SUPPORT FOR CAREGIVERS DURING PUERPERIUM TO ENHANCE THE PMTCT PROGRAMME

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DEDICATION

This study is dedicated to mothers and babies who died during periods of pregnancy, labour and puerperium due to complications associated with HIV infection. Their souls will always remain visible in our daily caring activities and their beloved family members. It is also dedicated to the women of the Anglican Women's Fellowship Church with this prayer of all of the women of the church: God our Father, who comes to us in the form of a Servant, teaches us and all women everywhere to offer ourselves in your service and in the service of all people so that in our day and generation our work may speak of your goodness and glory, through Jesus Christ, Amen.

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SUMMARY

An estimated 33.0 million people are currently living with HIV/AIDS worldwide. Of these, 15.5 million are women, and 2.2 million children under the age of 5 years who have mainly been infected through mother-to-child transmission. Mothers and babies are increasingly infected and about 90% of these are in sub-Saharan Africa. The same trend can be identified in South Africa, which has one of the highest incidences and prevalence rates of HIV/AIDS in the world with 5-6 million people living with HIV/AIDS. Women of childbearing age constitute 55% of all HIV positive adults and a quarter of pregnant women (28%) in South Africa are HIV positive.

The HIV/AIDS epidemic is overburdening hospital systems and it will continue to grow within the context of already massively overstretched public resources. This increase also impacts on health services in the North West Province which are facing an alarming increase in mothers and babies living with HIV/AIDS. One of the strategies that are implemented to reduce maternal deaths is the Prevention-of-Mother-to-Child Transmission (PMTCT) Programme and massive roll out of Antiretrovirals during puerperium. One of the goals of the PMTCT programme is to prevent transmission of HIV/AIDS from mothers to babies and reduce child, perinatal and neonatal morbidity and mortality. This strategy is integrated with Non-Governmental Organizations (NGOs) and community-based organizations (CBOs) in care of mothers and babies living with HIV/AIDS during puerperium. Successful implementation of this programme requires social support and community involvement because of short hospitalization during the postnatal period.

Caregivers are trained to perform various tasks and fulfil certain roles due to lack of human resources. Caregivers implementing the PMTCT programme experience problems which lead to stress and one of the causes of this stress manifests in feelings of inadequacy and isolation. They are faced with problems pertaining to mothers not adhering to treatment, and poverty is an additional source of stress as it negatively affects the quality of the PMTCT services they need to provide.

This research was conducted in the Bojanala region, Rustenburg Sub-District of the North West Province in South Africa. A descriptive, exploratory, qualitative research design was

utilized to explore and describe the lived experiences of caregivers while implementing the PMTCT programme as well as perceptions of health workers coordinating the PMTCT programme in order to gain a more thorough understanding of the support needed by caregivers during puerperium. Two populations were used. In population one, purposive sampling was used to select caregivers. In population two inclusive sampling was used to select health workers. In-depth interviews were conducted with both populations with the aim to collect data.

From the research findings similarities were identified between the two populations regarding support, namely:

(a) Caregivers need personal support in the form of counselling as well as support networks to enable them to deal with the problems they are faced with.

(b) Caregivers need financial support to afford basic essentials and better remuneration to meet their financial needs.

(c) Caregivers need to be trained in areas in which they lack knowledge – continued development and empowerment is essential. They also need to be trained specifically in PMTCT and they need a PMTCT consultant to always be available to support them.

(d) Improvement of the PMTCT services by providing transport to follow up mothers, protective resources to protect themselves against infections as they are at risk of infections, water is essential as a basic human right, provision with food parcels to mothers who are poverty stricken and the PMTCT health services to be intensified from the antenatal period.

(e) Management to establish a caring environment by displaying a caring attitude, respecting them and providing them with rewards to improve morale and performance.

Recommendations were made for the fields of nursing education, nursing research and community health practice with recommendations to establish a structure of support for caregivers to enhance the PMTCT programme during puerperium. These recommendations were discussed under the five themes presented above.

[**Key concepts:** support, caregivers, puerperium, enhance, PMTCT Programme]

OPSOMMING

'n Geskatte 33.0 miljoen mense lewe wêreldwyd tans met MIV/VIGS. Onder hierdies, is 15.5 miljoen vroue, en 2.2 miljoen kinders jonger as 5 jaar wat hoofsaaklik deur moeder-na-kindoordrag geïnfekteer is. Moeders en babas word toenemend geïnfekteer en ongeveer 90% van dié woon in sub-Sahara Afrika. Dieselfde neiging kan in Suid-Afrika waargeneem word, wat een van die hoogste verspreidings- en voorkomskoerse van MIV/VIGS in die wêreld het met 5-6 miljoen mense wat met MIV/VIGS lewe. Vroue van vrugbare leeftyd maak 55% van alle MIV-positiewe volwassenes uit en 'n kwart van die swanger vroue (28%) in Suid-Afrika is MIV-positief.

Die MIV/VIGS-epidemie is besig om hospitaalstelsels te oorlaai, en dit sal voortgaan om toe te neem binne die konteks van reeds geweldig oorbenutte openbare hulpbronne. Hierdie toename het ook 'n uitwerking op gesondheidsdienste in die Noord Wes Provinsie wat in die gesig gestaar word deur 'n verbysterende toename in moeders en babas wat met MIV/VIGS lewe. Een van die strategieë wat ingestel is om moedersterftes te laat afneem is die Program ter Voorkoming van Moeder-na-kindoordrag (PMTCT) (Prevention of Mother-to-Child Transmission – PMTCT) Programme) en 'n massiewe uitdeelaksie van Antiretrovirale middels gedurende die puerperium-periode. Een van die doelwitte van die PMTCT program is om oordrag van MIV/VIGS van moeders na babas te voorkom en kind, perinatale en neonatale morbiditeit en mortaliteit te voorkom. Hierdie strategie is met die Nie-Regeringsorganisasies (NRO's) en gemeenskap-gebaseerde organisasies (GGO's) wat moeders en babas wat met MIV/VIGS lewe gedurende puerperium versorg. Geslaagde implementering van hierdie program vereis maatskaplike ondersteuning en gemeenskapsbetrokkenheid weens kort hospitalisering tydens die postnatale periode.

Versorgers word opgelei om verskeie take te verrig en sekere rolle te vervul weens 'n tekort aan mensehulpbronne. Versorgers wat die PMTCT-program uitvoer, ondervind probleme wat tot stres lei, en een van hierdie oorsake van genoemde stres kom tot uiting in 'n gevoel van ontoereikendheid en van geïsoleerd te wees. Probleme rakende moeders wat hulle nie by die behandeling hou nie, staar hulle in die gesig, en armoede is 'n bykomstige bron van stres, aangesien dit die gehalte van die PMTCT-dienste wat hulle moet voorsien, nadelig beïnvloed.

Hierdie navorsing is in die Bojanala-streek, Rustenburg Sub-Distrik van die Noord Wes Provinsie in Suid-Afrika, gedoen. 'n Beskrywende, eksploratiewe, kwalitatiewe navorsingsontwerp is benut om die ervaringe wat die versorgers beleef tydens hulle toepassing van die PMTCT-program asook persepsies van gesondheidswerkers wat die PMTCT-program koördineer, te ondersoek en te beskryf met die oog daarop om 'n deegliker begrip te kan vorm van die ondersteuning wat versorgers tydens die puerperium-periode benodig. Twee populasies is gebruik. In populasie een is doelgerigte steekproefneming gebruik om versorgers te kies. In populasie twee is sluitende steekproefneming gebruik om gesondheidswerkers te kies. Deurtastende onderhoude is met beide populasies gevoer met die doel om data in te samel.

Uit die navorsingsbevindinge is ooreenkomste rakende ondersteuning tussen die twee populasies geïdentifiseer, naamlik:

(a) Versorgers het persoonlike ondersteuning nodig in die vorm van berading en ook ondersteuningsnetwerke om hulle in staat te stel om die probleme waardeur hulle in die gesig gestaar word, te kan hanteer.

(b) Versorgers het ook finansiële ondersteuning nodig om basiese benodigdhede te kan bekostig. Hulle het ook 'n beter vergoeding nodig sodat hulle in hul finansiële behoeftes kan voorsien.

(c) Versorgers moet opgelei word op gebiede waarin hulle nie oor genoeg kennis beskik nie – voortgesette ontwikkeling en bemagtiging is noodsaaklik. Hulle moet ook spesifiek in PMTCT opgelei word, en hulle het 'n PMTCT-konsultant nodig om altyd beskikbaar te wees om hulle te ondersteun.

(d) Die PMTCT-dienste moet verbeter word deur die beskikbaar stel van vervoer om moeders op te volg, beskermende hulpbronne om hulle teen infeksies te beskerm aangesien hulle gevaar loop om geïnfekteer te word, water wat as 'n basiese mensereg noodsaaklik is en voedselpakkies aan armoedige moeders. Verder moet die PMTCT-gesondheidsdienste meer intensief wees van die antenatale periode af.

(e) Bestuur moet 'n meelewend-omgewing skep deur 'n omgee-houding te toon, die versorgers te respekteer en belonings aan hulle te gee om hulle moreel te versterk en hul werkverrigting aan te wakker.

Aanbevelings is aan die hand gedoen ten opsigte van die verpleegonderrig-terrein, die verpleegnavorsingsterrein, en die gemeenskapsgesondheidspraktyk-terrein om 'n ondersteuningstruktuur vir versorgers te vestig om die PMTCT-program tydens die puerperium-periode te bevorder. Hierdie aanbevelings is bespreek onder die vyf temas soos hierbo aangebied.

[**Sleutelterme:** ondersteuning, versorgers, puerperium, bevorder, PMTCT-Program]

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ABBREVIATIONS

AIDS	-	Acquired Immune Deficiency Syndrome
ARVs	-	Antiretrovirals
CBOs	-	Community-Based Organizations
DOH	-	Department of Health
FBO	-	Faith-Based Organizations
HBC	-	Home-Based Care
HCW	-	Health Care Worker
HIV	-	Human Immunodeficiency Virus
MDGs	-	Millennium Development Goals
MRC	-	Medical Research Council
MTCT	-	Mother-to-Child-Transmission of HIV
NGOs	-	Non-Governmental Organizations
NWDoH	-	North West Department of Health
PCR	-	Polymerase Chain Reaction
PPP	-	Public Private Partnership
PMTCT	-	Prevention of Mother-to-Child Transmission

SA	-	South Africa
SAQA	-	South African Qualifications Authority
UNAIDS	-	Joint United Nations Programmed on HIV/AIDS

CHAPTER 1

OVERVIEW OF THE STUDY

1.1. INTRODUCTION AND PROBLEM STATEMENT

An estimated 38.6 million people are currently infected with HIV/AIDS worldwide. Women represent nearly half of all people living with HIV. The number of HIV positive women worldwide continues to grow at an estimate of 1.5 million per annum.. One out of ten young pregnant women living in sub-Sahara is HIV infected, and about one out of three children born to HIV-infected pregnant women will contract the virus. In 2006, 61% of people living with HIV in sub-Saharan Africa were women (UNAIDS, 2007:1-2). Over 90% of newly infected children are babies born to HIV positive mothers who acquire the virus during pregnancy, labour or delivery or through their mother's milk. Most infections can be averted, but the problem is that few of the world's pregnant women are being reached by prevention of mother-to-child-transmission (PMTCT) services (AVERTc: 2009:5) According to the Aids Foundation (2008:1), South Africa has the highest prevalence of HIV in the world with 18.8% of the population estimated to be infected and regarded as having the most severe HIV epidemic in the world (UNAIDS, 2007:1). The *Saving Mothers Report: Third Report on Confidential Enquiries into Maternal Deaths* (SA, 2006a: 176) mentioned that non-pregnancy-related infections remain the leading causes of maternal deaths and AIDS contributed 53.1% towards deaths at all levels of care.

Maneesriwongul, Panutat, Putwatana, Srirapo-Ngam, Ounprasetpong & Williams , (2003:28), supported by Orner (2006:236) maintains that the HIV/AIDS epidemic is overburdening hospital systems and this situation will continue to grow within the context of already massively overstretched public resources. This increase also impacts on health services in the North West Province which are facing an alarming increase in mothers and babies living with HIV/AIDS (SA, 2006c:4). The North West Province is situated centrally to the North of South Africa and is the fifth largest Province, occupying 9.5% (116320 km^2) of the total land area of South Africa. It is situated centrally, and to the North of South Africa as shown in Figure 1.1. Its neighbouring provinces are the South East is the Free State, to the East

Gauteng, to the South West the Northern Cape and Limpopo to the North. The North West Province is demarcated into the four districts, namely Bojanala, Dr Segomotsi Ruth Mompati (previously Bophirima), Ngaka Modiri Molema (previously Central)and Dr Kenneth Kaunda (previously Southern). (NWDoH, 2008:14). The focus of this research is in the Bojanala district which is divided into four sub-districts, namely Madibeng, Rustenburg, Kgetleng and Moses Kotane and the research will be conducted in Rustenburg Sub-District of the Bojanala region. The General Household Survey of 2005 reported that the total population of the North West Province was estimated at 3 825 000 as opposed to 3 669 349 as reported in Census 2001 (NWDoH, 2008:15).

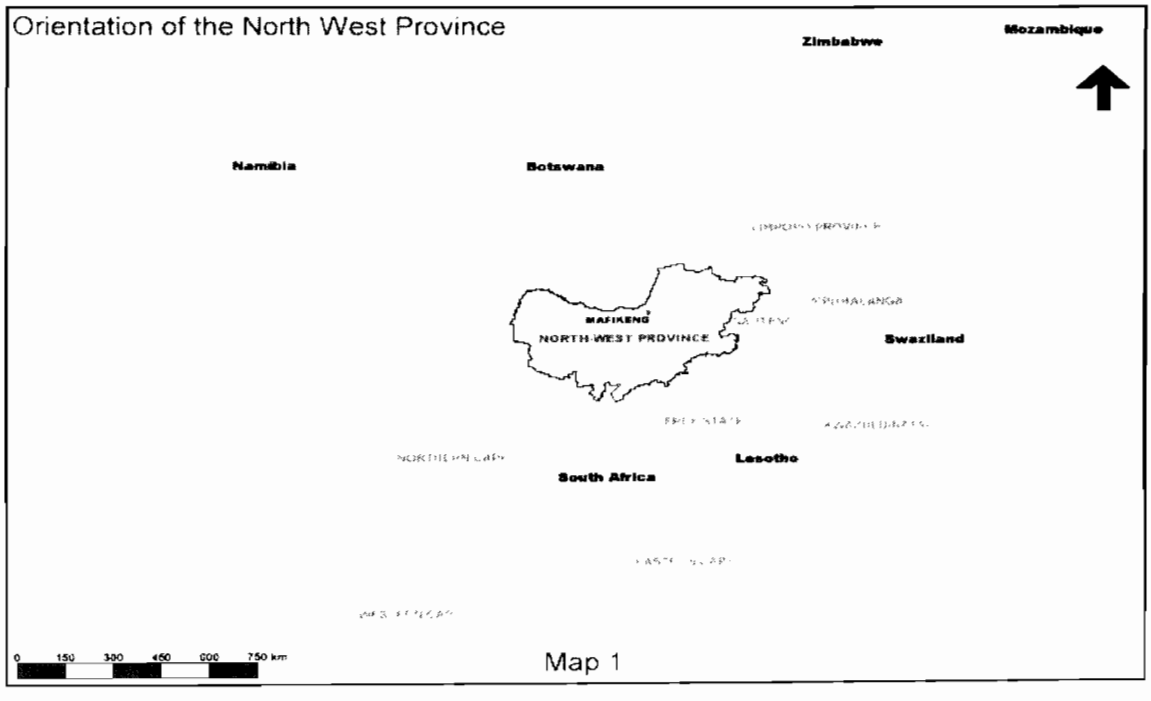

Figure1.1 Orientation map of the North West Province

Source: NWDoH Annual Performance Plan 2007/2008:1

The HIV prevalence in Bojanala and district is high compared to other districts as shown in the table below (Table 1.1). This is due to it being a mining district with migrant labourers with an increasing number of commercial sex workers and mushrooming of informal settlements. This prevalence showed the same steady increase of 1.0%, compared to the whole country. There has been a fluctuation in percentage from 2002 – 2006 in North West Province, although in 2005 the prevalence rate was 31.8% and in 2006 it declined to 29.0%.

TABLE 1.1 THE NORTH WEST PROVINCE DISTRICTS HIV PREVALENCE (2006)

HEALTH DISTRICT	2005 HIV PREVALENCE (95% CI)	2006 HIV PREVALENCE (95% CI)
BOJANALA	33.4 (30.1 – 36.7)	33.6 (30.9- 36.3)
BOPHIRIMA	22.2 (14.1 -30.3)	21.8 (18.2 – 25.5)
CENTRAL	31.2 (24.9 – 37.5)	23.6 (20.1 – 27.1)
SOUTHERN	37.9 (30.3 - 45.5)	31.5 (27.4 – 35.6)
NORTH WEST PROVINCE	31.8 (28.4 – 35.2)	29.0 (26.9 – 31.1)

Data source: National Department of Health: 2006 Antenatal prevalence report (SA, 2006b:4)

At the Millennium Summit in 2000, South Africa committed itself to achievement of the Millennium Development Goals (MDGs) with special reference to MDG 5 which targets at improving maternal health and MDG 6 which targets at combating HIV/AIDS (UNAIDS, 2000b) by 2015. In the HIV/AIDS Policy Guideline (SA, 2000:19) one of the strategies implemented to reduce maternal deaths is the Prevention-of -Mother-to-Child-Transmission (PMTCT) Programme and a massive roll out of Antiretroviral drugs during the puerperium. SA (2008:12-18) reported that the South African PMTCT programme, the largest in Africa, was conceptualized in 2001 and it has been implemented in pilot sites since 2001 and nationally since 2002. Since its inception, PMTCT services have been offered in all public hospitals and at more than 90% of primary health care centres. In line with International standards for a comprehensive strategy, the PMTCT policy recognizes that in order to prevent HIV among women and children, the following objectives of the PMTCT programme at national, provincial and local levels are integral:

TABLE 1.2 OBJECTIVES OF THE PMTCT PROGRAMME

NATIONAL	PROVINCIAL	CLINICAL FACILITIES
• Preventing HIV transmission from a woman living with HIV and her infant • Primary prevention of HIV, especially among women of childbearing age • Preventing unwanted pregnancies among women living with HIV • Providing appropriate treatment care and support • (SA, 2008:12 – 18)	• Ensure reduction of mother-to-child transmission of HIV/AIDS within the province • Improve efficacy of the PMTCT programme • To build capacity of health and caregivers on the implementation of the reviewed guidelines • To ensure a proper monitoring system • (SA, 2008:12 – 18)	• Providing an expanded coverage of PMTCT services • Integrate PMTCT interventions in routine maternal and child health • Capacity building • Establish management mechanism • Encourage managed Public Private Partership (PPP) • Participation of society (CBOs), (NGOs), (FBOs) • Ensure uninterrupted supply of materials • Develop a comprehensive communication strategy • (NWDoH, 2008:20)

The roll out of the PMTCT programme in the North is implemented in all four districts (NWPDoH, 2008:5). It is offered in all 25 hospitals within the North West Province and 287 out of 303 fixed primary health care facilities. A total number of 314 health facilities in the North West Province offer PMTCT intervention services. The specific roll out in the North West Province in accordance with the needs of the people is reflected in Figure 1.2. One of the strategic goals of the North West Province Department of Health is to provide **A**ccessible, **E**quitable and **A**ffordable **C**omprehensive Primary Health Care Services and to achieve this goal there should be social support and community involvement. This strategy is integrated with Non-Governmental Organizations (NGOs), Faith-Based Organizations (FBOs) and Community-based Organizations (CBOs) (NWDoH, 2008; 20). This is necessary because mothers and babies are discharged early. During this period adequate support is not available for mothers and babies for continuity of care. They are discharged and followed up by health workers and caregivers in the clinics and at home. Booysen (2007:5) points out that the postnatal period is the most vulnerable for the mother and the newborn. Every year

in Africa at least 125 000 women and 870 000 newborns die within six weeks post-partum. The *Saving Mothers Report: Third Report on Confidential Enquiries into Maternal Deaths* (SA, 2006a:180) stated that special attention needs to be paid to postnatal care as most mothers and babies succumb to ill health at this stage.

SA (2001:1) points out that health workers in the hospitals, community health centres and voluntary organizations are trained for two weeks in accordance with the PMTCT Training Guide. Trained health workers in the context of the North West Province refer to nurses who are registered. The objectives of the course are to provide knowledge and skills to health workers who work with mothers and babies to enable them to counsel HIV positive women with regard to infant feeding decisions, assisting women in feeding their infants effectively and referring women and their babies for further HIV services. The following is implemented by health workers in the community health centres and sites of voluntary organizations in accordance with the PMTCT programme during the postnatal period (SA, 2005:20-21)

- Visiting mother and baby regularly and stressing discharge instructions
- Ensuring PCR testing of babies is done at age 6 weeks
- Identifying potential common HIV-related features in the mother and the baby
- Identifying side–effects of ARTs severity and coping mechanisms
- Adhering to medication
- Growth monitoring and interpretation
- Encouraging and motivating family members to universal precautions.

Due to lack of human resources caregivers are trained in accordance with the PMTCT programme and infant feeding Field Guide (SA, 2004:1) in addition to training of home/community-based care. Schneider, Hlophe & Van Rensburg (2008:4-5) explain that caregivers include community members who have undergone training to provide specific basic health to members of the community. They may be volunteers or receive a salary and they are not civil servants or professional employees in the Department of Health. Training provided has been designed to help caregivers in the community to take pregnant women and mothers through the PMTCT programme, give advice, provide support needed to HIV negative women and women of unknown HIV status on information about pregnancy and feeding infants during puerperium. SA (2001:2) highlights the fact that training for caregivers equip them with knowledge and skills to provide home care, provide education and support

to clients, their families and significant others and to liaise with members of the health team in the community. These caregivers are also trained in line with guidelines for management of HIV-infected women during the postnatal period (SA, 2006:182).

The focus of this research is on the Bojanala region, Rustenburg Sub-District in the North West Province. As shown below in Fig 1.2 Rustenburg Sub-District has one level two hospital which provides antenatal services, delivery and postnatal services and is utilized as a referral hospital for complicated cases from various clinics in the region. North West Department of Health (NWDoH) (2007a:1), PMTCT annual statistics, remarks that this hospital had 5 441 deliveries per annum of which 1 060 were live births to women with HIV and these mothers and babies were discharged for continuity of postnatal care to various clinics around the district. There are three 24-hour community health centres which continue with postnatal care to mothers and babies living with HIV/AIDS as reflected in Table 1.2. Mothers and babies on the PMTCT programme are referred to continue with treatment and follow-up at these community health centres and various clinics in the district. These health centres have feeder clinics as follows: Tlhabane Health Centre: Classic House, Gateway, Marikana and Thekwane Clinic, Boitekong Health Centre: Kanana, Monakato, Hartebees, Rankelenyane and Bethanie clinic and Bafokeng Health Centre: Chaaneng, Luka and Phatsima Clinic. The focus of this research is on Tlhabane and Boitekong Health Centres. These health centres and clinics have professional nurses trained in the PMTCT and who coordinate the PMTCT programme. In the sub-district there is one HIV/AIDS coordinator who liaises with health centres, clinics and voluntary organizations. She is also responsible for the PMTCT training in the district and trains personnel of voluntary organizations in the PMTCT programme which she started in 2007. An organogram of services implementing the PMTCT programme in this region is illustrated below:

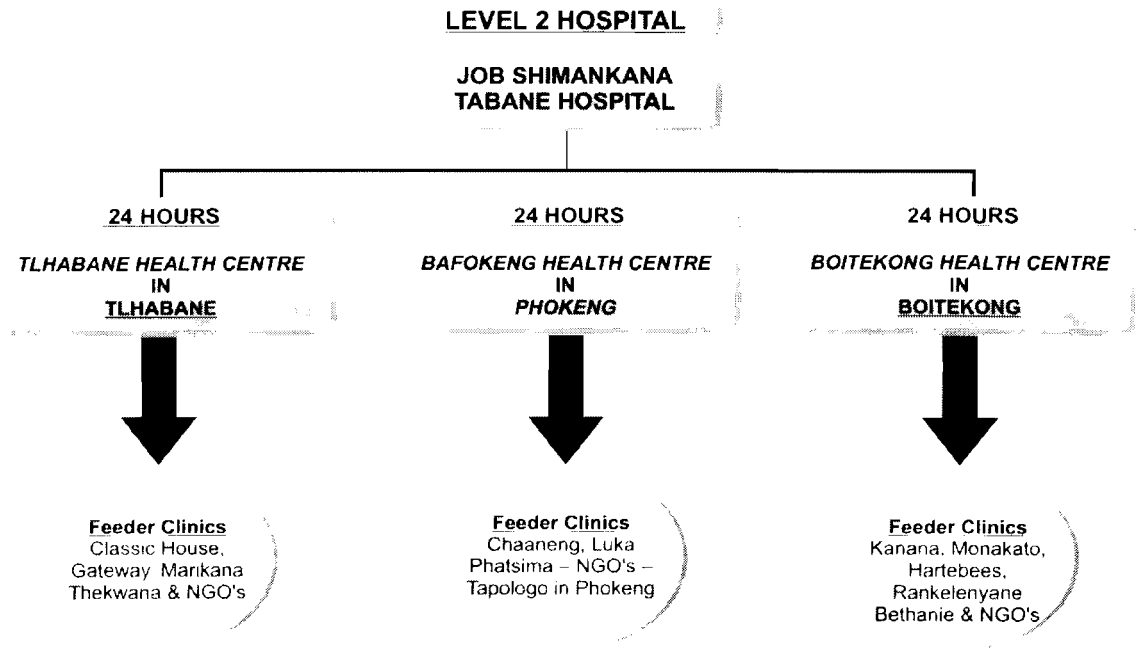

FIGURE 1.2 Referral organogram for PMTCT services in Bojanala region of Rustenburg Sub-District

The focus of this research is also on Tapologo home-based Organization which is one of the Non-Governmental Organizations using a home/community model as displayed in Fig 1.3, in Phokeng situated under NGOs around Bafokeng Health Centre. Shortage of personnel is one of the challenges of implementing the PMTCT programme; thus has been established to meet the diverse needs of communities and to implement the PMTCT programme to mothers and babies living with HIV/AIDS during puerperium as it is the only NGO that provides ARVs to pregnant women. The organization has one hospice which is located in Phokeng and is utilized for terminally ill patients. It is the administrative centre for Tapologo home-based organization. The organization has eight home/community care sites including the main site at Phokeng where ARVs are rolled out to pregnant women as shown in Table 1.3 below.

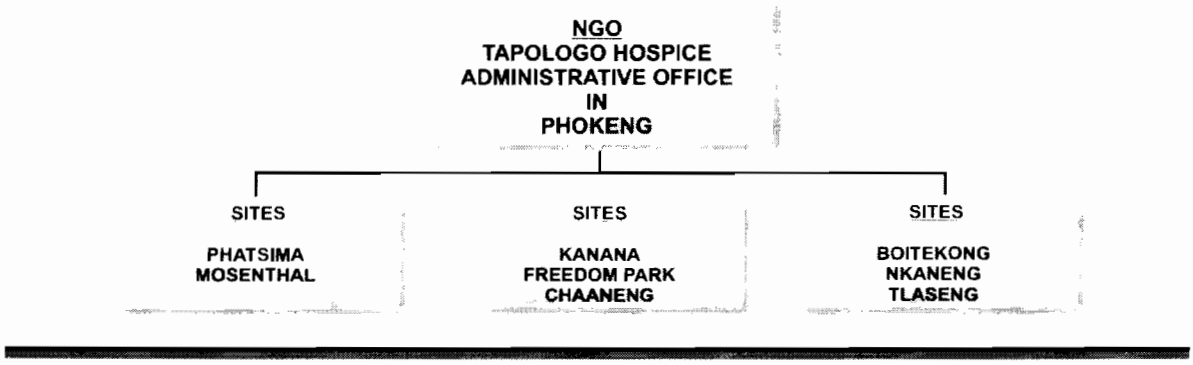

FIGURE 1.3 Organogram of Tapologo Home-Based Care Organization

TABLE 1.3 SITES OF TAPOLOGO HOME-BASED CARE ORGANIZATIONS, PERSONNEL AND ROLES

SITES	R/N	ROLE	E/N AUXILIARY NURSES	ROLES	CARE-GIVERS	ROLES
1.PHATSIMA	1 per site	Supervision	1 - 2	Health education	8 - 10	Guidance
2.MOSENTHAL	1 per site	Supervision	1	Health education	8 - 10	Guidance
3.CHAANENG	1 per site	Supervision	1	Health education	8 - 10	Guidance
4.FREEDOM PARK	1 per site	Supervision	1	Health education	8 - 10	Guidance
5.KANANA	1 per site	Supervision	1	Health education	8 - 10	Guidance
6.BOITEKONG	1 per site	Supervision	1	Health education	8 - 10	Guidance
7.NKANENG	1 per site	Supervision	1	Health education	8 -10	Guidance
8.TLASENG	1 per site	Supervision	1	Health education	8 - 10	Guidance

The sites operate from permanent buildings or mobile containers. There are medical practitioners who work on a voluntary basis visiting this hospice and sites on different days for consultation and review of patients' treatment and there is one social worker who provides social support to clients. Each site has one professional nurse who supervises and manages the centre, performs daily assessment and provides treatment to clients. There is one to two auxiliary nurses who provide health education to clients and monitor vital signs and, together with the professional nurse, they supervise caregivers. In each site there are 8 to 10 caregivers who work on a voluntary basis, provided with a stipend of R300-R500/month. These sites are visited once a week by the ARV team (consisting of visiting doctor, social worker, pharmacist and a professional nurse) and the other days during the week are used by the team for community-based care. Professional nurses meet weekly at the main centre in Phokeng for administrative issues, staff development and discussing their problems. The caregivers provide postnatal care to mothers and babies living with HIV/AIDS (NWDoH, 2007a:1). Monthly, an average of 25 mothers and babies on the PMTCT programme are seen by 8-10 caregivers per site.

Various researchers, De la Porte (2003:123 -128), De Figuereda (2001:638-640), Kipp *et al.* (2006:696), Robinson (2007:18), Strydom and Wessels (2006:4), Maneesriwongul *et al.* (2003:32), Moore and Henry (2005:160), Orner (2006:238-239) and Vithayachockitikhun (2006:123) conducted studies on problems and challenges experienced by caregivers. These researchers identified that caregivers experience stress and the causes include financial hardships, oppressive workloads, stigmatization, lack of an effective voice of decisions that affect them and their work, inadequate support, over-involvement with HIV/AIDS and their families and lack of referral mechanisms. They report on the effects of the above-mentioned on the personal and daily lives of caregivers. This manifests as loss of interest, neglect of duties, feelings of inadequacy and isolation, helplessness, guilt, loss of confidence, loss of self-esteem, irritability, loss of quality in performance of work, and powerlessness in their work (UNAIDS, 2000a:26-36). Caregivers implementing the PMTCT programme experience the same problems as all other caregivers. They are faced with many additional challenges during puerperium which include PCR-testing at 6 weeks, infant feeding options of which mixed feeding is a challenge, abandoned babies, dealing with orphans, non-adherence to medication, problems in tracing contacts, mothers not coming for follow-up care. They face many problems and cannot deal with all of those they are faced with. The researcher also observed that poverty is an additional source of stress because it reduces the quality of care in the region where the research was conducted. The researcher during accompaniment of learners observed that caregivers are overcome by emotions and

guilt when they experience the lack of basic resources in the households of these poverty-stricken families, since they have to implement the PMTCT programme in spite of the challenges they are faced with.

From the observation of the researcher, as supported by Uys (2002:101-105), still no formal continual support system exists for caregivers and this results in a high turnover of caregivers. The available support from health workers in community health centres and sites of voluntary organizations appears to be inadequate. If caregivers could be adequately supported, the care and implementation of PMTCT could be effective with a decrease in morbidity and mortality of mothers and babies. Thus the following questions need exploration:

- What are the experiences of caregivers during puerperium regarding support provided for implementing the PMTCT programme?
- What are the perceptions of health workers during puerperium with regard to support provided to caregivers implementating the PMTCT programme?
- How can caregivers be supported during puerperium in the maternal and child care programme to enhance the implementation of the PMTCT programme?

1.2. RESEARCH OBJECTIVES

The need for support to caregivers to render quality health care to enhance the PMTCT programme is a concern. Therefore the specific objectives for this research are:

- To explore and describe the experiences of caregivers during puerperium with regard to support provided for implementing the PMTCT programme.
- To explore and describe the perceptions of health workers during puerperium with regard to support provided for caregivers implementing the PMTCT programme.
- To formulate recommendations for the maternal and child care programme to develop a structure of support for caregivers during puerperium to enhance the implementation of the PMTCT programme.

1.3. PARADIGMATIC PERSPECTIVE

The paradigmatic perspective within this research is based on meta-theoretical (see Figure 1.4), theoretical and methodological statements.

1.3.1 Meta-theoretical statements

The framework of the paradigmatic perspective of this research is based on the assumptions of The Nursing Theory for the Whole Person which is based on the Judeo-Christian belief (ORU, 1990:136-142). This philosophy is based on the whole Bible as the source of the truth. *Discussion* of the meta-theoretical statements regarding man, health, environment and nursing follows:

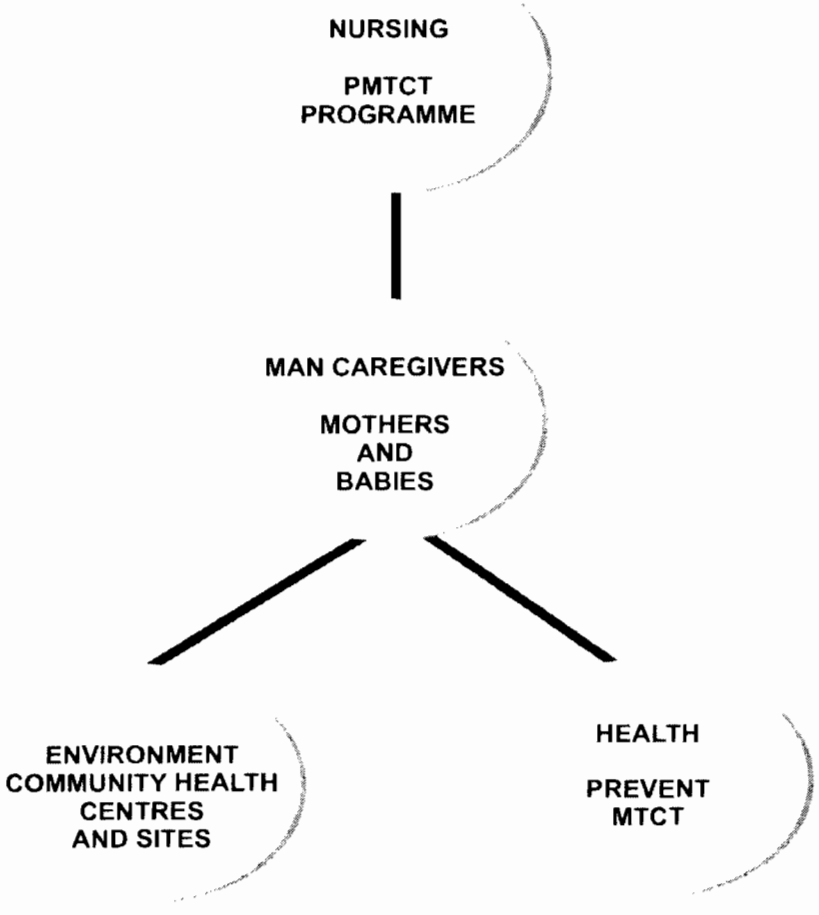

Figure 1.4 Meta-theoretical perspective

1.3.1.1 Man

In this research man entails the caregiver, health worker, mother and babies who are spiritual beings made up of body, mind and spirit created by God who function in an integrated bio-psychosocial manner to achieve their quest for wholeness (ORU, 1990:136-142).

1.3.1.2 Health

Health is a state of spiritual, mental and physical wholeness. Health is described on a continuum from maximum health to minimum health (ORU, 1990:136-142). Maximum health for purposes of this research refers to prevention of mother-to-child transmission of HIV/AIDS which is needed in the quest for wholeness. Minimum health refers to mothers and babies living with HIV/AIDS who need the PMTCT programme to be rolled out to them, as their wholeness is at stake.

1.3.1.3 Environment

The environment consists of the internal and external environment. The internal environment of man encompasses mind, body and spirit and the external environment comprises the physical, social and spiritual environment (ORU, 1990:136-142). Interaction takes place between the caregiver, health workers and the external environment in clinics, homes and sites of voluntary organizations where the PMTCT programme is implemented in order to prevent mother-to-child transmission of HIV/AIDS. The nature of this interaction influences their wholeness.

1.3.1.4 Nursing

Nursing refers to goal-directed activities provided to individuals, families and communities to promote maintain and restore health (ORU, 1990:136-142). Nursing is regarded as activities that are provided by caregivers implementing the PMTCT programme and health workers co-coordinating the PMTCT programme aimed at maintaining, promoting and restoring the health of mothers and babies living with HIV/AIDS to prevent mother-to-child transmission of HIV/AIDS.

1.3.2 Theoretical statements

Theoretical statements include the central theoretical statement and conceptual definitions applicable to this research.

1.3.2.1 Central theoretical statement

Insight in the experiences of caregivers during puerperium implementing the PMTCT programme and perceptions of health workers regarding support for caregivers will lead to formulation of recommendations in the maternal health programme to develop a structure of support for caregivers to enhance the implementation of the PMTCT programme.

1.3.2.2 Conceptual definitions

Caregiver refers to a person involved in providing health service to the user (SA, 2008:9) and who performs types of jobs as part of the programme that has been planned in conjunction with a registered nurse or doctor and refers patients for help and advice if problems are encountered and liaises with a professional person (SA, 2001:20)

Caregivers in this research are trained in accordance with the PMTCT programme and infant feeding Field Guide (SA, 2004:1) in addition to the training for home/community-based care. Training has been designed to help caregivers in the community to take pregnant women and mothers through the PMTCT programme, to give advice and support needed for HIV negative women and women of unknown HIV status and to give information concerning pregnancy and feeding infants during puerperium. These caregivers are trained to perform various activities and roles due to lack of human resources in health services. Training of the caregivers is in line with guidelines for management of HIV-infected women during the postnatal period (SA, 2008:18).

1.3.2.2.2 Health worker

In this research a health worker refers to a health worker co-coordinating implementation of PMTCT during puerperium in community health centres, clinics and sites of voluntary organizations. These health workers are registered nurses registered with the South African Nursing Council (SANC), enrolled nurses and auxiliary nurses enrolled with the South African Nursing Council and who have received training in accordance with the PMTCT and infant feeding Field Guide (SA, 2004:1).

1.3.2.2.3 The PMTCT Programme

One of the strategies that is implemented in South Africa to reduce maternal deaths is the Prevention of Mother-to-Child Transmission (PMTCT) and massive roll out of Antiretroviral drugs during puerperium (SA, 2008:12-18). In line with International standards for a comprehensive strategy, the PMTCT policy recognizes that in order to prevent HIV among women and children objectives at National, Provincial and clinical facilities must be implemented (refer to Table 1.2).

In this research it refers to implementation of the PMTCT programme in community health centres and sites of voluntary organizations in Rustenburg Sub-District with an aim to enable caregivers to provide appropriate treatment, care and support to women living with HIV and their babies and families (NWDoH, 2008:8).

1.3.2.2.4 Support

Seen from a sociological perspective, social support consists of provision of human and material resources that are of value to the recipient, such as counselling, training, skills acquisition and sharing of tasks and responsibilities. It may be obtained from relationships within social networks such as parents, children, extended family members, co-workers, mentors, social workers or other professionals. Support may be offered in crisis hotline services which can provide advice, referrals for individuals needing immediate assistance. Anonymity can also be offered to people who do not wish to discuss their problems with others (Thompson, 1995:43).

Social support, as clarified by Barrera (1986:413-445), provides recipients with emotional understanding, instrumental aid, counselling and guidance and referrals to other sources for assistance. It is stress preventative; it provides an individual with material and psychological resources that foster positive development. These resources include healthy practices, self-esteem, sense of belonging, social competencies, coping strategies, access to emergency aid, social monitoring, encouragement and social partners.

In this research, support refers to comprehensive support that needs to be provided to caregivers as they are faced with problems and challenges whilst implementing the PMTCT programme which will enable them to deal with problems they encounter in order to intensify the PMTCT programme during puerperium.

1.3.2.2.5 HIV /AIDS

AIDS (Acquired Immune Deficiency Syndrome) is caused by infection with the human immunodeficiency virus (HIV) which impairs cells of the immune system and progressively destroys the body's ability to fight infections and certain cancers (Enkin *et al.*, 2000:155). The Aids Foundation (2008:2) says HIV is most commonly spread by sexual contact with an infected partner; through contact with infected blood; through sharing contaminated needles, syringes or drug use equipment; through mother-to-child transmission in utero; and through infected breast milk.

1.3.2.2.6 Puerperium

Sellers (1993:583), as confirmed by Bennet and Brown (2000:695), states that puerperium is defined as the period from the completion of delivery and the third stage of labour to the end of the first six weeks postpartum. Bennet and Brown (2000:695) refer to this period as the period during which organs of the body return to their pregravid state. In this research it is a vulnerable period for mothers and babies with HIV/AIDS as it is associated with maternal and neonatal morbidity and mortality. The PMTCT programme is implemented to improve follow-up care to HIV positive mothers during this period as they need to be followed up weekly during the first month of life at the nearest clinic (SA, 2008:57).

1.3.3 Methodological statements

The methodological statements of this research are based on the Botes Model (1992:36-42), developed specifically for nursing research and therefore increases the rigor of this research. The focus on functionality enhances the purpose of improving the practice of nursing (Botes, 1992:37), in this case the implementation of the PMTCT programme.

Levels of nursing research activities in the model of Botes (1992:36-42) take place in three levels. The first level is the nursing practice, which forms the study field of nursing practice. The research activities are aimed at promotion, maintenance and restoration of health where caregivers interact with mothers and babies with HIV/AIDS to enhance the PMTCT programme during puerperium

The first level leads to a second level in which the theory of nursing and research takes place. The researcher will conduct the research to explore and describe the experiences of

caregivers implementing the PMTCT programme regarding support given to them, and to explore and describe the perceptions of health workers with regard to support whilst coordinating the PMTCT programme during puerperium in order to formulate recommendations for a maternal and child programme to develop a structure of support for caregivers to enhance the PMTCT programme during puerperium.

The third level entails the paradigmatic perspective from which this research is conducted. The Nursing Theory for the Whole Person (ORU, 1990:136-142) serves as paradigmatic perspective for this research.

1.4. RESEARCH DESIGN AND METHOD

A brief discussion of the research design and method follows with a more detailed discussion in Chapter 2.

1.4.1 Research Design

A descriptive, exploratory, qualitative research design (Burns & Grove, 2006:55; Polit & Beck, 2004:253–254) was followed to explore and describe the lived experiences of caregivers during puerperium while implementing the PMTCT programme as well as perceptions of health workers coordinating the PMTCT programme in order to gain a more thorough understanding of the support needed by caregivers.This will lead to formulation of recommendations in the maternal health programme to develop a structure of support for caregivers during puerperium to enhance the implementation of the PMTCT programme.

1.4.2 Research method

The research method includes the research sample, data collection and data analysis.

1.4.2.1 Research Sample

1.4.2.1.1 Population

For purposes of this study, two populations (Burns & Grove, 2006:341-342; Polit & Beck, 2004:289–290) were used:

Population one - It consisted of caregivers implementing the PMTCT programme during puerperium in community health centres and sites of Tapologo Voluntary Organization in Bojanala region, Rustenburg Sub-District of the North West Province.

Population two *-It consisted of health workers coordinating the PMTCT programme in puerperium in community health centres and sites of Tapologo Voluntary Organization in Bojanala region, Rustenburg Sub-District of the North West Province.*

1.4.2.1.2 Sampling Method and selection criteria

Population one: Caregivers

Purposive sampling was used for caregivers in community health centres and sites of voluntary organizations (Brink *et al.*, 2006:133-134; Burns & Grove, 2006:352; Polit & Beck, 2004:289-290) and health workers coordinating the PMTCT programme to select participants as they are knowledgeable about the issue to be researched. Selection criteria (Burns & Grove, 2006:342–343; Polit & Beck, 2004:290–291) for caregivers in the sample is that they should be currently providing home-based care to mothers and babies living with HIV/AIDS

Population two: Health workers

All inclusive sampling was used for health workers coordinating the PMTCT programme in all the clinics and sites of voluntary organizations (Polit & Beck, 2004:292). Selection criteria (Burns & Grove, 2006:342-343; Polit & Beck, 2004:290-291) for health workers in the sample is that they should already have been coordinating the PMTCT programme in clinics and sites of voluntary organizations.

1.4.2.1.3 Sample Size

The sample size was determined by the number of participants who volunteered and by means of data saturation. The latter occurs when no new themes emerge and when the amount of new data or diversity of themes is completed (Burns & Grove, 2006:358; Polit & Beck, 2004:308).

1.4.3 Data Collection

The researcher conducted individual in-depth interviews with both populations (Brink *et al.*, 2006:120-121). The researcher used communication techniques such as minimal verbal response, clarification, reflection, encouragement, comments, spur, reflective summary and listening during interviews, as recommended by Greeff (*in* de Vos *et al.*, 2004:294-295). Field notes were taken after having conducted each individual in-depth interview (see Appendix M & N). These field notes consisted of personal, observational and methodological notes (Polit & Beck, 2004:381-384). All interviews were voice-recorded with the permission of participants for purposes of data analysis.

1.4.3.1 The role of the Researcher

Permission to conduct the research was obtained from the Ethics Committee of North-West University (NWU, 2007:36) (Appendix A), North West Research Committee (Appendix B), and Chief Director of Health-Bojanala District (Appendix C), Board of Directors of Tapologo Hospice (Appendix D) and Sub-District Manager of Rustenburg Health Sub-District (Appendix E). The purpose and importance of the research was explained in the request for permission.

For population one, the researcher contacted health workers coordinating the PMTCT programme to act as mediators and provide the researcher with a list of caregivers who would be research participants. The researcher personally arranged appointments for interviews. Consent was obtained from participants and the researcher explained the significance of the study as well as the purpose and method thereof to them.

For population two, the researcher contacted the operational managers of clinics to identify health workers who coordinate the PMTCT programme in community health centres and sites of voluntary organizations in Rustenburg Sub-District of the North West Province. Consent was obtained from participants and the researcher explained the significance of the study as well as the purpose and method thereof to them.

1.4.3.2 Physical Setting

Private rooms in community health centres and sites of voluntary organizations were used to conduct the interviews for both populations to ensure privacy and confidentiality, since this was a real-life situation (Burns & Grove, 2006:359).

1.4.3.3 Data analysis

The researcher transcribed the voice-recorded interviews. Content analysis was performed in accordance with the coding process of Tesch (*in* Cresswell, 2009:142-145). All transcripts and field notes were scrutinised to obtain an overall idea. Important ideas were noted. Data were categorized in themes and sub-themes. A work protocol was given to an independent coder with experience in coding in qualitative research to independently analyze transcripts of the interviews. Consensus was reached between the independent coder and the researcher on the themes, categories and sub-categories, and relationships that had emerged from these themes.

1.5. TRUSTWORTHINESS

The goal of qualitative research is to accurately represent informants' experiences (Brink, 2006:118). Guba (*in* Krefting, 1991:215-221) suggests four criteria to ensure trustworthiness. These criteria are credibility, transferability, dependability and confirmability. The following strategies were used in this research and ensured trustworthiness to it.

1.5.1 Credibility

Sandelwoski (*in* Krefting, 1991:218) states that a study is credible when it presents accurate descriptions or interpretations of human experiences and that people who share those experiences would immediately recognize the descriptions.

The following strategies, as stated by Lincoln and Guba (*in* Krefting, 1991:221), were used to obtain credibility:

Prolonged engagement – the researcher came into contact with participants when she explained the interview process. During the interviewing process she spent an hour with participants, explaining further, repeating and elaborating on questions in order to increase credibility. The researcher also came into contact with participants when she accompanied learners in clinical practice and formed a relationship of trust.

The **reflexivity strategy** was applied in accordance with the suggestion of Ruby 1980 (*in* Krefting, 1991:223). Utilizing field notes the researcher continuously reflected on her background, perceptions and experiences and clarified how this influenced her data gathering and analysis.

Knoll and Beitmeyer (*in* Krefting, 1991:224) suggest **triangulation of data sources** (data was collected from different perspectives), experiences of caregivers, perceptions of health workers and literature control in order to check on all aspects of support to be provided to caregivers during puerperium implementing the PMTCT programme.

Structural coherence – the focus of interviews was on experiences of caregivers and perceptions of health workers (Marais & Poggenpoel, 2003:32) with regard to support provided to caregivers during puerperium implementing the PMTCT programme.

Member checking, as stated by Lincoln and Guba (*in* Krefting, 1991:224) the researcher continuously verified with participants on themes and sub-themes that emerge from the data collected and analyzed to ensure that their views were accurately translated. This was done by checking with participants the interpretations and the conclusions reached by the researcher.Again the researcher checked data collected with peers to enrich credibility of data analysed and participants were informed to avail themselves if there is need to for follow up on data collected.

1.5.2 Transferability ensures that sampling selection in both populations is representative of the population under study.

Field and Morse 1985 (*in* Krefting, 1991:216) mention that one strategy to address transferability is **nominated sample** – in this research coordinators of the PMTCT programme in community health centres and sites of voluntary organizations who were experienced and knowledgeable about this research field identified participants who complied with the selection criteria.

Dense description – There was dense description of participants in both populations under study and the research context. Lincoln and Guba (*in* Krefting, 1991:227) maintain that researchers should be able to identify similarities to this context; thus enabling other researchers to transfer their findings in other contexts.

1.5.3 Dependability

Guba (1981) *in* Krefting, 1991:227) points out that dependability relates to consistency of findings. The strategies that were used are:

Dense description of methodology – this included accurate description of methods of data collection, analysis and interpretation and it illustrates how unique the study is.

Code – recode procedure – after consultation with the co-coder with research expertise,coding was implemented to reach consensus on data analyzed.

1.5.4 Confirmability

Sandelwoski (*in* Krefting, 1991:218) indicates that confirmability will be achieved when the researcher ensures that the data is neutral. A criterion of neutrality is emphasized. The researcher was not biased; research findings reflected information solely provided by participants and conditions of the research. The following strategies were applied:

Confirmability audit – Field notes were kept for auditing which consisted of personal, observational and methodological notes, and the researcher conducted a literature control to ensure confirmability of research findings.

The use of the supervisor and co-supervisor with expertise in qualitative research was critical to validate scientific value of this study.

Reflexive analysis was essential to ensure that the researcher is aware of her influence on data collected by using field notes ensuring that researcher's ideas and what she identified were marked.

1.6. ETHICAL PRINCIPLES

The following ethical principles were implemented in the study in order to ensure that the research was performed ethically.

Informed consent – Participants were provided with consent forms requesting permission to conduct the study. The following information pertaining to the study was included in the application: introduction of research activities, objectives, purpose of the study, procedures, duration of participant participation, data collection methods to be used, sample and sampling method to be used, copy of consent to be signed by participants, names of the supervisor and co-supervisors of the study and ethical considerations to be adhered to.

Participants were being provided with the same information both verbally and in writing. Data was collected once permission to proceed had been obtained (Polit & Beck, 2004:150–153; MRC, 2006:16).

Confidentiality: Names of participants and places were not divulged. Recorded files on voice recorders and scripts were kept safe until publication of the research report.

Privacy: Participants had the right to determine conditions under which private information was shared and the extent to which this information would be shared (MRC, 2006:18).

Benefits: Benefits derived from the study will be communicated to participants and authorities, which will lead to recommendations in the maternal and child care programmes to develop a structure of support for caregivers to enhance the PMTCT programme and postnatal care provision (Polit & Beck, 2004:145–146) with the probability of reducing maternal and neonatal morbidity and mortality.

Protection from harm: No psychological or physical harm was foreseen by the researcher. If any emotional discomfort was experienced by participants it would have been referred to appropriate psychological services provided by a clinical psychologist in the region (Polit & Beck, 2004:145).

1.7. LITERATURE CONTROL

Available literature and research reports were investigated to verify the results of this research and to highlight new insight gained from it (Burns & Grove, 2006:95; Polit & Beck, 2004:94).

[Data bases consulted: Nexus (NRF), SA Periodicals, Medline, Social Sciences Index, Academic Search Premier (Internet)]

1.8. CHAPTER LAYOUT

CHAPTER 1 Review of the study

1.1 Introduction and problem statement

1.2 Research objectives

1.3 Paradigmatic perspective

1.4 Research design and method

1.5 Trustworthiness

CHAPTER 2 Research design and method

2.1 Research design

2.2 Research method

2.2.1 Sampling — population

— sampling method

— sample size

2.2.2 Data collection

2.2.3 Data analysis

CHAPTER 3 **Discussion of research findings and literature control**

CHAPTER 4 **Conclusions, limitations and recommendations for developing support for caregivers to enhance the PMTCT programme during puerperium**

CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1. INTRODUCTION

Chapter one dealt with the overview of the research which included the research problem and context, the objectives, the paradigmatic perspective and a brief orientation of the research methodology. The trustworthiness and applicable ethical principles were also discussed. This chapter gives a detailed description of the research methodology with attention to the research design and method.

2.2. RESEARCH DESIGN

A descriptive exploratory qualitative research design was followed with the aim of exploring and describing the lived experiences of caregivers whilst implementing the PMTCT programme and perceptions of health workers coordinating the PMTCT programme in order to gain a more thorough understanding regarding support needed by caregivers who implement the PMTCT programme during puerperium. Burns and Grove (2006:55) define qualitative research as a systematic interactive approach used by the researcher to understand the lived experiences and to explore the meaning of these experiences. This phenomenon was explored and described within the specific context (Mouton & Marais, 1996:22; Polit & Beck, 2004:247) of the Bojanala region of Rustenburg Sub-District in the North West Province, as described in Chapter 1.

2.3. RESEARCH METHOD

The research method followed by the researcher included research sample, data collection and data analysis.

2.3.1 Research Sample

The research sample consisted of two populations because they are involved in the research problem.

2.3.1.1 Population

Population one - It consisted of seven (7) caregivers implementing the programme during puerperium in community health centres and sites of voluntary organizations in Bojanala region, Rustenburg Sub-District of the North West Province.

Criteria for inclusion was set as follows:

- voluntarily participation without coercion in the research
- consent to be interviewed and to be recorded on audio-tape
- participate willingly in the research until data collection is complete
- explanation of significance as well as purpose and method of the research to participants
- currently providing home – based during puerperium to mothers and babies living with HIV/AIDS
- able to communicate in English or Tswana

Population two - It consisted of seven (7) health workers coordinating the PMTCT programme during puerperium in community health centres and sites of voluntary organizations in the Bojanala region, Rustenburg Sub-District of the North West Province.

2.3.1.2 Sampling Method and selection criteria

- **POPULATION ONE: Caregivers**

Purposive sampling was used for caregivers implementing the PMTCT programme in community health centres and sites of voluntary organizations (Brink *et al.,* 2006:133-134; Burns & Grove, 2006:352; Polit & Beck, 2004:289-290) to select participants as they were knowledgeable about the issue to be researched. The selection criterion (Burns & Grove, 2006:342–343; Polit & Beck, 2004:290–291) for caregivers in the sample was that they should already have been implementing the PMTCT programme in community health centres and sites of voluntary organizations.

Criteria for inclusion was set as follows:

- voluntarily participation without coercion in the research.
- consent to be interviewed and to be recorded on audio-tape.
- participate willingly in the research until data collection is complete.
- currently providing home-based care to mothers and babies living with HIV/AIDS.
- able to communicate in English or Tswana.

- **POPULATION TWO: Health workers**

All inclusive sampling was used for health workers coordinating the PMTCT programme in community health centres and sites of voluntary organizations (Polit & Beck, 2004:292). The selection criterion for health workers in the sample, as suggested by Burns and Grove (2006:342–343) and Polit and Beck (2004:290–291), was that they should currently implementing the PMTCT programme during puerperium in community health centres and sites of voluntary organizations.

Criteria for inclusion was set as follows:

- voluntarily participation without coercion in the research
- consent to be interviewed and to be recorded on audio-tape
- participate willingly in the research until data collection is complete
- explanation of significance as well as purpose and method of the research to participants
- currently co-ordinating PMTCT programme during puerperium to mothers and babies living with HIV/AIDS
- able to communicate in English or Tswana.

1.4.2.1.3 Sample Size

The sample size was determined by the number of participants who volunteered and by means of data saturation. The latter occurs when no new themes emerged and when the amount of new data or diversity of themes were completed (Burns & Grove, 2006:358; Polit & Beck, 2004:308).

2.3.1.3 Data collection

A dense description of the role of the researcher, the physical environment and the data collection method follows:

2.3.1.3.1 The role of the Researcher

Permission to conduct the research was obtained from the Ethics Committee of North-West University, Ethics number: NWU - 0068-08 - AI (NWU, 2007:36) (see Appendix A), North West Research Committee (see Appendix B) Chief Director of Health, Bojanala District, (see Appendix C), Rustenburg Health Sub-District Manager (see Appendix D), and the Board of Directors of Tapologo Hospice (see Appendix E). The purpose and importance of the research was explained in the request for permission to conduct the research and once permission had been granted, the researcher identified health workers in community health centres and sites of voluntary organizations who acted as mediators. The researcher contacted them personally and explained their roles as mediators in the research project and they did the following:

a) Identified and compiled a list of potential research participants

b) Explained the purpose, importance and benefits of the research project to potential research participants

c) Explained to research participants the methods of data collection, recording of data, utilization of voice recorders and duration of in-depth interviews that would last approximately 45 minutes to one hour

d) Arranged a meeting between the researcher and research participants prior to the research to get to know one another

e) Assisted the researcher in identifying a quiet, private room at the community health centres and sites of Tapologo Voluntary Organization for conducting the interviews and explained to research participant's avoidance of distracters during the interview such as opening of doors and talking very loudly.

On their agreement, the researcher explained the purpose, objectives of the research, method of data collection, their role as mediators and ethical principles relating to confidentiality and anonymity. Letters were sent (see Annexure F) after agreement had been reached with detailed information and criteria for inclusion of participants. The researcher explained to mediators that they should explain the content of the consent thoroughly to

potential participants using their home language. For population one, mediators were requested to submit a list of names of research participants, dates and times on which the researcher would meet participants and an agreement was reached on the settings where interviews would be held. All participants agreed to meet the researcher on the day of the interview.

For population two, the researcher personally approached health workers who met the selection criteria, to request them to participate in the research project. The researcher explained the background, purpose and objectives of the research in the arrangements, ethical principles, and method of data collection and what was expected from them as participants as outlined in the letter of consent. The researcher arranged interview appointments for those who agreed to participate personally and confirmed appointments for interviews a day in advance.

The researcher was at the community health centres and sites of voluntary organization and was shown private rooms provided with three chairs; one for the researcher, one for the participant and one for the research assistant who recorded field notes and a small table for voice recorders. Two voice recorders were arranged with additional batteries as back up, the room was decorated and refreshments were arranged.

Having ensured that participants from both populations understood the information, it was checked by asking participants questions regarding information provided. They were then requested to sign a consent form (see Appendix H). It was stressed that the interviews would be recorded and that participation was voluntary and they were informed that if they wished to withdraw from the research at any stage, they could freely do so. Psychological support available was explained to participants (see Appendix G).

2.3.1.3.2 The role of the research assistant

She is trained and knowledeable about the topic and to take field notes.

Her role was explained to participants for ensuring cofidentiality.

Permission of her presense was obtained from participants.

2.3.1.3.3 The physical environment

Data was collected in a natural setting as the researcher was interested in studying the context of participants' experiences. All interviews took place at community health centres and sites of voluntary organization in private rooms to ensure privacy and confidentiality. The environment enhanced participation and fostered psychological freedom. The time and setting for the interviews was ensured to be convenient for both the participant and the researcher (Brink *et al.*, 2006:159). The researcher ensured that the private rooms were free of distractions, that they were comfortable and that the temperature, light condition and noise of cellular phones and of telephones were controlled and furniture was arranged to enhance rapport between the researcher and participants. Personnel at sites of voluntary organizations were asked not to cause any disturbance. An "interview in progress" sign was placed on the door so as to remind everyone in the site not to disrupt the interviewing process.

2.3.1.3.4 Method of data collection

First an exploratory interview was held for population one with one participant to test the question and to assess the skills of the researcher. After this interview the question had to be altered to ensure that relevant data is obtained and also that appropriate interview skills of the researcher are applied.

In-depth interviews were conducted with both populations (Brink *et al.*, 2006:120-121) focusing on experiences of caregivers implementing the PMTCT programme and perceptions of health workers regarding support for caregivers whilst coordinating the PMTCT programme during puerperium. The purpose of this method was to describe the experiences as they are lived and to capture study participants' "lived experiences" (Burns & Grove, 2006:55). A process of engagement was used (Cresswell, 2003:15) where a small number of participants are studied to develop patterns and relationships of meaning. This process was utilized by the researcher to gather information from caregivers implementing the PMTCT programme during the puerperium in order to understand participants' views.

Mediators recruited nine (9) participants who met the criteria from population one (see Appendix F). Two participants could not be interviewed as one had passed away during the weekend before the interview was to take place and one was on sick leave. Seven (7) participants were interviewed who met the set criteria. Participants who were interviewed were all females residing in the Rustenburg Sub-District of the North West Province. Interviews were conducted in private rooms of community health centres and sites of voluntary organizations.

For population two, in order to explore perceptions of health workers co-ordinating the PMTCT programme with regard to support provided to caregivers (see Annexure H), seven (7) participants were interviewed – also from the same sub-district and same community health centres and sites of voluntary organizations where the PMTCT programme was implemented. All interviews were held on scheduled dates, although in some sites of voluntary organizations the researcher had to wait for health workers to complete their daily routines, as only one professional nurse was on duty so that patients were not delayed – also for participant to be interviewed at the time when she was relaxed.

All interviews were conducted by the researcher personally for both populations and followed the procedure mentioned below:

- The researcher presented herself at the community health centre or site of voluntary organization as scheduled. She arrived on the time that was arranged, dressed in a simple manner, and was provided with a private room where she conducted the interviews.
- The researcher ushered participants in and welcomed them.
- The researcher introduced herself and the research assistant who was collecting field notes and then briefly stressed the purpose of the research.
- The researcher made the participant to feel comfortable and reassured regarding confidentiality.
- The researcher allowed the participant to read and sign the consent form with regard to voluntary participation (see Appendix H).
- The researcher checked the two voice recorders before commencement of interviews to verify that that they were in good working order and that they were switched on and were on recording mode and that the batteries were fully charged for recording purposes.
- The files recorded were saved as caregiver number and health worker number. This was done to ensure that data would be correctly identified, and it ensure anonymity of the data.
- When the participant was ready both voice recorders were switched on and it was ensured that they were on recording mode. The interview then progressed.

As described by Greeff (*in* de Vos *et al.*, 2005:293-294), the researcher applied the following interviewing tips and techniques to ensure an effective interview:

- Minimal verbal response – is a verbal response correlating with occasional nodding, e.g. "mm-mm", "yes", "I see" will indicate that the interviewer is listening.
- Paraphrasing – is a verbal response indicating that the interviewer will enhance meaning uttering participant's words in another form with the same meaning.
- Clarification – to get clarity on an unclear statement, e.g.:"Tell me more about….."
- Reflection – for a participant to expand more on the idea reflected back on what the participant had said, e.g. "So you believe that support is essential?"
- Encouragement – Encourage the participant to pursue the line of thought, e.g. " I find that marvellous. Tell me more".
- Comments – Add own feeling or idea to encourage the participant to elaborate further, e.g. "I always interpreted that ….."
- Spur – Mention something to challenge and spur the participant to say more, e.g. "But isn't it wrong that…….?.
- Reflective summary – Summarizes the participant's feelings, ideas and thoughts verbalized to see if you really understood what he/she said, e.g. "So what you are saying is……"
- Listening – Interviewers should have excellent listening skills.
- Probing – the purpose of probing is to deepen the response to a question in order to increase the richness of data obtained and give cues to participants about level of response desired.

Field notes – During the interview, field notes were written by the research assistant. These field notes consisted of personal, observational and methodological notes (Polit & Beck, 2004:381-384). After each interview the researcher and the research assistant discussed field notes of that interview conducted so that both agree on aspects that might affect research findings and that helped in data analysis (Polit & Beck; 2004:382-383) and they were marked with number of interview, date and time.

2.3.1.4 Data analysis

All the interviews recorded on the voice recorder were transcribed verbatim and analyzed. The method of open coding, as described by de Vos *et al.* (2004:346-348) was used to analyze data. The steps that were followed were:

- All transcripts were read to obtain an overall idea
- One transcript was selected and reread.
- Using words and sentences as unit of analysis, transcripts were read once more, and spoken words and sentences were underlined.
- Underlined words and sentences were trnsfered to the left hand column of the transcript together with concepts that were detected as categories.
- Own perceptions were written in the right hand column of the transcript.
- Thereafter read categories were transferred to the right hand column so as to identify main categories, sub-categories as well as redundant categories.
- Underlined words were transferred (in the participant's own words) to the table indicating the main categories, the sub-categories and further categories.
- These categories were finalized by working through the table again.
- Spoken words were translated into scientific language with the possibility that categorization could be refined and kept in mind.

Interviews with caregivers formed a set of data, and interviews with health workers formed another set of data.

A co-coder reached consensus with the researcher after independent coding took place with the purpose of identifying and comparing similarities of emerging themes. Consensus was reached with regard to themes and sub-themes to be finalized.

2.3.1.5 Literature control

Available literature and research reports were investigated to verify the results of this research and to highlight new insight gained from the research (Burns & Grove, 2006:95) and (Polit & Beck, 2004:94). [Data bases consulted: Nexus (NRF), SA Periodicals, Medline, Social Sciences Index, Academic Search Premier (Internet)]

2.4 CONCLUSION

A detailed description of the research design and method was given in this chapter. The next chapter deals with a discussion on the research findings and the literature control.

CHAPTER 3

DISCUSSION OF RESEARCH FINDINGS AND LITERATURE CONTROL

3.1. INTRODUCTION

In the previous chapters background regarding support to be provided to caregivers to enhance the PMTCT programme to mothers and babies during puerperium and a detailed description of the research methodology was provided. Research findings relating to the experiences of caregivers (Table 3.2.1) and perceptions of health workers regarding support to be provided to caregivers (Table 3.2.2) follow in this chapter. The research findings are supported by examples of direct quotes from the interviews. Comparison and confirmation of research findings with literature that exist is done by the researcher regarding support to be provided to caregivers

3.2. RESEARCH FINDINGS

Findings of the research from two populations resulted in the identification of five (5) main themes from population one of caregivers and five (5) main themes from population two of health workers. The themes emerging from both populations showed similarity. Discussions of the two sets of data will be dealt with separately accompanied by quotes.

Population 1: Experiences of caregivers

Themes and sub-themes regarding experiences of caregivers with regard to support to be provided to caregivers to enhance the PMTCT programme for mothers and babies during puerperium were identified as follow:

TABLE 3.1 EXPERIENCES OF CAREGIVERS REGARDING SUPPORT TO BE PROVIDED TO CAREGIVERS FOR IMPLEMENTING THE PMTCT PROGRAMME DURING PUERPERIUM

THEMES		SUB-THEMES	
3.2.1	**Personal support to caregivers**	3.2.1.1	Counselling support
3.2.2	**Financial support to caregivers**	3.2.2.1	Money needed for basic essentials.
		3.2.2.2	Provision of donations.
3.2.3	**Training for caregivers**	3.2.3.1	Training needs and gaps in knowledge identified.
		3.2.3.2	Specific training in PMTCT.
		3.2.3.3	PMTCT consultant to be available.
3.2.4	**Improvement of PMTCT services**	3.2.4.1	Provision of transport.
		3.2.4.2	Provision of resources and equipment.
		3.2.4.3	Quality PMTCT health care to be provided.
		3.2.4.4	Support groups for mothers in the PMTCT programme.
3.2.5	**Management to establish a caring environment**	3.2.5.1	Caring attitude to be displayed.
		3.2.5.2	To be respected.
		3.2.5.3	Rewards need to be provided

3.2.1 Personal support to caregivers

The need for personal support to the caregivers to be able to deliver quality PMTCT services to mothers and babies during puerperium is reflected in the need for counselling.

3.2.1.1 Counselling support

Most of the respondents mentioned the need for personal support in the form of counselling to enable them to handle problems they are faced with during home visits. These are the comments from the transcripts of the interviews:

"Support that I need is personal support ..... I deal with patients that die in my own hands and have to counsel them, I need to be counselled"

"I do not know how to put it .... But I need to be supported; I can be able to address our problems."

"These things hurt us when we meet mothers and babies where there is no support."

Literature confirms experiences of caregivers regarding importance of counselling as noted by Orner (2006:239) that caregivers need counselling intervention to enable them to provide emotional support to mothers, to instil hope or optimism as this will have a positive impact on their lives. This counselling will make a difference in their mental and physical health and it will contribute to better health results.

3.2.2 Financial support to caregivers

All participants raised the need for financial support which should be met with provision of money for basic essentials and the need for donations to sustain their services.

3.2.2.1 Money needed for basic essentials

All participants in this research mentioned that they are desperately in need of financial support. They need money to enable them to buy food for their own children. Most of the caregivers were dissatisfied with the stipend they are receiving. They wanted their stipend to be increased so that they can be able to care for their own children and meet their basic needs. These are comments made by caregivers regarding their financial problems and their need for extra financial support:

"Support that I need ..... for the years that I have worked here as a woman, I earn less money with children that I'm having that are attending school, small children still growing, school fees has to be paid, paying societies, to buy food to ensure that children receive food, if it was possible the money would be increased"

"To do my work I must be motivated to keep on, we must be given something to buy soap. When you work and you tell your employer that you do not have money, sometimes she can give you something, you need such a thing. This support is essential as it will keep you going and you know that when you work you get something"

"I have 12 years experience; presently I get something that will sustain me at least something that I can put in my mouth..... The most important thing that I need is money to buy food"

"If they can provide me with R1 500.00..... it will help me to buy food for my children, pay school fees, to come to work being presentable, to eat and also for me to look better."

"I must get something that will sustain me"

Kangethe (2009:27) stated that many caregivers are poor and have no source of income and attributed their poverty and low quality of care-giving to lack of income-generating activity or any form of employment. Caregivers need monetary support. The income they receive is low compared to rising costs; thus they wanted to be provided with reasonable payment so that their financial problems could be lessened. This is supported by Health and Development Networks (HDN) and Southern Africa HIV and AIDS Information and Dissemination Source (SAFAIDS) (2008a:8) who mentioned that most of the caregivers are poor and Government and NGOs do not provide sufficient stipend, allowances or remuneration. Caregivers want their employers to consider care-giving as an emotionally draining activity that should attract some form of incentive.

3.2.2.2 Provision of donations

One participant advocated for donations in the form of money or a vehicle which will enable them to render services. Another caregiver also advocated for the hospice to be maintained to provide continued service to clients and community members. These are comments made by one caregiver regarding the need for extra financial support:

".....If we can have two (2) Ventures; one for transferring patients and one for clinic patients....."

"If we can be assisted to maintain the hospice, we are currently in arrears with water and electricity bills ..... If we can be assisted with financial support"

Home-based care requires funds from communities and Government and resources need to be effectively utilized. Schneider and Russell (2000:15) as well as UNAIDS (2000b:28) argue

that there is a need for consistency of support from donors. Cameroon, Coetzee & Ngidi (2009:104) remind us that uncertainty was raised regarding continued funding, creating anxiety and lack of security to caregivers in the work they are doing, unless this funding is consistent.

3.2.3 Training for caregivers

Caregivers identified training needs and gaps in knowledge in specific areas related to care they have to render, they need to be trained specifically in PMTCT, and the availability of a PMTCT consultant as a form of support to upgrade their knowledge was stressed.

3.2.3.1 Training needs and gaps in knowledge identified

Most of the caregivers identified gaps in knowledge and identified the following areas to meet their training needs, namely first aid, medication, TB, HIV, basic nursing, communication skills, counselling skills and confidential matters. One participant mentioned that they need to be motivated so that they can be encouraged to do their work. The following direct comments were identified from the transcripts of the caregivers regarding their knowledge deficit:

"I need to be upgraded in TB and HIV as HIV and TB go hand in hand.....I need basic nursing training as sometimes I assist with vital ..... urinalysis.....What else? .....I really need first aid....."

"I need to be trained in medication ..... I must ensure that treatment is taken appropriately and to encourage patients to continue with it at home....."

".....to be trained in counselling and again this will enable us to approach patients appropriately as one will be knowledgeable about counselling and to approach patients with courtesy"

"I need more information ....."

"Support that I need is motivation ....."

Demmer (2006:103) stressed that caregivers expressed interest in developing their skills and indicated that when opportunities arise they should be afforded the opportunity to attend workshops so that they can be kept updated and motivated. Confirmed by Van Dyk (2007:63), it was emphasized that training plays a significant role in the management of

stress and burnout in caregivers. This was confirmed in a research by (Van Dyk, 2007:52) that caregivers are incompetent in counselling skills and lacked confidence in counselling as HIV counselling is complex and is different from other types of counselling.

Employers should implement comprehensive training programmes, which can include on the job mentoring, refresher courses and innovative workshops to upgrade skills of caregivers. It can be implemented where caregivers will support families to manage stigma and cope with long-term problems associated with HIV/AIDS. Similarly the National Guidelines on Home-Based Care and Community-Based Care illustrate that insufficient empowerment of caregivers has been identified as one of the challenges and training and development is one of three main pillars of home-based care. A training co-ordinator has to be identified and be available to address the training needs of caregivers. According to the curriculum for caregivers, they have to be trained in HIV/AIDS, TB, Counselling, Communication Skills, Infection Control, Social Support, Basic Nursing Care, Nutrition and Palliative Care (SA, 2001:7-10)

Kangethe (2009:26) stated that most of the caregivers have low or no educational background and the challenges associated with caring for HIV/AIDS clients call for some relevant skills. With little or no skill due to inadequate training most of these caregivers are not able to ensure good quality care. Ehlers and Lazenby (2007:218) stress the fact that motivated people have passion for their work, thrive on creative challenges and enjoy learning constantly. Individuals that are motivated have loads of energy, are optimistic even during setbacks and are committed to their employers and their work.

3.2.3.2 Specific training in PMTCT

Significant in this research is the need to be trained and developed specifically in PMTCT, to be trained in relation to the work that they are doing so that they can function appropriately. It is mentioned that they lack knowledge on PMTCT. The following direct comments were identified from the transcripts of the caregivers:

"I need to be trained in PMTCT ..... I do not have much knowledge about PMTCT; I need to be provided so that I know how to care for mothers and babies"

The Policy and Guidelines for the Implementation of the PMTCT Programme (SA, 2008:70) emphasizes that training in PMTCT should be ongoing and is the key component in the implementation of the PMTCT programme. The South African HIV & AIDS and STI Strategic Plan 2007-2011 (SA, 2007**c**:53) prioritizes scaling up coverage of the PMTCT programme.

3.2.3.3 A PMTCT consultant to be available

The need for a consultant in PMTCT was identified by one caregiver. The consultant can act as a resource person with matters relating to PMTCT as they do not have this type of a professional who will provide them with the necessary support when needed. The quote follows:

"With regard to treatment I have with TB I consult Mr ..... With problems I encounter but with PMTCT I do not get help ....."

"If there can be a person specifically for PMTCT ..... As professional nurses that I meet in this clinic are always different on different days"

The Policy and Guidelines for the Implementation of the PMTCT Programme (SA, 2008:68) recommends that PMTCT co-coordinators should be available in each district with capacity to implement and facilitate training to personnel to ensure that they have the necessary skills and ensure that there is meaningful community involvement.

3.2.4 Improvement of PMTCT services

Caregivers identified the need to be provided with transport, resources and equipment in order to improve quality care of PMTCT services.

3.2.4.1 Provision of transport

Most of the participants mentioned the need to be provided with transport to enable them to follow up mothers who have been discharged from hospital but do not come for follow-up. One caregiver identified the problems she encounters when she has to refer patients to hospital as their requests are not considered. This needs to be improved especially when it is urgently needed. The following are direct quotes from the interviews conducted with the caregivers:

"..... I need transport to follow up patients and trace mothers post delivery who are defaulting"

"We travel for long distances from one area to another. Sometimes we travel until late and this poses a danger to us, we encounter difficulties to reach some of these areas ..... if we can be provided with transport this will resolve our problems. It will take us to and fro and we will be safe"

"……..Ambulance people don't help me …….. ambulance drivers not willing to provide me with transport. They will say patients should use their own transport……. Ambulance people take time to respond and they do not respond to calls from caregiver"

"…….. we walk for long distance and we get tired ……."

"…….. I do visit areas that are far ……. Presently I'm using a taxi …….. our sister is using her own car …….. "

Literature study on caregivers (Orner, 2006:238; UNAIDS, 2000:28 & Whittier, Scharlac & Dal Santo, 2005:57) elaborated that transport is one of the identified gaps. Jones, Sherman & Varga (2005:469) confirmed that in South Africa, the issue of transportation access has been a factor affecting patients' ability to seek health care in a timely and regular manner and this affects the success of PMTCT services, especially for mothers and babies in remote areas.

3.2.4.2 Provision of resources and equipment

Some of the participants mentioned that they need to be provided with resources such as protective clothing to protect themselves against infectious diseases as they are at risk of being infected. Most of the participants advocated that they should be provided with food parcels that they can hand over to poverty-stricken people. Another caregiver emphasized the need for availability of water as a basic need for prevention of mother-to-child transmission and also for maintenance of personal and environmental hygiene. Water is also essential for preparing feeds if the mother has opted for artificial feeding and in some areas the unavailability of water impedes their functioning on a daily basis. One caregiver identified the need to be provided with a uniform for identification purpose and one mentioned that they share their resources with patients to provide for the needs of their patients. These are comments from the transcripts:

"…….. we need to be provided with protective clothing like gloves as we fear to be infected"

"As most of our patients are poverty stricken there is no food……. If management can provide us with food parcels"

"……. Our clients hardly have water in their yards……."

"Clients will tell you that they were unable to …….wash because of lack of water"

"……..she must keep herself clean, wash daily…… keep herself clean …… the woman should keep her environment clean and keep the baby clean"

"…….. here water is bought……."

"……..we struggle with water. If there can be a tank of water in the yard so that water is available, mothers will be able to care for their babies and if water is available everything is possible"

"I need uniform …… so that we can be appropriately identified"

"……..I sometimes use my money to visit these families …….. I go to an extent of using money from my family"

"…….. together with my colleagues we used our resources ……."

Akintola (2006:242) and Van Dyk (2007:52) supported the issue that quality is compromised due to inadequate resources in clinics and also at homes as caregivers are not provided with gloves, sanitation towels, bleach or incontinent sheets to handle patients adequately and they are in frequent and close contact with mothers' excreta such as vomitus, faesces, blood and other excreta and this exposes caregivers to HIV and TB infections.

ACESS (2008) declares that the South African Government has committed itself to eradicate poverty by providing food parcels and agricultural support and tools for food production to vulnerable households which is an obstacle in achieving Millenium Development Goal 4. Akintola (2006:244) also highlighted that inadequate food contributes to poverty of caregivers and low quality care in general. In studies undertaken by Van Dyk (2007:57) as well as Kangethe (2009:29), poverty of some patients contributed to their stress and this affects the implementation of health education messages concerning nutrition, proper hygiene, healthy living and adherence to medication for mothers that are poor.

One of the strategic goals of South Africa's Department of Health and Forestry (ACESS, 2008) includes provision of basic water services to all households within 200 meters radius which is a challenge. Supported by Kangethe (2009:27), availability of water is important for clients who are occasionally incontinent; some caregivers did not have water in their compounds which posed a problem when washing clients and their clothing. The need for continued availability of water was emphasized by AVERTa (2009:5) and SA (2008: 48) that in some instances mothers with HIV are advised not to breastfeed if the use of breast substitutes is acceptable, feasible and affordable which necessitate the need for continued water supply.

Van Dyk (2007:57) added that most of the caregivers felt sorry for their patients and gave them some of their own money. They even provided them with their own clothes.

HDS and SAFAIDS (2008b: 36) confirm that uniforms give caregivers an identity and visibility within the community and also make it easy for clients to approach and open up to caregivers about their HIV status. In addition, uniforms give caregivers a high sense of pride in the work they perform and uniforms also help to enhance the accountability of caregivers. Furthermore, uniforms equalize the economic diversity of caregivers and allow for cohesive presentation as a group, thereby enhancing team spirit.

One of the commitments of the Government of South Africa (ACESS, 2008) is to provide financial support to households with grants which include child support grant for households that earn R2 200/month, foster grant and care dependency grants which are specifically targeted for children. For one to apply for these grants, both children and caregivers must be South African citizens and residents and need to have a bar-coded identity document provided by the caregiver

3.2.4.3 Quality PMTCT health services to be provided

Some caregivers emphasized the need for campaigns to teach pregnant women to visit antenatal clinics in order for PMTCT to be commenced from the antenatal period. One caregiver emphasized the need for provision of identity documents to mothers who are unable to access grants. These are comments from the interviews:

"Myself as a caregiver, I request campaigns to teach pregnant women to visit antenatal clinics so that the can be tested and get treatment"

"They should be provided with health talks during antenatal period about PMTCT, these talks will prepare them for delivery and how to handle themselves"

".....there should be people who should specifically care for people without Identity Documents .....to get grants for their children"

In a presentation by Rasmeni on Prevention of Mother-to-Child Transmission awareness road show (North West Provincial Government, 2007:1) the emphasis was on efforts geared towards improving capacity and strengthening the PMCT programme by addressing challenges experienced. There must be continued mobilization and education of communities about PMTCT so that they can be involved and assist in the situation, thus antenatal clinics (the mothers) become a primary target as this will assist in the aspect of uptake improvement.

No literature could be found to ensure that mothers who are unable to access grants are provided with identity documents.

3.2.4.4 Support groups for mothers in the PMTCT programme

One caregiver identified the importance of establishing support groups for mothers on the PMTCT programme which will make their work easier. This is a comment from the interviews:

"These support groups will help them to be independent, to have their gardens, how to take treatment, avoid alcohol, not to use un-prescribed medication, to alleviate stress and not to visit witchdoctors.

Literature indicates that formation of support groups is an effective strategy to be implemented to manage burnout and stress among caregivers in dealing with mothers that are HIV positive. These support groups can be facilitated by various professionals such as social workers, psychologists and nurses who are experienced in this skill. These support groups will encourage caregivers to share their feelings and experiences associated with their work and enable them to identify ways of coping with stresses along with others who are in the same boat. (Demmer, 2006:104; Schneider & Russell, 2000:15).

3.2.5 Establishment of a caring environment by management

Management has to establish a caring environment by displaying a caring attitude, respecting caregivers and providing them with rewards to enhance their morale.

3.2.5.1 Caring attitude to be displayed

One of the caregivers stressed the concern regarding management on the uncaring attitude displayed by some supervisors and the significance of management to address their needs and concerns. They mentioned that they are not considered; occasionally they are shouted at by their supervisors. These are comments from the transcripts:

"Sometimes we try to solve problems but as a sister ..... you howl at us ..... We are not free ..... and this hampers us to discuss our problems ..... we are not open..... we are not open ..... as a sister you are harsh"

".....we need to be cared for ..... I need to be provided with love"

Nair and Campbell (2008:48) indicated that caregivers lacked skills and channels to liaise with their supervisors and they need to be continually supported and provided with regular feedback and guidance.

3.2.5.2 To be respected

Caregivers requested to be respected and recognized and their supervisors to treat them fairly. These are comments from the transcripts:

"Here we are cursed because we are not educated..... we are not considered here..... and this place is where it is because of our efforts. The river is flowing with good prospects. It is nice, we are not considered now"

"Management should provide us with support....."

Supervisors of caregivers should treat them with integrity, there should be sound mutual relationship between caregivers and there should be mutual respect between caregivers and supervisors as they represent management (Booyens, 2002:294).

3.2.5.3 Rewards need to be provided

One participant mentioned that the need to be provided with a rewards was essential and mentioned other sources of generating these rewards. These are comments made regarding the need for rewards:

"..... We do not get anything, everything that comes here is given to patients ....."

"..... as caregivers we used to sell these clothes donated to us and save this money. At the end of the year we used to share this money and have bonus for ourselves"

Rewards in the form of certificates, bonus, trophies and tokens should be provided to caregivers as a form of recognition. Van Dyk (2007:64) and Kangethe (2009:31) reported that caregivers in Namibia are provided with Christmas and Easter bonuses, a funeral policy, salary on NS100 per month as a token of reimbursement for whatever the caregiver is performing related to their duties and in Zimbabwe caregivers receive as an incentive a year's pocket money in a lump sum. In Kwa - Zulu Natal caregivers receive monthly supply of basic foods which include mealie -meal, beans, rice, sugar and tea after six months of satisfactory service. Ehlers and Lazenby (2007:230) point out that rewards reflect

management's attitude to performance of subordinates and influence the culture of the organization and leadership style and will change the behaviour of employees.

3.3 POPULATION TWO: PERCEPTIONS OF HEALTH WORKERS REGARDING SUPPORT TO BE PROVIDED TO CAREGIVERS IMPLEMENTING THE PMTCT PROGRAMME DURING PUERPERIUM

The themes and sub-themes that emerged from the data obtained regarding their perception of support provided to caregivers implementing the PMTCT programme during puerperium showed a remarkable similarity with those of the caregivers. The layout is depicted in Table 3.2 and is followed by a discussion on these themes and sub-themes:

TABLE 3.2 PERCEPTIONS OF HEALTH WORKERS REGARDING SUPPORT TO BE PROVIDED TO CAREGIVERS IMPLEMENTING THE PMTCT PROGRAMME DURING PUERPERIUM

THEMES	SUB-THEMES
3.3.1 Personal support for caregivers	3.3.1.1 Ongoing counselling to be encouraged.
3.3.2 Financial support for caregivers	3.3.2.1 Provision of money for basic essentials and better remuneration.
3.3.3 Training for caregivers	3.3.3.1 Problems, gaps and needs in training identified. 3.3.3.2 How training should be provided.
3.3.4 Improvement of PMTCT services	3.3.4.1 Provision of transport and material resources 3.3.4.2 Caregivers to be encouraged to continue with home-visits.
3.3.5 Management to establish a caring environment	3.3.5.1 Continued motivation. 3.3.5.2 Caring attitude. 3.3.5.3 Communication to be improved 3.3.5.4 Monitoring of health status of caretgivers and reinforcement of universal precautions.

3.3.1 Personal support for caregivers

Health workers identified that caregivers need to be provided with ongoing counselling to enable them to function effectively.

3.3.1.1 Ongoing counselling to be encouraged

Almost all participants mentioned the need for caregivers to be counselled as they are faced with emotional problems. Participants emphasized the need for psychological support and counselling to be ongoing as this counselling will help them to deal with psychological problems they are facing. Sometimes psychological support in some of the facilities is provided by ministers of religion and in some areas by psychologists and social workers. Most of the health workers stressed the need for ongoing counselling implemented consistently as in some areas this service does not exist at all. These are direct quotes from the interviews conducted with the health workers:

"Caregivers have their own problems, some are emotional because if they have problems they won't be able to render care....."

"Caregivers.....they do become psychologically affected you consult her, you discuss with her about referral to a psychologist ..... they verbalize their problems, from time to time they need counselling"

"Ongoing counselling will minimize their work ..... there won't be more people to be followed up and everybody will understand their work"

"Debriefing only, you explain problems together ....."

"Ministers of Religion from different Religious Groups, Good Samaritans pray for us ..... This is one type of support we get from spiritual leaders. There is a priest from Methodist church who comes periodically to provide counselling".

"Other problems. You will find that a person does not disclose, you will find that a person did not disclose to the husband, the family or whoever it becomes difficult for them even do

explain to the mother. Aside they will tell you that I did not tell my mother, my husband if family members want to find out what do they want here."

Disclosure of HIV status and ongoing counselling are encouraged as this will assist caregivers in their work. The following are direct quotes from the interviews conducted with the participants:

AVERTd (2009:3) remarks that most mothers are not willing to disclose their HIV status due to stigmatization associated with the disease and this will impede the support caregivers should provide to mothers. If mothers disclose, this will enable caregivers to provide them with support, to urge them to practise safer sex and also encourage partners to get tested, and this will make the work of caregivers less heavy and minimize their stress. AVERTd (2009:5) indicated that disclosure will allay anxieties or fears that result due to misinformation and advocated that the mothers be advised on all aspects of HIV, which will enable mothers to feel that they are not alone.

3.3.2 Financial support for caregivers

Most of the health workers advocated the need for caregivers to be provided with money for basic essentials and the need for remuneration.

3.3.2.1 Provision of money for basic essentials and better remuneration

One health worker stated that caregivers need to be provided with money to meet their basic needs such as food and transport. Most of the participants stressed the need for remuneration to be improved to act as a retention and recruitment strategy for caregivers. These are the comments made by health workers:

".....with them they should be provided with money for food and transport, whilst working and travelling"

"If they can be given something and we can be able to retain them....."

"If they can be supported moneywise, they are part of health workers if they can be made to feel that they are part of us ....."

Literature confirms this view regarding the importance of incentives, as quoted by Huczynski (in Kangethe (2009:31) that the purpose of an incentive is to facilitate positive change or behaviour that will result in increased productivity. Inappropriate rewards sabotage and kill morale resulting in lowered productivity. Cameroon *et al.*, (2009:103) stated that care provided by volunteers is regarded as a cheap option to an extent that the remuneration they receive does not enable them to afford basic essentials. Supported by Demmer (2006:103) salaries offered by NGOs versus Government Departments are extremely low and were viewed as demoralizing.

3.3.3 Training for caregivers

Problems, gaps and needs in training for caregivers were identified and training that needs to be provided was tabled and how this training should be provided.

3.3.3.1 Identification of problems, gaps and needs in training

Problems in training were identified as a lack of specific training in PMTCT, limited funds and insufficient training. Gaps in knowledge, co-ordination, lack of political commitment in training and needs in training were identified. Health workers identified training needs and gaps in knowledge of caregivers in the following areas: ARVs, HIV, TB, confidentiality, dual therapy, feeding, how to care for patients and reporting of problems. These are direct quotes from the interviews conducted with the health workers:

"Nobody is trained in PMTCT specifically."

"..... training depends on availability of funds .....we depend on donors for funds and budget.....there is a need"

"**.....**is this debriefing sufficient to meet their daily need?.....No, it is not sufficient. She needs skills and also ideas"

"Co-ordinate with NGOs to help in training and provision of stipend."

".....who should provide this training?..... Department of Health"

"Training on confidentiality although it has not started .....coordinate with NGOs to help in training .....training in PMTCT itself, Dual Therapy, Feeding so that they understand when they do follow up to mothers and babies"

" They also need to be taught about care of ARVs because caregivers have a tendency of allowing patients to borrow one another's medication .....if they know that these patients use the same medication"

"Perseverance ..... so that should handle patients appropriately."

"If there is something beyond their scope, they must report back ..... If she is unable she reports and we make follow-up."

PMTCT programmes for caregivers to be able to achieve high success rates should have well trained supportive staff to ensure confidentiality, and be backed up by effective HIV testing and counselling programmes and good quality HIV/AIDS programmes (AVERTa, 2009:9). Thus caregivers need to be empowered on these issues.

Literature indicates that in other provinces in South Africa such as Limpopo and Mpumalanga, community outreach efforts were implemented where UNICEF sponsored workshops to encourage community members to be engaged in the PMTCT programme. In North West Province, Life Line was contracted to train lay counsellors but it did not include caregivers (Dudley *et al.*, 2003:60-81).

AVERTc (2009:5) explains that better training, greater support and motivation can improve efficiency of existing staff and will boost the morale of the caregivers. In provision of training there should be co-ordination between formal and informal sector. Caregivers need to be provided with appropriate training, training equipment and personnel to provide training, and training needs should be determined by caregivers themselves (SA, 2001:21).

SA (2008a:70) alerts one to the fact that caregivers also need to be trained in Dual Therapy, Infant Feeding, Data Management Process of the PMTCT programme, Nutrition and what should be covered in the training for PMTCT.

3.3.3.2 How training should be provided

One participant identified the need for caregivers to have regular workshops which should be ongoing and training to be correlated with theory and practice and assessment to be done at the end of training to assess caregivers for competency in the skills they have acquired. The following are supporting statements during interviews, confirming comments of health workers:

"..... As a junior I will arrange weekly workshops with caregivers to teach them about confidentiality. Some can be taught on the spot and these workshops have to be ongoing....."

"…….. teaching should be practical ……."

"There should be a period where they are provided with theory and practice and be assessed on what they have done"

Orner (2006:239) are of the opinion that caregivers need support in the form of training to enable them to provide optimal caring work. As confirmed by AVERTc (2009:5), better training, greater support and motivation can improve the efficiency of caregivers. If caregivers are not equipped with the necessary and required knowledge and skills they will not be able to function and cope as part of the multi-disciplinary team and they will not succeed in their function.

3.3.4 Improvement of PMTCT services

Quality PMTCT services need to be provided by providing adequate transport and material resources to caregivers.

3.3.4.1 Provision of transport and material resources

Health workers stressed the need for caregivers to be provided with transport to follow up patients and to reach areas that are far, and Government should provide this transport. These are comments from the transcripts:

"This transport will assist them to reach areas they are working at"

"Transport is essential for home-visit purposes as most of the places are not reached"

Poor infrastructure and lack of affordable transport is one of the difficulties in accessing care (Orner, 2006:238) confirmed in HDN and SAFAIDS (2008b:8). Caregivers travel long distances without shoes and take a long time before being replenished.

Caregivers need to be provided with material resources such as milk and medication to provide to mothers and babies in need, also stationary for record keeping purposes and with uniforms. These are direct quotes from the interviews conducted with the health workers:

"They should be provided with milk which they can give to mothers in need …….. also with medication"

"They should be provided with uniform, so that they are visible……"

"They need to be provided with stationary to write to keep records of mothers for reference, report their activities and problems they face"

Nair and Campbell (2008:48) identified that with low literacy levels and limited access to pen and paper, caregivers battled to compile reports and these reports need to be discussed with their supervisors so that they can be advised on how to address numerous problems they report.

3.3.4.2 Caregivers to be encouraged to continue with home visits

Health workers should encourage caregivers to visit mothers and babies and provide PMTCT services on a continued basis and if problems are identified they should report and health workers would intervene on problems identified. These are the comments made by health workers:

".....caregivers are the ones that are doing home visits and if there are problems they should report"

".....from our side, we go with them if there are problems, they report back"

Some women who test positive do not go to the clinics for follow-up and they fail to take drugs they have been given. This might be due to negative experiences they had interacting with clinic staff or they may have been poorly informed about HIV transmission and how it can be prevented; thus continued home visits are necessary so that mothers can be assisted (Averta: 2009:8).

3.3.5 Management to establish a caring environment

Management needs to keep caregivers continually motivated, and to display a caring attitude, they must give attention to the needs of caregivers and get mechanisms in place to monitor the health status of caregivers and reinforce universal precautions.

3.3.5.1 Continued motivation

Some participants who are managing facilities mentioned that management of health facilities organize Care of the Carers Function on an annual basis where caregivers are motivated by motivational speakers. These are direct quotes from the interviews conducted with the health workers:

"We've got Care of the Carers function annually..... Management invites motivational speakers, they motivate us on any topic and Ministers from all angles motivate us, that day we are treated like queens and kings"

Cameroon *et al.*, (2009:105) suggest that debriefing and team building sessions be provided and caregivers be allowed to participate in the decision-making process in their place of work.

3.3.5.2 A caring attitude

One health worker stressed the need for management to be visible, show appreciation for the work caregivers do, as they rarely do this, and for caregivers this is essential and of significance. These are the comments made by health workers:

"'Let them come down, visit the clinics, let the caregivers be made aware that they value the work they do"

"They should be given their rights, they should feel like people"

Van Dyk (2007:51) identified that caregivers often experience frustration, anger, inadequacy and helplessness because of organizational factors due to lack of practical support of supervision and mentoring.

3.3.5.3 Communication to be improved

Some health workers stressed the need for management to address the needs and concerns of caregivers. Continuous encouragement is essential and they should have regular meetings with stakeholders to discuss progress with their work and problems and challenges they are faced with. They should interact with other caregivers in order to share ideas. These are direct quotes from the interviews conducted with the health workers:

" .....we should always be willing to listen to their feelings ....."

'..... we have outings with them ..... we have regular meetings with them.....we send them to meetings with other caregivers....."

"They have meetings with other stakeholders ..... most of the time they discuss about progress..... things we need.....:"

Van Dyk (2007:64) emphasized that communication between employers and caregivers should be open, and frequent meetings to discuss policy and sharing of problems are all important. Working as a multi-disciplinary team is an effective way of protecting staff from stress.

3.3.5.4 Monitoring the health status of caregivers and reinforcing universal precautions.

One participant emphasized that the health status of caregivers should be monitored and evaluated regularly, which is unique and significant to this research which is done in this clinic but not other clinics. They should be motivated and encouraged to go for HIV and TB tests as they are vulnerable and at risk. After these tests appropriate interventions should be done and they should be referred to access health care. They are advised to apply universal precautions so that they practice safely and are protected from being infected. These are the comments made by the health worker regarding the issue:

".....every 3 months we encourage them to go for TB tests and we encourage them to go for VCT ..... they should know their status, especially related to HIV. If diagnosed .....We send them to Wellness for follow-up and those with TB we refer them to the clinic"

"Specifically related to infectious diseases, infection control ..... how to wear protective clothes so that they protect themselves"

Van Dyk (2007:64) believes that employers must create a safe working environment and should ensure that a clear policy on HIV testing, counselling and post-exposure prophylaxis is in place.

3.4 CONCLUSION

The findings of the research and literature control with regard to experiences of caregivers and perceptions of health workers with regard to support to be provided to caregivers during puerperium to enhance the PMTCT programme showed similarity in both populations. Findings were discussed in accordance with their different themes and sub-themes with unique findings in this research highlighted. Conclusions were that caregivers need to be provided with personal support in the form of counselling, financial support to afford basic essentials and remuneration, training to be provided, PMTCT services to be improved and management to establish a caring environment. In the next chapter, conclusions and

limitations of the research will be discussed. Focus on recommendations with regard to development of structure of support for caregivers to enhance the PMTCT programme for mothers during puerperium will be discussed as well as recommendations for nursing education, nursing research and midwifery practice.

CHAPTER 4

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS FOR NURSING EDUCATION, NURSING RESEARCH AND MIDWIFERY PRACTICE

4.1. INTRODUCTION

The research findings were discussed in the previous chapter. Findings of the research were supported by direct quotes from interviews with participants. Conclusions from the research findings, limitations of the research and recommendations for nursing education, nursing research and midwifery practice will be discussed in this chapter with reference to the formulation of guidelines in maternal health with regard to support to be provided to caregivers to enhance the quality of the PMTCT programme during puerperium.

4.2. CONCLUSIONS

The conclusions are based on the results obtained from the two populations, on field notes of the researcher and the assistant as discussed in the previous chapter as well as on supportive literature. Conclusions relating to experiences of caregivers and perceptions of health workers with regard to support to be provided to caregivers to enhance the PMTCT programme during puerperium will be discussed in accordance with the five main themes as reflected in Table 3.2.1

4.2.1 Personal support to caregivers

Caregivers need to be provided with personal support as they are faced with emotional problems which impede their functioning. Health workers are able to identify emotional

problems and they are able to have one–on-one consultations with caregivers, but this seems not to be effective – caregivers need to be counselled. Besides counselling it was not clear what other type of support they needed, but they were overburdened with problems. Although spiritual support provided by Ministers of Religion exists to solve their problems, caregivers are not aware of support structures nor of those provided in the form of counselling by social workers and psychologists.

4.2.2 Financial support to caregivers

- **Provision of money for basic essentials**

The harsh economic environment is impacting negatively on caregivers as they cannot afford basic commodities. This situation is aggravated by high inflation. Stipends offered by NGOs and Government are extremely low and often inconsistent and depressing for caregivers. These stipends are low in relation to the years of service they have worked. They do not have foodstuffs for themselves and their own families. They lobbied to be provided with reasonable, better remuneration but some caregivers, especially those with a matriculation certificate, have left this work for better job opportunities.

- **Provision of donations**

Some of the participants advocated for donations in the form of money for the maintenance of the hospice with water and electricity and transport which will enable them to provide PMTCT services, as there was inadequate funding for doing just that. Funding in some facilities is provided on a contractual basis. Hence when the contract is about to expire it causes caregivers to lack security as they fear that their stipends will not be provided.

4.2.3 Training for caregivers

The two populations identified similar problems regarding training for caregivers. Caregivers are interested in developing their skills and knowledge pertaining to their work, but training and development is not implemented adequately. They are not equipped with the required information and are thus not able to function with members of the health team. It appears that appropriate training is not implemented due to unavailability of funds. Lack of training has been identified by caregivers as one of the obstacles that affect their performance and their confidence to be able to perform their daily activities. The need for empowerment of caregivers was indicated by health workers who mentioned the responsibility of Government and the Private sector with regard to committing itself to this aspect. The researcher

identified the need for all stakeholders in employment of caregivers in any sector to ensure that caregivers are empowered so that they remain motivated and productive in their work.

4.2.4 Improvement of PMTCT services

- **Provision of transport**

Lack of transport is a major problem in following up mothers. This does not only affect follow up but also the referral system of the PMTCT programme. Due to lack of transport, caregivers end up using public transport which they cannot afford. This results in caregivers travelling long distances and this affects the effectiveness of the referral system. Caregivers highlighted lack of transport as a major obstacle. This aspect was supported by health workers who identified and stressed the urgency of provision of transport. The researcher observed that transport meant for referring mothers in need to other community resources was insufficient, and that this need was critical.

- **Provision of resources and equipment**

Fear of infection through coming into contact with excreta and secretions of mothers affected by HIV/AIDS is a major obstacle in providing care. Caregivers are not provided with adequate protective materials such as gloves. Furthermore, their care packages are ill-equipped and occasionally non-existent for use when they visit mothers at home. They end up using plastic bags to handle patients as they cannot leave mothers un-attended. This signifies caregivers' willingness to utilize available resources. On the other hand, they might not be effective in protecting themselves against infections.

Poverty is a common factor identified with most of the mothers and babies on the PMTCT programme; thus food security is a challenge for the affected family. Caregivers have to deal with mothers who are unable to afford basic food essentials. Thus caregivers advocated for Government to provide mothers with food parcels. Availability of food is essential, as some of the mothers have to take medication which they cannot take on empty stomachs so as to minimize the side-effects of ARVs. Apart from this, mothers on the PMTCT programme need to take a nutritious diet, which is a scarce commodity for some families.

Caregivers raised the lack of access to water to households in areas where they are performing their work. There are diminished water resources and in some areas no water is available whatsoever. Lack of water puts mothers at risk of being affected by other illnesses associated with poor hygiene. Caregivers stressed the need for the supply of quality and safe water for maintaining personal and environmental hygiene as being critical in impoverished

communities. Having water is a basic human right, it should be available free of charge, it should be feasible for families to get access to water – sustainably and adequately. This water should be made available to public places such as sites of voluntary organizations for constant supply of water but costs involved were not stated clearly.

Sufficient funding needs to be provided to NGOs so that uniforms can be given to caregivers, since the uniforms they wear are bought from their own money and are not identical. Caregivers need uniforms for identification purposes and for providing them with a sense of belonging and also for them to be respected by community members.

Access to child support grants is an obstacle due to lack of Identity Documents, especially for mothers who are on the PMTCT programme, and not South African citizens. Some of these mothers might not have the knowledge to acquire permanent citizenship of the country, which brings about that they are not eligible for these grants. They therefore need to be referred to appropriate community resources to acquire the relevant documents.

4.2.5 Lack of a caring environment

Caregivers indicated impaired communication between them and their supervisors, since they were not treated with respect and some of the supervisors were harsh on them. Caregivers felt they do not add value to their service, since management does not consider their efforts in their place of work, because supervisors do not approach them during visits to acknowledge the work they do. On the other hand, management does identify the role of caregivers and arranges annual functions to recognize their efforts, but from the caregivers' perspective this seems not to be effective and not to be making any impact. Health workers advocated for evaluation of the impact of this initiative by management to establish whether or not it is of value.

4.3. LIMITATIONS OF THE RESEARCH

The researcher experienced and observed the following shortcomings in this research:

Most of the caregivers interviewed were from one voluntary organization as it is the only one rolling out ARVs to pregnant women, and few were interviewed from clinics in the government sector in the Rustenburg sub-District of the North West Province; hence the findings cannot be considered representative of caregivers in the region.

Participants in management structures could have been included as population three, with the aim of gathering their inputs related to support to be provided to caregivers implementing the PMTCT programme. This could have assisted the researcher with regard to identifying

support available to caregivers so as to determine obstruction in the provision of support to caregivers.

4.4. RECOMMENDATIONS FOR NURSING EDUCATION, NURSING RESEARCH AND MIDWIFERY PRACTICE.

Subsequently, a discussion on recommendations for nursing education, nursing research and midwifery practice follows. Data of this research and conclusions drawn from it will be made as form of reference.

4.4.1 Recommendation regarding nursing education

- One of the goals of the new South African Anti-Retroviral Treatment Guideline (SA, 2010) is to contribute to strengthening public and private health sector capacity to deliver high-quality integrated health and wellness services. This has to be achieved by providing technical assistance and mentorship (Torpey *et al.* 2010:16), which should be provided by the Department of Health and NGOs by coordinating with the PMTCT consultant who will act as a resource person in every district. This training to be coordinated in consultation with HIV/AIDS/TB Directorate so that the PMTCT programme is implemented uniformly across the board.

- There should be political commitment by all with regard to provision of training.

- PMTCT guidelines to be incorporated in curriculum of comprehensive course of nursing to train caregivers.

- Regular refresher courses supported by HDN and SAFAIDS (2008b: 39) incorporating new developments in HIV/AIDS-related issues to be provided to caregivers.

- Budget for training to be available and budgeted for annually by managers of NGOs and Department of Health, and funds also to be secured with funders locally and internationally through appropriate channels to facilitate

implementation of the training programme. If funds are provided they should be managed appropriately by stakeholders (HDN & SAFAIDS, 2008b: 27 -28)

- Managers in training institutions should ensure that training is linked to the Department of Labour's National Skills Development Strategy (Schneider *et al.*, 2008: 6), which includes accreditation to the community-based training through structured learnership, as this is not implemented in most of the facilities where training is implemented.

- Training for caregivers should be provided in terms of the National Qualifications Framework, as registered by the Department of Health in 2006 (Cameroon *et al.*, 2009: 105), so that training provided will create the possibility of career pathways for caregivers as mid-level health workers. This will motivate caregivers.

4.4.2 Recommendations regarding nursing research

There is a need for further research in the field of expanding PMTCT services in communities, and research should be done in the following areas:

- Perceptions of the recipients of the PMTCT programme.
- Role of PMTCT consultants in providing PMTCT services at district level.
- Current support system provided to caregivers and health workers implementing the PMTCT programme in the country.
- Integration of PMTCT services between the public and private sector at community level.
- Problems and challenges faced by managers in implementing support programmes for caregivers in both the public and private sectors.
- The impact of the new Anti-Retroviral Treatment Guideline on reducing HIV/AIDS with a view to reduce mortality associated with non-pregnancy-related infections.

4.4.3 Recommendations for midwifery practice

Recommendations for Midwifery practice pertain to recommendations as stipulated under the objectives of this research with a view to formulate recommendations in maternal health to

provide a structure of support for caregivers to enhance the PMTCT programme during puerperium so that they can provide quality PMTCT services.

4.4.3.1 Recommendations regarding personal support to caregivers

- Stress management classes, motivational talks, support sessions and consultation with psychologists (Torpey *et al.*, 2010:9), which are not utilized, should be fully utilized. These are ways of alleviating strain placed on caregivers, ways of avoiding cases of burnout and ways of increasing the hopes of the caregivers. These sessions should be ongoing and can be held on an individual or group basis. Caregivers should be made aware of the existence of these services and that they should be utilized when they need it. Health workers to identify emotional problems and assist caregivers with referral to these services.

- Debriefing sessions, as recommended by Orner (2006: 237-239), should be provided, which should focus on anger, death, loss, grief and depression to provide caregivers with skills to cope with emotional problems, and personal growth to be conducted, during which caregivers look into their own needs in order to understand their own feelings, fears, ability to communicate and to work more effectively with others.

- Caregiver networks, as recommended by Pallangyo (2009:32), to be strengthened, structured and supported by Government and NGOs to provide the necessary support structures that would assist caregivers in fulfilling their roles. Team building sessions and platforms to be created where caregivers liaise with other caregivers to share their problems and these to be appropriately planned and organized

- Strategies to be developed to attend to emotional needs of caregivers with policies developed and in place and regularly updated and reviewed.

4.4.3.2 Recommendations regarding financial support to caregivers

- As recommended by HDN and SAFAIDS (2008a:11), HDN and SAFAIDS (2008b:8) and Schneider *et al.,* (2008: 11), Government and NGOs should set aside funds to provide meaningful allowances to caregivers, and caregivers to be provided with a fixed income.

- Local donors from the mines, for instance Anglo Platinum and Impala Platinum, to be secured, since Rustenburg is a mining town, also as a commitment to their social responsibility, and Government (HDN & SAFAIDSb, 2008:8), especially Department of Trade and Industry, to equip caregivers with income-generating projects to enable them to afford their own essentials.

- Caregivers to be integrated in the health system with application of the Labour Relations Act of 1995 considered (Bezuidenhout *et al.*, 2007:30), to protect caregivers against unfair labour practice. Implementation of this act will ensure that caregivers are provided with better remuneration and their remuneration to be improved regularly and secured similar to those of other public servants.

4.4.3.3 Recommendations regarding training of caregivers

- The new *South African Anti-Retroviral Treatment Guideline* (SA:2010), which came into effect on 1 April 2010, necessitates emphasis of training of caregivers in PMTCT. This should be intensified from the antenatal period to enable caregivers to assist in identifying mothers who need ARTs or ARVs for them to be rolled into the PMTCT programme, enable them to identify side effects of the drugs, adherence to medication during the ante and postnatal period and enable caregivers to assist in referral of mothers with HIV/AIDS Training in PMTCT will empower caregivers so that they implement the programme they are knowledgeable about, develop their existing skills and enable them to function to required standards.

- Training in interpersonal skills is critical so that caregivers can provide emotional support to mothers and refer them for counselling and to be incorporated in the curriculum of caregivers including updated relevant information.

- Training of caregivers in PMTCT will assist in reducing mortality associated with nonpregnancy-related infections, as this is one of the recommendations in reducing maternal deaths in South Africa, according to *The Saving Mothers Report: Third Report on Confidential Enquiries into Maternal Deaths* (SA, 2006a 176). This training is also critical as one of the goals of the new *South African Anti-Retroviral Treatment Guideline* (SA, 2010) is to be integrated into Mother and Child Health Services, HIV, TB and wellness.

4.4.3.4 Recommendations regarding improvement of PMTCT services

- Plans must be made to expand the PMTCT programme (Health Systems Trust, 2006:13). Department of Health at District level must ensure that CBOs and NGOs are involved in implementing the PMTCT programme at community level. Meetings at community level to be held to discuss how best collaboration between Government and NGOs can be enhanced.
- Transport and travel allowances to be provided on a monthly basis, depending on reports submitted. If no reports have been submitted, no allowances will be provided. Public sector transport to be revitalized. Another alternative would be to explore a strategy where tenders can be made available to local community members to provide transport to caregivers when needed.
- Government and NGOs to look into the feasibility of training caregivers in the importance of universal precautions and making home-based care kits available to HIV/AIDS-affected households These home-based care kits should be packaged with soap, gloves, bandages and simple pain killers, and caregivers should be allowed to take them home. This was explored by HDN & SAFAIDSa 2008: 37) and should be applied within the specific context of the Bojanala region of the Rustenburg sub-District in the North West Province.
- Food security in the form of food parcels to be provided for low-income households to enable them to adhere to treatment and alleviate poverty (Pallangyo, 2009: 32). Criteria should be set by means of which individual households are assessed for vulnerability in order to receive food parcels. PMTCT programmes should assist HIV positive mothers to supply them with free supplies of infant formula. This issue to be adequately addressed; thus the Department of Health and Social Development, the private sector and communities need to develop a strategy to meet the demands of vulnerable families.
- Consultations should be done with chiefs, mayors and councillors in every district and sub-district so that communities in need of water and electricity are provided with these services in order to improve the quality of life of communities (MAP, 2009:7 and HDN & SAFAIDS, 2008b:8). Water should be available to poverty-stricken communities free of charge and this to be expanded to ensure good and

hygienic provision of care to enable caregivers to implement the PMTCT programme.

- The Occupational Health and Safety Act of 1993 (Bezuidenhout *et al.*, 2007:32) stipulates that employers should provide a healthy and safe working environment by providing caregivers with protective equipment such as gloves when they visit mothers and that they should be provided with regular training on the use of protective materials.

- Managers need to manage organizations appropriately by providing resources in their organizations. They should ensure that there are reliable and improved supply chains of resources that should be integrated in the systems serving maternal and child health programmes. A list of essential equipment to be developed, as well as kits and an ordering system to ensure a consistent supply of necessary equipment and supplies. A specific person/department to be appointed to manage supplies and kits so that they are constantly available.

- Uniform or uniform allowance as recommended by HDN & SAFAIDS (2008b: 36), to be provided to caregivers by their employers to enhance their esteem.

- Department of Home Affairs and Social Development should be consulted to assist in providing Identity Documents to mothers and families with orphans that are eligible, also by using Mobile Home Affairs offices for areas that are far to reach (ACESS,2008)

4.4.3.4 Recommendations regarding establishment of a caring environment

- For caregivers to accept authority of management, as recommended by Bezuidenhout *et al.*, (2007:53), they expect their supervisors to project a caring attitude towards their subordinates. They need to make an effort to respect them as individuals and to create a sense of caring within the organization. Supervisors should display a caring attitude by taking the needs of caregivers into consideration, by creating a caring environment, guiding, interpreting, clarifying, adapting and evaluating situations.

- Caregivers should be recognized as individuals with potential, enabling them to contribute to the PMTCT programme they are implementing. Different leadership styles of supervisors which affect appropriate performance of caregivers should

be addressed in leadership courses or exercises during in-service training (Bezuidenhout *et al.*, 2007:53).

- Opening up and strengthening communication as recommended by Bezuidenhout *et al.*, (2007:41) by creating forums for talking about and trying to solve work-related problems, in order to improve productivity, improve quality of work situations and explore ways of improving the PMTCT programme, creating an environment where caregivers should feel that management is interested in them and encouraging a feeling of belonging and participation in the PMTCT programme.
- Caregivers are regarded as employees as they receive remuneration and they assist in conducting business of an employer. They should be provided with benefits as stipulated in the Basic Conditions of Employment of 1997 (Bezuidenhout *et al.*, 2007:28-29) such as payment for overtime, working over weekends and public holidays and also to be provided with and all types of leave such as annual, sick, maternity and family responsibility leave.
- System of rewards and incentives should be established to retain caregivers. Incentives might include further training, honouring caregivers at community gatherings, providing awards for outstanding performance. Caregivers might be supplied with T-shirts, bags, umbrellas and badges. They also need recognition from senior managers that their work is recognized and valued.
- To increase the morale of caregivers Cameroon *et al.*, (2009: 105) and HDN and SAFAIDS (2008a:14) recommended that debriefing sessions be arranged by management to build the morale of caregivers.
- Strategies for quality assurance to be developed and implemented, and evaluated for adherence to standards as they are not existing.
- Cameroon *et al.*, (2009:102) recommended monitoring and supervision of caregivers to be enforced so that they function within their their job description.

4.5. CONCLUDING REMARKS

The objectives of this research were attained, namely to explore and describe experiences of the caregivers and perceptions of the health workers with regard to support given to caregivers implementing the PMTCT programme during puerperium. This resulted in the

formulation of recommendations for a maternal and child health-care programme to develop a structure of support for caregivers to enhance the implementation of the PMTCT programme during puerperium.

In-depth interviews were utilized for data collection, and data was analyzed by the researcher with the assistance and guidance of an independent co-coder. The findings of this research described the experiences of caregivers and perceptions of health workers with regard to support to be provided to caregivers to enhance the quality of the PMTCT programme during puerperium. Literature was utilized to confirm the findings. Findings that were unique in this research were highlighted.

It can be concluded that caregivers during puerperium need to be provided with support to enhance the PMTCT programme. Health workers also shared the same views with regard to support to be provided to caregivers to enhance the PMTCT programme during puerperium. Recommendations of this research were made for nursing research, nursing education and nursing practice. Recommendations were formulated for a maternal and child health programme to develop support structures for caregivers to enhance the PMTCT programme during puerperium.

These recommendations will enhance the establishment and implementation of a support system to be provided to caregivers so as to provide quality PMTCT services. This will assist Government, the private sector, managers and a PMTCT co-coordinator to provide a support system and improve the implementation of the PMTCT programme.

From the research it has been identified that support provided to caregivers is minimal and this needs to be intensified to improve their performance and productivity.

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APPENDIX A

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN BOJANALA HEALTH DISTRICT

Prof M Lowes

North-West University Ethics Committee

Potchefstroom

2621

Dear Prof Lowes

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN BOJANALA HEALTH DISTRICT

I am currently registered as a learner for the MCur (Midwifery and Neonatological Nursing Science) degree at North-West University (Potchefstroom Campus). As part of the degree I need to conduct research and my topic is "Support for caregivers during puerperium to enhance the PMTCT programme". Ethical approval is requested from the Ethics Committee of North-West University to conduct this research.

The purpose of the research is to:

- explore and describe experiences of caregivers during puerperium implementing the PMTCT programme.
- explore and describe the perceptions of health workers with regard to support for caregivers during puerperium implementing the PMTCT programme.
- formulate recommendations for the maternal and child health programme to develop a structure of support for caregivers during puerperium to enhance the PMTCT programme.

In order to achieve these objectives, in-depth interviews will be conducted with caregivers providing postnatal care to mothers and babies living with HIV/AIDS in Bojanala region, Rustenburg Sub-District in the North West Province.

Criteria for inclusion are as follows:

- voluntarily participation
- to be interviewed and to be recorded on audio-tape
- currently providing home-based care during puerperium to mothers and babies living with HIV/AIDS
- being able to communicate in English or Tswana

The interviews with those who agree to participate in the research will be conducted during June 2008. It will be conducted in private rooms at the clinics and will last approximately 45 minutes to one hour per participant.

Anonymity and confidentiality will be maintained in all research proceedings. Your timeous response will be appreciated, which will enable me to make further arrangements.

If more information is needed with regard to this research, please contact me at the numbers indicated above.

Yours faithfully

.....

MM KHUNOU (Researcher)

.....

MRS E VAN DER WALT (Supervisor)

MS MM KHUNOU (Researcher)

MRS E Der Walt (Supervisor)

MRS A DU PREEZ (Co-Supervisor)

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

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Faks: (018) 299-4910
Web: http://www.nwu.ac.za

Mrs. E van der Walt

Ethics Committee
Tel +27 18 299 4850
Fax +27 18 293 5329
Email Ethics@nwu.ac.za

21 Oktober 2008

Dear Mrs Van Der Walt

ETHICS APPROVAL OF PROJECT

The North-West University Ethics Committee (NWU-EC) hereby approves your project as indicated below. This implies that the NWU-EC grants its permission that, provided the special conditions specified below are met and pending any other authorisation that may be necessary, the project may be initiated, using the ethics number below.

Project title: Support for caregivers during puerperium to enhance the PMTCT programme

Ethics number:

N	W	U	-	0	0	6	8		-	0	8	-	A	1
Institution				Project Number						Year			Status	

Status: S = Submission R = Re-Submission, P = Provisional Authorisation, A = Authorisation

Approval date: 1 September 2008 **Expiry date**: 31 August 2013

Special conditions of the approval (if any): None

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:

- *The project leader (principle investigator) must report in the prescribed format to the NWU-EC:*
  - *annually (or as otherwise requested) on the progress of the project,*
  - *without any delay in case of any adverse event (or any matter that interrupts sound ethical principles) during the course of the project.*
- *The approval applies strictly to the protocol as stipulated in the application form. Would any changes to the protocol be deemed necessary during the course of the project, the project leader must apply for approval of these changes at the NWU-EC. Would there be deviated from the project protocol without the necessary approval of such changes, the ethics approval is immediately and automatically forfeited.*
- *The date of approval indicates the first date that the project may be started. Would the project have to continue after the expiry date, a new application must be made to the NWU-EC and new approval received before or on the expiry date.*
- *In the interest of ethical responsibility the NWU-EC retains the right to:*
  - *request access to any information or data at any time during the course or after completion of the project;*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the project are revealed or suspected,*
    - *it becomes apparent that any relevant information was withheld from the NWU-EC or that information has been false or misrepresented,*
    - *the required annual report and reporting of adverse events was not done timely and accurately,*
    - *new institutional rules, national legislation or international conventions deem it necessary.*

The Ethics Committee would like to remain at your service as scientist and researcher, and wishes you well with your project. Please do not hesitate to contact the Ethics Committee for any further enquiries or requests for assistance.

Yours sincerely

Prof MMJ Lowes
(chair NWU Ethics Committee)

Prof HH Vorster
(Chairman: NWU Ethics Committee: Author)

APPENDIX B

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN BOJANALA HEALTH DISTRIC

NORTH-WEST UNIVERSITY
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Nursing Science
Tel: (018) 0182991835
Fax: (018) 0182991827
Email: Engela.duplessis@nwu.ac.za

Enquiries: MRS MM KHUNOU

Tel: (W) 014-590-5323

(Cell): 0732521024

(E mail: maggiek@lantic.net)

22 January 2009

ATTENTION:

North West Research Committee

Superintendent-General of the Province

Mafikeng

2745

Dear Madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN BOJANALA HEALTH DISTRICT

I am currently registered as a learner for the MCur (Midwifery and Neonatological Nursing Science) degree at North-West University (Potchefstroom Campus). As part of the degree I need to conduct research and my topic is "Support for caregivers during puerperium to enhance the PMTCT programme". Ethical approval has been obtained from the Ethics Committee of North-West University number NWU – 0068-08-S1.

The purpose of the research is to:

- explore and describe experiences of caregivers during puerperium implementing the PMTCT programme.
- explore and describe the perceptions of health workers during puerperium with regard to support for caregivers implementing the PMTCT programme.
- formulate recommendations for the maternal and child health programme to develop a structure of support during puerperium for caregivers to enhance the PMTCT programme.

In order to achieve these objectives, in-depth interviews will be conducted with caregivers and health workers implementing the PMTCT programme during puerperium in the Bojanala region, Rustenburg Sub-District in the North West Province.

Criteria for inclusion are as follows:

- voluntarily participation without coercion in the research
- consent to be interviewed and to be recorded on audio-tape
- participate willingly in the research until data collection is complete
- explanation of significance as well as purpose and method of the research to participants
- currently providing home-based care to mothers and babies living with HIV/AIDS
- able to communicate in English or Tswana

In-depth interviews with those who agree to participate in the research will be conducted during March and April 2009. In-depth interviews will be conducted in private rooms at the clinics and will last approximately 45 minutes to one hour per participant.

Anonymity and confidentiality will be maintained in all research proceedings. It will be appreciated if one health worker in each clinic and site of voluntary organization can be identified who can act as a mediator in recruitment of caregivers as research participants. Your timeous response will be appreciated, which will enable me to make further arrangements.

If more information is needed with regard to this research, please contact me at the telephone numbers indicated above.

Thanking you in anticipation.

Yours faithfully

MS MM KHUNOU (Researcher)

MRS E Der Walt (Supervisor)

MRS A DU PREEZ (Co-Supervisor)

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

HEALTH

DEPARTMENT:
HEALTH
NORTH WEST PROVINCE

2nd Floor Tirelo Building
Dr Albert Luthuli Drive
Mafikeng, 2746
Private Bag X2068

Directorate: Policy, Planning & Research

Enq: R Mosiane
Tel: (018) 387 5780
Fax: (018) 387 5617
E-mail: mosianer@nwpg.gov.za

TO : **Ms M Khunou**

FROM : **Mr K Rabanye**
Director: Policy, Planning and Research

DATE : **04 February 2009**

SUBJECT : **Support for caregivers during puerperium to enhance PMTCT Programme**

The above subject matter has the reference

1. **Purpose**

To give the researcher feedback regarding the application or request for funding of the above mention study by North West Department of Health.

2. **Background**

It is with regret to inform you that your application for financial assistance has been turned down. Your study have been recommended for approval by the HOD in order for you to conduct research, however the Department have no funds available to assist you.

We really appreciate your study and are very certain that it will benefit the Department.

Mr B.P Maboe
Acting Director: Policy, Planning and Research

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

APPENDIX C

REQUEST FOR PERMISSION TO CONDUCT RESEACH IN BOJANALA HEALTH DISTRIC

NORTH-WEST UNIVERSITY
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Nursing Science
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Email: Engela.duplessis@nwu.ac.za

Enquiries: MRS MM KHUNOU

Tel: (W) 014-590-5323

(Cell): 0732521024

(E mail: maggiek@lantic.net)

22 January 2009

ATTENTION:
Mrs M Rakau
Chief Director of Health
Bojanala District
Rustenburg
0300

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN BOJANALA HEALTH DISTRICT

Dear Madam

I am currently registered as a learner for the MCur (Midwifery and Neonatological Nursing Science) degree at North-West University (Potchefstroom Campus). As part of the degree I need to conduct research and my topic is "Support for caregivers during puerperium to enhance the PMTCT programme". Ethical approval has been obtained from the North-West University Ethics Committee number NWU-0068-08-S1.

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If more information is needed with regard to this research, please contact me at the telephone numbers indicated above.

Thanking you in anticipation.

Yours faithfully

MS MM KHUNOU (Researcher)

MRS E Der Walt (Supervisor)

MRS A DU PREEZ (Co-Supervisor)

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

Department:
Health
NORTH WEST PROVINCE

Physical Address
12 Kgwebo Avenue
Mabe Business Park
Old Pretoria road /
Kroondal & East Avenue
(Stand No: F114)
P/Bag x82090
Rustenburg 0300

BOJANALA DISTRICT

OFFICE OF THE CHIEF DIRECTOR

Enq.: Mr. C. Scholtz
Tel: +27 (014) 591 9700
Fax: +27 (014)

Cell: 082 886 9190

TO: MRS. M.M. KHUNOU

FROM: MRS. ME RAKAU
CHIEF DIRECTOR

DATE: 29 SEPTEMBER 2008

SUBJECT: PERMISSION TO CONDUCT RESEARCH IN BOJANALA

Your letter dated 4 September 2008 has reference.

Your request to conduct a research regarding the PMTCT program is granted.

It is therefore requested that you contact Dr. Tumbo (Family Physician) at 082 885 8332, and Mrs. M Bolokwe (Director PHC) at 082 683 8999 for the period that you required to do the survey, and the necessary arrangements.

Thank you

MS MMULE RAKAU
CHIEF DIRECTOR—BOJANALA HEALTH DISTRICT

APPENDIX D

REQUEST FOR PERMISSION TO CONDUCT RESEACH IN BOJANALA HEALTH DISTRIC

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
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Enquiries: MRS MM KHUNOU

Tel: (W) 014-590-5323

(Cell): 0732521024

(E mail: maggiek@lantic.net)

22 January 2009

ATTENTION:
Mr L Tlhowe

Sub-District Manager of Health

Bojanala District

Rustenburg

0300

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN BOJANALA HEALTH DISTRICT

Dear Sir

I am currently registered as a learner for the MCur (Midwifery and Neonatological Nursing Science) degree at North-West University (Potchefstroom Campus). As part of the degree I need to conduct research and my topic is "Support for caregivers during puerperium to enhance the PMTCT programme". Ethical approval has been obtained from the North-West University Ethics Committee number NWU-0068-08-S1.

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- formulate recommendations for the maternal and child health programme to develop a structure of support during puerperium for caregivers to enhance the PMTCT programme.

In order to achieve these objectives, in-depth interviews will be conducted with health workers and caregivers implementing the PMTCT programme during puerperium in the Bojanala region, Rustenburg Sub-District in the North West Province.

Criteria for inclusion are as follows:

- voluntarily participation without coercion in the research
- consent to be interviewed and to be recorded on audio-tape
- participate willingly in the research until data collection is complete
- currently providing home-based care to mothers and babies living with HIV/AIDS
- able to communicate in English or Tswana

In-depth interviews with those who agree to participate in the research will be conducted during March and April 2009. In-depth interviews will be conducted in private rooms at the clinics and will last approximately

45 minutes to one hour per participant.

Anonymity and confidentiality will be maintained in all research proceedings. It will be appreciated if health workers in clinics can be identified who can act as mediator

in recruitment of caregivers as research participants. Your timeous response will be appreciated, which will enable me to make further arrangements

If more information is needed with regard to this research, please contact me at the telephone numbers indicated above

Thanking you in anticipation

Yours faithfully

MS MM KHUNOU (Researcher)

MRS E Der Walt (Supervisor)

MRS A DU PREEZ (Co-Supervisor)

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

HEALTH
Department:
Health
NORTH WEST PROVINCE

Kerkstreet 125
PRIVATE BAG X 82055
RUSTENBURG
0300

RUSTENBURG HEALTH SUB-DISTRICT OFFICE

Enq: Mr.L.K. Tlhowe
Cell:: 0828070449
E-Mail: ltlhowe@nwpg.gov.za
Tel: 014 594 8300
FAX: 014 597 3667

TO: MS.M.M. KHUNOU

FROM: MR.L.K. TLHOWE
SUB DISTRICT MANAGER

DATE: 24TH MARCH 2009

SUBJECT: REQUEST FOR PERMISSION TO CONDUCT RESEARCH ACTIVITIES IN BOJANALA

PURPOSE

To give response to your request of conducting Research activities in the Sub District.

RESPONSE

This office appreciates your expression in conducting research activities in our Sub District. We have noted though that you have not specified the facilities that you are targeting and the period during which such activities shall be conducted. It is necessary that we advise you to provide such details to enable this office to adequately communicate the latter with the management team and the facilities affected by this undertaking.

This office is in support of your request and believes that you will be in a position to give report back on your findings in order to assist the management to intervene appropriately in the area of your research.

CONCLUSION

You are authorized to conduct research activities in Rustenburg Sub District on condition that the details of the research activities are communicated with this office. (Dates and Target institutions)

Kind regards,

L.K. TLHOWE (MR)
SUB DISTRICT MANAGER

Healthy Living for All

APPENDIX E

REQUEST FOR PERMISSION TO CONDUCT RESEACH IN TAPOLOGO SITES

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018) 299-1111/2222
Web: http://www.nwu.ac.za

Nursing Science
Tel: (018) 0182991835
Fax: (018) 0182991827
Email: Engela.duplessis@nwu.ac.za

Enquiries: MRS MM KHUNOU

Tel: (W) 014-590-5323

(Cell): 0732521024

(E mail: maggiek@lantic.net)

22 January 2009

ATTENTION:

Mrs Hilda de Bees

Board of Directors

Tapologo Hospice

Rustenburg

0300

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN TAPOLOGO SITES

Dear Sir

I am currently registered as a learner for the MCur (Midwifery and Neonatological Nursing Science) degree at North-West University (Potchefstroom Campus). As part of the degree I need to conduct research and my topic is "Support for caregivers during puerperium to enhance the PMTCT programme". Ethical approval has been obtained from the North-West University Ethics Committee number NWU-0068-08-S1.

The purpose of the research is to:

- explore and describe experiences of caregivers during puerperium implementing the PMTCT programme .
- explore and describe the perceptions of health workers during puerperium with regard to support for caregivers implementing the PMTCT programme.
- formulate recommendations for the maternal and child health programme to develop a structure of support during puerperium for caregivers to enhance the PMTCT programme.

In order to achieve these objectives, in-depth interviews will be conducted with health workers and caregivers implementing the PMTCT programme during puerperium implementing the PMTCT programme during puerperium in the Bojanala region of the Rustenburg Sub-District in the North West Province.

Criteria for inclusion are as follows:

- voluntarily be interviewed and to be recorded on audio-tape
- currently providing home-based care to mothers and babies living with HIV/AIDS
- being able to communicate in English or Tswana

The in-depth interviews with those who agree to participate in the research will be conducted during March and April 2009. It will be conducted in private rooms at the clinics and will last approximately 45 minutes to one hour per participant.

Anonymity and confidentiality will be maintained in all research proceedings. It will be appreciated if one health worker in each clinic and site of voluntary organizations can be identified who can act as a mediator in recruitment of caregivers as research participants. Your timeous response will be appreciated, which will enable me to make further arrangements.

If more information is needed with regard to this research, please contact me at the numbers indicated above.

Yours faithfully

MS MM KHUNOU (Researcher)

MRS E Der Walt (Supervisor)

MRS A DU PREEZ (Co-Supervisor)

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

TAPOLOGO PROGRAMME
PO Box 56
BOSHOEK
0301

TAPOLOGO

Tel No: (014) 566 4781
Fax No: (014) 566 4604
E-mail:

April 2009

Dear sir /madam

Research activity with our programme

This letter serves to confirm that Ms M Khunou is allowed to conduct a research in our premises between the month of April and May her thesis is on " support for caregivers to enhance PMTCT programmed during pueperium"

Hope you will all benefit from this
Yours
Hilda N de Bees
0823300352

APPENDIX F

REQUEST TO ACT AS MEDIATOR IN RESEARCH IN BOJANALA DISTRICT

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
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Enquiries: MRS MM KHUNOU

Tel: (W) 014-590-5323

(Cell): 0732521024

(E mail: maggiek@lantic.net)

22 January 2009

REQUEST TO ACT AS MEDIATOR IN RESEARCH IN BOJANALA DISTRICT

Dear Sir/Madam

I am currently registered as a learner for the MCur (Midwifery and Neonatological Nursing Science) degree at North-West University (Potchefstroom Campus). As part of the degree I need to conduct research and my topic is "Support for caregivers during puerperium to enhance the PMTCT programme". Ethical approval has been obtained from the North-West University Ethics Committee number NWU-0068-08-S1.

The purpose of the research is to:

- explore and describe experiences of caregivers during puerperium implementing the PMTCT programme .
- explore and describe the perceptions of health workers during puerperium with regard to support for caregivers implementing the PMTCT programme.
- formulate recommendations for the maternal and child health programme to develop a structure of support for caregivers during puerperium to enhance the PMTCT programme.

In order to achieve these objectives, in-depth interviews will be conducted with health workers and caregivers implementing the PMTCT programme during puerperium in the Bojanala region, Rustenburg Sub-District in the North West Province.

The role of the mediator together with the researcher is to:

- Identify and compile a list of potential research participants
- explain the purpose, importance and benefits of the research project to potential research participants
- explain the methods of data collection and recording of data utilizing an audio-tape to research participants and that duration of in-depth of interviews will last approximately 45 minutes to one hour per participant
- coordinate appointments for interviews between the researcher and research participant
- confirmation of the venue with research participant also with regard to suitability
- assist the researcher to identify a quiet private room at the clinic for conducting the interviews
- arrange a meeting between the researcher and research participant prior the research to get to know one another
- avoidance of distracters during the interview

Criteria for inclusion are as follows:

- voluntarily participation without coercion in the research
- consent to be interviewed and to be recorded on audio-tape
- participate willingly in the research until data collection is complete
- explanation of significance as well as purpose and method of the research to participants
- currently implementing the PMTCT programme during puerperium.
- able to communicate in English or Tswana

In-depth interviews with those who agree to participate in the research will be conducted during March and April 2009. In-depth interviews will be conducted in private rooms at the clinics and will last approximately 45 minutes to one hour per participant.

Anonymity and confidentiality will be maintained in all research proceedings.

It will be appreciated if you can submit the list of research participants that are willing to participate in the research and arrangements that have been made on behalf of the researcher. Your timeous response will enable me to make further arrangements.

If more information is needed with regard to this research, please contact me at the telephone numbers indicated above.

Thanking you in anticipation.

Yours faithfully

MS MM KHUNOU (Researcher)

MRS E Der Walt (Supervisor)

MRS A DU PREEZ (Co-Supervisor)

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

APPENDIX G

REQUEST TO REFER CAREGIVERS FOR COUNSELLING

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES UNIVERSITEIT
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Enquiries: MRS MM KHUNOU

Tel: (W) 014-590-5323

(Cell): 0732521024

(E mail: maggiek@lantic.net)

22 January 2009

Dear Sir/Madam

I am currently registered as a learner for the MCur (Midwifery and Neonatological Nursing Science) degree at North-West University (Potchefstroom Campus). As part of the degree I need to conduct research and my topic is "Support for caregivers during puerperium to enhance the PMTCT programme". Ethical approval has been obtained from the North-West University Ethics Committee number NWU-0068-08-S1.

The purpose of the research is to:

- explore and describe experiences of caregivers during puerperium implementing the PMTCT programme.
- explore and describe the perceptions of health workers during puerperium with regard to support for caregivers implementing the PMTCT programme.
- formulate recommendations for the maternal and child health programme to develop a structure of support during puerperium for caregivers to enhance the PMTCT programme.

In order to achieve these objectives, in-depth interviews will be conducted with health workers and caregivers implementing the PMTCT programme during puerperium in the Bojanala region, Rustenburg Sub-District in the North West Province.

In-depth interviews with those who agree to participate in the research will be conducted during March and April 2009. In-depth interviews will be conducted in private rooms at the clinics and will last approximately 45 minutes to one hour per participant. During interviews explanation of lived experiences of research participants may arouse depressive episodes.

I thus request your availability for debriefing and counselling of these research participants as an expert in this matter. Confidentiality will be maintained in consultation processes.

If more information is needed with regard to this research, please contact me at the telephone numbers indicated above.

Thanking you in anticipation.

Yours faithfully

MS MM KHUNOU (Researcher)

MRS E Der Walt (Supervisor)

MRS A DU PREEZ (Co-Supervisor)

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

APPENDIX H

CONSENT TO BE PARTICIPANT SUPPORT FOR CAREGIVERS DURING PUERPERIUM TO ENHANCE THE PMTCT PROGRAMME

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
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Email: Engela.duplessis@nwu.ac.za

Enquiries: MRS MM KHUNOU

Tel: (W) 014-590-5323

(Cell): 0732521024

(E mail: maggiek@lantic.net**)**

22 January 2009

A. PURPOSE AND BACKGROUND

Ms MM Khunou is conducting research to explore and describe experiences of caregivers implementing the PMTCT **programme** during puerperium. The researcher will be conducting an in-depth interview with you to explore your experiences regarding this matter.

The objectives of the research are to:

- explore and describe experiences of caregivers during puerperium implementing the PMTCT programme.
- explore and describe the perceptions of health workers during puerperium with regard to support for caregivers implementing the PMTCT programme.

- formulate recommendations for the maternal and child health programme to develop a structure of support during puerperium for caregivers to enhance the PMTCT programme.

You are requested to participate in this research because your input will help me in achieving the objectives.

B. PROCEDURE

If you agree to participate in this research the following will take place:

An in-depth interview will be conducted and questions will be asked by the researcher.

Information you provide will be transmitted to a tape-recorder so that all the information provided is stored and it will not be destroyed until data has been transcribed. Your participation in this interview will last approximately 45 minutes to one hour.

C. CONFIDENTIALITY

Data provided to the researcher will be dealt with confidentiality. No other person besides the researcher and research team members will have access to data provided. Anonymity will be ensured as no names will be used in collection and analysis of data and dissemination of research findings.

D. RISKS/DISCOMFORTS

Some of the questions will remind you of your past emotional experiences and you are at liberty not to answer them if they affect you emotionally.

You will be referred to a clinical psychologist for further counselling should there be such a need.

E. COSTS

No costs are involved in your participation in this research.

F. PAYMENT

No payment will be provided for you to participate in the research. Transport costs are not involved, as the researcher will transport you back home.

G. QUESTIONS

Should you still need further clarification and have questions to ask, consult Mrs MM Khunou or call her at 0732521024.

H. CONSENT

Copy of consent is provided for you to keep.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You are free to withdraw at any stage and you are also free not to accept to participate in this research. Your nonparticipation in this research will not have an impact on the present or future use of our health services.

....

DATE SIGNATURE OF RESEARCH PARTICIPANT

....

DATE SIGNATURE OF PERSON OBTAINING CONSENT

APPENDIX I

IN-DEPTH INTERVIEW SCHEDULE FOR CAREGIVERS

IN-DEPTH INTERVIEW SCHEDULE FOR CAREGIVERS ON THEIR EXPERIENCES WITH REGARD TO SUPPORT PROVIDED DURING PUERPERIUM WHILST IMPLEMENTING THE PMTCT PROGRAMME

- What type of support do you think needs to be provided to you as a caregiver during puerperium to implement the PMTCT programme to mothers and babies?

APPENDIX J

TRANSCRIPT OF AN IN-DEPTH INTERVIEW WITH A CAREGIVER

CAREGIVER 6

(R: Researcher, P: Participant)

Researcher	What type of support do you need as a caregiver to implement the PMTCT programme for mothers and babies during puerperium?	
Participant	Meaning specifically for mothers and babies, I need support as I follow up for mothers post-delivery; I usually find that they do not have food, sometimes the baby with nothing to be fed with. One day I was called at Mabelaapodi. I went there later as I was committed with the Bishop and I found that the baby was crying eagerly. I cuddled the baby as the mother was sick. I wanted to do something for the baby but there was nothing to cook, even paraffin was not available. I asked for paraffin next door. Thereafter I boiled water and made a bottle for the baby, the mother was not having any food available. I went to my house. I got food. The mother could not wash. The following day I went there as I could not sleep for the night to an extent that I woke up late the following day. I told my colleagues about this problem. The mother has three children. I washed her clothes and that of the baby. The other children were was at school. Together with my colleagues we used our resources. I reported the matter to my supervisor who gave me 10 kg Mealie Meal. I went to the school where the other children were attending school, I met the teachers and explained the problems to	

	the principal and appreciated my efforts. The principal gave me food parcels he gets from the mines although they were insufficient and promised to receive something from the church. These things hurt us when we meet mothers and babies where there is lack of support. I suggest that we can have financial support so that we can visit them and assist them. I sometimes use my money to visit these families. I suggest that if we can be provided with financial support and transport money as we work in areas that are far, I go to an extent of using money from my family.	
Researcher	Who can provide you with this support?	
Participant	I suggest that if there are problems like this there should be people from business to assist us with groceries and money as sometimes we get money to buy groceries. As we are an NGO, our sister is unable to help us. If they can give us something on monthly basis.	
Researcher	You said problems you identified from the mother and the baby stressed you. How did you cope with this stress?	
Participant	Okay, I do not know what did I do but I managed to get help from the school and feeding schemes.	
Researcher	What caused this stress? Was this due to unavailability of food?	
Participant	Lack of money.	
Researcher	You talked of transport money. How does it affect you?	
Participant	I do visit in areas that are very far, and prior my home visits I report on duty first and thereafter I do my home visits and also when I come back I have to report at work before I go off.	
Researcher	What type of transport can be used?	
Participant	Presently I'm using a taxi. If there could be people who can donate a Combi like Iveco. Currently the car we use is damaged and this poses a huge problem for us as we	

	have started with a Day Care. The difficulty we face is lack of transport to reach these areas. In addition we have to lift patients.	
Researcher	What do you use, as the current car is broken?	
Participant	Our sister is using her own car.	
Researcher	You talked of lack of food, stress, transport money and car problem. What type of support do you need?	
Participant	If we can be assisted to maintain the hospice, we are currently in arrears with water and electricity bills; we have problems of payment as there is no money. If we can be assisted with financial support.	
Researcher	If you say you should be assisted to maintain the hospice, does it mean that management is unable to maintain it?	
Participant	The manager is the sister and is an NGO. The problem is that the current sponsor contact is expiring month-end and we were relying on this sponsor for financial support.	
Researcher	Meaning that you are not going to be able to do home visits and the building is going to close?	
Participant	We will do home visits, but we anticipate financial difficulties as this sponsor is the one that providing us with financial aid.	
Researcher	Anything to add?	
Participant	If we can have people who can assist us with food parcels for our in-patients.	
Researcher	How many patients do you have?	
Participant	Currently four patients.	
Researcher	You said your contract is expiring month-end. What is going to happen to these patients?	
Participant	It does not mean that the building will close but we anticipate, if we can be provided with food. (Kept quiet) Maybe with food gardening. We are faced with difficulties. We are only three. We do not have sufficient plants. The	

	vegetables we get from the garden we also give to our patients in need. We also need equipment. If we can be provided with boots to use for gardening purposes as we use our own shoes to work in the garden.	
Researcher	You talked of food, stress, financial difficulties, transport to visit patients, maintenance of hospice as the contract is about to expire and gardening needs. Anything to add?	
Participant	Mmm..... Okay..... Sometimes you will find that the mother and the baby are not well. They need to be transported to the hospital and you'll find that there is no transport to transport them to the hospital; even airtime is not available to contact the sister. We travel for long distance and we get tired.	
Researcher	How far are these areas?	
Participant	From the clinic it takes a walk of 40 minutes. They are really far.	
Researcher	You talked of stress when you meet these mothers and how do you deal with this stress when you arrive at the clinic?	
Participant	I report to the problems I identify. She supports me by going to the mothers with me. She provides me with resources and this minimizes the stress I have.	
Researcher	Thank you.	

APPENDIX
A; B; C; D; E; F; G; H; I; J; K; L; M; N AND O

APPENDIX J

IN-DEPTH INTERVIEW SCHEDULE FOR HEALTH WORKERS WITH REGARD TO THEIR PERCEPTIONS DURING PUERPERIUM WITH REGARD TO SUPPORT PROVIDED TO CAREGIVERS IMPLEMENTING THE PMTCT PROGRAMME

- What type of support can be provided to caregivers during puerperium to implement the PMTCT programme to mothers and babies?

APPENDIX L

TRANSCRIPT OF AN IN-DEPTH INTERVIEW WITH A CAREGIVER

HEALTH WORKER 6

(R: Researcher: P: Participant)

Researcher	What type of support can be provided to caregivers to mothers and babies during puerperium?	
Participant	They should know what they should do. They should know how to care for the mother. If there is something unusual they should check on her and check sutured perineum whether it is clean.	
Researcher	Meaning that they should be provided with training?	
Participant	The sister must make sure that they train them as the caregivers are the ones that are doing home visits and if there are problems they should report.	
Researcher	When they come back they report how are their problems handled?	
Participant	If there is something beyond their scope, they must report back. If she is unable to wash the baby we must teach her. If the mother is unable to wash the baby we teach her and if she is unable she reports and we make a follow-up.	
Researcher	What type of support is currently available for caregivers.	
Participant	From our side, we go with them if they have problems. They report back but they do not all the problems of the patients or they phone.	
Researcher	In future what plans do you consider to solve problems identified.. Is there any form of support you consider?	

Participant	On our monthly reports we report about positive and negative things that they have identified. What are our suggestions? We mentioned that.	
Researcher	If the caregiver encounters psychological problems when she comes from visiting mother and baby. How are they handled?	
Participant	We provide counselling. We refer them to the social worker and if problems are psychological we refer them to the psychologist. We have psycho-social network mechanism in place to handle these problems.	
Researcher	You mentioned that you teach them. How do you teach them and how often do you teach them?	
Participant	Usually on Thursdays after home visits and when we are with them.	
Researcher	Another type of support mechanism that is available in Tapologo, what is it as a person managing the site? You said you educate them, if there are social problems you refer them to the social worker and if there are psychological problems you refer them to the psychologist.	
Participant	Caregivers they do become psychologically affected. You consult her. You discuss with her about referral to the psychologist. They verbalize their problems and from time to time they need counselling. Once a year we hold Care of the Carers function, I do not know whether it is enough?	
Researcher	You mentioned that they have psychological problems. Does this occur frequently?	
Participant	Presently I have not kept a record.	
Researcher	As part of management of Tapologo having this Care of the Carers function on annual basis, what impact does it have on the caregivers?	

Participant	From the feedback that we have received through evaluation forms, they mentioned that it was of no value.	
Researcher	What does management do with these evaluation forms as form of feedback?	
Participant	Nothing has been received. I think there is going to be change but I want to believe that things will be attended to.	
Researcher	When last was this function held?	
Participant	Now in July.	
Researcher	How long should this feedback be provided back to the caregivers so that management is able to provide feedback to the caregivers?	
Participant	They mention that they are not appreciated, that is their cry. From our side we do see that.	
Researcher	I appreciate that something has been done –feedback given. You said caregivers are not appreciated. What should be done to feel that they are supported?	
Participant	As we go along with them they should be provided with an increase on what they are getting. What they are getting is not enough. With our pressure something is going to be done.	
Researcher	I really value the pressure you highlight management about so that they are given something. What pressure can be applied in relation to support?	
Participant	Let them come down, visit the clinics, let them caregivers aware that they value the work they do.	
Researcher	Meaning that they do not come?	
Participant	Even if they come they do not say anything. There was something I expected to hear that they should be appreciated and they want feedback from management to appreciate their role. This year again nothing was said by	

	management to thank caregivers, just to say we thank you, but I kept that to myself. The caregivers even verbalized that they do not even thank them.	
Researcher	You mentioned verbal recognition is critical so that they feel that they are valued, which signify support. What other type of support should be provided to these caregivers?	
Participant	There are those who want to further their studies, they want to further their training, we are old we are going.	
Researcher	So training is essential. Besides training, what other type of support?	
Participant	Transport is essential for home-visit purposes as most of the places are not reached.	
Researcher	What type of transport is needed?	
Participant	If management can provide them with transport.	
Researcher	Thank you for the information you provided. I think it will be of value.	

APPENDIX M

FIELD NOTES FOR CAREGIVERS

CAREGIVER 1

Descriptive notes

The participant is a matured committed middle-aged woman with 7 years of experience in care giving. She is dedicated to her work and has real passion for her work. She is highly valued by staff in the clinic as she is very helpful and very able to liaise with personnel in the district office for her work activities. She is able to co-ordinate her activities with Hospices in her area and emergency services for referral of patients. She envisages herself running a Hospice and willing to further her knowledge and skills.

Reflective notes

Occasionally she is deeply affected by problems of her patients she visits and goes to an extent of sharing her meals with patients in need. She is independent in her work and able to resolve problems on her own. She is really dedicated to her work and does not give up despite the problems and challenges she encounters.

Demographic notes

The interview took place on 6 July 2009 at 07h45 in a quiet room in the clinic which was nicely prepared by the caregiver on her own and it showed that she treats visitors with the greatest of respect. Although it was a winter morning the room was cool as it faced the morning sunshine. The interview lasted 31 minutes.

CAREGIVER 2

Descriptive notes

The participant is a middle-aged woman, who is 54 years of age and has 12 years of care-giving experience. The caregiver has extensive knowledge of caring for mothers and babies during puerperium and is able to teach mothers about skills needed to care for mothers who are living with HIV/AIDS and for the management of their babies.

Reflective notes

The participant likes to talk in parables and uses questions-and-answer method when elaborating and also uses I messages. She explains herself as though her client is around asking questions and is responsive and gives scenarios and is fluent in Afrikaans, as she gave some of her explanations in Afrikaans.

Demographic notes

The interview was held on 8 July 2009 at 10h00 in a private room in the clinic. It was held privately because it was the participant and I. There were no distractions. Although there was a car hooting outside it did not disturb the interviewing process. The interview lasted 28 minutes.

CAREGIVER 3

Descriptive notes

The participant has 13 years of experience in care giving and she has been extensively trained in most of the courses specific to her work. She is the senior caregiver who has arranged all the interviews for me and she was interviewed last as she was busy with consultations of clients in the clinic and seeing to it that participants are available for interviews. She has an ability to apply the information she has acquired in her daily activities. She talked softly at the beginning as she seemed to be having flu although it was not severe. She was able, without fear and hesitation, to discuss problems that affect her genuinely in her working situation and to state her viewpoint.

Reflective notes

The participant talked softly and looked genuinely depressed when she elaborated on issues that were affecting her in her working situation that seemed not to be followed up. She was able to mention her real deep emotional problems that affect her as a caregiver. She verbalized these concerns openly and with real concern. She talked softly at the beginning as she seemed to be having flu although it was not severe. She tried to remain focused so that we could deal with one issue at a time as she does not attend to one issue and finish it. Occasionally she felt in a state of despair and heartbroken but still remained encouraged to continue talking.

Demographic notes

The interview was the last one with the group of caregivers to be conduct for the day and it was held on 8 July 2009 at 14h00 and lasted 19 minutes, although it was the last one, the participant did not seem tired, as it was not hot on a winter afternoon. There were no interruptions since the interview was held in a private room.

CAREGIVER 4

Descriptive notes

The caregiver is a middle-aged woman in her forties who is reserved and soft spoken. At the beginning of the interviewing process she seemed not to understand the question very well but with clarification she was able to answer. She seemed to be tense as she was not relaxed and talked softly and I requested her to raise her voice. She was requested to elaborate on her responses but failed even if she was probed and she responded with brief answers.

Reflective notes

She was unable to elaborate on information and responded less to what was asked and insisted on the points she elaborated on without giving much information.

Demographic notes

At the beginning of the interview there was noise outside but it did not affect the interview process. The interview was held on 2 September 2009 midday and lasted 11 min and 15 sec. It was hot outside but the room was comfortable and cool irrespective of the summer hot temperature outside. There was noise at the beginning but further interruptions were not experienced since the rest of the interview went well.

CAREGIVER 5

Descriptive notes

The participant is a matured lady, in her late forties, who is experienced in her work. She has been a caregiver for a long period and has the ability to deal with problems on her own. She is dedicated to her work and willing to resolve the problems she encounters in her daily activities and is able to cooperate with stakeholders for management of problems identified and consults her seniors regarding problems. She is able to elaborate extensively on the information she provides. Furthermore, she is able to respond relevantly to questions put to her. She is hardworking and multi-skilled and able to participate in any activity in her place of work.

Reflective notes

The participant presented an elaborate story at the beginning and elaborated on the information she gave. Occasionally she displayed self-pity and lobbied for support as she elaborated further on her problems.

Demographic notes

The interview was conducted on 3 September 2009 and lasted 27 min and 33 seconds midday, but the room was comfortable and well ventilated on a summer afternoon. The room was quiet with no disturbances identified and a relaxed atmosphere prevailed.

CAREGIVER 6

Descriptive notes

The participant is a young lady in her mid-20s with three years of experience as a caregiver who is determined to learn more to broaden her knowledge and has interest in her work. During the interviewing process she was relaxed and displayed passion for her work and clients and was determined to ensure that her clients are followed up to ensure that their needs are met. She is not afraid to openly, without hesitation, mention issues she is not clear on.

Reflective notes

She took a long time answering questions and needed to be probed to answer relevantly. She has a hoarse voice but she was audible during the interview and had good eye contact.

Demographic notes

The interview was held on 3 September 2009 on a hot afternoon but it was held in a well-ventilated, quiet, comfortable room. The environment was relaxed in comfortable couches and there were no interruptions, since the interview was held in a quiet room. The interview lasted 22 minutes and 10 seconds.

CAREGIVER 7

Descriptive notes

The participant is a matured lady in her late forties, willing to share information with an open mind and confident with the facts she presents. She shows interest in her work as a caregiver and is very familiar with the area she is working in and aware of problems experienced by clients in her vicinity and knowledgeable about referral systems in her area. She ensures that problems experienced by clients are addressed in that she presents them to relevant authorities on time. She openly acknowledges positive aspects that are provided by her managers and appreciates their efforts and willingness to address matters that are not implemented.

Reflective notes

She is elaborative and stresses her points in the form of action using her hands and is able to raise her concerns openly. She has a caring attitude as she is willing to travel long distances to reach her clients.

Demographic notes

The interview was held in a quiet room with no disturbances and distractions as it was held in the afternoon when the clinic was already closed with no one in the surroundings. The interview was held on 9 September 2009 and lasted 29 minutes and 44 seconds on a hot summer afternoon, but the room was well ventilated.

APPENDIX N

FIELD NOTES FOR HEALTH WORKERS

Descriptive notes

The participant is a 30-year old lady who has been relocated by management to manage the site due to her dedication and passion in care giving. She had recently qualified as an auxiliary nurse and she is responsible and accountable. She is also experienced. The interview was well organized but we had interruptions of noise outside and the manual tape recorder was unable to eject the recording tape; thus the interview was halted at a certain stage.

Reflective notes

She is responsible and dedicated and able to run the clinic in the absence of a professional nurse. She is able to liaise with members of the multidisciplinary team in the site to address the needs and problems of caregivers. She is confident and talkative.

Demographic notes

The interview was held on 26 March 2009 at 10h00 after tea. The participant was anxious to commence with the interview. She did not even finish her tea. It was hot but the morning session was preferred to avoid boredom and exhaustion during the day. The interview lasted 40 minutes.

HEALTH WORKER 2

Descriptive notes

Although being a newly qualified professional nurse, this participant is managing the ARV site working collaboratively with members of the multidisciplinary team. She has a vision and is willing to enhance the empowerment of her caregivers. She provided brief answers even when it was anticipated that she might elaborate further and where she seemed not to wish to explain further she was encouraged to nevertheless do so.

Demographic notes

The participant is a newly qualified professional nurse with two years of experience and who is passionate about the PMTCT programme which is coordinated in the ARV site. She is knowledgeable about the PMTCT programme. At the beginning she seemed not to be fluent in English but as the interview progressed she provided relevant information. Occasionally she would take time to answer but answered well later. She talked softly and did not experience problems when clarification was needed to give relevant information, which she provided with ease.

Reflective notes

The interview took place on 1 July 2009 in a private room in a clinic at 08h00 in the morning and lasted 24 minutes. No interruptions were experienced. She availed herself openly without hesitation to participate in the interview and the researcher found her to be all set.

HEALTH WORKER 3

Descriptive notes

The participant is a chief professional nurse who has been coordinating the PMTCT in the District and has been participating actively in its implementation in the district since its inception. She is intensively trained and well experienced in the information she shared during the interview. She provided relevant and up to date information at all times and flowed very well during data provision. She has a vision regarding the programme which she envisages to be implemented.

Reflective notes

The participant was relaxed, focused, calm and attentive during the interview. She was not hesitant with regard to the information she provided.

Demographic notes

The interview was held on 6 July 2009 at 14h00 in a private room in the clinic and lasted 26 minutes. There were interruptions in the beginning but as the interview progressed it went off smoothly. The audiotape was placed a little further away from the researcher and the participant.

HEALTH WORKER 4

Descriptive notes

The participant is a responsible, accountable, knowledgeable and respectful manager who is managing the clinic. When consulted in time she has an ability to delegate her personnel, and activities will be done accordingly. She is extensively and well trained in her work and able to see to it that her personnel are able to implement what has been taught appropriately and she is able to empower her personnel and has good supervisory skills. She knows her patients and personnel and is able to liaise with members of the multidisciplinary team for referral of clients and personnel problems. She is able to apply control mechanisms in the clinic to ensure that her personnel are well disciplined. She is familiar with activities taking place in the clinic and able to treat visitors with respect.

Reflective notes

She is confident and not hesitant when she sharing information. She stated her points clearly in chronological order. She is dedicated to her work and aware of problems and challenges facing her in the working situation and becomes deeply concerned when she shares problems affecting caregivers. She has empathetic understanding for her personnel's and patients' problems. She is a real Christian in heart and her activities denote a person who is religious who perseveres in times of difficulties. She repeated some aspects as a form of emphasis and elaborated extensively on points stated. She has a good sense of appreciation with regard to what her personnel are doing without overlooking the genuine challenges they are facing.

Demographic notes

The interview took place on 8 July 2009 at 13h30 and lasted 18 minutes. The participant was interviewed in the afternoon and it was a cool winter afternoon. There was a choir practice outside for preparation of their colleague who had passed away but it did not affect the interviewing process.

HEALTH WORKER 5

Descriptive notes

The participant is a middle-aged counsellor who has been trained by Lifeline and is living with HIV/AIDS. She shows interest in her work and was confident in what she was elaborating on and made good eye contact. She listened attentively and requested further clarification where she did not understand. She summarized repeatedly so that she stayed focused. She was relaxed during the interviewing process.

Reflective notes

She was talking freely, emphasizing with actions. She kept quiet on several occasions but responded relevantly and smoothly thereafter.

Demographic notes

The interview was held on 3 September 2009 and lasted 27 minutes. It was held in a quiet private room in the morning. During the interviewing process the door stood open but it did not disturb the interviewing process since it progressed well.

HEALTH WORKER 6

Descriptive notes

She is a matured professional nurse who is dedicated to her work and conversant with problems in her area and willing to address them. She displayed a respectful approach when being interviewed, as well as an attitude of receptiveness.

Reflective notes

The participant was relaxed during the process of the interview, sharing her information openly and freely. She was assertive as she was able to express, without hesitation, issues that need to be addressed, and was genuine with facts she presented. Acknowledges She acknowledged positive and negative issues that need to be addressed in her place of work and was willing to take the lead in rectifying problems. Furthermore, she has a vision to see desirable things being implemented.

Demographic notes

The interview was held on 2 September 2009 and lasted 35 minutes on a summer afternoon. Although it was hot outside the room was well ventilated. No distractions and no disturbances were experienced during the interviewing process.

HEALTH WORKER 7

Descriptive notes

She is a retired professional nurse with extensive knowledge in home-based care and the PMTCT programme and has the ability to integrate her services with other stakeholders in the region. She is dedicated to her work and willing to resolve problems her subordinates present to her. She is able to elaborate extensively on the information she provides. Furthermore, she responds positively to questions asked and she answers relevantly.

Reflective notes

The participant is soft spoken and when she presents information she is relaxed and confident. She had coughing episodes which stopped later on, but this did not interfere with the process of the interview. She presents information provided in a slow and consistent elaborative manner.

Demographic notes

The interview was conducted on 3 September 2009 and lasted 30 minutes during the morning and the room was comfortable and well ventilated on a summer afternoon. The room was quiet with no disturbances identified and a relaxed atmosphere prevailed.

APPENDIX O

WORK PROTOCOL FOR DATA ANALYSIS

Dear Dr Emmerentia du Plessis

Thank you for agreeing to be my co-coder for this research. The objectives of this research are as follows:

- To explore and describe the experiences of caregivers during puerperium regarding support to be provided whilst implementing the PMTCT programme.
- To explore and describe the perceptions of health workers during puerperium with regard to support for caregivers implementing the PMTCT programme.
- To formulate recommendations for the maternal and child care programme to develop a structure of support for caregivers during puerperium to enhance the implementation of the PMTCT programme.

Two populations were used, namely caregivers implementing the PMTCT programme for mothers and babies during puerperium and health workers co-coordinating the PMTCT programme for mothers and babies during puerperium.

In-depth interviews were conducted with the caregiver population, and the question was: "**What type of support do you think needs to be provided to you as a caregiver during puerperium to implement the PMTCT programme to mothers and babies?"**

In-depth interviews were conducted with the health worker population, and the question was: **"What type of support can be provided to caregivers during puerperium to implement the PMTCT programme to mothers and babies?"**

As per agreement with my supervisors, please find enclosed the transcripts of 7 (seven) of the interviews conducted with caregivers implementing the PMTCT programme for mothers and babies during puerperium, and those of 7 (seven) interviews with health workers co-coordinating PMTCT programme for mothers and babies during puerperium,

along with the individual field notes. The method of open coding, as described by de Vos *et al.* (2004:346-348) was used to analyze data. The steps that were followed were:

- Read all the transcripts to obtain an overall idea
- Select one transcript and reread it.
- Using words and sentences as unit of analysis, read the transcript once more, and underline spoken words and sentences.
- Transfer these underlined words and sentences to the left hand column of the transcript together with concepts that are detected as categories.
- Write your own perception in the right hand column of the transcript.
- Thereafter read categories that were transferred to the right hand column so as to identify main categories, sub-categories as well as redundant categories.
- Transfer the underlined words (in the participant's own words) to the table indicating the main categories, the sub-categories and further categories.
- Finalize these categories by working through the table again.
- Translate the spoken words into scientific language with the possibility that categorization can be refined and kept in mind.

The date, time and venue for the Consensus meeting will be held on a date suitable for us both following consultation thereon.

Thank you

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MS MAGGIE KHUNOU

(Researcher)