

**BEST PRACTICE GUIDELINES FOR
COUNSELLING FOR HIV TESTING DURING
PREGNANCY**

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ABBREVIATIONS

AIDS	Auto Immune Deficiency Syndrome
ANC	Antenatal care
ARV	Antiretroviral treatment
BPG	Best practice guideline
DoH	Department of Health
EBP	Evidence-based practice
HIV	Human Immuno Deficiency Virus
MTCT	Mother to child transmission
PMTCT	Prevention of mother to child transmission
VCT	Voluntary counselling and testing
WHO	World Health Organization

ABSTRACT

The 2005 National survey indicates that 30,2 % of South African pregnant women are HIV positive. The risk of transmission to their infants is about 30% unless prevention interventions are applied. The *Nevirapine* regime, safe intrapartum practices and safe infant feeding methods could limit the risk of mother-to-child transmission to 7%. Antiretroviral treatment is available to women who can afford it and women who qualify for subsidised medication. However, HIV positive women and their infants can only benefit from these strategies when their HIV status is known. Yet only about 50% of pregnant women consent to HIV testing after counselling. Contextual factors, organisational circumstances and pregnant women's personal circumstances determine whether they are tested.

This research aimed to develop best practice guidelines for pre-test counselling during pregnancy. This was achieved through four objectives: exploring and describing the factors that influence pregnant women's decision to be tested in selected antenatal clinics in the North West Province, identifying the factors that influence HIV counselling during pregnancy according to counsellors who practice in these clinics, exploring the current practices regarding counselling for HIV testing during pregnancy in the selected clinics, investigating research evidence regarding counselling for HIV testing during pregnancy by means of systematic review and finally developing best practice guidelines for counselling for HIV testing during pregnancy.

The research followed specific steps that consisted of two phases. Phase 1 was subdivided into four steps that related to the first four objectives and compiled evidence towards formulating best practice guidelines in phase 2. Data-collection methods included semi-structured interviews, semi-structured observation and a systematic review.

Phase 1's conclusions were integrated and synthesised as base for developing best practice guidelines in Phase 2. These guidelines were graded and recommendations for implementation were formulated. Finally, the research was evaluated, limitations were identified and recommendations were formulated for nursing practice, -education and -research.

UITTREKSEL

Volgens die 2005 nasionale opname is 30,2 % van swanger vroue in Suid Afrika MIV positief. Indien geen voorkomende stappe geneem word nie, is die risiko van moeder na baba oordrag omtrent 30%. Die *Nevirapine* regime, veilige intrapartumpraktyke en aanpassing van babavoedingswyse kan die risiko van oordrag beperk tot omtrent 7%. Vroue wat dit kan bekostig of wat kwalifiseer vir gesubsideerde medikasie, kan ook voordeel trek uit antiretrovirale behandeling. HIV positiewe vroue en hul babas trek slegs voordeel uit hierdie strategieë as hulle MIV status bekend is, maar slegs ongeveer 50% van swanger vroue stem in tot MIV toetsing na berading. Omgewingsfaktore, organisatoriese omstandighede en 'n swanger vrou se persoonlike omstandighede bepaal of sy 'n MIV-toets ondergaan.

Die doel van hierdie navorsing was om riglyne vir beste praktyk te ontwikkel vir berading vir MIV toetsing gedurende swangerskap. Die doel is bereik deur die ondersoek en beskryf van die faktore wat swanger vroue se besluit om getoets te word beïnvloed in geselekteerde voorgeboorte klinieke in die Noordwes Provinsie; die faktore wat die berading vir MIV toetsing gedurende swangerskap beïnvloed volgens die beraders werksaam in die geselekteerde klinieke; die huidige praktyke betreffende berading vir MIV toetsing gedurende swangerskap in hierdie klinieke en die navorsingsbewyse betreffende MIV toetsing gedurende swangerskap deur 'n sistematiese oorsig ten einde riglyne vir beste praktyk van berading vir MIV toetsing gedurende swangerskap te ontwikkel.

'n Stapsgewyse navorsingsontwerp bestaande uit twee fases is gebruik. In Fase 1 is bewyse versamel vir gebruik in fase 2 se riglynformulering. Fase 1 is onderverdeel in vier stappe wat verband hou met die eerste vier doelwitte. Semi-gestruktureerde onderhoude, observasie en 'n sistematiese oorsig is gebruik as data-insamelingsmetodes. Fase 1 se konklusies is geïntegreer en gesintetiseer as basis vir die ontwikkeling van die riglyne vir beste praktyk riglyne in Fase 2. Hierdie riglyne is gegradeer en voorstelle vir implimentering geformuleer. Ten slotte, is die navorsing geëvalueer, leemtes is geïdentifiseer en aanbevelings vir die verpleegpraktyk, -onderwys en -navorsing geformuleer.

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CHAPTER 1

GROUNDING OF THE RESEARCH

1.1 INTRODUCTION

The aim of this study was to develop best practice guidelines for counselling for HIV testing during pregnancy. Chapter one provides an overview of the study. This chapter starts with the background and problem statement in which the problem that inspired this study is discussed. The aims and objectives of this study flow from the problem statement. The objectives are followed by the meta-theoretical, theoretical and methodological assumptions. An outline of the research design and research method as well as rigour, ethical considerations and research report layout conclude Chapter one.

1.2 BACKGROUND AND PROBLEM STATEMENT

HIV/AIDS is one of the most serious health crises that modern man has yet been confronted with. An estimated 39.5 million people worldwide (Avert, 2006) and 5,54 million in South Africa (Department of Health (DoH), 2006:17) have already been infected. In South Africa, current figures indicate that 30,2% of pregnant women are infected (DoH, 2006:11). When pregnant women are infected their own lives and the lives of their unborn babies are at risk. According to the World Health Organisation (WHO) 700 000 babies are infected annually (WHO, 2007).

As much as one third of the babies who are infected through mother-to-child transmission, die within one year of birth (Spira *et al.*, 1999:1118) and 75% of babies whose mothers did not receive antiretroviral medication, die before the age of five (Olayinka *et al.*, 2000:316). During their short lifespan, HIV-infected babies and children suffer from conditions such as pneumonia, meningitis, septicaemia, abscesses, tuberculosis and chronic diarrhoea (Woods, 1999, Unit 34:10).

The report of the findings of the evaluation of the pilot project of the National Prevention of Mother-to-child transmission (PMTCT) programme (McCoy *et al.*, 2002:24), indicates that the implementation of strategies based on research findings have made it possible to limit mother-to-child transmission to a large extent. The *Nevirapine* regime, as it is presently used in South African state hospitals, reduces the risk of vertical transmission (during pregnancy and labour) from 23% to 13% (McCoy *et al.*, 2002:26). According to these authors, the risk of transmission during pregnancy is 7%. Additionally, the regime reduces the risk during the

birth process from 16% to 6%. Adapting the method of feeding that the baby receives can limit the risk even further. In their groundbreaking study, Coutsooudis *et al.* (1999:474) concluded that baby feeding that consists exclusively of milk formula or breast milk limits the risk of transmission to 17% in both groups (the percentage infected during the pregnancy or the labour process). In contrast, babies who receive a combination of breast milk and other fluids or solids run a transmission risk of 24%.

Initially, strategies merely focused on the prevention of mother-to-child transmission. This research focus is increasingly shifting towards strategies that would support the HIV positive pregnant woman (UNICEF/UNAIDS/WHO/UNFPA, 2000:5). According to Bernstein (2002), the emphasis in the developed countries has shifted from the care of terminal AIDS patients to treating HIV/AIDS as a chronic condition. Lifestyle adjustments and a healthy diet could enable women to stay healthy for longer – the concept “Living well with Aids”. Women, who can afford it and those who qualify for the subsidised treatment of the Department of Health, can benefit from antiretroviral treatment (which aims to promote the woman’s own health and not just prevent transmission to the baby). As the South African government’s antiretroviral therapy programme becomes more accessible, more women who qualify will also use the medication during pregnancy– provided that their HIV status is known.

However, according to the report of the interim findings of the pilot sites where the Prevention of mother to child transmission (PMTCT) programme was first introduced in South Africa, only 51% of the pregnant women who used the health services at these pilot sites were tested for HIV (McCoy *et al.*, 2002:45). In the research for my master’s degree in the Potchefstroom district of the North West Province, only 55,9% of the women indicated that they were tested for HIV during pregnancy (Minnie, 2003:143). Buch *et al.*, (2003:26) found that an HIV test was offered to 89% of the women who attended the antenatal clinics in the regional hospital in KwaZulu-Natal where they did their research. Seventy-two (72%) percent of the women gave their consent to be tested, 88% of this group returned for their results and 93% of the last-mentioned group eventually received their test results. Although a large percentage of the women had the opportunity, and was indeed tested, Buch *et al.* (2003:27) concluded that the cumulative effect of all the lost opportunities brought about that the HIV status of 14,8 % of the women who attended the antenatal clinic, was not known by the time of their babies’ births. Considering that an estimated 30,2% of pregnant women in South Africa are HIV positive (DoH, 2006:11), a large number of women and their babies do not benefit from the strategies available for preventing mother-to-child transmission and promoting the health of HIV positive woman. The question arises why do pregnant women decide not to be tested for HIV, when counselling is available and when knowing their status holds obvious benefits for themselves and their babies.

Contextual factors, organisational circumstances and a pregnant woman's personal circumstances determine whether she is tested for HIV. Novello *et al.* (2000:401) as well as Mosen *et al.* (1998:626) found that women are more inclined to be tested if they have access to medical care — in this case antiretroviral treatment. It can be expected that more South African women would be willing to be tested as antiretroviral therapy becomes more available and accessible. Other strategies that could be used to encourage women to be tested include the use of rapid tests (Nkohma *et al.*, 2004). Additionally, couples could be counselled and tested together (Painter, 2001:1402). The way in which counselling and practice is executed, will certainly contribute to a woman's decision to be tested or not (Beevor & Catalan, 1993:183). However, Skinner *et al.* (2004) point out that even when service providers display the best intentions and dedication, practical and social obstructions could lead to women not making use of PMTCT services.

Although it may seem evident that it is beneficial for a woman (and her baby) if she is aware of her HIV status, she does not necessarily experience it as such. A large number of women refuse to be tested. Some of the reasons that were raised by women in the USA were fear of a positive result, potential violent reactions from their partners, and fear of stigmatisation and discrimination (Aynalem *et al.*, 2004: 29; Parra *et al.*, 2001:89). Some also display a lack of knowledge regarding the implications of testing positive (Sanne & Smego, 1998:39). Parra *et al.* (2001:92) add that some women experience denial about a possible infected status and a fatalistic attitude. In Kenya, 15% of the women did not consider it to be beneficial, as it would lead to depression since AIDS is incurable (Gaillard *et al.*, 2000:334).

The HIV/AIDS policy guideline of the national Department of Health regulates counselling for HIV testing during pregnancy (DoH, 2000a:11-12). This policy is worded broadly and specific guidelines regarding counselling for HIV testing are not available.

The Department of Health's strategic plans regarding HIV and AIDS also identified the need for guidelines. In the 2000-2005 HIV/AIDS/STD Strategic plan for South Africa one of the selected strategies to improve access to HIV testing and counselling in ANC clinics was to develop counselling guidelines (DoH, 2000b:20). These guidelines have not yet been developed as it is again planned for in the HIV and AIDS and STI strategic plan for South Africa, 2007-2011 (DoH, 2007:64). This research project can contribute towards addressing this need.

The complexity of this problem in which both contextual and human factors play a role (with regard to the health workers and the pregnant women) is acknowledged. The influence of

factors such as stigmatisation and the subordinate position of the woman in society cannot be changed without a paradigm shift in the community. If changes in the community do indeed take place causing women to be more willing to be tested, practices must be effective to ensure maximum benefit for the women. Organisational factors that influence both the pregnant woman and the counsellor can be adjusted and are addressed in the best practice guidelines.

The figure below presents the field of investigation and the focus of the study schematically.

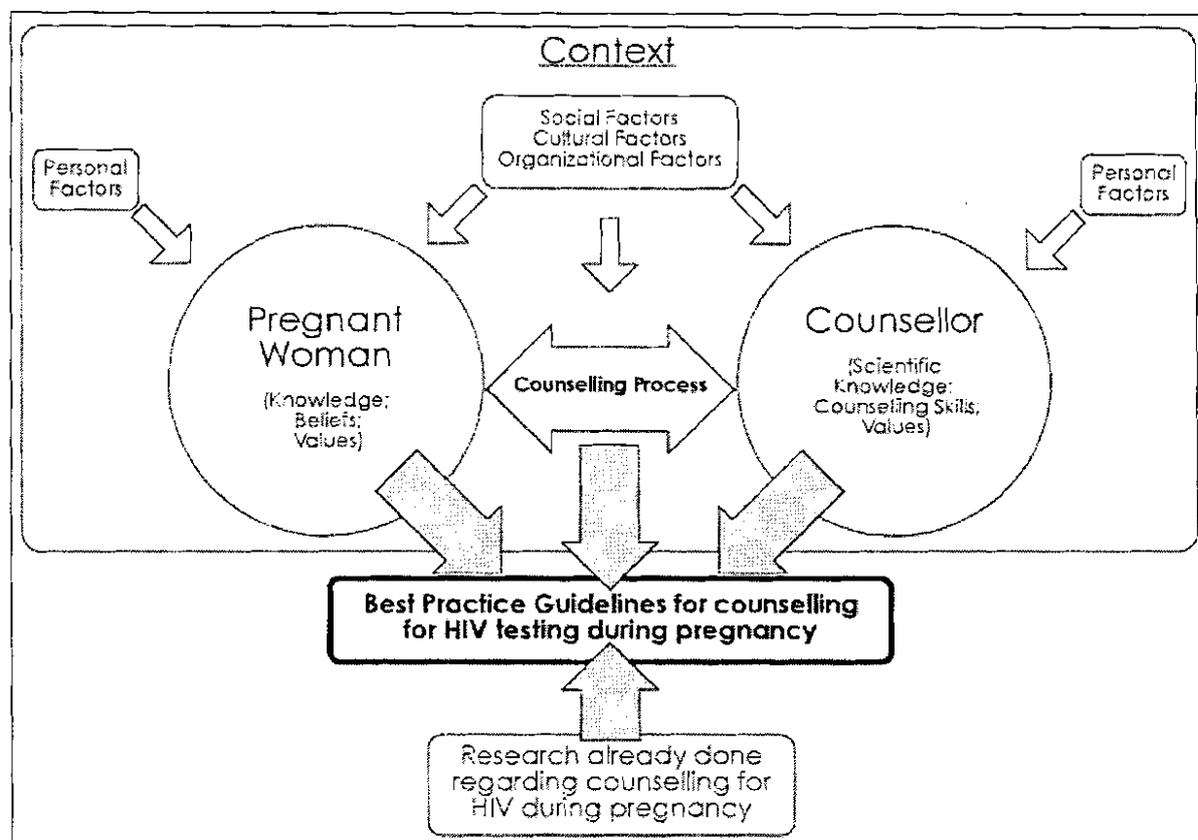


Figure 1.1: Schematic presentation of the field of investigation and the focus of this study

The field of study firstly addresses the context in which the counselling for HIV testing during pregnancy occurs. Certain factors that form part of the context (social, cultural and organisational factors) influence both the role-players and the counselling process. The two main role players in the counselling process are the pregnant woman and the counsellor. The pregnant woman's personal considerations when deciding whether or not to be tested for HIV play an important role in the question as to why so many women's status is not known. This counsellor, who could be the midwife who provides the antenatal care or a specifically trained lay counsellor who works under the midwife's supervision, is the expert regarding factors that influence the counselling and is also affected by personal factors.

The results of past research (not part of the context) will provide the base (enriched by knowledge of the factors already mentioned) for the best practice guidelines for counselling for HIV testing during pregnancy (see Figure 1.1).

The problem statement can be formulated as follows: A large number of HIV positive women and their babies who do not benefit from PMTCT strategies and antiretroviral treatment because the women do not give their consent to be tested. The quality of counselling for testing for HIV testing during pregnancy seems to be problematic.

The following research questions arise from the problem statement and supporting literature:

1. What are the factors that influence a pregnant woman's decision to be tested for HIV in antenatal clinics in the North West Province?
2. What are the factors that influence counselling for HIV during pregnancy according to the counsellors who practice in antenatal clinics in the North West Province?
3. What are the current practices regarding counselling for HIV testing during pregnancy in antenatal clinics in the North West Province?
4. What evidence exists concerning the strategies to promote counselling for HIV testing during pregnancy?
5. What should best practice guidelines for counselling for HIV testing during pregnancy entail?

1.3 RESEARCH AIM, OBJECTIVES AND CENTRAL THEORETICAL ARGUMENT

To answer the above research questions, the aim of this study is to develop best practice guidelines for counselling for HIV testing during pregnancy.

This aim will be achieved by means of the following objectives:

- To explore and describe the factors that influence pregnant women's decision to be tested for HIV in selected antenatal clinics in the North West Province;
- To explore and describe the factors that influence the counselling for HIV testing during pregnancy according to counsellors who practice in selected antenatal clinics in the North West Province;
- To explore and describe the current practices regarding counselling for HIV testing during pregnancy in selected clinics in the North West Province;

- To explore and describe the evidence regarding counselling for HIV testing during pregnancy by means of systematic review; and
- To develop best practice guidelines for counselling for HIV testing during pregnancy.

The central theoretical argument is as follows:

Everyone should be aware of their HIV status. This knowledge is vital during pregnancy as it is a critical period when mother-to-child transmission of HIV can be limited effectively. The aim of HIV testing during pregnancy is to prevent mother-to-child transmission whilst respecting the woman's rights and health.

Best practice guidelines based on evidence from practice and a systematic review, may lead to an increase in women whose status is known when their babies are born. This could enable them to benefit from strategies that would improve their own health and prevent mother-to-child transmission, should they be found to be HIV positive. Women who test HIV negative could also benefit from this knowledge as they could take steps to ensure that their status remains negative.

1.4 RESEARCHER'S ASSUMPTIONS

The explicit statement of the researcher's assumptions is important as it provides a point of departure for the research. This ensures clear communication between the researcher and the reader. Meta-theoretical, theoretical and methodological assumptions are stated.

1.4.1 Meta-theoretical assumptions

According to Mouton and Marais (1994:192) meta-theoretical assumptions are non-epistemic statements that are not intended to be tested. The argumentative nature of scientific communication demands that these assumptions are stated explicitly.

1.4.1.1 Religious view

The researcher uses a Christian worldview as departure-point. I believe God is in charge of the universe and He wants the best for His children. Although the world was created perfectly, man corrupted it through sin. The only way this corrupted state can be corrected is through Jesus Christ as saviour. As God is in charge He can use suffering to do well. The purpose of suffering could be to turn man to Him as saviour and to use a person who suffers as testimonial for Him to reach others.

As the researcher is also a sinner, in a sinful world, concepts such as the suffering of little children infected by their HIV-positive mothers are difficult to accept. Through this research I make myself available as an instrument in His hand to contribute to limit suffering in the world by promoting HIV testing during pregnancy through the development of best practice guidelines.

1.4.1.2 View of man

The researcher sees a person (in this study a pregnant woman, midwife or counsellor) as a holistic being. Each human being consists of physiological, psychological, social and spiritual dimensions.

Possible infection with the HI-virus influences, amongst other aspects, a pregnant woman's physiological dimension. Symptoms that she may experience due to her pregnancy or the infection and the possible transmission of HIV to her unborn child are aspects of the physiological dimension. If the best practice guidelines, as developed in this study, are implemented successfully, the woman and her baby's physical well-being can be restored and promoted.

The decision to be tested for HIV is influenced by all the dimensions that comprise the pregnant woman. She uses rational thinking (intellectual dimension) based on her understanding of information given by the counsellor, her own experience and information gained from other sources to make the best choice for her. She may experience psychological stress and various other emotions when taking this decision. Her maturity and self-assertiveness skills will also play a role. The counsellor uses her intellect during the counselling process and may also be influenced by emotional issues.

As a social being, the pregnant woman who has to decide whether to be tested for HIV forms part of a family as well as a community. The pregnant woman will consider the possible reaction of her partner, immediate family and the larger community to a potential HIV infection diagnosis, when making her choice. The reality that she may experience stigma cannot be ignored. Another aspect of the social dimension is her membership of a cultural group that has unique characteristics.

The spiritual dimension includes the possibility of anger against God or feelings of guilt for possibly being the cause her unborn child's infection. I believe, similar to the findings of Bodkin (2004:207) that women who are HIV-positive may bargain with God for the lives of their children.

1.4.1.3 View of society

I believe that society causes women to be more susceptible to HIV infection. The vulnerability and disempowerment of women, makes it very difficult for a woman of poor socio-economic status to demand safe sex or to disclose an HIV positive diagnosis to her partner. Her perception of powerlessness can cause her not to consent to HIV testing as she may not view getting tested as beneficial.

The importance of society's role in the management of HIV/AIDS is acknowledged by accepting that many women would continue to deny testing if their role in society is not changed. The public as a whole need to be educated about the importance of determining a woman's HIV status before her baby is born.

1.4.1.4 View of health

I agree with the World Health Organization definition (WHO, 1946) that health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. However, I also believe that health and illness could be viewed on a continuum where the health of a specific individual at a specific time can be represented on a line that ranges from maximum health to minimal health (health). The different dimensions of health (physical, mental, social and spiritual) are not necessarily at the same level and it is possible that someone can experience relative good health in one dimension yet experience severe 'unhealth' in some of the other dimensions.

In this research project the focus is on promoting HIV testing during pregnancy. If a woman's HIV status is known, her own as well as her fetus/baby's physical health can be promoted more efficiently. Her mental or social health may however suffer as she may fear a possible positive diagnosis. If she tests HIV negative her physical and psychological well-being would probably be enhanced as she would feel relieved and motivated to remain HIV negative by following a healthy life-style. When testing HIV positive, she may initially be shocked but could eventually accept her status and feel relieved to be able to plan for her future. She may also experience depression, while still being physically healthy.

The midwife's role is viewed as that of facilitator in the promotion of optimal health during the time when a family adapts to the arrival of a newborn member. In order to provide the best possible care, (facilitation), she needs all the relevant information that may influence her practice. Part of the information that she needs to practice optimally, is knowledge of a pregnant woman's HIV status. This information is partly gained by encouraging HIV testing

during pregnancy. The midwife practices in a specific context that is subject to specific external and organisational conditions. As the midwife she must always consider the woman's total wellbeing, encouraging the woman to undergo an HIV test should never sacrifice her psychological and social wellbeing. Best practice guidelines that consider all these above aspects, would enable the midwife to fulfil her role.

1.4.2 Theoretical assumptions

The theoretical assumptions include models and theories used in the study and definitions of the concepts that are central to this research's field of study.

1.4.2.1 Model

Only one model was found to be applicable to this study.

- **The JBI model of evidence-based healthcare**

The JBI (Joanna Briggs Institute) model of evidence-based healthcare conceptualises evidence-based practice as clinical decision-making that considers the best available evidence; the context in which the care is delivered; client preference and the health professional's judgement (Pearson *et al.* 2005:209). According to the authors, the traditional process of evidence-based practice should be placed within a broader context. Such a context should be grounded in practice, recognise different evidentiary bases, incorporate understandings of knowledge transfer and utilisation, and should be directed towards improving global health across vastly different practice contexts (Pearson *et al.*, 2005:207).

The authors conceptualise the components of evidence-based health care as a cyclic process that includes Healthcare evidence generation, Evidence synthesis, Evidence / knowledge transfer and Evidence utilisation (See Figure 1.2).

Each component includes essential elements. *Healthcare evidence generation* refers to healthcare interventions or activities (the FAME criteria – feasibility, appropriateness, meaningfulness and effectiveness) as well as the methods of utilisation. *Evidence synthesis* refers to theory, methodology and systematic reviews. *Evidence /knowledge transfer* refers to education, information and systems. *Evidence utilisation* refers to the evaluation of the impact on the system, process or outcomes, practice change and organisational change.

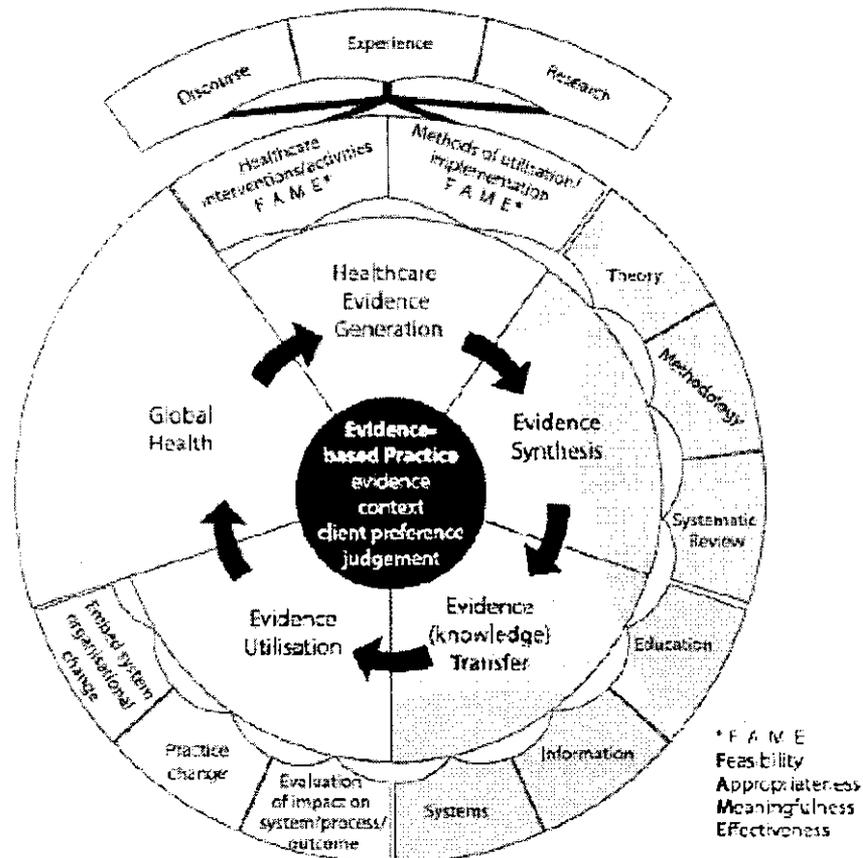


Figure 1.2 Conceptual model of evidence-based healthcare (Pearson *et al*, 2005:209)

In this research, the evidence generation originates from findings of the different steps followed regarding the practice of counselling for HIV testing that occurs in antenatal clinics. Pearson *et al.* (2005:210) defines evidence as the basis of belief and the substantiation or conformation required to believe that something is true. They include discourse, experience and research as legitimate means of evidence generation (Pearson *et al.*, 2005:210). This model regards any indication that a practice is feasible, appropriate, meaningful or effective (FAME) as a form of evidence.

The theory on which the research is based, the methodology that is followed and the systematic review conducted are discussed in detail in this and following chapters to explore the evidence. In the systematic review, the researcher follows a pluralistic approach as advocated by Pearson *et al.* (2005:211). In such a review, results from quantitative and qualitative research studies as well as expert opinion are acknowledged as legitimate forms of evidence. Since the studies reviewed and appraised differ in approach, method, focus and context, results were not combined in syntheses but were formulated as conclusion statements and combined with the findings of the empiric research steps to develop best practice guidelines.

This research project addresses evidence (knowledge) transfer by publishing journal articles and presenting papers at scientific conferences. Seminars and workshops to the policy-makers and practitioners who are directly involved are also planned to transfer the knowledge generated. This study does not address evidence utilisation directly. Instead, multiple interventions are planned as post-doctoral activities. These interventions will be implemented and evaluated.

In the following section, the researcher discusses the operationalised definitions of concepts used in this research project.

1.4.2.2 Discussion of concepts

The key concepts and their application in this research project are discussed.

- **Counselling for HIV testing**

Counselling can be defined as a process of helping someone to use information, make a decision and plan to solve or cope with a problem. For the purpose of this research, the focus is counselling that assists the pregnant woman in making a decision to be tested for HIV or not. Counselling for HIV testing involves transmission of information as well as provision of support. Related concepts are pre-test counselling and voluntary counselling and testing (VCT).

- **HIV testing**

HIV infection is diagnosed if antibodies against the HI virus are detected in bodily fluids – usually blood. HIV testing can be offered in different ways.

Richter (2006:40) compared four different models of HIV testing:

- A. Voluntary testing and counselling (VCT);
- B. Diagnostic (or symptom-responsive) HIV testing;
- C. Routine offer of HIV-testing by Health Care Providers
- D. Mandatory testing

The two types mostly associated with HIV testing during pregnancy are VCT and routine offer of HIV-testing by Health Care Provider. Model B is more applicable for patients who are already symptomatic and not associated with routine antenatal care, while Model D is usually discouraged and only allowed in cases like organ donation.

VCT (Model A) is described as client-initiated and contains pre- and post-test counselling. Pre-test counselling can be provided in a group situation, but post-test counselling is recommended on an individual basis. The special safeguards (3 C's) are intended to protect people with HIV and serve the inner fears and dread of people (Richter, 2006:14). People may shy away from being tested because the requirements relating to consent and counselling accentuate the differentness, distinctness and horror of AIDS – reinforcing stigma. Model A is the most common model used in South Africa - also in the clinics where the study was executed.

Routine offer of HIV-testing by Health Care Providers (Model C) occurs when a routine offer of an HIV-test is made to all patients who have a sexually transmitted infection, who are pregnant and who visits health facilities where HIV prevalence levels are high and ARV's available. The conditions of counselling, consent and confidentiality (3 C's) are applied, but counselling only includes limited information to warrant informed consent.

According to Richter (2006:13) Model A is considered a form of 'opt-in' testing, model C can be divided in 'opt-in' routine testing and 'opt-out' routine testing, where the former includes an offer of an HIV-test that the client must actively consent to, while the latter assumes the client accepts the test unless explicitly declining.

The World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) is presently busy investigating Provider-initiated Testing and Counselling (PITCT) similar to Richter's Model C (WHO & UNAIDS, 2006). In this model, pre-test counselling is modified with the aim of providing basic information to obtain informed consent. Consent for testing is assumed unless the patient expressly declines the test, and written consent is not required. Counselling is done when the test results are relayed to the patient in the form of post-test counselling (Richter, 2006:22).

Richter (2006:23) indicates the necessity of proper training of health workers when implementing the new model as the risk for cohesion and violation of human rights is greater with this model.

- **Evidence-based practice**

Evidence-based practice developed from evidence-based medicine (EBM) and was originally defined as “conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. Evidence-based medicine means

integrating "individual clinical expertise with the best available external clinical evidence from systematic research" (Sackett *et al.*, 1996:71). The definition was later adjusted to "the integration of best research evidence with clinical expertise, and patient values" (Sackett *et al.*, 2000:1)

In the latest definitions, four aspects are considered when deciding on the best practice:

- research evidence,
- clinical expertise,
- the patients values, preferences and individual circumstances, and
- the context of the situation in which decision needs to be taken (Haynes *et al.*, 2002: 384).

The relationship between the different aspects can be represented as follows.

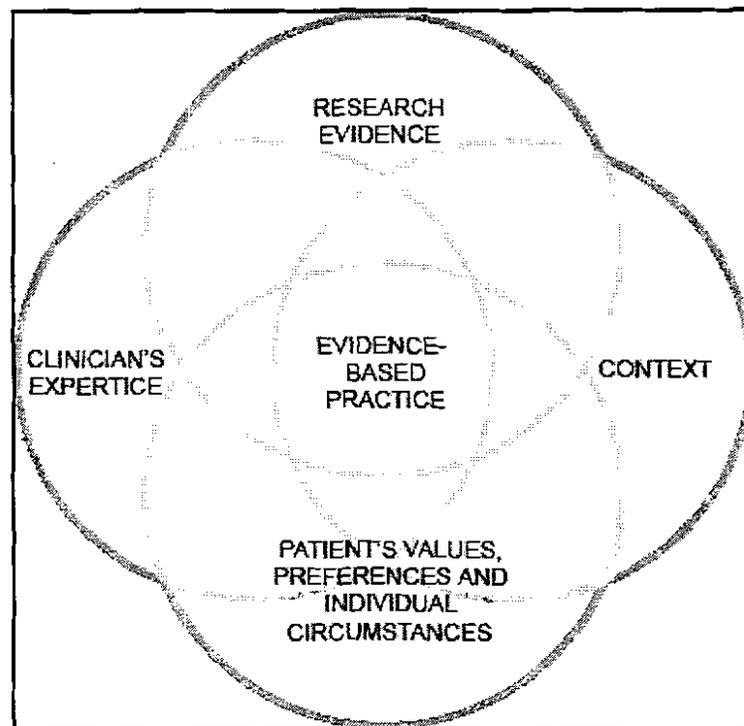


Figure 1.3 Relationship between the components of evidence-based practice

In this research best practice guidelines are developed as contribution to promote evidence based practice.

- **Best Practice Guidelines (BPG's)**

According to the Registered Nurses Association of Ontario (RNAO) (2005:91), best practice guidelines (BPG's) are defined as systematically developed statements (based on best

available evidence) that assist practitioners' and clients' decisions about appropriate health care for specific practice circumstances.

The main characteristics are:

- BPG's are systematically developed (rigorous methods such as systematic review are used, recommendations are based on research evidence when available and BPG's undergo an extensive review);
- BPG's are based on the best available evidence (originally mostly randomised control trials, but now also includes other types of research, including qualitative research); and
- BPG's are decision tools (aids to make decisions within the context of patient preferences, wishes, ethics and feasibility) (RNOA, 2005:91).

The most important benefits of clinical guidelines are their potential to improve both the quality of care provided by health care professionals and patient health outcomes (Grimshaw *et al.*, 1995:56). Some authors use the term 'clinical guidelines', but in this research the term 'Best Practice Guideline' is used to indicate guidelines that were systematically developed to guide practice and to produce the best possible patient outcomes. (In this study the promotion of HIV testing during pregnancy to ensure that more women's HIV status is known by the time that their babies are born).

1.4.3 Methodological assumptions

Two aspects of the methodological assumptions of this study are stated. The dimensions of social research (Mouton & Marais, 1994:7) as realised in this study, followed by the model for science practice in Nursing (Botes, 1992:36-42), including the determinants for research decisions, are discussed.

1.4.3.1 Realisation of the dimensions of social research

The following dimensions of social research are discussed namely, the ontological, epistemological and methodological dimensions.

- **Ontological dimension**

According to Mouton and Marais (1994:11) the ontological dimension of a research project comprises the essence of the reality that is researched. In this research project the phenomena under investigation entails different kinds of evidence regarding counselling for

HIV testing during pregnancy. Such evidence is necessary for developing best practice guidelines for evidence-based practice. In the strictest sense, evidence for evidence-based practice implies evidence from research studies, but in this research project other types of evidence is also included.

As the patient is central to the implementation of the evidence based practice (Sachett *et al.*, 2000:1) it makes sense to investigate the patient's point of view. In this research the patient's viewpoint is addressed by exploring the factors that influence the pregnant women's decision to be tested for HIV or not. This step enriches the observational and research (literature) evidence, when the researcher investigates the phenomenon from an emic (insider's) perspective.

In comparison with the ontological dimension that addresses the specific aspect of the social reality that is being investigated, the epistemological dimension, that will be discussed in the following paragraphs, focuses on how the reader can be assured that the understanding of the phenomena would be valid and reliable (Mouton & Marais, 1994:8).

- **Epistemological dimension**

The essence of the epistemology, as applied to a research project, refers to how it can be assured that the knowledge base that results from the research could be considered the truth (Mouton & Marais, 1994:14). Considering the complexity and impossibility to be absolutely sure in the human sciences, it is impossible to prove without doubt that assumptions are correct, but this remains every researcher's goal. The epistemological aim is therefore: striving to generate knowledge that is as near as possible to absolute certainty (Mouton & Marais, 1994:14, 15).

As previously stated, in this study the concept 'evidence' is used in a broader sense than the norm for evidence-based practice literature. Miller and Fredericks (2003:20) argue that the findings and conclusions of qualitative studies can not necessarily be considered evidence, unless the logic followed to reach the conclusion is explained. Sufficient reasons to believe that the resulting claims are true should be supplied (Miller & Fredericks, 2003:23). Becker (1996:65) also emphasises the importance of a detailed description to enhance the validity of a claim. Furthermore, Miller and Fredericks (2003:8) indicate that for qualitative research especially, the context of the research must be considered as the conclusion may only be true in a specific context. This kind of claim can be classified as potential evidence. They concluded that confirmation of the 'evidence' is the central issue and the logical constructs of necessity and sufficiency are foundational for every qualitative research study (Miller &

Fredericks, 2003: 23). Schwandt (1994:131) indicates that the answer to the critique against constructive interpretive approaches to human enquiry, that constructions exist only in an individual's self-reflective mind, is to acknowledge the social construction of knowledge.

▪ **Methodological dimension**

In the paradigm of post-modernism, the best method to answer the question is selected, although the underlying philosophy is not necessarily accepted. Aspects of Hermeneutical phenomenology is used for the first part of this study where the factors that influence the pregnant woman's decision to be tested for HIV are explored, while concepts used in evidence-based practice are used during the further collection of evidence through integrated literature review, before best practice guidelines are developed.

1.4.3.2 Application of the model for science practice in Nursing

The model for science practice in Nursing as adapted by Botes (1992:36-42) from Mouton and Marais' research model (1994:22) is used as methodological model for this research. One of the characteristics of this approach is the functional application of knowledge in practice. The functional application can be typified as post-modern. The post-modern approach is not applied in an "anything goes" manner, as all research still needs to be justified to ensure trustworthiness. This also links to the methodological approach that can be described as an open approach where the determinants of the research project form the framework, within which all research decisions must be made and justified. These decisions include the choice of the research strategy and methods for sampling, data collection, data analysis and methods to ensure trustworthiness (Botes, 1992:42).

Table 1.1 Application of the determinants for research decisions

Determinants for research decisions	Applications of determinants in this research
Researcher's assumptions - Meta-theoretical assumptions - Theoretical assumptions - Methodological assumptions	The researcher's assumptions are stated in 1.4
Research objectives - Explore - Describe - Explain	The objectives for this research are to explore, describe and develop.
Research context - Universal - Contextual	The research is contextual and no assumption of generalisation is made.
Attributes of field of research - Interpersonal relationship attachment - Intentional - Value attachment - Context attachment - Dynamic	Nursing, midwifery and counselling are interpersonal by definition. As the counselling in which the women are motivated to consent to HIV-testing is an interpersonal action, data-collection is conducted by way of observation and interviews. The actions are performed in an intentional way and not on

<p>- Multi-dimensional</p>	<p>impulse. The objective for the action is always kept in mind. If the counselling for HIV testing and the environment in which it occurs are optimal, the service will improve and hopefully more women's HIV-status will be known when their babies are born.</p> <p>Each midwife and counsellor act from her own as well as the institutions values. The profession's values, acts and regulations as well as the country's constitution are also considered. Each patient also has her own values that influence her decision to be tested for HIV or not.</p> <p>The manner in which actions are performed in nursing and midwifery vary from context to context. It is acknowledged that aspects such as staff issues, physical space (privacy for counselling) will differ.</p> <p>This links with the dynamic nature of nursing and midwifery. Situations change regularly and practice (as well as research) should adjust to these changes. This research problem is multi-dimensional as several factors contribute to the problem of pregnant women's unknown HIV-status at the time of the babies' birth. It is foreseen that a simple answer will be impossible.</p>
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1.5 RESEARCH DESIGN AND METHODS

The research design and research methods are not only seen as the specific paradigm or research methodology followed, but as the study's total strategy. In chapter one the design is discussed, while the specific methods and results of the different steps are detailed and discussed in the relevant chapters.

1.5.1 Research design

Qualitative and quantitative methods were used in the descriptive, exploratory, explanatory contextual design required to achieve the aim of the research.

The design is in line with a post-modern approach as both **qualitative and quantitative methods** were used. According to Polit and Beck (2004:19) a qualitative approach is suitable when a phenomenon that is relatively unknown is investigated, while a quantitative approach is used when a phenomenon has already been studied. Qualitative research methods were used for the semi-structured interviews to identify personal and organisational factors that influence a woman's decision to be tested for HIV as well as the factors that influence counselling for HIV testing. Through the qualitative approach the researcher hoped to add depth, richness and complexity to the study of counselling for HIV testing during pregnancy. A quantitative approach was followed when the existing research on counselling for HIV testing during pregnancy was explored by means of systematic review.

The design was **descriptive** in nature to provide a clear picture of the factors that influence a pregnant woman's decision to be tested for HIV, factors that influence counselling for HIV testing according to the counsellors as well as current practices regarding counselling for

HIV testing during pregnancy. Burns and Grove (2005:233) consider descriptive research mainly as quantitative but also illustrate the descriptive mode that describes the phenomenon in rich detail and addresses questions like “What is going on?”, as the initial step of research, grounded in the data from which it was derived (Burns & Grove, 2005:57). This study can be considered descriptive because important concepts are isolated during the analysis of the qualitative data and then defined (Woods & Catanzaro, 1988:463).

Polit and Beck (2004:718) define **exploratory research** as research that explores the dimensions of a phenomenon. It starts with observing and describing it, but continues by investigating the phenomenon’s full nature, the manner in which it is manifested and other factors to which it is related. Such research provides new insights. This study is exploratory as it provides increased insight into the personal and organisational factors that influence pregnant women in their decision to be tested for HIV, as described by women who attend and counsellors who practice in antenatal clinics as well as observation of current practice of counselling for HIV testing during pregnancy. The literature was also explored to identify research studies and other documents that could act as evidence for best practice guidelines.

According to Polit and Beck (2004:20) the goals of **explanatory research** are to understand the underpinnings of specific phenomena and to explain systematic relationships amongst phenomena. This type of research attempts to offer understanding of the underlying causes. This study is explanatory as its aim was to gain a deep understanding of the influencing factors and the meaning of the interview data was interpreted and explained.

The study was **contextual** since the findings are valid in the specific context in which the study was conducted. Additionally, no universal claims are made. It is proposed that the best practice guidelines would be applicable in similar contexts. French (2005:172) defined the context as the organisational environment of health care, composed of physical, social, political and economical influences.

The study was conducted within the context of the public health sector of South Africa. The Constitution of South Africa is considered one of the most progressive in the world (South African Government Information, 1996). Chapter 2 of the Constitution consists of the Bill of Rights, which has led to the patients’ Rights Charter (DoH, 2000c). The South African Department of Public service and Administration (DPSA) has also launched an ongoing programme to improve service to the public, the Batho Pele Principles and all public servants (including health workers) are held by these principles (DPSA, 2007).

The HIV/AIDS policy guidelines of the national Department of Health (DoH), regulate counselling for HIV testing during pregnancy (DoH, 2000a:11-12). It states that voluntary counselling and testing (VCT) must be available to all pregnant women. It also briefly states the following components of pre-test counselling: privacy, confidentiality, explain or determine reasons for testing, provide information about HIV and AIDS and pregnancy, provide information on HIV tests, include the concept of 'window period', review implications of positive and negative test results, provide information about testing procedures and informed consent. These guidelines are very broad and more specific policy and guidelines are not available.

The strategic plans regarding HIV and AIDS of the DoH have also identified the need for more specific policy and guidelines. In the 2000-2005 HIV/AIDS/STD Strategic plan for South Africa (DoH, 2000b) the selected strategies to improve access to HIV testing and counselling in ANC clinics were to develop counselling guidelines and to train counsellors (DoH, 2000b:20). The guidelines for counselling have not yet been developed, as it is again planned for in the strategic plan that followed the 2000-2005 plan. In the HIV and AIDS and STI strategic plan for South Africa, 2007-2011 (DoH, 2007) one of the strategies to up-scale coverage of PMTCT to reduce MTCT to less than 5%, is to develop a policy and guidelines about VCT in pregnancy, including consideration of provider initiated testing and frequency of testing during 2007 and review it annually. At the time when this research was conducted, the specific policy and guidelines were not yet developed. Local clinics had to develop their own protocols in the absence of clear guidelines.

In North West Province an opt-in policy of presenting HIV testing is followed. According to the Member of the Executive Council (MEC) for Health in North West Province, Ms. Nomonde Rasmeni, counsellors in the North West Province offer HIV testing after counselling (North West Province, DoH, 2006). The pregnant women who are willing to be tested must then sign a consent form.

The research is executed in a medium sized city (population approximately 250 000) situated in the North West Province of South Africa. The setting of data-collection is four of the seven clinics in the city. The Provincial Department of Health funds these clinics that are organised as a sub-district of the province. All the clinics function as primary health care clinics that offer a variety of health services (Antenatal and postnatal clinics, monitoring and immunisation of babies, integrated management of childhood illnesses, family planning, attending to minor ailments, monitoring and treatment of chronic illnesses e.g. hypertension, diagnosis and treatment of sexually transmitted infections and communicable diseases e.g. tuberculosis and HIV/AIDS). The clinics also offer health promotion activities and

counselling. The professional staff who work in the clinics must be multi-skilled to service the wide variety of patients.

Professional Nurses who are also registered as midwives, are the main deliverers of these services. The shortage of nurses in the country – especially in the public health sector, and the high prevalence of HIV/AIDS (31,8 % of pregnant women in North West Province according to the 2005 national survey (DoH, 2006:10)) leads to a high level of work pressure and elevated turnover of staff. Medical practitioners attend to some of the clinics on certain days of the week. There is also support staff such as lay counsellors/ health promoters, clerks and cleaners. Both registered nurses and lay counsellors do counselling for HIV testing. Rapid on-site HIV antibody tests are used. Only the nurses/midwives are permitted to obtain the blood sample and execute the test.

The clinics are spread evenly throughout the residential areas. Since 1995 all public health services for pregnant women and children up to the age of 5 years, are delivered free of charge. However, the staff-shortage and large number of patients often result in patients having to wait for a long time to receive care. The clinics of the sub-district provide antenatal services to about 320 new pregnant women every month. Of these about 250 consent to be tested for HIV (78%). Twenty eight percent (28%) of these women were found to be HIV positive (Derbyshire, 2006). According to McCoy *et al* (2002:9), clinics that achieve an uptake of 60-80% could be considered as doing fairly well.

The main languages spoken in this sub-district are Setswana, Afrikaans and English. Pregnancy out of wedlock is common (approximately 75% of pregnancies). This is partly due to a cultural custom that dictates that a woman must prove her fertility before marriage. It is however, not uncommon to find a woman who is having her third child without being married. Most of the Setswana women are partly westernised yet they still follow certain traditional cultural customs. Although the HIV/AIDS prevalence rate is very high, sex is still considered a taboo discussion subject and the level of stigma against people living with HIV is very high. All these factors may influence a woman's decision to undergo HIV testing.

1.5.2 Research methods

A stepwise approach consisting of two phases was used to develop the best practice guidelines for counselling for HIV testing during pregnancy. The first phase consists of four steps and the second of one step. Phase 1 involved the search for evidence on which to base the guidelines, while phase 2 involved the development of the best practice guidelines.

Table 1.2 Project exposition

Phase 1: Compilation of evidence as preparation for development of best practice guidelines	Phase 2: Development of best practice guidelines
Step 1: Exploring and describing factors that influence pregnant women's decision to be tested for HIV	Step 5: Formulation of best practice guidelines
Step 2: Exploring and describing factors that influence the counselling for HIV testing during pregnancy according to counsellors	
Step 3: Exploring and describing current practice regarding counselling for HIV testing during pregnancy	
Step 4: Exploring and describing of research studies regarding HIV testing by systematic review	

This section supplies a broad outline of the methods used. Detailed descriptions of the methods used are discussed in the chapters applicable to the different steps.

Table 1.3 indicates the research methods used in the different phases and steps.

Table 1.3: Research methods used in different phases

Phase 1: Compilation of evidence regarding counselling for HIV testing during pregnancy as preparation for development of best practice guidelines					
Objective 1: To explore and describe the factors that influence the pregnant woman's decision to be tested for HIV in selected antenatal clinics in the North West Province	Step 1: Exploring and describing the factors that influence pregnant women's decision to be tested for HIV	Data collection: Semi-structured interviews	Population and sample: Pregnant women who attend selected antenatal clinics in North West Province.	Data analysis: Open coding for interviews	Methods detailed in Chapter 2
Objective 2: To explore and describe the factors that influence the counselling for HIV testing during pregnancy according to counsellors who practice in selected antenatal clinics in the North West Province	Step 2: Exploring and describing the factors that influence the counselling for HIV during pregnancy according to counsellors	Data collection: Semi-structured interviews	Population and sample: Counsellors who practice in selected antenatal clinics in North West Province.	Data analysis: Open coding for interviews	Methods detailed in Chapter 3
Objective 3: To explore and describe the current practices regarding counselling for HIV testing during pregnancy in selected antenatal clinics in the North West Province	Step 3: Evaluating current practice regarding counselling for HIV testing during pregnancy	Data collection: Observation using an observation protocol based on Evaluation tools developed by UNAIDS and field notes	Population and sample: Practices during and the content of counselling sessions at selected antenatal clinics in North West Province	Data analysis: Inductive and deductive logic	Methods detailed in Chapter 4
Objective 4: To explore and describe the evidence regarding counselling for HIV testing during pregnancy by systematic review	Step 4: Reviewing research reports systematically	Data collection: Retrieval using multiple electronic data-bases and hard copy search	Population and sample: Quantitative and qualitative research reports	Data analysis: Critical appraisal of documents regarding strength of evidence and relevance in context.	Methods detailed in Chapter 5
Phase 2: Development of best practice guidelines					
Objective 5: To develop best practice guidelines for HIV testing during pregnancy	Step 5: Formulation of best practice guidelines	Data collection: Integrating & synthesising results from step 1-4	Population and sample: Evidence from step 1-4	Data analysis: Inductive and deductive reasoning, integrating, synthesising	Methods detailed in Chapter 6

1.6 RIGOUR

The rigour, applicable to the entire research, is discussed in this section. Specific strategies to ensure rigour as it applies to the different steps of the research project are discussed in the relevant chapters. Two aspects of rigour are discussed namely, trustworthiness and authenticity.

According to Manning (1997:93-116) there are two sets of criteria to address quality and rigor for research that wishes to make a difference in practice (constructivist inquiry). These criteria sets are trustworthiness and authenticity. Trustworthiness is the qualitative parallel of internal and external validity, reliability and objectivity but there is no quantitative parallel for authenticity. While trustworthiness addresses methods to ensure that the research method was carried out correctly (Guba & Lincoln, 1989:233), authenticity has to do with the meaningfulness of the research for society (Manning, 1997:94).

1.6.1 Trustworthiness

The framework of Lincoln and Guba (1985:289-311) and Krefting (1991:214-222) will be used to ensure the entire project's trustworthiness. The following criteria are continuously considered while executing strategies:

- **Credibility / Truth value**

According to Lincoln and Guba (1985:290) this issue deals with the question: How can one establish confidence in the 'truth' of the findings of a particular inquiry for the respondents with which and the context in which the inquiry was carried out? The researcher accepts that the truth may have different meanings for different respondents (participants) and used different methods and view points to address these multiple realities (Data from pregnant women, counsellors, observation of current practices and research studies identified by systematic review) as adequately as possible.

- **Transferability / Applicability**

To ensure applicability the following question must be answered: How can one determine the extent to which the findings of a particular inquiry have applicability in other contexts or with other respondents (Lincoln & Guba, 1985:290)? Each research study that employs a qualitative approach is unique as a particular researcher interacts with particular participants in a particular way (Krefting, 1991:216). To make a claim of transferability, one has to know both contexts. As the researcher only knows the details of the context that is investigated, the reader has to decide if the findings are transferable to his known context. The researcher is responsible for describing the theoretic foundation, context and method as clearly as possible (Lincoln & Guba, 1985:298). In this research these issues are described and discussed in detail.

- **Dependability/ Consistency**

The researcher's answer to the following question will determine if the findings are consistent: How can one determine whether the findings of an inquiry could be repeated, if the inquiry was replicated with the same respondents in the same (or similar) context (Lincoln & Guba, 1985:290)? In research done in a natural setting it is not possible to 'cross the same stream twice' as it will not be the same stream anymore. There is no consistent reality that can be used as benchmark. In a study that utilises a qualitative approach, multiple realities are accepted.

It is therefore not claimed that the research will repeatedly yield the same results, but that consistency is honoured (Krefting, 1991:218). The dynamic, complex nature of the research environment and each situation's uniqueness is acknowledged. Dependability is ensured by using appropriate data collection techniques to collect data from a variety of sources and by safe-keeping all documents that are used during data collection to enable a reliable audit of the process.

- **Confirmability / Neutrality**

To ensure neutrality the following question must be answered: How can one establish the degree to which the findings of an inquiry are determined by the respondents and

conditions of the enquiry and not by the inquirer's biases, motivations, interests or perspectives (Lincoln & Guba, 1985:290). In qualitative research the emphasis of neutrality is shifted from the researcher to the data. The researcher's objectivity is not claimed. The researcher's paradigmatic perspective is spelt out and personal reflections are recorded (see 1.4, 2.7 and 4.7) and can therefore be considered during the interpretation of the results.

1.6.2 Authenticity

Authenticity involves a set of criteria (fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity) applied in an evolving manner, which commits the researcher to a set of actions (balance of perspectives, learning by the researcher and respondents, shared knowledge and social action). If the researcher fails to meet these commitments, the quality of the research (meaningfulness, usefulness, ability to enact social change) is questionable (Manning, 1997:94). Fitting into the paradigm of constructivist inquiry's multiple realities, there is no singular or objective truth associated with authenticity, but rather potential actions, from which the researcher can choose to manage power inequities, manage relationships with participants, use the research findings and treat people fairly.

In Table 1.4 the actions taken in this study to meet the criteria based on Manning's guidelines (1997), are explained.

Table 1.4 Criteria for authenticity, treats and actions applicable to this research

Criteria	Threat	Preventative actions	Application in this research
Fairness (Providing a balanced view of all the heterogenic voices)	Mistrust and distance between researcher and participants lead to context-free interpretations.	<ul style="list-style-type: none"> - Obtaining informed consent - Openness about research purpose - Using direct quotes - Obtaining viewpoints of different role players - Member checking - Persistent observation 	In order to be fair to the participants the researcher gave information about the purpose of the research and what its expectations before obtaining their consent. The researcher committed herself to protect the participants' privacy when handling the data. The researcher gave all participants a voice, by using data and quotes from the interviews with both pregnant women and counsellors. During the interviews, the interviewer frequently confirmed that the participants understood her correctly. Factors that influence counselling for HIV testing were observed from different points of view.
	Overdirection with prior assumptions or guiding theory leads to only researcher's constructed interpretations.	<ul style="list-style-type: none"> - Reflection on researcher assumptions - Peer debriefing 	The researcher exposed her own viewpoints and assumptions right through the study to enable the reader to understand the context and the lens used when viewing at the data. The promoters also challenged the researcher to explain how and why certain interpretations were made.
Ontological authenticity (Promoting the participants' growth through the research)	Overly guiding by prior assumptions or theory leads to targeted questioning and one-way conversations	<ul style="list-style-type: none"> - Dialogical conversations - Openness about research purpose - Seeking an emic perspective 	Dialogical conversations were conducted and both interviewer and participant increased their understanding. The purpose of the research was stated clearly in the letter that accompanied the informed consent form and this was discussed with participants. The researcher strived to understand the emic perspective although the best endeavour is still only an approximation. The researcher engaged in persistent observation to attempt to understand the situation from the participants' point of view.
	Incomplete sharing of research purposes leads to unequal status between researcher and participants	<ul style="list-style-type: none"> - Developing a trusting researcher / participant relationship 	A trustful relationship developed. One of the counsellors who were interviewed declared: "It is nice to talk about HIV, especially to someone who doesn't know you." Considering the counsellors' need for support (See 3.6.4.1), she probably used the interview as informal debriefing – thereby growing through her participation in the research.

<p>Educative authenticity (Promotion of participants understanding of own and other participants constructions)</p>	<p>Researcher's limited skills or knowledge leads to misunderstanding about 'bias'</p>	<ul style="list-style-type: none"> - Reflexivity - Openness about researcher's assumptions - Member checking - Internal audit 	<p>In this research member checking occurred during interviews. All participants were invited to give their details to receive a final report of the study (including their own and other participants' constructions). The researcher was continuously aware of her own assumptions and the development of her understanding through reflection. The co-analyst and promoters acted as internal auditors who clarified and refined the themes and conclusions.</p>
<p>Catalytic authenticity (Usefulness of research to facilitate and stimulate action)</p>	<p>Privileging researcher's interpretation over participants' leads to implausible and constructed interpretations of the researcher only</p>	<ul style="list-style-type: none"> - Dialogical conversations - Jointly constructed interpretations - Research findings and end product disseminated through follow-up activities to all stakeholders 	<p>Data-collection conducted through semi-structured interviews using questions to provide structure but encouraging participants to express themselves freely in conversation. Although the participants did not contribute in the interpretation of the findings, the researcher did not plan the research or make conclusions without input from or checking with the co-analysts and experts (the promoters of the study). The end product of the research is best practice guidelines that will be disseminated in report form as well as in workshops to promote its use and adaptations in different contexts.</p>
<p>Tactical authenticity (Usefulness of research to empower participants to act on the findings)</p>	<p>Mistaken assumptions about who 'owns' data leads to disempowering participants and unethical use of data</p>	<ul style="list-style-type: none"> - Assuring confidentiality - Dialogical conversations - Opportunity for participants to get a copy of the research 	<p>Care is taken to ensure that particular participants will not be recognisable by community members, their peers. Participants have the opportunity to be empowered by the research as a copy of research report is available for each participant. Counsellors will be invited to participate in workshops where the use of the best practice guidelines will be discussed.</p>

According to Manning (1997:110) in a well-conducted, outstanding study, it would be possible to trace research conclusions to the study's field notes and data-analysis. She states that although these paths are often evident, they are usually ambiguous. The ambiguity reflects the human processes under investigation, which is likewise permeated with contradictions and complexities. To achieve "verstehen" or understanding the inquiry process must be as complex as the human process under study.

1.7 ETHICAL CONSIDERATIONS

HIV testing is a sensitive topic and vulnerable people participated in this study. The following internationally acknowledged ethical principles, as set out by Denosa (1997:1-8), Burns and Grove (2005:181-198) and Brink *et al.* (2006: 30-43), were applied:

1.7.1 The researcher's responsibility to protect the rights of the participants

- The right to benefit and avoidance of disadvantage
Although the participants may not immediately benefit from the research, the integration of the best practice guidelines will eventually be of benefit to pregnant women and their babies. If behaviour was noted during observation that could disadvantage the pregnant women, it was reported to the person in charge of the clinic.
- The right to fair selection and treatment
Certain groups of the population were not deliberately included or excluded. Participants were given the assurance that they could withdraw without discrimination, at any stage if they so wished.
- The right to confidentiality and anonymity
Participants were given the assurance that their data will be treated anonymously and confidentially. Information of specific participants can not be identified in report as codes are used. Raw data is locked up.
- The right to informed consent
Before any data collection concerning the participants (patients as well as health workers) took place, their informed consent was obtained. Participants received written and verbal information about the research before they were expected to consent in writing.
- The right to information

Participating clinics and participants received written information about the research's aim and objectives as well as the researcher's contact details. They also received the opportunity to obtain a report of the research findings after completion.

1.7.2 The researcher's responsibility to obtain permission for the research

- Permission was obtained from the Ethics Committee of the North-West University (Appendix 1.1) as well as the provincial Department of Health under which the antenatal clinics resort (Appendix 1.2).

1.7.3 The researcher's responsibility to do research of a high quality

- By maintaining high standards with regard to planning, implementing and reporting on the research. Planning, implementation and reporting were conducted as carefully as possible with the research committee and ethics committee acting as quality assurance mechanisms.
- By displaying integrity through stating both supporting and opposing points of view. It ensured that all points of view, as traced in the literature, are indicated. Plagiarism was avoided by giving credit where due.
- By acting honestly in that no results are disguised and by acknowledging the contributions of all co-workers and sponsors. It was seen to that everything is done as honestly as possible.

1.7.4 The researcher's responsibility to share the research results

- By giving feedback of the research to the participants and other role players. The results are shared with all the participants who gave their addresses and other role players by means of a report.
- By distributing information pertaining to the research to other scientists and service providers. The research results will be distributed by means of journal articles, congress papers and workshops.
- By implementing the formulated best practice guidelines to the benefit of pregnant women, their babies and the community as a whole.

1.8 RESEARCH REPORT LAYOUT

The thesis consists of the following sections:

- Chapter 1 Grounding of the research

- Chapter 2 Factors that influence pregnant women's decision to be tested for HIV

- Chapter 3 Factors that influence counselling for HIV testing during pregnancy according to counsellors

- Chapter 4 Current practices regarding counselling for HIV testing during pregnancy

- Chapter 5 Counselling for HIV testing during pregnancy: A Systematic review

- Chapter 6 Development of best practice guidelines regarding counselling for HIV testing during pregnancy

- Chapter 7 Final conclusion, evaluation and limitations of the study as well as recommendations for practice, education and research

1.9 SUMMARY

In Chapter one an overview of the study was provided. Firstly, the background and problem statement were described. Then the aim and objectives that flow from the research questions were stated. In the section that followed the researcher's meta-theoretical, theoretical and methodological assumptions were declared. The research design and research methodology, as applicable to the entire project, was then discussed and the detail of the research methods used in the different steps will be supplied in the following chapters. The rigour and ethical considerations as applicable to the entire project as well as the research report layout conclude Chapter one.

The first step, namely the exploration and description of the factors that influence the pregnant women's decision to be tested for HIV, is discussed in Chapter two.

CHAPTER 2

FACTORS THAT INFLUENCE PREGNANT WOMEN'S DECISION TO BE TESTED FOR HIV

(Phase One: Step One)

In Chapters two, three, four and five the research method, results and conclusions of the first four steps, that constitute the first phase, are discussed. Each of the steps in which evidence is gathered in preparation for developing practice guidelines, is discussed in a separate chapter that forms a complete unit. This includes the empirical work as well as the specific step's results.

2.1 INTRODUCTION

The research method including population and sampling, data-collection and data-analysis as well as literature control, rigour and research findings of the following objective is addressed in this chapter:

Objective 1: To explore and describe the factors that influence pregnant women's decision to be tested for HIV in antenatal clinics in the North West Province.

Table 2.1 Structure of research project indicating Step 1

<p>Phase 1: Compilation of evidence as preparation for development of best practice guidelines</p> <p>Step 1: Explore and describe the factors that influence pregnant women's decision to be tested for HIV</p> <p>Step 2: Explore and describe the factors that influence the counselling for HIV testing during pregnancy according to the counsellors</p> <p>Step 3: Explore and describe current practice regarding counselling for HIV testing during pregnancy</p> <p>Step 4: Systematic review of studies regarding counselling for HIV testing during pregnancy</p>	<p>Phase 2: Development of best practice guidelines</p> <p>Step 5: Formulation of best practice guidelines</p>
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2.2 RESEARCH DESIGN

The research design of the entire project is discussed in Chapter one (see 1.5). The study's first step contains explorative, descriptive, contextual and qualitative methods. It endeavours to achieve a deep understanding of all the factors that influence the pregnant women's decision to be tested for HIV in antenatal clinics.

In order to explore the personal and organizational factors that influence pregnant women's decision to be tested for HIV, it was essential to talk to the women themselves. Interviews with the women provide insight into their 'lived world' that could assist in understanding the dynamics that are at play when a woman has to make the decision to be tested. According to Kvale (1996:31) interviews are ideally suited when one attempts to understand an issue from the participant's point of view. The knowledge of the insider's (emic) perspective will contribute to the evidence when developing the best practice guidelines.

2.3 RESEARCH METHOD

The discussion of the research method in this chapter includes the population and sample, the data collection as well as the data analysis of the first step of the first phase.

2.3.1 Population and sampling

The population consists of women who attend the antenatal clinics in the Southern district of the North West Province and who have received pre-test counselling in the period September-October 2006. The Southern district of the North West Province was selected due to its accessibility for the researcher.

Sampling was conducted using the following structured steps to ensure every woman who met the inclusion criteria, had an equal opportunity to be selected:

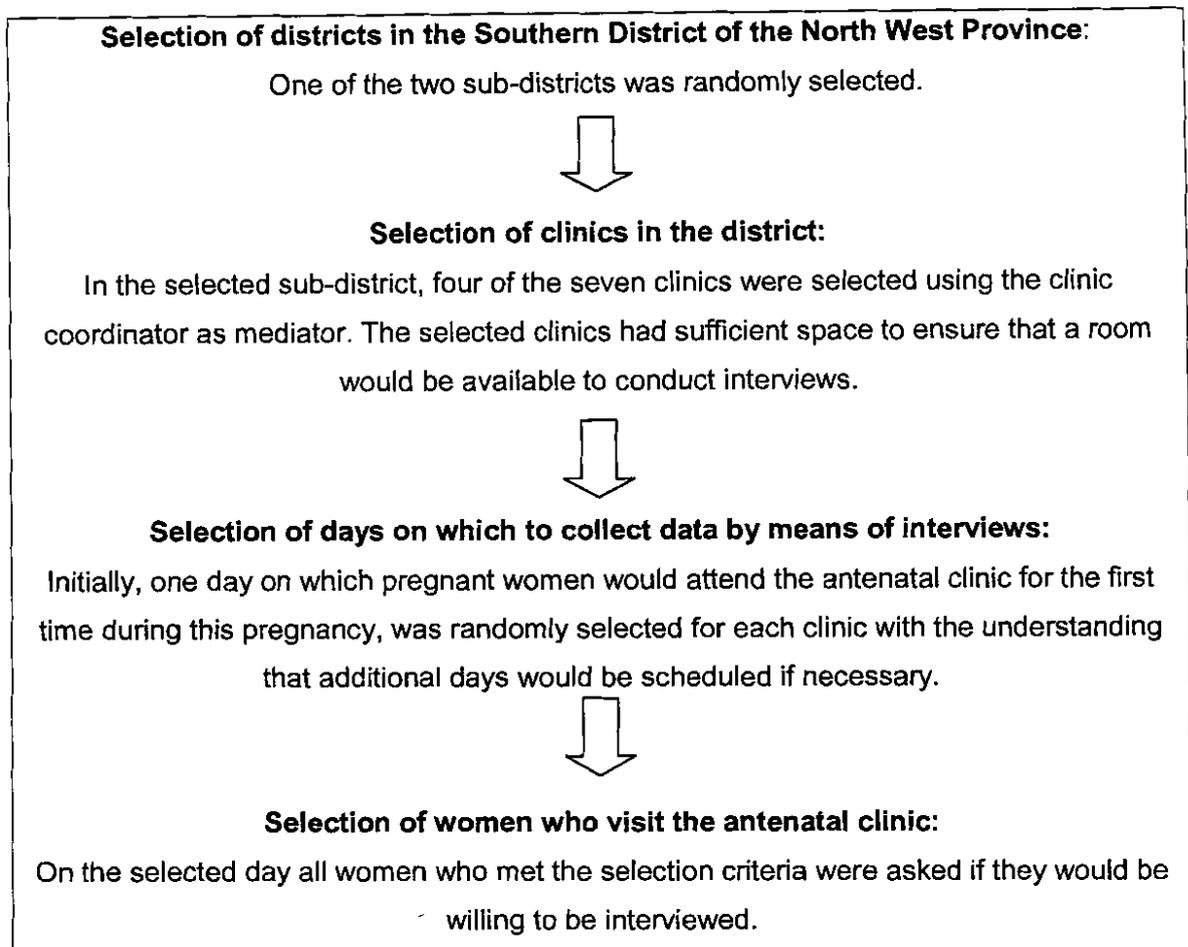


Figure 2.1 Stepwise selection-process of participants

The inclusion criteria for the sample dictated that participants had to be:

- A pregnant woman, who attended one of the selected antenatal clinics;
- Had received pre-test counselling at the selected clinic; and
- Consented to participating in the research project.

Whether the woman agreed to be tested or not was not used as criterion because of the high level of stigmatisation in the community. If only those who agreed or who did not agree to be tested were selected, women might be afraid to participate as they might have felt that their participation might have indicated their HIV-status to the community. Table 2.2 indicates how the selection realised.

Table 2.2 Realisation of sampling

	Number of participants who met the criteria on the day	Number of participants who gave consent to participate and who were interviewed
Clinic A	4	3
Clinic B	4	4
Clinic C	3	2
Clinic D	4	4

The size of the sample depended on when data-saturation was reached. If new themes continued to appear in the data at the end of the two-month period, the understanding was that data-collection would continue until data saturation is reached. There is no apparent reason to believe that data collected during this period would differ from data collected during another period. During this two month period a total of 621 pregnant women visited these clinics for the first time, during their pregnancy, and received counselling for HIV testing (Derbyshire, 2006).

After the participants were selected, the data-collection could continue.

2.3.2 Data-collection

Individual interviews were selected as data-collection method, for the study's first step. As both open ended and closed questions were used, this type of interview can be classified as semi-structured, according to Gillham's (2000:6) scale.

Table 2.3. Different types of research interviews according to Gillham (2000:6)

Unstructured				Structured		
Listening to conversation	Conversation	Open-ended interviews	Semi-structured interviews	Recording schedules	Semi-structured questionnaires	Structured questionnaires
Verbal observation	Using 'natural' conversation to ask research questions	Using a few key open questions	Using open and closed questions	Verbally administered questionnaires	Multiple choice and open questions	Simple, specific closed questions

According to Collins (1998,1.1) any interview is an interactional situation, in which the interviewer and interviewee both contribute to what happens. He also states that it is more useful to talk about data generation than data collection. Additionally, Collins (1998:1.4) indicates, that it is necessary to step back to scrutinise the relationship between the

method and the information that it enables one to collect, as well as how the relation between method and the kind of information collected, determines the eventual form of the research report. The interviews' interactive character will be considered during the data-collection process and during data-analysis.

Adding to Collins, Kvale (1996:105) considers interviewing a craft that does not follow the content- or context-free rules of method but rests on the judgements of the researcher. In his view the act of crafting defies homogeneity in that there are no standard methods to arrive at essential meanings and deeper implications of what is said in an interview, but that the *stated goal and purpose* of the interview provides some direction. During the interviews with the pregnant women, the interviewer kept the objective, to explore the factors that influences the decision to be tested for HIV, in mind and directed the interview when necessary.

In the following section, obtaining permission, and the planning, conducting and recording of the interviews are discussed to indicate the realisation of the data-collection.

2.3.2.1 Obtaining permission to collect data

Before data-collection commenced, permission was obtained from the Department of Health of North West province (Appendix 1.2). The Sub-district-manager under whose authority the selected clinics fall was notified by letter explaining the study's purpose, the research procedures planned at the clinic and the fact that the provincial authorities had permitted the study to be conducted in clinics under their authority (Appendix 2.1). The Registered nurses in charge of the clinics were also notified and suitable dates to collect data were agreed upon.

After displaying interest to participate but before the interview commenced, participants were provided with a document (Appendix 2.3) that first had to be discussed with them. The document consists of the following:

- information about the research;
- a consent form for participating in an interview and allowing the interview to be recorded, as well as
- a detachable page on which the participant could indicate her contact details if she wanted feedback after the research.

2.3.2.2 Planning of interviews

During the planning stage, decisions had to be made about the questions that would be asked, the selection and preparation of the interviewer as well as the environment. These aspects culminated in a pilot study to explore whether additional adjustments were required.

- **Interview schedule**

Closed ended questions were used to gather factual data such as the biographic information but most questions were open ended as this type of question is most suitable for exploring a topic or collecting in-depth information (Gillham, 2000:3). The number of questions had to be restricted to ensure that the interview remained focussed and that interviewees do not become exhausted or bored.

Gillham (2000:21) stressed the emergent character of the interview schedule. The questions that are most likely to answer the applicable *research question* had to be included, while care needed to be taken when formulating questions to ensure that the responses gained would be analysable. The questions also had to flow in a logical sequence.

The following interview schedule (See table 2.4) was adapted from the schedule used by Boyd *et al.* (1999:22) in their United Kingdom study on what pregnant women think about the HIV test used.

Table 2.4. Interview schedule for interviews with pregnant women

<p>The following central question was asked:</p> <p>In your opinion, what factors influence a pregnant woman's decision to be tested for HIV?</p> <p>The following were used as follow-up questions:</p> <p>What personal factors must be considered? / What are the things in their lives pregnant women first have to think about?</p> <p>What factors connected to the clinic must be considered? / What things in the clinic can make a</p>
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pregnant woman to be willing to be tested or not?

Can you tell me what the good aspects (if any) were about the pre-test counselling you received?

Can you tell me what the bad aspects (if any) were about the pre-test counselling you received?

How do you feel about the HIV test being available at the antenatal clinic?

How do you feel about the way the counsellor discussed the subject of HIV testing with you?

Was there anything about the way the test was offered to you that you were not happy about?

How do you think counselling for HIV testing can be improved?

Due to the sensitivity that surrounds HIV in the community, and the risk of harm caused by potential stigmatisation, the strategy to collect the relevant data by *indirect questioning* regarding 'the factors that influence a *pregnant woman's* decision' and not asking about the factors that influence her *own* decision, was originally selected to minimise discomfort for the women and thus reduce the harm that may be caused by this research project. As the interviews progressed it was decided to ask some of the women with whom good rapport was established, what the factors that influenced their own decision were. No apparent discomfort was observed.

- **Selection and preparation of interviewer**

When interviewing is selected as data-collection method, the interviewer can be described as the 'research instrument' (Gillham, 2000:25; Kvale, 1996:125,147). It was therefore vital to select and prepare the interviewer. The researcher decided to plan the interviews herself but use an interviewer, who was familiar with the context, to conduct the interviews. The selected interviewer has vast experience in conducting interviews, both as researcher and therapist. The researcher discussed the objectives and research method with the interviewer in detail to ensure that she was knowledgeable about the study and what was expected of her. The researcher was present during the first few interviews and provided guidance after which the interviewer continued on her own with the interviews. The researcher maintained daily contact with the interviewer.

- **Pilot study**

A pilot study was executed before the official data-collection commenced. The purpose of the pilot study was to determine if the semi-structured interview schedule was effective, if the interviewer conducted the interviews as the researcher had planned it, and to ascertain

if the process including the obtaining of informed consent, the selection of the setting and time and the interview technique was satisfactory.

After the pilot study the researcher brought aspects regarding the context (for example: since HIV testing is done while the women wait for consultations with the midwives, they do not need to spend additional time at the clinic for testing) to the interviewer's attention. It was also decided to directly ask the women about the factors that influenced her own decision, if the interviewer could establish good rapport with the interviewee. It was decided to include the interview conducted during the pilot study, as part of the collected data because within the qualitative paradigm it is not necessary that all the interviews must be conducted exactly the same and because the interview included valuable data.

- **Selection and preparation of environment**

During the week before the interviews commenced, the researcher and interviewer visited all the clinics to meet with the registered nurses in charge and to become familiar with the rooms in which the interviews could be conducted.

The interviews were conducted in private rooms at the different clinics during the women's routine antenatal visits. Some rooms were more spacious than others. Precautions (such as a 'Do not disturb' notice on the door) were taken to ensure privacy and limit interruptions. Despite these precautions some of the interviews were interrupted. However, the interruptions did not seem to influence the participants negatively.

Consideration was given to the furniture arrangement in the interview rooms. The chairs were placed at a 90° angle and not facing one-another squarely. A table that held the recorders was placed in-between the chairs. According to Gillham (2000:33) this set-up is less threatening to the interviewee and makes it easier to avoid excessive eye contact. Placing the interviewer and interviewee too close to one-another could cause the interviewee to feel that her personal space was invaded.

2.3.2.3 Conducting of interviews

The initiation of the interviews, the communication skills used, length of the interviews as well as the recording of the interviews are discussed.

- **Initiation of interviews**

On the day of the interview, all the pregnant women in the waiting room of the specific clinic who had already received counselling for HIV-testing, were briefed about the research and invited to participate. Women who indicated that they would be willing to participate in the study were taken to the private room for the interviews.

In a research interview, it is up to the interviewer to create contact that allows interaction that leads beyond a merely polite conversation or exchange of ideas, within a short time. The interviewer must establish an atmosphere in which the participant feels safe enough to talk freely about her experiences and feelings (Kvale, 1996:125). In this research project the interviewer established this atmosphere by welcoming the participant in the initiation phase of the interview. The interviewer then introduced herself and enquired about the participant's comfort. The participant was given an opportunity to read the information letter (Appendix 2.3) and was asked if she has any questions about the research or procedure. After answering her questions, the recorders were shown to her and her written consent to be interviewed and for the interview to be recorded, was obtained.

According to Kvale (1996:128) the first minutes of an interview are decisive as participants want to have a grasp of the interviewer before they will allow themselves to expose their experiences and feelings to a stranger. The interviewer started with a few general biographical questions. This acted as an ice-breaker that placed the interviewee at ease and gathered background information. The information was recorded as part of the field notes. The recorders were then switched on and the interview commenced.

- **Communication skills**

During the interviews the interviewer used communication techniques that are effective in establishing rapport according to Okun (2002:33, 81). Such techniques include making eye contact, using an open posture, displaying non-judgemental attitude and respect. Kvale (1996:128) mentions that good contact can be established by attentive listening, while the interviewer shows interest, understanding and respect for what the interviewee says.

As the aim is to *hear* the information from the interviewee, the interviewer practiced active listening, using minimum verbal and non-verbal responses. The non-verbal communication skills that the interviewer used included appropriate and responsive facial expression, occasional eye-contact as extensive eye-contact can cause the interviewee to feel embarrassed or dominated, economic use of head nodding use as encouragement and natural gesturing (Gillham, 2000:30).

The verbal dimension of active listening includes listening rather than talking and using appropriate natural sounding tone of voice (Gillham, 2000:34). Prompts and probes were used in addition to open-ended questions. Prompts were used to steer the direction of the interview to ensure that all aspects of the research question, namely all the factors that influence a pregnant woman's decision to be tested for HIV, were included. The role of probes is to stimulate the interviewee to expand on the response. The probes used included asking for clarification or an example, checking the relevance or accuracy of a response, summarising and reflection. When reflecting, the interviewer used the participant's own words to capture the essence of what was said and reflected it back to her. Summarising the overt content, focused the interviewee on the essence of what was said and also indicated the awareness of the emotional state behind what had been said (Gillham, 2000:51).

As advised by Kvale (1996:128) the interviews were rounded off by mentioning some of the main points learned from the interview. This served as debriefing of the tension or anxiety that can be experienced when sharing personal and emotional experiences. The interviewer also gave the participant an opportunity to state further comments and questions.

- **Length of interviews**

All the interviews lasted 20-40 minutes. Women were given ample opportunity to give their input and were probed when they did not contribute freely.

2.3.2.4 Recording of interviews

A tape recorder and an electronic voice recorder was used to record the interviews. It was switched on after permission to do so was obtained from the participant. The interviews

were transcribed afterwards (Example of a transcript of an interview with a pregnant woman - Appendix 2.4).

Directly after the interviews, the interviewer recorded field notes with her observations and interpretations of what happened during the interview (Greeff, 2005:298; Polit & Beck, 2004:382). Kvale (1996:129) mentions the value of the interviewer's personal reflection after each interview. These immediate impressions may provide valuable context for the later analysis of transcripts. The following notes were made of each interview: observational notes (information about the situation without interpretation), personal notes (information regarding the interviewer's own reactions with reflection on her own thoughts and feelings) and methodological notes (notes on the data-collection) (Appendix 2.5)

2.3.3 Data-analysis

The interviews were analysed by both the researcher and the interviewer as co-analyst. The co-analyst was selected on the basis of her experience in analysing interviews of this nature as well as her ability to be actively involved with the continuous reflection due to her involvement with the interviews. A process was followed to reach the final findings.

2.3.3.1 Preliminary data-analysis

Step 1 of phase 1 of the study is qualitative in nature and therefore data-analysis was not a once-off occurrence, but a process that started with the knowledge and anticipated meaning that the researcher gained through experience and contact with the literature (Creswell, 2003:190). Data analysis continued during data-collection as the researcher (and co-analyst) reflected on the data as the raw data became available and as the interviews were transcribed (Richards, 2005:68). Closer determination of the meaning of the separate parts eventually lead to the change of the originally anticipated meaning of the totality, which again influences the meaning of the separate parts, and so on (Kvale,1996:47). This first part of the data-analysis occurred in an informal way and each analyst recorded her ideas on dated memos as record of insights (Burns & Grove, 2005:550; Richards, 2005:74). As soon as all the transcripts were available the formal data-analysis started.

2.3.3.2 Formal data-analysis

After the informal data-analysis was conducted by means of reflection the rest of the data-analysis process continued when all the interviews were transcribed. An eclectic approach was used during the data-analysis process. The general principles of handling qualitative data as discussed by Richards (2005:67-82) and the steps of content analysis according to Gillham (2000:63-66) were combined with the data-analysis process as developed by Tesch in 1990 and summarised by Creswell (2003:192) to develop a protocol for the two analysts, to serve as guideline during the formal data-analysis.

The first step was to read all the transcriptions without locating specific topics within the script, to obtain a general sense of the information and to reflect on its overall meaning. An impression of the participants' general ideas, the interviews' general tone and the depth reached in the interviews could be formed.

During the second step all the interviews were read to get a feeling for the underlying meaning of the detail. The analysts wrote their thoughts on the underlying meaning in the margins of the text. They also highlighted all the participants' statements that make a substantial point. As advised by Gillham (2000:63), the transcripts were read through repeatedly to ensure that all the substantive statements were identified.

In step three all the substantive statements were listed, then clustered together as themes and arranged in columns. Each theme was allocated a draft code to identify it. These preliminary codes were of 'low inference' according to Gillham (2000:69), and called 'descriptive' by Burns and Grove (2005:549) and 'descriptive' and 'topic' codes by Richards (2005:88).

In the fourth step the analyst went through all the transcripts and marked the statements with the codes given to the themes. As the process continued, the grouping of the themes were revised to include new ones and to combine those that related to one another as new insights emerged when the coder became immersed in the data. Richard (2005:88) calls this revised codes 'analytical' as it refers to coding that comes from interpretation and reflection on meaning, where the coder must make judgements about the interviewee's latent meaning. Burns and Grove (2005:549) use the term 'interpretive', while Gillham (2000:69) refers to 'high inference' analysis. The highest level of codes - 'explanatory'

codes, involved justifying, supporting or making relationship claims (Huberman & Miles, 1994:432). At this stage the two analysts compared their work and discussed the differences in order to reach consensus.

In step number five the most descriptive wording for each theme was selected and themes divided into main themes and sub-themes. Again, the themes were reconsidered and changed where necessary. In step six a final list of themes was compiled.

In the seventh step all the data that belonged to each category was combined. The statements were marked with the interview number and the page number within the interview to enable reference back to the original transcription. *In vivo* quotations that are considered strikingly representative of the category or sub-theme, were selected for use in the discussion of the results. The content of each theme was closely reviewed for commonalities, uniqueness, confusion and contradictions as well as missing information and adjustments that were made. Data that was irrelevant to the research question and objective was discarded.

In the final step the researcher had to decide if recoding based on the final themes formulated in step 7, was necessary. At this stage another meeting with the co-analyst was held to discuss the final themes. A few minor adjustments were made. Once again all the categorised themes and codes were revised, keeping the research objective in mind.

In the next section the literature control is discussed.

2.4 LITERATURE CONTROL

After consensus was reached on the major and sub-themes, the literature was scrutinised to compare and contrast the findings. According to Creswell (2003:31) this approach is suitable for the 'inductive' process of qualitative research, as the literature does not guide or direct the study, but becomes an aid, once patterns have been identified.

Studies where researchers reached similar findings were identified. In cases where findings in the literature were not substantiated in this study, this study's unique findings were pointed out.

The following passages discuss the measures taken to assure rigour.

2.5 RIGOUR

According to Woods and Catanzaro (1988:452) qualitative research is often criticised for its lack of scientific rigor in drawing valid inferences. In contrast to this statement, Creswell (2003:195) sees 'validity' as a strength of qualitative research. The term, 'validity' is however not used in the same context as used in quantitative research and is not associated with reliability or generalisability. He states that the term, validity as used in qualitative research, is used to suggest determining whether the findings are accurate from the standpoint of the researcher, the participant, or the readers of an account.

The researcher decided to use a combination of Guba's model for trustworthiness as discussed by Krefting (1991: 215), the threats to reliability and validity according to Woods and Catanzaro (1988:136-137) together with the strategies to control it as proposed by Creswell (2003:196), as guideline for this aspect in this part of the research project. The terms of the criteria according to Guba's model can also be substituted by corresponding terms according to Lincoln and Guba (1985:300). These four criteria will now be discussed in a table indicating the relevance and application of strategies in this study.

- Truth-value / credibility
- Applicability / transferability
- Consistency / dependability
- Neutrality / conformability.

Table 2.5 The realisation of trustworthiness in phase 1 step 1

Criterion	Threats in this study	Strategies to control threats
<p>Truth-value / credibility</p> <p>Truth-value indicates whether the researcher has established confidence that the findings are a true reflection of the participants' opinions / experiences in the context in which the study was undertaken. If it is accepted that it is not possible to identify a single tangible as 'the truth' but that the different participants experience multiple realities, then the researcher's should represent those multiple realities revealed by participants as adequately as possible (Krefting, 1990: 215).</p>	<p>Selection of participants could be biased resulting in them not representing the best sources of information about the issue.</p> <p>Participants could hold back and not reveal the truth in the interview, or answer what they think the interviewer wants to hear.</p> <p>The interviewer could not be able to get the optimal information during the interview.</p> <p>The interviewer could forget or misinterpret what was said during the interview.</p> <p>Too little information could be available to make credible findings.</p> <p>The analysis could be ineffective and not capture the essence from the data.</p> <p>The researcher could state non-exciting findings from the data because of presumptions</p>	<p>All women in the population had an even chance of being selected as participants. The selection process was spelled out and the participants were informed that they could withdraw at any time.</p> <p>An experienced, well-briefed interviewer conducted the data-collection interviews.</p> <p>The interviewer established a trust relationship during interviewing to ensure that the participant felt comfortable to reveal her real opinions.</p> <p>Interview-recordings were used to ensure that the interviewer did not forget or misinterpret the participants own words.</p> <p>The interviewer noted field notes directly after each interview to ensure that no significant observations would be forgotten.</p> <p>The participant's own words were used in the reporting of the results to indicate the range and variety of responses representing each topic.</p> <p>Data-collection continued until data-saturation was obtained.</p> <p>Two data analysts analysed the data and a consensus discussion was held to ensure that the participants' true opinions were identified (Triangulation).</p> <p>Peers were consulted to check the process and the findings.</p> <p>The researcher reflected on her own experiences and declared her presumptions openly and honestly, for the readers to decide to which extend it influenced the findings.</p> <p>The findings were compared with published studies and other literature (Triangulation).</p>

<p>Applicability / transferability</p> <p>Applicability refers to the degree to which the findings can be applied to other contexts. As qualitative research projects (and also this research) are conducted in naturalistic settings, each situation is unique and research findings can therefore not be generalized.</p>	<p>No claim is made that the results would be the same for other settings and groups. It may however be applicable in similar contexts.</p> <p>According to De Vos (2005:346) it is also important to refer to the theoretical framework to indicate the base of data-collection and analysis.</p>	<p>A rich description to describe the whole research process, the characteristics of the participants as well as the context is supplied for the reader to determine to which extent the circumstances are similar to his/her own, to decide if the findings could be transferred to his/her own context (Krefting, 1990:216).</p> <p>In this research the researcher's paradigmatic viewpoint is declared in Chapter 1.</p>
<p>Consistency / dependability</p> <p>Consistency indicates the extend to which the findings would be consisted if the research were replicated with the same subjects or in a similar context.</p> <p>Due to the natural setting, it is accepted that various extraneous and unexpected variables may influence the findings. The aim in qualitative research is to learn from participants - not control them, and variation in experience rather than identical repetition is sought.</p> <p>The concept of consistency or dependability implies tractable variability.</p>	<p>For this step of the research, the researcher does not claim consistency, but auditability by providing detailed descriptions.</p>	<p>An audit trail with detailed descriptions of all occurrences during the research process, was kept.</p> <p>The two data analysts worked independently and compared their findings during a consensus meeting.</p> <p>Sources of variety that were identified can be attributed to increased insight for the interviewer and participant fatigue.</p> <p>Non-typical findings were identified as every participant's experiences are important even if it is not representative of the group's.</p>
<p>Neutrality / conformability</p> <p>Neutrality indicates to which extend the findings are a function of the participants opinions and conditions of the research and not of other biases. In qualitative research the focus is on neutrality of the data and not neutrality of the researcher.</p>	<p>In this research the researcher did not claim neutrality, but declared her assumptions in Chapter 1.</p>	<p>The researcher's assumptions were stated clearly.</p> <p>The researcher kept the original interview schedule and the recordings of the interviews, the transcripts, notes and memos to provide an audit tail.</p>

The research findings, according to the data-analysis, will now follow.

2.6 RESEARCH FINDINGS

In the following section the general impressions after reading through the notes made while conducting the interviews, the participants' biographical details and the findings following the data-analysis are discussed.

A total of twelve interviews were conducted before data-saturation was obtained. With some of the interviews a trust-relationship was established quickly and rich data was obtained. A few of the participants clearly valued the opportunity to speak about their experience. Notwithstanding the fact that all the participants volunteered to be interviewed some of the interviewees remained reserved and obtuse and the interviewer tried in vain to get them to contribute more. Mabunda (2006:23) also found in her study that some participants were reluctant to open up and discuss why they did not want to get tested and only gave brief answers. According to Watson (2002:72) cultural differences between the interviewer and interviewee can also cause interviewees to be reserved and passive.

Table 2.6 Biographic information of participants

Age	There was one teenager (19 years of age), seven participants were in their twenties and four were older than thirty.
Gestational stage	The participants' gestational ages ranged from fourteen to forty weeks, but most participants were in their first or second trimester of pregnancy, as the participants were selected at the first antenatal visit, shortly after they were counselled for HIV testing.
Gravity	There were two primigravidas, while nine were pregnant for the second time and two participants expected their third child.
Educational level	Most had between 10 and 12 years of schooling, while two were still scholars.
Marital status	Only one woman was legally married, but all were in stable relationships with the father of their baby, with the exception of one participant.
Place of residence	Most lived with the father of the baby, while two stayed with their parents and one with her grandmother.

All the participants were asked the following question:

In your opinion, what factors influence a pregnant woman's decision to be tested for HIV?

A variety of follow-up questions, prompts and probes as indicated in table 2.3 were also used to reach Objective 1, namely:

To explore and describe the factors that influence pregnant women's decision to be tested for HIV in antenatal clinics in the North West Province

The main themes and sub-themes found during data-analysis are summarised in Table 2.7.

Table 2.7. The main themes and sub-themes identified during data-analysis of step 1

Theme	Sub-theme
2.6.1 Factors that contribute to pregnant women's decision to be tested for HIV	2.6.1.1 Own decision 2.6.1.2 Influenced decision 2.6.1.3 Collective decision
2.6.2 Factors that contribute to pregnant women's decision not to be tested for HIV	2.6.2.1 Fear for personal changes if HIV positive 2.6.2.2 Fear for social changes if HIV positive
2.6.3 Organisational factors that influence pregnant women's decision to be tested for HIV	2.6.3.1 Format of counselling and testing 2.6.3.2 Support 2.6.3.3 Information 2.6.3.4 Logistical factors

Each theme, its related sub-themes and supporting literature are discussed. Extracts from the original transcripts are inserted to provide evidence that support themes and sub-themes. These extracts are referenced with the number of the participant, followed by the relevant page of the specific transcript. Themes and sub-themes were elaborated upon by means of a literature control, where corresponding or conflicting findings found in the literature were cited in relation with the present findings. Conclusion statements of each theme are provided before discussing the next theme.

2.6.1 Factors that contribute to pregnant women's decision to be tested for HIV

The first theme combines the comments related to factors that influenced the pregnant women to agree to be tested for HIV. This theme was divided in three sub-themes:

- **Own decision** when women decided on their own to be tested because they saw the benefits it held for themselves or their babies,
- **Influenced decision** when pregnant women did not make an independent decision, but were persuaded by others to be tested and chose the route of less resistance, and
- **Collective decision** when a group of women decided together to be tested.

2.6.1.1 Own decision

The women that decided on their own to be tested for HIV, had various reasons for making this decision.

- **“For the safety of the baby”**

A prominent reason why pregnant women decided to be tested mentioned by most of the participants, was that they wanted to know their HIV status for their baby's sake. They mainly saw benefit for the baby if the mother's HIV status is known. This motivation was based on knowledge about the measures that can be taken to prevent mother-to-child transmission of HIV, that have reached the women, as well as a well developed sense of responsibility for the baby's welfare. Counsellors, who participated in focus groups on calls received from women regarding mother-to-child transmission, recommend that women must receive even more education about the benefit for the baby as this acts as a powerful motivation for the mother to be tested (Birdsall *et al.*, 2004:7).

“I think it's very good to test for the safety of the baby.” (1:4)

“Ek gaan, ek moet vir die babatjie gaan, toe gaan ek.” (“I must go, I must go for the baby, then I went”) (2:4)

Awareness of HIV status for the baby's sake was also found in a qualitative study of Boyd *et al.* (1999:25) regarding pregnant women's opinions of HIV testing in Scotland. In this study the benefit for the baby was found to be one of the main motivators for the women to be tested. It was also considered an important reason by the participants in the study of Toivo (2005:34) as well as Romero-Gutierrez *et al.* (2007:26).

Some women were concerned about the effect on their own life if the baby is infected.

“For the sake of the baby, after all, if you have the baby, maybe he gets ill, maybe you will never know what is the cause of that sickness. So I think they (pregnant women) must be tested.” (3:5)

“No one wants to have a baby that is HIV positive and is going to die.” (1:6)

The focus on the benefits for the baby was logical in the period when antiretroviral drugs were only dispensed to prevent mother to child transmission, but not suitable anymore in an era when antiretroviral therapy is available as treatment. This general trend in HIV counselling for pregnant women lead Rosenfield and Figdor (2001:703) to ask ‘Where is the M in MTCT?’

One of the women indicated that although she thinks it is necessary for pregnant women to know their status to protect their babies against possible mother-to-child transmission of HIV, she does not see the benefit for herself and probably would not be tested if she was not pregnant.

“If I was not pregnant, I was not going to do the test.” (3:5)

Some women had another perspective.

- ***“It is important for me, not for someone else.”***

In contrast to the opinion that there is no self-benefit for a woman to know her HIV status, certain women consented to be tested mainly for their own sake. The motivation is evident from the following verbatim quotes from the interviews.

“Ek voel dit is belangrik vir my, ek moet weet wat aangaan, want ek het nog ‘n hele toekoms voor my.” (“I feel it is important for me, I must know what is going on, because I have an entire future ahead of me.”) (4:4)

“Ek wil weet wat makeer ek. Ek wil aan die einde van die dag weet.” (“I want to know what is the matter with me. I want to know at the end of the day.”) (7:2)

"Ek wil weet waar ek staan." ("I want to know where I stand.") (9:2)

"It was a must to do it, because I wanted to know my status. I wanted to know that I am clean or that if I am not clean, I can take good care." (12:1)

"They must know their status. It is important for me, not for someone else. For I, for myself." (12:5)

Romero-Gutierrez *et al.* (2007:26) and Fernandez *et al.*'s (2000:464) studies reveal that the perceived benefits for the woman herself was an important incentive to be tested. This contrasts with the findings of Boyd *et al.* (1999:25) where no one spoke of the perceived benefits to themselves, but only those for the baby. In contrast with the findings of Toivo's (2005:35) study, none of the participants associated access to antiretroviral therapy if found to be HIV positive as a benefit of being tested for HIV.

Irrespective of the motivation for testing, women can only take the decision once they are ready.

- ***"I'll tell you if I am ready"***

An important consideration for a woman who took a conscious decision to be tested for HIV was that she had to be ready to be tested.

"I'll tell you if I am ready. You'll tell yourself, I am ready to test." (8:4).

A number of the women indicated that they were scared and spend time to make the decision to be tested. Some thought about it before coming to the clinic, while others ponder about it after they received the pre-test counselling. They did not want to be pressured to make the decision, but wanted time to make a conscious decision. This train of thought is evident from the following quotes.

*"[Were you scared yesterday, when you think of coming today?]
Yeh, even this morning when I was coming, Joh!" (3:8)*

"You'll tell yourself, I am ready to test. You seewith no one forcing you to test." (8:4)

"Ek het nie dieselfde tyd (direk na die berading) gegaan nie. Ek het eers gesit en dink, moet ek gaan of moet ek nie gaan nie? Op die laaste toe dink ek, nee, laat ek gaan vir die toets, want ek wil weet waar ek staan." ("I did not go at the time of the counselling. I first sat and think, must I go or must I not go? At last, I thought, no, I will go for the test, because I want to know where I stand.") (9:2)

- ***"maybe some other day I will change my mind."***

With regard to readiness one participant mentioned that the counsellors must give pregnant women time to get ready to accept testing. She stated that counselling must not just be once-off but should continue until the woman feels ready.

"Sometimes they counsel us once, then I say no, I don't want to take the blood test. Then maybe if they come continuously, maybe some other day I will change my mind." (6:3)

The participant's suggestion is in agreement with other studies' findings (Maman *et al.*, 2001:602; De Paoli *et al.*, 2002:148). In these studies it was found that a one-time pre-test counselling session may not be sufficient for pregnant women who visit an antenatal clinic, unaware that HIV testing will be offered.

Readiness applies both to be notified of her own status as well as disclosing this information to others.

"..you don't want your friends or your mother, your parents, your family to know about it. You will tell them if you are ready to tell them." (3:3)

According to Bodkin (2004:230) HIV positive patients often postpone disclosure of their status until they have accepted the diagnosis themselves.

Some participants do not take a conscious decision to be tested for HIV, but are persuaded by someone else.

2.6.1.2 Influenced decision

Some of the participants' decisions were influenced by others and not made independently.

- ***“My grandmother told me to do the test.”***

Although other studies have found that the decision to be tested for HIV is often made with input from other family members or a woman's partner (Cartoux *et al.*, 1998:2339; Beevor & Catalan, 1993:3; Romero-Gutierrez *et al.*, 2007:26) it was not commonly found in this study. None of the women in the current study were married but most lived with their partner with whom they had a stable relationship or with their parents. Only one of the participants was persuaded by a family member - her grandmother.

“My ouma het gesê ek moet die toets maak.” (“My grandmother told me to do the test.”) (10:2)

This absence of input by significant others when making the decision to be tested, could be an indication that HIV testing is not discussed in the family as it is considered a taboo-subject due to the associated stigma.

One participant mentioned discussing possible infection with her friends.

“I am talking about it with my friends and they told me, yo, I am scared, what if I become positive, what am I going to do? What am I going to tell my parents? Something like that.” (3:5)

2.6.1.3 Collective decision

Certain participants decided together to be tested for HIV. The group received health education about HIV in a group during the antenatal clinic session.

- ***“...then everyone say - I want to test.”***

“When the first person says I want to test, then everyone say - I want to test.” (1:6)

Solomon *et al.* (2004:15) warns against the possibility that women who are part of a group that receives pre-counselling may feel pressured to 'consent' to testing. No evidence of women who felt coerced was found in this step of the present study.

2.6.1.4 Conclusion statements regarding factors that contribute to pregnant women's decision to be tested for HIV

The first major theme addresses factors that influence pregnant women who gave their consent to be tested for HIV.

- Pregnant women **decide on their own to be tested** for HIV due to their motivation of **perceived benefits for the baby**.
- Pregnant women **decide on their own to be tested** for HIV due to their motivation of **perceived benefits for themselves** if their HIV status is known.
- Pregnant women **need time to be ready** to be confronted with a possible positive HIV result.
- Some pregnant women **are influenced by family members and friends** in their decision to be tested but no one mentioned that a husband or partner needs to be consulted before the decision is made.
- Some pregnant women are tested for HIV after **collective decision making** where a group of pregnant women received pre-pest counselling together and decided together to be tested.

The next theme identified, focussed on the factors that could influence pregnant women who decide not to be tested.

2.6.2. Factors that contribute to pregnant women's decision not to be tested for HIV

The second main theme that crystallized combines the comments related to factors that contributed to the pregnant women's decision not to consent to be tested for HIV. Fear for change if found to be HIV positive was a major theme and was either related to their personal lives or their social life:

- **Fear for personal changes if HIV positive** includes fear regarding living conditions and health;
- **Fear for social changes if HIV positive** includes fear for change in her relationships with her partner, family and community.

According to the participants, one of the main reasons why women decide not to be tested for HIV is that they are afraid of how a positive HIV diagnosis will change their lives in different ways. One participant verbalised the possible effect of a positive HIV diagnosis as follows:

- ***“Everything would change today if I was positive, everything!”***

Some women decided not to be tested because they believe that an HIV positive diagnosis will change their lives totally and that this change will be negative. By not consenting to be tested, they want to postpone this possible negative change.

“Everything would change today if I was positive, everything!” (3:3)

“The world is going to be black – that is something!” (3:4)

They believe the change will influence both their personal and social lives.

2.6.2.1 Fear for personal changes if HIV positive

The fear of the change in one’s personal life could be enough of a detriment to convince someone not to consent to be tested for HIV. Both their living conditions and health can be negatively influenced.

- ***“Sometimes you don’t have a place to stay.”***

Some were worried about the possible changes to the security of their living conditions or income.

“... when you tell your partner or your parent ... sometimes you don’t have a place to stay.” (1:2)

"Hulle is bang dat hulle sal sukkel, hoe gaan hulle werk? Hoe gaan jy betaal vir alles?"
(*"They are afraid, ... that they may suffer, how are they going to work? How are you going to pay for everything?"*) (9:2)

This fear of losing security has also been noted in other studies (Pool *et al.*; 2001:612; Cartoux *et al.*, 1998:2343; Maman, 2003:4). Bodkin (2004:235) pointed the sense of powerlessness and dependency many women face, out. This feeling of powerlessness, contributes to pregnant women not wanting to know their HIV status.

Other women were more concerned about the changes to their health.

- ***"You are going to be sick that moment."***

A number of the participants mentioned the perception that a person would get ill more quickly as soon as they were aware of their HIV status. The participants believed that some pregnant women would prefer not knowing their status even though they may be infected, as they fear that they may get ill quickly after receiving the diagnosis.

"..hulle sê miskien jy is positive, jy word siek vinnig want hulle het vir jou gesê." (*"..they say, if you are positive, you get ill quickly because they told you."*) (2:2)

"The minute you get the results, and you're (positive), you are going to be stressed. You are going to be sick that moment." (3:6)

"They say they will get more sick, because they will have a lot of stress." (12:3)

Certain pregnant women who participated in Toivo's (2005:42) study also believe that it is better for them not to be tested as the knowledge of a positive status, would bring death nearer.

- ***"They are afraid their life will end right then."***

Furthermore, it is a widely accepted perception that a person who receives a HIV positive diagnosis, does not only get stressed and ill, but that death will follow soon after he/she received the news of their HIV positive status.

"Hulle is bang hulle lewe gaan net daarop eindig." ("They are afraid their life will end right then.") (4:2)

"..as hulle sê jy is HIV positive, jy het niks tyd nou." (If they say, you are HIV positive, you have no more time.) (2:3)

This belief regarding death that occurs soon after receiving a positive HIV diagnosis is supported in the literature (Van Dyk & Van Dyk, 2003b:120; Cartoux *et al.*, 1998:2343).

- ***"... there is a lot that may kill themselves."***

The participants linked the idea of death that rapidly follows a positive HIV diagnosis, to both death from AIDS and death due to suicide on receiving the news. This indicates severe despair and experiencing no hope for the future.

"Hulle dink net aan die dood." ("They just think about death.") (9:1)

"Party mense kan mos nie sulke goed hanteer nie. Ek meen daar is baie wat hulself dalk sal doodmaak." ("Some people can not handle such things. I mean there is a lot that may kill themselves.") (7:2)

"...if they just test you and you find out you have HIV, then you are going to be depressed and tell yourself, I'm going to kill myself ..." (8:4)

According to Toivo (2005:44) people in Namibia often regard suicide as a solution for problems caused by finding out their HIV positive status. Soon and Barnard (2002:16) as well as Marcenko and Samost (1999:39) also indicate the possibility that the despair experienced by HIV positive persons, could lead to suicide. Bodkin (2004:208) observed feelings of despair and hopelessness in the HIV positive women she interviewed. According to Warburton *et al.* (1997:463) HIV positive individuals who use a primary coping style such as seeking out (monitoring) or avoidance (blunting) of information to reduce their stress, do better than individuals who do not use a single primary coping style. Preferring not to know about your positive status (but suspecting it) may be considered blunting.

The intense devastation that could follow a positive HIV test cause pregnant women, not to consent to the test as they prefer not to be confronted with the possibility (and may be suspecting) that they are HIV positive.

2.6.2.2 Fear of social changes if HIV positive

That participants indicated that in addition to the fear for personal changes that may follow a positive HIV diagnoses, pregnant women could also be afraid of the social consequences.

- ***“HIV brings mistrust between people.”***

Some participants indicated that they believe that certain pregnant women prefer not to know their HIV status, because they are afraid of the possible effect it would have on their relationship with their partners. They believe that their relationships will suffer as blame and mistrust will occur.

“...Scared, because you can’t trust everybody, like your partner. Sometimes you don’t know what he is doing behind your back. HIV brings mistrust between people.” (6:5)

“En dan blameer haar man ook nog, maar dan het hy dit dalk nog vir haar gegee.” (“And then he blames her, but then maybe he gave it to her.”) (7:2)

“Want ek meen, ‘n mens slaap nie rond nie, maar jou boyfriend loop rond.” (“I mean, one doesn’t sleep around, but your boyfriend goes around.”) (7:3)

One of the participants told the interviewer of her own anguish before she had the test.

“Now me, I was scared, what if I am positive and my boyfriend is negative, where did I get it? Or my boyfriend is positive and I am negative, what will happen to us?” (12:2)

- ***“... they will be rejected....”***

According to the participants, they are afraid that they will be rejected when a positive HIV status becomes known.

According to Marcenko and Samost (1999:39), Soon and Barnard (2002:16) as well as Yoshioka and Schustack (2001:78), HIV positive women find it especially difficult to disclose their status to their parents, as they fear the consequences.

"Hulle families skryf hulle af." ("Their families write them off.") (7:2)

The following quote links the fear of rejection to both the family and the partner:

"They are afraid of having that disease and tell their partner or their parents because sometimes they will be rejected by their partners." (1:2)

According to one of the participants, a pregnant woman could fear the end of her relationship and rejection from her partner when her positive status becomes known.

"If she is positive, now her boyfriend is going to dump her." (12:2)

The participants in the studies of Maman *et al.* (2001:599), Rutenberg (2003:7) and Toivo (2005:37) also revealed that women feared that their relationships would end when their partners found out that they were HIV positive. Both these studies found that the fear was usually not substantiated as most of the partners were supportive and only 5% of relationships ended after disclosure.

None of the participants mentioned the possibility of physical danger that could face the woman if her partner becomes aware of her HIV-positive status. Violence is however, mentioned in the literature (Bodkin, 2004:230; Maman, *et al.*, 2001:600; Rutenberg, 2003:7; Stein & Samet, 1999:266; Temmerman *et al.*, 1995:969).

- ***"What will people say...?"***

The second point related to fear of changes to a pregnant woman's social life is the fear of stigma related to HIV in the community. It was an underlying theme in most of the interviews. It

seems as if the existence of stigma against HIV positive individuals is accepted as a fact of life and can be considered an underlying reason why pregnant women decide against having an HIV test.

What will people say if she is HIV? (12:2)

“Ander mense gaan sê, sy loop daar by die kliniek, sy het HIV. Daai ding gaan sit by my hart, want ander een gaan vir my sê as ek maer word, hulle gaan sê ek het AIDS.” (“Other people are going to say, she is going to the clinic, she has HIV. That thing is in my heart, because someone else will say, if I get lean, they are going to say I’ve got AIDS.”) (2:6)

“.. ek dink hulle voel seker skaam hulle goed is nie meer geheim by die kliniek.” (“I think they feel ashamed their things is not secret anymore at the clinic.”) (4:3)

Some women were even afraid that consenting to be tested could be perceived as an indication that she may be HIV positive and result in her being stigmatised. Aynalem *et al.* (2004:29) also found that women were afraid that they will be stigmatized by merely accepting HIV-testing. They believed that others may see it as an indication that she has engaged in high risk behaviour.

Although it is mentioned in the literature (Ayanlem *et al.*, 2004:29; Boyd *et al.*, 1999:24; Romero-Gutierrez *et al.*, 2007:26), not one of the participants in the current study mentioned that they think pregnant women do not want to be tested because they think they are at a low risk of being infected. According to Campbell and Bernhardt (2003: 549) a perception of a low HIV infection risk could be linked to inadequate HIV knowledge. Therefore, participants in the current study may be knowledgeable about the HIV infection risk factors and realise that everybody that is sexually active is at risk.

2.6.2.3 Conclusion statements regarding factors that contribute to pregnant women’s decision not to be tested for HIV

The second major theme relates to factors that influence pregnant women when they decide not to be tested for HIV.

Fear of the changes that a positive result will cause is the main factor that causes women to decide to not be tested for HIV. These possible consequences that are feared can be related to personal or social factors.

- Pregnant women may decide not to be tested for HIV due to fear that they may lose their **secure livelihood; get ill more quickly and that death soon may follow. The resulting despair that follows may lead to suicide.**
- **Fear of social changes that cause** pregnant women not to be tested for HIV, include fear of being **rejected** by her partner due to mistrust, although **no mention was made that women could be afraid of violent behaviour** by the partner following the disclosure of the diagnosis.
- Pregnant women can decide not to be tested for HIV due to fear of possible **stigmatisation in the community.**

In addition to changes feared in their personal and social lives, factors relating to the health services also play a role in the pregnant woman's decision when she considers HIV testing.

2.6.3 Organisational factors that influence pregnant women's decision to be tested for HIV

In the following section the aspects relating to the health services' role in counselling for HIV testing are considered. These factors include:

- **Format of counselling and testing:** counselling can be presented in a group or individually. Confidentiality is also addressed;
- **Support** include those aspects of counselling that deals with supporting the counselee;
- **Information** concerns the educational part of counselling;
- **Logistical factors** deals with issues such as having to wait a long time, whether HIV testing services should be integrated with other services, the attitude of staff members as well as the apparent shortage of staff.

The participants' suggestions on how to improve the service are integrated with their responses to the questions.

2.6.3.1 Format of counselling and testing

Clinics differ in the way in which they organise the pre-test counselling that pregnant women receive. In all the clinics counselling is conducted before the test and the advantages, disadvantages, consequences of a positive and negative result and the procedure are discussed. This usually takes place in a group where the counsellor speaks to all the pregnant women that visited the antenatal clinic for the first time. After this session, the women receive the opportunity to meet the counsellor in a private room to indicate if she would want to be tested or not. A rapid test is then executed if indicated. The relevant post-test counselling (for a positive or negative result) is then conducted. In two of the clinics, the pre-test counselling also occurs in private with only the woman and the counsellor present.

- ***“...if you are in a group... , it is nice.”***

The participants' responses seem to suggest that pregnant women like receiving the health education part of the counselling in group format as they receive support from the rest of the group.

“As jy alleen gaan vir die counselling, jy voel nie so, jy kry support maar nie so ..., maar as jy in 'n groep is – is lekker so.” (“If you go alone for the counselling, you don't feel so, you do get support but not so, but if you are in a group... , it is nice.”) (9:4)

Cartoux *et al.* (1999:200) found that pre-test counselling presented to a group is just as acceptable and effective as individual counselling, but more cost- and time effective. A few of the participants mentioned that it was difficult to ask questions in the group, but that they clarified information when they were alone with the counsellor. Birdsall *et al.* (2004:8) found that women often do not ask questions even though they are unsure of aspects they receive health education or counselling on.

- ***“Alone is better. They tell you on your own, you have HIV.”***

The pregnant women appreciated the privacy when declaring their intention to be tested or not to the counsellor. It also allowed them to ask personal questions and they appreciated the privacy when they received the test results.

"In the group they give the counselling, and if you tell them if you want to test and they do the test, you are alone with the counsellor. I think it is good." (1:5)

"Alleen is beter. Hulle sê vir jou alleen, jy het HIV. Jy kan sommer net soos die ander sit. Die ander mense weet nie." ("Alone is better. They tell you on your own, you have HIV. You can sit just like the others. The other people don't know.") (2:6)

In all the studies found, the testing and post-test counselling was conducted in private.

One of the participants' recommendations to improve patient care is that staff must be made aware that patients should be treated as individuals. According to the following quote, the pregnant women would appreciate individualised care.

"You see, we are not the same, we don't have the same heart, the same feelings....they treat us the same, but we are not the same." (8:3)

An important consideration of individualised care is keeping patients' personal information, their HIV status especially, confidential. Women will not consent to be tested for HIV when they do not trust the counsellors and other staff to keep their personal information, especially their HIV status, confidential.

- ***"They say it is confidential, it stays between you. But a person stays human...."***

From the number of interviews where this aspect was mentioned, it is clear that this one aspect, lack of trust that the clinic staff would honour confidentially, can definitely cause pregnant women to decide not to be tested for HIV. This is evident in the following verbatim quotes from the interviews:

"We are afraid to go to the hospital because my neighbour is working there; he is working with the test results. I can't go to the hospital." (3:7)

“Baie van die vrouens kla dat dit nie veilig is hier by die kliniek om die toetse te neem nie.” (“A lot of the women complain that it is not safe to take the tests here at the clinic.”) (4:2)

“Hulle sê dit is confidential, dit bly tussen julle. Maar mens is ook maar net mens. Nou werk ek en jy saam. Ek doen die AIDS kursus en dan sê ek, weet jy daai enetjie het ook AIDS.” (“They say it is confidential, it stays between you. But a person stays human. Now me and you work together. I do the AIDS course and then I say, you know, that one also has AIDS.”) (7:3)

“Maybe the nurse find out that you are positive and she doesn’t tell you. She tells the other nurses and they communicate, but they are afraid to tell you, you are positive... That’s what they do here at the clinic.” (12:2)

A lack of trust and fear of breach of confidentiality by the health personnel is a common theme in the literature (Fylkesnes, 2000:S43; Pool *et al.*, 2001:610; Toivo, 2005:40; Van Dyk & Van Dyk, 2003b:122). Maman *et al.* (2001:601) also mentioned that individuals who are aware of possible breach in confidentiality may choose not to be tested for HIV.

None of the participants could mention a specific incident where a patient’s HIV status became known because of the clinic staff’s misconduct, although one participant mentioned that her positive pregnancy test was not kept confidential! Van Dyk and Van Dyk (2003b:122) mentioned that although counsellors receive training to keep a person’s HIV status confidential, they sometimes feel obliged to inform the patient’s partner or family.

- ***“They must get someonewho doesn’t know me.”***

The fear for breach of confidentiality by the health workers was so intense that one of the participants mentioned that she preferred to be counselled and tested by someone from another community. She was very uncomfortable with the possibility that she may meet someone on the street who knows her HIV status. This indicates an intense fear of stigmatisation.

“I want to be tested by a white person, because they don’t know me.” (3:7)

“They must get someone from XXXXX who doesn’t know me, or someone from ZZZZZZ, a person that doesn’t know us, or a white person.” (3:7).

Fylkesnes (2000:S43) pointed out that participants in Lusaka were more willing to be tested in a location of their choice than at their local clinic. He attributed it to the high value people place on privacy and the perception that personnel at health facilities are not trustworthy.

- ***“ just take the blood”***

One of the participants prefers not to be confronted by the knowledge of her positive HIV status, but would not want to miss the opportunity to benefit from the treatment available. This preference to live in ignorance may be related to the perceived quick deterioration of an HIV positive person after receiving the diagnosis. She recommended that the clinic staff must not talk a lot, just do the test, write the results in scientific language so that patients do not understand and then give treatment, without informing the patient of her status.

“Hulle moet nie die mense vra nie, moet net die bloed vat, en skryf by jou papier dat jy nie verstaan nie, maar hulle gee jou die ARV’s.” (“They must not ask the people, just take the blood and write on your paper in a way that you cannot understand, but then give you ARV’s.”) (2:5)

It would be a violation of human rights to test someone without asking her consent, but there are ways to make the process less threatening. Bassett (2002: 350) and Temmerman *et al.* (1995:970) recommend a similar option where everybody are tested but that women could ‘opt-out’ from receiving the results and still receive treatment if indicated. The participants of the study of Boyd *et al.* (1999:24) mentioned that they would be more willing to consent to testing if they do not specifically have to ask for it.

2.6.3.2 Support

Regarding support-giving, the participants indicated that they appreciate the councillors’ effort to reduce their anxiousness.

“... if you are afraid, you calm down.”

The participants valued the counselling they received.

"She wanted to make me comfortable." (3:8)

"You see, it was very good, because if you are afraid, you calm down." (8:2)

"..maybe if you are not counselled ..and they just test you and you find out you have HIV, then you are going to be depressed and tell yourself, I'm going to kill myselfif you didn't get counselling." (8:4)

"Ek het free gevoel, baie free." ("I felt free, very free.") (9:3)

The participants in the study of Moosa (1998:66) also noted the counselling that they received to be satisfying and cited that it met their needs.

Some women stated their emotional reaction with regard to HIV testing. It is difficult to be clear about the specific emotional responses experienced as certain mothers had limited vocabulary with which to express themselves, but words such as afraid, stressed and scared were used. These emotions were experienced before and during counselling and testing and were related to the possible consequences of the test. The emotions experienced by the pregnant women emphasise the need for the support giving part of counselling.

No one in the current study mentioned the need for continuous post-test counselling. A possible reason may be the focus of the questions on counselling for HIV-testing (pre-test counselling). Van Dyk and Van Dyk (2003b:119) pointed out that to know one's HIV status without follow-up support services or treatment can be detrimental to a person's mental and physical well-being and could lead to feelings of fatalism and depression. Ongoing counselling and support was also recommended by Doherty *et al.* (2003:17) after evaluating the pilot project of the Mother-to-child transmission of HIV initiative in South Africa.

Although there were indications that women appreciated the support that they received from the counsellors, these comments contrast with the distrust they experience regarding respect for confidentiality at the clinics and the comments regarding the staff's uncaring and rude attitudes.

The second main component of the counselling was providing information.

2.6.3.3 Information

The participants, who consented to be tested because it would benefit the baby, took this decision based on their knowledge of measures that can be taken to prevent mother-to-child transmission. The interviews reveal that while they are educated during the pre-test counselling, they also receive information from other sources.

They counselled us about how to protect the baby ...when you are going to deliver, they give you something ...if you are HIV positive. I think it is good for the baby because he or she will not be infected with AIDS and then if you are HIV positive, you can breastfeed your baby for three months and not give her or him any water or anything, only breastfeeding.” (1:4)

“Daar was die vrou, sy het met my oor die HIV gepraat. As jy dit het is daar ‘n sekere pil wat hulle vir jou gee om te maak dat die kind dit nie kry nie.” (“There was this woman, she talk to me about HIV. If you’ve got it there is this tablet that they give you so that the child doesn’t get it”) (5:6)

“Hulle sê vir jou alles wat jy moet weet. Hulle gee vir jou pamflette. Dit kom oor die nuus, reg oor die wêreld, word vir jou gesê hoekom die toetse belangrik is.” (“They tell you everything you must know. They give you pamphlets. It is on the news, all across the world, you are being told why the tests are important.”) (4:3)

“Die ding wat gemaak het dat ek gaan vir die toets is omdat ek radio luister en na die televisie kyk.” (“The thing that made me going for the test is because I listen to the radio and watch television.”) (9:3)

The participants appreciated the health education they received.

- ***“.. she gave me all the information that I must know.”***

The following quote indicates the trouble taken to ensure that the patient understands the information.

"Sy was baie gaaf en sy het vir my al die inligting gegee wat ek moet weet. Van die dinge het sy vir my vier keer oor gesê sodat ek kon verstaan." ("She was very kind and she gave me all the information that I must know. She told me some of the things four times to ensure that I could understand".) (4:4)

The participants in the study reported by Rutenberg *et al.* (2003:4) also valued the information they received through counselling as they felt empowered and less helpless because of it.

- ***It would be nice if they can get something***

A number of the participants recommended more health education material. The information in the format of posters and pamphlets must be focussed on information about HIV testing for pregnant women.

"Ek dink meer plakkate, dat mense weet counselling is belangrik." ("I think more posters, that people know counselling is important") (4:6)

Dit sal lekker wees as hulle iets kry ... miskien 'n papier om te lees. Hoe dit sal wees, hoe moet hulle maak..("It would be nice if they can get something Maybe a paper to read. How it will be, what they should do...") (9:4)

One of the participants in the study of Boyd *et al.* (1999:25) warned against giving too much information on leaflets, as too much information will render people less inclined to read it and they will rather reject it.

- ***".. if they get more information . . It would be easier for them to come for testing"***

The broader public must also receive education on the benefits of HIV testing during pregnancy. Mass media such as radio, television or billboards is suitable for this aim. This may lead to better support for pregnant women while they decide if they want to be tested or not. It could also encourage the public to be tested.

"If people can go and tell the pregnant women about the HIV status. That if they do the HIV test, it doesn't mean they got the virus." (12:4)

"Miskien as die mense in die community, as hulle meer inligting kry, hulle sal makliker.. dit sal makliker wees vir hulle om te kom toets." ("Maybe if the people in the community, if they get more information, they would easier.... It would be easier for them to come for testing.") (9:6).

Pregnant women who participated in the study of Toivo (2005:49) also felt that community education was needed and that both women and men need to be educated. They hoped that the training would educate women about the importance of VCT to clarify the myths and misconceptions surrounding voluntary antenatal counselling and testing. They also felt that if men were educated, they would encourage their pregnant partners to be tested.

2.6.3.4 Logistical factors

Some participants mentioned logistical factors that may influence the HIV testing counselling that pregnant women receive at the antenatal clinics. These logistical factors include, long waiting periods, disrespectful behaviour from the clinic personnel and a suggestion to appoint more staff.

Some participants complained about the long periods that they had to wait before consultations at the antenatal clinics. However, a number of participants declared that they do not think it is a reason why some pregnant women decided not to be tested for HIV.

- ***"You are sitting in a queue"***

"You come at seven o'clock this morning and it's already after eleven and you're hungry. You are sitting in a queue." (6:4)

"Jy het wasgoed of iets by die huis wat jy moet doen en dan moet jy hier sit en wag." ("You have laundry or something at home that you must do, and then you must sit here waiting.") (7:4)

Rutenberg *et al.* (2003:3) found that women in East Africa also felt discouraged by long waiting periods at clinics.

The participants had a solution to this problem. They recommended that services should be organised to ensure that patients do not have to wait for long periods.

"If they say we must come for counselling, just counselling that day then tomorrow we must come again to see the doctor to see if all is well." (6:4)

"Laat hulle party dae net vir toetse gebruik. Dan weet jy mos.. Ek gaan in en ek gaan uit en dit is verby." ("Let them use certain days just for tests. Then you know.. I go in and I go out and it is finished.") (7:4)

In contrast with these recommendations, Rutenberg *et al.* (2003:3) found that women did not like returning on a separate day for counselling, but preferred the service to be integrated.

- ***You wait the whole day and then they even scold you***

Participants who attended different clinics complained that some clinic staff is rude to patients and also lazy.

"Van die personeel is baie onbeskof, jy kan nie met hulle werk nie. Jy wag die heeldag en dan skel hulle nog" ("Some of the staff is very rude, you can't work with them. You wait the whole day and then they even scold you.") (4:5)

They are too lazy! If you come, they say: I am going for coffee and they are gone for too long (12:4).

Unfortunately this perception of the clinic staff is not uncommon. Abrahams *et al.* (2001:245), Birdsall *et al.* (2004:8), Bodkin (2004:233) and Pretorius (2001:155) also found that pregnant patients perceive the actions of the staff of antenatal clinics as uncaring. Abrahams *et al.* (2001:246) concluded that this may be one of the reasons why women do not attend antenatal care.

One of the reasons why health workers are perceived as rude may be frustration caused by work overload. Couper (2004:2) explains how health workers become increasingly callous when

they continuously struggle to deliver services to an increasing number of ill people with inadequate resources. A common explanation for staff acting rudely is overwork due to staff shortage which leads to low morale. According to Bassett (2002:347) enough counsellors is a prerequisite for an effective VCT service.

- ***“They must appoint more people”***

Some of the participants in the present study recommend that more staff should be appointed, to ensure that they can be helped quicker.

“Hulle moet meer mense aanstel, want die personeel is min en van die personeel doen twee werke wat hulle ophou met die hele kliniek en dan word dit vol wat die mense dan ophou.”
(They must appoint more people because the staff is few and some of the staff do two jobs that detain them with the whole clinic and then it gets full which detains the people.) (4:6)

Rutenberg *et al.* (2003:3) found that appointing more staff and reorganising staff's work hours were successful strategies towards improving the uptake of HIV counselling services.

2.6.3.5 Conclusion statements regarding organisational factors that influence pregnant women's decision to be tested for HIV

The third main theme related to organizational factors that influence pregnant women's decision to be tested for HIV.

- Pregnant women like to receive the **health education part of the pre-test counselling in a group**
- Pregnant women appreciate **privacy when disclosing their decision regarding testing.**
- Pregnant women are suspicious about the **health personnel honouring confidentiality of their HIV status.**
- **Support during counselling could encourage pregnant women to be tested** but no-one specifically mentioned the need for on-going post-test counselling.
- Pregnant women **appreciate individualised care.**

- Pregnant women recommend that **health education material such as pamphlets** be used as they receive information about HIV and prevention of mother-to-child transmission from a variety of sources
- Pregnant women recommend that the **community receive more information about the importance of HIV testing** – especially during pregnancy.
- Pregnant women complain **about waiting in long queues** and suggest that certain days are designated for HIV testing to accelerate the process.
- Pregnant women complain that health **personnel are rude** to patients.
- Pregnant women recommend that **more staff be appointed**.

2.7 PERSONAL REFLECTIONS

According to the qualitative approach it is acceptable to reflect on aspects that the researcher became aware of while being engaged with the data. General trends that were evident, although there may not be specific direct quotes from participants to substantiate it, are discussed.

It was clear that the multilingual characteristic of the South African society, also affects the quality of counselling for HIV testing during pregnancy. Most of the counsellors and pregnant women were Setswana speakers, yet a few of them used another mother language. Although they could communicate superficially in a language that both of them understood, it was apparent that the counsellors found it difficult to explain complex concepts. During one of the interviews it was mentioned that a HIV positive woman receives a tablet during the birth process to ease her pain – she misunderstood the counsellor's explanations on the indication of the tablet (Neverapine to limit mother-to-child transmission of HIV).

Partner involvement in counselling and testing as strategy to increase uptake of testing is widely promoted in other countries but does not attract a lot of attention in South Africa. No woman even mentioned that she consulted with her husband before deciding to be tested or that she would like to be tested with her partner. This may be because only one woman in the group was married, but studies in similar contexts in Africa (Farquhar *et al.*, 2004:1620; Homsy *et al.*, 2006:149) where most mothers are not married, found partner counselling and testing a useful and effective strategy. Research on the applicability of such a strategy in South Africa is needed.

2.8 SUMMARY

The process to reach Objective 1: To explore and describe the factors that influence pregnant women's decision to be tested for HIV in antenatal clinics is described in Chapter 2.

In this chapter the research design, research method including population and sampling, data-collection and data-analysis as well as literature control, rigour and research findings of step 1 of phase one (compilation of evidence as preparation for development of best practice guidelines) were addressed.

The conclusions of the findings (together with the evidence compiled from the other steps) will be addressed again in Chapter 6.

Step 2 of phase 1 addresses the next objective and will be discussed in Chapter 3.

CHAPTER 3

FACTORS THAT INFLUENCE COUNSELLING FOR HIV TESTING DURING PREGNANCY ACCORDING TO COUNSELLORS

(Phase One: Step Two)

The previous chapter addressed the factors that influence the pregnant women's decision to be tested for HIV. Chapter 3 describes the factors that influence counselling for HIV testing according to the counsellors. Since the methods used for data-collection and -analysis in this step, are to a large extent similar to those discussed in the previous chapter, the reader is referred back to chapter 2 where relevant.

3.1 INTRODUCTION

The following objective is addressed in this chapter:

Objective 2: To explore and describe the factors that influence counselling for HIV during pregnancy according to counsellors who practice in antenatal clinics in the North West Province

Table 3.1 Structure of research project indicating Step 2

<p>Phase 1: Compilation of evidence as preparation for development of best practice guidelines</p> <p>Step 1: Explore and describe the factors that influence pregnant women's decision to be tested for HIV</p> <p>Step 2: Explore and describe the factors that influence counselling for HIV testing during pregnancy according to counsellors</p> <p>Step 3: Explore and describe current practice regarding counselling for HIV testing during pregnancy</p> <p>Step 4: Systematic review of studies regarding counselling for HIV testing during pregnancy</p>		<p>Phase 2: Development of best practice guidelines</p> <p>Step 5: Formulation of best practice guidelines</p>
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3.2 RESEARCH DESIGN

The entire project's research design is discussed in Chapter one (see 1.5.1). As step 2 of phase 1, this step of the study contains explorative, descriptive and contextual qualitative methodology.

In order to explore the factors that influence counselling for HIV testing during pregnancy, it was essential to gain the counsellors' perspective. The counsellors could contribute to the data, through reflecting on their work. This knowledge will contribute to complete the picture of evidence when developing the best practice guidelines.

3.3 RESEARCH METHOD

The discussion of the research method in this chapter includes the population and sample, the data collection and the data analysis of the second step of the first phase.

3.3.1 Population and sampling

The population consists of all counsellors who worked in antenatal clinics in the Southern region of the North West Province during the period February-March 2007. A labour dispute regarding lay counsellors' salaries occurred between October 2006 to January 2007, and this may have influenced the results. However, the counsellors were asked to give their views on the influencing factors at any time – not necessarily during this period.

The study planned to include both lay counsellors and registered midwives who attend to pregnant women. While the lay counsellors usually do the initial counselling and HIV counselling could be seen as their principle work, the registered midwives are also involved as the midwives train and supervise the lay counsellors. The midwives also counsel pregnant women as follow-up to the lay counsellors' sessions.

No further sampling was done and all the lay counsellors and registered midwives who work in the selected clinics, as indicated in 2.3.1, who were willing to participate in the study, were selected.

The inclusion criteria included the following:

- The participant had to be a lay counsellor or registered midwife
- Worked in a selected antenatal clinic during the period February-March 2007.
- Be involved with counselling of pregnant women who attend one of the selected antenatal clinics;
- Had to have provided written consent to participate.

Originally the plan was to let sample size be determined by the number of interviews required to reach data-saturation when analyzing the data. If new themes continued to appear in the data by the end of the selected two-month period, more interviews with counsellors who qualify would be conducted until saturation occurs. Eventually sample size was determined by the number of counsellors that were available for interviewing. The following indicates how the selection realised.

Table 3.2 Realisation of sampling

	Number of participants who met the criteria	Number of participants who consented to participate and were interviewed
Clinic A	3	1
Clinic B	4	2
Clinic C	3	2
Clinic D	3	2

3.3.2 Data-collection

As was the case in step 1, individual interviews was selected as data-collection method for step 2. See 2.3.2 for a discussion of the individual interview as data-collection method.

The obtaining of permission, planning, conducting and recording of the interviews is discussed to indicate the realisation of the data-collection.

3.3.2.1 Obtaining permission to collect data

The letter from the Department of Health of North West Province and the letters to the District-managers, under whose authority the selected clinics fall, as well as the

registered nurses in charge of these clinics addressed all three the initial steps of the project (Appendix 1.2, 2.1 and 2.2).

Appointments were made for specific days on which data-collection was to be conducted. On the day of the interviews, the counsellors who had met the inclusion criteria were provided with a document (Appendix 3.1).

This document included information about the research, a consent form for participating in an interview and allowing the interview to be recorded, as well as a form on which the participant could indicate if she would want feedback after the research.

3.3.2.2 Planning of interviews

As for step 1, decisions had to be made about the questions that would be asked, the interviewer, and preparation of the environment. The first interview was conducted as a pilot study to see whether adjustments were required.

- **Interview schedule**

Both closed ended and open ended questions were used to gather data.

Table 3.3. Interview schedule for interviews with counsellors

<p>The following central question was asked:</p> <p>In your opinion, what factors influence the counselling for HIV testing of pregnant women?</p> <p>The following were used as follow-up questions and prompts:</p> <p>What factors make counselling more effective?</p> <p>What factors make counselling more difficult?</p> <p>What do you consider the positive aspects of counselling as done in this clinic?</p> <p>What do you consider the negative aspects (if any) of counselling as done in this clinic?</p> <p>Do you consider your training sufficient to do effective counselling? In which aspects?</p> <p>What lessons have you learned from practice regarding counselling for HIV testing?</p> <p>How do you think counselling for HIV testing can be improved?</p>

- **Selection and preparation of interviewer**

The same interviewer, who conducted the interviews for step 1, interviewed the counsellors. The researcher's role was to plan the interviews and to ensure that the interviewer was knowledgeable about her role. Again, the researcher maintained contact with the interviewer during the data-collection period.

- **Selection and preparation of environment**

The same venues, as used in step 1, were used in the different clinics. Again, precautions were taken to ensure privacy and to limit interruptions. Despite these, certain interviews were interrupted.

- **Length**

All the interviews lasted between 20 and 40 minutes. The counsellors were given ample opportunity to contribute and were probed when they did not contribute freely.

3.3.2.3 Conducting of interviews

The interviewer used the same skills for initiating, conducting and concluding the interviews as applied in step 1 and discussed in 2.3.2.3.

After explaining the purpose of the research and obtaining the participants' informed consent, the interviewer started by asking general biographical questions. The answers to these questions were recorded as part of the field notes.

3.3.2.4 Recording of interviews

As in step 1, an electronic voice recorder was used to record the interviews. It was switched on only after permission to do so was obtained from the participant. After the recorder was switched on, the interview commenced (Example of Interview: Appendix 3.2). The voice recorder was then switched on and the interview commenced (Example of Interview: Appendix 3.2).

Again, field notes were recorded after each interview (Example of field notes: Appendix 3.3).

3.3.4 Data-analysis

Step 2 utilised the same coders and data-analysis strategy used in step 1 and discussed in 2.3.3.

3.4 LITERATURE CONTROL

As in step 1 of phase 1, the literature was scrutinised to compare and contrast the findings.

3.5 RIGOUR

Again, the combination of Guba's model for trustworthiness as discussed by Krefting (1991:215) and the strategies to check the accuracy as proposed by Cresswell (2003:196) as discussed in 2.5 were used in this step of the research project.

3.6 RESEARCH FINDINGS

In the following section the participants' biographical details as well as the findings after conducting content analysis of the interviews, are discussed.

A total of seven interviews were conducted. All the lay counsellors who provide counselling for HIV testing in the four selected clinics were interviewed. Unfortunately, the final sample included only lay counsellors, as all the registered midwives were unwilling to participate, due to their work load. The interviewer offered to conduct the interviews after work in a venue of their choice, but none saw their way clear. It is a limitation of the study as no contribution regarding factors that influence counselling for HIV testing during pregnancy was received from the registered midwives, who also counsel. The fact that they did not see their way clear to participate due to their heavy workload, provides an indication of the work pressure that they face.

The interviews were conducted in English or Afrikaans according to the participants' choice. Some of the participants were very talkative and rapport was established

early in the interview, while one communicated with difficulty. In this case, examples of answers to the questions had to be used as an additional communication strategy to help the participant to communicate more effectively. In two of the interviews, the participants became emotional due to their personal experience with a loved one who had died of AIDS. The interviewer granted these participants an opportunity to elaborate on their emotional experience as these experiences may influence their counselling-practices.

Table 3.4 Biographic information of participants

Age	Ages ranged from 24 to 60 and five of the counsellors were in their twenties.
Experience as counsellor	Experience ranged from 3 months to 12 years and most participants have been doing this work for about three years.
Marital status	Five of the counsellors were married, one has never been married and one was a widow.

All the participants were asked the following question:

In your opinion, what factors influence the counselling for HIV testing of pregnant women?

A variety of follow-up questions, prompts and probes as indicated in table 3.3 were used to reach objective 2, namely:

To explore and describe the factors that influence the counselling for HIV during pregnancy according to the counsellors who practice in antenatal clinics in the North West Province

A summary of the findings according to the data-analysis are stated in Table 3.5.

Table 3.5 The main themes and sub-themes identified during data-analysis of step 2

Themes	Sub-themes
3.6.1 Influencing factors regarding the counsellor	3.6.1.1 Motivational factors 3.6.1.2 Intrapersonal factors
3.6.2 Influencing factors regarding counselling	3.6.2.1 The counselling process 3.6.2.2 Difficult counselling sessions
3.6.3 Influencing factors regarding clients	3.6.3.1 Comprehension of counselling-information 3.6.3.2 Readiness for counselling and testing 3.6.3.3 Follow-up after counselling

3.6.4 Influencing organisational factors	3.6.4.1 Insufficient support structures for counsellors 3.6.4.2 Clinic infrastructure and routine 3.6.4.3 Job insecurity
3.6.5 Influencing factors regarding the community	3.6.5.1 Stigmatisation 3.6.5.2 Negative perceptions regarding the clinics 3.6.5.3 Practices in community

In the remainder of this section the main themes and sub-themes are discussed. Extracts from the transcripts of the interviews are discussed in combination with applicable literature. The extracts are referenced with the participant's number, followed by the page number of the transcript on which the extract appears.

3.6.1 Influencing factors with regard to the counsellor

The first theme combined the factors that influenced the counselling with regard to the counsellor as participant, herself. The theme was divided into two sub-themes:

- **Motivational factors** that describe the reasons that motivated the counsellors to select this career or continue with it, and
- **Intrapersonal factors** of the counsellor that may influence the counselling that she does.

3.6.1.1 Motivational factors

There are various reasons why the participants decided on counselling as a career and positive factors that motivate them to continue with it.

- **Motivation to be a counsellor**

Certain participants decided on this career because of the contribution they could make to society and because they felt touched by the burden of HIV/AIDS and wanted to make a difference in peoples' lives.

“So I was... I feel that it was important to... when I get that information, to spread the information to other people. That is why I become a counsellor, to give people information (4:4).”

“You ask them they have to protect themselves so that they cannot be HIV positive, because it is not nice to be HIV positive and you are dying of HIV and they are

suffering because of HIV. There are many orphans which is cause by HIV. And it's not nice. Especially for the children, they are just small (4:8)."

The World Health Organisation (1999:8) stresses the importance of motivated counsellors as they are then found to be more empathetic and proficient counsellors.

Some of the counsellors who participated in Grinstead *et al's.* study (2000:637) reported that the proximity of HIV in their personal lives had played a role in motivating them to work as HIV counsellors. One of the participants interviewed in the current research also told the interviewer about her daughter's death which motivates her to continue with this work.

"Want my worry né, ek het 'n kind gehad. Toe sterf die kind in 1999 maar ek het haar getoets, maar ek kan nie vir haar vertel nie. Nou daardie tyd toe kan ek nie self vir haar sê nie, want sy het self gesê sy gaan nie by die kliniek nie. Hulle gaan haar toets, sy gaan nie by die hospitaal nie, hulle gaan haar toets. (Because my worry is, I had a child. Then she died in 1999 but I tested her, but I could not tell her At that time I could not tell her myself, because she said herself, she is not going to the clinic. They are going to test her, she is not going to the hospital, they are going to test her.) (7:3)."

For some of the counsellors in Baggaley *et al's.* study (1996:157), the knowledge that they themselves were HIV positive led them to choose a career in HIV counselling. Although the researcher has heard anecdotes of HIV counsellors in South Africa being HIV positive themselves, none of the participants in this study disclosed their status during the interviews.

At one of the selected clinics, a counsellor had passed away from AIDS a month before the interviews were conducted. This fact would have impacted on the remaining counsellor and the new counsellor who replaced her.

Certain participants saw their job as HIV counsellor as a temporary steppingstone to earn money towards training for a different career.

"We don't have time to go outside and perform other duties or attend courses so that tomorrow you can also have benefit. If you can get training it can be considered that in future you are going to make some money, you are going to do something to help

your family. I try to save the money I make so that I try to maybe in the afternoon go to attend school some where ... so that in the future I can apply to certain jobs (6:4)."

In the reality of high unemployment rates, one can understand the motivation to try any employment opportunity, even when it is not ones passion. It can be expected that such a counsellor would not be as committed to counselling as someone for whom counselling is their career of choice.

- **Positive aspects of being a counsellor**

The participants found motivation to continue with counselling, especially when they received recognition and positive feedback.

"Being an HIV counsellor I am proud of myself, I meet so many people, they even come to me and say thank you (1:2)"

"As 'n persoon, byvoorbeeld, ek het die persoon getoets vir HIV en hy is positief en hy kom elke keer terug na my toe en hy vat die dinge toe wat ek hom gesê het, en dan voel ek goed, want dan voel ek hey, wat ek gedoen het, ek het bereik wat ek na gesoek het. (If a person, for example if I've test a person for HIV and he is positive, and he comes back to me every time and he takes the things I've told him, then I feel good because then I feel hey, what I've done, I've reached what I've been looking for.) (2:4)"

"For me it's when I'm advising people and you see that they are convinced. They will do what ever you teach them. You try to tell them to abstain or to use protection. Then when you see that they are doing what you told them. (6:3)"

The counsellors who participated in the study of Grinstead *et al.* (2000: 632) in Kenya and Tanzania enjoyed the opportunity to meet and interact with a large number of diverse of people. They felt valued as they could help people solve their problems, but found it discouraging when clients did not change their behaviour after counselling. Some of the participants in Grinstead *et al.*'s study (2000:632) also mentioned that they felt rewarded when clients showed their appreciation. Buwalda and Kruijthoff (1994:157) also reported that health workers who work with HIV/AIDS patients were of the opinion that they played an important role for their patients, and stated that their patients trust them and have confidence in them.

3.6.1.2 Intrapersonal factors

The participants reported personal issues that influenced their ability to counsel effectively.

- **Emotional involvement**

Most of the participants told the interviewer about their emotional reaction to HIV counselling.

“Anyway, it is not good to be a counsellor, because when it is tjaila time, you are just going to sit at home and think about a person (1:2).”

“You are stressing about people’s problems. You are taking people’s problems, you are making it yours (1:3)”

“In die aand droom ek eintlik van die mense, of as ek so stil lê dan kom alles terug wat ek die vorige dag gedoen het en dit maak my nie lekker voel nie, dit is nie lekker nie. (In the evening I dream about the people, or if I lay still everything I’ve done the previous day comes back and I do not feel nice, it is not nice.) (2:3)”

“...you know when you are new to this thing... you get these people who... maybe after telling them their results, they cry, they do stuff, that thing affect you also. (4:4)”

Solomon *et al.* (2004:62) as well as van Dyk (2005: 323-326) report on the difficulty and stress an HIV counsellor experiences. They deal with intense emotional issues when they inform people that they have a life threatening disease. Counsellors find it difficult to maintain professional boundaries in the relationships that develop between them and their clients. The lack of clarity as to professional roles and boundaries leads to stress and burnout. The confusion regarding the kind of relationship one should have with a client impacts directly on the nature of the counselling and the quality of support that the person receives.

Extreme emotional involvement over an extended period without a way to effectively deal with it, can lead to burnout.

One of the participants told of her experience:

“Daar was ‘n tyd wat ek baie krapperig gewees het en toe het ek uitgevind dit is as gevolg van die berading en ek kry nie self berading nie. Dit het opgeëindig dat ek al ‘n Maatskaplike Werkster gesien het wat my gehelp het met my en toe het sy nou ook wonde oopgekrap maar sy het gehelp want nou is ek ‘n ander mens. (There was a time when I was very irritable and then I realised it is because of the counselling, and I am not counselled myself. It ended up with me seeing a social worker who helped me... She has opened up wounds, but helped me as I am another person now.) (2:3)”

Another expressed her level of functioning as follows:

“Die enigste ding wat mens kan doen is (The only thing one can do is)... everyday, to turn up, do your job. Even if you know it is tough sometimes.... you justneed to go for survival (7:2).”

Burnout is conceptualised as consisting of three components: emotional exhaustion, depersonalisation and lack of personal accomplishment (Maslanka, 1996:195), while UNAIDS (1997:5) describes burnout as a state of emotional exhaustion that results when the counsellor has reached her limit in dealing with HIV and the emotional stress it causes. This may lead to a state of irritability and anger, directed at supervisors, colleagues or even clients. Trained counsellors may then leave their jobs and this could lead to a high turnover and subsequently, new counsellors have to be trained continuously. If counsellors are provided with proper support, the stresses that can build up and cause burnout could be reduced.

- **Keeping of emotional distance**

Counsellors can keep an emotional distance from their patients because they do not know how to manage their feelings. It could also serve as a self protection mechanism. Both reasons could play a role in the participants who expressed such behaviour.

“I don’t have to cry with the patient, I don’t have to feel shame with that patient (1:2).”

“I don’t have to feel sorry for my patients.... they will think this counsellor is weak.... I have to be in control (1:5).”

“Jy hou jou net sterk sodat die persone daar buite hulle moenie uitvind jy voel hartseer. As hulle kan sien jy voel hartseer hoe gaan jy werk en (You keep yourself strong so that the people outside do not to see you are sad. If they can see you feel sad, how are you going to work? and) counselling or counsellors they are also in the need to get some, to be counselled (7:2).”

During their training the participants were probably not sufficiently prepared to handle difficult emotional situations. UNAIDS (1997:5) states that because counselling is based on skills that are dependent on the personal qualities of warmth and understanding, it is often mistakenly assumed to require little in the way of preparation and practical training.

McCoy *et al.* (2002:20) recommend the establishment of a pool of experts and trainers with the commitment and time to focus on high quality training in each province.

There were also personal reasons why they felt the need to protect themselves. One of the participants was very young and immature and felt ill prepared for her work as counsellor, while another had lost two of her loved ones to HIV/AIDS, and may have felt the need to protect herself against more hurt.

- **Social support**

Social support is defined as emotional support that causes health workers to perceive that they are listened to, that they are helped by others, and that they can rely on others. The counsellors who participated in this research received informal support from colleagues, from the nurses and other counsellors. According to Maslanka (1996:196), health workers consider co-worker support as important as supervisory and spousal support.

“I am so happy here, because if I have a problem, I go to the other sister and tell her this and this and if I don't understand this problem with my patient, I just can go to the sister and ask what can I do with the patient, you know? I love them (1:5).”

“..we do talk, we are the two of us here né, so we share the load with each other and I think it also help (3:3).”

“Like I’m working with (other counsellor in Clinic A), ne? When I’ve had maybe a bad session you see, I talk to her and you know what .. I’m not all alone after counselling that person, so we sit down and talk about HIV and those things and I become better. I tell them yesterday I had a bad counselling session. So we talk. It’s better when you talk. But if you just shut up you don’t get better (4:4).”

“Sy’t my altyd gesê (She always said): You are a counsellor, be strong. En sy het altyd vir my woorde gegee wat goed is laat ek kan hou en ons het mekaar so opgehou (And she has always given me good words, and that is how we kept one another standing.)(7:3).”

The participants in Grinstead *et al.*'s study (2000:637) also shared that they used talking with other counsellors as an informal strategy to reduce their work related stress. Organisational support is discussed in 3.6.4.1.

3.6.1.3 Conclusion statements pertaining to factors regarding the counsellor

This first theme addresses factors that influence counselling with regard to the counsellor.

- Counsellors are **motivated to become or stay counsellors** because they want to make a contribution in the fight against HIV/AIDS or feel that they are appreciated and that they make a difference in peoples lives
- Some counsellors **use the employment** to save money to prepare for another career.
- Counsellors are influenced by intrapersonal factors when they become **emotionally involved** and this could lead to burnout.
- Some counsellors keep a deliberate **emotional distance** because they cannot manage their feelings, or to protect themselves.
- **Social support** from co-workers can be valuable.

3.6.2 Influencing factors with regard to counselling

The second major theme focuses on the factors that influence the counselling itself. It is discussed under two sub-themes:

- All factors that influence the **counselling process**, and
- Various **counselling sessions** that the counsellors find difficult.

3.6.2.1 The counselling process

Factors pertaining to the counselling process are work pressure, information as support in counselling, the need for continuous education, uptake of testing as the main counselling aim, different approaches to counselling, testing with male partners and group sessions.

- **Work-pressure**

Nearly all the participants expressed their frustration with the extreme workload. Both the counsellors and nurses/ midwives work under enormous pressure and staff shortages are common.

"There are so many people, they have to sit in a queue and it is a long process (1:3)."

"Hier werk jy dat jy vergeet om te eet (Here you work that you forget to eat.) (2:6)."

"Ye, sometimes uh uh uh the reason was the shortage of staff, but .you see now maybe three or four professional nurses with the queue, they can run freely but if there are a problem with clinic..... it's only one sister then there is the shortage of staff . That's why the people they are standing for a long time (5:4)."

"Sometimes you get so many clients and there's no way that you can say to them go back home or what. You have to do..... like Mondays we're dealing with the pregnant womenand they need HIV counselling. Sometimes you find that you are doing twelve, sometimes 10..... Its finish you, it is too much (6:2)."

"So die arme mense, dan hulle moet net dryf, dryf, dryf en as dit so halfpad vol is is hulle's nog steeds besig tot kwart voor vyf (So the poor people, then they must just rush, rush, rush and if it is half way full, they are still busy till quater to five.) (7:4)."

"Kan jy vir my glo as ek sê dat sewentien mense 'n dag help?(Would you believe me if I tell you that I help seventeen people during a day?) (7:5)"

According to van Dyk and van Dyk (2003a:5) the lack of sufficient human resources also impedes counselling for HIV testing. They caution that proper HIV counselling is

simply not possible in circumstances where limited resources (both counsellors and infrastructure) lead to long waiting periods and a heavy patient load.

Solomon *et al.* (2004:63) and Grinstead *et al.* (2000:635) also mention the impact that the workload has on participants and the counselling that they provide.

- **Information as support in counselling**

The participants in this study consider the provision of information as the main focus when they provide support.

"I support them by giving them information (1:6)."

"For you it's moving beyond the fear of the patient, giving them information. (4:3)."

"So you have to give information of what is HIV, why they have to do the test and all those things, so that they can understand why we... they have to do the HIV test. And it's not only for the sake of themselves, it's also for the sake of their babies Giving them information ... so that fear can go out (4:2)."

Although some participants provided evidence of other ways in which to generate support, the provision of information was a clear focus-area.

- **Need for continuous education**

As the provision of information is considered vital, the counsellors' own knowledge needs to be up to date. They expressed their need for additional training.

"HIV is changing every day, we need more training (1:6)."

"I think we need more in-service training (5:4)."

"..maybe if you can get courses now and then, now and then, because most of the time, things are changing, medication and so on (6:3)."

According to Creek *et al.* (2004) the success of preventing mother to child transmission services depends on the care givers. Care givers should provide correct

information and instil positive attitudes towards HIV testing. They found in their study that midwives and counsellors in Botswana need additional training and support to maximise programme uptake. The assessment of the public sector's voluntary counselling and testing services (Magongo *et al.*, 2002:31) found that two thirds of the counsellors indicated that they needed additional training. The counsellors who participated in the study of Grinstead *et al.* (2000:636) expressed their fear of not knowing enough to be able to answer their clients' questions about HIV transmission and other topics.

Grimes *et al.* (2001:589) found that when health workers receive regular educational sessions on HIV and HIV testing and PMTCT, the uptake of HIV testing by pregnant women stayed on a high level. But, this decreased when educational sessions were offered less frequently.

- **Uptake of testing as the main aim of counselling**

The participants measure the efficiency of their counselling primarily by the uptake in HIV testing.

"I explain everything to them so in the end they agree to do the test. (4:2)"

"Sometimes it's a problem because they deny testing, so we just tell them to go home and think about it. Then they really do come after a certain time and they get the testing (6:1)"

"Die dokter en susters stel meer belang in die toetsuitslag (The doctor and sisters are more interested in the test results.) (2:7)."

"Anyway, the patients that I work with, they all want to test (1:1)"

"..This year we haven't had anyone who didn't test (3:5)"

The participants stated that they do not force anyone to be tested but that nearly all women consent to be tested. These statements remind of the counsellors in De Paoli *et al.*'s study (2002:147), who stated that they are not supposed to impose their own values on women. Yet, they described a 'good' counsellor as someone who is able to convince pregnant women to do what the counsellor wants and to accept HIV testing.

They described a 'bad' counsellor as someone with whom many women refuse VCT. The pregnant women in the studies of Sherr *et al.* (2003:342) and Abdool Karim *et al.* (1998:640) felt that they did not really have a choice whether they wanted to consent to an HIV test or not. They felt that the power balance was in the health care professional's favour and that women invariably deferred.

Sometimes the ways of persuading to test can be seen as coercion.

"When she comes for the next visit, we would like to know where is the partner, because you did promise to bring the partner. So why are you here alone and not with your partner or are you still refusing to do the test? We cannot let you go if you don't want to test, leave it there, because the main focus is on the baby (3:5)"

The participants often use the baby's health to persuade pregnant women to consent to be tested for HIV. In the first step of this study, the pregnant women indicated that the health of the baby was found to be an important motivating factor (2.6.1.1).

"Ek kan vasstel hulle sien uit na die babatjie, en dan verduidelik ek vir hulle as jy nou nie toets nie, en jy weet nie jy is positief nie, hoe hartseer is dit as die kind gebore word en die kind is siek en daai kinders lewe nie lank nie, dan sterf hy. Dit gaan alles om die kind. (I can see they look forward to the baby, then I explain to them that if you do not test and you do not know you are positive, how sad would it be if the child is born and the child is sick and those children do not live long, then they die. Everything is about the child.) (2:3)."

"the clear information about the HIV test as well as the PMTCT as it goes hand in hand. So if the counsellor has been clear when giving the information about the HIV testing..., ? I think she would not have trouble to giving the consent. Its like in the first years of HIV ...the mother thinks, if I test then I test, I am positive, what about my baby. So I think she rather not know about the result than knows, that's way I say again it will go with the counsellor not giving that much information about PMTCT (3:1)."

- **Different approaches to counselling**

Provision of information and obtaining consent for testing is not the only important aspects of counselling (and giving of support). It reflects a directive task-orientated approach to counselling in contrast with a client-centred supportive approach.

According to Rohleder and Swartz (2005:398) a mixture of client-centred and more directive, health-advising counselling techniques is usually used in pre-test counselling in South Africa. They indicate that public health care in South Africa follows a task-orientated approach which tends to defocus from the emotional (and social) experience of illness and operates differently from a counselling model that emphasises holistic patient care. The participants in their research responded that in their experience the nurse manager was only interested in statistics, and did not understand that counselling may take longer than 15 minutes. Rohleder and Swartz (2005:403) further comment that the nursing staff seemingly view getting people tested and educating them on HIV transmission and prevention as the councillor's main task, while the participants view their main task as providing the client with emotional support.

In the current study, a counsellor who trained as a general health provider made a relevant comment that is applicable to her perception of the other counsellors:

"En die berader wat daarso sit is net oor HIV Hulle kyk nie dieper in die saak nie (And the counsellor that sit there is only on HIV... They do not look deeper into the issue) (2:5)."

The other counsellors' training (and experience) may not have prepared them to reach to this level of reflection that would enable them to comment on their counselling approach.

According to Lie and Biswalo (1994:147) the participants in their study, aimed at identifying key characteristics of an HIV counsellor in Tanzania, were more concerned about the disease's social consequences than technical facts about AIDS. They considered relationship orientated characteristics like being polite, showing respect to patients, installing confidentiality and being a good listener as more important than being knowledgeable about HIV and being able to explain the facts in simple language. The counsellors who participated in the study of Grinstead *et al.* (2000:629) considered patience, neutrality and understanding as the most important personal qualities. They listed the following professional qualities as important: knowledge, good listening skills and respect for clients and their confidentiality. According to Grinstead *et al.* (2000:631) the counsellors saw their role as informational, supportive and motivational.

In their study that assessed the knowledge, attitudes and practices of health care providers in Ontario, Canada regarding antenatal HIV testing, Guenter *et al.* (2003:95) reported that midwives were more supportive of the informed consent process than family physicians or obstetricians were.

Two communication approaches are used during consultations with patients. These are patient-centred and biomedical communication (Swenson *et al.*, 2006:200). Patient-centred communication includes identifying and responding to the patient's ideas and emotions regarding the illness and reaching common ground about the illness, its treatment and the roles that the health care provider and the patient will assume. The researchers found that although most patients prefer a patient-centred communication style, some prefer a biomedical style which encompasses a disease-orientated approach to the patient's problems and a health provider-centred orientation to decision-making. The patients' preferences were found to be based on their values and expectations. The authors promote individualised care where each patient's preference is taken into consideration.

- **Testing with male partners**

UNAIDS (2001:7,14) stresses the involvement of male partners in PMTCT. Males who agree to be tested with their pregnant partners, could be seen as taking a first step towards assuming more responsibility in the partnership. This includes being more understanding of, and involved in prevention of mother-to-child transmission of HIV. This also refers to using condoms during pregnancy and being supportive of HIV-positive women's baby feeding choices. Holmes (2005:12) points out that if organisations made an effort to involve men in counselling, more men would attend the service and lead more women to disclose their HIV status to their partners.

One of the participants talked about the advantage of ensuring both partners' status is known before they engage in unprotected sex.

"It would have been easier if both got tested before they had sex without a condom.Because if they tested before and then the mother knows that we did test and we were HIV negative, both of us. Or maybe we did test and my partner was HIV positive, so I took a risk. Then I don't think we would have any problem about testing ...but the fear that when I test and my results are positive, then my partner is going to

blame me although if they would have tested, both of them, it wouldn't be so much hard... (3:2)."

None of the participants mentioned pregnant women being tested with their partners and couple testing during pregnancy does not seem to be promoted in this sub-district, although it was recommended after the evaluation of the pilot of the PMTCT programme (McCoy *et al.*, 2002:39). Although pregnant women in the Eastern Cape would prefer to be tested with their male partners they acknowledge that this is not a realistic expectation in practice (Sherr *et al.*, 2003:341). When men participate in counselling and testing for HIV with their pregnant partners, both parties benefit. HIV-positive women are more likely to receive Nevirapine during follow-up visits, avoid breastfeeding their baby and use condoms, while men are more likely to access antiretroviral treatment sooner (Painter, 2001:1400).

- **Group sessions**

Two of the selected clinics use group sessions for pregnant women to transfer information about HIV/AIDS, pregnancy and PMTCT before individual counselling occurs. However, because of the risk of the 'spill-over' effect, education regarding feeding with breast-milk substitute must not be delivered in a group before HIV testing. It should only be presented to women who are already diagnosed as HIV positive (Minnie & Greeff, 2006:25; Doherty *et al.*, 2003:42).

"Na reg moet ek die berading individueel doen, maar as gevolg van daar is nie genoeg spasie en tyd nie, doen ek hulle as 'n groep saam, maar as ek die vrou vat om uit te vind of sy wil toets en of sy bereid is om die toets nou te doen is ons alleen (I am supposed to do individual counseling but because there is not enough space and time, I do it in a group, but if I take the woman to determine if she wants to do the test or if she is willing to do the test now, we are alone.) (2:2)"

According to van Dyk and van Dyk (2003a:5) group counselling can be used to provide information, but is not appropriate as 'counselling' because it lacks privacy and confidentiality. Their conclusion links with Mabunda's (2006:26) findings, where participants liked group counselling because they had an opportunity to ask each other questions and to learn from one another; but stated that there are some questions that cannot be asked in a group.

The combination of a group session followed by an individual counselling session to provide information is used successfully in Cameroon (Welty *et al.*, 2005:487) and in Kayelitsha, Cape Town (Mazwi *et al.*, 2002). The pregnant women interviewed in the first step of this research project expressed both their satisfaction and dissatisfaction with the group sessions conducted at the clinics (2.6.3.1).

3.6.2.2 Difficult counselling sessions

The participants found specific types of counselling sessions especially difficult. Ideally, lay counsellors should be supported with a referral system to professional counsellors for difficult cases.

- **Referred patients**

Some clients are referred to the counsellors by the doctor or registered nurse for HIV testing without being prepared for what to expect. This can cause the client and counsellor considerable stress.

“nou moet jy eers die persoon se vertroue kry. Nou vra ek ‘Toe jy nou hier gekom het, het die suster gesê wat kom kry jy hier? Nee, sy het gesê ek moet na jou toe kom en ek as hier klaar is dan kan ek my pille gaan haal. ...Ek verstaan die punt. Dit kan ‘n related siekte van HIV wees, maar doen dit op ‘n professionele manier.. waarsku die pasient dat jy dink dit kan ‘die siek’ wees, en dat sy jou na iemand stuur om met jou daaroor te praat (Now you must first get the persons trust. I ask, when you came, did the sister tell you what you should get here? No, she told me to come to you, and if I am finished, then I can go to fetch my pills..... I understand the point. It may be a HIV related disease, but do it in a professional way, warn the patient that you think it may be ‘the disease’ and that she send you to someone that would talk to you about it.) (2:6).”

One of the participants in the study of Rohleder and Swartz (2005:402) mentioned how patients are told that they are probably HIV positive and are then referred to the counsellor who must try to support the client. UNAIDS (1997:5) also notes problems with referrals if clients are send to a counsellor without being prepared that they may be HIV positive. The counsellor is then required to sort the situation out. The compilers of the reporter state that if this happens repeatedly, in spite of the counsellors' complaints, it may destroy their ability to cope.

- **Clients in denial**

Participants become discouraged when dealing with clients who deny their positive HIV status.

“Especially when you are still healthy, because sometimes you don’t know you have HIV, because HIV doesn’t ... when you have HIV you can feel fit and well and healthy ... but in the mean times you tell yourself I’m not HIV positive. I’m well, I’m not sick, so they tell themselves if you are not sick, you can’t be HIV positive. So they come with the mind of “I’m having my baby”, so when the results come out and it’s positive they start to be... It’s not me, it’s not true,.. They need the follow-up. Just to talk to them.. when you are still talking, you hear: “Do you think I am HIV positive? (4:7)”

- **Destitute clients**

Solomon *et al.* (2004:64) discusses the reality that many people in South Africa have to deal with numerous socio-economic burdens daily. Whether they are HIV-positive or negative is of little consequence to them, and may just be an additional burden over which they have no control.

Participants feel helpless when confronted with clients who have no livelihood.

“your client say they won’t know what to do after seeing their results, after knowing that they are HIV positive. Then you will see in their eyes that like they don’t work and then they don’t know what are they going to do like from here and like telling patients they need to eat like healthy food- fruit en vegetables and then they will ask - where am I going to get money to buy this vegetables and fruit because nobody at home works? (3:3).”

Support in the form of governmental grants, and faith-based and non-governmental welfare organisations that distribute food parcels, is available. However the need is much greater than what can be provided.

- **Young clients**

The participants also find it difficult to counsel young people or children.

"Dit sit nie aan 'n mens se klere nie. Vernaam as jy die persoon ken of vernaam as dit 'n meisie is wat miskien vir die eerste keer omgang gehad het en sy het swanger geraak, sy het nie gebeplan vir die swangerskap nie en vernaam as ek haar goed ken, dan breek dit my (It's not easy. Especially if you know the person or if it is a girl who maybe had intercourse for the first time and fell pregnant, she did not plan the pregnancy, and especially if I know her well, it breaks me.) (2:3)."

"To do counselling for a small child it's hurtful... painful... and when the results become positive... it's painful (4:4)."

- **Couples**

Couples counselling has advantages for all, especially if the woman is pregnant (3.6.2.1). Participants are overwhelmed when they need to conduct couples counselling as counsellors do not have the therapeutic skills required to do couples counselling.

"Sometimes a woman is positive, but her husband is negative. If they are getting at home, you think what is going to happen, are they going to what are they going to do to her That goes through the counsellor's mind You will just wait for the womanthe woman is positive. That one I can't accept (1:5)."

It is preferable that specialised cases such as discordant couples be referred to professional counsellors.

- **Family**

As can be expected, participants found it extremely difficult when their own family is touched by HIV/AIDS. Seventy percent of the counsellors who participated in the study of Baggaley *et al.* (1996:156) lost a family member to AIDS, but only twenty six percent of the participants felt able to discuss HIV with their family. The counsellors who participated in Grinstead *et al.*'s study (2000:638) also had experience of relatives who were infected with HIV. They expressed their frustration with the impossibility of discussing the diagnosis because of the severe stigma in the community.

"My cousin was HIV positive. She has passed away and I didn't tell her mother, my aunt. I was the one who counselled her and she asked me am I going to tell her mother she is HIV positive. It is something between you and your mother. It was very painful. I don't have to tell her mother that she was HIV positive and she was on ARV's. The mother, her mother always ask me what is the problem with my daughter? I tell her, you just have to ask her yourself.. You have to ask her what is the problem and if she don't want to tell you, that's that.But it is difficult (1:6)."

"Want my worry né, ek het 'n kind gehad. Toe sterfte die kind in 1999 maar ek het haar getoets, maar ek kan nie vir haar vertel nie. Nou daardie tyd toe kan ek nie self vir haar sê nie, want sy het self gesê sy gaan nie by die kliniek nie. Hulle gaan haar toets, sy gaan nie by die hospitaal nie, hulle gaan haar toets. (Because my worry is, I had a child. Then she died in 1999 but I tested her, but I could not tell her At that time I could not tell her myself, because she said herself, she is not going to the clinic. They are going to test her, she is not going to the hospital, they are going to test her.) (7:3)."

Van Dyk (2005:325) mentions that the closely-knitted community life and extended family systems in many African communities are factors that lead health care workers (also counsellors) to be familiar with most of their clients. They counsel people whom they know and this causes their roles as nurses, counsellors, friends and family to become blurred.

Baggaley *et al.* (1996:162) report that in Zambia (as in large parts of sub-Saharan Africa) HIV affects everybody as they face the deaths of friends, relatives, partners and even their own mortality. According to Baggaley *et al.* (1996:163) close personal contact with HIV enables the counsellors to empathise with their clients and helps them to understand their fears and their reluctance to be tested.

3.6.2.3 Conclusion statements pertaining to factors regarding counselling

With regard to factors that influence the counselling-process the participants reported the following:

- Counsellors feel that they cannot perform optimally due to large numbers of patients as well as frequent staff-shortage which lead to excessive **work-pressure**.

- Due to the emphasis placed on **information transfer as mode of giving support to clients** it is important that the counsellors have up to date knowledge of HIV/AIDS and PMTCT.
- **A directive, task-orientated approach** is used in pre-test counselling as evident by the counsellors' attitude that **obtaining consent for HIV testing** is the main aim of counselling.
- **HIV testing with the male partner** is advisable for all women at the beginning of a sexual relationship and is especially advantageous for pregnant women as her partner would be able to provide better support if PMTCT strategies need to be implemented.
- **Group counselling** can be used to give health education about HIV/AIDS, pregnancy and certain aspects of PMTCT before individual counselling commences.

The participants reported that they find certain types of counselling sessions especially difficult:

- Counsellors prefer that other **health professionals who refer patients** for HIV counselling and testing, first prepare them for what to expect.
- Counsellors become discouraged and feel helpless when counselling clients who **deny their positive HIV status, destitute clients or young clients**.
- Counsellors find it difficult to counsel discordant **couples**.
- Counsellors are badly affected by **HIV positive family members**. They may feel helpless when they are not able to discuss the patient's condition with the patient herself or with other family members but having personal experience with HIV also enable them to really understand and empathise with others.

3.6.3 Influencing factors regarding clients

The third main theme addresses factors that influence clients when counselled for HIV testing during pregnancy. The sub-themes discussed are:

- Factors that influence their **comprehension of the information** transferred during counselling,
- Factors that influence their **readiness for counselling and HIV testing**, and
- **Follow-up of clients** who do not want to participate in a test after counselling and clients who test HIV positive.

3.6.3.1 Comprehension of counselling-information

Considering the importance participants attach to the transfer of information, it is not surprising to see that they implement strategies to ensure that their clients understand the information.

- **Strategies to ensure that clients understand information**

The participating counsellors discussed their strategies to ensure that their clients understand the information that they provide them with.

"I speak to them in their language (1:4)

"Sê vir die persoon dat sy vry is om enige vrae te vra en dat sy nie moet skaam of bang wees nie of as dit 'n taal is wat sy nie verstaan nie, daar mense is wat kan help. (Tell the person that she is free to ask any questions and that she must not be shy or afraid or if it is a language that she cannot understand, there are people that can help.) (2:2)"

"Gebruik lieverste 'n taal wat hulle kan verstaan, daar onder, "'n liggaam het nie meer soldate" en as te hoog aan hulle verduidelik, dan kry jy die idee hulle verstaan niks. Nou praat jy van 'immune deficiency' met 'n mens wat nog nooit skool gegaan het nie. Jy moet hom opbreek dat die persoon verstaan (Rather use a language that they can understand, down under, 'a body does not have soldiers anymore' and if you explain it to high, you get the idea they do not understand anything. Now you talk about 'immune deficiency' with a person who has never attended school. You need to break it down to enable the person to understand.) (2:5)."

"you must be ... to work hard to, to know that person or that woman she understands you correctly or if she doesn't understand you, you must ask: Are you understanding or not, I must repeat again (5:2)."

"..we counsellors, we ... there for us, there for our people to help. If you don't understand correctly I tell them come back to me to make a, a, a, a following up to see you feel that information or you understand. So you come back to me to talk and to give information to give awareness again (5:3)."

However, the participants did not use any educational aids to help their clients to better understand the information.

- **Educational aids**

One of the participants expressed her observation that the clients need pamphlets in their own languages.

"...to make the pamphlet for HIV. Then you give them the chance to read, then to understand more. If she don't understand maybe a language of English, whatever then you can do a something like what do you call ...what called you give all of them you give that awareness for then to understand the pamphlet, where is the pamphlets or maybe in, the counselling of Tswana. Some people you can you read Tswana, some people you can read English or Afrikaans. So you must give the awareness..... you can read Tswana or English or what will be acceptable for her to read (5:2)

If pamphlets/ brochures are used, it is important that the content and language used is appropriate for the intended users. According to the assessment of the public sector's voluntary counselling and testing programme (Magongo *et al.*, 2002:15) as well as the evaluation of the National PMTCT programme (McCoy *et al.*, 2002:15) most of the services that offer VCT have limited posters and educational material available. The assessors stress that it is important that there must be local input in the development of educational material to ensure that it is relevant to the local setting and that the correct language is used for the specific area. They concluded that the limited availability of user-friendly material indicate the absence of a supportive strategy for developing educational material at a local level, in all the provinces. The participants in the study of Sherr *et al.* (2003:343) in the Eastern Cape found the health promotion material that was available, inappropriate. It was often written in a language that the women could not read or understand.

The World Health Organisation has also recognised the value of well-designed educational materials to assist counsellors in confidently delivering efficient and effective counselling for testing in PMTCT settings. The WHO developed a set of support tools in association with the Centres for Disease Control and Prevention (CDC) (WHO, 2006). These tools consist of wall charts, client information brochures

and various flipcharts. It may be worthwhile investigating to see if these tools are suitable for use in the clinics where this research was executed.

According to UNAIDS (2001:16) human interaction should ideally be provided when information is given. However, to accommodate time-, space- and staff-limitations, basic information on HIV infection, prevention, therapy and baby feeding, can be imparted on video. Videos have the advantage that their accuracy is assured and they are guaranteed to be informative and non-judgemental. UNAIDS (2001:16) added that people who receive information by video should always be given the opportunity to ask questions and to be counselled individually.

Smith *et al.* (2002) describe the use of a 16-minute video to provide standardised information on the benefits of preventing mother to child transmission (PMTCT) to pregnant women and their partners in a group before individualised counselling commenced. Both the levels of knowledge regarding the benefits of testing and PMTCT as well as the uptake of testing improved after the use of the video was implemented. The health workers reported that the video facilitated HIV counselling and saved time. A minority still had problems with leading a group discussion because of staff shortage. Mirembe *et al.* (2002) also report the advantages of audio visual displays followed up with a group discussion to enhance the women's understanding. According to these researchers, the women enjoyed the displays, arrived at the antenatal clinic early and were motivated to come again as they found the visit gainful. Women also used the knowledge that they gained to consider their actions regarding testing for HIV, and baby feeding options.

Considering the high volume of clients and the fact that group sessions are already used, it could be worthwhile to investigate whether existing videos would be suitable for these clinics to provide understandable information about HIV during pregnancy, PMTCT and HIV testing or whether new videos need to be produced.

3.6.3.2 Readiness for counselling and testing

Participants recognise the importance of determining if their clients are ready to be tested for HIV or not.

- **Level of preparedness**

They reported that some clients are totally unprepared when they first realise that they have to make a decision to be tested for HIV or not.

“Others they come to the clinic (for antenatal care) not knowing that they are coming to do the HIV test, So when you tell them that you are going to do the test, they become shocked and scared. They are not ready yet to do the test (4:2).”

The participants told the interviewer that some clients need more time to reach a decision.

“Hulle kry die berading so hulle word nie geforseer om te toets nie, maar nadat hulle gaan nadink het, oorslaap, dan kom hulle vrywillig, dan besluit hulle nou of nooit” (They get the counselling so they are not forced to test, but after they have thought about it, slept on it, then they come voluntary, then they decide – now or never.)(2:1)

“Give them time, maybe at the next visit they will tell you they want the test (1:2)”

One participant told the interviewer that she makes special arrangements for clients that come back after deciding at home to continue with the testing.

“...when the patients come and say they want to do the HIV test, we don't put the patient in a queue, because the time she sits in a long queue, waiting for sister or... to do all that forming, their minds change... it is like I no longer want to do that test (4:5).”

It is important that clients who do not take an immediate decision to be tested are followed up. This ensures that they do not lose an opportunity to potentially prevent MTCT and special care for the mother.

3.6.3.3 Follow-up after counselling

Both clients who do not want to be tested for HIV after being counselled because they are not ready and clients who tested HIV positive, needs to be followed up.

- **Assessment of readiness for testing**

McIntyre (1998:27) stresses the necessity of giving a woman time to decide if she wants to be tested for HIV or not. If she is unsure she should be counselled and allowed to take time to decide and return at a later stage.

The participants in this study reported different ways of managing clients who initially do not want to be tested for HIV. Certain participants do not conduct any follow-up and just leave the client to think about her choice without helping her to make up her mind. It appears that this participant does not understand that one can counsel and help someone to make her own decision without pressuring her.

"If the patient says I don't want to go for testing. You don't have to pressure her. So you have to leave her to think about it and she will come back if she comes back (1:4)."

At some clinics the counsellors and midwives have agreed on a system to ensure that clients who are not willing to be tested after the first counselling are followed up and counselled again at the follow-up antenatal visits.

"... ek skryf op hulle kaarte met 'n potlood en dan as die suster dit sien, dan sal sy haar sê sy moet na my toe kom. Dan doen ek weer berading en as sy dan nou wil toets, dan sê sy, nee, sy is nou gereed om te toets (I write on their cards with a pencil and when the sisters sees it, she will tell her to come to me. Then I counsel her again and if she now wants to test, she will say, no, now I am ready to test.)(2:2)."

Some participants pressurise clients who do not consent to testing after the first counselling. Their management can be considered coercion.

"...we have to do follow it up because like when she comes for the next visit, we would like to know where is the partner because you did promise to bring the partner. So why are you here alone or not with your partner or are you still refusing to do the test. We cannot just let you go and see that, you don't want to test and we just leave it there, because the main focus is on the baby (3:5)."

- **Support after testing**

Clients who are tested and found to be HIV positive receive post-test counselling with their HIV test result. The post-test counselling is supposed to include information on the implications of the result. If positive the client is supposed to receive information

on Nevrapine and baby-feeding options, staying healthy, the possibility of taking antiretroviral therapy if indicated according to CD4 count, making a decision to disclose and support available to her, her baby and family (WHO, 2006:49-65). After the post-test counselling, counsellors can still support their clients, especially during the antenatal period, when they visit the clinic regularly.

“En in die loop van die voorgeboortekliniek sê ek vir hulle as jy voel daar is iets wat jou pla, iets wat krapperig is, jy is vry om terug te kom na my toe en alles wat ons hier bespreek is hoogs vertroulik (During the antenatal clinic period, I tell them if there is anything bothering you, or irritating you, you are free to come back to me and everything that we discuss here is kept strictly confidential. (2:3).”

“I know my patients, especially those who are HIV positive. When they come to collect treatment, I see them when they sit there and I just go and talk to them and give them support (4:7).”

Various authors stress the importance of ongoing support for clients following the first post-test counselling (de Paoli *et al.*, 2002:152; Sherr *et al.*, 2003:346; Solomon *et al.*, 2004:50; Van Dyk & Van Dyk, 2003a:9). The news of a positive HIV status has a high psychosocial impact and the client's support-needs are ongoing.

According to Van Dyk and van Dyk (2003a:9) the participants in their study, expressed the need for follow-up counselling and support for themselves as well as their families. The researchers admit that the provision of follow-up support poses a challenge in a health care system that makes use of rapid HIV testing as clients may pay only a once-off visit to the clinic. This is however not the case in antenatal clients, as they usually visit the clinic repeatedly for antenatal care.

Although the participants realise the value of support groups for HIV positive people, they have not yet established such groups.

“Nou ek wil so graag 'n ondersteuningsgroep oprig, maar daar is nie genoeg fasiliteite nie. Daar is eerstens nie vervoer, hier's 'n tekort aan personeel, so as ek uit die kliniek onttrek word dan gaan die kliënte daaronder lei. Maar ek voel ek moet daai groep stig, maar vir Health Promotion, daar is nie budget nie (I really want to establish a support group but there is not sufficient facilities. In the first place there is no transport; here is shortage of staff, so when I am not in the clinic the clients would

suffer. But I feel I must establish that group, but for Health Promotion, there is no budget.) (2:4)."

"We don't have support for all our patients. We don't have support groups (4:4)."

UNAIDS (2002:72) warns that although support groups can be a source of comfort and strength, the establishment and maintenance of such groups is not easy. The participants in this research also mentioned the need for transport and a suitable venue as limitations to starting such a group.

Establishing support for HIV positive mothers need not involve additional staff. Counsellors can be instrumental in getting a group going, but, usually the members of the group do most of the work themselves, if they experience the value of it.

Doherty *et al.* (2003:22) report on a successful support programme for HIV positive pregnant women – the Mother-to-mothers-to be (M2M2B) programme run in Cape Town. Recently delivered HIV infected mothers who made use of the PMTCT programme, are invited to return to the antenatal clinic to act as mentors, educators, counsellors, friends and confidants for recently diagnosed women. Each HIV positive women who attends antenatal care for the first time is matched with a mentor who keeps her company, answer her questions, and reinforces messages about taking Nevirapine and choosing a feeding method. The mentor-mother also visits mothers in the labour and post-partum ward, providing valuable support regarding baby feeding practices. The mentor-mothers attend the clinic one day per week for six months and are paid a stipend for their work. The programme has resulted in an increase in pre-natal visits and knowledge on issues surrounding HIV and pregnancy. This has resulted in greater adherence to PMTCT strategies.

3.6.3.4 Conclusion statements pertaining to factors regarding clients

- Counsellors implement informal **strategies to ensure that their clients understand the information that** they provided them with.
- **Educational aids** must be suitable to local circumstances.
- Counsellors assessed **readiness for testing** and made provision for clients who do not want to be tested for HIV immediately.

- **Follow up of clients who do not want to be tested** after counselling, is not handled optimally in the clinics, some counsellors do no follow-up and others coerce clients to accept testing.
- **Follow-up of clients who test HIV positive** is currently being done informally and no support group has been established yet.

3.6.4 Influencing organisational factors

The third main theme addresses organisational factors that influence counselling for HIV testing during pregnancy. The sub-themes discussed are:

- Factors pertaining to **insufficient support structures** for counsellors;
- Factors with regard to the **clinic infrastructure and routine**, as well as
- Factors that lead to **job insecurity**

3.6.4.1 Insufficient support structures for counsellors

The participants' comments clearly indicate that they need formal support from the organisation in addition to the informal social support that they receive from their co-workers.

- **Need for formal support**

Buwalda and Kruijthoff (1994:159) as well as van Dyk (2005:330) recommend institutionalised support for health workers who work with HIV/AIDS patients.

The review of policies, programmes and guidelines regarding HIV/AIDS voluntary counselling and testing in east, central and southern Africa (Commonwealth Regional Health Community Secretariat, 2002:14) suggested the following strategies:

- weekly group meetings between counsellors and supervisors;
- weekly individual counselling sessions;
- after-session reflections amongst counsellors with a supervisor;
- regular variation in counsellor duties (counselling, outreach, lecturing),
- refresher training for counsellors and regular stress management workshops to alleviate burnout.

Whether the participants were aware of all the types of formal support that can be used, is questionable. They did, however mention counselling and debriefing for themselves.

“Daar was ‘n tyd wat ek baie krapperig gewees het en toe het ek uitgevind dit is as gevolg van die berading en ek kry nie self berading nie. (There was a time I was very irritable and then I realised it is because of the counselling, and I am not counselled myself.) (2:3)

“...councillors they are also in the need to get some, to be counselled (7:2).”

McCoy *et al.* (2002:15), Pronyk *et al.* (2002:863) and van Dyk (2005:329-331) stress the relevance of support and supervision of frontline staff. They recommend peer support groups to help prevent burnout as well as debriefing sessions with mental health care professionals.

“We have a need for debriefing (1:3).”

Debriefing (or venting) helps to create meaning after traumatic experiences. It can also be helpful when participants work through strong emotions (Achenbach & Arthur, 2002:45; van Dyk, 2005:329). Therefore, it would be useful if the counsellors are debriefed on a regular basis. It would be of limited value if it is rarely done.

The compilers of the report on the assessment of the public sector’s VCT services (Magongo *et al.* 2002:29) state that although support and supervision systems exist, it is considered inadequate in helping counsellors to deal with the personal and emotional trauma experienced in their jobs. They suggest a mentoring system and guidelines for support and supervision. In their report on the pilot of the national PMTCT programme, McCoy *et al.* (2002:37) also recommend regular support and supervision.

According to Schön *et al.* (2005:83) supervision can be defined as an opportunity for the counsellor to look at her role and the process of individual counselling sessions. Difficulties experienced are discussed to improve counselling skills. This can be done in a peer supervision group or individually with an experienced professional counsellor. It could provide education, training and emotional support. The need for ongoing support and supervision is also mentioned by Grinstead *et al.* (2000:626).

The participants in their study suggested that the clinical supervision must be conducted by an external supervisor who is not directly responsible for evaluating their job performance.

Shetty *et al.* (2005:758) claim that lay counsellors can provide an acceptable VCT service if their training is supplemented with ongoing supervision and mentoring, by a full-time professional counsellor while UNAIDS (2002:68-69) notes that mentorship is critical for both quality assurance and providing support. They state that VCT should not be introduced without providing psychological support for the counsellors. According to Patel *et al.* (2002) the counsellors (both lay counsellors and health workers) who work at the VCT service offered at primary health clinics in the Western Cape, are supported with weekly mentoring sessions with psychologists and ongoing training. Nzama and Welz (2004) reported on a mentorship programme for lay HIV counsellors in KwaZulu-Natal. These mentors provide both ongoing training and support to lay counsellors. According to the authors the lay counsellors developed personally and professionally. This benefited their counselling practice and led to an increase in uptake of HIV testing.

3.6.4.2 Clinic infrastructure and routine

Factors pertaining to the infrastructure as well as the clinic's routine could influence counselling.

- **Facilities for counselling**

Notwithstanding the physical need for a space in which to do counselling, privacy is important for effective counselling.

"We don't have our room for counselling (1:3)."

"Na reg moet ek die berading individueel doen, maar as gevolg van daar is nie genoeg spasie en tyd nie, doen ek hulle as 'n groep saam (I am supposed to do individual counseling but because there is not enough space and time, I do it in a group together.) (2.2)."

"We don't have enough room. Because sometimes I want to counsel, but the sister is there, the sister is there, the sister is there. Sometimes we wait in the room of

tea..... Maybe there are staff who needs to come to tea, that means you must wait for him or her to drink the tea, after that you can do counselling. So the problem is the clinic is very small (5:4)."

According to van Dyk and van Dyk (2003a:5) a lack of privacy because no separate rooms are available for confidential counselling and testing, creates a barrier to effective counselling for HIV testing. The World Health Organization (1999:7), Patel *et al.* (2002) as well as Ewing (2004) also mention no designated space for counselling as a constraint for effective counselling.

The participants in the study of Rohleder and Swartz (2005:402) noted their frustration with not having a designated counselling room, while they are expected to rush counselling because somebody else needs to use the room.

- **Scheduling of counselling**

The clinic's routine (seeing certain clients on specific days, pregnant women on Tuesdays for example) and the use of an appointment system can influence the counselling for HIV testing.

"So Mondays are for pregnant women, Tuesdays is for this (baby-clinic), Wednesday its the chronics "(1:5)

If certain types of patients are seen on certain days, the counsellor can prepare herself for the counselling that she would do on that day. Disadvantages are that the work may not be spread evenly as certain days may be very busy, while other days may be quiet and the opportunity for focused group education is lost (McCoy *et al.*, 2002:14). Specific days for specific types of clients could also be inconvenient for clients who are not aware of the arrangement and may have to visit the clinic more than once.

"...wat kan ons doen om dit te voorkom dat dit jou nie so baie affekteer nie. Daarom het ek vir die suster ook gevra, ek het haar gesê, sy het gevra wat dink ek, wat kan ek doen. Toe sê ek vir haar, ek dink dit sal die beste wees as ek net Maandag, Dinsdag, Woensdag en Donderdag berading doenEn as daar genoeg tyd is en ek is nie uitgeput nie, dan doen ek dit ook op gereelde afsprake (What can we do to prevent it influencing you so much. That is why I asked the sister, I told her when she

asked me what I think I can do. I told her it would be the best if I only do counselling on Mondays, Tuesdays, Wednesdays and Thursdays... If there is enough time and I am not exhausted, then I also do it according to arranged appointments.) (2:3)."

Seeing clients by appointment can be beneficial if the client can arrive at the arranged time and does not have to wait for a long time. Additionally, adequate time can be arranged for each counselling session. Disadvantages are that some patients' circumstances do not enable them to make or arrive according to specific times. An example is when one has to make use of unpredictable transport to come to the clinic. It may also involve more than one trip if the appointment can not be made by telephone. Patients who do not have appointments may have to wait even longer.

The participants in the study of Grinstead *et al.* (2000:635,637) also suggested that seeing fewer clients would enable them to be less overworked and thus prevent burnout. Grinstead *et al.* (2000:639) interpreted the request as a need for control as perceived control over one's circumstances can mitigate the effect of a stressful event or environment.

3.6.4.3 Job insecurity

Participants experienced job insecurity due to the irregular payment of their stipend and the uncertainty of their position in the hierarchy of the clinic.

- **Problems with stipend**

Some of the participants do not receive their stipend on a regular basis. They are employed by a non-governmental organisation (NGO), which is subsidised by the provincial Department of Health that does not have the necessary reserves to pay them when there is a delay in the payment from the government.

"Van die beraders het vir 4 maande nie salaris gekry nie. En hoe gaan die persoon werk toe kom as hy nie geëet het, as hy nie kos het om te eet nie, as hy nie busgeld het nie? Hy kom maar net daar aan dat dit geregistreer is dat hy tog net 'n salaris kan kry. Dit is frustrerend (Some of the counsellors did not receive a salary for four months. How does a person come to work, if he does not have food to eat.. if he

does not have bus fee? He just comes that it is registered that he can at least can get a salary. It is frustrating.) (2:5)."

"We have a problem of stipend... so the last three months, we need help, we really need help (1:7)."

There is also evidence that participants feel they are not paid enough. Mabunda (2006:24) as well as Doherty *et al.* (2003:3) mention the poor remuneration of counsellors as a reason why counselling and testing for HIV services do not function optimally. In the report of the evaluation of the PMTCT Pilot sites of South Africa (McCoy *et al.*, 2002:12), the evaluators mention the problems associated with the payment of lay counsellors. There is a marked difference between provinces in the amount they are paid, they are not paid the same as other community health workers and when the payment of counsellors are managed by NGO's, there may be times when the NGO's do not have the reserves to pay them. These factors influence the participants' morale and ultimately the effectiveness of their counselling. Doherty *et al.* (2003:3) also highlight that low counsellor salaries result in high turnover rates and a subsequent constant need for re-training.

- **Lack of acknowledgement of value of the counsellor**

The counsellors' low salaries can also be seen as lack of acknowledgement of their value. Grinstead *et al.* (2000:640) recommend that counsellors receive information about and appreciation for the 'emotional labour' that constitutes counselling as it would provide acknowledgement to the counsellors who feel tired and overworked in the context of supportive supervision.

In their literature review, Solomon *et al.* (2004:63) found a general lack of recognition for the problems that counsellors face daily and a perception that there is not enough support for those in the front-line.

The national report on the assessment of the public sector's voluntary counselling and testing programme (Magongo *et al.*, 2002:41) and the evaluation of the Prevention of mother-to-child transmission (PMTCT) of HIV initiative in South Africa (McCoy *et al.*, 2002:12) also stress the importance of structure regarding the counsellors' duties, roles and functions as the lack of structure leads to an unstable work environment and a high turnover of counsellors.

One of the participants expressed her frustrations with the lack of formal structure in which she is supposed to function.

“ maybe the Department of Health or whoever they can say to the counsellors, a day you have to do this, maybe five patients, or six. We don't have a number of people we're supposed to counsel...(6:2).”

Rohleder and Swartz (2005:398) indicated that lay counsellors experience additional work related stress because they have no formal place in the professional hierarchy, although they perform difficult emotional labour.

3.6.4.4 Conclusion statements pertaining to influencing organisational factors

- Counsellors need **formal support** in addition to the informal social support that they receive from their co-workers. This support can take the form of group or individual **counselling, supervision, mentoring or debriefing** and is essential to prevent burnout and high turnover of counsellors.
- Counselling suffers due to the **lack of suitable venues**.
- Both **scheduling certain clients for specific days** and seeing clients according to **appointments** have advantages and disadvantages.
- **Problems with their stipend** and the **lack of acknowledgement of their value** and structure regarding duties can cause counsellors to become discouraged, and cause them not to work optimally.

3.6.5 Influencing factors with regard to the community

The fifth main theme addresses factors regarding the community that could influence counselling for HIV testing during pregnancy. The sub-themes discussed are:

- The influence of **stigmatisation** on counselling for HIV testing during pregnancy;
- The **negative perceptions** held by the community regarding the clinics, and
- **Practices of the community** that may influence HIV counselling and testing.

3.6.5.1 Stigmatisation

Stigmatisation against people living with HIV/AIDS is rife in the community. It can also be “executed” by the counsellor and could contribute to the problem of stigma in the community. It could also be experienced by the counsellor herself because of her association with HIV/AIDS patients.

- **Stigmatisation by the community**

There is a high level of stigma against HIV positive people in South Africa, considering that nearly every family has been affected by the disease. Cameron and Kahn (2005:293) predict that stigma will only reduce when every household, every family and every workplace, church and community organisation is affected.

“like stigmatise, they say people wouldn't accept you, because they will think that maybe you were sleeping around without using any protection and then you find other people like those who drink to much and then maybe only have one partner. And then only because of they drink too much and then maybe the partner bring the virus at home and then will think this one, this lady, ... due to her drinking that is how she got this virus. So that is why maybe she will think, I would rather not test (3:4).”

“..their fear of discrimination. They say they are not going to be supported and that is why they don't want to do the test (4:6)”

As was found in the first step of this research (2.6.2.2), it can be expected that this high level of stigma would influence counselling for HIV testing during pregnancy negatively, as pregnant women would be reluctant to be tested. If found to be HIV positive, they may be targeted by stigmatisation.

One of the participants told the interviewer how she teaches community members not to discriminate but to help AIDS patients:

“ ..altyd as jy so 'n mens sien om altyd vir haar geselskap te hou... As jy nie sulke goete maak nie, hy gaan net daarso lê met hartseer alleen en dit gaan jou ook raak. Jy kan ook vir haar gesonde kos kook (Always, if you see a person like that to give her conversation... If you do not do things like that, he will lay sadly on his own and it will touch you too. You can also cook healthy food for her.) (7:1).

Counsellors can also contribute to stigma themselves.

- **Stigmatisation by the counsellor**

Although it has not been explicitly stated, the very high level of wanting to keep confidentiality, even when one's own family is infected, can indicate a high level of stigmatisation in the counsellors themselves. It could lead to the impression that it is acceptable behaviour to treat people with HIV/AIDS different than sufferers from other chronic conditions, although community members are generally encouraged to speak openly about it and 'normalise' it.

"Confidentiality. I don't have to tell your friend that you are HIV positive. Or your sister. I don't have to tell your mother that you are HIV positive. Unless you tell your mother that you are HIV positive, I have to keep the secret. Even if you are deteriorating, deteriorating and they are asking me, what is the problem I don't have to tell them. It is private and confidential. I like to tell them but I don't have to tell them. You are the one who don't speak to them but I am the one (1:6)."

Another explanation of this participant's attitude is that she is young, immature and that she feels ill prepared for her job as HIV counsellor.

- **Stigmatisation of the counsellor**

AIDS stigma by association or secondary stigma of health workers is a recognised concept in the literature (Brown *et al.*, 2003:51; Patel *et al.* 2002; van Dyk, 2005:324) but none of the participants in the current study expressed that they feel stigmatised because their work is related to HIV/AIDS. The finding that the participants in this study do not experience stigma can possibly be contributed to the community's knowledge that HIV can not be transmitted through casual contact, and the counsellors' contribution to help patients with HIV/AIDS (of which nearly everybody has experience through family or friends).

Although participants did not feel stigma directed at them, they reported negative perceptions against the clinics, and this could influence their counselling.

3.6.5.2 Negative perceptions regarding the clinics

Some participants reported that counselling for HIV testing can be hampered by negative perceptions in the community regarding the clinics.

- **Inappropriate behaviour and lack of respect for confidentiality**

The participants told the interviewer that they hear of negative client experiences at other clinics. This corresponds with the comments made by the pregnant women who participated in the first step of this research project (2.6.3.4)

“Ek sê vir haar: Gaan na jou naaste kliniek toe. Nee, hulle shout vir ons (I told her: Go to your nearest clinic. No, they shout at us.) (2:4).”

“Hulle voel vertroulikheid is daar nie, hulle is baie onvriendelik met die mense daarso (They feel there is no confidentiality, they are very unfriendly with the people there.) (2:5).”

“.....when I test, the sister, she maybe stays in the same street or somewhere, ne, and then obviously she is going to tell other people. And then maybe when you take the test in town, the sister in town will tell the sister from (Clinic A)..... that you came to do a HIV test (3:4).”

Thirty three (33%) percent of the participants in van Dyk and van Dyk's study (2003a:8), who were willing to be tested for HIV declared that they prefer to attend a clinic where nobody would know them as they fear that their results would not be kept confidential.

No evidence was found that confidentiality is not honoured at the clinics. One participant told the interviewer about the lengths the staff will go to protect the confidentiality of a patient's HIV status, at the clinic where she works.

“Even if you are my mother, you came with me and I am ill, very, very ill, you don't have to, if I think I don't want my mother to know my status and if the patient come with someone, we ask the patient do you want your mother to know your status. If the patient says no, she really means it, then we have to tell the mother to wait outside and we are seeing the patient alone if she says no. (1:7).”

- **Clients do not trust rapid test**

Participants told the interviewer that certain clients do not trust the results of a HIV test obtained with a rapid test.

“Other’s they don’t believe that the VCT kit that we use is effective: Is this thing real? You say yes it is. So they believe when you draw blood from the veins and it goes to the labs, that’s when they believe it.... Especially when it becomes positive. They ask you, yo, yo, This thing is ... no .. they take it and look at it ... Is it real they say .. and I say the AIDS test is actually true. Because when you take blood from the veins, the results are going to be the same (4:6).”

Hutchinson *et al.* (2004:109) reported that some participants in their study expressed their concern about the test’s accuracy. The perceived mistrust of the rapid test’s results could also be an indication of a client’s denial of his or her positive HIV status. Clients who do not trust rapid tests for HIV, increase the counsellors’ workload as extra trouble needs to be taken to explain the test’s accuracy.

3.6.5.3 Practices in community

Certain practices of community members can also influence counselling for HIV testing during pregnancy.

- **Conformation of status from different clinics**

Patients who do not trust the results of a HIV test done in one clinic can have the test repeated at another clinic, in the hope that the first result was incorrect.

“They say I didn’t do the test, but he has done it. He goes to the next clinic and say, it’s the first time I am doing the test to see if they will give the same results. They will tell you, I don’t have a clinic book (4:9).”

This practice adds to the counsellors’ workload as the patients need to be counselled and tested in more than one clinic.

- **Testing by proxy**

One of the participants told the interviewer of a way in which young men avoided being tested for HIV themselves.

“Die jong manne hulle maak die meisietjies swanger, met die gevolg die vrou trek aan die kortste end. Alle swanger vroue word getoets. So as daardie vrou, as sy positief is, dan weet hy hy is ook positief. As sy negatief is ... dan is hy ook negatief, dan kom hy vrywillig saam na die vensterperiode (The young men, they impregnate the girls, with the effect that the woman gets the shorter end of the stick. All pregnant women get tested. So, if the woman, if she is positive, he knows he is also positive. If she is negative.... then he is also negative, then he comes willingly with her after the window period.) (2:7).”

Levack (2005) also mentions the practice of ‘proxy testing’ were men do not want to be tested for HIV themselves, but consider their partner’s status as an indicator of their own. There is a general reluctance for HIV testing amongst men, as men account for only 21% of all clients who receive VCT in South Africa.

This practice influences testing in that a counsellor could realise that a woman was used in this way, and then she needs to consider how she is going to manage the situation.

3.6.5.4 Conclusion statements pertaining to factors regarding the community

The following factors with regard to the community, influence the counselling for HIV testing during pregnancy:

- The **stigma against people living with HIV** in the community can act as discouraging factor that hinders the pregnant women from HIV testing.
- **Stigma ‘executed’ by counsellors** can contribute to the stigma in the community and also sends a message that it is accepted behaviour.
- None of the counsellors experiencing stigma due to of their association with HIV/AIDS clients.
- Counselling can be negatively influenced at certain clinics which are overloaded with patients who do not want to attend **clinics with bad**

reputations, although no evidence could be found that confidentiality is not respected.

- Patients who do **not trust rapid tests for HIV** increase the counsellors' workload.
- **Clients who seek conformation for their HIV status from more than one clinic** add to the counsellors' workload.
- When **testing by proxy** is practiced, counsellors have to deal with the extra workload and difficult decision about how to manage the situation.

3.7 SUMMARY

Chapter 3 explored the process towards reaching the second objective (*To explore and describe the factors that influence the counselling for HIV during pregnancy according to counsellors*) and the findings that were obtained.

As the research design and method correspond to a large extent to those applicable to the first step of the research, the discussion of the research methods was not repeated but the reader was referred to the relevant discussion in Chapter 2.

The conclusion of the findings of this second step of the research together with the conclusions from the other steps of phase one, are readdressed in Chapter 6.

Step 3 of Phase 1 addresses the investigation of current practices of counselling for HIV testing and is discussed in Chapter 4.

CHAPTER 4

CURRENT PRACTICES REGARDING COUNSELLING FOR HIV TESTING DURING PREGNANCY

(Phase One: Step Three)

4.1 INTRODUCTION

In this chapter the procedure and findings of the research project's third step, of the first phase are discussed. The method that includes the sample, data-collection and -analysis is addressed. This is followed by the steps employed to ensure rigour and ethical considerations. This research step's findings are also explored.

The following objective is addressed in this step:

Objective 3: To explore and describe the current practices regarding counselling for HIV testing during pregnancy in selected clinics in the North West Province

Table 4.1. Structure of research project indicating Step 3

<p>Phase 1: Compilation of evidence as preparation for development of best practice guidelines</p>	<p>Phase 2: Development of best practice guidelines</p>
<p>Step 1: Explore and describe factors that influence pregnant women's decision to be tested for HIV</p>	<p>Step 5: Formulation of best practice guidelines</p>
<p>Step 2: Explore and describe factors that influence the counselling for HIV testing during pregnancy according to the counsellors</p>	
<p>Step 3: Explore and describe current practice regarding counselling for HIV testing during pregnancy</p>	
<p>Step 4: Systematic review of studies regarding counselling for HIV testing during pregnancy</p>	

Knowledge about the actual counselling practice for HIV testing will add valuable contextual evidence towards the formulation of Best Practice Guidelines, in addition to knowledge of factors that influence pregnant women's decision to be tested for HIV (Chapter 2), factors that influence the counselling for HIV testing, according to the counsellors (Chapter 3) and knowledge of existing research as identified by systematic review (Chapter 5). According to the UNAIDS document "Counselling and voluntary HIV testing for pregnant women in high HIV prevalence countries: Elements and issues" (2001:7), it is likely that the quality of pre-test information and counselling will be one of the key determining factors when a pregnant woman decides to be tested for HIV or not. Babbie and Mouton (2001:295, 299) note that people's actions are probably more telling than their verbal accounts. Benchmarking of existing practices against practices reported of high performance organisations or countries can be seen as an important step in developing best practice guidelines (Thurston & King, 2004: 240).

4.2 RESEARCH DESIGN

The research project's design is discussed in Chapter one (see 1.5). In this step, step three, an explorative, descriptive and contextual study was conducted, using a qualitative approach.

In order to explore and describe the current practice regarding counselling for HIV testing in selected ante-natal clinics in North West Province, sessions in which counselling was conducted, were observed.

4.3 RESEARCH METHOD

The discussion of the research method in this chapter includes the population and sample, the data collection and the data analysis of the third step of the first phase.

4.3.1 Population and sampling

The study population for this step constitutes the practises during counselling sessions for HIV testing at selected antenatal clinics, in the southern district of the North West Province of South Africa.

Sessions were observed at the four clinics used in the first and second steps of Phase one. Thus, the same clinics where interviews were conducted with pregnant women and counsellors were used for observation. Each clinic was visited on a randomly selected day on which antenatal consultations (and counselling for HIV testing) took place. All counselling sessions that were conducted on the day were observed. The number and selection of counselling sessions observed was determined according to the recommendations that accompany the data-collection tools (UNAIDS, 2000:39). This tool recommend observing 3-5 randomly selected sessions per clinic, representing as wide variety of counsellors as possible.

The following sampling plan was used:

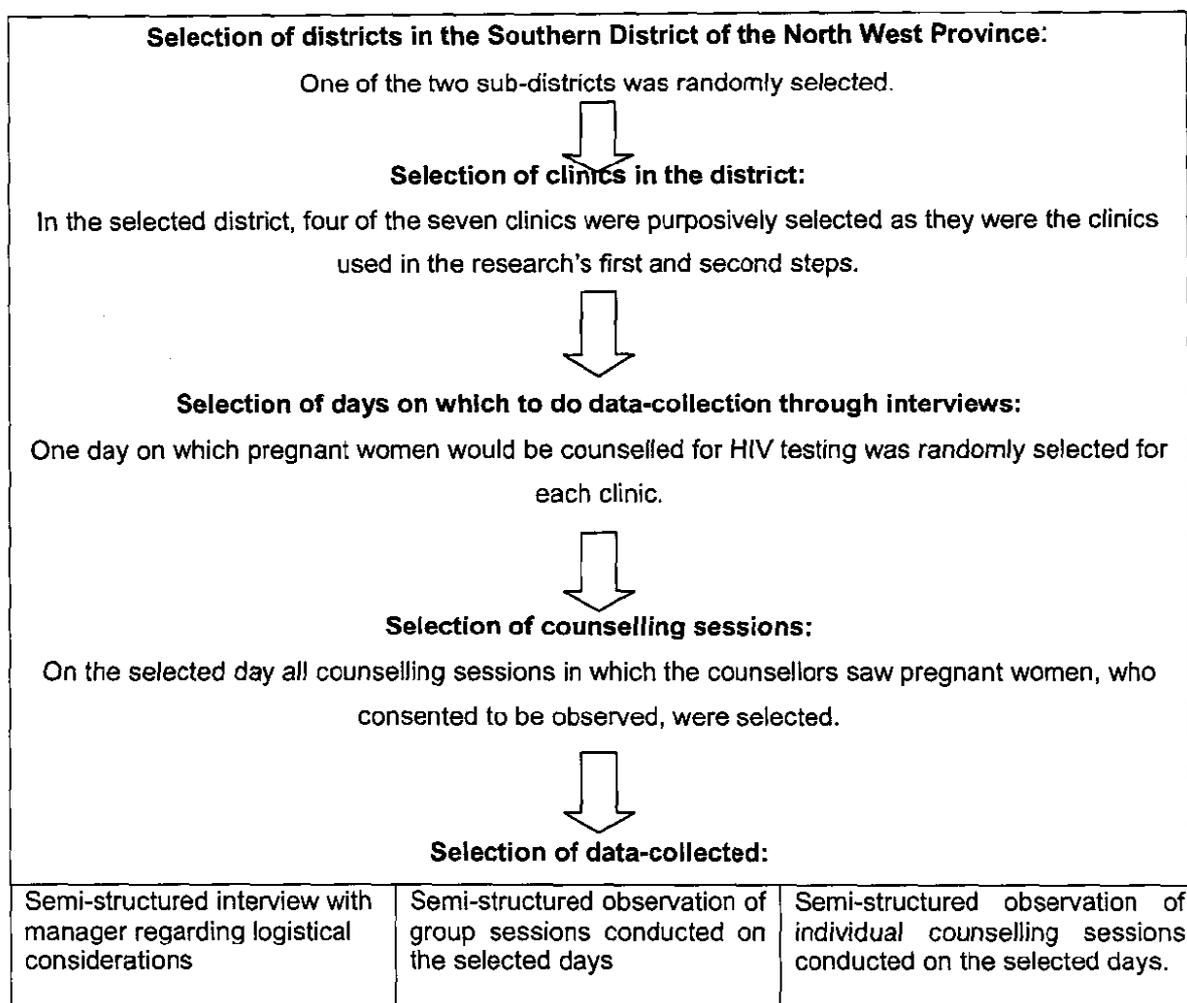


Figure 4.1 Stepwise selection-process

The sampling realised as follows:

- One manager of a clinic (Clinic B) was interviewed regarding the logistical considerations (Section 1 of observation protocol – Appendix 4.1). She was interviewed on behalf of all four clinics as the considerations correspond to a large extent. Individual differences were noted and reported on.
- Two group counselling sessions were observed in the two clinics where this procedure is followed.
- Eight individual counselling sessions were observed. Seven of these sessions were conducted by lay counsellors. On the four data-collection days, only one session was conducted by a midwife, and this session was observed.

4.3.2 Data-collection

The data was collected using structured interview and semi-structured observation as methods. A data-collection tool provided structure to ensure that all relevant practices were recorded, while field notes provided the opportunity to add richness and depth to the recordings (Burns & Grove, 2005:540).

A protocol (Appendix 4.1) as proposed by Creswell (2003:188) was used as data-collection tool. It was developed based on certain tools developed by the United Nations Programme on HIV/AIDS (UNAIDS) to evaluate voluntary HIV counselling and testing (VCT) services (2000:1-56). These tools were field tested in developing and industrialised countries. The developers encourage users to select and adapt the tools according to local circumstances and needs. These tools were used to evaluate antenatal HIV counselling in Kenya (Delva *et al.*, 2006:189-193) and HIV counselling and testing services for mineworkers in the Free State Province of South Africa (Ginwalla *et al.*, 2002:707-726).

Only four of the eight tools developed by UNAIDS (2000:1-56) were used as base for this study's observation protocol. The other four tools fall outside of this step's focus or is covered in the project's other steps, namely 'National preparedness for and commitment to VCT', 'Counsellor requirements and satisfaction', 'Client satisfaction' and 'Cost of VCT'.

The UNAIDS tools that were selected as base for the observation protocol are:

- The tool for VCT site evaluation: logistic considerations and coverage (Tool 2),
- The tool for evaluating counselling content for MTCT interventions. (Tool 5.2),
- The tool for evaluating counselling skills (Tool 4.1), and
- The tool for evaluating group counselling / group education (Tool 6).

The final protocol (Appendix 4.1) adapted from the UNAIDS tools consists of the following sections:

- Section 1 Logistical considerations
- Section 2 Content of counselling regarding HIV testing and MTCT
- Section 3 Counselling skills
- Section 4 Group sessions

The observation protocol provided for demographic (place, time of observation), descriptive (number and characteristics of participants, physical setting) and reflective (researcher's personal thoughts) data, recorded as field notes (Creswell, 2003:188-189).

The researcher collected the data herself. When counselling was conducted in Afrikaans or English the researcher observed on her own while an interpreter acted as research assistant when the counselling was conducted in Setswana, since the researcher's comprehension of Setswana is limited. Care was taken not to disrupt the clinic' normal routine.

A pilot study was conducted to evaluate the effectiveness of the observation protocol. It was found to be effective and the data was included as the first counselling session. The protocol required no adjustments, but it became clear that is application required adaptation to each setting.

4.3.3 Data-analysis

The data that was collected by means of observing practices during counselling sessions (using the observation protocol) was analysed using abstract thought processes (e.g. inductive and deductive reasoning) (Burns & Grove, 2005:561) and integrating the

findings with the researcher's personal reflections. It is acknowledged that the findings could be considered biased, and the researcher compensated by providing a rich description of the counselling sessions observed. Effort was also made to describe thought processes and reflections as clearly as possible.

4.4 RIGOUR

When using an instrument to collect data, validity – “trueness” according to Woods and Catanzaro (1988:292) must be assured. The content validity of the tools on which the observation protocol is based, can be considered assured as the tools were developed by the United Nations Programme on HIV/AIDS and tested by a group of experts in both developing and industrialised countries (UNAIDS, 2000:3).

During this step, various strategies as suggested by Krefting (1991:215) were used to ensure trustworthiness. Credibility was promoted by using an interpreter. She was used mainly to confirm that the researcher understood the content correctly and thus increased the credibility. The findings of the observation of counselling sessions are unique and context specific. A variety of clinics were observed and described in detail to fulfil the requirement of transferability.

Dependability was honoured by applying the data-collection techniques consistently and safe-keeping of the completed observation protocols of all the counselling sessions. This enables a reliability audit.

Different strategies were used to honour conformability. In this research step, different ways of observing the counselling sessions (logistical considerations, content and counselling skills), different kinds of participants (managers, counsellors who conduct counselling and the women who attend the sessions) as well as different clinics were used to triangulate the findings. The researcher's personal reflections were clearly differentiated from the conclusions obtained through data-analysis. The stakeholders' viewpoints complimented the researcher's conclusions. Relevant stakeholders include the pregnant women and the counsellors, as addressed in Chapter 2 and 3.

Rigorous research presents the researcher with an ethical obligation. Other ethical considerations are discussed in the following sections.

4.5 ETHICAL CONSIDERATIONS

In addition to the ethical clearance obtained from the Ethics Committee of the University (Appendix 1.1), the researcher obtained permission from the provincial Department of Health (Appendix 1.2), the Sub-District office (Appendix 2.2) and the person in charge of each specific clinic, to conduct this research. Before observing a counselling session the observer informed the counsellors and the pregnant women who were counselled of the research projects' aim, possible discomfort, benefit, the voluntary nature of participation and that they were allowed to withdraw at any time. After this information was shared participation was requested and their written consent obtained (Appendix 4.2). Although Angrosino (2005:734) note the discomfort that some researchers experience when they have to obtain informed consent when observation is used as data-collection technique as they do not consider this type of research as intrusive, the researcher considered obtaining informed consent from all stakeholders as pivotal.

Angrosino (2005:736) suggests a method of '*proportionate reason*' as a way to link social research to an ethical framework. This position assesses the relationship between the specific value at stake ("the value" is seen as the end product of the research) and the limitations, the harm or the inconvenience which will inevitably come about with trying to achieve that value. He proposes three criteria that can be used to decide whether a proper relationship exists between the specific value and the other elements of the act.

The first criterion is to ensure that *the means used to collect data will not cause more harm than necessary to achieve the value* (Angrosino, 2005:736). In this research, aspects that could possibly be harmful are the discomfort that the pregnant women could experience if they feel that privacy or confidentiality is threatened, or the counsellor could feel that she may suffer negative consequences due to something that the researcher observes. The researcher tried to limit these risks by explaining that the data collected will be used strictly as part of the research report and that it can not be linked to a specific individual.

The second criterion states that no *less harmful way to protect the value currently exists* (Angrosino, 2005:737). Although risk exists for the counsellor and pregnant women who

are observed, there is not a less harmful way to collect accurate data on the current counselling practices. If questionnaires or interviews were used, the data collected would not have been as accurate, as participants could have answered what they thought the researcher wanted to hear or could have attempted to place themselves in a more favourable light, than the truth (Hawthorne effect). According to Babbie and Mouton (2001:299) information shared by informants is usually a mixture of fact and point of view and is therefore not objective. The richness of the data obtained would also have been sacrificed as Babbie and Mouton (2001:295, 299) note that people's actions are probably more telling than their verbal accounts.

The third criterion indicates that the *means used to achieve the value, will not undermine it* (Angrosino, 2005:737). The means to achieve the value in this research (the presence of the observer in the counselling sessions) may cause the counsellors to act differently. Although it would probably be to benefit the client, the changed practices would not be a credible representation of 'current practices'. This possibility will be kept in mind, and its effect was minimised by observing a variety of counselling sessions (see 4.3.1).

In the following section the research findings are discussed.

4.6 RESEARCH FINDINGS

In the following section the findings according to the observation protocol (Appendix 4.1) used for data-collection, are reported. A discussion of the findings follows each sub-section.

The four clinics that were observed, function under the authority of one of the sub-districts, under the offices of the Provincial Department of Health. They are all supposed to follow the National and Provincial Departments of Health's policies. All the clinics offer comprehensive services including antenatal, postnatal, well baby-, immunisation-, family planning-, sexually transmitted infection-, tuberculosis-services and treatment of chronic diseases. Approximately 20-25 pregnant women are counselled and tested per month at each clinic. The average uptake of testing in the sub-district is 77, 6%.

Each clinic is managed by a registered nurse who is assisted by a team of nurses, counsellors and clerks. Most of the nurses are registered nurses who are also registered as midwives. They are responsible for the antenatal care of low risk pregnant women and refer high risk women to the high risk clinic at the local hospital, where these women are attended to by midwives and medical practitioners. HIV positive patients (including pregnant women) who qualify for antiretroviral therapy because their CD4 count is less than 200 cells / cm³ are referred to the Wellness clinic at the same hospital. All patients who use the provincial health services are issued with a booklet - a 'health passport', which is used for referral notes and to report back to the referral service. According to the manager interviewed, HIV positive patients are occasionally referred to social workers, non-governmental or faith-based organisations. The assessors of VCT services in the public sector expressed their concern about the limited referrals that are made to non-medical institutions such as support groups, non-governmental and faith-based organisations. In their view this is concerning since HIV is a social issue that requires social change, it is not only a bio-medical condition (Magongo *et al.*, 2002:39).

According to UNAIDS (2001:14) professional counsellors should ideally provide counselling for HIV testing during pregnancy. It is unlikely that enough funds will be available to train and employ as many professional counsellors as needed in the context of routine antenatal care. They therefore recommend that existing health workers be trained in counselling and testing for HIV. The advantage of this strategy is that these professionals are already familiar with many of the medical issues. However, additional staff would have to be employed to cope with the extra workload. Although nurses (and midwives) are usually trained and competent to provide counselling for HIV testing, Bassett (2002:348) and Shetty *et al.* (2005:755) explain that the competing demands on their time due to an increased workload and staff shortages makes a argument for using basic trained lay counsellors.

UNAIDS (2001:14) also admits that much of the routine provision of basic information about HIV transmission, prevention and testing can be done in groups and carried out by staff with little specialised training in counselling. According to the review of policies, programmes and guidelines in East, Central and Southern Africa of the Commonwealth Regional Health Community Secretariat (2002:15), South Africa has establish a precedent by assigning the primary counselling responsibility to lay counsellors. However, UNAIDS

(2001:15) adds that specialised counsellors need to deal with complex issues, such as the counselling of discordant couples, and that a referral system to such counsellors need to be established. No such a system is in place in the sub-district where data-collection was done and counselling is provided mainly by lay counsellors with some input by registered midwives.

Two types of lay counsellors work in the clinics observed (Seodi, 2007). The first type has been employed for a number of years as health promoters. Health promoters are trained in general principles of health education in a variety of topics. They are mainly responsible for providing health education on topics such as family-planning, immunisation and tuberculosis. In addition to this knowledge-base they have also attended courses on counselling, HIV and MTCT. They are employed by the provincial Department of Health. The counsellor who works in Clinic D was the only one observed who falls in this category.

The second type of counsellor has been trained specifically to be a HIV counsellor and attended a one-month training course. These counsellors are employed by a non-governmental organisation (NGO) that is also responsible for their training. This NGO is subsidised by the provincial Department of Health. Since they work in the clinics, the counsellors also report to the manager of the clinic that they are allocated to. The other five lay counsellors observed were all trained HIV counsellors.

The main sections and sub-sections of the observation protocol (Appendix 4.1) are used as themes in the discussion of the results.

Table 4.2. Themes and sub-themes used in the discussion of findings of Step 3

Theme	Sub-theme
4.6.1 Logistical considerations	4.6.1.1 Hours the clinics are open 4.6.1.2 Appointment system 4.6.1.3 Cost for the client 4.6.1.4 Infrastructure of clinics 4.6.1.5 Policy and documentation 4.6.1.6 Procedure followed during counselling and testing for HIV 4.6.1.7 HIV tests used
4.6.2 Content of counselling for HIV testing	4.6.2.1 Full information about HIV infection in pregnancy and the risk of transmission to the baby 4.6.2.2 Benefits of knowing one's status and interventions available if the result is positive 4.6.2.3 Implications of an HIV negative result

	4.6.2.4 Implications of an HIV positive result 4.6.2.5 Benefits of testing together with her partner 4.6.2.6 Implications and benefits of sharing an HIV positive result with her partner 4.6.2.7 Testing is not mandatory and health care will not be denied if she chooses not to be tested
4.6.3 Counselling skills	4.6.3.1 Establishing a trust relationship 4.6.3.2 Gathering of information 4.6.3.3 Providing information 4.6.3.4 Handling special circumstances
4.6.4 Group sessions	4.6.4.1 Establishing a group relationship 4.6.4.2 Ensuring group participation 4.6.4.3 Providing information 4.6.4.4 Handling special circumstances

Each theme and sub-theme is discussed with applicable supporting literature.

4.6.1 Logistical considerations

The information regarding the logistical considerations were collected using a structured interview according to section 1 of the data-collection protocol (Appendix 4.1). The following are discussed: the hours when the clinics are open, the appointment system, the cost for the client, the clinics' infrastructure, policy and documentation, the procedure followed during counselling and testing as well as the HIV tests used.

4.6.1.1 Hours the clinics are open

The interviewed manager reported that all the clinics are open during lunch hours and that each clinic has extended hours until 19:00 on one day per week, but are not open over weekends. This arrangement is applied according to UNAIDS' recommendation (1997:7), which states that the hours in which a counselling service is rendered should consider the needs of the community where it is situated. No information is available about such needs of the communities, where the clinics used in the present study, are situated. In the national report on the assessment of the public sector's voluntary counselling and testing programme, (Magongo *et al.*, 2002:12) three quarters of the clients and two thirds of the site managers from the stratified sample from all the provinces of South Africa, considered the clinic hours as convenient for the community.

4.6.1.2 Appointment system

The antenatal clinics use an appointment system. The system was implemented to spread the consultations evenly to prevent that some days are busier than others. Pregnant women are expected to phone or visit the clinic to make an appointment for an initial examination (booking visit) and to also be counselled for HIV testing. Women who arrive without an appointment on a "booking day" will be seen when it is possible to accommodate her, or will be given a date on which to return.

The clinics are spread through the residential areas enabling all pregnant women to visit the clinic nearest to her, a walking distance of 30 minutes (less than 5 km). This travel time is acceptable according to international standards (WHO, 1978). Some women prefer not to attend the nearest clinic and use public or private transport to attend another clinic.

4.6.1.3 Cost for the client

No money is charged for counselling or testing as all services for pregnant women and children under the age of 5 years who receive care at government funded clinics, has been free of charge since 1996. Travel costs can be considerable when women travel to a clinic more than once before receiving counselling or when they prefer not to attend the nearest clinic.

4.6.1.4 Infrastructure of clinics

The World Health Organization (WHO,1999:8) stresses the importance of providing suitable areas for counselling for HIV testing in private. They state that as discussion of risk factors and sexual relationship is part of counselling for HIV testing, these key issues will not be elicited unless the women can discuss it privately.

The clinics use different facilities for counselling. In two of the clinics, rooms were converted specifically for use by the counsellors. One of the rooms (Clinic A) was previously used as a storeroom for educational material and is situated at the end of a passage. There was no interruption during the counselling sessions and the women who

waited in the passage for their turn to be counselled could not hear the conversation inside the room. *This room is private and considered suitable for counselling.*

In clinic B the boardroom is used for individual counselling. While this is an attractive and spacious room, it was not private as the counselling session was interrupted twice by other clinic staff who stored their private belongings in the room. *This room is not private and is considered unsuitable for counselling.* The counselling conducted by the midwife took place in the consulting room while she examined the pregnant woman. *This arrangement ensures privacy and is suitable for counselling.*

The counsellors in clinic C do not have a dedicated room for counselling and had to wait for other staff to vacate a room before counselling could commence. They conducted group counselling in a consultation room, where it was not possible for everybody to sit in a circle. The setting was very noisy as the consulting room opens directly onto the waiting area. *The facilities are not private and are not considered suitable for counselling.*

In clinic D the group counselling is done in the staff tearoom and the individual counselling is conducted in a converted 'counselling room' which is part of a room that was converted from a bathroom. To get to the 'counselling room', one needs to go through a consulting room, enter the 'bathroom' with a toilet and washbasin that is used to wash instruments like kidney basins and speculums and then enter the 'counselling room' which is separated by a curtain. Both the group and individual counselling sessions were interrupted by staff members who entered the tea room to make tea or the 'bathroom' to wash instruments. *Both these rooms are not private and unsuitable for counselling.*

According to Doherty *et al.* (2003:14) as well as McCoy *et al.* (2002:14) limitations in facilities' physical infrastructure that have been adapted to accommodate counselling, impedes individual and confidential counselling. They also indicate that counselling and testing that takes place in inappropriate places impacts negatively on the people who use the service. In their evaluation report of the pilot sites when the PMTCT initiative was first launched in South Africa, Doherty *et al.* (2003:14) cautioned against conducting counselling in rooms that have dual purposes as this may result in frequent interruptions. Although a dedicated room for HIV counselling could potentially contribute to stigmatisation of clients who are seen to entering or leaving the room (Doherty *et al.*,

2003:19), this risk is reduced when counselling for HIV testing is considered as routine antenatal care for all pregnant women. Doherty *et al.* (2003:16) admit that the infrastructure of many clinics does not make provision for suitable accommodation for counselling-activities, but that the infra-structural constraints should not be regarded as a reason to not implement PMTCT in a facility. They do however stress that strengthening of the facility infrastructure should be seen as an ongoing priority towards enabling effective counselling.

Counselling sessions were interrupted in nearly all the clinics observed. Sherr *et al.* (2001:129) expressed their concern regarding the interruption of consultations (which included counselling for HIV testing) in antenatal clinics in London as it threatens the creation of trust and feelings of privacy. Inadequate privacy also leads to the perception that confidentiality is not respected.

4.6.1.5 Policy and documentation

According to the manager interviewed, all the clinics have a written policy on protecting the confidentiality of patients' HIV statuses. This policy is communicated regularly to all professional, administrative and ancillary staff. According to the assessment of the public sector's voluntary counselling and testing programme (Magongo *et al.*, 2002:24) more than 70% of the managers confirmed that guidelines on testing, confidentiality and informed consent were available but when the counsellors were asked about these guidelines, only half of them were aware of the guidelines on confidentiality. The assessors concluded that only the managers have access to the guidelines and that the counsellors do not.

Documentation can also impact on the confidentiality of a client's HIV status. After the HIV test is done, the result is reported on the antenatal card in code. This system depends on the name of the pregnant woman's mother. A code is allocated for HIV negative, HIV positive or HIV test not done, based on the first letter of her mother's name. The key to this code is kept confidential and is only available to health workers that need access to it and it is therefore not included in this research report. According to the counsellors this system is successful as patients can not identify each other's status and women can keep their status confidential from their families if they want to. The woman is in control of who she

wants to be aware of her status as she must provide her mother's name in order for the key to be used to interpret the code. Confidentiality is thus protected and the pregnant woman herself stays in control of whom she wants to disclose her HIV status to in accordance to the requirements of UNAIDS (2001:8).

A possible disadvantage of using such a complicated system to record the pregnant women's HIV status, is that a woman's status will not be known to health care providers who may need to implement strategies to prevent mother to child transmission.

Danzell *et al.* (1995:131) indicate problems that can occur if the documentation regarding antenatal testing for HIV is not completed and stress that it is necessary that the health professional who sees the woman later in pregnancy is aware whether she declined a test the first time to ensure that follow-up counselling is provided.

4.6.1.6 Procedure followed during counselling and testing for HIV

The following was observed regarding the counselling and testing procedure. In two of the clinics (A and B) only individual counselling was done. In clinic A the counsellor provided some initial counselling and obtained the pregnant women's consent to be tested for HIV after which she called one of the registered midwives to lance the pregnant woman's finger and obtain of a drop of blood for the on-site rapid-test. One of the two midwives observed provided health education while she was busy obtaining the blood sample, but the other just obtained the blood sample and left immediately without conversing with the pregnant woman. The counsellor showed the pregnant women how to interpret the test results themselves.

In Clinic B the lay counsellor gave a short introductory health talk on HIV. She then asked the woman if she wanted to be tested. If the woman gave her consent, the necessary forms were completed. The forms were then given to the woman and she was told to wait her turn to be seen by the registered midwife who would do the test. When the registered midwife saw the pregnant woman she checked if the woman had consented to the test. If she had signed the permission form the midwife obtained a drop of blood and did the test. Women who did not initially consent to be tested were then counselled further by the midwife.

In clinic C a group of six women were 'counselled' together by two lay counsellors who each did part of the presentation. The women then proceeded to the registered midwife for their antenatal examination. During the consultation the midwife asked the woman if she wanted to be tested for HIV and if she did, the midwife continued by obtaining the signed consent and doing the HIV test.

In clinic D the counsellor started with a group 'counselling' session followed by an individual session for each pregnant woman. She also called one of the registered nurses to obtain the blood drops for the test and showed the women to interpret their own results.

At all the clinics the midwives who attended to the women's antenatal health assessments are supposed to check if the women had been tested for HIV during the first visit. If a woman has not yet been tested the midwives must provide follow-up counselling and again stress the benefits of being aware of one's status. Midwives in Clinic D admit that they do not follow up but take it for granted that the counsellor will do it. They do not consider HIV counselling part of their responsibility, as they have too much work. McCoy *et al.* (2002:12) warn against the possibility of professional health workers abdicating their role as counsellors and moving the responsibility to lay counsellors. Following-up with women who did not initially want to be tested, and integrating HIV counselling and testing into routine antenatal care are widely recommended (BOTUSA, 2006:16; Branson, *et al.*, 2006:10; UNAIDS, 2002:21). It is disturbing that the midwives at this clinic do not want to be bothered with this important aspect of their practice.

4.6.1.7 HIV Tests used

Parallel testing as described by WHO (2006:86) is practiced in all the clinics as two HIV tests are used simultaneously. The advantage of this method of is that when both tests are reactive, no doubt exist that the result is positive and conformation is not required. Two different on-site rapid tests ('First response' and 'Pareekshak tri line' tests) are used for each patient. When indecisive or contrasting tests occur a blood specimen is taken and sent to the laboratory at the local state hospital for an ELISA test.

A blood specimen is taken from all patients who test HIV positive to determine their CD4 count, to identify the patients with a count less than 200 cells/mm³ who would qualify for

antiretroviral therapy. These samples are collected at the clinic and sent to the laboratory at the local state hospital. Patients are told to return in a week's time for the results. The patients who qualify for antiretroviral therapy according to their CD4 tests are referred to the Wellness clinic at the hospital for antiretroviral treatment and continued their antenatal care at the high risk clinic.

The interruption of the session to look for a registered nurse to obtain a blood sample for the rapid test is not conducive to privacy, building of a trust relationship or time management. McCoy *et al.* (2002:12) recommend that the use of a saliva test for HIV is investigated. Such a test would exclude the necessity of a registered nurse obtaining a blood sample and could be administered by the lay counsellors. It is possible to implement such a change of procedure as Welty *et al.* (2005:488) describes how lay birth attendants were trained to provide counselling for HIV testing and use oral fluid rapid HIV antibody tests in Cameroon.

4.6.1.8 Conclusion statements regarding logistical considerations

- Provision is made for women who are not able to visit the clinic during **office hours**, but pregnant women may find making appointments *inconvenient*.
- Antenatal care and counselling for HIV testing is presented *free of charge* and can therefore be considered **affordable** for pregnant women
- Pregnant women who prefer not to visit their nearest clinic must be able to pay for transport to the **preferred clinic**.
- **Privacy** during counselling can not be guaranteed in the clinics. Physical limitations cause counsellors to make do with the facilities that are available and counselling is often interrupted.
- No evidence (accept limited privacy during counselling) was observed that could be considered a threat to **confidentiality**.

Judgement about best practices can only be made once more aspects have been considered. Some of the aspects that should be considered are; the information that the counsellors transfer to the pregnant women during the counselling sessions and the counsellor's skills demonstrated during individual counselling and group sessions. These aspects are discussed in the next sections.

4.6.2 Content of counselling for HIV testing

In this section a general discussion about the content of the information presented as part of counselling for HIV testing during pregnancy is followed by a discussion on the criteria according to the observation Protocol (Appendix 4.1).

No educational aids were used in the clinics observed. Evidence was found in the literature that checklists, flipcharts and written information in the form of posters and patient information brochures are used in other programmes (WHO, 2006:39; BOTUSA, 2006:9).

Counsellors can use checklists as a reminder of all the topics that need to be included in the information giving part of the counselling. This simple list can be made by the counsellor herself or it could be supplied by the agency for which she works. The use of such a list ensures that all the necessary topics are addressed during counselling. Flipcharts are recommended in the Support tools developed by the CDC and WHO (WHO, 2006:39) and are used in the BOTUSA programme (2006:9). Their advantage, above that of checklists, is that pictures and messages are visible for the pregnant woman who is being counselled, enabling her to better understand and remember the information. If pregnant women are supplied with information brochures that incorporates the same pictures and messages as the flipcharts, as recommended by the CDC / WHO support tools (WHO, 2006:105-108), the messages can be further reinforced. The pregnant women can also show the brochures to their partners and family.

In the United States of America the emphasis has moved away from giving detailed information during all pre-test counselling sessions to a more simplified strategy. According to the new strategy all pregnant women should receive oral or written information that includes an explanation of HIV infection, a description of interventions that can reduce HIV transmission from mother to baby, and the meaning of positive or negative test results. Women should be allowed to ask questions and to decline testing (opt-out). The Centre for Disease control and Prevention (CDC) of the USA further recommends that HIV testing should not require additional processes or written documentation of informed consent beyond what is required from other routine antenatal tests (Branson *et al.*,

2006:10). It is questionable if such a policy is suitable in a developing country such as South Africa with a high HIV prevalence rate.

The criteria of the Observation Protocol (appendix 4.1) regarding the content of counselling for HIV testing and MTCT are as follows:

4.6.2.1 Full information about HIV infection in pregnancy and the risk of transmission to the baby

In Clinic A the counsellor gave information about HIV and AIDS as well pregnancy in general, but did not address the risk of HIV transmission from mother-to-child during pregnancy or the birth process. In Clinic B both lay counsellors did not provide information about mother-to-child transmission of HIV. The midwife who did the follow-up during the antenatal care consultation gave full information about HIV in pregnancy and the risk of transmission to the baby. In Clinic C, HIV in pregnancy and the risk of transmission were discussed superficially during the group information session (One of the counsellors admitted to the researcher that she does not know a lot about it). In Clinic D HIV in pregnancy was briefly discussed during the group session and the counsellor used the individual session to share information about the advantages of being aware of one's HIV status, the risk of mother-to-child transmission and strategies to limit the risk.

4.6.2.2 Benefits of knowing one's status and interventions available when the result is positive

The lay counsellor in Clinic A did not explore the women's views, feelings or knowledge. She also did not supply any motivation or specific information about risk of mother-to-child transmission of HIV. In clinic B the midwife explained the benefits that a known status hold for a pregnant woman and her baby as well as the strategies that can be implemented to limit the risk of MTCT. However, the lay counsellors did not address this issue at all. One of the pregnant women counselled flat out refused to be tested. The lay counsellor did not use the opportunity to tell the woman about the benefits of being aware of one's status and the interventions available to limit transmission to her baby if she was found to be HIV positive, to motivate her to be tested. In clinic C the benefits for a pregnant woman to be aware of her HIV status and the interventions available to limit

MTCT if she tests positive was briefly discussed during the group information session. Detailed information on the benefits and strategies was provided during the individual counselling session in clinic D.

In none of the sessions observed mention was made that ARV's are not given to women whose HIV status is not known. It is important to discuss the fact since some pregnant women believe that receiving Nevirapine without being tested for HIV as a possible way to avoid the distress of being aware of one's positive HIV status, while still avoiding the possible transmission of the infection to her baby.

4.6.2.3 Implications of a HIV negative result

The counsellors addressed the meaning of a negative test, in all the counselling sessions where HIV testing was discussed by the counsellors. They also pointed out that the test must be repeated after three months to ensure that a person was not already infected but still in the window period when antibodies cannot be identified by screening tests. They also told the pregnant women that if they test HIV negative, they should use condoms to stay negative.

4.6.2.4 Implications of a HIV positive result

The implications of a HIV positive result for the baby (possible MTCT, chronic illness, suffering and early death if infected) were not discussed in detail. The midwife in clinic B, the counsellors who conducted the group session in clinic C and the counsellor during the individual counselling session in clinic D addressed the risk of mother to child transmission, but did not tell the women what the babies life would be like if infected. This information can be a very powerful motivator for testing as most of the mothers interviewed in the second step of this research mentioned that they want to protect their babies against suffering.

The implications of a pregnant woman's HIV positive status for her future children (possible HIV infection because of HIV infection or growing up without a mother), were not discussed in any of the sessions observed.

All the counsellors addressed the decision that a HIV positive woman needs to take regarding baby feeding. The counsellor in clinic A asked the mothers if they wanted to use breast- or bottle feeding for their baby. All three women said that they prefer breastfeeding. The counsellor just said that it is good and that they must breastfeed exclusively for three months. She did not go into detail regarding the reasons why exclusive breastfeeding is important for babies of HIV positive and negative mothers. She also did not discuss practical aspects; for example how to avoid mixed feeding and how to wean the baby. In clinics B and C, options for safer baby feeding, when women test positive for HIV, were briefly discussed. According to the counsellors they explain the issue in more detail during post-test counselling of women who test HIV positive. In clinic D the counsellor used the time, while she waited for the test result to appear, to give education on safer baby-feeding practices.

While the implications that a positive HIV test result have when deciding about infant feeding were mentioned in the counselling sessions, it was not explored in enough detail to enable a woman to persist with her method of choice without putting her baby in danger with unsafe practices. It is acceptable if a detailed discussion is conducted during the post-test counselling of a HIV positive woman - especially if this is supported with a brochure that could be taken home.

4.6.2.5 Benefits of testing together with her partner

None of the counsellors told the pregnant women about the benefits of or possibility to be tested for HIV with her partner. It seems that it is still a foreign concept in this area and not yet practiced.

4.6.2.6 Implications and benefits of sharing a HIV positive result with her partner

The midwife at clinic B and the lay counsellor at clinic D were the only counsellors who discussed the implications of a HIV positive result for the relationship with the pregnant woman's partner and encouraged her to ask her partner to be tested. They did, however not discuss the benefits in detail.

Women need guidance on how to disclose their status to their partners as they may fear his reaction. Women can be helped by practicing how to disclose the result during role play.

The counsellors did not address sensitive issues such as high risk sexual practices and only told the women to use condoms. Women often find it difficult to insist that a condom is used during sexual intercourse and specific coping skills could be taught.

4.6.2.7 Testing is not mandatory and health care will not be denied if she chooses not to be tested

Women were told that they have to give their consent before they could be tested for HIV. Some of the counsellors pressurised the women by telling them that they must be tested 'for the file' or for 'hospital records', while others took no trouble to find out why the women did not want to be tested or to tell them about the benefits that knowing their status holds. Some women may be afraid that they may be denied antenatal care if they do not consent to testing, while other women may avoid antenatal care because they believe HIV testing is compulsory.

4.6.2.8 Conclusion statements regarding content of counselling for HIV testing

- Knowledge about HIV infection in pregnancy, the risk of transmission to the baby, the benefits of knowing one's status and interventions available if the result is positive can be **powerful motivators** to convince pregnant women to be tested.
- Implications of a negative test result and the implications of a positive result for baby feeding were discussed well but more **practical information** regarding baby-feeding needs to be added during the post-test counselling of women who test HIV positive.
- HIV positive women need **more direct information** on how to disclose their status to their partners. The implication of a positive result for future children and benefits of couple testing are not discussed.

4.6.3 Counselling skills

Chopra *et al.* (2005:359) used very simple criteria to determine communication skills in their study that assessed the quality of counselling for mothers on the prevention of HIV transmission to children. They concluded that the communication skills of the counsellors they observed were good, because they used a warm tone of voice and language that the mother understood. They further based their conclusion on the fact that 80% of the mothers observed, were given time to respond and an opportunity to ask questions. In contrast with the simple criteria, UNAIDS' definition (1997:3) clearly states that more is expected. UNAIDS (1997:3) defines HIV counselling as a confidential dialogue between a client (in this case a pregnant woman) and a counsellor aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. They define a counsellor as a person trained in counselling skills: listening to the client, asking supportive questions, discussing options, encouraging the client to make his or her own informed decisions, giving practical information and suggesting follow-up (UNAIDS, 1997:3).

In this section a report is given on how the counsellors who were observed performed in counselling according to the criteria from the Observation Protocol (Appendix 4.1) based on the tools from UNAIDS (2000:32).

4.6.3.1 Establishing a trust relationship

A good counselling relationship is based on trust and respect. Therefore, the first step in effective counselling is to build a relationship that encourages the client to share feelings and experiences without fear of being judged (WHO, 2006:74). Indicators as stipulated in the observation protocol (Appendix 4.1) are used to identify if the counsellor is able to establishing a personal relationship to communicate.

All the counsellors started the sessions by greeting the pregnant women and introducing themselves. Some of the counsellors engaged their clients in general conversation to put them at ease, but others started by asking directly if they wanted to be tested for HIV.

There was little evidence that the counsellors practice active listening as they did most of the talking and did not give the pregnant women an opportunity to reply or ask questions. No evidence was observed that suggests that the counsellors were non-supportive or judgemental. Although difficult to measure, some of them seemed to keep their clients at a distance and acted businesslike.

4.6.3.2 Gathering of information

According to UNAIDS (2001:8) one of the main tasks during counselling for HIV testing, is to give individuals the opportunity to assess their own risk of infection with the counsellor's help. The South African Department of Health's policy that deals with PMTCT of HIV (DoH, 2000a:12) states 'explain or determine reasons for testing' as one of the components of pre-test counselling.

While information can be provided in a group setting, sensitive matters should be addressed during private individual sessions. To explore each woman's sexual history in detail and to assess her risk of being HIV infected, would be very time consuming and could cause a lot of discomfort. It is more appropriate to supply the information about ways of transmission and high risk behaviour (including her sexual partner's) and let the woman assess her own risk. The counsellor must however let the pregnant woman know that she is available for any questions and that she could assist her in assessing her risk, if needed.

Since the counsellors did most of the talking in the sessions observed, there was little opportunity to evaluate if they used an appropriate balance between open and closed ended questions.

One incident was observed where a counsellor used silence to allow for self-expression. When one of the pregnant women at clinic B stated that she did not want to be tested, the counsellor enquired about her reasons and used silence effectively to give the woman opportunity for self-expression, but the woman just said she that she did not want to discuss it. The counsellor told the researcher that she suspected that the women is not yet ready to be tested, and that she would talk to her again at a follow-up visit. The counsellor was comfortable with the silence and did not try to fill it.

There was little opportunity to observe whether the counsellors clarify the information given and avoid premature conclusions, because the counsellors gave the women very limited opportunity to participate in the conversations.

An incident was observed where the use of probes would have been appropriate but not used. When another of the pregnant women in clinic B was asked if she wants to be tested, she said 'no'. The counsellor answered: 'Ok, you don't have to'. She did not probe for reasons but continued to complete a form that indicated that the woman denied testing for HIV. The translator who accompanied the researcher then asked the woman why she did not want to be tested for HIV. Her answer clearly indicated that the woman did not understand that the discussion was about HIV. The counsellor told her to wait for her turn to be seen by the midwife. After being counselled by the midwife this woman gave her consent to be tested and was very happy when she was found to be HIV negative.

When discussion took place, the counsellors summarised the most important issues.

4.6.3.3 Providing information

Providing information is (with providing of support) one of the main functions of counselling for HIV testing (DoH, 2000a:12). The content that needs to be provided has already been discussed in 4.6.2. In this section the techniques used to provide the information is discussed.

All the counsellors used appropriate language and explained the content of their presentations in clear and simple terms. Some of the counsellors (Clinics B and C) gave the information in small chunks and then allowed the client time to absorb and respond to it, but the counsellors in clinic A and D bombarded the pregnant women with information!

It was clear that the counsellors had up-to-date and sufficient knowledge about HIV in general to do counselling, but some of them lacked specific knowledge required to counsel pregnant women. One of the counsellors in clinic C confessed that she does not know enough about HIV in pregnancy and often can not answers her clients' questions.

The counsellors repeated and reinforced important information. No take-home materials like brochures that emphasise the main issues were available for pregnant women.

The counsellors did not consistently check for understanding or misunderstanding. They also did not always give the women the opportunity to ask questions. Chopra *et al.* (2004:8) reported in their assessment of the quality of counselling (mostly on baby feeding options) that the counsellors whom they observed scored high in most aspects of communication skills except correcting the mothers' inaccurate beliefs.

Most counsellors concluded their sessions by summarising the main issues discussed, although the counsellors in clinic B did not do this as they just gave the women their consent forms and told them to wait for their turn to see the midwife.

4.6.3.4 Handling special circumstances

The one incident observed where language difficulty was evident, was not handled satisfactorily. One of the pregnant women who were counselled in clinic B recently moved to the area, and is Shangaan-speaking. She could not understand any of the languages that the counsellor, researcher or researcher's interpreter could speak. There was no interpreter available in the clinic who could communicate with her and no counselling or health education could be done. The counsellor told the researcher that such language barriers were uncommon, but does occur occasionally. The woman was not tested for HIV, but other antenatal care was provided. All the findings and the return date was written on her antenatal card with the hope that a family member would be able to translate for her.

No counselling session observed touched on personal issues like negotiating condom use, but when sensitive issues like HIV were discussed, the counsellors or pregnant women did not seem embarrassed.

The counsellors varied in the time that they used for counselling. Individual counselling ranged from 5 minutes in clinic B to 30 minutes (on top of group counselling of 90 minutes) in clinic D. The WHO recommends a duration of 10-20 minutes for pre-test counselling (2006:18), while McCoy *et al.* (2002:11) recommend 60 minutes for the initial pre- and post-test counselling.

According to the assessment of public sector VCT services (Magongo *et al.*, 2002:16) the national average time spent during pre-test counselling was 25 minutes. In the study of Delva *et al.* (2006:190) where the UNAIDS tools were used in data-collection in Mombasa, Kenya, the mean duration of group sessions was 33 minutes, while the individual pre-test counselling sessions lasted for an average of 6,6 minutes. The duration of counselling compares favourably with the mean time of only 1,73 minutes spent in hospital based antenatal clinics in London, as reported by Sherr *et al.* (2001:129). The research of Jones *et al.* (1998:272-273), has shown that counselling lasting at least 5 minutes leads to a higher uptake of testing than a duration which is less than 15 minutes.

In two of the sessions observed, pregnant women received the news that they were HIV positive. In clinic A the woman read the result from the test herself. The counsellor ensured that she understood the result. She then informed her that she must use condoms in future, that blood will be taken for a CD4 count to determine if she qualifies for antiretroviral therapy, that she must take the Nevirapine as indicated and that her baby will be tested at age six weeks to determine if he/ she is infected. The counsellor gave her a few minutes of silence to compose herself but did not ask the women about her feelings or give advice about disclosure to or testing of her partner or her support system at home. She also did not determine if the newly diagnosed woman had any questions. The women did not show any emotion when she received the news. The pregnant woman in clinic D also did not react emotionally when she interpreted the test as positive. The counsellor was very supportive, and helped her to do short-term planning on how to handle the shock of the result. When the pregnant woman did not display emotional reaction, the counsellor said that she probably did not realise the consequences of the result yet, and that she is welcome to visit her again. She stood up and gave the woman a hug.

In Delva *et al.*'s study (2006:191) that used the UNAIDS tools in data-collection, emotional reactions were not dealt with in 80% of HIV positive women and in 84% of the HIV-positive cases the counsellor did not check if follow-up support was available.

4.6.3.5 Conclusion statements regarding counselling skills

If UNAIDS' definition (1997:3) of a counsellor (a person trained in the skills of counselling: listening to the client, asking supportive questions, discussing options, encouraging the

client to make his or her own informed decisions, giving practical information and suggesting follow-up), is applied, only a few of the 'counsellors' who conducted the sessions observed, can be considered counsellors. According to Sherr *et al.* (2003:345-346) good counselling skills are essential and brief factual discussion and consent is simply not enough.

The findings regarding counselling skills in this study contrast with the findings in the study of Delva *et al.* (2006:190) who used the same tools, where all the counsellors obtain high to maximum scores in social and communication skills.

- Counsellors are **skilled in basic conversational skills** and able to establish an interpersonal relationship but **they do not exhibit 'counselling skills'** such as using open and closed-ended questions, reflective listening, paraphrasing and probes.
- The counsellors **talk a lot, and do not ask and listen enough.**
- Counsellors do not ask about the women's personal circumstances and can therefore not help them to **make a truly informed decision about HIV testing.**
- **Language difficulty** was not handled well.
- The **best way for the counsellor to handle a newly diagnosed pregnant woman who experiences emotional distress** will depend on the specific situation and the personalities of the counsellor and pregnant woman involved.

4.6.4 Group sessions

In this section an introductory discussion about group sessions is followed by a description of the activities observed. The section concludes with a discussion based on the criteria of the observation protocol (Appendix 4.1). While the term group 'counselling' is widely used, the word 'counselling' is not appropriate for group sessions, and the term 'information sessions' as used by the WHO (2006:71) is more appropriate.

Group information sessions on a variety of issues concerning pregnancy and birth including HIV/AIDS, risk and prevention of MTCT and benefits of HIV testing, followed by in-depth discussion during individual counselling before testing, are used in successful projects like the DART (Demonstration of Antiretroviral Therapy) project of the Perinatal

HIV Research Unit at the Chris Hani Baragwanath Hospital (Oberzaucher & Baggaley, 2002:19) as well as the BOTUSA project of Botswana (BOTUSA, 2006:5).

According to WHO (2006:6) group information sessions save time, optimise human resources, allow for group interaction and can easily be integrated into antenatal care services. BOTUSA (2006:6) cite other advantages of group educational sessions and states that information can be given to a large number of pregnant women at the same time and that women may benefit from mutual support from the group members and this can continue even after HIV diagnosis.

Ideally the group session should be followed by individual (or couple) counselling. Mazwi *et al.* (2002) reported that HIV test uptake improved from 61% to 97,3% in a specific clinic after a system of individual counselling for pregnant women who were interested after attending a group education session was instituted, compared to the previous system where women were tested directly after the group session.

Two of the clinics use group 'counselling'. At clinic C the group session was attended by four pregnant women and facilitated by two counsellors. The one counsellor started by introducing herself and asking everybody to introduce themselves. She then asked the pregnant women what they know about HIV in pregnancy. The question led to a lively discussion in which all the pregnant women participated. She reinforced the important aspects, clarified the misunderstandings and told them about the window period and options for safer baby feeding. The other counsellor continued the session by using a poster to explain the test procedure and how to interpret the result. She asked a volunteer from the group to repeat what she heard. The other women in the group also participated and gave their ideas. The counsellors asked the women if they had any questions, but no questions were asked. After this session the pregnant women were all seen individually by a registered midwife for follow-up counselling and testing.

At clinic D the counsellor started the group counselling session in the staff tearoom with 3 pregnant women. During the 90 minute session another 3 women joined the group. The counsellor started by greeting the pregnant women, introducing herself and inviting everyone to introduce themselves. She also told them in which languages she could present the information and asked them which language they prefer. The counsellor

facilitated group interaction by asking everybody what they know about HIV. After everybody had an opportunity to participate she summarised what had been said. For the remainder of the session she was the only speaker. She gave a lot of information on management of discomforts during pregnancy, what to expect during antenatal care, danger signs of pregnancy, nutrition during pregnancy, what clothes to wear and what exercises to do. She did not specifically speak about HIV in pregnancy. The group session was followed by individual sessions for each pregnant woman with the same counsellor.

Group facilitation skills are used to create rapport between group members and the counsellor. Effective facilitation promotes discussion amongst group members and encourages sharing and learning (WHO, 2006:72). As the intention of the group sessions is to provide the pregnant women with information about HIV in pregnancy and the prevention of mother to child transmission, it can be considered important for counselling for HIV testing, that this information is transferred optimally.

4.6.4.1 Establishing group relationships

Effective group sessions start with establishing relationships between the members. In both groups observed the counsellors greeted the pregnant women and all three counsellors introduced themselves to the group members. They continued by asking the group members to introduce themselves to the other members of the group.

4.6.4.2 Ensuring group participation

According to the criteria of the Observation protocol (appendix 4.1) group participation can be ensured by using the following techniques.

All members should be encouraged to participate. In both groups the group members were asked what they know of HIV. The members all participated in this discussion but were not encouraged to partake except for one further question about the test procedure at clinic C. Very limited discussions occurred as the counsellors did not encourage group participation but 'lectured' on their own. Therefore, they also did not seek clarification of the information given by the group members.

At clinic C the group members' discussions were not summarised, but the counsellor in clinic D summarised the group members' replies to the question - what they know about HIV.

According to WHO (2006:72) effective facilitators promote discussion amongst group members and encourage sharing and learning. This requires specific skills that must be practiced. It is not clear if the counsellors observed did not receive training in facilitation skills, or whether they were trained, but neglected to practice these skills.

4.6.4.3 Providing information

As the content of the 'counselling' was already discussed in 4.6.2 this section focuses on the skills used to present information to a group.

When presenting information to a group the counsellor should give the information in clear and simple terms. During the group sessions observed the counsellors used appropriate language and explained the terms that they used.

During the individual counselling sessions the counsellors again did most of the talking, and did not ask for or encourage comments by the group members. They therefore did not give the participants time to respond to the information that was supplied.

It is important that counsellors who conduct group sessions have up to date knowledge about HIV and MTCT, just like it is vital for individual counselling. The counsellors in Clinic C were not sure of all their facts and it appeared as if their knowledge is limited, while the knowledge of the counsellor in clinic D was up to date. During the group session she mainly talked about pregnancy in general, but addressed HIV in pregnancy during the individual counselling.

As the sessions progressed the counsellors repeated and reinforced the important information. They also asked if the women understood and the group members replied that they understood. The counsellors did not ask specific questions to determine their comprehension. At the end of the sessions the main issues were summarised.

Other presentation skills mentioned in the WHO reference guide (2006:72) that could add value to the provision of information are: preparing for the session by tailoring the presentation for the specific group, preparing educational aids like a flipchart and hand-outs, using appropriate body movements and facial expression while presenting, speaking slowly and clearly and appearing enthusiastic. They also recommend using stories to explain complex concepts, managing time appropriately by keeping to the allocated time-frame and taking care not to rush or to spend too much time on any one concept.

4.6.4.4 Handling special circumstances

The members of the two groups observed were all from the same cultural and language groups. The counsellor in clinic D gave the group members the opportunity to select the language that they would prefer the session to be conducted in.

The counsellors who facilitated the group sessions handled sensitive issues in a way that was appropriate to the culture and group composition. The counsellors and pregnant women did not seem embarrassed.

Time was well managed in clinic C although the counsellors and women had to wait for a consulting room to be vacant before the session could start. The session started at 10:00 while the women were told to be at the clinic by 8:00, when they made their appointments. The group session in clinic C took 30 minutes. The WHO's guideline (2006:17) suggests 20 minutes as a appropriate duration for a group information session and as this session did not take much longer, the main issues were covered and each woman received an opportunity to participate in an individual follow-up with the midwife, this counsellors coped efficiently with the limited time.

In clinic D the group session started at 9:00 while group members had been waiting since 8:00. The group session was finished by 10:30 when the first pregnant woman started her 30 minute individual session, and this implied that the last woman in the group would only be attended to very late. The pregnant women became tired and lost concentration. The group information session in clinic D lasted 90 minutes. In relation with the recommended time of 20 minutes and considering that the pregnant women received individual counselling after the group session, this group session was very long. As a variety of

subjects and not just HIV in pregnancy and HIV testing were lectured, it seems more appropriate to spread the information and provide additional sessions during the follow-up antenatal visits.

No incidents where pregnant women experienced distress during group sessions were observed, therefore no judgement can be made on how such situations are managed.

4.6.4.5 Conclusion statements regarding group sessions

- The counsellors were **effective in establishing group relationships** but **did not demonstrate facilitation skills to ensure group participation** as they did nearly all the talking in the groups.
- Counsellors displayed basic **information giving skills**, but their presentation skills were not good.
- **Time is not managed well during group sessions** as the pregnant women became tired and the effectiveness of the sessions deteriorated when the session's duration was longer than 30 minutes.

4.7 PERSONAL REFLECTIONS

A few general impressions from the field notes are discussed as the researcher's personal reflections.

According to WHO (1999:7) pregnant women consider a service acceptable if they believe that confidentiality will be guaranteed and that there will be no coercion to be tested – not even well intended pressure.

Coercion takes place in some of the clinics observed. In clinic A the counsellor told the pregnant women that they must be tested because they are pregnant and that their status must be known 'for the file'. The counsellor was very proud of the fact that almost all the clients she counsels agree to be tested. This point of view corresponds with the counsellors in the study conducted by de Paoli *et al.* (2002:147) who perceived a 'good' counsellor as one who is able to convince pregnant women to 'do what the counsellor wants' and accept testing while a 'bad' counsellor was seen as one with whom many

women refuse HIV testing. Furthermore, the counselling at Clinic A did not seem 'informed' or totally 'voluntary'. The counsellor gave a lot of health education, but did not ensure that the women understood what she told them and did not give them an opportunity to ask questions. It also seemed as if the counsellor kept an emotional distance from the clients as she handled it very matter-of-factly when one of the women test HIV positive.

At Clinic B the 'counsellors' are not really counsellors. They do not educate, motivate or support. If pregnant women are tested for HIV it is because they have made up their mind before entering the clinic, or because of the trouble that the midwives took. A solution would have to be found for women who only speak and understand a language that is uncommon in the area. Pamphlets about HIV and other topics in languages not commonly used in the area such as Xhosa and Shangaan could help, but these women are often illiterate as they would at least understand Basic English if they had attended school.

In Clinic C the pregnant women were more active. They discussed their existing knowledge, and learned from one-another. The counsellors seemed interested in the women and did not do all the talking. They did however confess that they do not think they know enough about HIV in pregnancy, mother-to-child transmission or strategies to limit it. Although no evidence from emotional support was evident in Clinic C, the atmosphere was warmer and it seemed that women would have more confidence to raise their fears and uncertainties.

The pregnant women who visited clinic D for antenatal care certainly received a lot of information! It is questionable that they would remember all of the information. The counsellor in clinic D was the only counsellor observed who was willing to open up and become emotionally involved, (she hugged the pregnant woman after she was diagnosed as HIV positive) but she did not encourage her clients to open up. The group session that realised as a health education session about pregnancy issues, was frequently interrupted. The lack of privacy when discussing the woman's decision and the result of her HIV test is a cause for concern.

4.8 SUMMARY

The observation of counselling sessions were valuable as it revealed the gaps that exist between what is supposed to happen during counselling for HIV testing during pregnancy, and what happens in reality.

In this chapter the research design, research method including population and sampling, data-collection and data-analysis as well as rigour, ethical considerations and research findings of step 3 (explore and describe the current practice regarding counselling for HIV testing during pregnancy) of phase one (compilation of evidence as preparation for development of best practice guidelines) were addressed.

The conclusions of the findings (together with the evidence compiled from the other steps) will be addressed again in Chapter 6.

Step 4 of phase 1 addresses the next objective and will be discussed in Chapter 5.

CHAPTER 5

COUNSELLING FOR HIV TESTING DURING PREGNANCY: A SYSTEMATIC REVIEW

(Phase One: Step Four)

5.1 INTRODUCTION

The discussion of the research method in this chapter includes the population and sample (Search strategy), the data collection (Critical appraisal and data-extraction) as well as the data analysis (Conclusions) of the fourth step of the first phase.

The design of the entire research project is discussed in Chapter one. This step of the study is explorative and descriptive in nature. The literature relevant to counselling for HIV testing during pregnancy was *explored* by means of systematic review. Only the results from the studies that were found to be of high quality and potentially applicable were *described* and synthesised according to the main themes.

The following objective is addressed in this step:

Objective 4: To explore and describe the evidence regarding counselling for HIV testing during pregnancy by means of systematic review.

Table 5.1 Structure of the research project indicating Step 4

Phase 1: Compilation of evidence as preparation for development of best practice guidelines	Phase 2: Development of best practice guidelines
Step 1: Exploring and describing personal and organisational factors that influence pregnant women's decision to be tested for HIV	Step 5: Formulation of best practice guidelines
Step 2: Exploring and describing organisational factors that influence the counselling for HIV during pregnancy according to the counsellors	
Step 3: Explore and describe current practice regarding counselling for HIV testing during pregnancy	
Step 4: Systematic review of studies regarding counselling for HIV testing during pregnancy	

5.2 RESEARCH METHODS

It was essential to review the scientific literature on the subject as comprehensively as possible, to obtain a complete picture of the current best evidence regarding counselling for HIV testing during pregnancy. A systematic review was used rather than a traditional literature review, as a well conducted systematic review is considered the most powerful tool to review and summarise the best evidence available on which to base clinical decisions (Sackett *et al.*, 2000:133). According to Cook *et al.* (1997b:378), Davies and Crombie (2001:2) as well as Magarey (2001:377) a systematic review differs from a traditional literature review due to the scientific strategies that are applied to limit error in the systematic assembly, critical appraisal and synthesis of all relevant studies on a specific topic.

The process of a systematic review includes the following steps (Davies & Crombie, 2001:3; Kitchenham, 2004:3; Melnyk & Fineout-Overholt, 2005:9, 207; Sackett *et al.* 2000:42-45):

- 1 formulating a review question,
- 2 systematically searching the literature for all studies that may be relevant and then reviewing the studies for relevance,
- 3 assessing the scientific quality by critically appraising the studies,
- 4 extracting the data,
- 5 analysing the data (through meta-analysis or meta-synthesis as applicable),
- 6 drawing conclusions and
- 7 contextualising the results.

The resulting synthesis can be used to solve a clinical problem, or as in this study (in combination with evidence from the other steps of the study) to formulate best practice guidelines, that each user has to contextualise when applying it in the care of a specific patient. According to Evans (2001:2) the same principles and rigour applicable to primary research is expected when doing a systematic review and the researcher must therefore document all the steps of the process followed to enable users to appraise the quality of the systematic review.

5.3 RIGOUR

In this research, a systematic review of documents regarding counselling for HIV testing during pregnancy was performed. To demonstrate that all the hallmark studies were included and that a point of saturation was reached, detail on how documents were selected during the systematic review, how disagreements were handled (when working in a team) as well as the way in which information was synthesised are essential to ensure rigour (Cook et al., 1997a:210) and to provide an audit trail of analysis.

5.4 REALISATION OF THE RESEARCH

In the following section the detail of the process followed during the systematic review is explained.

5.4.1 The review question

According to Sackett *et al.* (2000:16), Evans (2001:2) as well as Melnyk and Fineout-Overholt (2005:30), an answerable, searchable question consists of the following components: **P**atient/ population, **I**ntervention, **C**omparison (if applicable) and **O**utcome. The element of **T**ime is also added when applicable. The review question for this step of the study “**What strategies are effective in improving counselling for HIV testing during pregnancy?**” answers to the criteria as follows:

P	I	C	O	T
Women	Counselling for HIV testing	Not applicable	Efficiency, uptake, experience	During pregnancy

5.4.2 Search strategy (Sampling)

A combination of sources was used to search (explore) the literature on the topic of counselling for HIV testing during pregnancy (population). This search was conducted as thoroughly as possible.

The following key words were used in the initial search strategy: (HIV OR human immune*) AND (counsel* OR VCT) AND (pregnant* OR antenatal OR prenatal OR *MTCT) AND research.

Combinations of the key words were used for each database and search engine. Search filters were not used as it was clear that terms are not yet standardised. Terms such as 'voluntary counselling and testing (VCT)' often did not address counselling and in articles relating to 'strategies to prevent mother-to-child transmission (PMTCT)', counselling was sometimes addressed.

The following sources were searched:

- Journal article databases: Medline, Cinahl, Academic search premier, African HealthLine, AIDSearch, Health Source: Nursing/Academic Edition, PsycInfo and ISAP by the National Library of South Africa;
- Organisational databases: Cochrane Library, Women, children and HIV (of World Health Organization), National Library of Medicine Gateway;
- Internet search engines: Google, Google scholar, Yahoo!: Medicine ;
- Hand search of journals and bibliographies of documents.

These databases were found to be most applicable as they are freely available, cover the study field of health sciences, research studies, studies published on issues related to HIV/AIDS as well as Women's Health and Africa.

The unit of analysis for the systematic review was research studies. It aimed to include all scientific studies, including primary research studies and reviews of research studies and not only randomised controlled trials. This broad focus ensured a higher probability that all relevant literature was considered. Both quantitative and qualitative research studies were included as the researcher was interested in outcomes that are of both a quantitative (e.g. uptake of testing) and qualitative nature (e.g. experience of counselling–process).

A multistage approach was used to select the relevant studies that were critically appraised. All studies that were retrieved by using the keywords were included in the **first stage** of the search.

In the **second stage** of the search, each paper was briefly examined to see if the exclusion criteria applied. Because terms were not consistently used in the same way (e.g. VCT and MTCT), a large number of studies had to be examined. Studies that depicted duplicate reporting of the same research were identified and only the latest or most detailed copy was included in the review.

The following exclusion criteria were used in the second stage of the search:

- Studies published before 1996 as the situation differed substantially before Antiretroviral therapy became available;
- Studies on counselling of pregnant women who were already diagnosed as HIV positive;
- Studies that obviously apply to contexts that are very dissimilar to the South African context.

Searches did not exclude literature published in languages other than English although only a small number (3) were retrieved in other languages. These articles were then excluded as it was clear from the English abstracts that they were all applicable to contexts that are very dissimilar to the South African context.

Abstracts were included in the original search. After scrutiny for relevance, full text articles of abstracts that seemed to add value to the evidence, were ordered. Three researchers were contacted because there was not enough information in the full text studies to make a decision regarding relevance.

Gray literature (conference presentations, dissertations and theses) were also included in the first stage of the search. A data base that specifically includes conference proceedings (NLM Gateway: Meeting Abstracts) and an international (ProQuest Digital dissertations) and South African (Nexus) databases with titles and other information about research in progress and completed studies were scrutinised for relevant studies. When abstracts seemed promising, the authors (two for conference presentations and two for dissertations) were contacted for more information.

Hand searching of the tables of contents from a number of key journals (*AIDS*, *Journal of Acquired Immune Deficiency Syndrome* and *AIDS and Behaviour*) was also conducted as Hopewell *et al.* (2002:11) concluded in their Cochrane review that hand

searching still plays a valuable role in identifying relevant studies for inclusion in systematic reviews. The biographies of key studies (identified during critical appraisal) were also hand searched for studies that were missed during the initial search (**Third stage of the search**). This revealed studies that are applicable to strategies to promote counselling for HIV testing during pregnancy that were missed during the original search strategy, for example studies on enhancement of decision-making skills.

A summary of all the relevant studies retrieved in the search was then compiled.

Table 5.2 Summary of the number of relevant studies retrieved

Source	Number of studies retrieved with search strategy (First stage of search)	Number of documents relevant re strategies for counselling for HIV testing of pregnant women (Second stage of search)	
			Unique for this database
Medline	63	9	6
Cinahl	16	7	4
Academic Search Premier	30	9	4
African HealthLine	123	9	5
AIDSearch	71	7	2
Health Source: Nursing/Academic Edition	21	7	0
PsycInfo	11	2	0
Cochrane Library	8	2	2
Women, children and HIV	21	6	1
ISAP	25	2	0
Documents retrieved in more than 1 data base			4
Google, Google Scholar and Yahoo! Medical			2
Hand search of relevant journals and bibliographies			3
Gray literature			
NLM Gateway: Meeting Abstracts	380	1	1
ProQuest Digital dissertations	10	0	1
Nexus	6	2	1
Total number of documents to be appraised			36

5.4.3 Realisation of sampling

The types of studies reviewed are discussed in the following section. The numbers of each type of paper is indicated in brackets and add up to the 36 indicated in Table 5.2.

- **Systematic reviews (5)**

In the context of evidence-based practice, evidence from a high-quality, recent systematic review of randomised controlled trials is usually regarded as the strongest evidence on which to base decisions about efficiency (Davies & Crombie, 2001:4; Melnyk & Fineout-Overholt, 2005:11). Although a broader approach that considers different kinds of literature and addresses a variety of outcomes is applied in this project, it seemed logical to start the discussion of the different kinds of studies with systematic reviews.

During the first stage of the search a total of 4 systematic reviews were found. The study of Solomon *et al.* (2004:1-68) can not be considered a conventional systematic review as the search strategy and evaluation process are unconventional, but the process was described in detail, reporting was done rigorously and the results can be considered applicable to this study.

Two Cochrane reviews (Briggs & Garner, 2006 and O'Connor *et al.*, 2003) were added in the third stage of the search when studies were found relating to themes about which more information was needed. One protocol for a Cochrane review on a relevant theme was also found, but was not included in the review as the review has not yet been completed (Madhivanan *et al.*, 2005). The author of the protocol has been contacted for an update of the progress of the review, but replied that there had been no further progress to date.

- **Randomised controlled trials (4 studies discussed in 7 papers)**

Seven papers discussing randomised controlled trials were identified during the search, but when it was appraised it became apparent that three of the papers merely addressed different aspects of the same large trial. These papers were therefore combined and discussed as a single trial (Simpson *et al.*, 1998:262-267; Simpson *et al.*, 1999:1- 80). A

total of four randomised controlled trials were appraised, three of these were conducted in Africa and one in the United Kingdom

- **Cohort (7) and other observational studies (10)**

A total of 7 cohort studies and 10 other observational studies were reviewed. According to the Critical Appraisal Skills Programme (CASP, 2005), the evidence from observational studies (including cohort studies and descriptive studies) must be used with caution as a single observational study rarely provides sufficient robust evidence to recommend changes to clinical practice or for health policy making. Some research questions can however only be answered by observational studies and such circumstances, observational studies are considered the most applicable type of study. The evidence from an observational study is considered stronger if confirmed by more than one study. In the appraisal of these studies, special effort was taken to find conformation for observational studies' findings.

- **Economic evaluations (3)**

Three economic studies were reviewed. The results of this type of study can add valuable evidence to consider when drafting Best Practice Guidelines as it may indicate which strategies would not be cost-effective. The applicability of the results of the studies done in the United Kingdom is limited as the circumstances differ regarding resources and HIV prevalence, although general trends may be similar.

- **Qualitative studies (4)**

Until recently, the evidence-based practice movement has been characterised for its narrow and rigid view on the research methods considered to generate sound evidence such as focus on randomised controlled trials and other types of intervention research (Dixon-Woods *et al.*, 2001:126; Miles *et al.*, 1999:98). The findings produced by qualitative research were considered a weaker form of evidence as compared with those from other types of research (Melnik & Fineout-Overholt, 2005:129). According to Dixon-Woods and Fitzpatrick (2001:765) more emphasis is presently placed on qualitative research's contribution. It is accepted that some questions can only be

answered by studies that employ a qualitative approach (Dixon-Woods *et al.*, 2001:125; Green & Britton, 1998:1230).

Three studies were retrieved and judged to be relevant to counselling for HIV testing during pregnancy. The findings of two of these studies were found to be transferable to the local context (De Paoli *et al.*, 2002:144-156 and Sherr *et al.*, 2003:337-347), but the third was conducted in a setting that displays very low HIV prevalence, and completely different social and cultural issues (Boyd *et al.*, 1999:21-29).

5.4.4 Critical appraisal and data-extraction (Data-collection)

The next step of a systematic review is critical appraisal of studies to evaluate the validity and credibility to determine if the findings can be considered 'good quality evidence' (Hill & Spittlehouse, 2001:2; Melnyk & Fineout-Overholt, 2005:76). Not all research is of a high quality and the developer of best-practice guidelines is therefore required to conduct critical appraisal before deciding on the research evidence's value.

The studies that were retrieved during the multi-stage search criteria were divided according to research design to be appraised with recognised instruments. Several instruments are available, and some reviewers prefer not to use specific instruments at all, but to assess studies according to generic principles of good research. In this study, the researcher used the Critical Appraisal Skills Programme's (CASP) instruments (2005), as these instruments and their instructions are freely available on the Internet. The instruments largely correspond with other instruments available.

The following instruments were used in the critical appraisal:

- Critical appraisal instrument for reviews (Critical Appraisal Skills Programme (CASP, 2005:41);
- Critical appraisal instrument for randomised controlled trials (CASP), 2005:17);
- Critical appraisal instrument for cohort studies (CASP, 2005);
- Critical appraisal instrument for economic evaluations (CASP, 2005:81);
- Critical appraisal instrument for qualitative research studies (CASP, 2005:63).

Descriptive studies (surveys, exc.) were appraised according to generic principals of critical appraisal as no suitable instruments could be found for these types of studies. Generic principles include: validity of the study, reliability and applicability of the results (Melnyk & Fineout-Overholt, 2005:80).

The appraisal of qualitative studies draws a lot of attention (Dixon-Woods *et al.*, 2001:125; Walsh & Downe, 2006:108-119). Dixon-Woods and Fitzpatrick (2001:765) point to the lack of agreement on how to assess the quality of qualitative research. Melnyk and Fineout-Overholt (2005:130) add to this and discuss the dilemma of diverse qualitative research designs and reporting styles, that complicate the defining of a set of criteria to evaluate if a study is valid and useful. In this study the CASP appraisal tool for qualitative studies was used as it supplements the rest of the set of tools used for the other studies and it corresponds, to a large extend, with the other instruments available (Cesario *et al.*, 2002:531-537; Mays & Pope, 2000:50-52; Russell & Gregory, 2003:36-40).

The fact that the critical appraisal of studies was done by a single person and not a team can be considered a limitation of this review. The review was done as part of a PhD study and as such must be the work of the student as researcher. Experts were consulted and the systematic review took place under guidance of the study's promoter and co-promoter. Completed Critical Appraisal instruments for each paper are available for audit purposes.

The results of the critical appraisal according to the type of study using criteria according to the applicable appraisal instrument are indicated in Table 5.3. As a huge amount of data had to be condensed for this summary all the detail could not be included and the researcher had to determine the most important aspects. Complete bibliographic information about all the studies is available in the list of references.

Table 5.3 Summary of appraisal of documents and data extraction

Reviews			
<p>Briggs & Garner (2006)</p> <p>Cochrane review on strategies for integrating primary health services (like PMTCT) in middle- and low-income countries at the point of delivery</p>	<p>Rigour</p> <p>A detailed search strategy was implemented to identify all relevant studies. Two reviewers independently assessed the methodological quality according to a Cochrane checklist. Study results were not combined as the studies' types of integration and outcomes differed. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>The studies reviewed evaluated three integration strategies: (i) adding on an additional component to an existing service, (ii) integrated versus single special services, and (iii) packages of services e.g. Integrated management of childhood illnesses versus routine child care. Interventions were complex.</p>	<p>Bottom line finding</p> <p>Reviewers concluded that the evidence is not strong enough to recommend integration of services, and recommend that more studies be conducted to investigate the issue from the patient's viewpoint.</p>
<p>Chou <i>et al.</i> (2005:38-54)</p> <p>Review of literature regarding risks and benefits of prenatal HIV screening</p>	<p>Rigour</p> <p>The search strategy reported was effective in identifying studies applicable to the stated question. Criteria for appraisal were recorded. Statistical combination of findings was not possible as different outcomes were measured in different studies. Study was well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>HIV testing uptake by pregnant women in US states with an Opt-out policy higher than in states with an Opt-in policy. More than 90% of HIV positive pregnant women in USA receive antiretroviral treatment during pregnancy. Different PMTCT strategies that can be implemented if status is known discussed.</p>	<p>Bottom line finding</p> <p>Reviewers concluded that the benefits of HIV testing are more than the risks and recommend universal testing. Applicability limited for South Africa because the aim was to find evidence applicable to the developed countries although more and more PMTCT strategies become available.</p>
<p>Doull <i>et al.</i> (2006:279-291)</p> <p>Review of literature on the needs of HIV-positive women regarding decision-making</p>	<p>Rigour</p> <p>Search strategy successfully located relevant documents. Studies not appraised for quality but 'rough' grading system was used. Stated that because of wide variety of evidence, general conclusions could not be made. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Reviewers could find no literature on dynamics of HIV positive women's decision making. Indicates how a coaching approach can empower women to take decisions based on information and their own values.</p>	<p>Bottom line finding</p> <p>Reviewers concluded that decision making is not yet addressed in MTCT literature. Decision-support framework merits attention.</p>

<p>O'Connor <i>et al.</i> (2003)</p> <p>Cochrane review on decision aids for people facing health treatment or screening decisions (Like having to decide on HIV testing during pregnancy)</p>	<p>Rigour</p> <p>Studies identified through databases and contact with researchers. Studies were assessed for quality according to previously set criteria. Results of the randomised controlled trials were pooled using weighted mean differences and relative risks. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Over 200 decision aids were identified. Compared with usual care the decision aids performed better and yielded greater knowledge, more realistic expectations, lower decisional conflict related to feeling informed, increased proportion of people active in decision making and reduced proportion of people who remained undecided.</p>	<p>Bottom line finding</p> <p>Decision aids (such as pamphlets describing the benefits and risks of options) can help individuals in taking a active role in making informed decisions about health issues but more research is needed.</p>
<p>Solomon <i>et al.</i> (2004:1-68)</p> <p>Three step literature review: Step 1: Content review of literature Step 2: Meta-analysis of VCT literature in Africa Step 3: Qualitative analysis of unpublished VCT literature in Africa</p>	<p>Rigour</p> <p>Search strategy discussed in detail, large number of unpublished studies included. Grading system specifically designed to grade quality of studies. Unconventional layout but motivated and described in detail. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Not on counselling for HIV testing <i>during pregnancy</i> per sé, but VCT in general. Qualitative content overview reveals: VCT more effective for secondary prevention than primary prevention regarding behaviour change. Couple counselling more effective than individual counselling with regard to behaviour change. Rapid testing leads to more clients receiving their test results but their readiness is questionable. From meta-analytical evaluation: Most documents retrieved were discussion documents. Research documents mostly observational surveys with self-reporting. More research regarding VCT process needed. Quality of retrieved studies relatively high but lack of reporting of analysis methods and ethical concerns. From qualitative thematic analysis: Emphasis on VCT mainly as way of getting informed consent to do test. Need for monitoring and evaluation of services providing VCT and problems experienced by counsellors were discussed.</p>	<p>Bottom line finding</p> <p>VCT more effective for secondary prevention than primary prevention regarding behaviour change. Couple counselling more effective than individual counselling with regard to behaviour change. Services that provide VCT need to be monitored and evaluated</p>

Randomised Controlled Trials			
<p>Abdool Karim <i>et al.</i> (1998:637-640)</p> <p>Investigation to determine if the decision of pregnant women to be tested for HIV is truly informed and voluntary</p> <p>– Durban, South Africa</p>	<p>Rigour</p> <p>Clearly focused issue stated. Participants were randomly assigned to groups. A second group were used to control possible sensitisation to the pre-test counselling questionnaire. Counsellor and interviewer were blind regarding groups. Follow up not adequate due to short time-span. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Both groups of women were well informed about HIV (98% know about MTCT) – even before counselling. Both the experimental and control groups thought that the hospital would not allow them to withdraw from the study and that the care they receive will change if they do not participate.</p>	<p>Bottom line finding</p> <p>Consent for HIV testing is truly informed as women were well informed about the test.</p> <p>Consent for HIV testing is not truly voluntary because women did not believe that they could withdraw without negative consequences.</p>
<p>Effect of rapid HIV testing on uptake of perinatal HIV intervention</p> <p>• Malonza <i>et al.</i> (2003:113-118)</p> <p>-Nairobi-Kenya</p>	<p>Rigour</p> <p>Randomisation effectively done. Research staff administering post-test questionnaire blinded for participants' HIV-status but not for study grouping. All participants who entered were accounted for. There was evident control of confounding factors. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Use of rapid testing compared to ELISA testing in pregnant women lead to more women receiving their results quicker but did not result in more women receiving MTCT prevention interventions.</p>	<p>Bottom line finding</p> <p>Although 'counselling' was not investigated, results indicated that more women's HIV status will be known if rapid testing is used in place of standard laboratory tests.</p>
<p>Randomised controlled trial of different approaches to universal antenatal HIV testing</p> <p>• Simpson <i>et al.</i> (1998:262-267)</p> <p>• Simpson <i>et al.</i> (1999:1-80)</p> <p>- Edinburgh City, Scotland</p>	<p>Rigour</p> <p>Power calculations used to determine sample size. Random assignment of participants to groups using a computer programme generated code. No blinding. All participants who entered were accounted for. Evident control of confounding factors. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Offering an HIV test lead to higher uptake than just notification that test is available on request. Pregnant women counselled by midwives who had a positive attitude towards HIV testing had a higher uptake than those counselled by midwives who did not have a positive attitude although the same procedure was followed and the midwives' knowledge about HIV did not differ significantly.</p>	<p>Bottom line finding</p> <p>Active offering of HIV test more effective to increase uptake than notification of availability. Attitude of midwives influences uptake of HIV testing.</p> <p>Applicability limited because outdated (study done in 1997) and context very different than South Africa (Low prevalence, less stigma)</p>

<p>The Voluntary HIV-1 Counselling and Testing Efficacy study</p> <ul style="list-style-type: none"> • Grinstead <i>et al</i> (2001:1045-1052) • The Voluntary HIV-1 Counselling and Testing Efficacy study group (2000a:103-112) • The Voluntary HIV-1 Counselling and Testing Efficacy study group (2000b: 5-14) <ul style="list-style-type: none"> - Nairobi, Kenya - Dar Es Salaam, Tanzania - Port of Spain, Trinidad 	<p>Rigour</p> <p>No evidence of power calculations to determine sample size. Random assignment of participants to groups stratified by site, sex and couple or individual status. No blinding. All participants who entered were accounted for.</p> <p>Evident control of confounding factors. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Use of voluntary counselling and testing compared, to health education only, lead to less unprotected sex.</p> <p>VCT did not lead to a significant increase of negative life events except break up of sexual relationship for HIV positive women.</p>	<p>Bottom line finding</p> <p>VCT effective in reducing unprotected sex.</p> <p>VCT can lead to break up of sexual relationships for HIV positive women.</p> <p>Results can be applied locally as study was done in Africa although study did not specifically address counselling during pregnancy.</p>
<p>Cohort Studies</p>			
<p>Buch <i>et al.</i> (2003: 1-42)</p> <p>Investigation to describe leakages in PMTCT care - District hospital, rural Kwazulu Natal, South Africa</p>	<p>Rigour</p> <p>Selection of participants in cohorts described. Possible bias (Hawthorne effect, recall bias and interviews bias) acknowledged and strategy to limit described.</p> <p>Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Although less than 10% of women were missed at each step, the cumulative effect of leakages at different stages of antenatal care (not counselled at first visit, not counselled at subsequent visit, HIV test not offered, test not accepted, not returning for test result, not given Nevirapine, Nevirapine not taken) caused more HIV positive women to not take Nevirapine than those who took it.</p>	<p>Bottom line finding</p> <p>Leakages at each step of the PMTCT (including counselling and testing) lead to more HIV positive women not getting Nevirapine as those taking it.</p> <p>Results comparable with Temmerman <i>et al.</i> (2003: 1239-1242).</p>
<p>Bulterys <i>et al.</i> (2004:219-223)</p> <p>Investigation of feasibility of rapid testing during labour and factors that influence</p>	<p>Rigour</p> <p>Recruitment of participants and inclusion criteria discussed. Procedure standardised. Odds ration and logistic regression used. Study well planned,</p>	<p>Results</p> <p>Implementation of rapid testing during labour is feasible. Fewer acceptances of testing in women admitted from 4pm to midnight and the least on Friday nights.</p>	<p>Bottom line finding</p> <p>Rapid testing for HIV is feasible during labour.</p> <p>Acceptance of testing is lower when staff has less time for counselling.</p>

the acceptability of this testing. - United States Hospitals	executed and reported on = Good rigour.	Most women, who were tested during labour, received antiretroviral prophylaxis against MTCT before the delivery except in few cases when women presented in advanced labour.	Results comparable with Bharucha <i>et al.</i> (2005: 553-555) and Homsy (2006:149-154).
Ethier <i>et al.</i> (2000:1448-1451) Investigation of impact of organisational factors on prenatal HIV counselling and acceptance of testing - Clinics and Community Health Centres in the United states	Rigour Research question clearly explained. Information of all patients who attended antenatal care at selected services, during a specified period were prospectively collected or collected from existing clinic databases. Multivariate logistic regression used to determine which variables were significant. Study well planned, executed and reported on = Good rigour.	Results Adolescents, Latina women, women who attend hospital-based services or clinics with fewer patients and who received counselling from their primary care giver, were more likely to be counselled. Women who receive care in community health centres, whose counselling sessions were longer than 15 minutes and who received counselling from a dedicated HIV counsellor, were more likely to accept HIV testing.	Bottom line finding Although pregnant women were more likely to receive counselling in clinics with fewer patients and when they were counselled by their primary care giver (doctor or midwife), those counselled for longer than 15 minutes by a dedicated HIV counsellor are more likely to accept HIV testing. Study done in USA but principles may be transferable to local settings. Results comparable with Jones <i>et al.</i> (1998:272-273).
Farquhar <i>et al.</i> (2004:1620-1626) Investigation to assess the impact of couple counselling and testing on use of interventions to prevent perinatal and sexual HIV transmission - Nairobi, Kenya	Rigour Stepwise recruitment strategy explained in detail. Pearson X^2 , Fisher exact and independent t tests used. Uni- and multivariate logistic regression statistics. Stated that other factors e.g. quality of relationship could influence compliance to PMTCT strategies. Study well planned, executed and reported on = Good rigour.	Results Nevirapine use, use of safe baby-feeding and condom use significantly increased with partner involvement: partner notification of HIV status, partner also counselled and tested but not together and couple testing. Found that condom use less when HIV – negative women disclose her status – dangerous because of risk of men's characteristics did not differ significantly.	Bottom line finding Low uptake of couple testing (5% of women who received pre-test counselling and were asked to notify their partners of VCT). Partner involvement can improve acceptance and utilisation of MTCT prevention strategies compared to individual counselling of pregnant women.

Shetty <i>et al.</i> (2005:755-759) Investigation into the feasibility of voluntary counselling and HIV testing for pregnant women using community volunteers in Zimbabwe	Rigour Clinic statistics were analysed. Limited information about research methods. No explanation why only 30% of women who attended clinic received pre-test counselling. Reporting not sufficient to make a statement regarding rigour.	Results Concluded that use of community volunteers is feasible, effective and acceptable by clinic staff and patients in settings where there is inadequate professional staff in clinics to do counselling in addition to other duties.	Bottom line finding Lay counsellors can be used if sufficiently trained, supervised and mentored by professional counsellors. Community counsellors also valuable to augment community support.
Stringer <i>et al.</i> (2001:1104-1108) Investigation to determine if change to routine antenatal HIV testing (opt-out) would lead to an increase of screening rates. - Clinics in Alabama, United States	Rigour Selection of cohort described. Intervention and control cohort similar or logistic regression analysis done to adjust for differing factors. χ^2 test used to compare HIV testing rates and demographic information. Study well planned, executed and reported on = Good rigour.	Results HIV testing rate increased from 75% when using opt-in strategy to 88% after routine HIV testing was implemented.	Bottom line finding Routine (opt-out) strategy of HIV testing effective to improve test uptake. Results comparable with Chou <i>et al.</i> , 2005:38-54)
Van't Hoog <i>et al.</i> (2005:344-349) Investigation to evaluate uptake of counselling, testing and Nevirapine after integrated MTCT programme was implemented. - Kisumu, Kenya	Rigour Two cohorts, patients who attend antenatal care and hospital before and after new integrated programme, described. χ^2 test to aggregate data comparison between groups and P value to determine statistical significance used. Study well planned, executed and reported on = Good rigour.	Results Uptake of testing after counselling as well as uptake of Nevirapine was significantly higher after integrated programme was implemented but percentage of women whose HIV status was known at delivery, did not increase.	Bottom line finding The percentage of HIV positive women who benefited from MTCT strategies can be increased significantly if MTCT services are integrated with antenatal services.
Observational studies			
Bharucha <i>et al.</i> (2005: 553-555) Investigation of feasibility, acceptability of rapid HIV screening and conditions of labouring women - Pune, India	Rigour No information about methodological quality. Reporting not sufficient to make a statement regarding rigour.	Results Feasible to implement VCT in a labour ward, but challenging because women arrive in advanced labour. Researchers recommend testing during post-partum period for women whose status is unknown before delivery.	Bottom line finding Feasible to do rapid testing during labour, but difficult if women arrive when already in advanced labour. Results comparable with Bulterys <i>et al.</i> (2004:219-223) and Homsy (2006:149-154)

<p>Cartoux <i>et al.</i> (1999:199-201)</p> <p>Comparison between the effect of group and individual pre-test counselling on uptake of VCT by pregnant women. - Bobo-Diouasso, Burkina Faso</p>	<p>Rigour</p> <p>Two groups of participants – one group attended antenatal clinic when group counselling was done and another when individual counselling was done. The groups compatible with regard to variables. Researchers cannot explain difference in prevalence between women who return for tests results and those who did not. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Significantly more women accepted HIV testing after individual counselling, but uptake high even after group counselling. Knowledge about HIV improved more after group counselling.</p>	<p>Bottom line finding</p> <p>Both group and individual counselling effective regarding knowledge transfer and increased uptake of testing. Choice between two strategies will depend on other issues e.g. number of patients and counsellors.</p>
<p>Delva <i>et al.</i> (2006:189-193)</p> <p>Investigation to evaluate the quality and quantity of voluntary HIV counselling. - Mombasa, Kenya</p>	<p>Rigour</p> <p>UNAIDS tools for evaluating VCT used to collect data. Descriptive statistics used to analyse data. Study well planned, executed and reported on but little information about selection and recruitment of participants is supplied = Rigour satisfactory.</p>	<p>Results</p> <p>Counsellors score high on social and communicative skills except for giving a summary, repetition of information and maintaining the patient's privacy. Emotional reactions on test results and ensuring follow-up support were not dealt with in 80% of HIV positive women. Information about the window period, possible false negative results, information about safer sex and VCT for her partner was not supplied in pre-test counselling or post-counselling of HIV negative women, while information on baby feeding and the Nevirapine regimen was not discussed with all the HIV positive women.</p>	<p>Bottom line finding</p> <p>Results setting specific but may also be applicable in South African.</p> <p>Emotional needs of women were not met during counselling.</p> <p>Pregnant women did not receive all relevant information during counselling.</p>
<p>Fernandez <i>et al.</i> (2000:460-468)</p> <p>Investigation of factors associated with pregnant women accepting HIV testing</p>	<p>Rigour</p> <p>Detail supplied about recruitment of participants and data-collection method. Data statistically analysed. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Main reasons for accepting HIV testing are believing it was good for baby's or mother's health, and perceiving that their health provider strongly endorsed testing. Women reported that administrative factors can be reason for not being tested.</p>	<p>Bottom line finding</p> <p>Information on risk of MTCT and prevention measures as well as endorsement for HIV testing – by individual health workers, organisations and government may increase</p>

<p>- Florida, Connecticut & New York City, United States</p>			<p>uptake of HIV testing by pregnant women. Process must be simplified to prevent administrative factors seen as barriers for testing.</p>
<p>Grimes <i>et al.</i> (2001:585-589)</p> <p>Investigation into effectiveness of continued education programme for staff in increasing uptake of HIV testing by pregnant women</p> <p>- Houston, United States</p>	<p>Rigour</p> <p>Information on content of continued education programme supplied but no information on recipients of programme. Information on uptake monitored for 5 years since the training programme was started. As other factors could have influenced uptake in the 5 years period, changes in uptake can not only be contributed to the education programme for the staff = Rigour questionable.</p>	<p>Results</p> <p>When regular education sessions were presented, the uptake stayed above 60% but declined when there were no education sessions on counselling and testing for HIV during pregnancy.</p>	<p>Bottom line finding</p> <p>Uptake of HIV testing can be kept on a high level if regular educational sessions are presented to health workers. Findings should be interpreted with caution as other factors could have played a role in increase of uptake over the research period.</p>
<p>Homsy <i>et al.</i> (2006:149-154)</p> <p>Investigation into acceptability, feasibility, and uptake of intrapartum HIV VCT by women, men and couples</p> <p>- Hospital in rural Uganda</p>	<p>Rigour</p> <p>Time period of cohort supplied but no explanation of inclusion criteria. No discussion on possible confounding factors. Detail on distribution of participants supplied. Study well planned, executed and reported on but little information supplied about selection and recruitment of participants and control of confounding factors = Rigour satisfactory.</p>	<p>Results</p> <p>88% of women discharged after delivery with known HIV status compared with 39% before VCT during labour was implemented. Nearly all men who accompanied their partners with unknown HIV status were tested with them.</p> <p>Not all women who tested positive received antiretroviral prophylaxis before the delivery because a large number arrived late in labour as the study was done in a referral hospital.</p> <p>Less testing was done during the night and over weekends.</p>	<p>Bottom line finding</p> <p>Rapid testing during labour is a valuable feasible strategy for women with unknown status.</p> <p>As partners of women who use public hospitals in South Africa do not usually accompany women during labour, couple testing during labour may not be as successful as it was in this study.</p> <p>Results comparable with Bulterys <i>et al.</i> (2004:219-223) and Bharucha <i>et al.</i> (2005: 553-555).</p>

<p>Jamieson <i>et al.</i> (2003:889-895)</p> <p>Pilot study to assess comprehension of informed consent by women in labour - Hospitals in United States</p>	<p>Rigour</p> <p>Sample size too small to confirm results statistically. Study well planned, executed and reported on but small sample size (28) = Rigour satisfactory.</p>	<p>Results</p> <p>After mock presentation of information was presented to women in labour, they were asked about the purpose, benefits, risks and ability to withdraw at any time to assess their comprehension of the information presented. Only one interview had to be stopped because the woman experienced too much pain but interviews were often interrupted. Most women could give the purpose and benefits of the study but only 25% could correctly state the risks.</p>	<p>Bottom line finding</p> <p>Women can comprehend most of the information presented during pre-test discussion.</p> <p>Presentation of information more effective when a flipchart is used.</p>
<p>Jones <i>et al.</i> (1998:272-273)</p> <p>Investigation of effect of midwife's characteristics and duration of pre-test discussion on uptake of HIV testing - London, Britain.</p>	<p>Rigour</p> <p>Used P value and odds ratio to determine significance regarding midwife's characteristics. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>24% of the pregnant women accepted HIV testing. Uptake of testing after counselling varied between midwives. Testing more likely if pre-test discussion lasted more than 5 minutes. Only significant differences regarding effect of midwife's characteristics on test uptake were age, experience (lower uptake for midwives between 30-39 years of age and with 5-9 years of experience than for older or younger midwives) and ethnic group (less uptake from white midwives).</p>	<p>Bottom line finding</p> <p>Uptake of HIV testing is two times more likely when pre-test counselling lasted more than 5 minutes than when the pre-test counselling was shorter.</p> <p>Results regarding midwife's characteristics probably not transferable to South African context because of training and cultural differences.</p>
<p>Kumar <i>et al.</i> (2004:242-248)</p> <p>Investigation into implementation of antenatal VCT for HIV in Barbados.</p>	<p>Rigour</p> <p>The antenatal records of all women who delivered were studied and women for whom no HIV result was recorded were interviewed for their knowledge about the availability of VCT. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Although the main reason why women's HIV status was not known at the time of birth, was because an HIV test was not offered (72%), 32% of the women were tested, but the results were not recorded. 13% of women were tested without receiving pre-test counselling</p>	<p>Bottom line finding</p> <p>VCT was not optimally implemented as not all pregnant women who received pre-test counselling were offered a HIV test. Poor documentation can cause women's HIV status to be unknown to health workers at the time of the birth.</p>

<p>Temmerman <i>et al.</i> (2003:1239-1242)</p> <p>Investigation of uptake of MTCT in order to recommend alternatives to improve strategies to prevent MTCT. - Mombasa, Kenya</p>	<p>Rigour</p> <p>Little detail on research methods. Reporting not sufficient to make a statement regarding rigour.</p>	<p>Results</p> <p>Only 16 out of a possible 77 perinatal infections were prevented because of leakages at every step of the programme. Only 21% of women who delivered in hospital attended an antenatal clinic with VCT services.</p>	<p>Bottom line finding</p> <p>Strategies were not effective in preventing enough HIV infections. Recommendations: More staff and training to increase antenatal counselling, promotion of attending antenatal clinics, expanding VCT services, routine rapid testing during labour for all women, women should get their results directly after counselling.</p>
Economic Evaluations			
<p>Ekwueme <i>et al.</i> (2003:112-121)</p> <p>Economic comparison between standard Elisa / Western blot with one step and two step rapid testing - United States.</p>	<p>Rigour</p> <p>Motivation for evaluation clearly stated. All costs were calculated. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>One step rapid testing least expensive. Influencing factors: prevalence rate and return rate if results delayed (as with standard or two step rapid tests).</p>	<p>Bottom line finding</p> <p>Rapid testing more cost-effective than standard laboratory tests.</p>
<p>Postma <i>et al.</i> (1999:1656-1660)</p> <p>Cost-effective comparison between cost of universal HIV testing of pregnant women and lifetime medical and social care cost of infected children whose mothers were not diagnosed in time to prevent mother-to-child transmission. - England</p>	<p>Rigour</p> <p>Motivation of study clearly stated. Cost of pre-test counselling was set at £40 but did not state how this was calculated. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Cost of PMTCT prevention strategies and treatment for mother if found to be HIV positive were compared with medical and social cost of mother and baby when her positive status was not detected before birth and possible transmission occurred. Find that in areas of high prevalence, universal screening of pregnant women for HIV is cost-effective.</p>	<p>Bottom line finding</p> <p>The researchers state that cut-off point for cost-effectiveness with regard to prevalence rate will differ in different areas and different times. The higher the prevalence, the more cost-effective is universal testing.</p>

<p>Postma <i>et al.</i> (2000:2383-2389)</p> <p>Cost-effective comparison between cost of expanded testing (partner testing and repeat testing late in pregnancy of women who tested HIV negative early in pregnancy) and lifetime medical and social care cost of infected children whose mothers became HIV positive after early testing.</p> <p>- England</p>	<p>Rigour</p> <p>The motivation clearly stated and all cost calculated. Study well planned, executed and reported on = Good rigour.</p>	<p>Results</p> <p>Expanded testing found to be more cost-effective than Hepatitis B screening which is already implemented in Britain.</p>	<p>Bottom line finding</p> <p>Researchers state that situations differ between countries. They also state that budgetary, ethical, social and psychological aspects as well as potential uptake should be taken into consideration before final decision is made on a policy for expanded HIV testing. South Africa is probably not ready for this step as basic VCT not yet optimal.</p>
<p>Qualitative studies</p>			
<p>Boyd <i>et al.</i> (1999:21-29)</p> <p>Views of pregnant women regarding HIV testing. Addition to large RCT (Simpson <i>et al.</i>, 1998).</p> <p>- Edinburgh, Brittan</p>	<p>Rigour</p> <p>Research methods superficially reported. The following was not addressed: specific research question, motivation for use of research design, or ethical issues. Interview schedule was supplied. Thematic analysis and literature control executed. Not all issues addressed in report = Rigour satisfactory.</p>	<p>Results</p> <p>88% of women appreciated being offered an HIV test but uptake was only 28%. No one sees advantages for themselves if they know their status. Women said HIV test does not cause more anxiety than other antenatal tests. Pregnant women want HIV test to be done routinely the same as other antenatal screening tests.</p>	<p>Bottom line finding</p> <p>Pregnant women prefer HIV testing as part of routine antenatal tests.</p> <p>Study done before anti-retroviral therapy was widely available. Context differs from South African context: low HIV prevalence, other social and cultural issues.</p>
<p>De Paoli <i>et al.</i> (2002:144-156)</p> <p>Counsellor's perspectives of antenatal HIV testing and baby feeding issues</p> <p>- Kilimanjaro region, Tanzania</p>	<p>Rigour</p> <p>Semi-structured interviews with counsellors involved in PMTCT project. Interview questions adjusted according to emerging themes. Used computer programme 'Open code' during data-analysis. Ethical approval gained,</p>	<p>Results</p> <p>Counsellors see 'good counsellor' as someone who can convince all her clients to be tested. Counsellors believe that women need more than one pre-test discussion to prepare them for handling a positive result. Counsellors believe partners and</p>	<p>Bottom line finding</p> <p>Counsellors coerce women to consent to HIV testing – not truly voluntary. More than once-off counselling needed. Partners and community should</p>

	fictitious names used to ensure anonymity. Study well planned, executed and reported on = Good rigour.	community as a whole must be more involved.	be involved. Findings may be transferable to South Africa as contexts are similar.
Sherr <i>et al.</i> (2003:337-347) Attitudes of pregnant women and counsellors regarding routine HIV counselling and testing. Four different groups: urban and rural: pregnant women and clinic staff. - Umtata, South Africa	Rigour Focus groups using questions based on literature. Responses recorded and translated if necessary. Good rapport established in groups. Anonymity and confidentiality ensured. Data analysis done with coding according to key themes. Study well planned, executed and reported on although findings not correlated with literature = Good rigour.	Results Women see need for HIV testing but are afraid. They prefer receiving the test results on the same day that the test was done. Women prefer to be tested with their partners but do not think it is possible in practice. Urban pregnant women and staff from urban and rural settings are worried about confidentiality and stigma, but rural women think family need to know their status to provide support.	Bottom line finding Women see need for HIV testing but are afraid – especially to disclose a HIV positive diagnosis. Although women would like to be tested with their partners, they do not think it is feasible because the men might be unwilling or it would be difficult to visit the clinic because the partners work and are often not in the same town. Rural women believe their families will support them if found to be HIV positive. Results may be transferable to similar contexts.
Toivo (2005:1-70) Perceptions and experiences of pregnant women towards HIV voluntary counselling and testing. - Oshakati, Namibia	Rigour Purposive sampling. Focus-groups using an interview guide, based on the literature, were used to produce dense in-depth information. Thematic content analysis used to analyse data.	Results Women had limited knowledge and understanding of HIV/AIDS. They had negative attitudes of health workers regarding protection of confidentiality. Women were not adequately prepared for testing by counselling.	Bottom line finding The quality of counselling provided to pregnant women could influence their decision to consent to HIV testing. Findings may be transferable in similar contexts.

During the data-extractions the existence of shared themes between studies became clear. The next section discusses the findings with regard to the synthesis of results of the individual studies.

5.5 DATA SYNTHESIS (RESEARCH FINDINGS)

In the following section, the findings from the appraised studies as indicated under 'Bottom line finding' in Table 5.3 are explored. Conclusion statements are drawn using themes related to counselling for HIV testing during pregnancy.

5.5.1 Effect of counselling

- Use of Voluntary counselling and testing (VCT) compared to health education alone is effective in reducing unprotected sex (Grinstead *et al.*, 2001:1045-1052, Voluntary HIV-1 Counselling and Testing Efficacy study group, 2000a:103-112; 2000b:5-14).
- VCT is more effective for secondary prevention (when someone is already HIV infected) than primary prevention with regard to behaviour change (Solomon *et al.*, 2004:1-68)
- VCT did not significantly increase negative life events, although break up of sexual relationship for HIV positive women can occur. (Grinstead *et al.*, 2001:1045-1052, Voluntary HIV-1 Counselling and Testing Efficacy study group, 2000a:103-112; 2000b:5-14).

Conclusion statements regarding effect of counselling

Counselling for HIV testing during pregnancy can generate positive or negative impact. Although **VCT is more effective than health education only, in persuading people to abstain from high risk behaviour such as unprotected sex**, VCT is unlikely to prevent primary HIV infection as the **positive behaviour change is more effective in people who are already infected**.

Negative life events are not common after exposure to VCT but the break up of the sexual relationship of women that test HIV positive can occur.

5.5.2 Quality of counselling

- Counselling for HIV testing is mainly seen as a way to obtain informed consent to do an HIV test (Solomon *et al.*, 2004:1-68; De Paoli *et al.*, 2002:144-156).
- Pregnant women in Kenya did not receive all the necessary information during counselling (Delva *et al.*, 2006:189-193).
- Emotional needs of women in Kenya were not met during counselling (Delva *et al.*, 2006:189-193).
- Uptake is higher if the health workers, organisations and government clearly endorse HIV testing (Fernandez *et al.*, 2000:460-468).
- Uptake of HIV testing is two times more likely if pre-test counselling lasted more than 5 minutes than when it is shorter (Jones *et al.*, 1998:272-273).
- Pregnant women in Durban had good knowledge about HIV – even before counselling, so consent for testing can be considered 'informed' (Abdool Karim *et al.*, 1998:637-640).
- Pregnant women in Durban believed that they could not withdraw from the study without negative consequences. Therefore, consent to HIV testing was not truly voluntary (Abdool Karim *et al.*, 1998:637-640).
- A coaching approach can empower women to take decisions based on information considering their own values (Doull *et al.*, 2006:279-291).
- The use of decision aids can empower women with greater knowledge, more realistic expectations and lower decisional conflict (O'Connor *et al.*, 2003).

Conclusion statements regarding quality of counselling

The quality of counselling for HIV testing during pregnancy varies. In certain circumstances the **main aim of counselling is seen as persuading women to consent to be tested. Pregnant women can not to be tested** when they are not informed that testing is voluntary.

While **some women are knowledgeable about MTCT even before counselling**, it is clear that **not all women's information needs are met**. The opportunity to supply

support to address pregnant women's emotional needs is also not utilised optimally during pre-test counselling.

Strategies to improve the quality of counselling for HIV testing could be as simple as **spending more than 5 minutes on counselling**. Educational material such as **posters can be used to display health workers and authorities' endorsement of HIV testing**, while pamphlets on benefits and risks of HIV testing during pregnancy, for example, can be used as **decision aids to empower women with greater knowledge, more realistic expectations and less decisional conflict** when they make their decision regarding HIV testing. A sophisticated strategy to improve the quality of counselling is **using a coaching approach** where women are helped to take decisions based on correct information and taking their own values into consideration.

5.5.3 Group counselling versus individual counselling

- More women accepted HIV testing after individual counselling, but test uptake was high even after group counselling (Cartoux *et al.*, 1999:199-201).
- Knowledge about HIV improved more after group counselling (Cartoux *et al.*, 1999:199-201).

Conclusion statements regarding group versus individual counselling

Both individual and group counselling have benefits. While **knowledge improves more after group counselling, uptake of testing is higher after individual counselling**.

5.5.4 Ways of offering HIV testing

- HIV test uptake is higher when the test is specifically offered to pregnant women versus notifying them that the test is available on request (Simpson *et al.*, 1998:262-267; 1999:1-80).
- HIV test uptake is higher when an Opt-out policy (routine testing) rather than an Opt-in policy is implemented (Chou *et al.*, 2005:38-54; Stringer *et al.*, 2001:1104-1108).

- Women prefer HIV testing as part of routine antenatal tests (Boyd *et al.*, 1999:21-29).
- Universal HIV testing of pregnant women is cost-effective as compared to lifetime medical and social care costs of infected children whose mothers were not diagnosed in time to prevent mother-to-child transmission (Postma *et al.*, 1999:1656-1660).

Conclusion statements regarding ways of offering HIV testing

The evidence suggest that the **more routinely counselling and testing of pregnant women for HIV is handled, the higher the uptake of testing**. Uptake is higher when the test is **specifically offered** than when women are just notified of its availability and is also **higher when an opt-out (routine) policy** is implemented as compared with situations where an opt-in approach is followed.

Other advantages of a routine approach to counselling and testing are that **women prefer HIV tests to be handled in the same way than other antenatal tests are conducted**. Routine HIV testing is a **cost-effective means to identifying the women towards whom strategies to prevent mother-to-child transmission of HIV should be focused**, this prevents lifetime medical and social care cost of infected children.

5.5.5 Rapid testing

- Both standard laboratory tests and the OraQuick rapid test were found to be >99% sensitive and specific (Chou *et al.* 2005:38-54).
- The use of rapid testing compared to ELISA testing in pregnant women lead to more women receiving their results quicker but did not lead to more women receiving MTCT prevention interventions (Malonza *et al.*, 2003:113-118).
- Some women may not be emotionally ready for the quick result of rapid testing and women should choose whether they want the test result immediately, or if they want to come back for the result (Solomon *et al.*, 2004:1-68).
- All costs considered, one step testing with a rapid test is the least expensive protocol as compared to standard laboratory testing or a protocol that uses two rapid tests (Ekwueme *et al.*, 2003:112-121).

Conclusion statements regarding rapid testing

It can be expected that rapid HIV testing will be more commonly used since it was found to be **just as accurate as standard laboratory tests**, and **more cost-effective**. Counselling for HIV testing may must be adapted as women **receive their results quicker**, while **they may not be emotionally ready yet**. Even though they get their results quicker, HIV positive women do not necessarily receive all the measures to prevent MTCT.

5.5.6 Couple counselling and testing

- Couple counselling is more effective than individual counselling with regard to behavioural change (Solomon *et al.*, 2004:1-68).
- Partner involvement can improve acceptance and utilisation of MTCT prevention strategies as compared to individual counselling of pregnant women (Farquhar *et al.*, 2004:1620-1626).
- Men who accompany their partners whose HIV status is unknown during labour are willing to be tested with her (Homsy *et al.*, 2006:149-154).
- Women in South Africa would like to be tested with partners, but they do not think it is feasible due to the men's unwillingness and scheduling difficulties (Sherr *et al.*, 2003:337-347).
- Expanded testing (partner testing and repeat testing late in pregnancy of high risk women who tested HIV negative early in pregnancy) is cost effective in the United Kingdom as compared with the lifetime medical and social care costs of infected children whose mothers became HIV positive after early testing (Postma *et al.*, 2000:2383-2389).

Conclusion statements regarding couple counselling and testing

Involving a pregnant woman's partner has several benefits. **Couple counselling is more effective** than individual counselling with regard to behavioural change and **partner involvement improves** acceptance and utilisation of **PMTCT strategies**. Testing the **partners of pregnant women who follow a high risk life style** (and the women themselves for a second time later in pregnancy after a first negative result), is

cost-effective as compared with the lifetime cost when a woman becomes infected during pregnancy and her baby is infected unknowingly.

Women prefer to be counselled and tested with their partners although doubt was expressed whether it would be possible as partners may be unwilling and it may be difficult to schedule a time for the couple to go for testing as the men often work out of town.

Even when a woman is in labour in hospital, the opportunity can be used to test the couple as it was found that **men who accompany their partners for the birth** are usually willing to be tested for HIV with their partners whose HIV status is unknown.

5.5.7 HIV testing during labour

- Women comprehend most of the information when counselled for HIV testing during labour, but aids such as a flipchart would make transfer of information more effective (Jamieson *et al.*, 2003:889-895).
- HIV testing during labour is feasible (Homsy *et al.*, 2006:149-154; Bulterys *et al.*, 2004:219-223; Bharucha *et al.*, 2005: 553-555).
- Less testing during labour was done during times when fewer staff members were on duty e.g. during the night and on weekends (Homsy *et al.*, 2006:149-154; Bulterys *et al.*, 2004:219-223; Bharucha *et al.*, 2005: 553-555).
- Most women tested during labour, received antiretroviral treatment before the delivery except in a cases when women presented in advanced labour (Bulterys *et al.*, 2004:219-223; Homsy *et al.*, 2006:149-154; Bharucha *et al.*, 2005: 553-555).

Conclusion statements regarding HIV testing during labour

It is worthwhile to counsel and test women whose HIV status is unknown, even when in labour as it was found to be **feasible, women comprehend** most of the information they receive, are able to take an informed decision when they consent to be tested and most women who qualify **get antiretroviral therapy as strategy to limit MTCT in time**. It is not always possible to attend to counselling for HIV testing **when a woman presents in**

advanced labour or when the staff members are limited during the night and over weekends, due to the nature of a labour ward.

5.5.8 Counsellor factors

- Midwives with a positive attitude towards HIV testing had a higher uptake of testing than midwives who did not have a positive attitude (Simpson *et al.*, 1998:262-267; 1999a:1- 80).
- Lay counsellors can be used to provide counselling if they are sufficiently trained, supervised and mentored by professional health workers (Shetty *et al.*, 2005:755-759).
- Uptake of HIV testing can be kept on a high level if regular education sessions are presented for health workers (Grimes *et al.*, 2001:585-589).

Conclusion statements regarding counsellor factors

Factors regarding the person who conducts the counselling, for which evidence was found, are the type of health workers utilised as counsellors and the role that the counsellor's attitude plays in the effectiveness of the counselling. **Both professional and lay persons who undergo specific training can act as counsellors**, although care must be taken to ensure that the **lay counsellors are sufficiently trained, supervised and mentored** by professional health workers. **Regular educational sessions** for all health workers involved with counselling and testing of pregnant women can help to sustain a high of uptake of HIV testing. A counsellor's **positive attitude towards HIV testing** can influence on the uptake of testing positively.

5.5.9 Organisational factors

- Women who attend hospital-based services or clinics with fewer patients and who receive counselling from their primary care giver (doctor or midwife), are more likely to be counselled (Ethier *et al.*, 2000:1448-1451).
- Women who receive care in community health centres, those who attend longer counselling sessions and those who receive counselling from a dedicated HIV counsellor, were more likely to accept HIV testing (Ethier *et al.*, 2000:1448-1451).

- Care must be taken at each step of the PMTCT programme (counselled at first visit, counselled at subsequent visit, HIV test offered, test accepted, returning for test result, given Nevirapine, taken Nevirapine) to minimise leakages as the cumulative effect of all the leakages can cause more HIV positive women not taking Nevirapine than those taking it (Buch *et al.*, 2003:1-42, Kumar *et al.*, 2004:242-248).
- Uptake of HIV testing after counselling as well as uptake of Nevirapine is significantly higher after counselling for HIV testing is integrated with other aspects of antenatal care (Van't Hoog *et al.*, 2005:344-349) although reviewers in a Cochrane review concluded that the evidence is not strong enough to recommend integration of services, and recommended additional research (Briggs & Garner, 2006).

Conclusion statements regarding organisational factors

The way in which counselling for HIV testing is organised could influence its effectiveness. Although pregnant women are more likely to receive counselling in clinics with fewer patients and if they are **counselled by their primary care giver** (doctor or midwife), those **counselled for longer than 15 minutes by a person dedicated specifically to HIV counselling** are more likely to accept HIV testing.

Patients who are lost or not followed up at several stages of the PMTCT programme can contribute to HIV positive women not receiving optimal care to prevent mother to child transmission of HIV. **Integrating counselling and testing for HIV with other aspects of antenatal care**, increases the uptake of testing.

5.6 SUMMARY

In this chapter, the fourth step of the first phase, the collection of evidence as preparation for developing best practice guidelines, was discussed.

Evidence from research studies were collected by means of systematic review, where studies were searched, retrieved, evaluated regarding relevance, and critically appraised

on validity. Finally, extracted findings from applicable research studies were combined logically, in conclusion statements.

In Chapter 6 the formulation of the Best Practice guidelines will be discussed.

CHAPTER 6

DEVELOPMENT OF BEST PRACTICE GUIDELINES REGARDING COUNSELLING FOR HIV TESTING DURING PREGNANCY

(Phase 2)

6.1 INTRODUCTION

In this chapter, the evidence compiled during Phase 1 is synthesised and used as base for developing best practice guidelines (BPG's).

The following objective is addressed in this step:

Objective 5: To develop best practice guidelines for counselling for HIV testing during pregnancy.

Table 6.1. Structure of the research project indicating Step 5

<p>Phase 1: Compilation of evidence as preparation for development of best practice guidelines</p>	<p>Phase 2: Development of best practice guidelines</p>
<p>Step 1: Explore and describe factors that influence pregnant women's decision to be tested for HIV</p>	<p>Step 5: Formulation of best practice guidelines for counselling for HIV testing during pregnancy</p>
<p>Step 2: Explore and describe factors that influence the counselling for HIV testing during pregnancy according to counsellors</p>	
<p>Step 3: Explore and describe current practice regarding counselling for HIV testing during pregnancy</p>	
<p>Step 4: Systematic review of studies regarding counselling for HIV testing during pregnancy</p>	

The evidence compiled in phase 1, is used in the development of best practice guidelines in phase 2. The researcher follows a specific development process which culminates in the formulation of best practice guidelines for counselling for HIV testing during pregnancy. The process that was followed is discussed in the section below.

6.2 DEVELOPMENT OF THE BEST PRACTICE GUIDELINES

This section discusses the philosophy behind the paradigm of evidence-based practice and best practice guidelines, as well as the grading system used to indicate the sufficiency of the supporting evidence and the strength of the recommendation for implementation. This is followed by a discussion of the development process followed using logical reasoning. Finally, an audit trail of how the phase 1 conclusion statements were synthesised, is presented, starting with a summary of all the conclusion statements from steps 1-4, followed by the combination of the conclusion statements according to themes. In the next section (6.3) the formulation of the Best Practice Guidelines is discussed.

In the paradigm of evidence based practice, systematic review is used either to find guidance on the best management for a specific patient, or to compile Best Practice Guidelines (BPG's) for use by health practitioners, who would use their expertise to adapt the guidelines to their context, for specific patients. In this study the aim was to compile best practice guidelines.

Best Practice Guidelines are defined as systematically developed statements (based on the best evidence available) to assist practitioners' and clients' decisions about appropriate health care, for specific practice circumstances (Registered Nurses' Association of Ontario (RNAO), 2005:91).

Best Practice Guidelines are usually based on the results of a systematic review (and not on the results of primary empiric research) by teams that consist of all role players and is verified by experts (Melnik & Fineout-Overholt, 2005:232; RNAO, 2006:18-47). In this research project the input of role players (pregnant women and counsellors) was obtained with empiric research and the study promoters provided expert opinion.

6.2.1 Grading system

Various hierarchies have been developed to grade the quality of evidence and the strength of recommendation of Best Practice Guidelines. Examples are the systems used by the Oxford Centre for Evidence-Based Medicine (2001), the Joanna Briggs Institute (JBI) (2006) and the Registered Nurses Association of Ontario (RNAO) (Keast

et al. 2006:35). Usually, the grading systems consider findings from randomised controlled trials (or a systematic review that combines these findings) as the ultimate type of evidence to guide decisions regarding the effectiveness of interventions.

Both Glasziou *et al.* (2004:39-41) and Schünemann *et al.* (2003:677-680) discuss the problems experienced with grading systems. According to Glasziou *et al.* (2004:39) different types of research problems (concerning prognosis, diagnosis or economics for example) require different types of evidence and one type of study (for example randomised controlled trials) can not be considered the ideal type of study for all research problems. Glasziou *et al.* (2004:40) also indicate that the results from a variety of types of studies may be needed to guide practice for complicated problems comprising more than one aspect.

Determining the most beneficial practices in counselling for HIV testing during pregnancy, could be considered a complicated problem because it must be effective but should also acknowledge limited resources and respect for human rights. To make provision for a variety of research problems the grading systems can be very complex (Oxford Centre for Evidence-based medicine, 2001; JBI, 2006). Glasziou *et al.* (2004:40) recommend the use of a tailored approach that briefly summarises and motivates why the evidence was assessed in the way in which it was, instead of a complicated grading system. Schünemann *et al.* (2003:677-680) discuss the confusion and incomprehension created by complicated grading systems for quality of evidence and grades of recommendations. They also recommend simpler ways and ways that are easier to understand, to indicate the quality of evidence on which a recommendation (e.g. BPG) is based, as well as ways to indicate how strongly a guideline (e.g. BPG) is recommended.

One grading system that is fairly simple and easy to understand and was considered for use in this research, is the "Rating scheme for the strength of recommendations". It was used in the clinical practice guidelines for secondary prevention of coronary artery disease (Kaiser Permanente Care Management Institute, 2006). This grading system differentiates between recommendations that are evidence-based and those that are consensus-based. They considered the evidence (from a systematic review) by weighing the benefits, harms and costs when implementing the recommendations. The more evidence indicate that the benefits outweigh the harms and costs, the higher the

evidence-based rating is (A, B, C, D or I= insufficient). Recommendations classified as consensus-based result from the consensus or expert opinion of the Guideline Development Team (Kaiser Permanente Care Management Institute, 2006). The rating scheme could not be used as is in the current study, because the guidelines were not developed by a team and the evidence consists of findings generated by a systematic review and empiric (qualitative) research.

In this study a simple grading system is used to indicate the **sufficiency of evidence** (based on quality and quantity of evidence sources) as well as the **strength of the recommendation for implementation**. The term 'sufficiency' is used to indicate the degree to which the supporting evidence is sufficient, to be relied on as basis and to believe that the recommendation is true (Pearson *et al.*, 2005:210). Evidence from a variety of sources (in this study from a systematic review and findings from qualitative research with different categories of participants) that support one another is considered more sufficient than studies based on fewer sources. It is therefore allocated a higher grade.

The grade for the strength of recommendation for implementation is allocated according to the degree in which implementation of the BPG will positively impact on practice as well as the difference between the benefits and harms / costs. The FAME criteria (feasibility, appropriateness, meaningfulness and effectiveness) from JBI (Pearson, *et al.* 2005:210) were considered when deciding on the grade for the strength of recommendation for implementation, allocated to a BPG. The grading system used for the Best Practice Guidelines developed in this study is indicated in table 6.2.

It is acknowledged that verification of the two aspects of the grading system is necessary and such action is planned as follow up for the present study.

Table 6.2 Grading system used for Best Practice Guidelines.

Sufficiency of evidence		Strength of recommendation for implementation	
Definitely sufficient evidence (Supporting evidence from at least three of the steps in phase 1)	A	High priority (Implementation is essential for counselling for HIV testing to be feasible, appropriate, meaningful and effective)	1
Probably sufficient quality (Supporting evidence from two of the steps in phase 1)	B	Recommended (Implementation would definitely improve counselling for HIV testing)	2
Sufficiency of evidence not guaranteed (Supporting evidence from one of the steps in phase 1)	C	Low priority (Implementation would probably improve counselling for HIV testing)	3

The process followed in the development of the guidelines is now discussed. Firstly, the logical reasoning that directed the development of the Best Practice Guidelines is discussed. In the following section the conclusion statements from step 1- 4 are summarised. Conclusion statements from the different steps that address similar themes were firstly integrated according to the themes. Similar themes were then arranged together to generate the headings for the BPG's. Finally, the BPG's were formulated from the relevant evidence as stated in the conclusion statements. The strength of the evidence on which the guideline is based and the proposed grade of implication for each of the BPG's are then motivated. Finally, recommendations for implementation are supplied for each BPG.

6.2.2 Logical reasoning

The process that guided the formulation of Best Practice Guidelines employed different kinds of reasoning. **Deductive reasoning** was used when different findings (premises) regarding one theme had to be merged into a single conclusion that is greater than the findings on their own. Because the single conclusion is deduced from findings proven to be true, the conclusion's truth is assured (Babbie & Mouton, 2001:643; Burns & Grove, 2005:8).

In this final step of the project, conclusion statements from the four previous steps are synthesised into Best Practice Guidelines (inductive reasoning), for which recommendations for implementation are then formulated. During the formulation of the recommendations for implementation **inductive reasoning** is used. This entails progression from the specific to the more general. The recommendations can be considered as probably true (Babbie & Mouton, 2001:643; Burns & Grove, 2005:7).

The conclusion statements from phase 1 were used as base to formulate Best Practice Guidelines

6.2.3 Summary of conclusion statements from Phase 1

Table 6.3 depicts a combination of the conclusion statements from the four steps of Phase 1.

- ❖ Step 1: Factors that influence pregnant women's decision to be tested for HIV;
- ❖ Step 2: Factors that influence the counselling for HIV testing during pregnancy according to counsellors;
- Step 3: Current practices regarding counselling for HIV testing during pregnancy; and
- Step 4: Systematic review of research studies regarding counselling for HIV testing during pregnancy.

The statements are numbered from 1 to 90 and statements will be referred to according to their numbers in the rest of the chapter.

Table 6.3 Summary of conclusion statements from step 1-4.

STEP 1: Factors that influence pregnant women's decision to be tested for HIV (Refer to Chapter 2)
1. Pregnant women decide on their own to be tested for HIV due to their motivation of perceived benefits for the baby.
2. Pregnant women decide on their own to be tested for HIV due to their motivation of perceived benefits for themselves when their HIV status is known.
3. Pregnant women need time to be ready to be confronted with a possible positive HIV result.
4. Some pregnant women are influenced by family members and friends in their decision to be tested but no one mentioned that a husband or partner needs to be consulted before the decision is made.
5. Some pregnant women are tested for HIV after collective decision making, where a group of women received

pre-test counselling and together decided together to be tested.

6. Pregnant women may decide not to be tested for HIV due to fear that they may lose their secure livelihood, get ill more quickly and that death soon may follow. The resulting despair may lead to suicide.
7. Fear of social changes that cause pregnant women to decide not to be tested for HIV, include fear of being rejected by her partner due to mistrust, although no mention was made that women could be afraid of violent behaviour by the partner following the disclosure of the diagnosis.
8. Pregnant women can decide not to be tested for HIV due to a fear of possible stigmatisation in the community.
9. Pregnant women like to receive the health education part of the pre-test counselling in a group.
10. Pregnant women appreciate privacy when disclosing their decision regarding testing.
11. Pregnant women are suspicious about health personnel honouring the confidentiality of their HIV status.
12. Support during counselling could encourage pregnant women to consent to be tested but no-one specifically mentioned the need for on-going post-test counselling.
13. Pregnant women appreciate individualised care.
14. Pregnant women recommend that health education material such as pamphlets be used as they receive information about HIV and prevention of mother-to-child transmission from a variety of sources.
15. Pregnant women recommend that the community receive more information about the importance of HIV testing – especially during pregnancy.
16. Pregnant women complain about waiting in long queues and suggest that certain days are designated for HIV testing to accelerate the process.
17. Pregnant women complain that health personnel are rude to patients.
18. Pregnant women recommend that more staff be appointed.

**STEP 2: Factors that influence the counselling for HIV testing according to the counsellors
(Refer to Chapter 3)**

19. Counsellors are motivated to become or stay HIV counsellors because they want to make a contribution in the fight against HIV/AIDS or feel that they are appreciated and that they make a difference in peoples' lives.
20. Some counsellors use the employment to save money to prepare for another career.
21. Counsellors are influenced by intrapersonal factors when they become emotionally involved and this could lead to burnout.
22. Some counsellors keep a deliberate emotional distance because they cannot manage their feelings, or to protect themselves.
23. Social support from co-workers can be valuable.
24. Counsellors feel they cannot perform optimally due to large numbers of patients as well as frequent staff-shortage which lead to excessive work-pressure.
25. Due to the emphasis placed on information transfer as mode of giving support to clients it is important that counsellors have up to date knowledge of HIV/AIDS and PMTCT.
26. A directive, task-orientated approach is used in pre-test counselling as evident by the counsellors' attitude that obtaining consent for HIV testing is the main aim of counselling.
27. HIV testing with the male partner is advisable for all women at the beginning of a sexual relationship and is especially advantageous for pregnant women as her partner would be able to provide better support if

PMTCT strategies need to be implemented.

28. Group counselling can be used to give health education about HIV/AIDS, pregnancy and certain aspects of PMTCT before individual counselling commences.
29. Counsellors prefer that other health professionals who refer patients for HIV counselling and testing, first prepare them for what to expect.
30. Counsellors become discouraged and feel helpless when counselling clients who deny their positive HIV status, destitute clients or young clients.
31. Counsellors find it difficult to counsel discordant couples.
32. Counsellors are badly affected by HIV positive family members. They may feel helpless when they are not able to discuss the patient's condition with the patient herself or with other family members but having personal experience with HIV also enable them to really understand and empathise with others.
33. Counsellors implement informal strategies to ensure that their clients understand the information that they provided them with.
34. Educational aids must be suitable to local circumstances.
35. Counsellors assessed readiness for testing and made provision for clients who do not want to be tested for HIV immediately.
36. Follow up of clients who do not want to be tested after counselling, is not handled optimally in the clinics, some counsellors do no follow-up and others coercing clients to accept testing.
37. Follow-up of clients who test HIV positive is currently being done informally and no support group has been established yet.
38. Counsellors need formal support in addition to the informal social support they receive from their co-workers. This support can take the form of group or individual counselling, supervision, mentoring or debriefing and is essential to prevent burnout and high turnover of counsellors.
39. Counselling suffers due to the lack of suitable venues.
40. Both scheduling certain clients for specific days and seeing clients according to appointments have advantages and disadvantages.
41. Problems with their stipend, a lack of acknowledgement of their value and structure regarding duties can cause counsellors to become discouraged, and not work optimally.
42. The stigma against people living with HIV in the community can act as discouraging factor that hinders pregnant women from HIV testing.
43. Stigma 'executed' by counsellors can contribute to the stigma in the community and also sends a message that it is accepted behaviour.
44. None of the counsellors reported experiencing stigma due to their association with HIV/AIDS patients.
45. Counselling is influenced when certain clinics are overloaded with patients who do not want to attend other clinics with bad reputations, although no evidence could be found that confidentiality is not respected.
46. Patients who do not trust rapid tests for HIV increase the counsellors' workload.
47. Clients who seek conformation of their HIV status from more than one clinic add to the counsellors' workload.
48. When testing by proxy is practiced, counsellors have to deal with the extra workload and difficult decision about how to manage the situation.

STEP 3: Current practices regarding counselling for HIV testing during pregnancy

(Refer to Chapter 4)

49. Provision is made for women who are not able to visit the clinic during office hours, but pregnant women may find making appointments inconvenient.
50. Antenatal care and counselling for HIV testing is presented free of charge and can therefore be considered affordable for pregnant women.
51. Pregnant woman who prefer not to visit their nearest clinic must be able to pay for transport to the preferred clinic.
52. Privacy during counselling can not be guaranteed in the clinics. Physical limitations cause counsellors to make do with the facilities that are available and counselling is often interrupted.
53. No evidence (accept limited privacy during counselling) was observed that could be considered a threat to confidentiality.
54. Knowledge about HIV infection in pregnancy, the risk of transmission to the baby, the benefits of knowing one's status and interventions available if the result is positive can be powerful motivators to convince pregnant women to be tested for HIV.
55. Implications of a negative test result and the implications of a positive result for baby feeding were discussed well but more practical information regarding baby feeding needs to be added during post-test counselling of women who test HIV positive.
56. HIV positive women need more direct information on how to disclose their status to their partners. The implication of a positive result for future children and benefits of couple testing are not discussed.
57. Counsellors are skilled in basic conversational skills and able to establish an interpersonal relationship but they do not exhibit 'counselling skills' such as using open and closed-ended questions, reflective listening, paraphrasing and probes.
58. The counsellors talk a lot themselves, and do not ask and listen enough.
59. Counsellors do not ask about the pregnant women's personal circumstances and can therefore not help them to make a truly informed decision about HIV testing.
60. Language difficulty was not handled well.
61. The best way for the counsellor to handle a newly diagnosed HIV positive woman who experiences emotional distress will depend on the specific situation and the personalities of the counsellor and pregnant woman involved.
62. The counsellors were effective in establishing group relationships but did not demonstrate facilitation skills to ensure group participation as they did nearly all the talking in the groups.
63. Counsellors displayed basic information giving skills, but their presentation skills were not good.
64. Time is not managed well during group sessions as the pregnant women became tired and the effectiveness of the sessions deteriorated when the session's duration was longer than 30 minutes.

STEP 4: Evidence from systematic review of research studies (Refer to Chapter 5)

65. VCT is more effective than health education only, in persuading people to abstain from high risk behaviour such as unprotected sex but, VCT is unlikely to prevent primary HIV infection as the positive behaviour change is more effective in people who are already infected.

66. Negative life events are not common after being exposed to VCT but the break up of the sexual relationship of women that test HIV positive can occur.
67. In some circumstances the main aim of counselling is seen as persuading women to consent to be tested. Pregnant women can be coerced to be tested when they are not informed that testing is voluntary.
68. While some women are knowledgeable about MTCT even before counselling, it is clear that other women's information needs are not met.
69. The opportunity to supply support to address pregnant women's emotional is not utilised optimally during pre-test counselling.
70. Spending more than 5 minutes counselling a woman is more effective than shorter sessions.
71. Educational material such as posters can be used to display the health workers and authorities' endorsement of HIV testing, while pamphlets on the benefits and risks of HIV testing during pregnancy, for example, can be used as decision aids to empower women with greater knowledge, more realistic expectations and less decisional conflict when they make their decision regarding HIV testing.
72. The quality of counselling can be improved by using a coaching approach where women are helped to take decisions based on correct information and taking their own values into consideration.
73. While knowledge increases more after group counselling, the uptake of testing is higher after individual counselling.
74. The more routinely counselling and testing of pregnant for HIV is handled, the higher the uptake of testing. Uptake is higher when the test is specifically offered than when women are just notified of its availability and is also higher when an opt-out (routine) policy is implemented as compared with situations where an opt-in approach is followed.
75. Women prefer HIV tests to be handled in the same way that other antenatal tests are conducted.
76. Routine testing is a cost-effective means to identify the women towards whom strategies to prevent mother-to-child transmission of HIV should be focused, this could prevent lifetime medical and social care cost of infected children.
77. Rapid HIV testing is just as accurate as standard laboratory tests, and more cost-effective.
78. Counselling for rapid HIV testing must be adapted as women receive their results quicker, while they may not be emotionally ready yet. Even though they get their results quicker, HIV positive women do not necessarily receive all the measures to prevent MTCT.
79. Couple counselling is more effective than individual counselling with regard to behavioural change and partner involvement improves acceptance and utilisation of PMTCT strategies.
80. Testing the partners of pregnant women who lead a high risk life style (and testing the women themselves for a second time later in pregnancy after a first negative result), is cost-effective as compared with the lifetime cost involved when a woman becomes infected during pregnancy and her baby is infected unknowingly.
81. Women prefer to be counselled and tested with their partners although doubt was expressed whether it would be possible as partners may be unwilling and it may be difficult to schedule a time for the couple to go for testing as the men often work out of town.
82. Even when a woman is in labour in hospital, the opportunity can be used to test the couple as it was found that men who accompany their partners for the birth are usually willing to be tested for HIV with their partners whose HIV status is unknown.
83. It is worthwhile to counsel and test women whose HIV status is unknown, even when in labour, as it was

- found to be feasible, women comprehend most of the information that they receive, are able to take an informed decision when they consent to be tested and most women who qualify receive antiretroviral therapy as strategy to limit MTCT in time.
84. It not always possible to attend to counselling for HIV testing when a woman presents in advanced labour or when the staff members are limited during the night and over weekends due to the nature of a labour ward.
85. Both professional and lay persons who undergo specific training can act as counsellors, although care must be taken to ensure that the lay counsellors are sufficiently trained, supervised and mentored by professional health workers.
86. Regular educational sessions for all health workers involved with counselling and testing of pregnant women can help to sustain a high of uptake of HIV testing.
87. A counsellor's positive attitude towards HIV testing can influence on the uptake of testing positively.
88. Although pregnant women are more likely to receive counselling in clinics with fewer patients and if they are counselled by their primary care giver (doctor or midwife), those counselled for longer than 15 minutes by a person dedicated specifically to HIV counselling are more likely to accept HIV testing.
89. Patients who are lost or not followed up with at several stages of the PMTCT programme can contribute to HIV positive women not receiving optimal care to prevent mother to child transmission of HIV.
90. Integrating counselling and testing for HIV with other aspects of antenatal care, increases the uptake of testing.

In the next section, the 90 conclusion statements were combined according to themes.

6.2.4 Conclusion statements according to themes

The next step in the development of the BPG's, was to arrange the 90 conclusion statements according to themes that could be combined to act as headings for the BPG's.

Table 6.4 Conclusion statements and themes

Conclusion statements according to themes	Combination of themes
<p>Informing the community of the benefits of HIV testing during pregnancy. Conclusion statements: 4 (Step 1), 5 (Step 1) & 15 (Step 1)</p> <p>Mistaken beliefs and community practices Conclusion statements: 6 (Step 1), 46 (Step 2), 47 (Step 2), 48 (Step 2)</p> <p>Powerlessness of women Conclusion statements: 6 (Step 1), 7 (Step 1) & 66 (Step 4)</p> <p>Stigmatisation Conclusion statements: 8 (Step 1), 42 (Step 2) & 43 (Step 2)</p>	<p>Creating a suitable community environment for optimal counselling for HIV testing during pregnancy</p>
<p>Privacy during individual counselling Conclusion statements: 10 (Step 1), 39 (Step 2), 53 (Step 3)</p>	<p>Creating a suitable clinic environment for optimal counselling for HIV testing during pregnancy</p>

<p>Honouring confidentiality Conclusion statements: 11 (Step 1), 45 (Step 2), 51 (Step 3), 53 (Step 3)</p> <p>Scheduling of and time allocated to counselling Conclusion statements: 16 (Step 1), 40 (Step 2), 49 (Step 3), 64 (Step 3), 70 (step 4), 88 (Step 4)</p> <p>Integration of counselling in antenatal care Conclusion statement: 90 (Step 4)</p> <p>Opt-out policy Conclusion statements: 74 (Step 4), 75, (Step 4), 76 (Step 4)</p> <p>Rapid testing Conclusion statements: 77 (Step 4), 78 (Step 4)</p> <p>Commitment of Health workers Conclusion statements: 17 (Step 1), 26 (Step 2), 29 (Step 2), 50 (Step 3), 67 (Step 4), 87 (Step 4), 88 (Step 4), 89 (Step 4)</p>	
<p>Selection of counsellors Conclusion statements: 19 (Step 2), 20 (Step 2), 85 (Step 4)</p> <p>Training of counsellors Conclusion statements: 25 (Step 2), 57 (Step 3), 62 (Step 3), 63 (Step 3), 72 (Step 4), 86 (Step 4)</p> <p>Support for counsellors Conclusion statements: 21 (Step 2), 22 (Step 2), 23 (Step 2), 30 (Step 2), 31 (Step 2), 32 (Step 2), 38 (Step 2), 85 (Step 4)</p> <p>Recognition of counsellors Conclusion statements: 19 (Step 2), 41 (Step 2), 44 (Step 2)</p> <p>Staff-shortage Conclusion statements: 18 (Step 1), 24 (Step 2)</p>	<p>Enabling counsellors to provide optimal counselling for HIV testing during pregnancy</p>
<p>Motivation of pregnant women to test for HIV Conclusion statements: 1 (Step 1), 2 (Step 1), 54 (Step 3)</p> <p>Readiness for testing Conclusion statements: 3 (Step 1), 35 (Step 2), 36 (Step 2), 78 (Step 4)</p> <p>Health education Conclusion statements: 9 (Step 1), 14 (Step 1), 28 (Step 2), 33 (Step 2), 34 (Step 2), 55 (Step 3), 56 (Step 3), 60 (Step 3), 68 (Step 4), 71 (Step 4), 73 (Step 4)</p> <p>Establishing a trust relationship and communication on a deeper level Conclusion statements: 12 (Step 1), 13 (Step 1), 58 (Step 3), 59 (Step 3), 61 (Step 3), 65 (Step 4), 69 (Step 4)</p> <p>Follow-up support for HIV positive pregnant women Conclusion statements: 37 (Step 2)</p> <p>Couple counselling Conclusion statements: 27 (Step 2), 79 (Step 4), 80 (Step 4), 81 (Step 4)</p> <p>HIV counselling and testing during labour Conclusion statements: 82 (Step 4), 83 (Step 4), 84 (Step 4)</p>	<p>Achieve optimal counselling for HIV testing during pregnancy</p>

6.3 FORMULATION OF BEST PRACTICE GUIDELINES

The conclusion statements related to the themes were used as the evidence for the Best Practice Guidelines that were subsequently formulated. The BPG's were arranged under the headings developed from the themes (Table 6.4).

- Guidelines for creating a suitable community environment for optimal counselling for HIV testing during pregnancy,
- Guidelines related to the clinic to create a suitable environment for optimal counselling for HIV testing during pregnancy
- Guidelines to enable counsellors to provide optimal counselling for HIV testing during pregnancy, and
- Guidelines to achieve optimal counselling for HIV testing during pregnancy.

Each BPG is followed by a grade allocated for the sufficiency of evidence on which the guideline is based (the conclusion statements as in table 6.3), as well as a grade for the strength of recommendation for implementation (See table 6.2) and supplied with a motivation for the grades allocated. Finally recommendations for implementation for each Best Practice Guideline are formulated.

6.3.1 GUIDELINES FOR CREATING A SUITABLE COMMUNITY ENVIRONMENT FOR OPTIMAL COUNSELLING FOR HIV TESTING DURING PREGNANCY

BEST PRACTICE GUIDELINE 1

Information, Education and Communication (IEC) is used to educate the community on HIV testing.

Sufficiency of evidence: B

Evidence from two steps of phase 1 (Step 1 & 2) support this BPG.

Step 1: Conclusion statements 4, 5, 6, 15.

Step 2: Conclusion statements 46, 47, 48.

Strength of recommendation for implementation: 1

If this BPG is implemented, the community (including the women's families and male partners) would be more supportive of pregnant women who are tested for HIV and mistaken beliefs that cause pregnant women not to be tested would be rectified.

Implementation recommendations:

- Make provision in the budget to appoint professionals or companies to plan and conduct IEC campaigns.
- Plan local IEC campaigns with the target recipients in mind and adapt the message content accordingly.
- Do research about mistaken beliefs that contribute to pregnant women not wanting to be tested for HIV in each community, and research community practices that could contribute to the counsellors' workload.
- Include corrections of mistaken beliefs considering local customs, being culturally sensitive.
- Make use of radio, television and billboards to reach the general public (including and specifically also males).

BEST PRACTICE GUIDELINE 2

Clinic staff participate in programmes that address social issues like disempowerment of women and stigmatisation.

Sufficiency of evidence: A

Evidence from three steps in phase 1 (Step 1, 2 & 4) supports this BPG.

Step 1: Conclusion statements 6, 7, 8.

Step 2: Conclusion statements 42, 43.

Step 4: Conclusion statement 66.

Strength of recommendation for implementation: 1

Social issues like disempowerment of women and stigmatisation have a serious effect on counselling for HIV testing during pregnancy and counselling would be more effective, if these issues could be reduced.

Implementation recommendations:

- Initiate and support programmes that promote education of girls and females.
- Initiate and support programmes to teach women assertiveness skills.
- Launch and support awareness campaigns on HIV/AIDS and how to live with people who are HIV positive.
- Support People living with HIV (PLWH) who are willing to disclose their status to the community as they can make an important contribution in the fight against HIV.
- Train counsellors not to contribute to the stigma, but to treat HIV positive patients with respect and to care for them in the same way that they care for patients with other diseases.

6.3.2 GUIDELINES RELATED TO THE CLINIC TO CREATE A SUITABLE ENVIRONMENT FOR OPTIMAL COUNSELLING FOR HIV TESTING DURING PREGNANCY

BEST PRACTICE GUIDELINE 3

Privacy is assured during individual counselling.

Sufficiency of evidence: A

Evidence from three steps of phase 1 (Step 1, 2 and 3) supports this BPG.

Step 1: Conclusion statement 10.

Step 2: Conclusion statement 39.

Step 3: Conclusion statement 53.

Strength of recommendation for implementation: 1

If this BPG is implemented pregnant women would be more willing to attend the clinic for counselling. Counsellors can only perform optimally when privacy is assured.

Implementation recommendations:

- Priority must be given to ensuring suitable, private rooms for individual counselling in clinics that were built before the need for a counselling room was recognised. A curtained-off cubicle is not suitable.
- Budgetary provision must be made for purchasing of a mobile home or caravan if no suitable room is available.

BEST PRACTICE GUIDELINE 4

All clinic staff honour the confidentiality of patients' information (especially HIV status).

Sufficiency of evidence: A

Evidence from three steps of phase 1 (Steps 1, 2 & 3) supports this BPG.

Step 1: Conclusion statement 11.

Step 2: Conclusion statement 45.

Step 3: Conclusion statements 51, 53.

Strength of recommendation for implementation: 1

Trust that counsellors (and other health workers) will honour confidentiality regarding a patient's HIV status is critical in a pregnant woman's decision to be tested for HIV or not. A clinic with a reputation that confidentiality is not honoured will not be used by patients and this overloads other clinics.

Implementation recommendations:

- Regularly remind all staff who frequently work in clinics of the importance to keep patients' information confidential through in-service training.

- Display posters with the procedure to encourage members of the public to report incidences where confidentiality was broken by health personnel (anonymously if so wished, but in detail to enable and investigation of the accusation).
- Disclose the disciplinary action taken against staff members who are found guilty of such a breach of confidentiality.

BEST PRACTICE GUIDELINE 5

All staff members are committed to counselling for HIV testing during pregnancy

Sufficiency of evidence: A

Evidence from step 1, 2, 3 and 4 of phase 1 support this BPG.

Step 1: Conclusion statement 11.

Step 2: Conclusion statement 45.

Step 3: Conclusion statements 51, 53.

Strength of recommendation for implementation: 1

Counselling for HIV testing during pregnancy can only be successful if all staff members who work in clinics are committed to it and do everything in their power to ensure its success.

Implementation recommendations:

- Formulate procedures to ensure that opportunities to counsel pregnant women for HIV testing are not lost.
- Professionals who refer clients for HIV counselling and testing should prepare them regarding what to expect.
- In a project to promote a caring ethos in health workers, community members should be involved and asked what they consider as good care. Community members can also be involved by voting for the clinic and individual health worker who is seen as the most caring. Sponsors could be used to provide further incentives for clinics and individuals to perform. This must not be a once-off occurrence, but should be repeated on regular basis e.g. every three months.

- A system must be developed where members of the community can report inappropriate behaviour by health personnel (anonymously if so wished, but in detail to enable investigation of the accusation's validity).
- Disclose the disciplinary action taken against staff members who are found guilty of such inappropriate behaviour.

BEST PRACTICE GUIDELINE 6

Routine counselling and testing for HIV with an opt-out option is offered.

Sufficiency of evidence: C

Evidence from the systematic review (step 4) supports this BPG.

Step 4: Conclusion statements 74, 75, 76.

Strength of recommendation for implementation: 2

If this BPG is implemented the uptake of HIV testing during pregnancy would be higher than when the opt-in testing is used.

Implementation recommendations:

- Educate health-workers, pregnant women and community members regarding routine counselling and testing with opt-out before the new policy is implemented. If everybody is not well informed, the perception can originate that clients are tested against their will.
- Ensure that all pregnant women receive health education about HIV/AIDS and pregnancy and that they are informed that an HIV test will be done with the other blood tests, but that they can decline any of the tests. Individual counselling must be available.

BEST PRACTICE GUIDELINE 7

Consider the community's and counsellors' needs in the scheduling of counselling and time management.

Sufficiency of evidence: A

Evidence for this BPG is based on all four steps (1, 2, 3 & 4) of phase 1.

Step 1: Conclusion statement 16.

Step 2: Conclusion statement 40.

Step 3: Conclusion statements 49, 64.

Step 4: Conclusion statements 70, 88.

Strength of recommendation for implementation: 2

If this BPG is implemented both clients and counsellors would be more satisfied, clients would spend less time waiting and the counsellors' workload could be spread more evenly.

Implementation recommendations:

- Do a survey to discover which of the following scheduling methods is preferred by clinic clients – and pregnant women specifically:
 - scheduling specific types of services (e.g. antenatal care) on specific days;
 - helping clients as they arrive (the supermarket principle, all types of patients any time), or
 - attending to clients according to appointments.
- Investigate the implications of the different scheduling methods for the health workers – specifically the counsellors.
- Continue with practice where clinics stay open after hours and investigate the possibility of extending service to weekends.
- Develop guidelines for the duration of group and individual counselling sessions e.g. minimum of 20 minutes, maximum of 40 minutes. Distribute the guidelines

and see that counsellors adhere to it. The guideline would also give guidance on how many clients can be counselled on a day by each counsellor.

BEST PRACTICE GUIDELINE 8

HIV counselling and testing is integrated with antenatal care.

Sufficiency of evidence: C

Evidence from the systematic review (step 4) supports this BPG.

Step 4: Conclusion statement 90.

Strength of recommendation for implementation: 2

If this BPG is implemented HIV-testing would be "normalised" and seen in the same light as other tests performed during antenatal care. The flow of the antenatal care would be less fragmented.

Implementation recommendations:

- Ideally the midwife, who conducts the woman's routine assessment and antenatal care, should counsel and test her for HIV.
- The lay counsellors could be used to
 - (1) provide health information regarding HIV (and other relevant topics), and
 - (2) establish and maintain support groups for HIV positive pregnant women.

BEST PRACTICE GUIDELINE 9

Rapid HIV testing is available and used.

Sufficiency of evidence: C

Evidence from the systematic review (step 4) supports this BPG.

Step 4: Conclusion statements 77, 78.

Strength of recommendation for implementation: 2

If this BPG is implemented, pregnant women can receive their results during the counselling session and would not have to return to the clinic to obtain it.

Implementation recommendations:

- Use rapid on-site HIV tests where possible.
- Pregnant women should be given a choice about when they want to be notified of the result as some women may prefer not to receive their results immediately.
- Where HIV testing is not integrated into the antenatal care conducted by a midwife, training of lay counsellors to execute rapid tests themselves (blood drop or saliva) must be considered. This will ensure that they do not have to call a registered nurse to obtain a blood sample, which would allow the process to flow more fluently.

6.3.3 GUIDELINES TO ENABLE COUNSELLORS TO PROVIDE OPTIMAL COUNSELLING FOR HIV TESTING DURING PREGNANCY

BEST PRACTICE GUIDELINE 10

Staffing norms for professional and lay health workers are developed and staff is appointed accordingly.

Sufficiency of evidence: B

Evidence from two steps of phase 1 (step1 & 2) supports this BPG.

Step 1: Conclusion statement 18.

Step 2: Conclusion statement 24.

Strength of recommendation for implementation: 1

If this BPG is implemented patients would not have to wait for long periods that cause them to become unsusceptible to counselling. Because staff shortages contribute to

health workers being overworked, implementation of this BPG can lead to less burnout, uncaring behaviour and high staff turnover.

Implementation recommendations:

- Develop guidelines on how many midwives, counsellors and other health workers should be employed at a clinic, according to the services offered and clients seen per day.
- Create posts and appoint both professional (midwives) health workers, clerical workers and lay counsellors accordingly, as the work of all staff members suffer when they need to perform tasks that are not usually part of their duties.
- Provision must be made in the budget to fill all vacant posts and priority must be given to the speedy appointment of replacements when posts become vacant.
- Seeing the reality of a shortage of nurses (and midwives) in South Africa, every attempt must be made to keep those who work at the clinics with incentives (good salary) and good working conditions.

BEST PRACTICE GUIDELINE 11

Counsellors are selected carefully.

Sufficiency of evidence: B

Evidence from two steps of phase 1 (steps 2 & 4).

Step 2: Conclusion statements 19, 20.

Step 4: Conclusion statement 85.

Strength of recommendation for implementation: 1

If this BPG is implemented the selected counsellors would be more committed to their task and not leave shortly after training.

Implementation recommendations:

- If possible give midwives a choice, if they want to be involved with counselling and testing for HIV.
- Carefully consider the personality, motivation and abilities of candidates who want to become lay counsellors, to select the most suitable ones.

BEST PRACTICE GUIDELINE 12

Priority is given to the training of counsellors.

Sufficiency of evidence: A

Evidence from three steps of phase 1 (Steps 2, 3 & 4) supports this BPG.

Step 2: Conclusion statement 25.

Step 3: Conclusion statements 57, 62, 63.

Step 4: Conclusion statements 72, 86.

Strength of recommendation for implementation: 1

If this BPG is implemented and training is presented on both the content of the health information that must be conveyed and skills development, counsellors would be better equipped to counsel optimally.

Implementation recommendations:

- Invest in the training of counsellors, by appointing professionals counsellors/ educators to develop a high quality curriculum consisting of accredited modules for the training of counsellors. This should include information about HIV/AIDS, PMTCT as well as communication, counselling, coaching, group facilitation and presentation skills.
- Professional counsellors/ educators must present training for lay-counsellors.

- Include training in coping skills to handle emotional involvement with clients, and training on how to establish a trust relationship to help each pregnant woman to make an informed decision about HIV testing. Use role-play to practice skills.
- Ensure that the above mentioned content and skills-training is also included in the education of midwives.
- As this is a dynamic field, regular updating of knowledge about HIV is essential to keep counsellors up-to-date with new developments.

BEST PRACTICE GUIDELINE 13

A support system is available for counsellors.

Sufficiency of evidence: B

Evidence from two steps (2 & 4) supports this BPG.

Step 2: Conclusion statements 21, 22, 23, 30, 31, 32, 38.

Step 4: Conclusion statement 85.

Strength of recommendation for implementation: 1

In addition to informal support counsellors need formal support due to their emotional involvement with their patients.

Implementation recommendations:

- Provide formal support for counsellors in the form of mentoring, supervision, group support and individual counselling by professional counsellors.
- Appoint professional counsellors to specifically support the HIV counsellors. Each professional counsellor can be responsible for a number of counsellors (not more than 10). The counsellors could have weekly group meetings for debriefing and monthly individual supervision/ counselling sessions.
- Develop a referral system to professional counsellors for complicated cases.

BEST PRACTICE GUIDELINE 14

The value of the role of counsellors is recognised.

Sufficiency of evidence: C

Evidence from one step of phase 1 (step 2) supports this BPG.

Step 2: Conclusion statements 19, 41, 44.

Strength of recommendation for implementation: 1

If this BPG is implemented counsellors would feel appreciated and would be more motivated to continue their work. Burn-out and staff turnover would be reduced.

Implementation recommendations:

- Establish the place for the counsellor in the hierarchy of the clinic.
- Provide structure to counsellors by developing guidelines regarding how many clients must be seen as well as the duration of counselling sessions (See BPG 7).
- Show recognition for the value of the counsellors in the size of their stipend and clarity of their work conditions.

6.3.4 GUIDELINES FOR OPTIMAL COUNSELLING FOR HIV TESTING DURING PREGNANCY

BEST PRACTICE GUIDELINE 15

Pregnant women are provided with information on HIV/AIDS, HIV testing and PMTCT.

Sufficiency of evidence: A

Evidence from four steps of phase 1 (1, 2, 3 & 4) supports this BPG.

Step 1: Conclusion statements 1, 2, 9, 14.

Step 2: Conclusion statements 28, 33, 34.

Step 3: Conclusion statements 54, 55, 56, 60.

Step 4: Conclusion statements 68, 71, 73.

Strength of recommendation for implementation: 1

If this BPG is implemented a pregnant woman would be more empowered to take an informed decision on whether she wants to be tested for HIV or not.

Implementation recommendations:

- Include all the content as stipulated by UNAIDS (2001) and Department of Health (2000a) in the health education before testing for HIV.
- Provide information by means of individual or group health education sessions and through educational material like posters and brochures. Audiovisual materials such as flipcharts or videos can also be used.
- Make provision in the clinics' budgets for educational/ audiovisual materials. If centrally provided brochures are found not to be suitable for a specific community, adapt the material or develop and publish new material.
- Women can be overwhelmed with the amount of information and it is good practice to supply the women with printed media to take home and read in their own time, after the initial information session
- List speakers of different national languages, employed by the Department of Health sub-district, who could be used as interpreters for women who do not understand the local language. Ensure the availability of brochures in all the official languages.
- Ask questions after information sessions (either in the group or privately) to ensure that every woman understands the information.
- Provide information about the safe preparation of breast milk substitute to HIV positive women who have decided to use it exclusively as baby feeding method,

privately. This topic must not be discussed in a group where some are HIV negative, as this could lead to spill over if women believe clinic staff endorses the use of breast milk substitutes instead of breastfeeding, as this could lead to unsafe practices by women for whom it is not indicated.

BEST PRACTICE GUIDELINE 16

Counsellors assess each pregnant woman for readiness for HIV testing and follow-up with those who do not want to be tested immediately.

Sufficiency of evidence: A

Evidence from three steps of phase 1 (steps 1, 2 & 4) supports this BPG.

Step 1: Conclusion statement 3.

Step 2: Conclusion statement 35, 36.

Step 4: Conclusion statement 78.

Strength of recommendation for implementation: 1

If this BPG is implemented pregnant women who are not ready for HIV testing, immediately after counselling, will be recognised and given other opportunities for testing.

Implementation recommendations:

- Inform pregnant women that they can delay HIV testing to think about it and can be tested at a later opportunity if they wish to.
- Give pregnant women the option to be tested but to receive their results later.
- Each service must develop a formal procedure on how to identify and manage pregnant women who do not want to be tested for HIV, immediately after counselling, to ensure they get other opportunities at follow-up antenatal visits. (Refer to BPG 5)

BEST PRACTICE GUIDELINE 17

Counsellors establish a trust relationship with the women who they counsel privately.

Sufficiency of evidence: A

Evidence from three steps of phase 1 (Steps 1, 3 & 4) support this BPG.

Step 1: Conclusion statement 12, 13.

Step 3: Conclusion statement 58, 59, 61.

Step 4: Conclusion statement 65, 69.

Strength of recommendation for implementation: 1

Counselling, in the full sense of the word, is only possible if this BPG is implemented. If a trust relationship can be established at the first antenatal visit, pregnant women who experience problems would be more willing to discuss it later on in their pregnancy or thereafter.

Implementation recommendations:

- Ask each pregnant woman who is counselled privately about her circumstances and help her to make informed decisions by considering her circumstances.
- Empower pregnant women with skills to be assertive and to disclose their status to those who they want to inform. Use role-play to let the woman practice how she could break the news.

BEST PRACTICE GUIDELINE 18

Follow-up support is provided for HIV positive pregnant women and pregnant women are made aware of this support.

Sufficiency of evidence: C

Evidence from one step (Step 2) supports this BPG.

Step 2: Conclusion statement 37

Strength of recommendation for implementation: 2

If this BPG is implemented and pregnant women know that support is available to them, should they be found to be HIV positive, they may be more willing to be tested.

Implementation recommendations:

- Invite pregnant women to return for counselling after testing.
- Give guidance and encouragement to counsellors regarding the establishment and maintenance of support groups.
- Allocate money specifically for the establishment and maintenance of support groups at the clinics. Use the money to provide transport, refreshments or material for handcraft activities for the group.
- Ask mothers who coped well with their HIV positive diagnoses to continue to be involved in the ante-natal clinic and to act as support persons for newly diagnosed pregnant women.

BEST PRACTICE GUIDELINE 19

Pregnant women are counselled (and tested) with their male partners

Sufficiency of evidence: B

Evidence from two steps of phase 1 (steps 2 & 4) supports this BPG.

Step 2: Conclusion statement 27

Step 4: Conclusion statement 79, 80, 81.

Strength of recommendation for implementation: 2

If this BPG is implemented it could strengthen the couple's relationship and facilitate behaviour change that could prevent further HIV infection.

Implementation recommendations:

- Encourage pregnant women to bring their partners along to be counselled and tested with them.

- Supply pregnant women with brochures that explain the benefits of testing so that they can study these with their partners.
- Adjust the clinic hours and/or environment to make it more 'male-friendly'.

BEST PRACTICE GUIDELINE 20

Counselling for HIV testing is provided for pregnant women whose HIV status is unknown during labour

Sufficiency of evidence: C

Evidence from the systematic review (step 4) supports this BPG.

Step 4: Conclusion statements 82, 83, 84.

Strength of recommendation for implementation: 1

Transmission of the HIV virus from the mother to her baby during labour can be prevented, even if the mother is only diagnosed as such during labour.

Implementation recommendations:

- Inform all women with unknown HIV status who visit the hospital for the birth of their babies about PMTCT and inform them that they can still be tested for HIV during labour.
- Use a rapid test if the woman gives her consent to be tested and administer Nevirapine to the mother and baby if she is found to be HIV positive.
- Provide the opportunity to be counselled and tested after the delivery when a woman with an unknown HIV status is admitted in advanced labour and is not susceptible to counselling.
- Offer couple counselling and testing if the woman's partner has accompanied her to hospital.

6.4 SUMMARY

In Chapter 6 the process followed to develop the guidelines was discussed. After the logical reasoning that directed the development of the Best Practice Guidelines was explained, the 90 conclusion statements from the first phase (step 1- 4) were

summarised. The conclusion statements from the different steps were then integrated according to themes and twenty BPG's were synthesised from it. The sufficiency of the evidence on which the guideline was based as well as the proposed strength of recommendation for each of the BPG's was then motivated. Finally recommendations for implementation were supplied for each BPG.

In Chapter 7 the final conclusion, evaluation and limitations of the study are discussed. Recommendations for practice, education and research are also provided. Some of these recommendations specifically address the utilisation of the BPG's in practice.

CHAPTER 7

FINAL CONCLUSION, EVALUATION AND LIMITATIONS OF THE STUDY AS WELL AS RECOMMENDATIONS FOR PRACTICE, EDUCATION AND RESEARCH

7.1 INTRODUCTION

In this final chapter the project is completed by stating the final conclusions, evaluating the study with relation to the achievement of the objectives and rigour, indicating the identified limitations and making recommendations for research, practice and education.

7.2 FINAL CONCLUSIONS

In Chapter one the question was asked: why do pregnant women decide not to be tested for HIV, when counselling and testing is available and when knowing their status holds obvious benefits for themselves and their babies?

After considering the data collected in all the study's steps, the following conclusion can be drawn: 'Counselling' for HIV testing is part of the reason why pregnant women may decide not to be tested. The lay counsellors are ill-prepared, ill-supported and have to help pregnant women in settings that are less than ideal settings. They provide health information but not 'counselling'. Since they have a multitude of other responsibilities, registered midwives, abdicate their counselling responsibility to the lay counsellors.

The 2000-2005 HIV/AIDS/STD Strategic plan for South Africa (Department of Health (DoH), 2000b:20) has selected the development of counselling guidelines and training of counsellors as strategies to improve access to HIV testing and counselling in antenatal clinics in 2000. In the follow-up strategic plan, the HIV and AIDS and STI strategic plan for South Africa, 2007-2011 (DoH, 2007:64), one of the strategies to elevate coverage of PMTCT to reduce MTCT to less than 5%, is again stated as the development of a policy and guidelines about VCT in pregnancy that includes consideration of provider initiated testing and frequency of testing during 2007, and then to review these policies and

guidelines annually. At the time when this research was conducted, the specific policy and guidelines were not yet developed and the Best Practice Guidelines developed in this study could make a valuable contribution to the development of the national guidelines.

If the Best Practice Guidelines formulated in this study are implemented, evidence based practice will be realised to the benefit of pregnant women, health workers and the community. In 6.5.2 recommendations are made for the utilisation of the BPG's in practice.

7.3 EVALUATION OF STUDY

The study is evaluated in two stages. Firstly the researcher assesses whether the stated objectives were achieved and then the rigour of the entire study is evaluated.

7.3.1 Evaluation of achievement of objectives

Chapter 1 provided an overview of the study. Initially, the background was sketched and this served as an introduction to the statement of the problem. The study's aim and the objectives stated to achieve the aim, flowed from the problem statement. The objectives were followed by the researcher's meta-theoretic, theoretic and methodological assumptions. The research design was discussed in detail and was followed by an outline of the methodology. The chapter concluded with a discussion on the methods to ensure rigour and ethical considerations.

The aim of this study was to develop best practice guidelines for counselling for HIV testing during pregnancy.

In order to achieve this aim, the following objectives were set:

- To explore and describe the factors that influence pregnant women's decision to be tested for HIV in selected antenatal clinics in the North West Province;
- To explore and describe the factors that influence the counselling for HIV during pregnancy according to counsellors who practice in selected antenatal clinics in the North West Province;

- To explore and describe the current practices regarding counselling for HIV testing during pregnancy in selected clinics in the North West Province;
- To explore and describe the evidence regarding counselling for HIV testing during pregnancy by means of a systematic review; and
- To develop best practice guidelines for counselling for HIV testing during pregnancy.

The process to develop the best practice guidelines was divided into two phases: Phase 1 involved the compilation of evidence in preparation of the development of the best practice guidelines, while Phase 2 comprised of the development of the best practice guidelines themselves. The whole process was divided into steps. Phase 1 included steps 1-4, while Phase 2 consisted of step 5.

Table 7.1 Division of phases into steps that address the stated objectives

Phase 1:	Phase 2:
Compilation of evidence as preparation for development of best practice guidelines	Development of best practice guidelines
Step 1: Exploring and describing factors that influence pregnant women's decision to be tested for HIV	Step 5: Developing best practice guidelines for counselling for HIV testing during pregnancy
Step 2: Exploring and describing factors that influence the counselling for HIV testing during pregnancy according to counsellors	
Step 3: Exploring and describing current practice regarding counselling for HIV testing during pregnancy	
Step 4: Exploring and describing of research studies regarding counselling for HIV testing by systematic review	

The steps followed to achieve these objectives were presented schematically. (Fig 7.1)

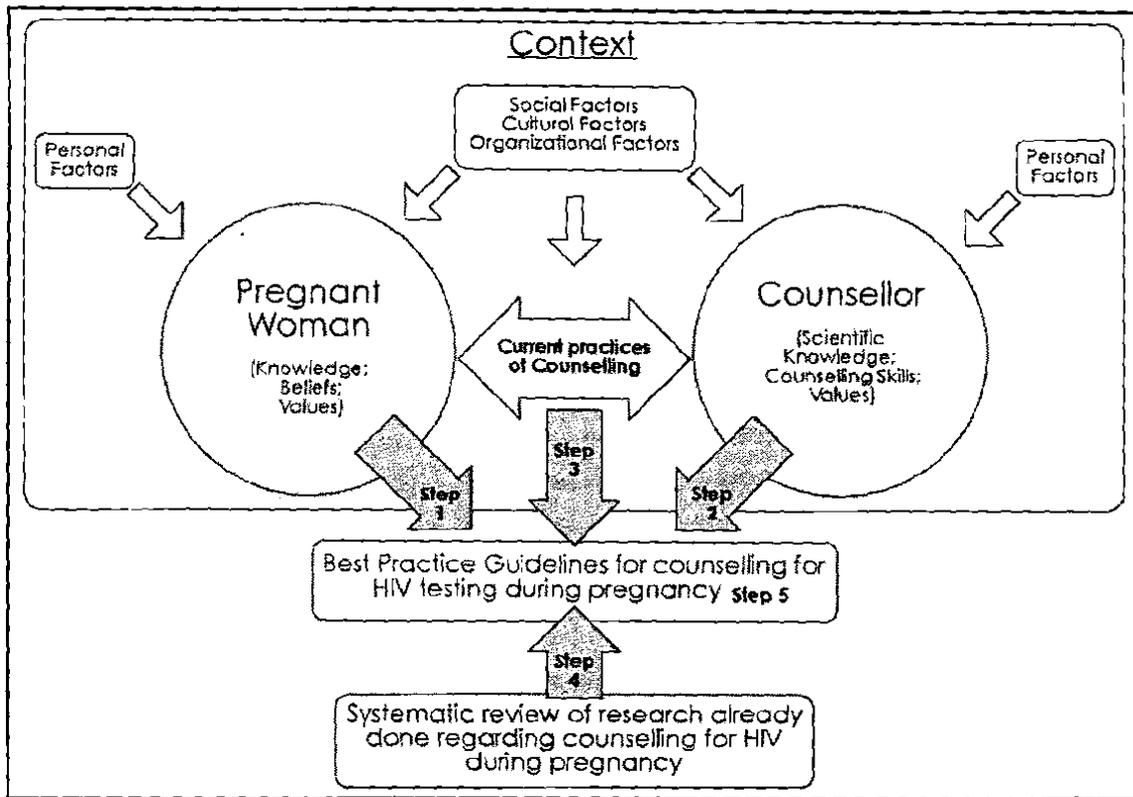


Figure 7.1 Schematic representation of research steps to achieve objectives

- **The first objective was to explore and describe the factors that influence pregnant women's decision to be tested for HIV in selected antenatal clinics in the North West Province**

In Chapter 2 the methods and results of the first step, to achieve the first objective, were discussed.

A step-wise process was followed to sample pregnant women who received counselling for HIV testing and who attended antenatal care at one of the selected clinics. Semi-structured interviews were used to collect data and open coding was employed to analyse the data.

The following themes and sub-themes crystallised during the data-analysis

Table 7.2 Results of Step 1.

Theme	Sub-theme
1.1 Factors that contribute to pregnant women's decision to be tested for HIV	1.1.1 Own decision 1.1.2 Influenced decision 1.1.3 Collective decision
1.2 Factors that contribute to pregnant women's decision not to be tested for HIV	1.2.1 Fear for personal changes if HIV positive 1.2.2 Fear for social changes if HIV positive
1.3 Organisational factors that influence pregnant women's decision to be tested for HIV	1.3.1 Format of counselling and testing 1.3.2 Support 1.3.3 Information 1.3.4 Logistical factors

A total of 18 conclusion statements were formulated from the findings of step 1.

- **The second objective was to explore and describe the factors that influence the counselling for HIV testing during pregnancy according to counsellors who practice in selected antenatal clinics in the North West Province**

The methods and results of the second step, to achieve the second objective were discussed in Chapter 3.

All health workers (midwives and lay counsellors) who counsel pregnant women for HIV in the clinics selected for step 1, who consented to be interviewed for this research, were selected. Unfortunately the final sample included only lay counsellors, as all the registered midwives were unwilling to participate due to their workload. Data-collection was conducted by means of semi-structured interviews and open coding was used for data-analysis.

The following table indicates the themes and sub-themes identified during data-analysis.

Table 7.3 Results of Step 2

Themes	Sub-themes
2.1 Influencing factors regarding the counsellor	2.1.1 Motivational factors 2.1.2 Intrapersonal factors
2.2 Influencing factors regarding counselling	2.2.1 The counselling process 2.2.2 Difficult counselling sessions
2.3 Influencing factors regarding clients	2.3.1 Comprehension of counselling-information 2.3.2 Readiness for counselling and testing 2.3.3 Follow-up after counselling

2.4	Influencing organisational factors	2.4.1 Insufficient support structures for counsellors 2.4.2 Clinic infrastructure and routine 2.4.3 Job insecurity
2.5	Influencing factors regarding the community	2.5.1 Stigmatisation 2.5.2 Negative perceptions regarding the clinics 2.5.3 Practices in community

A total of 30 conclusion statements were formulated from step 2's findings.

- **The third objective was to explore and describe the current practices regarding counselling for HIV testing during pregnancy in selected clinics in the North West Province.**

Chapter 4 discussed this step's methods and results towards achieving the third objective.

A step-wise sampling plan was followed to sample practices regarding counselling for HIV testing. The practices were explored in semi-structured interviews with a representative manager regarding logistical considerations and semi-structured observation of group- and individual counselling sessions. The observation protocol (Appendix 4.1) was developed based on some of the tools developed by the Joint United Nations Programme on HIV/AIDS (UNAIDS) to evaluate voluntary HIV counselling and testing (VCT) services (UNAIDS, 2000:1-56). Data was analysed using abstract thought processes (e.g. introspection, inductive and deductive reasoning).

The following themes and sub-themes crystallised during data-analysis.

Table 7.4 Results of Step 3

Theme	Sub-theme
3.1 Logistical considerations	3.1.1 Hours that the clinics are open 3.1.2 Appointment system 3.1.3 Cost for the client 3.1.4 Infrastructure of clinics 3.1.5 Policy and documentation 3.1.6 Procedure followed during counselling and testing for HIV 3.1.7 HIV tests used
3.2 Content of counselling for HIV testing	3.2.1 Full information about HIV infection in pregnancy and the risk of transmission to the baby 3.2.2 Benefits of knowing one's status and

	<p>interventions available if the result is positive</p> <p>3.2.3 Implications of an HIV negative result</p> <p>3.2.4 Implications of an HIV positive result</p> <p>3.2.5 Benefits of testing together with her partner</p> <p>3.2.6 Implications and benefits of sharing a HIV positive result with her partner</p> <p>3.2.7 Testing is not mandatory and health care will not be denied if she chooses not to be tested</p>
3.3 Counselling skills	<p>3.3.1 Establishing an interpersonal relationship</p> <p>3.3.2 Gathering of information</p> <p>3.3.3 Providing of information</p> <p>3.3.4 Handling special circumstances</p>
3.4 Group sessions	<p>3.4.1 Establishing group relationship</p> <p>3.4.2 Ensuring group participation</p> <p>3.4.3 Providing of information</p> <p>3.4.4 Handling special circumstances</p>

A total of 16 conclusion statements were formulated from the third step's findings.

- **The fourth objective was to explore and describe the evidence regarding counselling for HIV testing during pregnancy by means of a systematic review.**

In Chapter 5, the outcome of the fourth objective was addressed and step 4's methods and results were discussed.

Research evidence was explored by means of a systematic review which included the following steps:

1. formulating a review question,
2. searching the literature systematically for all potential studies and reviewing such studies for relevance,
3. assessing the scientific quality by critically appraising the studies,
4. extracting and analysing the data, and
5. drawing conclusions.

A total of 33 studies, published between 1995 and 2007, regarding strategies to improve counselling for HIV testing during pregnancy were reviewed and critically appraised. Data was then extracted and analysed.

Twenty six conclusion statements, based on the data from the systematic review, were arranged under the following headings:

- Effect of counselling;
 - Quality of counselling;
 - Group counselling versus individual counselling;
 - Ways of offering HIV testing;
 - Rapid testing;
 - Couple counselling and testing;
 - HIV testing during labour;
 - Counsellor factors; and
 - Organisational factors.
- **The fifth objective was to develop best practice guidelines for counselling for HIV testing during pregnancy.**

The final objective was achieved during the fifth step of the research and was discussed in Chapter 6.

The 90 conclusion statements from step 1- 4, were combined according to themes. Twenty best practice guidelines, with recommendations for implementation, were formulated under the following headings:

- Guidelines for creating a suitable community environment for optimal counselling for HIV testing during pregnancy,
- Guidelines related to the clinic create a suitable clinic environment for optimal counselling for HIV testing during pregnancy
- Guidelines to enable counsellors to provide optimal counselling for HIV testing during pregnancy, and
- Guidelines to achieve optimal counselling for HIV testing during pregnancy.

All five objectives were therefore achieved. In the following section the study is evaluated with regard to rigour.

7.3.2 Evaluation of rigour

According to Wittemore *et al.* (2001:530), Lincoln and Guba's criteria (1985:289-311) for trustworthiness are still considered the gold-standard for research done in a natural setting and the researcher decided to use these criteria to self-assess the project.

- Credibility / Truth value

Smith and Hodkinson (2005:917) state that claiming a totally objective point of view on an issue is impossible ("God's eye" point of view). They indicate that, at most, various points of view from different perspectives can be achieved. The strength of this project is that the issue 'counselling for HIV testing during pregnancy' was explored from different perspectives towards compiling evidence for the best practice guidelines. During the first step the emic-perspective of the pregnant women themselves was explored to gain in-depth insight of the factors that influence their decision to be tested for HIV or not. The view from the counsellors' perspective was investigated in the second step when the counsellors gave their opinion on factors that influence counselling for HIV testing during pregnancy. Then the researcher observed the current practices in the third step. In the fourth step a systematic review was conducted to explore existing research to provide the evidence needed to clarify the issue as much as possible.

According to Lincoln and Guba (1985:295) credibility in research, which was executed in natural circumstances, can not be measured against an ultimate benchmark that can be considered true, since there are multiple realities at play. The inquiry must be carried out in a way that will find the probability of the results credible.

In this research various techniques were used to increase the probability of credible findings. The first technique is prolonged engagement. Data-collection was conducted over a period of six months and the researcher has been visiting the clinics for five years in her capacity as advanced midwife and for clinical accompaniment of midwifery

students. She is therefore familiar with the 'culture' and would be able to identify misinformation. She has also been able to build a trust relationship with the clinic staff and members of the community.

Triangulation was used when different sources (pregnant women, counsellors and published research) and different methods (semi-structured interviews, semi-structured observation and systematic review) were utilised. The use of a co-coder during data-analysis of the qualitative data, collected with the interviews, could also be considered triangulation.

A last technique used to strengthen the study's credibility is structural coherence. The researcher strived to ensure the absence of any unexplained inconsistencies between the data and the interpretation. This was ensured by clearly indicating the thought process when drawing conclusions and by combining the conclusion statements to develop the best practice guidelines.

It can therefore be stated that the findings can be considered credible.

- Transferability / Applicability

To ensure applicability the researcher must establish to which extend the particular inquiry would apply to other contexts or to other respondents (Lincoln & Guba, 1985:290). This study is unique because it was conducted by a particular researcher, who interacted with particular participants, in a particular way, in a particular context. To enable the reader to decide if the findings are transferable to his/ her known context, the researcher must describe the theoretic foundation, context and method as clearly and densely as possible (Lincoln & Guba, 1985:298). In this research these issues are described and discussed in detail.

Provision was made for this study to be applicable.

- *Dependability/ Consistency*

According to Lincoln and Guba (1985:290) a study's findings are considered consistent when it could be repeated, should the inquiry be replicated with the same respondents in the same (or similar) context. The authors themselves (Lincoln & Guba, 1985:299) declared that this is impossible to obtain, since it is impossible to 'cross the same stream twice' when research is conducted in a natural setting, as the 'stream' changes. If repeated, this study could possibly yield different results.

The researcher did, however honour consistency by ensuring that the research process is auditable. When this technique is used another researcher can clearly follow the discussion trail that the investigator used. Dependability was further ensured by using appropriate data collection techniques to extract data from a variety of sources. Such sources include field notes, the use of a co-coder and safe keeping of all documents that were used during data collection.

The researcher ensured consistency in this study.

- *Confirmability / Neutrality*

Neutrality is ensured when it is possible to establish the degree to which an inquiry's findings are determined by the respondents and conditions, versus the inquirer's biases, motivations, interests or perspectives (Lincoln & Guba, 1985:290). The researcher did not claim to be neutral, but reflected and declared her assumptions and personal observations that could not be confirmed by other sources (see 1.4; 2.7; 4.7). The reader can decide how the researcher's personal beliefs may have influenced the findings. The dense description of the study's theoretic foundation, context, methods, findings, interpretations, recommendations and audibility also contribute to the confirmability.

According to the researcher's assessment, this research project achieved its aim and objectives in a rigorous way.

7.4 LIMITATIONS

The following limitations were identified:

- The interviews with the pregnant women and counsellors were not conducted by the researcher herself. If the researcher conducted the interviews herself, different issues may have been emphasised, additional data may have been obtained and the data-analysis may have been conducted differently.
- Interviews were conducted in Afrikaans or English and some participants might have found it difficult to express themselves. However, the aim of the study was not to explore the experience of being counselled or counselling, but exploring influencing factors.
- Only lay counsellors were interviewed during Step 2 as none of the midwives were willing to be interviewed. Input from midwives on factors that influence counselling for HIV testing could have added a valuable perspective.
- The best practice guidelines were developed by an individual and not a team as this was done as part of an individual's thesis. If more individuals participated, additionally insights might have produced improved BPG's.
- The BPG's can be considered draft guidelines as it has not yet been validated and tested in a pilot site. Adjustments may be necessary after validation and piloting and additional guidelines for implementation (a tool kit) must still be developed.

7.5 RECOMMENDATIONS

Recommendations are provided for research, implementation in practice and nursing education.

7.5.1 Recommendations for practice

Recommendations are provided for implementation of the Best Practice Guidelines in antenatal care clinics as well as recommendations for management of Health Services:

- After the BPG's are verified and tested at a pilot site (see 7.5.3), it could be implemented on a wider scale. Strategies identified by research must be used for the implementation. The implementation should be well planned and additional implementation guidelines (toolkit) need to be developed. This toolkit could include guidelines for the content of a workshop(s) to inform different role players (managers, midwives, lay counsellors, community members) of the BPG's, brochures, posters as well as the identification, preparation and support of champions.
- Regular evaluation is essential after implementation to maintain high compliance/ performance. Measurable indicators of outcomes must be used (see 7.5.3) and feedback must be given to individuals and services. Evaluation results can be presented on a graph that could be posted on the notice board to act as constant reminder. Incentives for individuals and the clinic as a whole could be included to reward performance at a certain level.
- Midwives who work in antenatal clinics should be reminded of their responsibility to their clients. Even when they are not directly involved in counselling for HIV testing, they must be committed to the counselling. They should also support lay counsellors in any way possible and supervise them conscientiously.
- Managers can be held accountable for the counselling for HIV testing that occurs in the health services that they are responsible for, by evaluating the clinics' performance according to the measurable outcomes in their Key Performance Areas (KPA'S).
- Policy makers need to be informed of the Best Practice Guidelines to ensure wider implementation. This can be accomplished in different ways, for example

presentations during appointments with individuals, presentations at meetings or workshops, sending reports to key persons and electronic communication. Initial communication needs to be followed up.

7.5.2 Recommendations for education

Recommendations for education include:

- Information on HIV in pregnancy and prevention of mother to child transmission must be included in the curriculum of basic midwifery-learners.
- Communication-, counselling- and presentation skills need to be included in the curriculum. This must also be practiced and assessed until learners are found to be competent.
- Practicing midwives' knowledge and skills must be updated regularly during in-service training, workshops and courses.
- Registered nurses and midwives must receive formal education on practical aspects of supervision of counsellors.
- The principles of improving practice by means of research (research utilisation) and searching systematically for evidence to improve the effectiveness of interventions (evidence based practice), need to be integrated in all areas and at all levels of nursing education. Learners and practitioners should understand the need to test all nursing care actions against the best available evidence, considering the practitioners expertise, the patient's values, preferences and individual circumstances as well as the specific context.

7.5.3 Recommendations for research

The following recommendations are provided for research:

- The grading system used to indicate the **sufficiency of evidence** (based on quality and quantity of evidence sources) as well as the **strength of the recommendation for implementation** of the BPG's has not yet been validated. This is planned as a follow up project.
- The final steps in the development of Best Practice Guidelines, namely verification by key role players and testing in pilot sites still need to be concluded before general implementation can be recommended.
- Research is needed to investigate which strategies would be most effective for implementing the BPG's (and promotion of evidence based practice in general). Different strategies are available but these need to be contextualised for local circumstances.
- Research is needed to identify outcomes that could be used as indicators for evaluation of the implementation of the BPG's.
- Both the BPG's as well as implementation strategies need to be tested in other settings in South Africa or similar contexts.

7.6 SUMMARY

In this chapter the final conclusions were stated. The aim, to develop best practice guidelines for counselling for HIV testing during pregnancy was achieved. All the objectives were achieved, as described in the various chapters. Self-assessment, conducted according to the criteria of Lincoln and Guba (1985), found the study to be executed rigorously.

The evidence from the first four steps provided different perspectives on counselling for HIV testing during pregnancy. The conclusion statements of four of the steps (including evidence from semi-structured interviews and observation) were used to develop the best practice guidelines, in addition to the evidence obtained by the systematic review.

Finally the study's limitations were stated and recommendations were formulated for research, practice and education.

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APPENDICES

Appendix 1.1

Approval from the Ethics Committee of the North-West University



NORTH-WEST UNIVERSITY
YUNIBESITHI YA BOKONE-DOPHINAMA
NOORDWES-UNIVERSITEIT

Mrs C S Minnie
Internal Box 520
Potchefstroom Campus
North-West University

Ethics Committee
Tel (018) 299 2564
Faks (018) 297 5308
E-Mail Ethics@nwu.ac.za

15 May 2007

Dear Mrs Minnie

APPROVAL FOR EXPERIMENTING WITH HUMANS (QUALITATIVE RESEARCH)

Hereby I wish to inform u that your project with the title "HIV testing during pregnancy" has been approved on 8 December 2004 with a project number 04K26.

Please use the number mentioned in paragraph 1 in all correspondence concerning the above mentioned project. Also note that it is expected from project leaders to complete an annual report in June which will be send to the Research Ethics Committee regarding ethical aspects as well as publications produced from the research.

Approval is valid for 5 years (according to a Senate Decision on 4 November 1992, art 9.13.2). For the continuing of projects after the expiring date of the project, new approval is needed for the project.

We wish you all the best with your research.

Kind Regards

RONEL PIETERSE
SECRETARIAT

INSTITUSIONELE KANTOOR
• Privaatsak X6001 • Potchefstroom • Suid-Afrika 2520 • Tel: (018) 299-1111 • Faks: (018) 299-2799 • <http://www.nwu.ac.za>

Appendix 1.2
Permission from the Department of Health of North West Province



North West Province

NORTH WEST DEPARTMENT OF HEALTH

Healthy Living for All



Republic of South Africa

3rd Floor Tirolo Building
Dr Albert Ludluf Drive
Mafikeng, 2745
Private Bag 22025
MMASAT-10, 2725

OFFICE OF THE DDG

Gen: K. Mangonyane
Tel: (018) 387 5833/6
Tel: (018) 387 5816
o2@nwde.org.za
www.nwdehealth.gov.za

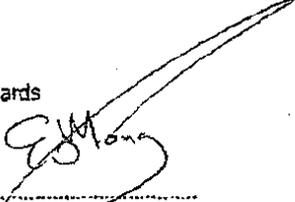
29 August 2005

Ms C.S Minnie
North West University(Potchefstroom Campus)
North West Province

SUBJECT: Approval for Research: HIV Testing in Pregnancy in the North West Province

Approval is granted to conduct the above study in the North West Province, kindly make relevant arrangements with the management for suitable dates and times. Detail at the bottom of this letter has to be completed by you and returned to the Knowledge Management Directorate before your study may commence.

Regards


O. Mongale
NWDOH Head of Department

The NWDOH will be furnished with final research report by

31/5/2007
Submission date of the final report

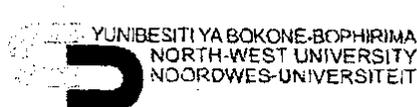

C.S Minnie

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Page 1

30/11/2005 

Appendix 2.1. Letter to Sub-District Manager

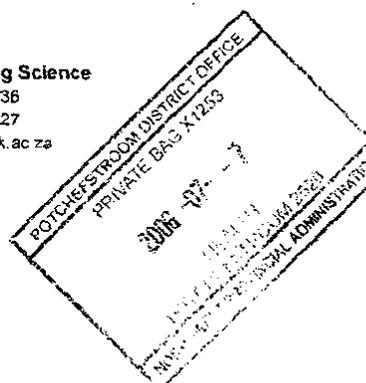


YUNIBESITHI YA BOKONE-BOPHIRIMA
NORTH-WEST UNIVERSITY
NOORDWES-UNIVERSITEIT

Ms A Mohutsioa
The Manager
Sub-district: Potchefstroom

School of Nursing Science
Tel: (018) 299 1836
Fax: (018) 299 1827
e-mail: vpkcsm@puk.ac.za

07 July 2006



Dear Ms Mohutsioa

RESEARCH AT ANTE-NATAL CLINICS

I am a PhD student (and lecturer) at North-West University (Potchefstroom campus). I am the project-leader of a National Research Foundation -sponsored project on HIV testing during pregnancy. I have already received permission to do the research from the Ethics committee of the Potchefstroom campus of the North West University and the Research office of the North West province. (Letters attached)

This part of the project focuses on the development of best practice guidelines for counselling for HIV testing during pregnancy. I plan to collect data for the first three steps of the research project.

- Semi-structured interviews with pregnant women regarding factors that influence the decision to test for HIV;
- Semi-structured interviews with counsellors (lay counsellors and registered midwives) regarding factors influencing the counselling for HIV testing during pregnancy;
- Observation of current practice regarding counselling for HIV testing during pregnancy.

I plan to use a variety of clinics offering ante-natal services as data-collection sites. Which clinics would you recommend in the Potchefstroom sub-district as examples of clinics with a high uptake and a low uptake of testing? I plan to do the data-collection from 14 August 2006 and will contact the clinics for arrangements as soon as I heard from you.

The research protocol is attached for your information. I can be contacted by e-mail or telephonically on my cell phone.

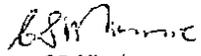


POTCHEFSTROOM CAMPUS
Private Bag X6001, Potchefstroom, South Africa, 2520
Tel: (018) 299-1111 • Fax: (018) 299-2799
Internet: <http://www.nwu.ac.za>



In accordance with section 23(1) of the Higher Education Act, 1997 (Act No. 101 of 1997), as amended, the Potchefstroom University for Christian Higher Education and the University of North-West merged to form the North-West University on 1 January 2004. In accordance with section 24(1) of the Higher Education Act, 1997 (Act No. 101 of 1997), as amended, the staff and students of the Sothoeng Campus of the Vista University were incorporated into the North-West University on 2 January 2004.

Yours sincerely



Mrs CS Minnie
Senior Lecturer: Midwifery

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Appendix 2.2 Permission from Sub-District Manager



North West Province

Private Bag X1253
Potchefstroom
2520

Healthy Living for All

**Potchefstroom
Sub-District Office**



Republic of South Africa

Tel: (018) 297 5062/3/4/5
Fax: (018) 294 4508

Enquiries: Ms Mofutsa
Reference:

Ms C. S. Minnie
North West University (Potchefstroom Campus)
North West Province

SUBJECT: PERMISSION TO CONDUCT RESEARCH AT ANTE NATAL CLINICS

Your letter regarding the above mentioned matter has been received. Permission is thus granted for you to access our facility to conduct your research project.

Since that you plan to use a variety of clinics as data collection sites, my recommendation would be that you personally meet with our Assistant Director for Community Health Services Mr Phillip Ledimo who will assist you accordingly and serve as an entry point his numbers are 083 4119814 or (018) 297 5062

It would be greatly appreciated if the results can be communicated with our District Research committee lead by Dr Claire van De Venter.

Sub District Manager

19 July 2006

Appendix 2.3 Information letter and consent form for pregnant women

Dear participant

I am a PhD student of the Potchefstroom-campus of the North-West University. You are invited to participate in a research study regarding counselling for HIV testing during pregnancy.

The Nature and purpose of the study

The purpose of this study is to develop best practice guidelines for counselling for HIV testing during pregnancy. You are asked to participate in the phase of the study that entails interviews with pregnant woman.

During the interview you will be asked to give your opinion about factors influencing pregnant women in the decision to be tested for HIV or not. The interview will be conducted at a time and venue most suited for you. It can be done at the clinic while waiting or after your consultation in a private room or at your home if you prefer. It will last about 30 minutes. Your permission is also asked to record the interview to be transcribed and analysed afterwards. The recording will be locked away in a safe place and the final reports will not be traceable back to individual participants.

Approval to do research

The protocol of this study was submitted to the Ethics committee of the Faculty of Health Science of the Potchefstroom Campus of the North-West University and approval has been granted. The provincial authorities and the person in charge of the clinic are also aware of this research being done in this clinic.

Risk or discomfort involved.

An experienced interviewer will conduct the interview and it is not foreseen that you will experience any discomfort although the sensitivity of the topic is acknowledged. If you experience any psychological discomfort professional counselling will be available after the interview.

Possible benefits of this research

The interview may be of therapeutic value to you because of the opportunity to get clarity on your decision to be tested for HIV. Your contribution will add to the knowledge of and insight into the factors influencing pregnant women's decision to be tested for HIV or not. This will contribute to the formulation of best practice guidelines to improve the counselling women receives. These guidelines may be to the benefit of patients, health workers as well as the community as a whole.

Right to withdraw

Your participation in this research is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. There will not be discriminated against you if you prefer not to participate.

Confidentiality

Any information that you supply will be kept strictly confidential. The results will be published or presented in such a fashion that all participants will remain unidentifiable.

Information

If you have any question about the research you are welcome to contact the researcher, Mrs. CS Minnie at telephone XXXXXXXX. You are also welcome to indicate on the attached document if you would like to receive a report of the study after it has been completed.

CONSENT TO PARTICIPATE IN THE STUDY

I have read the above information before signing this consent form. The content and meaning of the information is clear to me. I have been given opportunity to ask questions. I understand that if I do not participate it will not be to my disadvantage. I hereby volunteer to take part in this study.

Participant's signature

Person obtaining informed consent

Witness

Date

VERBAL PARTICIPANT INFORMED CONSENT

(For patients who cannot read or write)

I, the undersigned, have read and have explained to the participant, named, the patient information letter, which has indicated the nature and purpose of the research in which I have asked the patient to participate. The explanation I have given included both the possible risk and benefits of the research. The participant indicated that she understands that she will be free to withdraw from the research at any time for any reason.

I hereby certify that the patient has agreed to participate in the research.

Participant's name

Person obtaining informed consent

Witness

Date

Participant's particulars for feedback regarding the research

I would like to receive a report of the research: "Best practice guidelines for counselling for HIV testing during pregnancy", after it has been completed.

Name:

Address:

Appendix 2.4

Example of a transcript of an interview with a pregnant woman

I: Interviewer

P: Participant

I: XXXXX, thank you very much for participating in this interview. I want to ask you first how old are you?

P: 33

I: 33?

P: mm

I: And how far are you pregnant?

P: 5 months.

I: And do you have other children?

P: mm

I: How old are they?

P: 9 and 7

R: Good family planning today (lag) we this is nice spaces (lag) ja

I: And uhm do you work?

P: Yes

I: What type of work do you do?

P: General assistance

I: Where

P: ****

I: Say again?

P: ***

I: Ok

R: O by die ***** ahh!

I: You are a colleague of ours. We are from the nursing department. And uhm XXXXX are you married?

P: Mmeh I am not married.

I: Ok but you have the same partner for the other children?

P: Yes

I: Ok and are you Tswana?

P: Tswana

- I: Nou XXXXX, I wants to ask why do pregnant women that receive HIV counselling not going for testing what can we do to make it better so I want to ask you today what do you think are the reason influencing women that they don't go for testing?
- P: I think they are scared, stressed up.
- I: Scared and stressed up about what?
- P: About the results.
- I: Why?
- P: Might be positive.
- I: Ok
- P: And me also I was scared I go only for the baby I didn't if I was positive what I am going to do I think it's the question of scare.
- I: So you where very scared?
- P: Yeh
- I: Uhm did do you think that's one of the reasons why people don't want to go for the testing?
- P: Mmm Ee sometimes I think miskien the person that counselling miskien she she...
- I: That maybe she's going to tell maybe some friends of her, understand?
- P: So you are scared. Some of them are are uhhh neighbours our neighbours yeh something like that.
- I: So you are not quite sure about how safe the information is kept here?
- P: Yeh because our ..our friends I know they are most of them they are positive we we you get that information from the other one the other one mm I think that's the reason.
- I: Any other reason why women receive counselling but don't want to come for the test?
- Silence
- P: I think it's the question of scare.
- I: So you think the most important reason is they are scared?
- P: Mm yeh
- I: Of the results?
- P: Yeh

- I: Of hearing the results and then they are also scared of that the information will not be kept safe here it will around into the streets and people will know about?
- P: Yeh
- I: Why is it bad?
- P: Sometimes I don't know you don't want the person your friend or your mother or your parents you're your family to know it about to know about it mm you will tell them if you are ready to tell them mm.
- I: And why are they afraid of hearing to have the virus?
- Silence
- P: Eish it's difficult
- I: Is it a difficult question for you, why do you think people are afraid to hear they have HIV?
- Silence
- I: Let me ask it in another way. Why were you afraid to go for the test ?
- P: You see me I have 2 children I must take good care of them so when they tell me I am positive everything will change everything!! You see?
- Silence
- P: I'm I'm not going to be free like I'll always be free. I'm going to be maybe not going out you see those things I think so.
- I: So you don't want to have that burden?
- P: Yeh ja Everything will change today if I was positive yeh I think everything will change I was going to ask myself many questions mm.
- I: And XXXXX, do you think the counselling that they give here to the women is good?
- P: Yeh
- I: What type of information do they give you?
- P: We are going to get nevaripine and after that you know the thing that I am not sure about anti-retroviri I don't know why you should give the people the anti see that's just when you are positive eethey can give you that treatment but they they want to give you if you are sick I think it's that.
- I: So that something you don't understand?
- P: Yes why why should they give you if you are sick and you take it it takes time to recover that illness mm.
- I: After the interview XXXX will be able to explain it to you.

P: Mm

I: Ok

P: And uhm ... If miskien if there were testing me positive I am going to give this and this now and it will be alright again I will I will never be stressed you see...

I: So when you get the counselling do you get scared when you hear the counselling.

P: Ee do you want to test I ask you what if come negative what if it come positive. What am I going to do to tell my parents or my children or my friends.

Silence

P: What is going... The world is going to be black that is something!

I: And you have all these questions in your head do you get any support here?

P: I didn't said that I have many questions I said ok I'll get tested I will test

I: So you had good news today? Are you glad you you had the test?

P: Yes but I was scared first

I: Ye

P: The test I was scared.

I: What made you decide ok I'll do the test even if I am scared I want to do the test?

P: The sake of the baby.

I: So dit is that is hoekom you heard they can do something for the baby did you hear it at the clinic or is it something that you heard on the radio or the tv.

P: yeh the radio and the tv.

I: so you know about the things like nevaripine and things like that so you think it's a good thing that pregnant women knows her status for the baby's sake.

P: yeh for the babies sake.

Silence

I: Do you think there are other reasons beside counselling, why the people don't want to go for the test? Besides being afraid. Do you think pregnant women have other reasons?

P: I don't think so... I don't think so because I am talking about it with my friends and they told me yo I am scared what if they will become positive what am I going to do what I am going to tell my parents something like that.

- I: When .. when the counsellor give the information to all all the people uhm do they tell you what to do if you are scared or what to tell your family how to go back and tell your family.
- P: Yes she ... she told me you can to pick one of your friends or one person whose can discuss this with that person.
- I: And your you decide to go for the test although you where scared?
- P: Yeh
- I: Because you you were informed that it will be good for the baby (yeh) to take nevirapine (yeh).
- P: If I was not pregnant I was not going to do the test.
- I: Yes ja so if you wouldn't forced in the clinic to be part of the getting the counselling going into the system of counselling and sitting in a row you wouldn't have done the test.
- P: Yes
Silence
- I: Do you think its good for pregnant women to go for testing?
- P: Ja I think so.
- I: Why?
- P: For the sake of the baby after one you have a baby miskien hy sal siek word or something maybe you'll never know what ... what is the causes of that sickness so I think they must be tested.
- I: Do you think its good for women that is HIV negative to go for counselling and testing.
- P: Askies? (Sorry?)
- I: Do you think it's good for pregnant women that is HIV negative to also go for counselling and testing?
- P: Yeh
- I: Why?
- P: To see whether your status is there you are still negative or you are positive things are the same.
- I: Did the counsellors talked to about how to stay negative?
- P: Mmuh – no.
- I: How to prevent en to get positive?
- P: She didn't told me but I know.

- I: You know about it. But XXXX, you think they main reason is because people are afraid.
- P: Yeh they are afraid.
- I: They are afraid of the changing message in getting that results your whole life will change.
- Silence
- I: And you also said stressed out?...
- P: And the minute you get the results your positive I am going to be stressed you are going to be sick that moment ja many many many people my friend also was positive and she didn't she didn't test she died after a week she died and she hasn't except it that she was positive she didn't tell anyone but the other day when I was at home I saw the the (silence) the counsellor go to her home so I go to her I asked her she visited her for what she didn't she wasn't checking on her.
- I: So because the counsellor went you knew that she had HIV (ja) don't you think that's also a reason why people don't want to come for testing they associate the counsellor...
- P: I am not sure the other person or the other neighbours know know that man, but I I know that man he goes around with that car after her baby died so I think it's the family that.
- I: If she told you that day she is positive how would you would you be kind to her and help her or would you also tell your friends you know what...
- P: No no I would talk to her and tell her its not the end of the world you see things are happening on we are living on I would talk to her nicely.
- I: And that's why people are afraid to disclose that at the end support will help them?
- P: Yeh, I was also scared ne that you know what you have 2 kids and its not the end of the world accept it if I was positive I talked those things in my head I am going to accept it I am going to go on with my life something like that. You know its going to be shock at first (ja). It's not easy to accept it.
- I: And the counsellors at the clinic the service you get at the clinic that's good they are kind to you and help you and...
- P: Yeh (Silence)
- I: So at the end you still feel the main reason is they are scared...
- P: Yeh

I: of hearing hearing the diagnosis that they'll become ill sooner that they are stressed out about it. It will also make them sicker quite quicker...

P: Yeh

I: and they are afraid that they don't know how safe that information...

P: Yeh

I: is with the counsellors...

P: Yeh

I: the counsellors are associating with AIDS

P: uhmm

I: Do you know of counsellors that will tell neighbours or friends that I saw her at the clinic I know she is positive. Do you know of counsellors in the town in the township that talks like that?

P: I don't know them but my neighbour ne mm that man is working there at the hospital. So we are afraid to go to the hospital because my neighbour is working there, he is working with the test results. Ee I can't go to the hospital because I know my neighbour is working there he is going to he is a man he is he is going to look.

I: So you thinks sometime people are going to another clinic it's not the clinic where people know them. If you stay next to top city you go to XXXXXXXX clinic.

P: Something like that and I want to be tested by white people because they don't know... something like that

I: Ja its not someone you going to see in the street again (yeh)

I: Anything else you want to add?

I: If you can make a suggestion to the government help to make counselling make better for pregnant women what will you suggest?

P: (Sigh) If I just think they must get someone from XXXX who doesn't know me or from XXXX the person that doesn't know us or the white person cause she doesn't know us ja nie my neighbour nie.

I: And what else?

P: About ee about the status ne. They must give the person the anti now the sick one that must be the person if they find right now when they find out they positive when your still strong your body fighting your not weak because when your weak they take the time to combat with you immune system e I think they must give it when they find your positive you must be give the anti...

- I: And do you do you think there is any recommendations you want to make about the information that they give in HIV counselling?
(Silence and en sigh)
- P: What is the meaning of recommendation?
- I: Do you think do you want do make any suggestions to make counselling better for patients?
- P: (Sigh) I think this one is better they counsel me very well the way they counsel me today was a nice way this how I feel.
- I: When you were so very scared, did she talk to you nicely she talk nice to you not to make you scared (ja) try to make you a bit comfortable?
- P: And also she want to make me comfortable.
- I: Where you scared yesterday when you think of trying tomorrow?
- P: Yeh even even in the morning when I was coming joh!
- I: You were not she scared of the blood pressure or anything else or you worry about the HIV?
- P: mmuh
- I: So now you're going to have good afternoon. XXXXXX, Thank you very much
- P: Thank you.

Appendix 2.5

Example of field notes of an interview with a pregnant woman

Observational notes

21 yrs of age, unemployed, first pregnancy. 36 weeks pregnant, speaks Tswana and had completed grade 12. Participant keen to talk, speak English well, kept eye contact. Used staff room for interview, sat at table and relatively private but lots of interruptions and environmental noise.

Personal notes

I felt comfortable and like this participant. I think we are nearing data-saturation.

Methodological notes

Used reflection, exploring, reflecting and regular summaries. It was easy to keep to the aim as participant was keen to discuss the topic. Fear for a positive diagnosis and readiness for testing were main themes in this interview.

Appendix 3.1 Information letter and consent form for counsellors

Informed consent of counsellors to be interviewed

Dear participant

I am a PhD student of the Potchefstroom-campus of the North-West University. You are invited to participate in a research study regarding counselling for HIV testing during pregnancy.

The Nature and purpose of the study

The purpose of this study is to develop best practice guidelines for counselling for HIV testing during pregnancy. You are asked to participate in the phase of the study that entails interviews with counsellors – both lay counsellors and registered midwives.

During the interview you will be asked to give your opinion about factors influencing the counselling of pregnant women regarding HIV-testing. The interview will be conducted at a time and venue most suited for you. It will last about 30 minutes. Your permission is also asked to record the interview to be transcribed and analysed afterwards. The recording will be locked away in a safe place and the final reports will not be traceable back to individual participants.

Approval to do research

The protocol of this study was submitted to the Ethics committee of the Faculty of Health Science of the Potchefstroom Campus of the North-West University and approval has been granted. The provincial authorities and the person in charge of the clinic are also aware of this research being done in this clinic.

Risk or discomfort involved.

An experienced interviewer will conduct the interview and it is not foreseen that you will experience any discomfort although the sensitivity of the topic is acknowledged. If you experience any psychological discomfort professional counselling will be available after the interview.

Possible benefits of this research

Although you will probably not personally benefit from this research, your contribution will add to the knowledge of and insight into the factors influencing counselling of pregnant women regarding HIV-testing. This will contribute to the formulation of best practice guidelines to improve the counselling women receives. These guidelines may be to the benefit of patients, health workers as well as the community as a whole.

Right to withdraw

Your participation in this research is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. There will not be discriminated against you if you prefer not to participate.

Confidentiality

Any information that you supply will be kept strictly confidential. The results will be published or presented in such a fashion that all participants will remain unidentifiable.

Information

If you have any question about the research you are welcome to contact the researcher, Mrs. CS Minnie at telephone XXXXXXXXXX. You are also welcome to indicate on the attached document if you would like to receive a report of the study after it has been completed.

CONSENT TO PARTICIPATE IN THE STUDY

I have read the above information before signing this consent form. The content and meaning of the information is clear to me. I have been given opportunity to ask questions. I understand that if I do not participate it will not be to my disadvantage. I hereby volunteer to take part in this study.

Participant's signature

Person obtaining informed consent

Witness

Date

Participants particulars for feedback regarding the research

I would like to receive a report of the research: "Best practice guidelines for counselling for HIV testing during pregnancy", after it has been completed.

Name:

Address:

Appendix 3.2 Example of a transcript of an interview with a counsellor

I: Interviewer

P: Participant

I: Thank you very much, we are recording now this interview and I want to thank you for participating. I want to ask you in your opinion, what factors influence the counselling for HIV testing of pregnant women?

P: They don't want to do the test.... Anyway, the patients that I have worked with, they all want the tests.

I: All of them want?

P: They all want to do the test. Because I just give them the options, and it is up to them to choose that they want the test or they don't want the test. It is for their best interest to do the HIV, because we've got this thing, which they call Nevirapine. Nevirapine helps the baby. The babies do not test for the virus, but the mother they have the virus. .. but it is not 100%, because some babies they do get the HIV virus while they got the Nevirapine.

I: So according to you, you try to give them all the options, but you accentuate the benefit, the importance of the medicine.

P: Yes, I do give them the importance and the advantage and the disadvantages of the test.

I: And do you experiencing then that some of the women are reluctant and afraid to go for the testing or do they go immediately after the counselling?

P: Some they don't go immediately. They have sort of.... and sometimes they are afraid. You just leave them as it is and give them time, maybe at the next visit they will tell you that they want the test. They just go home and think and think and then

I: How do you know which woman received counselling and will come back? Do you have any kind of record or documentation on these patients?

P: Now if you want the tests, we give you the consent form and you sign for us, but if you don't want these tests, on your card we do write that, that you don't want to test. You just go to think and you come at the next visit.

I: And how do you experience being an HIV counsellor?

- P: How do I experience? I don't know what can I say, but being an HIV counsellor, I am proud of myself. I pick up so many, I meet so many people, they even come to me and say thank you.
- I: How did you become an HIV counsellor?
- P: I've been training at a school at so, Life Line they came to our school and give us the training, so that is why I've been in HIV training.
- I: Okay, so you personally felt compelled to be an HIV counsellor (Ye) and is it difficult?
- P: You know, it is very difficult, the first time....
- I: Why?
- P: People crying to you..... crying, crying What do you do as counsellor? . You know I am the counsellor, I don't have to cry with the patient and I don't have to feel shame with that patient. Anyway, it is not good to be a counsellor, because when it is tjaila time, you are just going to sit at home and think about a person..... it is good, but sometimes it is not good being a counsellor.
- I: So it really affects you as a person.
- P: Yeah, sometimes it affect me ... but if we just do this ... what can I call it, the in the brief...?
- I: Debriefing.
- P: Debriefing. I think we can, we will be okay, debriefing.
- I: Do you get any debriefing here?
- P: No.
- I: No support is giving to the counsellor?
- P: No.
- I: And you have a need for debriefing?
- P: Yes, and we have a need for debriefing.
- I: Do you think there is any reason on the clinic's side that patients don't want to want to do the test?
- P: I haven't.....
- I: Aspects like for example travelling far, sitting in a queue.
- P: Some they are staying far from the clinic and they just come early and for anything you just have to queue.... There are so many people and they have to queue and it is a long process. They have to go to the sister, and then the sister will come and ask us to do the counselling. After doing counselling they have we do

counselling and they have to go back to the sister to prick them and to treat them and it is a long process. And some they are... what can I say? They are not patient, maybe because of the long process, because there are so many people.

I: Okay,, but that all could be very exhausting for you.

P: Yeah, for me it is. Because, here, we don't have our room for counselling. We just use the administration room and then we counsel at this room and then if the sister comes, I have to go back and I have to leave here with the patient.

I: So there is no room here for the counsellor, private and comfortable where you can be confident. Where you can do your counselling. You have to move with the patient.

P: Yeah. We ask the patient to get in here and we have to come here and I have to go out again and see the patient and I can come back again and gave him counselling.

I: And what is the best part of HIV counselling?

P: The best part is pre- and post counselling.

I: Both of them?

P: Yeah, both of them.

I: And the worst thing of being a counsellor?

P: The worst thing of being a counsellor is that you are stressing about people's problems. You are taking people's problems, you are making it yours.

I: So, the worst thing for you is the fact that your work is affecting you as person and at the end of the day when you leave the clinic you are still affected by it.

P: Ya. That's why I need debriefing.

I: And do you ever voice these stress to any of your seniors?

P: Yes, I do talk to my seniors, I am working

I: I want to know, I am a therapist, but I am not a HIV counsellor. Basically, what do you tell your patients?

P: What do I tell them? Em...I tell them to accept themselves if the results come, they have to accept themselves. If you have accepted yourself, you don't have..., you are going to face the problem, you have accepted your past and you are going to lead a normal life. You don't have to change your life like, you are not going to sit at home alone, lonely, you have to think how did you get HIV. This HIV virus. You have to accept yourself. If you have accepted yourself and use medication daily

you are going to have a normal life like anyone who is not HIV positive. So you have to live a normal life and accept your problem.

I: And do you feel that the patients understand what you are telling them?

P: Yeah, they do understand. Because, I am speaking to them in their language. They do understand me.

I: Just to summarize, and then we can go on. I asked at the beginning and we talked about it - in your opinion why do you think pregnant women receive HIV counselling but don't accept testing? and according to you, you tried to give them options but you focus on the importance of the benefits of HIV and the treatment available for HIV pregnant women and according to you most of the patients do go for testing and those who feel that they want to wait, you write on the file the patient, they do not want to test now, but will come back again when they are ready and you don't pressure them?

P: You don't have to pressure them because it is voluntary. If the patient says I don't want to go, I don't have to pressure him or her. So I have to leave her and think about it and she will back if she comes back.

I: You also gave me some physical or practical information about the clinic, you said that you have a need for debriefing or support which aren't available at the clinic although you really enjoy working at the clinic. You have to move between cubicles. You don't really have a place. The counsellors do not have their own office or a private comfortable place, where the patients come in and they can be quite exhausting. But still you can voice these complaints to your supervisors.

P: The problem is the building is too small. We've got only five cubicles and the sisters are inside them. There are still people at the cubicle. So they don't have any space because the thing is too small. They can't do anything. But it is okay, we are used to working like this.

I: You have adapted in other words.

P: We don't have any problem anyway. Maybe they will build a clinic, then we have our own counsellors room, like at the (Clinic A) clinic. At the (Clinic A) clinic, their thing it is so big they have their own counselling room. We are working happily ever after. We are so, I am so happy here because if I have a problem, I go to the other sister and tell her this and this and if I don't understand this problem with my patient I just can go to the sister and ask what can I do with the patient, you know? I love them.

- I: But there is good collaboration between you as a counsellor and the sisters.
- P: Yeah, good communication, good.
- I: Do the sisters also do HIV counselling?
- P: Yeah, if you are not in, they are doing HIV counselling, because we have been struggling because of our salaries it is now for 3 months and they have been working for 3 months and they've been doing their jobs.
- I: And you also said to me that you want to be a HIV counsellor and its been a good experience for you although it does affect you personally. When you leave at the end of the day, do you feel that you were a help for other people?
- P: Especially the couples. Sometimes a woman is positive, but her husband is negative. If they are getting at home, you think what is going to happen, are they going to what are they going to do to herThat goes through the counsellors mind You will just wait for the womanthe woman is positive. That one I can't accept
- I: A lot of painful real life scenarios that you have to cope with.
- P: Yeah, especially the couples. This thing of the couples.
- I: Is it something that you have to do often?
- P: No, not often.... It just happen sometimes.
- I:, you have a great sensitivity for couples and I might be wrong, for woman or for men and women
- P: Pardon?
- I: Do you feel very sorry for woman?
- P: I don't have to feel sorry for my patients. for my clients and they will think this counsellor is weak. She can't talk to me. They will just go to another clinic. And I don't have to show them that I am sorry for them, I will just have to go at a private room and I will have to stay there. I don't have to show them that I am sorry for them.
- I: So the view that they must have is is in control.
- P: Yes, complete control. I have to be in control. I don't have to cry in front of the patient. Just because you are crying, I don't have to cry. I will just give you a glass of water to comfort you but I don't have to cry, I don't have to show that I am sorry for them
- I: And how do you support your patients?
- P: How do I support my patients? I am supporting them, giving them information

Appendix 4.2

Information letter en consent form for observation of counselling sessions

Dear participant

I am a PhD student of the Potchefstroom-campus of the North-West University. You are invited to participate in a research study regarding counselling for HIV testing during pregnancy.

The Nature and purpose of the study

The purpose of this study is to develop best practice guidelines for counselling for HIV testing during pregnancy. You are asked to participate in the phase of the study that entails observation of counselling sessions.

During the observation the counselling session will continue as usual, while the researcher will observe and record all occurrences.

Approval to do research

The protocol of this study was submitted to the Ethics committee of the Faculty of Health Science of the Potchefstroom Campus of the North-West University and approval has been granted. The provincial authorities and the person in charge of the clinic are also aware of this research being done in this clinic.

Risk or discomfort involved.

An experienced interviewer will observe the sessions. In case of language differences a trained research assistant who will act as interpreter will also attend sessions. They will be as undistruptive as possible during the counselling session and are bound by ethical restrictions to uphold confidentiality of all personal information that they become aware off.

Confidentiality

Any personal information that may become known to the researcher will be kept strictly confidential. The results will be published or presented in such a fashion that all participants will remain unidentifiable

- I: In your opinion, the nursing sisters are they keeping the patients HIV results confidential?
- P: Yeah, they do know how to keep a secret. Even if you are my mother, you came with me and I am ill, very, very ill, you don't have to, if I think I don't want my mother to know my status and if the patient come with someone, we ask the patient do you want your mother to know your status. If the patient says no, she really means it, then we have to tell the mother to wait outside and we are seeing the patient alone if she says no.
- I: At the beginning before we started the interview you said to me how busy you are counselling. What type of assistance do you want to see
- P: I just want to,... I only want to get more information about HIV and AIDS We talk from our old counselling but we need more training and we have a problem of stipends anyway, so the last three months we were not working, because we were struggling. You can't come to work, you don't have food, you don't have you don't have anything, so why do you have to come because you need money, we have children. We have to put food on the table for our children We don't get anything so we need help, we really need help.
- I: You are playing such an important roll. At this stage a lot of patients need counselling, but then you also want to get money for it on a continuous bases and you really have a need for follow-up training and debriefing. So finally, do you at the end feel that most of the women here do go for testing, they get sufficient counselling, they understand the counselling and in the counselling the focus is on the benefits of knowing your HIV status and if patients don't want to do the test, then you have a system that they can get back.
- P: Yes, We have a system that they can come back, we are telling them,..... which you don't have to tell, your baby is going to suffer from this and this. That's why they are here for the counselling and if she doesn't understand she come back too. What was this and this and this and how can we do and what can I do. Then I just give them the information and the information they need too much.
- I: And then you also said that information is the way you support your patients. You empower them with information.
- P: Ya.....

I:, Thank you very much. It was a very insight interview for me. I think it was a good starting point and I really appreciate that. I want to confirm to you in this recording. That the recording will be handled anonymous and confidential and the researcher will publish her report. Okey .Good luck with your hard work.

Appendix 3.3 Example of field notes of an interview with a counsellor

Observational notes

Female, 24 years old, unmarried, no children, black. She did a Love Life course in HIV counselling.

The participant is well groomed and gives a good first impression. We sat in a nursing cubicle as there wasn't any room or office in the clinic for the HIV counsellor. Privacy was confirmed and the counsellor was comfortable. On my arrival she complained of tooth ache, I provided pain tablets to the counsellor and confirmed that she was willing and able to participate. Written consent was given.

Personal notes

We were able to have a good and in-depth conversation in English. It felt to me as if the counsellor was a bit immature for her occupation and she didn't know how to support patients on a deeper level. It did seem as if the counsellor enjoyed being a counsellor and that she found meaning and purpose in this occupation.

Methodological notes

Started with single open-ended question but progressed later to more close-ended questions but good response. Good rapport was established early in the interview.

Appendix 4.1

Observation Protocol for data-collection of current practices regarding counselling for HIV testing during pregnancy

(This observation protocol is based on a selection of the tools included in the document: "Tools for evaluating HIV voluntary counselling and testing" developed by UNAIDS in 2000).

Demographic notes:

NAME OF CLINIC..... DATE OF OBSERVATION

NUMBER OF COUNSELLING SESSION

- Section 1 Logistical considerations – representative of managers.
- Section 2 Content of counselling for HIV testing - all counselling sessions
- Section 3 Counselling skills – all counselling sessions
- Section 4 Group sessions – in clinics where this strategy is followed

SECTION 1 Logistic considerations

(The UNAIDS document recommend that a representative of the managers for each category of VCT site should be made – in this case antenatal clinics as part of primary health clinics)

Hours the clinic is open:

Is the clinic open at the following times?

- Early evening (after 17:00) No Yes How many evenings?
- Lunch hour No Yes
- Weekends No Yes Specify which days.....

Does the clinic use an *appointment system*? Yes No

If Yes, what happens if someone comes without an appointment?

- They are asked to make a future appointment
- They will always be seen the same day
- They will usually be seen the same day

Privacy:

Does the clinic have adequate space to ensure counselling sessions can be private?

- Yes, there is adequate space
- There is some private space, but not enough
- No
- Specify: Private office Cubicle
- Curtained-off area Other (Describe):.....

Where is group counselling done?

Where is individual counselling done?

Confidentiality:

Does the site have a written policy on confidentiality? Yes No

Describe the steps that are taken to ensure confidentiality:.....
.....
.....

Have any of the following staff received specific guidance about the role of counselling and confidentiality?

- Counsellors
- Non-counselling professional staff
- Receptionists/ clerks
- Ancillary staff (cleaners and guards)

Counselling and testing:

Is group counselling for pregnant women carried out?
.....

How many pregnant women are usually present during group counselling on average?
.....

Who present the counselling at this clinic?

- Group counselling:
- Individual counselling:

HIV testing methods:

What type of tests are used at this clinic?
.....

Where is HIV tests carried out?

- All testing done on site
- Screening tests done on site, follow-up testing at laboratory
- All testing at laboratory

Describe the counselling and testing procedure followed at the clinic:
.....
.....
.....
.....
.....

Appendix 4.2

Information letter en consent form for observation of counselling sessions

Dear participant

I am a PhD student of the Potchefstroom-campus of the North-West University. You are invited to participate in a research study regarding counselling for HIV testing during pregnancy.

The Nature and purpose of the study

The purpose of this study is to develop best practice guidelines for counselling for HIV testing during pregnancy. You are asked to participate in the phase of the study that entails observation of counselling sessions.

During the observation the counselling session will continue as usual, while the researcher will observe and record all occurrences.

Approval to do research

The protocol of this study was submitted to the Ethics committee of the Faculty of Health Science of the Potchefstroom Campus of the North-West University and approval has been granted. The provincial authorities and the person in charge of the clinic are also aware of this research being done in this clinic.

Risk or discomfort involved.

An experienced interviewer will observe the sessions. In case of language differences a trained research assistant who will act as interpreter will also attend sessions. They will be as *undisruptive as possible during the counselling session* and are bound by ethical restrictions to uphold confidentiality of all personal information that they become aware of.

Confidentiality

Any personal information that may become known to the researcher will be kept strictly confidential. The results will be published or presented in such a fashion that all participants will remain unidentifiable

Right to withdraw

Your participation in this research is entirely voluntary and you can refuse to participate or stop at any time without stating any reason. There will not be discriminated against you if you prefer not to participate.

Possible benefits of this research

Your contribution in this research project regarding occurrences during counselling for HIV testing will contribute to the formulation of best practice guidelines to improve the counselling pregnant women receives. These guidelines may be to the benefit of patients, health workers as well as the community as a whole.

Information

If you have any question about the research you are welcome to contact the researcher, Mrs. CS Minnie at telephone XXXXXXXXXXXX. You are also welcome to indicate on the attached document if you would like to receive a report of the study after it has been completed.

CONSENT TO PARTICIPATE IN THE STUDY

I have read the above information before signing this consent form. The content and meaning of the information is clear to me. I have been given opportunity to ask questions. I understand that if I do not participate it will not be to my disadvantage. I hereby volunteer to take part in this study.

Participant's signature Person obtaining informed consent

Witness Date

VERBAL PARTICIPANT INFORMED CONSENT

(For patients who cannot read or write)

I, the undersigned, have read and have explained to the participant, named, the patient information letter, which has indicated the nature and purpose of the research in which I have asked the patient to participate. The explanation I have given included both the possible risk and benefits of the research. The participant indicated that she understands that she will be free to withdraw from the research at any time for any reason.

I hereby certify that the patient has agreed to participate in the research.

Participant's name Person obtaining informed consent

Witness Date

Participant's particulars for feedback regarding the research

I would like to receive a report of the research: "Best practice guidelines for counselling for HIV testing during pregnancy", after it has been completed.

Name:

Address: