

ANTENATAL CARE FOR HIV POSITIVE WOMEN

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DEAR MUMMY

I am your unborn child.
Who you so dearly carry under your heart,
In lovely depth captured in your womb.
In no time will you know how I look, While I am warmly soft and protected
ruptured in your love, will I communicate with you.

Because we know that the two of us are alone and that with a smile,
Proudly you caress over your body.
I know your silent thoughts because if you think of me,
Your baby received in love.
Then it becomes silent within you.
Everything seems to be unimportant to you.
Only you and God know the secrets of my slowly growing.

I am so dependent from you that formed and feed me.
So are you Mummy, the carrier of life.
You guard over this undeadly soul, which is being given to you.
And one of these days shall the two of us alone, experience the need crude.
Emergency of my birth just the two of us through pain and joy.

By then we will experience how greater life is than death even if the pain is
Unbearable and sometimes so cruel...
And Mummy, when I lay in your arms, shall the peace of fulfilment
Soften the glance in your eyes.
Your sweetly mouth shall smile and your heart shall bonds.
Because life is again, so beautiful and shiny without wrinkles?

You will look down upon me with a prayer in your heart
Father God goes along with my child on the path.
Where it be short or let there always be a resting place on the way.

Strengthen his soul for a further journey.
And when my child is cold, and is tender outside in the dark.
O Lord open a door where there is light, warmth and protection.
O Lord in your hand I give my child.

Thank you Mummy for the prayer
Thank you for the months of pregnancy
Thank you Mummy for the preparations of coming.
I will come Mummy to bring you into your heart and to enrich your life with love

Your own baby
(Author unknown)

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SUMMARY

Approximately 29.1% of South African women of childbearing age tested HIV positive during their first antenatal visit in 2006 (DoH, 2007). This rate of HIV amongst the women of childbearing age reinforces the importance of understanding the management of HIV during pregnancy. During antenatal visits the general health of the woman and her unborn baby is assessed and managed. Management includes antiretroviral therapy to the HIV infected women with a CD4 count below 200 cells/mm³, while women with a CD4 count above 200 cells/mm³ receive a single dose of *nevirapine* with the onset of labour provided to them by their local clinics. Currently, in Potchefstroom, women receive antenatal care at local primary health-care clinics and antiretroviral drugs at the antiretroviral clinic. There is little or no collaboration between the various clinics and the question arises if the needs of the women are being met.

The aim of the research was to promote the health of HIV positive pregnant women by providing insight into the needs of these women and to formulate recommendations for antenatal care. The specific objective is to explore and describe the needs of HIV positive pregnant women regarding antenatal care.

An explorative, descriptive, contextual design, following a qualitative approach was used during the research. Semi-structured interviews were used to collect data. Interview questions were compiled from the research problems. Before the commencement of data collection, permission was obtained from the district health manager and Potchefstroom Hospital. A total of sixteen (16) HIV positive women were interviewed after informed consent had been obtained. Data analysis was done after each session and themes were categorised according to the women's needs.

From the interviews it was found that each woman has her own specific needs regarding antenatal care. The needs of the participants followed a similar pattern and for this reason it could be divided into various categories. These categories

include a need for support, a need for education, a need for improved services and a need for a non-judgemental environment. Conclusions were drawn and recommendations were made for nursing practice, nursing education and nursing research.

[Key concepts: HIV/AIDS, HIV positive, pregnant and pregnancy, antenatal care, needs, antiretroviral therapy.]

OPSOMMING

Ongeveer 29.1% van Suid-Afrikaanse vroue het MIV positief getoets tydens hul eerste voorgeboortebesoeke in 2006 (Department van Gesondheid, 2007). Die omvang van MIV onder vroue in hul vrugbaarheidsjare onderstreep die belangrikheid van begrip om MIV tydens swangerskap te hanteer. Met voorgeboortebesoeke word die vrou en baba se algemene gesondheid geassesseer en hanteer. Die hantering sluit die beskikbaarstelling van antiretrovirale terapie aan vroue met 'n CD4-telling laer as 200 selle/mm³ in, terwyl vroue met 'n CD4-telling hoër as 200 selle/mm³, 'n enkeldosis *nevirapine* kry wat met die aanvang van die geboorte geneem word. In Potchefstroom ontvang vroue tans voorgeboortesorg by hul primêre gesondheidsorgklinieke en antiretrovirale middels by die antiretrovirale kliniek. Daar is min of geen samewerking tussen die onderskeie klinieke en die vraag ontstaan of daar aan die behoeftes van MIV-positiewe swanger vroue voldoen word.

Die doel van die navorsing projek is om die gesondheid van die MIV positiewe swanger vrou te bevorder deur insig te lewer na hul behoeftes en om aanbevelings te formuleer vir voorgeboorte sorg. Die spesifieke doelwit is om die MIV positiewe swanger vrou se behoeftes ten opsigte van voorgeboorte sorg te verken en te verduidelik.

'n Verkennde, beskrywende, kontekstuele ontwerp wat 'n kwalitatiewe benadering volg, is tydens die navorsing gebruik. Semi-gestruktureerde onderhouds is gebruik om die data in te samel. Die onderhoudsvrae is saamgestel uit die navorsingsprobleem. Voor die aanvang van data-insameling is toestemming vanaf die distriksgesondheidsbestuurder en Potchefstroom Hospitaal verkry. Daar is met 'n totaal van sestion (16) HIV-positiewe swanger vroue onderhouds gevoer nadat ingeligte toestemming verkry is. Data-ontleding

het na elke onderhoud plaasgevind en die resultate is in kategorieë verdeel volgens die vrou se behoeftes.

Uit die onderhoude blyk dit dat elke vrou individuele spesifieke behoeftes het ten opsigte van voorgeboorte sorg. Die behoeftes van die verskillende deelnemers toon ooreenstemming en kon daarom in verskillende kategorieë verdeel word. Hierdie kategorieë sluit in 'n behoefte aan ondersteuning, 'n behoefte aan opvoeding, behoefte aan verbeterde dienste en 'n behoefte aan 'n nie-veroordelende omgewing. Gevolgtrekkings is gemaak en aanbevelings is gedoen vir die verpleegpraktyk, verpleegopleiding en verpleegnavorsing.

[Sleutelwoorde: MIV/VIGS, MIV-positief, swanger en swangerskap, behoeftes, voorgeboortesorg, antiretrovirale terapie.]

STRUCTURE OF MINI-DISSERTATION

The mini-dissertation on "*Antenatal care for HIV positive women*" is divided into three parts.

PART 1

GROUNDING OF THE RESEARCH

In this section the background of the research is discussed, the problem statement given and the research questions asked. The research method and design and paradigmatic view are also explained in this section of the mini-dissertation.

PART 2

ARTICLE: ANTENATAL CARE FOR HIV POSITIVE WOMEN

This section contains an article based on the research, the research findings, conclusions and the recommendations formulated from the research results.

PART 3

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS FOR THE PRACTICE OF NURSING, RESEARCH AND EDUCATION IN NURSING TO PROMOTE NEEDS-BASED ANTENATAL CARE FOR HIV POSITIVE WOMEN

Part 3 consists of the conclusions drawn from the research, recommendations made and limitations of the research.

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PART 2

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PART 3

**CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS FOR THE PRACTICE OF
NURSING, RESEARCH AND NURSING EDUCATION IN NURSING TO PROMOTE
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PART 1
GROUNDING OF THE RESEARCH

1.1 INTRODUCTION

In Part 1 the grounding of the research, including a review of the different aspects of antenatal care, the problem statement, research purpose, the assumptions of the researcher and the research method and design are discussed.

1.2 BACKGROUND OF THE RESEARCH

Two decades have passed since the first diagnosis of HIV was made and it still remains a major threat and continues to have a devastating impact on the population. At the end of 2006, approximately 42 million people worldwide were living with HIV (WHO, 2007), with some 70% living in Africa (Knight, 2006; DOH, 2005:1). Loutfy and Walmsley (2004:472) state that women of childbearing age represent over 40% of people infected with HIV worldwide. Sub-Saharan Africa has one of the highest incidences of HIV (Department of Social Development, 2004:9; Kennedy, 2003:17) with approximately 81% of the world's HIV-infected women being of childbearing age (Herz, 2002:1). Knight (2006) states that 51% of people tested for HIV in South Africa are women of childbearing age. In a national survey done by the Department of Health in 2006, a percentage of 29.1% pregnant South African women tested HIV positive during their first antenatal visit (DOH, 2007). The maternal mortality rate in this country is as high as 150 deaths per 100 000 deliveries, mainly due to HIV and HIV-related conditions (DOH, 2007).

This rate of maternal death due to HIV reinforces the importance of understanding the management of HIV in pregnancy (Loutfy & Walmsley, 2004:471). For this reason the HIV status of the woman must be known, as also stated by Minnie (2003:3). Only if a woman's HIV status is known, the best available antenatal care can be provided, including antiretroviral treatment to prevent mother-to-child-transmission and to prolong the life of the woman (DOH, 2000:12; Minnie & Du Preez; 2004:19-4; Woods, 2000:31-2).

As in Europe and the United States of America, South African Health Care Services provide HIV tests not only during the first antenatal visit, but also upon the woman's request (Anderson, 2000:222; DOH, 2002:10; Kennedy, 2003:83). Health-care workers

must encourage women who tested HIV negative in early pregnancy to repeat the test after six months. If she became infected during her pregnancy, the necessary actions can be taken to provide comprehensive antenatal care (DOH, 2002:10).

The following discussion relate to a review of literature on antenatal care in relation to HIV positive women, treatment for HIV positive pregnant women and current HIV antenatal care in primary health-care clinics focussing on the needs of these women.

1.2.1 Antenatal care for HIV positive women

Antenatal care includes attention to physical and psychological aspects. Woods (2000:32-6), Kennedy (2003:85) and Evian (2003:210) emphasise the importance of providing counselling, encouragement and support for the woman and her partner during the pregnancy. Studies done in Zambia and California (USA) indicate that women who are HIV positive are more prone to show signs and symptoms of clinical depression if not provided with counselling, encouragement and support (Kwalombota, 2002:431; Murphy *et al.*, 2002:633). The DOH (2002:8) suggests that the optimum management of HIV positive pregnant women include expanded counselling services and not only strengthening of intrapartum and post-delivery care programmes, but also antenatal care programmes.

According to Bodkin *et al.* (2006:736), HIV/AIDS places a burden on the women's body to cope with pregnancy. For this reason, HIV positive women are more prone to complications such as abortions, ectopic pregnancies, stillbirth, intra-uterine growth retardation, placenta abruptio and preterm labour (Nolte, 1998:358; Woods, 2000:32-3). Antenatal visits should be more frequent than is the case of women who are HIV negative.

Watts and Minkoff (2003:383) suggest that women receiving antiretroviral therapy should be encouraged to make more frequent prenatal visits during their third trimester of pregnancy to measure fundal height, blood pressure and other parameters. Sonograms for fetal growth and fluid volume at approximately 32 and 36 weeks gestation should be done. The women should be instructed on daily assessment of fetal movements during their third trimester and urged to report any significant decrease to their health-care

provider or midwife. Furthermore, nutritional supplements are indicated for these women, including iron, folate and vitamin A (DOH, 2002:7). The folate and iron improve pregnancy outcome, including a reduction of the incidence of stillbirth, prematurity and low birth weight (DOH, 2002:7). Previously, it was thought that vitamin A decreases the risk of transmitting HIV to the unborn baby, but recent studies have shown that vitamin A increase in women with a deficiency will improve the general health of the mother, which in return improves the outcome of the baby, but that it does not have a direct influence on preventing the baby from being infected (Villamor *et al.*, 2002:1080).

Villamor *et al.* (2002:1081) also suggest that liver function tests should be done to determine the effect of vitamin A on the liver of the women. In addition to the liver function test, a full blood count and electrolytes tests should be done six-monthly on women who are on antiretroviral treatment. The CD4 count of women not on antiretroviral treatment should be tested on a six-monthly basis to determine if antiretroviral treatment is needed.

Accordingly, the HIV-positive pregnant women must receive health education in order to promote her general health for as long as possible. Health education on the antiretroviral therapy, the correct use of ARV drugs and also signs and symptoms of adverse reactions and the management of the adverse reactions must be provided (DOH, 2004:11). Furthermore, health education with regard to a healthy diet, regular antenatal visits, safe sexual practices, prophylactic treatment in the preventing of opportunistic infections and issues regarding the prevention of mother-to-child-transmission (PMTCT) must be provided (Minnie & Du Preez, 2004:19-4; DOH, 2004:11).

1.2.2 Treatment for HIV positive pregnant women

All pregnant women receive *folate* and *folic acid* to prevent and treat anaemia. HIV positive women, however, are also supposed to receive prophylactic treatment to prevent opportunistic infections, and antiretroviral therapy.

1.2.2.1 Prophylactic treatment to prevent opportunistic infections

According to Woods (2000:32-6), tuberculosis, pneumocystis carinii pneumonia (PCP), oral thrush, herpes simplex and herpes zoster are common opportunistic infections associated with HIV. Both the DOH (2002:10) and Woods (2000:32-6) suggest that HIV positive women must receive *cotrimoxazole* as prophylactic treatment to prevent opportunistic infections, especially where the CD4 count is below 200 cells/mm³ or when there are clinical signs of advanced immune deficiency – including pregnant women after 14 weeks of gestation (Walter, 2006:1).

In a study done by Walter (2006), it was found that *cotrimoxazole* given as prophylaxis after 14 weeks gestation significantly improved the labour outcomes of the HIV infected women. According to the study, African women, particularly women with advanced disease, have a high risk of adverse labour outcomes, including stillbirths, miscarriages, preterm deliveries, low birth weight babies and infant mortalities. The results of the study also showed a significant decrease in preterm deliveries, a decline in chorioamnionitis, an increase in birth weights and a reduction in neonatal mortality with the use of antiretroviral therapy.

1.2.2.2 Antiretroviral therapy in pregnancy

In November 2003, the South African Government announced its plans for a national antiretroviral therapy rollout to treat HIV positive people whose CD4 count was below 200cells/mm³, irrespective of the stage of HIV or clinically having a HIV-related condition (DOH, 2004:3; RHRU, 2005: 3). The primary goal of the antiretroviral treatment is to decrease HIV-related morbidity and mortality. It is expected that the patient should experience fewer HIV-related illnesses, the patient's CD4 count should rise and remain above the baseline count and the viral load should become undetectable. The secondary goal is to decrease the incidence of HIV through an increase of voluntary testing and education on safe sexual practices, reducing transmission in discordant couples and reducing the risk of transmission from mother to child (DOH, 2004:2).

When the South African Government adopted the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa (Huitt, 2006), the goal

of the plan was to provide all South Africans living with HIV with antiretroviral therapy by 2009. This plan also included prevention of transmission of the virus, adequate counselling, good nutrition and healthy lifestyles as well as the treatment of opportunistic infections - including use of traditional medicines (Huitt, 2006).

Antiretroviral therapy may be used during pregnancy as effective combination treatment for maternal HIV if the woman requires treatment for her own health (Highly Active Anti Retroviral Therapy – HAART) or as single, dual or triple drug prophylaxis to prevent HIV infection of the unborn infant.

Women using public health services whose CD4 count is above 200 cells/mm³ do not receive full antiretroviral therapy at the time this study is done. The women do, however, receive *nevirapine* 200mg as single drug to carry with her to be taken with the onset of labour as part of the PMTCT programme. Once she has given birth, the same prophylaxis is given to her newborn baby in the form of *nevirapine* syrup (DOH, 2004:11; RHRU, 2005:8). This regime is successful and cost-effective, but not without problems.

Studies done in Uganda and the United States of America suggest that women who receive a single dose of *nevirapine* may become resistant to the drug which cannot then be used as part of future treatment (Eshleman & Jackson, 2002:59; Lyons *et al.*, 2004:63). For this reason, women on the South African regime may not completely respond to future antiretroviral treatment or a second dose of the *nevirapine* tablet may not be effective (RHRU, 2005:8). Furthermore, by treating the women only to prevent infecting the child ignores the fact that the illness and death of the mother profoundly impacts on the future health of the child. In 2006 the World Health Organisation recommended that all pregnant HIV positive women in developing countries should receive dual therapy that consists of *nevirapine* 200 mg and a short course of *zidovudine* to prevent mother to child transmission (Cullinan, 2007).

The DOH (2004:23) drew up a treatment protocol for pregnant women with a CD4 count below 200 cells/mm³, using a triple regime (Figure 1). The South African guidelines recommend *stavudine* (d4T), *lamivudine* (3TC) and *nevirapine* (NVP) as part of the triple therapy (DOH, 2004:23; RHRU, 2005:21).

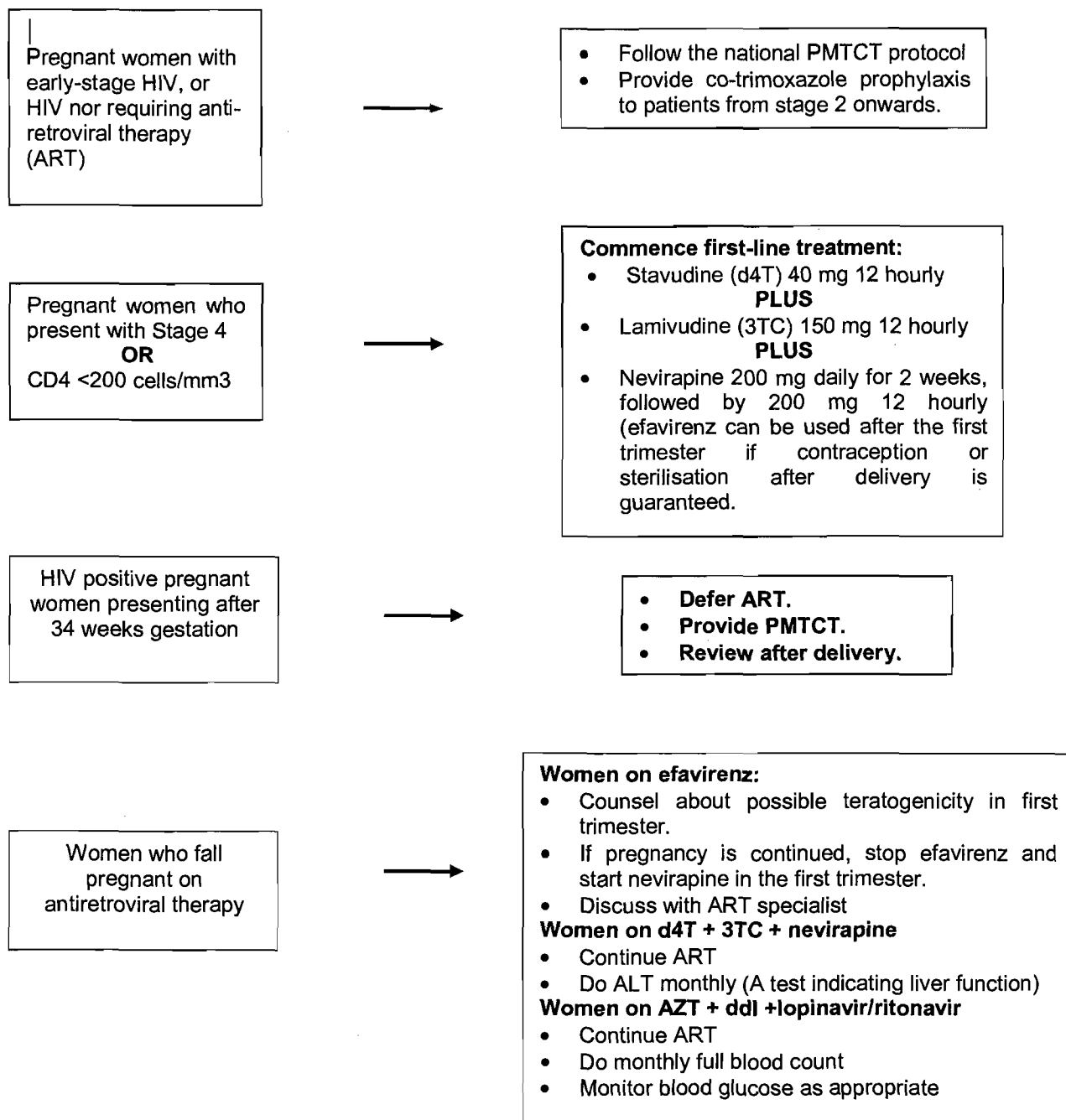


Figure 1: Treatment protocol for pregnant women as recommended by the DOH (2004:23).

1.2.2.3 Management of adverse reactions due to antiretroviral treatment

The physiological changes that occur during pregnancy affect the absorption, distribution, metabolism and elimination of drugs (World Health Organisation, 2004:15), which could lead to adverse reactions.

These adverse reactions that could occur with the use of the different antiretroviral treatments and the recommended strategies to monitor it, are presented in Table 1 according to DOH (2004:64); RHRU (2005:21); Watts and Minkoff (2003:383) and the World Health Organisation (2004:18).

Table 1: Important antiretroviral drug adverse reactions and safety-test monitoring

Antiretroviral	Adverse reactions	Recommended safety monitoring
<i>Nevirapine</i>	Skin rash, nausea, vomiting, fever, fatigue, somnolence and hepatitis.	Alanine aminotransferase (ALT) as baseline and at 2, 4 and 8 weeks. 6-monthly thereafter (taken with CD4 and viral load or when symptomatic)
<i>Stavudine</i> (d4T)	Peripheral neuropathy, hepatic steatosis, lactic acidosis, pancreatitis	Clinical management
<i>Zidovudine</i> (AZT)	Fatigue, headache, muscle pains, bone-marrow suppression (anaemia, neutropenia) gastro-intestine track symptoms, myopathy, lactic acidosis.	Full blood count with differential count at baseline, then monthly for 3 months, thereafter six-monthly with CD4 count and viral load
<i>Lamivudine</i> (3TC)	Diarrhoea, pancreatitis, lactic acidosis	Clinical management

According to the DOH (2004:65), adverse effects such as nausea should be managed clinically. Anti-emetics can be ordered and should be taken half an hour before the antiretroviral drug. If the nausea does not settle, the woman should be referred for expert advice.

Nevirapine may cause various skin reactions, with the most common being a rash (DOH, 2004:65). A clinical assessment must be done to rule out other causes of the rash. Enquire about any other symptom occurrence and monitor the temperature of the patient. Gastro-intestinal symptoms should be treated symptomatically (DOH, 2004:66).

According to the DOH (2004:66), pregnancy increases the risk of lactic acidosis. Symptoms are non-specific and can include symptoms of generalised fatigue, weakness, gastro-intestinal symptoms, dyspnoea or tachypnoea and neurological symptoms. Antiretroviral therapy should be stopped and the woman must be commenced on *Ringers Lactate*. Other causes of raised lactic acidosis such as sepsis, renal failure and diabetic ketoacidosis must be excluded.

If *zidovudine* (AZT) is the cause of anaemia or neutropenia, the woman's dose must be reduced to 200 mg 12-hourly. If the anaemia or neutropenia does not improve after the dose adjustment, the *zidovudine* (AZT) may be replaced with *stavudine* (D4T) (DOH, 2004:68).

All therapy should be stopped if hepatitis, pancreatitis, lactic acidosis or Stevens-Johnson syndrome occurs (DOH, 2004:65). Women may develop different adverse reactions and therefore their needs regarding the management of adverse reactions will be individualised. These adverse reactions can be managed at the hospital or the primary health-care clinics, depending on the severity of the adverse reaction.

1.2.3 Current HIV antenatal care in primary health-care clinics focussing on the needs of the women

For the midwife to provide comprehensive antenatal care to the HIV positive pregnant woman, she must establish the needs of the woman. According to Maslow's hierarchy of needs, as adapted by Huitt (2006) and Kozier *et al.* (2000:191), needs can be divided into physiological needs, safety and security needs, love and belonging needs, esteem needs and the need for self-actualisation. The most basic need is the physiological need, which is mostly focussed on in antenatal care.

An example of health-care services addressing all needs is the antiretroviral clinic within Johannesburg Hospital's antenatal clinic. This service was established as part of a comprehensive HIV care package to meet the needs of HIV infective pregnant women who qualify for antiretroviral therapy. The staff at this antenatal HIV clinic gradually prepares a woman for the rigorous demands of treatment using two weekly visits preceding initiation of treatment (RHRU, 2005:18). One of the services provided is counselling to explain the pregnancy terminology and HIV/AIDS terminology. Should the pregnant woman choose, she could make use of ongoing counselling at the clinic throughout her pregnancy. Not only are the counsellors available for private sessions, there is also a support group for the women attending the antenatal HIV clinic (RHRU, 2005:14). Counselling is provided to ensure and measure whether women are taking their drugs at the prescribed times on any given day (RHRU, 2005:16).

A similar programme was successfully started in Kenya where the women's needs form a central component of the programme. The programme in Kenya includes:

- All elements of the essential ANC package;
- promotion of mother-friendly, continuous care;
- HIV counselling and testing;
- counselling and planning for infant feeding;
- postpartum contraceptive planning;
- counselling and provision of *nevirapine*, or other antiretroviral therapy regimes;
- involvement of partner and family; and
- referral to support groups (Calton, 2005:11).

Both these programmes focus on the needs of the HIV positive pregnant women. In a study done by Saxman *et al.* (2005) in Seattle, it was found that HIV positive women have their own specific needs. These needs include a variety of needs, from basic needs to complex needs that include needs for improved services, antenatal care, assistance in finding proper housing, the provision of transport to clinics, support in the work setting and antiretroviral treatment. Currently, antenatal care and antiretroviral services in the Potchefstroom sub-district are not focussed on the needs of HIV positive pregnant women.

1.3 PROBLEM STATEMENT

When a woman enters the antenatal service, she might have a number of needs, the most fundamental of these being good antenatal care. It is believed that better antenatal care can be provided if the HIV status of the women were known. This project forms part of a bigger project on HIV testing in pregnancy, sponsored by the National Research Foundation (NRF) (TTK2006061200001).

Currently, there are no recommendations for providing need-based antenatal care in the Potchefstroom sub-district. Based on the above discussion, the following questions arose:

Research questions

1. What are the needs of HIV positive women regarding antenatal care?
2. How should antenatal care be rendered in order to address these needs?

1.4 RESEARCH PURPOSE

This research project aims to promote the health of HIV positive pregnant women by providing insight into the needs of these women and to formulate recommendations for antenatal care.

The specific objective is to explore and describe the needs of HIV positive women regarding antenatal care.

1.5 ASSUMPTIONS OF THE RESEARCHER

The following assumptions of the researcher are used as basis for the research, as proposed by Botes (1995:9). Assumptions consist of the following: meta-theoretical assumptions, theoretical assumptions and methodological assumptions. Each of these assumptions will be discussed.

1.5.1 Meta-theoretical assumptions

These assumptions consist of the researcher's views regarding human beings, environment, health and illness. In this study the assumptions are based on a Christian view.

1.5.1.1 Human being

The human being is created in God's image, with the demand to control the world and be accountable to God. There is a lifelong process of regeneration that occurs within man when he chooses to obey God and stand in a close relationship with Him. Human beings in this research are HIV positive pregnant women, unborn infants and the midwives providing the care to these women.

1.5.1.2 Environment

The nature of the environment includes the physical, social and spiritual aspect of the HIV positive pregnant women.

In this research the environment of the women is the environment that the participant creates according to herself. The environment could include the area that the nurse creates to provide antenatal care to the HIV positive pregnant woman.

1.5.1.3 Health and illness

Health is a state of spiritual, mental and physical well-being. The human being's pattern of interaction with his internal and external environment determines his health status. Health can be explained on a continuum from maximum health to minimum health. Both health and illness are states that reflect a person's interactive patterns with stressors in the internal and external environment. Illness can also be described on a continuum from severe illness to minimum illness.

Although the woman is HIV positive and therefore can be placed on the continuum of illness, she can remain spiritually, mentally and emotionally healthy and asymptomatic, which place her on the continuum of health. As she physically progresses from being HIV positive to having AIDS, she can be placed on the continuum of minimum health and maximum illness.

1.5.1.4 Nursing

The term implies the direct nursing action provided to the community. In the research the nursing action is the antenatal care that is provided to the HIV positive women that form part of the community.

1.5.2 Theoretical assumptions

Theoretical assumption consists of the formulation of the central theoretical argument as well as the theoretical description of the key terms.

1.5.2.1 Central theoretical argument

The knowledge of the various needs of the HIV positive pregnant woman will lead to the formulation of recommendations for the midwife to render antenatal care that meet the needs of the woman. The results of this research might indirectly serve as a motivation for pregnant women to undergo voluntary HIV testing, as the availability of appropriate antenatal care for HIV positive women might be promoted.

1.5.2.2 Theoretical descriptions

Key terms used in the research are discussed both theoretically and operationally. Theoretical definitions are the use of words to describe a word or concept, where as in operational definitions activities are specified to measure the word/concept (De Vos, 2002:34).

The following terms will be discussed: HIV positive, pregnancy, antenatal care and needs.

HIV positive

The term HIV positive is the term used when a human being's blood test shows the antibodies of the human immunodeficiency virus (HIV) (Vlok, 2001:600). It infects mainly the immune system, particularly the lymphocytes, but may also infect other organs such as the central nervous system and intestines (Woods, 2000:31-1). The routes of transmission of HIV include directly from person to person by sexual contact, direct inoculation with contaminated blood products, including syringes and needles, and from the infected mother to her fetus or newborn (Green-Nigro, 1999: 2190).

Within this research pregnant women tested positive for the HI virus. This could have been before pregnancy, during a previous pregnancy or with the current pregnancy. The most probable mode of transmission might have been through sexual contact with a HIV positive partner.

Pregnancy

The condition of a female after conception until the birth of the baby, ± 280 days (Dirckx, 1997:708).

Antenatal care (ANC)

Antenatal means the period preceding the birth of the fetus (Dirckx, 1997:709) whilst the concept of care includes health care, support, reassurance and comfort (Woods, 2000:1-98).

According to Nolte (1998:77), antenatal care has the following goals, namely to:

- Reduce maternal and fetal mortality and morbidity;
- promote and maintain the physical and mental health of the mother;
- educate and prepare the family for the duration of the pregnancy, the birth and puerperium;
- diagnose and treat complications of the pregnancy;
- prevent complications of labour by early diagnosis and management of possible problems;

- educate the family on the advantages of breastfeeding;
- select the method of delivery; and
- give family planning education for after the birth of the baby.

Therefore, antenatal care can be seen as the health-care support, reassurance and comfort given to women in the time frame from conception until the delivery, whilst incorporating the antenatal goals.

Needs

Needs in this research are structured within Maslow's hierarchy of human needs, who ranks the needs on an ascending scale according to how essential the needs are for survival (Kozier *et al.*, 2000:191). The needs according to Maslow, as adapted by Kozier *et al.* (2000:191) in ascending order, are as follows, physiological needs, safety and security needs, love and belonging needs, esteem needs and the need for self-actualisation.

○ *Physiological needs*

Physiological needs are crucial for survival. These needs include food, water, shelter, air, sleep and rest. These needs of the woman are essential to remain physically healthy. The physiological needs can also be described as the needs of the organisms, those needed for homeostasis, and take first precedence on the hierarchy (Huitt, 2006). This mainly consists of the needs to breath, drink water, eat, hemostasis and sexual activities (Boeree, 1998).

○ *Safety and security needs*

The need for safety and security has both a physical and psychological aspect (Kozier *et al.*, 2000:192). The second level of the hierarchy is the need for safety and security. According to Huitt (2006) and Boeree (1998) safety and security needs arise from physiological needs and include the feeling of being safe physically, feeling secure in a family environment and feeling safe in the own health and health settings. The HIV positive pregnant woman might feel the need to feel safe and secure in her physical environment and relationships.

- *Love and belonging needs*

This entails giving and receiving affection (Kozier *et al.*, 2000:191). Humans generally need to feel belonging and acceptance, whether it comes from a large social group (religious groups, professional organisations, sports teams) or small social connections (family members, intimate partners). They need to love and be loved (sexually and non-sexually) by others (Huitt, 2006). In the absence of these elements, many people become susceptible to loneliness, social anxiety, and depression (Boeree, 1998). The HIV positive pregnant woman might have the need to feel part of her group or community and maintain a feeling of belonging.

- *Esteem needs*

The woman needs both self-esteem and esteem from others. According to Maslow, all humans have a need to be respected, to have self-respect, and to respect others (Huitt, 2006). People need to engage themselves in order to gain recognition and have an activity or activities that give the person a sense of contribution, to feel accepted and self-value, be it in a profession or hobby. Imbalances at this level can result in low self-esteem, inferiority complexes, or an inflated sense of self-importance (Huitt, 2006; Boeree, 1998). This is also known as need to know and understand and aesthetic needs. The woman must have a feeling of independence, competence and self-respect and must receive recognition, respect and appreciation from others.

- *Need for self-actualisation*

When the need for self-esteem has been satisfied, the woman may strive for self-actualisation. Self-actualisation is the instinctual need of humans to make the most of their abilities and to strive to be the best they can (Boeree, 1998). She may develop her maximum potential and realise her abilities and qualities.

1.5.3 Methodological assumptions

The Botes Model (Rand Afrikaans University, 1995) will be used during the research, due to the fact that it is specifically suitable for application in nursing.

The Botes Model consists of three levels (Rand Afrikaans University, 1995:6). The first level is the nursing practice. Within the research, the nursing practice is the antenatal care that is provided by the midwives for HIV positive pregnant women.

The second level of the Botes Model is nursing research. During this level the researcher followed the research process. Knowledge collected from the process can be used in the nursing practice. In the case of this research, the data collected and analysed might help to meet the needs of HIV positive pregnant women regarding antenatal nursing care.

The third level consists of the paradigmatic perspective. The paradigmatic perspective consists of the researcher's meta-theoretical, theoretical and methodological assumptions (Rand Afrikaans University, 1995:7). The meta-theoretical assumptions in the research, is based on the Christian view while the theoretical assumptions addresses the researcher's central theoretic argument as well as theoretical descriptions of concepts used in this research. The methodological assumptions are based on the Botes Model (Rand Afrikaans University, 1995).

1.6 RESEARCH DESIGN AND METHOD

In this section, the research design and method is discussed, as it is the framework that supplies the structure used during the research.

1.6.1 Research design

An explorative, descriptive, contextual design, following a qualitative approach was used for the research. The descriptions are used when the need exists to identify a phenomenon, identify variables within a phenomenon and develop conceptual and operational definitions of variables (Burns & Grove, 2001:795). Explorative design is used to learn from the experience from others and to become aware of their feelings and opinions (Strydom, 2003:212). On the other hand, a descriptive design is used to develop conceptual and operational definitions of variables (Burns & Grove, 2001:795). These aspects are combined to explore the phenomenon (the women's needs) and define their emotions and opinions regarding the antenatal care they receive.

Qualitative research is an inductive approach to discover or expand knowledge, in this case the needs of HIV positive pregnant women in the Potchefstroom district regarding antenatal care (Babbie & Mouton, 2004:270; Brink, 2000:119; Brockopp & Hastings-Tolsma, 2003:328). Characteristics of a qualitative approach involve merging of data to formulate strategies (Polit *et al.*, 2001:207), meaning that data obtained from the participant is used to formulate recommendations for antenatal care of HIV positive pregnant women.

1.6.2 Context

Potchefstroom forms part of the Southern district of the North-West Province. According to the census of 2001, the Potchefstroom-sub-district has a population of about 170 000 (Potchefstroom City Council, 2005). The languages most spoken are Afrikaans, English and Tswana. The cultures are specific to the ethnics groups that live in Potchefstroom. The majority groups include European, Muslim and Tswana. Minority groups include Zulu, Sotho and Xhosa. An estimated 55% of Potchefstroom's population is unemployed (Potchefstroom City Council, 2006) and live in poor socio-economic conditions. Since 1994 all maternity services are free in the public health sector.

The city of Potchefstroom has eight primary health-care facilities, including the antiretroviral clinic. These clinics provide antenatal and postnatal care by professional midwives to all pregnant women. The antiretroviral clinic is available where treatment is provided to the HIV positive community in Potchefstroom. The Potchefstroom Hospital provides antenatal, intrapartum and postnatal services. During the antenatal period, sonograms are done at the Gynaecology and Obstetrics Department of the hospital to detect fetal abnormalities and determine the expected date of delivery (Potchefstroom City Council, 2006).

According to statistics compiled by the Potchefstroom City Council in 2005, a total of 4687 women attended local clinics for their first antenatal visit. Only 1568 women tested for HIV, of which 514 tested HIV positive (See Figure 1). This means that 33% of women that were tested during their first antenatal visit, tested HIV positive. It was found that by October 2007 a total of 62 pregnant HIV positive women were attending the antiretroviral clinic in Potchefstroom (Antiretroviral Clinic, 2007).

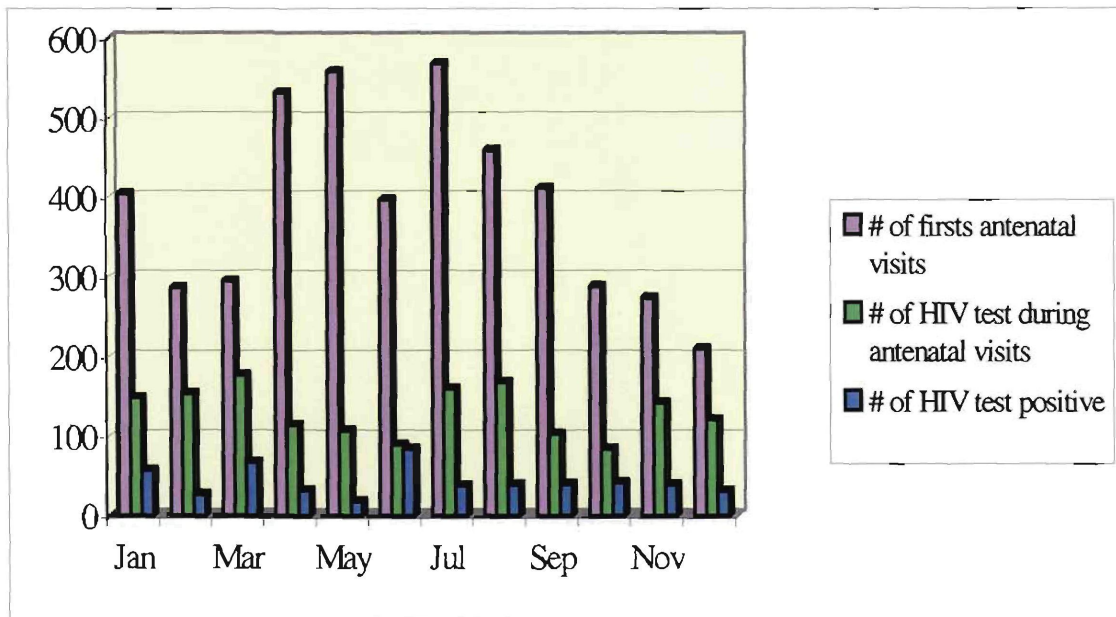


Figure 2: Women attending antenatal care for the first time that tested HIV positive in 2005 (Potchefstroom City Council, 2006)

1.6.3 Research method

The following concepts will be discussed under research method: sample, data collection and data analysis.

1.6.3.1 Sample

Discussion of the sample entails the following concepts: population, sampling and sample size.

Population

The population is the group, persons or objects in which all the sampling criteria are met (Brink, 2000:132; Strydom & Venter, 2003:198). The population for this research is HIV positive pregnant women attending public antenatal care in Potchefstroom.

Sampling

Purposive sampling is implemented by the researcher selecting women from the population that are typical representatives of the phenomenon. An advantage of purposive sampling is its allowance for the researcher to handpick the sample, based on her knowledge of the phenomenon under study (Fain, 2004:116). These women should not only meet selection criteria, but also participate in the study voluntarily (Brink, 2000:14; Strydom & Venter, 2003:197; Burns & Grove, 2001:366).

The selection criteria for the women were that they:

- Attend public antenatal care clinics;
- are taking antiretroviral therapy or making use of the PMTCT programme; and
- give informed consent to participate in the research voluntarily
- and that the interview may be recorded on audio cassette.

Sample size

The sampling size was determined by data saturation. This means that a sufficient number of participants were necessary to ensure that enough data was available to a point where a sense of closure could be attained when analysing (Polit *et al.*, 2001:470).

Data saturation refers to the repetition of information, with no new themes emerging during the interviews with the women (Fain, 2004:227; Speziale & Carpenter, 2003:68). (See Part 2 for further discussion of data saturation.)

1.6.3.2 Data collection

Data collection commenced after permission had been obtained from the Ethics Committee of the North-West University (Potchefstroom Campus) (Appendix A) and the district health manager of Potchefstroom (Appendix E). The researcher also obtained permission from the Ethics Committee of Potchefstroom Hospital to conduct data collection at the antiretroviral clinic (Appendix C).

Letters (Appendix D) were delivered to the professional nurses of the various identified clinics. The research method and the clinic's role within the research were explained in the letters. An appointment was set up between each participant and the researcher with the professional nurse as mediator.

During the contact session informed consent was obtained from the participant. Informed consent is the process of providing the HIV positive pregnant woman with sufficient understandable information regarding her participation in the research project (Brockopp & Hastings-Tolsma, 2003:169). Information was provided both verbally and via a letter (Appendix F) and willing participants were asked to sign a consent form (Appendix G).

Data was collected via individual semi-structured interviews. This method of interviewing gives the researcher and the participant flexibility, enabling the researcher to follow up topics that emerge from the interview. This created a fuller picture of the topic, in the case of this research, the needs of the HIV positive pregnant women (Greeff, 2002:302). Both close-ended and open-ended questions were included in the interviews (Brink, 2000:158).

The researcher formulated an interview schedule (Table 2) that provided a set of predetermined questions that were used to engage the interview and designate the narrative terrain (Greeff, 2002:302; Fain, 2004:159). The questions were formulated from the research problem. The interviews were conducted in English and Afrikaans. The

questions were first submitted to a panel of skilled researchers to promote the trustworthiness of the research.

Table 2: Interview schedule

Questions asked to pregnant women

- When did you find out about your HIV status?
- When did you start antiretroviral therapy?
- What do you expect from antenatal care?

Follow-up questions were formulated from answers given by the participants during the interviews or were set in different terms for the participant to understand. The interviews took place at a time and place that were mutually convenient for the researcher and the participant (Brink, 2000:159). The interviews were conducted at the clinic during the women's antenatal visits in a private environment. A room was selected where there was little activity. All staff was informed about the interviews and a sign was put up to ensure privacy.

Each interview was audiotaped for later transcription and data analysis. Field notes (Appendix J) were taken to record information and to synthesise and understand the data that was obtained during the interview (Burns & Grove, 2001:421; Polit *et al.*, 2001:283). The following critical points as in Greeff (2002:304) were followed to minimise the loss of data when writing the field notes:

- The researcher wrote the field notes immediately after the interview.
- The data was not discussed before the notes were made.
- The notes were written in a quiet environment.
- The events were written down in the sequence that they occurred.

1.6.3.3 Data analysis

Data analysis followed data collection. The recorded data was transcribed verbatim after each session. A data analysis protocol was set for use by researcher and the independent co-coder to ensure that the same procedure was followed during analysis (Appendix H). An analysis style during which the coders read through the data in search of meaningful segments was used. Identified segments were reviewed and a

categorisation scheme developed. The researcher searched for patterns and structures and then linked them to one of the categories (Polit *et al.*, 2001:382). The analysis was done after each interview and guided further data collection (Burns & Grove, 2001:487; Polit *et al.*, 2001:381). The data-analysis process was based on the Tesch method (1999) for open coding:

- The researcher obtained a sense of wholeness by reading all the transcriptions.
- The researcher went through the interview that seemed the most interesting. She went through and identified the underlying meaning of the information. This was written down in the margin.
- When the researcher completed this task with several informants, a list of all topics was made.
- Similar topics were clustered together. These topics were formed into columns that might be arrayed as major topics, unique topics, and left-overs.
- After this was done the researcher again read through the data. The topics were abbreviated as codes and the codes were written down next to the appropriate segments of the text. This preliminary organisational scheme was used to see whether new categories and codes emerged.
- The researcher found the most descriptive wording for the topics and turned them into categories by reducing the total list of categories by grouping topics that relate to each other. Lines were drawn between the categories to show interrelationships.
- A final decision on the abbreviation for each category and alphabetising these codes was made.
- The data material belonging to each category was assembled in one place and a preliminary analysis was performed.
- If necessary, the existing data was recoded. After data analysis a meeting was held between the researcher and co-coder to reach consensus regarding the research findings.

The results of the research are discussed in Part 2.

1.7 LITERATURE CONTROL

Having completed the collection and analysis of the data, the findings were related to the existing body of knowledge on HIV/AIDS and antenatal care (Fouche & Delport, 2002:269). A comparison was made between the existing literature on HIV/AIDS in pregnancy and the needs of HIV positive people and the findings of this research regarding the needs of HIV positive pregnant women in Potchefstroom. Any unique new findings not traced in the literature were pointed out, as well as common findings also found in other studies.

1.8 RIGOUR OF THE RESEARCH

According to Burns and Grove (2001:810), rigour is the striving for excellence in research through the use of discipline, adherence to detail and strict accuracy. Researchers need alternative models appropriate to qualitative designs that will ensure rigour without sacrificing the relevance of the research (Krefting, 1991:3).

One model suitable for qualitative research is Guba's Model for Trustworthiness, as described by Krefting (1991). Guba's model consists of four criteria for trustworthiness, namely credibility, transferability, dependability and confirmability (Krefting, 1991:3).

Credibility establishes the truth of findings (Krefting, 1991:3). During the study, the data should present an accurate description or interpretation of human experience. People who had the same experience should immediately recognise the descriptions and depth in at least five consecutive interviews. During the study, the following strategies were followed to ensure credibility:

- **Reflexivity** ~ The researcher assessed her own background, perceptions and interest in the qualitative research process and the topic under investigation before commencing to gather data. This enabled her to determine her own viewpoint, as well as to differentiate between her own perceptions and that of the participants.
- **Peer examinations** ~ The researcher continually discussed the research process and findings with colleagues who have had experience with qualitative methods.

- **Interviews technique** ~ The researcher reframed and expanded the questions as the data gathering and analysis process continued to increase the depth of the data as well as credibility.
- **Structural coherence** ~ The researcher ensured that there were no unexplained inconsistencies between the data and the interpretation thereof by meeting with the co-coder for a consensus discussion on the results.
- **Triangulation** ~ The researcher looked for different types of sources that could provide insight into the research. In the case of this research, field notes were made, the audio tapes were transcribed and two co-coders analysed the data.

The researcher is responsible for providing sufficient details to enable the reader to decide on transferability (Krefting, 1991:4). For this to be achieved, the sample should be representative of the phenomenon. During the study, the following strategies were applied to ensure the transferability of the study:

- **Dense descriptions** ~ The researcher ensures detailed description of context to enable the reader to decide for him/herself if the context is similar.

Dependability relates to the consistency of the research findings. In qualitative research, variability is expected, since qualitative research emphasises the uniqueness of the human experiences (Krefting, 1991:4). Dependability can be ensured as follows:

- **Peer examination** ~ The researcher discusses her research plan and implementation with experienced colleagues.
- **Dense descriptions of methodology** ~ This includes an accurate description of data gathering, analysis and interpretation methods.
- **Stepwise replication** ~ The researcher and co-coder analyse the data separately and then compare the results.

Confirmability is achieved when truth-value and applicability of research data are established. This data should be free from bias (Krefting, 1991:5). The following strategies are used to ensure confirmability:

- **Confirmability** ~ The researcher keeps field notes consisting of observational, theoretical, methodological and personal information.

- **Literature control** ~ The researcher compares existing literature with her research findings.

1.9 ETHICAL ASPECTS

Before the research commenced, the researcher obtained permission from the Ethics Committee of the North-West University, Potchefstroom Campus (Appendix A). After permission had been granted, the research proposal was submitted to the district manager of Health Services of the Potchefstroom District (Appendix D). Permission was obtained from managers of the identified clinics (Appendix E) and the Potchefstroom Hospital (Appendix C). This secured a positive relationship of trust during the research.

During the research, various principles were implemented to ensure that the rights of the participants were protected. According to the International Council of Nurses (2000) and Brink (2000:38-49), the three basic ethical principles include respect, beneficence and justice.

Although HIV/AIDS is a well-known disease, people that are HIV positive live in fear of stigmatisation. During the study, the participants were treated with respect in order to convey a non-judgemental attitude towards them. The identity of the participants was kept anonymous. The participants signed informed consent out of free will. If a participant decided to terminate her participation in the research, her decision was respected. The assurance was given that all information provided by her would be kept confidential by using code names.

The principle of beneficence involves the effort to secure the well-being of others. The participants in the study were pregnant and might be living in difficult socio-economic circumstances. During the interviews, the researcher protected the physical and psychological comfort of the participants. The "do good, no harm" approach was followed. The participant did not leave the interview feeling negative and guilty for being HIV positive. If the researcher saw the need for referral, she referred the woman, e.g. if the woman should say that she did not have enough to eat to improve her physical well-being, she was referred to the clinic or a non-governmental organisation so that she could benefit from a food scheme. The participant was informed during the data

collection interview that a professional counsellor was available if needed for psychological support.

The participants were entitled to fair selection and treatment. During the interviews, privacy was upheld and information provided by the participant was kept confidential. If the researcher wished to discuss a participant's situation with a member of the multi-disciplinary team, permission was obtained from the participant. The identity of the participant was kept anonymous during such a discussion.

The researcher will publish the results of the research and provide the results to the various clinics and the hospital to implement the findings about the care of the women.

1.10 RECOMMENDATIONS

From the results and conclusions, recommendations were formulated regarding antenatal care for HIV positive women. These recommendations are discussed in Part 3.

1.11 STRUCTURE OF MINI-DISSERTATION

The structure of the mini-dissertation is as follows:

Part 1 ~ Grounding of the research

Part 2 ~ Article - Antenatal care for HIV positive women

Part 3 ~ Conclusion, limitations and recommendations for research, education and the practise of antenatal care for HIV positive women.

1.12 SUMMARY

It is apparent that the needs of HIV positive pregnant women are not known and that antenatal care is not needs-based. Therefore, the aim of the research study was to promote the health of HIV positive women by using knowledge about the needs of these women in antenatal care. The final aim was to provide recommendations based on the findings to the local clinics and the antiretroviral clinic at the Potchefstroom Hospital for the provision of antenatal care according to the needs of the women.

An explorative, descriptive, contextual design following a qualitative approach was used. Semi-structured interviews were used as method of data collection. Data-analysis was done after each session and themes were categorised according to the women's needs.

In Part 2 the article and results of the research are discussed.

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PART 2
ANTENATAL CARE FOR HIV POSITIVE WOMEN

HEALTH SA GESONDHEID AUTHOR GUIDELINES

Part 2 will be submitted to Health SA Gesondheid for publication. For this reason Part 2 is already in publication format. Health SA Gesondheid Author Guidelines are included to explain the format.

- Body text paragraphs should be in double spacing, not indented, left aligned (not justified) and an open (empty) paragraph after each text paragraph.
- Body text font type and size should be Arial size 10.
- Article must be submitted in MS Word format or recent compatible software format.
- Abstracts in English and Afrikaans of no more than 200 words must be included in the article. The abstract must accurately reflect the content of the article.
- Five key words describing the contents of the article should be submitted.
- The article itself may not compromise more than 20 pages and authors must supply a word count. In exceptional cases longer articles may be accepted.
- The journal has a policy of anonymous peer review. Authors' names are withheld from the referees, but it is the authors' responsibility to ensure that any identifying material is removed from the article.
- The article must be ready for the press, in other words, it must have been revised for grammar and style. The author must provide a letter from a language editor confirming this.
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- All references to source books must be acknowledged according to the revised Harvard method (see examples at the end of the author guidelines).
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- All illustrations, figures and tables must be numbered and provided with titles. Each illustration, figure and table must, in addition, appear on a separate page and must be graphically prepared (be press ready). Illustrations, figures and tables must be black and white - NOT in colour. The author is responsible for obtaining written permission from the author(s) and publisher for the use of any material (tables, figures, forms or photographs) previously published or printed elsewhere. Original letters granting this permission must be forwarded with the final article.
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- Refer to articles in recent issues for guidance on the presentation of headings and sub-headings.
- Requirements for publication
- Articles should preferably be submitted via email to lviljoen@uj.ac.za
- If the article is not submitted electronically, one printout of the article must be submitted. In addition to the above-mentioned printout, a data disc containing the full article must also be submitted. The latter disc must clearly be marked with the name of each author and co-author and the name of the file.
- A further copy of the article should be retained by the corresponding author.
- The article must be accompanied by a cover letter.
- The title page must be submitted on a separate page and must give the following particulars:
 - The title of the article.
 - The surname, first name and, if any, the other initials of the author(s) and co-author(s).
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- The capacity in which author(s) and co-author(s) is acting and the name of the organisation/institution they are attached to.
- The postal addresses and email addresses of ALL the authors. Please indicate who the corresponding author is.
- The Editor must be notified immediately of any change of address.

- **Examples of text references:**

- The ethical measures adhered to during this research process are those set out by DENOSA (Democratic Nurses Association of South Africa, 1998:3-7).
- Stein, Brailowsky and Will (1995:105), however, note that points of divergence are seen even within rodents of the same species. Yet sex differences do occur both in response to injury and in recovery of function, female rats in normal oestrus showing less oedema following frontal cortical contusions than males, and more severe oedema than females who are not in oestrus (Stein et al. 1995:105).
- Headings and fonts used in Health SA Gesondheid:
- MAIN HEADING (font size 12, CAPITAL LETTERS, bold)
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Key concepts: HIV/AIDS, antenatal care, needs, antiretroviral therapy

SUMMARY

HIV and AIDS have had a large impact on pregnant women in South Africa. For this reason it is important for a midwife to be aware of the needs of the HIV positive woman regarding antenatal care. Research was conducted, following an explorative, descriptive, contextual design within a qualitative approach. Sixteen HIV positive pregnant women participated in this qualitative research to determine their needs regarding antenatal care. It was found that each woman has specific needs, but similar to those of the other participating women. For this reason the needs could be classified into categories. From these categories as well as literature control and conclusions, recommendations for antenatal care for HIV positive pregnant women could be compiled. These recommendations were made available to the clinics of Potchefstroom.

OPSOMMING

MIV en VIGS het 'n groot impak op swanger vroue in Suid-Afrika. Vir dié rede is dit belangrik dat 'n vroedvrou bewus is van die MIV-positiewe swanger vroue se behoeftes rondom voorgeboorte sorg. Navorsing is gedoen deur gebruik te maak van 'n verkennende, beskrywende konseptuele ontwerp binne 'n kwalitatiewe benadering. Sestien MIV-positief swanger vroue het deelgeneem aan die kwalitatiewe studie om te bepaal wat hul behoeftes is ten opsigte van voorgeboorte sorg. Daar is gevind dat elke vrou spesifieke behoeftes het, wat tog soortgelyk is aan die van ander deelnemende vroue. Vir dié rede kan die behoeftes in kategorieë ingedeel word. Uit die kategorieë, literatuurkontrolle en gevolgtrekkings, is aanbevelings vir voorgeboorte sorg vir MIV-positiewe swanger vroue saamgestel. Die aanbevelings is beskikbaar gestel aan die klinieke van Potchefstroom.

INTRODUCTION AND PROBLEM STATEMENT

HIV/AIDS continue to have a devastating impact on populations worldwide, including women of childbearing age, who represent 40% of the world's HIV population (Loutfy & Walmsley, 2004:472). In a national survey done by the Department of Health in 2006, a percentage of 29.1% South African women tested HIV positive during their first antenatal visit (Department of Health, 2007).

This prevalence of HIV infection amongst women of childbearing age reinforces the importance of understanding the management of HIV in pregnancy, and for this reason her status must be known (Loutfy & Walmsley, 2004:471; Minnie, 2003:3). A pregnant woman may decline HIV testing due to various factors (Minnie, 2003:3). The benefits of HIV testing must be brought to her attention, namely that if her status is known, the best available antenatal care can be provided, including antiretroviral treatment to prevent mother-to-child-transmission and to prolong the life of the woman (DOH, 2000:12; Minnie & Du Preez; 2004:19-4; Woods, 2000:31-2).

South African health-care services usually provide the opportunity for women to test for HIV during the first antenatal visit. If the woman is not ready to be tested, the test can be done at any stage of pregnancy (Anderson, 2000:222; DOH, 2002:10; Kennedy, 2003:83). Women who test negative in pregnancy must be encouraged to test again before the 36th week of gestation. The women who test HIV positive after the 36 week of gestation, irrespectively of the stage of HIV, is provided with *nevirapine 200mg* that should be taken with the onset of labour to prevent mother-to-child transmission of the HI virus (DOH, 2002:10). During the last year the South African Department of Health has started to provide antiretroviral therapy to promote their health to HIV positive individuals (including pregnant women) whose CD4 counts are less than 200 cell/mm³. Appropriate antiretroviral treatment in pregnancy is *zidovudine (AZT)*, *nevirapine (NVP)* and *lamivudine (3TC)* (Evian, 2003:231; Watts & Minkoff, 2003:383). The DOH (2004:23) recommend

stavudine (d4T) and *lamivudine* (3TC) where the woman's CD4 count is less than 200 cells/mm³ or where the woman has an HIV-related disease.

An antiretroviral therapy service has been established within the Johannesburg Hospital's antenatal clinic as part of a comprehensive HIV care package to meet the needs of HIV positive pregnant women who qualify for antiretroviral therapy. The antenatal HIV clinic gradually prepares a woman for the rigorous demands of treatment during two weekly visits preceding initiation of treatment (RHRU, 2005:18). Should the pregnant woman choose so, she can make use of ongoing counselling at the clinic throughout her pregnancy. Not only are the counsellors available for private sessions, there is also a support group for the women coming to the antenatal HIV clinic (RHRU, 2005:14). Counselling for readiness is provided to ensure and measure whether women are taking their drugs at the prescribed times on any given day (RHRU, 2005:16).

Contrastingly, the antiretroviral clinic at the local hospital in the sub-district under investigation, provides antiretroviral therapy to adults, but do not specifically focuses on pregnant women. Antenatal care is provided by local clinics, but apparently there is no collaboration between these clinics and the antiretroviral clinic. Care provided to HIV positive pregnant women is fragmented and not based on the needs of these women.

It is apparent that midwives must establish the needs of pregnant women to enable them to provide effective antenatal care. According to Maslow, as adapted by Kozier *et al.* (2000:191), needs can be divided into physiological needs, safety and security needs, love and belonging needs, esteem needs and the need for self-actualisation. . Additionally, the ideal is that the antenatal care should be provided at a clinic where the staff members have experience in managing HIV positive pregnant women, this including women on antiretroviral treatment (Woods, 2000:32-6).

From the discussion it is apparent that HIV positive pregnant women are in need of antenatal care according to their needs. Not only must these pregnant women deal with their own HIV status and health, but also with the fear of transmitting the deadly virus to their unborn babies (Woods, 2000:35-10). Furthermore, Woods (2000:35-10) suggests that the infected woman must be prepared for taking care of the child, who might die before her, the practical aspects of taking care of the child and other children and consider who will take care of the child/children if she dies. This preparation, as part of antenatal care, might be enhanced if her specific needs are known.

Therefore the questions raised are:

- What are the needs of HIV positive women regarding antenatal care?
- How could antenatal care be rendered in order to address these needs?

This research project aims to promote the health of HIV positive pregnant women by using insight into the needs of these women in the improvement of antenatal care. The specific objective is to explore and describe the needs of HIV positive women regarding antenatal care.

RESEARCH DESIGN AND METHOD

An explorative, descriptive contextual design was used to explore the needs of the HIV positive women regarding antenatal care in one sub-district in the North-West Province of South Africa. A voluntary sample was obtained by means of purposive sampling, as discussed later on. The criteria for the participants were that the women:

- Attend public antenatal care clinics in the selected sub-district;
- are taking antiretroviral therapy or are on the PMTCT programme; and
- gave informed consent to participate in the research voluntarily and that the interview may be recorded on audio cassette.

Possible participants were recruited, while attending the antiretroviral clinic or after the birth of their babies while still in the local hospital.

REALISING OF SAMPLING

Various factors influenced the sample size. These included that various potential participants identified by the mediators that passed away due to AIDS-related conditions. Some identified women had spontaneous abortions or decided to terminate their pregnancies.

The sample included HIV positive women of various ages, gestation of pregnancy and social backgrounds. Data saturation was obtained after 16 interviews. Women from the following age groups participated:

Table 3: Age distribution of participants

15-20 years	20-30 years	31-40 years	>41 years
2	8	6	0

Most of the participants were between the ages of 20-30 years. Fourteen (14) of the sixteen (16) participants were of African decent, with one Indian participant and one white participant. Four (4) of the women were primigravidas and all four of them became aware of their status during their first antenatal visit. Five (5) of the participants had precious miscarriages, abortions or intra-uterine deaths due to HIV-related circumstances. Six (6) of the sixteen participants had three (3) or more pregnancies and were aware of their HIV status prior to their current pregnancy. One participant received antiretroviral therapy from another facility, with nine (9) participants attending the antiretroviral clinic in Potchefstroom and six (6) participants on the PMTCT programme.

REALISATION OF DATA COLLECTION

It was found that the women were afraid to grant interviews at their local clinic, as initially planned. Many participants were found through the antiretroviral clinic and local hospital, where they were admitted for various conditions. Appointments for interviews were made in hospital on discharge of the women. It became known that the women were afraid to grant interviews at the clinic due to the fear of stigmatisation by others and the discomfort of putting their local clinic in an uncomfortable situation by the information given. By having interviews away from the clinics, the women felt more at ease and were comfortable talking about their needs. All participants were able to communicate in English and Afrikaans, and for this reason a Tswana translator was not needed, as initially planned.

DATA ANALYSIS

The recorded interviews were transcribed verbatim and open coding was carried out, as set by the Tesch Method (Tesch, 1999). The service of an independent co-coder was utilised and a consensus discussion was held regarding the categories of needs present in the data.

RESULTS AND DISCUSSION

The results of the research are reflected in this section. The results are compared within what is known about the topic by means of a literature control.

After analysis it was found that each woman has very specific needs, but that some of these needs are similar amongst the women. Because of these similarities the needs could be categorised into the following:

Table 4: Needs identified by HIV positive women

Need for support	❖ Support from the multi-disciplinary team ❖ Support from the nursing staff ❖ Support groups ❖ Support for relatives
Need for education	❖ Self-care ❖ Baby care ❖ Antiretroviral treatment
Need for treatment	❖ Informed when to start antiretroviral treatment ❖ Why antiretroviral therapy is important ❖ Goal and function of the antiretroviral clinic
Need for improved services	❖ Clinics ❖ Staff
Need for safe and non-judgemental environment	❖ Respect from staff ❖ Environment

The format of the discussion of the results is as follow: theme, quotations and the discussion of the relevant literature.

Need for support

All 16 women interviewed reflected that they were in need of a form of support. Phrases like "*I need support*" and "*I want support*" were commonly mentioned during the interviews.

According to Holmes (2005), HIV-infected mothers face various challenges during and after their pregnancies. For this reason adequate support must be provided to the women. The

HIV/AIDS/STD Strategic Plan for South Africa 2007-2011 confirms that various means of supporting all people living with HIV and AIDS are necessary (2007).

The forms of support mentioned by the participants include support from the multi-disciplinary team, support from the nursing staff, a support group for HIV positive and support for their relatives.

Support from the multi-disciplinary team

Participants expressed the need to be supported by the multi-disciplinary team. This multi-disciplinary team includes the doctors, counsellors, psychologists and social workers.

Medical doctors

The need for support by the medical doctors expresses the need of the participant to be treated with respect and also adheres to the physiological needs of Maslow's Hierarchy.

"Then the doctor shouted at me."

Literature support that medical doctors play a crucial role in making the decision whether a patient is physically ready to start antiretroviral treatment (DOH, 2000). Studies done in South Africa, Kenya and the United States of America suggest that doctors need further training in the comprehensive management of pregnant HIV positive women (Bekker *et al.*, 2006: 317). Comprehensive care includes supporting the women to start antiretroviral treatment (Bekker *et al.*, 2006:317; Buvè *et al.*, 2003:42; Rahimain *et al.*, 1998:42).

Counsellors

Furthermore, literature suggests that HIV positive women face many challenges during their pregnancy, depending on when they became aware of their status. There has been a tendency by health-care workers to focus predominantly on the care of the women to prevent mother-to-

child-transmission (Holmes, 2005). In this research though, it was found that the women have the need to talk to somebody regarding their emotions and the acceptance of the disease rather than preventing mother-to-child-transmission.

"Iemand wat hoor wat binne is." (Somebody who hears what is inside) and "I need someone to talk to. I'm scared that I'm going to lose my baby again." "My fears, how to stay healthy and how to take care of my baby." "I only met with the counsellor once. I think... if I can talk to someone I'll be less afraid."

Fourteen (14) participants identified counsellors as one of the means of support. The need for support by counsellors relates to all the levels of Maslow's Hierarchy of Needs, as the participants' specific need for support by counsellors might vary. Counsellors do not always address the needs of the participants satisfactory as is evident from the following quotes.

"And I don't feel counsellors have the training to talk to the patients to deal with their problems." Yes, but I didn't listen. They talked and talked and talked, but I didn't hear anything."

International research has also shown that there are not enough counsellors available with adequate training (Bekker *et al.*, 2006). Guidelines have been prepared to assist counsellors in managing the HIV positive mothers-to-be (Bekker *et al.*, 2006:314; Holmes, 2005:). Holmes (2005) states that the deployment of non-professional staff and volunteers that are trained as counsellors was a huge success in South Africa. In contradiction to Holmes (2005), the participants felt that counsellors need further training in the counselling of HIV positive pregnant women.

The participants stated that they do not want just one counselling session to determine readiness to start antiretroviral therapy, but regular sessions. Women who tested HIV positive during their first antenatal visit highlighted the fact that counselling needs to be provided again after the

results have been made known, because they do not absorb information given due to shock and disbelief. The HIV/AIDS/STD Strategic Plan for South Africa (2007) states that counsellors should be available for counselling at any time when the need for counselling arises in the HIV positive person. From the research findings it can be stated that counsellors are not available for re-counselling and that this must be addressed to meet the HIV positive woman's need for counselling during pregnancy. Furthermore, literature suggests that a pregnant woman is more prone to accepting and disclosing her HIV status to relatives if she has received continuous counselling during her pregnancy (Rahimian *et al.*, 1998:41).

Social workers

The women identified the social worker as support system for various reasons. Especially, women from lower socio-economic circumstances identified the social worker as support in helping them to gain social grants for taking care of themselves and their children.

"Sy het my na social worker gestuur dat ek die grant kan kry." (She sent me to the social worker so that I can receive a grant).

"En ek wil hê hulle moet my in my pregnancy help om die grant te kry." (And I want them to help me in my pregnancy to get the grant).

"Ek soek die grant vir my kinders." (I want the grant for my children.)

Participants also expressed the need that a social worker should be present at the local clinics to assist them when they felt the need for, for instance, assistance in the adoption process.

"Dit sou gewerk het as die clinic a social worker gehad het."

"Maybe...iemand wat verstaan soos die social worker." (Maybe...somebody who will understand like the social worker).

"Ek het hier ook met die social worker gepraat." (I talked with the social worker).

Similar literature suggests that the social worker takes on the role of advocate, mediator, therapist and the management of HIV programmes (Wentworth, 2007).

Psychologist

Only one participant with a strong sense of fear of transmitting the virus to her baby said that she felt the need to see the psychologist to help her to reach a state of accepting that she was HIV positive. The psychologist would help the participant through all the levels of Maslow's Hierarchy of Needs and by doing this, self-actualisation could be met.

"...ek dink die sielkundige kan my beter help..." (I think the psychologist can help me better.)

Literature suggests that the psychologist plays a role in the support of HIV positive pregnant women in both adherence to the treatment and emotional support of these women, and therefore improve the emotional outcome of the pregnant women (Nachega *et al.*, 2006:127).

Nursing staff

From the interviews it became apparent that the women felt that the nurses did not listen to their problems, as mainly questions on general health and the pregnancy were asked by the nursing staff. The women verbalised that they were in need of being asked about their problems. One participant pointed out that her needs change as the pregnancy progresses and for this reason it was important that the nurse ask her about her needs.

"Hulle (the nurses)...moet my eerder support." (They (the nurses) must rather support me.)

"Ek wil hê die susters moet my help....ek kan nie cope nie." (I want the sisters to help me...I can't cope.)

"Nurses' attitudes influence the patients. If they are nice, like the staff at the antiretroviral clinic, people will test more."

Nurses are central in providing antenatal care to pregnant women. Studies done in Kenya suggest that nurses/midwives should be equipped with skills to provide the essential support to pregnant women (Colton, 2005:5). In South Africa, the HIV/AIDS/STD Strategic Plan (2000) underlines the importance that nurses/midwives should be trained in dealing with pregnant women.

Surprisingly, participants pointed out that they were aware of the lack of staff and staff exhaustion and felt that it influenced the quality of their antenatal care.

"My need sal wees dat daar meer staff by die clinics is." (My need will be that there are more staff at the clinics.)

"Hulle probeer hulle bes, maar is moeg. Dit is dan wanneer hulle annoyed raak." (They try their best, but they are tired. That is when they get annoyed).

"By die clinic verstaan die susters nie. Hulle is besig." (At the clinic the sisters don't understand. They are too busy).

"I feel like the clinic nurse...they don't have the time to talk"

The DOH (2000) is aware of the shortage of staff and for this reason stresses the importance of existing staff being equipped with the necessary skills in supporting and managing HIV positive pregnant women.

Support groups

Participants mentioned and emphasised the need for support groups. Participants who received antiretroviral therapy from other health-care facilities mentioned during the interviews that they had regular support groups. They discussed various topics that arose from their needs. These topics included their own fears, baby care, feeding options, their general health and preventing mother-to-child-transmission. The women also had a sense of belonging and a feeling of being safe between other HIV positive women.

*"In ***** , we have support groups and we talk and were educated in various topics."*

"Our fears...our feelings. We understood one another and we did not judge. We were like sisters.

We cried if somebody died or lost her baby...I miss the support."

"My fears, how to stay healthy...how to care for my baby."

The participants attending the antiretroviral clinics in Potchefstroom also raised the need for support groups. They mentioned that women in a support group could relate to each other and support one another.

"Like first I was 'wow I'm positive and I'm pregnant' and now I see there are other women that are positive and pregnant. I feel better."

"Maybe get all the women together to talk. Like a group. If that can be started, please. We can talk to each other and the counsellor can talk to us. They can give us education as a group."

Support groups were successfully started in Kenya. Women can share their feelings, seek social support, access food and participate in income-generating activities. These support groups also ensure follow-up after delivery. Women living positively, women who have been successful in exclusive breastfeeding, and women with HIV negative infants in support groups serve as role models for other women in their communities (Colton, 2005:10). A support group programme was started in the Western Cape. The women in the group were not only equipped with skills to enhance their lives, but also sent a positive message to the women in their community to test for HIV (DOH, 2000).

Support for relatives

Participants admitted during the interviews that they have not yet disclosed their status to their relatives and children. Reasons given by the participants for this were fear of rejection and many of the women are unsure how to approach their relatives to inform them about their HIV status.

Minnie (2003) also mentions these reasons. The need therefore arose for support from the clinics to inform their relatives.

"I am afraid to tell my mother because they believe it is a gay disease."

"My boyfriend does not know."

The participants also felt that they needed guidance in informing and explaining their HIV status to their other children.

"En ok...hulle vra na die pille...die ARV. Ek weet nie om die HIV aan hulle te verduidelik nie."

(Also...they ask about the tablets...the ARV. I don't know how to explain the HIV to them.)

Literature suggests that HIV positive women are faced with the challenge of disclosing their status to their partners, children and relatives due to the fear of rejection or stigmatisation (Holmes, 2005). Statistics show that by 2010 an estimated 40 million children in developing countries will be orphaned by HIV/AIDS (Lyons, 2006). Many of these children care for their dying parents and end up supporting their siblings. Lyons (2006) suggests that children must be informed by their parents about their status. Children must be reassured and need counselling to deal with their parents' dying. Lyons (2006) and Compassion International (2005) stress the fact that it is the parents' responsibility to be honest with their children and prepare them for death and inform them about treatment and other ways that HIV is going to affect their lives. Furthermore, the parents must appoint suitable guardians for their children to prevent children from losing their childhood.

Holmes (2005) clearly states the fact that women are anxious about their children growing up without parents, how the HIV is going to affect their relationship with their family members and also the impact on their relationship with their partners. Other women felt that their relatives also needed support. In many cases, it is the woman's mother who is her primary support system. The

mothers need to deal with their own feelings about the possibility of losing a child and becoming the caretaker of their grandchildren.

"I think it is important for our support system also to get support. They also need support and get information on the treatment and the care of the HIV patient."

"Support for the family. The family also needs support and education on dealing with women on ARV. I think if the woman is sick and can't take care of herself, her relatives must be able to give her her treatment."

The support groups in Kenya took up the initiative to involve the primary support system in support groups. It was found that the women felt more reassured if their support system was provided with knowledge and skills to support them (Colton, 2005). Relatives also felt more comfortable in accepting the HIV status of a loved one if support were provided to them.

Need for education

The second main theme relate to the participants need for education. The participants revealed various educational needs in accordance with their socio-economic background and education level. They feel that nurses should listen to their educational needs and provide the information according to those needs. Holmes (2005) supports this statement by saying that women do have individual educational needs and these needs must be taken into account by the nurses/midwives when providing education.

The HIV/AIDS/STD Strategic Plan 2000-2005 by the DOH (2007) states in the guiding principles that "the government has a crucial responsibility with regard to the provision of education, care and welfare to all HIV positive people in South Africa". Topics identified by the National DOH in this Strategic Plan are safe sexual practices, prevention of mother-to-child-transmission, feeding options, future pregnancies and the importance of partner testing for HIV.

A topic for education identified during the research is the effect of HIV on the pregnancy and *vice versa*. Participants identified that they did not take in information during a post-counselling session. Therefore, a need for more education arose. Holmes (2005) and Colton (2005:13) state that continued counselling sessions would provide crucial education and reassurance to the women.

Another educational need that came to light was that women were confused about feeding options. Education regarding the advantages and disadvantages of breastfeeding and formula feeding must be given. Women need to be informed that milk supplements will be provided to them by the government for up to 6 months.

"By my clinic sê die suster ek mag nie breast gee nie, maar ek hoor ek kan. Ek is confused." (At my clinic the sister told me I'm not allowed to breastfeed, but I hear I can. I'm confused).

"Maar ek het nie money vir melk nie. Ek het nie 'n job nie." (But I don't have money for milk. I don't have a job).

"I hear from the other women about breastfeeding. And others..they say I must give my baby the bottle. But I can't afford the milk."

The HIV/AIDS/STD Strategic Plan 2000-2005 also state that women should receive education with regard to the advantages and disadvantages of breastfeeding, but also the risk of transmitting the virus to the infant, situations when to discontinue breastfeeding and what the effect of breastfeeding is on the progress of the disease. Furthermore, education must be given on how to give supplement feeding, the equipment for preparation of the feeding and how to prepare the supplement feeding (DOH, 2000; Colton, 2005:12). By doing this, the risk of malnutrition and diarrhoea is avoided. Holmes (2005) encourages that education must be provided honestly and all questions women might have must be answered. This will enable women to make an informed decision about the best feeding option for her situation.

Participants that are on the programme for the prevention of mother-to-child-transmission (single *nevirapine 200 mg* tablet) do not understand why they were not started on antiretroviral treatment.

"I don't understand. Why can some women start treatment and I can't?"

"Ja...maar ek gaan dit nie drink nie. Die kind het klaar die siekte."

"And one tablet when I go into labour."

"I think they call it CD3 or something. I would like to know more."

They are in need of education on the protocol for starting antiretroviral treatment, including the meaning and significance of the CD4 count. These participants want the best means of staying healthy to take care of their child/children. They feel that antiretroviral treatment can provide them with the means to stay healthy for longer. This need for more knowledge is supported by Buvè *et al.* (2003:44); Colton (2005: 22) and Holmes (2005).

Other education topics include general health, baby care and the method of delivery.

"I don't know what to expect from a baby."

"Breastfeeding, formulas, our treatment, how to prevent transmission to the baby, diet, safe sex and transmitting of the virus to their unborn babies."

"Information on care of the baby."

An interesting educational need that was identified was that a participant was of the opinion that the HIV caused her pregnancy "so that more people can die". This misunderstanding need to be discussed and may be rectified through health education

"Die siekte wil meer mense hê...nou maak hy my pregnant sodat die een ook kan sterwe." (The disease wants people...it made me pregnant so that this one can also die.)

Need for treatment

The third main theme focuses on the participants need for treatment. It was found that the participants felt that they were in need of antiretroviral treatment to promote their health and to prevent the transmission of the virus to their unborn babies. Antiretroviral treatment can cause side effects like nausea and vomiting, which can be treated symptomatically as stated by Colton (2005:15) and Holmes (2005). Women that are HIV positive may experience symptoms such as pain and these symptoms must be treated symptomatically.

"Hulle gee my pille vir die pyn." (They give me treatment for the pain.)

"Hulle kan my al met die treatment begin het." (They could have started me on the treatment.)

"I would just like to start my treatment."

Need for improved services

The participants expressed various needs for improved service delivery. Many of the participants said that they would like one central point for receiving antenatal care and their ARV treatment. The view was also expressed that antenatal care for all HIV positive women must be provided at one specialised clinic. The participants also expressed the need that one midwife should take care of them during their pregnancy. This would enable a relationship between the woman and her nurse, motivating the woman to tell the nurse about her needs. The women feel that the nurses at the clinics need further training in managing HIV positive pregnant women and pregnant women on antiretroviral therapy.

"Dit sal dalk goed wees om die antenatal hier te gee." (It will be good if the antenatal care was provided here [the antiretroviral clinic]).

"Dalk hier by die hospitaal die clinic loop." (Maybe attend clinic care here at the hospital.)

"The clinics don't really work together. And I don't think the staff at the clinics really understand ARVs."

"Like maybe that Gateway Clinic and this clinic can work together."

"...it will be nice to have one nurse taking care of you throughout your pregnancy. She'll know you and you won't feel scared...as if somebody else will judge you."

Buvè *et al.* (2003:45) agree that in settings where public health services are barely able to cope with the increasing number of HIV infected patients, it is important to work cost-effectively and use resources wisely.

Participants focussed mostly on their own physical care and then antenatal care for their unborn babies. The women raised the need that they would like more regular antenatal visits and more sonograms to reassure them about their babies' growth and health.

"...better physical care. It is as if they only focus on the baby."

"Maybe more antenatal visits."

"...more sonars...the mothers will feel better if we know our babies are is fine."

"Ek wil hê hulle moet mooier na my kyk. Hulle moet luister as ek praat. Hulle vra net altyd na die baby." (I want them to take better care of me. They must listen when I speak. They just ask about the baby.)

"I think the nurses must take better care of me."

Literature confirms that the HIV positive pregnant woman might be more content with her own health if she has a sense that by remaining healthy she could reduce the risk of transmitting the virus to her unborn baby and take care of her child/children (Buvè *et al.*, 2003:45; Colton, 2005; Holmes, 2005).

Need for a safe and non-judgemental environment

The women feel unsafe in their surroundings and are afraid that members of the community might judge and discriminate against them. The isolation of the antiretroviral clinic from the other clinics creates a feeling of discrimination. This feeling is enhanced when the woman is referred to as "the patient" and when addressed rudely. The women feel that the staff at the clinics must treat them with respect and dignity.

*"I don't feel safe in *****."*

"I'm very much aware of how I'm supposed to be treated...So, basically treat me with respect and...um...dignity." "They can treat me with respect."

"They should treat me like a human." "I don't like being called 'the patient'."

"Everybody knows we are HIV positive. It feels as if it is discrimination against us."

"Die sisters daar by die clinic hulle moet mooier werk. Hulle moenie skree nie." (The sisters at the clinic must work better. They shouldn't shout)

"That doctor...he should learn to treat people better."

"Hulle praat lelik met my. Hulle sê ek weet ek is HIV positive en ek hou aan pregnant raak."

(They talk rude to me. They say I know I'm HIV positive but I continue to fall pregnant.)

"Die mense weet vroue wat die bottel gee het AIDS. Hulle sê die vrou is sleg. Ek wil dit nie hê nie." (The people know that women who give formula feeding have AIDS. They say that the woman is bad.)

"Die wit mense verstaan nie. Hulle verstaan nie ons culture nie." (White people don't understand. They don't understand our culture.)

If the staff at the clinic creates a positive non-judgemental environment for all women, the women will feel comfortable in conveying their needs to the nurses/midwives. Other women will be encouraged to test for HIV and the community will also adopt a non-judgemental attitude. Behaviour changes in the multi-disciplinary team and other health professionals play a role in

changing the community's attitudes and behaviour towards people living with HIV (Buvè *et al.*, 2003:43).

Holmes (2005) states that the human rights of all HIV positive people must be upheld at all times. This is reinforced by the Constitution of South Africa and the Batho Pele principles.

CONCLUSIONS

Conclusions were deducted by comparing the five categories in the results of the research with the relevant literature, Maslow's Hierarchy of Needs and the HIV/AIDS/STD Strategic Plan formulated by the Department of Health.

From the results and the literature it is apparent that the core of HIV positive pregnant women's needs lies the need for a trust relationship. The trust relationship must extend between the women and the members of the multi-disciplinary team, the women and their relatives and the multi-disciplinary team and the relatives of the women.

A trust relationship will ensure that the HIV positive pregnant woman is comfortable to express her educational needs to her health care worker, supporting the woman in the readiness to start and continue with her antiretroviral treatment. Improved services and a safe and non-judgemental environment will help to improve the trust relationship.

When comparing the five need categories found in the results of the research with Maslow's Hierarchy of Needs, it becomes apparent these categories are linked to each other and to all the levels of Maslow's Hierarchy of Needs. Furthermore, it is clear that the needs identified by the women are highly similar to the HIV/AIDS/STD Strategic plan of both 2000 and 2007. This indicates that the goals were not met in the context the research took place, but also that the women are indeed in need of the implementation of the HIV/AIDS/Strategic Plan as it is currently formulated.

RECOMMENDATIONS

Recommendations are made for nursing practice, nursing research and nursing education.

Recommendations in the practice of nursing include improvement in clinics' settings and nursing care. Topics that have arisen from the research that are recommended for future research are effectiveness of the recommendations at the clinics, stigmatisation in the community regarding feeding options, the management of side-effects of antiretroviral therapy and the role of the social worker during pregnancy, and informing the relatives about the status.

Furthermore, recommendations are made to nursing training facilities that students need to be trained in need-based antenatal care. In-service training should also be presented to existing staff on need-based antenatal care for HIV positive pregnant women and the implementation of the HIV/AIDS/STD Strategic Plan. Both undergraduate and qualified staff should also be educated in specific adjustments that need to be made in antenatal care of HIV positive women using ARV.

SUMMARY

The Guiding Principles in the HIV/AIDS/STD Strategic Plan 2000-2005 state the following goals:

- People with HIV and AIDS, their partners, families and friends shall not suffer from any form of discrimination;
- The vulnerable position of women in society shall be addressed to ensure that they do not suffer discrimination, nor remain unable to take effective measures to prevent infections;
- Education, counselling and health care shall be sensitive to the culture, language and social circumstances of all the people at all times;
- Full community participation in prevention and care shall be developed and fostered.

The HIV/AIDS and STI strategic Plan for 2007-2011 still focus on the above guiding principles, but now include prevention of mother-to-child-transmission (DOH, 2007).

It is clear from the data obtained from the participants that the goals set in the HIV/AIDS/STD Strategic Plan 2000-2005 have not been reached, although the participants expressed a need therefore. Therefore a conclusion can be made that the HIV/AIDS/STD Strategic Plan should be implemented by all health care workers.

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PART 3

**CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS FOR
THE PRACTICE OF NURSING, RESEARCH AND EDUCATION IN
NURSING TO PROMOTE NEEDS-BASED ANTENATAL CARE
FOR HIV POSITIVE PREGNANT WOMEN**

3.1 INTRODUCTION

In Part 3 conclusions are deducted from the results, limitations are discussed and recommendations formulated for the practice of nursing, research and nursing education.

3.2.1 CONCLUSIONS

As mentioned in Part 2, five categories crystallised from the data, namely the need for support, the need for education, the need for treatment, the need for improved services and the need for a safe and non-judgemental environment. Conclusions will now be deducted from the results and the relevant literature, taking Maslow's Hierarchy of Needs and the HIV/AIDS/STD Strategic Plan (Department of Health, 2005; Department of Health, 2007) into consideration.

3.2.1 HIV-positive pregnant women experience a need for a trust relationship

From the results and the literature it is apparent that at the core of HIV-positive pregnant women's needs lies the need for trust relationships between the women, the multi-disciplinary team, from which the nurse is the team member working most with the women, and the relatives in order to make their needs known and share concerns. Once the needs and concerns are known, support can be provided by the relevant member of the team. Furthermore, the trust relationship will ensure that the woman will feel comfortable enough to inform the nurse about her own needs for education.

Women specifically expressed the need for treatment, most importantly antiretroviral therapy. A trust relationship will support the woman in her readiness to start and continue with her antiretroviral treatment. By improving services, the women will not just feel that they receive better service, but will also feel safe in the environment. The women did relate the need for a safe and non-judgemental environment and improved services and a trust relationship will ensure this.

3.2.2 Pregnant women experience needs in relation to Maslow's Hierarchy of Needs

When comparing the five categories and Maslow's Hierarchy of Needs, it became apparent that the five categories are linked to each other and also linked to all the levels of Maslow's Hierarchy. This might mean that by satisfying one of the needs identified by the women, other needs might also be met.

By providing antenatal care as indicated by the participants, not only the physiological needs are met, but a relationship of trust might be formed. As mentioned in section 3.2.1, a trust relationship will lead to the woman confiding her needs to the midwife, meaning antenatal care can be provided according to the woman's needs. By having a trust relationship, respect is formed that will lead to a safe and non-judgemental environment. From this it is apparent that according to Maslow's Hierarchy, the levels of safety and security needs and esteem needs are met. These levels can also be met by providing support, education and treatment. Furthermore, the physiological needs and the love and belonging needs are met. Once all these needs have been met, the woman might reach the level of self-actualisation, which is the highest level of needs according to Maslow (Huitt, 2006).

3.2.3 Pregnant women's needs are not met according to the HIV/AIDS/STD Strategic Plan

It is clear that the needs identified in the five categories by the women, are highly similar to the goals of the HIV/AIDS/STD Strategic Plan of 2000 and 2007. This indicates that these goals were not met in the context where the research took place, but also that the women are indeed in need of the implementation of the HIV/AIDS/STD Strategic Plan as it is currently formulated.

3.2.2 LIMITATIONS

During the research the participants spoke English or Afrikaans. This might have led some participants not to express their needs freely. The difference in culture between

the researcher and the participant might have led to the participant not expressing all her needs to the researcher.

In certain clinics, there was limited space for interviews leading to privacy being invaded during interviews. Although the staff was aware of the interviews, they still entered the room to continue with their work. This also led to the participants not answering the questions freely.

During the period of data collection a number of the proposed participants had spontaneous abortions or passed away. This led to the decrease in the planned number of participants. Fortunately data saturation could still be reached.

3.4 RECOMMENDATIONS

From the results, literature and conclusions, the following recommendations can be made for the practice of nursing, research and education in nursing.

3.4.1 Recommendations for the practice of nursing

The following recommendations can be made in the field of nursing practice, in this case the antenatal clinics, regarding the five categories identified by the participants.

Support

It is recommended that a woman should receive her antenatal care from the same nurse throughout her pregnancy. This will create a trust relationship and the woman will be able to express her needs.

A room should be allocated in each clinic for individual and group counselling sessions. Other staff members should be aware of the fact that a counselling session is in progress and should therefore not enter the room. Ongoing counselling sessions should be provided to the women to accept their status and support them in their fears. Family members of the women should also be included in counselling. Support groups can be started where women can discuss their problems and education on various topics can be given. Family members can be included in the support groups.

Education

Educational topics should arise from the needs indicated by the women. Examples of possible topics are all the aspects of antiretroviral treatment, including the difference between full antiretroviral treatment and PMTCT, side-effects of antiretroviral treatment and the importance of the woman taking her antiretroviral treatment with her to hospital when she goes into labour. Other topics include baby care, including feeding options and general care to maintain her general health.

The education can be provided individually or in a group setting. Education can be provided during support groups. Furthermore, nurses at the clinics can give women questionnaires to complete to identify needs. The results from questionnaires can be compiled into posters and pamphlets. The posters can be put up in the clinic for the women to read while waiting for their antenatal appointment. Pamphlets can be distributed to the women to educate them.

Education should also be provided to the family members of the women. Education can be provided most effectively if they are aware of the woman's status. Educational topics for the relatives can include their role in supporting the women, antiretroviral treatment and how to improve and maintain the health of the women. The feeding options should also be explained to the relatives so that they can support the women in their choice of feeding.

Treatment

The antiretroviral treatment and antenatal care should be provided at one clinic or all local clinics should provide both the antiretroviral treatment and antenatal care. By doing this, a safe environment is created where the women feel safe and not stigmatised. By providing antenatal care and antiretroviral therapy at all the local clinics, both the pregnancy and the effect of the antiretroviral therapy on mother and baby can be monitored. Furthermore, treatment should be provided for other symptoms that might arise. It is important for staff to receive training in the management of the HIV positive women on antiretroviral treatment.

It can also be recommended that a programme similar to the DOTS programme for TB patients on treatment be commenced. A pregnant woman can disclose her status to somebody she feels comfortable with. The person can accompany her to antenatal visits and visits to the antiretroviral clinic. The person can also make sure that the woman takes her antiretroviral treatment as ordered.

Furthermore, it is recommended that the woman's status and the fact that she is on antiretroviral therapy should be indicated on her antenatal card for reference if she is admitted to hospital for treatment or the delivery.

Improved services

Central to improved services is the implementation of the HIV/AIDS/STD Strategic Plan (Department of Health, 2000; Department of Health, 2005) in the clinics. Staff members should receive in-service training on the HIV/AIDS/STD Strategic Plan and other developments in HIV/AIDS, treatment and antenatal care.

Clinic staff should be utilised more appropriately, e.g. one midwife should provide the antenatal care to establish a bond with her patient and can therefore identify the needs of the woman. Antenatal care should be provided according to the woman's needs. Furthermore, antenatal care and antiretroviral treatment should be provided at a central clinic(or all clinics). All staff members should be trained in antiretroviral therapy so that they are aware of the protocols, side-effects and management of the side-effects.

Safe and non-judgemental environment

Staff should treat all women with respect and dignity and have a non-judgemental attitude. All the members of the multi-disciplinary team, and not just the nurse, should work as a team in providing the best antenatal care to the HIV infected women.

A safe environment can also be created by combining the antiretroviral clinic with a local clinic to prevent the stigmatisation of attending the antiretroviral clinic. Within the clinic a private environment can be created where women can receive counselling or have group discussions.

3.4.2 Recommendations for research

Various future research topics arose from the research, including:

- The effectiveness of the recommendations made to the clinics;
- stigmatisation by the community regarding feeding options;
- the management of the side-effects of the antiretroviral therapy in pregnancy;
- the importance of different means of support, especially support groups;
- informing the relatives of the HIV status and preparing the relatives for the possible death of a loved one; and
- the integration of the antiretroviral clinic with primary health-care services.

3.4.3 Recommendations for nursing training

Training facilities for nurses should be made aware of the research findings and recommendations. Information on need-based antenatal care for HIV positive women should be incorporated into the curriculum of these facilities. Furthermore, staff members at the clinics must receive in-service training on the management of HIV positive pregnant women and the provision of antenatal care to them according to their needs, the importance of a trust relationship and the linked nature of needs.

3.5 EVALUATION

This research project was aimed at promoting the health of HIV positive pregnant women by using insight into the needs of these women in the improvement of antenatal care. The specific objective was to explore and describe the needs of HIV positive women regarding antenatal care.

It is apparent that the purpose was met because women did express their needs for antenatal care. These needs were described and explored in such away that they can be used to improve antenatal care, as seen in the recommendations formulated. If the recommendations based on it are implemented, antenatal care might possibly be improved.

3.6 SUMMARY

In this research the background study focussed on antenatal care, including treatment, provided to the HIV positive pregnant women. According to the problem statement women are in need of need-based antenatal care and that these needs are not known. From the background and problem statement the research questions were asked and the research purpose was formulated, namely that the research project aimed to promote the health of HIV positive pregnant women through insight into the needs of these women to formulate recommendations for antenatal care. The specific objective was to explore and describe the needs of HIV positive women regarding antenatal care.

The necessary permission was obtained from the Ethics Committee and the district health manager. After permission was granted, an explorative, descriptive, contextual design, following a qualitative approach, was followed during the research. Sixteen participants participated in the research and data was obtained from them using semi-structured interviews.

The data obtained was analysed by using the Tesch method. The researcher and the co-coder had a consensus meeting and the results was categorised into five categories, namely the need for support, the need for education, the need for treatment, the need for improved services and the need for a safe and non-judgemental environment.

Conclusions were deducted by comparing the results to the relevant literature, Maslow's Hierarchy of Needs and the goals of the HIV/AIDS/STD Strategic Plan. From these results and conclusions recommendations were formulated for the nursing practice, nursing research and nursing education. These recommendations will be made available to local primary health-care facilities and are also described in a manuscript that will be submitted for publication in a scientific journal (see Part 2).

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APPENDIX

Appendix A

Permission from Ethics Committee of North-West University (Potchefstroom Campus)

Akademie Administrasie
Privaatsak X6001
(Interne Bussie 358)
POTCHEFSTROOM 2531
Tel (018) 299-2640
Faks (018) 293-5260
E-Pos akaemd@puk.ac.za

20 Februarie 2006

Mej C Doubell
104 Kockstraat
**POTCHEFSTROOM
2531**

Geagte Mej Doubell

REGISTRASIE VAN TITEL: M.CUR. (VERPLEEGKUNDE)

Die Fakulteitsraad van Gesondheidswetenskappe het op hul jongste vergadering u titel soos volg goedgekeur:

Antenatal care of HIV-positive women

Let asseblief daarop dat bogenoemde titel **glad nie** mag verander word sonder dat u daaroor met u studieleier oorleg gepleeg het en die goedkeuring van die Dagbestuur verkry is nie.

U moet asb. drie maande voor u beplan om in te dien, ondergetekende skriftelik kennis gee.

U aandag word gevestig op die volgende publikasie:

Handleiding vir nagraadse studie.

Hierdie handleiding is by die *Van Schaik-boekwinkel* beskikbaar en bevat uitgebreide riglyne en wenke ten opsigte van skripsies, verhandelinge en proefskrifte.

Die volgende paragrawe in bogenoemde publikasie het veral betrekking op administratiewe aspekte wat deur u nagekom moet word:

1.9 Indienings- en eksamineringsprosedure

U word aangeraai om ook weer die volgende A-regulasie in u Jaarboek na te gaan om te verseker dat vereistes op u van toepassing is, nagekom word:

Indieningsdatums: Eerste week in November om vir Mei gradeplegtigheid te kwalifiseer

Eerste week in Mei om vir September gradeplegtigheid te kwalifiseer

Indien u laat indien in November en nie vir die Mei gradeplegtigheid kwalifiseer nie, moet u weer vir die nuwe jaar registreer, om sodoende graad in September te verwerf.

Regulasie A 11

Eksaminatore is benoem.

'n Voorspoedige studietydperk word u toegewens.

Die uwe

MEV. E. M. DANILATOS

n. DIREKTEUR: AKADEMIESE ADMINISTRASIE

APPENDIX B

Permission for executing research at the Potchefstroom Hospital

Tel (018)
Fax (018)
E-mail
30 January 2006

The General Manager

Dear Mr.

PERMISSION TO CONDUCT DATA COLLECTION

I have acquired permission to do research in Potchefstroom as part of the research project on health services to HIV/Aids patients in Potchefstroom (letter attached). I am hereby requesting permission to undertake data collection at your hospital, as needed.

The topic of my research is:

Antenatal care of HIV positive women.

The purpose of the research is:

- o This research project aims to promote the health of HIV positive pregnant women through insight into the needs of these women to formulate recommendations for antenatal care.

Should you agree and grant permission, the data collection at the Potchefstroom Hospital will be done by means of the collection of statistics on HIV in the hospital. The participants might be interviewed postpartum.

Included is the research proposal that will provide in-dept information about the research as well as the letter of permission from the Ethics Committee of the North-West University (Potchefstroom Campus) and the local Department of Health.

I will contact you by February 2006 to find out if permission has been granted and to finalise the arrangements. I am available for any enquires at cell number 082..... or at Potchefstroom Hospital, Ward.....

Yours sincerely

C Doubell
M. Cur. student

Mrs. C.S. Minnie
Supervisor

Mrs. E. du Plessis
Co-supervisor

Appendix C

Permission from Potchefstroom Hospital for data collection



North West Province

NORTH WEST DEPARTMENT OF HEALTH

Healthy Living for All



Republic of South Africa

All correspondence to be
addressed to:

The Hospital General Manager
Potchefstroom Hospital
C/o Botha- and Kruis Street
Private Bag X938
POTCHEFSTROOM
2520



POTCHEFSTROOM HOSPITAL

Tel: (018) 293 4700
Tel: (018) 297 7011
Fax: (018) 293 1729
Eng: Dr OSG Mfikwe
Email: Omfikwe@nwpg.gov.za

2006-03-31

TO WHOM IT MAY CONCERN

RE: Research Proposal regarding the Antenatal Care of HIV Positive Women

This is to confirm that the Patient Safety Group at Potchefstroom Hospital has granted Ms. Chantell Doubell approval to go ahead with her research project regarding the above named subject. The approval is subject to the following conditions:

- That the Rights of Patients are not infringed
- That the Research Project does not cost the department nor the hospital any funds
- That the results of the research will be made known to the hospital and the North West Department of Health.
- That the Information and Knowledge Management Directorate will be informed of the Research Proposal by the student.

Regards,

DR O S G MFIKWE
MEDICAL MANAGER
POTCHEFSTROOM HOSPITAL



APPENDIX D

Written request for data collection at local clinics

The Chief Professional Nurse

Dear Sister

PERMISSION TO CONDUCT DATA COLLECTION

I have acquired permission to do research in Potchefstroom as part of the research project on health services to HIV/Aids patients in Potchefstroom (letter attached). I am hereby requesting permission to undertake data-collection at your clinic.

The topic of my research is:

Antenatal care of HIV-positive women.

The purposes of the research are:

- ❖ To explore and describe the needs of HIV-positive pregnant women in Potchefstroom regarding antenatal care.
- ❖ To formulate guidelines for antenatal nursing care to meet the needs of HIV-positive woman.

The role of the midwife at the clinic for the research is to identify participants according to the set criteria and act as mediator between myself and the identified woman.

Included is the research proposal that will provide in-dept information about the research and permission letter from the Ethical Committee of the Northwest University (Potchefstroom Campus) and the local Department of Health.

I will contact you by February 2006 to find out if permission was granted, and to finalise the arrangements. I am available for any enquires at cell number 0820767279.

APPENDIX E

Permission for data collection at local clinics



North West Province

NORTH WEST DEPARTMENT OF HEALTH

Healthy Living for All



Republic of South Africa

Private Bag X1253
Potchefstroom
2520

**Potchefstroom
Sub-District Office**

Tel: (018) 297 5062/3/4/5
Fax: (018) 294 4509

Enquiries: A.M. Mohutsioa
Reference:

Chantell Doubell
12293938

PERMISSION TO CONDUCT RESEARCH

The Potchefstroom Sub District Office would like to acknowledge receipt of your letter requesting permission to collect data for your research proposal.

Please be informed that your proposal has gone through our research committee and it has been accepted. It is also important for you to note that the department would like you to share with us the outcome of your research.

For further information and for appointments with relevant managers please liaise with Mr Phillip Ledimo directly.

As a department we wish you well in your studies and hope that the outcome will benefit the community.

Thank you.

Sub District Manager

15.03.2006

APPENDIX F
Written information to the participants

Dear participant

REQUEST TO PARTICIPATE IN RESEARCH

I am currently registered at the North-West University (Potchefstroom Campus) for an M.Cur. Degree in Obstetrics and Neonatal Nursing Science. I have acquired permission to do the research in Potchefstroom.

The topic of my research is:

Antenatal care of HIV positive women.

The purposes of the research are to

- ❖ Explore and describe the needs of HIV positive pregnant women on ARVs in Potchefstroom regarding antenatal care; and
- ❖ formulate guidelines for antenatal nursing care to meet the needs of HIV positive woman.

I hereby wish to obtain your permission to take part in this research. As part of the investigation to achieve the first goal, you are requested to take part in interviews over a period of time. The interviews will be conducted on a monthly basis at the clinic during antenatal visits or at home from the second trimester of pregnancy until delivery. During the interviews, you will explain your needs during antenatal care that will be recorded on an audiotape for analysis. An interpreter may be present during the interview. A counsellor will be available to assist you in any emotional problems that might arise during the interviews.

You can be assured that all information will be handled confidentially. Your name will not be mentioned during the interviews. Participation in the research is voluntary and you may withdraw at any stage without being discriminated against.

You are welcome to ask questions if anything is not clear. My cell phone number is 076..... You are welcome to supply your particulars in order to be supplied with a report of the research findings after completion.

Yours sincerely

Ms. C. Doubell

Mrs. C.S. Minnie

Mrs. E. du Plessis

M. Cur. student

Supervisor

Co-supervisor

.....

APPENDIX G
Written permission from participants

I,....., hereby declare my willingness to participate in
research regarding my needs during antenatal nursing care.

.....
Participant's signature

.....
Researcher's signature

.....
Witness' signature

.....
Date

APPENDIX H
Work protocol

POTCHEFSTROOM
2531

Attention: _____

Dear _____

WORK PROTOCOL FOR ASSISTANCE AS CO-CODER TO THE RESEARCH
PROJECT ENTITLED: ANTENATAL CARE FOR HIV POSITIVE WOMEN.

Thank you for your assistance as co-coder in this research project.

The aim of the research is:

- To explore and describe the needs of HIV positive pregnant women in Potchefstroom regarding antenatal care.

Your assistance in the research entails the analysis of the data by hand by following the following guidelines.

- Please read through the transcriptions.
- Read through the transcriptions a second time and highlight key concepts.
- Write down the key concepts in the right-hand margin.
- Read through the concepts in the right-hand margin and code them according to needs, using columns.
- As you read through the transcriptions, keep in mind that the following questions were asked to initiate the collection of data from the participant:

QUESTIONS TO HIV POSITIVE PREGNANT WOMEN

- When did you find out about your HIV status?
- When did you start antiretroviral therapy?
- What do you expect from antenatal care?

Questions were also formulated from information gained during the interviews or asked in a different way for the participant to understand the questions.

A consensus meeting will be held on date as provided by you. Field notes of interviews are submitted with the data.

Your assistance as co-coder is highly appreciated. You can reach me at the following number if further information is required:

- Tel: (018) (W)
- Tel: (076) (H)

Thank you

Ms. C. Doubell
Researcher

Mrs. C. Minnie
Study leader

APPENDIX I
Segment of an interview

Researcher: You said that you are new here.

Participant: Yeah.

Researcher: What can we do to help you?

Participant: (Pause) Like...uh...with my pregnancy?

Researcher: Yes.

Participant: Everything... Anything that will help me (pause). I don't know what the other women think. But help me for the future. You know, I don't like being called "the patient". Because when you call me "the patient", I feel like some creature... Yeah... So... I don't know. Anything. Um...what do you say...

Researcher: You can say it anyway you want.

Participant: Okay...Firstly, I don't know if...if you were to help me, maybe... like uh...uh...I'm a "HIV positive mother to be". Like supply me with information and care for the baby. Or...or like more care for the baby. Yeah like where I'm staying...People are not supposed to treat you different. People should...I don't know how to say it. Like when we come to the clinic. Everybody knows we are HIV positive. It feels as if it is discrimination against us. Anything that can help us.

Researcher: Do you think or feel like you're discriminated against by attending the Wellness Clinic?

Participant: Yeah. I don't know if it is just me. Like maybe that Gateway Clinic and this clinic can work together. People who are HIV positive can go to that clinic and get their treatment here. Like first I was "wow I'm positive and I'm pregnant" and now I see there are other women that are positive and pregnant. I feel better.

Researcher: So you say you feel discriminated against by attending this clinic, but you feel better knowing you are not alone?

Participant: Yeah. It helps a lot. But with the doctor I was scared. And maybe was scared if I take the ARVs may hurt the baby or get a miscarriage. I don't know much about the treatment.

Researcher: Do you think if you had more information about the ARVs you might have started the treatment sooner?

Participant: Yeah. Education will help.

Researcher: Do you think education plays a big role in starting ARVs?

Participant: Yes, it would.

Researcher: And do you feel the HIV influence the care the clinic gives you?

APPENDIX J

Field notes

Interview 1

Theoretical notes

- Questions are asked according to the information given by the participant.
- The interview is viewed as successful.

Observational notes

- Participant focuses on poster behind me.
- Plays with file on table

Personal notes

- Seems as if participant rushes to give answers.
- Seems relieved when interview is over.
- Seems as if she is scared to ask questions.

Interview 2

Theoretical notes

- Questions had to be asked throughout the interview to get information from the participant.
- Interview was stopped due to the participant becoming emotional.

Observational notes

- Attitude changed from closed to open as the interview progressed.
- Eye contact is held during the interview.
- Touches abdomen when the pregnancy or baby is mentioned.

Personal notes

- Participant is scared of losing another child due to HIV.
- Is worried that her mother is not getting enough support.

Interview 3

Theoretical notes

- Participant has low level of education and questions had to be asked in “plat Afrikaans”.
- Questions and terms had to be explained to her.

Observational notes

- Seems distant from pregnancy and unborn baby.
- Touches shoulders during interview when own care or baby is mentioned.
- Eye contact is held during interview.

Personal notes

- Participant is more focused on own health and well-being.
- Refers to baby as “the baby”.
- Asks what she can do with the baby after “it” has been born. Seems as if pregnancy is unwanted.
- Is referred to social worker for further management.

Interview 4

Theoretical notes

- Educated woman.
- Questions arise from her answers.

Observational notes

- Eye contact is kept throughout the interview.
- Emotions change from calm to anger to becoming very emotional.
- Swears during interview when upset

Personal notes

- Participant is aware of risk keeping her status disclosed to health-care workers and family
- Is afraid of stigmatisation.
- Lack of proper counselling is influencing current attitude.
- Refuses counselling sessions with counsellor.

Interview 5

Theoretical notes

- Educated woman.
- Initially closed questions are asked, but as interview progresses, questions arise from participant's answers.

Observational notes

- Open body language throughout the interview.
- Eye contact is kept.
- Becomes emotional during interview but decides to continue with the interview.

Personal notes

- Culture plays a role in emotional state of participant.
- Parents are unaware of pregnancy and status.
- Participant did disclose to aunt.
- Participant stereotypes how an HIV positive person looks
- Needs guidance to choose between the *nevirapine* programme of antiretroviral treatment.

Interview 6

Theoretical notes

- Educated woman.
- Talks openly about needs and feelings.

Observational notes

- Participant initially upset and refers to "the child".
- Calms down during interview. Refers to "my baby" and touches abdomen
- Open body language.

Personal notes

- Participant seems scared and unsure about the future effect of the HIV.
- Is focused on own needs not just the care of the unborn baby.
- Feels she must be treated at her education level.

Interview 7

Theoretical notes

- Educated woman.
- Reflection used to get relevant information.

Observational notes

- Has open body language.
- Is focused on own needs.
- Crosses arms across abdomen during interview.

Personal notes

- Is focussed on own needs to create better life for unborn baby.

Interview 8

Theoretical notes

- Educated woman.
- Was dismissed from work after her status became known.
- Participant discusses needs openly. Questions arise from answers and reflection.

Observational notes

- Participant has strong personality.
- Is open about needs and how she is treated without sign of fear.
- Open body language.

Personal notes

- Participant feels that clinic discriminates against her due to status.
- Is ready to start ARVs even after the doctor told her to wait.
- Accepted referral to social worker to be referred to AIDS Legal to follow up her dismissal from work.

Interview 9

Theoretical notes

- Poorly educated woman.
- Was unaware of pregnancy until 32 weeks gestation.

- Uses alcohol on daily basis.
- Questions had to be asked to get relevant information from participant.

Observational notes

- Body language and verbal language are aggressive.
- Eye contact is not always made.
- Admits to unwanted pregnancy.
- Swears during interview.

Personal notes

- Participant clearly not happy with pregnancy. Refuses *nevirapine* tablet because she believes that baby is already infected.
- Focuses on better care by the nurses.

Interview 10

Theoretical notes

- Uneducated woman.
- Initially questions had to be asked to get relevant information from participant. As interview progresses, questions arise from answers and reflection.

Observational notes

- Closed body language.
- Keeps on looking at door.
- Opens door during interview and checks if any body is listening to interview.
- Participant folds arms around abdomen during interview.

Personal notes

- Participant afraid that information given during interview will be used against her at the clinic.
- Wants to start ARVs, but does not understand why she is only on *nevirapine* programme.
- Culture played a role in her becoming pregnant again.

Interview 11

Theoretical notes

- This interview is conducted while participant is hospitalised.
- Attend antiretroviral clinic in other town, before Potchefstroom

Observational notes

- Keeps open body language during interview.
- Seems angry when she refers to the treatment she receives from medical staff.
- Touches abdomen when she refers to her unborn child.

Personal notes

- Still seems afraid of infecting her baby.
- After interview admits she would like to help decrease stigmatisation in community regarding HIV

Interview 12

Theoretical notes

- Educated woman.
- Speaks openly about various needs.

Observational notes

- Open body language.
- Looks out of window when talking about feelings.
- Makes eye contact at all other times.
- Smiles spontaneously during interview when baby is mentioned.

Personal notes

- Gets support from boyfriend who is also infected.
- Has accepted that she is HIV positive.
- Was educated on various topics, but feels she must be educated on her level of intelligence.
- Focuses on better physical care, not just antenatal care.
- Raises worry that not all women are being supported as she is.

Interview 13

Theoretical notes

- Educated woman.
- Questions arise from answers.

Observational notes

- Is at ease during interview.
- Open body language.
- Seems detached from the baby.

Personal notes

- Used *stocrin* early in pregnancy – found out about pregnancy at 29 weeks gestation.
- Unsure if baby will be affected.
- Wants to put baby up for adoption.
- Verbalises that she has no one to lead her in adoption procedure

Interview 14

Theoretical notes

- Low sosio-economic status.
- Questions asked to get information.

Observational notes

- Closed body language.
- Afraid of answering – keeps looking at the door.
- Refers to “the child”.

Personal notes

- Emotionally detached from child.
- Needs emotional support.
- Upper educational needs regarding feeding options.
- Referred for counselling.

Interview 15

Theoretical notes

- Educated woman.
- Expresses needs

Observational notes

- Open body language.
- Seem at ease.

Personal notes

- Different than other participants.
- Focuses on shortage of staff.
- Not guided back to personal needs during interview.
- After interview admits that she does not have any personal needs, only the shortage of staff.

Interview 16

Theoretical notes

- Low sosio-economic status.
- Questions arise from answers.

Observational notes

- Seems emotional.
- Initially closed body language, but relaxes during the interview.

Personal notes

- Verbalises the need for support.
- Is emotional, but does not cry.
- Not a regular clinic attendee - ? adherence to ART.

APPENDIX K
The needs of HIV positive women

NEED FOR SUPPORT	NEED FOR EDUCATION	NEED FOR TREATMENT	NEED FOR IMPROVED SERVICE
❖ Support from the multi-disciplinary team - Doctors - Counsellors - Psychologists - Social worker ❖ Support from the nursing staff ❖ Support groups ❖ Support for relatives	❖ The effect of pregnancy on HIV ❖ Prevention of mother-to-child-transmission ❖ The effect of anti-retroviral therapy (ART) on the fetus ❖ Side effects of anti-retroviral therapy ❖ PMTCT vs ARTs ❖ General health ❖ Care of the baby ❖ Delivery of the baby ❖ Education	❖ Informed when to start ARTs ❖ Why ARTs are important ❖ Goal and function of the Wellness Clinic	❖ Antenatal care at Wellness Clinic ❖ The training of staff at local clinics regarding ARTs ❖ More staff at clinics ❖ Collaboration between local clinics and Wellness Clinic ❖ Staff must listen to the women's individual needs ❖ Staff must inform the woman about her status ❖ Assist women that are HIV positive in

	for relatives regarding ARTs ❖ Feeding options ❖ Adoption of the baby		planning the pregnancy
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NEED FOR A SAFE AND NON- JUDGEMENTAL ENVIRONMENT
❖ Respect from staff at clinic ❖ Respect from staff regarding culture ❖ Non-judgemental attitude from staff ❖ Wellness Clinic to be part of local clinics to avoid judgement from the community