THE EXPERIENCES OF CAREGIVERS CARING FOR PATIENTS WITH HAEMOPHILIA IN RURAL AREAS

by

Zodwa Mosoma

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Supervisor: Dr J. Sekudu

DECLARATION

I declare that this is my original work and all the sources used have been acknowledged and referenced according to the requirements of the University of Pretoria.

Zodwa Mosoma

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DEDICATED TO MY HUSBAND

ANDRIES MOSOMA

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SUMMARY

THE EXPERIENCES OF CAREGIVERS CARING FOR PATIENTS WITH HAEMOPHILIA IN RURAL AREAS

Candidate : Zodwa Mosoma

Supervisor : Dr J. Sekudu

Department : Social Work

Degree : M.A. (SW) Social Health Care

Some patients with haemophilia from rural areas miss most of their clinic appointments and visit a clinic only when the complications of haemophilia have already set in. The observations from the daily practice motivated the researcher to investigate the experiences of caregivers caring for patients with haemophilia in rural areas with the aim of making recommendations that will promote a service that is responsive to these caregivers' actual needs.

A theoretical framework was obtained by doing a literature study on haemophilia as a condition. An empirical study was also conducted on an availability sample of ten caregivers who were at the Haemophilia Clinic at the Pretoria Academic Hospital. The sample was selected from a population of caregivers who brought patients to the Haemophilia Clinic. A qualitative approach was used; in-depth interviews were conducted and recorded on an audiotape. Interviews were later transcribed for analysis and interpretation.

The researcher used Creswell's model to analyse the data. The findings of the study include internal and external experiences of the caregivers. Internal experiences relate to issues around an emotional dimension, a spiritual dimension, cultural beliefs and future considerations. External experiences relate to negative and positive experiences encountered by caregivers in dealing with different systems, namely the health system, the education system, the transport system, a religious system, a cultural system, the social welfare system, the socio-economic system and the family system.

The research focused only on a small sample of caregivers who brought the patients to the clinic at the Pretoria Academic Hospital. Therefore, future research could be conducted to include more caregivers from different areas.

The study concludes that caregivers caring for patients with haemophilia in rural areas face unique challenges because of the rarity of the disorder and the scarcity of resources. Most people in rural areas lack insight on bleeding disorders because of their cultural beliefs; as a result, they fail to be supportive of the patients and their caregivers. However, there are a few people who do understand the nature of haemophilia as a disorder when it is explained to them and therefore give the necessary support to caregivers and the patients.

Haemophilia as a disorder is associated with an array of psychosocial challenges. It is concluded that social work intervention in haemophilia care can ensure that the psychosocial problems of caregivers caring for patients with haemophilia in rural areas are properly addressed.

Key concepts

Caregiver(s)	Versorger(s)
Caring	Versorging
Haemophilia	Hemofilie
Patient	Pasiënt
Rural areas	Platteland/Landelike gebiede
Experience(s)	Ondervinding(s)
Social worker	Maatskaplike werker
Disciplinary team	Dissiplinêre span
Bleeding	Bloeding
Treatment	Behandeling

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND

Jones (1995:257) comments: “Whenever I visit haemophilic families in the developing world, I am both heartened by their spirit, and dismayed by the way many of them are subjected to misleading information about treatment.” This observation reflects the reality that, because of the comparative rarity of haemophilia, most people, including many doctors, are not familiar with the “dos” and “don’ts” of haemophilia care. This implies that the situation of caregivers caring for patients with haemophilia living in rural areas and that of these patients is often desperate.

Haemophilia is a congenital disorder characterized by spontaneous and post-traumatic bleeding events in joints, muscles and other soft tissues. If these manifestations are not prevented, they inevitably lead to severe pain and disability (Lee, Berntorp & Hoots, 2005:345). Describing the complications of haemophilia, Solovieva (2001:4) says that haemophilia frequently produces several musculoskeletal complications, including acute episodes of extreme pain, a range of motion loss, joint swelling, chronic joint disease and accompanying pain and disability. The researcher has observed that patients with haemophilia living in rural areas often suffer such complications when they are referred to the Pretoria Academic Hospital for tertiary services.

Srivastava (1998:33) indicates that a number of major advances have been made over the last two decades in every aspect of care for patients with haemophilia. However, he also points out that such advances have mainly benefited patients in developed countries. For most other patients, particularly those who live in the developing world, severe haemophilia continues to be a personal and social disaster (Srivastava, 1998:33). Patients who live in rural areas are the ones who suffer most. It is therefore vitally important to explore caregivers’ experiences regarding their daily struggles in caring for these patients, as well as other factors involved in the treatment process.

Lee *et al*. (2005:366) argue that in developing countries a limited healthcare budget is usually directed toward alleviating nutritional and infectious diseases (high volume, low-cost conditions) rather than toward treating haemophilia or other hereditary bleeding disorders. However, they also clarify that while there is no doubt that resource limitations have a significant impact on the ability of countries in the developing world to spend on haemophilia care, another critical factor in this regard is the attitude of the people and their government toward healthcare in general and haemophilia in particular.

Specifically referring to South Africa, Srivastava, Chuansumri, Chandy, Duraiswamy and Karagus (1998:474) acknowledge that comprehensive management teams that include nurses, social workers, physiotherapists and orthopaedic surgeons have been developed in medical centres. Unfortunately, they have not yet been given the necessary recognition by government for assistance in their work. The authors add that tertiary hospital funding in South Africa has been reduced in the last few years, and that treatment for haemophilia is becoming less and less affordable, leading to preventable morbidity and mortality.

It is estimated that about 400 000 people worldwide have haemophilia. About 80% of these people live in the developing countries. In South Africa, there is a population of 43 million people; and it is estimated that about 4 300 people have haemophilia. By 1990, only 2 400 people had been diagnosed with haemophilia. That means there are around 1 900 people who do not even know that they have the disorder, because of its rarity and the limited information available about it (South African Haemophilia Foundation, 2000:2-13).

The researcher has observed how the team at the Haemophilia Clinic at the Pretoria Academic Hospital collaborates to give optimal treatment to the patients who come to the clinic. The researcher also noted that some patients from rural areas tended to miss their clinic appointments and that they mostly attended the clinic only when the complications of the disorder had already set in. Hence, this study aimed to explore the experiences of caregivers caring for these patients, as well as associated factors that could enhance services.

As a member of the multidisciplinary team at the Haemophilia Clinic at the Pretoria Academic Hospital, the researcher has been rendering services to the patients of the clinic, including those who come from the rural areas. Through her interventions, the researcher realized that one patient from the rural areas had a poor support system: his biological mother had a mental disability; and his caregiver was his maternal grandmother (who herself had a visual impairment). The patient was already using crutches as a result of complications resulting from the disorder. A few weeks later, it was reported that the patient had experienced intracranial bleeding and had died after being admitted to the intensive care unit. This incident suggested that not only the patients, but also the caregivers of patients with haemophilia who live in rural areas often experience difficult circumstances that needed to be investigated for appropriate service delivery to be made available.

The problems noted in her daily practice motivated the researcher to investigate the experiences of caregivers caring for patients with haemophilia in rural areas with the aim of providing a service that will be responsive to their actual needs. The study will benefit social workers and health care personnel involved with haemophilia care, particularly the ones in rural areas, to improve the service available to these patients and their caregivers in clinics and hospitals.

The researcher consulted with two experts in the treatment of haemophilia to obtain their input and professional opinions.

Sister Mokoena from the Johannesburg Hospital was contacted about the challenges faced by families affected by haemophilia living in rural areas. Some of the problems she mentioned include the fact that some local hospitals in the rural areas do not supply haemophilia treatment to the patients because of their limited health care budget. Patients from Moloto, KwaMhlanga, Mpumalanga and other areas all have to attend the Haemophilia Clinic at the Pretoria Academic Hospital, but that means that they have to travel approximately fifty kilometres or more to reach the hospital, and this has considerable financial implications for these patients (Mokoena, 2007).

Mrs Wright from the Haemophilia Foundation in Pretoria was also contacted. She explained that the best way to manage the disorder is to respond timeously once any bleeding occurs. Families in the rural areas are usually forced to travel to tertiary hospitals even in emergency situations in order to get treatment, and delays often result in the occurrence of preventable morbidity and mortality (Wright, 2007).

It became evident that caregivers faced many problems. Therefore, this study investigated meanings that these caregivers attach to their daily experiences with haemophilia as a disorder.

1.2 PROBLEM FORMULATION

Bless and Higson-Smith (1995:29) claim that a well-formulated problem is already a half-solved problem. Grinnell (1997:50) strongly emphasizes that personal interest on the part of a researcher is usually the main motivating factor in the selection of a research problem and suggests that such an interest should be deep and abiding. It is therefore clear that a research topic should not only emerge from the daily practice, but the researcher needs to have a deep interest in the topic as well. Grinnell (1997:55) suggests that no final decision can be made about the problem to be studied until the researcher has determined that the prospective problem meets four criteria. These criteria are that the research problem must be relevant, researchable, feasible and ethically acceptable.

According to Solovieva (2001:6), thus far, published research has not adequately addressed changes in the quality of life determined by the physical and emotional well-being, experience of pain and changes in the social environment of patients with haemophilia. Lee and Kessler (2002:493) elaborate on Solovieva’s views, writing that the long-term stressful situations associated with chronic diseases have motivated a large number of scientific publications on coping strategies related to the illness, but that there is a lack of published information about rural families who live far from health care clinics or hospitals. They conclude that this lack of relevant facilities is a critical setback.

The researcher agrees with the abovementioned authors, because caregivers in rural areas do not receive the attention they deserve with regard to their daily struggles with haemophilia as a disorder. Srivastava *et al.* (1998:475) also argue that insufficient knowledge about bleeding disorders in the medical community and the absence of a proper health care infrastructure preclude the development of appropriate services for haemophilia patients, particularly in developing countries.

A lack of information regarding the experiences of caregivers caring for patients with haemophilia in rural areas makes it difficult to render an appropriate service – one that is relevant to their needs. Such a lack of information often results in the occurrence of preventable morbidity and mortality.

This study therefore aimed to enhance understanding of the experiences of caregivers caring for patients with haemophilia and the meanings they attach to their everyday lives and experiences as caregivers. Haemophilia is known to be a costly disease, both financially and emotionally. Therefore, this study wanted to explore the experiences of caregivers in remote areas where there are limited resources. The researcher believes that acquiring this information will result in a better understanding of patients and their families by social workers and other team members, enabling teams to develop the necessary supportive service to be responsive to the actual needs of patients and their caregivers.

1.3 GOAL AND OBJECTIVES OF THE STUDY

Fouché and De Vos (2005:104) argue that the terms “goal”, “purpose” and “aim” are frequently used interchangeably; their meaning implies the broader, more abstract conception, “the end to which effort or ambition is directed”. They differentiate between a goal and objectives, stating that the goal is the “dream” while objectives are steps one has to take, one by one, realistically, at grass-roots level, within a certain time span, in order to attain the dream.

The researcher has undertaken a number of tasks in order to reach the desired goal and those tasks were performed within a specified time period.

1.3.1 Goal of the study

Babbie and Mouton (2001:79) mention three of the most common and useful purposes or goals of social research, namely exploration, description and explanation. They also point out that a large proportion of social research is conducted to explore a topic; and this approach is typical when a researcher examines a new interest or when the subject of study itself is relatively new. In the current study, the researcher also intended to explore a subject of study that is relatively new.

The goal of the research was **to explore the experiences of caregivers caring for patients with haemophilia in rural areas**.

1.3.2 Objectives of the study

In order to ensure that the abovementioned goal was reached, the researcher took the following steps:

- a theoretical conceptualization of haemophilia as a condition;
- an exploration of the experiences of caregivers caring for patients with haemophilia in rural areas; and
- a formulation of conclusions and recommendations for future research and improved service delivery with regard to caregivers caring for patients with haemophilia in rural areas.

1.4 RESEARCH QUESTION

Fouché and De Vos (2005:103) distinguish between a researcher who undertakes a qualitative study and one who undertakes a quantitative study. If a researcher is doing a quantitative study, he/she would write a formal problem formulation and might include the formulation of a hypothesis. If a qualitative study is done, then a research question would be formulated.

Mark (1996:82) cautions that, before researchers conduct a study, a clear definition of the research problem is required. Researchers need to know the answer to the question, “what exactly do I want to find out?”. Thus, a clear research question makes it easier to conduct a study, as the researcher is then able to maintain a clear focus.

In the current study, the researcher opted for a qualitative study and a research question was formulated, instead of a hypothesis. The following research question was formulated: **What are the experiences of caregivers caring for patients with haemophilia in rural areas?**

1.5 RESEARCH APPROACH

A number of authors (Babbie & Mouton, 2001:49, 53; Bless & Higson-Smith 2000:37; Fouché & Delport, 2005:17) acknowledge two types of approaches: the qualitative and the quantitative approach. These two approaches can be used either separately or in combination with each other, depending on the study.

According to Fouché and Delport (2002:79), the main aim of a quantitative study is to measure the social world objectively, to test hypotheses and to predict and control human behaviour. It may therefore be defined as an enquiry into a social or human problem, based on testing a theory composed of variables and analysed with statistical procedures. By contrast, a qualitative study aims mainly to understand social life and the meaning that people attach to everyday life. Thus, in its broadest sense, according to the authors, a qualitative study refers to research that elicits participants' accounts of meaning and of their experiences.

In the current study, the researcher followed a qualitative approach. The researcher attempted to tap into the deeper meanings that the respondents attached to the phenomenon under review by exploring their experiences.

1.6 TYPE OF RESEARCH

Rubin and Babbie (1993:99) argue that when we say that social work research sets out to solve practical problems in social welfare, the connotation of "applied" research is inescapable. Neuman (2000:23) claims that researchers who seek an understanding of the fundamental nature of social reality are engaged in basic research, and explains that applied researchers primarily want to apply and tailor existing knowledge to address a particularly practical issue.

Applied research is the type of research used in this study, because the researcher was concerned with practical results that will contribute to the improvement of services. The researcher had no intention of developing or refining a theory regarding haemophilia, but instead set out to understand the experiences of caregivers caring for patients with haemophilia in rural areas so as to improve the services provided to them by the team at a clinic, based on their needs.

1.7 RESEARCH DESIGN AND METHODOLOGY

The terms “research design”, “strategies” and “methods” are used interchangeably by different authors (Fouché & Delport, 2002:271). Bless and Higson-Smith (1995:29) refer to a research design as the planning of any scientific research from the first to the last step. In this sense they say it is a programme to guide the researcher in collecting, analysing and interpreting observed facts.

Terre Blanche and Durkheim (1999:29) hold similar views as the above authors. They define a research design as a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research. These authors also refer to designs as plans that guide “the arrangement of conditions for collection and analysis of data in a manner that aims to combine relevance to the research purpose with economy in procedure”.

The abovementioned definitions indicate that a research design is a form of planning that has to be done by the researcher before the research project is undertaken. The planning therefore guides the research process from the initial stages to the end.

For a researcher to effectively use a phenomenological research design, Babbie and Mouton (2001:271) suggest that the researcher has to make a deliberate attempt to put himself/herself in the shoes of the people he/she is observing and studying and try to understand their actions, decisions, behaviour, practices and rituals from their perspective(s).

A phenomenological research design was used in this study, because the researcher aimed to explore and understand, as well as interpret, the meanings of the respondents' experiences with regard to the problems of haemophilia care in the rural areas.

1.7.1 Data collection

The research took place at the Haemophilia Clinic at the Pretoria Academic Hospital from September 2007 to November 2007. As a method of data collection, the researcher used in-depth interviews to elicit information about the experiences of caregivers caring for patients with haemophilia in rural areas. According to Greeff (2002:293), the purpose of conducting an in-depth interview is not to get answers to questions, but rather to understand the experience(s) of other people and the meaning(s) they make of that experience. This implies that an interview is focused and that it allows the researcher and the respondents to explore an issue.

One central question was used with all the respondents. It is the following: "How would you explain your daily experiences of caring for a patient with haemophilia?" A tape recorder was used in the data collection, with the respondents' permission.

Using the in-depth interview method was relevant to this study because it enabled the researcher to obtain in-depth information about the experiences of caregivers caring for patients with haemophilia in rural areas.

1.7.2 Data analysis

After the data collection had been completed, the researcher analysed the data that had been collected. Henning (2004:101) says that the true test of a competent qualitative researcher comes in the analysis of the data, a process that requires analytical craftsmanship and the ability to capture understanding of the data in writing.

The researcher used Creswell's model of data analysis. According to De Vos (2005:334), this model contains a series of steps which include collecting data and doing a preliminary analysis, managing the data, reading and writing memos, identifying the salient themes and presenting the data.

In this study, data were analysed and interpreted through themes extracted from the interviews; these were categorized and interpreted. The experiences of caregivers caring for patients with haemophilia were also presented *verbatim* to emphasize their experiences. The findings of the study are presented in tables and in excerpts from the transcripts in Chapter Four of this research report.

1.8 PILOT STUDY

A pilot study is defined in the *New Dictionary of Social Work* (Terminology Committee of Social Work, 1995:45) as the "process whereby the research design for a prospective survey is tested", which means it can be referred to as a small-scale trial of all the aspects the researcher plans to use in the main inquiry. Bless and Higson-Smith (2000:155) use similar definition, defining a pilot study as a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate.

The researcher conducted a pilot study with the purpose of identifying possible pitfalls that could hinder the research process in the main investigation. However, it must be noted that each in-depth interview is unique; therefore, the pilot study assisted the researcher only to determine the feasibility of the envisaged study.

Two caregivers who possessed the same characteristics as the ones that were to be used in the main study were interviewed. These caregivers did not form part of the actual study.

1.8.1 Feasibility of the study

The researcher discussed the intention of conducting the proposed study with Dr Opperman, the Head of the Haemophilia Clinic at the Pretoria Academic

Hospital (Opperman, 2005). Dr Opperman was very supportive and even introduced the researcher to one of the nursing sisters involved with the Haemophilia Foundation in Johannesburg.

The research study was feasible because 37% of the patients that attended Haemophilia Clinic at the Pretoria Academic Hospital were from rural areas. These areas include Nelspruit, KwaMhlanga, Moloto and other places where haemophilia treatment is usually not available. A formal written letter of permission was received from Dr Tanna, who is one of the hospital's senior superintendents. The researcher also received permission for the study from the Hospital Ethics Committee.

The researcher works at the Pretoria Academic Hospital as a social worker and as a team member at the Haemophilia Clinic. Therefore she did not have problems concerning the time and finances needed to conduct the study.

1.9 THE POPULATION, SAMPLE AND SAMPLING METHOD

1.9.1 The population

Bless and Higson-Smith (2000:85) refer to a population as a "target population" and therefore see it as a set of elements which the research focuses upon and to which the results obtained by testing the sample should be generalized. Seaberg (in Strydom & Venter, 2002:148) also defines a population as a total set from which individuals or units are chosen.

In this study, caregivers who were caring for patients with haemophilia receiving their treatment at the Pretoria Academic Hospital and living in rural areas were the population from which the respondents were drawn. As the researcher is also a team member at the Haemophilia Clinic, it was easy to identify and approach these caregivers for possible inclusion in the study.

1.9.2 Sampling and sampling method

The term "sample" always implies the simultaneous existence of a population or universe of which the sample is a smaller section or a set of individuals selected from the population (Strydom, 2005a:193).

Strydom (2005a:204) explains that sampling is done to increase the feasibility, cost-effectiveness, accuracy and manageability of a prospective survey. The researcher shares this view, because it was impossible for the researcher to identify, contact and study the entire relevant population, as time and cost limitations would make the completion of the study difficult.

There are two types of sampling methods, namely probability and non-probability sampling. In probability sampling, each element in the population has the same known probability of being selected, which means that probability sampling is based on randomisation, while non-probability sampling does not implement randomisation (Strydom, 2005a:196).

Availability or convenience sampling was used in this study, because the researcher targeted the caregivers who brought the patients to a particular clinic on a monthly basis. Thus, caregivers caring for patients with haemophilia living in rural areas were drawn as the actual sample from the Haemophilia Clinic at the Pretoria Academic Hospital. The results of the study should not be generalized because the sample was selected without randomization.

Therefore, the sample consisted of ten caregivers caring for patients with haemophilia living in the rural areas, attending the Haemophilia Clinic at the Pretoria Academic Hospital. They were all South African citizens.

1.10 ETHICAL ISSUES

Emphasizing the importance of ethical issues, Strydom (2005b:56) states that the fact that human beings are the objects of the study in the social sciences brings unique ethical problems to the fore which would never be relevant in the pure, clinical laboratory settings of the natural sciences. That implies that social science researchers need to be very cautious not to harm their respondents.

Strydom (2005b:57) defines ethics as a set of moral principles suggested by an individual or group. These principles are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.

For the purposes of this study, the researcher considered the ethical issues set out below.

1.10.1 Avoidance of harm

Subjects can be harmed in a physical and emotional manner, and the responsibility of protecting respondents against harm reaches far further than mere efforts to repair, or to minimize the effects of such harm afterwards (Strydom, 2005b:58). Rubin and Babbie (1993:59) emphasize that social work research should never injure the people being studied, regardless of whether or not they volunteer for the study.

The researcher ensured that respondents were protected against any form of harm that would emerge during the course of the study. The researcher realised that emotional harm was often more difficult to predict and to determine and was more likely to emerge than physical harm, although physical harm was not ruled out completely. To prevent harm, respondents were informed about what the investigation entailed. This was done in a briefing session with the respondents before the interviews commenced.

1.10.2 Informed consent

Informed consent is one of the most fundamental aspects in social science research. It implies the communication of all possible or adequate information on the goal of the investigation, the procedures which will be followed during the investigation, and the possible advantages, disadvantages and dangers to which respondents may be exposed. Emphasis must be placed on accurate and complete information, so that respondents are able to make a voluntary, thoroughly reasoned decision about their possible participation (Strydom, 2005b:59).

In order to adhere to this ethical guideline, the researcher informed the respondents about the purpose, procedure, advantages and disadvantages of the study. The respondents were then requested to sign the consent forms, which were co-signed by the researcher, before the data collection process began.

1.10.3 Deception of respondents

According to Neuman (2000:229), deception occurs when a researcher intentionally misleads subjects by way of written or verbal instructions, the actions of other people, or certain aspects of the setting. Sharing similar views, Strydom (2005b:60) writes that deception involves deliberately withholding information, or offering incorrect information in order to make sure that the respondents participate in the study when they would otherwise possibly refuse.

The researcher did not deceive the respondents and made sure that the following information was included in the consent form: the researcher's name, the title of the study, the purpose, and procedure of the study, the participant's rights, the issue of financial compensation (there was none) and confidentiality.

1.10.4 Violation of privacy

Strydom (2005b:61) refers to privacy as the right to self-determination and confidentiality. He adds that privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a confidential manner.

The researcher ensured that the identity of respondents was never disclosed. Because anonymity could not be guaranteed since interviews were conducted with respondents, the researcher ensured that the collected data was dealt with in a confidential manner.

1.10.5 Actions and competence of researcher

In order for a research project to run its course in an ethically correct manner, a researcher must be competent and adequately skilled to undertake the proposed investigation (Strydom, 2005b:63). However, Strydom (2005b:63) points out that even well-intentioned and well-planned research can fail or can produce invalid results if the researcher or fieldworkers are not adequately qualified and equipped, and there is not adequate supervision of the project.

To avoid such negative consequences, the researcher acquired extensive knowledge on the research topic by means of a literature review. The research was also done under supervision and the researcher was knowledgeable regarding research methodology.

1.10.6 Release or publication of the findings

Rubin and Babbie (1993:61) issue a strong warning that social work researchers have ethical obligations to their professional colleagues, and, to the same degree, to their subjects in the study. The authors add that it is important to avoid the temptation to save face by describing findings as the product of a carefully preplanned analytical strategy when that is not the case, because such dishonesty tends to mislead inexperienced researchers. They conclude that, in general, science progresses through honesty and openness, and it is retarded by ego-defenses and deception.

Strydom (2005b:65) explains that the information in the study must be formulated and conveyed clearly and unambiguously to avoid or minimise misappropriation of subjects, the general public and even colleagues.

The researcher adhered to the above guidelines on this ethical issue by reporting the shortcomings of the study, as well as errors encountered throughout the study, to benefit other researchers and the public. The respondents were made aware of the fact that the data that was collected was to be compiled into a research report that would be shared with the reading public.

1.10.7 Debriefing of respondents

Strydom (2005b:66) is of the opinion that debriefing participants is more effective when the feelings of the participants are discussed immediately after the session or when a newsletter telling them the basic intent or results of the study is sent to them. This process helps to correct problems generated by the research experience.

The researcher conducted debriefing sessions with the respondents immediately after data collection sessions. If it seemed that respondents needed therapy, the researcher referred them to her colleague at the Pretoria

Academic Hospital. This was done after the data collection process was completed.

1.10.8 Cooperation with contributors

Strydom (2005b:64) writes that research projects are often so expensive and comprehensive that a researcher cannot afford them financially and may not cope in terms of time. Consequently, a sponsor may be required. He explains that the relationship between the researcher and the sponsor can also sometimes raise ethical issues, for instance, when the researcher does not disclose the real findings, in compliance with the expectations of the sponsor. Babbie and Mouton (2001:528) also caution that one should be especially careful not to promise or imply acceptance of any conditions that are contrary to one's professional ethics.

This ethical aspect was not applicable to this study, because the researcher conducted the study without involving any sponsors or contributors.

1.11 DEFINITION OF KEY CONCEPTS

Conceptualization and operationalization are viewed as the form of reference to be used as a guide in verifying the meaning of each concept and identifying the relationship between those concepts (Rubin & Babbie, 1993:120). For the purposes of this study the concepts below are defined as follows:

1.11.1 Caring

The *New Dictionary of Social Work* (Terminology Committee of Social Work, 1995:06) defines care as provision for people's physical, psychological and material needs where they are unable to provide these for themselves. According to *Mosby's Medical, Nursing & Allied Health Dictionary* (2002:299), care refers to actions characteristic of concern for the well-being of a patient, such as sensitivity, comforting, attentive listening and honesty.

For the purposes of this study, care refers to the provision by caregivers of what is necessary for the health and well-being of patients with haemophilia.

1.11.2 Haemophilia

Lee and Kessler (2005:345) define haemophilia as a congenital disorder characterized by spontaneous and post-traumatic bleeding events in joints, muscles, and other soft tissues. If these manifestations are not prevented, they inexorably lead to severe pain and disability. *Stedman's Medical Desk Dictionary* (1990:701) defines haemophilia as a disorder of blood coagulation characterized by a permanent tendency to haemorrhages, spontaneous or traumatic, due to a defect in the blood coagulation mechanism.

In this study, haemophilia refers to a disorder of blood clotting that interferes with the person's well-being.

1.11.3 Patient

Mosby's Medical, Nursing & Allied Health Dictionary (2002:1294) defines a patient as a recipient of a health care service or as a health care recipient who is ill or hospitalised. *Stedman's Medical Desk Dictionary* (1990:1151) refers to a patient as a person who is suffering from any disease and is under treatment for it.

In this study, a patient refers specifically to someone who is suffering from haemophilia and is receiving treatment.

1.11.4 Rural

The Oxford Concise Dictionary (1990:1057) defines the word rural as suggesting the country, a pastoral or agricultural setting in rural seclusion, or a rural district which is made up of a group of country parishes governed by an elected council. The *Oxford Advanced Learner's Dictionary* (1995:1032) simply refers to the rural area as the countryside or an agricultural, remote and isolated area.

The definition of rural areas that is used for this study is isolated areas where there are limited resources.

1.11.5 Caregiver

Mosby's Medical, Nursing & Allied Health Dictionary (2002:298) refers to a caregiver as one who contributes the benefits of medical, social, economic or environmental resources to a dependent or partially dependent individual, such as a critically ill person. The *New Dictionary of Social Work* (Terminology Committee of Social Work, 1995:6) simply says a caregiver is a person who provides care for other persons.

For the purposes of this study, a caregiver refers to a person who contributes the benefits of medical, social, economic resources and care to a patient who has haemophilia, on a daily basis. This person can be a parent or a member of the patient's extended family.

1.11.6 Experience

The Oxford Concise Dictionary (1997:474) defines experiences as actual observations on practical acquaintance with facts or events. According to the *Oxford Advanced Learner's Dictionary* (1995:405), experience is the process of gaining knowledge or skill over a length of time by seeing and doing things through studying.

In this study, experience refers to the views, beliefs, perceptions, knowledge and skill of caregivers.

1.12 LIMITATIONS OF THE STUDY

The researcher encountered the following limitations and problems during the research study:

- There was very limited information about the topic in social work literature. As a result, most of the literature used was taken from the medical field.
- During the data-gathering phase, the researcher experienced problems because most of the respondents did not attend the clinic as expected.
- The researcher had some problems in obtaining ethical clearance from the Hospital Ethics Committee: the process took a long time, delaying the progress of the study.

1.13 OUTLINE OF THE STUDY

Chapter 1

This chapter consists of a general introduction to the entire study, allowing the researcher to conceptualize the proposed study theoretically.

Chapter 2

In the second chapter, the researcher gives a theoretical overview of haemophilia and its effects, as well as of the care provided by the caregivers.

Chapter 3

Chapter Three presents the empirical findings that were verified with reference to the literature.

Chapter 4

In the final chapter the researcher draws conclusions regarding the study and outlines the essence of the findings. Recommendations are made for further research on this and similar topics, as well as improved service delivery.

CHAPTER 2

HAEMOPHILIA AND ITS EFFECTS ON CAREGIVERS

2.1 INTRODUCTION

Haemophilia as a disorder is associated with an array of psychosocial challenges. There are unique challenges, both medical and psychosocial, which patients and their caregivers living in rural areas must face. These challenges involve not only limited medical infrastructure, healthcare personnel and the unavailability of treatment, but also the rarity of the disorder itself. Among the few healthcare professionals available in these areas, ignorance about the disorder poses another challenge to the caregivers of these patients. The comparative rarity of haemophilia means that most people, including many doctors, are not familiar with the “dos” and “don’ts” of haemophilia care (Jones, 1995:257).

The life expectancy and quality of life of patients with haemophilia is linked directly to the level of resources available for diagnosis and treatment. In this context, haemophilic patients in the developing world are more exposed to problems in healthcare than those in developed countries, because developing countries have various economic and social problems (Antunes, 2002:199). Antunes also comments that developing countries are making tremendous efforts to change their diagnosis and treatment methods to improve their healthcare. The aim of making such efforts is to promote better life for all patients, including those with haemophilia. It is also mentioned that the goals of these countries are threatened when there are many social needs and few economic resources.

This chapter focuses on the following aspects: haemophilia as a medical condition, its genetics, diagnosis, levels of severity, common sites of bleeding, treatment, medical complications, haemophilia care in developing countries, rural-urban discrepancies and inequalities in health care delivery, the psychosocial impact of haemophilia on the patient, and his/her family and the challenges of caregiving and the role of social workers as team members.

2.2 LIST OF MEDICAL CONCEPTS

A number of key medical concepts are defined below to make it easier for the reader to understand the chapter.

- *Amniocentesis*

  This is "an obstetric procedure in which a small amount of amniotic fluid is removed for laboratory analysis. It is usually performed between the sixteenth and twentieth weeks of gestation to and in the diagnosis of fetal abnormalities" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:81).

- *Arthropathy*

  This refers to "any disease or abnormal condition affecting a joint" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:136).

- *Chorionic villus*

  This is "the multilayered outermost fetal membrane consisting of extraembryonic somatic mesoderm, traphoblast and on the maternal surface villi bathed by maternal blood" (*Stedman's Medical Desk Dictionary*, 2000:343).

- *Coagulation*

  "It is the process of transforming a liquid into a solid, especially of the blood" (*Mosby's Medical, Nursing & Allied Health Dictionary,* 2002:383).

- *Factor VIII*

  This is "a coagulation factor present in normal plasma but deficient in the blood of persons with haemophilia A. It is a macromolecular complex composed of two separate entities, one which when deficient results in haemophilia A, and the other when deficient results in Von Willebrand's disease" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:653).

- *Factor IX*

  This is "a coagulation factor present in normal plasma but deficient in the blood of persons with haemophilia B" (*Mosby's Medical, Nursing & Allied Health Dictionary,* 2002:653).

- *Haemophilia*

  This is "an inherited disorder of blood coagulation characterized by a permanent tendency to hemorrhages, spontaneous or traumatic, because of a defect in the blood coagulation mechanisms" (*Stedman's Medical Desk Dictionary,* 2000:805).

- *Haemophilia A (Classic haemophilia)*

  "It is due to deficiency of factor VIII, an X-linked recessive condition occurring almost exclusively in human males and also affecting several breeds of dogs, characterized by prolonged clotting time, decreased formation of thromboplastin and diminished conversion of prothrombin" (*Stedman's Medical Desk Dictionary*, 2000:805).

- *Haemophilia B (Christmas disease)*

  "It is a clotting disorder resembling haemophilia A caused by hereditary deficiency of factor IX, also seen as an X-linked recessive condition in the Cairn terrier breed of dogs" (*Stedman's Medical Desk Dictionary,* 2000:805).

- *Haemorthrosis*

  "It is the extravasation of blood into a joint" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:792).

- *Hematoma*

  This is "a localized mass of extravasated blood that is relatively or completely confined within an organ or tissue, a space or a potential space, the blood is usually clotted or partly clotted" (*Stedman's Medical Desk Dictionary,* 2000:796).

- *Hemarthosis*

  This refers to "the extravasion of blood into a joint" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:793).

- *Inhibitor*

  It is "an agent that restrains or retards physiologic, chemical or enzymatic action, a nerve stimulation of which represses activity" (*Stedman's Medical Desk Dictionary*, 2000:901).

- *Intracranial haemorrhage*

  This is "a hemorrhage within the cranium" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:918).

- *Intravenous infusion*

  This is "a solution administered into a vein through an infusion set that includes a plastic or glass vacuum bottle or bag containing the solution and tubing connecting the bottle to a catheter or a needle in the patient's vein" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:922).

- *Iliopsoas*

  "It is one of the pair of muscle complexes that flex the thigh and the lumber vertebral column, consisting of the psoas major, the psoas minor and iliacus" (*Mosby's Medical, Nursing & Allied Health Dictionary,* 2002:869).

- *Prophylactic*

  This refers to the "prevention of disease or of a process that can lead to disease" (*Stedman's Medical Desk Dictionary,* 2000:1458).

- *Prothrombin*

  This refers to "a glycoprotein molecular weight approximately 72,500 formed and stored in the parenchymal cells of the liver and present in blood in a concentration of approximately 20 mg/100ml" (*Stedman's Medical Desk Dictionary*, 2000:1465).

- *Thrombin*

  This is "an enzyme formed from prothrombin, calcium and thromboplastin in plasma during the clotting process. Thrombin causes fibrinogen to change to fibrin, which is essential in the formation of a clot" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:1707).

- *Thromboplastic*

  This is "a substance present in tissues, platelets and leukocytes necessary for the coagulation of blood" (*Stedman's Medical Desk Dictionary*, 2000:1831).

- *Truncated*

  This refers to something "cut across at right angles to the long axis, or appearing to be so cut" (*Stedman's Medical Desk Dictionary,* 2000:1881).

- *Synovium*

  This is "the thin layer of tissue lining the articular capsule surrounding a freely movable joint. The synovial membrane is loosely attached to the external fibrous capsule. It secretes into the joint a thick fluid that normally lubricates the joint but that may accumulate in painful amounts when the joint is injured" (*Mosby's Medical, Nursing & Allied Health Dictionary*, 2002:1670).

- *X-linked recessive inheritance*

  This is "a pattern of inheritance in which the transmission of a recessive allele on the x-chromosome results in a carrier state in females and characteristic of an abnormal condition in males" (*Mosby's Medical, Nursing & Allied Health Dictionary,* 2002:1841).

2.3 HAEMOPHILIA AS A MEDICAL CONDITION

Haemophilia is defined as a congenital disorder of coagulation that affects approximately 1 in 10 000 males worldwide. Haemophilia A is due to a deficiency of factor VIII in the circulating blood. Haemophilia B (also known as Christmas disease) is caused by factor IX deficiency (Giangrande, 2005:184).

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:64) clearly explains that haemophilia is a sex-linked, genetic disorder characterized by the deficiency or absence of one of the clotting proteins in plasma. The result is delayed clotting in an affected individual. While deficiencies of any of the clotting proteins can occur, factor VIII deficiency (haemophilia A or classic haemophilia) and factor IX (haemophilia B or Christmas disease) are the most common (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:64).

Haemophilia is described in very simple terms by Jones (1995:3). He says that normally, when one injures oneself, the blood clots in a few minutes and wound healing can begin; but in haemophilia this does not happen, because one of the ingredients needed for making a blood clot does not work properly. Jones (1995:3) also mentions that this deficiency in the activity of the ingredient may be complete or partial. Therefore, this means that when the deficiency is complete, the person is said to have severe haemophilia, while, if it is partial, the condition would be moderate or mild.

Adding to the views presented by Jones (1995:3) above, Taylor (2004:149) states that haemophilia is an X-linked, recessive trait blood coagulation disorder caused by deficiencies of clotting proteins such as factor VIII (haemophilia A) or factor IX (haemophilia B or Christmas disease). Individuals with haemophilia experience recurrent bleeding into muscles and joints. Frequent and prolonged episodes of bleeding into susceptible joints are said to lead to arthritis, which in turn is responsible for most of the pain, long-term physical disability, psychosocial stress and financial hardship experienced by individuals with severe haemophilia and their families (Taylor, 2004:150).

Haemophilia is thus a sex-linked genetic disorder that affects only males. Timely replacement of the deficient factor is important to treat frequent and prolonged episodes of bleeding. Failure to provide the needed treatment can lead to long-term physical disability which can be prevented.

It is appropriate to examine the question of genetics (how the disorder is inherited in a family).

2.4 GENETICS OF HAEMOPHILIA

Haemophilia is referred to as an inherited disorder. This means that it can be passed down in a family from one generation to the next (Jones, 1995:4).

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:64) explains that haemophilia is a sex-linked recessive disorder and the abnormal gene responsible for haemophilia is carried on the x-chromosome. Females have two x-chromosomes, so the presence of the haemophilia gene on one x does not cause haemophilia, because of the presence of a normal gene on the other x-chromosome. A female with one haemophilia gene is called a haemophilia carrier. The presence of the abnormal gene in a male results in the deficiency or absence of factor VIII or IX, because there is no normal gene on the male y-chromosome. Affected men do not transmit the disorder to their sons, but all their daughters are obligate carriers.

Healthline (2006) explains that both haemophilia A and B are sex-linked diseases that are passed on from a female to male offspring. All humans have two chromosomes determining their gender, that is, females have xx, and males have xy. Because the trait (disorder) is carried only on the x chromosome, it is called sex-linked. It is also logical that, because a female child always receives two x chromosomes, she will nearly always receive at least one normal x chromosome, while a male child will have high probability of having the disease.

Giangrande (2005:185) comments that the genes for factors VIII and XI are both located at the telomeric end of the x-chromosome and thus haemophilia is inherited as an x-linked recessive condition. According to him, the daughters of affected males are obligate carriers but the sons are normal. The phenotype is said to remain constant within a family, so the daughter of a man with only mild haemophilia may be reassured that she will not pass on a severe form of the condition.

However, it is necessary to mention that approximately one third of all cases of haemophilia arise in the absence of a previous family history and are due to a new mutation. The most famous example is that of Queen Victoria, who had a son with haemophilia and two daughters who turned out to be carriers (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:64).

Cases of haemophilia that arise in the absence of a previous family history become a point of concern to everybody, because it would mean that anyone can give birth to a child with haemophilia without having the disorder in the family. This implies that proper carrier screening for families should be encouraged, as well as community education programmes about the disorder. Genetic counselling at the primary level can be an important tool in ensuring that communities are educated about the disorder. This will enhance the community member’s ability to deal with haemophilia if it does occur in a family. Rural communities should also be targeted in such awareness campaigns.

2.5 DIAGNOSIS

Healthcare professionals are highly aware that haemophilia is a hereditary disorder; however, in many countries today, it is still less well recognized that the majority of babies born with haemophilia actually represent sporadic cases, that is, the families in question have no known history of haemophilia. This lack of knowledge is claimed to be a major cause of delay in the diagnosis of the disorder, since physicians simply overlook the risk of haemophilia in previously unaffected families (Ljung, 2005:120).

Jones (1995:14) states that, because haemophilia is so rare (it is estimated to occur only in around 1 in 10 000 people), its diagnosis may be delayed for some time and doctors may look for other causes of bruising, including, in some cases, non-accidental injury. An investigation into the possibility of non-accidental injury can be awful for any parent, and unfortunately reflects an ugly reality our society and the fact that babies who have been injured intentionally form a normal part of the life of any hospital. Nevertheless, clotting tests soon lead to the right diagnosis.

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:64) emphasizes that if there is no family history of the disease present, haemophilia must still be suspected if prolonged bleeding from circumcision occurs or if raised hematomas or prolonged mouth bleeding are problems in the first year of life. When a baby is born to a known or suspected carrier of the factor VIII deficiency, plasma can be obtained from an umbilical cord blood sample for a factor VIII assay to rule out haemophilia in the child.

Early diagnosis and adequate treatment are of the utmost importance in preventing severe disability. This early diagnosis can be achieved by focusing on early bleeding events and family history (Hazewinkel, Hoogerwerf, Hesseling, Hartley, MacLean, Peters & Wessels, 2003:794). Various diagnostic tests are available to measure, under carefully controlled conditions, the length of time it takes to produce certain components of the final fibrin clot. The activated partial thromboplastin time (APTT) test is performed and is likely be normal (Healthline, 2006). Factor assays, measurement methods performed by a clinical laboratory, can determine the percentage of factors VIII and IX present, compared to normal percentages. This information is helpful in confirming a diagnosis of haemophilia and identifies the type and severity of haemophilia present.

Similarly, Roberts, Escobar and Whitell (2006:1874) say that patients with severe haemophilia A characteristically have a prolonged activated partial thromboplastin time (APTT). The prothrombin time (PT), thrombin clotting time and bleeding time are normal, although some investigators have reported minor increases in bleeding time. Thus it is emphasized that a definitive diagnosis of haemophilia A should be based on a specific assay for factor VIII activity.

It seems that laboratory tests have to be done in order to reach a correct diagnosis of haemophilia. Seeing that there are few well-equipped laboratories in South African hospitals, doctors need to refer the patients to tertiary hospitals where such resources are available. The researcher would also like to mention that a lack of knowledge in health care professionals who are unable even to identify the symptoms of the disorder often adds to unnecessary delays in the patient’s receiving proper treatment, even resulting in severe disability and even mortality. Unfortunately, patients in the rural areas are the ones most adversely affected by this state of affairs.

2.5.1 Prenatal diagnosis and carrier detection

All women who are potential carriers of haemophilia should be tested for carrier status, ideally before they become pregnant (Kulkarni, Ponder, James, Soucie, Koerper, Hoots & Lusher, 2006:205; Giangrande, 2005:190). It is also recommended that the emotional impact of carrier status and family planning be recognized and that genetic counselling for women be available (Taylor, 2004:150). Taylor argues that a tandem of geneticist and social workers can help women and couples grapple with decision-making about proceeding with pregnancy, feelings of diminished sexuality, guilt and fear, and truncated expectations of “normal” parenthood.

Like Taylor, Roberts *et al.* (2006:1870) explain that a prenatal diagnosis of haemophilia can now be performed almost routinely. There is little concern regarding whether a female foetus is a carrier, because carriers usually have no bleeding tendency. Conversely, if the foetus is a male, Roberts *et al.* (2006:1870) say that sufficient cells can be obtained to perform DNA analysis using the methods described above.

Giangrande (2005:191) maintains that the ideal approach to identify carriers, from a theoretical point of view, is to characterize the precise genetic defect responsible for haemophilia within a family. Giangrande also mentions that once the molecular defect has been identified in an individual with haemophilia A or B, direct screening for that defect could be applied in subsequent generations for both carrier testing and antenatal diagnosis. Genetic counsellors and social workers are role-players in assisting such families with relevant information about the potential risks of passing a genetic defect to their offspring. The role of a social worker goes beyond educating these families, as he/she can also offer supportive counselling to patients and their caregivers throughout.

It is clear that prenatal diagnosis and carrier testing are very important for families, as they give families time to adjust to the situation through proper counselling by the social worker on whether or not to continue with the pregnancy. It must also be noted that people living in rural areas are not able to access these services, leading to their giving birth to children with haemophilia and then having to deal with the challenges of raising these children. It would be beneficial for people living in rural areas if prenatal screening services were taken to them at primary health care clinics in order to prevent the almost unbearable circumstances of dealing with a child born with haemophilia.

2.6 LEVELS OF SEVERITY IN HAEMOPHILIA

Differentiating the levels of severity in haemophilia, Jones (1995:04) explains that when all clotting factors are abnormal, the resulting disorder is called severe. Conversely, when some of the factors are normal, the disorder is only moderate or even of mild severity. In terms of percentages, someone with severe haemophilia A has a level of factor VIII in his blood of 0%, while someone with mild haemophilia A has over 0.05 units per millilitre of blood (or >5%). According to Jones (1995:04), knowing the level of the affected factor is important for three reasons:

- The level usually, but not always, indicates what can be expected in terms of physical problems.
- The level indicates the sort of treatment that is likely to be successful.
- Usually the same level runs in a family, in that a baby with a family history of mild haemophilia will have mild haemophilia.

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:65) clarifies the fact that the amount of bleeding that can be expected in an individual with haemophilia depends on the severity of the deficiency. This means that normal plasma levels of factor VIII or IX range from 50% to150%. People with no measurable factor VIII or IX (<1%) are considered to have a severe form of haemophilia. Severe haemophilia can result in frequent bleeding episodes. The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:65) indicates that factor levels of 1% to 5% of normal coagulation are considered moderate haemophilia and that these patients may have abnormal bleeding after minor trauma, but should not experience spontaneous bleeding. Persons with more than 5% of factor activity can be considered to have mild haemophilia and are expected to have relatively few problems with bleeding, except during surgery or after severe trauma. Carrier women can have lower than normal plasma levels of factor VIII or IX and can thus have mild haemophilia.

Further clarity on different levels of severity is given by the *Treatment Guidelines for Haemophilia in South Africa* (2006:3) which state that haemophilia is classified as severe, moderate or mild, according to the levels of circulating factor VIII or IX as follows:

- Severe: Factor VIII or IX is <2%, which means that factor VIII or IX replacement is needed several times per month for traumatic or apparently spontaneous bleeding.
- Moderate: Factor VIII or IX is between 2% and 5%, which means that less frequent bleeding occurs, usually following trauma, surgery or dental work.
- Mild: Factor VIII or IX is between 5% and 25%, which means that occasional bleeding occurs, usually only after severe trauma or surgery.

Hazewinkel *et al.* (2003:794) caution that patients with severe haemophilia develop joint and muscle bleeds without adequate treatment and this may result in chronic arthropathy.

This implies that to determine the level of severity is as important as the diagnosis, in that a person with severe haemophilia should know how careful he/she should be when encountering trauma, while a moderately or mildly affected person only has to be careful when going through a severe trauma or surgery. Also, it is vitally important for families in rural areas to have such information, as it equips them with appropriate skills to deal with these circumstances.

2.7 SITE OF BLEEDING

Bleeding into joints and muscles is the most common manifestation of haemophilia (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:65). Bleeding can occur in any part of the body, and complications depend on the site of the bleeding. Bleeding into the head, neck, abdomen, or gastrointestinal tract is considered life-threatening and must be treated as an emergency.

In line with the *National Hemophilia Foundation orientation manual for healthcare professionals* (2001), the *Treatment Guidelines for Haemophilia in South Africa* (2006:4) states that major bleeding episodes usually occur in the central nervous system, gastrointestinal tract, neck/throat, hip or iliopsoas, in an advanced joint/muscle and forearm compartment. The guidelines caution that such bleeding episodes may cause death or disability. Therefore it is necessary to start appropriate factor replacement urgently. Hospitalization is usually required to maintain an adequate factor level.

Giangrande (2005:184) explains that the hallmark of severe haemophilia is recurrent and spontaneous haemarthosis; typically, hinge joints such as the knees, elbows and ankles are affected, but the bleeds may also occur in the wrist or shoulder. Giangrande also mentions that there is a significant risk of intracranial haemorrhage in severe haemophilia and that this was a significant cause of mortality in the past when treatment was not so readily available.

The *Treatment Guidelines for Haemophilia in South Africa* (2006:5-7) further categorize the signs and symptoms of bleeding according to the sites as set in Table 1.

Table 1: Signs and symptoms of bleeding per site

Haemorthrosis	**Muscle and soft tissue bleeding**	**Head injury**
Tingling sensation (early) Stiffness Pain Limited range of motion Swelling Limp or refusal to use limb	Muscle tightness (early) Pain Swelling Limited range of motion Bruising Warmth Refusal to use limb (young child)	Headache Vomiting Irritability/ convulsions Lethargy/drowsiness Vision disturbance Focal neurological deficits Ataxia

Source: *Treatment Guidelines for Haemophilia in South Africa* (2006:5-7).

Taking proper precautions when the patient bleeds by timeously providing factor treatment to the bleeding site does not only stop the bleeding, it also prevents other health complications that can develop as a result of prolonged bleeding. People with severe haemophilia should be aware of dangerous sites of bleeds that warrant urgent consultation of a medical practitioner, as some can be fatal. Providing treatment in time remains a challenge to patients and caregivers in rural areas. Thus, there is a need to provide a service that is responsive to the actual needs of these patients in isolated areas, making services accessible to them within their communities at primary health care clinics.

2.8 TREATMENT

The treatment for bleeding in haemophilia involves replacing the deficient factor. This requires an intravenous infusion of the clotting factor, specific doses and additional drugs, depending on the site and severity of bleeding (*National Hemophilia Foundation orientation manual for healthcare professionals,* 2001:65).

Giangrande (2005:185) also states that the treatment of bleeding episodes involves the intravenous injection of coagulation factor concentrates. The total dose and frequency of treatment is determined by the severity and site of bleeding. Giangrande explains further that the vast majority of joint bleeds can be resolved with a single infusion of material if the bleed is recognized early and treated promptly. There is an increasing move to prophylactic therapy in which the patient gives himself/herself injections of coagulation factor concentrate two or three times a week to prevent bleeds, rather than just treating on demand when bleeds occur. As a result, patients on prophylactic therapy experience few or even no spontaneous bleeds and therefore progressive joint damage and arthritis can be avoided (Giangrande, 2005:186).

Roberts *et al.* (2006:1877), like Giangrande (2005), claim that the clinical benefit of prophylaxis is warranted, as evidenced by a significant improvement in the clinical condition of patients and an improvement in their quality of life.

The most important aspect of care for children with haemophilia is the treatment regimen that is used. It varies considerably between countries, owing to differences in the levels of health care that are generally available. The quality of factor VIII or IX replacement therapy in a country usually evolves from sporadic or on-demand treatment of bleeding episodes, to secondary prophylaxis for those with frequent bleeds and finally to individually tailored primary prophylaxis for all children with severe or moderate haemophilia (Ljung, 2005:120).

The use of prophylactic treatment seems to be closely linked to quality of life, in that it prevents spontaneous bleeds which could progress to joint damage and arthritis. According to Ljung (2005:120), if prophylaxis is started early in life, it can prevent the occurrence of joint damage, which in turn, greatly improves the quality of life of patients with haemophilia.

However, prophylactic treatment is almost non-existent in rural areas because of economic constraints. Dennill, King, Lock and Swanepoel (1995:37) admit that training and education for health personnel in South Africa is still curative and hospital-based, rather than primary health care-oriented and community-based. This implies that it may be difficult to get health practitioners to recognise the need to use prophylactic treatment on patients with haemophilia in rural areas, if health practitioners are using primarily a curative approach. However, secondary prophylaxis on patients who have already experienced joint bleeding (as is often the case with patients in rural areas) can still help to decrease bleeding episodes, even if it does not stop further deterioration of the damaged joints.

The situation is made even more difficult when one considers that factor treatment for curative purposes in rural clinics and hospitals is almost completely unavailable. Prophylactic treatment can be seen by some to be as an unnecessary waste of resources. This is why most patients with haemophilia in rural areas have poor quality of life.

One of the objectives of primary health care in South Africa is to make information concerning the prevailing health problems and the methods of prevention available to the population (Dennill *et al.* 1995:32). Although primary health care could play an important role in improving the quality of life of patients with haemophilia, the lack of availability of resources remains a great challenge in rural areas. The researcher believes that if primary health care principles could be applied in haemophilia, patients in rural areas could benefit, and could enjoy improved quality of life.

2.9 MEDICAL COMPLICATIONS IN HAEMOPHILIA

There are specific complications of bleeding disorders, both medical and psychosocial, which require special knowledge and effort on the part of health care professionals at a haemophilia treatment centre (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:80). According to the *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:80), HIV and AIDS, hepatitis/liver disease, joint damage/arthritis and inhibitors continue to be a challenge in the medical field. These challenges are therefore discussed in detail below.

2.9.1 HIV and AIDS

The incidence of HIV in the blood supply, in the late 1970s and up to 1980, was a catastrophe for people with haemophilia and for others who relied on human blood products. Although progress has been made with regard to the purification of blood products, HIV remains a problem for people with bleeding disorders, because they have witnessed first hand the hysteria that gripped the world when HIV was first discovered, the promise of early antiretroviral therapy and the disappointment when it did not work for everyone (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:80).

In line with the views of the aforementioned source, Hoots (2005:200) states that the realization that people with haemophilia who are treated with replacement clotting factor concentrates (CFCs) are at particular risk of transfusion-associated infection from the treatment antedated the theoretically earliest date for widespread exposure to human immunodeficiency virus (HIV). Eyster (in Hoots, 2005:200) reported on a study conducted in one Hemophilia Treatment Centre in Hershely and Pennsylvania which found that the HIV infection rate among the population of patients with severe haemophilia A approached 90%. It was also reported that the percentage of the infected (based on the analysis of stored serum specimens from the 1970s into the early 1980s) increased exponentially between 1981 and late 1983.

The true impact of viral transmission through clotting factor concentrates was not appreciated until the magnitude and consequences of the HIV epidemic in patients with haemophilia became evident in the mid-1980s (Yee & Lee, 2005:532). According to Yee and Lee (2005:532), patients with haemophilia were at especially high risk as a result of infusions of factor VIII or factor IX concentrates, both of which are derived from the plasma of thousands. However, it is remarkable that in the developing countries, the rate of seropositivity of HIV and HCV infections in patients with heamophilia is much lower than that in the developed countries, probably as a result of the overall scarcity of treatment in these countries (Yee & Lee, 2005:533).

From the literature, it seems that the presence of HIV in the population of people with haemophilia presented new challenges to both patients and the medical field itself. The researcher is of the opinion that to be diagnosed with a chronic illness like haemophilia is difficult enough to contend with on a daily basis, and that being infected with HIV as a result of the treatment process aggravates the situation. It is perhaps a blessing in disguise that in the developing countries, the rate of seropositivity of HIV in patients with haemophilia is lower than that in the developed countries, as a result of the scarcity of treatment, as indicated by Yee and Lee (2005:533). One could deduce that the rates of infection are even lower in rural areas where access to treatment is still a problem. However, it is important to note that progress has been made with regard to the purification of blood products, thus such fears need to be properly addressed with patients and their families prior to the commencement of the treatment process.

2.9.2 Hepatitis / liver disease

Hepatitis C Virus (HCV) infection is the leading cause of chronic hepatitis in the United States. Among people with haemophilia, it is the major comorbid complication of treatment and the second leading cause of death (Ragni, 2005:207). According to Giangrande (2005:197), the first products used for the treatment of haemophilia were derived from human plasma, but unfortunately the use of pooled plasma products before 1985 resulted in the transmission of serious viral infections to many patients, including HIV and hepatitis. On the other hand, Yee and Lee (2005:530) state that patients with haemophilia in the parts of the world with limited resources are likely to have depended on treatment with blood components rather than large-pool plasma-derived or recombinant clotting factors, implying that developing countries have low rates of hepatitis infection as they have been more dependent on blood components for treatment than on pooled plasma.

According to Taylor (2004:150), Hepatitis C Virus is now recognized as being far more malevolent than the medical community initially thought in the 1980s. This virus may progress to cirrhosis of the liver and life-threatening conditions such as hepatic encephalopathy and liver cancer. Liver disease has become the third most common cause of death after AIDS and bleeding complications for people with haemophilia (Taylor, 2004:150).

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:80) also lists exposure to hepatitis as another complication of bleeding disorders that is seen most often in moderately and severely affected patients. It is further acknowledged that there are now vaccines to prevent hepatitis A and B, but that most adolescent and adult patients with severe forms of the disorder have already been exposed to these viruses, as well as to hepatitis C.

Even though there has been remarkable progress regarding the purification of blood products, it seems that infections are always a step ahead of the medical scientists. It is, however, only fair to acknowledge that vaccines have been developed to prevent hepatitis A and B, as is indicated by the *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:80). What remains crucial is the role of the multidisciplinary team in assisting the patients and families with information about the advantages and the disadvantages of treatments. Such information can help the patients and their families to make informed decisions regarding the type of treatment they choose, especially people from rural areas.

2.9.3 Joint damage

The knee is the joint most commonly affected in haemophilia (in approximately 50% of cases) and, despite every effort, there is still a group of young adults who have a severe degree of knee joint destruction as a result of repeated articular bleeding episodes during their early years. This, in turn, leads to the onset of pain and significant functional disability at a time when the patient requires the best possible quality of life (Goddard, 2005:164). Goddard also indicates that the elbow is the second most common site for arthropathy in haemophilia patients. He also mentions that destructive changes occur insidiously, as the elbow is not a classical weight-bearing joint and early limitations of flexion and extension seldom interfere with overall function. The ankle joint is said to be the third most commonly affected joint, accounting for 14.5% of recorded bleeds (Goddard, 2005:164).

Roberts *et al.* (2006:1871) hold similar views as Goddard, and state that bleeding into joints accounts for approximately 75% of bleeding episodes in patients severely affected by haemophilia A. Roberts *et al*. (2006:1871) also explain that the normal synovium has few cells, but that numerous capillaries beneath the synovial layer can be damaged by the mechanical trauma associated with the daily use of joints. The joints most frequently involved (in decreasing order of frequency) are knees, elbows, ankles, shoulders, wrists and hips.

Jones (1995:143) concludes that whichever type of bleeding is experienced in the joint, the most important treatment is the immediate replacement of the missing factor.

The researcher noted that the patients who are most likely to experience joint damage are those with severe haemophilia A. Timeous replacement of the deficient factor seems to be the only treatment that can prevent complete destruction of the joints. The researcher has seen that most patients from rural areas have knee and ankle joint damage. This can be a result of the unavailability of factor treatment in their local hospitals, as financial constraints are usually a major problem.

2.9.4 Inhibitors

One very frustrating complication for patients is the development of inhibitors or antibodies to a particular clotting factor (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:81). Explaining the complications of developing inhibitors, Giangrande (2005:189) indicates that a minority of patients with haemophilia develop immunoglobulins directed against infused factor VIII (or IX) after exposure to these blood products in the treatment of bleeding episodes. Giangrande also warns that this is potentially very serious, as patients are then refractory to conventional doses of coagulation factor concentrates and bleeding is then difficult to control. However, an important strategy in the management of patients who develop inhibitory antibodies, according to Giangrande (2005:81), is immune tolerance. Immune tolerance involves the daily administration of coagulation factor concentrate over a period of some months. Eventually the antibodies will disappear as the body becomes tolerant of the protein, and inhibitor formation is suppressed.

Within the population of haemophilia A patients, the overall incidence of inhibitor formation appears to affect approximately 20% over a long follow-up (Roberts *et al*., 2006:1878). Roberts *et al.* (2006:1879) caution that even though several approaches to treatment of factor VIII inhibitors are available, their use requires knowledge of whether the patient with the inhibitor is a “high” or “low” responder and whether the bleeding episode requiring treatment is minor or major. It is therefore concluded that the most promising approach to the eradication of an inhibitor is the use of immune tolerance regimens

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:81) comments that inhibitors are managed medically, but admits that they can also become a psychosocial issue if a patient considers immune tolerance therapy. This approach is used to eliminate the inhibitors by “overwhelming” them with large amounts of clotting factor infused on a daily basis for as long as a few years. Therefore patients need to adjust their daily schedule to accommodate infusions and must occasionally have factor recovery studies done to assess the efficacy of the factor. Social workers need to help patients understand all these requirements before the commencement of the treatment and to help them plan to meet them. The other reason for this is that immune tolerance therapy is very expensive and not widely understood; as a result medical aid schemes often refuse to cover the costs. Social workers, along with the other members of the multidisciplinary team in the clinics therefore need to advocate on the patient's behalf (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:81).

The development of inhibitors in a patient complicates the situation, in that haemophilia treatment is known to be very expensive, and with the manifestation of inhibitors costs escalate. Unfortunately, patients in rural areas are the ones who usually feel the impact most, as it is difficult for them even to access the normal treatment for the disorder. Social workers are in a unique position to influence policy development by articulating relevant connections between personal problems and social structure. For example, social workers can convey how the health and adaptation of people with haemophilia are affected by the larger community, including socio-economic trends (Taylor, 2004:151).

The medical complications of haemophilia discussed above are just some of the challenges faced by patients with haemophilia. At the same time, they reflect the invaluable role that needs to be played by the multidisciplinary team in assisting the patients and their families to cope with these complications, especially in the rural areas, where there are limited resources. Patients in rural areas also need to be accommodated by haemophilia care teams who liaise with their local medical doctors with regard to other medical complications associated with the disorder.

2.10 HAEMOPHILIA CARE IN THE DEVELOPING WORLD

International organizations estimate that there are half a million people with haemophilia worldwide. Prevalence rates are estimated at 105 to 160 per million of the male population, of whom less than one third are diagnosed. In Australia, the USA and other developed countries, 90% of the patients are diagnosed, whereas some developing countries have records of only 5% of their patients, or no registries whatsoever (Pinto & Ortiz, 2004:14). This is clearly a true reflection of the situation in the developing countries, particularly in rural areas where there is usually a lack of infrastructure including proper record system. One can reason that if there is no registry whatsoever with correct information of the patients with haemophilia, it is impossible even to advocate for the needs of the patients.

As many as 75% of patients with haemophilia in developing countries receive no treatment or inadequate treatment and they often do not survive to adulthood (Isarangkura, 2002:205). The latter author also acknowledges that with efficient organization, the disorder is treatable and becomes part of normal life. Chuansumrit (2003:387) suggests that haemophilia care should be integrated into the existing health care system of a primary care centre, a treatment centre, a comprehensive care centre and a referral centre.

Srivastava and Viswabandya (2005:366), like Chuansumrit (2003), argue that providing comprehensive care to people with haemophilia in developing countries requires a few core components to be established. These are

- appropriate medical infrastructure;
- identification and registration of people with haemophilia;
- selection of appropriate models of care-protocols and products;
- educating patients and families about haemophilia care; and
- improving social awareness of haemophilia and promotion of advocacy.

These components are discussed below.

2.10.1 Appropriate medical infrastructure

Discussing the importance of an appropriate medical infrastructure, O'Mahony and Black (2005:564) relate that the World Federation of Haemophilia (WFH) aims to set up a national haemophilia care programme within the health care system under an agreed national plan, defined by key clinicians and the national haemophilia organization within the country in question. This will include setting up at least one haemophilia treatment centre designating dedicated clinicians and other team members with a specific interest in haemophilia.

According to Chuansumrit (2003:387), the achievement of haemophilia care in developing countries requires several supporting factors. These include education for medical personnel and health care infrastructure.

Like Chuansumrit, authors Srivastava and Viswabandya (2005:367) recommend that there must be at least one centre in each country that can provide comprehensive care of an international standard. However, the researcher agrees with these authors' suggestion that it would be best to integrate these services with the existing health care system, so that the diagnostic and clinical facilities at these centres would also be useful for patients with other bleeding disorders.

2.10.2 Identification and registration of people with haemophilia

The identification of patients with haemophilia remains a major problem in the developing countries. Even in countries which have already made concerted efforts to establish haemophilia care facilities, only 10% to 60% of the expected number of patients in the population have been registered (Srivastava, 1998:34).

According to Srivastava and Viswabandya (2005:363), the importance of creating a national registry cannot be overemphasized. These authors posit that the challenge of detecting affected people and making an accurate diagnosis of haemophilia in developing countries needs to be met at different levels, which includes educating health care personnel, increasing awareness in society, establishing laboratories capable of performing tests of haemostasis, instituting quality control of these tests and monitoring these services and their long-term impact on haemophilia care.

The researcher appreciates the views of Srivastava and Viswabandya, because any improvements in haemophilia care in the developing countries depend mainly on the accurate identification and registration of patients with haemophilia. This can be achieved by educating all the health care personnel in the hospitals and clinics, as well as increasing community awareness with the aim of reaching even people in the rural areas.

According to Dennill *et al.* (1995:20), successful use of statistics in primary health care depends on the effectiveness of the information system at every level of management and such accurate information may motivate policy-makers to take action. This is also the case in rural clinics and hospitals: accurate information with regard to the registration of patients with haemophilia can assist health care system policy-makers in making appropriate provision for patients.

2.10.3 Selecting appropriate models of care

According to Chuansumrit (2003:389), the blood components that are used in developing countries include frozen and lyophilized forms of fresh frozen plasma (FFP), cryprecipitate and cryo-removed plasma. Chuansumrit (2003:389) admits that these blood components are not virus-inactivated, but they are the only affordable blood components available in most developing countries. This is mainly because the plasma-derived or recombinant products of factor concentrate are far beyond the reach of the patients in developing countries due to their high price.

The abovementioned fact is also emphasized by Srivastava and Viswabandya (2005:368), who explain that much factor replacement therapy in haemophilia is based on following convention and practice rather than on evidence regarding optimum protocols. As a result, the guiding principle in developed countries seems to be to use high doses that guarantee efficacy. However, these authors admit that this approach is mostly impractical in developing countries, and treatment requires a prudent selection of the protocols that are most cost-efficient, since more than 90% of this cost is made up of factor concentrates.

Srivastava *et al*. (1998:479) acknowledge that South Africa has a well-developed transfusion service that collects enough plasma for fractionation. As a result, two locally produced virus-inactivated intermediate purity factor VIII concentrates and prothrombin complex concentrate (PCC) are now used for factor replacement in South Africa. They mention that management quality depends greatly on where treatment is given, but in many small centres, patients receive acute treatment only for a few days or until pain disappears, follow-up is inadequate and no interval (non-acute) assessments are made.

Home therapy has been practised since the early 1970s. Emphasizing the importance of home therapy, Chuanmsumrit (2003:387) states that home care treatment for early bleeding episodes is very important, especially in developing countries with limited health care resources, because transportation may be too inconvenient and expensive for these patients to reach a treatment centre.

Interestingly, in South Africa, several patients at each treatment centre are receiving secondary prophylaxis for prolonged periods to prevent further deterioration of target joints at a dose of 25 to 40 i.u/kg on alternate days for haemophilia A and twice weekly for haemophilia B (Srivastava *et al.* 1998:479).

The researcher agrees with Srivastava and Viswabandya (2005:368) that selecting suitable protocols for use in each country is important. While alternative measures can be used to control bleeding in patients, factor replacement to treat certain complications of haemophilia is crucial. Therefore each country needs to consider the needs of the patients first when making decisions on treatment issues. Furthermore, much consideration needs to be given to people with haemophilia in rural areas. It is understandable that there are economic and social problems in these areas that might be a priority. However, cost-effective treatment specifically for emergency bleeds in patients in rural areas can at least be considered in order to prevent morbidity and mortality.

2.10.4 Educating patients and families about haemophilia

According to Jones (1995:257), 50% of the problems he sees in patients with haemophilia in developing countries could have been avoided simply by education. Jones also argues that it is the responsibility of everyone concerned with haemophilia and especially of affected families to learn all they can about the disorder and to teach others the rules.

Like Jones, Srivastava (1998:34) suggests that once the diagnosis is established, the patient and family should be given adequate information about the disorder and therefore highlights the following positive aspects:

- An informed patient and family can cope better with the hazards of living with severe haemophilia, especially when factor replacement therapy is scarce.
- Familiarity with measures other than factor replacement that can be taken to manage minor bleeding can greatly help in reducing morbidity.
- Knowledge of the risks of bleeding and how to minimize them allow the family to let a child with haemophilia grow up as normally as possible, without being overprotected.
- Understanding the genetics of the disease will encourage partners to seek counselling and antenatal diagnosis when facilities become available.

Srivastava and Viswabandya (2005:369) agree that educating patients and families about haemophilia is extremely important everywhere, and add that it is even more important in situations where medical care is inadequate. Apart from providing information related to the principles of managing this condition, Srivastava and Viswabandya (2005:369) suggest that the family should also be made aware of the support systems available to cope with the disorder socially and financially. At the time of the diagnosis and registration, it is recommended that a standardized information booklet in the local language be given to each patient and family. This would not only provide essential information immediately, but would also compensate to some extent for a lack of proper counselling facilities at the hospital where the diagnosis is made.

Despite the fact that resources are limited in developing countries, particularly in rural areas, educating patients and families about haemophilia and how to handle some levels of bleeding can help these families to cope well with the disorder. Education can prevent disabilities and mortality brought about by prolonged episodes of bleeding. Multi-disciplinary teams can encourage group work and community awareness as a means of reaching everyone in a community with information about haemophilia.

2.10.5 Improving social awareness and promoting advocacy

Increasing social awareness of haemophilia is important because it helps identify more people affected by the condition, as families with individuals who may have haemophilia seek medical attention (Srivastava & Viswabandya, 2005:369). This implies that as soon as families start seeking medical treatment for haemophilia, it becomes easier for them to inform other families in the community that are also affected by the disorder.

According to Chuansumrit (2003:389), the pattern of haemophilia inheritance creates misunderstanding among people in society; as a result, discrimination and negative attitudes towards haemophilia lead to withdrawal by people with haemophilia and their families. Emphasizing the importance of health education programmes, Dennill *et al*. (1995:87) describe them as planned opportunities for people to learn about health and to undertake voluntary changes in their behaviour with regard to health. Health programmes may include providing information, exploring attitudes and values, making health decisions and acquiring skills to enable behavioural change to take place (Dennill *et al.,* 1995:87).

The researcher is of the opinion that the promotion of a positive public awareness and acceptance of haemophilia, through multiple media such as the radio, television and magazines, can overcome such misunderstandings. Such social awareness programmes could prove very beneficial to patients and their caregivers in the rural areas.

An important question still remains, namely how health care services are delivered in rural areas. It is therefore appropriate to look at rural-urban discrepancies and inequality in health care.

2.11 RURAL-URBAN DISCREPANCIES AND INEQUALITY IN HEALTH CARE

The process of urbanization that commenced in South Africa in the latter part of the 19th century as a result of the discovery of diamonds and gold left the rural areas to a large extent underprovided and understaffed with regard to health care services (Van Rensburg, 2004:71). The Fao Corporate Document Repository (2006) notes that health care is one of the most important issues and major problems pertaining to quality of life in Africa today. It states that hospital facilities are not remotely adequate and that a considerable number of people living in rural areas in Africa continue to rely on traditional medicines for health care. The popularity of traditional medicine may be attributed to a number of reasons, including the following:

- Accessibility: traditional healers are easily accessible and often available in remote areas where hospital facilities are not close by (Fao Corporate Document Repository, 2006).
- Confidence in the system: the belief in traditional medicine is still very strong in rural areas and some people believe that such medicines are better and more potent for certain types of ailments than modern medicine. For example, snake haemotoxin and neurotoxins are used in the treatment of haemophilia and in sedatives and pain-killers.
- Financial limitations: the cost of both the healers' services and traditional medicines are far lower than that of modern medical facilities; in many cases, the curative powers of certain wild species are common knowledge and self-medication is practised regularly.

Cohn (1995:3) claims that traditional healers and medicines are used by a significant proportion of the population. He adds that access to primary health care is often not easy and medical staff in rural areas may in fact know little about the clinical signs of blood disorders.

In Canada, the problem of accessing health care services by people in rural and isolated communities is attributed to the struggle to attract and keep nurses, doctors and other health care providers in these areas (Romanow, 2002). It has been noted that a minimal amount of information is available on issues as rural and remote health and health care delivery, or interprofessional collaboration in primary health care settings is a major obstacle. Therefore, health research challenges in these and other applied research areas require immediate attention and an associated investment of resources, both human and financial (Romanow, 2002).

However, it is commendable to note significant progress that has been done by countries like Malaysia. The Malaysian government has always viewed the development of the health sector as an integral part of the country's socio-economic development. As a result, the strategy of ensuring equity and access to health care for all originated in the Rural Health Services (RHS) initiative of the 1950s to provide health care to 75% of the population in rural villages (Hussein, Soe Nyunt-U, Baba & De Geyndt, 2003:426).

In South Africa, 12 October 2005, a National Inherited Disorder Day celebration was held at Witraantjies Village in the North West Province of South Africa. Ms Rasmeni, speaking on behalf of the Minister of Health, mentioned the value of the Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities, which was launched in 2001. She added that, according to these guidelines, families should be able to access genetic services at the primary health care service outlets (Department of Health, 2005). The researcher notes that policy guidelines have been developed, but argues that the patients in rural areas do not benefit from these policies, as these policies have still not been implemented in local clinics and hospitals. There seems to be a big gap between the policies and their actual implementation, particularly in rural areas, where medical facilities and health care professionals are scarce resources.

Discussing the status of health care services in South Africa, Robertson (2006:264) argues that the health sector's response to children with chronic conditions is varied because many academic hospitals are responding to the needs of urban children who have access to these hospitals. By contrast, rural residents cannot easily access this care and services as their resources are very limited. Additional reasons for the inequitable care are discussed by Robertson (2006:264) as follows:

- Tertiary services are inequitably distributed – most sub-specialist services are currently situated in the four major urban centres of Gauteng, the Western Cape, the Free State and KwaZulu-Natal. They are funded and mandated to provide tertiary services to people from all nine provinces, but the reality is that children from rural areas do not access these services as frequently as their urban peers.

- Many children are referred too late for effective treatment – this may be due either to late recognition of the illness or to bottlenecks in the referral system.
- Health care is too centralized at present – tertiary services treat many patients who could be treated at Level 1 and 2 hospitals, but they continue to be managed at tertiary level because of inadequate services or a lack of medication at Level 1 and 2 hospitals.
- Dysfunctional specialist services – secondary (specialist) level services, which are seen as the hub of care for children with long-term health conditions – are poorly developed. This results in a large communication and service gap between Level 1 and 3 services.
- Transport for many patients between hospitals is a problem – it usually results in missed appointments and opportunities for care.

Resources available in rural areas are so limited that disadvantaged people often have to move closer to urban areas to survive. The government needs to provide efficient skills training, develop a small-scale business economy and invest in the infrastructure of rural areas (*Rekord North,* 2007:13).

It is evident from the information given above that there is a lot of inequality in the distribution of health services between urban and rural areas. Also, the difficulties faced by patients with haemophilia in respect of proper medical treatment in rural areas are a point of concern. The availability of traditional medicine does not meet the need for accessible medical treatment for these patients. There is a need for collaboration between government authorities and rural community leaders to look at ways of addressing these issues with the aim of improving service delivery.

2.12 PSYCHOSOCIAL IMPACT OF HAEMOPHILIA ON THE PATIENT

People with bleeding disorders face life-long physical, psychological, financial and employment challenges. How well they meet these challenges depends on many issues, such as the severity of their disorder, the quality and availability of medical care, their level of insurance coverage and ability to pay for care and the strength of their personal support networks (National Hemophilia Foundation 2006:1). According to the National Hemophilia Foundation (2006:1), in adults and children alike, the physical hardships and limitations imposed by bleeding disorders often have an emotional and a social impact. So, for example, hospitalization or a period of limited mobility is stressful as well as disruptive to school, work and family life.

Chronic illness can be especially problematic when the chronically ill patient is a child, because children may not fully understand the nature of their diagnosis and treatment and thus experience confusion when they are trying to cope with illness and treatment (Taylor, 2003:376). Taylor suggests that, because chronically ill children often cannot follow their treatment regimen by themselves, the family must participate in the illness and treatment process even more than is the case with a chronically ill adult.

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:82) maintains that haemophilia and bleeding disorder patients, like anyone else, are susceptible to anxiety, depression and other emotional problems. Perhaps these patients, with their histories of frequent medical problems, hospital visits, misdiagnoses, painful bleeding episodes, surgeries and joint damage are even more susceptible than others to mental illness and emotional disorders (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:82).

According to the *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:82), there are at least eight psychosocial implications of haemophilia. These include emotional problems, chemical dependence, educational issues, employment issues, disability issues, poverty, inadequate health insurance and relationship implications. These psychosocial implications are discussed briefly below.

2.12.1 Emotional problems

The range and impact of chronic illness upon patients' and their relatives' lives are frequently underestimated by health care professionals, who gain brief and privileged insights into their circumstances (Price, 1996:275). Price explains further that chronic illness is a lived experience involving permanent deviation from the normal, caused by unbearable pathological changes and a reappraisal of that which may be hoped for in terms of function and health.

Daily activities that most children take for granted, for example, riding a bicycle, may pose serious health risks for children with haemophilia. As a result they may become resentful of the care that they must exercise as they watch peers play without restriction (Casey & Brown, 2003:577). Periods of hospitalization may result in a disruption of their routine, and may involve painful medical procedures and a separation from their family and friends. This can provoke anxiety in children.

The researcher's experience as a team member at the Pretoria Academic Hospital has shown that patients with haemophilia suffer anxiety when they are transferred from rural areas. More emotional problems are experienced by these patients because they are usually from poor families, and family members cannot even afford transport to visit them at the hospital. A child whose parents cannot visit him/her whilst he/she is in hospital, may have a perception that he/she has been abandoned. This can result in serious emotional scarring in the child.

2.12.2 Chemical dependence

In the bleeding disorder field, where chronic pain is prevalent, addiction to analgesics or other central nervous system depressants, especially alcohol, is not uncommon (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:83).

Roberts *et al.* (2006:1875) warn that addictive narcotic agents should be used with great care and only when clearly indicated, because drug dependency can be a major problem in this disease. Social workers can therefore be referral agents, by networking with drug and alcohol organizations that assist such families. Children can also develop drug addiction through peer pressure and as a means to escape pain.

Patients at risk of drug dependency may be ones residing in rural areas, because when they experience bleeding and have no hope of getting treatment, illegal drugs might be chosen as an option to eliminate the pain temporarily.

2.12.3 Educational issues

Jones (1995:319) indicates that, in the past, before adequate treatment and counselling were available, about a third of the more severely affected children with haemophilia missed 25% of their schooling because of their bleeding, but nowadays children with even severe haemophilia rarely miss school, as treatment is more widely available.

It is clear that children with haemophilia should be encouraged to attend school just like any other children, but those who are severely affected, even with good treatment, may still miss many days of school due to bleeding episodes, where they would require some rest. The situation of patients staying in rural areas is more difficult, as these patients may even be transferred to tertiary hospitals that are far away from their homes, because of limited resources. However, it is important for social workers to play an advocacy role liaising with teachers to accommodate such children by providing them with additional teaching, so that the parts of the curriculum that are being missed can be covered.

2.12.4 Employment Issues

Most people with haemophilia and other bleeding disorders are capable of working; unfortunately, some otherwise healthy patients are discouraged from pursuing careers by family members who recall older relatives who were rendered severely disabled by their bleeding disorders (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:84).

Regarding employment issues, Jones (1995:325) points out that a person with haemophilia has the additional burden of his/her disorder to contend with when for the first time, he/she is in direct competition with unaffected people. Jones admits that the choice of career will depend upon the severity of the disorder, but there are certain occupations that must be excluded from their career list. These include the armed forces, the emergency services, mining, heavy labour and other work involving prolonged physical effort.

Patients with severe haemophilia who are employed may face several challenges in their workplaces. Therefore social workers may need to advocate for adaptations in the workplace to accommodate these patients.

2.12.5 Disability issues

Jones (1995:327) emphasizes the argument that just as a child with haemophilia should be brought up in the same way as a normal child in a normal environment, the same is true with regard to employment. Jones (1995:327) strongly believes that the labels “impaired”, “disabled” or “handicapped” confer no special status or automatic benefit; therefore, they should be reserved for use when all else fails. However, the *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:84) differs from Jones in this regard, as it states that, despite the great advances in bleeding disorder treatment, some patients are disabled; therefore social workers should play an instrumental role in helping patients decide if and when to apply for social security, compiling information for the application and assisting patients with the process (if necessary).

While the researcher appreciates the merits of both arguments, she would argue that patients in rural areas are usually the ones most affected by the disorder and that the complications of the disease often disable them. Thus, the aspect of applying for a disability grant becomes a necessity rather than a case of special status, because of their poor family background.

2.12.6 Poverty

Individuals living in slum settlements within or around cities have little access to urban hospitals, and the problem is critical for rural dwellers as well (Riviera & Hylton, 1999:62). According to Riviera and Hylton (1999:62), long distances, poor roads, unreliable public transport, regional conflicts, and expense can all make travelling to a medical facility a major undertaking.

Poverty is not in itself a condition of haemophilia or bleeding disorders, but, because of inadequate education and unemployment or underemployment, poverty is not uncommon in this population. Some families exhaust their financial resources to pay for factor and other necessary medication (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:85).

Inequalities in health care delivery are a major setback to the patients and their families, in that the expenses of travelling to tertiary hospitals where the treatment of haemophilia is available is usually a major setback. The situation is more critical to families in rural areas who care for patients with haemophilia, because they cannot always afford transport to medical facilities, resulting in a patient's not getting treatment on time. Thus, poverty remains a big challenge for these families, as they have to put food on the table while paying medical bills and transport, which are the demands of the disorder.

2.12.7 Inadequate health insurance

Economic factors directly exclude many people from receiving quality health care. In some cases, the poor can only secure services that are free and close by (Riviera & Hylton, 1999:63). It is not surprising to measure person's health by the resources the person has, in that health insurance or medical aid can only be afforded by employees who are subsidized a certain percentage by their employers.

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:85) states that inadequate health insurance can affect all patients with haemophilia, regardless of socio-economic status, because factor (treatment) and other medical costs are so high that even well-insured patients may find themselves being charged co-pays and other out-of-pocket expenses.

It is important to note that some medical aid schemes are not always willing to pay for the treatment of haemophilia, perhaps because of the high costs associated with the treatment. Those who cannot afford health care insurance can only use public health care services. These services usually charge very little, but most of them do not supply haemophilia treatment in their hospitals because of limited resources. The ones that do are usually very far from where these patients stay. This has a highly negative impact on poverty-stricken families, mainly those in rural areas.

2.12.8 Relationship implications

Jones (1995:21) cautions that failure to come to terms with haemophilia leads to isolation, loneliness and a lessening of opportunities for marriage and a decent career. One of the best ways to avoid over-protection toward a child is to encourage activity with family and friends, and this will result in a child's being able to explore relationships with other people in a normal way.

Casey and Brown (2003:577) add that, in some cases, children with haemophilia choose to hide their illness from their peers rather than face the potential isolation that revealing their diagnosis might bring. It is therefore suggested that this problem may be addressed by offering an opportunity to discuss their concerns, providing appropriate education about the illness for classmates and friends. Introducing activities that might provide opportunities for increased self-esteem and positive peer interaction can also be helpful.

People diagnosed as both HIV positive and as suffering from haemophilia face extreme stress related to changes in relationships, lifestyles, behaviours and the anticipation of death (Stewart, Hart & Mann, 1995:1102). Through individual and family counselling, social workers can help families affected by haemophilia to restore their relationships, as social support is very important in the effort to improve the quality of life of any patient, regardless of the diagnosis.

The psychosocial impact of haemophilia on the patient is huge, as reflected by the issues discussed above. Therefore, it is important for multi-disciplinary teams to take these psychosocial aspects into consideration when dealing with patients and their families.

2.13 PSYCHOSOCIAL IMPACT OF HAEMOPHILIA ON THE FAMILY

Chronic illness in a child produces stress for both the child and the family of which he/she is a part (Mussatto, 2006:110). Explaining further what the impact of the illness may be, Mussatto says that children and families may feel that they are riding a rollercoaster that includes uncertainty about long-term prognosis, the chronic need for medication, repeat interventions, persistent symptoms and the prospect of physical or developmental delays. Therefore, families facing this crisis are in need of support, education and understanding in order to help them, initially to adjust and ultimately to reach a level of adaptation to this challenge.

Drotar and Eckl (1997:138) acknowledge that many children with chronic health conditions and their families present with a wide range of psychological and social difficulties that may necessitate psychosocial intervention at some point during the course of their medical treatment.

The National Hemophilia Foundation (2006:1) emphasises that parents raising a child with a bleeding disorder have many issues to address. Some are practical concerns like health insurance coverage and choosing the best treatment for the child. Another concern is how to deal with the child’s emotional responses to living with a chronic health problem.

The feelings and behaviours of parents or children with impairments, after the time of being told the diagnosis, have been likened to a bereavement process, in that, for most patients, there is a period of shock followed by sadness and frequent anger and sometimes denial (Baird & McConachie, 1995:18). These stages are regarded as normal in grieving parents in order for them to adjust. The authors also indicate that for some families, diagnosis can be a positive relief. One can deduce that in families where the symptoms of the illness have been prevalent but where doctors have made no correct diagnosis, eventually getting a correct diagnosis might be a relief, however, emotional support at this stage may be vital for these families.

Elaborating on the difficult situation in which families find themselves, Barry (1996:284) refers to a major illness as a crisis-precipitating event in the life of a person and his/her family; as a result, coping skills come to the fore:

- Denying or minimizing the seriousness of the illness: until the ego is able to accept the implications of the illness fully, it will use many defence mechanisms to protect itself. Denial, projection, displacement and avoidance are common.
- Seeking relevant information: by learning more about the illness, its cause, treatment, prognosis and other related information, the family gains a sense of control. Intellectual understanding relieves some of the anxiety experienced by the family.
- Requesting reassurance and emotional support: many patients and families look to friends and hospital caregivers for support when they are threatened by illness. However, anxiety can be aroused if too much support is given.
- Learning specific illness-related procedures: patients and families are often threatened by their lack of skills in providing self-care or care to their loved ones with newly acquired conditions. Formal in-patient teaching programmes and informal teaching sessions with staff nurses can help patients and their family members acquire the technical skills required.
- Setting concrete limited goals: for a patient who is adjusting to a catastrophic illness or an illness that has a long recuperative period, it is important to help the family in structuring signs of progress into achievable objectives for the patient.
- Rehearsing alternative outcomes: rehearsing alternative outcomes is slightly more sophisticated than information-seeking. The patient and family might think through, in advance, future surgery, the recuperation period and other events that create anxiety.
- Finding a general purpose or meaning: after the initial effects of the illness have been dealt with using the coping skills mentioned above, some thoughtful patients and families will continue to probe for the reason why the event occurred (Barry, 1996:288).

Mussatto (2006:110) explains that the response of families to the diagnosis of a chronic illness in their children is a complex and multifaceted process. He mentions that this process occurs in stages, with multiple intervening variables. Initially, families experience a period of adjustment, involving early responses and changes to cope with the stress of the diagnosis of chronic illness. A parent, for example, can take leave of absence from employment. Over time, most families progress to a state of long-term adaptation to the demands of the chronic illness suffered by their child, demonstrating the inherent resilience of the human spirit (Mussatto, 2006:111).

Gravelle (1997:742) highlights strategies involved in managing changes that are brought about by the illness, as reported by the parents in his study:

- Seeking information: gaining knowledge was empowering for parents. Parents sought information regarding the physical progression of their child's condition, how to provide care for their child, what services were available and how to access them, and how to be heard as parents.
- Planning/preparing: all parents looked ahead for the future. The incurable nature of their child's condition prompted some parents to "live one day at a time" and not to plan too far in advance.
- Negotiating: as their child's care needs increased, time became a precious commodity. One important aspect of negotiation related to the great amount of time required in the care-giving role. As primary caregivers, mothers rearranged their daily lives in order to care for their children and the amount and significance of change was greater for them than for fathers.
- Utilising resources: utilising resources was closely connected to seeking information, planning and preparing, and negotiating. Resources considered most valuable included respite care, a government organization to fund the equipment, support systems and community education about children with chronic illnesses.

Ross and Deverell (2004:15) agree that chronic illness can place intolerable strain on the family due to the need for high levels of physical care and support, the emotional connotations of giving and receiving help and changes in family roles and relationships. According to Ross and Deverell (2004:15), even where family members are willing and able to provide help, the person with a chronic disabling illness may feel that he/she is a burden and may refuse the assistance that is needed.

It is obvious that most patients with haemophilia in rural areas are children, as these patients seldom survive to adulthood as a result of limited resources. Therefore, this implies that the caregivers of these patients face various challenges, as they have to learn to live with haemophilia as a disorder within their families under difficult circumstances, such as a lack of availability of treatment and other necessary resources.

Talking about the financial impact of chronic illness on the patient and family, Taylor (2003:369) explains that one difficulty related to the vocational problems associated chronic illness concerns the enormous financial impact that chronic illness can often have on the patient and the family. This is said to be caused by the fact that a number of people are not covered by sufficient insurance to meet their needs. According to Taylor (2003:369), if family members' resources are already stretched to the limit, accommodating new demands is very difficult.

Families caring for chronically ill patients not only experience difficult psychosocial aspects of care, there are also challenges of care-giving that the caregiver encounters on a daily basis. Therefore it is appropriate to discuss such challenges.

2.14 THE CHALLENGES OF CARE-GIVING

In a study done by Gravelle (1997:742), the care-giving role was divided into direct and indirect care. Direct care was defined as "hands-on care" and included any care that directly assisted the child, for example, assisting a child with the activities of daily living (ADL) and administering medication. Indirect care was described as "hands-off care", and included any care for the child that did not involve direct interaction with the child, for example, negotiating for a service, arranging wheelchair transportation and learning how a piece of equipment worked.

The notion of "family" care-giving obscures the fact that women do most of the care-giving (*Marriage & Family Encyclopedia,* 2007). Gender norms that prescribe nurturing and domestic roles for women “naturally” assign women the responsibility for caring for sick family members.

Stewart *et al*. (1995:1101) describe the care-giving role as one that is usually played by women. According to these authors, care-giving burdens encompass physical care, co-ordination of health services, disrupted family relationships, socio-emotional demands and role movements outside the care-giving role. According to Drotar and Eckl (1997:138), it is not surprising that parents who assume the burden of caring for children who have haemophilia and HIV infections demonstrate high levels of psychological distress.

Rodgers and Jones (1999:45) also point out that no longer are grandparents, especially grandmothers, caring for the grandchildren on an as-needed basis, but they often assume full-time care-giving responsibility. Such full-time responsibilities of caring have resulted in role confusion, stress and financial difficulties for grandparents.

Caregivers often report experiencing increased anxiety, strain and diminished quality of life as a result of the emotional, physical and financial burden of their role-related stress (Minor, Carlson, Mackenzie, Zernicke & Jones, 2006:93). According to Minor *et al.* (2006:93), the challenges that are brought about by a diagnosis of a life-altering or life-threatening condition are often experienced as traumatic for both the caregiver and the child. When combined with inadequate coping skills, this can lead to feelings of caregiver burnout.

Taylor (2003:373) acknowledges that people who take on the role of caregiver are at substantial risk for both depression and diminished quality of life. Caregivers fare better when they have a high sense of personal mastery and active coping strategies.

The *Marriage and Family Encyclopedia* (2007) distinguishes between primary stressors (caused by performing the work required to care for the sick family members) and secondary stressors (problems that emerge in social roles and relationships as a result of care-giving). This distinction highlights the fact that care-giving work is not only stressful because it requires the performance of difficult physical and emotional tasks (for example, supervising, monitoring, encouraging, medicating, lifting, bathing and feeding) but also because of secondary stressors (which include marital discord, social isolation, economic strains and family dysfunction).

According to Carpenito (1993:186), the stress process related to caregiver role strain arises from four domains:

- Background / content of stress
    - caregiver characteristics (age, education, financial, and social status);
    - care-giving history;
    - networks; and
    - resources available.
- Stressors (primary, secondary)
    - Primary (directly related to the needs of the care receiver)
        - impaired cognitive status;
        - problematic behaviour (e.g. verbal abuse, wandering);
        - extent of dependency;
        - resistance to caregiver’s help;
        - fatigue of caregiver; and
        - relational deprivation (parent).
    - Secondary (derived from primary stressors)
        - family conflicts about the care receiver’s condition or care;
        - economic strain;
        - constriction of social life; and
        - intrapsychic strain (loss of self, loss of control, feelings of inadequacy).
- Mediators of stressors
    - efficacy of coping; and
    - social support.
- Outcomes of stressors
    - depression;
    - anxiety;
    - cognitive disruptions;
    - physical problems; and
    - yielding of role (Carpenito, 1993:187).

The abovementioned stressors relating to the care-giving role show that the background of the caregiver, as well as the needs of the patients, play a vital role in successfully carrying out this role. Therefore, it is necessary for caregivers to identify their coping skills and seek assistance.

Novick (1996) suggests that the best way for caregivers to avoid burnout is to plan moments of relief from the constant demands of giving care. Novick also recommends that every caregiver should find opportunities to stimulate the immune system, regain perspective and enrich the spirit through small, pleasurable activities. Pushing impulses down below consciousness, losing personal boundaries, giving in to self-neglect, exhaustion, apathy and even depression are all potential dangers for any caregiver.

From the information discussed above, one can deduce that the care-giving role imposes a number of challenges which stem from primary stressors (caused by performing the work required to care for the sick family member) and secondary stressors (problems that arise due to social roles and relationships as a result of care-giving). The challenges are even greater for patients and caregivers in rural areas, as they experience these problems with no health care services available in their areas, and those that are available do not supply any treatment for haemophilia.

2.15 THE ROLE OF THE SOCIAL WORKER AS A TEAM MEMBER

The goal of comprehensive haemophilia care is to provide individuals with inherited bleeding disorders and their families with medical, nursing, physical therapy and counselling services. The social workers become important members of the interdisciplinary team (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:7). This notion is also expressed by Cowles (2000:133), as he argues that a social worker’s claim to a place on the interdisciplinary team must be based on expertise, in that communication with other members about issues related to patient and family adjustment requires more than a shallow grasp of the biopsychosocial aspects of an illness. This is also true for bleeding disorders: the social worker has to possess a clear knowledge base of his/her profession and a thorough background on bleeding disorders.

Discussing the skills essential for a medical social worker, in a health care setting, Carbonatto and Du Preez (1990:319) highlight the following:

- acquiring sufficient knowledge of various diseases, the symptoms, the causes, the treatment and implications for the patient and his/her family;
- acquiring thorough knowledge of the specific diseases related to each area the person is appointed in, in a hospital or medical setting (for example, in a haemophilia clinic), including the symptoms, the causes, the treatment and implications of the disease, treatment or disability for the patient and his/ her family;
- being able to work in a hospital or medical setting;
- being able to work with sick and sometimes mutilated people on a daily basis;
- understanding and intervening in the psychosocial implications of hospitalization, illness, trauma, treatment and disability for the patient and his/her family and offering the necessary support and atmosphere for emotional catharsis;
- being able to remain objective, with the necessary empathy in these highly emotional circumstances;
- having effective communication skills;
- having adequate skills in implementing the social work methods and technique;
- being able to do a thorough psycho-social assessment in a short period of time;
- functioning in an inter-disciplinary team or the ability to collaborate;
- having assertive skills, especially of necessity in the inter-disciplinary team; and
- maintaining a professional image.

These are some of the skills and areas of expertise that a social worker needs to possess in order to render an effective and comprehensive health care service to patients and families with haemophilia. Such expertise distinguishes and automatically places the social worker in his/her rightful position in a team without role blurring.

It is true that many of the tasks of psychosocial professionals can be difficult to articulate, or at times even to identify, however, the focus is often unseen emotions and feelings, the hurts and distress of people of the haemophilia community (Spilsbury, 2004:26). Spilsbury argues further that psychosocial workers can provide intervention in the areas of cognitive functioning, self-esteem, loss and grief, anger management and communication skills.

The social worker's role has expanded in response to the complex haemophilia-related complications and their impact on the haemophilia population. Areas of expansion have included counselling aimed at reducing the risk of viral transmission from infected persons with haemophilia to family members, sexual partners and household contacts; coping with dual/triple diagnoses; progressive disabilities; and loss and bereavement (*National Hemophilia Foundation orientation manual for healthcare professionals*, 2001:9).

It is therefore appropriate to mention that the social worker's role in haemophilia care is shaped by the mission, philosophy and concept of comprehensive haemophilia care, which promotes accessibility and quality care services to individuals with haemophilia and their families, as they work to achieve maximum health and functioning. This calls for the social worker to take the initiative to learn more about the condition, so as to provide an appropriate and specific service to the patients and their families.

2.16 SUMMARY

The literature that has been reviewed has provided a theoretical background on haemophilia and its effects on caregivers. Haemophilia is defined as a sex-linked, genetic disorder characterized by a deficiency or absence of one of the clotting proteins in plasma. While deficiencies of any of the clotting proteins can occur, factor VIII deficiency (haemophilia A) and factor IX deficiency (haemophilia B) are the most common. It is noted that haemophilia disorder affects males almost exclusively, because it is passed on from a female to male offspring.

The treatment for bleeding in haemophilia involves replacing the deficient factor. Timely factor replacement of the deficiency is very important, because prolonged episodes of bleeding can lead to long-term physical disability and even mortality, depending on the site of the bleeding.

Rural-urban discrepancies and inequalities in health care have been observed among patients residing in rural areas. The treatment that is most easily accessible to these patients is traditional medicine, but the use of such medicine still does not reduce the need for accessible medical treatment.

People with bleeding disorders and their families face life-long physical, psychological, financial and employment problems. The way they deal with these problems depends on many elements. Such issues include the severity of their disorder, the quality and availability of medical care, their ability to pay for care and the strength of their personal support system.

Caregivers caring for patients with haemophilia do a very important and demanding job, as they perform the work required to care for the sick family members. As a result of this care-giving role, these caregivers often experience problems which include anxiety and depression.

The role of social workers in assisting the patients and their families to cope with haemophilia-related complications is crucial. The social worker assumes this role with skills and expertise that distinguishes him/her and automatically places him/her in a rightful position in a team without role blurring.

CHAPTER 3

THE EMPIRICAL FINDINGS

3.1 INTRODUCTION

In this chapter, the research findings are presented using tables and themes extracted from the respondents' experiences. The focus is on the researcher's analysis and interpretation of the data collected. Therefore, the research methodology used in this study is briefly discussed before analysing the results.

3.2 RESEARCH METHODOLOGY

Applied research is the type of research used in this study because the researcher wanted to understand the experiences of caregivers caring for patients with haemophilia in rural areas to make recommendations towards improving the service provided at clinics. According to Neuman (2000:23), applied researchers primarily want to apply and tailor knowledge to address a specific practical issue. Phenomenology as a research design was used to explore the experiences of caregivers caring for patients with haemophilia in rural areas. This research design was found to be applicable in the study, as it enabled the researcher to explore and understand, as well as interpret, the meanings of the respondents' experiences with regard to the problems of haemophilia care in the rural areas.

The population in this study consisted of caregivers who brought their patients to the Haemophilia Clinic at the Pretoria Academic Hospital every first Wednesday of the month between September 2007 and November 2007.

In this study, non-probability sampling, which is availability sampling, was used to select the participants. Strydom (2005a:196) says that this type of sampling is based on the availability of the respondents, in that the respondents are usually those who are nearest and most easily available. The researcher interviewed all the caregivers caring for patients with haemophilia from rural areas who were available at the haemophilia clinic until the desired sample of ten caregivers was reached. However, before the interviews were conducted, the researcher asked the participants if they resided in rural areas. This question was posed to each participant, because the researcher targeted only participants from rural areas in her sample. Two of the participants had more than one patient with haemophilia.

In-depth interviews were conducted to collect the information from participants. Greeff (2002:293) explains that the purpose of conducting an in-depth interview is not to get answers to questions, but rather to understand the experiences of other people and the meaning they make of those experiences. The researcher facilitated the interviews and a tape recorder was used to capture data, after permission for its use was given by participants.

The aim and objectives of the study were explained to the participants before the interviews commenced. Confidentiality and privacy were ensured by means of voluntary recruitment. The participants were then requested to sign the consent forms. The interviews were based on the following central question: “How would you relate your experience of caring for a patient with haemophilia?” The debriefing of participants was done immediately after the data collection session was completed. Debriefing was done to counteract any emotional disturbance that could have been evoked by participating in the study.

3.3 RESEARCH FINDINGS

Since a qualitative research approach was used, data were analysed and interpreted qualitatively by means of themes extracted from the massive information. Main themes and sub-themes of the experiences of caregivers caring for patients with haemophilia in rural areas are highlighted. In order to convey the nature of the responses of the participants, *verbatim* responses and tables are set out below.

3.3.1 Description of the findings

Table 2 (overleaf) illustrates the main themes and sub-themes that emerged in the internal experiences of the caregivers of patients with haemophilia in rural areas.

Table 2: Main themes and sub-themes of the internal experiences of the caregivers

Main theme	Sub-themes
Emotional dimension The respondents experience different emotions as they continue to care for the patients with haemophilia.	Sadness and helplessness were experienced by respondents when patients were in pain and had to go through medical procedures. Irritation was felt related to the curiosity of the people in the community as they watch the caregiver carrying the bleeding patient to hospital, and to questions asked by these people regarding the disease. Exhaustion was experienced, related to sleepless nights when caring for the patient while he is in pain.
Spiritual dimension The respondents prayed to God and hoped for his intervention when the patients were bleeding severely. They also requested priests to perform miracles.	Respondents repeatedly prayed to God to keep the patient alive while hospitalized and also request priests to perform some miracles by healing the patients from the disorder.
Cultural beliefs The respondents had doubts that the patients were suffering only from haemophilia disorder. They observed how the disease interrupted the patient's school performance, especially during the final examinations and therefore associated the disorder with witchcraft.	The patients are always bleeding and have had to be admitted to the hospital during final school examinations. Respondents associated such coincidences with witchcraft.
Future considerations The respondents expressed their thoughts and concerns with regard to the future of the patients as far as the disorder is concerned.	The respondents struggled with the thought of what might happen to the patients if they do not complete school, as they cannot perform certain jobs because of the disorder. The respondents worried about the future, i.e. who will be able to care for the patient when the caregiver is no longer alive.

Table 3 (overleaf) illustrates the main themes and sub-themes that emerged in the external experiences of the caregivers of patients with haemophilia in rural areas.

Table 3: Main themes and sub-themes of the external experiences of the caregivers of patients

Main themes	Sub-themes (positive experiences)	Sub-themes (negative experiences)
The respondents referred to the following systems as their points of interaction:	Respondents expressed the following positive experiences:	Respondents expressed the following negative experiences:
Health system	• Received the correct diagnosis and treatment from tertiary hospitals. • Given home treatment.	• Received incorrect diagnosis from local private doctors and hospitals and at times child abuse was suspected within the family. • Unavailability of treatment in clinics and hospitals in the rural areas. • Challenges of home treatment.
Education system	• Cooperation when the patient is absent from school for medical reasons. • Special schools are willing to register patients who are not coping at the mainstream schools.	• Most injuries on patients are sustained at school. • Long periods of hospitalization affect the patient's performance at school.
Transport system	• Buses are the most available and affordable means of transport during the week.	• Challenges related to transport remain a problem on weekends and at night when the emergencies arise. The distances from homes to the bus stops and from the tertiary hospitals are large.
Religious system	• Intervention of the priests and prophets from church, performing some spiritual healing through praying over the patient using water.	• Methods used were unsuccessful, so much so that even the needles that were used to take out the "dirty blood" worsened the condition.
Cultural system	• Traditional healers helped with traditional medicine and ceremonies.	• Traditional healing (cutting the vein to put the medicine in the bloodstream) proved dangerous for patients.

Social **welfare** system	• Social workers assisted with care dependency grant applications. • Social workers also assisted in placing the patients in special schools that cater for the needs of children with disabilities.	• None
Socio-economic system	• Some employers were supportive when the participants had to take time off because of the patients.	• Some employers complain a lot when the participants have to take time off for the patients. • Most respondents are struggling financially because they are unable to work full-time, as they have to care for the patients.
Family systems	• Some family members provide support, including financial support, to the participants.	• Lack of involvement and support from the family when it is most needed.

3.4 CENTRAL THEMES

The above themes are discussed in detail below.

3.4.1 Internal experiences of the caregivers

3.4.1.1 *Emotional dimension*

Participants experienced different emotions related to their daily activities of caring for patients with haemophilia. They reported feelings of sadness and helplessness when the patients were in pain and also going through painful medical procedures which involved injecting factor treatment intravenously. Some participants reported sometimes even shedding tears. Most of the participants felt irritated and embarrassed when they carried the patients to the hospital using public transport, because of a lot of questions asked by people who realized that the patients were old enough to walk by themselves, and who did not know about the complications of the disorder. These emotions are discussed below.

- *Sadness and helplessness*

Participants felt helpless and sad when the patients felt pain from internal bleeding and also when some medical procedures had to be performed to relieve the pain. Most parents are unable to bear the pain of looking at their children suffering without sharing their emotions, and they experience feelings of helplessness. The following statements reflect their emotions:

> *"He was still small when they started to inject him with the factor treatment and he used to cry a lot. That was affecting me emotionally, I just could not cope. But with time I got used to the process, I was no longer crying with him."*
>
> *"He cried the whole night at the hospital and I was feeling helpless as I could not take the pain away from him."*
>
> *"I used to stay up the whole night because he would not stop crying. I would feel confused and helpless as I did not know what I was supposed to do for him."*

The statements above reflect the findings of Eiser (1993:117) that mothers of children with chronic diseases are more likely to be anxious and depressed. They also report more mental and physical health complaints, compared to the mothers of healthy children. The researcher is of the opinion that caregivers need support in order to care effectively for patients with haemophilia. They also need to understand that the patient must undergo intense and painful medical procedures. Support groups for the caregivers might be able to give them an opportunity to share their challenges and emotions in a safe environment facilitated by the social worker.

- *Irritation*

Most of the participants felt irritated when people asked them about the illness of the patients when they were going to the bus stop or used another mode of public transport. Some caregivers would carry the patients on their backs while others used wheelbarrows in order to access the public transport, and this attracted people's attention, hence the questions. The following statements reflect the irritation and the embarrassment indicated by the respondents:

"When he cannot walk because of severe bleeding, I use a wheelbarrow to take him to the bus stop and it is irritating, as everybody you meet would ask questions."

"When the patient is limping as we would be walking to the bus stop, people would be asking questions like 'what is wrong' and this is very irritating."

"When he was five years old, I used to carry him on my back when he could not walk and people in the bus used to ask me a lot of questions and I would be irritated."

These statements echo findings by Ross and Deverell (2004:15) who state that chronic illness can place an intolerable strain on the family, due to the need for high levels of physical care. This indicates some of the unique challenges faced by caregivers in rural areas. The rarity of the disorder and scarcity of resources disturb the normal process of caring for the patients in a more appropriate and dignified manner.

- *Exhaustion / tiredness*

Most participants experience exhaustion, as they spend sleepless nights with the patients. Participants reported that during times of painful bleeding episodes, particularly prior to getting the correct diagnosis of the disorder, they had to stay awake at night trying to comfort the patients to stop them crying and even taking them to the hospital at night in certain situations. The following excerpts indicate that:

"Before knowing about the disease, I never used to sleep on the bed. I used to sleep with him on my back and kneel on the floor while my head is on the bed."

"My child was bleeding day and night, if I just go to sleep for an hour I would find him in a pool of blood all around him. I did not know why he had to bleed excessively. As a result I would stay the whole night watching him."

"Because of the painful bleeding he would cry the whole night and I would feel helpless and exhausted because it is impossible to sleep under such circumstances."

According to Minor *et al.* (2006:93), caregivers often report experiencing increased anxiety, strain and diminished quality of life as a result of the emotional and physical burden of their role-related stress. It is not surprising that participants reported having been stressed by the care-giving that they had to provide, day and night, as needed.

The participants caring for these patients often have to stay up at night when the patients are not well, with minimal help from other family members. Most of the respondents were women and also single parents. Caregivers feel that to care for the patients with haemophilia is their responsibility alone, to the extent that they feel guilty if they have to ask for help. Social workers can encourage caregivers to take breaks and vacations or do things that replenish their batteries, like home exercises or even taking walks and meditation, without feeling guilty about it.

3.4.1.2 Spiritual dimension

- *Prayer and requests for a miracle*

The participants expressed their spiritual beliefs and values during difficult times, especially when patients were hospitalized. They prayed and regarded God as their source of support. Some even requested the priests from the charismatic churches to perform some miracles for them by miraculously healing the patients. The following statements reflect that:

"I took my child to ZCC church where they used hot water that the priest had prayed over."

"We took the younger one to the priest of ZCC who is his uncle as well because he was bleeding more often and severely."

"I continued praying to God that he must help my child to be well."

According to Van Rensburg (2004:533), the religion of the black South African peoples traditionally involved only ancestral spirits and witches, and the unrestrained process of cultural exposure has resulted in the introduction of new spiritual entities. Thus Christianity was introduced, but some ancestral aspects are still used. Spirituality can be a great source of comfort to the patient and the caregiver. Social workers have a responsibility to assist caregivers to have reasonable expectations from the priests and to emphasize the benefits of spiritual counselling more than miraculous healing, because caregivers' expectations of seeing the patient completely healed by the priests may not be met.

3.4.1.3 Cultural beliefs

The participants doubted the diagnosis of the patients at times, as they observed how the disorder interrupted their school performance during the final examinations. This caused the caregivers to suspect that witchcraft was also involved in the haemophilia.

- *Bleeding occurring during final school examinations*

The participants did not understand why the patients were always ill during final school examinations, which made them suspicious of witchcraft. The following excerpts show their concern:

> *"He misses school a lot because of this disorder and I am now concerned because he has become a slow learner."*
>
> *"He always bleeds when he has already received his final school examination timetable. I know that he has haemophilia, but witchcraft is also playing a part."*
>
> *"He has delayed at school because every year when it is examination time he would be ill and unable to complete the exams. There is really more to this disorder than we can observe."*

According to the National Hemophilia Foundation (2006), in adults and children alike, the physical hardships and limitations imposed by bleeding disorders often have an emotional and a social impact. Referring to cultural aspects and health, Gilbert, Selikow and Walker (2002:47) clearly explain that cultural differences are significant in the interpretation of symptoms, because every community has well-established ways of maintaining health, preventing disease and treating the sick. It is therefore not surprising that some participants associate the disorder with witchcraft. However, social workers can educate the caregivers about the fact that the frequency of bleeding depends mostly on the severity of the disorder, for example, patients with severe haemophilia experience regular bleeding per month from trauma and spontaneous bleeding. Such information can help caregivers to understand the disorder better, and not simply to attribute the incidents to witchcraft.

3.4.1.4 Future considerations

The participants had several thoughts related to the future of the patients as far as schooling and care is concerned.

- *Thoughts about finishing school*

It was the wish of the participants that the patients complete their schooling because their employment opportunities are limited as a result of the disorder. The following statements demonstrate their thoughts:

> *"I encourage my boys to finish school because I am concerned that they will have problems taking care of themselves in future."*
>
> *"I hope that he will continue with school because he will not be able to work hard like doing gardening."*
>
> *"I am concerned that he is not doing well at school and I hope he is still going to improve."*

This finding supports the argument of Jones (1995:325), who states that there are certain occupations that must be excluded as the careers for patients with haemophilia including the armed forces, mining, heavy labouring and other work involving prolonged physical effort. It is reasonable for any caregiver to be concerned about the schooling of the patient with haemophilia because, without proper qualifications, it would be almost impossible for the patient to find proper employment.

- *Future care of the patient*

Participants were concerned that if they die, there will be no one to care for the patients. They expressed their concerns as follows:

> *"I am getting old, when I die, who will care for him?"*
>
> *"I do not know what will happen to him because nobody cares about him, even his own grandmother never visits him when he is in hospital."*
>
> *"I have been struggling with my child alone and if something happens to me I don't know what will happen to him."*
>
> *"My concern is that my family never liked my child because of the disorder. As a result I had to leave home, I don't know who will care for him if something happens to me."*

It is not surprising that most patients with haemophilia are being cared for by single parents with either limited or no support at all from the family. Therefore it is always a point of concern to the caregivers that when they are no longer alive the family may not assume the responsibility of caring for the patient. Realizing that some family members are not supportive at this stage is a concern for the caregivers. It is therefore necessary that social workers facilitate discussions of such concerns among family members, because when these issues are addressed by the whole family, different options can be explored; and a unanimous decision will put everyone at ease.

3.4.2 External experiences of the caregivers

The participants in this study commented on different systems that they had to deal with in their experiences of caring for a patient with haemophilia. Both positive and negative experiences were expressed by respondents regarding these systems. The systems are discussed as indicated in Table 3.

3.5.2.1 Health system

The participants expressed their positive and negative experiences regarding their interaction with the health system as discussed below.

(a) Positive experiences

- *Diagnosis and treatment*

Most participants expressed relief at getting the correct diagnosis for the patients, as they could then be given the right treatment as well. Such relief is reflected by the following statements:

"I was glad that the doctor told me the diagnosis. I was scared that he was going to die before I could know even the disease he suffered from."

"Before I was told about the correct diagnosis I never used to sleep but since he started attending the treatment here, things are very much better and I am able to sleep."

"My employer suspected that I was abusing the child, but after I was told the correct diagnosis, she was comfortable talking about the disorder."

Such statements corroborate Jones's (1995:14) argument that haemophilia is so rare (around 1 in 10 000) that its diagnosis may be delayed for some time, as the doctors may look for other causes of bruising, including, in some cases, non-accidental injury. Most of the time caregivers know when there is something wrong with their children, even though the doctors might not be able to give them a correct diagnosis. Thus getting a correct diagnosis usually brings relief and facilitates speedy acceptance as it instils hope of the relevant treatment.

- *Home treatment*

The few participants who can administer the treatment were very appreciative of the fact that they were given the option of home treatment, because it saved them hospital travelling costs, as well as time. Their appreciation is shown by the following statements:

"If he bleeds at home, I am able to administer the factor treatment. I only go to the hospital if the bleeding does not stop and the treatment is finished."

> *"He has also been taught how to administer the treatment himself at the haemophilia clinic, he is now able to mix it and inject himself at home. This is such a relief as it saves me time."*
>
> *"My two boys have attended some workshops on haemophilia, therefore they are able to administer the treatment, but their brother is still very young to do it. This brings some relief because I don't have to take them to hospital all the times."*

These statements support the finding of Chuansumrit (2003:387) who says that home care treatment for early bleeding episodes is very important, especially in developing countries with limited health care resources. Transportation may be inconvenient and expensive making it hard for these patients to reach the treatment centres.

Very few of the participants in the current study reported using home treatment. Most caregivers prefer not to take this option because of the complications in administering it. Haemophilia treatment has to be injected intravenously, and that poses a problem for caregivers, as they have difficulties finding the vein. Local clinics are unable to assist them as well. As a result, most of the home treatment becomes a waste, as it expires over time. It is therefore important that all the caregivers receive regular training on how to administer this home treatment to save them the costs of travelling to distant tertiary hospitals on regular basis. A multi-disciplinary team effort could be a solution in addressing such problems.

(b) Negative experiences

- *Misdiagnosis*

Most participants struggled a lot before they could get the correct diagnosis for the patients. They went to different clinics and hospitals, where patients were misdiagnosed. They expressed their struggle as follows:

"I took my child to several doctors but could not get the exact diagnosis. Some doctors told me that the patient had high blood pressure after three unsuccessful operations on his swollen knee."

"The private doctor told me that my child had poison in his blood which is more like acid. He even told me that he must stop eating fatty foods, caffeine and sugar."

"The nursing sister at the clinic just touched my child and told me to go home because there was nothing wrong with the child."

According to Jones (1995:257), the comparative rarity of haemophilia means that most people, including doctors, are not familiar with the "dos" and "don'ts" of haemophilia care. Knowing that there was something wrong with a patient, with no doctor being able to come up with the correct diagnosis, was very frustrating to the participants and it also brought about feelings of sadness and helplessness.

In order to address the issue of misdiagnosis, Dennill, King, Lock and Swanepoel (1999:106) point to the need to adjust current approaches with regard to the training and education of health care personnel. This will ensure that health care students and health personnel are equipped with the knowledge, competence and attitude to respond comprehensively to the health needs of the population. Strategies for primary health care in South Africa recommend networking at national and international levels in order to facilitate the exchange of ideas and resources (Dennill *et al.,* 1999:36). This will facilitate the process of diagnosis, hence ensuring that early intervention is implemented.

- *Unavailability of treatment*

The participants expressed their difficulties in accessing treatment for haemophilia in local clinics and hospitals. They reported that they had to travel to tertiary hospitals to get treatment. The following excerpts illustrate their experiences:

"The clinic could not help me with the treatment and I had no money to go to the big hospital."

"Our local hospital does not have factor treatment, so we have to travel to big hospitals."

"I was referred from one hospital to another in order to find the factor treatment but none of those hospitals had the treatment. Now I have learnt my lesson that I need not waste time with local hospitals, I have to come to this big hospital."

These statements support the findings of Antunes (2002:199), who states that although developing countries are making tremendous efforts to improve their diagnosis and treatment methods, their efforts are being threatened by the many social needs and the limited economic resources within their countries. Gilbert *et al.* (2002:104) point out that the most socio-economically disadvantaged group in South Africa is African people who live in rural areas. Gilbert *et al.* (2002:104) further argue that the existing situation in South Africa clearly indicates that, for the majority of the population, particularly in the rural areas, health services are inadequate and inappropriate; and because of that, diseases that are easy to treat become killers. This is true of the patients with haemophilia residing in rural areas, because inadequate services and financial constraints make it impossible for these patients to receive their treatment in local clinics and hospitals.

- *Challenges of home treatment*

Some participants expressed their disappointment when they could not be assisted by nursing staff at the local clinics to administer the factor treatment that they had received from tertiary hospitals to use as a home treatment. Some of the participants experienced difficulty locating the veins of the patients in order to administer the treatment and therefore would go to the local clinics for assistance. Unfortunately, they were disappointed, as they could not be assisted. The following statements confirm their disappointment:

"The nursing sister at the local clinic refused to help me administer the treatment to the patient and told me to go to the hospital."

"She told me that they did not know anything about haemophilia treatment and how to administer it, I therefore realized that my child was going to bleed to death there. I went to another hospital."

"They are just not helpful, when my child had an internal bleed they just touched him and said there was nothing wrong with him."

According to Jones (1995:143), whichever type of bleeding is experienced, the most important aspect is the immediate replacement of the missing factor. The inability or unwillingness of nursing staff to administer the home treatment when it is available delays the process of receiving timely treatment, resulting in preventable complications of the disorder. Such practices are in direct contrast to the principles of primary health care stipulated by Dennill *et al.* (1999:06). The principles of a successful strategy of primary health care affirm that health care services must be functionally accessible, in that the appropriate type of care must be available to meet the needs of the specific community. Therefore the nursing staff's lack of necessary skills and knowledge with regard to haemophilia care can be properly addressed through continuous in-service training. Sharing knowledge and expertise within the health care sector is necessary for the benefit of patients with haemophilia in rural areas. Continuous haemophilia workshops can be proposed by the social workers to the multi-disciplinary team members as a means of improving service delivery in the rural areas.

3.4.2.2 Education system

The education system also affects the respondents and the patients both positively and negatively.

(a) Positive experiences

- *Absenteeism from school*

Most participants were pleased that the teachers were able to understand when they explained to them that the patients had to be absent from school on certain days in order to attend their follow-up treatment at the Haemophilia Clinic. This is confirmed by the following statements:

"I always report to the teachers when he is coming for his treatment as I did today and they are always cooperative."

"My child goes to the special school and they are always very cooperative when he is not well. They even told me that it is always better for him to be at home when he is not well than at school."

"Though it was difficult for the teachers to understand the disorder and its follow-up treatment demands, when I brought them a letter from the hospital it became very easy for them to cooperate."

"While he was at the primary school, he was always ill and had to be absent from school more often but the teachers understood the situation."

According to Jones (1995:319), in the past, before adequate treatment and counselling were available, about the third of the more severely affected children with haemophilia missed 25% of their schooling, but nowadays children with even severe haemophilia rarely miss school, as treatment is more widely available. The opposite is, however, true for children in rural areas, because it is difficult for them to access treatment in their local clinics and hospitals. As a result, patients have to travel and spend a full day at the hospital, while they are absent from school.

- *Special schools*

Few participants realized that their children could not cope at the mainstream schools because they experienced problems at the crèches. They have placed them in special schools that accommodate children with disabilities. Those whose children were still young also intended to place them in such schools. The following statements reflect their realization:

"Realizing that this child could not go to a normal school, I started seeking help and I was assisted to get him to a special school where there are nursing sisters."

"I had to take him out of the crèche because he was getting injuries everyday, at a later stage I was advised to take him to a special school."

"He just could not cope at the crèche because other children play very rough so I am in the process of enrolling him at the special school."

Casey and Brown (2003:577) also found that daily activities that most children take for granted may pose serious health risks for children with haemophilia. It is therefore necessary for some families to take their children out of mainstream schools and move them to special schools that accommodate their needs and where they can receive proper education and care despite their illness. This could motivate these children to aim high in life, and hence improve their chances of being educated, leading to improved quality of life.

(b) Negative experiences

- *Injuries sustained at school*

Most participants whose children go to mainstream schools complained that teachers continued to use corporal punishment on the patients and other children at school play roughly with them as well. This happened despite the fact that the participants made an effort to explain to the teachers what the nature of the patient's illness is. Their dissatisfaction is shown by the following statements:

"You find that some of the teachers would hit the child hard and even against the wall and he would sustain injuries."

"Most of his injuries he sustained from school. His knee has been bleeding from inside because one of the children from school pushed him down the stairs."

"Though I was given a letter from the hospital explaining the nature of the disorder, the teachers continue to give him a hiding so much that his hand is disabled at present."

"My child bled for the whole week after he was beaten up at school by two children and I intend to go to the teachers and discuss this matter."

In this regard, Dennill *et al.* (1995:87) emphasize the importance of health education programmes which give people opportunities to learn about health and undertake voluntary changes in their behaviour regarding health. These health programmes may include providing information and skills to enable behavioural change to take place. Thus, both teachers and children at the mainstream schools can benefit from such health programmes, as they can acquire skills that will enable a behavioural change towards children with haemophilia.

Adhering to the social model of disability outlined in the *White Paper on Integrated National Disability Strategy* (South Africa, 1997:12), social workers can empower community schools by informing them of the rights of patients with haemophilia that they have the right to access benefits enjoyed by other members of the society. Such benefits include education and training, job opportunities and community development programmes.

- *School performance*

Most participants were concerned about the school performance of the patients. They felt that when they were ill and sometimes hospitalized these children missed a lot of their school work and that affected their performance negatively. Their concern is confirmed by the following statements:

"He is lagging behind at school because during exams he would be admitted at the hospital."

"His first year of schooling has been disturbed by regular hospital admissions, as a result he is not performing well at school."

"He gets ill more often, and when I don't have money to take him to the hospital, he takes a long time to recover and misses a lot of school."

These statements bear out the National Hemophilia Foundation's (2006:1) statement that the limitations imposed by the bleeding disorders often have an emotional and a social impact; for example, hospitalization or a period of limited mobility is stressful, as well as disruptive, to school and family life. Reporting on their study on the effects of childhood chronic illness on families, Feeman and Hagen (1990:50) also reveal that children's academic performance and extra-curricular activities were affected by chronic illness. As a result, provision of interventions in the context of the school and advocacy in the community environment are recommended. While service delivery in health care should be the primary concern for patients with haemophilia, social workers can intervene by working closely with teachers, toward the common goal of compensating for the curriculum activities missed by patients with haemophilia.

3.4.2.3 Transport system

Most participants expressed both positive and negative experiences regarding the transport system.

(a) Positive experience

- *Availability of transport*

Most participants indicated clearly that it was easy for them to take the patients to the hospital during the week, because buses and taxis were readily available. The following statements indicate this aspect:

> *"We travel by bus to the hospital during the week and they are always available."*
>
> *"I use a taxi to the hospital because it is the only available means of transport in our area."*
>
> *"I always make sure that at least I keep some money aside for the taxi in case he gets ill."*
>
> *"When I do not use the bus, my neighbour, who has a car, usually helps us with transport."*

Public transport and the assistance that some of the participants receive from the neighbours is remarkable. However, transport issues are closely related to economic factors. These families can only use public transport when money is available, while payments terms with the neighbours can be negotiated.

(b) Negative experiences

- *Challenges related to transport during emergency*

Most participants complained about the long distances they have to walk to get the public transport and also the unavailability of transport during weekends. These problems are mostly experienced during emergency periods, especially because of the fact that tertiary treatment institutions are far from where these families live. Their situation is expressed in the following responses:

"I remember when I had to take him to the hospital around three in the morning, there was just no transport at all."

"The bus stop is too far to an extent that I have to use a wheelbarrow when we go to the hospital if he cannot walk due to his ill health."

"When he is bleeding at night or during the weekend, I try to use ice-blocks and wait till Monday to take him to the hospital because I know I won't find any transport, which is really causing a lot of stress for me as it can be fatal."

These statements bear out Robertson's (2006:264) comment that transport is a problem for many patients and that it usually results in missed appointments and opportunities for care. Caregivers of patients with haemophilia living in rural areas have to contend with long roads, unreliable public transportation and high travelling expenses to tertiary hospitals for treatment, even on emergency occasions. This can be very stressful to both the caregivers and the patients.

Thus social workers can propose a long-term plan to assist patients with haemophilia in rural areas to the health personnel of their local clinics. Statistics can also be used as a means of emphasizing the need to provide a service that would be responsive to the actual needs of the patients with haemophilia.

3.4.2.4 Religious system

Most participants put faith in their religion to intervene with the hope of helping the patient to heal from the disorder through a miracle. In difficult times, especially when patients were hospitalized they turned to God in prayer.

However, some of the methods tried by the priests were unsuccessful and that brought disappointment to the respondents.

(a) Positive experiences

- *Religious intervention*

Some participants put faith in their religion and they prayed to God to intervene when the patients were hospitalized. They also believed that the patients were going to be healed from the disorder through the miracles performed by priests. The following statements reflect their belief:

> *"I took my child to the priest to be healed."*
>
> *"When he was hospitalized he had no blood left and I prayed to God and said 'please help, you can see that my child has no blood anymore'."*
>
> *"When I see that the situation is beyond my power, I just put my hope in God so that I can maintain my sanity."*
>
> *"In trying to perform some healing, the priest used a needle on the patient's feet saying he was taking out the dirty blood."*

It is clear that most participants regard religion as their source of support and as the only hope when they feel that the situation is beyond their power. According to Srivastava and Viswabanya (2005:369), in educating families with patients who have haemophilia, it is important to make them aware of support systems available to them in order to cope socially. Although religion may serve as one of their support systems, it is also reflective of the cultural belief within the community. As a result, diagnoses like "dirty blood" are made by religious people, but they have been more common with the traditional healers who believe in witchcraft. Van Rensburg (2004:532) states that Africans employ both religious and magical beliefs to explain and control misfortune. It is therefore not uncommon that African priests talk about "dirty blood" when trying to heal the patients.

Religion plays a very important role in the community because of the support system that is inherent to it. However, when the people of the community are vulnerable, as it is the case with the caregivers that are caring for patients with haemophilia in rural areas, their expectations may be too high. It is therefore necessary that social workers extend invitations to religious leaders when doing haemophilia workshops in the communities.

(b) Negative experiences

- *Unsuccessful methods used by the priests*

Some participants expressed their disappointment when the methods used by the church only made the situation worse. The following statements reflect their disappointment:

> *"The priest used hot water on him as he was swollen and that actually made things worse because his temperature went up even more."*
>
> *"He was cut on the nose by the priest and he bled excessively."*
>
> *"The medicine that was prepared by the priest for him to inhale did not work."*

In order to help their children to get well, the participants asked the priests to intervene, but their intervention could be fatal due to ignorance on the part of the priests. Caregivers tried a number of places and different treatment options to help the patients recover because they could not cope with seeing the patients suffering. Social workers can play a very important role by offering supportive counselling to the caregivers and the patients. This is only possible at tertiary hospitals, which makes life very difficult for people living in rural areas.

3.4.2.5 Cultural system

Most participants associated haemophilia with witchcraft, therefore the intervention of traditional healers was very relevant to them in helping them to address the condition. Also the accessibility of traditional healers in rural areas is greater than that of health care facilities, which aggravates the situation.

Therefore participants had both positive and negative experiences resulting from the traditional healers' intervention.

(a) *Positive experiences*

- *Treatment by traditional healers*

Most participants took their patients to traditional healers with the aim to getting healing, as they could not understand the disorder themselves and even associated it with witchcraft. The following statements are illustrative of the efforts they made to have the patient assisted:

> *"The traditional healer diagnosed him with a lot of blood and therefore cut him with a razor in the vein on the forehead and tried to put some traditional medicine."*
>
> *"After the traditional ceremony was done as the traditional healer recommended, he stopped bleeding for two years and this gave me hope."*
>
> *"She told me to take a spade and let his blood fall into the spade as he was bleeding. After that I had to put that blood on the fire and give it to him to drink. When I followed all those instructions the bleeding stopped for a while."*

These statements supported the Fao Corporate Document Repository's (2006) data that the belief in traditional medicine is still very strong in rural areas and that some people believe that such medicines are better and more potent for certain types of ailments than modern medicine. According to Janz, Champion and Stretcher (2002:47), people will take action to prevent, to screen for, or to control ill-health conditions if they regard themselves as susceptible to the condition, if they believe it could have potentially serious consequences, if they believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition.

Caregivers in the rural areas therefore believe in witchcraft and that when patients are bewitched they need to be taken to the traditional healers to be healed. Social workers can assist families in making informed decisions about the treatment regime by outlining the advantages and disadvantages of each treatment regime. Alternative health care is well recognized in South Africa, therefore, patients have to make their own choices, together with their families. At the same time, the treatment of traditional healers can be toxic and otherwise dangerous to the patients, resulting in preventable morbidity and mortality.

(b) Negative experiences

- *Negative results of traditional medicine*

Some participants whose patients were cut with a razor or other dangerous instruments expressed their shock and disappointment when the patients nearly died of severe bleeding. The following excerpts reveal their experiences:

> *“I have never seen the amount of blood that came out after he was cut by the razor by the traditional healer. It was like water coming out of a tap. As a result we had to rush him to the hospital as he was already collapsing.”*
>
> *“The traditional healer tried very hard to stop the bleeding by putting the medicine to the cut, but the bleeding could not stop; he was only becoming weaker.”*
>
> *“He nearly died as he was already losing his consciousness from severe bleeding.”*

Talking about accessibility, Cohn (1995:3) points out that traditional healer’s are easily accessible and are used by a significant proportion of the population. Unfortunately, negative consequences of their treatment are almost inevitable and they affect the most vulnerable patients in the rural areas. Though they cannot make decisions for caregivers and patients in rural areas, social workers can play a vital role in empowering these families with information about the consequences of having incisions. It is important for caregivers to know that excessive bleeding from the disorder can be fatal for the patients, therefore informed decisions regarding traditional healers are crucial.

3.4.2.6 Social welfare system

Most participants expressed positive experiences in dealing with the social workers. They related how the social workers assisted them in applying for care dependency grants and also in getting the patients to special schools.

(a) Positive experience

- *Care dependency grant*

In their struggle to care for patients with haemophilia, the participants experienced some relief after the social workers assisted them to apply for care dependency grants in respect of the patients. The following statements reflect their relief:

> *“Before getting the grant, the situation was difficult because I had to leave my child for work even if he was in need of care in order to survive.”*
>
> *“The grant is very helpful because though I have a part-time job I am able to cater for his needs much better than before.”*
>
> *“The social workers helped me with the grant to make things easier for me. I used to spend a lot on hospital fees for all the boys. By the way I have four boys suffering from haemophilia.”*
>
> *“We would not have afforded the special school if I did not get assistance to access the grant from the social workers.”*

According to the *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:84), despite the great advances in bleeding disorder treatment, some patients are disabled. Therefore social workers have played an instrumental role in assisting patients to receive a care dependency grant, which can make a positive effect in alleviating the food nutrition needs of a patient and his/her family; hence improving quality of life.

- *Special schools*

A few participants reported that they had succeeded in placing the patients in special schools that cater for the needs of children with disabilities with the help of the social workers. The following statements are indicative of the assistance they received:

> *"After reporting to the hospital that the patient was no longer at the crèche because he could not cope, the social workers helped me to apply for his admission at the special school."*
>
> *"When I realized that he was not going to cope at the normal school, I went to the social workers who helped me to get him admitted at a special school in the city."*
>
> *"I am in the process of finding a special school through the social workers because at the crèche he is just not coping."*

The *National Hemophilia Foundation orientation manual for healthcare professionals* (2001:9) indicates that the social workers' role has expanded in response to the complex haemophilia-related complications today and their impact on the population with haemophilia. This is also true of the role that social workers play in assisting patients in being admitted to special schools that accommodate children with disabilities because of the severity of the disease. It is necessary to mention that such schools are very scarce in rural areas, therefore, patients that are accommodated in these schools are in the cities, using the hostels within the schools. However, during weekends they are released to go back to their homes. Although this is helpful, it is not an ideal situation, as each child needs to spend time with his/her family.

3.4.2.7 Socio-economic system

While a few participants indicated that their employers were supportive towards them when they had to take time off from work to care for the patients, most stated that their employers were not supportive at all. As a result, they preferred to work part-time or even not to work at all so that they can have more time to care for the patients.

(a) Positive experience

- *Supportive employers*

A few participants felt that their employers were very supportive towards them when they had to take time off work to take the patients to the hospital or to care for them at home. The following statements are illustrative of such support:

> *"My employer was always willing to borrow me some money to take the child to the hospital and also gave me some off days from work."*
>
> *"The employer would sometimes offer to take us to the hospital when there was an emergency."*
>
> *"My supervisor and my colleagues are very supportive and understanding of my situation especially if I have to take the boys to hospital."*

In support of the above statements, Stewart *et al.* (1995:1101) state that care-giving burdens encompass physical care, co-ordination of health services, socio-emotional demands and role movements outside the care-giving role. Referring to families of chronically ill patients, Gravelle (1997:739) mentions that these families develop specific ways of coping in an attempt to meet the needs of its members and that equilibrium is achieved when emotional and physical support is available to meet these needs.

Thus being a caregiver of a patient with haemophilia is a demanding role. The situation is even more stressful for caregivers who have a full-time job. Taking patients to hospital for treatment is also part of the care-giving role, whether the caregiver is employed or not. Therefore, the support that these caregivers receive from their employers is significant as it helps them to cope better in fulfilling their roles.

(b) Negative experience

- *Unsupportive employers*

Some participants complained that their employers were not supportive. As a result some were contemplating leaving their full-time employment, while others have already left their jobs. The following statements reflect this situation:

"I am working in a café for employers who do not care about labour laws and are very unsupportive and demanding long hours."

"I cannot afford to work because he gets ill at anytime and I have to be there for him."

"I had to leave my full-time employment in order to care for him at home and also to make sure that he was attending his follow-up treatment on regular basis."

"When I have to take him to the hospital, my employer complains a lot and he would even tell me that my work is not done because I always go to the hospital."

According to Jones (1995:257), it is the responsibility of everyone concerned with haemophilia and especially affected families to learn all they can about the disorder and to teach others the rules. In this regard, therefore, caregivers need to take the initiative, together with the social workers to educate their employers about haemophilia. It might be that some employers are not supportive, because they lack understanding of the demands of caring for a child with haemophilia. Educating them might bring about some changes in their perceptions, which might make it easier for them to release the caregivers to attend to the demands of their roles.

- *Financial problems*

As has already been indicated, for some caregivers it is difficult to hold a full-time job or even to work at all. Most participants commented on their financial difficulties, particularly when they have to take patients to hospitals. The following statements reflect their problem:

"Sometimes he would sustain an injury and there would be no money to take him to the hospital for him to receive treatment immediately to avoid excessive bleeding."

"His elbows and knees are damaged because most of the time I do not afford to take him to the hospital on time. I would use ice-cubes and if the bleeding does not stop I would keep him in bed, which is not the best treatment option. I am doing this because of the financial constraints that I am experiencing from time to time."

"Money for transport is a big problem for me because I am unemployed and he does not get any grant at this stage. This impacts negatively on my son's medical treatment."

"I would have to borrow money from the neighbours because I am unemployed and also a single mother. When I finally reach the hospital the doctors would shout at me asking why did I take long to bring him because the joints have already been damaged. This is so hurtful because I am really struggling financially and the doctors do not understand. It is as if I am a neglectful mother, which I am not."

The above statements are similar to comments of Riviera and Hylton (1999:62) who state that long distances, poor roads, unreliable public transportation and expense can all make travelling to a medical facility a major undertaking. The situation is of particular concern in rural areas, because people cannot always afford transport to the hospitals. It is important to mention that the issue of transport is also compounded by the poor public transport system in the whole country. As a result, patients do not always get to their treatment on time and that causes preventable morbidity and mortality. Understanding and intervening in the psychosocial implications of treatment and disability for the patient and family is an important role for social workers who want to provide relevant services.

3.4.2.8 Family system

Participants expressed both their positive and negative experiences about their families. Some indicated that their families provided them with emotional and financial support. Other families were not involved at all and even accused the participants of being overprotective towards the patients.

(a) Positive experiences

- *Family support*

Some participants reported on financial and emotional support that they receive from their families. The following statements reflect this support:

“My sisters commend me saying that I am very brave to raise all my boys with haemophilia being a single parent and this really keeps me going.”

“My uncle advised me to take my child to a good paediatrician in Johannesburg and this made me realize his care towards me and my son.”

“My brother is very supportive towards us he even assists with taking him to the hospital and sometimes helps us financially.”

“My family assists me with transport fees sometimes when I have to take my child to the hospital, which makes a difference because without this help my child would always miss his follow-up appointments.”

According to Mussatto (2006:110), the response to the diagnosis of a chronic illness in their children is a complex and multifaceted process. However, over time most families progress to a state of long-term adaptation to the demands of the chronic illness. This process of adaptation usually helps the family to be more supportive towards the patient and the caregiver.

Understanding the nature of the illness and its treatment makes it easy for the families to be supportive to the patient and the caregiver. The medical social worker possesses sufficient knowledge of the disease and its implications for the patient and the family; therefore, he/she is in a better position to disseminate such information to all the family members. Such dissemination of information can make it easier for the family to be supportive towards the patient and the caregiver.

(b) Negative experiences

- *Unsupportive family*

Some participants complained that their family members are not supportive towards them and the patients. They often criticized them for being “overprotective” towards the patients. The following statements reflect these concerns:

“My family is not involved at all in assisting us and there was even a complaint from one of my relatives saying that my children were spoilt because they were even told that they were not supposed to be given a hiding.”

“My husband is just not interested in us and he would not even bother to help us with transport fees to the hospital, I have to borrow money from the neighbours.”

“Though his father left us while he was still a baby, my family also pushed us away complaining that my child was always bleeding.”

“My child’s step-father is very abusive, once he drinks alcohol he would beat us up though knowing that my child has haemophilia. There is just no support that we get from him. I have had enough of his abuse and reported the matter to the police. I have now moved out to a small shack with my children.”

Referring to the importance of identifying families and patients at risk, Feeman and Hagen (1990:50) stipulate that an assessment of the ill patients’ functioning as well as an assessment of the impact on the family due to the illness and subsequent family functioning is necessary, as it determines what type of services should be offered to such families. The rarity of the disorder can result in ignorance in some families and this puts the patient and the caregiver in a disadvantaged position as far as the illness is concerned. It is therefore necessary for social workers to identify families that manifest signs of being at risk and offer relevant services which include family therapy. Most families in rural areas, including extended family members, might lack insight on health issues as a result of their limited education, resulting in unsupportive behaviours towards the patient and the caregiver.

3.5 CONCLUSION

The findings of this empirical study have revealed that caregivers caring for patients with haemophilia are faced with numerous challenges regarding their daily care-giving activities. Different systems that respondents and the patients deal with were explored, as related by the respondents, in respect of their internal and external experiences. Despite the difficulties that the caregivers experience in their role, they also have to deal with other problems, which include the unavailability of treatment in their local clinics and hospitals, financial, employment and transport problems.

It is evident that caring for a patient with haemophilia in rural areas is very difficult.

CHAPTER 4

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

The aim of this chapter is to provide a summary of the research process, to draw conclusions from the findings and make recommendations. Applied research is a type of research that was used in this study because the researcher wanted to understand the experiences of caregivers caring for the patients with haemophilia in rural areas so as to provide recommendations towards improving the service provided at clinics. The researcher therefore presents the summary, conclusions and recommendations in accordance with the following aspects of the research process: the goal of the study, the objectives of the study, conclusions and recommendations.

4.2 THE GOAL OF THE STUDY

The goal of this study was to explore the experiences of caregivers caring for patients with haemophilia in the rural areas.

Chapter One provided an explanation of the motivation for conducting the research. The researcher was motivated by the fact that patients with haemophilia residing in rural areas were the ones who mostly presented with complications of the disorder. Due to financial problems, most patients missed their appointments at the clinic and visited the clinic when the complications of the disorder had already set in. It became apparent that there were many challenges that caregivers caring for patients with haemophilia in rural areas faced, hence the study was done.

4.2.1 Summary

Haemophilia is associated with an array of psychological challenges. There are unique challenges, both medical and psychosocial, which are faced by caregivers caring for patients with haemophilia in rural areas. These challenges include receiving incorrect diagnosis from local private doctors and hospitals, the unavailability of treatment in rural clinics and hospitals, resulting in harmful intervention by traditional healers, transport problems to tertiary hospitals, socio-economic problems related to care-giving activities, poor performance at school because of long periods of hospitalization and lack of support from family members.

In chapter three of this report, therefore, the goal of this study was achieved.

4.3 THE OBJECTIVES OF THE STUDY: RESULTS

4.3.1 Objective One

To theoretically conceptualize haemophilia as a condition.

This was met by means of a literature study in chapter two and consulting experts in the field.

Haemophilia is defined as a sex-linked, genetic disorder characterized by deficiency or absence of the clotting proteins in plasma. While deficiencies of any of the clotting proteins can occur, factor VIII deficiency (haemophilia A) and factor IX (haemophilia B) are the most common. It is noted that haemophilia affects males almost exclusively, because it is passed on from a female carrier to a male child. Haemophilia is referred to as a sex-linked genetic disorder because it is only carried on the x-chromosome. However, though haemophilia is defined as a genetic disorder, one third of all cases of haemophilia arise in the absence of a previous family history and are due to a new mutation.

The levels of severity in haemophilia differ, in that when all clotting factors are abnormal, the resulting disorder is called severe, conversely, when some of the factors are normal, the disorder is only moderate or even mild. Haemophilia can be diagnosed through various diagnostic tests that are available under carefully controlled conditions.

The treatment for bleeding in haemophilia involves replacing the deficient factor. Timely factor replacement of the deficiency is very important because prolonged episodes of bleeding can lead to long-term physical disability and even mortality, depending on the site of bleeding. Rural-urban discrepancies and inequality in health care has also been observed among patients residing in the rural areas. The problems faced by patients with haemophilia regarding receiving proper medical treatment remain a point of concern because they have to travel long distances to tertiary hospitals with high costs. The treatment that is easily accessible for these patients and their families is traditional medicine.

4.3.2 Objective Two

To investigate experiences of caregivers caring for patients with haemophilia in rural areas.

This was met by means of an empirical study as described in Chapter Three.

Applied research is the type of research that was used in this study because the researcher wanted to provide recommendations towards improving the service provided at clinics for patients with haemophilia residing in rural areas. In order to comprehensively explore the experiences of caregivers caring for patients with haemophilia in rural areas, phenomenology was used as a research design.

The population in this study consisted of caregivers who brought their patients to the Haemophilia Clinic at the Pretoria Academic Hospital every first Wednesday of the month between September 2007 and November 2007. In this study, non-probability sampling (which is availability sampling) was used. Since a qualitative research was the approach used, data were analysed and interpreted qualitatively by means of themes extracted from the massive information obtained from participants.

In relating their experiences of caring for a patient with haemophilia, caregivers expressed both their internal and external experiences. Internal experiences included an emotional dimension, a spiritual dimension, cultural beliefs and future considerations. External experiences included negative and positive experiences encountered in dealing with different systems. The systems involved were the health system, the education system, the transport system, religious systems, cultural systems, the social welfare system, the socio-economic system and the family system.

Positive experiences of different systems are summarized as follows:

- the correct diagnosis and treatment from tertiary hospitals;
- home treatments to use during emergency bleeding;
- cooperation from teachers when the patient is absent from school for medical reasons;
- special schools catering for children with disabilities willing to register patients who are not coping at the mainstream schools;
- buses which are the most available and affordable means of transport during the week;
- the intervention of the priests and prophets from the ZCC church who prepared some spiritual healing through praying over the patient using water;
- help from traditional healers with short-term traditional medicine and ceremonies;
- social workers' assistance with accessing care dependency grants;
- social workers' assistance in placing the patients in special schools that cater for the needs of the children with disabilities;
- some employers' support when the caregivers had to take time off from work to care for patients; and
- some family members' support, including financial support, to caregivers and patients.

Negative experiences of different systems are summarized as follows:

- receiving an incorrect diagnosis from local private doctors and hospitals;
- the unavailability of treatment in local clinics and hospitals;
- challenges and difficulties in using home treatments;
- patients' sustaining most of their injuries at school;
- long periods of hospitalization affecting patients' performance at school;
- challenges related to transport on weekends and during emergency periods;

- long distances from homes to the bus stations and also from tertiary hospitals;
- unsuccessful methods used by the priests and prophets worsening the condition of the patients;
- traditional healing methods of cutting the veins on patients in order to put medicine in the blood stream proved harmful;
- employer's complaints when caregivers had to take some time off from work to care for the patients;
- financial struggles of caregivers as they have to care for the patients, some even have to sacrifice their full-time employment; and
- a lack of involvement and support from the family when it is most needed.

4.3.3 Objective Three: Conclusions

To provide conclusions and recommendations for future research and improved service delivery with regard to caregivers caring for patients with haemophilia in rural areas.

The following conclusions are drawn from the literature review and the empirical study.

4.3.3.1 Conclusions

- Life expectancy and quality of life of patients with haemophilia is linked directly to the level of resources for diagnosis and treatment.
- Frequent and prolonged episodes of bleeding into susceptible joints lead to arthritis, which in turn is responsible for most of the pain, long-term physical disability, psychosocial stress and financial hardship.
- Timely factor replacement of the deficiency is important to treat frequent and prolonged episodes of bleeding.
- Failure to provide the needed treatment can lead to long-term physical disability which could have been prevented.
- Haemophilia is defined as a genetic disorder, but one third of all cases of haemophilia arise in the absence of a previous family history and are due to

a new mutation. This indicates that anyone can give birth to a child with haemophilia without having a family history of the disorder.

- Haemophilia is so rare (around 1 in 1 000 people) that its diagnosis may be delayed for some time and doctors may look for other causes of bruising, including in some cases non-accidental injury.
- In order to reach a correct diagnosis of haemophilia, laboratory tests are necessary.
- There are few well-equipped laboratories in South African hospitals; therefore patients are usually referred to tertiary hospitals.
- Treatment of bleeding episodes in haemophilia involves intravenous injection of coagulation factor concentrates and the total dose and frequency of treatment is determined by the severity and site of bleeding.
- The use of prophylactic treatment is closely linked to the quality of life in that it prevents spontaneous bleeds which could progress to joint damage and arthritis.
- Prophylactic treatment is almost non-existent in rural areas because of economic constraints and this is one of the reasons that patients with haemophilia in rural areas have poor quality of life.
- Traditional healers are easily accessible and often available in rural areas where hospital facilities are nowhere close by, but their intervention is not always appropriate.
- Long distances, poor roads, unreliable public transportation and cost can make all travelling to a medical facility a major undertaking.
- Chronic illness places intolerable strain on the family, due to the need for high levels of physical care and support, the emotional connotations of giving and receiving help and changes in family roles and relationships.
- Caregivers often report experiencing increased anxiety, strain and diminished quality of life as a result of the emotional, physical and financial burden of their role-related stress.

- Some families in rural areas lack insight on bleeding disorders because of their cultural beliefs, as a result, they fail to play their role by being supportive to the patient and the caregiver.
- The rarity of the disorder and scarcity of resources in rural areas disturb the normal process of caring for the patients in a more appropriate and dignified manner.
- Spirituality can be a great source of comfort to the patient and the caregiver; however, social workers can help them to have reasonable expectations with regard to their priests.
- Cultural beliefs have a great influence on how the caregivers understand and interpret the illnesses.
- Health care personnel in rural areas are not well trained about haemophilia care.
- School performance of patients attending schools is negatively affected by the illness, as they frequently have to be hospitalized.
- The goal of comprehensive haemophilia care is to provide patients with inherited bleeding disorders and their families with medical, nursing, physical therapy and counselling services and the social worker becomes an important member of the interdisciplinary team.
- Social workers should be able to understand and intervene in the psychosocial implications of hospitalization, illness, trauma, treatment and disability for the patient and his/her family and offer the necessary support and atmosphere for emotional catharsis.
- The social worker’s role has expanded in response to the complex haemophilia related complications and their impact on the haemophilia population.
- Areas of expansion have included counselling aimed at reducing the risk of viral transmission from infected persons with haemophilia to family members, sexual partners, household contacts, coping with dual or triple diagnoses and progressive disabilities.

4.3.3.2 Recommendations

- Haemophilia is a rare disorder, therefore it is the responsibility of everyone concerned with haemophilia, and especially affected families, to learn all they can about haemophilia and to share the information with other community members. The more people understand this condition, the better the quality of life for the patients.
- Health care personnel in rural areas should be educated and trained on bleeding disorders particularly haemophilia, in order to assist patients with haemophilia at the primary level of health care. As stipulated in the *White Paper for Social Welfare*, there is a serious need to retrain and reorient personnel for improved service delivery.
- Haemophilia care should be integrated into the existing health care system of a primary care centre by providing all the necessary resources like trained personnel and medication.
- A standardized information booklet in the local language should be given to each patient and family after diagnosis in an effort to spread the knowledge on this condition. This would make life easier for the patients and caregivers.
- Promotion of a positive public awareness and acceptance of haemophilia through multiple media such as radio, television and magazines can help to overcome misunderstandings about haemophilia.
- Social workers should be more involved with haemophilia care, particularly at primary health care levels. This can only be achieved through specialized training in health care to have knowledgeable personnel deal appropriately with the consumers of the service.
- Awareness campaigns about haemophilia should be promoted at schools in rural areas for the benefit of patients with haemophilia.
- Seeing that the curriculum cannot be adjusted to accommodate children with chronic illness, it is recommended that these children be treated as having special needs and their needs be accommodated by providing extended extracurricular activities.

4.3.3.3 Recommendations regarding further research

Further research which focuses on a bigger sample of caregivers caring for patients with haemophilia in rural areas is recommended. This will help to generalize the results and create a broader understanding of the caregivers' experiences. This study focused only on caregivers who were bringing patients with haemophilia to the Pretoria Academic Hospital. Further research that can also focus on a different method than availability sampling is recommended. It is also recommended that social workers should be more involved in research regarding haemophilia care, as this will help to attract other social workers to be part of multi-disciplinary teams in this specialized field. Another focus for further research could be the emotional needs of the patients, so that appropriate intervention could be implemented. This could be done through using play therapy techniques.

Only by increasing knowledge and doing more research on haemophilia in South Africa can we hope to improve the lives of patients with haemophilia and their caregivers.

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ADDENDA

University of Pretoria

THE INFORMED CONSENT FOR RESPONDENTS

Researcher’s Name: Ms Zodwa Mosoma

Address: P.O. Box 83446

Doornpoort

0012

Name of institution: University of Pretoria

1. Title of the study

The experiences of caregivers caring for patients with haemophilia in rural areas.

2. Purpose of the study

To explore the experiences of caregivers caring for patients with haemophilia in the rural areas regarding their daily struggles as well as other factors involved in the treatment process.

3. Procedure of the study

In-depth interviews will be utilized to collect data. One central question will be asked to all respondents regarding their experiences of caring for a patient with haemophilia and a tape recorder will be used to capture the data. I have been informed that the data will be stored for 15 years before it could be destroyed, according to the requirements of the University of Pretoria and it will be used for research purposes only.

4. Risks and discomforts

Participation in this study might lead to me experiencing emotional discomfort, because I will be expected to talk in-depth about my experiences of caring for patients with haemophilia. I have been reassured by the researcher that I will be provided with emotional support and should I need further therapy I will be refereed to a qualified social worker within the hospital.

5. Benefits

The benefit of participating in this study is that I will be given a chance to talk about my daily struggles of caring for a patient with haemophilia in rural areas where there are limited health care facilities and resources. The findings of this study will also benefit other caregivers, as recommendations will be made to improve service delivery in health care centers regarding haemophilia care in the rural areas.

I do not expect any financial compensation for participating in this study, as I will not incur any costs. I will be contacted at the Haemophilia Clinic at Pretoria Academic Hospital.

6. Participant's rights

I am aware that participation is voluntary and I may withdraw from the study at any time should I feel that I am unable to endure the emotional discomfort.

7. Confidentiality

I have been informed that a tape recorder will be used to capture all the information that I share and have been assured that all information that I will share will be treated in a confidential manner and will remain anonymous. The researcher will only share the information with the authorized supervisor, in this case, her supervisor at the University of Pretoria. Furthermore, I have been assured that the information I will give, will be used for the research purposes only.

8. Access to the researcher

If I have any questions or concerns I can access the researcher at the following telephone numbers: 012 354 1086 or 083 2927 030.

9. Declaration

I, ………………………………………… understand my rights and voluntarily consent to participate in this study. I also understand what the study is about and why it is being done.

……………………………	………………………	……………………..
Respondent's signature	Place	Date
……………………………	………………………	………………………
Researcher's signature	Place	Date
…………………………..	………………………	………………………
Supervisor's signature	Place	Date

University of Pretoria

Department of Social Work and Criminology

Tel. +27 12 420-2325

Fax. +27 12 420-2093

10 April 2007

IMVUME YALABO OKUXOXWA NABO ABAYINIKEZA BENOLWAZI

Igama Lomcwaningi: Nksz Zodwa Mosoma

Ikheli: P.O. Box 83446

Doornpoort

0012

Igama Lenhlangano: Inyunivesi yasePitoli

1. Isihloko socwaningo

Amava abanakekeli abanakekela iziguli ezine-*haemophilia* (isifo esenza igazi lingakwazi ukuba amahlule, bese wopha kakhulu) ezindaweni zasemakhaya.

2. Injongo yalolu cwaningo

Ukuthola amava abanakekeli abanakekela iziguli ezine-*haemophilia* ezindaweni zasemakhaya mayelana nomshikashika wazo wansuku zonke nezinye izici ezihilelekile ekwelashweni.

3. Inqubo yalolu cwaningo

Kuzoba nezingxoxo ezinzulu ukuze kuqoqwe ukwaziswa. Kuzoba nombuzo owodwa oyinhloko ozobuzwa bonke okuzoxoxwa nabo mayelana namava abo okunakekela iziguli ezine-*haemophilia* futhi kuzosetshenziswa umshini wokuqopha ukuze kuqoqwe loko kwaziswa. Ngitshelwe ukuthi loku kwaziswa kuzogcinwa iminyaka engu-15 ngaphambi kokuba kulahlwe, ngokwezimfuneko zeNyunivesi yasePitoli futhi buzosetshenziselwa ukucwaninga kuphela.

4. Ubungcuphe Nokungaphatheki kahle

Ukubamba iqhaza kulolu cwaningo kungase kungibangele ukungaphatheki kahle emphefumulweni, ngoba kuzolindeleka ukuba ngigeqe amagula ngamava okunakekela iziguli ezine-*haemophilia*. Umcwaningi ungiqinisekisile ukuthi ngizothola ukusekelwa emphefumulweni futhi uma ngidinga okunye ukwelasha ngizoyiswa kusisebenzi sezenhlalakahle oqeqeshiwe esibhedlela.

5. Izinzuzo

Inzuzo yokubamba iqhaza kulolu cwaningo ukuthi ngizonikezwa ithuba lokukhuluma ngomshikashika wami wansuku zonke ekunakekeleni iziguli ezine-*haemophilia* ezindaweni zasemakhaya lapho zimbalwa izinto nezikhungo zokunakekela. Okuzotholakala kulolu cwaningo kuzosiza nabanye abanakekeli, futhi kuzoshiwo okuthile kokuthuthukisa ukunikezelwa kwezinsizakalo ezikhungweni zempilo mayelana nokunakekela abane-*haemophilia* ezindaweni zasemakhaya.

Angilindele kukhokhelwa mali ngokubamba iqhaza kulolu cwaningo, njengoba kungekho zindleko engizongena kuzo. Kuzoxhunyanwa nami eHaemophilia Clinic ePretoria Academic Hospital.

6. Amalungelo obambe iqhaza

Ngiyazi ukuthi ngibamba iqhaza ngoba ngithanda futhi ngingayeka noma nini uma ngizwa ukuthi angisakwazi ukubekezelela ukungaphatheki kahle emphefumulweni.

7. Ukuba yimfihlo

Ngitsheliwe ukuthi kuzosetshenziswa umshini wokuqopha ukuze kuqoshwe konke engikushoyo, ngitsheliwe nokuthi konke engikushoyo kuzoba yimfihlo futhi ngeke kwaziwe ukuthi kushiwo ubani. Umcwaningi uyoxoxa ngaloku kwaziswa nomphathi ogunyaziwe kuphela, okungumphathi wakhe waseNyunivesi yasePitoli. Ngaphezu kwalokho, ngitsheliwe ukuthi loko engikushoyo kuzosetshenziselwa ukucwaninga kuphela.

8. Ukuxhumana nomcwaningi

Uma nginanoma yimiphi imibuzo noma ukukhathazeka ngingaxhumana nomcwaningi kulezi zinombolo zocingo ezilandelayo: 012 354 1086 noma 083 2927 030.

9. Isimemezelo

Mina, ……………………………………………. ngiyawazi amalungelo ami futhi ngivuma ngoba ngithanda ukubamba iqhaza kulolu cwaningo. Ngiyazi nokuthi lolu cwaningo lumayelana nani nokuthi lwenziwelani.

………………………………	………………………	……………………..
Isignesha yalo okuxoxwa naye	Indawo	Usuku
………………………………	………………………	………………………
Isignesha yomcwaningi	Indawo	Usuku
…………………………….	………………………	………………………
Isignesha yomphathi	Indawo	Usuku

University of Pretoria

Department of Social Work and Criminology

Tel. +27 12 420-2325

Fax. +27 12 420-2093

10 April 2007

<u>TUMELLO YA BAARABI BA DIPHUPUTSO E BONTSHANG KUTLWISISO</u>

Lebitso la Mofuputsi: Mof. Zodwa Mosoma

Aterese: P.O. Box 83446

Doornpoort

0012

Lebitso la institjhuti: Yunivesithi ya Pretoria

1. Sehlooho sa dipatlisiso

Boiphihlelo ba bafani ba tlhokomelo ba hlokometseng bakudi ba nang le lefu la ho madi a sa etseng mahlwele (*haemophilia*) dibakeng tsa mahaeng.

2. Morero wa dipatlisiso

Ho fuputsa boiphihlelo ba bafani ba tlhokomelo ya bophelo ba hlokometseng bakudi ba nang le lefu la madi a sa etseng mahlwele dibakeng tsa mahaeng mabapi le mathata a bona a letsatsi le letsatsi hammoho le mabaka a mang a amanang le kalafo.

3. Tsamaiso ya dipatlisiso

Ho tla sebediswa dipuisano tse batsi tsa dipotso ho bokella lesedi. Potso e nngwe ya sehlooho e botswang baarabi ba diphuputso e tla ba mabapi le boiphihlelo ba bona mabapi le ho fana ka tlhokomelo mokuding ya nang le lefu la madi a sa etseng mahlwele mme motjhini o hatisang mantswe o tla sebediswa ho hatisa lesedi lena. Ke boleletswe hore lesedi lena le bokellwang le tla bolokwa ka dilemo tse 15 pele le lahluwa, ho ya ka ditlhokahalo tsa Yunivesithi ya Pretoria mme le tla sebediswa mererong ya diphuputsong feela.

4. Dikotsi le ho se phutholohe

Ho kena ha ka dipatlisisong tsena ho ka etsa hore ke se phutholohe, ka hobane ke tla be ke lebelletswe hore ke phetle sefuba sa ka kaofela mabapi le boiphihlelo ba ka ho hlokomela bakudi ba nang le lefu la madi a sa etseng mahlwele. Mofuputsi o ntlhapanyeditse hore ke tla fuwa tshehetso ya maikutlo mme haeba ke hloka kalafo e nngwe ke tla romelwa ho mosebeletsi wa setjhaba (*social worker)* ya tshwanelehang hona sepetleleng sena.

5. Melemo

Molemo wa ho kena dipatlisisong tsena ke hore ke tla fuwa monyetla wa ho bua ka mathata a ka a letsatsi le letsatsi mabapi le ho hlokomela mokudi ya nang le lefu la madi a sa etseng mahlwele ya dulang dibakeng tsa mahaeng moo ho nang le dibaka tse fokolang haholo tsa tlhokomelo ya bophelo le thepa ya tlhokomelo ya bophelo. Lesedi le fumanwang diphuputsong tsena le tla untsha bafani ba bang ba tlhokomelo molemo, ka hobane dipuello di tla etswa mabapi le ho ntlafatsa ho isuwa ha ditshebeletso tsa tlhokomelo ya bophelo ditsing tse dibakeng tsa mahaeng mabapi le tlhokomelo ya bakudi ba nang le lefu la madi a sa etseng mahlwele.

Ha ke a lebella hore ke fuwe ditlhapiso dife kapa dife tsa tjhelete ka lebaka la ho kena ha ka dipatlisisong tsena, ka hobane nke ke ka ba le ditjeho leha e le dife. Ho tla ikopanngwa le nna Haemophilia Clinic ya Pretoria Academic Hospital.

6. Ditokelo tsa monka-karolo

Ke a lemoha hore ho kena dipatlisisong tsena ho etswa ka boithaopo mme nka ikgula dipatlisisong tsena ka nako efe kapa efe haeba ke ikutlwa hore ke sitwa ho mamella maikutlo ana a ho se phutholohe.

7. Lekunutu

Ke boleletswe hore motjhini o hatisang mantswe o tla sebediswa ho hatisa lesedi lohle leo ke fanang ka lona mme hape ke fuwe tiisetso ya hore lesedi lohle leo ke fanang ka lona le tla bolokwa e le lekunutu le hore lebitso la ka le ke ke la tsejwa. Mofuputsi o tla arolelana lesedi lena feela le mookamedi ya dumeletsweng ho utlwa lesedi lena, boemong bona, e tla ba mookamedi wa hae Yunivesithing ya Pretoria. Ho phaella mona, ke ile ka fuwa tiisetso ya hore lesedi lena leo ke fanang ka lona le tla sebediswa mererong ya diphuputsong feela.

8. Ho fihlella mofuputsi

Haeba ke na le dipotso dife kapa dife kapa ke tshwenyehile ka taba efe kapa efe nka fihlella mofuputsi dinomorong tse latelang tsa mohala: 012 354 1086 or 083 2927 030.

9. Phatlalatso

Nna, **…………………………………………** ke utlwisisa ditokelo tsa ka mme ke ithaopela ho dumela ho kena dipatlisisong tsena. Hape ke utlwisisa hore na dipatlisiso tsena di mabapi le eng le kamoo di etswang ka teng.

…………………………… **………………………** **……………**

Mosaeno wa moarabi Sebaka Letsatsi

………………………… **…………………** **……………**

Mosaeno wa mofuputsi Sebaka Letsatsi

…………………………… **…………………** **………………………**

Mosaeno wa mookamedi Sebaka Letsatsi

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

AD DESTINATUM PERSEQUOR

University of Pretoria

Department of Social Work and Criminology

Tel. +27 12 420-2325

Fax. +27 12 420-2093

10 April 2007

TUMELLO YA BAARABI BA DIPHUPUTSO E BONTSHANG KUTLWISISO

Lebitso la Mofuputsi: Mof. Zodwa Mosoma

Aterese: P.O. Box 83446
Doornpoort
0012

Lebitso la institjhuti: Yunivesithi ya Pretoria

1. Sehlooho sa dipatlisiso

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9. Phatlalatso

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…………………………….	………………………..	……………
Mosaeno wa moarabi	Sebaka	Letsatsi
…………………………..	…………………	……………
Mosaeno wa mofuputsi	Sebaka	Letsatsi
…………………………….	…………………	………………………..
Mosaeno wa mookamedi	Sebaka	Letsatsi

PIC 3

INFORMATION LEAFLET AND INFORMED CONSENT FOR NON-CLINICAL RESEARCH (e.g. educational, health systems or non-clinical operational research)

Consent and assent:

If there are children younger than 7 years in your study, the parents give consent on their behalf and you will need to adapt the information leaflet by substituting “you” with “your child”.

For children between 7 and 18 years, parents give consent for their child to participate in the study and the child gives assent. Adapt the form below for that purpose too. Both information leaflets and the consent /assent form have to be included with your application.

TITLE OF STUDY: ...The experiences of caregivers caring for patients with haemophilia in rural areas..

....
....

....
....

Dear Participant

1) INTRODUCTION

We invite you to participate in a research study. This information leaflet will help you to decide if you want to participate. Before you agree to take part you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the interviewer Zodwa Mosoma.

2) THE NATURE AND PURPOSE OF THIS STUDY

The aim of this study is to explore the experiences of caregivers caring for patients with haemophilia in rural areas regarding their daily struggles as well as other factors involved in the treatment process. This study will assist social workers and other team members to come to a better understanding of your experiences and assist you in identifying the relevant support system.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves in-depth interviews that will take place within the hospital and the tape recorder will be used to capture data. These tapes will not be used with anyone other than the supervisor of the study. In the final report of the study, examples of the interview will be given, but quotes will remain anonymous; participants will not be recognised as pseudonyms will be used. I have been informed that data will be stored for 15 years before it could be destroyed, according to the requirements of the University of Pretoria and it will be used for research purposes only.

4) RISK AND DISCOMFORT INVOLVED

Participating in this study might lead to you experiencing emotional discomfort, because you will be expected to talk in-depth about your experience of caring for a patient in rural areas. You will be provided with emotional support and should you need further therapy you will be referred to the social worker within the hospital after research project is completed.

Some of the questions we are going to ask you may make you feel uncomfortable, but you need not answer them if you don’t want to.

The interview session will take about 1 - 2 hours of your time.

5) POSSIBLE BENEFITS OF THIS STUDY

Although you will not benefit directly from the study, the results of the study will enable us to make recommendations to improve service delivery in rural hospitals where there are limited health care facilities and resources for other caregivers who might be sharing your experiences in caring for patients with haemophilia. However, as means of compensating for any fatigue, emotional stress or inconvenience, participants will receive counselling and emotional support.

6) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You can refuse to participate or terminate the interview without giving any reason. Your withdrawal will not affect you or the patient’s access to health care services in any way.

7) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study was submitted to the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria. The committee has granted written approval (56/2007). A copy of the approval letter will be made available if you wish to have one.

8) INFORMATION AND CONTACT PERSON

The contact person for the study is Zodwa Mosoma. If you have any questions about the study please contact me at tel 012 354 1086 / cell 083 2927 030.

9 COMPENSATION

Your participation is voluntary. No financial compensation for participation in this study should be expected as you will not incur any costs.

10 CONFIDENTIALITY

All information that you give will be kept strictly confidential. Once we have analysed the information no one will be able to identify you. Research reports and articles in scientific journals will not include any information that may identify you as a participant in this study.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect any treatment or access to health care services in any way.

I have received a signed copy of this informed consent agreement.

Participant's name ………………………………………………………………………(Please print)

Participant's signature: ……………………………………
Date……………………….

Investigator’s name ………………………………………………………………………(Please print)

Investigator’s signature ……………………………………
Date……………………….

Witness's Name ………………………………………………………………………(Please print)

Witness's signature ……………………………………….
Date……………………….

VERBAL INFORMED CONSENT[1]

I, the undersigned, have read and have fully explained the participant information leaflet, which explains the nature, process, risks, discomforts and benefits of the study to the participant whom I have asked to participate in the study.

The participant indicates that s/he understands that the results of the study, including personal details regarding the interview will be anonymously

---

[1] Include this part in the leaflet if there are participants who cannot read

processed into a research report. The participant indicates that s/he has had time to ask questions and has no objection to participate in the interview. S/he understands that there is no penalty should s/he wish to discontinue with the study and his/her withdrawal will not affect any treatment or access to health care services in any way. I hereby certify that the client has agreed to participate in this study.

Participant's Name ....(Please print)

Person seeking consent ....(Please print)

Signature .... Date.................................

Witness's name[2] ....(Please print)

Signature ....Date..............................

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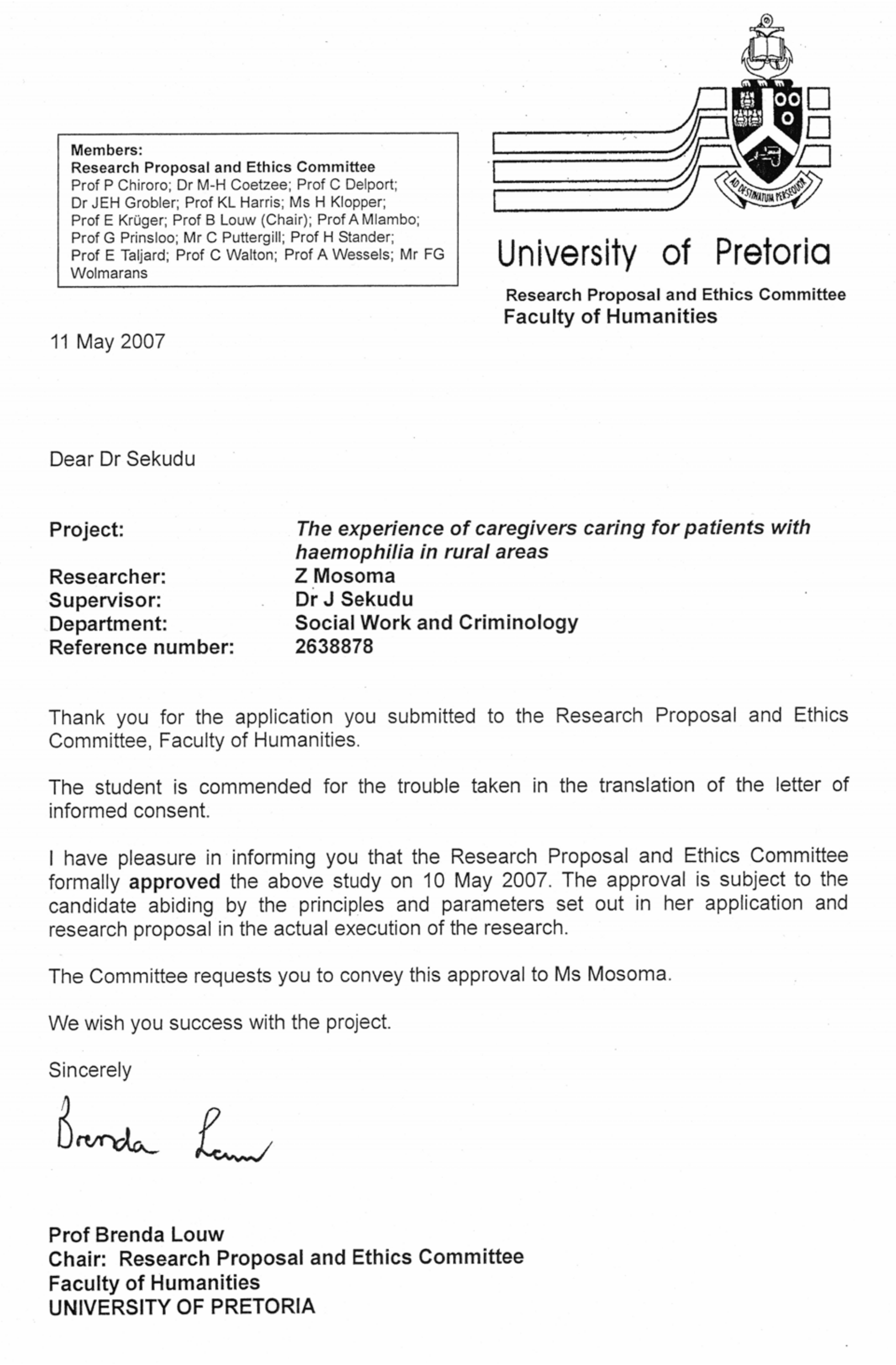
[2] The witness signs that he/she has witnessed the process of informed consent.

Unstructured Interviews

One central question will be asked to all respondents which reads: How would you relate your experience of caring for a patient with haemophilia?



University of Pretoria
Research Proposal and Ethics Committee
Faculty of Humanities

11 May 2007

Dear Dr Sekudu

Project:	***The experience of caregivers caring for patients with haemophilia in rural areas***
Researcher:	**Z Mosoma**
Supervisor:	**Dr J Sekudu**
Department:	**Social Work and Criminology**
Reference number:	**2638878**

Thank you for the application you submitted to the Research Proposal and Ethics Committee, Faculty of Humanities.

The student is commended for the trouble taken in the translation of the letter of informed consent.

I have pleasure in informing you that the Research Proposal and Ethics Committee formally **approved** the above study on 10 May 2007. The approval is subject to the candidate abiding by the principles and parameters set out in her application and research proposal in the actual execution of the research.

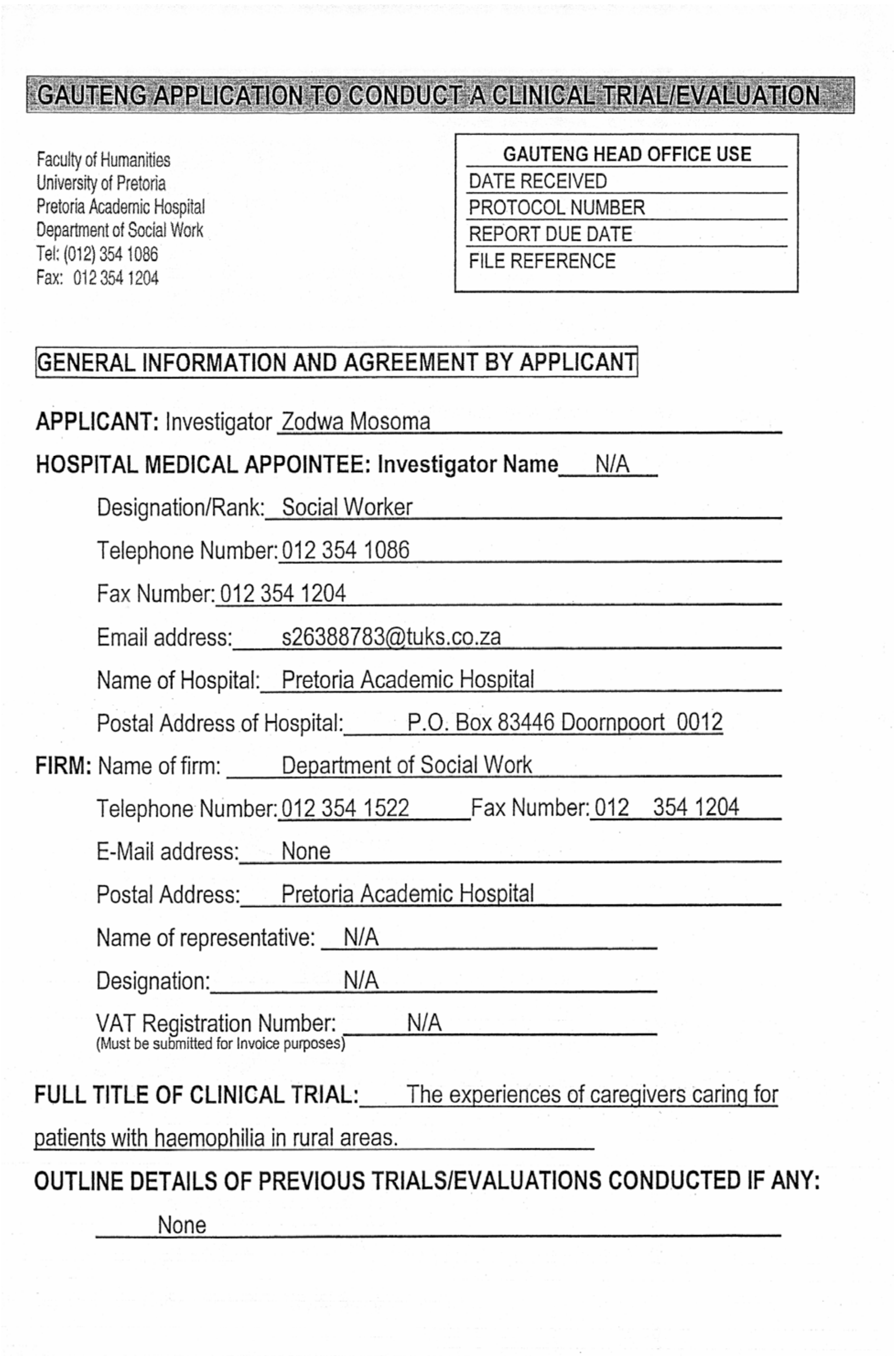
The Committee requests you to convey this approval to Ms Mosoma.

We wish you success with the project.

Sincerely

Brenda Louw

Prof Brenda Louw
Chair: Research Proposal and Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA



GAUTENG APPLICATION TO CONDUCT A CLINICAL TRIAL/EVALUATION

Faculty of Humanities
University of Pretoria
Pretoria Academic Hospital
Department of Social Work
Tel: (012) 354 1086
Fax: 012 354 1204

GAUTENG HEAD OFFICE USE
DATE RECEIVED
PROTOCOL NUMBER
REPORT DUE DATE
FILE REFERENCE

GENERAL INFORMATION AND AGREEMENT BY APPLICANT

APPLICANT: Investigator Zodwa Mosoma

HOSPITAL MEDICAL APPOINTEE: Investigator Name N/A

Designation/Rank: Social Worker

Telephone Number: 012 354 1086

Fax Number: 012 354 1204

Email address: s26388783@tuks.co.za

Name of Hospital: Pretoria Academic Hospital

Postal Address of Hospital: P.O. Box 83446 Doornpoort 0012

FIRM: Name of firm: Department of Social Work

Telephone Number: 012 354 1522 Fax Number: 012 354 1204

E-Mail address: None

Postal Address: Pretoria Academic Hospital

Name of representative: N/A

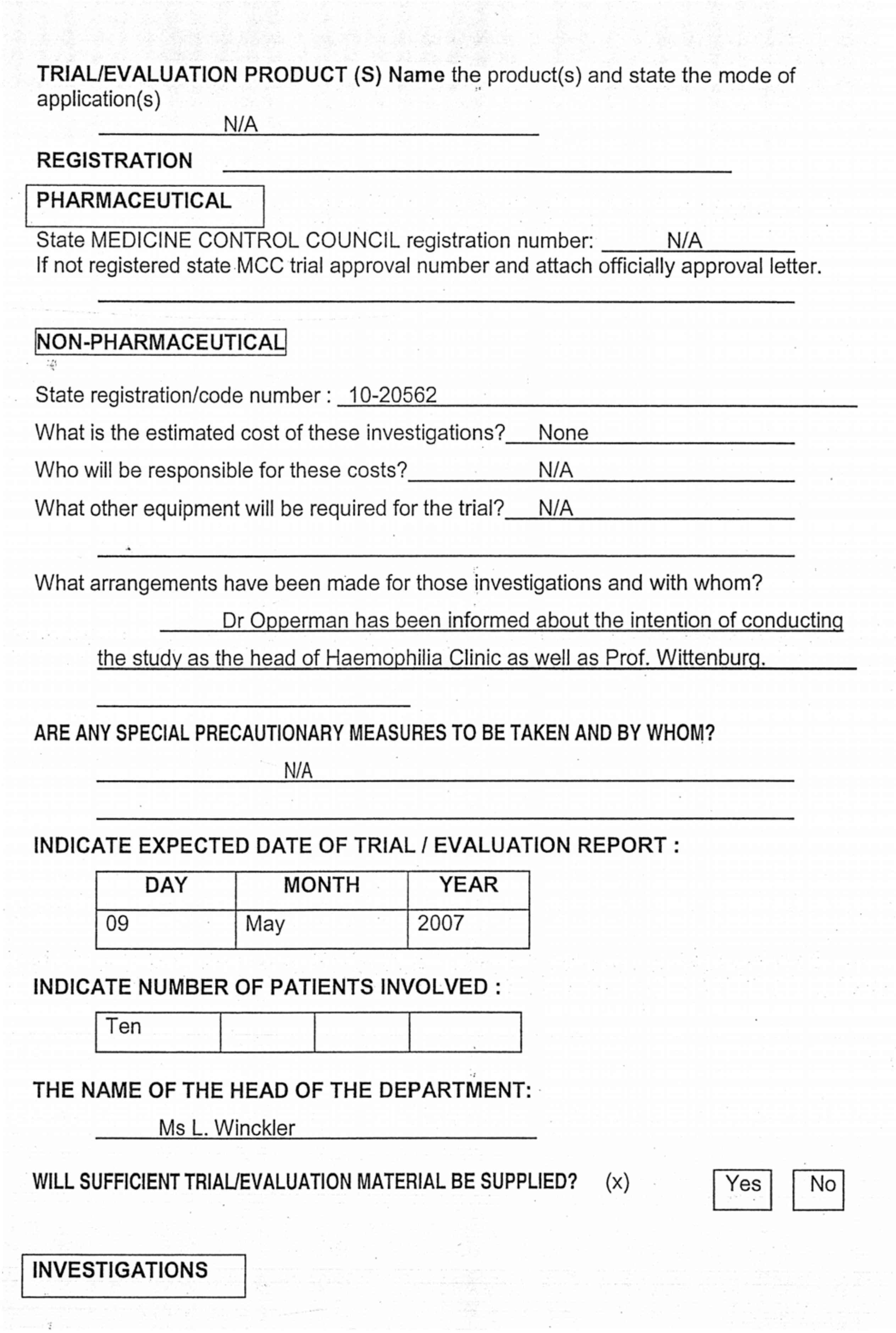
Designation: N/A

VAT Registration Number: N/A
(Must be submitted for Invoice purposes)

FULL TITLE OF CLINICAL TRIAL: The experiences of caregivers caring for patients with haemophilia in rural areas.

OUTLINE DETAILS OF PREVIOUS TRIALS/EVALUATIONS CONDUCTED IF ANY:

None



TRIAL/EVALUATION PRODUCT (S) Name the product(s) and state the mode of application(s)

N/A

REGISTRATION

PHARMACEUTICAL

State MEDICINE CONTROL COUNCIL registration number: N/A

If not registered state MCC trial approval number and attach officially approval letter.

NON-PHARMACEUTICAL

State registration/code number : 10-20562

What is the estimated cost of these investigations? None

Who will be responsible for these costs? N/A

What other equipment will be required for the trial? N/A

What arrangements have been made for those investigations and with whom?

Dr Opperman has been informed about the intention of conducting the study as the head of Haemophilia Clinic as well as Prof. Wittenburg.

ARE ANY SPECIAL PRECAUTIONARY MEASURES TO BE TAKEN AND BY WHOM?

N/A

INDICATE EXPECTED DATE OF TRIAL / EVALUATION REPORT :

DAY	MONTH	YEAR
09	May	2007

INDICATE NUMBER OF PATIENTS INVOLVED :

Ten			

THE NAME OF THE HEAD OF THE DEPARTMENT:

Ms L. Winckler

WILL SUFFICIENT TRIAL/EVALUATION MATERIAL BE SUPPLIED? (x) ☐ Yes ☐ No

INVESTIGATIONS

WHAT LABORATORY AND OTHER INVESTIGATIONS WILL BE REQUIRED OVER AND ABOVE THOSE NORMALLY REQUIRED.
N/A

AGREEMENT BY APPLICANT

- The applicant(s) agree(s) as follows
- To conduct the trial/evaluation recorded in and under the conditions set out in this application form.
- To conduct this trial/evaluation at no additional expense to the Gauteng Department of Health whatsoever.
- To accept full responsibility for any or all-possible harmful effects on a patient using my/our/ the product recorded in his application form.
- To exonerate the Gauteng Department of Health from all liability of damages, legal,financial or otherwise, including my claim instituted by a patient using my/ our/ the product recorded in this application form, but excluding negligence on the part of the medical officer and/ or employee of the Gauteng Department of Health using the said product on the patient's concerned: provided that the medical officer and/ or employee is not the applicant.
- To inform the Superintendent General: Gauteng Department of Health and other relevant authorities should it be deemed necessary to deviate from protocol or stop this trial/ evaluation.
- To make available without delay all the results of this trial/ evaluation to the Superintendent General: Gauteng Department of Health.
- I/ We understand that the Superintendent-General: Gauteng Department of Health having allowed this trial/ evaluation to be conducted places himself or herself or the Gauteng Department of Health under no obligation whatsoever and to leave the final choice of the institution where the trial/ evaluation will be conducted to the Superintendent- General: Gauteng Department of Health.

THE APPLICANT MUST SIGN HERE

APPLICANT- INVESTIGATOR			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
	Z.	Mosoma	28	03	07

Designation/ Rank:

FIRM - IF THERE IS A FIRM INVOLVED- THEY MUST SIGN HERE

MANAGING DIRECTOR OR REPRESENTATIVE			DATE		
Signature	Initial(s)	Surname	Day	Month	Year

Designation/ Rank:

IT IS VERY IMPORTANT THAT 2 WITNESSES MUST SIGN IF A FIRM IS INVOLVED!

WITNESSES			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
1.					
2.					

INITIAL CONSENT BY DEPARTMENTAL HEAD

I ZELDA KUNGOANE (ACTING) head of SOCIAL WORK department of PRETORIA ACADEMIC hospital in consultation with the Chief Executive Officer / Superintendent of this Hospital grant permission to submit an application to conduct a clinical trial/evaluation to the Chairperson (s) of the relevant Ethics, Research and Therapeutic Committees of this Hospital.

The officer conducting the trial/evaluation will be MRS ZODWA MOSOMA

Designation / Rank SOCIAL WORKER

THE HEAD OF THE DEPARTMENT MUST SIGN HERE!

HEAD OF DEPARTMENT			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
	Z.M.	KUNGOANE	28	03	2007

THE APPLICANT MUST SIGN HERE

TRIALIST-INVESTIGATOR			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
ZMosoma	Z	Mosoma	28	03	07

THE APPLICANT THAT APPLY FOR THIS STUDY MUST SEE TO IT THAT THE SUPERINTENDENT / C.E.O. OF THE HOSPITAL WHERE THE STUDY WILL BE DONE - SIGN HERE BEFORE THE ETHICAL COMMITTEE RECEIVE THIS APPLICATION FORM.

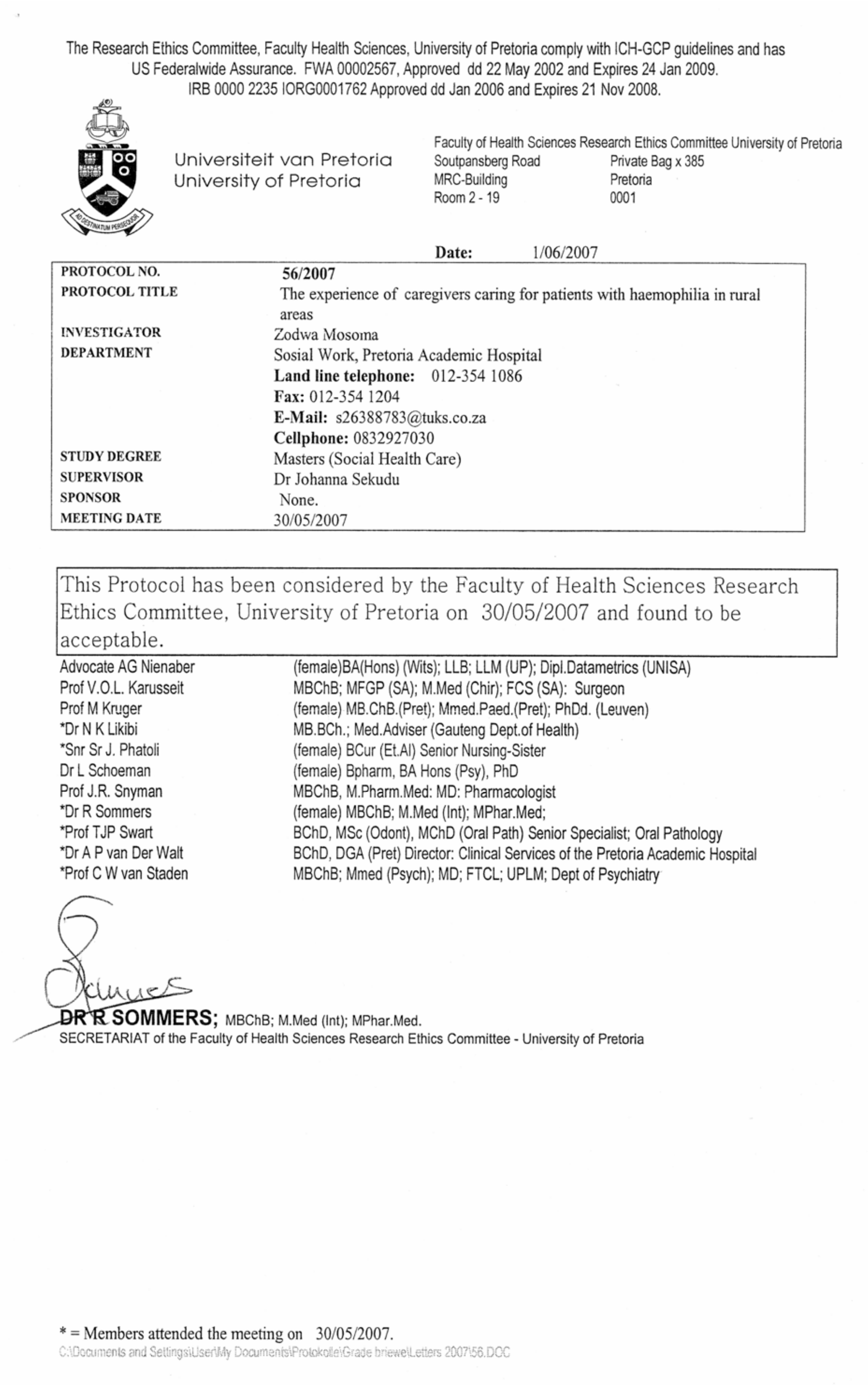
APPROVAL BY HOSPITAL CHIEF EXECUTIVE OFFICER:

I DR H. TANNA ~~Chief Executive Officer~~ / superintendent of PRETORIA ACADEMIC Hospital, hereby agree that this trial / evaluation be conducted in the HAEMOPHILIACLINIC OF PAEDIATRIC Department of this hospital.

The officer conducting the trial will be: ZODWA MOSOMA.

The officer controlling supplies will be: ____________________

HOSPITAL C.E.O. / (Superintendent)			DATE		
Signature	Initial(s)	Surname	Day	Month	Year
HTanna	H.	TANNA	28	03	2007



The Research Ethics Committee, Faculty Health Sciences, University of Pretoria comply with ICH-GCP guidelines and has US Federalwide Assurance. FWA 00002567, Approved dd 22 May 2002 and Expires 24 Jan 2009. IRB 0000 2235 IORG0001762 Approved dd Jan 2006 and Expires 21 Nov 2008.

Universiteit van Pretoria
University of Pretoria

Faculty of Health Sciences Research Ethics Committee University of Pretoria
Soutpansberg Road
MRC-Building
Room 2 - 19

Private Bag x 385
Pretoria
0001

Date: 1/06/2007

PROTOCOL NO.	**56/2007**
PROTOCOL TITLE	The experience of caregivers caring for patients with haemophilia in rural areas
INVESTIGATOR	Zodwa Mosoma
DEPARTMENT	Sosial Work, Pretoria Academic Hospital **Land line telephone:** 012-354 1086 **Fax:** 012-354 1204 **E-Mail:** s26388783@tuks.co.za **Cellphone:** 0832927030
STUDY DEGREE	Masters (Social Health Care)
SUPERVISOR	Dr Johanna Sekudu
SPONSOR	None.
MEETING DATE	30/05/2007

This Protocol has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 30/05/2007 and found to be acceptable.

Advocate AG Nienaber	(female)BA(Hons) (Wits); LLB; LLM (UP); Dipl.Datametrics (UNISA)
Prof V.O.L. Karusseit	MBChB; MFGP (SA); M.Med (Chir); FCS (SA): Surgeon
Prof M Kruger	(female) MB.ChB.(Pret); Mmed.Paed.(Pret); PhDd. (Leuven)
*Dr N K Likibi	MB.BCh.; Med.Adviser (Gauteng Dept.of Health)
*Snr Sr J. Phatoli	(female) BCur (Et.Al) Senior Nursing-Sister
Dr L Schoeman	(female) Bpharm, BA Hons (Psy), PhD
Prof J.R. Snyman	MBChB, M.Pharm.Med: MD: Pharmacologist
*Dr R Sommers	(female) MBChB; M.Med (Int); MPhar.Med;
*Prof TJP Swart	BChD, MSc (Odont), MChD (Oral Path) Senior Specialist; Oral Pathology
*Dr A P van Der Walt	BChD, DGA (Pret) Director: Clinical Services of the Pretoria Academic Hospital
*Prof C W van Staden	MBChB; Mmed (Psych); MD; FTCL; UPLM; Dept of Psychiatry

DR R SOMMERS; MBChB; M.Med (Int); MPhar.Med.
SECRETARIAT of the Faculty of Health Sciences Research Ethics Committee - University of Pretoria

* = Members attended the meeting on 30/05/2007.
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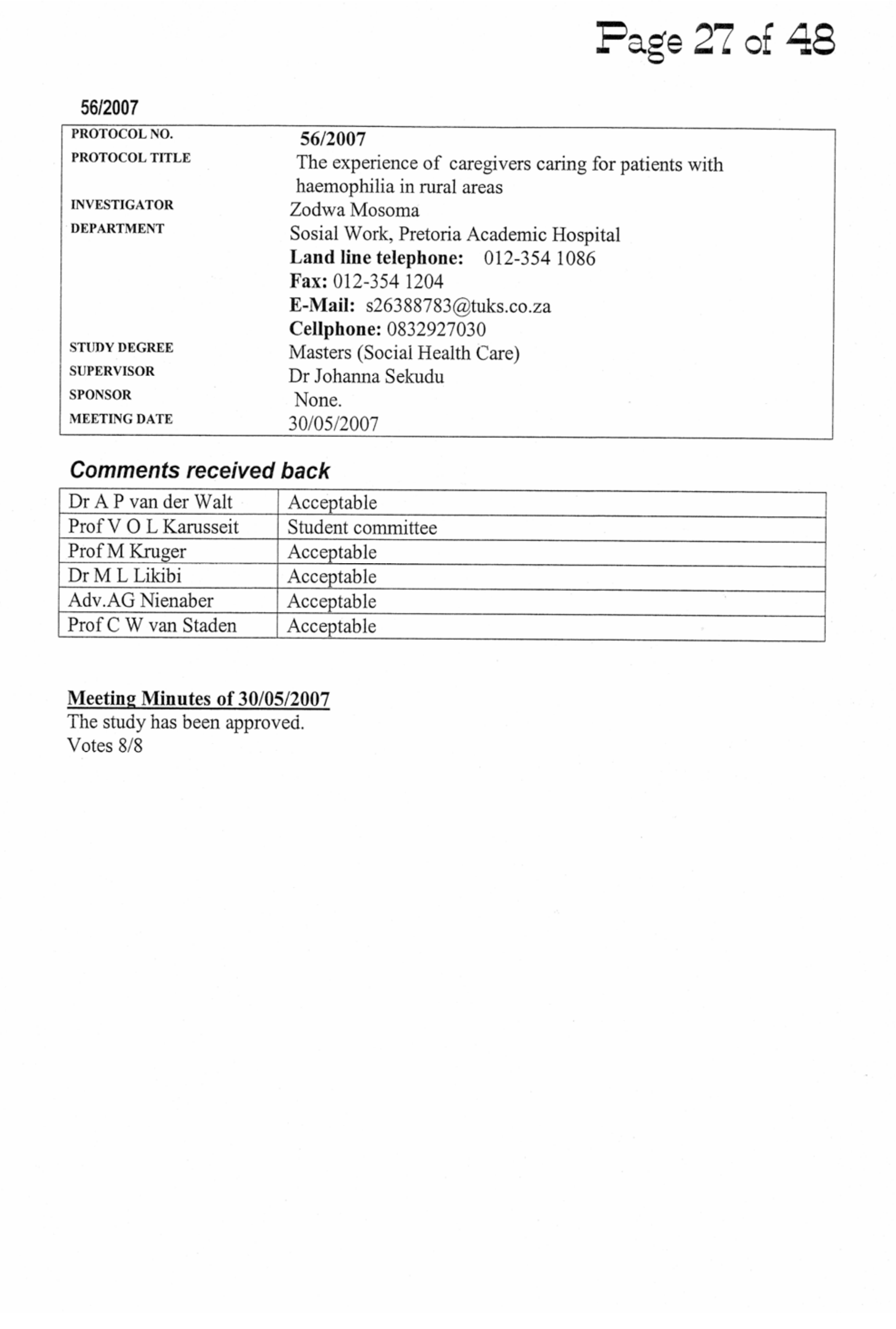

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56/2007

PROTOCOL NO.	**56/2007**
PROTOCOL TITLE	The experience of caregivers caring for patients with haemophilia in rural areas
INVESTIGATOR	Zodwa Mosoma
DEPARTMENT	Sosial Work, Pretoria Academic Hospital **Land line telephone:** 012-354 1086 **Fax:** 012-354 1204 **E-Mail:** s26388783@tuks.co.za **Cellphone:** 0832927030
STUDY DEGREE	Masters (Social Health Care)
SUPERVISOR	Dr Johanna Sekudu
SPONSOR	None.
MEETING DATE	30/05/2007

Comments received back

Dr A P van der Walt	Acceptable
Prof V O L Karusseit	Student committee
Prof M Kruger	Acceptable
Dr M L Likibi	Acceptable
Adv.AG Nienaber	Acceptable
Prof C W van Staden	Acceptable

<u>Meeting Minutes of 30/05/2007</u>

The study has been approved.
Votes 8/8