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EXPERIENCES OF FAMILY MEMBERS CARING FOR TUBERCULOSIS PATIENTS AT HOME AT VHEMBE DISTRICT IN LIMPOPO PROVINCE

by

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DECLARATION

I Tshavhuyo Joyce Sukumani declare that **‘EXPERIENCES OF FAMILY MEMBERS CARING FOR TUBERCULOSIS PATIENTS AT HOME AT VHEMBE DISTRICT IN LIMPOPO PROVINCE `** is my own work, that all sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted for any other degree at any other institution.

Sukumani
T.J.SUKUMANI

September 2011
DATE

DEDICATION

This thesis is dedicated to:

- My late father Jack Masia Thenga and my late mother Emma Munzhedzi Masia Thenga
- Special gratitude to my loving husband Petrus Mashudu Sukumani, my son Tendawaita Percy and my two lovely daughters Khodani Faith and Livhuwani Sukumani who kept on supporting me during this study. Thank you for your encouragement. You will always be in my mind.

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ABSTRACT

Tuberculosis (TB) is a potentially serious infectious disease which enters the body by inhalation and mostly affects the lungs. TB is ranked among the leading infectious diseases worldwide, and in South Africa (SA) it has become an epidemic, because of its high prevalence and there are multiple factors that were found to be attributing to its existence and spread. This was reiterated by the then Minister of Health during the World TB day on the 24th March 2009 that the community and family should be responsible for caring for the patients at home (Minister of Health speech, 2009).

The purpose of this study was to explore and describe experiences of family members caring for TB patients at home at Vhembe District of Limpopo Province. The objectives of this study were to explore and describe the experiences of family members caring for TB patients at home, identify and describe caring behaviour of family members when caring for TB patients at home, identify and describe challenges faced by family members while caring for TB patients at home.

The study was qualitative, explorative, descriptive, phenomenological and contextual in nature. A purposive sampling method was used. Data was collected through semi-structured interviews guided by four questions. Tech`s eight steps of qualitative data analysis was used. Measures to ensure trustworthiness and ethical issues were observed. The results of the study revealed that family members are experiencing difficulties when caring for TB patients at home. These difficulties include providing food, attending to hygienic needs, lack of equipments, financial constraints and this was said to contribute to physical and psychological exhaustion. Recommendations in relation to caring for TB patients at home, nursing practice, policy makers and research were also made.

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LIST OF ACRONYMS

AIDS	ACQUIRED IMMUNO DEFICIENCY SYNDROME
ANC	AFRICAN NATIONAL CONGRESS
DOH	DEPARTMENT OF HEALTH
HIV	HUMAN IMMUNOVIRUS
MDR	MULTIDRUG RESISTANCE
MEC	MEMBER OF EXECUTIVE COUNCIL
MTB	MYCOBACTERIUM TUBERCULOSIS
SANPAD	SOUTH AFRICA NETHERLANDS RESEARCH PROGRAMME ON ALTERNATIVES IN DEVELOPMENT
TB	TUBERCULOSIS
WHO	WORLD HEALTH ORGANISATION

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Tuberculosis (TB) is ranked among the leading infectious diseases worldwide. It is a potentially serious infective disease caused by mycobacterium tuberculosis (MTB), also known as tubercle bacilli which enters the body by inhalation and mostly affects the lungs (WHO, 2004: 23; DoH, 200: 11). The magnitude of the global TB epidemic, which is fuelled by its relationship with HIV, demands urgent and effective control measures to be undertaken to stop this preventable and curable disease (WHO, 2004: 23).

The HIV-fuelled TB epidemic is outstripping the coping ability of health services in many countries in sub-Saharan Africa (Stop TB 2006- 2015). The National TB control Programmes do not often achieve adequate case detection and treatment outcomes, management and follow up, hence the necessity to explore ways of complementing government health service provision of TB care (Stop TB 2006 - 2015).

During the WHO - AFRO Regional Committee meeting held in Maputo in 2005, 46 Ministers of Health unanimously declared TB as an emergency in Africa. A resolution at this meeting warned that unless “urgent extraordinary actions” are in place, the situation will worsen and the 2015 Millennium Development Goals will not be met (Stop TB 2006 - 2015). The stop TB partnership has developed a Global Plan to stop TB in the period 2006-2015. The plan envisages new improved TB drugs and TB diagnostic tools by 2010 and a TB vaccine available by 2015. A concerted effort is being made by the World Health Organization (WHO) together with the national

TB programmes, to expand the coverage of effective TB control measures based on the Directly Observed Treatment Strategy (DOTS) ((DoH, 2007-2011: 6). The United Nations Millennium Development Goals include a target for incidence of TB to have been halted and on its way to being eradicated by 2015 (DoH, 2007- 2011: 6). The Stop TB partnership has agreed on a target to halve the prevalence and the number of deaths from TB by 2015 in comparison to 1990 (DoH, 2007-2011: 6). At the same time most countries with high burden TB had developed comprehensive plans for DOTS expansion in collaboration with WHO and other organization aiming to stop TB (Atun, Weil, Eang & Mwakyusa 2010: 2169).

It has also been noted that the family is considered as important in the control of TB because it is regarded as a support system which is important in supervising the TB patient to take the treatment (Newell, Baral, Pande, Bam & Malla 2006: 878). In a study by Lidell (2002: 152) on family support the family was considered as a vital support system in achieving the millennium development goals in order to stop TB. Lidell (2002: 152) also indicated that interactive support between family members is clearly seen when one family member is ill. If one family member suffers the whole family system is affected and changes occur. Like other systems the whole system strives to reach new balance. Keeping former balance is an important source of burden to the family. The family may experience poor marital quality or functioning, intimacy and communication (Lidell, 2002: 153).

1. 2 BACKGROUND OF THE STUDY

The background of the study gives an overview of research report that has been conducted in the area of this study interest. The following themes were drawn from literature consulted and will be discussed; Overview of TB in South Africa; Overview of TB in Limpopo; The family as primary provider of care; Challenges faced by family members caring for TB patients, The relationship between family members and the patient.

1.2.1 Overview of TB in South Africa

TB was first discovered in South Africa (SA) in the late eighteenth and nineteenth century due to the arrival of the European colonists who came to SA as diamond miners. TB then spread among miners and consequently to their families and it became a public concern (Balt, Edington, Lotki, Preller & Margot, 1998: 5; Van Rensberg, Meulemanas & Rigouts, 2005: 12). A review conducted in relation to TB control in the country has identified that South Africa has the highest rate of TB or the worst TB epidemic in the world. This review then led the government to declare TB a national emergency and also a national priority in South Africa in 1996. On 24 March 2005, the Minister of Health declared TB a national crisis. The government also increased efforts to determine that diagnoses and treatment for TB is free and ensured increased access to the poor (South Africa TB Country Profile, 2003). The seriousness of TB led the South African government to strengthen the TB management at all levels by adding resources in TB training and control, strengthening DOTS and putting emphasis on monitoring patients progress (WHO, 2007; Nwanyanwu, 2008: 9).

Van Rensberg, Meulemanas and Rigouts (2005: 5) describe TB as an epidemic because there are multiple factors that were found to be attributing to its existence and spread. These include failure to eradicate the macro conditions that create a breading ground for TB, new disease conditions like Human Immune Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) and Multi Drug Resistance Tuberculosis (MDR TB), insufficient resources and health workers responsible for TB, ignorance, delay in seeking care and failure to adhere to treatment regimens by TB sufferers (Van Rensberg et al, 2005: 5). According to Van Rensberg et al, (2005: 37) and Newell, Bral, Pande, Bam and Malla (2006: 879), TB control programmes fail due to other factors, such as ignorance, negligence, non-adherence to treatment, absconding from treatment centers resulting in delays in diagnoses and treatment failures, Health service staff distanced from contact with the patient by family member who conduct DOTS. TB may also be triggered by poor living conditions, poor working conditions, poverty, deprivation, low immune systems, bad diet and fatigue. Tang and Squire (2004: 104) in a study on what lessons can be drawn from tuberculosis control in China in the 1990s also identified four main problems facing TB control in China such as low case finding, a substantial proportion of TB patients failing to complete treatment increasing the proportion of MDR patients and lack of co operation between health facilities (Van Rensberg et al, 2005: 6).

The reasons, as stated by Van Rensberg et al, (2005:5) are similar to those reflected in TB records in Limpopo, which show that Limpopo has high HIV/AIDS co-infection rate at 52.2%; MDR TB at 2.4% (DoH, 2006; DoHSD Limpopo Annual Performance Plan, 2007/8-2009/10). The South African Department of Health also showed that there are three main challenges in the fight against TB. These are the late presentation to health facilities, late detection of TB and high interruption rates which lead to the failure of TB patients finishing their treatment (Dennill, 2005:39).

Balt, Edington, Lotki, Preller and Margot (1998: 6) also noted other contributory factors causing TB epidemics as HIV infection, poor TB control programmes, urbanisation, climate and the mining industry. The authors further emphasises the association between TB and HIV as the high HIV infection rate has an influence on an increase in TB in South Africa. In addition to HIV, the TB epidemic is said to be influenced by urbanisation which result in housing shortages which favour TB transmission (Nwanyanwu, 2008: 9).

In South Africa (SA), after the new government was established in 1994, a revised National TB Control Programme (NTCP) was established in 1996 to take advantage of the new opportunities being offered by the reform process. As a result, DOTS was adopted as a cost-effective, safe, and effective mainstream strategy for TB control. Despite the fact that the NTCP exist to supervise the control of the TB epidemic countrywide, the availability of effective drugs, short course regimens, and the implementation of the DOTS for several years now, SA is still failing to conquer the TB epidemic (Stop TB 2006: 16).

The HIV-fuelled TB epidemic is outstripping the ability of health services to cope in many countries in sub-Saharan Africa, South Africa included. National TB control programmes do not often achieve adequate case detection and treatment outcomes. Therefore, it is necessary to explore ways of complementing government health service provision of TB care. The implementation of the DOTS was then introduced to assist in solving the TB epidemic in South Africa (Dye, Harries, Maher, Hosseini, Nkoma & Salaniponi, 2001: 3).

Other problem in the management of TB is the delay in making the TB diagnosis (Newell et al, 2006: 879). The cause of the delay might be patient related or health worker related. According to Matebesi et al, as (cited by Van Rensberg et al, 2005: 155) there is often considerable delay between the onset of symptoms and contact with health care providers. Some of the factors causing delays in seeking health include the attitudes and beliefs, risky health seeking behaviours, the age of the individual, the educational level, poor perception of health services, economic constraints and long distances to clinics and these delays affect the desired treatment outcomes negatively (Van Rensberg et al, 2005: 155; Newell et al, 2006: 879).

Research conducted by Hudelson (1996: 398) has identified that cultural, environmental, family relationships and institutional factors are some of the factors responsible for lack of utilisation of health services, as well as delay in presentation by symptomatic patients. It is further stated that factors such as experiences with TB, cultural beliefs and poverty determines the individual responses to treatment and subsequent behaviour (Hudelson 1996: 398; Liefooghe, Michiels, Habib, Mran & De Munynck, 2000: 1692).

Historically, TB has been stigmatized as a disease of the poor, being thought of as “dirty”, eating bad food, having bad hygiene and “the low class kind of society” (Westway & Wolmarans, 1998: 447; Liefooghe, Michiels, Habib, Mran & Munynck, 1997: 809). Another factor that has been associated with TB stigma is lack of knowledge or awareness of the cause of TB, however it has been identified that emotional and social distress of individuals is less frequently mentioned as a consequence of the TB (Bennstam, Strandmark & Diwan 2006: 299).

1.2.2 Overview of TB in Limpopo Province

According to the status of TB in Limpopo, the rate of defaulters is still high at 7.6% it is expected to be 5% and below (WHO, 2004). It has been reported that the health services in the proposed site, Limpopo Province, Unless immediate action is taken, the situation in Limpopo may worsen and the 2015 millennium development goals will not be met. Within the framework of Millenium Development Goals, the principal target for TB control is to ensure that the global incidence rate falls by 2015. The Millenium Development Goal 6 refers to combating HIV and AIDS, malaria and other diseases and TB included. The partnership’s goal is to eliminate TB as a public health problem and ultimately, to secure world free of TB. The partnership aims to strengthen by meeting the 70% detection. Vhembe District was identified as one of the four districts with both high number of TB cases and low cure rates. These four districts are focus areas for the TB plan (Communication with Provincial TB statistics, 10/ 18/07). However, lack of information about the socio-cultural, family involvement and other determinants contributing to the problem. (DoH, 2006; Limpopo DoHSD Annual Performance Plan, 2007/8-2009/10).

1.2.3 The family as primary provider of care

A family is a group of people who are related to one another either by blood, marriage or adoption and who live together for longer periods (Van Staden, 2000: 156). The father, the mother and children are the members who form the nuclear family. The adults in the family assume responsibility for taking care of the young ones. The other members of the family take care of those who are ill because they are incapacitated cannot care for themselves. These people include those who are ill, like TB patients and others (Van Staden, 2000: 156). When the patient is receiving treatment at home, he/she expects practical services to be delivered by any member of the family who is responsible enough to take care of the sick. The patient expects emotional support and guidance from family members and he/she considers home as the haven for rest and recuperation (Du Toit & Van Staden, 2007: 143).

The family member, as a caregiver has many roles when caring for a TB patient. These include the assessment of the patient for adverse effects of medication such as deafness, gastrointestinal upset, skin rash, hypotension and many other medical problems. Adherence to medication should also be monitored and a schedule for drug taking kept by the caregiver. Practicing safe hygiene and consuming a nutritious diet should be monitored. Caregivers should also supervise patients` level of activities and monitor scheduled appointments of the patient with the Primary health care provider (Lewis, 2000: 548; Smeltzer & Bare, 2003: 441). These factors may exert pressure on the family member who is caring for the patient at home. This may indicate that family members may be having different experiences and challenges when caring for TB patients at home.

Living with and caring for a TB patient may cause problems within the family, sometimes difficult problems to deal with. Besides the pain of watching a loved one suffer, family members may experience a lot of shame, resentment and guilt. It may often be very difficult for family members to accept the illness and adjust to the fact that despite their effort of caring for them, the condition of their loved ones may get worse (South African Depression and anxiety group, 2008: 5). Members of the family have an important role to play in caring for a patient discharged from hospital and maintaining continuity of care according to PHC approach as indicated by the South African National Health Plan (ANC, 1994: 43). Family members' roles may include caring for the patient after early discharge from the hospital, providing social support, and carrying out other activities such as going to work every morning despite the fact that they are acting as caregivers (Thomas, 2002: 371). In support of the above statement, Roberfroid (2000: 2) indicated that family care practices, coping mechanisms and family care systems are done by family care givers and have been the foundation of communities for generations.

1.2.4 Challenges faced by family members caring for TB patient

A study conducted by Shetty, Shemko and Abbas (2004: 81) noted that close family members do not ostracise or stigmatise patients. It has also been noted that some patients reported that they are not treated well by members of the community and relatives (Shetty, Shemko & Abbas, 2004: 81; Morankar & Suryawanshi, 2000: 3; Needham, Bowman, Foster & Faussett, 2004: 98). These authors argued that family members were ostracised by the community for staying with a TB patient. The extent of social stigma to the family may also affect the way in which the family cares for the TB patient. In the Bible, patients were also isolated in a Sanotarium and were kept away from society. Patients were not given emotional, social and physical support by their family members (II Kings, 7: 3). Family members with TB have also been stigmatised as poor because TB is said to be the disease of the poor, Those with TB have been thought to be dirty, eating bad food and having bad hygiene (Westway & Wolmarans, 1994: 447; Liefooghe, Balidawa, Kipruto, Vermeire & Munynck, 1997: 812). TB has been considered as a disease with a potential negative impact as seen by the delayed diagnoses or poor TB treatment adherence. (Liefooghe et al, 1997: 812; Cambanis, Mohammed, Yassin, Ramsey, Squire, Arbide & Cuevas, 2005: 334 ; Eastwood & Hill, 2004: 73).

Research conducted in Sub-Saharan Africa also noted that stigma was mostly found in women more than men. Some of the men in the study indicated that TB was found mostly amongst women with boyfriends. This belief about women with TB might influence the type of care that women with TB are given by family members. Some marriages may be destroyed due to social stigma related to TB. Most men may prevent their wives from seeking medical help; TB may also affect the relationship between family members and the patient. As some members of the family may also be reluctant to give social support to the patient due to the stigma (Jaramillo in Peltzer, Onya, Seoka, Tladi & Malema, 2000: 63).

Jaramillo cited in Peltzer et al, (2000: 63) states that family members giving care to the patient may feel discriminated against by society and because of that they may be reluctant to care for the patient. The patient may be affected psychologically if he/she notices that members of the family are reluctant to give care. In the study by Edington (2002: 1078) family members were said to have infringed cultural rules if they took care of a patient with TB because TB was considered to be a disease of bad people. Close associates or family members were, therefore, likely to be stigmatised by community members. Family members may then also leave in fear and isolation due to the disease and fear of being discriminated against.

A study conducted by Bennstam, Strandmark and Diwan (2006: 304) concluded that members of the family experience isolation while caring for a person with TB. This isolation may lead to challenges for family members, as they may need to change what they used to do, how they used to act and where they used to spend their time. Isolation of the family can in turn also influence family members to isolate the patient. This may affect the way that the patient is cared for at home.

Social relationships between family members caring for a patient with TB and the community were also reported to be affected. It was also identified by Bennstam et al, (2006: 306) that husbands or wives may abandon their spouses. This however does not happen in all families. Young persons with TB may not get married even after recovery. Some may have difficulties in finding a partner because of a TB history. This experience may affect the way family members care for the TB because of fear of transmission, there may be isolation by one`s spouse (Bennstam, Strandmark & Diwan, 2006: 306; Demissie, Getahun & Lindtjorn, 2003: 13; Liefooghe et al, 1997: 812).

1.2.4.1 Family and social support

Family support assists patients to be mentally stable during caring. Females who receive support from their husbands can be optimistic of cure. Family support is of great importance in caring for the patient because it is the responsibility family members to prepare a nutritious meal for the patient before the patient takes the treatment (Morankar & Suryawanshi, 2000: 3). The family member gives the patient support by also supervising treatment taking. All TB patients are expected to go to hospital or to the primary health care for follow up visit and the family member assists by providing the patient in transportation fee. Lack of family support also affects adhering to the treatment, and the experience may affect the way care is given (Morankar & Suryawanshi, 2000: 3).

It has also been identified in a study that most patients are supported by their family members both socially and financially which emphasises that fact that families do have experience in caring for patients at home (Macq, Solis, Martinez, Martiny and Dujardin, 2005: 5).

1.2.4.2 Financial constraints

Poverty has been identified in the literature as another factor contributing to financial constraints. According to Needham et al, (2004: 98) some families are facing poverty. Financial constraints as experienced by family members in many households may affect the care for TB patients. Caregivers may need money for traveling with the patient to the health service centre or clinic. Some patients may not be able walk long distance due to the illness. Sometimes caregivers may use wheelbarrows to carry patients when going too far away health service for care. Transport expenses may also double when caregivers accompany patients. The burden of transport is particularly heavy for caregivers. This may affect the way the patient is cared for (Needham et al, 2004: 98).

Needham et al, (2004: 98) describe the problem of unrecognised costs that may be faced by caregivers. The family might not be able to meet the cost for special food such as eggs, meat, milk, oranges and vegetables. Caregivers might also absent themselves from work due to the illness of the patient. When the caregiver is no longer working, the burden of caring may be highly affected by financial constraints (Needham et al, 2004: 98). In other families where the husband is a carer, the husband may lose income and risk his job as he might need to escort his wife to the clinic. Some families share resources in times of crisis, for example in a family where the grandmother is getting a grant the patient may go and stay with her. This may affect caring by the mother who may not be working and is financially insecure (Needham et al, 2004: 98).

Eastwood and Hill (2004: 73) and Liefooghe et al, (1997: 812) also stated that family members living with TB patients might experience financial difficulties. In other families, the husband may pay fees for the wife to seek health care. Fares may be paid by family members if one is to visit the health service centre. Financial constraints such as getting money for transport, was said to be difficult (Eastwood, 2004: 73; Liefhooghe et al, 1997: 812; Harper, Ahmadu, Ogden, Adam & Lienhardt, 2003: 17). In South Africa, for example, Limpopo, use of public transport to access the clinic is a problem due to financial constraints. Lack of food in the family also, affects the care for TB patients. Care givers are aware that tablets or treatment should not be taken in an empty stomach. It is expected that husbands and parents should give wives and adolescents money for transport to go to the clinic for consultation (Rowe, Makhubele, Hargreaves, Porter, Haussler & Pronuk, 2005: 265).

1.2.5 The relationship between family members and the patient.

The relationship between family members is said to be affected when caring for an ill family member. This is supported by research by Liefooghe et al, (1997: 815) where it is stated that relatives may stop children from having contact with parents who have TB. Children may be instructed by family members not to get close to their parents. This result in most patients not getting the care they should be given because in some families children are the ones who care for their parents when they are ill. Some husbands may divorce their wives and some men may stop caring for their wives if they consider that the misconceptions are true (Liefooghe et al, 1997: 815; Eastwood et al, 2004: 72; Demissie et al, 2003: 13).

Edington et al, (2002: 1078) also state that there can be social disharmony between husbands and wives because it is other people believed that engaging in sexual activities render treatment ineffective therefore the patient should not engage in sex when he or she is on treatment. The unaffected family member, who is caring for the patient, may be in a predicament and may look for sexual fulfillment elsewhere. This may cause disharmony in the family. In order to please their partners for a while some patients may prefer to stop the treatment rather than to abstain from sex. They may resume the treatment at a later date (Edington, Sekatane & Goldstein, and 2002: 1078).

The relationship between family members was said to be affected after the intensive phase of the disease when the patient no longer go to the clinic for the Streptomycin injection. It is reported that members of the family think that the patient is cured and should go and look for a job to assist in paying of rent and other household requirements (Harper, Ahmadu, Ogden, McAdam, Lienhardt, 2003: 508;). In other instances the mother as a main caregiver to the patient and as a breadwinner in the family may lose her job and end up begging and being unable to feed the sick child or partner. The mother might stop collecting the treatment so as to look for a job in order to feed all her children. The other relatives and neighbours may also stop assisting the family when they see that the patient looks fine (Sagbakken et al, 2008: 7; Harper et al, 2003: 508).

Culturally family members may have problems when caring for the TB patient at home because family members are expected to share food and meals within the family. In African tradition, family members are expected to eat and drink from the same plates and cups. Culturally, other patients also have the belief that their treatment should be collected by someone in the family whom they trust and know. This may pose problems among family members because the patient would prefer one person in the family to take care of her. It is possible that the preferred member could be held up by some other things. The issue of being bewitched is feared most and strangers as caregivers may not be preferred (Edington et al, 2002: 1078).

Apart from cultural beliefs that may affect caring, religion and other behaviours may have an effect on caring. A patient who is a Rastafarian may not take chemicals or drugs. The caregiver `s religion might also affect the way treatment is taken of the patient. Sometimes some caregivers may be drunkards and may not be role models. In such a situation, the caregiver may fail to make effective decisions when caring for the patient as he/she is always may be always drunk (Edington et al, 2002: 1078).

1.3 PROBLEM STATEMENT

Vhembe district where the study was conducted had the highest number of TB patients in Limpopo Province. The honorable MEC of Health and Social Development Seaparo Sekoati in his address during the World TB day on the 24th March 2009 expressed concerns regarding the escalating statistics in Vhembe District of Limpopo Province. The Minister further indicated that the Vhembe District had a high number of TB cases and low cure rates. This makes it one of the focus areas for the government plan on TB that seeks to improve systems that are necessary to support the TB programme (World TB day Limpopo, 2009).

According to South African National Health Plan strategy (1994:143) patients are admitted at hospital for a short period such as 14 days and discharged home to be cared by the family. Some of the patients are very ill to care for themselves. There is a need for family members to care and supervise this treatment at home. It is also noted that these family members have other duties to perform besides caring for discharged patients and they face some difficulties. The researcher reviewed the literature and identified that no study on experiences of family members caring for TB patients at home has been conducted at Vhembe district among Venda speaking people. Hence, the study seeks to explore the experiences of family members in caring for TB patients at home.

1.4 RESEARCH PURPOSE

The purpose of this study was to increase the understanding of the experiences of family members caring for TB patients at home.

1.5 RESEARCH QUESTIONS

The study addressed the following questions:

- What are the experiences of family members caring for TB patient at home?
- What are the caring behaviours of family members when caring for TB patients at home?
- What are the challenges that are faced by family members while caring for TB patients at home?

1.6 RESEARCH OBJECTIVES

The objectives of this study were to:

- Explore the experiences of family members caring for TB patient at home;
- Identify and describe the caring behaviour of family members when caring for TB patients at home; and
- Identify and describe the challenges faced by family members while caring for TB patients at home.
- Make recommendations based on the results of the study.

1.7 SIGNIFICANCE OF THE STUDY

It is hoped that the study is going to provide recommendations on how best can a patient be supported in order to complete the regimen for TB and maintain adherence. Recommendations on family support may assist family members on how to cope with the extra burden of caring and patients will be well cared for by family members without complains. The study may facilitate development of community support groups that may assist family members in caring and to develop coping mechanisms when caring for TB patient at home.

The study may influence the TB directorate to increase the number of DOT supporters in the community so as to assists families in monitoring of TB treatment especially those that are illiterate. Cure rate, adherence rates as well as defaulter rates may improved as the study will unfold problems that are associated with this factors and how these issues can be addressed.

Recommendations from this study might influence the Department of Health to develop guidelines that will assist primary health care nurses in supporting family members caring for TB patients at home. Primary health care nurses at the clinics will have an increased number of patients who come for follow-up care because family members will not be reluctant to supervise the patient at home to come for follow-up. Therefore costs utilised for patients with MDR TB and Extreme Drug Resistance (XDR) TB will be minimised as patients will be taking treatment as prescribed.

1.8 THEORETICAL FRAMEWORK

A theory is a set of interrelated concepts, definitions, propositions or hypotheses with specified and measurable relationships to predict and control phenomena under study among the patient and the family members (Kozier, Berman & Snyder, & 2004: 39). The Theory of Planned Behavior was used in this study. This theory of planned action postulates three conceptually independent determinant of intention which was used as the basis of the study (Ajzen, 1991: 180). The three independent determinants are behavioral beliefs or intention, normative beliefs and control beliefs. Behavioural beliefs or intention refers to the degree to which a person has favourable evaluation or appraisal of the behaviour in question (Ajzen, 1991: 180) Normative evidenced by subjective norm refers to perceived social pressure to perform or not to perform the behaviour (Ajzen, 1991: 180). Lastly Ajzen (1991: 180) showed that the third independent determinant is controlled beliefs. This is characterised by perceived behavioural control and it refers to the ease or difficulty of performing the behaviour as well as reflecting past experiences and anticipated obstacles (Ajzen, 1991:180). The family member should have the intention to care for the member of the family who is ill. Favourable evaluation of the sick was expected from the family member during caring for the sick. Social pressure and the ease or difficulty of performing the behaviour was perceived by the family member caring for the patient. This theory was applied in this study because family members were expected to care for the TB patients at home at their own will and this choice depend upon their attitudes and personal experiences. The family member's attitudes, perspectives and subjective norms determine whether the family member is willing to care for the patient.

1.9 CONCEPTUAL AND OPERATIONAL DEFINITIONS

- **Tuberculosis patient**

This is a person who has been diagnosed with TB (pulmonary TB) by positive sputum with mycobacterium bacillus, which is a specific chronic infectious disease characterised by formation of tubercles in the tissue (Blackwell, 1994: 696). In this study, a TB patient is a person who is on TB treatment and is receiving it while being at home under the care of a family member.

- **Family member**

A family member is usually defined in kinship. Family is membership within a societal structure that gives children an ascribed status for example son, daughter, brother, sister, and later husband, wife, father or mother. The members of the family have certain rights and duties that are recognised generally by tradition but also legally. Family members live together for long periods of time and adults assume responsibility (Du Toit & Van Staden, 2007: 143) In this study, a family member is one who may be the son, daughter, brother, sister, husband, wife, father or mother of the patient, and is caring for the TB patient.

- **Experience**

Experience is the actual observation of or practical acquaintance with facts or event (Thompson, 1995: 474). In this study, an experience is an exposure which the family member had while caring for the TB patient.

- **Caring**

Caring is the way one behaves in interpersonal and group situations. Caring needs the presence of a caregiver whose responsibility is to watch, provide for and look after another person. Care responsibility includes provision of help when the person is confronted with specific things to be done; things that he or she is unable or unwilling to do. A care giver, as a care agent, is also expected to bring about and maintain environmental conditions conducive to the personal development of others (Orem, 2001: 26). In this study, caring implies providing physical, social and psychological support for a TB patient at home.

- **Home**

The fixed residence of a family where one lives (Fowler & Fowler, 1995: 649). This study indicates the home as the place where the TB patient lives with other family members.

1.10. RESEARCH DESIGN AND METHODS

Detailed items of the design and methods will be discussed in chapter 2. The designs for this study were qualitative, exploratory and descriptive in nature whereas the phenomenological approach was used. The researcher was interested in these designs because the study purpose was to increase understanding of family members experiences in caring for TB patients at home. At the same time the researcher observed and described phenomena as it was and summarised the data.

In this study the population consisted of all family members in the Vhembe district caring for TB patients at home. Whereas, the target population of the study comprised of family members residing at Tshifulanani village, A non probability purposive sampling technique was also used to sample 13 family members who participated in the study.

Data was collected using the unstructured interview to explore the following the research questions described on item 1.5. The interviews were guided by saturation of data.

1.11 DATA ANALYSIS

Data was analysed qualitatively according to the useful analysis process in eight steps as indicated by Tesch (Creswell, 2003:192). Measures to ensure trustworthiness of the data or findings was ensured by credibility, transferability, conformability and dependability process. Ethical considerations were also ensured.

1.12 LIMITATION OF THE STUDY

The study is limited at Vhembe district only and it was done on members of the family caring for TB patients only.

1.13. DISSEMINATION OF THE FINDINGS

The findings will be disseminated through presentations during national and international conferences and articles in accredited journals. The report will be written to the Department of Health and Social Development specifically to Primary Health care component and the University of Venda. Workshops will be conducted to the local chiefs of the villages where the study was conducted. Presentations to the participants as well as to the patients themselves will also be conducted.

1.14 OUTLINE OF THE STUDY CHAPTERS

Chapter 1: Overview of the study.

Chapter 1 discusses the overview of the study which include the following; introduction, background and rationale of the problem, problem statement, research question, purpose of the study, objectives, significance of the study, literature review, research design and methods, measures to ensure trustworthiness, data analysis, limitation of the study, as well as ethical considerations.

Chapter 2: Research design and methods.

Chapter focuses on the research strategy and approach, study setting, sampling methods and sample, data collection method, data analysis measures to ensure trustworthiness as well as ethical consideration.

Chapter 3: Discussion of findings.

Presentation of findings according to themes, categories and subcategories and discussion of findings are described in this chapter.

Chapter 4: Summary, recommendations and conclusions.

This chapter discusses recommendations, evaluation, conclusion and limitation this study. Evaluation of the study against the purpose and objective as set out in chapter one is also described.

1. 15 SUMMARY

This chapter outlined the overview of the study which included introduction and background of the study, problem statement, objectives, research questions and research design and methods. The next chapter discusses the methodology of the study in detail.

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

Description of an overview of this study was given in chapter one. The background of the study, problem statement, research question, purpose and objectives of the study as well as limitations of the study were explained. The researchers' choice of method to conduct the study was inductive. According to Mouton (1999: 74), inductive reasoning starts with observations and not with a preconceive conclusion or major premise. To induce is to draw a conclusion from a number of particular facts also called phenomena or pieces of evidence. Qualitative strategy therefore forms the basis of this research design and method. This chapter dealt with research design and methods, population and sampling, data collection method, analysis, measures to ensure trustworthiness as well as ethical consideration.

2.2 RESEARCH DESIGN

The research design is viewed as an emergent design which is iterative in nature, con ducting a study that guides the researcher in planning and implementing the study in a way that is most likely to achieve the intended goal (Burns & Grove, 2001: 223). The design for this study was qualitative, explorative and descriptive in nature whereas the phenomenological approach was used. The experiences of participants caring for TB patient were explored. The researcher was interested in this design because its goal is to understand the experiences participants caring for TB patients at home.

2.2.1 Qualitative

In qualitative research, the researcher eschews measurement and focuses on interpretative, non numerical narrative interpretation (Polit & Beck, 2006: 210). The researcher was interested in this design because its goal was to understand behaviour or actions within their naturally occurring context and it is flexible, elastic and capable of being learned during the course of data collection (Polit & Beck, 2006:210). The design influenced the researcher to commit herself to discovery through the use of multiple ways of understanding and continually examine and interpret data. After continually examining and interpreting data the researcher then made decisions about how to proceed based on what has been discovered. The design also required the researcher to be the research instrument as it tended to be holistic, striving for an understanding of the whole (Polit & Beck, 2006: 210; Stommel & Wills, 2004: 178). Stommel and Wills (2004: 291) indicate that qualitative design is also indispensable and can be criticized for placing too much trust in the credibility and integrity of the individual researcher. In this study the researcher was able to explore and describe the experiences of participants caring for TB patient at home. The experiences were freely explained during an interview and non verbal cues were recorded in a pocket note book.

2.2.2 Exploratory

Exploratory begins with the phenomena of interest such as simply observing and describing (Polit & Beck, 2006: 21). Exploratory research is also undertaken when a new area or topic is being investigated and it is designed to shed light on various ways in which a phenomenon is manifested and is an underlying process (Polit & Beck, 2006: 21; McMillan & Schumacher, 2006: 68). In exploratory design, the researcher uses the initial qualitative phase with a few individuals to identify themes, ideas/ perspectives and beliefs that can then be used to design a larger scale. This design enabled the researcher to explore the experiences of participant caring for TB patients at home in order to gain insight and comprehend the information gathered during data collection. Participants experiences of caring for TB patient at home in their day to day lives were explored. This design is also aimed at exploring the dimension of the phenomena, the manner in which phenomena manifest itself and other related factors (Brink, 1996; 219). Exploratory studies are designed to increase the knowledge of the field of study but are not intended for generalisation to large populations (Burns & Grove, 2001: 373).

2.2.3 Descriptive

Descriptive studies are a way of discovering new meaning, describing what existed and determine the frequency how something occurs (Burns & Grove, 2001: 30). The information is then catergorised or classified for use at the end. The purpose of descriptive research is to observe, describe and document aspects of a situation. In descriptive studies, the researcher observes and describes phenomena as it is. The researcher observed, described and later documented lived experiences as related by the participant. The researcher chose descriptive research because it summarised the findings of the problem investigated (Burns & Grove, 2001: 30; Polit & Hungler, 1991: 19; Polit & Beck, 2006: 189). Descriptive study also focuses on the situation as it is without manipulating variables. This focus might include conditions that exist, practices that prevail, beliefs and attitudes that are held on going process and developing trends (Cormack, 1996: 179). It also enables the researcher to gain more information about the characteristics within a particular field of study with purpose of providing a picture of the situation as it naturally occurs (Burns & Grove 2001: 223; Struebert & Carpenter, 1999: 52). For example, Mashau (2007: 14) in her study on experiences of HIV and AIDS home based caregivers as they provide care to patients at their homes described the experiences of HIV and AIDS home based caregivers as they provide care to patients at their homes. The findings of the study indicated that descriptive studies are effective in describing experiences as they occur.

Use of bias can easily occur in descriptive design. In order to prevent bias in this study conceptual and operational definitions were clearly described in item 1.9 of chapter one and the study described ensuring trustworthiness of the researcher and the sample was selected purposively guided by data saturation (Burns & Grove, 2001: 248).

2.2.4 Phenomenology

The researcher was interested in phenomenological approach in this study. Phenomenology is a science whose purpose is to describe particular phenomena. This approach investigated subjective phenomena in the belief that essential truths about reality are grounded. The researcher gathered the lived experience, according to the phenomenological school of thought. This design allows open room for personal experience to be shared subjectively. The important thing was the experience as it was presented (Polit & Beck, 2006: 220; Struebert & Carpenter, 1999: 49).

The researcher followed descriptive phenomenology as it stimulates one's perception of lived experiences, while emphasising the richness, breadth, and depth of those experiences. In descriptive phenomenology, the researcher emphasised the careful description of conscious experience of everyday life, and how things were described as people experience them. Things that the researcher described included hearing, seeing, believing, feeling, remembering, acting, deciding and evaluating. In order for the researcher to accomplish this, the researcher went to the participant's living environment. (Struebert & Carpenter, 1999: 49; McMillan & Schumacher, 2006: 26; De Vos, Strydom, Fouche & Delport, 2006: 270; Polit & Beck, 2006: 220).

allowed to facilitate a complete description by the participant. The researcher attempted to immerse herself in the data in ways that allow the intended meaning to emerge. Bracketing may occur when the researcher immerse herself and identifies personal biases about phenomena of interest to clarify how personal experiences and beliefs may colour what is heard and reported. The researcher set aside personal biases to bracket them when engaged with the participant by avoiding to immerse herself and identifies personal biases (Wood & Haber, 1994: 262). In this study the researcher tried to avoid asking personal questions but followed the semi-structured questions and more questions emanated from the discussion.

2.5 CONTEXTUAL AND THE STUDY SETTING

Contextual describes the uniqueness of the research settings. In qualitative research the meaning of social action depends on the context in which the study is taking place (Neuman 1997: 33). In this study the experiences of family members caring for TB patients at home were explored jn the Limpopo Province in Vhembe district. Interviews were conducted at TB patients' homes. Limpopo Province is divided into five districts, namely, Mopani, Vhembe, Capricorn, Waterberg and Sekhukhune. Vhembe where the study has been conducted consist of four sub districts which are; Thulamela, Makhado, Mutale and Musina.

Vhembe district consists of seven hospitals, 112 clinics and eight health centres. Thulamela municipality has two sections, A and B. Thulamela A has four local areas namely Mhinga, Xingwedzi, Mphambo and Tshaulu. Thulamela B consists of three local areas which are Shayandima, Tshidimbini and Makhado local areas. Each local area under Thulamela municipality has nine clinics. Total number of clinics in this local area is twenty seven, mobile clinics and two health centers.

Tshifulanani village where the study was conducted is situated within Shayandima local area and does not have a clinic but it is catered for by the mobile services from Shayandima local area. TB patients travel to the next village at Dzwerani clinic to collect the treatment. Tshifulanani village is plus minus 10 kilometers away from Dzwerani clinic. DOT supporters are stationed at the clinics and are also available at Tshifulanani village which falls under Lwamondo tribal authority. Tshifulanani has six zones with the population of approximately 8000. The village is also served by home based caregivers. When a patient is discharged, he/she is linked to a clinic or health centre which is nearest to the family. There are also DOT supporters who assist the family in giving the treatment to the patient but not all families have this support.

2.6 POPULATION, SAMPLING METHOD AND SAMPLE

2.6.1 Population of the study

Population is all the elements that meet the criteria for inclusion in the study (De Vos: 2006, 193). In this study the population consisted of all family members who cared for TB patients at home and accessible population is the portion of the target population to which the researcher has reasonable access. It might be elements within a state, city, hospital or nursing unit but in these study members of the family are accessible population (Stommel & Wills, 2004: 297). Entire population is the target population of the study. The entire population may be very small and well defined. In this study the entire populations are family members caring for TB patients in Vhembe district (Burns & Grove, 2001: 366; Wood & Haber, 1994: 289).

Target population is the entire set of individuals or elements who meet the sampling criteria (Wood & Haber, 1994: 288). In this study family members caring for TB patient in Tshifulanani village are the target population.

2.6.2, Sampling methods and sample

In research there are two sampling methods that can be used namely probability and non probability methods. This study focused on non probability sampling technique, implying that not all family members caring for TB patients were sampled. (Polit & Beck, 2004: 50). There are four types of non probability sampling designs and each addresses a different research need. Convenience or accidental sampling, quota sampling, network sampling as well as purposive sampling are examples of non probability sampling techniques (Burns & Grove, 2001: 374).

Purposive sampling design was chosen in this study because it involves conscious selection of certain participants to be included in the study by the researcher. The researcher selected participants based on personal judgment about which one is the most representative (Polit & Beck, 2004: 729; Burns & Grove, 2001: 376). The researcher used purposive sampling technique to arrive at choosing a sample of 13 families that participated in the study. The researcher further used purposive sampling to sample Tshifulanani village in the Thulamela municipality based on the high prevalence of TB statistics as reflected in one clinic.

In qualitative research there is also a tendency of focusing on smaller samples. A sample is a subset of the population selected for the particular study (De Vos, 2006: 193). Only one or two members of the family were chosen depending on the size of the family. Males and females were chosen. The inclusion criteria followed were that

- Participants were chosen from families where there was a TB patient on treatment during the time of data collection.
- Participants were family members directly caring for the patient during data collection.

2.7 DATA COLLECTION METHOD

The researcher used the unstructured interview because it is more flowing with its structure limited only by the focus of the research. An unstructured interview leaves the wording and organisation of questions and even the topic to the discretion of the interviewer (Brink, 1996: 158). This method is appropriate to qualitative or explorative research studies. The interview was conducted as normal conversations with a purpose and produced more in-depth information on the subjects (Brink, 1996: 158). The unstructured interview can also be called a non- scheduled interview. The interview was prearranged. The researcher established rapport with participants by paying attention to what the participants were saying. The researcher did not interrupt the participant; was non-judgmental; and developed a healthy appreciation for silence. Listening and interviewing skills were used by listening intently to the participants' stories (Polit & Beck, 2005: 347). Discussions proceeded in a relaxed conversational manner. In this study, the interview was conducted as a normal conversation. The following questions guided the conversation.

"Can you tell me about your experiences in caring for the patient with TB at home?
How can you describe your caring behaviors towards your patients?
What challenges do you experience when caring for the TB patient?"

Participants were encouraged to explain all the experiences in their own language. The conversation was free flowing but limited to the experiences of caring for patients with TB. Participants were interviewed as individuals. Duration of the individual interview depended upon the way the subject answered the open-ended questions. The language used was the language best understood by the subject.

Data was tape recorded and transcribed verbatim. The researcher also observed for non- verbal cues. The interview was conducted at the patient's household so that all participants are accessible. Data collection was terminated when saturation was reached. Data saturation occurs when information being shared with the researcher becomes repetitive and ideas conveyed by the participants have been shared before by the other participants. When other participants were included it did not result in new ideas (Wood & Harber, 1994: 257).

Communication strategies used by the researcher during the interview process were as follows:

- **Clarifying**

During the interview process with the family members caring for TB patients, the researcher asked the participants to clarify some concepts to get the meaning of some statements in relation to their experiences of caring for TB patients in their homes. The researcher again asked some questions where there was no clarity and also requested for elaboration if necessary. These ensured clarity and avoid misunderstandings (De Vos, 2005: 297; Henning et al, 2004: 7; Streubert & Carpenter, 1999: 58).

- **Scene setting**

This is a process of introducing the topic, the purpose of the study and the role of the interview to the participant. The researcher started the interview by introducing the research topic and explained the role of the interview to family members caring for TB patients at home (Henning at al, 2004: 7; Van Rensburg & Smit, 2005: 75).

- **Minimal responding**

The researcher encouraged the participants to freely express their experiences of caring for TB patients at home by listening without interrupting them. The researcher demonstrated respect and sincere interest throughout the interview process with family members caring TB caring (Streubert & Carpenter, 1999: 58).

- **Reflecting**

This is a process of summarising some of the conversation during the interview process to check if the interviewer`s understanding corresponds with that of the participant (Henning, et. al, 2004: 75). The researcher repeated some statements that were said by family members to find out if the understanding is the same and to allow for clarity on some issues regarding their experiences as they care for TB patients.

- **Probing**

The researcher asked probing questions during the interview with family members at home to encourage them to clarify some sentences, fill in missing information and to keep the conversation on their experiences of participants caring for TB patients (Rubin & Rubin, 2005: 164).

- **Field notes**

These are written in the field and they are temporary key words, cues or drawings that help to trigger the memory of the researcher of what was happening during data collection. It is a system for remembering, retrieving and analyzing observations (Neuman, 1997: 353). The researcher took notes of observations that cannot be picked up by an audio-tape recorder on a notepad in the presence of participants after explaining the purpose to them. Observations, key words and non-verbal cues were recorded and used as the basis for analysis (Wilson, 1993: 222).

2.8 DATA ANALYSIS

Data was analysed qualitatively using Tesch `s Open Coding method whereby data was broken down into discrete parts, closely examined, compared for similarities and differences and questions were reflected in the data. Themes, categories and sub-categories were developed. Useful eight steps in analysis process as indicated by Tesch in (Creswell, 2003: 192) are the following:

- **Getting a sense of the whole.**

The researcher read through all of the transcriptions several times carefully in order to understand the information provided by participants caring for TB patients at home clearly. The researcher immerse in details trying to get a sense of the interview as a whole before breaking it down into parts. Some ideas were jotted down as they came to the researcher`s mind (Creswell, 2003: 192).

- **Picking one document**

The researcher picked up the most interesting, shortest interview and read through it analysing its underlying meaning. Thoughts were written on the margin (Creswell, 2003: 192).

- **Making a list of all topics**

After reading several interview documents from participants, the researcher made a list of all topics derived from the interview reports. Similar topics were clustered together, formed in columns that were arranged as major topics, unique topics and leftovers (Creswell, 2003: 192).

- **Take the list of topics and go back to the data.**

The researcher took a list of the topics, went back to the data, abbreviate topics as codes and codes were written next to the appropriate segments of the interview report (Creswell, 2003: 192).

- **Turn topics into categories**

Topics derived from the interview reports that relate to each other were grouped together then the researcher classifies the qualitative information by looking for categories, themes or dimensions of information. General themes and sub themes were then identified. The researcher drew columns between categories to show how they are interrelated (Creswell, 2003: 192).

- **Make a final decision**

The researcher made a final decision and themes were made by assembling data material belonging to each category.

The data material belonging to each category was assembled in one place and a preliminary analysis was performed. Re-coding of the existing data was done as the researcher found it necessary during the process of analysis. The researcher was able to generate themes, categories and sub-categories from the collected data Tesch, 1990:42 (in Creswell, 2003: 192).

2 .10 MEASURES TO ENSURE TRUSTWORTHINESS.

Trustworthiness is when the data collected is reliable, can be trusted, valid and bias free (Lincoln and Guba 1985: 219). In this study trustworthiness was ensured by credibility, transferability, conformability and dependability of the findings according to Lincoln and Guba (1985: 219).

- **Credibility (Truth value).**

Truth value asks whether the researcher has established the truth of the findings for the subjects or participants and the context in which the study will be undertaken (Lincoln & Guba 1985, 301). Credibility was ensured by prolonged engagement of the researcher with participant and by investing sufficient time with the participant during an interview. The researcher established rapport by negotiating entry to the household, gaining consent and getting to know each other and this enabled the participant to open up. Opening up is seen when the participant start to feel free to talk to the researcher and by increasing the duration of engagement (Lincoln & Guba, 1985: 301).

- **Transferability (Applicability).**

Transferability is the capacity to transfer the conclusion to another setting (Lincoln & Guba, 1985: 316). In this study thick description and verbatim quotations were presented so that researcher could judge the appropriateness of transferring the study to another setting. A dense description of the research method was given to enhance transferability. In this study applicability was ensured by doing purposive sampling of participants and dense description of the experiences of family members caring for TB patient at home. The researcher considered that the data found can be applicable to other setting

- **Dependability (Consistency).**

Dependability according to Lincoln & Guba (1985: 316) is the degree to which the same research that would yield the same results either by different researchers over a time or replicated with the same subjects in a similar context will be the same throughout. The researcher will adequately describe the research method in order to ensure consistency. Dependability was ensured by playing back what has been taped (Lincoln & Guba, 1985: 316). Coding and re-coding of the study findings was done. Findings were recorded by an independent coder and other postgraduate as well as doctoral students (Streubert & Carpenter, 1999: 29).

- **Conformability (Neutrality).**

Conformability refers to criterion for evaluating quality of data referring to objectivity or neutrality. In conformability the researcher's concern can be of ascertaining if the findings are grounded on data. Findings that appear to be more bizarre or unusual may be tracked back .The researcher judged if the findings are logical, quality of interpretations and the researcher also looked for the possibility of equally attractive alternatives by checking if negative evidence was taken and checked if there was any accommodation of negative examples (Lincoln & Gubal, 1985: 319). Conformability was ensured by also playing the tape back to verify with participants if what they said was what they meant. (Polit and Hungler 1993: 443).The researcher also achieved that by prolonged engagement with participants during in-depth interviews, reflection and verification. Multiple data sources was used to ensure that the researcher `s opinions are not reflected instead of participants `views.

2.11 ETHICAL CONSIDERATIONS

- **Permission to conduct the study**

Permission to conduct the study was sought from the following:

- ➢ University of Venda Ethics Committee (Annexure D)
- ➢ The Tshifulanani Tribal Authority (Annexure B).
- ➢ Family members.

Letters were written to the chief to ensure that the researcher accesses the village where family members were interviewed.

- **Informed consent**

Informed consent means that participants have adequate information regarding the research, comprehend the information and have the power of free choice, enabling them to consent voluntarily to participate in the research or decline participation. The participants were allowed to make informed decisions regarding participation in the study. The researcher explained the purpose of the study, the procedures that were involved, how confidentiality was maintained and the right to withdraw from participations. Written consent was sought from those who are able to write and verbal consent from those that cannot read and write. The researcher considered the participants` comprehension when explaining (Polit & Beck, 2006: 93). See Annexure A

- **Confidentiality and anonymity.**

The promise of confidentiality to the participant is a pledge that any information they provide will not be publicly reported or made accessible to parties not involved in the research (Polit & Beck, 2006: 95).

Participants were assured that the information revealed to the researcher will not be made known to the public nor will it be made available to the other people, This right may however, be waived when the information collected is made known through the research report (Polit & Beck, 2006: 95). The information revealed will be made known to the University of Venda in the form of article publication however anonymity will be maintained. Anonymity occurs when even the researcher cannot link a participant with his or her data. In this study the researcher ensured anonymity of participants by using the following measures.

- Names of families were not used;
- Subject's names were anonymous; and

All raw data was destroyed after completion of the report (Polit & Beck 2006: 95). Subjects freely decided to participate and justification for refusal was not asked for. Use of tape recorder was also agreed by participants.

- **Privacy**

The researcher ensured that the participant's privacy was maintained throughout the study. Privacy is the right of the individual to determine the time, extent and general circumstances under which personal information will be shared or withheld from others (Burns & Grove, 2001: 196). Participants` private information was not shared without the participant's knowledge or will. Participant's dignity, friendship, shame or employment was not lost. Participants were interviewed in their homes in a quiet place. Participants were informed that the tape, CD or cassettes used will be destroyed after the results have been published. Subjects freely decided to participate and justification for refusal was not asked for. Use of tape recorder was also agreed by participants.

2.11 SUMMARY

Description of research design and methods, data analysis, as well as measures to ensure trustworthiness was explained. Provision of detailed data analysis study findings and literature control will be in the third chapter.

CHAPTER THREE

3.1 INTRODUCTION

A discussion of the research methodology which is the research method and research design was discussed in the chapters. The objectives of this chapter were to analyse raw data and reduce to themes, categories and sub-categories, to reflect participants' experiences through quotations from what has been said and lastly to discuss findings against relevant literature. This chapter presents research findings according to themes, categories and subcategories. Analysis was done taking into consideration the theory of reasoned action and planned behavior. This theory view intention as the proximal determinant of behavior (Ajzen, 1991: 180).

Research questions for this study were the following

- What are the experiences of family members caring for TB patient at home?
- What are the caring behaviours of family members when caring for TB patients at home?
- What are the challenges that are faced by family members while caring for TB patients at home?

3.2 DESCRIPTION OF THE SAMPLE

In depth unstructured interviews were conducted on 13 family caregivers from one village in Vhembe District. Two of the participants were males with the age that ranges from 38 and 60 years. One male caregiver was also employed as a security officer who requested to only resume duty at night in order to care for the wife during the day. Another caregiver was an old man and was also a pensioner. The other 11 participants were females with ages that ranged between 35 - 60 years. Most of the caregivers were working as domestic servants and some were eventually retrenched due to absenteeism from work because of caring for TB patients. Similar views were raised in the study conducted in India on `socioeconomic consequences of TB in women` which concluded that most male patients expect their wives to care for them although infected wives rarely receive the care from their husbands. The study revealed that caring is mostly done by women instead of men in India (Stevens, 2009: 31). In this study the caregiver were either father husband sister aunt but mostly mothers or grandmothers to the patient. The next table shows the caregivers characteristics.

Table 3.1 Participants` characteristics

Sex	Caregiver's age	Relationship with the patient	Family type	Family size	Occupation of the family member
F	+60	mother	4 people in the family	Staying with the mother and the patient `s two sons	pensioner
F	_+60	mother	5 people in the family	Staying with the mother and other children	pensioner
F	48	daughter	4 people in the family	The caregiver , a daughter to the patient .Staying with her five children together with her mother who is ill	Retrenched due to absenteeism caring for the mother
F	60	grandmother	6 people in the family	The grand mother to the patient staying with the old man her other two children together with the grandson who is ill	pensioner
F	30	sister	4 people in the family	Sister to the patient staying with the father who is an old man with her other brothers and sisters together with brother who is ill	unemployed
F	25	aunt	5 people in the family	Aunt to the patient staying at home with her parents and her brother who has divorced as well as her brother son who is ill and was left by the mother after divorce. The aunt is not married	unemployed
F	38	husband	3 people in the family	Husband to the patient staying with his wife who is ill and his mother	Security officer
M	58	father	6 people in the family	The father to the patient staying with four other children including the one who is ill	pensioner
F	30	sister	6 people in the family	The patient`s sister staying in a family of six.	Retrenched domestic worker
F	40	mother	7	Mother to the patient with other five members of the family as well as the one who is ill patient	unemployed – do not have time to go and seek employment because of caring for the sick
F	58	mother	6 people in the family	The mother to the patient staying with other four family members , having children who are not married yet	pensioner
F	30	sister	2 people in the family	Parents are late , staying with younger sister who is ill	Retrenched domestic worker
F	62	mother	2family members	Staying with own child. No any other family member	pensioner

The table above indicates that some patients are taken care of by pensioners who are 60 years and above. This shows that some participants are experiencing difficulties when caring because they may be having their own physical ailments due to aging process. The aged `s coping methods may be affected. Lim & Zebrack (2004: 8) in the study on caring for family members with chronic physical illness a: critical review of caregiver literature identified that caregivers tend to suffer from physical ailments as coping responses during caring (Lim & Zebrack, 2004: 8). Difficulties experienced by aged carers was also noted by Ganguly, Chadda and Singh (2009: 99) in their study, the noted that some caregivers who are aged fail to do the work because of aging process. Three participants in this study were young adults who still need to socialise in the community but fail to do so because of caring. This is confirmed by Lim & Zebrack (2004: 10) also indicated that social life and life satisfaction are needed by any caregiver. This young adult's lack time to socialise with others in the community due to caring for the patient and their social life tend to be affected. (Lim & Zebrack, 2004: 10).

3.3 PRESENTATION OF RESULTS

Tables 3.2 show the themes, categories and sub-categories that emerged from the analysis of raw data. Presentation of the data is done according to findings from participants who were caring for a TB patient at home.

Table 3.2 Themes, categories and subcategories related to experiences of caregivers.

THEME	CATERGORY	SUBCATERGORIES
1.Participants experiences related to caring for the patient	-Participants were responsible for providing nourishing food to the patients	- Plant fruit and vegetables, buys groceries ,also cooks for the patient who is sick and also cleaning the equipment after use
		- -feeding of helpless patient
		- Provision of information regarding balanced diet to the patient and the family member
	-Participants were responsible attending to hygiene needs of the patient	- Bathing the patient who is unable to bath self ,cutting the patient's nails as well as buying the patient's toiletries like soap to help in bathing
		- Cleaning the environment as well as washing the patient's clothes especially the patient `s hut
	--Participants were responsible for assisting with administration of medication	- Giving support during administration of medicine
		- Ensure compliance to medication
		- DOT supporter visit and assist in administration of medication
		- Recording and monitoring of the use of medication in the chart provided
		- Participant accompanies

THEME	CATERGORY	SUBCATERGORIES
		- person to collect medication, equipment and for check-up
2.Challenges experienced by participant and expression of difficulties encountered	-Participants experienced psycho-social challenges when caring for TB patients	- participant experienced social isolation ,stigmatization and fear of the disease, HIV/AIDS and death
		- the participant experiences anxiety ,rejection because of the person's disease
		- the participant was sometimes demotivated to care due to the other difficulties encountered for example lack of knowledge of the disease
	- Participants experienced physical exhaustion due to overwork when caring for TB patients at home.	- the participant feels exhausted by caring for the patient as she cares for the patient alone and by waking up very early in the morning
		- some caregivers are exhausted because of their own ill health
	-Participants experienced lack of resources when caring for TB patients	- follow up for the equipment such gloves,soap,washing detergents,disposable nappies and towels as gloves
	Participants experienced financial constraints when caring for TB patients at home.	- difficulties of having no income to support the ill person , for transport, for buying food
		- caring restraining the family member from going to work

THEME	CATERGORIES	SUBCATERGORIES
Participants roles related to caring behavior	Participant`s experiences positive attitudes when caring for TB patients at home	- love - sympathy - counseling
	Participants experiences negative attitudes when caring for TB patients at home.	- Hatred - Impatient

3.4 DISCUSSION OF FINDINGS

Family members expressed different experiences related to caring for patients with TB at home. Two major themes emerged from the data with categories, subcategories. Appropriate quotes from raw data and literature substantiate the themes. The themes that emerged are the following:

- Participants' experiences related to caring for the TB patient at home.
- Participants' expression of difficulties encountered while caring for a patient with TB at home.
- Participant's roles related to caring behaviour.

3.4.1 Participants experiences related to caring for a person with TB at home

Results of the findings indicated the existence of categories under this theme which are the following: providing food to the patient, attending to patients hygienic needs and assisting with administration of medication. From the theory of Planned Behaviour, intention was viewed as a determinant of behavior. For family members to undertake their caring role they need to have an intention to care for a TB patient. Their intention is influenced by their attitudes which can either be positive or negative (Ajzen, 1991: 180). This is evident in the presented findings.

➤ Providing food for the patient

Providing food for the patient involves different aspects as explained by the care givers. Six sub-categories emerged from this category which are; planting fruit and vegetables, buying groceries, cooking for the patient, feeding of helpless patient, cleaning utensils after feeding and provision of information in relation to balanced diet. Almost all the participants expressed their roles related to caring for the patient as planting fruits and vegetables, buying groceries, cooking for the sick, cleaning utensils after feeding and giving information regarding balanced diet. Few care givers expressed their roles as including feeding of a helpless patient and encouraging them to eat. The following are some of the quotations from the informants. Not all participants planted fruits and vegetables.

Participant A said ***`I cook soft porridge from the powder that I had collected from the clinic every morning and give to the patient. The patient can feed herself nowadays but at first I used to feed her when she was still helpless and very ill`.***

Another participant M said ***'I always feel tired of caring for the patient because it is now six months and as I told you that I wake up very early in the morning and prepare warm water for the patient to bath and prepare food so that the patient can take medication in a full stomach.***

Another participant B said ***`You know it is frustrating because I don't work and it is difficult to assist the patient with proper food as one does not have money to buy with. I have even tried to plant vegetables and fruit in that small garden (pointing) as you can see but the place is small and sometimes the taps run dry as water is scarce but with fruit it is seasonal but in Venda fruits are plenty but they sometimes need to be bought. Hey!! Money is another problem (sigh)`.*** The researcher went to the garden and found that the plants were not watered and they were dry. This also emphasise lack of time from the carer.

Rowe, Makhubele, Hargreaves, Porter, Hausler and Pronyk (2005: 266) and Needham et al, (2004: 98) indicated in the studies how family members are expected to provide special food for patients which the caregiver cannot afford such as eggs, meat, milk, soft drink, oranges and vegetables. Rowe et al, (2005: 266) further concluded that TB patients should not take tablets on an empty stomach and this emphasises the need to provide food for the patients before medication by family members.

In addition Rowe et al, (2005: 266) and Chinwaza (2005: 104) also identified the importance of ensuring that patients taking TB and HIV medication have sufficient food to eat because drugs are known to work at its optimal in a full stomach. Chinwaza (2005: 104) also states that medication taken in a full stomach minimises side effects. This means that when insufficient food is taken side effects may occur; this is also a contributing factor for patients to default; furthermore most caregivers lack the nutritious food; and there was few patients who reported that they were assisted by relatives by giving them some food Chinwaza (2005: 104).

Chanda and Gosnell (2003: 6) also indicated in their study the need for good nutritional needs for TB patients and also emphasised the burden this creates for family members caring for TB patients at home. Evans and Thomas (2009:19) identified that lack of food in the family can lead to ill feeding and tension in the family and this affects the family member who is caring for the patient as the family member is aware that the health and nutrition of the TB patient is important in the healing process.

➢ Attending to hygienic needs of the patients

Almost all care givers indicated that they provide hygiene to the patient in one form or another. In providing hygiene to the patient the following subcategories emerged from the analyses which are: assisting with bathing patients who are very ills, Cutting patients nails and buying toiletries for the patient, cleaning the environment, fetching water for the patients who are staying alone as well as washing the patients clothes.

- Bathing and cutting of nails for the patients

This is one of the subcategory which emerged from the data. Most of the care givers mentioned that they assist patients who are very weak with bathing and they also buy toiletries for them when they cannot reach the shops. Some of the care givers indicated that most of the time the patients do not have money to buy these toiletries especially patients who are not receiving the grant so the care givers are forced to assist them with the hope of being refunded. The issue of buying toiletries for the patient was expressed as a challenge to most of the care givers as most of them indicated that they have to make means to get money from relatives in order to buy toiletries for them. It was also indicated that some patients were not keen to buy toiletries as they thought that it was a waste of money.

Participant C said **'*I used to wake up early in the morning at about 4 am to make fire outside and boil the water so that he can get warm water to bath. He was unable to bath himself and since he is my husband I am the one who was suppose to bathe him and I did not have a choice. Hey!! It was hard I mean like turning him alone to bath his back by the end of the day I was so tired. You know he recovered very fast and now he can bath himself''***

Macq, Solis, Martinez, Martiny and Dujardin, (2005:5) concluded in their study that family members caring for TB patients seem to have the most harmonious and most supportive behaviour to overcome hardship during illness. Family members are said to motivate the patient to stay healthy and show concern when other members of the family show reluctance to care for patients. This is in contrast to the study conducted by Bennstam, Strandmark and Diwan (2006:299) where family members were said to be creating a distance from patient suffering from TB as the one caring for the patient is not supported by other family members.

The researcher concluded that caregiver's are experiencing hardship when attending to the hygienic needs of patients because they have to turn and bath the patient alone which is tiring. The caregivers find doing everything for the patient too exhaustive, especially when other family members don't assist them.

Bathing the patient was identified by Chinwaza (2005:92) as the one causing physical strain to caregivers especially when assisting the patient during bathing or turning the patient alone and assisting with toileting. This caring was described as hard job and cause of physical strain (Chinwaza (2005:92,150).

Chinwaza (2005:149) indicated that caregivers were expected to assist the patient in bathing, keeping the body clean, cleaning the soiled clothes, bedding with soiled linen, soiled with faeces and menstrual blood. Other caregivers had challenge of washing without soap due to lack of money to buy the soap.

- Cleaning the environment especially the hut as well as washing the patient's clothes

Participants described how they sometimes assist patient with cleaning of the environment and washing the patients clothing. This was said to be most common when the patient is still very weak and fails to care for self. This was said to be tiring as care givers had some home chores that they are required to fulfill. Most of the caring behavior described by the care giver included cleaning of patient's crockery, washing patient's clothes and cleaning the environment especially the patient's hut. Water was also said to be the basic need to human life and this need was sometime not met as some givers described the problem of shortage of water in the villages as being problematic. They described how they are required to fetch water for the patients for the purpose of washing and bathing. They also complained about the distances from the households to the tap which is far most of the time. When water does not come out from the taps they said that they are forced to buy from people with bore holes.

Participant B again described her feeling of cleaning the environment especially the patient's hut as well as washing the patient's clothes as follows:

'When my son was from hospital he was weak and could not do anything for himself so I used to wash and iron his clothes. The hut where he was sleeping also needed to be taken care of as he could not do it himself so i also cleaned the environment as well as his hut where he sleeps'

Participant D said ***'Yooo!! It is very difficult you know one has to fetch water for patients from the tap which sometimes is far and sometimes the water does not come out and we have to buy from people who have boreholes in their yards hey!!! This is tiring'***

Cleanliness of the patient's clothes and the environment is usually done by all members of the family in most families, but in these situation family members caring for the patient should ensure that the environment is clean and free from dust. Ngang, Ntanganira, Kalk, Wolter and Ecks, (2007:1110) identified that factors contributing to spread of TB are polluted environment and overcrowding. The family member as a caregiver felt the need for cleaning the environment. Mazonde (1998:9) concluded in the study that dusty work or mine work is named as the cause of the disease.

The work of cleaning the patient's environment as well as washing the patient's clothes was also found to be tiring for the caregiver because most members of the family do not assist as they fear contracting the disease. The caregiver does this as is aware that TB is caused by droplet infection and the environment should be clean every day. Therefore by the end of six to eight months the caregiver would be suffering from exhaustion and fatigue.

- Assist patient with administration of medication

The care givers also described their role as that of assisting patients with taking of prescribed treatment. The participants explained the need for taking prescribed treatment for the recommended duration by patients as being important in facilitating their recovery. The care givers explained their role in the success of this treatment as that of ensuring that treatment is recorded and accompanying patient to the clinic for follow up treatment. The caregiver gives medication, records, and monitors the patient when taking the medication. This experience assists in patient's recovery. The researcher realized that family members as caregivers are coming across difficulties as one should know what to monitor such as side effects, how to record and to adhere to time when giving medication .

Liefooghe, Baliddawa, Kipruto, Vermeire and Munynck (1997:815) described treatments as rough, agonizing and even devastating to the patient hence the need to have family members supervising taking of treatment by the patient. The following sub-categories emerged from this category namely: giving support during administration of medicine by ensuring compliance to medication, DOT supporter visit and assist in administration of medication , recording and monitoring of the use of medication in the chart provided and the participant` accompanies person to collect medication , equipment and for check-up.

- Giving support during administration of medicine by ensuring compliance to medication

Caregivers explained the support that they give to patients taking TB treatment as being very important to ensure compliance to treatment. It was also indicated that for those patients that are being supported by DOTS there is a need for a DOTS supporter to wake up early and go to the patients home so that the patients can take treatment during their presence and recording be done by them.

Participant F said **‘*My grandson started taking treatment last year, I wake up early in the morning to prepare soft porridge and take him to the people who help him to take the treatment. I feel good when taking care of my grandson.***

Participants who were unable to give the treatment to the patient take responsibilities of accompanying the patient to the DOT supporter every morning after giving the patient the food. Some DOT supporters stay far away from the patient`s home.

Participant G ***' I used to go to hospital with him for check up'*** Accompaniment of the patient to the hospital for follow-up and treatment should be done compulsory because the phases of treatment taking changes as the patient continues with the treatment. Department of health in Limpopo(2008) announced that Intensive phase for the medication is given for the first two months .the patient is expected to take four to five tablets depending on body weight everyday. Emphasis on completion of treatment was mentioned in order to reduce the risk of drug resistant strains of the disease. Medication should be taken for seven days instead of five days (DoH Limpopo province,2008). The second phase is continuation phase which last for the next four months. Two to three tablets are taken daily depending again on body weight.

Sagbakken, Frich and Bjune (2008: 9) reported that there are factors which causes interruption of TB treatment and affect compliance. The factors that were identified were illness of a relative or when the relative have to attend the funeral. Lack of family support during administration of medication has also been found to be the major cause of interruption thus affecting compliance to treatment (Sagbakken, Frich and Bjune, 2008:9). Sagbakken et al (2008 : 9) also indicated that dynamics of social support mechanisms in the family causes practical changes related to completion of the first stage of treatment which is the intensive phase and that social support by the family members is also withdrawn when the patient is having prolonged diseases.

The study therefore indicated that social support structures beyond relatives seems to be important in order to ensure compliance to treatment such as formation of TB clubs with the aim of encourages each other to take the treatment the full course of treatment. Chanda and Gosnell (2006:6) also indicated that family members sometimes lose interest in

Participant H said ***'there is a DOT supporter who comes every morning to see to it that the patient takes treatment and record in the book. You see she is helping because I cannot read or write so I would not be able to do what she is doing I think she is doing a great job'.***

Travis, Bethea and Winn (2000: 412) reported that when family caregivers assist the patients in medication administration there are hassles which occur when assisting the patient such as scheduling logistics, whereby giving the medication on time is a problem. Giving other family members the responsibility and multiple prescriptions of the patient together with the caregivers` own medication is also a problem which affects compliance of the patient to treatment (Travis, Bethea & Winn, 2000:412). The other hassle which affect compliance is administration procedures which can be: administering painful, embarrassing or noxious medication and making decisions at night or during the holidays or weekends and whether to reduce the dose or hold the dose together under certain circumstances. In addition the safety issues were to be looked upon by the family caregiver where adverse or toxic effects should be monitored as compliance may be affected (Travis, et al, 2000: 412). Travis et al (2000:417) also emphasised that in safety issues the caregiver should remain constantly vigilant. Labeling of medication prescribed and changes made by the physician causes major distress to the caregiver when there are changes in the drug which was used, when and how to give it. Recording and monitoring of the use of medication in the chart provided and accompanying the patient to collect medication, equipment and for check-up was sometimes a problem for caregivers.

3.5.1 THEME TWO - Participant `s expression of difficulties encountered when caring for TB patient at home.

All participants expressed in some way the difficulties encountered during caring. Four categories were identified from this major theme namely:

psychological problem expressed during caring, physical exhaustion due to overwork, equipment resources and financial constraints experienced by the caregiver.

- Psychological problem experienced during caring.

Three subcategories were identified namely: participants experienced social isolation, stigmatization, and fear of the diseases, HIV/AIDS and death, the participant experiences anxiety, rejection in relation to the person\` disease, the participant was sometimes demotivated to care due to the other difficulties encountered for example lack of knowledge of the disease.

- Participant experiences social isolation, stigmatization, and fear of the disease, HIV/AIDS and death.

Some of the care givers expressed fear of contracting HIV and AIDS as they thought that people with TB are also HIV positive and this was a problem to caregivers. In contrast some caregivers felt that they need to be given equipments to protect themselves and more information on how to care for these patients. It was also indicated that the community always label these patients as HIV positive and isolate them. This was said to be stressful to both the patients and the caregivers.

Participant F said **'*Some people even my neighbours think that my child has AIDS. Even the relatives do not come and visit my family anymore because of this disease. I feel rejected as I am out of contact with others because of this isolation. I no longer attend funerals because of caring for my child.***

Participant J Oh! The worst thing is that I fear that the disease will infect me and I may die'

The issue of stigmatisation was reported by Shetty et al, (2004:81); Morankar and Suryawansh, (2000:3) as a problem expressed by family members as having the effect in caring for TB patients. Some family members are influenced as the emotional supporters of the patient. Some are ostracised by the community for staying with TB patient. Bennstam, Strandmark, & Diwan, (2006:299) reported that social isolation affects the family members on how to act in the community and where they can spend their time. Social relationship of the family member and the community is also affected. Some husband and wife abandon each other and not take care of each other. Bennstam et al, (2006: 299) and Edington et al, (2002:1078) in their findings indicated that respondents fear contracting the disease during sexual intercourse and husband and wife abandon each other. .Fear of sharing food with the sufferer by the carer in the family was also said to be socially disruptive.

The caregiver when not being accepted by family members seems to be in a dilemma and having psychological stress due to fear of the disease, rejection and isolation. The caregiver feels ostracised by family members. It is very painful to be ostracised by your own family just like the husband abandoning his wife .because of caring for the patient wit TB.

- Participants expressed de-motivation due to lack of knowledge and difficulties encountered.

Most participants indicated the feeling of being demotivated to continue with caring due to lack of knowledge, lack of support from family members and many other difficulties they encounter during caring.

Participant E *'I sometimes feel tired of caring for the patient because there are still many months left to care for the patient. Ohhoo!!!!!!!!!!!!! Six months is too much and the sister at the clinic also told me that the patient such as this one can be treated for a period of six to eight months oh!!!!!!!! It is so tiring. I feel so tired, nobody comes and give*

me some advice or some training on how to cope or to continue with caring in such a long period of time`.

Travis et al, (2000: 412) emphasised the need of ongoing support of family caregivers preparing them for the shared long term responsibility and accountability to assume complex care such as medication administration. The need for education on recognising the classic adverse drug effects printed in the literature and understanding the myriad atypical presentation that they may see over the long term is solely needed.

- Equipment and financial constraints experienced by the caregiver.

Informants described the lack of equipment that they face on the daily basis. It was indicated that gloves are not easily available as the clinics frequently run out of stock. It was also mentioned by other informants that the clinic is far and they have to use the taxi which is expensive and most of the time they do not have money. Caregivers also experience financial problems where the patient is not receiving a grant as they most often buy food for the patient so that he/she can take medication.

Participant J said ***'At times I pull it hard when caring for my mother because she soils herself but nowadays she no longer soils herself. I pull hard because when I go toe the clinic to collect gloves and nappies I sometimes find them out of stock. I had to improvise by using plastics which I buy in the Indian shop nearby. The plastics are 30cents each yaa!!!!!!!!!!!!!!! Life is tough sometimes. She is my mother I cannot neglect her and I am her only daughter`.***

Another participant K said '***I do not work , nobody support the family we use to get some few from the social worker, ever since my husband went to Johannesburg he does not sent us money at home and it is***

long that he does not come back . My daughter is not married but she has the child who is not getting the grant because the mother does not have the I.D Book I used to look for piece jobs but nowadays I am taking care of my daughter I cannot look for the work. My other problem is the money to go for check-up. Last month the sister at the clinic assisted me by borrowing me her money so that we go to the hospital by bus'.

Participants showed the financial strains associated with caring for the patient. Some participants do not have good source of income have difficulties in curtailing everyday necessities in the family as well as caring for the patient.

According to Needham, Bowman, Foster, Faussett, (2004: 98) some families face poverty and the financial constraints which then affect care given to patients at home. Needham et al, (2004:98) also describes the problem of unrecognised costs that may be faced by caregivers. The costs for special food of which the family could not afford such as eggs, meat, milk, soft drinks , oranges and vegetables. The caregivers can also be absent from work due to illness of the patient and care seeking and this also add to costs.

Eastwood and Hill, (2004:73) added that the family members living with TB patient experience financial difficulties as the husband may pay fees for the wife to seek health care. Fares may be paid by the family members if one should visit the health services. Financial constraints will be there as there may be difficulty in getting the money for transport and food. In South Africa financial costs related to caring for patients has also been reported which sometimes involve money to go to the clinic and money to buy food which affects caring (Rowe, Makhubele, Hargreaves, Porter, Haussler & Pronuk, 2005:265-266; Ganguly, chadda & Singh, 2009: 102).

On going support from other family members seems to be the best solution but the long term responsibility and long term accountability can be sustained by the caregiver who is being supported by other family members continuously (Lim & Zebrack,2004: 12).

- Physical exhaustion due to overwork

Most of the informants expressed how they become exhausted daily by the activities that they do when caring for the TB patient. Although there was an expression of exhaustion and overwork almost all participants felt that they were providing an essential service to their loved one and this gave them a sense of satisfaction. Overwork was also cited as another problem facing caregivers as most of the time other family members were not willing to assist with caring for the sick person.

- Participants feeling of exhaustion while caring for the patient

Participant L said that '***I cannot continue like this, this is killing me***'. The participant experiences physical and psychological exhaustion when caring fot the patient.

Participant G ` *I feel tired about this work. What makes things worse is because nobody is willing to assist me and other family members also feel that I must also care for them'.*

Chinwaza (2005:103) identified that some caregivers get support from friends and relatives whereas other's get support with limitations. Other caregivers experience no support at all. Visitors rarely come and pay a visit to the caregivers .Some caregivers are not visited at all. This affects the caregiver socially and psychologically (Chinwaza, 2005:103).

Ehlers, (2005: 657) recommended that caregivers need physical, social and emotional support from the community and friends because without the support caregivers can suffer from physical, emotional fatigue and burnout.

In addition Thomas (2006:18) also indicated how caregivers experience physical strain and emotional consequences when caring for patients and this was said to lead to inability to provide adequately for the patient. The caregivers also become fatigue by caring for the patient for a long time and some caregivers do not eat or eat less when the patient is seriously ill (Thomas 2006;16; Campbell, Nair, Maimane, Sibiya, 2007: 529).

Caregivers showed caring fatigue due to the duty they perform daily and this is affecting their social life, physical and emotional life. Some caregivers end up being affected mentally.

3.5.2 THEME THREE

Participant's roles related to caring behavior

Positive and negative attitudes were experienced by most participants during caring. These attitudes affected the caring behavior given by the participant to the TB patient. Positive behavior was seen from the participant when an experience of love, sympathy was shown by other members of the family to the participant. Five participants indicated this positive behavior while caring for the patient at home. The following are some of the quotations from the informants.

Participant H and E one of them said ***`I sometimes feel tired while caring for my child and all of a sudden a telephone call will ring, two children who are away from home always phone me, encouraging me to continue caring for him even if I did not tell them anything. They always tell me that they love me and if it was not because of my***

presence in the family things were going to be bad to their younger brother whom I am caring. Some relatives keep on paying me a visit and encourage me to continue caring for my child. Most of the relatives show sympathy to me. Some also booked me to the psychologist for counseling as they realized that I am sometimes down. Hmmmm…….i appreciated that and it helped me oh thank God for that.

Some participants also showed that they had negative attitudes that they are experiencing while caring for the patient at home. Three participants indicated that they experienced negative attitudes such as hatred. Few showed inpatient to caring. Participants started hating the patients because patients also hate participants in return. Patients started hating the participant because of the tablets that are to be taken by them. One informant said:

Participant A `***When i start giving him the treatment, he sometimes refuses. He always tells me that this many tablets he is tired about the many tablets. He will say that he hates me nowadays because of that. I do not care what he says, he is my son I cannot stop giving him the treatment. He is my son. I will take care of him until he is cured. He always shouted saying mummy hate you, I hate what you are doing to me`***

Participants experienced hatred towards caring. Hatred towards caring can be due to the manipulative patient. Hateful patients can stimulate series of negative feeling in most caregivers. Hateful feelings require less effort than bearing them. The participant is expected to set limits towards the patient to limit dependency.

Groves (1978:887) indicated in the study on taking care of the hateful patient that participants end up developing hatred while caring for a hateful patient. The researcher also identified that there are classes of patients who can provoke one to develop hatred towards caring Groves (1978:887). Different classes of hateful patients are those that request for reassurance to repeated cries for explanation, love and all forms of attention imaginable, those that are called entitled demanders because they use intimidation, devaluation and guilt induction taking place and put the carer in the role of inexhaustible supply depot.

The patient may try to control the carer. Others use their symptoms as an admission ticket to a relationship that is controlled by presence of symptoms. Lastly is when the patient is having self destructive deniers which is seen when the patient displays unconsciously self murderous behaviours such as continued drinking. All this classes affect the caregiver and the caregiver end developing the hate towards the patient also (Groves 1978:887).

The other two participants C and J who also showed the negative behaviour of caring one said: `***Firstly I felt impatient when she refuses to take the treatment for TB. She said that I should leave her alone. She will be ok even if she has stopped the treatment. I sometimes shouted at her because of feeling impatient to her. The worse day that made me feel very impatient was when I found her asleep snoring after explaining to her to prepare herself so that we can go to the clinic for check-up.***

Two participants showed impatience when caring for the TB patients. Participants showed that the action of the patients affect them that they become impatient and also become angry. Heald (2005: 26) also showed in his study that the disease that the family member can suffer from can project the hatred among family members and not just the infected person. Chinwaza (2005:135) in the study on experiences of caregivers of AIDS patients in Malawi showed that the caregivers can also be tired of caring for the patient and then become impatient because of that.

Some caregivers showed sympathy indicating (Chinwaza, 2005:131). that they had the positive attitude towards caring for the TB patient at home. Sympathy is when one is feeling pity for one another.(C

One of the Four participants F, I,K,M said who mentioned one and the same information said ` I am working too much looking after you my son who is suffering from TB and also caring for my mother who is disabled because of arthritis in old age. I cook for both of you, wash your clothes, as well as cleaning the environment. The patient cried when I told her that. The other informant sympathizing with the caregiver said ` my son don't worry God is going to heal you. Mommy where did you get all this support you are giving me, and I said I always go searching around from relatives to support us. I feel sorry for you my son. I want you to get the best diet to be healthy.

Some caregivers indicated that some patients showed sympathy to them because of the workload they are doing. Chinwaza (2005:116) stated that the caregivers sympathised with the patient so that they get the care they deserve meanwhile the patients themselves also sympathising with carergivers that the work they are doing is physically, emotionally, psychologically and financially exhausting to the caregiver.In some instances patients sympathise for the caregivers indicating that caregivers are pulling hard for their sake.

Most participants showed that the positive attitude of love was the most important to be considered by each participant.

One informant said ***Caring for my mother allows me to show her how much she matters to me. It is my chance to give her something back***

to her. Sometimes you love someone and do not tell that person. I love my mother. No one can replace her in the whole world. I think I have to spend the time I have with my mother, I have to care for her needs as my mother. I am glad to have been given this chance by God`

Chinwaza (2005:72) on experiences of caregivers caring for AIDS patients in Malawi showed that though participants had to love the patients they felt that it is their responsibility to love them and care for them even if they do not wish to do that.

3.3 CONCLUDING REMARKS

Data from participants indicate that family members as caregivers have experiences showing that there is a need for education to the caregiver to assist them in monitoring of side effects, administration of medication and the hassles of medication giving , caring roles to be performed by the caregiver. The issue of lack of finances seems to be one of the problems as equipment, food, and other resources are needed everyday. This should be attended to urgently.

Social, physical, and emotional support that the caregiver is not given may affect the caregiver in such a way that may feel demotivated to care and burnout can set in.

3.4 SUMMARY

This chapter focused on data analysis, literature control and discussion of findings. Conclusion can be drawn from data collected on family members as they have different experiences some of which are leaving them in dilemma which is not attended by anybody such as the need for support, fear of the disease which is a world wide problem HIV/AIDS and TB.

Most literatures reviewed indicated some similar experiences.

CHAPTER FOUR

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY.

4.1 INTRODUCTION

Descriptions of findings were discussed in chapter three. This chapter focuses on evaluation, conclusions, recommendations, limitations as well as a brief overview of this study which investigated the experiences of family members caring for TB patient at home Evaluation against purpose and objectives of the study as set out in chapter one was discussed. Recommendations on nursing practice, policy makers and on research were provided. Conclusions of the study were based on findings and limitations of the study.

4.2 STUDY OVERVIEW

The purpose of this study was to explore and describe experiences of family members in caring for patients with TB at home. Experiences were explored and described against relevant literature.

The objectives of this study as set in chapter one were also evaluated.

Objectives of the study were to:

- Explore the experiences of family members caring for TB patient at home;
- Identify and describe the caring behaviour of family members when caring for TB patients at home; and
- Identify and describe the challenges faced by family members while caring for TB patients at home.

In objective one and two the exploration, identifying and description of caring behaviour of family members caring for TB patients at home was done. Exploration and description of challenges faced by family members while caring for TB patient at home was met also. The first and second objectives were met during data collection when experiences by family members were explored. These two objectives were met through in-depth individual interviews. One central question directed the structure of the Interviews.

The research design for this study was qualitative, phenomenological, exploratory, descriptive and contextual in nature. Research methods described were the following: the setting, sampling, sampling method, sampling criteria and sample size. The researcher chose the following villages from Vhembe district based on TB statistics. In this study the population consisted of all family members who were caring for TB patient at home.

One or two members were chosen from each family and the sample size was determined by data saturation. The researcher chose between 13 family members and saturation of data occurred on the 13th subject. Experiences were tape recorded and transcribed verbatim for analysis. The researcher also had time to capture speech pattern, emphasis, ensured competencies and reviewed interview frequently to glean further understanding. Data was analyzed qualitatively using Tesch`s Open Coding method (Creswell, 1990:145) that is Useful eight steps in analysis process as indicated by Techs. (Applicability), conformability (neutrality) and dependability of the findings according to Lincoln and Guba. The researcher strived or tried to consider ethical measures throughout the research.

Findings of the study revealed that

- Participant's explanation of roles related to caring for a person with TB at home and results of the findings indicated the existence of categories under this theme which are the following: providing food to the patient, attending to patients hygienic needs and assisting with administration of medication.
- Participant `s expression of difficulties encountered when caring for TB patient at home.

All participants expressed in some way the difficulties encountered during caring. Participants reported the difficulties in various ways indicating that they are in hardship and are just enduring the difficulties. Four categories were identified from this major theme namely: psychological problem expressed during caring, physical exhaustion due to overwork, equipment, resources and financial constraints experienced by the caregiver.

Based on these results, recommendations can be made because the one central question of the study has been answered and objectives and the purpose of the study have been achieved

Objective three and four will be met in this chapter where in recommendations that will assist FM in dealing with challenges that they meet while caring for TB patients at home will be drawn.

4.3 RECOMMENDATIONS

Recommendations were drawn to ensure that TB patients were cared for and are taking treatment until it is finished.

4.3.1 Recommendations regarding roles related to caring for TB patient at home.

Results of the study indicated that family members caring for TB patient have roles of caring that they accomplish such as providing food to the patient, bathing the patient, cooking for the patient, cleaning the patient's environment, buying groceries and assisting in administration of medications considering compliance , follow-up to the clinic or hospital as well as assisting in monitoring adverse effects and recording, Evans et al (2009:6) indicated that caring include everything that one does to maintain, continue and repair the bodies and that one seek to interweave in a life sustaining web and it involves taking the concern. According to The Theory of Reasoned Action, for the family member to care for the patient, the family member must have the intention and motivation to do so. The family member must be motivated to do so he/she may have negative or positive attitudes. The intention to care for the patient comes from within the individual and the individual plans to do that. (Ajzen, 2005: 180).

There are four phases of caring process which are as follows: caring about, taking care of, care giving and care seeking. Four ethical values also emerged from this phases which are attentiveness to the needs of others, responsibility, competence to good care and availability of resources (Orem, 2001:26).

Recommendations regarding providing food, attending to hygiene needs and assisting in administration of medication.

- Members of families who are living with TB patient should undergo the training for some days before the patient is discharged home in order to be able to cope with the roles and difficulties encountered during caring for the period of six to eight months. This will ensure patient's` compliance to treatment and will prevent the adverse effects that may be due to failure to complete treatment such as MDR and XDR.
- Financial constraints should be curbed by temporary grant of the family member because the roles which were played by the family member who is now a caregiver such as being a

breadwinner should not stop but still continue in the family. Other members of the family who were cared for by the family member should not be stranded or remain uncared for the period of the patients illness.

- At least one main caregiver in the family should be given the special grant which should be temporary for the period of the patient's treatment taking. The family member as a caregiver has his or her own needs to be met and all are no longer done because of resuming duty because of caring for the patient. Lack of finances in the family added to the difficulties.
- Remuneration of comprehensive community care workers such as DOTS supporters should be standardised so that there should be enough in order to assist the family members in treatment supervision at home.
- Incentives should be given to caregivers as motivation such as food, financial incentives which be for transport as well as letters as reminders.
- Crash courses on nutrition done by counselors at clinics should be provided to family members caring for the patient because most of family members lack the knowledge on how to prepare the required nutritious diet for the TB patient as well as the knowledge on what to buy for the patient .The importance of balanced diet, the importance of taking the treatment before meals and what to do if the patient does not want to take the necessary food.
- Training of more DOTS supporters in the area where there are few or where there are no DOTS supporters so that they will assist families who have illiterate caregivers who cannot read and write. DOT supporters will assist in administration of medication recording and ensuring compliance.

- DOTS supporters to be as close to patients `s homes or their workplace if possible.
- Family DOTS supporters to be encouraged.
- Consultation with the department of Water Affairs to provide tap waters in areas where there are no taps and where there is shortage of water.

4.3.2Recommendation related to participant expression of difficulties encountered when caring for TB patient at home.

People caring for TB patients at home were found to be having multiple problems like mental exhaustion, financial constraints, isolation, and stigmatization, fear of the disease and rejection by family members and the community members.

Family members giving care to the patient feel discriminated by the society and reluctant to care for the patient. The patient is affected psychologically if the patient notices that family members are reluctant to give care as Jaramillo cited in Peltzer, Onya, Seoka, Tladi, Malema (2000:63).

Members of the family experience isolation while caring for a person with TB. This isolation may lead to challenges on family member, as they may need to change what they used to do, how they used to act and where they used to spend their time. Isolation of the family can also influence the family members to isolate the patient in return and this may affect caring that is given to the patient. Social relationship between the family members caring for a person with TB and the community was said to be affected. It was also identified that husband or wife may abandon their spouse but this may not happen in all families, this mean that the husband may not take care of the wife and visa versa. Bennstam, Strandmark & Diwan, (2006:306).

The following recommendations may assist in resolving these difficulties

- There should be counseling sessions that family member who is a caregiver as well as the other members of the family staying with the patient in order for them to be able to understand the disease. They should undergo this counseling during the period of caring for the patient in order to get rid of the problems that can erupt during the course of the patient's treatment taking. This will lessen the caregiver's work as they will assist each other. At least one session per month can be beneficial. Counseling should also include the other members of the family in order to understand the disease and accept the patient. This will also assist in relieving the caregiver during his or her absence. Physical exhaustion will be overcomed.

- Counseling sessions for the patient should also be provided because some problems starts from patient's themselves for example when the patient decided to stop taking the treatment because the patient is tired or because patient is thinking that he or she is a burden to the caregiver in the family and another example is when the patient decided to stop taking the treatment because of shortage of treatment so pharmacists are encouraged to order enough supplies so that there should not be shortage as that will discourage the FM in caring as the caregiver may end up also infecting himself such as when there is shortage of gloves. FM to be given enough supplies every time when visiting the health provider for follow up. At least one session per month may be beneficial.

- Drug supply management to be strengthened to prevent shortage of stock.

4.3.3 Recommendations regarding nursing practice

There are many updates in TB research for example there is a proposal that TB /HIV and AIDS should be integrated and be treated in one roof or one ceiling as indicated by in the 2nd International TB conference held in June 2010 in Durban. It is important for all nurses to be aware that these diseases are treated comprehensively. The following recommendations will assist:

- In Nursing Education the curriculum to include TB and changes in management of TB should be known by tutors and students immediately.
- Workshops for TB should be attended by all nurses in order to update them.

4.3.4 Recommendations regarding policy makers

Results from this study also indicate that family members caring for TB patients at home are experiencing problems of finance as the carers The problem is seen when the was lack of food in the family where the family lacks the food to give the patient. The community is encouraged to have community gardens, gardens at home and community soup kitchens.

- The National TB Directorate should voice the problem of financial constraints when caring for the TB patient. This should be known to the Finance minister during planning for the budget of the new financial year that TB caregivers need to be compensated and all patients need to get the reasonable grant. All DOT supporters should get remuneration.

- TB should be in the number one list of the MDG Goals and in the Strategic plan and should be given priority as a twin for HIV/AIDS.
- Posts for TB counselors should be provided and they should be stationed in every clinic.

4.3.5 Recommendations regarding research

Community members are encouraged to participate in research and develop monitoring and evaluating systems to improve care of TB patients. Research topics should include TB prevention, treatment and care as they are important areas of disease control especially in most South African Provinces.

Research is encouraged because new vaccines, diagnostics and new drugs are needed. Research on short treatment schedule should be undertaken as patients and family members become tired of supervising treatment. It is also important for the research to be undertaken as other studies also revealed that there is a need for someone to encourage the TB patient to take all his or her treatment as a treatment supporter.

- Members of the public are encouraged to undertake research on all TB topics related to the patient and the caregiver.
- The government should provide enough funds for Operational research.
- Scholarship should be provided in order for people to research on TB.

4.4 LIMITATION OF THE STUDY

The study is limited at Vhembe district only and it was done on members of the family caring for TB patients only. The researcher had the difficulty of accessing enough participants in one village which led the researcher to collect data in four villages. Data saturation was not reached until the data was collected in the fourth village. The issue of opening up was difficult at first but all participants opened up and described all experiences freely.

4.5 CONCLUSION

Experiences of family members caring for TB patient at home were explored in this study. Family members expressed the roles and challenges or difficulties they encountered when caring for TB patients at home. The study revealed that family members are encountering difficulties that can also affect treatment completion by the TB patient at home. It was discovered that caregivers also have needs that should be met. Family members `s roles and difficulties should be urgently addressed in order for the TB patient to receive the best care at home. Family members as caregivers need support as recommended for example financial support, psychological support and others. They also need education and counseling when caring for the patient at home.

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ANNEXURE A

INFORMED CONSENT

I am a Masters student at the University OF Venda. I am presently engaged in a research study entitled “The experiences of family members in caring for patients with tuberculosis at Thulamela Municipality in Vhembe District, in Limpopo Province”.

The study is conducted under the supervision of Professor L. B Khosa and Dr R Lebese of the Department of Advanced Nursing Science.

The objectives of the study are to explore and describe the experiences of family members in caring for TB patients at home and to develop recommendations that may improve the caring of TB patients.

I need to conduct interviews with family members who care for the patients. The interviews will be conducted within 30-45 minutes, and will be audio taped for verification of the findings by my supervisors and an independent coder.

The name and dignity of each participant will be preserved by observing the following ethical standards throughout the research process:

- Voluntary participation and freedom to withdraw without a penalty;
- Informed consent;
- Names of the participants and their community will not be mentioned during discussions;
- Raw material will be kept under lock and key to ensure confidentiality;
- Information related to the interviews will only be accessible to my supervisors and the independent coder;

- Field notes will be destroyed and audio tapes will be erased as soon as possible;
- The summary of the research will be made available to the participant if they wish.

Your participation in this study will benefit other family members when caring for TB patients.

I………………………………………………hereby understand the content of this research after the researcher's explanations.

Thank you,
SUKUMANI TSHAVHUYO JOYCE
Researcher.

Signature of the participant ……………………………………

Signature of the researcher ……………………………………

Date: 15 March 2010

ANNEXURE B

REQUEST FOR INFORMED CONSENT FROM LOCAL AUTHORITY

I am a Master's student at this University of Venda. I am presently engaged in a research study entitled "THE EXPERIENCES OF FAMILY MEMBERS IN CARING FOR PATIENTS WITH TUBERCULOSIS AT THULAMELA MUNICIPALITY IN VHEMBE DISTRICT, LIMPOPO PROVINCE".

The study is conducted under the supervision of Professor L. B Khosa and Dr R Lebese of the Department of Advanced Nursing Science.

The objectives of the study are to explore and describe the experiences of family members in caring for TB patients at home and to develop recommendations that may improve the caring of TB patients.

I need to conduct interviews with family members who care for the patient. The interviews will be conducted within 30-45 minutes, and will be audio taped for verification of the findings by my supervisors and an independent coder.

The name and dignity of each participant will be preserved by observing the following ethical standards throughout the research process:

- Voluntary participation and freedom to withdraw without a penalty;
- Informed consent;
- Names of the participants and their community will not be mentioned during discussions;
- Raw material will be kept under lock and key to ensure confidentiality;
- Information related to the interviews will only be accessible to my supervisors and the independent coder;

- Field notes will be destroyed and audio tapes will be erased as soon as possible; and
- The summary of the research will be made available if the participants they so wish.

Your permission to conduct this study in your municipality will benefit other family members when caring for TB patients.

I…………………………………………hereby understand the content of this research after the researcher's explanations.

Thank you,
SUKUMANI TSHAVHUYO JOYCE
Researcher.

Signature of the member of local authority ……………………………
Signature of the researcher ……………………………………………
Date 15 March 2010

ANNEXURE C

INTERVIEW TRANSCRIPT: TRANSLATED FROM TSHIVENDA TO ENGLISH TO DEMONSTRATE HOW THE EXPERIENCES OF FAMILY MEMBERS WERE ANALYSED

KEY: Researcher = R
Participant = p

R: Good morning

P: Good morning

R: What are your experiences in caring for tuberculosis patient at home?

P: I cook soft porridge from the powder that I had collected from the clinic every morning and give to the patient. The patient can feed herself nowadays but at first I used to feed her when she was still helpless and very ill. You know it is frustrating because I don't work and it is difficult to assist the patient with proper food as one does not have money to buy with. I have even tried to plant. vegetables and fruit in that small garden (pointing) as you can see by the place is small and sometimes the taps run dry as water is scarce but with fruit it is seasonal and in Venda fruits are plenty and they sometimes need to be bought. Hey!! Money is another problem (sigh). I need to be there every time she looks better now and was very thin, the medication has helped her even her appetite has improved'

R: HMM tell me more

P: I do not work , nobody support the family , we used to get some food from the social worker, ever since my husband went to Johannesburg he does not sent us money at home and it is long that he does not come back . My daughter is not married but she has the child who is not getting the grant because the mother does not have the I.D Book. I used to look for piece jobs but nowadays I am taking care of my daughter I cannot look for the work. My other problem is the money to go for check-up. Last month the sister at the clinic assisted me by borrowing me her money so that we go to the hospital by bus'.

R : tell me more about the issue of money

P: Money is a very big problem in my family I, it makes me pull hard when caring for this patient because I am the breadwinner and he is no longer coming back from Johannesburg ***(O liwa nga makhada tshikhuwani ha tsha vhuya mukalaha wanga , zwi khou vhavha ngoho)*** He is supporting other women in Johannesburg and he no longer comes back . I used to work as a domestic servant to earn a living but now I am retrenched due to absenteeism from work caring for the patient. ***(Zwiliwa zwothe ndi tou pala ngoho zwi a konda hafha mudini uri na mulwadze ale)*** I make plans in order to get food in the house even for the patient to get something to eat.

R : and what else

P: I also feel tired of doing the follow-up when I take the patient for check-up and for collection of equipment like gloves, disposable nappies and disinfectants. I feel bored when nurses do not quickly attend to me and when the equipment is out of stock .at the clinic. Follow-up date worries me a lot when it arrives and find myself without a cent to pay for the transport to the hospital or to the clinic as this patient is weak and cannot travel long distances. I had to borrow money from people of which returning it back is a problem to me`( **ha!!! *Hezwi zwithu zwia konda nau vhavha zwi a vhavha usi na tshelede zwa vhukumakuma `)***

This is difficult and it's a burden if you do not have money truly.

R. HM and what else

P: Yooo!! It is very difficult you know one has to fetch water for patients from the tap which sometimes is far and sometimes the water does not come out and we have to buy from people who have boreholes in their *yards hey! This is tiring'*

R: HMMM

P:I used to wake up early in the morning at about 4 am to make fire outside and boil the water so that he can get warm water to bath. She was unable to bath herself and I am the one who was supposed to bathe her and I did not have a choice. Hey!! It was hard I mean like turning her alone to bath her back by the end of the day I was so tired. You know she recovered very fast and now she can bath herself''

R: E

P: When she was from hospital she was weak and could not do anything for herself so I used to wash and ion her clothes. The hut where she was sleeping also needed to be taken care of as she could not do it herself so i also cleaned the environment as well as her hut where she sleeps'

R: MMMMM

P: Treatment was started last year, early in the morning I prepare soft porridge and the people who help her take the treatment. I feel good when taking care of my child I used to go to Elim hospital with her for check up' Sometimes in my absence during treatment taking her sister cooks food for the patient before giving her the medication as her sister was always at home but I need to be there every time as she sometimes refuse to take medication or take half of the medication. She looks better now she was very thin the medication has helped even her appetite has improved'

R: HM continue

P: There is a DOT supporter who comes every morning to see to it that the patient takes treatment and record in the book. You see she is helping because I can not read or write so I would not be able to do what she is doing I think she is doing a great job'

R: HMM

P: Sometimes feel tired of caring for the patient because there are still many months left to care for the patient. Ohhoo!!!!!!!!!!!!! Six months is too much and the sister at the clinic also told me that the patient such as this one can be treated for a period of six to eight months oh!!!!!!!! It is so tiring. I feel so tired; nobody comes and give me some advice or some training on how to cope or to continue with caring in such a long period of time

R: HMM

P: 'At times I pull it hard when caring for her because she soils herself but nowadays she no longer soils herself. I pull hard because when I go to the clinic to collect gloves and nappies I sometimes find them out of stock .I had to improvise by using plastic which I buy in the Indian shop nearby. The plastics are 30cents each yaa!!!!!!!!!!!!!!! Life is tough sometimes. I cannot neglect her and she is my daughter.

R: HMM

P: ***‘Ndi pfa ndo no tou neta u mu thogomela ngauri zwino hono vha nwedzi wa vhutanu na vhuthihi ndi tshi khoum u londa , sa zwe nda amba ndi vuwa nga matsheloni-tsheloni nda mu dudedzela madi a u tamba nda mu bikela zwa ula a kona ha u nwa mishonga yawe sa izwo hut shi pfi a i liwi muthu e na ndala .Ndi pfa ndo no neta nga hoyu mushumo Ndi nana u neta ngauri a huna o di imiselaho nthusa na vhanwe mirado vha muta vha lavhelela uri ndi vha thuse nga zwila na zwlila mutani sa kale`.*** ‘I always feel tired of caring for the patient because it is now six months and as I told you that I wake up very early in the morning and prepare warm water for the patient to bath and prepare food so that the patient can take medication in a full stomach I feel tired about this work. What makes things worse is because nobody is willing to assist me and other family members also feel that I must also care for them like before ’

R : hmm continue

P:I sometimes feel so lonely when I think about this disease because most of the people around no longer pay us a visit. I was greatly concerned when other relatives do not also come and visit the patient .Anyway I understand that they have fear of the disease. Mmmm!!!!!!!! I To tell you the honest fact, I am also afraid of the disease. I'm doing this caring job because the patient is my child.

R MMM continue

P: I feel so rejected and isolated when caring for this patient because I no longer socialize with most of my friends in the social clubs because I must always be next to the patient giving the patient the care the patient needs .I feel lonely and sometimes bored . Relatives used to come and visit the patient at first but now nobody is coming to see me and the patient. I sometimes feel anxious when I think about this entire task that m` doing yaa!!!! I feel rejected as I am out of contact with others because of this isolation. I no longer attend funerals because of caring for my child.

R: continue

P: You know what , I think it was better if I had known what this disease is , if may be one can come and teach me what I can expect when caring for the TB patient ,what is TB ,what are the side effects when taking TB treatment . If I can get more information I think I can cope with all this experiences. But I don't mind because there is no one to do this, this patient will get better as days goes by.

R: HMMM…….

P: Some people even my neighbours think that my child has HIV/AIDS. Even the relatives do not come and visit my family anymore because of this disease. Oh! The worst thing is that I fear that the disease will infect me and I may die'

R: ok nodding the head can you tell me more about the fear of the disease

P: I am afraid of the disease because many people are dying. Some people say that TB is linked with HIV/AIDS. This patient was not tested yet and I am afraid that I may have the disease. What will happen if I may also be infected.

R: do you still have anything to say

P: I no longer have anything to tell you I think that I told you everything from the depth of my heart unless if you still have other questions to tell ask me .

R: no I think I have exhausted all the questions, you said a mouthful thank you so much for the information. You gave the answers the way I wanted them to be.

RESEARCH AND INNOVATION

OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:

Mrs. Sukumani T.J (Student No. 8901485)

PROJECT TITLE: Experiences of family members caring for tuberculosis patients at home at Vhembe District, Limpopo Province.

PROJECT NO: SHS/10/PH/001

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ISSUED BY:

UNIVERSITY OF VENDA, HEALTH, SAFETY AND RESEARCH ETHICS COMMITTEE

Date Considered: 22 October 2010

Decision by Ethical Clearance Committee Granted

Signature of Chairperson of the Committee:

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16 May 2011

To whom it may concern

I completed the editing of the dissertation of **Tshavhuyo Joyce Sukumani,** entitled *Experiences of family members caring for tuberculosis patients at home in the Vhembe district of Limpopo Province* and sent it to her via email on Friday 27 May 2011.

To my knowledge the manuscript is free of obvious language errors. In some instances the student was required to decide on certain corrections herself. I cannot take responsibility for these decisions.

Yours faithfully

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(signed)

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