

## **CHAPTER 4**

### **METHODOLOGY**

#### **4.1. INTRODUCTION**

The primary aim of this study was to determine the type of, and level of emotional and psychological support offered by home-based caregivers within Home Community- Based Care programmes, and to explore the type of issues that home-based caregivers are dealing with on a day-to-day basis. A secondary aim of this study was to evaluate and determine the level of emotional and psychological support that is offered and received by home-based caregivers themselves, as well as the type of training that they receive. In order to address the aims of this study both a qualitative and quantitative approach to methodology was adopted. This chapter essentially includes a description of the setting in which the study was conducted, the sample, the research design, the data analysis, the procedure followed, and several ethical considerations.

#### **4.2. THE SETTING**

The Catholic Diocese of Rustenburg has been involved in various community activities and programmes in the Rustenburg area for several years. The majority of these programmes have focused on issues such as health care, education, and poverty relief. Furthermore, as a result of the close contact that the Diocese enjoys with the local community, it soon realized that the HIV infection rate and the number of people with AIDS was reaching pandemic proportions in the region, and that the resources available to deal with the effects of the disease were limited, often non-existent, and not effectively coordinated.

Thus, in approximately 1993/4, and in response to this, the Bishop of the Diocese of Rustenburg, brought together representatives of various organizations from the Rustenburg region, including local health workers, NGO's, CBO's, traditional leaders, government departments and others, in the hope of initiating a holistic assault on HIV/AIDS pandemic, whilst recognizing the limited resources available in the region. The Tapologo HIV/AIDS Programme was therefore formally conceptualized and born in 1993/4, and was managed

under the auspices of the Catholic Diocese of Rustenburg, in the North West Province of South Africa. According to the researcher's key informant the concept of Home-Based Care was first conceptualized as early as 1989 at the Catholic Diocese of Rustenburg.

The initial concept of the Tapologo HIV/AIDS Programme aimed to include:

- The establishment of and support to AIDS clinics in target areas, such as mines, informal settlements, and so forth.
- Community Based Outreach Programmes, providing volunteer home-based care and education in the home and in the community using volunteers.
- Tapologo AIDS Hospice; a functional facility providing the necessary care for AIDS patients in the terminal phase of the disease, as well as providing an atmosphere of compassion and caring to both patients and significant others.

More recently, the Orphaned and Vulnerable Children's Care and Support Programme was developed and included as a project, as well as the AIDS Orphans Foster Care and Day Care Centre.

Hence, the Tapologo HIV/AIDS Programme can essentially be seen to extend outreach and home-based care services to both rural and tribal villages, suburban areas of Rustenburg, as well as the burgeoning informal settlements. The following communities are serviced: Boitekong; Freedom Park; Sunrise Park; Ledig; Ledig Ext. 2; Sesobe; Chaneng; Tlaseng; Luka; Kanana; and Phokeng. The communities focused on for the purposes of this study were, Boitekong and Phokeng, and the area of interest rested primarily with the home-based care aspect of the programme, and the volunteers or home-based carers working for the programme. The sample for the current study was drawn from the Boitekong and Phokeng programme sites.

Finally, The Tapologo Programme appears to essentially adopt a 'Community-Driven' approach to HCBC. According to the Department of Health (DOH, 2002, p. 7) the 'Community-Driven Model' is essentially based on the premise of "integrated service provision through community and locally- driven initiatives". Furthermore, unlike other models, where there is a central structure or coordinating organization, this model does not necessarily need to be attached to a community structure or organization (DOH, 2002; 2001).

Instead a community developer is designated responsibility for liaising with partner organizations and training volunteer caregivers, who then deal directly with patients and their families as necessary. Government departments or NGOs may also be approached for resources where and when required, as is evident within the Tapologo HIV/AIDS programme (DOH, 2002).

### **4.3. SAMPLE**

The sample consisted of nine home-based caregivers from Boitekong and six home-based caregivers from Phokeng. The home-based caregivers' supervisor for the entire programme was also interviewed (key informant). She is responsible for all the home-based caregivers working for the programme. There are approximately one hundred and eight home-based caregivers in total, and the sample was selected from this total number of home-based caregivers at two different sites, Boitekong and Phokeng. All of the home-based caregivers are from the communities in which they operate, and thus previously disadvantaged backgrounds. The sample population group was also exclusively African. All participants mother tongue was Setshwana, however all participants were capable of speaking and conversing in English.

### **4.4. BIOGRAPHICAL INFORMATION OF PARTICIPANTS**

Table 1 presents the distribution of the sample by age.

**Table 1: Distribution of the Sample Age**

<b>Age Groups</b>	<b>Frequencies</b>
30-39	4
40-49	5
50-59	5
60-69	2
<b>Total</b>	<b>16</b>

The majority of the sample fell in between the 40-59 age range. The mean age was 51 years of age.

Table 2 presents the distribution of the sample by the highest level of education (HLOE) achieved by the sample

**Table 2: Distribution of the Sample by the Highest Level of Education Achieved**

<b>Highest Level of Education</b>	<b>Frequencies</b>
Tertiary Education	3
Grade 12	2
Grade 11	0
Grade 10	5
Grade 9	3
Grade 8	3
<b>Total</b>	<b>16</b>

The education level ranged between secondary level education (Grade 8) and tertiary level education (e.g, Professional Nurse, Teaching Diploma). The majority of the sample has completed their Grade 10 level of education (n=5).

Table 3 presents the distribution of the sample by length of service of the sample.

**Table 3: Distribution of the Sample by the Length of Service**

<b>Length of Service</b>	<b>Frequencies</b>
3 years	1
4 years	5
5 years	7
6 years	3
<u>Total</u>	<b>16</b>

The mean length of service in years for the sample was 4.75 years. The majority of the sample had a 5 year length of service at the programme.

#### **4.5. SAMPLING PROCEDURE**

Prior to drawing the sample, the researcher visited the Tapologo HIV/AIDS Programme in order to acquaint herself with the programme's work, facilities and various community sites. A sample was then drawn from Boitekong and Phokeng, both of which are community sites forming part of the Tapologo HIV/AIDS Programme. Approximately 10 home-based caregivers work at each respective site. Permission from the ART Programme Manager was then obtained. Thereafter the manager organized and scheduled a meeting for the researcher to interview and liaised with the participants on a voluntary basis.

Thus, a purposive, non-probability sample was used for the purposes of this study (Neuman, 1997; Mouton, 1996). Purposive samples are samples which are selected with a specific purpose in mind, and which are depicted as being specifically informative (Neuman, 1997). Non-probability samples may be defined as samples that consist of individuals that are easily accessible and willing to respond (Rosenthal & Rosnow, 1991). A disadvantage of using such a sampling technique is that we may not be as confident about the conclusions drawn, since the sample may not be an accurate reflection of the population (Welman & Kruger, 2001; Neuman, 1997).

This procedure of sampling was chosen as the cases selected were regarded as being especially informative with regards to the aims of this study. Furthermore, the researcher also aimed to identify particular types of cases for in-depth investigation, and was not primarily concerned with generalizing her findings to the larger population. These aspects may result in a lack of representativeness and the sample being attenuated. However, it should be kept in mind that the aim of this research is essentially exploratory and that its primary purpose is to generate insights, anomalies, paradoxes, and an evaluation which may later be formalized into hypothesis that can be more rigorously tested (Hochschild, 1981, as cited in Neuman, 1997).

#### **4.6. RESEARCH DESIGN**

An exploratory approach was primarily adopted for the purposes of this study. Both qualitative and quantitative research methods were employed. Qualitative techniques were employed by the researcher in order to elicit and explore as many salient issues and themes as possible (Breakwell, Hammond & Fife-Shaw, 1995). Qualitative techniques allow for respondents' "lived experiences" to be elicited, ultimately locating subjective meaning within various contexts.

#### **4.7. METHOD OF DATA COLLECTION**

The interview method was the main method of data collection for the current study. The interview method permits an in-depth analysis and exploration of sensitive key issues, and allows the researcher to potentially probe what individual caregivers convey (Neuman, 1997). Both the surroundings and any nonverbal communication can also be observed using this method (Mouton, 1996).

Eagle (1998) identifies four primary benefits in using the interview method. These benefits include: the interview method provides access to subjective meaning; they permit investigation of complex phenomena; they allow for reflexivity on the part of the researcher; and they can address any presenting power relations in the research.

##### **4.7.1. Instruments**

Two semi-structured interview schedules were used to collect data. This approach is particularly useful when conducting research in areas in which minimal research has previously been conducted or administered (Saunders, Lewis & Thornhill, 1992). It allows for the facilitation of greater flexibility through the use of a combination of open and closed questions, as well as the use of the technique of probing, which allows for a fuller, more comprehensive and complete response to be elicited, than would a structured interview or questionnaire schedule (Saunders, Lewis & Thornhill, 1992; Marshall & Rossman, 1989).

The interview schedule essentially sought to provide both biographical data, as well as more detailed data around central issues, for example training, beneficiaries, emotional and psychological support and so forth. The interview schedule ultimately provided both qualitative and quantitative indicators of the types of emotional and psychological support being provided by and for the caregivers at the Tapologo HIV/AIDS Programme, the degree of training, as well as the type of issues that they are dealing with on a day-to-day basis.

Two separate interview schedules were devised as instruments for data collection, one for the home-based caregiver themselves, and one for the supervisor of the home-based caregivers. The supervisor of the home-based caregivers served as the key informant for the purpose of this study.

#### *i) Interview Schedule for the Home-Based Caregivers*

The interview schedule for the home-based caregivers included two sections; Section A and Section B (See Appendix A).

Section A required general background information pertaining to gender, age, education level, length of service as a home-based caregiver at the Tapologo HIV/AIDS Programme, the average number of hours worked on a day-to-day basis, days worked per week, allocation of leave, motivational factors, and incentives. Closed questions were used predominantly here in order to obtain some basic statistical/numerical data and information.

Section B required information pertaining to issues such as the main focus of psychological support, the main and central concerns of the Home Based Care beneficiaries and home-based caregivers themselves in relation to both the provision and reception of psychological care and support within Home Based Care, the level of training received, and methods of coping and so forth. (See Appendix A)

#### *ii) The Interview Schedule for the Supervisor of the Home-Based Caregivers*

The interview schedule for the supervisor of the home-based caregivers requested descriptive statistics such as the length of the programme, the supervisor's length of service, and number of home-based caregivers working for the programme in general. The format of these questions was relatively closed. More circular, exploratory and open-ended questions were also requested, referring to issues such as the overseeing role of the supervisor, the selection

criteria in terms of choosing home-based caregivers, the home-based caregiver's training, the allocation of patients to home-based caregivers, the beneficiaries of the programme, home-based caregiver's level of supervision and debriefing, and strengths and weaknesses of the programme (See Appendix B).

#### **4.8. RELIABILITY AND VALIDITY**

Reliability refers to the degree to which measures are consistent, reproducible and or stable across time (Rosenthal & Rosnow, 1991). It should, therefore, be noted that the researcher, under the supervision of her supervisor, essentially developed the interview schedules herself, and thus the reliability of the measuring instrument may be queried. No other identified or appropriate measuring instrument/s were found to be available, and the interview schedules were constructed by referring to various literature in the field.

Nevertheless, the questions constructed in the interview schedule are believed to be a relatively reliable exploration of the Home-Based Caregivers perceptions, as they were asked in a consistent and premeditated manner, except for the occasional probing questions asked to elicit a particular response.

Validity refers to the extent to which "what is observed or measured is the same as what was purported to be observed or measured" (Rosenthal & Rosnow, 1991, p. 632). It therefore relates to the fit between the theory and practice of a measure. As mentioned above the interview schedule was constructed primarily in accordance with the presenting literature in the field of study. Thus, it can be argued that the degree of validity of the questions is fair (i.e, they seemed suitable in answering the research questions proposed).

Finally, it should also be noted that the instruments were given to an expert in the field once constructed. This was done in order to further ensure the reliability and validity of the instruments in general. According to Rosenthal and Rosnow (1991), when no other instruments are available, the evaluation by an expert opinion is appropriate and necessary to access the content validity of given measure.



#### **4.9. PROCEDURE**

The researcher initially visited the setting prior to conducting her research in order to acquaint herself with the programmes work, facilities and community sites, as well as to choose which community sites she was interested in researching. Following this, both written and verbal consent from the ART Programme Manager was sought and obtained (see Appendix C). The researcher then began data collection upon her arrival at the allocated sites, Boitekong and Phokeng. She approached caregivers working at these sites to participate in the study by explaining the aims and procedures of the study, and that participation was completely voluntary (see Appendix D). It was also asserted that the disclosure of information would be held in the strictest of confidence. Hence, the general ethical rights were explained and ensured. The researcher collected data for over 2 days.

Willing to participate home-based caregivers were then asked to participate in the one-on-one interview process, lasting approximately 20-30 minutes. The interviews were conducted at the respective Home Based Care sites and were audiotaped, given that permission to do so was obtained from the participants first (see Appendix F). The researcher also took note of any relevant non-verbal communication/information elicited within the interview process.

A translator was not provided as most participants were able to speak English. However, as and when the need for translators arose, at the request of home-based caregiver themselves, a member of the home-based caregivers team was utilized.

In terms of transcribing the data, an experienced and fluent SeTswana-speaking transcriber was utilized. It was felt that this would be beneficial in order to accurately translate any interactions recorded between participants and the researcher in their mother tongue, SeTswana, as well as to tap in to any language or cultural themes. Most participants had a working knowledge of, and were adequately conversant in English in order for the interviews to be conducted in this language.

#### **4.10. ETHICAL CONSIDERATIONS**

This research aimed to fulfill the University of the Witwatersrand's standard of ethics for research. In so doing, the person and property of all participants was respected to the utmost. Permission was initially sought from the respective manager of the programme. Informed consent from all participants was also obtained (see Appendix F). Participants were assured of confidentiality, and that their participation was completely voluntary. They were advised and assured that they were free to withdraw from the study at any point and that withdrawal would not result in the presence of any negative consequences for them. Permission was obtained from participants to audiotape the interview. Once the researcher has completed her Masters degree at the University of the Witwatersrand, these audiotapes will be destroyed.

The issue of potential psychological harm was also accounted for. If any of the Home-Based Caregivers found that they experienced uncomfortable and or distressing feelings as a result of the interview process, a referral number was supplied to them in order to seek necessary counselling/debriefing assistance.

#### **4.11. DATA ANALYSIS**

In general data analysis refers to the systematic search for patterns of data, whether it be patterns of recurrent behaviours, experiences, expressions, objects or bodies of knowledge (Neuman, 1997). Furthermore, it involves examining, sorting, categorizing, evaluating, comparing, synthesizing and contemplating the coded data as reviewed from the raw and recorded data, in a constant flux of circulation and transition (Hollway, 1989; Neuman, 1997).

For the purposes of this study the method of data analysis used is essentially qualitative in nature. The qualitative data analysis included thematic content analysis. Some quantitative data analysis included the provision of percentages and frequencies of occurrence.

##### **4.11.1 Thematic Content Analysis**

The methodological technique that has essentially informed the qualitative analysis of data in the current study is content analysis. According to Weber (1985) and Krippendorff (1980), content analysis utilizes a set of procedures or steps to make inferences from specified texts. Hence, content analysis can be regarded as a methodological technique which can be used for making inferences from a given text utilizing systematic procedures (Eagle, 1998). The procedures employed are primarily designed to reduce, marginalize and categorize large quantities of data in to more meaningful units for interpretation, and should be as inclusive and exhaustive as possible (Singleton, Straits & Straits, 1993).

For the purposes of the current study, the data was coded and analyzed according to specific themes, rendering the analysis more specifically to the method of thematic content analysis. A thematic unit can be described as an “assertion about a subject” (Guba & Lincoln, 1985, as cited in Eagle, 1998). Hence, the thematic content analysis which was identified as pertinent and recurrent, both served to yield and guide the thematic units for analysis, and formed the basis for systematic scrutiny (Eagle, 1998). Furthermore, the analysis primarily incorporated the experience of three subjects: “the sender of the message, the message itself and the audience of the message” [the interviewer] (Weber, 1980, p. 264).

The use of the thematic content analysis approach also allowed for the investigation of both latent and manifest meanings to emerge from the interview schedules, which allowed for a more complex model of analysis to be developed (Krippendorff, 1980). The thematic units were essentially guided by both the development of manifest and latent meanings. Manifest content for the purpose of this study, referred to that content which was pertinent or directly observable, whereas latent content referred to that content which was “beyond the surface” messages or dialect (Krippendorff, 1980, p. 17). These themes were subjectively formulated and hence, the investigation primarily relied upon the researcher’s own insight, intuition and imagination to draw inferences about both manifest and latent content. The manifest and latent content was discussed circularly and interchangeably, and thus no specific reference was made to which method of meaning was that being referred to. The researcher therefore attributed meaning to the original and manifest (surface) data when applicable, commenting on latent meanings more subtly (Ritchie, Spencer & O’Connor, 2003).

Empiricism and theory also guided the categorical units for analysis, however, the former rather than the latter was of primary significance. Hence, the nature of this study can be said to be primarily inductive, although implicitly anticipated relationships were outlined and directed through the construction and acknowledgement of relatively tentative theoretical underpinnings, and hence aspects of a deductive paradigm are both evident yet implicit in the formulation of thematic units.

#### **4.11.2. Steps of the Thematic Content Analysis**

The thematic units of analysis were essentially devised according to the purpose of the study (Eagle, 1998). The sampling unit comprised each interview transcription and the recording unit within each interview comprised the thematic units inclusive of a single sentence, statement, or group of statements pertaining to the particular topic or theme. Using content analysis to analyze the data, the data was essentially reduced into coherent, manageable themes, allowing for the identification of central issues and themes.

The steps used were informed by both Berg (1989) and Eagle (1998), and included the following procedures:

1. The recording units were specified. The analysis in this case was based upon identification of thematic units. The thematic units were defined in terms of their logical coherence around a specific topic (category). Recording units vary in length from one line to extended paragraphs. Units were coded from the interviewee material only.
2. The themes of analysis were defined. To begin with numerous thematic units were apparent, however through working them and re-working them, and through reading and re-reading the interview transcripts nine prominent thematic units were eventually derived for analysis. The thematic units included manifest and latent content and units. The encoding units were then placed within the appropriate thematic units. An attempt was made to ensure that the analysis was as comprehensive as possible, however, recording units perceived as irrelevant for the purposes of this study may have been excluded, and could perhaps be used in a more extensive study or may be included in future research within this area. A sample of text was codified to assess the utility and accuracy of the units and themes specified and modifications were

made where necessary. It became apparent here, for example, that several themes would benefit from being divided into sub-themes, for example the thematic unit 'Home-Based Caregivers' General Working Conditions' was divided into four sub-themes: 'The Art of Volunteering', 'An Incentive for Work Done', 'The Working Hours', and 'Taking a Break: Annual Leave'.

3. Each interview was then systematically scrutinized and coded according to the thematic units of analysis. Hence, all 16 interview schedules (including the interview schedule with the key informant) were subject to within text analysis, and these findings and related inferences were then compared across interviews, i.e., all 16 interviews were analyzed in conjunction with each other according to specific categorical units, and not individually.
4. The thematic data was then analyzed at a higher level of abstraction. For example, trends and highlights were identified and comparisons across interviews were made. Some comparisons were also made in conjunction to pre-existing theories and findings.
5. Conclusions were extrapolated for each thematic unit, using direct quotations from various participants in order to substantiate these conclusions.

#### **4.12. CONCLUSION**

This chapter has presented the methodology that was used to conduct this study beginning with the setting in which the study was conducted. This was followed by a description of the sample. The sampling procedure, research design and data analysis were then described. Finally, the ethical considerations were detailed providing specific information regarding confidentiality and additional safety measures to protect the participants.

The following chapter is a description of the analysis of the results of the study as conducted according to the methodology presented above. The results are largely presented according to the interview format and according to themes (thematic content analysis).