIL 2003.
TIME:	09:00 - 09:45

Facilitator:

"Good morning, my name is Lilly. I am doing the interview for Thami for the research pilot study, and you can please feel free to speak up and say what you feel free to speak and say what ever because I'm not going to ask your names and so there is no mentioning of names on the tape and we destroy the information after she transcribed it. So please you can answer in English or Afrikaans. Okay the question is this: I would like to talk about your experience of support provided by hospice manager in your caring for AIDS patients?"

Participant (2):

"The support we get, the support is there but not satisfactory for us because they got funds but they even come from overseas but they don't even speak to us about the funds and the allocation of that, so the support is there but not satisfactory."

Facilitator:

"So would you mind to explain a little bit a little bit more what do you mean by not satisfactory?"

Participant (2):

"First of all if you render a service, you do it from your heart then thank you must be there and a thank you mustn't be quiet sometimes. Okay we are not expecting them to pay us as volunteer but the thank you is there and was said by the minister of health that we get thank you of R500.00. Sometimes we get it even it on monthly a R500.00 but you find out that the first week of the month end and we don't get the money that you will not get money because of 1,2,3 second week we earned or third week we earned. The date for the salary we don't, we don't have the specific date of the salary, and so you pay after, after maybe a week time after the month end."

Participant:

(1)said something about volunteers and laughs…(inaudible)

Facilitator:

"So you say you don't get the money, but you don't know the specific date?"

Participant (2):

"Yes, and the thing that makes us to be unfortunate is that these people if it was not being said that we are going to get something to get pay for what we are doing, maybe we wouldn't take it so seriously."

Facilitator:

"Is that a problem on your side?"

Participant (2):

"Yes is a problem."

Facilitator:

"What is the conne…"

Participant (2):

"The support uh they give us, like if you are in the child care centre, the managers will come and ask you how are you doing with that patient, so they don't give us that support, being there about this problem."

Facilitator:

"So…?"

Participant (2):

"In other, we need the support when we care for the patient who is sick, the other thing is the support is that we, if they were giving us a it was that the thing that we are getting to is the support they are getting outside, we must be supported in everything for example from outside or within what is going on, so that we can give more work, like the other thing is that there are some of us who get the salary, so I don't know because people don't highlight us, but I think they don't get R500.00, they are earning more than us and they pay the salary and the people who are getting the salary must do more work, we are doing the same job, the treatment differ especially with time."

Facilitator:

"How could you make suggestion? So what do you experience?"

Participant (2):

"The volunteers they use their time in volunteering, not that there are some that are working night duty. The time must differ because others they earn more according to the salary and is not enough to us."

Participant (3):

"They should do anther extra job except the one they are doing."

Facilitator:

"Does some of you work night duty?"

Participant (2):

"Yes, some of us and we are time to time told that we must remember that we are volunteer and we are still a volunteer."

Facilitator:

"So you don't …does it really mean...?"(Inaudible)

Participant (2):

"According to my knowledge, hospice is receiving too many funds and volunteering, volunteers is there because very they must create job because I did office practice in secretary."

Participant (3):

"But she treated as if I have nothing because some she is like someone from the street who is not having anything which is wrong."

Participant (2):

"Of which is wrong what hospice is doing to us. They are going out there we are going to influence the other, don't go there because they are treating us differently meanwhile we are, treating our people suffered and instead of motivating us, they are discouraging us."

Facilitator:

'Let's talk something about the job satisfaction."

Participant (3):

"By going to work it doesn't mean you must go and sit at the bench of your work. You must enjoy doing your job. So when you see people waking up in the morning speaking that they are going to work and then when you come to work you are not doing your job."

Participant (3):

"Ons moet werk as julle lekker werk, so kan werk dat julle rus, ons kan so gaan werk. You are sitting and gossiping when are you going to finish the work…"(inaudible)

Participant (2):

"I think the job is endless, we are there to relieve each other because there is night and day duty, so that job is endless if it could come to an end then this will be something…"(Inaudible).(other Participants nod.

Facilitator:

”Any other suggestions regarding the support you would like to make?”

Participant (2):

“Our supervisors are not satisfied with the work, they criticised us all day work is done but not good enough…”(inaudible)

Facilitator:

“Any other suggestion regarding the support?”

Participant (3):

“They don’t give us the feedback of what was discussed in the meeting, we volunteers we feel as if we are not part of hospice because we are excluded in the meetings, they say you are voluntary workers you don’t go to the meeting. Another thing is that they don’t give us feedback.”

Facilitator:

“Any other suggestions…opinions?”

Participant (3):

“Ja ons is genoeg, wat ek kan nou sê, want ons het nie genoeg voorrade van pasiente.” “Yes, what I can say presently we are satisfied, we don’t have enough stock for the patients."

Participant (2):

"And the other thing is that when you are ill is your own is your own, you must go to the doctor yourself. If you are ill you will see what to do about it and even if we need something to lift our spirit up so that at the end of the day you don't end up saying hey...(Inaudible). The R500.00 is too little because we buy soap, that support will make us smile. You won't wash yourself without soap. We are suppose to be clean, they should provide us with stock, like for instance, yesterday babies were having diarrhoea. So the, the in charge told us that there were no nappies will be taken out because a day we should use a certain number of napkins, so is painful we struggle."

Participant (3):

"Really no one can control the diarrhoea, it makes us to work but the work is uncomfortable and diarrhoea is uncontrollable."

Facilitator:

"So what did you do about it?"

Participants:

"We did nothing because there were no nappies, but children suffered."

Participant (2):

"The other thing is that the 500.00 we get is too little, we know is thank you, but we used for transport and we spent 200.00, and we buy soap to wash, we cannot work patients dirty. So from that R500.00, you still buy food, and another thing, if you are sick you responsible, no medical fund for us."

Facilitator:

"So you want medical fund."

Participants:

"Yes."

Participant (2):

"Again the hours of work should improve."

Facilitator:

"How they should improve?"

Participant (2):

"They should improve for voluntary caregivers, should not work shift hours, the full time workers should do shift hours."

Facilitator:

"How many hours do you work a week?"

Participant (2):

"We work twenty four (24) hours, and the transport allowance disappeared into thin air as it used to be there."

Facilitator:

"Were you getting transport money?"

Participant (2):

"Yes, we were getting it, but since the government give us the thank you of R500.00, it was stopped without consultation and food prizes are up."

Facilitator:

"Anything else?"

Facilitator:

"Okay, I would like to thank you for participating in the study and for the suggestion you made. So please uh keep it up with the good work you are doing."

ANNEXURE J

Focus group 2

TRANSCRIPTION

INTERVIEWS: FOCUS GROUP 2

FACILITATOR:	Dr L. van Rhyn
RECORDER:	Dr A. Joubert
RESEARCHER:	R.N. Gxabuza
FOCUS GROUP:	Nine (9) Participants
VENUE:	Free State Psychiatric Complex
DATE:	25 MAY 2003
TIME:	11:50 - 12:25

Facilitator:

"Good morning, my name is Lilly, I'm doing interviews, for Thami for the research she is doing. And you can please feel free to speak up and what you feel free because I'm not going to ask your names. And so there is no mentioning of names on the tape and we destroy this after this after she transcribed it so we are asking you to speak Afrikaans or English. I am going to ask you the question is that I want you to tell me about the support you receive from management in your work as volunteer."

Participant (9):

"The answer is we are not getting any support from work, from the management. So we are getting uh…transportalize money from the department of health. So we don't know cause hospice does nothing for us, she does nothing for us."

Facilitator:

"If you say nothing support and you do get financial support from Department of Health that's what you say…?"(Inaudible)

Participant (9):

"You know what miss the only thing that the R500.00 is not enough because we are working at Botshabelo institution, so because we are part of the hospice, hospice must be give us and then get R500 from the Department of Health, at least give us R300.00 to make R800 because we are working for the patient and we must wear skoon (clean) clothes and you go to the location."

Facilitator:

"So you are suggesting that they should add so that you can put clean clothes and for transport is what you say?"

Participant (1):

"Included last month we wrote letter to the hospice and give them the letter till now we don't have any answer from us. Since from last year we enclosed six or seven letters ask them don't immediately respond properly till we go to Bloemfontein and till ask Miss Joan here at Bloemfontein hospice and they say they don't have money. When they say don't know because the money that comes from outside those people. They fundraise each and every month and when there is money they become from don't bring money or say this is for Botshabelo, they don't tell us that this is for…so we don't have some money something like that."

Participant (3):

"And the other thing we got reported of them patient because they need the doctor sometimes but we don't have the doctor for their patients."

Facilitator:

"How does it affect you?"

Participant (3):

"It affects us because always the patient needs a doctor but you don't know what to do, you take to the clinic but sometimes they say they don't have the treatment, so we got a problem of the treatment in Botshabelo on an HIV and AIDS people."

Facilitator:

"I am going to link everything you said back to you as a person, so do you said that it is a problem for you when there is no doctor available for the patients?"

Participant (3):

"Yes."

Facilitator:

"Can you elaborate a little bit on that, what does it cause for you?"

Participant: (3):

"We got a patient who were very ill, them need a doctor because we take them to the clinic, the clinic don't have the treatment. Sometimes they don't have even a cough mixture, so if we have that doctor, the special doctor just like here in Bloemfontein, they can give something for them after they checked that patient but they didn't."

Facilitator:

"How does that make you feel?"

Participant (3):

”Sad, because if you work on a patient and is very ill and you don’t know what to give her to do is very painful.”

Facilitator:

“So the affect of that is really emotional?”

Participant (8):

“Is emotional, is emotional.”

Facilitator:

“So we have moral response and we have emotional part when you see patient who need some help and you don’t know what to do. Any other….anything about support?”

Participant (1):

“The other thing is that the management of hospice they don’t support us. Because of in Botshabelo is a branch of Naledi and they don’t the, is something like a co-operation between the Department of Health and Botshabelo. Maybe hospital or the clinic because these people they don’t treat us correctly because they don’t attend there to tell the people, clinic of Botshabelo to know us then that thing cause the negative attitude.”

Facilitator:

"So you say that the management doesn't know you?"

Participant (1):

"They know us but as management they don't, they don't attend we, need something like a sister or a professional nurse, to supervise us then we don't have it."

Facilitator:

"you don't have a supervisor?"

Participant (1):

"Yes we don't have it."

Facilitator:

"May I ask you, who is supervising you?"

Participant (4):

"Presently, we because we know the work."

Facilitator:

"But that you say that cause a negative attitude?"

Participant (1):

"Sometimes we take a patient to the clinic, then maybe the sister in charge for, but that time, they don't accept the patient. Why because she say hospice is a big organisation so why you came here to attend the patient at the clinic, hospital because hospice is getting funds from the government and from the outside the company."

Facilitator:

"So you think that causing a negative attitude in you is that because you are not supervised."

Participant (4):

"There is no.."

Facilitator:

"Do you want to say something?"

Participant (8):

"The other thing as we are volunteers from hospice we don't have a centre we are working at the church."

Facilitator:

"How does that affect you?"

Participant (8):

"We want to have our centre."

Facilitator:

"Uh.. You are working from church?"

Participant (5):

"Yes."

Facilitator:

"From church you go out to patients houses."

Participant (8):

"On Wednesday we go to the church and on Monday and Thursday we go home, we are fieldworkers so they say if you get an accident when you are on the way a patient is, is nothing to do with the hospice..." (Inaudible)

Facilitator:

"So what are you suggesting?"

Participant (1):

"It must uh.. Maybe I get injured then an accident, they must see to it that I

go to hospital and give money for that to pay that for me…"(Inaudible)
Facilitator: "So you are not insured?"

Participants:

"No."

Participant:

"So you are not injured?"

Participant (1):

"No."

Participant:

"So when you get injury on duty…so what do you get when you are injured on duty?"

Participants:

"Nothing, nothing we don't get anything when you get an accident going to the patient, there is nothing that you will get."

Participant (9):

"When we ask they say is our business, can I ask you a question ma'am?"

Facilitator:

"You can ask a question."

Participant (9):

"I want to know ... last year we, we, only get R500.00, that is funds from AIDS donation, from the department of health, we don't know when that R500.00 started when they promised that to give us in April, but we got it on November. We want to know what is going on there at hospice…"(Inaudible)

Facilitator:

"So you are asking that there was this promise about R500.00, but you don't know when it actually have started?"

Participant (9):

"This promise started in November."

Facilitator:

"Maybe is a question to ask the management."

Participant (9):

"Of hospice?"

Facilitator:

"Ja."

Participant (9):

"Shuu"

Facilitator:

"There is confusion ja, what you are saying, your concern is that there is confusion about when should you started paying this R500.00"

Participants:

"Ja"

Facilitator:

"What do you think you can do about it?"

Participant (9):

" I don't know what we can do but…"

Participant (7):

"And the other thing is that when we are making a report, we are make the, the, the district Motheo report and the hospice report but we get only

R500.00 from the Department of Health, from hospice we get nothing we are just their volunteers."

Participant (9):

"We want to know why do we write for hospice yet we don't get nothing maybe that report why it goes to hospice because they don't give us nothing. If it goes to maybe, if report goes to that person who gives us something it was good…"(Inaudible)

Facilitator:

"So you feel that. …"

Respondent (3):

"We Botshabelo hospice, we, we get funds from AIDS foundation but we don't use that funds know where it goes because we get that R500.00 from the Department of Health. This R300.00 of AIDS donation we don't know where it goes."

Facilitator:

"Is that a person that R300.00…Respondent (9): And that is not from hospice management?"

Participant (1):

"Hospice management gives us only food for day care for other volunteers."

Facilitator:

"What is the problem then?"

Participant (7):

"The communication…"

Facilitator:

"Would you like to say something?"

Participant (1):

"She maybe she want to say that the hospice support us only for food for the patients and for the orphans only from there…Respondent: (7) " They sent groceries every month."

Facilitator:

"So do you need some more funds for food, is what that you say?"

Participants:

"Yes."

Facilitator:

"For whom?"

Participants:

"For patients…

Facilitator:

"That is at home?"

Participant (9):

"Because they care for patients and children that are HIV and so that children come on Monday and Friday, so they use that food. They go to the centre because there is no food at home. So our side as caregivers they don't support us. The patient go to centre to us, they don't support us."

Participant (3):

"And we do the work for hospice"

Facilitator:

"You think you should get support in the form of food for yourself?"

Participants:

"Not we, for the patients because others don't get a grant."

Facilitator:

"They don't?"

Respondent (8):

"They don't receive grant other patients."

Facilitator:

"Okay, so what suggestion in what..."

Participant (2):

"They give food parcels every month those who don't receive grants"

Facilitator:

"Give them food parcels?"

Participants:

"Yes food parcels."

Participant (8):

"And other thing at Bloemfontein and Botshabelo we do the same work but we get a different money, in Bloemfontein they get more money in Botshabelo we get only R500.00 and when you ask R250.00 is coming from hospice and R250.00 comes from Department of Health."

Facilitator:

"You say something different now, what is being said is that R500.00 comes from Health. You say now half of that is coming from hospice. The fund is coming from department of health."

Participant (3):

"We said that in this R500.00 is come from Department of Health and R250.00 comes from AIDS foundation."

Facilitator:

"But you say there is a different in payment between Bloemfontein workers and Botshabelo workers."

Participant (1):

"Yes, here at Botshabelo there are some volunteers who don't, but at Bloemfontein there is no one."

Participant (9):

"If something is happening in Bloemfontein it should happen at Botshabelo. Every time when you come here is not happening we get a new volunteer. When you ask when it started he/she would say after three months, about three months. But we here for six years is not happen that's why we say maybe is, so that we say favour of people of Bloemfontein here in Botshabelo, we don't know what is going on…"(Inaudible).

Facilitator:

"Are you say are you left or you don't know what is going on. You don't have enough information is what you say?"

Participant (9):

"So because they don't tell us anything that is maybe there is changes, maybe something that is happening with the hospice, they must tell us that this, this and this of hospice or maybe this is a hospice week, they must tell us anything something like that. They don't treat us well. They don't treat us. Sister doesn't phone us if somebody ask us about today is hospice we say we don't know nothing, something…"(Inaudible)

Facilitator:

"So there is a communication lack?"

Participant (9):

"Lack of communication. They don't treat us well, they treat us just as volunteers, even when there is a meeting. They don't tell us something, there is a meeting or something like this an this and we don't have any person from Botshabelo who is included in the management of hospice, everything that happen we don't know about."

Facilitator:

"But what you say manager or the supervisor can attend the meeting, something like that and give you feedback, but now there is this lack of communication. Something else…ja?"

Participant (3):

"Hospice didn't care for us, but when for example there is a guest from Overseas they take them to Botshabelo."Facilitator: "Uh…" "as if hospice fundraise with us and we get nothing from that people."

Facilitator:

"So they use Botshabelo as an example for overseas visitors?"
"In order to get some funds?"

Participants:

"Yes."

Participant (3):

" And they use these funds for themselves we don't have a cent."

Participant (9):

"And last year on the December there were some other guest that came so they ask me, they question my name and I say my name is mang-mang (so and so). They ask: Are you employed?" "I say, no." "They say awu (really)." " I say yes." "So how do you manage?" "I say I'm getting only transport allowance." They say: " why because this place is a big place and must be permanent job." " I say I don't know maybe you can talk to our managers and they say they must no do that. And they ask me the, they say that thing is not good we must have our, and again they don't come in Botshabelo since they come from Botshabelo last year…"(Inaudible).

Facilitator:

"Now what would you suggest or talk about some suggestion regarding the support that you should receive. We have some suggestions already, but I would like to add on some suggestion about poor communication you said that with supervisor, maybe can improve communication, that is the suggestion, if you…what suggestion you have further on to regarding the… provision of… support?"

Participant (2):

"And they must come. Come to us they must n't think okay we know our work, we are doing a good work but they didn't to us even once a month, to come and sit with us to have just a meeting with us they didn't come and we need that."

Facilitator:

"From management?"

Participant (8):

"From management. The management have must put something on that R500.00. Because we are going to the patient with that R500.00 and then we have to be clean before we go to the patient. And we have to eat sometimes, when you at the patient there is no food to eat before the treatment so, so you had to take out of your pocket and buy some bread for the patient, they must put something out of that R500.00. The R500.00 is too little because we travel many different sections.

Facilitator:

"in the community."

Facilitator:

"So there is a lot of transport?"

Participants:

"Yes."(Inaudible)

Participant (8):

"for example, like me I had to travel double before I go to the centre."

Participant (1):

"Even to me to meet a patient we travel double and we attended a patient the whole week."

Facilitator:

"You go daily?"

Participant (1):

"Daily, the whole day. We are attended the patient. And the other thing is that I, we wrote some many, many letters to Bloemfontein management of hospice but I ask now if we, we suggest many suggestion here they will come right or what? Because we wrote so many letters to the management of hospice."

Facilitator:

"Now we can't promise but that I think is that we can make suggestions and the researcher is going to take that up. But it will take time before the result is available. The researcher will part of the Ethics of the research is that you publish the results to the institution like hospice and it will be available for everybody who participated in research but that's all can do from outside. Is to make them aware of the suggestion that was found in the study. What they do about it is unfortunately, you know. But the research is there to improve the situation. There that's why we do the research, if they let's say maybe we hear from the researcher's side there is a possibilities they will react. Maybe they haven't react to hear it. From your side, but this is scientific knowledge because, because we get experience you had in support to receive and suggestions you've made to improve. We can't just go and say. It is like the scientific proof."

Participant (9):

"And the other because I maybe, they ask me a question. why they don't give us something because the government is, they said and in hospice why they don't us R200.00, they the Department of Health and the hospice, so I ask myself why they don't do that because we are helping the community, at the community, so I don't know."

Facilitator:

"But the concern is stays with the financial."

Participants:

"Mmh…"

Participant (9):

"Because we are breadwinners."

<u>Facilitator:</u>

"Ja…."

<u>Participant</u> (3):

"And we are doing a good job for her and some other times we are, when we are sick I don't have other money to go to the doctor,"

<u>Facilitator</u>:

"Does that affect you?"

<u>Participants</u>:

" Yes."

<u>Facilitator</u>:

"What else? How does that affect you, in which ways can affect you?'

<u>Participant</u> (8):

"They also promise us that will even get something for example will get the injection but we didn't receive."

<u>Facilitator</u>:

"What type of injection."

Participant (8):

“Protection…yes.”

Facilitator:

“And you haven’t receive?”

Participant (3):

“Mme, this job of volunteering is dangerous because as we are caregivers we are going to visit that patient and the HIV and AIDS patient sometime got TB, sister promise us to get that injection but they didn’t give us until now.”

Facilitator:

“At the protection of this HIV?”

Participant (3):

“HIV and TB, some of us, we don’t know maybe we are having that TB.”

Facilitator:

“So you are saying you are concerned about contacting illness like TB?”

Participants:

"Yes."

Facilitator:

"Would you like maybe talking a little bit about dangers of the job."

Participant (1):

"What I want to say is that the dangerous of the job is so many, dangerous because the other thing is that, as a community they expect something, like good hope from us. Maybe I attend patient at home, then some patients they stay alone or a child only they leave their child. So the community they judge us as if we the, we the hospice, we give some money or the department they give the money to assist that patient, they died, they died and the families and the relatives of this patient they expect something to assist to bury the patient."

Facilitator:

"Because they think you get the money from the hospice?"

Participant (1):

"Yes, they think I get money from…and the other thing about the resource. They don't have linen and gloves, we are struggling to get from, to the Bloemfontein and transport. Maybe to give us that there if the patient to protect the to us, we don't have it sometimes, we use the plastics for maybe that and that for patients."

Facilitator:

"So there is lack of equipment? It is only gloves or is there other equipment also lacking?"

Participant (1):

"It is only the gloves, sometimes they are lacking, sometimes why because they don't, they don't go out and ask you should be doing what then they come.. ha ke tsebe (I don't know) when and what and what."

Participant (9):

"Last time we ask a medical kit or maybe the patients medical kit to protect yourself and to help the patient, the hope." patient is have a hope to us."

Facilitator:

"So what happen to you when you visit patient and you need some medical equipment to help the patient and you can't do it because you don't have medical equipment?"

Participant (9):

"I must have something to treat the patient because the patient he/she expect something from me, because. So I don't have that, I speak with her, so I felt that, I go so that look I must help that patient why because that is my job I do with risk."

Participant (8):

"I can't do my job because they told us to help a medical cleaning, sometimes is the first time you go to the patient and then you reach the place and there is that smell in the house you can't breathe and that thing can affect you."

Facilitator:

"And then…?"

Participant (8):

"Smell, smell."

Facilitator:

"How does that affect you?"

Participant (8):

"When they have bedsores there is smell."

Facilitator:

"Does that affect your health?"

Participant (8);

"Health."

Participant (6):

"We will be glad if department give us R500.00 after deductions even if it deducts for funeral plan or pension for retirement when we had for retirement we don't get money because we are volunteers."

Facilitator:

"So you say there is nothing like pension fund? Is what you say? Sick or when you get sick?"

Participant (6):

"No benefit."

Participant (8):

"And we like our work and the other thing we need transport for the patients to take them to clinic or doctor to hospital."

Facilitator:

"But how we see we don't see now it as new complaining and sort of about managers talking bad about them we talk about since, that's why I'm glad to see you enjoy your job. Research is there to help you to make easy and let you keep you doing this job because you are doing a good job."

Participant (8):

"And the other painful thing is that the hospice management always launch the partnership with other companies and they use us to make a research for that company and partnership and as habit, they use us to do the research after that we get nothing and then, launch the partnership between them and hospice and they always, but we get nothing from hospice."

Participant (3):

"The other thing is that, the management of hospice, I'm sorry to say that they undermine their Botshabelo community, Botshabelo why I would am saying because they don't accept us like human. Because we don't have opportunity like maybe the industry or firm like in Bloemfontein why because Bloemfontein, they are rich rather than Botshabelo."

Facilitator: "They use the poverty for their benefit?

"

Participant (1):

"For, for their own, Bloemfontein… they undermine us."

Facilitator:

"Any suggestions…comments?"

Participant (9):

"The suggestions that I think is that if Botshabelo they…maybe the Bloemfontein management they get a delegate to include at the management. Maybe then will be better for us the first suggestion that may be to include one of us to the management maybe it will be better."

Facilitator:

"As part of management."

Participants:

"Ja."

Participant (9):

"As volunteer at hospice we want to, we don't want to work longer time in a church because we are not working the people of the church, say is their church cause we don't know for how long are we going to work there. They don't know about us, so there is a problem and with the management of the board and the board church. There is a lack of communication, they don't take us."

Facilitator:

"Anything else…questions. Regarding the support?"

Participant (4):

" I think for now it will be better if can fundraising to be independent, ask them that they don't accept."

Facilitator:

"You say Botshabelo shouldn't be a branch, should be independent?"

Participant (9):

"We ask them they don't accept."

Participant (4):

"If we have no food for the children, we know is our problem, no one can help us, unless we can see how we get that."

Facilitator:

"Okay, other support suggestion?"

Participant (9):

"I am having a question?"

Facilitator:

"Is it regarding this subject?"

Participant (9):

"No."

Facilitator:

"I would like to thank everyone for coming, we appreciated a lot. Thank you for you time and inputs I think you are doing a great job, keep on doing it and the results will take time, it will depend to students how fast she is going but thank you and good luck. She is doing .She chose the topic for research to look at the support of volunteers at hospices."

ANNEXURE K

Focus group 3

TRANSCRIPTION

INTERVIEW: FOCUS GROUP 3

THE FACILITATOR:	Dr. L. Van Rhyn
THE RECORDER:	Dr. A. Joubert
THE RESEARCHER:	R. N. Gxabuza
FOCUS GROUP:	(10 Participants)
VENUE:	Free State Psychiatric Complex
DATE:	27 May 2003-07
TIME:	09:00 - 10:15

Facilitator:

"It's colds outside. Okay, I want you to feel relax. I wanted you to say anything you would like to. I' m not going to ask you your names and there is reason and we can't identify you on the tape if we don't know your name. So I won't address you by name, is just part of confidentiality and anonymity. So, I'm going to start by asking you one broad question and I would like you to elaborate on that. So I would like you to tell me about the support you receive from your Hospice Managers."

Participant (6):

"There is poor, they don't take care of us, if sometimes we call them and we want to have meeting with them, they don't come they always try to postpone, even if they come they don't answer us the way we ask them."

Facilitator:

"Can you elaborate a little bit what the need of meeting you call?"

Participant (6):

"Sometimes we get our money late our stipend, so we call them to ask them about (he stipend, why we get that late, they told us that we will always receive on the 30th. On the 30th but sometimes we get them f on the 20th, sometimes they double them 3the next month, so on the other side when we call them don't answer us on that, they only tell us you will always remain being volunteers we won't be permanent."

Facilitator:

"So is the main thing that you would like to have a meeting so that you talk about the money, and then you experience is that they don't come…?"

Participants:

“Yes…”(Inaudible)

Facilitator:

“So you get some counselling from your managers?”

Participants:

“Yes, yes.”(Coughing)

Facilitator:

“And then you experience if they don’t come…”

Participant (9):

“About the support. We don’t get any support from them, even by stipend each and everything, by equipment and all sort of things they don’t support us because we are, if you have some patients that are (critical you have to make a way on your own to get equipment from Health Department and then they promise that some of management in the, the hospice they don’t know they just tell with you the equipment, you know because as a volunteer you are not recognised as someone who is doing something that is very important, and then in the issue of the stipend5 and all that say, that I mean since we get them last month and then they promise us that we will get the stipend 6) on the 10th, somewhere somehow the 20th.And then we left behind with three months. So is just that we cannot rely e on them because our lives. We have children that we have to support, we have accounts, and we have the rooms that are paid and then if you promise someone to pay and then you go to the bank. And then you don't receive the money, and then is very detrimental because you promise. The person all that on the 10th I am going to give you the money and then and then when you come back and you give an excuse and then when you call them, they say on the 17th. On the 17th of April, when you go to the bank again. You don't receive that money. And then you go back to the person to give him another excuse. That is why I say, the issue of hospice I don't know whether, I don't see any necessarily for them to say that is a co-ordinating NGO that is taking care of the caregivers because there is no care that we are talking about."

Facilitator:

"So you talked …I just want to follow-up, you talked equipment can you be more specific about that?"

Participant (9):

"Okay, about the equipment I mean like dressing equipment, gauze and all that and medication, gloves we lack them because somewhere we go to the clinic they don't have gloves, they said we must use plastic bag, so is not safe to use a plastic bag"

Facilitator: "Is that equipment that actually got from hospice?"

Participant (10):

"As a co-ordinating NGO we expect them to make sure that all our needs they fulfil them .You see we don't expect them they call themselves a co-ordinating NGO. But they don't implement all their mandate that has been issued by the Department of Health because somewhere somehow they don't know our patients, they don't pay a visit to see, they don't know that nothing."

Facilitator:

"Ja."

Participant (9):

"On that note as hospice is a co-ordinating NGO they need to know about needs and needs about the patient, like if you are in-charge they need to know what is really happening on the grassroots level. The only thing they know is that the they all need statistics that is the only thing they wanted every month three months statistic, then what about our patients? What about materials that are needed? They don't even provide. They are suppose to be they're, asking us. What really need, what is happening there, then we call the meeting with them. The work will go easily and smooth, but they don't do that. The only thing they know is just statistic and the money will come late that is the only thing they know. They don't have good working relationship with us but when they appear there in front of the people they will say " you know we've the people that work who are under us we are working very well there is a good relationship. But is not there, they can't even co-operate when they call we them and please, what about, they only give an excuse that what they only know very well, so we need that to be straightened up we are not satisfied."

Facilitator:

"So you say they don't know what is going on up there?"

Participant (9):

"Ja, they don't know they know just only just statistic that's one thing that would like to have, from there they don't know what is needed."

Participant (7):

"The other thing that I would like to add on behalf of that I would like we need a policy."

Facilitator:

"Of what…?"

Participant (7):

"Because we are affected, we don't have nothing."

Facilitator:

"Okay, I will come to you…is that one of the suggestions because at the end we will follow up. I'm going to ask you what are some of the suggestion you have regarding the support that you receive, but before we get to the suggestions can we. I would like us to really uh elaborate on your own experience of the support that you receive at the moment."

Participant (3):

"On top of that, when step-down was open on the 17 April 2002. Hospice promise us that they will come regularly every after month-end of the month to come and look around everything but it never happen like that. For instance in our environment, the ward that we are using on the weekend there is nobody who is cleaning and is very wrong for the patient of TB because they had to be admitted on a clean environment. So it does n't like that. It is difficult for us to go to the management of the hospital because I think the hospice they are the one who will have to come to the hospital to contact with the management. So one weekend the whole wards was very dirty and you can even go you will see on your own."

Facilitator:

"But this absence of cleaners, how it affect you experience that?"

Participant (3):

"The thing is like, if the patient is urinating on the room and sometimes the urine is on the floor, the family is come and visit-you'll understand if you can go there and visit you and that smell is not quietly okay and you will never forget, so the family they will look to us think that is our problem and our carelessness."

Facilitator:

"Okay, I see, any other suggestion?"

Participant (4):

"We call a meeting every time. The hospice promise to give a uniform, but until now they have not."

Facilitator:

"You would like that, what you would like to discuss about in the meeting, how that meeting will help you?"

Participants:

" Yes."…. (4): " And they must communicate with us in the meeting for problems in the ward."

Participant (6):

"I was adding on that on the purpose, so I think the purpose was they told us that they will come every month to see did we deal with the patient and how the sisters manage us, so they never do that and they like to promise us many things but even one they don't fulfilled we always suffer the promises of them."

Participant (5):

“Some of the things is that they don’t even know us. Sometimes I go there and talk about the, our stipend, they don’t even know me, unless I told them that I am the supporter, so and so, so they don’t take us seriously, not at all, they don’t even visit hospital. And one other thing, today they told us about something, somebody who is in charge, next time when we go there, they told us he/she no more there, they take someone, so you don’t know where to cry or who to talk to when you have some problems. So we are not sure about our stand. Yes.”

Facilitator:

”Do you want to say something?”

Participant (6):

”On top of the stipend- if we don’t phone they don’t care so if we don’t phone they don’t care, if we don’t phone to tell us what is going on with the stipend then we must phone first to ask.”

Participant (10):

“On that note you know that issue of stipend the department, we don’t know whether who is who. Because when we call them they say the department they didn’t give the money on time. When you go to the department gave money to them, so that makes us confused and then in the issue of uniform you know uniform is important because we go in the township and then is a good way to identify ourselves. Because when you go in a house hold of someone you have to be well identified and the person cannot trust you if you don't have any uniform and then it is difficult to do your job without a uniform."

<u>Participant</u> (3):

"The other thing that we are not considered they don't take us into consideration. There is a time when we needed our stipend and then nobody contacted us or solves our problem. We were the one who are supposed to phone them. When we phone them is the minute we know that they come across the problem that somebody who was in charge of the money for stipend he revenged. So we are suffering from somebody who has lost the pin code or what ever. So I think if would be considered they should have contacted us to tell us."

<u>Facilitator:</u>

"So you say there is a lack of communication?"

<u>Participant</u> (3):

"Lack of communication that is why I say we are not taken in consideration they just take us for granted."

<u>Participant</u> (6):

"Two months back step-down was closed and no one called us and tell us that step-down is closed. We went there with our transport and find nothing in the ward; the only thing is that when we asked the sister in charge she told us she don't know nothing. The only thing is we must go back to our co-ordinators to tell us what's going on. But it is very difficult to go to the co-ordinators to us them because we are working with the sister. The only thing is that the sisters ask what is going on why she can't tell us and last time I was on night duty and I went there it was nothing I found the ward is dark and no light."

Participant (9):

"To elaborate on that there is a lack of communication at hospice they don't like to communicate with us. They just keep on promises which they don't fulfil is not right."

Participant (10):

"The other thing is that when you are volunteering they keep on telling us that we are volunteers as if we don't know that. We were many when we started volunteering so others lose hope as we were not paid before and they decided to quit. Maybe one day we will be employed permanently. I don't know what will happen because the number we had before is decreasing. I don't know what to do, I'm thinking to quit, sometimes you go to the house hold and find a patient in a mess and you don't have material to work and the family of the patient think that you are lying when you say you don't have material or equipment, unlike in the ward or something because in the ward you have at least somewhere we don't have masks and then some one has just messed him or herself and then this mess affect you because right now my chest doesn't know what is happening, I don't know whether maybe I am sick or something."

Facilitator:

"Any other comment or suggestions?"

Participant (8):

"The other thing I am addressing is that when we are raising issues with them they told us that if you are a volunteer you will remain being a volunteer, so, that thing makes us hopeless because we are trying to know something and we want and experience although we know that we are not nurses. So that thing makes us hatred to them."

Facilitator:

"Hatred?"

Participant (8):

"Yes, because they don't take us seriously and they told us if you are not going to work you can leave a job at any time but now we are hungry we are suffering yes."

Participant (3):

"The other thing of equipment I think the situation that we are experiencing is still the same as we every time when we want to change the patient there is no gloves, is still the same, so like for instance when step-down was closed somebody from the department of health came and the only thing she told us, she said to us when you are a volunteer you have to be responsible meaning that you had to be specific to be on the dot as specially for us we are we are travelling double transport so that responsibility, I mean yes, you are responsible for yourself but, I mean we need encouragement even maybe if they come through the ward to see our environment and then maybe they can say something to encouraging. If you did something better I think even to say thank you have done yourself, I mean is more than anything thank you, just to be thanked. We don't get, we don't even had it."

Facilitator:

"Any other opinions or experiences about the support that you receive from your managers?"

Participant (4):

"Another problem there on the National, if ward 5 or ward 6 that are running short of nurses, they come to step-down and take out of the volunteer, and if, so to start there if you are getting infection is your problem is not the problem of the in charge. Sister in charge who is staying all the time in the office. But, yesterday, that I was working there alone. Matron she came with me she tell me to go to ward 5 to work there the nurses are short in ward 5 then I told her that I am, don't go there because if I'm getting the infection is my problem."

Facilitator:

"They don't responsibility for that?"

Participant (6):

“Their only thing is that, they from the first time when we start at step-down, they told us that, (coughing. I’m sorry) after a year we are permanent, so we asked that question and they looked at us, all the people who were working at the step-down if they know that you are up to date about that information they promise us to take out to take us out there and give us a salary and I’m one of those who were taken out of step-down and go to other job, they promise me to give a salary, but when I got there, I get a lot of problems, so I told them that, I told you told me after a year I will be permanent, so why you don’t give me my money, I’m still getting a stipend, why they still don’t give me a chance to talk to them, they are running away from me, so…”

Facilitator:

“ You feel your problem is not solved?”

Participant (6):

“Yes.”

Facilitator:

“So promises were not fulfilled?”

Participant (6):

“No, the promise is already made, but they never give me that money they challenge to give me.”

Facilitator:

“Yes, you want to say something?”

Participant (7):

“Hospice is looking for our statistic, and they told us that when we don’t do statistic we don’t get our stipend, so they only looking for only statistic not our needs.”

Participant (3):

“The other thing I don’t know if I’m right or wrong, hospice, they, they are crooks, I can put it that way, because they know very well that every step-down there must be fourteen (14) staff, they took two from us, meaning that, we are remaining twelve (12) neh, so we don’t know if because the other one is here, it was the other way, so the shortage is on our side, they don’t tell us what happened to those two, and then the other one she is permanent, what about us? What about us? So there is that thing, it creates a friction, a friction more especially into us as a staff because we don’t know nothing, they never told us anything.”

Facilitator: “You want to say something on that?”

Participant (6):

"Yes on that. By the time they call us, step down was closed and on that month we received R500.00, now we still get R500.00, they told us that we are not permanent there we are only occupying the space for that time because we were hospice volunteers, so they don't, don't want us go back to the location, because maybe next month on the second or third we are going back to step-down, they told us that."

Facilitator:

"So you say that?"

Participant (3):

"On to that, me too, I'm still a member of the hospice, so why are they taking only two because they fall under their organisation…what about us? The other two you see, is unfair we are four, we are falling on hospice, yes, so why they took and left two. Even that time…?"

Facilitator:

"I'm not sure now I understand about that hospice"

Participant (6):

"From Naledi, the thing she is saying neh, she is saying that the step-down was closed and they don't know how long will be closed. I think it happen for a week; it was only for a week. So where are they? What about us? We are four. So why they took two? Because all of us I mean I can say we are very stranded to work, you see.. Yes!"

Facilitator:

"You think they did that because of shortage?"

Participant (6):

"Not actually short of staff but there it not know it very well step-down to operate with fourteen staff members."

Facilitator:

"Do you want to add on that?"

Participant (6):

"Yes, I can answer on that, the only thing that I can tell you, I think I was in a group of ten (10) people first volunteer at hospice by the time we, when they group people, those group they were at Sunflower. I was pregnant that time, so by the time when the step-down opens they call me at the location to go and step-down for a time because the group that I started volunteering with are permanent there, that' why they take me out of step-down and put me at Naledi, but the only thing they told me that I'm going back to step-down."

Participant (3):

"What about the other one with you?"

Participant (6):

"We are going back both of us."

Participant (6):

"No, no I understand your problem. What I want to know I understand, she started long time ago what about the other one. So what I can say hospice, they are crooks and they are very unfair and they don't take us into consideration we are nothing."

Facilitator:

"Okay…you…?

Participant (1):

"I was talking about when we are going to help on other one to work at ward 5 wards, maybe we are two carers, they will take one to help ward five, to work inward (5), we leave patients alone."

Facilitator:

"What is this five (5) and (six) you are talking about?"

Participant (1):

"Is the ward at National hospital."

Facilitator:

"Is not part of hospice?"

Participants:

"No."

Facilitator:

" So you go and work at other places which are not part of hospice?"

Participants:

"Yes."

Facilitator:

" I see."

Participant (1):

"And at that time we leave our patients alone."

Participant (3):

"On top of that we are under pressure, we were being pressurised on to that, because there was a thing that if you don't agree to go to ward 5 or 6 nobody would recommend you if anything come out or maybe a vacancy or whatever, meaning you don't know where you are, you are just….I don't know how can I put it. But you know nothing, you see, so everybody is we want to be recommended meaning that there is a matter of must that you have to go there and leave your patients unattended and which is wrong."

Facilitator:

"I just want to…"

Participant (8):

"The other thing I dislike about hospice, first they say they need volunteers, now they say they only need standard ten, what about those who don't have matric."

Facilitator:

"Should all volunteers have metric?"

Participant (6):

"The only thing that I dislike with those people of ward 5 & 6 if you go there and help them, they leave you with a lot of work and they can't tell you if it's tea time or lunch time, you will work there until you feel that I worked hard."

Participant (3):

"The other thing led to management to complain because at the management they heard that we are having a problem like a complaint but they don't like to listen to our problem, you see. They just say, okay the management, she said you disagree, you are complaining about helping in other wards, so I've got nothing to do, so the better thing is for you to stay on your ward, I don't want to see you anymore in that ward. So it never solve anything, you see so we are not being supported anyway."

Participant (4):

"To go to the, another ward, the permanent worker, she is lost in the mist, the corpse is there. She is telling you that the corpse is there is your job. She will give you the corpse."

Facilitator:

"Are you saying that she will leave you with the corpse?"

Participant (1):

"The hard work they leave it with you."

Participants:

"Yes."

Participant (6):

"The other thing is that, last time, we told hospice that we ask a leave because we are women, sometimes we get pregnant, how will you deal with that. So, they told us that we are not permanent workers so we can't have a leave; the only thing is that when you feel to go, go without informing them that is not their own sick. Is your own sick that is another problem. Is another thing we get from hospice"

Facilitator:

"Any other suggestion about the support that you should receive as a caregiver?"

Participant (1):

"One thing when you are ill, let me say I'm ill, I'm not at home, I must phone doctor or someone to work for my place, (emotions are high) let me say I am at hospital I must make the arrangements to send someone to work for my duty and at that time I am ill."

Facilitator:

"You don't get sick leave?"

Participants:

" No, nothing not at all."

Participant (4):

"And should the baby is sick we are not getting a day off, when the child is sick"

Participant (10):

"And I would like to take a conclusion about what is just said. A volunteer is that, is for a permanent person. We do the job that is for a permanent sister or nurse, you know, because I was there in a hospital before what they are saying is the truth, all the dirty job is for you is just that you are nothing and then you know what we are doing, we are doing it from your heart, we are doing by love, so when you are like demoralized or something you have the feeling a person. You don't know you have your own emotions, somewhere, somehow you feel like you know let me just leave this because is said I'm not recognised. You know because why I'm saying this because why I am saying that you work in a township and then you have to present a patient to the clinic and then whilst you have to, you don't just take a patient like you know as you are a helper of some, somewhere, some department or something you expect to be treated like at least you are working there and then you don't have to be in a cue like any ordinary person, you see. When you have to go to take a medication you have to be in the queue and then you have another patient. You don't have only one patient you see and there we wait in the queue sometimes for the whole day because you are just a community member, you are not recognised or something you know. I mean we don't have to be taken like a nurse or someone who is coming from the university or something for the job that we are doing, at least that recognition, at least to show that person is doing such and such a job."

Facilitator:

" So you need some recognition?"

Participants:

"Yes."

Participant (5):

"Some of the thing is that, we got TB patients, those who get streptomycin for forty (40) days, we are not allowed to inject them, so we had to ask ward 5 & 6, some of the nurses to come and inject them." (Interruption, cassette full).

Participant (9):

"I want the people of hospice to recognise us, as we are workers doing the job and there is any information they have, they must first come and address us and they must and then there are those posts that are available, we must be the first priority before the community and those who are outside that just recognition and they need to make sure that everything they need whatever it is possible for us to reach, they must give us those chances that we can move further that's the other part of recognition that the…"

Facilitator:

"Any suggestion about the support or something?"

Participant (6):

"The other thing is that we don't want anymore stipend, we want salary."

Participant (3):

"And the other thing is that, if they see, if there might be problem, they must tell us in time, so that we cannot get confused and get different stories, they have to contact us if they think there might be a problem, they have to tell us first."

Participant (10):

"One other thing is that the issue of support, I mean, they have to support us, like when you are dealing death, he/she is just died and at least they can get something because we have several of caregivers who have died and then they don't have nothing when, you are doing something the members of the family they expect, that at least so and so is doing this at the end of the day when she is dead she is going to receive the support at least something to help to, for the and all the thing, so we don't get such a support and then if you die some of the parents, no one is working and then you are waking up every morning, washing yourself, dressing navy blue and white. People they are thinking that you are doing something that is better or something and then, when they hear that you are, you are just like they see the, the children are owing the donations and all that things, you see."

Facilitator:

"Okay."

Participant (9):

"At least if they can do something to help the caregivers, on what he said we as caregivers we need emotional support because, sometimes we have problems that are heavy on us and they need to make a way of supporting and uplifting each and everyone of us because, they cannot only want us to do the work, but they don't give us support. So emotional support we need and physical to get the support we need so that we need that to make the work move on."

Facilitator:

"I will start the…you talked about the financial support, emotional support and what do you mean by physical support?"

Participant (9):

"When I talk about physical support like as I said sometimes we have sickness that are appearing you know in the community, then you find that we don't have any access or the money that is not enough to get the particular medicine, and we just want the to help on that other note of having that access of medication."

Participant (3):

"And the other thing is that we would like them, to do, they should come down to pay a visit, they are very up, to come to us because they are functioning because of us. If it was not because of us those patient will never be where they are today."

Facilitator:

"That means that they should communicate with you, …yes?"

Participant (3):

"To communicate exactly."

Participant (10):

"One other thing is that when you are working as if they have to have that policy when you are getting injured during the working hours at least, you see you can get help somewhere, somehow, and then if someone is saying when you are getting injury is your own problem you see, sometimes you are getting afraid of helping someone who is that, you know that you help that when I am getting the injury is the problem of my family and then of my own, you see because you can be infected by uh anything even when you are working as a professional, somewhere, somehow, the accident just come, and then when the accident comes what will happen after."

Facilitator:

"There is no policy?"

Participants:

"Yes."

Facilitator:

"So a policy like injury on duty?"

Participants:

"Yes."

Participant (10):

"I just want to add on what they said. We need uniform and there is this issue, like if someone is dead amongst us, we need to have that recognition. Even if when I die like let me say. Patient, out patients they need to have strategy that we can use to help this whenever, let me say I'm old, I don't have the power to go to work. Now is the time for, I know I have at least something to survive after this. So they need to come out with that strategy. Yes another suggestion in that issue of the uniform, I would like to add, is that yes, because is a good suggestion for identification you know because our shoes are getting finished completely. Now and then in the issue of stipend you cannot buy a shoes and a shirt at the same time and transport because you have a rent to pay and everything you know. "(Others laughing).

Facilitator:

"In the issue of uniform you were suggesting to have your own uniform?"

Participant (10):

"Yes transport allowance."

Participant (3):

"No money, where is the money nothing."

Participant (9):

"I just want to add on what they said we need to have that recognition, like at least I have something to survive when it is the time for retirement."

Participant (6):

"We want to be treated equal, just like if you come from another organisation, they must treat you the same like one which is a volunteer from hospice because they like to isolate us others if you come from the organisation, they don't take you into consideration, so if you come from them they take you to consideration."

Facilitator:

"If you come from specific institution they take you into consideration?"

Participant (2):

"Yes

Participant (6):

"By doing that it cause confusion in us cares."

Facilitator:

"I see."

Participant (3):

"And those things are not good because I have a problem in the ward, I was on duty and I'm even afraid to go the X–Ray because I think I have a serious problem, and what if I go to the operation and my life is in danger."

Facilitator:

"Apparently there is no injury?"

Participant (10):

"And one other thing I would like to say, yes we are volunteering, but you know you have that vision that one day I'll have my own house, at least my own car but with issue of stipend where can you get because years are going very fast now and then we are getting old and then what will happen in the future you see, and at least that recognition, you know the issue of hospice to get to know the government because is our government to know, they had to recognise us let us employ these caregivers you and give them a living wage not just salary."

Facilitator:

"Not just salary?"

Participants:

"Yes."

Participant (6):

"And next time when they say they need volunteers, they must inform these people who are going to be volunteers that they want the people who have standard ten or up to that because that thing is not clear to us."

Facilitator:

"Is not clear to you."

Participant (6):

“Yes, and now they can’t give us a chance to go back to school to have standard ten, because they told, when we say that to them they told you what were you doing at that time when you don’t finish your studies.”

Participant (3):

“And the other thing they said that they offered us training like nursing assistant because I think it was two weeks back we went to hospice and they said they are not responsible for that they just are just offering volunteer, so we just...”

Facilitator:

“anything else about the support or you as a volunteer?”

Participant (9):

“Ja, I want to elaborate on that. Sometimes you find a situation where you have information on that.”

Facilitator:

“So you need a training that is giving enough to development change and then everything about nursing.

Participant (9):

"We need that training so that we can develop us on our work, not just knowing basically, just wash do that we need all the necessary training that are being done that's one thing we need."

Facilitator:

"I just want to no more about the training."

Participant (10):

"No, we are saying a training like you decide you find out that there are some people who are coming with different sickness and symptom. And is there HIV those infection that are coming, the minor one you'll find that this person does not only have TB or HIV, but there is another one sickness that this already person has. So I have come to nurse this patient and I don't even know that how person has already have, so I have come to nurse this patient and I don't even know that of how, what is happening with this patient."

Facilitator:

"But you also mention the opportunity to further your studies…yes, anything else that you would like to suggest on the support?"

Participant (6): "On uniform, if there is a chance, I don't know others, but I say if they give us a uniform, we ask them not to give us the other colour, not white, white or navy blue white, not that one, we ask the other colour."

Facilitator:

"But you also…"

Participant (6):

"We ask if there is that chance that they can give us uniform, we don't want navy blue or white dresses and men white pants and white shirts, we ask other colours."

Participant (4):

"I want to know about that we are not getting standard ten, but we are doing the job then we are out of job."

Facilitator:

"And you would like some information on what's going to happen to you?"

Facilitator:

"Okay, I would like to thank you all for participating in the study and the suggestion you made, that's why the research is done usually when you see something that is problematic, you do research so that problem can be solved."

ANNEXURE L

Focus group 4

TRANSCRIPTION

INTERVIEW: FOCUS GROUP 4

FACILITATOR: Dr L.van Rhyn

RECORDER: Dr A. Joubert

RESEARCHER: R.N.Gxabuza

FOCUS GROUP: (10 Participants)

VENUE: Free State Psychiatric Complex

DATE: 27 MAY 2003

TIME: 10:30 - 11:45

Facilitator:

"Good morning everybody. I'm Lilly van Rhyn; I am lecturing at the university. I'm actually a Mental health nurse there and Tami asked me to do the interviews because it is something uh we prefer that research is done to the interviews themselves we so that we got out the view and uh I'm not going to ask your names, the reason for is that it's part of confidentiality and anonymity because we don't want to identity you on the tapes, now you won't believe it that this is a tape recorder, uh is the first time in my life time I' ve seen one like that. Okay, I want you, to feel free and open up and give your experience and feelings you like to. First of all I would like you to tell me about the support that you receive from hospice managers."

Participant (8):

"In the first place, we don't receive any support from the hospice, when we have a meeting, they didn't come and they say the problems and in the case of a stipend we don't have the specific date, week and we receive the, our stipend."

Facilitator:

"What are the implications for you, if that doesn't happen?"

Participant (2):

"If the money does not, we go to the bank, and the money is not there, we take initiative to phone hospice and ask them where is our money, they said that tomorrow, go and check the money tomorrow at the bank, they don't phone us and tell now the money is there, they do nothing they don't care."

Facilitator:

"They don't care?"

Participant (2):

"They don't care."

Facilitator:

"Can you just follow-up on what you said about the meetings, what can you just explain a little bit more?" "What the meeting is about?"

Participant (8):

"When we arrange a meeting and we tell them to listen our problems, they didn't come and they didn't give the feedback why they didn't come."

Facilitator:

"I see."

Participant (3):

"Yes."

Facilitator:

"Okay, you want to say something else?"

Participant (3):

"To add on what she said, actually to call the meeting is to try to tell them how and what we want for us to. What we want them to do for us cause we are having so many problems that if we don't inform them to come they don't, they, they just, although we are doing our job properly."

Participant (2):

"And uh, hospice every month they want uh statistics, every month, if you don't give them statistics, you don't get money, but till now our money we don't know what happen to our stipend."

Participant (6):

"To add on that, the stipend of R500.00 is nothing, is just like peanuts because the distance that I travel from where I stay to my patients, is a distance, my shoes, my heels are finished, I don't have money to repair again, so it give us a physical problem of that and still that R500.00 is too little. We have family, our children go to school, we must pay the crèche, to wear warm clothes, that R500.00 is too little."

Participant (3):

"And on top of that stipend we try to ask them whether they can't try to do something so that they can increase the stipend that is the money that comes from other this company they are, when time goes on, it will improve but after all, after sometime when we ask about whether they focus the way to increase the stipend. They say no, they are still thinking the other way to get the funds so that they can increase for us."

Participant (2):

"They keep on promising."

Participant (6):

"Sometimes you stay three months, you didn't get your stipend. The next month if you go, they will pay you one month, the rest they didn't pay you, that month."

Participant (8):

"And then where we are working we are struggling with the equipment, we have to travel go to another ward and hunting something that we are going to use."

Facilitator:

"What type of equipment are you talking about?"

Participant (8):

"Sometimes we have corpse, we have to..."

Participant (3):

"To pack the corpse, we don't have the shrouds."

Participant (8):

"The shrouds and then we and go and ask for them. You suppose to go to another ward and ask them."

Facilitator:

"So there is no support that you receive then?" I will come back to you."

Participant (9):

"As we are carers, some of us they get money from last year, but some they don't get their money, we get our money this year on April only R1 500.00, but two years back we don't get, we don't know but we are still giving the uh statistics we get them every month."

Facilitator:

"You are saying you haven't been paid last year then you got R1 500.00, is that what are you saying?" "Okay."

Participant (10):

"The other thing is that their words are hurting us, they said to us we are volunteers, we don't know how many years, so we don't know how long, months or years we should volunteer and we know that is not a pay is not a salary when you go they say is not our responsibilities, so you don't know where you should go and every month they said, you should make a statistic every month and then they have that thing for we don't have exact date and the words and they don't speak to us nice words."

Participant (7):

"Okay my question for hospice is for how many years must be a volunteer, if the Department of Health want the assistant nurse, why they shouldn't take from us because at least we know something about the patient."

Facilitator:

"Are you saying that your... don't feel happy being a volunteer continuously?"

Participant (7):

"Yes, how many years?"

Participant (6):

"And to add on this issue, they say they want standard ten for the assistant nurse, but they uh sent those people that volunteer and again where I am working at the clinic there is no co operate between volunteer and them."

Facilitator:

"The clinic staff?"

Participants:

"The clinic staff."

Participant (5):

"Can I speak Afrikaans?"

Facilitator:

"Ja, I wanted to say, sorry Ek wou gesê het die wat wil praat Afrikaans, kan Afrikaans praat."

Participant (5):

"Wat ek, wat hart seer maak is die, ons werk swaar en ons is die hart, uit die hart wat om te doen vir die sink mense waneer hulle siek en le. Ons het lank tyd by die veld geloop vir die siek mense en lokasie. Ons het daarom rond te loop vir die mense dat ons kan die mense sorg gee hulp die mense gewas, ons het alles gedoen. Wat is nou baie kort, dit is hospice se saamwerker by hospice. Hospice het nie saamwerker, ons het probeer mooi te vra, ons het altyd gaan vra by hulle, so hulle weier om ons hulp te gee. Die eerste ding soos nou, ons, ons, ons het daar tyd wat by ons die voete te loop, ja hiernatoe uh National dat ons gaan die mense kon hulp. Ons kry vir die mense jammer want partykeer ons nie kan nie kom nie soos hulle uh, uh, ons nie geld gee nie toe kan ons nie kom nie want ons kan nie so ver loop tot hierso. Daar was die tydjie wat die plek toegemaak want toe kan ons nie, kom nie want ons nie die geld, wat, wat ons, ons nie kry nie. So hier kry die ander ding wat hulle ons hartseer maak soos nou ons is nie uitbetaal nie. Ons het nie die stipend kry nie. Ek het geprobeer om te bel vir en van die, die management, management, hy se vir my, hulle het die ander uh, uh hy praat nie mooi met my nie. Hy gooi die woorde wat nie lekker nie, hy se:ja, is reg tyd om die geld te kry en joune uh, wie het om te se jy weet jy gaan geld uittetrek. Ek se nou hou net daar hoe kan dit so wees. Hy se nie ek weet nie. Ek se, ek vra vir nou waneer gaan dit gaan kry? Waneer want ek het nie om werk toegegaan nie. Hy se ek weet nie, ek promise jou nie waneer die gaan die geld te kry nie and then hulle gooi die woorde wat nie lekker nie vir ons te antwoord. Hy praat nie mooi met ons nie. Hy is altyd hy, hy praat met so wat die mense wat nie ken wat soek, wat moet kry, ons sukkel baie, uh die mense het nie saamwerker nie, ons het swaar, ons het onse hart het gee om te hulp maar ons is wat ons terug kry is net hartseer swaar. Ons kry net swaar, so wat ons vra is dat die mense net kan is dink, ons is ook mense, en ons kry swaar soos nou die weekend ek sal nie kan National te gaan om mense te help, dit is weer hartseer vir die mense want ek het niks gekry nie, en ek het nie ek is so baie vir die mense om het daai mense kan gaan hulp dan jy voel."

Participant (5):

"What breaks my heart is that we work. We are working weakly and we the heart, out of the heart, we are doing for sick people, when they are sick and admitted. We had a long time walking on the field for sick people so that we can give them care and help. We were washing them. We were doing everything. What we are doing now is very short of hospice co-operation. Hospice doesn't have co-operation. We have tried nice to ask. We always go to them. So they refused to give us help. The first thing like now, we've been there walking with feet. Yes, to National so that we can help the people. We are feeling sorry for the people. But sometimes we cannot go so far up to there. There was a time when the place was closed, because when we cannot come, because we had no money that we didn't get. Now we get another things that break our heart. We didn't get our stipend tried to phone for and from the management said to me 'you got the other, he is not talking nice to me. He throws the words that are not nice. He said, yes is the right time to get the money to withdrawal. I say hold it there, I'm going to get it, how can that be? He said he doesn't know. I say I'm asking for now. When am I going to get because I didn't go to work. H e said I don't know I'm not promising you when are you going to get the money and then he throws the words that are not nice. He always for the answer. He is not talking nice to us. He always, he talks like this with people who don't know what they want. What they must get, we are suffering. The people don't have co-operation. We are weak, we have given out our hearts to help but, but is what we get back is hurting. We only get weak, so what we are asking is that people must think. We are also human beings we are getting weak. Like now on weekend, I will not go to National at to help people. It's again heart breaking for the people because I didn't get anything. I don't have."

Facilitator:

"Okay, I'll give you a chance and then you. Okay, ja."

Participant (3):

"Okay, as we are volunteers and we are working on behalf of uh hospice, what we don't like is that hospice must give us that respect and it must, they must pay attention to us. We are volunteers we agree with them, as we are volunteers we are expecting them to give something in future, we are working for the government, even the government must be, we want the government to consider us not only cause now we okay we are struggling hospice to fight for us, to help us as we are risking with our lives, we are working with the people who are HIV positive, we are working with TB patients, even different patients they are, but even the gloves that we are using, I can say that they are offering us the expired gloves, because while you are working with the patient, the gloves they are torn, so is it the cross infection and we are not actually life covered. They offered us the indemnity form to sign it as we are volunteers, any problem that can appear to you if you can be injured while you are on duty, there is no cover up you can get from hospice, then it is your own risk."

Facilitator:

"You saying they are not helping you and support you too…against the risk of being infected?"

Participant (1):

"The only thing I don't want from hospice, so the hospice, hospice makes a friction between the organisation. I remember last year the management of hospice called us the leaders the of the organisation then, they told us like in an organisation we only find out that some of the people, they get money from hospice and another people they didn't get the money from hospice, then every month they want their statistic. So really we find out that hospice make a friction between the organisation because they are favouring other organisation, other now since they promise other people to get their stipend but they didn't fulfil their promises, so some of other people they get the stipend."

Facilitator"

"So that cause friction?" "So they fight each other?"

Participant (3):

“Yes, even the management of hospice as we are volunteers we come across with the problem on the field, so when we go back to them, and report that, okay as we are caring for the patients we came across on this and this and this and this, how can we solve that as you sacrifice your life to heal for the patient you are expecting each and every situation you can come across so that handle it by your own, whether I say to the managers, okay I came to you to just try to help me how can I solve this because I don’t how can I handle the patient maybe if I respond for patient in this manner. I think maybe is a wrong way is not a right way. So I came to you just to advice me. So the management of hospice they are selfish they. They just care for themselves and what we are doing is just because that word ‘volunteer’ they are taking as it is. And the other thing our MEC, I mean is, is unfair to announce some of the things about the volunteers to promise the volunteers at the end of the day they don’t fulfil the promise because our intentions we had that, we as volunteers we are going to get this and this we are waiting for that maybe as the government said we are going to that they don’t fulfil their promise and they said is a job creation, so today we are nowhere, they left us hanging with question mark, where are we? So hospice must do something even our government must feel for us because we are out there on their behalf. Now, nowadays there is a shortage of nurses in the whole region, where do they go and recruit some of the South African nurses, they go to overseas. We don’t have nurses; we are running short of doctors, we are here volunteering. Sometimes, we are to taken to orphanages to help but at the end of the day we only hear that they recruited the cleaners to be the assistant nurses and those uh cleaners they don’t even have standard five (5), but they are recruited, what about us. Who are having metric, standard nine, standard eight? Why don't they consider us because really we came out the, our family, we ask the money from our parents to, for the transport to go to work for the week, is our community which is dying and government must just sit down and check the statistic of death it has decrease."

Facilitator:

"You are saying there is a lot of uncertainty about what is going to happen you are saying that there is some sort of uncertainty of what is going to happen to you as a volunteer?"

Participant (5):

"I just to say really, really hospice management don't respect us. Die man wat laaswerk gesê het soos ek gebel het een se vir my ek vra as ek vra van stipend en hulle se, ja julle soek die geld en hulle wil my reeds weg jag hierso ander een is reeds weg so ek weet nie as so aangaan en julle soek geld as so aangaan hulle soek geld. Hoe gaan julle maak as hulle my hier, julle gaan bietjie beter sukkel."

Participant:(5)

"As for the man who said last week when I was calling. One said to me: you ask stipend and you say you want money you already chase here the other one is already gone. I don't know if you go like this and you want money. How are you going to do when you want money, you will suffer better."

Facilitator:

"Uh."

Participant(10):

"Sometimes you come with the patient to the clinic you have to wait at the long queue but you are assisting to those patient at the clinic, but you have to wait in the long queue and if you ask maybe the management at the clinic, they say you are a volunteer, what you can say, so you ask yourself you are helping the community, but why they talk to the people you are a volunteer is always, they discrimination."

Facilitator:

"Discrimination, between you as volunteer?"

Participant (1):

"To tell you as a volunteer, they don't call us by name."

Participant (10):

"The other thing is that, sometimes, we as volunteer, we should work at the clinic alone without a sister and the matron told us the sister they go to workshop or meeting and so we should do the work from 08:00 until 15:45, they say this thing usually happen, so we don't know what treatment they give."

Facilitator:

"So you tell me that sometimes you take a responsibility?"

Participant (10):

"And the other thing uh, uh, we are working at the TB clinic too, so the patients sometimes we know that we will get MDR patients."

Facilitator:

"What type of patients?"

Participants:

"Multi Drug Resistant."

Facilitator:

"Okay."

Participant (10):

“So we don’t have we treat, we ask the government to give us injection and then at home of the patient, you know something wrong with your skin ‘hlalosa hle’ (explain please) because the people of hospice ke hore wa otloa ho re (you can feel that there is some itching on the skin) they don’t come and see what is happening.”

Facilitator:

“Okay.”

Participant (3):

“The other thing about the people of hospice as we are crying, we really do cry and we are still going to cry. So I should think and we are to just do something as we are having so many problems and those problems I don’t think they don’t know about our problems. We do each and everyday is almost everyday we phoned, we walked to their offices and is worse we go to the offices, they keep us waiting outside. We don’t even enter we wait outside until they finished their work is when they will come to you and approach you what was the problem. When you tell them the problem, they just say okay, we will call the meetings with the managers and discuss. This issue it will be solved and when it will be solved and how am I going to know that the problem is solved because every problem that we bring to you don’t bring a feedback. Is like the one we, I faxed a letter to our MEC as we are volunteers that we don’t have a stipend. In the message and where this stipend is coming from because she sends a list that hospice is responsible for the stipend. If they don't give us the stipend for R500.00, they don't give us. So we actually, we just want to know where we got the stipend is coming direct from the government or it comes from the hospice, and the second thing on that fax what I was asking MEC what if we got a problem as volunteers. We should go to hospice or we must to you as MEC because is you who are taking cheque and proposing the people to volunteer for department of health. So now as we are struggling for this and this and this and this when we go to seek a help, she answer on the meeting, she called that she said she is no longer expecting any fax from anyone. No one must fax and I think we faxed her just because of the problem we have because it was the simplest way to get her by fax. Because when we go to her office, she is not in her office, so that was the easiest way as a volunteer to reach her, so there is no solution for us for our problems."

Facilitator:

"Can you give an example of the problems you have experiencing, you have talked about stipend and equipment, are there other sort of problems that you are experiencing?"

Participant (3):

"Ja, actually the problem that, the problem that I can raise, the same problem is that we really need to be employed to be permanent that's what we are in need of that because the problem, we are asking ourselves until when are going to volunteer until when? So if we are permanent, we are registered as an assistant nurse maybe we will further more see and see how can we be trained further because, actually this stipend is only for, is even not even for grocery. We can't buy I mean I bought a shirt for myself, we buy nothing so we are asking hospice why can't they give us the old shirt to change uniform, why they don't offer the old shirts so that we can be clean outside that we are volunteers and we are neat."

Facilitator:

"Are you saying that to give you uniform?"

Participants:

"Yes."

Participant (2):

"I have two kids and I stay in a one room house and I must pay R150.00 for the room, R100.00 for my little kid to crèche and food for that stay at house I must give my mother R100.00 food for that kid, me too I want clothes and they want us to wear Uniform, we must buy uniform with that R500.00, no, man is too little and I want the house because I stay in a little house, one room house. I want the car and with that R500.00…"

Participant (3) "As we are people we are having high expectations so, after those expectations we think is the only dream that will come true because of the stipend even though they don't have the I mean when, they can put us to work why don't increase the stipend. They The easiest way to increase that stipend maybe we can be a little bit satisfied life, because a human being can't be satisfied. If they co operate with us we are working hand in hand with them, we are going to be satisfied because we see that these people are trying to give us although they, they, it is hard for them but they try."

Participant (2):

"As carers we need salary not stipend, we need insurance, UIF"

Facilitator:

"Salary."

Participants:

"Yes."

Facilitator:

"Can I just ask you to elaborate a little bit on the insurance."

Participant (2):

"That covers us and provided children education and family."

Facilitator:

"Your family? Children? Okay I want to know…. I know, I don't want to lead you, but I need to clarify you talk something about when injured on duty."

Participants:

"Yes."

Facilitator:

"Okay."

Participant (8):

"And they take us from our ward and take us to another ward to go and work there and then when we are coming there the staff of that ward, they disappeared you are going to work alone until you finish that work."

Facilitator:

"Okay."

Participant (8):

"Yes."

Participant (3)"So in other words the staff they are misusing us."

Participants:

"Yes."

Participant (3):

"To help the, the registered nurse, actually hospice took us to National to help at National as the HIV patients they are admitted there so they took us for help as we are allocated for step-down. So as we are allocated for step-down, they take us they don't communicate, come with the manner of approach, they just take us just go to the ward 6 to help we are running short of nurses, so when we report it back to hospice, when you allocated us, are you allocated us for ward 5 and ward 6 and step-down? They say no. We only allocated you for step-down because step-down is only in National but it does not fall under National or their control. So I said now we are reporting this issue, we are misused here and even if we complain about the wards they don't pay attention, they don't call us and give considerate the attention for our problems, so as we report here, they said we will come and solve that problem out, it will be solved."

Facilitator:

"You feel misused because ward 5 is not part of hospice?"

Participant (3):

"Is not part, is not part of hospice." (8) "They are permanent."

Participant (3):

"And to add when we call the meeting because we, every week we call the meeting with the hospice, so the managers must every month come to hear our problems. They come, we give them the problems they say okay, we will go back and solve these problems, we then wait to our managers and to see what they can do, then will come back. Next month, we call another meeting, every first week of the month we call a meeting with the managers. What about the previous problem before we could do another problem, so it seems as if we just pile the problems, which are not solved. So hospice must only try to find solution, they must fulfil our needs. If we ask they must try to do something."

Facilitator:

"So something must be made for problems?"

Participants:

"Yes."

Facilitator: "Ek gaan net vir haar eerste vat."

Participant (5):

"Ek wil response te maak, ons was gesê van die management ons het nie gaan National nie. National ken ons nie, so as ons TB kry niemand sal ons help nie maar na werk na ons toe die fondse gekry het hull het ons gevat. Na party keer ons het so straf gewerk, ek doen my werk as ek klaar om my werk te maak gaan jy werk tot jy voel jy kan nie meer staan nie jy wil net die skoene uit en kal voet te loop. Party keer jy rok gespoil jy gaan management uh tien dat beteken, miskien daar ander, so jy doen alles die een is a volunteer en hulle ken niks. In the meantime ons doen die observasie. Ons gee die medikasie. Ons lê die corpse, alles in die werk en ons doen met mooi hart, so dat die pasiente kan ook baie op so voel beter. Onse, ons is vrede gesê, vader ons gaan dit doen, so ons lewe uitgegee vir die mense maar ons voel hartseer."

Participant (5):

"I would like to make a response on what was said about the management. We didn't go to National. National doesn't know us, if we contact TB nobody will help us. But after work they withheld the funds. Sometimes we worked so strenuous. I do my work, when I finish my work I'm going to work and feel as if I won't be able to stand up again, I would just take my shoes and walk with bare feet. Sometimes your dress become spoilt and you go to the management maybe there is another, so you do everything and they don't know anything. In the meantime, we do observations, we give medication, and we pack corpse, everything at work we do it with open heart so that the patients can also feel better. We are satisfied and we said, Father, we are going to do it. We give our lives for the people but we are hurt."

Facilitator:

"En jy voel…?"

Participant (9):

"That's why we ask the management of hospice to make us permanent because we work as nurses, we don't work as a volunteer because always we do nurses job, we don't do volunteer's job, that's why we ask we told the management to make us permanent, yes."

Participant (10):

"Sometimes we had to go to phase 7, far away next to Grootvlei, to go there by feet. So when we came there we find the patient is lying there and so you want you want to take your patient to the clinic. So you don't have a transport and the, the patient they, she cannot walk and uh so there is far away. So when you take her to the clinic the staff management, they told you must go to the queue and then your patient, your patient, so they will look on the other patient that is on the queue. So the other thing your, your child is sick and, at home, when you came to the clinic, they must help you when, when you, they just get angry and we don't know what, where we should go because we work there, they said go to the queue."

Facilitator:

“What the people get there, they help them?”

Participant (10):

“The management?”

Facilitator:

“Of the clinic.”

Participant (10):

“And the other thing is that when we get sick at the work uh suddenly go to the sister and tell her. No sister I’ve got headache, she will not give you a treatment you are in the job and so they don’t give you the, the treatment. They said no take that panado and then get your file, she will not give you the, the right ntho (thing) she will said to you take and do your file and go to the doctor. They just said to you hey take a panado, you see. And the other thing is that at the clinic we are… when we go to the tea time we are suffered we don’t know where to stay, they use the kitchen to counsel. So we should we should go out uh to the room to sit there but we, they have uh, they have their kitchen, so we will take the kitchen for the counsel there so you must stay there like a stupid.

Facilitator:

"So you can't hardly sit down?'

Participants

"Yes."

Participant (6):

"Just like now they will tell you early in the morning you have to go to the patient and give a patient a pill before he or she can eats, if you got the flue is your own problem."

Facilitator:

"That sick patient?"

Participant (9):

"If maybe you are sick you don't go to the work. Tomorrow if you are coming, the matron or the sister. She becomes cross, why you didn't come to work yesterday. You see the patients are here and are suffering that and is not your job you are going there as a volunteer as we are volunteering you go from 09:00 o'clock to 12:00 o'clock but we work as permanent workers from 08:00 to 04:00 o'clock. Sometimes we have no money to buy food. What management say is that you will stay until 04:00 o'clock."

Participant (5):

"I just want to say we carers we just treated like an animal."

Participant (8):

"Mmh."

Participant (3):

"Okay when I came back from hospice. I think the management of hospice. They are not, they never responded, they are not caring, so now we just want to express our feelings to them in which way we don't know. Because, I think last two weeks on Monday before we receive the stipend. I went to the management to handle those problems with the money the stipend I found that guy and I asked him why do you send our stipend late he said is because of the claim forms, we receive the claim forms late."

Facilitator:

"Okay."

Participant (3):

"I said no you are wrong our claim forms, our claim forms we submit them early before the month end as we schedule them from the process, so we had to receive the claim form month end. We submit them early, so why will you say is late we submit late the claim forms. He said no actually the main problem is that we are waiting for other for other claim forms that are from other organisation from Botshabelo, Dewetsdorp, Thaba Nchu, so they are submitting late. I said to him is unfair, the management is unfair because we are here in Bloemfontein. Our claim forms we submit them, every time early and month end as if we submit them month end, so why we suppose to wait for the Botshabelo people. Because you can process our stipend early then you will process their stipend after they have submitted their claim forms. So now we are dying, we are struggling just because of other people's problems and I mean we are state organisation if they delay to report their problem. As we report our early we had to be considered because we are first people to submit we are struggling because of other people's problem. He said, I would report that and the other thing it was. So he mention the problem that they are working with computers. They are having three computers, so it seems as if one of the managers, the, the, the staff she used the other computer, do she deleted the whole information of carers. So I said why don't you pick up the phone and report to us that your stipend is going to delay. Just because of this and this and this problem you cannot cross it just delay the handling that we had to stand up and go to enquire to him, so in the meantime you are misusing, he, we only accept what we are doing. I mean you don't do something for us, he just said we will solve it."

Participant (8):

"On top of that when they take money ho tsenya tjhelete ko bankeng"

Participant (3):

“To process the money to the bank.”

Participant (8):

“When we go to the bank to collect the money at the bank we don’t receive the R500.00, we had to find bo R440.00, R460.00, we don’t receive.”

Facilitator:

“And what you do then?’

Participant (8):

“We just sit back.”

Participant (3):

“We just withdraw that four something. What are we implying is that, they promise us to get that stipend R500.00, so previously we were receiving the stipend through the cheque, they give us cheque then they decided to open up the accounts is whereby they ask that when you open the account that stipend is no longer going to be a stipend, they say no even if when we withdraw it won’t be the bank won’t charge you too much. I said no the main issues here is that you promise us R500.00, so why don’t you just leave us with that cheque, sign for us the cheque rather than to open an account and get the R400.00 because is no longer R500.00. So in other words we were proposing the increment, then, so that when we draw we get that R500.00."

Facilitator:

"Anything else?"

Participant (4):

"Now on top of that last year we happen to receive an amount of R250.00 but they said it only continue with this one month because they only continue with this as we have problems with other stipend with one month two months you only get at one month and you don't get with other. They don't give, they give us three months later."

Participant (6):

"What I want to say is that our MEC told us that we are too many volunteers so we have to be cutted by doing interviews, so I don't know others where they will go if they fail that interview."

Facilitator:

"So what you are actually saying is that there is an uncertainty about it, you think there will be a cut?"

Participant (3):

"To also add on what she said as our MEC asked the volunteers, the people to volunteer. Firstly, she didn't mention that we only need the people who are educated, who are having standard ten. She just said we are looking for people who will volunteer and this thing of volunteering I think even our MEC, she just took it as a volunteer and we are here. In our culture when you are doing volunteering, there is something when you go to the field plant grow the mealies and potatoes on the field there is a food that while you are working, they are cooking."

Facilitator:

"Okay."

Participant (8):

"So this voluntarism it seems as if we must only volunteer. So to announce the things on the meeting, she must start think before she said anything because the people they are going to pay attention what I am saying and they are going to expect what I'm saying, so I think she must think."

Participant (5):

"The people are jealous now want as ons die tyd begin om te hulp ons het vir die government, die government het gepraat met mense dat kan hulp, so ons ingeval om vorentoe die government te hulp nou die mense is baie jaloers.

Die government maak beter, hulle werk alles klaargemaak kan dit nie saam om gaan om die government te hulp, hulle, ja gooi, destroy, hulle destroy laat ons aangee dat ons kan los want toe ons begin dit met die volunteering hulle, hulle het vir onse gelag."

Participant (5):

"The people are jealous now, because the time we started to help we had for the government, The government had talked with people. So we volunteer to help the government. Now, people are jealous. The government make better, they work everything can that no co-operation to go forward to help the government. Yes throw, destroy, let us give up and leave because when we started volunteering they were laughing at us."

Facilitator:

"Wie hulle gejag nou?"

Participant (5):

"Die management, ja, hulle het ons vir gelag ons het gelyk soos mense is. Okay nou soos ek praat management was gevra as ek hoor dit, ek se ja hulle kom hierso en daar is baie mense wat geleer is, onse mense sit daar wat geleer het en hulle het nie werk om te doen. So hulle maak so dat jy kan kwaad wees en los die werk."

Participant (5):

"The management, yes, they were laughing at us as if we are people who are mad. Okay, now as I speak, management asked and hears this. I say yes, they come here and there.Many people who are educated.We people sit there who are educated, they don't have work to do. So they make, so that we can get cross and leave the work.

Facilitator:

"Is dit nou die management wat jaloers is op hulle eie mense dit doen?"

Participant (10):

"We are asking MEC and management of hospice to come down to us where we work and see our problems"

Facilitator:

"You want them to visit you?"

Participant (10):

"And we are asking for the hospice management to put our stipend in time because we are suffering to get our stipend, we are buying food, we are travelling from location to National and we are using double transport and that R500.00 hy is baie klein (is too little)".

Participant (3):

"Lastly I would like to ask from the hospice management as they, as they put us at National, it seems as if they put us up, they dumped us because they don't pay any attention, they don't come just to supervise how we do our work, so we ask them even if is not always everyday, but once a week they must send someone to come and check us because sometimes we are running short of uh medication or anything that we are doing at the step-down, why they uh, uh accept the, the proposal they will care for step-down because they sacrifice that they will take care of step-down and staff because we are there just because of them we are their, on their behalf, we are helping them."

Participant (1):

"To add on that uh the only thing I want, I ask from hospice, to buy a uniform for us as we are volunteers because really we don't have uniform. They give out uniform to the sisters who are working in the clinics that is why they take us like that is because maybe they see the way we look."

Participant (3):

"And we ask hospice to consider the problem of we may or as the registered nurses they are given an injection for not to be infected, we think we are human beings, they must just put their status aside and consider that we are human beings we still need that uh injection to be given not to be infected.

So they must work hand in hand with us. They must talk to even the staff of National, I'm sorry to mention the name, to work hand in hand with us."

Facilitator:

"Can I just ask… while we are all safety…only injections. Other sort of suggestion regarding the improvement of your safety?"

Participant (3):

"Actually we don't have anything that we can say, any medication or any injection we are just working."

Facilitator:

"Can you mention the thing about gloves, I will come to you."

Participant (8):

"When we are making beds we didn't, we do have the, when we are helping the sisters, we are working we didn't suffer from the equipment, we have the equipment in time but since we are alone we suffering."

Facilitator:

"I see."

Participant (8):

“Really, the time we have the sister we didn’t suffer, but since we are working alone then, we are suffering”

Facilitator:

“When is that, can you just talk about the time when you the sister.”

Participant (3):

“The time we having the sisters, those sisters were hired by uh Charisma. So we didn’t have the problems because they were supervisors.”

Facilitator:

“I see.”

Participant (3):

“Equipment was there, everything was there. We were not suffering so Charisma took them to children’s ward and allocated them to children’s ward, so and the hospice started the thing of stock controlling, there is no one who is taking care of stock control in our ward. When we are reporting to hospice they said no we don’t get anything to do with the National they are doing their own equipment of having the things. I said to management why don’t you send your sister, you can just take the retired nurse outside and put him/her in the ward to take care of everything to supervise, she said no, the hospice don't have a nurse or doctor, that's why we put you there."

Facilitator:

"Are there no sister to help there to supervise you?"

Participant (8):

"And when we are going to another ward to go and ask for the gloves or what, they didn't treat us nice."(3): "Why don't you have your own."(8): "They give us words before they give us a glove."(3): "They like to make the remarks."

Participant (5):

" Ek wil net vra…ek wil weet reeds as of as jy gaan vra iets wat ek soek vir die pasient dan hulle se nee jy, weer oh die step-down mense ons is so moeg."

Participant (5):

"I would like to ask…I would really know if you go and ask something for the patient, then they say no is these step-down people again we are tired."

Facilitator:

"Jy wil net vra."

Participant (5):

"As die mense kan die saamwerker gee ons kan voel daar is nie ek gaan en dit lyk of ek wil a rondstuur en dit en die hospice management as ons vra dat die mense dat kan ons saamwerker, hulle kan vir ander dat hulle kan ons as carers ons weet ons volunteers dat hulle maar kan vat ander regtig laat hulle dink van ons, ons is ook a mense, ons is nie diere nie."

Participant (5):

"If people can give co-operation, we can feel there is no go' And it seems as if I will go around and this and the hospice management. If we ask that people can co-operate, they can for other, that they can we as carers, we know we are volunteers that they but can take otherwise to think about us. We are also people, we are not animals."

Facilitator:

"Ja?"

Participant (10):

“The other thing at the clinic we should move like, so the other time the matron said to us we should move to another room. So that room is small, so the sister told the matron they we told the patient that they must stay in the room and also that day they don’t have the like. The matron said we must move to that room. So our sister said I want she want those workers to that room so feel that because we volunteers we work uh TB patients and the matron does not want to hear, so they took the sister and go. So we stay there in small room as volunteers. So see that management and the matron she don’t consider our help and we will get infected so and then the other thing is that the TB patients must take the pills before they take the food, so we say the uh, uh, the volunteers in the they just maybe, we don’t recognised in the job, so they said to our volunteers you must wait to your volunteers, so it is not our job is her job but they promise uh, they promise uh that she will not help us and they at that time, if they, so we ask the hospice, they must come and to interfere, other thing is…”

Participant (8):

“I ask the hospice management to come and see the go thoe keng”

Participant (3):

“The situation”

Participant (8):

"The situation that we are working how, how, how much we are working under the, under pressure of other person, they must come, hulle moet kom dat hulle kan sien, yes. (So that they can see)."

Facilitator:

"Daar waar jy werk?" (Where you work?)

Participant (8):

"And how much we are suffering."

Participant (3):

"Lastly but not least."

(Laughter).

Facilitator:

"You must talk as much as you want."

Participant (3):

"Our government try, must do something as they announced that there is no job. Sometimes she will try to do a job creation. What we are wondering and what we ask ourselves is that when are, we, until when are we going to volunteer, to do this voluntary work and we are doing the great job I guarantee. The job is great, The South African Statistic, the death rate has gone down, but still they don't consider us. We need to be reconsidered and to be put in a better direction…(Inaudible). We would like to end up being something."

Facilitator:

"What could that better direction?"

Participant (3):

"To be something in future, we are expecting to be something in future, it's very nice to be permanent to work for your family to support we are working we call ourselves just as a worker but we don't get even the R500.00 is nothing and now is like uh we get that R500.00, what about the previous years when we were just working without money and our parents were fighting. Why you just quit the job because you are wasting your time, you better just sit down doing nothing rather than to go out as if you are going to work but you take my money. It seems as if it's me who hired you, I pay you everyday. So the government must just sit down and think and take this problem of ours and put it on its own child compare what was if it was my child waking in the morning going out on the field, do work and get nothing at the end of the day." (8): "Helping the community." (3): 'We are really crying."

Participant (5):

“ Ek wil net daar volmaak, die R500.00 is niks want ons nie invest om te maak kry nie.”

Participant (5):

“I would like to add on that, the R500.00 is nothing we cannot even invest.”

Facilitator:

“Jy se jy kan nie invest nie?”(Are you saying you can’t invest?”)

Participant (10):

“In the clinic one day, we have so many, so we should not answer the telephone they said you are a volunteer why you should answer the phone. So maybe sometimes is a school, maybe your child is sick at home or school or your husband or your mother or what, so they don’t want us to be near the office. When they see you next to the office they will shout you, what you want, what you are a volunteer we don’t want you here is not a volunteer’s office.”

Participant (5):

"Ek maak vol daar so, net daar en dat sel phone ons so, jy verwag enige dan moet ons die management gese, ons moet onse sel afsit maar ons mag nie die telefoon gebruik."

Participant (5):

"I would like to add on that, just there and that cellphone. We wait for any, then our management told us, we must switch off our cel but we must not use the phone."

Participant (3):

"Okay, to this hospice management, they are really crooks and consider them because is them this stipend according to the stipend we receive the stipend late, I mean we have to receive every month but we don't receive it, we struggle before we get it, so is with. They are sitting there in their offices. There are using it for their own good. So they must come forward and tell us agreement about the stipend. If they stopped it they must tell us, we are volunteering for nothing. We don't get stipend, so if I sacrifice myself I' m still going to work tomorrow although I know that I don't get stipend, is my work so they must be fair with us. We only need to be sorrow and sacrifice."

Facilitator:

"Ja?"

Participant (5):

"Because they tell us now, hierdie geld ons sal teruggevat, ons sal terug vat, hierdie geld is by ons, so hoe kon kry die geld, die stipend is by die management waar staan ons? Wie? Waneer?"

Participant (5):

"They tell us now, this money they will take it from us. This money is with us, so how are you going to add the money. The stipend is with management. Where do we stand? Who? When?"

Facilitator:

"…Some redes that the stipend. Het uit kantoor die stipend te kry nie."

Participant (3):

"No actually I was suggesting if they want to, they must tell us."

Facilitator:

"They must not keep quiet."

Participant (2):

“They must n’t, when they say they want volunteers we were working with our heart, knowing that there was no salary, nothing but they told us you are going to get that R500.00. So we are waiting hoping that R500.00 is coming, when that R500.00 doesn’t come whuu..”(Screaming)

Participant (5):

“Die government het gedink van ons want hy se vir ons, ons is nie dankbaar nie. Ons gaan en ons wil hulp dis die maand wat alles so swak nie. So jy kan nie elkedag op en af maak so sonder om te eet en sonder om skoene te dra nie. En hulle soek op die, die so moet weet met die stipend niemand kan lewe met klip af neh. So die stipend vra die management, die management moet rerug dink vir ons.”

Participant (5):

“The government had thought because what to us is not thankful. We go and we will help is only this month that everything is so poor. So you cannot everyday up and down without a food and without shoes to wear and they want to the must know with stipend. Nobody can live with stones. This is what management should think of,” Participant (2): "Because at the, in the morning maybe I don't have food at my place, I go to see a patient, I found out the patient is still hungry, ask food to me, where am I going to get that food because I don't have the money to buy food for myself."

Participant (6):

"What I'm asking from hospice is that a promise is a promise it has to be fulfilled."

Participant (3):

"They mustn't promise us and leave us without fulfilling those promises because I remember last month when I was going to ask about the stipend when the problem. I also asked the management, can't you join venture with other hospitals that are offering training. They said each and every person who needs training to be assistant nurse he/she must see by him/herself how to get that training. And the managers asked me where did you get that information of joining venture, which faculties are joining ventures? I said Universitas hospital, they are training their staff and even the Pelonomi hospital they are doing that training of assistant nurse. They, we approached them, what will they put us as we have experience of nursing. They said no, we don't take outsider we only take our people inside, is whereby maybe next year we will take outside. I said okay, do you have any joining venture with other faculty? She said no, we are joining ventures with old age homes, so we are having their staff. Is where I went to hospice and I hear that they are having joining venture? They said no, the reason, they don't have a reason, is better if you say no because of this and this and this and this. I am going to be satisfied, but only just no and turn back leaving us just in that is very painful, they don't consider us."

Participant (10):

"I remember one time when we were asking the matron and you ask her about our stipend and about and the training and the other time when the MEC and she have, uh she said to us, maybe in July she will come to us and interview. She said those who, those who passed the interview she will, so when we tell matron, she said no you must not listen to a politician. She is a politician, she will stick to her party and the, the vote is coming, she will promise anything. So you don't know they are what MEC is trying that's why we say to the MEC to come down together with the hospice management think to come again we what we have at hospice is the physical problem."

Participant (1):

"To add on that I think the people who are volunteer themselves is not the people maybe finished the metric and then so, I don't understand when the MEC said they want the people who passed metric and then is the people that they going to take for interview. So there are many people, who passed the metric staying outside, so they don't want to volunteer. They volunteer maybe the people who got standard five (5) or two (2) most of the people that their educated they don't want to volunteer because they say they are waste their time."(Laughter).

Participant (10):

"Mostly you will find those people in the squatter camp may go by and help then metric people don't they will not go there and are working the squatter camp or go to, to wash at the patient maybe in the location, they will not do that. So why all of a sudden they said they should said to us that. She will want they say always, yhuu! Door to door, (Laughter). I can't do that."

Participant (2):

"I think maybe if they first say when they want volunteer, they say, come if you want volunteer here are interview, it was better. Now we come all of us to volunteer, all of a sudden interviews and standard ten (10), have nothing."

Facilitator:

"And how they set some criteria?"

Participants:

" yes."

Participant (8):

"And we are working long distance from last year April. We are starting working in the voluntarism but at the end they want standard ten (10) and then they want uh the person who passed the metric. Why should be didn't tell us in the first place they want a person who has a metric. Is now two years now in volunteering, we have experience, we have but they don't, not going to be hired. They will go outside and take those who didn't volunteer."

Participant (10):

"Or the cleaners and we are asking that maybe they have a fear when you have you, you, you don't volunteer to do that job. So they can give us a salary, maybe they can give us a salary and say and give us not a volunteer or leave work and not a volunteer and maybe they can give us a health worker, they can not or train an assistant nurse."

Participant (2):

"And we know we are volunteers, we know, we know, but all over where we are going, volunteers, volunteers, we know, we know."

Facilitator:

"You want to be a little bit more status and respect?"

Participants:

"Yes."

Participant (4):

"We want to change the name, we want to change."

Participant (1):

"Especially the people who call us volunteers more almost they are management."

Participant (5):

"When we begin this in step-down the people told the warders whoa! They are also HIV imagine they must be afraid of them."

Facilitator:

"Is that so…? Did they talk about you?"

Participants:

"Yes."

Participant (5):

"But we don't worry. We don't worry."

Facilitator:

"Can we gather another information, we just had before but I don't want the any..are you sure that you expressed all your feelings you left about the support you receive from management about the hospice or if you want to still make any suggestions regarding the support that you should be provided to you can do that to finish, find that you are still welcome if you have any suggestion to think right now."

Participant (8)

"And then we had the rumours other volunteer who are working there from Sunflower in National. They are taking them permanently and they come, go thoe ke ka morao (behind our back) (Figurative translation, literally meaning behind us), but now they are permanent and they come go thoe ke eng ka mora rona (behind our back) but now they are permanent."

Facilitator:

"I see, the case is sort of discrimination."

Participants:

"Yes, mmh."

Participant (3):

"Because we are allocated as fourteen volunteers at hospice at the National. When we walk, we were working they just disappeared that the two volunteers they the two taken back to hospice by the management. They didn't inform us and they are permanent. So when we try to follow this up. We try to ask them as these two volunteers are working there and are permanent. Why don't you do us permanent we are here. They said no we will just come to that point after the staff meeting, which is, they don't do their thing. There they are working with the other."

Participant (5):

"And they don't satellite us with a permanent."

Participant (8):

"They get their money their salary every month."

Facilitator:

"Is the two who has been away now."

Participant (8):

"The other one for them is here."

Participant (5):

"This is unfair, really."

Facilitator:

"Okay then I would like to thank you all for your open heart and the information you shared with us. The purpose of doing research is to scientifically identify problems and to make suggestion and help to improve situation, so there is no writing, maybe the report saying the caregivers are satisfied but if we can do research and doing interviews. So that's why your inputs really appreciated and I think you are doing a great job, sorry about all the problems, but I think you are doing a great job, keep it up, thanks for coming."

ANNEXURE M

Work schedule

WORK SCHEDULE

TIME PERIOD	ACTIVITIES
11 February 2003	Consultation with supervisor in preparation for submission of the proposal
20 February 2003	Establish of rapport with supervisor and prospective participants
04 March 2003	Submission of proposal to Ethics Committee
22 April 2003	Pilot study undertaken in the availability of the facilitator and supervisor
24 April 2003	Submission of transcriptions of the pilot study to the supervisor
25 April 2003	Data collection in the presence of the facilitator and the supervisor
05 May 2003	Submission transcriptions of focus group interviews to supervisor
19 May 2003	Consultation with the facilitator and supervisor, re-setting date for data collection of focus group in attempt to reach the saturation principle
27 May 2003	Data collection of focus group interviews
11 June 2003	Submission of focus group transcriptions to the supervisor
13 June 2003	Consultation with the facilitator re-N VIVO orientation program
19 June 2003	Continuation of N VIVO program with the facilitator
30 JULY 2003	Consultation with supervisor re-additional information of the transcriptions
20 August 2003	Literature review
09 September 2003	Consulting with supervisor re-chapter 3 remarks
08 October 2003	Submission of chapter 3 and 4 to the study-leader
06 November 2003	Round up the work in consultation with supervisor
10 November 2003	Submission of the document for editing
30 November 2003	Submission for examination

ANNEXURE N

Budget

BUDGET

EXPENDITURE CATEGORY	AMOUNT
Travelling expenditure	R1500.00
Typing (computer, cartrigde,paper, costs etc	R8000.00
Duplication and binding	R2000.00
Other expenses of participants such as beverages and transport	R700.00
Facilitator of interviews	R900.00
Telephone costs	R400.00
Editing	R2000.00
TOTAL	**R15 000.00**

ANNEXURE O

N VIVO SAMPLE

The tree diagram of focus group using the N VIVO program

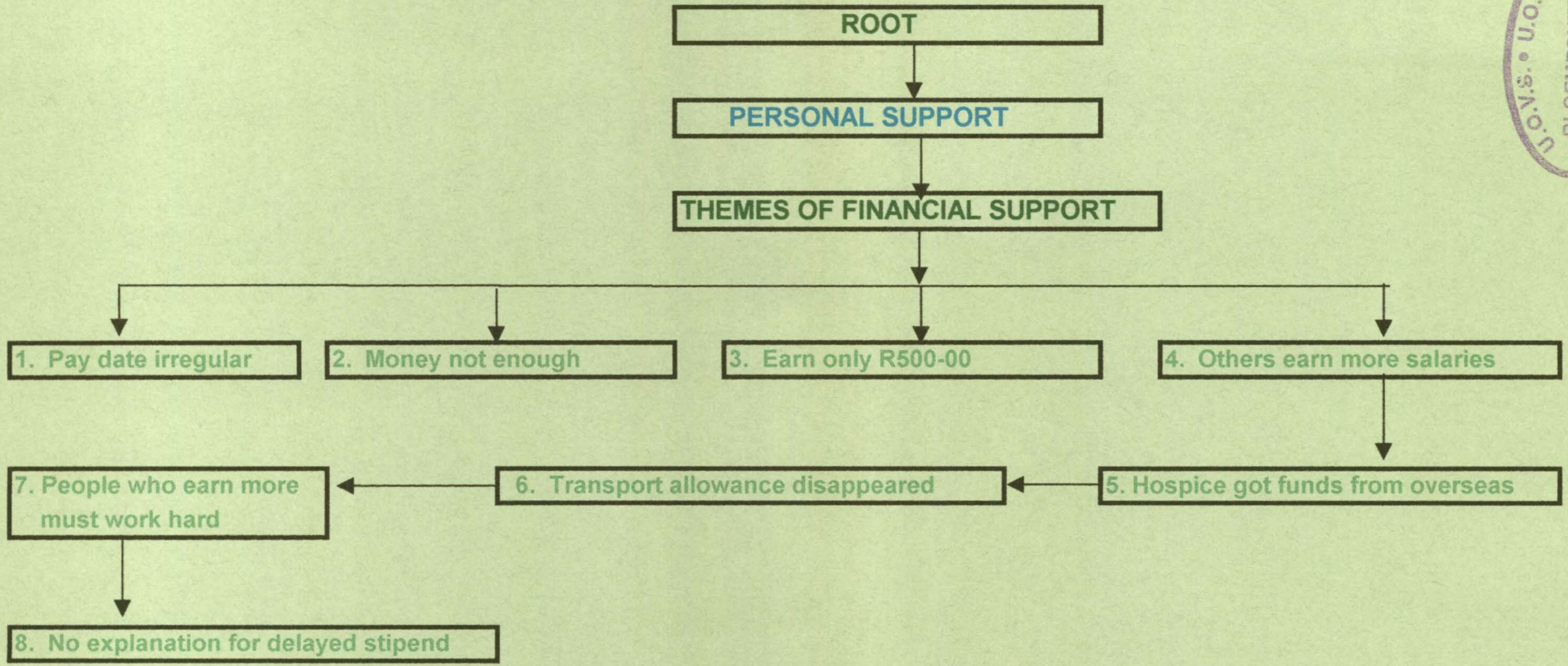
All participants in a study of the perceptions of voluntary AIDS caregivers concerning hospice managers' provision of support talked about financial support.

The researcher created a category **"node"** in **N VIVO** called personal support and selected text in each focus group subcategory transcript where participants talked about financial support and merged it into the personal support node.

The researcher retrieved information in the node and print out the different ways in which the participants talked about financial support.

In diagramming the process of categorising the information, categories identified and these developed into a *visual picture* of categories that display their interconnectedness. In **N VIVO** this is called a *tree diagram,* a hierarchical tree of categories base on a **root** node at the top.

TREE DIAGRAM FOR CATEGORIES OF FOCUS GROUP USING N-VIVO PROGRAM



INTERPRETATIONS

1. No consistency regarding date
2. Stipend insufficient to meet basic needs
3. Unequal stipend to volunteers
4. No transparency on transport allowance

PILOT STUDY (FINANCIAL SUPPORT)