Strategies used by professional nurses to manage newly diagnosed HIV positive pregnant women who fail to return within a month for further management and care.

By

JAMA NONTEMBISO MARY

A thesis submitted in partial fulfilment of the requirement for The Degree Master of Nursing Science (Magister Curationis)

In the Faculty of Science and Agriculture at the University Of Fort Hare

Name of the supervisor: Dr N. Tshotsho Name of the co- supervisor: Ms N. Nkutu

Date submitted: 22.11.2011

DECLARATION

I, Nontembiso Mary Jama declare that the research reported in this dissertation is my own work except where indicated. It is being submitted for the degree of Master of Nursing Science. It has never been submitted before for any other degree or any examination at this or any other University.

Candidate: N.M. Jama

Date.....

ABSTRACT

This study explored and described the strategies used by nurses to manage newly diagnosed HIV positive pregnant women who do not return to the clinic within a month following diagnosis, for continuity of care. The main aim was to prevent mother-to-child transmission of HIV (PMTCT).

Method: The study sites were two accredited antiretroviral- ante-natal care (ARV-ANC) clinics at the Dimbaza community health centre (CHC) and the East London Hospital Complex (ELHC) which comprises of Cecilia Makiwane and Frere hospitals, in the Buffalo City Metropolitan Municipality (BCM). The majority of health personnel at these clinics are professional nurses.

An in-depth semi structured interview guide was used to collect data through focus group interviews from professional nurses who work in these units. They were required to share their experiences about intervention strategies used for newly diagnosed HIV- positive, pregnant women who fail to return for continuity of care within a month after diagnosis.

Results: Follow up of these women is done by tracking them (by calling them; calling the clinic nearest to their homes and doing home visits). Decentralisation of further management and care to the nearest clinic was also cited, especially for the patients who stay far from these accredited sites. Family support was also mentioned as a strategy to intervene for the non-compliant patients.

Challenges: The challenges that were encountered with these interventions include wrong contact details, wrong addresses and being evasive when visited at home. Another challenge cited was related to the stigma attached to the diagnosis and the tracking devices used, for example, the car as it is familiar to the community it serves.

Despite known benefits for early initiation of HIV treatment newly diagnosed HIVpositive, pregnant women continue to refrain from accessing care after diagnosis, thus posing a risk to the transmission of HIV to the baby and further comprising their own health. They miss out on general HIV management and ante-natal care. Conclusion:

The identified intervention strategies used by nurses to follow up newly diagnosed HIV- positive, pregnant women need to be reinforced and strategies put in place to control the related challenges for a better response by the patients.

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ACKNOWLEDGEMENTS

I am grateful to the Almighty for teaching me to endure to the end and to my late grandparents and parents who would love to participate in this achievement. My deepest thanks to my supervisors Dr. Tshotsho and Ms. Nkutu for their tireless encouragement, valuable advice, dedication and support. I would also like acknowledge the following who made this research possible:

Participants for their willingness to sacrifice their time and participate in the study. Without them there would be no study. My children Olwethu and Sisipho for understanding why my light was on at crack of dawn. My colleagues and friends who assisted in one way or another.

I also appreciate the following institutions for granting permission and their support to conduct the study.

UFH Research Ethics Committee, Epidemiological Research & Surveillance Management; Department of Health, Govan Mbeki Research and development Centre, East London Hospital Complex and Buffalo City Sub district manager

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ACRONYMS:

HIV:	Human Immunodeficiency Virus
AIDS:	Acquired Immune Deficiency Syndrome
HAART:	Highly active antiretroviral therapy, usually a combination
	of 3 or more antiretroviral drugs.
ARV:	Antiretroviral
ART:	Antiretroviral therapy/treatment
ANC:	Ante Natal Care
AZT	Zidovudine
CDC	Centres for Disease Control
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

KEYWORDS:

HIV-positive: Mother-to-child transmission Newly diagnosed Strategies Professional nurse Accredited Antiretroviral sit

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND OF THE STUDY

This research will explore and describe the strategies used by nurses to manage newly diagnosed HIV- positive pregnant women who do not return to the clinic within a month following diagnosis, for continuity of care. The main aim is to prevent mother-to-child transmission of HIV (PMTCT).

The Human Immuno-deficiency virus (HIV) is a leading cause of mortality among women of reproductive age (Smit, Diergaardt, Fourie, Matshikwe and Letsoale, 2011:11). In South Africa, HIV is transmitted through heterosexual sex with mother-to- child transmission (MTCT) being the other main infection route. According to the United Nations General Assembly Special Sessions on HIV/AIDS (UNGASS, 2010) the national transmission rate of HIV from mother- to- child is approximately 11%.

The number of premature deaths due to HIV/AIDS has risen significantly over the last decade from 39 percent to 75 percent in 2010 (Harrison 2009). Children born to HIV- positive mothers have a three (3) to five (5) times higher risk of death, regardless of their status (Smit et al, 2011:11). This study will contribute to the "Countdown to Zero, a Global Plan Towards The Elimination Of New HIV Infections Among Children By 2015 And Keeping Their Mothers Alive" (Childs, 2011:6-7).

Almost all women who keep their pregnancy to term expect to deliver healthy babies without HIV infection. It is their responsibility to be in control of their health by attending a health facility to access care. Sometimes challenges such as a lack of knowledge related to HIV, psychological and socio- economic problems may hinder the mother from accessing these facilities. The Global Plan emphasizes the important role played by women living with HIV in turning this important vision into a reality.

The International Council of Nurses (ICN) Code of Ethics for Nurses (2001), identifies four fundamental responsibilities of the nurse: to promote health, to prevent illness, to restore health, and to alleviate suffering. It is important therefore that newly diagnosed HIV- positive, pregnant women receive appropriate pre-natal care. South Africa is one of the countries severely affected by the Acquired Immune Deficiency Syndrome (AIDS) epidemic, with the largest number of HIV infection in the world (Abdool Karim, Abdool Karim, Gouws, Baxter, 2007: 1-17).

The United Nations General Assembly Special Sessions on HIV/AIDS (UNGASS, 2010), estimated that in 2009 the total number of persons living with HIV in South Africa, was 5.7 million. According to the Epidemiological Fact Sheet on HIV and AIDS (2008), in South Africa 3,700,000 women were estimated to be infected with HIV. One-in-three women aged 25-29 years in the child- bearing age, is living with the Human Immune Virus (HIV) (Statistics South Africa, 2009). In 2009, around 400,000 children aged under 15 years became infected with HIV (UNAIDS, 2010).

Almost all 119 health facilities; 2 complex hospitals; 4 district hospitals and 5 community health centres in the Buffalo City sub- district offer "perinatal HIV testing to reduce the risk of mother- to- child transmission" (Aids Info, 2008; Maman, 2008: 195-200). There is no known system where one is able to retrieve information related to statistics of newly diagnosed HIV- positive, pregnant women who do not return for services.

Following up a month after diagnosis is crucial for doing assessments, determining the stage of HIV infection and eligibility to treatment, managing opportunistic infections like Tuberculosis and sexually transmitted infections, and for the initiation of anti-retroviral therapy (ART). Failure to return for further management and care puts the health of the mother in danger of opportunistic diseases, and her unborn baby at risk of acquiring HIV infection from the mother. Non -attendance for antenatal care carries an approximately four times increased risk of maternal deaths compared to the general pregnant population (Maternal and Child Health, 2003).

There has been a tendency to focus predominantly on the care, support and treatment needs of women who test positive during pregnancy within PMTCT programmes. More attention needs to be given to strengthen follow- up care and support for pregnant women who test HIV- positive (Holmes, 2005). Jones, Sherman & Varga (2005: 466-470), reported that many PMTCT programs report very high loss to follow- up with losses of more than 80% recorded in South Africa.

Loss to follow- up has become a major challenge and it impacts on the quality of PMTCT during antenatal care and the postnatal period. This impact further on the implementation of extended maternal and infant antiretroviral prophylaxis as recommended by WHO (2009). Nurses are committed to the global plan for the

future generations as it encourages them to finally bring an end to HIV among children, and ensure that their mothers are alive.

Nurses play a primary role in providing health information to assist the client in making informed decisions. An HIV- positive diagnosis requires a long term, trusting relationship between a nurse and a client (Fraser, Allen, Bailey, Shin and Blaya, 2007). This relationship will prevent further loss to follow- up that may occur during the initiation of the treatment and baby follow -up care.

Strategies used by nurses to ensure that newly diagnosed HIV- positive, pregnant women return for further management and care within a month of diagnosis, are unknown. It is necessary to identify and describe these strategies and make recommendations for developing guidelines for managing the challenge of follow -up care. An action plan should be in line with policies, guidelines and protocols of the Department of Health on prevention of mother-to-child transmission of HIV.

The Policy and guidelines for the implementation of the PMTCT programme (2008), explain that women enrolled in the PMTCT/Highly Active Anti Retroviral Treatment (HAART) programmes must be given a two week follow- up date after their CD4 count has been taken. Guidelines further state that each facility should have a mechanism in place to follow- up results and discuss them with clients. Women who do not return for a follow- up should be traced.

Understanding action taken in relation to follow- up will help to ensure that newly diagnosed pregnant mothers gain early access to comprehensive HIV care, support and treatment services (Maman, 2008: 195-200). Access to pre-natal care is a major determinant of the rate of mother- to- child transmission of HIV.

1.2 PROBLEM STATEMENT

A problem statement is a descriptive methodology of the issues and the problems which are to be resolved. It gives a concise and precise description of the nature, scope, causes, severity and the effect or impact of a problem. It also gives a specific purpose to be achieved. The primary aim of the problem statement is to converge the attention of the target audience towards one point (www.blurtit.com, 2009).

The researcher who is a professional nurse noticed that in the HIV/PMTCT/ ARV unit where she was working at the public hospital, there were newly diagnosed HIV-positive, pregnant women who do not return for continuity of care within a month following diagnosis. The strategies used by nurses to follow- up on these women were unknown. It is assumed that the lack of knowledge with regard to what is done to ensure that the newly diagnosed HIV-positive, pregnant women return for further management and care has a potential to contribute to the escalation of MTCT.

The researcher observed that almost all newly diagnosed HIV- infected, pregnant women who do not avail themselves for continuity of care after learning about their diagnosis, deprive themselves of proper prenatal care and other support services.

Blood test for CD4 count is taken and when one is diagnosed HIV- positive it becomes necessary for the patient to return for the results and further management.

The clinic usually holds weekly morbidity and mortality multi-disciplinary team meetings (MMM). At these meetings, most patients who are discussed, have booked early for antenatal services but fail to return until delivery. It is assumed that the reason for failure to return is associated with an HIV-positive diagnosis. In such meetings the discussions centre on identifying possible missed opportunities for intervention to provide care to the patients.

In monthly multi-disciplinary team (MDT) meetings for the unit a list of clients who defaulted HAART is usually submitted to the social worker for tracking, but none for newly diagnosed HIV- positive patients who do not honour their care, and as such there are no known strategies to intervene in such cases.

Scientists have evidence that early treatment of HIV can help prevent transmission. Clients are 96% less likely to infect their partners, which provide a major weapon in the fight against HIV/AIDS, (National Institute of Allergy and Infectious Diseases,

2011).

1.3 AIM OF THE STUDY

The researcher seeks to explore and describe activities undertaken by professional nurses in tracking newly diagnosed HIV- positive, pregnant women who fail to return within a month following diagnosis, for further management and care to prevent mother- to- child transmission of the HIV.

1.4 PURPOSE OF THE STUDY

The purpose of the study is to contribute to the reduction of mother- to- child transmission of HIV (MTCT), by gaining more knowledge of the care offered to newly diagnosed HIV- positive, pregnant women who do not return for continuity of care within a month after diagnosis.

1.5 RESEARCH QUESTION

Interest in a particular topic usually begins the research process, but it is the familiarity with the subject that helps define an appropriate research question for a study (Brian, 2006: 881-886). Questions arise out of a perceived knowledge deficit within a subject area or field of study (Hulley, Cumming & Browner, 2007).

A research question usually specifies the population to be studied, the intervention to be implemented and other circumstantial factors (Fisher and Wood, 2007: 66-72). In this study crucial gap has been identified between initial HIV diagnosis of pregnant women and comprehensive prenatal and HIV care. The question asked in this study is, what actions do professional nurses, working at the ARV-ANC accredited clinics, take when the newly diagnosed HIV- positive, pregnant women do not return for further management and care in order to prevent MTCT?

1.6 RESEARCH OBJECTIVES

The research objectives are active statements about how the study answers the specific research question. They are important because they not only help guide the development of the protocol and design of study but also play a role in sample- size calculations and determining the power of the study (Hanson, 2006: 583-594).

Objectives of this study are as follows:

To explore and describe the views of professional nurses with regard to intervention strategies used when newly diagnosed HIV-positive, pregnant women do not return for continuity of care within a month's period following diagnosis.

To make recommendations for the development of guidelines for the management of non - compliant pregnant women.

1.7 RESEARCH SETTING

The research setting is the environment within which studies are run, the type of data that can be collected and the interpretation of results (http://www.ncbi.n/m.nin.gov/pmc.html).

This study was carried out at the Dimbaza Community Health Centre (DCHC) and in the East London Hospital Complex (ELHC) which comprises of Cecilia Makiwane and Frere hospitals. All these facilities have antenatal, PMTCT and ART services. Most clients are referred from various clinics, with some already having tested for HIV and others not. HIV counselling and testing (HCT) is then offered to all those who have not yet tested. These facilities are staffed with doctors, midwives and lay counsellors.

1.8 SIGNIFICANCE OF THE STUDY

The significance of this study is that it has the potential to contribute to the PMTCT and HAART programmes in BCM, by ensuring that appropriate strategies are adopted to motivate non- compliant patients to return for comprehensive care and management for the well- being of the mother and the baby. The strategies recommended for intervening might be used to develop guidelines for intervening when newly diagnosed HIV-positive women do not return.

1.9 DEFINITION OF CONCEPTS:

HIV-positive:

Refers to people who have taken an HIV test whose results have been confirmed positive and who know their results (Policy and Guidelines for the implementation of the PMTCT Programme, 2008).

Mother-to-child transmission:

Mother-to-child transmission is the transmission of HIV from an HIV-positive woman during pregnancy, delivery or breastfeeding to her child. The term is used because

the immediate source of the infection is the mother, and does not imply blame on the mother (Policy and Guidelines for the implementation of the PMTCT programme, 2008).

Newly diagnosed:

In this study newly diagnosed refers to a month's period following confirmation of the HIV- positive status.

Strategies:

Strategies refer to intervention methods used by professional nurses when a newly diagnosed HIV- positive, pregnant woman does not return for further management and care.

Professional nurse:

A professional nurse is an individual who is qualified and competent to independently practice comprehensive nursing in a prescribed manner. One who is capable of assuming responsibility and accountability for her/his actions (Nursing Act No 33:2005). In this study they carry out their professional duties at the ARV-ANC accredited clinics in the BCM in the Eastern Cape Province.

1.10. CONCLUSION

In conclusion this chapter has provided an overview of the research study, the problem statement, purpose and ethical considerations. The next chapter presents the literature review for a broader understanding of the phenomenon under study based on the views of other authors.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Literature review is defined as a process that involves finding, reading and forming conclusions about the published research and theory on a particular topic (Brink, 2008). Burns & Grove (2009: 91-121), further state that a literature review refers to those sources that are highly important in providing the in-depth information needed to study a selected problem.

This chapter presents a theoretical literature study on related strategies used for follow- up care in the management of HIV and AIDS. Conceptual frameworks that focus on different perspectives of understanding loss of follow- up are presented. One framework is based on individual factors whilst the other is based on institutional factors. Both frameworks are useful in understanding the complex phenomena of loss to follow- up care as defined below.

2.2 LOSS TO FOLLOW- UP DEFINED

Various theoretical perspectives in loss to follow- up can be found in literature although there is no agreed-upon definition. "Lateness" for scheduled appointments is often used to describe the phenomenon, but the actual time intervals employed vary greatly among programs. Chi, Cantrell, Mwango, Westfall, Mutale, Limbada, Mulenga, Vermund and Stringer (2010:746-756), indicate in their study that nearly one-third of patients (n=10,196) were at least one (1) day late for an appointment.

Stringer, Zulu and Levy (2006: 782-793), classified patients who are more than 30 days past their last scheduled appointment date as 'late', whilst Médecins Sans Frontières (Doctors Without Borders) has defined loss to follow- up as being more than two (2) months late for a scheduled appointment (Calmy, Pinoges, Szumilin E, 2006:1163-1169).

In Yu, Chen, Wang's (2007: 550-554) view, loss to follow- up is a three (3) month interval from the time of a missed appointment. Walensky (2009), defined lost to follow-up as not showing up for care for at least (one) 1 year. Time since the last clinic visit has also been used to define loss to follow-up.

In this study the interval selected to define loss to follow-up is a period of one (1) month. This is the time that elapses since the last visit to the clinic and after the

pregnant woman has been diagnosed HIV- positive for the first time. These patients have not been reported as transferred to other facilities, or deceased.

Before we can better understand the phenomenon of patient attrition, there is a need for standardized definitions of loss to follow-up, based on observed evidence, to permit consistent comparisons across and within programs (Chi et al, 2010: 746-756).

2.3 HIV AND AIDS IN THE BUFFALO CITY METROPOLE:

An HIV/AIDS impact assessment was conducted in 2002, which estimated the provincial HIV prevalence rate at 6.6%, and 7.5% within BCM. The most recent national prevalence study estimated the HIV prevalence rate in the Eastern Cape at 29.9% (South African HIV/AIDS statistics, 2010. www.avert.org southafrica_hiv-aids-statistics-htm) and 9% in BCM. (www.childrensrights centre.co.za/site files/...Prov_prof)

Although follow-up care and support are mentioned in policy documents, intervention on non-compliant patients is not included in the aims or suggested indicators for monitoring and evaluating these programs, and little attention has been given to incorporating strategies during antenatal care to maximise (UNICEF, 2005).

The problems identified by Project Mwana (2010), are how to ensure efficient followup; how to remind mothers to return to the health centre for antenatal care services and how to remind them to return for their CD4 test results. There were no definite answers to these questions.

In examining the issues raised in Project Mwana, a study had been conducted in BCM on early infant diagnosis by 'mothers2mothers' in 2009, a non - governmental organisation (NGO). Results show an increase in the number of infants who were brought to the clinics where there was active client follow- up, compared to where there was no active client follow- up (Besser, 2009: 9).

Scaling up of HIV testing, tracing defaulting clients on HAART and treatment of virological- complicated, pregnant mothers have been the main problems that have been addressed up to date. If there is to be any change in the status quo, this should be done in a way that maximises its benefit to all HIV- infected populations

(Schulz-Herzenberg C, 2007), especially newly diagnosed HIV- positive, pregnant women.

The continued number of new cases of acquired HIV- infection among infants, indicates an ongoing risk of perinatal transmission with an emphasis on the need for strategies to ensure that HIV- infected mothers have access to, and receive adequate prenatal care (CDC, 1998).

2.4 INDIVIDUAL AND INSTITUTIONAL FRAMEWORK

2.4.1 INDIVIDUAL FRAMEWORK

Retention of care by HIV- positive patients, who are eligible for ARV treatment, seems to be a problem elsewhere as well, as reported by Zachariah (2010). In a retrospective study on retention of care among adults registered as eligible for antiretroviral treatment in Malawi and in Kenya, 23% and 33% respectively, were lost to follow-up before they started treatment and nothing was done to get them back into the system (Zachariah, 2010: 37-44).

Mortality and morbidity rates are reported to be high amongst the patients who are lost to follow- up (Bassett, Regan, Chetty, Giddy, Uhler, Holst, Ross, Katz, Walensky Freedberg and Losina, 2010). This could be assumed to apply to the pregnant women who fail to return within a month after diagnosis for continued care and management, thus endangering their own lives and those of their babies.

The problem of the patients who do not return for follow -up care is common amongst those who are asymptomatic on diagnosis and who lack knowledge of their treatment plan (Fraser, Allen, Bailey, Douglas, Shin & Blaya, 2007). In a Johannesburg study, Vetten and Haffejee (2008: 24-26), argue that during the interview some women stated that they were not in a state to listen to the instructions while some were deliberately trying to forget the entire experience.

Such behaviours may be linked to the negative emotional reactions following confirmation of the diagnosis, such as suppression, denial, shock, depression, blaming and guilt feelings. Such negative emotions could be reasons why HIV-positive, pregnant women fail to return for continued care immediately after diagnosis.

Since HIV- infected patients are so challenging to find and re-engage after they are lost, few studies report their clinical outcomes. The data shows a much higher risk for death among patients who are lost and return to care, than among those who remain in care. It is reasonable to assume that the patients who never returned to care, fared even worse. Studies like this one are critical for assessing the magnitude of the problem of loss to follow-up and for starting to identify the best ways to prevent it (Walensky, 2009).

2.4.2 INSTITUTIONAL FRAMEWORK

Since the appearance of HAART, the process of HIV/AIDS becoming a chronic disease in the industrialised world has led to a dramatic change in the illness paradigm. Patients who would previously have been terminally ill are now chronically ill, and palliative care has become chronic care. This situation requires a completely new approach to care of the HIV/AIDS patient (http://dxcrossref.org/10.137 1journal.pone.0014515).

ARV medication for preventing MTCT can reduce the likelihood of an infant becoming infected with HIV during gestation and delivery. With the introduction of the HAART regimen during pregnancy and labour, vertical transmission of HIV has

been largely eliminated in resource- rich settings, such as the USA and Western Europe. However, MTCT of HIV remains the predominant source of infection in children in resource- limited countries, particularly in sub-Saharan Africa where this mode of transmission accounts for 90% of paediatric infections and up to 15% of new infections worldwide (Teasdale and Besser, 2008: 60-64).

The current practice of accreditation allows 'down referral' of clients from the hospitals to primary healthcare centres (PHC), instead of integrating the service into PHC's. This challenges the implementation of ARV rollout (Gaede, 2006: 362-368). Inadequate healthcare infrastructure, including weak linkages between MTCT and HIV- treatment programmes, a chronic shortage of and overextended health care workers, and management of drug supply (drug stockouts) are some obstacles faced by institutions (Ford, Reuter, Bedula, Schneider, & Reuter, 2006: 19; Teasdale and Besser, 2008: 60-64). The efficacy of PMTCT programmes depends on the capacity of the healthcare system to deliver services (Teasdale and Besser 2008:60-64). Such challenges may be contributory factors to loss of care.

Studies have highlighted that people living with HIV express strong concern about an HIV- stigma, discrimination and lack of confidentiality; health worker discrimination; and discrimination based on gender identity or sexual orientation (Sprague, Sprague and Simon, 2011: 16-19). If the institutions are not addressing these concerns they will continue to be barriers in scaling up HIV prevention, treatment, care and support services.

The success of HIV programmes is usually measured by assessing and monitoring the effectiveness of those started on treatment, excluding those eligible but who did not return for whatever reasons (Raguenaud, Isaakidis, Zachariah, Te, Soeung, Akao and Kumar, 2009). Zachariah (2010: 37-44) found that reporting and intervening in cases where the patients who do not return for continued care, has the potential of reducing the attrition rate.

2.5 ROLE OF NURSES

Nurses are the gatekeepers of the health system and the first point of contact for individuals seeking healthcare services whether at primary or tertiary level of care. They are often faced with women who do not have access to ARVs or who present

themselves too late (Stender, 2010). Nurses are committed to playing a bigger role in HIV and AIDS prevention, treatment and care and are concerned that there is not enough preventative work done for pregnant mothers (Penn-Kekana and Kunene, 2010: 33).

The preventative work includes identification and care of newly diagnosed HIV- positive women who do not return for comprehensive HIV care. Determining who has missed a follow-up appointment in a health facility is almost impossible with paper based records alone. Nurses need to adopt several strategies of intervention to effectively address the non-return of patients.

2.6 INTERVENTION STRATEGIES USED FOR FOLLOW- UP

Studies on newly diagnosed HIV- infected clients, have up to now focused largely on immediate problems of definition and measurement rather than actions taken by nurses to newly diagnosed HIV- infected, pregnant mothers (Paterson (2002:21-30 and Liu, 2001: 968-977).

In an effort to increase access to prevention, treatment and care, South Africa launched a national HIV Counseling and Testing (HCT) campaign in April 2010 as a strategy to test 15 million people for HIV and to reach 1.5 million people with ART by June 2011 (Ministry of Health and SANAC, 2010).

Deputy President Kgalema Motlanthe's opening remarks in an XV111 International AIDS 2010 conference was showing and encouraging commitment of everybody to join hands and fight against HIV and AIDS when he stated that "I am responsible, we are responsible, South Africa is taking responsibility". This statement was used as a theme for the World AIDS day.

2.6.1 Updating records

One of the intervention strategies is related to the updating of several records within the health care system, for example, the PMTCT register; as well as daily notebook and admission registers. This is based on the realization that HIV- positive patients need to be assessed and decisions on treatment need to be reviewed continuously and the losses to follow-up, need to be monitored. Newly diagnosed HIV- positive, pregnant women who do not return need tobe found (Lawn, Myer, Harling, Orrell, Bekker & Wood, 2006: 770-776).

2.6.2 Health cards

Another strategy to promote compliance by the patients is to provide them with healthcards to monitor progress. The acronym used for healthcards is "to come again" (TCA) healthcards. The challenge with the TCAs is that they do not support the monitoring and surveillance of patient care. Such a situation puts the burden on the patient to remember the return date and to come for follow-up visits (Fraser, Allen, Bailey, Douglas, Shin & Blaya, 2007). On initial diagnosis pregnant women should not be overloaded with information as they are often too emotionally affected to listen carefully to the instructions, let alone to wait for a TCA card (Vetten and Haffejee, 2008: 24-26).

2.6.3 Task shifting

Task shifting is defined by the World Health Organisation as a process whereby specific tasks are moved, where appropriate, to health workers with shorter training and fewer qualifications.

Task shifting is supported by many campaign groups and they claim that it is crucial to the goal of making HIV- treatment widely available. Four prominent HIV/AIDS organisations called on the national and regional health departments to issue directives permitting the transfer of certain responsibilities and asked professional medical, nursing and pharmacist bodies to support task-shifting (http://www.avert.org/aidssouthafrica.htm and http://www.msf.org.za/viewnews.php?n=275.

A recent study in South Africa supported task-shifting to nurses, after it found that the care of patients receiving antiretroviral treatment was not inferior when they were monitored by nurses rather than by doctors (The Lancet: 2010).

In another study in a rural district of Lusikisiki, Ford, Reuter, Bedula, Schneider & Reuter (2006: 19), point out that task shifting is necessary in response to a gross shortage of nurses. Through use of task shifting the overall utilisation of services doubled though the number of professional nurses had not changed. The nurse-patient ratio (number of patients seen per nurse per clinical work day) also increased when compared with the national average of 29.4 (Health Systems Trust, 2006).

Task shifting may be a solution to newly diagnosed, HIV- pregnant mothers who do not return for continuity of care. Community health workers could bring results reporting if the woman is too sick to attend; or is attending another facility; has left the area; or is alive or not.

2.6.4 Involving partners of pregnant women

PMTCT consists of the provision of medical and sometimes psycho-social follow-up of HIV- positive, pregnant women, so that appropriate medical treatment can be administered to prevent infection of the baby. Findings in a study 'Involving partners of pregnant women in Africa to improve AIDS prevention' were that many women are reluctant to access HIV- programmes because men are considered to be an obstacle to acceptance, as they are scarcely involved in prevention programmes. Involving men in PMTCT programmes encourages women to participate and promotes a change in attitude towards HIV- prevention programmes http://www.plosmedicine/org=True

2.6.5 Mobile phones

Cell phones as a method of tracking patients, had been used elsewhere to assist in

patient follow-up and provide access to medical data such as laboratory tests (Fraser et al, 2007). In South Africa, cell phones have been tested as a way to encourage patient compliance with TB treatment (Bridges.org, 2005). In a study in BCM for early infant diagnosis cell phones were used to remind mothers to come with their babies for Polymerase Chain Reaction (PCR) testing and to confirm that the mother knows the results of the baby (Besser, 2009:9).

While mobile phones have shown good results in tracing clients, their use needs to be strengthened for better results in following up newly diagnosed, HIV- positive, pregnant mothers. These patients are faced with a dual problem of being pregnant and HIV- positive. They need to be constantly supported and monitored.

2.6.6 Electronic medical information systems

In Zambia and in Rwanda, community healthcare workers used an electronic medical information system to track patients lost to follow- up. Patient follow-up visits are logged through the entry of follow-up forms, and patients who fail to return are highlighted in monthly reports. Data is linked to the records of HIV- positive, pregnant women in the PMTCT clinic to ensure that they receive treatment (Fraser et al, 2007 and Allen, Jazayeri, Miranda, Biondich, Mamlin, Wolfe, 2007: 382-386).

The challenge with this strategy is that, although it had shown success in following up clients, it failed to identify newly diagnosed, HIV- positive, pregnant women who are not on treatment. As such it turned out not to be an ideal method for the patients who are still waiting for their CD4 count results (Allen et al, 2007:382-386). This strategy has little bearing on the Buffalo City district health care system which uses a paper- based system for HIV- positive clients who are not yet on treatment.

WHO (2008) is aware that there are poor and rich countries and states that, while expanding access to modern diagnostics should be a goal of global AIDS control, the absence of such diagnostics should not preclude the implementation and scale-up of comprehensive HIV programs. In fact, much of the care of HIV patients can be followed up based on clinical assessment alone.

A study conducted by Cartoux, Meda, Van de Perre, Newell, de Vincenzi & Dabis (1998), reveals that poor and marginalised women are less likely to attend antenatal care, less likely to return for their results, and less likely to receive the interventions due to personal and resource- based challenges. This is supported by a Thai study of 24,465 women, 99% consented to be tested but 12% of women who tested positive, failed to return for their CD4 results or return to the clinic after receiving their HIV results (Koetsawang, Stewart, Hemvuttiphan, 2000).

2.7 CONCLUSION:

This chapter covers literature reviewed in relation to different views on the importance of tracing non-compliant patients, the related intervention strategies used to trace non-compliant HIV and AIDS patients, and the benefits of continuous follow-up care. Literature on reasons for failure to return to the facility for further management and care were also reviewed and this includes literature on the practices and processes that support the caring role of nurses.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

Previous chapters provided a description of the background information to the study and literature review regarding intervention strategies used on the loss to follow- up care. In this chapter, the researcher describes the research methodology that was applied to explore and describe strategies used for follow- up care.

3.2 AIM OF THE STUDY

The aim of the study was to explore and describe the strategies used by professional nurses to manage newly diagnosed, HIV- positive, pregnant women who fail to return within a month for further management and care at the Buffalo City accredited antiretroviral ante-natal care (ARV-ANC) clinics.

3.3 RESEARCH OBJECTIVES

The objectives were:

To explore and describe the views of professional nurses with regard to intervention strategies they use when newly diagnosed, HIV- positive, pregnant women do not return for continuity of care within a month's period following diagnosis. To make recommendations for the development of guidelines for the management of non-compliant women.

3.4 RESEARCH QUESTION

The research question in this study was as follows:

What actions do professional nurses who work at the accredited ARV-ANC clinics, namely, the Dimbaza Community Health Centre (CHC) and the East London Hospital Complex, take to manage newly diagnosed, HIV- positive, pregnant women who fail to return within a month of diagnosis, for further management and care?

3.5 RESEARCH METHODOLOGY

Research methods are defined as techniques used in the process of conducting the specific steps of the study (Burns & Grove, 2009: 218). A qualitative exploratory research method will be used as 'little is known about the research topic' (Bless, Higson-Smith and Kagee, 2006: 43-52).

In this study, the researcher used an explorative, descriptive, qualitative research

method to investigate the actions taken by professional nurses when pregnant women who have been diagnosed HIV- positive, do not return for further management within a month.

The qualitative approach enabled the researcher to explore the depth, richness and complex, inherent, lived experiences of the participants, in relation to the lack of information about their interventions with regard to non-compliant pregnant women. The qualitative approach also enabled the researcher to understand the thoughts, feelings and experiences of study participants as the investigation was done using unstructured focus group interviews. This approach assisted the researcher to analyse in- depth, the problem of a lack of information about the actions taken by professional nurses on non-compliant, recently diagnosed, HIV- positive, pregnant women.

This study was descriptive as it sought to provide an accurate description of what was being studied, that is, the lack of information with regard to actions taken by the professional nurses on failure of newly diagnosed, HIV- positive, pregnant women to return within a month for further management and care (Burns & Grove, 2009: 218).

3.5.1 The Research Settings

This study was conducted at the Dimbaza Community Health Center (CHC) and at the East London Hospital Complex (ELHC) comprising of Cecilia Makiwane and Frere Hospitals in the Buffalo City Metropolitan. Both these sites have accredited ARV-ANC clinics. ELHC has been accredited to roll out ARV's as well as Dimbaza CHC. At these clinics pregnant women are tested for HIV. If diagnosed HIV- positive, they are advised to come within a month for follow- up care and management.

3.5.2 Research design

A research design is a plan or blueprint of how one intends to conduct research (Burns & Grove, 2009: 218-228). The research approach for this study was qualitative and it's design was phenomenological. Qualitative research describes an event in its natural setting (Abusabha, & Woelfel, 2003: 566-575). It is a subjective way to look at life as it is lived and is an attempt to explain the studied behaviour (Walsh, 2003: 66-75).

3.5.3 Study population

The study population refers to the entire set of objects or people which is the focus of the research and about which the researcher wants to determine some characteristics (Bless et al, 2006: 43-52). The population in the study was professional nurses working at ELHC and DCHC located in the Amathole District of the Eastern Cape Province offering comprehensive HIV- care. The term population refers to all elements (individuals, objects or substances) that meet a certain criteria for inclusion in a given universe (Burns and Grove, 2009: 42).

In this study, the population was all registered nurses working in the three accredited anti- retroviral antenatal (ARV/ANC) clinics, that is, the two at the ELHC and the one at DCHC, between July and September 2011. A monthly change list of all staff allocated to the accredited ARV/ANC clinics for July, August and September 2011 was obtained from the management of the three facilities and was used to identify the population for this study.

3.5.4 Sample and Sampling

A sample is the subset of the whole population which is actually investigated by a researcher, and whose characteristics will be generalized to the entire population (Bless et al, 2006: 43-52). The sample was selected from professional nurses working in three accredited ARV- ANC clinics in the BCM.

Sampling: Sampling is a process of selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest (Brink 2008: 191-200). In this study the sample comprised of the appropriate informants, that is, those professional nurses who had knowledge and experience of working in the accredited ARV-ANC clinics.

The researcher used purposive sampling technique which is one of the nonprobability sampling techniques to select individuals for study. Speziale and Carpenter (2007:94) refer to the purposive sampling method as sampling which selects individuals for study participation based on their knowledge of the phenomena for the purpose of sharing that knowledge. The logic and power of purposive sampling lies in selecting information -rich cases for the study. In- depth, information- rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research. This sampling method is suitable in this phenomenological inquiry because the researcher intended to gain insight and an in- depth understanding of what the nurses do to manage noncompliance by newly diagnosed, HIV- positive pregnant women.

The sample size:

The targeted sample size for this study was five focus groups, of at least six participants in each group. Speziale and Carpenter (2007: 460), state that in qualitative research, data generation or collection continues until the researcher believes saturation has been achieved, that is, when no new themes or essences have emerged from the participants and the data are repeating. In this study, the researcher considered the purpose of the study, as well as the depth of the information generated.

Data was collected by means of focus group interviews until saturation took place. The saturation took place when the researcher had conducted three focus group interviews of four participants in each group. Other participants who had initially agreed to participate, did not honour the appointments.

3.5.5 Measuring instrument

A measuring instrument is a tool used to collect data from participants (Mack, Woodsong, MacQueen, Guest and Namey, 2005: 66-67). The appropriate tool for this study was a semi-structured interview guide (Bless et al, 2006: 43-52). An in-depth, semi structured interview guide was designed and submitted to the supervisor for approval. Interview questions were derived from the objectives of the study.

The interview guide consisted of questions related to the strategies used by nurses to manage newly diagnosed, HIV- positive, pregnant women who do not turn up for further management and care. The following statements were used to guide the discussion, namely:

Actions taken on confirmation of diagnosis

Actions taken on failure by the women to return for further management and care. Reasons for not returning.

Suggestions on effective interventions.

3.5.5.1 The Researcher as an Instrument

The first data collection instrument was the researcher herself. The researcher as a person was totally involved in perceiving, reacting, interacting, reflecting, attaching meaning and recording. The researcher addressed data collection issues

related to the relationship between the researcher and participants. The researcher made sure that she communicated clearly, audibly and was careful not to use other non-verbal messages that would disrupt data generation. The researcher explained the reasons for the study and rules about the focus group discussion. This was done to reinforce the information that was in the letter of request to participate in the study.

3.5.5.2 Unstructured Interviews

The second data collection instrument used in this phenomenological inquiry was unstructured interviews, during which the researcher sought to gather insight into how the participants make sense of their experiences (Merrium, 2002). The interviews provided a way of generating empirical data about the social world through asking the professional nurses to talk about their own experiences and interventions (Silverman, 2005:333).

3.5.6 Data collection process

The data collection process is the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions, or hypotheses of a study (Burns & Grove, 2009: 695). In this research, data was gathered through focus group interviews. A focus group is a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment (Burns & Grove, 2009: 695-700). Focus groups were held to gather a wide range of data on the phenomenon under study. The interviews were geared towards exploration, discovery and description of actions taken by professional nurses.

The researcher visited institutions, requested and explained the purpose of the study. Permission to conduct focus group interviews was requested from the participants in each of the three facilities. Dates and times were scheduled to suit the availability of the professional nurses. Each facility was visited at least thrice between July and September 2011.

The visits were scheduled as follows: to submit a request to the facility manager to conduct a study in his/her facility; on approval another request was made to the facility staff to participate in the focus group meeting and lastly, on reaching agreement to conduct a study on a scheduled date and time. In each facility a focus group of at least four (4) participants of consenting registered nurses, working in an

accredited ARV-ANC unit was conducted. The researcher spent one (1) week to select the sample for this study. Ethical considerations and adherence thereto were observed.

Consent forms were read and signed. Included in the consent forms were the purpose, procedure, risks, and benefits of the study (see Annexure E). On agreeing with the contents, the participants signed the consent forms. A voice recorder was used to record the discussion and brief field notes were taken and later used as part of the data analysis.

The medium of instruction was English but participants sometimes added one or two words in vernacular. They felt comfortable in doing that. All the words in vernacular were interpreted in English ensuring that the meaning in which it was spoken was not lost. Open- ended questions on their day to day experiences with newly diagnosed, HIV- positive, pregnant women were asked. A total of six (6) participants in each group agreed to participate, but only four (4) turned up on the day of the interviews.

The researcher used open-ended questions in order to elicit a description of participants' views with regard to the phenomenon under study. The interviews were conducted as an open conversation in which each participant could comment, ask questions from other participants and respond to comments made by others, including the researcher.

Each interview took place in a quiet place with few distractions. The participants were made comfortable during the entire session. The seating arrangement was a semi-circle, to facilitate that all participants be in full view of one another. A voice-recorder was used and placed strategically in order to capture the process of discussions between the facilitator and the participants, and among the participants. The broad question that guided the focus group discussion was, "What do you as professional nurses working in these accredited sites do when the newly diagnosed, HIV- positive, pregnant women do not return for follow- up care and management within a month after diagnosis? The discussion was directed at obtaining information on the following: action taken on diagnosis and actions taken on failure to return and what could be recommended to encourage the women to come for follow-up care and management.

During the interview, the researcher, as an instrument, probed for more information, wrote notes on the contents of the process of the discussion, and clarified issues that sounded vague from the participants, in order to capture the intended messages and observed both verbal and non-verbal messages. The researcher also used non-verbal messages to facilitate interactions such as nodding the head, or making minimal verbal responses that indicated interest. The researcher's emphasis was to allow or facilitate participants to talk freely about their own interventions. Any question posed to them was there for clarification and to keep them on track. The researcher tried to "bracket" her presuppositions about the phenomena under study (Speziale and Carpenter, 2007). The researcher guided the process of the discussions to avoid deviations from the subject of discussion.

The researcher also took field notes which were used to describe what had been observed and which was noteworthy. The length of the focus group interviews varied from each group because of the different group dynamics. The average time taken for each discussion was approximately 40 minutes. A tape recorder was used throughout the focus group process. The interviews were recorded in order to prepare verbatim transcripts for analysis. The researcher sought permission from participants before using the tape recorder to allay anxiety. The researcher allowed the discussions to continue until saturation was reached, that is, the same statements or concepts were heard over and over again, without any new themes or essence emerging from the participants.

Dates and times for interviews were scheduled as follows:

12 July 2011 at 08h30 at Frere hospital;

- 14 August 2011 at 14h00 at CMH and
- 15 September 2011 at 14h00 at Dimbaza CHC.

3.5.7 Pilot study

Drummond (2003:156) defines a pilot study as a small preliminary investigation of the same study whose aim is to identify potential problems in the data collection and to show that the study design is both appropriate and feasible. It is designed to acquaint the researcher with problems that can be corrected in preparation for the larger research project. It has the same general character as the major study. The researcher conducted the pilot study before she conducted the actual study. The pilot study helped the researcher practice conducting interviews, and to gain artistic skills and refine the research instruments which included the researcher. It was done to identify potential problems in the data collection and to show that the study design was both appropriate and feasible. During this process the researcher gained experience in carrying out the project.

The pilot study of one focus group discussion was conducted at a clinic site different from that of the actual study, to find out if the interview process and guide to be used had problems and were not ambiguous and unreliable. Thus, finding out if the instruments were able to elicit the necessary responses from the participants before the actual data collection. Data were analyzed and sent to the experts of qualitative research which were the supervisors. The researcher was given a goahead to proceed with the actual data collection for the main study by both supervisors.

The tool was modified several times before it was implemented. The supervisors encouraged the researcher to study material related to qualitative and quantitative research methods so that she can understand the differences and similarities between the two research methods.

3.5.8 Ethical Consideration

Research ethics deals primarily with the interaction between researchers and the people they study. Professional ethics deals with additional issues such as collaborative relationships among researchers, intellectual property, fabrication of data and plagiarism, among others (Mack et al, 2005: 9-12). This study was ethical as its design and execution conformed to a set of standards or conventions guiding research (Polgar and Thomas, 2008: 70-72).

Voluntary Participation: Voluntary consent was obtained after the prospective participant had been given essential information about the study and had shown comprehension of the information. The researcher explained to the participant of this study the purpose, benefits and risk of the study in clear language. The participants were also informed about the scope of the study and the type of questions that would potentially be asked. These participants were given sufficient information to help them decide whether they wanted to be research participants or not.

Apart from explaining to the participants about the study, the researcher gave each participant a copy of the information sheet (see Annexure E). The contents of the

information sheet were: An introduction of who the researcher was, the purpose of the researcher and the participants in the study, the duration of the interview and assurance of anonymity and confidentiality. It also included a statement that participation was voluntary and any refusal to participate would not involve any penalty or loss of benefits to which the participants were entitled.

The information sheet also included that the participants were free to withdraw at any stage of the interview. After going through the information sheets, each participant was also given a written consent form to read and sign if they were in agreement with the contents of both the information sheet and the consent form. All the participants signed the consent forms which indicated that they were ready to participate in the study. Participation in this study was voluntary.

Confidentiality and Anonymity: Participants were assured of confidentiality and anonymity. They were assured that any information divulged would not in any way be connected to them personally when feedback and recommendations were given to the institutions. Participants were also assured that they would be treated with respect and dignity. Burns and Grove (2009: 695), state that anonymity exists if the participant's identity cannot be linked, even by the researcher, with his or her individual responses. The researcher made sure that the names and addresses of participants did not appear anywhere because they were not necessary in this kind of study. The researcher was only interested in finding out participants' views and experiences about the phenomena. Participants were assured that they would be treated with respect and dignity.

The focus group interviews were carried out in quiet, closed rooms away from people for confidentiality and privacy and to avoid any distractions. The researcher made sure that the information gathered from the interviews was not reported in a manner that identified the participants. The information (transcripts) was only accessible to the researcher herself, the specialist of qualitative research and the supervisors. The transcripts were kept in a safe place and no-one accessed them. Field notes were made immediately after each interview to describe the whole interview situation and the researcher's impressions. This was done also to ensure that no collateral information was lost.

A proposal together with the questionnaire was submitted to the University of Fort Hare (UFH) Research Ethics Committee for approval and to obtain the Ethics Clearance certificate. A letter requesting approval to conduct the study and an information sheet explaining to the participant what the study was all about had been written. Permission from the provincial Department of Health, East London Hospital Complex and Buffalo City sub -district manager to conduct the study was arranged.

Participants were given a consent form to sign if they agreed to participate. Polgar and Thomas (2008:70-72), state that a project is ethical to the extent that its design and execution conforms to a set of standards or conventions guiding research.

Reliability regarding data analysis was assured by peer examination during which the researcher solicited a colleague's help in examining the transcripts and field notes. The purpose of using peers was to determine whether they would identify the same categories and themes within the data as the researcher. This review helped to identify trends in the data which were not discovered by the researcher. It also helped to open new avenues for exploration and to reach consensus in categorizing themes.

3.5.9 Validity

In this study validity was ensured by:

Selecting participants who meet the criteria of the sampling technique; Reminding the participants that they are the experts in the topic of the study; Questioning commonly assured meanings of words and concepts; Doing comparative analysis and validity checks with participants by playing back the tapes after each interview to verify the contents with them.

3.6 Authenticity and Trustworthiness of the data

Denzin and Lincoln (2000: 84), state that trustworthiness in qualitative research refers to validity and reliability. Rigour in qualitative research is demonstrated through the researcher's attention to and confirmation of information discovered. The goal of rigour in qualitative research is to accurately represent study participants' experiences.

Speziale and Carpenter (2007: 48-52), state that the issue of rigour in qualitative research is important to the practice of good science. The trustworthiness of the question put to study participants depends on the extent to which they tap the participant's experiences apart from the participant's theoretical knowledge of the

topic. Consistent use of the method and of bracketing of prior knowledge helps to ensure pure description of data.

To ensure the trustworthiness of the research analysis, each and every step of the research process was supervised by two supervisors, and the researcher presented the proposal at a seminar at the University of Fort Hare (UFH), Department of Nursing Science for quality control. Two examiners did quality control of the research report and finally, the University Examination Committee. An audit trail was used by engaging an independent auditor to draw conclusions about authenticity and trustworthiness of the data.

There are different terms to describe the process that contribute to rigour in qualitative research. Lincoln and Guba (1985) as well as Speziale and Carpenter (2007: 48-52)) had identified the following terms that describe operational techniques supporting the rigour of work, namely; credibility, dependability, conformability and transferability.

For the purpose of this study, the criteria as described by Lincoln and Guba (1985) were applied.

3.6.1 Credibility

Credibility refers to whether the inquiry was conducted in such a manner so as to ensure that data gathered and emerging themes were accurately identified and described (Speziale and Carpenter, 2007: 48-52). To achieve credibility of the data, the interviewer verified data collected, as well as the conclusions drawn from the information collected during the interview with participants to ensure that the interpretations made were correct. Speziale and Carpenter (2007: 48-52), have called this activity "member checks." Polit and Beck (2008), state that member checking with participants can be carried out in an ongoing way as data are being collected (e.g. through deliberate probing) to ensure that interviewers have understood participants meanings. The interviews were tape recorded to accurately capture the responses of the participants. The transcribed data was checked with the audio tapes from time to time for accuracy.

3.6.2 Dependability

This is a criterion met once researchers have determined the credibility of findings. Polit and Bates (2008: 536-537), state that dependability refers to the stability (reliability) of data over time and over conditions. The dependability question is would the findings of an inquiry be repeated if it was replicated with the same participants in the same context? Credibility cannot be attained in the absence of dependability, just as validity in quantitative research cannot be achieved in the absence of reliability. In this study, the transcribed data recorded during the interview

were verified by the participants themselves. The data was also verified for authenticity and accuracy and that it was the actual data as recorded during the interview. The analysis of the data was further verified by two (2) supervisors and an expert of qualitative research.

3.6.3 Conformability

Conformability of findings refers to an audit trail which is a recording of activities over time, that another individual can follow. This process can be compared to a fiscal audit (Speziale and Carpenter, 2007: 48-52). The objective is to illustrate as clearly as possible the evidence and thought process that led to conclusions. The researcher left an audit trail by documenting clearly all the steps involved in the study. The initial coding of the data was done by the researcher and the two supervisors. It was later given to the experts of qualitative data analysis to review the categories and themes identified from coded data for validation.

3.6.4 Transferability

Transferability refers to the probability that the study has to others in similar situations. Transferability has also been labeled "fittingness" (Speziale and Carpenter, 2007: 42-48). It also refers essentially to the generalizability of the data, this is the extent to which the findings can be transferred to, or have applicability of the data to other contexts. A qualitative study does not strive for generalizability. However, according to De Vos (2000:346), it maybe generalizable if the study is based on a theoretical framework. In this study sufficient information had been given about the characteristics of the sample for judgments to be made about the extent to which findings could be expected to apply more widely.

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3.7 CONCLUSION

This chapter described in detail research methodology that was applied to explore and describe strategies used for follow- up care. Included are the research methods that took place in the study, research design, population, sampling process and ethical considerations. In chapter four (4), an analysis and interpretation of research result is presented.

CHAPTER 4: DATA ANALYSIS AND INTERPRETATION

4.1 INTRODUCTION

The findings of the study have been presented and discussed in this chapter. The data reflected the views of professional nurses with regard to the strategies they used to manage newly diagnosed, HIV- positive, pregnant women who fail to return within a month for further management and care.

4.2 METHOD OF ANALYSIS

The researcher transcribed all the tape recorded interviews verbatim. The transcripts were read and re-read word for word, sentence by sentence in the process of searching for themes or recurring regularities until the researcher was convinced that the data was interpreted correctly, thereafter it was translated into themes.

The method of data analysis utilized comes under the umbrella of interpretative analysis. Through interpretative analysis the researcher was able to safeguard the uniqueness of each participant's lived experience, whilst ensuring that there is an understanding of the phenomenon under investigation (Terre Blanche et al, 2006: 323).

The different stages of the data analysis are outlined in table 4.1 below. The following table displays the approach used in this study for data analysis.

Stages of data analysis	Analysis process
Familiarisation and	Transcribed descriptions read by the researcher
immersion	
Inducing themes	Significant statement and phrases extracted
Coding	Meanings formulated from significant statements and
	phrases
Elaboration	Meanings clustered into themes and sub-themes emerged
Interpretation and	Results integrated into a thorough description of
checking	phenomena

Table 4.1: Approach to data analysis

4. 2.1 Familiarisation and immersion transcription of data

Familiarisation started during the verbatim transcription of the tape recorded on focus group interviews to initiate the process of data analysis. Most of the transcriptions were done on the same day the particular focus group took place. In cases where this was not possible, it was done within 24 hours of recording. In this manner the researcher became familiar with the data as it was gathered.

Immersion:

The researcher familiarized herself with the text by engaging with it to the point of knowing where particular quotations occured in it and getting a feel for the overall meaning and the different types of meanings in the text. This helped the researcher to develop a sense of the respondent's characteristic language usage e.g. metaphors. The researcher then read through all the transcribed data and field notes many times and began to draw diagrams and brainstormed about emerging themes (Terre Blanche et al, 2006: 356).

4.2 2 Inducing Themes

Inducing themes refers to the extraction of significant words, phrases and statements from the text. The researcher began to lay out the meanings of words and images, as a stock- taking activity. The list of selected words and statements helped the researcher to generate an overall idea of what she had by developing maps showing how these words and statements relate to one another. Those which were more predominant in responding to the research question were classified and clustered into possible themes and sub-themes, a process referred to as coding (Terre Blanche et al, 2006: 356).

4.2.3 Elaboration

Through the process of elaboration, the researcher began to interpret the material in relation to a broader theoretical framework with regard to the phenomenon under investigation. This process involved making associations amongst the newly emerging meanings. This meant speaking freely and spontaneously about what was coming to mind and repeatedly referring to the contexts in which the texts were

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created and the field notes, in order to understand the fullness of the meaning of the themes (Terre Blanche et al, 2006: 356-359).

4.2.4 Interpretation and checking

Interpretation and checking involved continued asking and refining questions leading to the identification and regrouping the themes and statements to describe the full picture of the emerging story (Terre Blanche et al, 2006: 356-359). The themes that emerged were the outcome of the process of coding, categorization and analytic reflection (Saldana 2009: 13).

4.3 Themes that emerged

Data were presented according to clusters of themes that emerged from the transcripts of the three focus group discussions. The four questions in the interview guide, were used to group the themes as follows, namely,

- action taken by professional nurses on confirmation of the HIV- positive status of pregnant women,

- action taken by professional nurses on failure of the HIV- positive women to return for further management and care within a month after diagnosis,

- reasons for failure to return and
- recommended strategies to promote compliance.

4.3.1 Action taken by professional nurses on confirmation of the HIV- positive status of pregnant women:

The focus of this study was on what the professional nurses did in the accredited ARV- ANC units to manage newly diagnosed, HIV- positive, pregnant women who fail to return for further management and care within a month of diagnosis. The data on the actions taken on diagnosis helped the researcher to gain insight into the research project by getting a sense of the whole picture and background on the issue of actions on failure to return within a month of diagnosis. Themes on action taken on confirmation of diagnosis are shown in Table 4.2.

	<u>.</u>
Theme	Subthemes
Further investigations	Specimen for full blood count, CD 4 count, viral
	load
	Screening for Sexually Transmitted Infections
	(STI's) and Tuberculosis (TB)
Health Education	Family planning
	Prevention of Mother- to- child HIV transmission
	(PMTCT)
	Infant feeding options
Counselling	Psychosocial support
	Coming in a month's time for further
	management and care
	Disclosure

Table 4.2: Themes on Action taken on diagnosis

4.3.1.1 Action taken on diagnosis

Themes and subthemes that emerged were as follows:

Firstly, further investigations are done by taking routine blood specimen for CD4 count, viral load, full blood count and urea and electrolytes (U&E). Screening for sexually transmitted infections and tuberculosis is also done. Secondly, health education about family planning, prevention of mother-to-child transmission of HIV (PMTCT) and infant feeding options are offered. Thirdly, counseling is done with special focus on psychosocial support, weekly follow- up care for further management and care and disclosure on HIV- positive status.

The following statements affirm above information.

"We also check for FBC – to check for all HIV- positive pregnant women, FBC is compulsory so that we know whether the patient is having anaemia as they are usually prone to anaemia."

"Eh ... information given comprised of importance to come back in the next month for treatment and also on infant feeding options to prevent mother- to- child transmission of the virus, treatment and its side effects; disclosure."

"Women receive also information from supporting organizations."

"Something I'd like to add, the support group also."

"They are also educated by the 'mothers2mothers' team where they join the support group and attend the support group on a weekly basis and they get more information there."

"We also educate about the side effects of treatment, importance of disclosure, diet and condomising. Also checking of PCR at 6weeks after delivery."

The results on actions taken on confirmation of the diagnosis were not discussed as this question was not the focus of the study. It is important to note that the PMTCT programme has the potential to integrate with other services like TB, family planning, STI, child health and supporting organizations. (PMTCT Clinical guidelines 2010: 25). Despite the identified actions taken by professional nurses on confirmation of the HIV- positive status, the phenomenon of failure by pregnant women to return within a month persists and the actions taken to address the problem were identified as discussed in the next section.

4.3.2 Action taken on failure to return

Themes that emerged from the data on action taken by professional nurses when the newly diagnosed, HIV- positive, pregnant women fail to return within a month after diagnosis were as follows: namely ''tracking', 'decentralisation', 'family involvement' and involvement of stakeholders.

Theme	Sub-themes
Tracking	Phoning the client
	Phoning the clinic
	Home visits
	Task shifting
	Integration with other stakeholders
Decentralisation	ARV's to nearest clinic
	Further management and care
Family involvement	Assistance through family members or partners

Table: 4. 3: Themes and sub-themes on action taken on failure to return

4.3.2.1 Theme: 'Tracking'

Tracking refers to tracing the patient using her contact details as obtained from the clinic records. Five sub-themes that emerged from tracking were: 'phoning the patient'; 'phoning the nearest clinic', 'home visits', 'task shifting' and integrating with other stakeholders.

These methods can be used either individually or combined for tracking the patients.

Sub-theme: 'Phoning the patient' This is done to remind the patient about her

appointment and to invite to come for further assistance and care.

Examples of statements for phoning the patient:

"We call them, follow them up by phone."

"If we see that there is a need to call the client, we call them."

"... but we are facing a problem with their contact numbers."

"Sometimes they don't even reply or they give us the wrong contact numbers."

Sub-theme: 'Phoning the clinic'

The other method used to track the patient was to call the local clinic, for assistance in tracking the patient or to take over the management and care of the patient, for example:

"... we are a referral hospital, so these clients are referred to us. We start by phoning the clinic, because they were referred by the clinic"

"… because they know where these women stay." "We tell the clinic."

Sub-theme: 'Home visits'

Another method used to track the patient, more especially those who cannot be reached by phone, was to visit them at their homes, for example:

"For others we check their addresses in the maternity register and request a car…" "... wrong addresses and wrong contact numbers."

Sub-theme: 'Task shifting'

Another method used to track the patient, more especially those who cannot be reached by phone or through home visits, is 'task shifting', by using patient advocates, for example:

"...patient advocates (PAs) are walking to visit the homes nearer to where they live. ...They come when we are admitting the patient and then they take the names of the patients and so it is easy for us now to liaise with them so that they can go and check the patient for us."

"PA's are selected per their areas... so you check the address and then you send somebody who is staying in that area."

"...and the PA has been there, she is not there and she has been told that she is not staying here."

Challenges related to Tracking:

Another sub-theme that is related to tracking, is 'challenges' encountered during tracking, for example:

"We usually have their addresses, but sometimes others give wrong addresses."

"Sorry, we also have a big challenge. We use to have people who come and track those clients but now, transport, is no more available from the NGO which is supporting us...."

"But not anymore because it's not funded."

"Number two some patients will know the vehicle that the NGO people are using when they see it they'll run and run."

"If I can dwell more, they like to use their own transport because when the neighbours has seen hospital car that means the client has defaulted, and promotes disclosure. Also seeing doctors and nurses and they say (whispering) 'there is something - nurses and doctors were here'. So they don't like that, they are trying to hide even with their cars."

"Don't send a PA to my house I'd rather come to the clinic and talk to the P.A here".

4.3.2.2 Theme: 'Decentralisation'

The theme 'Decentralisation' is about promoting the accessibility of HIV and AIDS related services by delegating the functions of an accredited clinic to a lower level facility, like a Primary Healthcare clinic or a mobile clinic closer to the community. Examples of statements:

"Decentralisation, that is, nearest clinic ."

"And others are staying faraway ... but they don't attend there they want to attend here, ...The other day I ask the other girl outside she said to me 'oh no just leave me I am fed up of those people in that clinic' ... I am sure she doesn't want to face the people there as if they are going to divulge the information."

Such behaviour seems to defeat the purpose of decentralization.

4.3.2.3 Theme: 'Family involvement'

Family involvement was related to liaison with the family or partners, to provide support and assistance to the affected family member, thus ensuring compliance with the treatment regimen, for example:

"She must bring a partner or parent not just anyone, like a friend or cousin." "We need also to promote accompaniment like by husband, partners and relatives, for example mothers...."

"She is married but we need to go to her biological mother to ask her. ...we need to use some other information when we are asking her. It is only that we need that information. We have been phoning and phoning but she is not replying." "Families to know each others' status. If all families know everyone's status in the family they will support each other, there will be free disclosure."

4.3.2.4 Integrating with other stakeholders

Beside collaborating with other services, the PMTCT programme also joins hands with external stakeholders to promote smooth- running of the programme. The following statements support this view,

"some patients will know the vehicle that the (International Centre for Aids Programme) ICAP people are using and when they see it they'll run and run".

"... Khetimpilo, they have got PA's that side who help us".

"They are also educated by the mothers2mothers team where they join the support group"

In summary, the participants used several methods to intervene in the cases of noncompliant patients. For each of the methods used, there were related challenges which negatively impacted on the effectiveness of the methods used. The researcher put the following question to the participants, "what do you think are the reasons for the failure to return?" The responses to this question enriched the discussion on the strategies used on failure to return and also helped to substantiate the recommendations made for future interventions.

4.3.3 Themes and sub-themes on: Reasons for failure to return

The participants were also asked to give their own views, based on their experience in the field, about the reasons why patients do not return for further management and care. This question was asked to obtain information to enrich and support the recommendations on the promotion of compliance as a means of preventing motherto-child transmission. Five themes emerged from the reasons for not returning for further management and care, namely,

negative emotional reactions; lack of knowledge, teenage pregnancy, socio-economic challenges and cultural practices.

Theme	Subthemes
Negative emotional	Denial; anxiety, non-disclosure; concern about
reactions	confidentiality and stigma.
Lack of knowledge	Lack of awareness and misinformation
Teenage pregnancy	Peer pressure and abortion
Socio-economic	Lack of money; far from the clinic
challenges	
Cultural influences	Health related cultural practices
Unsuspected issue:	AZT protocol

4.3.3.1 Theme: Negative emotional reactions

Negative emotional reactions refer to the range of negative feelings related to the confirmation of the diagnosis mainly due to the absence of a cure and the stigma attached to the disease. Fear of disclosure is one of the reasons for failure to access further HIV management and care,

The sub-themes identified on negative emotional reactions, were 'denial'; 'anxiety', 'disclosure'; 'concern about confidentiality' and 'stigma'. These sub-themes impact negatively on the mental well-being of the woman.

For example:

"... and also not accepting their results, others they don't accept their results, thinking that something may change if they visit other clinics."

"I am sure she doesn't want to face the people there as if they are going to divulge the information."

"This problem -the disclosure problem, really or the stigma ... it is a problem because others will tell us 'don't send a PA to my house I'd rather come to the clinic and talk to the P.A here'. It's a lot with this status thing.

4.3.3.2 Theme: 'Lack of knowledge'

The theme lack of knowledge is related to lack of awareness as well as misinformation on HIV and AIDS related issues. Although HIV and AIDS has been around for the past two decades, it was identified from the data, that some patients were still lagging behind in terms of knowledge about HIV and AIDS, for example: *"And with us, dealing with pregnant women, they think that if you have taken treatment during pregnancy, so when you have delivered there is not much as you have saved the baby."*

"Because sometimes they do not know what is the difference...."

4.3.3.3 Theme: 'Teenage pregnancy'

Teenage pregnancy has been identified as one of the reasons for failure to return for further management and care.

"Teenage pregnancy."

"Do you know, most people who are attending TOP services are the school kids, not old married people. ... early sexual intercourse with no protection."

"... unwanted or unplanned pregnancy."

"... sugar daddy and peer pressure."

"Problem of HIV and pregnancy... end up terminating the pregnancy."

4.3.3.4 Theme: 'Socio- economic challenges'

Socio-economic challenges impact negatively on accessibility of services, mainly due to lack of or shortage of financial and material resources. Although ARV, TB

family planning and ANC services are free many clients are poor and unemployed. They solely depend on social and/or a child support grant for survival. Examples of socio economic challenges mentioned,

"Money, money."

"... transport challenges".

"Problems of transport as others are staying far from here."

"They don't have transport to come here";

"They are walking"

4.3.3.5 Theme: 'Cultural practices'

Health- related cultural beliefs and practices play a big role in HIV and AIDS management, due to the promotion of the use of traditional medicine as against the western methods of treatment, for example:

"Mother in laws, for example, is going to say, when she has yet not disclosed to the mother in law or are in adherence counseling, they will ask 'why are you taking these many tablets, when so and so can give you one bottle to cure you."

4.3.3.6 Theme: 'Unsuspected issue: AZT protocol'

On reasons for not coming back, the theme AZT protocol emerged. This was related to HAART/PMTCT policies such as treatment, implementation processes, treatment supporter, for example:

"We have noticed this and discussed it with Sister from another facility. They've got the same problem when they initiate AZT before HAART."

"When they have taken AZT and when now you introduce HAART they become less interested in taking HAART. We noticed that those for HAART need not be given AZT and they need a treatment supporter. Those who are to start HAART we tell them to come immediately even if it is tomorrow. They usually come, but those who were on AZT will not come."

"They know that HAART is for life and AZT is stopped after sometime."

In conclusion, the professional nurses, based on their experiences, seem to understand the challenges they are faced with in relation to their attempts to intervene. After listening to the strategies and assumptions of the participants as to why the patients do not return, the researcher asked the participants; "what would you recommend to promote compliance with further treatment and care?"

The following section discusses the views of professional nurses.

4.3.4 Themes and subthemes that emerged on recommended strategies to promote compliance

The following eight (8) themes emerged as recommendations of what needs to be done to promote compliance by the patients, namely: 'psycho-social support'; 'information sharing'; 'decentralisation'; 'task shifting'; 'social mobilisation', 'health advocacy', 'tracking' and 'funding'. Interviewees' suggestions were as follows:

4.3.4.1 Theme: 'Psycho-social support'

A need for psycho-social support was highlighted as a means to curb negative emotions and to be able to deal with the stigma attached to HIV and AIDS, for example:

"... firstly, she must bring a partner or parent not just anyone- like a friend or cousin." "Disclosure to partner and parent, fight and decrease loss to follow- up follow- up ." "If you were not practicing safer sex it will be difficult to introduce it unless you disclose."

"Others do not want to divulge, some they do not disclose to their partners and husbands and we don't know what is happening. For example, a pregnant woman comes to the clinic you ask 'have you told the partner or husband' she will tell you 'no I do not want to' which is difficult."

"...the problem that they do not come back is disclosure because they can't disclose to their relatives."

"Disclosure to partner. It is very difficult for the partner to understand why you always go to the toilet at 8 o'clock. Why 8 o'clock? You are always taking treatment at 8 o'clock. It is sometimes difficult for you to take treatment regularly. He becomes suspicious. You'll miss- taking and taking treatment."

"We need also to promote accompaniment by husband, partners, relatives for

example, mothers." "Usually they are afraid of their mothers - to know about their status. To them it is better with friends or sisters"; .it is better with nearest next of kin. Others they come and enjoy that accompaniment but not all of them." "Families to know each others' status. If all families know everyone's status in the family they will support each other, there will be free to disclosure."

4.3.4.2 Theme: 'Information- sharing'

Information- sharing is about being able to simplify issues related to HIV and AIDS when educating or sharing information with patients. The following information speaks to this point:

"The other thing is that, make sure that as much as we educate them they go home with clear and understanding information, you will find out that some of them they are afraid to ask questions. ... maybe they are afraid of being shouted."

4.3.4.3 Theme: 'Decentralisation'

Professional nurses acknowledge the importance of decentralising HIV and AIDS management and care to clinics nearest to the patient's home, for example: *"Decentralisation, that is, nearest clinic."*

"Clinic staff knows where one stays."

"Decentralisation, because they know where these women stay."

4.3.4.4 Theme: 'Task shifting'

Task shifting was identified as a theme for encouraging compliance using DOT supporters who work as community liaison officers and patient advocates (PAs).

For example:

"train community health workers"

"If one is allocated an area to work in and your client is in that vicinity for example ...you tell her to also check so and so there because she is already there."

"... when they don't respond let's say within two days we need to send a PA."

4.3.4.5 Theme: Social mobilisation

Social mobilisation has been suggested as a strategy to promote access to health

and social services. There are different outreach strategies and they all link to different programmes.

"...more outreach for the community"

"You can involve communities in HIV related matters- improve, go to communities" "Home visits; school visits; door to door campaigns"

"... obtain views of families"

"Schools"

"Educate also when attending the funerals .We mean all partners must get involved."

4.3.4.6 Theme: 'Tracking'

Following statements indicate tracking as a recommended strategy. *"Home visits"*

"I am sure to contact them, it can be better then when they don't respond let's say within two days we need to send a PA". "We also need to go to the long ago procedures visit them at home though it is impossible (some giggling) because of staff shortage and stigma attached"

4.3.4.7 Theme: 'Socio- economic support'

Funding as a theme was mentioned because the supporting NGO does not have funds to continue offering transport services so that clients who are not returning can be tracked.

"more funding"

4.3.4.8 Theme: 'Health Advocacy'

Advocacy emerged as a theme for promoting compliance, for example, "... if not working with HIV not to educate because of new policies every day, otherwise they give false information."

"It is important for us who are not working in the HIV clinic not to educate clients because we usually give false information. For example a client was told by a clinic nurse that she was not supposed to take Efevarenz whilst pregnant. I have been allocated everywhere in hospital. I have worked in orthopaedic ward but now you cannot ask me to put traction as I will not know. I have to ask the nurses working there." In summary, psycho- social support was the main recommendation as it repeatedly appeared in all the transcripts. Professional nurses need to continue reinforcing the use of health advocacy, health education, social mobilisation and decentralization.

4.4 CONCLUSION

This chapter dealt with methods used to analyse the data and to present the findings of the study. In chapter 5, discussion of the findings, conclusions, limitations and recommendations pertaining to this study are presented.

CHAPTER 5: DISCUSSION, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In previous chapters, the researcher explained the reasons for this study and presented the applicable research methodology and data analysis. The results were also presented. In this chapter, the researcher presents the discussions, conclusions on the findings, limitations and recommendations on strategies to be used by professional nurses when HIV- positive, pregnant women fail to return for follow-up care and management within a month following diagnosis.

5.2 DISCUSSION

The goal of the study was to explore strategies used by professional nurses to manage newly diagnosed, HIV- positive, pregnant women who fail to return within a month for further management and care in ARV-ANC accredited clinics.

Objectives of this study were:

- To explore and describe the views of professional nurses with regard to intervention strategies they use when newly diagnosed, HIV- positive, pregnant women do not return for continuity of care within a month's period following diagnosis.
- To make recommendations for the development of guidelines for the management of non-compliant, pregnant women.

5.2.1 Discussion on findings

Findings were based on the results of data analysis. The discussion of findings included the summary and interpretation of findings together with the recommendation, in relation to the questions raised in the introduction, research objectives and recommendations (Bless et al, 2006: 60-161).

The problem statement for this study arose due to lack of knowledge related to the strategies used by professional nurses to manage newly diagnosed, HIV- positive, pregnant women who do not return within a month's period following diagnosis. A period following diagnosis is crucial for assessments, for example, CD 4 count is taken on the day of diagnosis. Whilst waiting for results the woman is put on prophylaxis AZT. A full blood count is taken at weekly intervals to exclude anaemia.

The CD4 count results are to be communicated and discussed with the woman within two weeks for eligibility to treatment. If the CD 4 count is above 350 the woman continues with AZT and if the CD 4 count is below 350 she is prepared for HAART.

This is a critical stage even for nurses. If they miss the woman at this stage, by the time she comes back she may have a high viral load and a low CD 4 count. She will have missed out not only HIV and AIDS support services, but also on ante- natal care services. The lives of the unborn child and that of the pregnant woman are compromised due to non-compliance or a late response. The woman may be admitted and need specialized care or she may present with complications associated with HIV and pregnancy. Such a situation compromises the baby's life. BCM, where the study sites are located, was in the newspapers in previous years due to an increase in neo-natal deaths. (Daily Dispatch, 2007:July 12). Assumptions were made about possible contributory factors, but none were related to the newly diagnosed, pregnant women who fail to access comprehensive HIV and AIDS care and management.

In Louisiana, between 1995 and 2003, 9.89% of infants born to HIV- positive mothers who did not receive appropriate medical care, delivered infants who became infected. However, only 3.59% of infants born to HIV-infected mothers who received appropriate medical care became infected. No client should wait longer than a month from the time blood is taken for CD4 count to the time of clinical assessment, staging and referral (Guidelines for expedited anti-retroviral initiation and emergency triage, 2009).

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Themes:

Four themes emerged from the study. These are tracking, decentralization, family involvement and integration with stakeholders, with their respective sub-themes. Professional nurses' conduct tracking by firstly, phoning the patients, secondly by calling the local clinics that are closer to the patients' home, and thirdly by visiting at their homes. The family members and support systems are used to assist with the tracking of pregnant women.

The professional nurses also used task shifting as strategy to track newly diagnosed HIV- positive pregnant women. Patient advocates; community health workers; Direct Observation Tuberculosis Treatment (DOT) supporters are tasked with the responsibility of tracking the patients. For example,

"even then it is a problem because others will tell us 'don't send a PA to my house I'd rather come to the clinic and talk to the P.A here'. It's a lot with this status thing." Tracking is done to ensure that the patients continue with their treatment programs to prevent mother- to- child transmission of the HIV and to prevent complications associated with HIV infection and pregnancy.

The data revealed that tracking as a strategy, is rendered ineffective by various challenges, for example, patients give incorrect contact details in the form or wrong telephone numbers and physical addresses and some refuse to have anything to do with local clinics in an attempt to hide the HIV- positive status from their own community members. They even run away from community health care workers and NGOs which are contracted to trace them. The same challenge of patients who do not want to attend local clinics due to the stigma attached to HIV and AIDS in the communities has also been highlighted in decentralisation.

There was an emergent issue on highly active, anti-retroviral treatment (HAART)/PMTCT protocol that arose when participants explained reasons for failure to return. Once HIV- positive, pregnant, women are put on AZT they refuse to take HAART as they believe AZT is enough to save the baby. All the strategies used to intervene seemed to have challenges which interfere with their effectiveness.

These challenges are mainly related to non-disclosure with no other alternative measure to safeguard the unborn child. Failure to respond to continuity of comprehensive HIV care and management carries a high risk in relation to PMTCT. The challenges as identified will need to be controlled for an improved response to follow -up care.

In spite of all these strategies, newly diagnosed, HIV- positive, pregnant women continue to fail to return for continuity of comprehensive HIV care. Assumptions by professional nurses as to the reasons for patients' failure to return, were related to negative emotional reactions on confirmation of HIV diagnosis; lack of knowledge about HIV and Aids; teenage pregnancy; socio economic issues and as well as health- related cultural practices.

5.2.2 Summary findings were as follows:

The actions taken by professional nurses on confirmation of the HIV- positive status on a pregnant woman were also identified. These were not the focus of the study as the focus was on strategies used to manage newly diagnosed, HIV- positive, pregnant women who fail to return within a month for further management and care. The researcher asked a question related to actions taken on confirmation of diagnosis to form a baseline of the whole scenario of interventions.

Action taken on diagnosis

On diagnosis, the professional nurses investigated further for the levels of CD 4 count, viral load and FBC to confirm the stage of infection in preparation for ARV therapy and to exclude anaemia. Screening of patients for sexually transmitted infections and tuberculosis is done. Isoniazid (INH) prophylaxis given where applicable. They also provide health education on family planning, prevention of mother- to- child HIV transmission (PMTCT) and on infant feeding options. Before pregnant women leave the institution they are offered iron supplements and prophylaxis which comprise of AZT and/or bactrim (broad spectrum antibiotic) to take at home. If the woman is anaemic, AZT is withheld until anaemia is treated. Professional nurses also counsel the patient focusing on the emotional well- being of the individual; promoting acceptance and disclosure of HIV status; availability of

support groups and the importance of coming back in a week's time for further management and care.

The results show that HIV care is administered on diagnosis. Participants indicated that although they educate the women, they also encourage them to attend support group sessions where they receive more HIV and AIDS related information. Benefits of attending support group sessions include information -sharing, peer education, and they also address psycho-social problems related to disclosure, stigma, and discrimination and promote early access to treatment. mothers2mothers support group members act as role models as they understand and know how it feels to be diagnosed as HIV- positive whilst pregnant.

The above findings are supported by Kranzer et al,(2009) who state that comprehensive HIV and AIDS care given to HIV- positive, pregnant women includes assessment for eligibility to treatment, screening for TB, preventive therapy, iron supplements, family planning, counseling services and psycho-social support. The outcome of this research is also consistent with the prescripts of the National PMTCT guidelines (2010).

Professional nurses know and implement what needs to be done on confirmation of the diagnosis. Despite this intervention there are patients who do not continue with their treatment regimen as they do not return for further management and care.

Reasons for not returning:

The professional nurses' exposure and experiences in the field of prevention of mother-to-child transmission of HIV, with all its successes and failures, are in a position to arrive at and develop their own perceptions and draw conclusions about the phenomenon. They perceive the reasons for failure to return for further management and care as related to negative emotional reactions; socio-economic factors, mainly associated with stigma against HIV and AIDS, and lack of resources, that is, financial and infrastructural resources. For example, lack of money for transport as some of them stay far from the clinics and they have to walk long distances to access care. Some patients are from under- resourced rural areas.

They are unemployed and live in extreme poverty. Most of them depend solely on social and or child support grant. The socio-economic challenges contribute to inaccessibility of services, for example, low or no income (Denscombe, 2007: 76-149).

The negative emotional reactions are associated with the fatality and the incurable nature of HIV and AIDS as well as the stigma attached to it and the negative attitudes of the community towards the infected. HIV and AIDS related stigma has highly damaging consequences and it limits the impact of public health interventions through delays. Tackling the identified HIV and AIDS related problems in the South African setting is likely to require strengthening clinical primary level services to reduce the need for hospital visits, as well as improving transport provision (Goudge et al, (2009: 94-104).

Other reasons for not returning were associated with cultural beliefs and lack of knowledge. These findings are related to the socio-economic and psycho-social challenges. Knowledge is not easily available to under- resourced areas and those communities have their own health related cultural belief systems, which in some instances may clash with the western approaches to health care. Some health related cultural practices influence the patient against using western treatment methods in the form of ARVs. The frequency and the amount of ARVs is interpreted as self -disclosure and therefore avoided. Without sufficient knowledge of their condition or treatment, some patients switch numerous times between healers, unclear as to who could provide relief (Goudge et al, 2009: 94-104).

Teenage pregnancy was found to be a barrier in assessing comprehensive HIV care. Reasons vary from peer pressure, unmarried, unplanned and or unwanted pregnancies, negative emotional reactions, stigma attached to the diagnosis and health care facilities and availability of termination of pregnancy services (TOP). These findings support the discussions from other studies which state that young, unmarried adolescents do not go to public HIV/AIDS services because of the stigma attached to the diagnosis and public health services. (WHO, 1994). Another reason for non-compliance is related to Highly Active Anti- Retroviral (HAART) and Prevention of Mother- to- child Treatment (PMTCT) policies on treatment, the implementation process, treatment supporter and others, for example: *"We have noticed this and discussed it with a Sister from another facility. They've got the same problem when they initiate AZT before HAART."*

"When they have taken AZT and when now you introduce HAART they become less interested in taking HAART. We noticed that those for HAART need not be given AZT and they need a treatment supporter. Those who are to start HAART we tell them to come immediately even if it is tomorrow. They usually come, but those who were on AZT will not come. They know that HAART is for life and AZT is stopped after sometime." This shows that they do not want to commit themselves with long term treatment.

Action taken on failure to return:

Tracking

Professional nurses in the accredited ARV-ANC facilities in Buffalo City Metropole take the following strategies to intervene on patients who fail to return within a month following diagnosis; tracking patients by calling them telephonically; by calling the clinic closest to them; by conducting home visits through task shifting and also by involving internal and external stakeholders.

Clients are called using landlines to remind them to come for comprehensive HIV care. As part of the integration of services local clinics are called and requested to assist in finding the woman. Calling the client and or clinic has been an effective strategy in tracking newly diagnosed, HIV- positive pregnant women who are lost to follow- up. In his study Besser (2008: 9) found out that active client follow- up has increased access to care and treatment.

Secondly, professional nurses promote a decentralisation process, management and continuation of care by the clinic nearest to the patient's residence. During the study five local clinics had been accredited to continue with the follow- up and management of patients. The theme 'Decentralisation' was based on the prescripts of the operational plan for comprehensive HIV and AIDS care, management and

treatment for South Africa (2003). The plan states that 'where access to a district hospital is limited, ARV accreditation may occur at lower level facilities and mobile clinics where the requisite expertise is available'.

Thirdly, professional nurses involve the family and partners, to provide support, encouragement and guidance to the patient on the importance of returning to the clinic for further management and care in order to prevent the transmission of the virus from the mother to the unborn child. Accompaniment is related to the support provided to the patient by either partners, husbands, relatives or treatment supporters. Participants stated that women should be supported by their partners or husbands. If the partner or husband is unable to do so, they prefer close relatives, not friends or children. Involvement of partners has been found to be effective as it promotes access to HIV prevention programmes and instils a positive attitude towards women, http://www.plosmedicine/org=True

Accompaniment also promotes disclosure. Participants noticed that friends are not reliable and when friendship ends there is no treatment supporter and there is a possibility of one's status being disclosed. It was also noted that women brought children to the facilities as their treatment supporters. Children below 13 years of age are regarded as unsuitable treatment supporters. *"They can support one in the facility but not at home."*

Home visits are also done by a midwife accompanied by the doctor and they also liaise with the DOT supporters to assist. Although transport is available in the institution they like to use their own, private transport to minimize the stigma associated with HIV and AIDS. Their cars do not have an HIV/AIDS or Eastern Cape Department of Health emblem. Mukherjee and Eustache (2007: 73-82), reported on similar findings of combining patient tracking with the duties of community health care workers (CHW) who are linked to the patients.

Patient advocates were also used to conduct home visits. Patient advocates are familiar with the women as they are allocated women who live in their vicinity. Patient advocates are CHW who have been trained and are competent to take over some nurses' duties, like home visits and giving HIV and AIDS- related health education.

They are given different names according to the supporting NGO or the work they perform. Some of the names given to them are 'mentor mothers', 'peer educators', 'community liaison officers'. Use of CHW was put in place because of the gross staff shortage in health services (Fraser et al, 2007).

No one strategy is enough to trace a client. One or more strategies may be used for the actions taken to track on non-compliant patients. In Hofstee (2006: 155), it is reported that each system works well with one category of clients in comparison to another.

All these strategies are used to improve treatment compliance and to reduce the emergence of dangerous drug resistance, which has become increasingly difficult and costly to treat HIV and AIDS. These approaches could also be of benefit to the management of other chronic diseases that are of growing importance worldwide, including diabetes, hypertension, and heart failure (Fraser et al, 2007).

Tracking, when used correctly, could help to ensure that women are followed, started and maintained on treatment. It is of importance to note that the best medication and clinical expertise are of limited use if large numbers of patients are lost to the health system. Tracking can also result in other potential benefits, including preventing adverse effects to medication, as well as supporting less experienced healthcare workers in the follow-up of HIV- positive patients (Fraser et al, 2007).

Task shifting

Task shifting is the creation of new, lower cadre posts using a strong community engagement to support the health system. It is about the delegation of duties to a lower category of health workers, in some instances it may be community health workers. Task -shifting has helped to address many health- related problems. Participants felt that community healthcare workers are very helpful in following up on newly diagnosed, HIV-positive pregnant women who fail to return to the facility and also to ease the workload. Another finding was that some of the nurses' duties were delegated to CHW. These duties include health education, HIV counseling, tracking and home visits. Use of task shifting as a strategy to address follow- up is supported by the study, which found that through the use of task shifting the overall utilisation of services doubled though the number of professional nurses had not changed. The number of patients seen per nurse per clinical work day, also increased when compared with the national average of 29.4 (Ford et al, 2006: 19).

Decentralisation

It was proposed in the operational plan (2003) that HIV- treatment must be initiated by almost all primary healthcare facilities. This view was based on the assumption that there will be few women lost to follow -up and that they would access treatment nearer to their homes. In this study the professional nurses contacted the clinic to assist with the follow- up, as clinic staff usually knew where the women live.

During the time of the study, five (5) primary health care facilities were already issuing ARVs. Findings in Goudge (2009: 94-104), confirm that decentralising from hospitals to clinics, and strengthening outreach activities, such as home visits by community health workers would also reduce the cost- burdens faced by households significantly, as well as directly increase access to services.

5.2.3 Challenges encountered with the above strategies

Data revealed that all the strategies used to intervene in non-compliant patients have challenges. Some clients do not respond to the telephone calls. Participants stated that they were given wrong contact numbers. At times the sim card was changed or the phone was lost. Another reason was that some did not respond to 'private telephone numbers'. All public facilities' phones register 'private number' to the recipient. While landlines have shown good results in tracing clients they also pose a problem because many people do not answer private numbers, for personal reasons.

Another challenge is that women do not want to be visited in their homes by officials. When visited they hide and some run away. Sometimes they give wrong addresses. When they are visited in their homes they are not known at those addresses. Some newly diagnosed, pregnant women do not want to attend their local clinics, mainly because of the stigma attached to HIV and AIDS, and also fearing for involuntary disclosure. They prefer to go to faraway clinics for further management and care. Another challenge faced is that many clients are attached to the initial health centres where they have started treatment and do not want to utilize the local clinic because they are concerned about confidentiality.

Negative emotional reactions delay the process of acceptance of the HIV status which may ultimately lead to disclosure. Disclosure is also a process and as long as the client has not disclosed her status it is difficult for her to come regularly to the health facility, especially if she has to bring a treatment supporter.

In one facility there were no more home visits during the study because the supporting NGO had no funds for transport. A contingency measure was not applied by the facility to continue with implementation of nursing care. This does not only affect task shifting, but also the integration of services with external stakeholders. Task shifting has been found to be necessary in addressing the gross shortage of nurses (Ford et al, 2006: 19). There is a need for facilities to put in place a contingency plan, should the supporting stakeholder be unable to continue with agreed- upon services.

5.2.4 Suggestions

Following the participants' responses on action taken on diagnosis; assumptions for reasons for the non- compliance by the patients; the action they take when the patients do not return for further management and care, the researcher requested the participants, due to their experience in this field, to suggest possible interventions to promote compliance by the patients.

Eight (8) themes emerged from the recommendations made by participants. These are: psycho-social support; information- sharing; decentralisation; task shifting; social mobilisation, tracking; socio-economic support, and health advocacy.

5.2.4.1 Theme: Psychosocial support

The findings were that not all HIV- positive clients are psychologically supported as they are afraid to disclose their status to their partners, spouses and/ or parents. Partners and parents were seen as barriers to the access to PMTCT services. Involvement of families, especially the spouse or partner in PMTCT prevention will have multiple benefits to the newly diagnosed, pregnant woman, namely, disclosure; acceptance; support; love and to be able to address issues related to sexual activities and compliance with treatment. It has been stated that disclosure fights and decreases loss to follow- up. It also promotes a trusting relationship (Fraser et al, 2007).

Concerning accompaniment by husbands, partners and close relatives, families were encouraged to support each other and to know each others' status. "*If all families know everyone's status in the family there will be free disclosure.*"

5.2.4.2 Theme: Information- sharing

Although nurses are the first point of contact to offer psychosocial support to clients it has been found out that they are not friendly and they possess poor communication skills. Some clients are afraid to ask for clarity as a result they leave the facility with no understanding of their illness and their concerns not properly addressed. Nurses recommended that they should display a positive attitude at all times and give clear targeted messages to clients. Patient education is of utmost importance in encouraging continuous follow- up care.

5.2.4.3 Theme: Decentralisation

There was also a recommendation that all Primary Health Care clinics should be accredited as ARV sites, so as to address some of the challenges mentioned in relation to the actions taken, namely: socio- economic issues, transport problems and long walking distances. Decentralisation has the potential to promote easy accessibility of health services and to track the patients.

Several clinics are already accredited. Down- referrals have been effected to those clinics. Some of the clinics are busy with the infrastructure whilst others have started

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initiating clients on treatment. Another finding was that the decentralisation process is being implemented in BCM.

5.2.4.4 Theme: Task -shifting

The notion that nurses encourage the training of more health- care workers demonstrates a sense of appreciation for their contribution. There are many benefits related to having healthcare workers in the facility. Apart from tracking, they assist with psycho-social support that they offer to newly diagnosed, pregnant women; health education; information- sharing and imparting some practical skills to the patients. This provides nurses with more time to perform clinical responsibilities.

5.2.4.5 Social mobilization

Social mobilization has been found to be essential when different outreach programs are implemented to address different issues. Outreach programs suggested include school visits to address issues like abstinence, family –planning and teenage pregnancy and door- to- door campaigns to obtain views of families related to their healthcare needs. There was a cry for more outreach to the community which indicates that although they are done, many are limited to the facilities.

Participants felt that their communities should be involved in HIV- related matters even if it is during their social events (funerals), addressing issues like HIV services available; revised PMTCT and Child health policy. Below statements speaks to this point.

"Our communities lack this information"

"Because sometimes they do not know what is the difference".

Besides health, outreach programmes are also linked to other programmes, such as social services and school health services.

5.2.4.6 Theme: Tracking

Home visits as a strategy still proved to be effective over the years. They have been used to address issues related to TB. Home visits by nurses were recommended not knowing that it is practiced in other areas. *"We also need to go to the long ago procedures, visit them at home though it is impossible because of staff shortage and stigma attached".*

5.2.4.7 Socio-economic support

Socio-economic support is a barrier to newly diagnosed, HIV- positive, pregnant women and to the health service. A poor transport system, *("They don't have transport to come here. They are walking"*) poor infrastructure and lack of resources all contribute to lack of funds. The finding from this theme proves that there is need for more funds in order to offer qualitative HIV care.

5.2.4.8 Health advocacy

The data revealed that not all nurses possess the current knowledge about the new developments related to HIV and AIDS. Participants suggested that those who are not working in the field should not give advice to patients, as their knowledge in the field may be outdated. The phenomenon of HIV and AIDS is quite dynamic mainly because of newness of the condition, the absence of a cure and the mutation of the virus. This shows that there is a need for all professional nurses to be subjected to on-going training courses about the new developments in HIV and AIDS.

Some suggestions were contradictory to the statements given earlier, for example, decentralization to local clinics, might be affected by the following statement, e.g. "but they don't attend there they want to attend here, … it is these rights of theirs." "P.A's are not welcomed in some homes".

Another suggestion was to bring a parent, husband, or partner as a treatment supporter and also to disclose to them,

for example:

..."But they are afraid to disclose"

"I do not want to";

"I am sure they are not used to it and we need to emphasise that when educating."

PMTCT guidelines explain that women enrolled in the PMTCT and/or HAART programmes need more frequent follow- ups. Women should be given a two-week follow- up date after their CD4 cell count has been taken. Each health facility should have a mechanism in place to follow- up on CD4 cell count results from the laboratory, and to discuss results with clients and trace women who do not return for results.

A reduction in HIV transmission rate is achievable using regimens containing dual- or triple-drug combinations. Decisions around supporting women's choices of infant feeding to avoid mixed feeding and reducing MTCT need to be made during pregnancy. The HIV- disease should be prioritized to initiate HAART at any stage of pregnancy. If an HIV- infected, pregnant woman is not followed up all these will be impossible to achieve.

5.3 Summary of contributions

Nurses play a key role in fighting loss to follow- up of newly diagnosed, HIV- positive, pregnant women. No one strategy will be sufficient for every newly diagnosed, HIV- positive woman. At times one or two may be used simultaneously, more especially with regard to reducing the negative impact of HIV transmission during pregnancy and childbirth.

5.4 Further research

The results of this study imply that research in the field on non- compliance with the treatment regimen by HIV- positive, pregnant women needs to be ongoing to control and prevent MTCT. Non- compliant, pregnant women are one of the contributory factors to the increase in MTCT during pregnancy and during childbirth. Such non-compliance also compromises the health of the woman.

5.5 Recommendations

Recommendations based on the results of this study, are that professional nurses need to reinforce the current strategies used and devise means to address the related challenges. They need to strengthen HIV- testing and counseling services so that newly diagnosed HIV- positive pregnant women return voluntarily without being traced or tracked.

When reporting on an HIV and AIDS programme, with a special focus on PMTCT, reporting on Pre-ART defaulting should be encouraged to ensure retention in care between testing and ART (Kranzer, Zeinecker Ginsberg, Orrell, Kalawe, Lawn, Bekker, and Wood, 2009). This could be one of the indicators reported for PMTCT.

5.6. CONCLUSIONS

In conclusion, the findings of this study had shown that professional nurses working in the accredited ARV-ANC facilities need to devise guidelines for intervention to promote compliance with treatment regimens by patients immediately on confirmation of the HIV- positive status. The themes identified need to form the basis of the guidelines. The broader benefit of this intervention is the possibility of reducing the Mother-to-Child Transmission of the Human Immune Virus (HIV).

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APPENDIX A : UNIVERSITY OF FORT HARE RESEARCH & ETHICS COMMITTEE CLEARANCE CERTIFICATE



Application for clearance from the University of Fort Hare's Ethics Committee

Project Title: Strategies used by professional nurses to manage newly diagnosed HIV positive pregnant women who fail to return within a month for further management and care.

Chief Researcher: JAMA NONTEMBISO MARY

Supervisor/co-supervisor: Dr N Tshotsho / N. Nkutu

Date of application: 29 May 2009

Having consulted the Dean of Research, I hereby grant permission to conduct the

research.

Professor J R Midgley

Deputy Vice-Chancellor: Chairperson of the interim Ethics Committee

APPENDIX B: APROVAL LETTER FROM DEPARTMENT OF HEALTH



Eastern Cape Department of Health

Enquiries:	Zonwabele Merile	Tel No:	040 608 0830	
Date: e-mail address:	22th June 2009 zonwabele.merile@impilo.ecprov.gov.za	Fax No:	043 642 1409	

Dear Ms NM Jama

Re: The action taken by nurses to follow up newly diagnosed HIV infected pregnant mothers who do not avail themselves for continuity of care within a month's period, in accredited facilities for Anti Retroviral Therapy (ART) in Buffalo City Sub-District

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

- 1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
- 2. You are advised to ensure observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants. You will not impose or force individuals or possible research participants to participate in you study. Research participants have a right to withdraw anytime they want to.
- 3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
- 4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
- 5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT



APPENDIX C: APPROVAL LETTER FROM EAST LONDON HOSPITAL COMPLEX



EAST LONDON HOSPITAL COMPLEX

Frere Hospital, Amalinda, Private Bag/Ingxowa Eyodwa X 9047, East London, 5200 South Africa • Tel: (043) 709 2135 • Fax: (043) 709 2443 • Website: www.ecdoh.gov.za

INTERNAL MEMORANDUM

To:	Ms. J. Nontembiso; Post Graduate MCur Student, Fort Hare University	
From:	Dr. Z. Jafta; Acting Director Clinical Governance, ELHC	
CC:	Mrs. T. Mguli; Deputy Director, Nursing Services Frere Hospital Mrs. D. Sixishe; Deputy Director, Nursing Services CMH	
Subject:	Request for Research: Follow up by Nurses on Newly Diagnosed HIV infected pregnant mothers	
Date:	5 November 2009	

Your correspondence dated 14 September 2009 refers. Your request to conduct a Research Project (Follow up by Nurses on Newly Diagnosed HIV infected pregnant mothers) has been approved.

It is requested that a copy of the completed analysis be submitted to this office for record purposes.

You can liaise with the following people to coordinate the research:

- 1. Mrs. Mguli at Frere Hospital, her contact details are: Tel: (043) 709 2786
- 2. Mrs. Sixishe at CMH, her contact details are: Tel: (043) 708 2113

Regards,

Dr Uafta Z

Acting Clinical Governance Director: ELHC Nmp/cjr

United in achieving quality health care for all

Ramva eligagambileyo!

24 hour call centre: 0800 0323 64 Website: www.ecdoh.gov.za

APPENDIX D: PERMISSION LETTER FROM BUFFALO CITY SUB DISTRICT MUNICIPALITY



Thank you.

DM LUSASA

15/08/2011

DATE

BUFFALO CITY SUB-DISTRICT MANAGER

APPENDIX E: CONSENT FORM

Exploration of strategies used by nurses to manage newly diagnosed HIVpositive pregnant women who fail to return for further management and care

Consent to be a Research Participant

Introduction

This research study is being conducted by Nontembiso Jama, a student at University of Fort Hare, and her supervisor Dr. Tshotsho, to learn more about strategies used by nurses to newly diagnosed HIV- positive pregnant women who do not return within a month following diagnosis, in Buffalo City Municipality.

Procedure

If you agree to participate:

The interview will be audio taped to ensure accuracy in reporting statements.

The interview will take place at a time convenient to you.

The total time commitment will be approximately 30 minutes.

Risks/Discomfort

There are minimal risks for participation in this study. However, you may feel some discomfort when answering questions or when audio recorded. If you feel embarrassed about answering a question, you may choose to decline or excuse yourself from the study.

Benefits

There will be no direct benefits to you. However, it is hoped that through your participation researchers will learn more about strategies for and what can be done to help you in the decision making process.

Confidentiality

All data will be stored on a password-locked computer for the duration of the study, and only the researcher will have access to it. Upon completion of the final report, all data (recorded and written) will be destroyed. No names or identifiers will be used in any article of this data.

Participation

Participation in this study is voluntary, although all participants must be over 18 years of age. You have the right to withdraw at anytime or refuse to participate entirely.

If you have any questions regarding the study you may contact: nontembiso@yahoo.com/072 123 1569

Signature:

Date:

APPENDIX F: INTERVIEW GUIDE: EASTERN CAPE 2011

Exploration of strategies used by nurses to manage newly diagnosed HIVpositive pregnant women who fail to return for further management and care

Section 1:

Action taken on diagnosis

1.1 What are the services available in your facility for the pregnant women testing HIV- positive for the first time?

1.2 What information you give to them after they have been diagnosed HIVpositive for the first time?

 Section 2

Action taken on failure to return

2.1 What action do you take if a newly diagnosed pregnant woman does not come back within a month for further management and care?

2.2 What do you think are the reasons why women are not coming back?

3. What do you recommend to get clients back within a month after diagnosis?

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4. Is there any other thing that you would like to add?