

**Feasibility of the Ottawa decision support tool to assist HIV positive mothers' infant feeding choice**

**By**

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## DECLARATION

I declare that **Feasibility of the Ottawa decision support tool to assist HIV positive mothers' infant feeding choice** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other Institution.

SIGNATURE

..........

(Ncheke Moloimang Sezarinah)

Date

 November 2014

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## Abstract

The study investigated the feasibility of the Ottawa decision support tool to assist HIV positive mothers' infant feeding choice. The aim was to explore and describe the feasibility of the Ottawa Decision Support Tool (ODST) in counselling HIV infected pregnant women on decision-making regarding the choice of safe infant feeding. The finding of this study will assist and support HIV positive mothers to be independent decision makers in choosing an infant feeding option for their babies.

A descriptive qualitative research approach guided the researcher to explore and describe the feasibility of the ODST to assist HIV positive mothers' infant feeding choice. This study is based on the Ottawa decision support framework (ODSF). Three focus group that comprised midwives as participants were conducted. The first focus group was conducted in January 2013 and the two subsequent ones in August 2013. Data was analysed using a framework approach.

The following themes emerged from data-analysis:

- Appropriateness
- Receptiveness of intervention
- Effectiveness

Conclusions were drawn based on the attained objectives of the study. The overall conclusion was that the ODST is feasible to assist HIV positive mothers' infant feeding choice. Limitations of the study were identified and recommendations were made for nursing practice, nursing education and further research.

Key words: feasibility, Ottawa decision support tool, Ottawa decision support framework, HIV positive mothers, infant feeding, choice

## Abbreviations

AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
ART	Anti-retroviral treatment
HIV	Human Immunodeficiency Virus
IMCI	Integrated Management of Childhood Illness
LHA	Lay Health Advisors
MTCT	Mother-to-child transmission
NDOH	National Department of Health
ODST	Ottawa Decision Support Tool
OHRI	Ottawa Hospital Research Institute
PMTCT	Prevention of mother-to-child transmission
WHO	World Health Organisation

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## CHAPTER 1

### OVERVIEW OF THE STUDY

#### 1.1. INTRODUCTION

Due to the change in disease patterns, decision-making regarding the choice of infant feeding has become very complicated. In the past, breast feeding was regarded as the best and safest feeding method for nearly all babies, but in the context of the Human Immune deficiency Virus (HIV) pandemic, HIV positive mothers are faced with the difficult task of deciding which infant feeding method will be the best for their babies. It is very important that HIV positive mothers make the correct choice of infant feeding option, as the life of the baby will be at risk of either vertical mother-to-child transmission (MTCT) of HIV from breast milk or malnutrition and infectious diseases such as diarrhoea and pneumonia if he or she is deprived of the protection from breast milk. The latter are the risks associated with not breast feeding. To avoid such risks, the Tshwane declaration strongly recommends breast feeding by declaring South Africa as country that actively promotes, protects and support breast feeding (NDOH 2011a:214). The declaration further recommends that all HIV infected mothers should breast feed their infants and receive antiretroviral drugs to prevent HIV transmission.

Socio-economic, cultural and environmental factors need to be considered when HIV positive mothers have to make a choice of a safe infant feeding. Decision-making regarding safe infant feeding should be a joint effort between a mother and a health care worker where the health care worker provides information on the advantages and disadvantages of various infant feeding options supports and advises the mother who in turn will make an informed choice. Tools to facilitate decision-making may be of value. The aim of the study is to explore and describe the feasibility of the Ottawa Decision Support Tool (ODST) in counselling HIV infected pregnant women on decision-making regarding the choice of safe infant feeding.

#### 1.2. BACKGROUND

When a decision regarding safe infant feeding has to be made, care must be taken that the lives of infants should not be jeopardized. The statement is confirmed by the South African National Department of Health (NDOH, 2008:15) stating that all infants have the right to be fed in the safest possible way that optimizes health and reduces the risk of MTCT of HIV.

The World Health Organization (WHO, 2010:3) also stresses that HIV free survival of children will be achieved by balancing Prevention-of-Mother-to-Child Transmission (PMTCT) with the nutritional requirements and protection of infants from HIV morbidity and mortality. HIV positive mothers end up being uncertain whether to breast feed and risk MTCT of HIV through breast milk or to deprive their infants of the benefits of breast feeding. Although the widespread use of anti-retroviral treatment (ART) has reduced the prevalence of MTCT of HIV infected babies, the problem has not been resolved completely as not all women who need ARVs get them consistently. The results of the study on the Evaluation of the Effectiveness of the PMTCT programme (NDOH 2012:16), showed that babies are still continuing to be infected by HIV due to mixed feeding and missed opportunities. Factors that influence, infant feeding choice is therefore still relevant.

Breast milk is optimal for infant feeding because it contains all the nutrients that are required by babies for their growth and development. Unfortunately breast milk has been identified as a mode of MTCT of HIV since Ziegler and colleagues published the first paper on the subject (1985:896). There is an estimated risk of about a third of all babies born from HIV positive mothers to be infected if no measures to prevent mother to child transmission of HIV is implemented, although various factors influence the risk of transmission through breast milk (Minnie & du Preez, 2004:19-4). Credible sources differ in their estimation rate of MTCT through breast feeding specifically. The World Health Organization (WHO) (2004:82) and Coutsooudis *et al.* (2008:214) estimate that 5-20% of the babies of HIV positive mothers could contract HIV in this manner. According to the guidelines for maternity care of the National Department of Health (2007:132), the risk of MTCT of HIV through breast milk increases in cases where the mother's CD4 count is low, viral load is high and when the mother has Vitamin A deficiency. If breast milk could be avoided, the risk of MTCT of HIV through this route could be eliminated but it is not the best choice for all women either. There are also risks associated with not breast feeding which include pneumonia, gastro-enteritis, malnutrition and infant deprivation from natural immunity and protection from breast milk (WHO 2011:2).

These risks lead to HIV positive mothers in the developing countries to experience a decisional conflict regarding safe infant feeding choice. To resolve the decisional conflict regarding infant feeding option, HIV positive mothers should be enabled to make decisions on a safe infant feeding choice by providing them with proper counselling on infant feeding as well as support and guidance. That was confirmed by Desclaux and Alfieri (2009:821) who stated that women need counselling and support to enable them to make an informed choice that is suitable to their situation when it comes to infant feeding option.

The counselling and support that women receive is often inadequate. Bundotich-Mosol (2011:33) found that that decision support for HIV positive mothers in Kenya regarding infant feeding was poor. She found that the health care workers that were supposed to provide the counselling and support were often unsure of what information to give. The findings of Bundotich-Mosol are supported by the findings of a study conducted in Tanzania where nurse counsellors expressed their lack of self-confidence and knowledge regarding HIV and infant feeding (Leshabari *et al.*, 2008:3). During interviews with nurses in the Tanzanian study, nurse counsellors expressed that they felt helpless and identified with patients who needed support from them (Leshabari *et al.*, 2008:13). Identifying with patients in this case means that nurses show a patient that they do understand and feel sorry about the patients' problems when they are supposed to provide support to them.

A possible way that nurses handle their insecurities is by being prescriptive instead of being supportive. In studies conducted in Burkina Faso, Cambodia and Cameroon, the counselling provided on infant feeding consisted of a recommendation of only one option that nurse counsellors thought to be the most suitable, leaving the mothers with no choice (Desclaux & Alfieri, 2009:824). Women were not informed of both the benefits and risks associated with each option, but counsellors only provided information regarding the option they considered the most appropriate. When the mothers were interviewed they expressed that they did not have freedom or the means to choose, but only to select the feeding option proposed by the health care provider (Desclaux & Alfieri, 2009:824). Counsellors should bear in mind the infant feeding objectives which are: to provide HIV positive mothers with information on infant feeding options, to guide them to choose, as well as supporting them in implementing the method of their choice (WHO 2005:4). Ideally mothers should be able to make a decision freely after being informed of all the options.

When counselling on the choice of an infant feeding option, the World Health Organization (2005:13) recommends that health care workers should explore with the woman her home and family situation and find out which option can be suitable for her, considering her socio-economic background. The demographic situation needs to be taken into consideration, before a replacement feeding can be considered to be a safe choice. Conditions of acceptability, feasibility, affordability, sustainability and safety (AFASS) should first be met.

The WHO (2005:6) unravels AFASS as follows:

- Acceptable - The mother has no barriers to choosing the option for cultural or social reasons or fear from stigma and discrimination.

- Feasible - The mother or family has adequate time, knowledge, skills and other resources to prepare replacement food and feed the infant and the support to cope with family, community and social pressures.
- Affordable – The mother and family, with community or health system support if necessary can pay the cost of purchasing or providing, preparing and using and replacement feeding including all ingredients, fuel, clean water, soap and equipment without compromising the health and nutrition of the family.
- Sustainable – Availability of a continuous and uninterrupted supply and dependable system of distribution for all ingredients needed for safe replacement feeding. There should be little risk that the formula will be unavailable or inaccessible.
- Safe – Formula should be correctly and hygienically prepared by clean hands, using clean water and clean utensils. Nutritionally adequate quantities of formula milk should be regularly available.

Even if there is a risk of MTCT of HIV, exclusive breast feeding is the safest choice if the AFASS criteria cannot be met.

Decision-making is a process of choosing between alternatives which may include doing nothing. Factors such as a desired course of action, a possibility of positive or negative effects and values of effects need to be considered by decision makers (O'Connor & Jacobsen, 2007:3). Every decision has both advantages and disadvantages, none can be 100% perfect, and so to enable an individual to make the best choice, she needs to be provided with information about the pros and cons of each alternative.

A decisional conflict is defined by O'Connor and Jacobsen (2007:3) as an uncertainty about which course of action to take when the choice among competing actions involve risk, loss, regret or challenge to personal life values. In this study, HIV positive mothers having to choose a safe infant feeding option are experiencing a typical decisional conflict characterized by uncertainty in identifying the best alternative due to the risks regarding the benefits or harms, the need to make value judgments and regret over the possible aspects of rejected options. O'Connor and Jacobsen (2007:5) identified the following factors making a decision-making process to be difficult:

- Lack of knowledge
- Unrealistic expectations or perception of outcomes
- Unclear values
- Unclear perception of others, including opinions and practices
- Social pressure to choose one option

- Lack of support
- Lack of skills such as self- confidence
- Lack of resources.

To facilitate the decision-making process, the women need to be supported through counselling and information on advantages and disadvantages of the different feeding options to enable them to make choices that are consistent with their beliefs and values.

To resolve the issue of a decisional conflict, the use of decision-making tools can be valuable if utilized by health care providers to assist clients experiencing a decisional conflict. The most prominent researchers in the field, O'Connor *et al.* (1999:731-734), did a systematic review to determine whether decision aid tools are effective to improve decision-making and outcomes for patients facing treatment or screening decisions. Their main conclusion was that decision aids were better than usual care in improving patients' knowledge, comfort, and participation in decision-making without increasing anxiety but had little effect on satisfaction and persistence with choice and quality of life (O'Connor *et al.*, 1999:734).

The steps towards the development of a Decision Support Tool are presented in the form of a flow chart designed by the researcher in the next page, followed by further explanation.

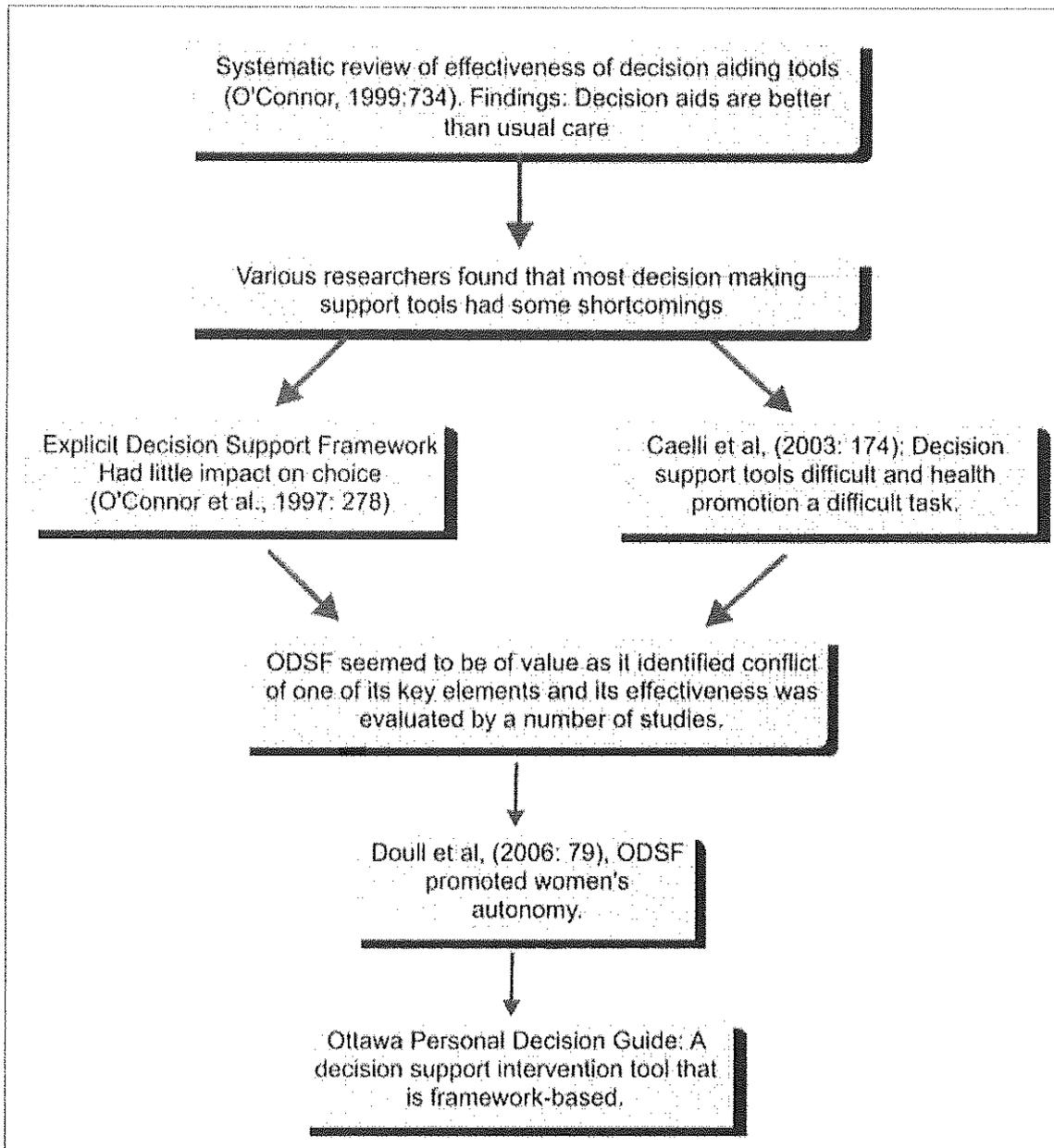


Figure 1.1 Flowchart: Of the development of Ottawa Decision Support Tool [Designed by the researcher].

Most of the decision support tools identified had shortcomings. The Explicit Decision Support Framework which was developed to assist clients to make a choice regarding the use of hormone replacement therapy, but little impact on the choice itself and the efficacy and efficiency of the choice remained in question (O'Connor *et al.*, 1997:278). In the study of Caelli *et al.* (2003:174) health promotion practitioners found decision support tools difficult, describing health promotion practice as an extra-ordinarily difficult task.

The Ottawa Decision Support Framework (ODSF) which was developed more recently, seems to be of value as it identifies conflict as one of the key elements in decision-making. The ODSF helps in health care decision-making in the context of uncertainty seeking to verify that the decisions taken by clients are informed by the best evidence and in line with their values (Le'gare' *et al.*, 2006:381).

A number of studies evaluated the effectiveness of the ODSF. Doull *et al.* (2006:279) used the ODSF to assist HIV positive women with their reproductive decision-making needs and found that the framework was useful in promoting women's autonomy and involvement in MTCT. In the same study, the ODSF was also found to be effective in decision-making such as voluntary testing and counselling, disclosure of status, treatment, pregnancy termination, delivery method and feeding options. The study addressed the determinants of decisions that have to be taken by the HIV positive mothers which might be barriers or facilitators of decision-making (Doull *et al.*, 2006:280). To add to that, the health coaching approach while using the ODSF, showed to support women to make their own choices that were in line with their values and beliefs (Doull *et al.*, 2006:288). In a study on the views of primary health care professionals on barriers and facilitators to the implementation of the ODSF in practice, it was found that it helped to clarify patient values, were compatible with the patient-centred and evidence-based approach, easy to understand and implement, as well as to share responsibility and be communicable (Le'gare' *et al.*, 2006:385).

The Ottawa Decision Support Tool (ODST) (Annexure A) was developed from the ODSF. The ODST is a decision support intervention tailored to clients' needs (O'Connor & Jacobsen 2007:7). Among the decision support interventions the Ottawa Personal Decision Guide is defined by O'Connor and Jacobsen (2007:13) as a framework-based tool to help people and their practitioners to structure, record and communicate needs and plans.

The feasibility of using the Ottawa Decision Support Tool (ODST) is not known yet. According to the study of Caelli *et al.* (2003:174) health promotion practitioners found decision support tools in general difficult to use. More research is needed regarding the

feasibility of using the Ottawa Decision Support Tool (ODST) before it could be widely implemented.

In this study, the feasibility of the Ottawa Decision Support Tool (ODST) in supporting HIV positive mothers in their decision-making regarding the choice of safe infant feeding was explored and described in terms of its feasibility according to the counselling midwives.

### **1.3. RESEARCH QUESTION**

The background and problem statement led to the following research question:

What is the feasibility of the use of the ODST by midwives to counsel pregnant HIV positive mothers on an infant feeding choice in terms of time needed and user-friendliness?

### **1.4 RESEARCH OBJECTIVES**

In order to answer the research questions, the following objective was stated:

To explore and describe the feasibility of the use of the ODST by midwives in counselling pregnant HIV positive mothers regarding the choice of infant feeding option in terms of time needed and user-friendliness.

### **1.5. PARADIGMATIC PERSPECTIVE**

According to Polit and Hungler (1993:442), a paradigm is a way of looking at natural phenomena that encompass a set of philosophical assumptions and that guide one's approach to enquiry. As explained in Brink *et al.* (2006:22), assumptions and ways of knowing are untested givens that guide and influence the researcher's investigations. Furthermore, Burns and Grove (2005:39) state that assumptions are implanted in the philosophical basis, framework or study design.

The paradigmatic perspective of the researcher is set out in meta-theoretical, theoretical and methodological assumptions.

#### **1.5.1. Meta-theoretical assumptions**

Mouton and Marais (1994:192) state that meta-theoretical assumptions contain non-epistemic statements that cannot be tested. In nursing research, they reflect the researcher's worldview and assumptions of the concepts of man, society, health and nursing. These

concepts are interrelated and they collaboratively reflect the researcher's meta-theoretical beliefs as explained below.

#### **1.5.1.1 View of human being**

The researcher views a human being as a creature created in the image of God, being unique from others. The human being is the focus of nursing practice, and in this study a human being is an HIV positive mother and the midwife using the ODST. Due to the presence of HIV infection in her body, there is a risk of vertical MTCT of HIV through breast feeding.

#### **1.5.1.2 View of society**

An HIV positive mother is a human being who lives in a particular society and is in constant interaction with the environment around her, which may have positive and negative influences on her way of life. In the society where she lives, her ability to make a decision on a safe infant feeding option will be determined by socio-economic and cultural factors, as well as environmental factors and the quality of counselling she receives. In a society where breast feeding is highly valued, a mother who prefers replacement feeding may experience a decisional conflict as her choice of infant feeding may not be accepted. This mother will also have to consider other conditions such as affordability, feasibility, sustainability and safety of a replacement feeding before she makes a choice of infant feeding.

#### **1.5.1.3 View of health**

The researcher agrees with WHO's definition of health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO 2014:1). In the context of HIV infection in the mother, the goal is PMTCT of HIV. This mother may experience a decisional conflict (discomfort) regarding the choice of a safe infant feeding option that will minimize the risk of vertical transmission of HIV to her baby through breast feeding. Supporting her through the use of the ODST may lessen her discomfort, and thereby increase her health. If MTCT of HIV or morbidities related to not breastfeeding were prevented by better decision-making, the health of the infant can also be enhanced

#### **1.5.1.4 View of nursing and midwifery**

I agree with the definition of nursing by the American Nurses Association (2014:1) that states that nursing is the protection and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response and advocacy in the care of individuals, families, communities and populations. Nursing care

is rendered where quality of care is threatened by disease and disability. In this study, the type of health professionals who render nursing care are nurses who are also professional midwives. According to the International Confederation of midwives (ICM) (2011:1), a midwife is a person who has successfully completed a midwifery education programme that is recognised in the country where it is located and that is based on the ICM Essential Competencies for Basic Midwifery Practice and the framework of the ICM Global Standards for Midwifery Education; who has acquired the requisite qualifications to be registered and/or legally licensed to practice midwifery and use the title 'midwife'; and who demonstrates competency in the practice of midwifery. ICM further identified counselling and education as important tasks of a midwife.

Regardless of the fact that the health of an HIV positive mother is threatened by disease, she still needs to be capacitated with information on how to live with it, as well as to prevent its transmission to her unborn baby. I believe that an HIV positive mother who received appropriate counselling on safe infant feeding options will be able to make an informed choice regarding a safe infant feeding option.

### **1.5.2 Theoretical assumptions**

Theoretical assumptions can be tested and described by research and they form part of the theoretical and conceptual framework of a discipline.

#### **1.5.2.1 Central theoretical argument**

The Ottawa Decision Support Tool can be used to assist clients who face decisional conflict regarding the choice of infant feeding options. Knowledge of the feasibility of the ODST may lead to more health workers using it and more HIV positive mothers and their infants benefitting from it.

#### **1.5.2.2 Concept clarification**

**Feasibility** is the possibility and practicality of an intervention to be achieved easily (Oxford advanced learner's dictionary, 2005:539). In this study the feasibility of the ODST was explored and described according to the perceptions of the midwives who have counselled the mothers on an infant feeding choice.

**Decision support** is a form of clinical counselling, decision aid and coaching with the aim of improving decision quality by addressing unresolved decisional needs (O'Connor & Jacobsen 2007:8). Decision support was offered to the HIV positive mothers to assist them to resolve their decisional conflict regarding their choice of infant feeding.

**HIV positive** means a person who has tested HIV positive and therefore has been exposed to the HIV virus and is infected with the virus (Evian, 2003:334). In this study HIV positive mothers were assisted in decision-making regarding the choice of infant feeding to minimize MTCT of HIV.

**The Ottawa Decision Support Tool (ODST)** is defined by O'Connor and Jacobsen (2007:7) as a decision support intervention tailored to the client's needs. In this study the ODST was used to counsel and guide the HIV positive mothers and to assist them in decision-making regarding a safe infant feeding option for their babies.

### **1.5.2.3 Theoretical Framework**

As defined by Burns and Grove (2005:121), a conceptual framework is an abstract logical structure that guides the development of a study and enables the researcher to link the findings to nursing's body of knowledge. An appropriate conceptual framework for this study is the Ottawa Decision Support Framework.

The Ottawa Hospital Research Institute (2013:1) defines ODSF as an evidence-based mid-range theory for guiding patients making health or social decisions. The ODSF has the following key elements in it as in the picture in the next page:

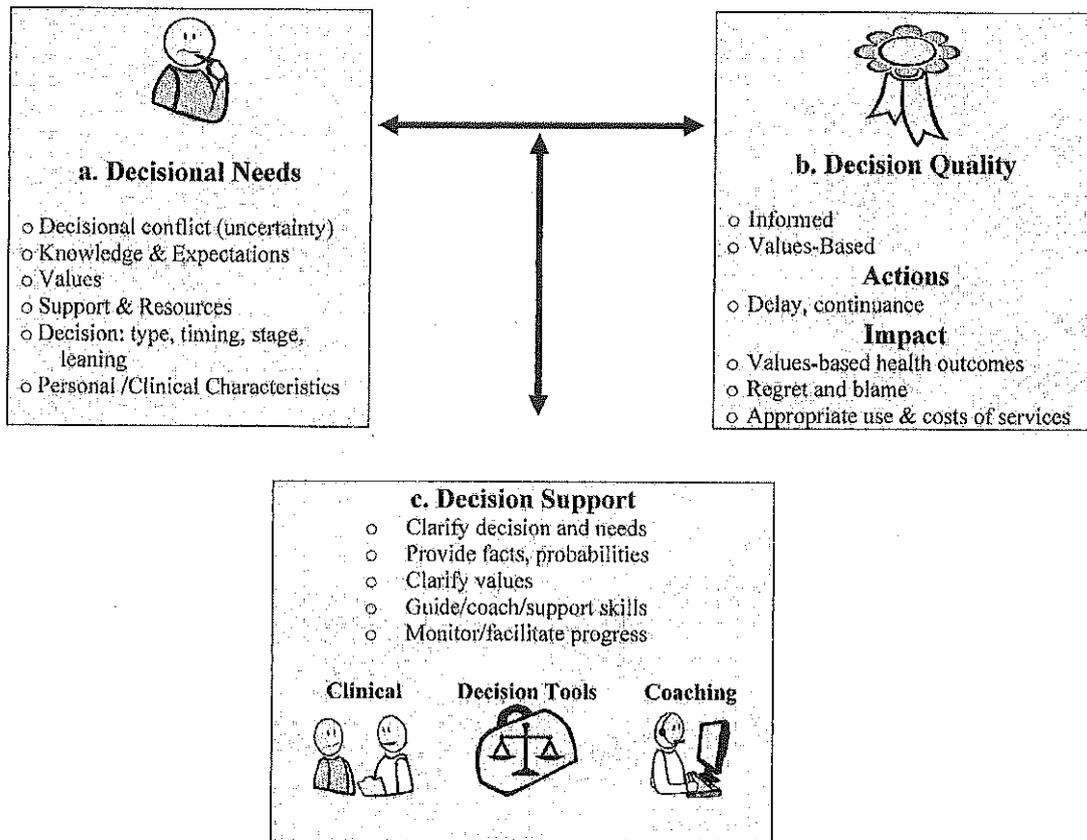


Figure 1.2. Ottawa Decision Support Framework [Adopted and adapted from O'Connor and Jacobsen (2007:7)]

The key elements will now be discussed.

### A. Decisional needs

When people are faced with decisions to make, they are uncertain about which option to choose. They also lack knowledge, have unrealistic expectations, unclear values, inadequate support resources and constraints such as physical, social, economic and educational. All these factors need to be resolved to before making a decision.

### B. Decision quality

To enable people to make best choices, they need to be informed about the benefits and harms disadvantages of each alternative. The decisions that they take have to tally with their values.

### **C. Decision support**

To support people in decision-making, they need to be offered clinical counselling, decision tools, and coaching to improve decision quality. Their progress with their decision has to be monitored and facilitated (O'Connor & Jacobsen, 2007:7).

Furthermore, to address a decisional conflict, (OHRI 2014:1) the Ottawa Decision Support Framework is applied in the following three steps:

(a). Assessing clients' and practitioners' determinants of decisions to identify their decision support needs. This is done by verifying values and knowledge of the client and the practitioner's as well as the available support system.

(b). Provide decision support tailored to clients' needs. This step is achieved by providing clients with information regarding the advantages and disadvantages of each alternative to enable them to make the best choice.

(c). Evaluating the decision-making process and outcomes. This last step of the process is achieved by checking as to whether the decision taken by the client is an informed one that is in line with her values. The Ottawa Decision Support Framework provides the theoretical base for this study.

According to the ODSF, unresolved decisional needs will have adverse effects on decision quality (O'Connor & Jacobsen 2007:7). From the ODSF, the Ottawa Personal Decision Guide, which is a framework-based tool was developed to assess needs and plan decision support (O'Connor & Jacobsen 2007:13).

#### **1.5.3. Methodological Assumptions**

Methodological assumptions deal with the purpose, methods and criteria for validity of the research. The methodological approach for this study was influenced by the researcher's philosophy. The researcher believes that a descriptive design is the best way to gather evidence for this study as it provides a picture of a situation as it naturally happens. She further believes that purposive sampling is relevant for this study as the participants selected in that manner would be the ones that are knowledgeable about the question at hand. The findings of this study will be utilized in practice to improve the quality of decisions where decisional conflicts, experienced by HIV positive mothers regarding the choice of a safe infant feeding option, will be resolved by supporting them with counselling, using the ODST, contributing to PMTCT.

## **1.6 RESEARCH DESIGN AND METHODS**

In the next section the research design and methods will briefly be discussed. A more detailed discussion follows in Chapter 2.

### **1.6.1 Research design**

A qualitative explorative descriptive design was used in this study to explore and describe the feasibility and the value of the use of the ODST in supporting HIV positive mothers in their decision-making regarding the choice of an infant feeding option.

### **1.6.2. Research methods**

In this section population and sampling will firstly be discussed, followed by data-collection and data-analysis.

#### **1.6.2.1. Setting, Population and Sampling**

This study was set in an economically disadvantaged area situated in a deep rural area. An economically disadvantaged area is discussed in detail in chapter 2. In this particular local area, there is no specific infant feeding counselling tool to assist HIV positive mothers to choose a feeding option for their babies during the antenatal period. To counsel these HIV positive mothers on infant feeding, the midwives use the information from the Integrated Management Childhood Illness (IMCI) as a guideline. The IMCI guideline recommends exclusive breast feeding for the first 6 months then complimentary feeding thereafter with no breast milk (NDOH 2011b:22). Alternatively, the guideline recommends replacement feeding provided the AFASS criteria are met. The guideline does not say anything regarding provision of information on the advantages and disadvantages of each infant feeding option. However there are clinical guidelines on PMTCT in place. The PMTCT guidelines state that trained personnel should provide quality information on the risk of HIV transmission through breast feeding and ART prophylaxis to reduce transmission as well as the risks of replacement feeding (NDOH 2010:32). To avoid such risks of replacement feeding, the Tshwane declaration strongly recommends that all HIV infected mothers should breast feed their infants and receive antiretroviral drugs to prevent HIV transmission (NDOH 2011a:214).

The population was all the midwives working in the clinics of a particular local area. The sample that was used to reach the stated objective was the midwives who received in-service training on the use of the ODST. Purposive sampling was used to select participants because they were the best sources to answer the questions for the study.

Data was collected until no new themes emerged during the data-analysis that was done concurrently with the data-collection.

### **1.6.2.2. Data-collection**

Before data collection, midwives had to be capacitated on the Ottawa Decision Support Tool (ODST) through an in-service training.

Focus group interviews were used to collect data. The core question for the focus group interviews was: Please tell me about your experience of using the ODST to counsel HIV positive mothers to select an infant feeding for their babies. Interviews were conducted by the researcher and recorded with an electronic voice recorder.

### **1.6.2.3. Data-analysis**

In this study, data was collected in the form of words. Data-analysis started just after data-collection. Collected data was converted into smaller and more manageable units as themes emerged from the data

## **1.7 RIGOR**

Rigor is defined by Burns and Grove (2005:55) as openness, scrupulous and adherence to a philosophical perspective, thoroughness in collecting data and consideration of all data in a subjective theory development phase. In this study, trustworthiness of collected data was evaluated against the four criteria of credibility, transferability, dependability and conformability (Krefting, 1990:214).

## **1.8 ETHICAL CONSIDERATIONS**

The researcher made sure that the rights of the participants were protected by adhering to ethical principles that guide researchers: respect for persons, beneficence and justice (Brink *et al.* 2006:31). The participants' rights include the right to self-determination, right to privacy, right to autonomy and confidentiality, right to fair treatment and the right to protection from discomfort and harm (Brink *et al.*, 2006:31). Ethical considerations are discussed in detail in chapter 2.

## **1.9 CONCLUSION**

This chapter provided an overview of the study which included the paradigmatic perspective. Since HIV has been isolated in breast milk, HIV positive mothers are faced with a decisional conflict as they have to make a choice on a safe infant feeding option in order to minimize

the risk of MTCT of HIV. Decision-making tools can be valuable to resolve the issue of a decisional conflict. Among the various decision-making tools that have been evaluated, the ODSF is found to be of value as it identifies conflict as one of the key elements in decision-making and helps the interventions supporting health care decision-making. The ODST was developed from the ODSF and can be of value to support HIV positive mothers in their choice of an infant feeding method if found to be feasible by midwives providing counselling. The next chapter will focus on the methods in detail.

## **CHAPTER 2**

### **RESEARCH METHODS**

#### **2. 1. INTRODUCTION**

The previous chapter provided a description on the background of the problem, the purpose of the study, the research question and objectives. In this chapter the details regarding the research design, the research methods, rigor and ethical considerations that were applied in this study will be discussed. The research design and methods will be discussed in line with the objectives of the study and the rigor will be discussed as applied to the design.

#### **2.2. RESEARCH DESIGN**

A research design is defined by Burns and Grove (2005:211) as a blue print for conducting a study that maximizes control over factors that could interfere with the validity of the study findings. A qualitative explorative descriptive design was used in this study to explore and describe the feasibility of the use of the ODST in supporting HIV infected mothers in their decision-making regarding the choice of an infant feeding option. According to Burns and Grove (2005:232) the purpose of a descriptive design is to provide pictures of situations as they naturally happen and it is important in acquiring knowledge in areas in which limited research has been conducted. In the preliminary literature review of this study, it was evident that very little has been researched on the decision support tools that will help HIV positive mothers in decision-making regarding the choice of a safe infant feeding option. In this study, the opinions of the midwives regarding feasibility were investigated via qualitative research.

#### **2.3. RESEARCH METHODS**

In this section population and sampling will firstly be discussed, followed by data-collection and data-analysis.

##### **2.3.1. Setting, Population and Sampling**

This study was set in an economically disadvantaged area situated in a rural area. In an economically disadvantaged area, there is usually a high rate of unemployment, poverty, lack of sanitation, scarcity of water, a high disease prevalence rate and a low literacy level. The majority of the child-bearing aged women in this area are from the poor socio-economic background and most of them are illiterate, so an infant feeding choice is a challenge in the

HIV pandemic context. The inhabitants in the farms of these areas get health services at a mobile clinic that comes only once a month. During rainy days, it is difficult to deliver services in such areas because of the gravel roads that are slippery and it is also difficult for the inhabitants to go out and wait for a mobile clinic at the access point. To get to a nearest fixed clinic, some of these farm inhabitants who live very far where there is no public transport have to spend R700 to hire a special vehicle. Financial constraints, shortages of human and material resources as well as weather conditions make it difficult for clients to access their chronic treatment including Anti-retroviral treatment (ART). The total population in this area is 59138 with 643 births per year. The total live births is actually higher than that as some of the mothers who are high risk cases are usually referred to a regional hospital outside the local area for delivery. There are nine clinics in the particular local area which comprise six fixed clinics and three mobile clinics. The HIV prevalence rate among pregnant women in the district was 30.7% in 2010 with the district rated number 3 of the highest HIV prevalence rate in the province (NDOH 2011c:52). These prevalence rates are escalating as they were 31.9% in 2011 and 33.5% in 2013 (NDOH 2013:24-25).

In this study, the population was all the midwives in the 9 clinics of a particular local area which comprised of 27 midwives.

The sample that was used to reach the objective of the study were midwives who worked in clinics in the particular local area who received in-service training on the use of the ODST and have counselled HIV positive mothers to assist them to choose an infant feeding option. Purposive sampling was used to select participants because they were the best sources to answer the questions of the study. Brink *et al.* (2006:133), defines purposive sampling as a type of non-probability sampling that is based on the judgment of the researcher regarding participants who are especially knowledgeable about the question at hand.

The selection criteria for the sample were as follows:

- Midwives should be working in the selected clinics and have received in-service training on the ODST; and
- Had counselled at least two pregnant HIV positive mothers regarding choice of infant option using the ODST.

The sample size was not determined beforehand as it was guided by data-saturation. Participants were recruited and data was collected and analysed until no more new themes emerged. The local area has nine clinics of which six are fixed facilities and three mobile

clinics. The size of the final sample was nine and comprised all the midwives who met the selection criteria as the Antenatal program was allocated to only one midwife in each facility. Six midwives were from fixed clinics and three were from mobile clinics. All of the midwives who participated in the study were registered midwives without additional advanced training.

### **2.3.2. Preparation for data-collection**

Before their perceptions regarding the feasibility could be explored and described, midwives had to be knowledgeable about the Ottawa Decision-making Tool (ODST) and have experience in using it. Midwives were trained on the use of the ODST in counselling HIV infected mothers on an infant feeding choice to capacitate them in decision support and guidance skills. As an experienced nurse educator, the researcher was able to conduct in-service education to the midwives using teaching methods such as lecture, question and answer method, as well as role play. The ODST and an overhead projector were used as teaching aids. The lesson plan is included as in Annexure F.

Each midwife was given an opportunity to practice during role play, acting as a counsellor, using the ODST. Role-play is defined as a learning activity in which the participants behave in the way somebody else would behave in a particular situation (Oxford advanced learners' dictionary 2005:1268). Quinn (1995:172) further elaborates that it utilizes acting and imagination to create insight into the learners' own behaviour, beliefs and values and those of other people. The advantages of role play as a teaching method is that it creates empathy with other people's point of view and encourages learners to think in different ways in a given situation (Quinn 1995:172). That is also supported by Ehlers (2002:51) who further states that it helps learners to learn about decision-making. The disadvantage of role play is that some of the learners may lack initiative to participate actively and some may judge a role player's actions instead of becoming aware of their own actions and emotions (Ehlers, 2002:51).

As a teaching method, role play consists of acting out real life situations and problems. In this study, learners who were midwives acted roles as counsellors and some acted as HIV positive mothers while others were observers. Midwives using the Ottawa Decision Support Tool provided information on the advantages and disadvantages of various infant feeding options to HIV positive mothers, as well as offering support and advice to assist them in decision-making regarding an infant feeding choice.

Preparations of a hospital boardroom and other venues were done beforehand with all necessary teaching aids such as the ODST (Annexure A). The players occupied a central place, surrounded by the observers.

Learners were provided with a description of a situation, what is expected of the persons in the situation, and rules, goals and instructions of the role play. A scenario that was given was that of being faced with a 34 weeks pregnant mother who tested HIV positive and needed assistance in decision-making regarding a safe infant feeding option to minimize the risk of MTCT of HIV.

At the end of the learning experience, the group discussed what had happened during the role play, shared their feelings, and how the learning can be applied in the real world as well as shared insight gained. De-role was also done to help role players to be in contact with reality as role play generates a great deal of emotions. Six training sessions were conducted, from September 2012 until January 2013. Due to the clinics that are far apart, it was not possible to conduct one training session for all midwives. The total number of midwives trained was 19 and each session lasted for 1-3 hours depending on the number of midwives who attended.

After in-service training, the midwives started to use the ODST. After two weeks, follow-up visits were done to check if they encountered any problems regarding the tool. Each trained midwife was provided with a management register to record the clients who had been counselled on an infant feeding choice using the ODST. The total number of mothers who were counselled on the ODST was 36.

### **2.3.3 Data-collection**

After obtaining ethical approval from NWU ethical committee, (Annexure B), permission to conduct this study was requested from the Provincial Head of Department of Health, (Annexure C) of the district manager, the local area manager, clinic supervisor and managers of selected clinics. Once the Provincial HOD's permission (Annexure E) had been obtained, appointment dates were set with managers to explain to them what the study was about, and the purpose and significance of the study. After that, permission to provide in-service training (Annexure G) was requested. Following that, explanation was done to the staff at the facility level where the appointments for training and data collection were set. Introduction to the participants were done, objectives of the study and ethical considerations were explained to them and they were requested to sign consent forms, (Annexure H).

### 2.3.3.1 Data-collection methods

The method of data collection used was focus group interviews. Brink *et al.* (2006:151) defines interview as a method of data collection in which the interviewer obtains information from the participants in a face to face encounter, by telephone or by electronic means. It is frequently used in exploratory and descriptive research. Since the purpose of this study was to explore and to describe the feasibility of the use of the ODST in counselling HIV positive mothers in decision-making regarding the choice of a safe infant feeding option, interviews were a suitable method of data collection for this study.

Focus group interviews are defined by Polit and Beck (2008:754) as an interview with a group of individuals assembled to answer questions on a given topic. De Vos *et al.* (2005:299) further state that focus group interviews are a means of better understanding how people feel about an issue or service. Both Polit and Beck (2008:395) and De Vos *et al.* (2005:299) agree that the participants should have similar characteristics to make them feel at ease and to reduce conflict. In this study, the participants for the focus group interview were the midwives who were responsible for antenatal care and have counselled HIV positive mothers on an infant feeding choice using ODST.

Just like any other data collection method, focus groups have advantages as well as disadvantages. De Vos *et al.* (2005:301) and Polit and Beck (2008:395) identify the advantages of focus group interviews as: enabling the researcher to obtain viewpoints of many individuals in a short time, leading to richer or deeper expression of opinion and stimulation of respondents. Furthermore, they state that focus groups are a powerful means of exposing reality and of investigating complex behaviour and motivation. Focus groups were suitable for the midwives because they stimulate a secure setting where the participants would be able to share their thoughts with each other and generate new ideas (Brink *et al.*, 2006:152). Focus group also make people feel supported and empowered in a group situation where they are surrounded by others similar to them.

However, focus groups also have disadvantages which Polit and Beck (2008:395) identify as: making some people uncomfortable in expressing their views and fostering of a group culture that could inhibit individual expression. Since the researcher was aware of the disadvantages, she tried to minimize them.

Focus group interviews for midwives were used as data-collection technique to reach the research objective. Three focus group interviews were conducted, where the first group comprised two midwives, four midwives in the second group and three midwives in the third

group. Each interview session lasted for 20 to 30 minutes. The rationale for the number of midwives interviewed in each focus group was because of the proximity of the clinics. The local area is small with the clinics far apart from each other and as a result, midwives could not be assembled in one place. The midwives at the different clinics are each responsible for specific programs and therefore there is only one midwife allocated to do the antenatal program in each facility. There are six fixed clinics and three mobile clinics in the local area; hence only one midwife met the selection criteria in each facility. The focus group were conducted on a day, time and venue that were suitable for all. One of the conditions for granting permission to conduct the study was that the services should not be disrupted during the process.

The core question for the focus group interviews was: Please tell me about your experience of using the ODST to counsel HIV infected mothers to select an infant feeding option for their babies. The core question was followed up with probe questions. (See annexure I). Because of her background training in mental health nursing, researcher was able to clarify misunderstanding and obtain in-depth responses during the interview session.

The participants were ensured that their identity would not be revealed, their participation was voluntary and they were free to withdraw at any time without facing any consequences

In this study, the researcher was the key instrument of data collection as she conducted the interviews and wrote field notes herself after transcription of the first focus group was sent to the supervisor to establish quality (Creswell, 2009:175). All the focus groups were conducted in English as it is the medium of communication at the participants' workplace. All interviews were recorded with an electronic voice recorder (after the participants granted their permission that the interview could be recorded) and field notes were taken immediately after the interviews and were used during transcriptions of the interviews to generate a deeper understanding of what had happened. Polit and Hungler (1997:457) define field notes as notes regarding the unstructured observations they have made in the field during or just after data-collection and researchers' interpretations of those observations.

These field notes included:

- Observation of non-verbal behaviour and mannerisms.
- Theoretical field notes to derive meaning and insight, making sense of the situation.
- Personal notes, which entail comments about the researcher's own feelings during the research process (Polit & Hungler, 1997:273).

#### 2.3.4 Data-analysis

De Vos *et al.* (2005: 333) define data-analysis as a process of bringing order, structure and meaning to the mass of collected data. According to Polit and Beck (2008: 507), the purpose of data-analysis is to organize and to provide a structure to elicit meaning from research data. Neuman (1997: 421) explains it as a process of organizing data on a basis of themes, concepts or similar features. During this process the volume of data is reduced into small categories. Data-collection was done concurrently with data-analysis and it involved examination of words.

Data was analysed according to a framework approach using the thematic analysis method that described and interpreted participants' views (Smith & Firth, 2011: 54). The reasons for utilizing this particular data- analysis method are well detailed in chapter 3.

Before data-analysis, all recordings were transcribed and these transcriptions, as well as the field notes, were then read to make sense of it and each topic to be addressed provided with a code.

According to Smith and Firth (2011: 56), the framework approach comprises three stages that include data management, descriptive accounts and explanatory accounts.

- Data management - data is read and re-read to identify initial themes, developing a coding matrix, assigning data to themes and categories.
- Descriptive accounts – summarizing coded data, refining initial themes and categories, identifying associations between themes until the whole picture emerges, developing more abstract concepts.
- Explanatory accounts – developing associations or patterns within concepts and themes, reflecting on analytical stages to ensure participants' accounts are accurately presented and to reduce the possibility of misinterpretations, interpreting meaning and explaining concepts and themes seeking wider application of concepts.

Themes from the participants were classified into categories from which themes developed. The researcher and an independent co-coder worked separately, analysing data into categories to determine the final themes. Afterwards these themes were verified through reflection and discussion to reach a consensus with the independent data-analyst encoding same data.

## **2.4. RIGOR**

Rigor is defined by Burns and Grove (2005:750) as the striving for excellence in research through the use of discipline, scrupulous adherence to detail and strict accuracy. Krefting (1990:214) defines it as the assessment of trustworthiness. In this study, trustworthiness of the data that was collected was evaluated against the four criteria of credibility, transferability, dependability and conformability (Krefting, 1990:217).

### **2.4.1 Credibility**

Credibility is defined by Polit and Beck (2004: 539) as confidence in the truth of the data and interpretation of them. According to Krefting (1990:217), confidence in the truth of the findings can be established through strategies like prolonged engagement with the participants, member checking, interview technique and establishing authority of the researcher. In this study, the researcher developed a core question and then an interview schedule that was checked by the supervisor prior to the actual interview. Furthermore the researcher had prolonged engagement with the informants as she has worked with them during school holidays for the past seven years and that enhances credibility of the findings. During the interview process, questions were repeated and reframed to increase credibility. To establish confidence in the truth of the findings, the audio tape was played back to the participants after each interview session to ensure that the data reflected their experiences accurately.

### **2.4.2 Transferability**

As defined by Brink *et al.* (2006:119), transferability is the degree to which the findings of the study can be generalized to other settings. The background information about the informants and the research context as well as setting were, are described in detail to enable the reader to judge how similar their context is to the context in which the research was done (Krefting 1990:220).

### **2.4.3 Dependability**

Dependability is a trackable variability that can be ascribed to identify sources (Krefting, 1990:216). Polit and Beck (2008:448) define dependability as the stability of data over time and over conditions. In this study dependability of the data were established by having an experienced researcher as co-coder who also analysed the data independently. Written and recorded raw data is also available for audit to ensure dependability. Furthermore, dependability was ensured by code and re-code (Krefting 1990:221).

#### **2.4.4 Conformability**

Conformability is defined by Brink *et al.* (2006:119) as a criterion that guarantees that the findings, conclusions and recommendations are supported by data that is an internal agreement between the investigators' interpretation and actual evidence. Polit and Beck (2004:756) define it as referring to the objectivity and neutrality of data. In this study, tape recordings and interview transcriptions are available for audit to establish conformability of the study findings. Audio-tape recordings were played back to the participants to confirm that the collected data is a true reflection of their experiences. The researcher also supported the research findings and interpretations by analysed data to enhance conformability.

#### **2.5 ETHICAL CONSIDERATIONS**

The participants' rights include the right to self-determination, right to privacy, right to autonomy and confidentiality, right to fair treatment and the right to protection from discomfort and harm (Brink *et al.*, 2006:31). Respect for persons, beneficence and justice were ensured by submission of the proposal as addendum to NWU 00003-07-A3. (Support for HIV positive mothers). Ethics approval was granted, ethics number NWU 00022-11-A1 (Annexure B). Permission to conduct the study was requested from and granted by the Provincial Department of Health, District Manager, the manager of the selected local area as well as the clinic managers. Original data and transcriptions will be kept for a period of five years at INSINQ Focus Area of the Potchefstroom Campus of the North-West University.

After meeting the interested participants just before the interview, they were given information about the study, requested to sign consent forms and re-assured that their participation was voluntary and that they were free to withdraw at any time without facing the consequences. The researcher, who was the data collector, requested consent to record data and to take some notes during the interview session. Data was collected in a private room to maintain confidentiality. The researcher ensured that all the participants' rights were protected by adhering to ethical principles that guide researchers: respect for persons, beneficence and justice (Brink *et al.*, 2006:31).

With regard to self-determination and autonomy, the participants were informed regarding the purpose of the study, the potential benefits and risks, the measures to protect anonymity and confidentiality, the contact details of the researcher in case of questions, as well as their right to withdrawal, before they were requested to sign a consent form. Risks and benefits as in the consent form were explained as follows:

**'Risks:** Minimum risk is expected from my participation in this study. My decision to whether or not to participate in this study will not have any positive or negative repercussions for me. I have been assured that the researcher will keep confidential and anonymous any responses I provide during the focus group interview. I have been reassured by the researcher that every effort will be taken to minimize the risks and that my organisation has given me permission to participate in the research. I know that at the end of the interview, I will be asked if there is any portion of what I have said that I do not want to be quoted on and that this will be recorded on tape and in written note by the researcher/ interviewer.

**Benefits:** My participation in this study will capacitate me in counselling HIV positive mothers on choice of infant feeding options using the ODST and to reflect on the strengths and weaknesses of the tool in helping mothers to make a decision on a safe choice. The summary that will result from this study will contribute to PMTCT program.'

With regard to privacy, each participant was allocated a code to identify them on the transcriptions. To protect their identity, the quotes of the participants were labelled alphabetically in the first interview session, then numerically with subsequent sessions. The informed consent forms were kept separately from the transcribed interviews to ensure that consent forms cannot be linked with the data.

To protect participants' right to fair treatment and right to protection from discomfort and harm, each member of the population who met the selection criteria had a fair chance of selection. They were informed that if they felt uncomfortable during the focus group they could withdraw, and that counselling would be provided if they experienced psychological stress.

## **2.6 CONCLUSION**

In this chapter design and data collection methods were discussed in detail and choice of specific method motivated. Rigor was also discussed in relation to a qualitative design. The trustworthiness of the collected data was evaluated against the four criteria of credibility, transferability, dependability and conformability. Ethical considerations were also discussed. The researcher adhered to the ethical principles that guide researchers: respect for persons, beneficence and justice to ensure that the rights of the participants were protected. Participants' rights included right to autonomy, fair treatment and protection from harm and discomfort. The next chapter will include the findings of the study and discussions.

## CHAPTER 3

### RESEARCH FINDINGS AND DISCUSSIONS

#### 3.1 INTRODUCTION

Chapter 2 discussed the research design and methodology of the study. This chapter includes data analysis, the research findings and discussion. The results are presented in the form of categories, themes and core concepts. Furthermore, the results have been integrated with the Ottawa Decision Support Framework and literature with findings of similar or related studies on which to relate the analysis of the current study.

#### 3.2 DATA-ANALYSIS

As the first stage of data-analysis, the researcher read and re-read all the field notes and listened to the audio-taped focus groups interviews over and over after each interview session. Audio-taped data was transcribed after which transcripts were read and re-read to make sense out of them.

According to Seers (2012: 2), one needs to look for quotations from the participants that could indicate categories and themes to keep the analysis firmly grounded in data. In this study, the identified quotations were marked in colours, using one colour for similar responses.

After that data was indexed into categories, then themes, using a framework approach. Ritchie and Lewis, 2003 (cited by Smith & Firth, 2011:55) assert that the framework approach is used to manage data and undertake data-analysis systematically, enabling the researcher to explore data in depth and at the same time maintaining an effective and transparent audit trail, enhancing rigour of the analytic process and credibility of the findings. The reasons for choosing the framework approach are that it suited the cross-sectional descriptive data, enabling different aspects of data under investigation to be captured. The second reason is that there is transparency of the researchers' interpretations of the participants' experiences. The third reason is that the interconnected stages in the framework approach explicitly describe the processes that guide the systematic analysis of data from initial management through to development of descriptive to explanatory account (Ritchie & Lewis, 2003 as cited by Smith & Firth, 2011:55). This approach was suitable for this study as the collected data was in the form of words and field notes. The researcher and an independent co-coder worked separately, allocating data into categories and themes and

eventually, the final concepts were formulated. Afterwards these themes were verified through reflection and discussion to reach consensus with the independent data-analyst encoding the same data. Data-analysis by the independent data analyst is available in annexure M. The co-coder is experienced in qualitative research and his background and experience are available in annexure K. The focus of the study was feasibility. The whole process resulted into 1 core concept, 3 themes and 10 categories.

### **3.2.1 Framework approach to data-analysis**

According to Smith and Firth (2011:55), the framework approach comprised three stages which include data management, descriptive accounts and explanatory accounts.

- Data management - data is read and re-read to identify initial themes, developing a coding matrix, assigning data to themes and categories.
- Descriptive accounts – summarizing coded data, refining initial themes and categories, identifying associations between themes until the whole picture emerges, developing more abstract concepts.
- Explanatory accounts – developing associations or patterns within concepts and themes, reflecting on analytical stages to ensure participants' accounts are accurately presented and to reduce the possibility of misinterpretations, interpreting meaning and explaining concepts and themes seeking wider application of concepts.

An example of one focus group interview transcript to illustrate how coding of similar responses were done, is presented in Annexure I.

## **3.3 APPLICATION OF THE FRAMEWORK APPROACH**

The framework has three interconnected stages that explicitly describe the processes that guide systematic analysis of data from initial management through to the development of descriptive to explanatory accounts (Smith & Firth, 2011:55). Each stage of analysis is presented in a table format.

### **3.3.1 Data management using theme based approach**

Initial categories were developed using transcripts with key phrases highlighted and comments written in the margin to record preliminary thoughts. Key phrases were summarized using participants' own words (Smith & Firth, 2011:56). Table 1 shows the coding matrix to identify initial categories.

**Table 3 1 Formulation of initial categories (Process followed from data in interview transcripts)**

Quotations addressing similar ideas (Initial categories) are marked in colour.

Quotations from interview transcripts	Description (in-vivo codes)	Preliminary thoughts	Initial categories
<p>'I have realized that tool gives you more guidance'. (FG 1; p2; P A).</p> <p>'I think the tool is good and I even prefer to use it as my own tool, so we must continue using it'. (FG 2; p 5; R 3).</p> <p>"You can identify the needs of the patient by using this tool". (FG 3; p 3; R 5)</p>	<p>'The tool gives you more guidance'.</p> <p>'The tool is good'.</p>	<p>Ottawa tool is seen as a source of information and guidance to midwives</p>	<p>Information provision and guidance to the midwives are seen as advantages</p>
<p>'As you compare this tool with the tool that we use at the clinic, this one is very concise. I think this one is the relevant tool to be used'. (FG 3, p 1, R 7).</p> <p>"This new tool is very specific". (FG 3; p 1; R 5)</p> <p>'This is the correct tool according to my opinion.' (FG 3; p 6; R 7).</p>	<p>'The tool is very concise and relevant'.</p>	<p>The Ottawa Decision Tool is assessed as ease of use and facilitating the midwives' work</p>	<p>Ease of use an facilitation of midwives' work is seen as an advantage</p>
<p>'The tool is ok because everything is there and it is</p>	<p>'The tool is specific'.</p>	<p>The Ottawa Decision</p>	<p>The comprehensiveness of the tool is seen as an</p>

<p>clear'. (FG 2; p6; R 2).</p> <p>'I think everything has been covered in the tool'. (FG 2; p5; R 4).</p> <p>'I think it embraces everything.' (FG 3; p 1; R 7)</p> <p>"I think the tool does not need any modifications. It has all the important information that the patient has to know." (FG 3; p 6; R 6).</p> <p>"All the things you have to ask from the patient are there and they are clear and straight forward." (FG 2; p 3; R 3).</p> <p>'According to me it covers everything'. (FG 3; p 5; R 1).</p>	<p>'The tool lets you identify patient's needs'.</p> <p>'This is the correct tool'.</p> <p>'The tool is ok and clear'.</p> <p>'The tool covers everything'.</p> <p>'It embraces everything'.</p> <p>'It has all the important information'.</p> <p>'Everything is there, clear and straight forward'.</p> <p>'It covers everything'.</p>	<p>Tool is comprehensive</p>	<p>advantage</p>
<p>'It is also user friendly'. (FG 1; p 3; P A).</p> <p>"In a way it's user friendly". ( FG 3; p 3; R 5</p> <p>'Yes the tool is user friendly". (FG 3; p 3; R 6).</p>	<p>"It is user friendly".</p>	<p>Ottawa Tool is user friendly.</p>	<p>The user-friendliness of the tool is seen as an advantage.</p>
<p>'It saves time as well'. (FG 1; p 3; P A).</p> <p>'It saves time because you don't have to repeat the</p>	<p>'It saves time.'</p>	<p>Ottawa Tool saves time for the midwives.</p>	<p>Time saving is seen as an advantage.</p>

<p>whole information'. (FG 1; p 4; P B).</p> <p>'It's not time-consuming because you give them knowledge and support'. (FG 2; p 3; R 1).</p> <p>"It's short." (FG 3; p 1; R 7)</p> <p>"This one is specific. More precise.' (FG 3; p 2; R 5).</p> <p>"According to my opinion, I think it's not time-consuming". (FG 3; p 3; R 5).</p> <p>"It saves... a lot of time". ( FG 3; p 3; R 6 )</p>			
<p>'It needs you to go deep, give information'. (FG 1; p 2; P A).</p> <p>'Ottawa gives them more information on all infant feeding options'. (FG 1; p 2; P A).</p> <p>'They feel more comfortable about this one because it gives them information'. (FG 1; p 2; P B)</p> <p>"Lots of them didn't know that it is safe but afterwards they opted for breast feeding, knowing exactly the consequences". (FG 3; p 4; R 5)</p> <p>'There is more information and more patient participation'. (FG 1; p 2; P A).</p>	<p><u>'You give the clients information'.</u></p>	<p>Ottawa Tool is a source of information to the clients.</p>	<p>Provision of information is seen an advantage.</p>

<p>They are able to choose an option that is suitable for them'. (FG 1; p 2; P A).</p> <p>'So they are interested in this one'. (FG 1; p 3, P A).</p> <p>'It gives them more options to choose from. It makes it easier because they are the ones who make a choice'. (FG 1; p 3; P A).</p> <p>'This tool for them is more suitable, most suitable because each and every decision they take is theirs'. (FG 1; p 3; P B)</p> <p>'It's easier when you use the Ottawa'. (FG 2; p 2; R 2).</p> <p>'It's easier because it's their choice'. (FG 2; p 2; R 4).</p> <p>'Yes it's easier because they are given the right to choose'. (FG 2; p 2; R 1).</p> <p>'I think this one is easier because it's their choice'. (FG 2; p 2; R 4).</p> <p>"I think for me it makes it easier for them to make</p>	<p>'Clients feel comfortable'.</p> <p>'Clients participate actively'.</p> <p>'Patients have freedom of choice'.</p>	<p>Ottawa Tool offers freedom of choice / facilitates decision-making.</p>	<p>Freedoms of choice and decision making- facilitation are seen as advantages.</p>
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<p>choice". (FG 3; p 4; R 5)</p>			
<p>'If they are well informed about feeding choice, it becomes easier'. (FG 3; p 4; R 7)</p> <p>'This tool makes them feel comfortable because they have the guide'. (FG 1; p 3; P A).</p> <p>'It builds a relationship between you and the patient'. (FG 1; p2; P B).</p> <p>'They demand the tool to be attached to their clinic cards'. 9FG 1; p 5; P B).</p> <p>'I find it easier for them because they have that support'. (FG 2; p 4; R 3).</p> <p>"it covers all the aspects like you see the support, knowledge".(FG 3; p 1; R 7)</p>	<p>'It is easy to choose when you use the Ottawa'.</p> <p>'It builds rapport and provides support'.</p>	<p>Ottawa Tool is a source of support / empowerment or family involvement.</p>	<p>Provision of support and empowerment are seen as advantages.</p>
<p>It is useful for the sake of the patient. For the sake of...,mmh... it benefits the patient".(FG 3; p 3; R 5)</p> <p>"Yes, for me counselling women prepares them for the support from the in-laws".(FG 3; p 4; R 7)</p> <p>"So the patients feel free to express their emotions</p>	<p>'Clients are free to talk'.</p>	<p>Ottawa Tool offers freedom of expression.</p>	<p>Freedom of expression to the patients is seen as an advantage.</p>

<p>how they feel about their status'. (FG 1; p 2; P B).</p> <p>'Most of them were disclosing'. (FG 3; p 5; R 5).</p> <p>"When we are two, it's me and her; she can talk about to me about anything" (FG 3; p 3; R 6)</p>			
<p>They are well informed and they feel they are in control'. (FG 1; p 4; P A).</p> <p>'They feel free because they take everything for themselves'. (FG 1; p 4; P B).</p> <p>'It depends on their level of education'. (FG 2; p 5; R 2).</p> <p>'Some of them it depends on their level of maturity'. (FG 2; p 4; R 4).</p> <p>"Most of the women that I have counselled like they were independent" (FG 3; p 5; R 6)</p> <p>"Yes, they were independent to make their own choice". (FG 3; p 5; R 6)</p> <p>"What I can say is that it depends on the marital status of the woman and one other thing on their</p>	<p>'Clients are independent to make their own choices'.</p> <p>'Educational level determines ones independence'.</p> <p>'Maturity level determines level of independence'.</p> <p>'Marital status and educational level determines ones independence'.</p>	<p>Various factors determine if a woman can take independent decisions, but the Ottawa Tool can enable them to be more independent.</p>	<p>The ability of the tool to enable women to be more independent is seen as an advantage.</p>

<p>level of education and on their economic status." (FG 3; p 6; R 7).</p>			
<p>"It considers the beliefs of the mothers". (FG 2; p 4; R 1)</p> <p>'When it comes to beliefs it depends on who that person is, so it helps them to retain their beliefs'. (FG 2; p 4; R 2)</p> <p>"It also supporting their cultural beliefs" .(FG 2; p 4; R 4)</p> <p>"It covers all the aspects like you see the support, knowledge and values". (FG 3; p 1; R 7)</p> <p>"I think on the basis that values are also being included it is easier you see". (FG 3; p 4; R 7)</p> <p>"It addresses their values". (FG 3; p 5; R 6).</p>	<p>'It considers values and beliefs of the clients'.</p>	<p>Consideration of beliefs and values of the clients.</p>	<p>Consideration of beliefs and values is seen as an advantage.</p>
<p>"What I can say about this ODST tool neh, ODST, is that it's some sort of confidential and it's one to one interview between you and the patient". (FG 3; p 3; R 5)</p>	<p>'Confidentiality and privacy are maintained'.</p>	<p>Ottawa Tool ensures privacy.</p>	<p>Privacy is seen as an advantage.</p>

<p>'When it comes to beliefs it depends on who that person is, so it helps them to retain their beliefs'. (FG 2; p 4; R 2)</p> <p>'It also supports their cultural beliefs'. (FG 2; p 4; R 4)</p> <p>'It covers all the aspects like you see the support, knowledge and values'. (FG 3; p 1; R 7)</p> <p>'I think on the basis that values are also being included it is easier you see'. (FG 3; p 4; R 7)</p> <p>'It addresses their values'. (FG 3; p 5; R 6).</p> <p>'It makes them stand by their decision and it gives them comfort knowing that the option is theirs and they are going to stand by their decision as they know why they chose it.' (FG 1; p 3; P A).</p>	<p>'Patients become responsible and adhere to their decisions'.</p>	<p>Ottawa Tool improves adherence and responsibility.</p>	<p>Adherence and responsibility are seen as advantages.</p>
<p>'For me it's time-consuming because you got to see to it that they really understand'. (FG 2; p 3; R 2)</p> <p>'For me I can say it takes, it takes a little bit longer'. (FG 3; p 3; R 5)</p>	<p>'Ottawa tool application takes longer and consumes time'.</p>	<p>Ottawa Tool is time-consuming.</p>	<p>Time consumption is seen as a shortcoming.</p>

<p>'It's just that the level of understanding takes time if you find a low I.Q., then you got to spend more time'. (FG 2; p 5; R 2).</p>			
<p>'It should include questions for the buddy'. FG 1; p4; P B)          'I think there should be a follow up tool'. (FG 1; p5; P A)</p>	<p>'The tool should have questions for the buddy and should have a follow up tool'.</p>	<p>Ottawa Tool lacks questions for the buddy.</p>	<p>Lack of questions for the buddy is seen as a shortcoming.           Unavailability of a follow up tool is seen as shortcoming.</p>

### 3.3.2 Identifying and testing a thematic framework

A coding matrix was developed from the three focus group transcripts where participants' own words (in-vivo codes) were grouped into broad categories. Similar categories were brought together to form broader initial themes, then the coding matrix at a later stage. The coding index was constantly refined throughout data-analysis as new insights emerged (Smith & Firth, 2011:56). Refer to table 3.2 for coding matrix.

**Table 3.2: Coding matrix**

Initial categories	Initial themes
<p>Advantages:</p> <p>Information provision and guidance to the midwives are seen as advantages.</p> <p>Ease of use and facilitation of midwives' work is seen as an advantage.</p> <p>Comprehensiveness is seen as an advantage.</p> <p>User-friendliness is seen as an advantage.</p> <p>Time saving is seen as an advantage.</p>	<p>Feasibility relating to midwives.</p>
<p>Disadvantages: Only few participants mentioned that the tool is time-consuming. Majority of the participants verbalized that it saved them time. Few participants suggested that the tool should include questions for the buddy and there should be a follow up tool as well.</p>	
<p>Provision of information is seen as an advantage.</p> <p>Freedom of choice and decision-making facilitation are seen as advantages.</p> <p>Provision of support and empowerment are seen as advantages.</p> <p>Freedom of expression to the patients is seen an advantage.</p> <p>Independence is seen as an advantage.</p> <p>Beliefs and values consideration is seen as an advantage.</p> <p>Privacy is seen as an advantage.</p> <p>Adherence and responsibility are seen as advantages.</p>	<p>Feasibility relating to clients.</p>

### 3.3.3 Development of descriptive and explanatory accounts

This involves summarizing and synthesizing range and diversity of coded data by refining themes and categories. Data was synthesized by refining initial themes and categories until the whole picture emerged. The researcher constantly referred to original transcripts to

ensure that data themes are grounded in the participants' descriptions. Abstract concepts were developed by identifying key dimensions of synthesized data, making associations between themes and concepts (Smith & Firth, 2012: 59).

To ensure that the experiences of the midwives regarding the use of the ODST in counselling HIV positive mothers on the choice of a safe infant feeding option for their babies were accurately reflected and to minimize misconceptions, explanatory accounts began with reflection on the original data and on the analytical stages.

Through the use of the framework approach, a core concept that appeared to reflect the midwives' accounts of the use of the ODST to counsel HIV positive mothers on an infant feeding choice was developed: feasibility. The relationship between the core concept, established literature and theoretical perspectives relating to feasibility were explored to make sense of the concepts and themes in relation to the participants' experiences.

**Table 3.3 Developing the core concepts and final themes**

Initial Themes	Initial categories	Refined categories	Final themes	Core concept
Feasibility relating to midwives	Information provision and guidance to the midwives are seen as advantages. Ease of use and facilitation of midwives' work is seen as an advantage. Comprehensiveness is seen as an advantage. User-friendliness is seen as an advantage Time saving is seen as an advantage.	Capacity building to midwives.  User-friendliness Comprehensiveness  Time saving	Appropriateness Feasibility	Feasibility
Feasibility relating to the clients	Provision of information is seen an advantage. Freedom of choice is seen as an advantage. Provision of support and empowerment are seen as advantages. Freedom of expression of the clients is seen as an advantage. Independence is seen as an advantage. Beliefs and values consideration is seen as an advantage. Privacy is seen as an advantage. Adherence and responsibility are seen as advantages. Decision-making facilitation is seen as an advantage.	Rapport building between midwife and client. Support and empowerment to the clients.  Values and beliefs consideration. Confidentiality maintenance. Improved adherence and responsibility. Easy decision-making.	Receptiveness of professional intervention.  Effectiveness	Feasibility

Data was analysed by the researcher and the independent co-coder who worked separately. The findings of the researcher and the independent co-coder are discussed below.

### **3.4. COMPARISON OF DATA-ANALYSIS**

Both the researcher and the independent analyser came up with similar themes though each used slightly different terminology. The summary of the comparison is as follows:

- The researcher came up with a theme that she identified as benefits to the midwives while the independent analyser identified the same theme as nurses' perspective.
- The researcher named the second theme benefits to the clients while the independent analyser used the name perspectives about the clients.
- The researcher came up with an all-embracing theme that included consideration of the clients' beliefs and values when the independent analyser identified it as effects on the clients' cultural beliefs.

The agreement between the researcher and the independent analyser was that a lack of questions for the buddy and the lack of a follow-up tool should be regarded as suggestions as the participants were not criticizing the tool. They said it was acceptable but should include them. By a buddy the midwives meant a person accompanying an HIV positive mother though it is not what was being investigated.

### **3.5. FINDING INTERPRETAION**

The results are discussed according to the core concepts and themes that emerged from data-analysis. Literature is provided to augment the findings. In this current study, the focus was on the feasibility of the ODST. The core concept that emerged from data-analysis was indeed feasibility. Before an intervention could be implemented there should be evidence supporting its feasibility. Evidence is defined by the Oxford advanced learner's dictionary (2005:502) as facts, signs or objects that make one believe that something is true. In the nursing profession, an intervention has to be evidence-based before it can be considered. Burns and Grove (2005:641) define evidence-based practice as the integration of research evidence with clinical expertise and patient values and needs in the delivery of quality cost-effective health care. Evidence plays an important role in clinical decision-making as everything needs to be based on evidence. Pearson (2008:4) summarized evidence interests into the following headings:

- Feasibility- evidence about the extent to which an intervention is practical.
- Appropriateness- evidence about the extent to which an activity or intervention is ethical or culturally apt.
- Effectiveness- evidence about the effects of a specific intervention on specific outcomes.

The third heading of Pearson's summary of evidence is meaningfulness but it was not addressed in this study as the focus was feasibility.

The findings of this study are compatible with the above evidence interests as well as the theoretical framework (ODSF) and are discussed below. The following themes emerged from data analysis:

### **3.5.1 Theme 1: Appropriateness**

From the focus group interviews, it was evident that the ODST is appropriate for counselling HIV positive mothers. Most of the respondents mentioned that the tool is good, precise and a relevant tool to be used and does not need any modification as it covers everything. One of the respondents also mentioned that she thought they should continue using it. The majority of the respondents mentioned that the ODST is not time-consuming and only a few mentioned that they do consider it as time-consuming. This tally with the results of the study by Hungerford *et al.* (2003:18) that showed with regard to the time factor, the majority of the staff reported that the intervention fitted into their normal routine and rarely interrupted clinical operations. Only a few participants reported that the process caused patients to spend additional time.

Some of the midwives mentioned that the ODST gave information to clients and guided midwives on how to go about counselling. Furthermore, the midwives also mentioned that the ODST took the mothers values and beliefs into consideration. That means that the ODST is appropriate as an intervention in decisional conflict to enable the HIV positive mothers to make an informed choice on safe infant feeding option. The participants also mentioned that it was easy for the mothers to make a choice after receiving infant feeding counselling using the ODST. This findings are similar to those of the study by Hungerford *et al.* (2003:17) indicated that the intervention was acceptable to staff and patients. The majority of the staff reported that the patients were co-operative. They also supported the project and agreed that it should continue.

### **3.5.2 Theme 2: Receptiveness of intervention**

Some of the participants in this current study did indicate that the mothers prefer being counselled with the ODST and were comfortable about the use of it as it gave them information and they felt free and happy to make their own decisions. According to the participants, with the use of the ODST, there was more participation of the mothers where they have freedom of choice with their values being respected. They also found the tool understandable. This agrees with the finding in the study by Hungerford *et al.* (2003:17) that the use of a screening and management tool was acceptable to patients as they expressed that the intervention was helpful and informative. HIV positive mothers' preference of the ODST also tallies with the study findings of Flax and Earp (1999:19) in their study where they used lay health advisors for health promotions, where they found that the participants were comfortable with the lay health advisors.

Furthermore, the findings of the this study are also similar to those in the study of O'Connor (1999:732) who stated that decision aids improved, the average knowledge and patients' perceptions by making them feel informed and clear about personal values and supported in decision-making. O'Connor (1999:733) further asserted that decision aids helped patients to feel more comfortable with their choices as they participated actively in decision-making, hence reduced decisional conflict.

In this current study, it was evident that the ODST provided support and empowerment to mothers as some of the participants mentioned that counselling the mothers using the ODST built a relationship with the mothers disclosing their status and feeling free to talk about anything. Both of the statements confirm the findings by (Flax & Earp, 1999:19) that the participants in their study had close relationships with the Lay Health Advisors (LHAs) who counselled them and tended to increase the frequency of interactions. Flax and Earp (1999: 20) further asserted that the participants expressed that they received social, emotional, physical and informational support from the LHAs.

### **3.5.3 Theme 3: Effectiveness**

Effectiveness regarding the decision-making of the HIV positive mothers as perceived by them was not determined in this study. The effectiveness of the ODST is based on the perception of the midwives who used the tool. Basically, information that is given to patients or an intervention that is used during service rendering is directed at a change in behaviour or towards resolution of a decisional conflict. Looking at the current study, the participants indicated that after they had counselled the HIV positive mothers on an infant feeding choice

using the ODST, it was easy for them to make a choice. One of the participants also mentioned that the mothers stood by their decision, meaning that the ODST improved adherence and responsibility of the mothers. After receiving counselling using the ODST to assist them in making a safe infant feeding option, the decisions taken by HIV positive mothers were informed ones that tallied with their values, hence they adhered to them.

This confirms the assertions made by Stacey *et al.* (2006:5) in their study that effective interventions prepare patients for many value sensitive decisions by helping them become informed and clarifying their values for each option. When considering the outcome aspects in the study of Hungerford *et al.* (2003:18), the outcome scores improved significantly during a follow up interview. Flax and Earp (1999:20) also indicated that counselling influenced the counselled women's way of life and enabled them to get free intervention, knowledge about where to get it, as well as motivating them to go for regular check-up consultations.

In a study by Douillet *et al.* (2006:288) about the health coaching approach while using the ODSF, the findings showed that it supported women to make their own choices that were in line with their values and beliefs. Table 3.3 indicated that the ODST is feasible based on the themes and concepts that emerged from data analysis. This means that the ODST assists HIV positive mothers in an infant feeding choice, thus resolving their decisional conflict.

### **3.4 FEASIBILITY CORE CONCEPT**

An overall feasibility core concept was developed from the themes that emerged. According to the themes that emerged from data analysis of the current study it is evident that the ODST is feasible for counselling HIV positive mothers regarding an infant feeding choice. Undre (2006:1714) indicated that Observational Teamwork Assessment for Surgery was feasible as an intervention method. In the study by Hungerford *et al.* (2003:18), the screening and brief intervention for alcohol problems was feasible as it met the three feasibility aspects of acceptability, practicality and outcome. Based on the above findings, the ODST is also feasible as an intervention to assist HIV positive mothers' infant feeding choice.

### **3.5 CONCLUSION**

This chapter presented the analysis of interview results, including themes and the core concept that emerged, using the framework approach. The reason for using a framework approach was for a transparent audit trail. The whole process resulted into 10 categories, 3

themes and 1 core concept: Feasibility. The results of the study were discussed according to themes and the core concept that emerged from the data-analysis.

## CHAPTER 4

### CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

#### 4.1 INTRODUCTION

The previous chapter presented the data-analysis process, the research findings and discussions with reference to the literature. This chapter presents the conclusions, limitations and recommendations for nursing practice, nursing education and recommendations for further research.

#### 4.2 ATTAINMENT OF OBJECTIVES

The purpose of this study was to explore and describe the feasibility of the Ottawa Decision Support Tool in counselling HIV positive mothers on decision-making regarding the choice of a safe infant feeding option. The objective of the study will be discussed for conclusion purpose.

The objective of the study as stated in chapter 1 was to explore and describe the feasibility of the use of the ODST by midwives in counselling pregnant HIV positive mothers regarding the choice of an infant feeding option in terms of time needed and user-friendliness. From the themes that emerged from data analysis, it is evident that the study objective has been attained, meaning that the ODST is feasible in assisting HIV positive mothers' infant feeding choice.

##### **Theme 1: Appropriateness**

##### **Category 1.1: Capacity building to basic midwives**

The following conclusions were drawn from this data:

From the focus group interviews, it is evident that the ODST gives more guidance to midwives. One of the participants mentioned the fact that the ODST enabled them to identify the needs of the mothers. Provision of information and guidance to midwives are seen as an advantage.

##### **Category 1.2: User-friendliness**

From the midwives' responses, the ODST is user friendly based on the fact that when compared with the usual tool at the clinic, the ODST is concise, clear, relevant and specific.

The tool was rated as user friendly, containing all the information that the mothers needed to know. Ease of use is an advantage and therefore the objective of the study in terms of user-friendliness has been achieved.

#### **Category 1.3: Time saving**

The majority of the participants indicated that the ODST saved them time, but there were a few participants who indicated that they found the tool to be time-consuming. It is evident that the objective of the study in terms of time needed has been achieved.

#### **Category 1.4: Comprehensiveness**

From the focus group interviews, it is evident that the participants regarded the tool as embracing everything needed, and found it to be clear and straight forward and did not need any modification. The fact that the ODST is comprehensive is an advantage. This confirms the feasibility of the use of the ODST by the midwives.

### **Theme 2: Receptiveness of professional intervention**

#### **Category 2.1: Rapport building between midwife and client**

Although the researcher does not have direct data from the mothers, the conclusions that were drawn were based on the information from the midwives who had close contact with them. According to the participants' accounts, it is evident that due to the rapport that the ODST builds, the mothers feel free to talk to the midwives and they end up disclosing their status to their relatives.

#### **Category 2.2: Support and empowerment**

The participants in this study indicated that with the use of the ODST, there was more participation on the mothers' side where they had freedom of choice, with their values being respected and the tool was understandable as it was well formulated. The ODST empowers HIV positive mothers with information and guidance to be independent decision makers.

### **Theme 3: Effectiveness**

From the midwives perceptions it is clear that the ODST brings about change in behaviour and the mothers do not regret their choices. Based on these perceptions, the quality of the decision that the mothers make, is high because the decisions are informed and value based as they have guidance and information.

### **Category 3.1: Values and beliefs consideration**

From the focus group interviews of the current study, it is evident that the ODST provides guidance on how to ensure that the values and beliefs of the mothers are taken into consideration. The decisions that are taken by the mothers tally with their values.

### **Category 3.2: Confidentiality maintenance**

In this study, one of the participants mentioned that using the ODST was confidential and a one to one counselling. This implies that the ODST takes human rights regarding confidentiality into consideration. This gives mothers comfort to realize that their confidentiality is respected.

### **Category 3.3: Improved adherence and responsibility**

The participants in this study mentioned that with the ODST, the mothers were happy with their choices and stood by their decision. Mothers are the ones who know best about their situation, so it is easy for them to adhere to decisions of their choice.

### **Category 3.4: Easy decision-making**

The participants mentioned that after they had counselled the mothers on the risks and benefits of all infant feeding options it became easier for the mothers to make a choice. This implies that the ODST is feasible in assisting HIV positive mothers' infant feeding choices.

## **4.3. APPLICATION OF THE ODSF (Ottawa Decision Support Framework)**

Findings of this study are based on the adapted and adopted theoretical model of Ottawa Decision Support Framework (O'Connor & Jacobsen, 2007:7). The picture showing this framework is displayed in the next page.

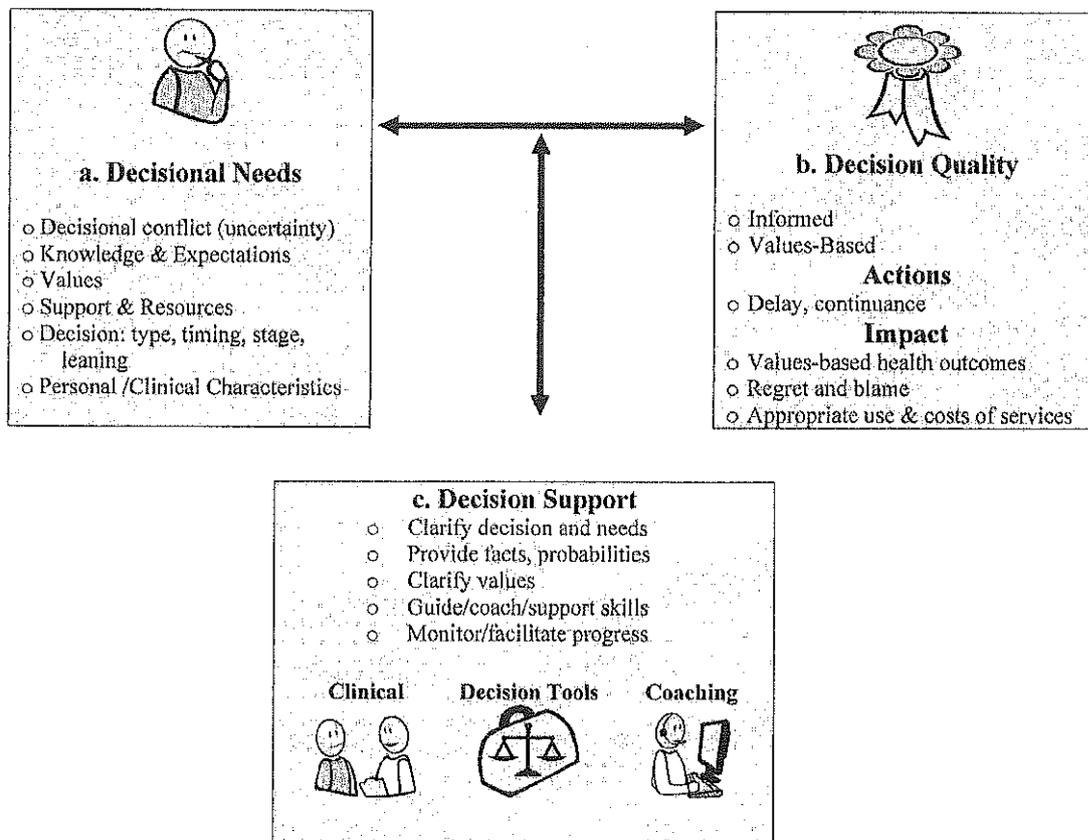


Figure 4.1 Ottawa Decision Support Framework

Adopted and adapted from O'Connor and Jacobsen (2007:7)

The model is aimed at guiding patients in making health or social decisions. The ODSF, to which the findings of this study will be linked, is used for supporting people experiencing uncertainty about options affecting their health. With regard to this ODSF, to enable people to make best choices, they need to be informed about the benefits and harms of each alternative. The decisions that they take have to tally with their values and will have an impact on behaviour like adherence to one's choice. Furthermore, there should not be any blame or regret over the benefits of the rejected alternative.

The key elements of the ODSF are decision needs, decision quality and decision support. To enable a person to make a good decision, they need to be supported through clinical counselling, decision tools and coaching, thus improving decision quality (O'Connor & Jacobsen 2007: 7). Furthermore, the ODSF has 3 steps that are applied in addressing a decisional conflict: (a) Assess clients' and practitioners' determinants of decision support

needs; (b) Provide decisional support tailored to clients' needs and (c) Evaluate the decision-making process and outcome (OHRI 2013:1). The ODST is a decision support intervention that was developed from the ODSF to facilitate these steps. The findings under the three key elements are concluded below:

#### **4.3.1 Decisional needs**

From the focus group interviews, the respondents indicated that the ODST guided them and helped them identify the clients' needs. The respondents also mentioned that the values and beliefs of the mothers were taken into consideration when they used the ODST in counselling HIV positive mothers regarding the choice of a safe infant feeding option. This accomplishes the first step of assessing clients' and practitioners' determinants of decision support needs.

#### **4.3.2 Decision quality**

From the midwives accounts, it is evident that:

- The mothers were feeling comfortable about the tool as it gave them information.
- They were well informed about the benefits and harms of all infant feeding options.
- There was more client participation whereby the mothers were given more options to choose from.
- Clients were guided and supported and given freedom of choice to choose what was suitable for them with their values taken into consideration.

Based on the respondents' accounts, the second step of providing decision support tailored to clients' needs was addressed.

#### **4.3.3 Decision support**

From the midwives accounts, it is evident that it was easy for HIV positive mothers to make an infant feeding choice after they had received counselling using the ODST. These mothers were supported with information to enable them to make informed decisions and the findings indicated that the midwives perceived that:

- It was easy for them to make choices independently and they felt that they were in control.
- The choices that they made were informed ones and they were able to adhere to their decisions.
- The decisions that they took tallied with their values.

That accomplishes the third step of providing decision support tailored to clients' needs. The findings of this study lead to a conclusion that the ODST is indeed feasible in assisting HIV positive mothers' infant feeding choice.

#### **4.4 LIMITATIONS**

The sample of the study was only limited to one local area. The local area is small with six fixed clinics and three mobile clinics. The antenatal program is allocated to one midwife per facility. This had an impact on the sample size as there was only one midwife who met the selection criteria in each facility. Though generalizability is not the aim of a qualitative study, there might have been a wider spectrum of perceptions if the researcher could have had a larger sample size. As a result of a small sample size, focus groups did not have large enough participants as recommended and it might have had an influence on the richness of data.

Only the midwives were interviewed. Initially, the researcher intended to interview the mothers who received counselling using the ODST to explore and describe the value of the ODST, but it was difficult to get access to them.

The reasons for the difficulty in access were: some of the mothers who received counselling with the ODST were from other provinces who only came to their parents' house for the confinement and they returned to their places of permanent residence soon after that and could therefore not be traced; other mothers were students at institutions outside this province and before six weeks post-delivery they had gone back to resume their studies; in other cases they had moved from the physical address or were not available on the cell phone numbers they provided; and the few that could be reached were not willing to participate in the study. Therefore, the findings of the study comprised the experiences of the midwives in using the tool and their perceptions on the experiences of HIV positive mothers.

#### **4.5 RECOMMENDATIONS**

In order to empower HIV positive mothers to be independent decision makers, the following recommendations are made for nursing practice, nursing education and further research:-

##### **4.5.1 Recommendations for nursing practice**

PMTCT guidelines with Ottawa Decision Support Tool as one of the infants feeding counselling tools should be developed. This will curb a situation whereby midwives find themselves commanding or prescribing for HIV positive mothers which infant feeding option to choose. The use of the ODST will resolve the helplessness experienced by some

midwives during infant feeding counselling, as well as resolving a decisional conflict experienced by the mothers.

There must be copies of the tools available in all facilities providing ante-natal care services.

#### **4.5.2 Recommendations for nursing education**

The ODST should be introduced in the midwifery training program to capacitate midwives in their infant feeding counselling skills. Midwives that are already in practice should be given in-service training on the ODST as part of infant feeding counselling during PMTCT with the charts developed on it. Role play should be used as a teaching method to enable the students to apply what happens in a real world. This will help them to further develop counselling skills.

#### **4.5.3 Recommendations for further research**

Further research need to be done to explore and describe the feasibility of the ODST, interviewing HIV positive mothers to get their life experiences in terms of its value. Furthermore, studies on ODST should be rolled out to other fields where clients have to make decisions, for example family planning to explore its feasibility.

### **4.5 CONCLUSION**

This chapter presented conclusions, limitations and recommendations. It is evident that the ODST is feasible to assist HIV positive mothers' infant feeding choice. Therefore, the use of the ODST in counselling HIV positive mothers regarding infant feeding choice may empower them to be independent decision makers. It may also support the HIV positive mothers to disclose their status to their relatives; hence they will stop mixed feeding due to fear of disclosure, thus minimizing the risk of MTCT of HIV. Although the ODST was developed in the first world countries and was found to be feasible, it can still be used to assist in decision-making in third world countries like South Africa.

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# Annexure A: Ottawa decision support tool

## Ottawa Personal Decision Guide For People Facing Tough Health or Social Decisions

You will be guided through four steps:

- 1 Clarify the decision.
- 2 Identify your decision making needs.
- 3 Explore your needs.
- 4 Plan the next steps.

### 1 Clarify the decision.

What decision do you face?

What is your reason for making this decision?

When do you need to make a choice?

How far along are you with making a choice?

- I have not yet thought about options       I am close to making a choice  
 I am thinking about the options       I have already made a choice

Are you leaning toward one option?

- Yes       No

If yes, which one?

### 2 Identify your decision making needs.



Support

Do you have enough support and advice from others to make a choice?  Yes  No

Are you choosing without pressure from others?  Yes  No



Knowledge

Do you know which options are available to you?  Yes  No

Do you know both the benefits and risks of each option?  Yes  No



Values

Are you clear about which benefits and risks matter most to you?  Yes  No



Certainty

Do you feel sure about the best choice for you?  Yes  No

People who answer "No" to one or several questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps three and four that focus on your needs.

### 3 Explore your needs.



Support

Who else is involved?

Name:

Name:

Name:

Which option does this person prefer?

Is this person pressuring you?

Yes  No

Yes  No

Yes  No

How can this person support you?

What role do you prefer in making your choice?

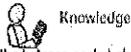
I prefer to share the decision with \_\_\_\_\_

I prefer to decide myself after hearing the views of \_\_\_\_\_

I prefer that someone else decides. Who? \_\_\_\_\_

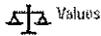
Decisional Conflict Scale © 2006 O'Connor





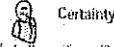
Knowledge

In the balance scale below, list the options and main benefits and risks you already know. Underline the benefits and risks that you think are most likely to happen.



Values

Use stars (★) to show how much each benefit and risk matters to you. 5 stars means that it matters "a lot". No star means "not at all".



Certainty

Circle the option with the benefits that matter most to you and are most likely to happen. Avoid the option with the risks that are most important to avoid.

	⊕ BENEFITS Reasons to choose this option	How much it matters Add ★ to ★★★★★	⊖ RISKS Reasons to avoid this option	How much it matters Add ★ to ★★★★★
Option #1				
Option #2				
Option #3				

⊕ Plan the next steps based on your needs.

✓ Things making the decision difficult



Support

You feel you do NOT have enough support

You feel PRESSURE from others to make a specific choice



Knowledge

You feel you do NOT have enough facts



Values

You are NOT sure which benefits and risks matter most to you

Other factors making the decision DIFFICULT:

✓ Things you are willing to try

Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends)

Find out what help is on hand to support your choice (e.g. funds, transport, child care)

Focus on the opinions of others who matter most.

Share your guide with others.

Ask others to complete this guide.

Find areas of agreement. When you disagree on facts, agree to get information. When you disagree on what matters most, respect the other's opinion. Take time to listen, never back what the other has said matters most to him or her.

Find a neutral person to help you and others involved.

Find out about the chances of benefits and risks.

List your questions and note where to find the answers (e.g. library, health professionals, counsellors);

Review the stars in the balance scale to see what matters most to you.

Find people who know what it is like to experience the benefits and risks.

Talk to others who have made the decision.

Read stories of what mattered most to others.

Discuss with others what mattered most to you.

List anything else you need:

## Annexure B: Ethical Approval



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

Private Bag X6001, Potchefstroom  
South Africa 2520

Tel: (018) 299-4900  
Faks: (018) 299-4910  
Web: <http://www.nwu.ac.za>

### ETHICS APPROVAL OF PROJECT

**Ethics Committee**  
Tel +27 18 299 4850  
Fax +27 18 293 5329  
Email [Ethics@nwu.ac.za](mailto:Ethics@nwu.ac.za)  
2012/05/29

This is to certify that the next project was approved by the NWU Ethics Committee:

<p><b>Project title :</b> "Support for HIV positive mothers"</p> <p><b>Project leader:</b> Dr. CS Minnie</p> <p><b>Student :</b> MS Ncheka Feasibility of the Ottawa decision support tool to assist HIV positive mothers' infant feeding choice</p> <p><b>Ethics number:</b> <b>NWU-00022-11-A1</b></p> <p><b>Expiry date:</b> 2016/05/10</p>
--

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

The formal Ethics approval certificate will be sent to you as soon as possible.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Marietjie Halgryn'.

Me. Marietjie Halgryn  
NWU Ethics Secretariate

## Annexure C: Application for permission to conduct the study

Panorama East

Bethlehem

9701

14<sup>th</sup> July 2012

Free State Provincial Department of Health

The Head of Department

Attention: Dr S. Kabane

Bophelo House

Cnr. Maitland & Harvey Road

BLOEMFONTEIN

Dear Sir

Re: Request for permission to conduct a research: **Feasibility of the Ottawa Decision Support Tool to assist HIV-positive mothers' infant feeding choice.**

I, professional nurse Ncheke M.S. is a student registered for Masters in Community Nursing Science with the North-West University and currently employed in Nketoana local area, Thabo Mofutsanyane District. I hereby request permission to conduct a study on the above mentioned topic as a requirement for the completion of my studies. I have already received approval to conduct this study by the North-West University Ethics Committee (letters attached)

## Introduction

Due to the change in the disease patterns, decision-making regarding the choice of infant feeding has become very complicated. In the past, breast feeding was regarded as the best and safest feeding method for nearly all babies, but in the context of the Human Immune deficiency Virus (HIV) pandemic, HIV infected mothers are faced with the difficult task of deciding which infant feeding method will be the best for their babies. It is very important that HIV infected mothers make the correct choice of infant feeding option, as the life of the baby will be at risk of either vertical mother-to-child transmission (MTCT) of HIV from breast milk or malnutrition and infectious diseases such as diarrhoea and pneumonia if they are deprived of the protection from breast milk.

Socio-economic, cultural and environmental factors need to be considered when HIV positive mothers have to make a choice of a safe infant feeding. Decision-making regarding safe infant feeding should be a joint effort between a mother and a midwife where the midwife provides information on the advantages and disadvantages of the various feeding alternatives supports and advises the mother who in turn will make an informed choice.

**Purpose of the study:** The purpose of the study is to explore and describe the feasibility and value of the use of the Ottawa Decision Support Tool (ODST) in counselling HIV infected mothers on decision-making regarding the choice of safe infant feeding

### **Objectives of the study:**

1. To explore and describe the feasibility of the use of the ODST by midwives in counselling HIV infected pregnant mothers regarding the choice of an infant feeding option in terms of time and user-friendliness.
2. To explore and describe the value of the use of the ODST to support pregnant HIV positive mothers in decision-making regarding the selection of the infant feeding option in terms of satisfaction and clarity.

**Significance of the study:** This study will be on support for HIV positive mothers. Feasibility of using the Ottawa Decision Support Tool (ODST) is not known yet. More research regarding the feasibility of using the ODST is needed before it can be widely implemented. Feasibility and value of the ODST in supporting HIV positive mothers in their decision-making regarding the choice of safe infant feeding will be explored and described in terms of its feasibility according to the counselling midwives and values according to HIV positive mothers who were counselled.

## **Setting, Population and Sampling**

This study will be set in one of the economically disadvantaged local areas situated in the deep rural area of the Nketoana local area in Thabo Mofutsanyane District. The majority of

the child-bearing aged women in this area are from the poor socio-economic background and most of them are illiterate, so decisional conflict in an infant feeding choice is a challenge in the HIV pandemic context.

In this study, the population will be all the midwives in Nketoana local area's fixed and mobile clinics and HIV positive mothers participating in the PMTCT program bringing their babies for follow up at these clinics.

Two samples will be used in this study to reach the two objectives:

**Sample 1 to reach objective 1:** Midwives who received in-service training on the use of the ODST

**Sample 2 to reach objective 2:** HIV positive mothers who received infant feeding counselling, using ODST at 34 weeks of gestation, coming in six weeks post-natal visit in the selected clinics.

Purposive sampling will be used to select participants because they will be the best sources to answer the question for the study. In this study, midwives doing counselling and who are willing to act as mediators will be utilized to recruit HIV positive mothers who meet the selection criteria. The recruiters will record contact details of the mothers and the researcher will contact them to hear if they are interested to participate.

At this stage it is not possible to state what the sample size will be, but data will be collected until there will be no more new themes emerging.

**Duration of the study:** The study will be conducted over a period of four to five months.

### **Data-collection**

Before their perceptions regarding the feasibility, can be explored and described, midwives must first be knowledgeable about the Ottawa Decision-making Tool (ODST) and also have experience in using it. Midwives will be provided with in-service training on the use of the ODST in counselling HIV positive mothers on an infant feeding choice to capacitate them in decision support and guidance skills. As an experienced nurse educator, the researcher has skills that will enable her to conduct in-service education to the midwives using teaching methods such as lecture, question and answer method, as well as role play

After in-service training, a follow-up visit will be done to check if the midwives encounter any problems regarding the tool. Each trained midwife will be provided with a management register to record the clients who have been counselled on an infant feeding choice using the ODST.

Focus Group Interviews for midwives will be used as a data-collection technique to reach the first objective where each group will comprise three midwives. Focus Group interviews will be suitable for the midwives because they stimulate a secure setting where the participants will be able to share their thoughts with each other and generate new ideas (Brink *et al.*, 2006: 152). Midwives training and focus group interviews will run over two to three months.

Individual semi-structured interviews will be for HIV positive mothers to reach the second objective. Individual semi-structured interviews will be suitable for the HIV positive mothers because the information that will be gathered will be first hand, obtained directly from the participants who will be able to tell their story and explain their perception of the value of the ODST during counselling. As the participants will be from the economically disadvantaged area, the majority of them will not be able to read or write, and therefore an interview is considered to be a suitable method for this study. The researcher, by virtue of her experience with conducting interviews, will be able to clarify misunderstanding and obtain in-depth responses. During interviews of HIV positive mothers, the local language that the subjects are conversant with, that is Sesotho and Zulu, will be used. The interviews will be conducted in a consultation room at the clinic to ensure privacy and at the mothers' homes depending on their preference. These individual interviews will be conducted over two to three days.

Both types of interviews will be recorded with an electronic voice recorder after the participants have given their permission and field notes will be taken to be used with the transcriptions of the interviews to generate a deeper understanding of what happened. Polit and Hungler (1997: 457) define field notes as notes regarding the unstructured observations they have made in the field and their interpretations of those observations. These field notes include:

- Observation of non-verbal behaviour and mannerisms.
- Theoretical field notes to derive meaning and insight, making sense of the situation.
- Method related field notes regarding instruction and information that need to be shared with the team core such as issues that entail a summary of the day's progress.
- Personal notes, which entail comments about the researcher's own feelings during the research process (Polit and Hungler, 1997: 273).

## **ETHICAL CONSIDERATIONS**

Data will be collected in a private room to maintain confidentiality. As the study participants will be human subjects, the researcher will make sure that all their rights will be protected by adhering to ethical principles that guide researchers: respect for persons, beneficence and justice (Brink, 2006:31). The participants rights include the right to self-determination, right to privacy, right to autonomy and confidentiality, right to fair treatment and the right to protection from discomfort and harm (Brink 2006: 31).

Respect for persons, beneficence and justice will be ensured as the proposal has already been approved by the North-West University Ethical committee, **ethics number: NWU - 00022-11-a1 (Support for HIV positive mothers)**. Permission to conduct the study will be requested from the Provincial Department of Health, the District manager, the local area manager, as well as the clinic managers. Original data and transcriptions will be kept for a period of five years at the School of Nursing Science of the Potchefstroom campus of the North-West University.

With regard to self-determination and autonomy, the participants will be informed regarding the purpose of the study, the potential benefits and risks, the measures to protect anonymity and confidentiality, the contact details of the researcher in case of questions, as well as their right to withdrawal, before they will be requested to sign a consent form.

With regard to privacy, each participant will be allocated a code to identify themselves on the transcriptions. The informed consent form which will be kept separately from data to ensure that consent forms cannot be linked with the data.

To protect participants' right to fair treatment and the right to protection from discomfort and harm, each member of the population who meet the selection criteria will have a fair chance of selection. Considering the fact that being HIV infected is a traumatic experience and some of the participants might be emotionally traumatized as a result of exploration, a counsellor will be available to comfort the participants when the need arises so as to protect them from discomfort and harm.

Your positive response to grant approval will be greatly appreciated.

Sister Ncheka M.S.

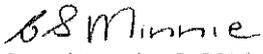
Research supervisor: Dr C.S Minnie

## Annexure D: Signed Provincial letter

To protect participants' right to fair treatment and right to protection from discomfort and harm, each member of population who meet the selection criteria will have a fair chance of selection. Considering the fact that being HIV infected is a traumatic experience and some of the participants might be emotionally traumatized as a result of exploration, a counselor will be available to comfort the participants when the need arises so as to protect them from discomfort and harm.

Your positive response to grant approval will be greatly appreciated.

Sister Ncheka M.S.  
Cell: 0781553029  
Email: [ncheka.s@webmail.co.za](mailto:ncheka.s@webmail.co.za).

  
Research supervisor: Dr C.S Minnie  
Tel: 0182991836  
Email: [Karin.minnie@nwu.ac.za](mailto:Karin.minnie@nwu.ac.za).

## Annexure E: Permission to conduct research



health

Department of  
Health  
FREE STATE PROVINCE

24 October 2012

Ms M.S. Ncheka  
17 Dr Herman Van Schaikwyk Street  
Panorama East  
BETHLEHEM  
9701

Dear Ms Ncheka

**Subject: PERMISSION TO DO CONDUCT RESEARCH STUDY ON FEASIBILITY OF THE OTTAWA DECISION SUPPORT TOOL TO ASSIST HIV -POSITIVE MOTHER' INFANT FEEDING CHOICE**

The above mentioned correspondence bears reference.

Permission is hereby granted for the above -- mentioned research on the following conditions:

- Participation should be by informed consent.
- Study should not interfere with service delivery.
- Confidentiality of information will be ensured and no names will be used
- Adverse events to be reported.
- Copy of final report to be sent to the Head of Department

Trust you find the above in order.

Kind Regards,

Dr S Kabane  
HEAD: HEALTH  
Date: 31/10/2012

Head: Health  
PO Box 227, Bloemfontein, 9300  
4<sup>th</sup> Floor, Executive Suite, Bopzani House, c/o Matieland and Harvey Road, Bloemfontein  
Tel: (051) 405 1107/3 Fax: (051) 405 1055, e-mail: hdp@sahealth.gov.za/051 405 1055

www.fs.gov.za

## **Annexure F: Lesson Plan**

Target group: Midwives responsible for mother and child program

Date: 18<sup>th</sup> July 2012

Time: 10h00 – 13h00

Venue: Nketoana hospital boardroom

Topic: Counselling HIV positive mothers to assist them in decision-making regarding infant feeding choice, using the Ottawa Decision Support Tool

Duration: 3 hours

Presenter: Ncheka M.S.

<p><b>1. Introduction</b></p>	<p>Due to the changes in disease patterns, decision-making regarding the choice of infant feeding has become very complicated. In the past, breast feeding was regarded as the best and safest feeding method for nearly all babies, but in the context of the HIV pandemic, HIV mothers are faced with a difficult task of deciding which infant feeding option will be best for their babies. It is very important that HIV positive mothers make the correct choice of an infant feeding option as the life of their babies will be at risk of either vertical transmission of mother to child transmission (MTCT) of HIV from breast milk or malnutrition and infectious diseases such as diarrhoea and pneumonia if they are deprived of the protection from breast milk. HIV positive mothers therefore need to be empowered to be independent decision makers.</p>	<p>5 minutes</p>	<p><b>Lecture</b></p>
<p><b>2. Learning Outcomes</b></p>	<p>At the end of the learning experience learners should be able to:</p> <p>2.1 Define HIV</p> <p>2.2 List modes of the spread of HIV</p> <p>2.3 Identify the risk of HIV infection in a pregnant mother</p> <p>2.4 List modes of MTCT of HIV</p> <p>2.5 Describe different infant feeding options to minimize the risk of MTCT of HIV.</p> <p>2.6 Identify the advantages and disadvantages of each feeding</p>	<p>5 minutes</p>	<p><b>Lecture</b></p>

	<p>option</p> <p>2.7 Discuss the factors that need to be considered before deciding on a replacement feeding option</p> <p>2.8 Define decision-making</p> <p>2.9 Define a decisional conflict.</p> <p>2.10 Describe how a decisional conflict regarding infant feeding choice can be resolved. Counselling Support Guidance</p> <p>2.11 Clarify with the client as to what decision she is faced with</p> <p>2.12 Verify with the client the reason that prompts her to make a choice</p> <p>2.13 Establish with the client why she is to make a decision</p> <p>2.14 Establish whether she is leaning towards a particular option</p> <p>2.15. Explore decision-making needs to be considered before a decision can be made</p> <p>2.16. Discuss the 4 steps needed to be followed to make an informed decision.</p>		
	<p>2.17. Offer counselling in the given scenario:</p> <p>A 34 weeks pregnant HIV positive mother who attends ante-natal clinic at your facility is experiencing a decisional conflict regarding infant feeding choice. Intervene to assist her make an informed decision using the</p>		<p><b>Role play</b></p>



<p><b>3.9. Decision-making needs</b></p>	<p>making tools providing clients with counselling, support and guidance. One of the decision support tools is the Ottawa personal decision guide.</p> <p>3.9.1. Support</p> <p>3.9.2. Knowledge</p> <p>3.9.3. Values</p> <p>3.9.4. Clarity</p>	<p>10 minutes</p>	
<p><b>3.10. Steps to be followed to arrive at a decision:</b></p>	<p>3.10.1. Support</p> <p>3.10.2. Knowledge</p> <p>3.10.3. Values</p> <p>The venue will be prepared beforehand with all necessary teaching aids. The players will occupy a central place, surrounded by the observers. Learners will be told of what is expected of them and rules, goals and instructions of the role play will be given</p>		
<p><b>3.11. Role play.</b></p>	<p>3.11.1. Offer counselling in the given scenario below:</p> <p>A 34 weeks pregnant HIV positive mother who attends Ante-natal clinic at your facility is experiencing a decisional conflict regarding infant feeding choice. Intervene to assist her to make an informed decision using the Ottawa Personal Decision Guide</p> <p>3.12.1. At the end of the learning experience learners / the group will discuss what happened</p>	<p>45 minutes</p>	<p><b>Role play</b></p> <p><b>Group</b></p>



**Annexure G: Request to provide in-service training**

17 Dr Herman Van Schalkwyk Street

Panorama East

Bethlehem

9701

21/07/2012

To: The local area Supervisor

Attention: Mr Mkhwanazi M.J.

Nketoana local area

From: Sister Ncheka M.S.

Re: Request for permission to provide in-service training

I hereby request permission to provide in-service training to the professional nurses in the fixed and mobile clinics in Nketoana local area. The topic that will be addressed will be: Counselling HIV positive mothers to assist them in decision-making regarding an infant feeding choice, using the Ottawa Decision Support Tool. The purpose of providing in-service training is to capacitate midwives on the use of the Ottawa Decision Support Tool in counselling HIV positive mothers regarding an infant feeding choice. Later on the midwives will be interviewed on their experiences of using the tool. The venues and times for the training will be their respective clinics during their routine days and times for their staff meetings and in-service trainings.

I will contact clinic managers for arrangements as soon as I have heard from you.

Hope to hear from you soon.

Kind regards,

Ncheka M.S.

## **Annexure H: Consent form**

### **Feasibility of the Ottawa Decision Support Tool to assist HIV positive mothers' infant feeding choice**

#### **INFORMATION SHEET AND CONSENT FORM FOR MIDWIVES**

##### **Support for HIV infected mothers**

**Invitation to participate:** You are being invited to participate in the above mentioned research study

**Overreaching study purposes:** The purpose of this study is to provide support to HIV infected mothers to help them make informed decisions on the choice of infant feeding options so as to minimize mother to child transmission of HIV through breast feeding in the selected economically disadvantaged local area

**This specific study purpose:** The purpose of this study is to explore and describe the feasibility and value of the use of the Ottawa Decision Support Tool (ODST) in counselling HIV infected mothers on decisions regarding the choice of safe infant feeding option.

##### **The specific objective of this study is to:**

1. To explore and describe the feasibility of use of the ODST by midwives in counselling HIV positive pregnant mothers regarding the choice of infant feeding options

**Which objective is relevant to the research that I am asked to participate in:** My participation will contribute to objectives two: To explore and describe the feasibility of the use of the ODST by midwives in counselling HIV positive pregnant mothers regarding the choice of infant feeding option.

**Participation:** My participation will involve undergoing in-service training on the use of the ODST in counselling HIV positive pregnant mothers regarding the choice of infant feeding options. The researcher will come for follow up to support me in case I encounter any problems.

I will help the researcher in recruiting 34 weeks pregnant HIV infected mothers, counsel them on choice of infant feeding options using the ODST and giving her contact details of willing participants. I will be provided with a management register to record the HIV positive mothers that I offered counselling on the choice of feeding using the ODST. After counselling sessions I will participate in focus group interview by the researcher to reach the objective of the study.

**Risks:** Minimum risk is expected from my participation in this study. My decision to whether or not to participate in this study will not have any positive or negative repercussions for me. I have been assured that the researcher will keep confidential and anonymous any responses I provide during the focus group interview. I have been reassured by the researcher that every effort will be taken to minimize the risks and that my organisation has given me permission to participate in the research. I know that at the end of the interview, I will be asked if there is any portion of what I have said that I do not want to be quoted on and that this will be recorded on tape and in written note by the researcher/ interviewer.

**Benefits:** My participation in this study will capacitate me in counselling HIV positive mothers on choice of infant feeding options using the ODST and to reflect on the strengths and weaknesses of the tool in helping mothers to make a decision on a safe choice. The summary that will result from this study will contribute to PMTCT program.

**Confidentiality anonymity:** I have received assurance from the researcher that any information I share in the focus group interview will remain strictly confidential. I understand that the contents will only be used for the purpose of study and that my confidentiality and anonymity will be protected by the researcher. The consent will only be discussed within the research team. Anonymity will be protected by not recording my name or the name of my institution. This information will be aggregated and will never be released individually and no one will be able to identify me. Aggregate results will be published so my identity or that of my institution will not be revealed in any report or publication.

**Conservation of data:** Any information collected from me will be kept in a locked filing system in the project office in North West University, Potchefstroom campus of South Africa. All computers in which data will be stored will be password-protected. The data will only be accessible to the study's investigators, audio-tape transcribes and graduates. Everyone who has access to the raw data will be asked to sign a confidentiality agreement. The study data will be stored for ten years following completion of the study.

**Compensation:** There will be no monetary compensation for my participation in the study.

**Voluntary participation:** I am under no obligation to participate and if I choose not to participate, I can choose to withdraw from the study at any time or refuse to be interviewed

This study has received ethics approval from the North West University. Furthermore the research has received ethical approval from:

- North west University Research Ethics Board
- Department of health – Free State Province
- The relevant permission letter from district level and institutional level.

**For ethical queries please contact:**

Research supervisor: DR C.S Minnie

Please see next page for consent form

**Feasibility of the Ottawa decision support tool to assist HIV-positive mothers' infant feeding choice**

Consent

I ..... (print name) have understood to my satisfaction the information regarding my participation in the research project *Support for HIV infected mothers* and agree to participate. In no way does this waive my legal rights nor release the investigators, or involved institutions from their legal professional responsibilities

- I agree to participate in the Focus group interview by the researcher,  
Yes..... No.....
- I agree to be quoted but all personally identifying information shall be removed or altered and contents of the quote shall not reveal my identity. ....
- I do not wish to be quoted at all. ....
- If I choose to withdraw, I agree that data gathered from me during the individual exercise, may continue to be used in the study. ....
- I agree that data may be used for pedagogical purposes such as in classes by professors, workshops, presentations and case studies. All personally identifying information will be removed or altered and shall not reveal my identity  
Yes .....No.....

There are two copies of this consent form, one of which is mine to keep

Participants signature..... Date.....

Sister Ncheka M.S., R/N, R/M, B.A. (Cur) University of South Africa.

## **Annexure I: Focus group interview schedule**

### **INTERVIEW SCHEDULE FOR FOCUS GROUP INTERVIEWS**

(a) Please tell me about your experience of using the Ottawa Decision Support Tool (ODST) to counsel HIV positive mothers to select a safe infant feeding option for their babies.

**-WHEN YOU COMPARE THE ODST TO THE USUAL COUNSELLING TOOL/GUIDELINE THAT YOU NORMALLY UTILIZE AT YOUR FACILITY, WHERE DO THEY DIFFER?**

**-AS YOU COUNSEL THEM USING THE ODST, DO YOU THINK IT IS EASIER FOR THEM TO MAKE A CHOICE COMPARED TO WHEN YOU COUNSEL WITH THE USUAL TOOL?**

(b) Based on the ODST, how feasible is it to support HIV positive mothers to make decisions regarding a choice of infant feeding in terms of time consumption and user-friendliness?

**-AFTER YOU HAVE COUNSELLED THE MOTHERS USING THE ODST, DOES IT BECOME EASIER FOR THEM TO MAKE A DECISION REGARDING THE CHOICE OF AN INFANT FEEDING OPTION? (TELL ME MORE ABOUT IT).**

(d) How do you find the ODST to be in terms of consideration of the values and beliefs of the clients?

**-WHILE YOU WERE PROVIDING COUNSELLING, HOW WAS THEIR LEVEL OF INDEPENDENCE?**

(e) Tell me about any adjustments that you think should be made on the tool.

## Annexure J: Example of Colour coded interview transcript

Record number: 006

Date: 6<sup>th</sup> August 2013

Interviewer: Ncheka M.S.(I)

Respondents: Midwives, 3 from mobile clinics and 1 from a fixed clinic (R 1, 2, 3 & 4)

I: Morning colleagues.

All respondents: Morning madam.

I: Eh..., my name is sister Ncheka, eh..., I would like to welcome and thank you for participating in this study, Feasibility of the Ottawa Decision Support Tool to assist HIV positive mothers' infant feeding choice as you are the ones who implemented the tool. Myself I have never implanted it; I only gave you in-service training the tool. So I would like to hear your views today while you were implementing the tool, what challenges did you encounter and how did you find it. Please feel free to answer all questions as there is no wrong or right answer and you are not going to be penalized for whatever answer that you give. So without a waste of time lets' go to question one. I'm sure all of you have signed the consent forms.

All respondents: Yes.

I: I would like to thank you once more for participating in this study. **Please tell me about your experiences of using the ODST to counsel HIV positive mothers to select a safe infant feeding option for their babies.** For confidentiality's sake, I will not mention your names; I won't call your names. I will call you **respondent number 1, 2, 3 and 4**. So each time you answer please indicate your number like I have been giving you the numbers, you will say respondent number 1, 2, 3 and 4 and give the answer afterwards. Are we together?

All respondents: Yes madam.

I: Ok, lets' hear answers for question: Please tell me about your experiences of using the ODST to counsel HIV positive mothers to select a safe infant feeding option for their babies. So what can you say about it?

**R no. 2:** They choose breast feeding, exclusive breast feeding.

I: Ok, that's respondent no.2, that's her experience; according to her experience the mothers are choosing exclusive breast feeding.

**R:** Mothers who are working...

I: Ok, that's respondent 3, ok.

**R no. 3:** Mothers who are working are choosing exclusive formula feeding.

I: Did u...enquire their reasons for choosing exclusive formula feeding?

R no.3: Yes, they say most of the time they are not at home, so they leave babies with caregivers they bought some milk for their babies.

I: Ok, that's a brilliant idea for them. Any other view?

R: Eh, like I'm...

I: Respondent 4.

R no. 4: Like I'm dealing with farm people, most of them choose exclusive breast feeding; they are still practicing the old method of exclusive breast feeding.

I: Ok, did you try to find out why do they choose exclusive breast feeding?

R no. 4:Cul... It's based on their cultural values, so they do believe that breast feeding is best for their children.

I: Ok, thank you. Another view?

R: Eh... another view...

I: That's respondent 1.

R no.1: Most of the women when you explain the importance of exclusive breast feeding and formula feeding, they choose exclusive breast feeding.

I: Ok, thank you, any other view? Ok, let me find out a little bit more: **As you counsel them using the ODST, do you find it easier for them to make a choice compared to when you use the usual tool, the one that you normally use at the clinic?** We normally use the WHO 2005 tool to counsel mothers regarding infant feeding choice.

R no. 2: Yes, it's easier when you use the Ottawa tool.

I: Ok, compared to the old tool?

R no. 2: Yes.

R no. 3:Yes, it's easier when you use the ODST.

I: Ok thank you.

R no. 4: I think this one is easier because it is their choice.

I: Yes they are not coerced or commanded to choose whatever method that the midwife prefers. Respondent no. 1, can you hear me?

R no. 1: Yes, it is easier because they are given the right to choose.

I: Ok, thank you. So they enjoy being given that opportunity to choose.

R no. 1: Yes.

I: Ok thanks. The next question: **Based on the ODST, how feasible is it to counsel HIV positive mothers in terms of time consumption and user-friendliness?** So when you consider user-friendliness and time consumption, is it user friendly or time-consuming? I will hear that one from you, that tool.

R no. 3: It is user friendly because all the things that you have to ask from the patient are and they are straight forward on the tool.

I: Respondent no. 2, you had something to say?

R: no.4: I think everything is clear and straight forward for them, so it is user friendly this one.

I: Respondent no. 1, your hand was up?

R no.1: M..., eh... it is not time-consuming because you give them, knowledge, support, eh..., so their choice is..., meaning they make the choice themselves.

I: Respondent no.2, do you have something to say?

R no. 2: Eh..., for me it's time-consuming because you must see to it that they really understand. You can choose quickly but if you follow up to see that they understand.

I: Mm..., because you got to go through all the steps again?

R no. 2: Yes, so it's time-consuming.

I: Any other view? Ok, without a waste of time lets proceed to the next question, it's actually a follow up to the previous question: **After you have counselled them using the ODST, does it become easier for them to make a choice of infant feeding option?**

R no.2: It is easier.

I: It's easier, tell me more about it, and how is it easier?

R no. 2: It is easier because they got to understand and to understand how the baby will benefit and how it will benefit her, the baby to feel that love because if you are breast feeding, the baby can feel that warmth, the attention.

I: Respondent no. 1, you hand was up?

R no. 1: Come again?

I: Ok, it said: **After you have counselled them using the ODST, does it become easier for them to make a choice of infant feeding option?**

R no. 1: yes, it is easier because when you tell them about the benefits of breast feeding and benefits of formula feeding like breast feeding, you tell them it is cheap, you are not buying it, it is always available but that one you will have to spend money to buy it and it can cause constipation to the baby.

**R no. 4:** For them it's easier because after you have giving information to them on the advantages and disadvantages whatsoever, they do understand that economically that they are also going to benefit

I: Respondent no. 3, do you have something to say?

**R no. 3:** Yes, I find it easier for them because they they have that support maybe from mmm....

I: From midwife, family?

**R no. 3:** Yes from midwife, family, especially those who are working, they will tell you that: "I am working and I will be able to do that formula feeding." So they will have the money to buy milk.

I: Any other view? Next question, the last but one: **How do you find the ODST to be in terms of the consideration of the values and the beliefs of the clients?** How do you find it to be? Does it take their values into consideration or does it say you should coerce to choose whatever method even if it suitable for their situation? Respondent no. 1?

**R no. 1:** I consider the beliefs of the mothers because you tell them about exclusive breast feeding their importance

I: Ok, any other view? Respondent no. 4, you got something to say?

**R no. 4:** I think I do agree with respondent no. 1 because also supporting the cultural beliefs, it is practical for them.

I: Ok, respondent no. 2, do you have something to say?

**R no 2:** Yes, I was going to say when comes to beliefs I depends on who who that person so it helps them to retain their beliefs

I: Would you expatiate a bit further on that, in what way?

**R no 2:** If I believe in exclusive breast feeding, and then someone talks about formula feeding my belief is that while I'm breast feeding my child is nearer me and I can be able to offer my love and the child is going to feel that warmth

I: So you stick to your belief?

**R no.2:** Yes, that's my belief.

I: Respondent no. 3, do you have anything to say?

**R no. 3:** Mm..., everything has been said Me.

I: Ok. Ok the last question now: **While you were counselling them, how was their level of independence?** These mothers as you know some are coerced by in-laws to choose a particular method of feeding, or the partner is coercive, that's she will practice the method preferred by him. Were they independent or submissive?

**R no. 2:** That one depends on their level of education. Someone who is learned understands better but someone who is not learned depends on someone's decision. So, for me that one depends on the level of education.

**I:** Ok, on somebody' decision, like maybe that one is a provider and so she will have to take their decision by force?

**R no 1:** Most of the scholars depend on their parents, they will tell you." No, my mother said she will buy milk for the baby and I can breast feed after school."

**I:** So it's just like Mme? R no. 1

**R no. 4:** I support their statement, **some of them it depend on their level of maturity**, because like an adolescent child, she does not know everything , most of the time she will depend on the mother or mother-in law if it's a young daughter in-law, so everything will be decided by the mother in-law.

**I:** Respondent no. 3, do you have anything to say?

**R no. 3:** Yes, mmm..., their choice is contributing, contributed from the in-laws, maybe those who are not working, they will say: "My in-laws have said I must give breast feeding." While she is maybe not always at home. When she is not around, then she will start mixed feeding, they will do give the child water. If their choice is exclusive breast feeding, it is fine for them too, that choice of exclusive breast feeding is right for them and for their babies.

**I:** Ok thank you. Now I would like to hear you views, your opinion regarding the tool. **Are there any modifications or anything that you like about the ODST or anything that you feel is lacking?**

**R no. 1:** **According to me it covers everything**

**I:** That's respondent no. 1.

**R no 3:** **According to me the tool is good and I even prefer to use it as my tool while I'm doing my job**

**I:** Ok, thank you.

**R no. 4:** **According to me I think everything has been covered in the tool, so we must continue practicing it**

**I:** Respondent no.2, do you have any opinion regarding the tool?

**R no. 2:** **The tool is ok because everything is there and is clear.** It's just that the level of understanding takes time if you find a low I.Q. then you got to spend more time.

**I:** Ok. Thank you for your time and sacrifice.  
All respondents: thank you mistress.

### **Annexure K: Background and Experience of the independent data-analyst**

The independent co-coder was Mr Ngako Kgalabi Jacob. He is a nurse who has a Postgraduate Diploma in Public Health and Master's degree in Nursing Science, currently studying towards PhD in Health studies. He has worked as a nurse in public and private sector and at Medical Science Research Council as a project Manager for HIV related research projects. His is experienced in qualitative studies includes qualitative data analysis applied during his Masters dissertation and phase one of PhD studies. Furthermore he has published his work on qualitative studies in peer reviewed scientific journals and presented in national conferences. His current position is a Deputy Director in monitoring and evaluation in the Department of Health, Gauteng Province. His curriculum vitae are detailed in Annexure L.

### **Annexure L: Curriculum Vitae of the independent data-analyst**

## Annexure M: Data-analysis by Independent data-analyst

Feasibility of the Ottawa decision support tool to assist HIV-positive mothers' infant feeding choice			
Central storyline:			
Midwives' view the use of ODST to counsel pregnant HIV positive mothers on infant feeding choice as feasible, taking less time, being user-friendly and taking into consideration the client's cultural beliefs and values. Midwives suggest that the tool be used as it is, but should further include buddies.			
Themes	Categories	Subcategories	Supporting quotes
1.Nurses perspectives	1.1 Easy to administer	Less time, user-friendly and short Everything is clear It is practical  Allows follow up, Less time consuming during follow up	According to my opinion, I think it's not time consuming. That's how I view it, that's my opinion because as go with the tool, it guides you and then it's easier to know where the client lacks.
	1.2 Informative	Gives more guidance, Gives more information  It goes deeper, covers everything	First of all, I have realized that the tool is gives you more guidance, patient centred and there is more information on it, more patient participation. That's what I experienced regarding this tool. Well, with the Ottawa, this tool needs you to go, give the patient information. You go deep into it, and then with the ordinary tool, you tend to choose for the patient information that is suitable for them, you don't go deeper. This one needs you to go deep, give information regarding all infant feeding options. Well, you don't just give information but it needs you to go deep into it, they are able to choose the option that is more suitable for them. With the Ottawa it gives them more information on all infant feeding options.
	1.3 More	To the point ,Concise, Specific	Like I said, the maternity guidelines does not have questions,

	focused	<p>Talk about things that are within reach</p> <p>One to one confidentiality maintained</p>	<p>specific questions that you should ask from the woman regarding breast feeding problems or family support, who is going to support her. Like if ever the woman chooses formula feeding, who is going to, to support her with milk for the child? This new tool is very specific because it addresses, addresses such issues.</p> <p>... more precise, precise. The questions are stated like what you should ask; enquire about knowledge of the patient. If the patient lacks knowledge you can add to that or educate the patient further, unlike the group interview. Mmm... Thank you.</p>
2.Perspectives about the client	<p>2.1 Empowering patient</p> <p>2.2 Freedom and satisfaction</p>	<p>Is patient-centred, relationship building</p> <p>Patient participation, Patients make their own choice, It gives more option</p> <p>Patient feel free, Feel more comfortable Gives them comfort, They are happy Make their own decisions</p>	<p>Yes, regarding the tool, when you counsel the patient, you recognize that you build a relationship with the patient. So the patient feels free to express their emotions how they feel about their status regarding breast feeding.</p> <p>I think for me it makes it easier for them to make choice because you'll find that 90% out of 100 women they just don't know that it is safe to breast feed when you HIV positive. Just like the one that I interviewed, lots of them didn't know that it is safe but afterwards they opted for breast feeding, knowing exactly the consequences.</p> <p>Yes, regarding the tool, when you counsel the patient, you</p>

			<p>recognize that you build a relationship with the patient. So the patient feels free to express their emotions how they feel about their status regarding breast feeding</p> <p>Yes, it is easier because they are given the right to choose.</p>
3.Effect on client's cultural beliefs	<p>3.1 Misconceptions</p> <p>3.2 Beliefs and values</p>	<p>Reduces myths, misconceptions and misunderstanding</p> <p>Address values and misconception</p> <p>Considers client's culture and beliefs</p> <p>Covers beliefs and values</p> <p>Holistic, covers the whole family</p>	<p>What I was going to say that it addresses values and misconceptions about breast feeding. These women... values is something that a person believes is right for her. Like these women believe that if you are HIV positive and you breast feed your child is going to be positive. It addresses the values.</p> <p>I think I do agree with respondent no. 1 because it also supporting their cultural beliefs, it is practical for them.</p> <p>Regarding the beliefs I think the myths are more reduced here with the Ottawa. Because most of them believe cow's milk is the best. So you just talk about broad information, you talk about different types of milks, which one is the best. Somewhere somehow myths and misconceptions as well as misunderstandings of the information are more reduced.</p>
4.Strengths and suggestions	4.1 Strengths	User friendly, The tool is clear Everything is there, does not need modification	I think the tool does not need any modification. It has the important information that the client has to know.

ns	4.2 Suggestions	<p>To include buddy, should have questions on the buddy</p> <p>Should be used for a follow up</p>	<p>According to me I think everything has been covered in the tool, so we must continue practicing it.</p> <p>I think regarding the adjustment of the tool, it should include the buddy. A pregnant woman should have a buddy. So it should have questions for the buddy as to how do they think they are going to support the lady or the woman because sometimes I have a lady that ask me: "If I give my husband information how will it be?" Then I said its' fine there is no problem.</p> <p>It should also involve the buddy or whoever. I think it should also involve them. There should be a follow up tool on this one.</p>
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