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EXPERIENCES OF PREGNANT WOMEN LIVING WITH HIV/AIDS AT VHEMBE DISTRICT IN THE LIMPOPO PROVINCE

By

Malindi Fhulufhedzani Constance

Thesis Submitted in Fulfillment of the Requirements for the Degree

Magister Curationis (MCur)

Department of Advanced Nursing Science

University of Venda

Supervisor: Dr RT Lebese

Co-Supervisor: Ms J Ramakuela

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DECLARATION

I,**Fhulufhedzani Constance Malindi**, declare that "**Experiences of Pregnant Women Living with HIV/AIDSat Vhembe District in the Limpopo Province**" is my own work, that all sources that I have used or cited have been indicated and acknowledge by means of complete references. I declare that this work has not previously been submitted for a degree at this or any other institution, and that it is my own work in design and execution.

Signature: .....

Fhulufhedzani Constance Malindi

Date: October 2012 23/04/2013

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DEDICATION

This thesis is dedicated to:

- My late father ,Mutshutshu Alfred Malindi Thagwana, and my mother ,Mbangisen iNyawasedza Malindi Thagwana.
- My loving and supportive children, Fhumulani, Thilivhali, Rudzani and Mikovhe. Thank you for your love and support during this study. I love you so much .Nothing in this world can ever replace you.

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ABSTRACT

One of the greatest health challenges that threaten the human race in our time is the Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS). About 5.3 million South Africans are infected with the virus, of which 3 million are women above 15 years of age and 220 000 are children. The impact of death due to AIDS related illness is a tragic reality experienced by families, communities and the nation at large (National Department of Health Report, 2009:2). Amongst the women who were HIV-positive, about one in four pregnant women attending antenatal clinic were HIV-positive (Van Der Spuy, 2009:1).The purpose of this study was to explore and describe experiences of pregnant women who are living with HIV/AIDS at the Vhembe District of Limpopo Province.The objectives of this study were to explore and describe the experiences of pregnant women who are living with HIV/AIDS,toidentify the challenges they faced and to determine the level of support they needed.The study was qualitative, explorative, descriptive, phenomenological, and contextual in nature. A purposive sampling method was used. Data were collected through in-depth individual interviews, guided by unstructured questions. Tesch's eight steps of qualitative data analysis were used. Measures to ensure trustworthiness and ethical issues were observed. The results of the study revealed that pregnant women who are living with HIV/AIDS were experiencing fear to disclose their status to their spouse/boyfriend, their in-law, their parents and siblings. They also experienced difficulties and challenges related to the support they received, fear related to being pregnant and living with HIV/AIDS. Recommendations in relation to the experiences of pregnant women living with HIV/AIDS, nursing practice, society, policymakers and research were thus made.

Key words: Experiences, HIV, Pregnancy, Living with HIV/AIDS.

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TABLE OF CONTENTS

TITLE PAGE..... i

DECLARATION..... ii

DEDICATION..... iii

ACKNOWLEDGEMENTS..... iv

ABSTRACT..... vi

TABLE OF CONTENTS..... vii

KEYWORDS..... xiii

LIST OF ABBREVIATIONS..... xiv

LIST OF TABLES..... xv

LIST OF ANNEXURES..... xvi

CHAPTER 1: OVERVIEW OF THE STUDY..... 1

1.1 Introduction..... 1

1.2 Background to the Study..... 2

1.2.1 History of HIV/AIDS in South Africa..... 2

1.2.2 HIV/AIDS Prevalence in Teenage Pregnancy in South Africa..... 3

1.2.3 HIV/AIDS Prevalence Among Antenatal Attendees in South Africa..... 3

1.2.4 Prevention of Mother-to-Child Transmission (PMTCT)..... 3

1.2.5 Maternity and Neonatal Services..... 5

1.2.6 Becoming Adherent..... 7

1.2.7 Challenges Faced by HIV-Positive Pregnant Women..... 8

1.2.8 Disclosure of HIV-Positive Status..... 8

1.2.9 Abuse Faced by HIV-Positive Pregnant Women..... 10

1.2.10 Gender Inequalities..... 10

1.2.11 Discrimination..... 11

1.2.12 Stigma..... 12

1.2.13 Fear..... 12

1.2.14 Physical and Sexual Violence..... 13

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Creating Future Leaders

1.2.15 Depression 14

1.3 Problem Statement 15

1.4 Research Purpose 16

1.5 Research Question 16

1.6 Research Objectives 16

1.7 Significance of the Study 17

1.8 Theoretical Framework 18

1.9 Conceptual and Operational Definitions 19

1.9.1 Experiences 19

1.9.2 HIV-Positive 20

1.9.3 Pregnancy 20

1.10 Research Methodology 20

1.11 Data Analysis 21

1.12 Limitations of the Study 21

1.13 Dissemination of the Findings 21

1.14 Thesis Outline 22

1.15 Summary 22

CHAPTER 2: RESEARCH DESIGN AND METHODS 23

2.1 Introduction 23

2.2 Research Design and Methods 23

2.2.1 Qualitative Research 24

2.2.2 Descriptive Research 25

2.2.3 Explorative Research 26

2.2.4 Phenomenology 27

2.3 Context and Study Setting 28

2.4 Population and Sampling 29

2.4.1 Population 29

2.4.2 Sampling Methods and Sample 29

2.4.3 A Representative Sample 30

2.4.4 Purposive Sampling 30

2.4.5 Advantages of Purposive Sampling 31

UNIVERSITY OF VENDA
LIBRARY

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2.4.6 Disadvantages of Purposive Sampling 31
2.4.7 Sampling of Health Centres 32
2.4.8 Sampling of Participants 32
2.4.9 Inclusion and Exclusion Criteria 32
2.4.10 Sample Size 32
2.5 Data Collection Methods 33
2.5.1 Field Notes 34
2.5.2 Observational Notes 35
2.5.3 Theoretical Notes 35
2.5.4 Methodological Notes 35
2.5.5 Personal Notes 36
2.5.6 Intuition 36
2.5.7 Reflective Remarks 36
2.5.8 Bracketing 36
2.5.9 Exploring and Probing 37
2.5.10 Minimal Verbal Responding 37
2.5.11 Paraphrasing 37
2.5.12 Clarifying 38
2.5.13 Focusing 38
2.5.14 Validation 38
2.5.15 Encouragement 38
2.5.16 Using Silence 39
2.6 Data Analysis 39
2.7 Trustworthiness 39
2.7.1 Truth Value (Credibility) 39
2.7.2 Applicability (Transferability) 42
2.7.3 Consistency (Dependability) 42
2.7.4 Neutrality (Conformability) 43
2.8 Ethical Considerations 43
2.8.1 Permission to Conduct the Study 43
2.8.2 Rights of the Participant and Right Not to be Harmed 43

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2.8.3 The Right to Privacy 44

2.8.4 Confidentiality 44

2.8.5 Anonymity 45

2.8.6 The Right to Maintain Self-Respect 45

2.8.7 The Right to Refuse 45

2.9 Limitations of the Study 46

2.10 Summary 46

CHAPTER 3: DATA ANALYSIS AND DISCUSSION OF THE FINDINGS 47

3.1 Introduction 47

3.2 Description of the Sample 47

3.3 Presentation of the Results 48

3.4 Discussion of the Findings 52

3.4.1 Theme 1: Participants' Experiences Related to Disclosure of HIV Status 52

3.4.1.1 Category 1.1: Participants Experienced Fear Related to Disclosure to Spouses/Life Partners 53

3.4.1.1.1 Sub-Category 1.1.1: Fear of Rejection and Divorce 53

3.4.1.1.2 Sub-Category 1.1.2: Other People Would Disclose the Status to the Husband 55

3.4.1.1.3 Sub-Category 1.1.3: Fear to be Being Blamed for Bringing Disease to the Home 56

3.4.1.2 Category 1.2: Participants Experienced Fear to Disclose to Their In-Laws 57

3.4.1.2.1 Sub-Category 1.2.1: Fear to be Rejected and Blamed 58

3.4.1.2.2 Sub-Category 1.2.2: Fear that People Would Talk Behind Their Backs 59

3.4.1.2.3 Sub-Category 1.2.3: Fear of Being Blamed for Killing the Husband 60

3.4.1.3 Category 1.3: Participants Experienced Fear to Disclose To Their Own Parents and Siblings 62

3.4.1.3.1 Sub-Category 1.3.1: Fear that Own Parents May Be Stressed 62

3.4.1.3.2 Sub-Category 1.3.2: Sharing Confidential Information with Siblings Who Will End Up Telling Others 64

3.4.2 Theme 2: Participants' Experiences Related to Support Received 65

3.4.2.1 Category 2.1: Participants' Experienced Financial Problems 65

3.4.2.1.1 Sub-Category 2.1.1: Dependence on Grants and Maintenance 66

3.4.2.1.2 Sub-Category 2.1.2: Dependence on Husbands 68

3.4.2.1.3 Sub-Category 2.1.3: Too Weak to Work 70

3.4.2.1.4 Sub-Category 2.1.4: Financial Support Related to Transport and Collection of Medication 71

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3.4.2.2 Category 2.2: Participants Experienced Lack of Emotional Support 73

3.4.2.2.1 Sub-Category 2.2.1: Husband No Longer Engages in Sexual Intercourse 73

3.4.2.2.2 Sub-Category 2.2.2: Lack of or Poor Communication Between the Spouses 75

3.4.2.2.3 Sub-Category 2.2.3: Boyfriends and Relatives No Longer Visit or Answer the Phone 76

3.4.2.2.4 Sub-Category 2.2.4: No Longer Accepted in Social Gatherings 77

3.4.2.2.5 Sub-Category 2.2.5: Next-Door NeighboursWouldDivulge Status During Quarrelling 79

3.4.3 Theme 3: Participants' Experiences of Fear Related to Being Pregnant and Living with HIV/AIDS .. 80

3.4.3.1 Category 3.1: Participants Feared that the Baby May Be Affected 80

3.4.3.1.1 Sub-Category 3.1.1: Failure to Use Condoms May Kill the Baby 81

3.4.3.1.2 Sub-Category 3.1.2: Fear that the Baby May Die After Birth 82

3.4.3.1.3 Sub-Category 3.1.3: Fear Related to Breastfeeding 84

3.4.3.2 Category 3.2: Participants Feared that Their Partners May Become Infected or Die 85

3.4.3.2.1 Sub-Category 3.2.1: Fear that Their Husbands May Die As They Refuse to be Tested..... 86

3.4.3.2.2 Sub-Category 3.2.2: Husbands Refuse to Use Condoms 87

3.4.3.2.3 Sub-Category 3.2.3: Husband Want to Make Babies 88

3.4.3.3 Category 3.3: Participants Feared that People Will Involuntarily Know About Their HIV/AIDS Status 90

3.4.3.3.1 Sub-Category 3.3.1: Status Would Become Known Because of Loss of Weight 90

3.4.3.3.2 Sub-Category 3.3.2: Status Would Become Known Because of Not Breastfeeding 91

3.4.3.3.3 Sub-Category 3.3.3: Status Would Become Known Due to Prolonged Hospitalization 92

3.4.4 Theme 4: Challenges Experienced by Pregnant Participants Living With HIV/AIDS 93

3.4.4.1 Category 4.1: Participants Feared for Their Own Death 94

3.4.4.1.1 Sub-Category 4.1.1: Low $CD4^+$ Cell Count, Too Weak and Anaemic 94

3.4.4.1.2 Sub-Category 4.1.2: Re-Infection Because of Not Using Condoms 95

3.4.4.2 Category 4.2: Participants Feeling Physically Ill and Constant Tiredness 96

3.4.4.2.1 Sub-Category 4.2.1: Experiencing Physical Illness and A Feeling of Tiredness and General Body Weakness 97

3.4.4.2.2 Sub-Category 4.2.2: Admitted to Hospital 98

3.5 Summary 99

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CHAPTER 4: EVALUATION, CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY **100**

4.1 Introduction 100

4.2 Study Overview 100

4.3 Recommendations 102

4.3.1 Recommendations Related to Disclosure and Relationship With Spouses/Life Partners and Family Members 103

4.3.2 Recommendations Regarding Financial and Emotional Support 104

4.3.3 Recommendations Regarding Experiences Related to Fears 105

4.3.4 Recommendations Regarding Challenges Experienced by Participants 106

4.3.5 Recommendations Regarding Society 107

4.3.6 Recommendations Regarding Policy Making 107

4.3.7 Recommendations Regarding Nursing Practice 108

4.3.8 Recommendations Regarding Research 108

4.4 Limitations of the Study 109

4.5 Summary 109

REFERENCES 111

ANNEXURE I: INFORMATION LETTER 117

ANNEXURE II: INFORMED CONSENT FOR PARTICIPATION IN RESEARCH 118

ANNEXURE III: REQUEST FOR INFORMED CONSENT FROM LOCAL AUTHORITY 119

ANNEXURE IV: REQUEST FOR PERMISSION TO CONDUCT RESEARCH 120

ANNEXURE V: INTERVIEW TRANSCRIPT:REPRESENTATIVE SAMPLE 1 121

ANNEXURE VI: INTERVIEW TRANSCRIPT:REPRESENTATIVE SAMPLE 2 124

ANNEXURE VII: LETTER FROM SCIENTIFIC AND MEDICAL EDITOR 127

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KEYWORDS

- Acquired Immune Deficiency Syndrome
- Continuing Medical Education
- Health Promotion and Awareness Programmes
- Human Immunodeficiency Virus
- Notifiable Disease
- Nursing Education Curriculum
- People Living with HIV/AIDS
- Policymakers
- Pregnant Women Living with HIV/AIDS
- Prevention of Mother-to-Child Transmission
- Voluntary Counselling and Testing

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Anti-Retroviral Treatment
ARV	Anti-Retroviral Drugs
AZT	Zidovudine or azidothymidine
CME	Continuing Medical Education
DoH	Department of Health and Social Development
DoJ	Department of Justice
HIV	Human Immune Deficiency Virus
ICU	Intensive Care Unit
LP	Limpopo Province
NEC	Nursing Education Curriculum
MDG	Millennium Development Goals
MMR	Maternal Mortality Rate
MTCT	Mother-to-Child Transmission
NVP	Nevirapine (viramune)
PHC	Primary Health Care Center
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
RSA	Republic of South Africa
SA	South Africa
STI	Sexually-Transmitted Infections
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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LIST OF TABLES

Table 1.1: Estimated HIV/AIDS prevalence (%) among antenatal attendees by age 4

Table 1.2: Estimated HIV/AIDS prevalence (%) among antenatal attendees by province 4

Table 2.1: Tesch's eight steps of systematically analyzing textual data collected through interview questions 40

Table 3.1: Participants' characteristics 49

Table 3.2: Themes, categories and sub-categories related to experiences of pregnant women who are living with HIV/AIDS 50

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LIST OF ANNEXURES

ANNEXURE I:	INFORMATION LETTER	117
ANNEXURE II:	INFORMED CONSENT FOR PARTICIPATION IN RESEARCH	118
ANNEXURE III:	REQUEST FOR INFORMED CONSENT FROM LOCAL AUTHORITY	119
ANNEXURE IV:	REQUEST FOR PERMISSION TO CONDUCT RESEARCH	120
ANNEXURE V:	INTERVIEW TRANSCRIPT:REPRESENTATIVE SAMPLE 1	121
ANNEXURE VI:	INTERVIEW TRANSCRIPT:REPRESENTATIVE SAMPLE 2	124
ANNEXURE VII:	LETTER FROM SCIENTIFIC AND MEDICAL EDITOR	127

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 Introduction

Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) is a worldwide health and social problem that requires global intervention to combat it. The latest statistics of the world epidemic of HIV/AIDS in 2010 to 2011 estimated that there are 34 million people living with HIV/AIDS (PLWHA), of which 15.9 million are women (UNAIDS, 2009).In Sub-Saharan Africa it has been reported that there are about 22.9 million PLWHA (UNAIDS, 2009).It is also estimated that South Africa is one of the countries with the largest number of HIV/AIDS infections in the world with 5.6 million PLWHA with prevalence among pregnant women at 29.4%(UNAIDS,2009).Prevalence of HIV/AIDS infections amongst antenatal patience represents a huge problem throughout South Africa (DoH,2007).

HIV prevalence trends among antenatal women in Limpopo Province are estimated to be 22.5%, whilst the Vhembe District has 17.2% of pregnant women who are HIV-positive. In Thulamela Municipality where the study was conducted, about 12.5% of pregnant women who underwent HIV/AIDS testing in 2010, tested positive. It can be assumed that there are many pregnant women living with HIV/AIDS. Hence, this study seeks to explore and describe the experiences of pregnantwomenliving with HIV/AIDS (DoH,2009).

1.2 Background to the Study

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The background of this study provides abrief account of research that has been conducted in the area of this study's interest. The following themes were drawn from the literature consulted and will be discussed: history of HIV/AIDS in South Africa; estimated HIV/AIDS prevalence of teenage pregnancy according to province; estimated HIV/AIDS prevalence among antenatal attendees according to province and age; prevention of mother-to-child transmission (PMTCT); challenges; maternity and neonatal services; becoming adherent; risk of HIV in pregnancy; confidentiality of care; disclosure; fear; abuse; gender inequality; physical and sexual violence; discrimination; stigmatization and depression.

1.2.1 History of HIV/AIDS in South Africa

In 1983, AIDS was diagnosed for the first time in two patients in South Africa. The first recorded death owing to AIDS occurred in 1983. By 1986, there were 46 recorded AIDS diagnoses. Estimates from 2000 indicated that 5% of actual infections and only 1% of actual deaths due to AIDS were reported prior to 1990. AIDS was more common among homosexual people. By 1990, less than 1% of South Africans had AIDS. By 1996, the figure stood at around 3% and by 1999 the figure had reached 10%. HIV infection started reaching pandemic proportions around 1995 (Orr& Patient, 2008).

HIV prevalence among pregnant women is highest in KwaZulu-Natal province (37%) and lowest in the Western Cape (13%), Northern Cape (16%) and Limpopo (18%) provinces. In the other five provinces (Eastern Cape, Free State, Gauteng, Mpumalanga and North West) at least 26% of women attending antenatal clinics in 2006 tested HIV-positive(Orr &Patient, 2008).

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The latest HIV/AIDS data collected at antenatal clinics suggest that HIV/AIDS infection levels might be leveling off, with HIV/AIDS prevalence in pregnant women being at 30% in 2005, 29% in 2006, and 28% in 2007. The decrease in the percentage of young pregnant women (15–24 years) found to be infected with HIV/AIDS also suggests a possible decline in the annual number of new infections (Orr &Patient, 2008).According to City Press (December 4th 2011) it is estimated that 95% of anti-retrovirals (ARV) in South Africa is provided to eligible pregnant women who are living with HIV/AIDS to prevent new HIV/AIDS infections among children.

1.2.2 HIV/AIDS Prevalence in Teenage Pregnancy in South Africa

City Press (December 4th 2011)reported that girls as young as 10 years are falling pregnant and testing HIV-positive, raising fears that they are engaging in intergenerational sex. A survey released to City Press found that HIV prevalence among 10-14 year old pregnant girls was around 9.1% of the 121 girls, 14% of 6 171 girls between the ages of 15 and 19 years.

1.2.3 HIV/AIDS Prevalence Among Antenatal Attendees in South Africa

Table 1.1 shows the estimated HIV/AIDS prevalence (%) among antenatal attendees by age and Table 1.2 shows the estimated HIV/AIDS prevalence (%) among antenatal attendees by province (City Press: 4th December 2011).

1.2.4 Prevention of Mother-to-Child Transmission (PMTCT)

Due to the high rate of pregnant women who are HIV-positive, the WHO has introduced prevention of mother-to-child–transmission (PMTCT) programmes in 2000. South Africa

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started to implement the PMTCT programme nationally in 2001 to 2002(PMTCT Guideline; 2008).

Table 1.1: Estimated HIV/AIDS prevalence (%) among antenatal attendees by age

Age group (years)	2006	2007	2008	2009	2010
10-14	N/A	N/A	7.3	7.9	9.1
15-19	13.7	13.1	14.1	13.7	14.0
20-24	28.0	28.0	26.9	26.6	26.7
25-29	38.7	37.5	37.9	37.1	37.3
30-34	37.0	39.6	40.4	41.5	42.6
35-39	29.3	33.0	32.4	35.4	38.4
40-44	21.3	22.2	23.3	25.6	30.9
45-49	15.5	20.6	17.6	23.9	28.2

Source: DoH, 2010

Table 1.2: Estimated HIV/AIDS prevalence (%) among antenatal attendees by province

Province	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Kwazulu-Natal	33.5	36.5	37.5	40.7	39.1	39.1	38.7	38.7	39.5	39.5
Mpumalanga	29.2	28.6	32.6	30.8	34.8	32.1	34.6	35.5	34.7	35.1
Free State	30.1	28.8	30.1	29.5	30.3	31.1	31.5	32.9	30.1	30.6
Gauteng	29.8	31.6	29.6	33.1	32.4	30.8	30.5	29.9	29.8	30.4
North West	25.2	26.2	29.9	26.7	31.8	29.0	30.6	31.0	30.0	29.6
Eastern Cape	21.7	23.6	27.1	28.0	29.5	28.6	28.8	27.6	28.1	29.9
Limpopo	14.5	15.6	17.5	19.3	21.5	20.6	20.4	20.7	21.4	21.9
Northern Cape	15.9	15.1	16.7	17.6	18.5	15.6	16.5	16.2	17.2	18.4
Western Cape	8.6	12.4	13.1	15.4	15.7	15.1	15.3	16.1	16.9	18.5
National	24.8	26.5	27.9	29.5	30.2	29.1	29.4	29.3	29.4	30.2

Source: DoH, 2010

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Since its inception, PMTCT services were offered in all public hospitals and in more than 90% of primary health care centres. South Africa has the largest PMTCT programme in Africa (Van der Spuy, 2009). During the years 2005-2006, 70%of antenatal care (ANC) attendees were counseled and tested for HIV of whom 26% tested positive. About 60% of pregnant women who tested HIV-positive received nevirapine (PMTCT Guideline, 2008). Other studies have indicated that since the introduction of dual therapy, which is nevirapine(NVP) and zidovudine(AZT), there is a slight decrease in the number ofbabiesaffected, hence the researcher will explore and describe the experiences of pregnant women who are living with HIV/AIDS (Van der Spuy, 2009).

PMTCT programmes expand both in coverage and quality. The programme's characteristics and activities deliberately disclose a woman's HIV status and initiate stigma in the process.A study conducted in Malawi indicated that the PMTCT programme has a potential initiator of HIV/AIDS-related stigma by the physical location of PMTCT programme, which is situated away from other antenatal care facilities. The incentives that are given to PMTCT participants such as formula feeding increases the challenges so much that some pregnant women who are living with HIV/AIDS deliberately default follow-up, which puts their health and that of their unborn babies at risk (Chikonde, 2009). PMTCT terminology such as pregnant women living with HIV/AIDS sounded as if the pregnant women are solely responsible for the transmission of HIV/AIDS to their newborn babies (Chikonde, 2009).

1.2.5 Maternity and Neonatal Services

Van der Spuy (2009) reported that in the Peninsula, maternity and neonatal services in Cape Town have established a programme to improve maternal and neonatal care, but

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there has been an increase in Maternal Mortality Rate (MMR) due to HIV/AIDS. GrooteSchuur Hospital, which offers tertiary services for maternity care, conducted an audit on MMR and the results indicated that one in four pregnant women who required high care were HIV-positive against a background of 12% in the local obstetric population and the main common indication for admission to the high care unit was sepsis in pregnant women living with HIV/AIDS in contrast to complication of gestational proteinuric hypertension in HIV-negative pregnant women(Van der Spuy,2009).The mortality of pregnant women living with HIV/AIDS was 13.6% versus 0.4% in HIV-negative pregnant women.

Van der Spuy (2009) indicated thatHIV-positive women are facing the challenges of spontaneous miscarriage, stillbirth, fetaland prenatal mortality. There is higher prevalence of interfering growth retardation, low birth weight and pre-term delivery. IT was also reported that HIV-exposed infants continue to present particular challenges even though the mother- to- child transmission has been reduce to 2%.HIV-positive mothers require more obstetric input and their babies require more neonatal admission (Van Der Spuy,2009).

Pregnant women who are living with HIV/AIDS have other potential maternal health problems, such as diabetes and hypertension, maternal nutritional problems; they also face other challenges such as tobacco smoking, alcohol and drug use. Most of pregnant woman living with HIV/AIDS are staying in abusive relationships and are also victims of domestic violence (Van der Spuy,2009).

Over the counter medication, and nutritional agents are also challenging the health of pregnant women living with HIV/AIDS. Familiar genetic history and infectious diseases

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such as sexually-transmitted infections (STI) challenge the health status of pregnant woman living with HIV/AIDS. Also, congeniality tuberculosis remains a problem to babies born to HIV-positive mothers (Van der Spuy, 2009).

1.2.6 Becoming Adherent

Gray (2007) reported that an HIV-infected person has to adjust him/herself with anti-retroviral medication. Pregnant women who are HIV-positive also have to take drugs most of the time, because of their fluctuating hormones. Moreover, they have to adjust to anti-retroviral treatment (ART). PLWHA are expected to adhere to complex regimens over an indefinite period of time, with strict adherence necessary for complete suppression of the virus. Hence, the pregnant woman will have to adhere to the treatment regimen to prevent the virus passing from mother-to-child. Side effects of ARV, symptoms of HIV/AIDS and denial of HIV/AIDS status remain a concern. The pregnant woman's view of her own life and the life of her unborn baby help her to adjust fast and adhere to treatment which is too much for a pregnant woman who is living with HIV/AIDS (Reproductive Rights Organisation, 2005).

Reproductive Right Organization (2005) reported that ART reduces mother-to-child transmission (MTCT) and affects the health of a pregnant woman because even if the anti-retroviral drugs (ARV) are outweighed by the benefits in preventing MTCT of the virus, the pregnant woman must be fully informed of medical uncertainties and potential risks involved. As it was reported that one dose of nevirapine can cause drug resistance and this brought a thought of PMTCT programmes and drugs aimed at protecting the health of the foetus rather treating a pregnant women living with HIV/AIDS (Reproductive Rights Organization, 2005).

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1.2.7 Challenges Faced by HIV-Positive Pregnant Women

Pregnant women who are HIV-positive are faced with possible risks associated with pregnancy and child bearing. While HIV-infected, young women living with HIV/AIDS face difficult reproductive decisions, one significant risk is the transmission of infection to the newborn baby even if AZT was introduced to the pregnant women to prevent transmission of the virus, there is still a chance of MTCT as only 8% of all births to infected mothers compared to 25% transmission to those mothers who did not receive AZT (Chinkonde, 2009).

An additional reproductive concern for pregnant women living with HIV/AIDS is the risk of uninfected prospective biological fathers who may become infected while attempting conception, if the biological father is already infected there is a risk of re-infection with another strain of virus (Gray, 2007). Infected pregnant women also worry about the potential negative impact on their own health from the physiological and psychological stresses of pregnancy. Uncertainty regarding their future health and ability to fulfill the responsibility of motherhood may also be a concern for infected pregnant women. The percentage of termination of pregnancy is high for pregnant HIV-positive women and some may opt for backstreet abortion putting their deteriorating health at further risk (Gray, 2007).

1.2.8 Disclosure of HIV-Positive Status

The prospect of being abandoned, stigmatized, discriminated against, violently abused, blamed, accused of infidelity, socially isolated, loosing economic and emotional support, and the risk of other people knowing about a seropositive status may discourage disclosure (Antelman et al., 2009). Pregnant women living with HIV/ADS were reported choosing

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not to disclose to their sexual partners as a result of such factors or they are in denial. Religious belief is another barrier to disclosure, denial of the diagnosis also plays and important role in failure to disclose.HIV/AIDS is often regarded as an infection resulting from sexual immorality, therefore, it contributed to the unwillingness to disclose their status within religious circles. Pregnant women living with HIV/AIDS are often inhibited from disclosing because of possible violence from their partners. Moreover, stigma is still an oppressive concern. They are also concerned about facing divorce, separation, physical attack and acts of murder (Antelman et al., 2009). A study in the Ukraine reported that disclosure by nursesof the HIV-positivestatusof women resulted in spousal abuse, rejection, and abandonment. In India, a pregnant woman's HIV status is disclosed to the husband in the belief that the woman will not understand the condition (Reproductive Rights, 2005).

Giving formula feeding while other women are breastfeeding discloses the mother's status and some of the mothers are still in denial. Formula feeding adds to the pain and frustration that the women already have (Reproductive Rights, 2009). It was reported that in some hospitals the bed letter will be written HIV-positive in big letters for everyone to see, especially when they have to collect treatment in the dispensary (Reproductive Rights, 2005). At the outreach meeting of maternal health held at Tshilidzini, primary health care midwives were complaining of pregnant women who are HIV-positive tearing off the corner of ANC card, some even use Tipp- ex to rub the HIV/AIDS codes.

Igwegbe&Ugboaja (2010) reported that in order to remain married, women's fear of divorce was identified as a barrier to disclosure, whilst single mothers who may be in a stable relationship and hence very suspicious of their partner's reaction are associated with a greater likelihood of non-disclosure. Low educational level, lack of self-esteem and low

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socioeconomic status were reported as barriers to disclosure (Igwebe&Ugboaja, 2010).Women whose partners are educated and agreed with the spouse before testing, experienced lessviolence and financial dependence, andfound it easier to disclose their HIV-positive status (Makin at al., 2007).

1.2.9 Abuse Faced by HIV-Positive Pregnant Women

According to Van Rensburg (2006), abuse and violence againstwomenmakes womenmorevulnerable to HIV/AIDS. Most abused women are unable to negotiate safer sex practices, while their partners are having affairs that further put them at risk of contracting HIV and becoming pregnant without a choice. Women who are abused, HIV-positive and pregnant have complex issues to deal with and have to contend with being stigmatized or isolated because of being pregnant, abused and also living with HIV/AIDS (Van Rensburg, 2006). Sowell R.L, Phillips K.D, Seals B, Murdagh C& Rush C,(2002) also indicated that women reported experiencing lifetime physical and/or sexual abuse and were more likely to disclose their HIV-seropositive status to their sex partner. Women are victim of intimate or domestic violence at the hands of husbands, sex partner or former boyfriend (Scherr et al, 2003).

1.2.10 Gender Inequalities

Gender inequalities in sexual relationships are associated with increased risk of HIV-infection. Sociocultural norms about masculinity and femininity increase risk of HIV-infection. Unequal power relations between men woman that arise from those norms, interact with biological and physiological factors that compound a pregnant woman's risk of infection, resulting in the epidemic (Commonwealth Fund,1999). Differentials ingender power dynamics affect the behavior and ability of pregnant women living with HIV/AIDS

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to protect themselves, as well as to access treatment, care and support once infected. Most women predispose to poverty, forcing young women to have male partners who are much older than themselves who are more likely than young mento be HIV-initiated. Gender inequalities make it much more difficult for women to negotiate condom use. Furthermore, sexual violence damages vaginal tissue and increases the risk of HIV transmission. Pregnant women who are living with HIV/AIDS often face gender inequalities which increase their vulnerability to HIV-infection. Also,their disproportionally high levels of responsibilities as caregivers for the sick and dying predispose them to such risks (van Rensberg, 2006).

Lack of power over their bodies and their sexual lives supported and reinforced by their social and economic inequality make women such vulnerable group. This is compounded by human rights issues, including lack of adequate access to the information, education and service necessary to ensure sexual health,harmful traditional or customary practices affecting reproductive health ofwomen, such as early and forced marriages and by lack of legal capacity and equality in family matters. Gender inequality and intimate violence directed at female partners have already been established as risk factors in contracting HIV (El-Bassel et al., 2000).

1.2.11 Discrimination

Research conducted by Mfusi(2009) reported that one of the pregnant women verbalized that when it was found out that she was HIV-positive nobody talked about her well-being. The doctor told her to terminate the pregnancy as if she did not have rights to pass on the infection to her baby. Literature also indicated that a woman in Koudougou stated that if a pregnant woman finds herself HIV-positive, she has signed three death sentences, namely

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psychological death, social death and later physical death which is too much for a pregnant woman who is HIV-positive (Mfusi, 2009).

1.2.12 Stigma

Bond V, Chase E &Aggleton (2002) define stigma as subtle actions to the most extreme degradation, rejection and abandonment. Bond et al, (2002) indicated that women with HIV-seropositive and pregnant are repeatedly subjected to extensive forms of stigma, particularly once they become sick or their child dies. HIV/AIDS related stigma drives the epidemic underground and is one of the main reason that people does not wish to know their HIV status (Bond et al, 2002).

The stigma attached to pregnant women who are living with HIV/AIDS lead to severe consequences for them, such as abandonment by partners, rejection by other family members, blamed for bringing the diseased baby into the family, eviction from homes, loss of economic support and physical and emotional abuse (UNAIDS & WHO, 2005).

Stigma remains a significant issue for pregnant women living with HIV/AIDS. Alison (2010) reported that disease-related stigma is experienced differently by men and women - health status may contribute more to disease-related stigma in women compared to men. Gossip, verbal abuse and name calling that occur in many settings, blame assigned to pregnant women living with HIV/AIDS and assumptions made about their sexual history also increases stigma to pregnant women living with HIV/AIDS (Alison,atal, 2010).

1.2.13 Fear

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Research indicated that pregnant women living with HIV/AIDS experience fear of rejection - they find it difficult to tell those close to them, particularly parents, friends, and spouses. Occasionally, they give blank responses while inside they feel different (Mapisi, 2003, cited by Chokoe N.R,2005).They experience great uncertainty over their sexual practices and the future of their relationships which become strained - they also worry about the reaction in future relationships. They also fear anticipated loss from the death of partners. Sometimes the HIV/AIDS increase distancing of partners while it is time for them to support each other, especially while one partner is not only HIV-positive, but also pregnant. There is fear of termination of a relationship; others fear to be ostracized from their families and neighbours (Chokoe,2005).

1.2.14 Physical and Sexual Violence

According to the DoJ (2008), 68% of pregnant woman living with HIV/AIDS are experiencing lifetime physical or sexual abuse. Woman who are experiencing physical or sexual abuse are more likely to disclose their status to their sexual partners. Pregnant women living with HIV/AIDS experiences with violence is frequently a result of living in poverty, substance abuse, and living in poor communities where violence is the norm and they witness neighborhood muggings, and shooting. However, pregnant women living with HIV/AIDS are victims of intimate or domestic violence at the hand of husbands, sexual partners or other family members.

An estimated 4 million pregnant women living with HIV/AIDS are physically abused by former boyfriends, a husband, or a live-in partner every year (DoJ, 2008).This situation has significant public health implications not only to the health of pregnant women, but also their unborn babies. This group of women is at high risk of violence at the hands of

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intimate partners. The stigma associated with HIV/AIDS in pregnant women and potential relationship between HIV risk taking behavior and violence may be expected to place pregnant women at increased risk for violence, and they also experience greater distress and immunological suppression.

The fact that pregnant women are not only poor, have children, and are alsoHIV-infected, potentially further limit their options in escaping violent relationships and the greater their intent to have another dependent child to love and to return their love and to add value to their lives. Violence against pregnant women living withHIV/AIDS can indirectly undermine their health and serve as a barrier for accessing health care services (Mfusi&Mahabeer, 2000).

Many abused women are experiencing fear and the terrible likelihood of being victimized. Social care workers are also more likely to respond negatively and blame those who are at risk or infected (El-Bassel et al 2000).Gender inequality and intimate violence directed at female partners have been established as risk factors in contracting HIV. Many abused women who are also experiencing domestic violence are finding it difficult to negotiate condom use. Sexual violence is certainly leads to HIV infection. Women fear immediate violence more than possibly contracting HIV, and therefore they often resign themselves to sexual demands (El Bassel et al., 2000).

1.2.15 Depression

Wiluiplan et al.(2010) indicated that depressivesymptomsare associated with non-adherence to ART and it causes faster disease progression and poor quality of life. Depressive symptoms amongst pregnant women who are living with HIV/AIDS are

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caused by hormonal changes, poor physical health, unplanned pregnancies and higher parity.

Beck (2006) indicated that depression in pregnant women who are HIV-positive is brought about by low self-esteem, lack of emotional support, abandonment by spouse or life partner, physical symptoms and worrying about the infant's health status. Lack of acceptance of HIV status and paucity of social acceptance by the community increases chances of depression in pregnant women who are living with HIV/AIDS. Depressive symptoms may be increased by stigmatization, and pregnant women living with HIV/AIDS consider themselves as inferior or incapable women and fear being condemned on both moral levels and failure Fear of the baby being HIV-positive also increases depression levels in pregnant women who are living with HIV/AIDS. Lack of proper health education is also one of the contributing factors to depression (Beck, 2006).

1.3 Problem Statement

The researcher is rendering antenatal care (ANC) in the workplace. During 2010 and 2011, about 35% of pregnant women who attended ANC were HIV-positive. The researcherrealized that about 10% of pregnant women who were HIV-positive verbalized that they did not disclose their HIV status to their partners and family members, some indicated that they did not disclose their status to their partners and family members because of fear of losing their marriage or being blamed for bringing the disease in the family. Some stated that as they were not working they were afraid to disclose their status to their partners or refuse sex without protection, fearing loss of financial support.

About 35% of those who have disclosed their HIV-positive `status verbalized that their relationship with their spouses or life partners have deteriorated and about 30% of those

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who have disclosed their status were having sex without using condoms, whilst their partner or spouse refused to be tested. Hence, this study aims to explore and describe the experiences of pregnant women living with HIV/AIDS.

1.4 Research Purpose

The purpose of the study was to explore and to describe the experiences of pregnant women who are living with HIV/AIDS in rural areas of Vhembe District of Limpopo Province in South Africa.

1.5 Research Question

In order to accomplish the purpose of the study, the researcher generated the following questions:

- What are your experiences as a pregnant woman living with HIV/AIDS?
- Did you disclose your HIV/AIDS status to your spouse/life partner and family members?
- How is your sexual relationship between you and your spouse/life partner after you were diagnosed with HIV/AIDS?
- Who is currently supporting you financially?

The research will thus focus on probing the experiences of pregnant woman living with HIV/AIDS, disclosure of their HIV-positive status to partners and family members, sexual relationships after the disclosure of positive results of HIV/AIDS, and financial support.

1.6 Research Objectives

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The objectives of this study were to:

- Explore and to describe the experiences of pregnant women who are living with HIV/AIDS.
- Identify challenges that are faced by pregnant women who are living with HIV/AIDS.
- Determine the level of partner and family support.
- Strengthen a coping mechanism that pregnant women living with HIV/AIDSmay utilize in order to deal with their daily challenges.

1.7 Significance of the Study

- The study will assist in achieving four of Millennium Development Goals (MDG), namely MDG 3 - promoting gender equality and empowering women; MDG 4 - reducing child mortality rate; MDG 5 - improving maternal health; MDG 6 - combating HIV/AIDS.
- It is hoped that the study will strengthen recommendations on how the spouse/partner and family members can support the pregnant woman living with HIV/AIDS.Thestudywill help with the establishment of support groups in which pregnant women living with HIV/AIDS can support each other.
- The community may utilize the recommendations as a tool for community awareness where the community is involved with the support of pregnant women living with HIV/AIDS. The study may influence the government to utilize the

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recommendations for future planning of care for pregnant women who are living with HIV/AIDS. Health care workers may apply the recommendations in management and continuity of care of pregnant women living with HIV/AIDS.

- Recommendations from this study might influence the Department of Health tostrengthen the development of policies and guidelines that will assist primary health care nurses in supporting spouses/partners and family members to support pregnant women living with HIV/AIDS

1.8 Theoretical Framework

Theory is a supposition or system of ideas explaining something, based on general principles independent of the particular things to be explained. It is a speculative view, abstract knowledge or speculation thoughts, exposition of the principles of science, collection of propositions to illustrate the principles of subject (South African Oxford Dictionary, 2007).

The point of departure for this research study is *Adaptation Theory*. This approach defines adaptation as way to adjust, make suitable for a purpose, modify, or adjust to a new conclusion. The person is an adaptive system. System inputs include three classes of stimuli which are focal, contextual, and residual that rise from within the person and the external environment and the adaptation level. Adaptation level is composed of all three classes of stimuli, and represents the person's standard or range stimuli in which responses will be adaptive. (Roy 1989, cited by Chinn & Kramer, 1997).

Inputs are mediated by the control process subsystem of cognate and regulator coping mechanisms. The regulator mechanism is an automatic neuroendocrine response, whereas

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the cognator subsystem represents perception, information processing, and judgments influenced by learning and emotions. Coping activity may or may not be adequate to maintain integrity (Roy 1989, cited by Chinn & Kramer, 1997).

The adaptive system (person's) output is a response that may be adaptive or ineffective. Adaptive responses are those that contribute to adaptation goals such as responses that promote growth, survival, reproduction and self-mastery. Adaptation is an ongoing purposive response. Adaptive responses contribute to health and the process of being and becoming integrated (Roy, 1989, cited by Chinn& Kramer, 1997).

In this study, adaptation theory has been used; where the women have to adapt to the situation of living with HIV-positive while they are pregnant. They have to adjust themselves to the changes of their health status, challenges that they are facing from their spouses, family members, relatives, health care system, society, medication (ARV), and the stigma that goes along with the disease. The coping mechanism results in this study were dependent on the level of knowledge about the disease, educational status, economical status and the support received from the spouse, family members, nursing staff and the community where the pregnant woman who is living with HIV/AIDS stayed.

This theory was applied in this study because HIV-positive pregnant women were expected to adapt to their status, deal with fear, disclosure to spouse and family members as well as the community, their emotions, their deteriorating health status, loss of financial support, pregnancy, ARV and the stigma attached to the disease.

1.9 Conceptual and Operational Definitions

1.9.1 Experiences

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Experience as a general concept comprises knowledge of, skill in, or observation of some thing or some event gained through involvement in or exposure to that thing or event. The history of the word experience aligns itself closely with the concept of experiment (South African Oxford Dictionary, 2007). In this study, experiences refer to exposures that pregnant women who are living with HIV/AIDS encounter.

1.9.2 HIV-Positive

HIV-positive denotes a test performed on an individual that is positive for the human immunodeficiency virus. In this study, a pregnant woman is said to be HIV-positive after counselling and testing has been done and the results werepositive(The Merck Manual of Medical Information, Home Edition, 1997).

1.9.3 Pregnancy

Pregnancy in a woman is the carrying of one or more offspring, known as a foetus or embryo, inside the uterus of a female (South African Oxford Dictionary, 2007). In this study, pregnancy applies to a woman who is between the ages of 15 and 49 years old who is HIV-positive and pregnant.

1.10 Research Methodology

Detailed items of the design and methods will be discussed in Chapter 2. The designs of this study were qualitative, exploratory and descriptive in nature and the phenomenological approach was used. The researcher was interested in these designs because the study purpose was to explore and describe the experiences of pregnant women

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who were living with HIV/AIDS. At the same time the researcher observed and described phenomena as they occurred, and summarized the data.

In this study, the population consisted of all pregnant women who were living with HIV/AIDS in Vhembe District, whereas the target population of the study comprised of HIV-positive pregnant women who were attending ANC at Thulamela Municipality Primary Health Care. A non-probability purposive sampling techniques was also used to sample pregnant women who were living with HIV/AIDS. Datawere collected using semi-structured interviews to explore the research questions described in section 1.5.The duration of interview was between 45 minutes to 1 hour. The interviews were guided by saturation of data.

1.11 Data Analysis

Data were analyzed qualitatively according to the useful analysis process in eight steps as indicated by Tesch (Creswell, 2003). Measures to ensure trustworthiness of the data or findings included credibility, transferability, conformability and dependability processes. Ethicalconsiderationswere alsoobserved.

1.12 Limitations of the Study

The study was limited to ThulamelaMunicipality of Vhembe District and it was done on pregnant women living with HIV/AIDS.

1.13 Dissemination of the Findings

The findings will be disseminated through presentations during national and international conference and articles in accredited journals. The report will be written to the Department

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of Health and Social Development, specifically primary health care components, and the University of Venda. Workshops will be conducted to primary health care practitioners to enhance patient care of pregnant women living with HIV/AIDS.Imbizo(Tshivhidzo)will be utilized todisseminate information to encourage spousal and family support.

1.14 ThesisOutline

Chapter 1 **Overview of the Study**	Chapter 1 provides an overview of the study which includes the following: introduction, background of the study, problem statement, research question, purpose of the study, objectives, significance of the study, research design and methods, measure to ensure trustworthy, data analysis, limitations of the study as well as ethical considerations.
Chapter 2 **Research Design and Methods**	This chapter focuses on the research strategy and approach, study setting, sampling methods and sample, data collection methods, data analysis, measures to ensure trustworthiness as well as ethical considerations.
Chapter 3 **Data Analysis and Discussion of the Findings**	This chapter is a presentation and discussion of findings according to themes, categories and sub-categories in relation to a literature control.
Chapter 4 **Evaluation, Conclusions, Recommendations and Limitations of the Study**	This chapter discusses recommendations, evaluations, conclusion and limitations of the study. Evaluation of the study against the purpose and objectives set out in Chapter 1 is also described.

1.15 Summary

This chapter outlined the overview of the study which included introduction and background of the study, problem statement, objectives, research question and research design and methods. The next chapter discusses the methodology of the study in detail.

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CHAPTER 2

RESEARCH DESIGN AND METHODS

2.1 Introduction

The first chapter outlined the overview of this study which included the introduction, background, problem statement, research question, aim, objectives, research methodology, significance and limitations of the study. This chapter focuses on the research design, population and sampling, data collection methods, data analysis, measures to ensure trustworthiness as well as ethical considerations.

2.2 Research Design and Methods

Research design and methods are techniques and procedures that are employed in the process of implementing the research design or research plan as well as underlying principles and assumptions that underline their use (Babbie&Mouton, 2008).The research design is a set of guidelines and instructions to be followed in addressing the research problems, plan or blueprint of how you intend conducting the research. Various designs used by the researchers depend on the purposes of the study, the nature of the research, questions and the skills available to the researcher (de Vos et al., 2005). Polit&Beck (2008) define research design as the overall plan for addressing a research question, including specification for enhancing integrity, methods, strategies of inquiry, or tools that can be used to design qualitative research (de Vos et al., 2011). The design for this study was qualitative, explorative and descriptive in nature, and the phenomenological approach

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was used. The experiences of pregnant women living HIV/AIDS were explored. For the purpose of this study, the researcher was interested in this design because its goal is to understand the experiences of pregnant women living with HIV/AIDS.

2.2.1 Qualitative Research

According to Barker et al. (2005), qualitative research approaches use language as their raw material in order to examine participants' thoughts, feelings, behavior or linguistic strategies. In this design, the researcher had been committed to discovery through the use of multiple ways of understanding. A qualitative design had been chosen because it is flexible, adaptable and capable of being learned during the course of data collection (Stommel& Wills, 2004). This design also required the researcher to be the research instrument and it turned to be holistic striving for understanding of the whole (Polit& Beck, 2008).De Voset al. (2011)define the qualitative design method as strategies of inquiry, or tools that can be used in research. The qualitative researcher is more concerned with understanding than explanation (Brink, 2011). In qualitative designs, researchers make decisions in planning the study and developing their own strategiesor tools as an aid or guideline (de Vos et al., 2011).Qualitative methods would be more appropriate and effective to this research study as the researcher would be exploring the experiences of pregnant women living with HIV/AIDS which is very difficult to quantify. Qualitative methods focus on the qualitative aspects of meaning, experience and understanding and thusanalyzehuman experiences from the viewpoint of the research participants in the context in which the action takes place (Brink, 2011).

The qualitative paradigm consequently has splintered into various directions which have brought growing pains in discovery and rediscovery. Moreover, qualitative research is

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constantly in flux and changing. It strives to make sense of the social world and create new knowledge or revisit already known information. New research perspectives evolve in an effort to answer the unanswered philosophical question related to the representation.(Brink, 2011). In this study, the researcher will strive to make sense, to revisit and understand the experiences of pregnant women living with HIV/AIDS

In qualitative research, the researcher used measurement and focuses on interpretative, non-numerical narrative interpretation (Polit& Beck, 2006). The researcher was interested in this design because the goal was to understand behavior or actions within their naturally occurring context. In this study, the researcher was able to explore and describe the experiences of pregnant women living with HIV/AIDS. The experiences were freely explained during interviews and non-verbal cues were recorded in a pocket notebook.

2.2.2 Descriptive Research

According to Polit&Beck (2008),the main objective of descriptive designs is the accurate portrayal of the characteristics of persons, situations, or groups, and the frequency with which certain phenomena occur. Descriptive designs present a picture of the specific details of a situation and focus on how or why questions. Description is more likely to refer to a more intensive examination of phenomena and their deeper meanings, thus leading to thicker description. Descriptive seeks to depict what already exists in a group or population. In descriptive studies, the researcher observes and describes phenomena as they happen. The purpose of descriptive research is to observe, describe and document aspects of a situation (Polit& Beck, 2008). Descriptive research also focuses on the situation as it is experienced without manipulating variables. This focus might include conditions that exist, practices that prevail, beliefs and attitudes that are held, ongoing

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process and developing trends (Cormerck, 1996). Descriptive research also enables the researcher to gain more information about the characteristics within a particular field of study with the purpose of providing a picture of the situation as it naturally occurs (Burns & Grove, 2001).In this sturdy the researcher was able to gain more information from pregnant women living with HIV/AIDS(de Vos et al., 2011).

2.2.3 Explorative Research

De Voset al. (2011) indicated that exploratory research is normally done when the researcher encounters an issue that is already known and has a description to it, butprompted toask why things are the way they are. It is also referred to as a casual question; therefore, such a study builds an exploratory and descriptive research, but goes on to identify the reason why something occurs. Exploratory research seeks to develop initial understanding of phenomena and attempts to test predictions and hypotheses in order to identify causes of events and the factors or mechanism that produce them (de Voset al., 2011).This method is often used when the problem is unclear or the subject is new to researcher.

In an exploratory design, the researcher use the initial qualitative phase with a few individuals to identify themes, ideas, perspectives and beliefs that can then be used to design a larger scale (McMillan & Schumacher, 2006). It also begins with the phenomena of interest rather simple observing and describing it. Exploratory research is undertaken when a new area or topic is being investigated and it is designed to shed light on various ways in which a phenomenon is manifested and is an underlying process (Polit& Beck, 2006).This design enabled the researcher to explore the experiences of pregnant women

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living with HIV/AIDS in order to comprehend theinformation gathered during data collection.

2.2.4 Phenomenology

Phenomenology is a science whose purpose is to describe particular phenomena. This approach investigates subjective phenomena in the belief that essential truths about reality are grounded. The researcher gathered the lived experiences of pregnant women living with HIV/AIDS according to the phenomenological school of thought. This design allows opportunity for personal experiences to be shared subjectively (Polit& Beck, 2008). In this study, phenomenology was used to describe the lived experiences of pregnant women living with HIV/AIDS. The researcher attempted to describe the lived experiences by focusing on what was happening in the lives of the participants, what was important about the experiences and what alterations could be made toalleviate the challenges faced by pregnant women living with HIV/AIDS. In this study, the researcher has listened to the participants as they shared their lived experiences, and these experiences are presented in quotations to support the descriptions of findings. These design allowedfreedomfor personal experiences to be presented (Polit&Beck, 2008).

Phenomenology is aimed at understanding the phenomena under study, on their own terms, and therefore to provide a description of human experience as it lived through by the subjects. In order to accomplish this, the researcher had to enter the subject's life settings or real-life world by placing herself in the subject's shoes (Struebert& Carpenter, 1999; McMillan& Schumacher, 2006). Van Manen(1990) cited in Stommel& Wills(2004) showed that phenomenological research has four areas of lived experiences which can constitute meta boundaries such as space, bodily experiences, human relationships and

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time. The researcher will consider all these aspects in order to meet the objectives of this research (Stommel& Wills, 2004). In this study, pregnant women living with HIV/AIDS were expected to describe theirlived experiences, and these experiences were presented as quotations to support the descriptions of findings. The time spent by researcher with the participants assisted the participants to explore and describe their experiences of living with HIV/AIDS while pregnant. Human relationships play an important role in phenomenology. In this study, a good relationship existed between the researcher and the participants, so theparticipants were free to explore and describe their experiences of living with HIV/AIDS while pregnant to the researcher (Stommel&Wills,2004).

2.3 Context and Study Setting

In qualitative research, the meaning of social action depends on the context in which the study is taking place (Neumen, 1997).In this study, the experiences of pregnant women living with HIV/AIDS were explored in the Vhembe District of the Limpopo Province. Interviews were conducted inside ANC cubicles in the Health Centres and surrounding clinics of Thulamela Municipality in Vhembe District. Limpopo Province is divided into 5 districts, namely Mopani, Vhembe, Waterberg, Capricorn, and Sekhukhune. Vhembe, where the study has been conducted, consists of 4 sub-districts: Thulamela, Makhado, Mutale and Musina. VhembeDistrict has7 hospitals, 112 clinics and 8 health centres. ThulamelaMunicipality has 2 sections, A and B. Thulamela A has 4 local areas, namely Mhinga, Mphambo, Tshaulu and Xingwedzi.Thulamela Bconsists of3 local areas which are Shayandima, Tshidimbini and Makhado. Each local area under ThulamelaMunicipality has 9 clinics. The total number of clinics in this local area is 27, whereas the area also has 3 mobile clinics and 2 health centres.

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2.4 Population and Sampling

2.4.1 Population

Population is a term that sets boundaries on the study units. It is the totality of persons, events and organizational units where the research problem is concerned (de Vos et al., 1998). Population also refers to all the elements,that is, individuals, objects, events or substances that meet the criteria in a given (identified) universe (Brink, 2006).In this study, the population consists of all pregnant women who are living with HIV/AIDS. An accessible population is the portion of the target population to which the researcher has reasonable access. The entire population is the target population of the study. In this study, the entire population was pregnant women living with HIV/AIDS in the Vhembe District. The target population is the entire population in which a researcher is interested and to which s/he would like to generalize the study results (Polit& Beck, 2008). In this study, pregnant women who living with HIV/AIDS in Thulamela Heath Centres and surrounding clinics were the target population.

2.4.2 Sampling Methods and Sample

In research there are two sampling methods that can be used, namely probability and non-probability methods. Probability sampling is the selection of sampling units or participants from a population using random procedures such as random sampling and cluster sampling, whilst non-probability sampling selection of sampling units or participants from a population use non-random procedures such as purposive sampling, convenience, accidental and quota sampling(Polit& Beck,2008). This study focused on the non-probability sampling technique implying that not all pregnant women living with HIV/AIDS were sampled. In qualitative research there is a tendency of focusing on

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smaller samples (Polit& Beck, 2008). A sample is a subset of population selected to participate in a study (de Vos et al., 2006).

2.4.3 A Representative Sample

A representative sample means that sample must be similar to the population in as many ways as possible. The former should replicate the population variable in approximately the same proportion as they occur in the latter. The demographic information that the researcher commonly looks at includes educational level, gender, ethnicity, age and income level, as they tend to influence the study variable, for example if age and educational level are variables or population parameters relevant to the study then the representative sample will have closely similar properties or representativeness, or the same age group and level of education as the target group. Representativeness is extremely important when the research wants to generalized from the sample to the target population, by drawing conclusion about the population from which the sample came (Polit & Beck, 2008). In this study, pregnant women living with HIV/AIDS will represent the sample.

2.4.4 Purposive Sampling

In purposive sampling, the sample is hand-picked for the research. The term is applied to those situations where the researcher already knows something about the specific people or events, and deliberately selects particular ones because they are seen as instances that are likely to produce the most valuable data. They are selected with a specific purpose in mind, and that purpose reflects the particular qualities of the people or events chosen and their relevance to the topic of the investigation from researcher's point of view with the already known topic and range of people with what is likely to provide the best information (Polit & Beck, 2004: Burns & Grove,2001). In this study, the researcher

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purposively sampled only pregnant women living with HIV/AIDS who were attending antenatal clinic at ThulamelaMunicipality health Centres and surrounding clinics in the Vhembe District.

2.4.5 Advantages of Purposive Sampling

The researcher can concentrate on instances which will display a wide variety and possibly even a focus on extreme cases to illuminate the research question at hand. In this sense it will be economical and informative in a very way that conventional probability sampling cannot be. Purposive sampling offers the prospect of authentic accounts of complex phenomena. It is a humanistic style research. Purposive sampling is suited to small-scale research. With purposive sampling, the description of experience can tell an interesting story. In this study, the researcher deliberately selected a sample of pregnant women living with HIV/AIDS.

2.4.6 Disadvantages of Purposive Sampling

Purposive sampling lacks scientific rigor. It is associated with description and there is no analysis. There is generalization from phenomenological studies and it pays attention to mundane features of life. There is also feasibility of suspending common sense (de Vos et al., 2011). In this study, the researcher used purposive sampling, where the researcher has used her own judgment to select subjects that represent the phenomena being studied or who are knowledgeable about the question of issue. The researcher has hand-picked the sample based on the knowledge of the phenomenon of the study. The researcher has selected pregnant woman who are living with HIV /AIDS and only those who attended antenatal care atThulamela Municipality Health Centres and surrounding clinics of

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Vhembe District. The sample chosen depended on whether saturation was reached (Polit& Beck, 2008).

2.4.7 Sampling of Health Centres

The researcher utilized health centresand surrounding clinics in the Thulamela Municipalities and chose them purposively based on their high statistics of pregnant women living with HIV/AIDS.

2.4.8 Sampling of Participants

In this study, non-probability methods were used and the researcher applied purposive sampling by hand-picking the sample. The researcher used her own judgement to select subjects that represented the phenomena studied or who were knowledgeable about the question of issue.

2.4.9 Inclusion and ExclusionCriteria

According to Neuman (2011), inclusion and exclusion criteria are parameters in which the study is limited or excluding subjects according to set characteristics. In this study, the researcher interviewed all HIV-positive women who were eligible to a legal consent. Those who were immigrants or foreigners have been excluded from the study as follow-up interviews would have been difficult in case they left the country.

2.4.10 Sample Size

In qualitative research, when purposive sampling is used, the researcher does not know in advance how many participants are needed. Data are collected until data saturation is

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reached (Brink, 1996). Data saturation occurs when no new information is given and then new participants are giving the same information that was given by others (Brink, 1996). The sample of this study consisted of all pregnant women who were living with HIV/AIDS, withages that ranging from 18to 45 years and attending ANC clinic at Thulamela Municipality Health Centres and surrounding clinics. A sample size of 10 to 30 pregnant women living with HIV/AIDS was utilized and it was determined by data saturation.

2.5 Data Collection Methods

The unstructured interview is sometimes referred as the in-depth interview and it is also known as conversation with a purpose. The researcher used the unstructured or semi-structured interviewbecause it is more flowing with itsstructure limited only by the focus of the research. Unstructured interviews are conducted without utilizing any of the researcher's prior information experiences or opinions in particular area. It is focused and discursive and allows the researcher and participant to explore an issue. It is used to determine individuals' perceptions, opinions, facts and forecasts, and their reactions to initial findings and potential solutions (de Vos et al., 2011).

This method is appropriate to qualitative or explorative research study. The interviews were conducted as normal conversation with a purpose and produce more in-depth information on the subjects (Brink, 1996). The interview was prearranged. The researcher established rapport with participants by paying attention to what the participants were saying. The researcher did not interrupt the participants, and the researcher was non-judgmental, and developed a healthy appreciation for silence. Listening and interviewing skills were used by listening intently to the participants' stories (Polit&Beck,

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2005).Discussions proceeded in a relaxed conversational manner. In this study, the interview was conducted as a normal conversation. The following question guided the interview:' *Can you explain to me how it feels to be HIV-positive and pregnant?*'

Participants were encouraged to explain all the experiences in their own language. The conversation was free flowing, but limited to experiences of living with HIV/AIDS during pregnancy. Participants were interviewed as individuals and ranged between 45 to 1 hour. Duration of individual interviews depended upon the way the subjects responded to questions. The language best understood by subjects, which is Tshivenda, was used. Data were recorded and transcribed verbatim in Tshivenda, then translated into English by a language expert. The researcher also observed non-verbal cues. The interview was conducted in one of the cubicles that were not in use. Data collection was terminated when saturation was reached. Data saturation occurred when information shared with the researcher became repetitive and ideas conveyed by the participants have been shared before by the other participants (Wood&Haber, 1994).

2.5.1 Field Notes

Field notes were taken by the researcher to record the unstructured observations made in the field to facilitate interpretation of such observations (Polit& Beck, 2008).After the researcher had conducted the interview impressions were written down. The notes helped the researcher in remembering the process of interview and how all activities unfolded. The researcher used them as a piece of evidence in support of recorded experiences, as a record of context or situation could not be recorded (de Vos et al., 2005).These were descriptive accounts in which the researcher objectively recorded what was happening in the setting, in order to capture the life experiences of the participants (Neuman, 1994).

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2.5.2 Observational Notes

These are the *'who, what, where* and *how'* of human activity (de Vos et al., 2005).Observations are basically similar and depend to a greater or lesser extent on participation, thus necessitating direct contact with the subject of observation. Observation may be regarded as a research procedure that is typical of the qualitative paradigm, which implies that data cannot really be reduced to figures. It is assumed that the real world of the participant of the research project can only be understood and revealed in the words and expressions they use in a specific situation. Observations can be utilized to discern conditions, events, feelings, physical settings and activities through looking and asking. Observations were noted regarding facial expressions in relation to certain experiences and this evidence wasused to emphasize the experiences of pregnant women who were living with HIV/AIDS.

2.5.3 Theoretical Notes

These are self-conscious, systemic attempts by the researcher to derive meaning from all observational notes. In this study, the researcher thought about what she had experienced and made whatever private declaration of meaning she felt that would bear conceptual results (de Vos et al., 2005).

2.5.4 Methodological Notes

Methodological notes are the researcher's instructions, reminders and critical collection - they are notes on how the subsequent observation will bemade. The researcher made notes of changes in methodology especially in relation to data collection (Polit& Beck, 2008).

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2.5.5 Personal Notes

These are notes on the researcher's own ideas, reactions, feelings and experiences, in other words, they are the researcher's own feelings during the research process (Polit& Beck, 2008). In this study the researcher manage to bracket her own ideas, reflections, feelings and experiences.

2.5.6 Intuition

Intuition occurs when the researcher tries to develop an awareness of the lived experiences without forcing prior expectations or knowledge in the process. In this study, the researcher reviewed the collected data again and again until there was common understanding (Brink, 2006).

2.5.7 Reflective Remarks

In this study, the researcher has reflected thoughts, feelings, ideas and insights and explored personal feelings, and experiences that may influence the study (Burns & Grove, 2005).

2.5.8 Bracketing

This is the process of identifying and setting aside any preconceived beliefs and opinions one might have about a phenomenon under investigation - it involves laying aside what information related to the topic is known (Brink, 2006).In this study, the researcher haslaidaside preconceived beliefs and opinion in order to obtain true experiences of pregnant women living with HIV/AIDS.

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2.5.9 Exploring and Probing

According to Newman (2000), a probe is a neutral request to clarify an ambiguous and incomplete question, finish and unfinished question, or complete an incomplete question. DeVosetal.(2006) supported this view indicating that a probe is used to clarify the answer or request or to request further examples, including evidence. This was further reinforced by Rice &Ezzy (2001) who indicate that there are various types of probes which can be used to elicit information such as continuation, clarification attention completion and evidence probes. In this study, the above types of probes were used and further questions were asked emanating from the participants answers to allow the participants to give more information.

2.5.10 Minimal Verbal Responding

According todeVosetal. (2002), this is a verbal response that correlates with occasional nodding which assures the participant that the researcher is still listening. In this study, the researcher nodded her head, and use "mm," "continue" and "oh" in response to what the participant was saying to allow free flow of information and to encourage the participant to talk.

2.5.11 Paraphrasing

According to de Vos et al.(2006), this is a verbal response where the researcher tries to rephrase what the participant has said in a different way, but meaning the same thing, to let the participant confirm if that is what they meant. In this study, the researcher stated the participants' words in another form but with the same meaning. Thisencouraged the participants to give more information.

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2.5.12 Clarifying

According to de Vos et al.(2006) and Henning, Van Rensburg&Smith (2004), clarifying is a technique used to get clarity on an unclear statement. In this sturdy, the researcher asked follow-up questions and redesigned the questions throughout the interview so that the participants could clarify and consolidate information.

2.5.13 Focusing

Focusing is a non-verbal response in which the researcher makes participants to give their attention to the phenomenon under study (Longman, 2003). In this study, the researcher kept the interview on track: full attention was given throughout in order to help participants to focus on their experiences of being pregnant while living with HIV/AIDS.

2.5.14 Validation

The researcher observed the participants and interpreted their own verbal communications such as vocalization, facial expressions and body gestures and transcribed them for analysis (Brink, 1996). In this study, all non-verbal communication collected during interviews as field notes were transcribed and analyzed.

2.5.15 Encouragement

According to de Vos et al. (2006), the participant has to be encouraged to pursue a line of thought. In this study, the participants were encouraged to tell more about living with HIV/AIDS while they are pregnant.

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2.5.16 Using Silence

Silence allows the participants to do the talking while the researcher listened and observed (Babbie& Mouton, 2002). In this study, the researcher kept quiet and observed what was happening to allow the participants to think and continue narrating at their own pace without disturbance.

2.6 Data Analysis

Data were analyzed qualitatively using Tesch's open-coding method whereby data were broken down into discrete parts, closely examined, compared for similarities and differences and questions were reflected in the data. Themes, categories and sub-categories were developed. Useful eight steps adopted for theanalysis process were according toTesch(Tesch, 1990; Creswell 1994, 2003), and are summarized in Table 2.1.

2.7 Trustworthiness

Trustworthiness is when the data collected is reliable, can be trusted, valid and bias free (Lincoln &Guba, 1985). Guba's model (Lincoln &Guba, 1985) for ensuring and assessing trustworthiness were used for this study. Trustworthiness is a method of establishing rigor in qualitative research without sacrificing relevance. The four criteria that were used to ensure trustworthiness as identified by Lincoln &Guba (1985) are the considered in turn.

2.7.1 Truth Value (Credibility)

Truth value asks whether the researcher has established the truth of the findings for the subjects or participants and the context in which the study was undertaken.

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Table 2.1: Tesch's eight steps of systematically analyzing textual data collected through interview questions

1.	**Getting a sense of the whole**	The researcher read through all of the transcriptions several times carefully in order to understand the information provided by participants, pregnant women living with HIV/AIDS. The researcher immersed into the topics in detail, trying to get a sense of the interviews as a whole before breaking them down into parts. Some ideas were jotted down as they came to the researcher's mind (Cresswell, 2003).
2.	**Picking one document at a time**	The researcher picked up the most interesting, shortest interviews and read through them, analyzing their underlying meanings. Thoughts were written in the margin (Cresswell, 2003).
3.	**Making a list of all topics**	After reading several interview documents from participants, the researcher made a list of all topics derived from interview reports. Similar topics were clustered together, formed in columns that then arranged as major topics, unique topics and left overs (Cresswell, 2003).
4.	**Taking the list of topics and going back to the data**	The researcher took a list of the topics, went back to the data, and abbreviated topics as codes and codes were written next to the appropriate segments of the interview report (Cresswell, 2003).
5.	**Turning topics into categories**	Topics derived from the interview reports that relate to each other were grouped. Then the researcher classified the qualitative information by looking for categories, themes or dimensions of information. General themes and sub-themes were then identified. The researcher drew columns between categories to show how they were interrelated (Creswell, 2003).
6.	**Making a final decision**	The researcher made a final decision and themes were made by assembling data material belonging to each category.
7.	**Assembling the data**	The data material belonging to each category was assembled in one place and preliminary analysis was performed.
8.	**Recoding data, if necessary**	Re-coding of the existing data was done as the researcher found it necessary during the process of analysis. The researcher was able to generate themes, categories and sub-categories from the collected data, Tesch 1990 (in Creswell, 2003).

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It establishes how confident the researcher is with the truth of the findings based on the research design, participants and context. Credibility is also defined as the truth value obtained from the discovery of human experiences as they are lived and perceived by the research participants (Lincoln &Guba, 1985).

The researcher ensured credibility by presenting accurate descriptions and interpretations of human experiences - people who also shared the experience would immediately recognize the descriptions. The researcher spent sufficient time with the participants by interviewing them more than once in individual interviews, verifying, summarizing and reflecting. Extended periods of engagement were by increased rapport as participants volunteered to give sensitive information. The researcher used numerous interviews, reframing questions and observation periods to achieve this. The researcher interviewed participants at different times, days and in different settings, which were at ANC and this enabled the researcher to sample all possible situations.

The researcher used reflexivity to guard against being so much involved with the participants, that the researcher might have difficulty in separating her own experience from that of the participants. The researcher kept a field journal throughout the research process where the daily schedules and logistics of the study were kept. The researcher's thoughts, feelings, ideas and hypotheses generated by contact with participants were reflected. The frustrations, questions and problems concerning the whole research process were written down so that the researcher could be aware of biases and preconceived assumptions. Data triangulation was ensured by using different data-collection methods. The researcher collected data through field notes and in-depth individual interviews. The data that had been collected by various means were compared.

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Member checking was ensured because the researcher revealed research material to the participants so that they could confirm whether the researcher had accurately translated the participant's point of view and this decreased the chances of misrepresentation. The researcher discussed the research process and findings with impartial colleagues with experience in qualitative research. The researcher reframed repeated questions or expanded questions on different occasions as the researcher was the instrument of collecting data, and adequately prepared in understanding qualitative studies (Lincoln &Guba, 1985).

2.7.2 Applicability (Transferability)

Transferability refers to the degree to which the findings can be applied to another context and setting or with other groups (Lincoln &Guba, 1985). Transferability is ensured by densely describing the background information about the participants. The research context and setting described should allow others to assess how transferable the findings are. The purposive sampling technique ware used to select participants who fit the criteria described (Lincoln &Guba, 1985). The results together with supporting direct quotations from participants were densely described.

2.7.3 Consistency (Dependability)

The concept "dependability" implies traceable variability, that is, variability that can be ascribed to identify sources (Lincoln &Guba, 1985). The researcher adequately described the research methods. The researcher coded the data, and waited for a certain period and then returned to recode the same data to ensure accuracy. The researcher made use of experts to check the research plan and implementation (Lincoln &Guba, 1985).

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2.7.4 Neutrality (Conformability)

Neutrality refers to the degree to which the findings are a function solely of the participants and conditions of the research and not of other biases, motivations and perspectives (Lincoln &Guba, 1985). The researcher achieved this by prolonged engagement with participants during in-depth individual interviews, reflection and verification. An auditor, who is also the supervisor appointed at the beginning of the project ensured that the nature of the audit trail could be determined (Lincoln &Guba, 1985).

2.8 Ethical Considerations

In this section ethical measures as laid down by the Democratic Nursing Organization of South Africa (Denosa, 1998:23, 1-2.3.4) are described briefly.

2.8.1 Permission to Conduct the Study

This is the authorization granted to do the study. Permission to conduct the study wassought from the following institutions as follows: The researcher wrote a letter to ask for permission for approval of the study to Limpopo province, regional office and district concerned as well as the Higher Degrees andEthics Committee of the University of Venda.Permission was also sought from the institution where the research was conducted. These documents are outlined in annexure at the end of the thesis.

2.8.2 Rights ofthe Participant and Right Not to be Harmed

Participants were informed that the research will not cause them any physical or psychological harm. The researcher responded appropriately and humanely to the

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participants. The researcher did not probe for information that could harm the participants - she deferred the questioning until a later stage since the researcher had prolonged interaction with the participants to gain their trust and understanding (Brink, 2006).

The researcher provided a therapeutic session for the participants, as they were able to talk freely without being judged about the experiences of living with HIV/AIDS while pregnant. The purpose of the project was explained to the participants. An annexure was attached which is a consent form for the participants to be enrolled for the study. Possible pains, discomfort, stress and loss of dignity that might accompany the research process were discussed with the participants. Privacy, confidentiality and anonymity were maintained (Burns & Grove, 2005).

2.8.3 The Right to Privacy

Privacy is a state of being free from intrusion or disturbance in one's private life or affairs. The researcher ensured that when interviewing the participants, privacy was protected by conducting interviews in one of the cubicles in the Health Centre and surrounding clinics which was not utilized by the staff. The relationship of the participants and researcher were so enhanced.

2.8.4 Confidentiality

Confidentiality refers to the researcher's ability to keep data source protected. It means entrusting another person with one's confidence or secret affairs. Participants were assured that any information they have provided would not be published or reported in a manner that identified them. Research information was not shared with other people unless the respondent agreed. Information was kept for the purpose of analysis and destroyed after

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the publication of the study .In this study; confidentiality was maintained by allocating numbers in the place of names to protect the subject (Polit&Hungler, 2004).

2.8.5 Anonymity

Anonymity is state or quality of being anonymous. To maintain anonymity, the names and addresses of the participants were omitted from the study and participants were assured of that. Each participant was provided with a code. Participants were asked to generate their own identification codes where possible (Polit &Hungler, 2004).

2.8.6 The Right to Maintain Self-Respect

Self-respect is the proper esteem or regard for the dignity of one's character. The researcher was not judgmental over the participant - the researcher took what the participant was saying as the truth. The researcher asked probing question and responded humanely towards the participants' emotions.

2.8.7 The Right to Refuse

Participants were told that they had the right to refuse to participate in the study without any penalty. The researcher was not influencing the participants or forced them to do take part in the study. The participants were told that they could withdraw from the study at any time they like (Burns & Grove, 2005).

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2.9 Limitations of the Study

Due to sensitivity of the research stigma attached, it might be possible that participants found it difficult to participate in the study. Some pregnant women who are HIV-positive might have preferred not to talk about this issue as it was painful. Moreover, the results cannot be generalized based on the fact that the study was conducted only at certain study sites and the responses from participants were limited.

2.10 Summary

The purpose of this study was to explore and describe the experiences of pregnant women living with HIV/AIDS who were attending ANC at the Health Centres and surrounding clinics of Thulamela Municipality at Vhembe District of the Limpopo Province. To achieve the objectives, attention has been given to the background, problem statement, research design and methods. It was, therefore, proposed that the study be approved as it will benefit clients/pregnant women who are living with HIV/AIDS and will reduce fear to disclose their status to the family members and their spouses. The study would enable participants to feel free to seek help from health facilities, and enable them to care for themselves and their unborn babies. By conducting this study, the researcher hoped to achieve these objectives and to identify the support systems and interventions for pregnant women who are living with HIV/AIDS at Thulamela Municipality at Vhembe District as well as the entire Limpopo Province.

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CHAPTER 3

DATA ANALYSIS AND DISCUSSIONOF THE FINDINGS

3.1 Introduction

A discussion of the research design and methods was addressed in Chapter 2. The objectives of this chapter were to analyze raw data and reduce it to themes, categories and sub-categories, thus reflecting participants' experiences through quotations on what has been said, and to discuss findings against the background of relevant literature. Analysis was done considering the theory of adaptation. This theory views the person as an adaptive system who needs to develop coping mechanisms in order to deal with challenges of life. In this context of this study, pregnant women living with HIV/AIDS were envisaged to adapt to the challenges that accompanied their health status. The research question of this study was:

"What are your experiences as a pregnant woman living with HIV/AIDS?"

3.2 Description of the Sample

Participants' characteristics, namely age, parity, gestational age, marital status, educational level, number of ANC visits, disclosure of HIV/AIDS status, protection (condomising), employment, and types of financial support are summarized in Table 3.1. The number of participants this study were only 12. All the participants were pregnant women aged between 23 to 43 years. Their gestational age ranged from 12 to 39weeks. Nine of them

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were married, 2 were single and 1 participant separated from her husband. Their educational levels ranged from Grade 6 to Grade 12. Eight of the participantshad disclosed their HIV/AIDS status whilst 4 did not. Six participants were not using protection (condomising), 2 were not engaging in sex as their partners were no longer interest in sex after the disclosure of their HIV-positive status. One participant reported that after she disclosed her HIV-positive status to her husband, he no longer comes home, whilst 1 participant stated that after disclosure her boyfriend went back to his former wife. One participant verbalized that she separated from her husband as he was refusing to condomize, while only 1 participant was condomising. Ten participants were unemployed, 2 were employed. Six out of 9 married participants were financially supported by their husbands, 5 were depended on grants, 1 participant depended on her father-in-law for financial support, whilst 1 participant was working and her husband supported the family.

3.3 Presentation of the Results

Textual data collected through interview questionswere systematically analyzed according toTesch's eight steps outlined in Table 2.1 (Tesch, 1990; Creswell 1994, 2003). Briefly, the steps are asfollows:getting sense of the whole, picking one document, making a list of all topics, taking the list of all topics and going back to the data, turning topics into categories, making a final decision, assembling the data, and recoding data, if necessary. Table 3.2 summarizes the themes, categories and sub-categories that emerged from the analysis of raw data. Presentation of the data was done in accordance with the experiencesarticulated by the participants who were living with HIV/AIDS during their pregnancy.

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Table 3.1: Participants' characteristics

Participant	Age (Years)	Parity	Gestational Age (Weeks)	Marital Status	Educational Level (Grade)	ANC Visits	Disclosure	Protection (Condomising)	Employment	Financial Support
1	39	P8G9	39	Married	11	6	Yes	No, after diagnosis they just stopped having sex	Unemployed	The husband is working and he is supporting the family
2	32	P4G5	28	Separated	11	3	Yes, she's an HIV activist	Separated after husband refused protection	Unemployed	No financial support from husband, she depends on child grant and an unemployed mother
3	34	P3G4	34	Married	10	4	Yes	Couple no longer interested in sex	Unemployed	Depends on child grants, husband doing piece jobs
4	26	P1G2	32	Married	12	3	No	No protection	Employed	Husband no longer sends money, supports herself
5	23	P1G2	28	Married	11	2	No	No protection	Unemployed	Supported by father-in-law
6	40	P2G3	28	Single	11	4	Yes	No, partner no longer visits	Unemployed	Depends on mother's grant and R500 from partner
7	26	P1G2	32	Married	12	4	Yes	No, partner no longer comes home	Employed	Husband not supporting, she supports herself, no financial problems
8	26	P1G2	32	Married	12	3	No	No protection	Unemployed	Husband working and supporting the family
9	29	P2G3	34	Married	12	3	Yes	No, no sex since diagnosis	Unemployed	Husband working and supporting the family
10	24	P1G2	26	Married	12	3	Yes	No protection	Unemployed	Husband working, no financial problems
11	43	P4G5	28	Single	6	2	Yes	No protection, boyfriend went back to former wife	Unemployed	Depend on child grant and R280 from partner
12	26	P1G2	12	Married	11	2	Yes	No protection	Unemployed	Husband working, no financial problems

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Table 3.2: Themes, categories and sub-categories related to experiences of pregnant women who are living with HIV/AIDS

Theme	Category		Sub-Category	
1. Participants' experiences related to disclosure of HIV status	1.1	Participants experienced fear related to disclosure to spouses/life partners	1.1.1	Fear of rejection and divorce
			1.1.2	Other people would disclose the status to the husband
			1.1.3	Fear of being blamed for bringing disease to the home
	1.2	Participants experienced fear to disclose to their in-laws	1.2.1	Fear of being rejected and blamed
			1.2.2	Fear that people would talk behind their backs
			1.2.3	Fear of being blamed for killing the husband
	1.3	Participants experienced fear to disclose to their own parents and siblings	1.3.1	Fear that own parents may be stressed
			1.3.2	Sharing confidential information with siblings who will end up telling others
2. Participants' experiences related to support received	2.1	Participants experienced financial problems	2.1.1	Dependence on grants and maintenance
			2.1.2	Dependence on husbands
			2.1.3	Too weak to work
			2.1.4	Financial support related to transport and collection of medication
	2.2	Participants experienced lack of emotional support	2.2.1	Husband no longer engages in sexual intercourse
			2.2.2	Lack of or poor communication between the spouses
			2.2.3	Boyfriends and relatives no longer visit or answer the phone
			2.2.4	No longer accepted in social gatherings
			2.2.5	Next-door neighbourswoulddivulge status during quarreling

Continued/...

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Table 3.2: Themes, categories and sub-categories related to experiences of pregnant women who are living with HIV/AIDS (Continued)

Theme	Category		Sub-Category	
3. Participants' experiences of fear related to being pregnant and living with HIV/AIDS	3.1	Participants feared that the baby may be affected	3.1.1	Failure to use condoms may kill the baby
			3.1.2	Fear that the baby may die afterbirth
			3.1.3	Fear related to breastfeeding
	3.2	Participants feared that their partners may become infected or die	3.2.1	Fear that their husbands may die as they refuse to be tested
			3.2.2	Husbands refuse to use condoms
			3.2.3	Husbands want to make babies
	3.3	Participants feared that people will involuntarily know about their HIV/AIDS status	3.3.1	Status would become known because of loss of weight
			3.3.2	Status would become known because of not breastfeeding
			3.3.3	Status would become known due to prolonged hospitalization
4. Challenges experienced by pregnant participants living with HIV/AIDS	4.1	Participants feared for their own death	4.1.1	Low $CD4^+$ cell count, too weak and anemic
			4.1.2	Re-infection because of not using condoms
	4.2	Participants feeling physically ill and constant tiredness	4.2.1	Experiencing physical illness and a feeling of tiredness and general body weakness
			4.2.2	Admitted to hospital

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3.4 Discussion of the Findings

Pregnant women living with HIV/AIDS expressed different experiences which translated into4 major themes with categories and sub-categories thatemerged from the data analysis (Table 3.2). Appropriate quotations from raw data and a literature control were included to substantiate thediscussion of the themes.

The following themes emerged from raw data:

- Participants' experiences related to disclosure of HIV status
- Participants' experiences related to support received
- Participants' experiences of fear related to being pregnant and living with HIV/AIDS
- Challenges experienced by pregnant participants living with HIV/AIDS

3.4.1 Theme 1: Participants' Experiences Related to Disclosure of HIV Status

This theme emerged from the data that reflected that pregnant women living with HIV/AIDS were experiencing problems of disclosure to their spouses or life partners, fear to disclose to their in-laws, fear to disclose to their own parents and siblings.Participantsfeared that they may be rejected or divorced, that other people would disclose their status to their husbands, that they would be blamed for bringing the disease to their homes, that other people might talk behind their backs, that they would be held responsible for killing the husband, that their own parents might be stressed, and that their parents may share confidential information with other siblings.

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The following categories were identified from the data:

- Participants experienced fear related to disclosure to spouses/life partners
- Participants experienced fear to disclose to their in-laws
- Participants experienced fear to disclose to their own parents and siblings

3.4.1.1 Category 1.1: Participants Experienced Fear Related to Disclosure to Spouses/Life Partners

Participant'senvisaged fears in relation to disclosing their HIV-positive status to their partners. Fear was said to be caused by uncertainties that they had about their partners' reaction to the news. This was also exacerbated by the stigma that is attached to the disease. From this category, 3 sub-categories emerged: fear of rejection and divorce, fear that other people would disclose the status to the husband and fear of being blamed for bringing disease to the home.

3.4.1.1.1 Sub-Category 1.1.1: Fear of Rejection and Divorce

Data indicated thatthe majority of participants experienced fear of rejection and divorce if they disclosed to their spouses/life partners. For these reasons, participants verbalized that they were not likely to disclose their HIV-positive status to their partners. Participants indicated that they experienced fear as stigma and discrimination is attached to the disease. The following are some of the quotations from the participants:

One participant said, *"I cannot disclose my status to my husband, he may reject me or even divorce me."*

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"You know what - my husband was attending a course and he was tested at the course and brought back a certificate with HIV-negative results."

Another participant said, *"I got married this year and this is my first pregnancy in this relationship. I cannot disclose my HIV/AIDS positive status to my husband, he may reject me, I am afraid if I disclose I may lose him."*

Lawrence et al. (2006) indicated that pregnant women living with HIV/AIDS, married and unemployed are the group of people who are economically disadvantaged, and therefore they fear divorce or rejection by the husband who is supporting the family (Lawrence at al., 2006). This view was also shared by Lauwo&Cjacre (2007) who indicated in their study that pregnant women who are living with HIV/AIDS fear to disclose their HIV/AIDS status as they fear to be rejected or divorced, reactions that would leave them with economic challenges. Stigma attached to the disease is caused by preconceived stereotypes regarding HIV/AIDS, including the belief that the disease only affects promiscuous, immoral or drug using females, which is not acceptable to society. Other sources indicate that pregnant women living with HIV/AIDS fear the consequences of disclosure, such as being stigmatized, blamed, discriminated against or even abandoned by their husbands and left with children to support (Kasenga et al., 2008). These assertions are in agreement with studies conducted in Malawi which found that women's major concerns were reactions of their male partners to their positive HIV/AIDS test (Kasengaet al., 2008).

In this study, the researcher is of the opinion that it is likely that the participants feared rejection, blame and divorce more than the disease itself and they chose to suffer in silence rather than facing such aftermaths.

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3.4.1.1.2 Sub-Category 1.1.2: Other People Would Disclose the Status to the Husband

Data analysis indicated that the participants were apprehensive about other people disclosing their HIV-positive status to their husbands before they got the chance to do so themselves, thus putting them in a very challenging situation, as they were still shocked by the results. The participants verbalized that they needed time and chance to disclose their status to their husbands in their own way, as they know their spouses better. The following quotations illustrate these sentiments:

"Vhonnese (nurse) do you know what, as I was still in shock, trying to get ways to disclose my HIV/AIDS positive status to my husband, somebody called my husband using private number and told my husband that I was HIV-positive. Huh, I was so hurt."

"My neighbor is very cruel. One day as we were quarrelling about other things that doesn't concern my HIV status, she said she knew that I was dying of HIV/AIDS and that my previous husband died due to HIV/AIDS. She was screaming for everybody to hear, and you know what my husband was there and that's how he got to know about my HIV/AIDS positive status before I could gather strength to disclose my status to him by myself!"

Lawsonet al.(2006) indicated that when pregnant women tested HIV-positive in the village, people will gossip about their HIV-positive status and eventually somebody will divulge the status publicly. Sometimes, nurses are the ones who divulge the patient's HIV-positive status to their own friends and relatives who end up gossiping about it (Lawson et al., 2006).

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Chikonde (2009) stated that in the communities people know each other and if a pregnant woman tested HIV-positive people will know due to the location of PMTCT programme at the clinic which is situated away from other antenatal care (Chikonde et al, 2009).In the Ukraine, pregnant women's HIV-positive status is disclosed to the husband by nurses because it is thought that women do not understand HIV/AIDS and their diagnosis, especially when the wife is uneducated (Reproductive Rights, 2005).

Thisstudy suggest that ANC should be a joint responsibility for both the husband and his pregnant wife toregister for PMTCT so that both will be part of the HIV-positive status to make it easy for the pregnant women who fear disclosure to their husbands or life partners.

3.4.1.1.3 Sub-Category 1.1.3: Fear of Being Blamed for Bringing Disease to the Home

Data revealed that participants experienced fear of being blamed for bringing the disease into the family. Participants feared that since they will be the first in the family to disclose their HIV-positive status, they would be singled out asthe likely ones who have contracted the disease and brought it home first. HIV/AIDS is still carrying the stigma as it is associated with unfaithfulness or being a disease of those who are immoral. Participants reported that they feared that if their spouses/life partners found out about their HIV-positive status their partners might blame themed think that they were not faithful, especially if their partners were not their first or the only man they have slept with. The following are some of the quotations from the participants.

One participant said, *"I cannot disclose my status to my husband because he may blame me for bringing the disease at home."*

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Another participant said, *"I cannot disclose my status to my husband because I got married this year, my husband may blame me that I am the one who have brought the disease in this marriage, he may divorce or reject me, no (vhonnese) I cannot risk my marriage."*

Lauwo&Muga (2007) pointed out that HIV/AIDS is associated with being loose or having an extramarital affair, being badly brought up or being promiscuous. Research indicates that when an HIV-positive diagnosis is brought home by the wife who is expected to be loyal to herhusband, problems arise in the marriage (Liamputtong et al., 2009).According to Kalipeni (2008), married women who are unemployed are easily judged as it is difficult to accuse the husband, especially if she is the first person in the family to break bad news, thus leaving the husband to be viewed as if he is the victim of a disloyal wife. Carr&Gramling (2004)also indicated that women also blamed themselves because of preconceived stereotypes regarding HIV/AIDS, believing that the disease only occurs in the promiscuous, immoral and drug-abusing female (Carr &Gramling, 2004). The study that was conducted in Malawi highlighted that HIV-positive women rarely saw their spouses as a source of support and trust as spouses refused to be tested (Kasenga, 2008).

In view of the aforementioned, the researcher argues that due to lack of economic empowerment of pregnant women living with HIV/AIDS are easily targeted and held liable for bringing the disease to their homes, whilst it is difficult to apportion blame on their husbands.

3.4.1.2 Category 1.2: Participants Experienced Fear to Disclose to Their In-Laws

Data indicated that participants experiencedfear to disclose their HIV-positive status to their in-laws due to fact that they may be rejected and blamed for killing the husband.

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Participants also feared that people would talk behind their backs. From this category three sub-categories emerged, namely fear to be rejected and blamed, fear to be talked about and blamed for killing the husband.

3.4.1.2.1 Sub-Category 1.2.1: Fear of Being Rejected and Blamed

From the interview statements, participants expressed fear that if they disclosed their HIV-positive status to their in-laws they might be rejected and blamed for being responsible for infecting their husbands. The participants also verbalized that they cannot disclose to their in-law fearing that they may be condemned for infecting their son since every parent loves their own children unconditionally and is difficult to speak bad about your own child.

The following are the quotations of some of the participants:

"If my in-laws find out that I am living with HIV/AIDS they will reject me and blame me for infecting their son, they may think that I am involved with another man."

"I cannot disclose my HIV/AIDS status to my in-laws because they cannot blame their own son. They will put the whole blame on me, and because they love their son, they will end up blaming and rejecting me."

Lekganyane& du Plessis (2011) indicated that Africans believe that women should act appropriately without being loose or engaging in extra-marital affairs. Thus, when there is HIV/AIDS in the family the woman is often blamed as men are classified as responsible people that they cannot bring the disease home (Lekganyane&du Plessis, 2011). It is also said that African women are expected to keep the family well. HIV/AIDS exposes their inadequacy as they failed to perform their expected roles predisposing them to being

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blamed for the disease and to be rejected (Lawson, 2002).Other research reported that women are usually the group of people who are less recognized in the family due to lack of economicpower, education and low socioeconomic background. Hence, their situation puts them at risk of being blamed for bringing the disease home (Lawson et al., 2005).

The researcher identified that married women have a need to be accepted and loved by their in-laws, as they have a positive influence on their sons. Women, therefore, think that if the in-laws find out about the disease, they may be blamed.

3.4.1.2.2 Sub-Category 1.2.2: Fear that People Would Talk Behind Their Backs

Interview statements indicated that most of the participants feared that people would talk behind their backs. Participants reported that when the in-laws are frustrated or fear loss of the life of their sons, they may say bad things about them to protect their own sons. Participants verbalized that if their in-laws have to choose, they would ultimately choose to protect their sons' image over the participants. Participants also felt that their in-laws would gossip about them with their other children which may end up disclosing their HIV/AIDS status to other people whom they would not want to disclose to. The following are quotations from the participants:

"I cannot disclose my HIV/AIDS status to my in-laws, they may talk about it everywhere with anybody, especially with their other children, and these children may eventually spread the news, eish (sighs). It's difficult."

"I didn't disclose my status to my in-laws fearing that they may talk about it with other people resulting in disclosure of the status involuntarily."

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Lekganyane& du Plessis (2012) indicated that [illegible] are used to staying together in a household and village where everybody knows each other (unlike in the urban areas where everybody is independent and does not care about what is happening next door). When one becomes pregnant everybody will know about the pregnancy and if the pregnant woman is HIV-positive, theinhabitants of village will know and talk about it. Pregnant women choose to keep their status to themselves until the illness can no longer be concealed fearing that people will talk about or they will be stigmatized (Lekganyane& du Plessis, 2011). Bond et al. (2002) also indicated that women fear to disclose their status to avoid gossip, verbal abuse and name calling that occurs in many instances. With the assumption made about their past history, women are believed to be more vulnerable to such gossip and accusation. Women with HIV/AIDS are referred to as prostitutes (Bond at al., 2002). This view was also revealed in the study conducted in Malawi where participants verbalized that they would never disclose their status fearing that if they told one person, that person would tell other people and everybody will know (Kasenga et al., 2008).

In this study, the researcher deduced thatthe stigma attached to HIV/AIDS makes the in-laws prone to blame shifting from their own son to their daughter-in-law, thinking that she is the one who have infected their son deliberately.

3.4.1.2.3 Sub-Category 1.2.3: Fear of Being Blamed for Killing the Husband

Data from the participant'sindicated that there is a myth within their communities that if a man dies the wife has killed the husband because she wanted to have other man. It was also said that other people normally say the husband was killed by a boyfriend of the wife or the wife killed the husband because she wanted to use his money. The participants

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verbalized that they feared to be blamed for killing their husbands. Data analysis also suggeststhat most of the in-laws were not on good terms with their daughters-in-law, and it was easy to blame their daughters-in-law. Participants said that in-laws often tell other people that their son is good as a way of protecting their son from stigma that goes along HIV/AIDS death. As most of the participants were unemployed, they also feared to disclose to their in-laws who may think they have infected their sons deliberately for financial gain or to inherit his assets. These are some of the quotations from the participants:

"I cannot disclose my status to my in-laws, they may think I am the one who brought the virus home from my boyfriend in order to kill their son, you know that his brother passed away last year and my in-laws are blaming his wife."

"Disclosure will make my in-laws to blame me for killing their son, they may think that I have infected their son so that after his death I will enjoy his money or I want to kill him for me to have other boyfriends."

Adam et al. (2008) indicated that HIV/AIDS is strongly associated with promiscuity and female promiscuity is viewed more negatively as men are less stigmatized. In women the promiscuity is more demonizing (Adam et al., 2008).Therefore, HIV-positive pregnant women choose to keep their status quiet and to themselves fearing that they would be blamed, especially by their in-laws, for killing their husbands. With married women in Africa it is believed that HIV is only transmitted through extramarital sex and in Africa women are not expected to behave that way (Adam et al., 2008). Women are often blamed that they have been promiscuous, sleeping with men anyhow. In certain households, such

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remarks were mixed with disappointment and with feelings of being discredited and dishonored by women living with HIV/AIDS (Bond et al., 2002).

The researcher identified that pregnant women living with HIV/AIDS are criticized forbeing promiscuous and, as a result, they do not disclose their HIV-positive status to their in-laws fearing being blamed for killing their husbands.

3.4.1.3 Category 1.3: Participants Experienced Fear to Disclose To Their Own Parents and Siblings

Participants expressed their reluctance to disclose to their own parents fearing that their parents may encounter stress as HIV/AIDS is stigmatized and associated with death. In this category, two sub-categories emerged, that is; parents may be stressed and sharing confidential information with siblings who will end up telling others.

3.4.1.3.1 Sub-Category 1.3.1: Fear that Own Parents May Be Stressed

During the interviews, participants verbalized that they were apprehensive to disclose their HIV/AIDS status to their own parents whomay, as a result, suffer from stress. From the sample used, it was found that most of the participants had not disclosed their HIV-positive status to their own parents. Participants mentioned that their parents (especially mothers as none of the participant mentioned their fathers) loved them so much that they thought disclosing their status would cause their parents to die before their time due to stress. Some participants indicated that their mothers were already suffering from chronic disease and, therefore, they did not want to exacerbate their condition, especially sincethere is currently no cure for HIV/AIDS. Most participants felt sorry for their mothers, more so than their own health.

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The following are some of the statements made by the participants:

"I don't want to tell my mother about my HIV/AIDS positive status, she may suffer from stress. When I looked at my mother I don't know how to tell her about my HIV/AIDS positive status. My mother loves me so much she may develop diseases like heart problems and high blood pressure. She will worry about my health; she may think that I will die."

"I don't want to disclose my HIV/AIDS status to my mother, it will be too much for her and she is always sick, she may die."

According to Lekganyane& du Plessis (2011), HIV/AIDS is assumed to be transmitted only through extramarital sex which brings shame on the women's parents, or their mothers may be blamed for beingimmoral or brought up badly. This shame is extended to the parents and they are unable to socialize with other parents. Pregnant women who are living with HIV/AIDS choose to keep quiet about their HIV/AIDS status to protect their parents - especially their mothers, from the shame associated with giving birth to a girl who is now HIV-positiverote failure to raise their girls in an acceptable manner. Other research has shown that pregnant women living with HIV/AIDS experienced fear of rejection - they found it difficult to tell those close to them, particularly parents, friends and spouses. Frequently, they gave blank responses while inside they felt different (Mapisi 2003, cited by Chokoe, 2005).

The researcher concluded that participants were afraid to disclose their HIV-positive status to their parents mainly because they feared that their parents might be stressed due to the fact that HIV/AIDS is generally associated with stigma and shame.

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3.4.1.3.2 Sub-Category 1.3.2: Sharing Confidential Information with Siblings Who Will End Up Telling Others

During interviews the participants expressed fear about disclosing their status to their parents who may tell their siblings who, in turn, will end up telling their partners. Participants did not trust their siblings with their secret. Many waited until the progression of the disease rather than disclosing their HIV/AIDS status beforehand. These sentiments are borne out by the following quotations:

"I cannot disclose my status to my mother since my mother may tell my sister about my status. I don't want my sister to know about my HIV/AIDS status as she is too talkative. She may tell people about my status, vhonese (nurse) I don't trust my siblings with my status."

"I don't want to disclose my HIV/AIDS positive status to my parents, they may tell my siblings who will also tell their partners, and before long everybody will be talking about it and this will be too much for me to handle.''

Lauwoet al. (2012) indicated that HIV/AIDS is associated with shame, gossip and stigma. It has previously reported that the fear of disclosing anHIV-positive status to parents stems from the concern that parents may be affected by their children's HIV/AIDS status, as it would bring them shame and pain(Lauwo at al., 2012). Infected individuals share the information with other siblings trying to share the burden and the sibling, in turn may, tell other people as they are also trying to get around the stigma that comes with HIV/AIDS (Lauwoet al., 2012). Other studies indicated that HIV/AIDS brings shame to those infected as it is associated with immorality or being brought up badly, the shame extends to the parents who are unable to socialize with other parents, shunned or cut off from the

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community (Kasengaet al., 2008). Another study noted that in Malawi pregnant women living with HIV/AIDS deliver at home with a birth attendant, their grandmothers and sisters, but take nevirapine in secret and do not disclose their status due to stigma attached to the disease (Kasenga et al., 2008).

The researcher concluded that the shame, gossip, and stigma that is associated with HIV/AIDS make it very difficult for participants to disclose their HIV-positive status to their parents in an effort toprotect them from stress and shame associated with HIV/AIDS.

3.4.2 Theme 2: Participants' Experiences Related to Support Received

This theme emerged from the data that reflected that pregnant women living with HIV/AIDS had financial problems as most of them depended on grants, maintenance, husbands and some of them were too ill and weak to supplement their child grants. Data also reflected that participants experienced emotional problems as husbands/boyfriends no longer talked toand supported them or engaged in sexual relationship. Participants were also not accepted at social gatherings.

The following sub-categories emerged from the theme:

- Participants experienced financial problems
- Participants experienced lack of emotional support

3.4.2.1 Category 2.1: ParticipantsExperienced FinancialProblems

Theparticipantsexperienced financial problems and most of them were unemployed. They expressed their difficulties concerning finances as some of them are depending on child

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grants, parents' social grants or support from either their husbands or boyfriends and many of them were too weak or sick to do full – or part-time jobs which was previously their sources of income. Four sub-categories emerged from this category, namely dependence on grants and maintenance, dependence on husbands, too weak to work, and lack of money to travel to the hospital to collect medication.

3.4.2.1.1 Sub-Category 2.1.1: Dependence on Grants and Maintenance

Data analysis indicated that most of the pregnant women living with HIV/AIDS experienced financial problems. After disclosure of their HIV/AIDS status, most pregnant women experienced abandonment and lack of financial support from their husbands. Some of them were dependent on their child support grants, mothers' socialgrant or maintenance from former boyfriends or husbands. Participants also said that most of them were unemployed. They described how they ended up with a lot of children as most of the time they were not given a chance to negotiate the number of children they wanted. Thissituation made it difficult for them to support their big families with the grant they received from government since there were a lot of needs, school fees, transport money, and money to fill lunch boxes. Some of the participants verbalized how they used to do part time jobsincludingplowingthe fields to supplement the grants. They also described the difficulties they were experiencing at the time of data collection due to general body weakness.

The following are some of the quotations from the participants:

"My husband is refusing to support me and my four children plus this pregnancy (pointing finger at her abdomen) even though he is working as a security guard. He told me that since I'm the one receiving grant to support the children I should support them. Now that

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I'm ill, weak and unable to do part-time jobs, the child's grant is too little for food, school fees and also have to go to the hospital for checkups or to collect medication. I am struggling with the little amount of money I receive from my children's grant."

"I used to work in my field in order to have food for my children by ploughing and selling vegetables. Now these days I am so weak I am no longer able to work in my field. These days I depend on my two children's grant and the maintenance of my second born son from his father which is only R280. It is very difficult because those two children are at secondary level. They need money for Saturday school, transport money and also food at home. This is too much. Before I disclosed my status to my boyfriend, he used to support me and my children. He also paid for my field to be ploughed. These days I am really struggling financially."

Literature indicated that most pregnant women living with HIV/AIDS are unemployed and separated from their husbands/boyfriends and experience economic difficulties. The same study described how the little money they get is used to buy food which they cannot afford such as eggs, meat, milk and vegetables (Sukumani, 2011). This view was also reported by (Visser et al., 2012) that most of the mothers were unemployed and financially dependent on partners, family members and disability and child support grants, and had difficulties keeping children in school, paying school fees and buying school uniforms (Visser et al., 2012).

In addition, it was reported that pregnant women living with HIV-positive have a need to provide for their children before taking care of their own well-being. The fact that they were not only poor, but also had children whom they have to support financially to uplift

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the standard of their children's lives, also put pregnant women under stress (Mays&Cochran, 2009).

The researcher concluded that many of pregnant women living with HIV/AIDS are unemployed, abandoned by their spouses, uneducated with many children to feed whilst their health status does not allow them to do full- or part-time jobs because they are too weak. The researcher thinks that lack of financial resources contributes to a sense of helplessness in the participants.

3.4.2.1.2 Sub-Category 2.1.2: Dependence on Husbands

Most of the married pregnant women living with HIV/AIDS depended on their husbands for financial support becausethey were not employed on a full-time basis. Most of them were doing part-time jobs and had no stable finances to depend upon. Data indicated that dependence on husbands for financial support also predisposes pregnant women to re-infection HIV-infection and unprotected sex from the husbands/boyfriends who refused to use condom or get tested. Pregnant women described how they resigned themselves to stay in abusive relationships for the sake of financial support. Participants verbalized that after disclosure of their status to their husbands/boyfriends they were no longer supporting them financially. These ledto difficulties in financing their children and their families as well as buying staple food for which is necessary to improve their health condition. Lack of financial support also exposes them to stress whilst stress to a pregnant women living with HIV/AIDS can worsen the condition. The following responses illustrate these views:

"I am unemployed and I depend on my husband who is working on a part-time basis as a welder. I do not want to breastfeed my baby. I think my breast milk is not 100% free from the virus and I do not want to expose my baby to the virus therefore I am choosing formula

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feeding for which I know that my husband cannot afford as he works on a part-time basis. I really don't know what to do."

"After I disclosed my HIV/AIDS positive status to my husband he stopped sending money like he used to do. These days he no longer comes home during month end, I am depending on child's grant and I am also working on part-time basis. The little money I get I use it to support my child. I don't know what will happen to me and my child if I start to develop symptoms. The part-time job is not guaranteed, they may tell me that my period is over and get other people to work also."

The literature suggests that most pregnant women living with HIV/AIDS are unemployed and depend on their husbands/boyfriends for financial support and when they found out about their wife's HIV-positive status they abandontheirpregnantwives and usually marry other women. Male partners leave relationship after disclosure (Lawson et al., 2006). This view was also corroborated by Kasenga (2008) that when husbands discover that their pregnant wives tested HIV-positive, they leave home, and their unemployed wives with children without support.

It has been noted that dependency on their husbands for financial support also predisposes women to re-infection and unprotected sex from the husbands/boyfriends who refuse to use condoms and get tested. Lawson et al.(2006) also indicated that women are experiencing difficulties in negotiating condom use as they depended on their husbands for financial support. As a result, they submit themselves to their husbands' sexual demands in exchange for financial support. In many societies it is a taboo for a wife to negotiate condom use (Sharon&Crosby, 2006).

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The researcher identified that due to financial challenges women are experiencing difficulties in negotiating condom use. Many participants appeared willing to risk HIV/AIDS infection rather than to suffer financial hardship.

3.4.2.1.3 Sub-Category 2.1.3: Too Weak to Work

From the data collected it was observed that two of the participants were hospitalized for about three months. Due to their illness and general body weakness, they were no longer able to work on a part-time basis for them to supplement grants they were receiving for maintenance from their former boyfriends/husbands. Participants who were discharged after their hospitalization came home to face the huge problem of lack of funds to raise their children and meeting the demands of their own children. They verbalizedthat they were very frustrated as the situation was beyond their control. Lack of funds increased the burden on A the participants as they were used to earn something on a part-time basis to minimize financial constraints. Financial constraints were related to money for transport to school and school fees, paying for Saturday school, lunch boxes, and groceries for the whole month and money to travel to the hospital to collect medication. The following are some of the quotations from the participants.

"I was hospitalized for 3 months. For the first 2 months I was so sick that I couldn't recognize people. I was so amazed when I was told that it was the third month in hospital. Since I came back from the hospital I am too weak to perform any duty. The grant is not enough to support four children and this one (pointing at the abdomen). I cannot afford to keep the home as if everything is alright. Money is a problem since I am no longer able to do part-time job."

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"My boyfriend used to support me financially; he also used to help me to plough my field. After disclosing my status he went back to his former wife, and now that I was admitted to the hospital I am too weak to do part-time job, even to work in my field, in order to supplement the child's grant and maintenance I am receiving."

Van der Spuy (2009) indicated that when the disease is in an advanced stage of pregnancy accelerated deterioration of the health of pregnant women results in them being too weak to perform any duties. It is also said that repeated pregnancy of women living with HIV/AIDS does not only accelerate deterioration of their health, but also speed up the death of the pregnant woman and her unborn baby (van der Spuy, 2009).

Lawson et al.(2006)indicated that the time when they are so weak is when the need to have financial support is greatest as they will have to travel to the hospital for follow-up and collection of treatment. Sukumani(2011) also point out thatpregnant women living with HIV/AIDS also need money to buy food such as milk, eggs, meat and vegetables, as food plays an important role in improving their condition (Sukumani,2011).

The researcher identified that lack of funds increased the burden of the participants as they were used to work on part-time basis to minimize financial constraints.

3.4.2.1.4 Sub-Category 2.1.4: Financial Support Related to Transport and Collectionof Medication

Due to lack of financial support, participants described difficulties to obtain money for transport when they had to go to the hospital to collect medication. With the shortage of medication in Limpopo Province, participants indicated that they had to move from one clinic to another in order to get their medication. Sucheffortsdemandmoney. Participants

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indicated that they experienced difficulties accessing money for transport to honor follow-upvisits to the hospital and to collect medication as it was important to take medication on a daily basis to improve compliance and their health status. The following are some of the quotations from the participants

"I was hospitalized for a long period. After being discharged I had to go to the hospital for follow-up and to collect medication. But it is so difficult because I find myself with no money at all and I have to borrow from others and relatives and sometimes they also don't have money. If I was strong enough I would make a plan and find a job to assist myself with this transport money."

"I was told to come back for follow-up, but it is very difficult for me because I didn't have money for transport. I wish if I was to do all my follow-up here and now that I am so sick and weak I am unable to do some part-time job in order to get money for transport."

Sukumani (2011) indicated that lack of transport money is still a major problem for pregnant women living with HIV/AIDS as they are unemployed, their husbands are not supporting them and they usually depend on child support grants and still have to transport themselves to the hospital for follow-up and collection of treatment (Sukumanil,2011). This view was also expressed byMoneyham et al. (2010) that many pregnant women who are living with HIV/AIDS lived in small towns and rural communities which are far away from health care services, making it difficult to access care. Most of them lack personal transport and they have to depend on family and friends for transport money (Moneyham et al., 2010).

Lawson et al.(2006) alluded to the fact that pregnant women living with HIV/AIDS are mostly abandoned by their husbands, putting pressure on them as they are expected to go

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to the hospital for collection of treatment and follow-up while they are living with financial constraints to theextent that they skip follow-ups (Lawson et al.,2006).

The researcher identified that lack of funds and being economically dependent on others pose a major challenge to the participants, especially since they have to transport themselves to collect medication and for follow-up visits to the hospital.

3.4.2.2 Category 2.2: Participants Experienced Lack of Emotional Support

The majority of participants indicated that they were experiencing lack of emotional support as their husbands were no longer interested in sexual relations after disclosure. Some participants verbalized that there was lack of communication between them and their spouses or boyfriends, and the community no longer acceptedthem. From this category 5 sub-categories emerged: husband no longer engages in sexual intercourse, lack of communication with spouses, boyfriends, and relatives no longer visited or answer the phone, they were no longer accepted in social gatherings and next-door neighboursdivulged their HIV/AIDS status during quarrelling.

3.4.2.2.1 Sub-Category 2.2.1: Husband No Longer Engages in Sexual Intercourse

The majority of participants said that since they disclosed their pregnancy and their HIV-positive status, their husbands/boyfriends were no longer interested in sexual intercourse. Some were staying with their husbands/boyfriends, but the latter were no longer interested in sexual relationships. The following are some of the responses from the participants:

"My husband is supporting me financially, but he is no longer interested in having sexual intercourse with me. He buys food and everything we need in the family, but we no longer

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have time for each other as he doesn't want to talk. When I ask him he just keeps quiet. Ritoungakhaladzinakhaladzi (we are like brother and sister). I don't know what he is thinking."

"We used to be happy my boyfriend and I. We used to enjoy sex, but after I disclosed my HIV/AIDS status he went back to his former wife and children. He no longer visits me, let alone engages in sexual intercourse."

Lawson et al.(2006) indicated that there is a change in intimate relationship after the diagnosis of HIV/AIDS. This is said to be caused by the fact that HIV/AIDS is associated with death. Due to fear men are no longer interested in a sexual relationship with the diagnosed partner. HIV/AIDS instills fear so much and fear of death or worsening of the condition are fundamental contributory factors that cause men to be afraid to engage in sexual intercourse, so much so that most of them leave the relationship to propose to other women or go back to their previous relationships, or former wives and children (Lawson et al., 2006). In African culture sex is not discussed openly, so it is hard to find a couple discussing their sexual needs. Men are expected to initiate and never to negotiate sex with the wife. Women who try to negotiate sexual matters are labeled as promiscuous (Van Rensburg, 2006).This view was also shared by Kasenga et al. (2008) that when the husband discovers that the wife tested HIV-positive he stayed away from home, never visited, regarded the wife as a prostitute and was unwilling to help the wife and children financially (Kasenga et al., 2008).

The researcher concluded that due to fear and stigma attached to HIV/AIDS, couples are no longer interested to sex, resulting in a dysfunctional marriage. Most men do not enjoy sex when they have to use condoms, especially with their own wives.

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3.4.2.2.2 Sub-Category 2.2.2: Lack of or Poor Communication Between the Spouses

Participants experienced emotional problems because after they disclosed their HIV-positive status, theirhusbands no longer talked to them. Husbands who were usually communicating with their wives just stopped to do so. Those participants who had boyfriends verbalized that their boyfriends no longer talked to them and when they tried to phone, their boyfriends did not answer their phones. The following quotations illustrate such responses from participants:

"After I disclosed my pregnancy and my HIV/AIDS positive status, my husband just kept quiet. He did not utter a word, positive or negative and when I talk to him he just keeps quiet. When I ask him why he is not saying anything he says that we will talk about it later as he is still busy with other things."

"When I disclosed my pregnancy and my HIV/AIDS positive status to my boyfriend, he didn't say anything. He just took his clothes and went back home to his former wife and since then we have never talked to each other. When I call him he doesn't answer his phone."

Lawson at al. (2006) noted that sex and HIV/AIDS is not a topic to be discussed openly in African culture. HIV/AIDS is such an awkward andagonizing diseasethat people would rather avoid talking about it. There is a huge silence about HIV/AIDS, more especially in marriage (Lawson et al., 2006).Moreover, causing a couple to blame each other is also a symptom of the bad effect caused by HIV/AIDS. As HIV/AIDS is a silent killer where a couple can live for many years without showing signs and symptoms it is difficult to trace back who might have brought the virus home and, as a result, both husband and wife blame each other resulting in tension in the family (UNAIDS & WHO, 2005).

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The researcher identified that most of the husbands and boyfriends did not want to talk about HIV/AIDS due to fear of the disease to the point where they were left speechless by theshock of disclosure of anHIV-positive result. In most cultures, males are accepted to assume the role of household heads and have responsibilities to take control of any situation. HIV/AIDS, however, is above their ability as it cannot be reversed or they may be blamed for contracting the disease.

3.4.2.2.3 Sub-Category 2.2.3: Boyfriends and Relatives No Longer Visit or Answer the Phone

Participants indicated that they experienced problems with their boyfriends and relatives who no longer visited them or answered their phones. The participants verbalized a feeling of isolation from those whom they love and are related to. The following are some of the responses from the participants:

"My boyfriend no longer answers when I call him. He no longer visits me since I disclosed my HIV/AIDS positive status to him, but we used to stay together as he had left his wife to stay with me. But now he no longer answers my calls or even visits me."

"I was ill and weak. After being discharged from the hospital I went back home to stay with my mother. I disclosed my HIV/AIDS positive status to my relatives. To my amazement my relatives who were always visiting us no longer came to our house, and even when my mother informed them that I wasn't well, they don't come."

Lawson et al.(2006) indicated that due to the stigma attached to HIV/AIDS relatives do not want to be associated with an infected person fearing that the community will avoid them. Stigma produces social inequality, discreditation and discrimination against those

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infected and affected by HIV/AIDS (Lawson et al., 2006). Sukumani (2011) added that the husband would no longer come home. The woman would have to depend on relatives and friends for support.

Male partners usually leave relationships after disclosure of anHIV-positive status. Marital relations also suffer consequences of anxieties and suspicion around HIV/AIDS and breakups occur. Men usually send the wives away or run away from the relationship than women leaving their husbands. Besides, the fact that man leave one relationship for another has a negative impact on the pregnant women living with HIV/AIDS (Baylies, 2001).

The researcher concluded that relatives do not want to be associated with someone who is HIV-positive fearing that they will no longer be accepted by society. Due to lack of knowledge, the society still discriminates against those who living with HIV/AIDS through name calling, shaming and stigmatizing.

3.4.2.2.4 Sub-Category 2.2.4: No Longer Accepted in Social Gatherings

Participants indicated that theyfaced discrimination when they attended social gatherings or tried to help in community gatherings, for example preparing food at funerals. People always ask them not to participate or dish food prepared by them. The following are quotations from the participants:

"I was trying to help at a funeral in our village by peeling vegetables. As I started peeling potatoes some women politely asked me to stop peeling as they had said there were more than enough people to do the job. They asked me to join those who were attending prayer which amazed me since other women were busy preparing food. It was like I was not

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accepted in the preparation of the food and I thought it is because I could cut myself and put them at a risk of contracting the virus. It is really painful."

"My sister in-law called me and say it is better if you do not come to attend the (social gathering) I heard that people will not eat the food if you participate in the preparation of food."

According to WHO (2005), pregnant women living with HIV/AIDS are experiencing discrimination and stigmatization by community members. It is also reported that women are disowned, shunned by their families and communities and sometimes are even killed. Women are more likely than men to be held responsible for spreading the disease and labeled as promiscuous while promiscuity is not accepted by society especially bywomen (WHO, 2005).

Literature in a study conducted in Ethiopia women described how they never talk about HIV/AIDS as it is strongly associated with promiscuity and female promiscuity is viewed more negatively and frowned upon. Men are less stigmatized because with women the promiscuity is more demonized resulting in them keeping their HIV-positive test to themselves to prevent being labeled or no longer accepted in social gatherings (Lawson et al., 2006). Carr &Gramling (2004) also reported that the brother of the pregnant woman living with HIV/AIDS asked her to keep her diagnosis a secret to avoid embarrassment to the family. When family members learnt of her diagnosis, they asked her not to attend family gatherings (Carr &Gramling, 2004).

The researcher identified that participants were experiencing discrimination in their society, and despite the wealth of information about the mode of HIV spread, the society still has fear to associate themselves with somebody who is HIV-positive.

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3.4.2.2.5 Sub-Category 2.2.5: Next-Door NeighboursWould Divulge Status During Quarrelling

Data analysis indicated that pregnant women living with HIV/AIDS experienced challenges regarding neighbours, friends or relatives who "diagnose" them without full knowledge of the status of the participants. Participants verbalized being put to shame by those who thought that they were the ones who have infected their husbands and blamed them for the deaths of a previous husband. Divulging of their HIV-positive status in public, to be told that you are going to die is a worst ill-treatment of pregnant women living with HIV/AIDS by the society. The following quotation from one of the participants, exemplify this:

"My neighbor is very cruel. One day as we were quarrelling about other things that doesn't concern my HIV status. she said she knew that I was dying of HIV/AIDS and that my previous husband died due to HIV/AIDS. She said that I was going to die and that I wanted to kill my current husband with my AIDS. She was screaming for everybody to hear, but I just kept quiet."

The literature suggests that when pregnant women tested HIV-positive in a village, people will gossip about them and eventually somebody will divulge the status publicly (Lawson et al., 2006).Bond et al.(2002) indicated that pregnant women are diagnosed to have HIV/AIDS by the community if they are emaciated, have Herpes Zoster, is sick, or have given birth to a sick or premature baby which dies before three months(Bond et al., 2002).It is also said that the community may impose a negative impact on pregnant women living with HIV/AIDS, especially if they rely on the community for support contributing to stigmatization, gossip and divulging the status against their willwhich leads

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to social ostracism causing them to seek health advice and opt to remain silent until the disease has reached advanced stages (Lawson et al., 2006).

The researcher identified that society is still ignorant especially those who are uneducated. They lack the knowledge that divulging someone's HIV-positive status is a criminal offence.

3.4.3 Theme 3: Participants' Experiences of Fear Related to Being Pregnant and Living with HIV/AIDS

This theme emerged from the data that reflected that pregnant women living with HIV/AIDS experienced fear that the baby may be affected or die, fear that the baby may die afterbirth, fear related to breastfeeding. Participants also feared that their husbands might also die as most of their husbands refused to condomize and kept on making babies as if there was nothing wrong. The following are the categories identified from this theme:

- Participants feared that the baby may be affected
- Participants feared that their partners may be infected or die
- Participants feared that people will involuntarily know about their HIV/AIDS status

3.4.3.1 Category3.1: Participants Feared that the Baby May Be Affected

Some of the participant'sfeared thattheir babies they may be affected due to failure to condomize which will increase viral load causing re-infection which will put the baby in

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danger of becoming infected and dying. From this category three sub-categories emerged: failure to use condoms may kill the baby, the baby may die after birth and fear related to breastfeeding.

3.4.3.1.1 Sub-Category3.1.1: Failure to Use Condoms May Kill the Baby

Most of the participantsverbalized fears of their babies contracting the virus as their husbands practice sex without using condoms and they feared that their babies may die. From the descriptions of the participants it was brought out that they did not have a say in sexual choices as they were married and unemployed. Participants indicated that their situation compelled them to accept that having sex with their husband is not a choice, but an obligation. Participants described how they unwillingly engaged in unprotected sexondemands from their husbands, while inwardly they were crying for the safety of their babies. They said that dependency on their husbands for financial support caused them to endure their painful and difficult situations. The following were the responses of the participants:

"My husband is refusing to use condoms and when I ask him to go for an HIV/AIDS test he refuses. When I ask him to use condoms he just keeps quiet but continue to have sex with me without the condom. Each time we have sex I just feel like screaming as I know that my baby is not safe. I have a fear that my baby may be born with HIV/AIDS and my baby may die (the participant looks down and up as if she is looking at something and she cries)."

"We are both HIV/AIDS positive, we were both told at the clinic that we must use condoms to protect our baby, but when I ask my husband to use a condom he refused and beat me if I refuse to have sex without condom (she cried),my husband wants to kill my baby."

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According to Baylies (2001), pregnant women living with HIV/AIDS expressed concerns about difficulties in negotiating condom use in heterosexual relationships, which put them at risk of re-infection. Their situation was further complicated as they could not control fertility and to achieve a truly safe motherhood could be jeopardized as married women are discouraged from using condoms as an effective anti-fertility measure above thesexual needs of their husbands as condoms are promoted to be used outside marriage (Baylies, 2001).

Sharon &Crosby (2004) indicated that men reported that sex with condom does not work because of complete lack of sensation; they reported that with a condom they do not feel if they are inside or outside, they thought it is just a "fucking drag" to have so little sense of being inside of someone. It was also reported that for men toenjoysex at some point they pull the condom off to enjoy the intensity of sex (Sharon & Crosby, 2004).

The researcher identified that participants feared that their children would become infected and die as most of their husbands/boyfriends refused to condomize as if they did not know about the increased viral load and re-infection.

3.4.3.1.2 Sub-Category3.1.2: Fear that the Baby May Die After Birth

Data indicated that due to failure to negotiate protected sex, most of the participants feared that their babies may die after birth. These are some of the responses from the participants:

"Vhonese (nurse), I heard from the radio that if you are pregnant and you are engaging in unprotected sex the baby might die. And now that we are not using condoms, I fear that my baby will die after birth or the virus may be passed to my baby."

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"We were both health educated by nurses at the clinic that we have to condomize to protect our baby, but my husband is refusing to condomize (vhonnese) nurse, I am afraid that my baby will die after birth, my husband want to kill my baby (participant looks down for few minutes)."

In their study, Mohlaba& Anthony (2007) observed that participants experienced fear that their babies may die after death as pregnant women living with HIV/AIDS are still blamed for being responsible for transmitting HIV/AIDS to their innocent children and being compelled to be tested for HIV/AIDS on a routine basis. It is also assumed that some pregnancies among women living with HIV/AIDS are the result of pressure from their partners, even when the women's partners are informed of their HIV/AIDS status and complications thereof (Mohlaba& Anthony, 2007).

Reproductive Rights (2005) also indicated that the risk of transmission increases when a woman has a higher viral load, for example if she is newly infected with HIV/AIDS, or when she is at the advanced stage of the disease, or if the infant is directly exposed to the mother's infected body fluids during birth. Studies estimate that a child has a 5-20% chance of acquiring the virus from the mother's milk if breastfed (Reproductive Rights, 2005).

The researcher concluded that participants feared that their babies might die after birth, especially those who were an advance stage of disease, or where the woman has a history of death with a previous pregnancy.

3.1.3 Sub-Category3.1.3: Fear Related to Breastfeeding

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Since it was discovered that breast milk is better than formula feeding for the health of the baby, the participants verbalized fear that breast milk may pass the virus to their babies- as health care practitioners advised. Now that information keeps on changing due to new discoveries, participants indicated that they were confused. They said that their previous babies who were exposed to HIVAIDS are HIV-negative because they were not breastfed. The following quotations demonstrate such sentiments:

"I don't trust this new information of breastfeeding because my previous baby was given formula feeding and she is HIV-negative. Here she is, she is so healthy. I don't have enough money to buy milk as it is said there will be no more milk supply. I would rather buy milk than putting my baby at danger, my baby may die."

"I am afraid I cannot breastfeed my baby, no, my baby may die, the only problem that I have is that my husband is not fully employed, he is doing a part-time job and sometimes he goes without a job, money is a problem, but I really don't want to breastfeed my baby."

According to the literature, there is overwhelming scientific evidence of the benefits of exclusive breastfeeding and acknowledgement of evidence that ARV are significantly reducing the risk of HIV/AIDS transmission and improve HIV/AIDS free survival of HIV-exposed infants.

The Tshwane declaration of support for breastfeeding in South Africa agreed that they would commit themselves and call all stakeholders to support and strengthen efforts to promote breastfeeding, declaring South Africa to be the country that actively promote, protect and support exclusive breastfeeding. It is recommended that all HIV-infected mothers should breastfeed their infants and receive ARV to prevent HIV/AIDS transmission. Recently, updated guidelines on HIV and infant feeding to extend maternity

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leave and support mothers to exclusively breastfeed their infant for six months have been published (Tshwane Declaration, 2011).

Coutsoudis (2012) indicated that the findings that HIV-infected women may transmit HIV during breastfeeding led to the call for women to formula-feed their infants. This poses a serious problem in developing countries which do not have the resources to compensate for increased malnutrition and mortality resulting from formula feeding. It was reported that mortality from diarrhoea, acute respiratory infections, and other infectious disease is five to six times higher in infants who are not breastfed than in those who are breastfed for the first two months of life (Coutsoudis, 2012). Vignarajar (2004) previously reported that the United States Public Health Service recommended that pregnant women who are living with HIV/AIDS should not breastfeed their children to prevent risk of transmission.

The researcher thus identified that women are still confused about the changes that are happening in PMTCT regarding breastfeeding and formula feeding.

3.4.3.2 Category3.2: Participants Feared that Their Partners May Become Infected or Die

In this category, participants expressed fear that their partners may become infected and die due to the fact that they refused to be tested or use a condom while they still want to make babies. From this category, three sub-categories emerged: fear that their husbands may die as they refuse to be tested, husband refuse to use condoms and want to make babies.

3.4.3.2.1 Sub-Category3.2.1: Fear that Their Husbands May Die As They Refuse tobe Tested

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During interviews the participants reported that they experienced fear that their husbands may die as they refused to be tested. Most of the participants verbalized that they were unemployed and depended on their husbands for financial support. Data indicated that participants feared the death of their husbands more than HIV/AIDS itself. They feared that they might suffer loss of financial support as they were unemployed. These sentiments are borne out by the following statements:

"I am afraid that my husband may die because he is refusing to be tested. I am afraid that he may die and I am not working. I depend on him. I do not know what will happen to me and the children if he happens to die. I have asked him to come and be tested, but each time he just says he will come, but up to now he hasn't been tested. Today he drove me to the clinic, and before he went back I asked him to come and be tested, but he just told me not to worry since he was busy and would be tested another time."

"I am worried about my husband as he is refusing to be tested, but we are continuing with unprotected sex as if there is nothing wrong, when I tried to talk about it he just keeps quiet,I depend on him financially since I am not working, I am afraid he will die."

Lawson et al.(2006) indicated that due to lack of education and unemployment, pregnant women fear the loss of their husbands through death more than the illness itself as they depend upon their husbands financially. Economic hardship causes pregnant women living with HIV/AIDS to worry about the health of their husbands while the husbands prepare to maintain their status in the community than to seek medical attention. Literature also indicated that men do not want to be tested as they diagnose themselves with the status of their wives/life partners. Men usually wait until the illness cans no longer be

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concealed; sometimes they are diagnosed professionally on their death beds leaving their wives and children with nobody to support them financially (Lawson et al., 2006).

Sanders (2009) indicated that women usually push their partners to be tested, but men refuse to be tested whilst the study that was conducted at Adelphi University reported that sexual partners usually shift responsibilities in regard to safe sex and testing. Having a spouse or a steady partner increasesthe chances of unsafe sex and decrease the desire to be tested(Sanders,2009).

The researcher identified that since the women were dependent on their husbands for financial support and they refused to be tested, they feared that their husbands might die due to illness, and their husbands' deaths will predispose them to poverty.

3.4.3.2.2 Sub-Category3.2.2: HusbandsRefuse to Use Condoms

During interviews, the participants reported that their spouses or life partners refused to use condoms even though they knew that they wereHIV-positive. Most of the married participants verbalized that their husbands refused to condomize and said that they would only condomize when they have sex with their girlfriends, not their wives as they paid lobola to earn rights to have sex without restrictions. The following quotations illustrate these responses from participants:

"We both know that we are HIV/AIDS positive, but he is refusing to condomize. I tried to negotiate for condom use, but it just fell on deaf ears, he is refusing to use condoms! When I refuse sex without condom he beats me, hey this men will kill me. (She was sad)".

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"When I tried to negotiate condom use my husband told me that - I am not going to use a condom as you are not my girlfriend you are my wife I have the right to have sex with you, we cannot enjoy sex with condom."

Mapisi (2003) cited by Chokoe, 2005).documented that African husbands are not socialized to use condoms in marriage and they would rather use condoms with their mistresses, especially elderly men. African traditions believe that sex is not good when using condoms. Many African men verbalized that rubber (condoms) hinders the pleasure of sex. It is also said that one cannot eat something good covered by a plastic. African men would rather suffer from STIs than use condoms. This view was also shared by Sheon& Crosby (2003) who indicated that men who have sex with other men prefer sex without condoms as they say sex without condoms is incredibly intense and is the best sexual experience. Loubiere et al.(2009) reported that there is a misinterpretation and overestimation of the potency of ARV, namely that when there are no symptoms and no detectable trace of the virus in the body one can be regarded as being cured and the couple stop using condoms.

The researcher identified that men think that condomising robs them from pleasure of sex and there is the belief that because both the husband and wife are HIV-positive there is no need to condomize.

3.4.3.2.3 Sub-Category3.2.3: Husbands Want to Make Babies

Participants reported that they experienced problems because even though their husbands knew their HIV/AIDS status they still wanted to make babies, putting the women's health at risk. The following are quotations from the participants:

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"We both know that we are HIV-positive, but my husband is insisting that we have a baby, he even made a hole on the tip of the condom for me to be pregnant. I also heard that he bought tablets from Indians which is said to be strong that even if I were on family planning, I must become pregnant."

"We got married knowing that we are both HIV/AIDS positive, and we have agreed that we are not going to make babies, but to my surprise he no longer usescondoms, when I asked he told me that he wants a baby."

Myers (2006) indicated that in Africa, fertility is valued for many reasons. It often completes relationships, or is a control of a marriage agreement. It is also said that children bring happiness and love. The literature indicated that even if a couple knew that they wereHIV-positive it does not stop their need to reproduce their own offspring. Despite the risk associated with pregnancy, available data suggest that HIV-infected women are less likely to become pregnant than uninfected women (Myers, 2006).

Siegel &Scrimshaw (2001) reported that they actively weighed both the potential risksversusthe benefits of pregnancy in HIV-infected females - the major reason is that the husbands/boyfriends really wanted to have children; they believed that a child would make them feel complete, fulfilled and happy or God will protect their child. The literature also indicated that social and personal pressure influence women to become pregnant. Husbands/boyfriends also encourage and pressurize the women in addition to the perceived social disapproval of childlessness (Siegel&Scrimshaw, 2001).

The researcher identified that being HIV-positive does not eliminate the desire to reproduce or to give birth. Men still want to make babies to prove that they can reproduce or to leave a child who will carry on the name of the family.

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3.4.3.3 Category3.3: Participants Feared that People Will Involuntarily Know About Their HIV/AIDS Status

Most of the participants revealed that they experienced fear that people will know their HIV-positive status involuntarily due to loss of weight, not breastfeeding and prolonged hospitalization. From this category three sub-categories emerged: status would become known because of weight loss, status would become known by not breastfeeding, involuntary divulging of HIV/AIDS status due to prolonged hospitalization.

3.4.3.3.1 Sub-Category3.3.1: Status Would Become Known Because of Loss of Weight

During the interviews, the participants reported that they experienced fear that when they become thin peoplewould know their HIV/AIDS status involuntarily. Data analysis revealed that participants were afraid of HIV/AIDS symptoms so much that they were worried more about the symptoms than the disease itself due to the stigma attached to it. The following statements are examples of responses from the participants:

"I am afraid that when I become lean because of this disease people will know about my status without me telling them."

"I am afraid because I was admitted for three months and I am so lean, I am afraid that the people are speaking about me behind my back, I am afraid that people are diagnosing me, hey!!!!! This disease is cruel."

Gaskins (2006) indicated that pregnant women living with HIV/AIDS fear that when they start to show the symptoms of HIV/AIDS, that is becoming thin, they would be judged, rejected and gossiped about. Pregnant women living with HIV/AIDS fear rejection by

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people and their loved ones, causing them to keep their HIV/AIDS status to themselves (Gaskins, 2006). It was noted that HIV/AIDS is the disease that has been nicknamed the 'slimming disease' due to the stigma attached to, and those who are living with HIV/AIDS are afraid to lose weight as they still wanted to be accepted bysociety (Mohlaba& Anthony,2007).

The researcher identified that even though people have health education through radio, television and newspapers, they are still afraid of the stigma associated with living with HIV/AIDS. One of the symptoms is losing weight and, as such, HIV is nicknamed the 'slimming disease'. Fear of this stigma is still prevailing inPLWHA, and society is still 'diagnosing' people based on them losing weight.

3.4.3.3.2 Sub-Category3.3.2: Status Would Become Known Because of Not Breastfeeding

Data indicated that formula feeding disclosed the status of the woman involuntarily associety'diagnoses' women by knowing if they are breastfeeding or not. From the interviews, participants reported that in villages it is known that if you come back from the clinic after giving birth and you start giving your baby formula feed everybody will assume that you are HIV-positive. The following are some of statements from participants:

"I am trying to accept my HIV/AIDS status, but I am having a problem of what people will say when I stop breastfeeding and start formula feeding."

"Vhonnese (nurse) I am afraid that if I breastfeed my baby it may be infected, but I also have a problem, my husband is working and we don't have money problem we can buy

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milk, but when I start to formula feed my baby people will know that I am HIV/AIDS positive, I really don't know what to do."

Vignarajah (2004) indicated that since the introduction of PMTCT, mothers were encouraged to use formula feeding as a way to prevent MTCT of the virus. As the community knows that mothers who are formula feeding are HIV-positive, the community makes it hard for mothers to formula feed as they will be gossiped about and within a short space of time everybody in the village will know. Formula feeding discloses the mother's status involuntarily (Vignarajah, 2004). Communities criticize and shun mothers who do not elect to breastfeed as neglecting their maternal responsibility, or take it as a confession of HIV/AIDS infection (Vignarajar, 2004).

The researcher concluded that there is still mixed feelings among the participants and a sense of dilemma as those who are breastfeeding fear that the virus may pass to their babies or they may suffer from side effects of Nevaropine. Those who are formula feeding are afraid of being stigmatized or their status becoming known involuntarily.

3.4.3.3.3 Sub-Category3.3.3: Status Would Become Known Due to Prolonged Hospitalization

Participants alsoreported that they feared that people will know their status involuntarily as they were admitted in hospital for a long time and they had lost weight and suffer tiredness. The following are some of the statements from the participants:

"It is very clear that everybody knows that I am HIV/AIDS positive because I was so sick and for the past three months I was admitted in hospital. I can see that even if I didn't

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disclose my status when people look at me I know that in their hearts they are saying I'm HIV-positive."

"This pregnancy is very difficult I am on and off hospitalized, this time I was admitted for a long time and I am so weak, my last pregnancy was fine even though I was HIV-positive, this time people will know that I am positive."

Van der Spuy (2009) indicated that as the condition of pregnant women living with HIV/AIDS deteriorates, they end up being admitted to hospital, the most common indication for admission to the high care unit for HIV-positive women is in contrast to complications of gestational proteinuric hypertension in HIV-negative women. The mortality of HIV-positive women was reported to be 13.6% versus 0.4% in HIV-negative patients (Van Der Spuy, 2009).

The researcher identified that when the condition due to HIV/AIDS deteriorated to the extent that participants were too ill, and spent most of the time in hospital that is the time when the HIV/AIDS patients cannot conceal their disease anymore.

3.4.4 Theme 4: Challenges Experienced by Pregnant Participants Living With HIV/AIDS

Most of the participantsexpressed that theyfearedtheir own deaths, particularly when they spent most of the time being admitted to hospital due to being too weak and ill and while in hospital they were unable to helpthemselvesand depended on nurses to take care of them. Two categories were identified from this theme, namelyparticipants feared for their own deaths and participants experienced physically illness and a feeling of tiredness. The following categories were identified from this theme:

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- Participants feared for their own death
- Participants feeling physically ill and constant tiredness

3.4.4.1 Category 4.1: Participants Feared for Their Own Death

Participants verbalized that they feared for their own deaths due to being weak, anemic and low $CD4^+$ cells, and also the fact that they spen: most of their pregnancy time admitted in hospital. From this category two sub-categories emerged: low $CD4^+$ cells, too weak and anemic, and re-infection because of not using condoms.

3.4.4.1.1 Sub-Category 4.1.1: Low $CD4^+$ Cell Count, Too Weak and Anemic

Participants indicated that they experienced fear of their own deaths due to low $CD4^+$ cells, anemia and being too weak as the pregnancy advanced. Most of the participants were admitted to hospital where their condition was deteriorating, and they found themselves so ill that they feared that they would die. The following are some of the responses from the participants:

"I am too weak to carry on. I am from the hospital, I was admitted. I don't know if I will make it this pregnancy worsened my condition."

"Vhonese (nurse), I'm from the hospital, my CD4 cells are too low. At the hospital they tried everything to help me, but I'm really ill."

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"Since this pregnancy, my health is deteriorating. My hemoglobin (Hb) is too low. It was fine before the pregnancy. I was told at the hospital that I am suffering from anemia."

In his study, Stewart (2002) observed that participants experienced fear related to their deteriorating health and own death. Due to the stigma attached to HIV/AIDS, pregnant women often wait until the sickness is an advanced stage before seeking medical attention, thus putting their lives and those of their unborn babies at risk (Stewart, 2002). Van der Spuy(2009) also indicated that the mortality rate is higher in pregnant women living with HIV/AIDS, usually due to septicemia and other infections.

The researcher also identified that pregnant women are at risk of dying because of their deteriorating health status due to low$CD4^+$ cells and anemia.

3.4.4.1.2 Sub-Category 4.1.2: Re-Infection Because of Not Using Condoms

During the interviews the participants indicated that they feared that their husbands might die because they refused to condomize and be tested. Participants also feared that since they were unable to convince their husbands/boyfriends to condomize they may become re-infected which would lead to their death. The following were responses from the participants:

"My husband was refusing to condomize, but we were both health educated by the nurses at our clinic that if we have sex without condoms we would be re-infecting ourselves and that re-infection shortened our lives. Now that he didn't want to condomize I went back to my parents."

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"I don't know why my husband is so quiet. I have disclosed my status to him, but to my amazement he is refusing to use condoms. I am afraid of re-infection and I heard that this will make us to die faster."

Adam et al. (2008:759) indicated that pregnant women living with HIV/AIDS who have disclosed their statuses expressed concern about HIV-related difficulties in negotiating condom use with their heterosexual partners, putting them at risk of re-infection. Pregnant women living with HIV/AIDS discussed the difficulties they faced in negotiating condom use with their husbands, whichpredispose them to re-infection (Adam et al., 2008:759).

This view was also shared by Calavathy&Vijayanced (2000) who reported that men who are HIV-positive do not disclose their HIV/AIDS status or condomize, wanting to fulfill their wishes of impregnating their wives before they die. The Botswana government proposed HIV disclosure when, on the 10th August 2000, the Minister of Health - Joy Phumaphi- considered legislation. Disclosing anHIV-positive status to a sex partner has become mandatory - if you have tested HIV-positive without informing your partner would thus be a criminal offence (Mogale, 2000).

The researcher identified that men who are infected do not disclose their HIV/AIDS status to their wives as they want to have a baby before they die, putting their wives at risk of contracting HIV/AIDS.

3.4.4.2 Category 4.2: Participants Feeling Physically Ill and Constant Tiredness

In this category participants expressed being physically ill and tired, symptoms brought by progression of the disease. From this category, two sub-categories emerged: participants

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experience physically illness and feeling of tiredness and weakness, and admitted to hospital.

3.4.4.2.1 Sub-Category 4.2.1: Experiencing Physical Illness and A Feeling of Tiredness and General Body Weakness

During the interviews participants reported that they experienced physical illness and tiredness. Most of those participants who reported a physical ill feeling and tiredness were participants who have fallen pregnant for the second or third time while living with HIV/AIDS. They indicated that due to their condition they were being taken care of by their own mothers. They verbalized that they needed somebody to help them as they were facing physical challenges. The following are some of the statements from the participants:

"I used to work very hard with my children at my field. I wanted to win the prize of best farmer, but since I fell pregnant I am physically ill and feeling tired. I am no longer able to work in the field as it is difficult to encourage the children while I cannot work with them."

"This pregnancy is very difficult because I am always feeling tired. It is not like me, I am physically ill. I am anemic and always tired. My mother is the one who is taking care of me. My children are also helpful."

Van der Spuy (2009) indicated that when one is in the advanced stage of the disease and pregnant, the pregnancy accelerates deterioration of the health of the pregnant woman. It is also acknowledged that repeated pregnancies in woman living with HIV/ AIDS do not

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only accelerate deterioration of their health, but also speeds up the death of the pregnant woman and her unborn baby (van Der Spuy, 2008).

The researcher concluded that those participants who were physically ill and always tired need to be supported by relatives in order to meet their demanding health needs. Hospitals should be able to admit them until delivery for specialized management and observation.

3.4.4.2.2 Sub-Category 4.2.2: Admitted to Hospital

During interviews, participants with their 2nd pregnancy since HIV/AIDS diagnosis reported being so ill that they ended up in hospital for quite a long time. Participants verbalized that their 1st pregnancy with an HIV-positivestatus wasmore manageable with minimum complications, but with the second pregnancy, their condition deteriorated, they were seriously ill with severe complications that needed emergency medical assistance. The following were some of the statements made by the participants.

"I was admitted in hospital for three months because I was so sick."

"I spent 3 weeks in the hospital. I was admitted and they are the ones that referred me to this clinic."

"I was hospitalized because my hemoglobin (Hb) was too low. I even received blood transfusion. That is why I am better."

Van der Spuy (2009) reported that pregnant women who are living with advanced HIV/AIDS spent most of their time admitted in the intensive care unit (ICU). About 80% of pregnant women admitted ICUwere HIV-positive rather than those who were suffering from high blood pressure (van Der Spuy, 2009).Balaile et al. (2007) indicated that

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pregnant women living with HIV/AIDS got sick frequently with complications such as skin rashes, weight loss, numbness of the feet, general weakness, feeling ill and frequent fever.

The researcher identified that those participants who were pregnant for the second or third time while living with HIV/AIDS experienced a rapid deteriorationin their health status, to an extent of being close to death and some of them lost their lives and their babies.

3.5 Summary

This chapter focused on the data analysis, literature control and discussion of the findings. Dataanalysis of the responses from the participants indicated that pregnant women living with HIV/AIDS are in dire need of emotional, financial and psychological support to adapt to their deteriorating health status. These needs call for immediate acceptance and attention to the ramifications of the disease, and ideally should involve the hospitals, health care providers, spouses/life partners, parents, family members, the community and the society at large. Important also is the tenet that disclosure should beencouraged toremove the prevailing stigma attached to HIV/AIDS. These impressions corroborate literature reports on similar experiences expressed by pregnant women living with HIV/AIDS.

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CHAPTER 4

EVALUATION, CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

4.1 Introduction

Chapter 3 focused on data analysis and discussion of the findings in the context of relevant literature. This chapter brings together an overview, evaluation, conclusions, recommendations and limitations of this study which investigated the experiences of pregnant women living with HIV/AIDS. Evaluation against purposes and objectives of the study as set out in Chapter 1is presented. Recommendations for nursing practices, policymakers and on research are provided. Conclusions of the study are based on the findings and limitations of the study.

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4.2 Study Overview

The purpose of this study was to explore and describe the experiences of pregnant women living with HIV/AIDS. Experiences were explored and described against relevant literature. The objectives of this study as set out in Chapter 1 were to:

- Explore and describe experiences of pregnant women living with HIV/AIDS
- Identify challenges faced by pregnant women living with HIV/AIDS
- Determine the level of partner and family support

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- Develop a coping mechanism that pregnant women living with HIV/AIDS may use in order to deal with daily challenges

An exploration, description and identification of challenges experienced by pregnant women living with HIV/AIDS were done for the first and second objectives. These objectives were met through in-depth individual interviews. One central question directed the structure of the interview: "What are your experiences as a pregnant woman living with HIV/AIDS?"

The research design for this study was qualitative, phenomenological, exploratory, descriptive and contextual in nature. Research methods described were the following: the study setting, sampling, sampling method, sampling criteria and sampling size. The researcher chose the health centres and clinics around Thulamela B Municipality in Vhembe District based on statistics of HIV-positive women. In this study, the population consisted of all pregnant women living with HIV/AIDS who attended ANC at Thulamela B Municipality Health Centres and surrounding clinics.

Individual pregnant women living with HIV/AIDS were chosen based on the knowledge of HIV/AIDS status and the sample size was determined by data saturation which had occurred on interviewing the 12thparticipant. Experiences were tape recorded and transcribed verbatim for analysis. The researcher also captured speech patterns, emphasis, ensured competencies and review interviews for further clarification and understanding. Data wereanalyzed qualitatively using Tesch's Open Coding method (Tesch, 1990; Creswell 1994, 2003) consisting of eight steps. Applicability, conformability, neutrality and dependability of the findings were tested essentially according to Lincoln &Guba (1985). Ethical measures were considered throughout the research as laid down by the

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Democratic Nursing Organization of South Africa (Denosa, 1998:23, 1-2.3.4).Adaptation theory was used in this study, where participants were confronted with contextual stimuli. The contextual stimuli are internal or external stimuli that may have a positive or negative influence on the situation (George, 1995).

Findings of the study revealed that disclosure of living with HIV/AIDS is still a challenge to most of the participants as some of them verbalized fear of rejection, blame and divorce, being blamed for bringing the disease home, people speaking behind their back, losing financial support, being blamed for killing the husband and mothers stressing about their illness. The findings of the study also clearly indicated that the participants experienced financial problems. Emotional problems were also verbalized as spouses/life partners were no longer communicating or engaging in sexual intercourse with the participants. Relatives and boyfriends also no longer answered the phone or visited the participants. Uncertainty was reported in this study as participants reported fear of the deaths of their husbands or their babies or infecting them with HIV. Participants also experienced fear of their own deaths due to low $CD4^{+}$ cells, anemia, physically illness, tiredness and general body weakness.

Objectives three and four will be met in this chapter by making recommendations to assist pregnant women living with HIV/AIDS, namely to adapt to their changed health status, to deal with the stigma that is still a challenge in the lives the women who are living with HIV/AIDS

4.3 Recommendations

These section embodiesthe recommendations that arose from the study and targeted towards society, policymakers, research and nursing practice.

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4.3.1 Recommendations Related to Disclosure and Relationship With Spouses/Life Partners and Family Members

- Couples should be encouraged to undergo voluntarycounselling and testing (VCT) as part of planning of pregnancy in order to promote support where one or both tested HIV-positive.

- Intensive health education about the mode of spread and transmission of the virus and preventative measures should form part of health promotion and awareness programmes, particularly at ANC and during VCT.

- Family members should become actively involved in caring and helping pregnant women living with HIV/AIDS.

- Community members should be educated about the progression, manifestation and symptoms of HIV/AIDS through health promotion and awareness programmes so that they can better understand the importance of caring for pregnant women living with HIV/AIDS and to encourage those who are affected to seek medical help and to disclose their status.

- HIV/AIDS must be classified as a Notifiable disease to prevent stigmatization and fear to disclose so that people develop empathy with pregnant women living with HIV/AIDS. Many health conditions are currently listed as Notifiable diseases (http://www.doh.gov.za/show.php?id=2662#list), for example cholera, congenital syphilis, leprosy, tuberculosis and viral hepatitis, and most of these conditions do not carry the same stigma attached to HIV/AIDS.

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- Information of HIV/AIDS and pregnancy must be blended with cultural activities to educate the community about HIV/AIDS, its mode of spread, prevention and how to careforPLWHA to reduce stigma.

4.3.2 Recommendations Regarding Financial and Emotional Support

- Financial constraints, based on the history of unemployment and lack of financial support from the husbands/boyfriends, should be alleviated by a limited temporary grant for the pregnant women living with HIV/AIDS to enable them to support their family with food, school fees, buying food for the family and transporting themselves to the hospital for check-ups or to collect medication.

- Family members should be educated and trained how to carefor pregnant women living with HIV/AIDS. They should also beurgedto form part of a wider financial support system to lessen the burden of disease on those infected with HIV/AIDS.

- Husbands/boyfriends should be included in the care plan of pregnant women living with HIV/AIDS and encouraged to accompany them to ANC visits.

- A law should be enacted to protect PLWHA from blatant and actuated malice related to the disclosure of their HIV/AIDS without their expressed permission.

- Couples should be educated about preventative measures to protect the father of the baby and the baby. Men should be encouraged to be sincerely involved in such planning as women are usually the ones who yield totheir husbands' sexual demands.

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- Mothers-to-be must be educated about the health benefits of breastfeeding versus formula feeding. Towards this end, the Tshwane declaration should be communicated to pregnant women living with HIV/AIDS.

- Research results of the benefits of Nevaropine syrup as a protective measure to prevent transmission of virus from breast milk to the baby must be published in the mother tongue or vernacular (that is, the language or dialect most widely spoken by ordinary people in a particular region) for everybody to see, read and understand.

- Establishment of support groups among pregnant women living with HIV/AIDS should be advocated so that they can espouse their common health cause.

- Home-basedcaregiversshould become more involved inthe care and support of pregnant women living with HIV/AIDS.

4.3.3 Recommendations Regarding Experiences Related to Fears

- Couple counselling and testing should be encouraged to prevent blame shifting among couples.

- Compulsory counselling and testing should be encouraged so that not only the pregnant women should be the one to announce bad news, but couples have to be encouraged to do it as a family.

- Emphasis on condom use should be taken as a first priority as most men do not want to condomizecausing their wives great stress as they are afraid of re-infection, the safety of their unborn babies and their own health.

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- Stigma related to HIV/AIDS should be dealt with vigorously using all alternative ways to remove fear of people gossiping about those who are infected.

4.3.4 Recommendations Regarding Challenges Experienced by Participants

- Pregnant women who have tested HIV-positive should be encouraged to stop having another pregnancy as it hastens the progress of the disease which further puts their lives in danger.

- Women should be empowered to be able to negotiate the use of condoms during sexual intercourse. The days when women were not able to talk about sexual matters with their husbands have long gone.

- Couples should be educated to speak openly about sexual matters and preferences.

- Women should be empowered economically as the spouse with the money usually has the upper hand.

- Every woman should be trained to be able to be financially stable so that when they enter into a relationship it must not be to acquire financial support.

- Women should know and exercise their rights. They have to be empowered to refuse to stay in abusive relationships.

- Accessible ways to report abuse of any kind must be available to pregnant women living with HIV/AIDS.

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4.3.5 Recommendations Regarding Society

- The researcher recommends that the society should accept and support pregnant women living with HIV/AIDS.

- The researcher further recommends that society views HIV/AIDS as an issue that affects the whole society and not just an individual. Society should also stop diagnosing, gossiping, shunning and stigmatizing pregnant women who are living with HIV/AIDS.

4.3.6 Recommendations Regarding Policy Making

Results from this study indicate that pregnant women living with HIV/AIDS experienced financial problems fear of rejection, stigmatization and a devastating sense of feeling ill as the disease progresses. Therefore:

- Policymakers must ensure that HIV/AIDScounselors, social workers and trained PMTCT nurses are available at clinics and health centres to provide comprehensive care to pregnant women living with HIV/AIDS.

- Policymakers must certify policystipulations that make it easier and clear when and how pregnant women living with HIV/AIDS qualify for social grant assistance.

- Policymakers should also confirm that when pregnant women report to clinics for the first time for ANC bookings they must be accompanied by their husbands/life partners.

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- Policymakers should make sure that the government has in place a budget for caring for pregnant women who are too ill to take care of themselves or are abandoned by their husbands/boyfriends and family members.

4.3.7 Recommendations Regarding Nursing Practice

- Attendance of workshops or continuing medical education (CME) initiatives by all HIV/AIDS counselors and nurse categories (including PMTCT trained nurses) should be emphasized so that they can enhance their learning experiencesand update their knowledge and skills to improve the quality of healthcare provided in the management of pregnant women living with HIV/AIDS.

- Management of pregnant women living with HIV/AIDS must be included in the Nursing Education Curriculum (NEC) and CMEcourses and it should be understood and applied by tutors and students.

4.3.8 Recommendations Regarding Research

- Community members should be encouraged to participate in research and develop monitoring and evaluating systems to improve health care of pregnant women living with HIV/AIDS.

- Research topics should include reducing stigma to pregnant women living with HIV/AIDS, empowering women financially and experiences of pregnant women who are on ARV.

- Research should beinspiredbecause society still needs instruments to break the scourge of stigma attached to HIV/AIDS.

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- There is a dire need for research into the development of strategies to involve husbands/boyfriends and family members to support pregnant women living with HIV/AIDS.

- Future researchers should direct their focus about HIV/AIDS in pregnant women from an African perspective focusing on African literature about HIV/AIDS and pregnancy so that they can help policymakers in terms of implementing policies that will cater for the citizens of the country.

- The government should provide adequate funds for operational research.

- Scholarships should be provided in order to promote researchon HIV/AIDS in pregnancy.

4.4 Limitations of the Study

The study was limited to pregnant women living with HIV/AIDS in the Vhembe District. The researcher collected data from Thulamela B health centres and surrounding clinics. Data saturation was reached at the last clinic based on the good rapport between the researcher and participants, that is, the success of the research relied heavily on the experiences articulated freely by the small sample of participants.

4.5 Summary

Experiences of pregnant women living with HIV/AIDS were explored in this study. Pregnant women living with HIV/AIDS expressed the challenges or difficulties they encountered whist living with HIV/AIDS. The study revealed that the participants experienced numerous difficulties and challenges, including problems inherent in

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disclosure of an HIV-positive status, breakdown in communication and relationships with spouses/boyfriends and family members, loss of financial and emotional support, and fears related to rejection, isolation, discrimination,stigmatization, gossiping, blame and bias judgement by society, divorce, partners may become infected or die, owndeaths due to low $CD4^+$ cells, anemia, physically illness, tiredness and general body weakness, that breast milk may pass the virus to their babies, failure to use condoms may kill their babies, and that their parents might be stressed.

The recommendations in this study are based on the experiences and challenges faced daily by pregnant women living with HIV/AIDS and are aimed at reaching a wide audience, including pregnant women living with HIV/AIDS and their spouses/life partners and family members, society, community members, support groups, health care providers, home-based caregivers, HIV/AIDS counselors, health and nurse educators, government, health managers,policymakers and researchers. It is hoped that this study will contribute constructively towards the establishment of a more comprehensive and personalized health care management system for pregnant women living with HIV/AIDS.

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ANNEXURE I

INFORMATION LETTER

I am a Master's degree student at this university. I am presently engaged in a research study entitled "The experiences of pregnant women who are HIV-positive at Thulamela Municipality of Vhembe district in Limpopo Province".

The study is conducted under the supervision of Dr RT Lebese and Mrs. NJ Ramakuela.

The objective of the study is to explore and describe the experiences of pregnant women who are HIV-positive to develop recommendations that may improve their experiences.

I need to conduct interviews with pregnant women who are HIV/AIDS positive.

The interviews will be conducted within 30-45 minutes. and will be audio taped for verification of the findings by my supervisors and an independent coder.

The name and dignity of each participant will be preserved by observing the following ethical standards throughout the research process:

- Voluntary participation and freedom to withdraw without a penalty
- Informed consent
- Names of the participants and their community will not be mentioned during discussions
- Raw materials will be kept under lock and key to ensure confidentiality.
- Information related to the interviews will only be accessible to my supervisors and the independent coder
- Field notes will be destroyed and audio tapes will be erased as soon as possible.
- The summary of the research will be made available to you if you wish.

Your participation in this study will benefit other pregnant women who are HIV/AIDS positive.

Thank you

MalindiFhulufhedzani Constance
Researcher

I ..... hereby understand the contents of this research after the researcher's explanations.

Signature of the Participant: .....

Signature of the Researcher: .....

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ANNEXURE II

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH

I ..... on this day of ..... of.....2012 hereby consent to:

1. Being interviewed..... on the topic '**The experiences of HIV-positive pregnant women in Vhembe district of Limpopo Province in South Africa**'.
2. Follow-up interview if necessary
3. The use of data derived from these interviews by the interviewer in a research report as she deems appropriate

I ALSO UNDERSTAND THAT:

1. My participation is voluntary and that I am free to end my involvement, or to recall my consent to participate in this research at any time.
2. Information given up to this point of participation could however still be used by the researcher.
3. Anonymity is granted by the researcher at that the data will under no circumstances be reported in such a manner that my identity is revealed
4. More than one interview might be necessary
5. I allow the interview to be video/audiotape
6. No reimbursement will be made by the researcher for information given on my participation in this study
7. I may refrain from answering questions, should I see an invasion of my privacy
8. I will be given an original copy of this agreement on signing it.

I HEREBY ACKNOWLEDGE THAT THE INTERVIEWER/RESEARCHER HAS:

1. Discussed the aims and objectives of this research project to me
2. Informed me about the contents of this agreement
3. Pointed out the implications of signing this agreement

IN CO-SIGNING THIS AGREEMENT, I, THE RESEARCHER, UNDERTAKES TO:

1. Maintain confidentiality, anonymity and privacy regarding interviewee's identity and information given by the interviewee.
2. Arrange in advance time and place where interview will take place
3. Safeguard the duplicate of this agreement

INTERVIEWEE: ..... **INTERVIEWER:** ..... **DATE:** .....

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ANNEXURE III

REQUEST FOR INFORMED CONSENT FROM LOCAL AUTHORITY

I am a Master's student at the University of Venda. I am presently engage in a research study entitled "**THE EXPERIENCE OF PREGNANT WOMEN WHO ARE LIVING WITH HIV/AIDS AT THULAMELA MUNICIPALITY IN VHEMBE DISTRICT, LIMPOPO PROVINCE**".

The study is conducted under the supervision of Doctor RT Lebese and Mrs. TJ Ramamakuelaof the Department of Advance Nursing Science.

The objectives of the study are to explore and describe the experiences of pregnant women living with HIV/AIDS to develop recommendation that may improve the life of pregnant women living with HIV/AIDS.

I need to conduct interview with the pregnant women who are living with HIV/AIDS. The interview will be conducted at the unused cubicles of Thulamela B Municipality Health centres and surrounding clinics. The interview will be conducted within 30-45 minutes. and will be audio taped for verification of the findings by my supervisor and an independent coder.

The name and dignity of each participant will be preserved by observing the following ethical standards through the research process:

1. Voluntary participation and freedom to withdraw without a penalty;
2. Informed consent;
3. Names of the participant and their own community will not be mentioned during discussions;
4. Raw material will be kept under lock and key to ensure confidentiality;
5. Information related to the interview will be only be accessible to my supervisor and the independent coder;
6. Field notes will be destroyed and audio tapes will be erased as soon as possible; and
7. The summary of the research will be made available if participants they so wish.

Your permission to conduct this study in your Health Centres and surrounding clinics will benefit other pregnant women living with HIV/AIDS.

Thank you

MalindiFhulufhedzani Constance

Researcher

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ANNEXURE IV

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

UNIVERSITY OF VENDA

Department of Advanced Nursing Science



THE HEAD OF DEPARTMENT
PROVINCIAL DEPARTMENT OF HEALTH
POLOKWANE

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am presently doing my Magister Curations at the University of Venda for Science and Technology. I am presently engaged in a research study entitled "**The experiences of pregnant women who are HIV-positive". The study will be conducted at Vhembe District in Limpopo Province"**.

The study is conducted under the supervision of DrRT Lebese who is a senior lecturer at the university. The study has been approved by the Ethics Committee of the School of Health Sciences at the University of Venda.

The objectives of the study are to:

- Explore and describe experiences of pregnant women who are HIV-positive
- Develop guidelines for caring for pregnant women who are HIV-positive.
- Conduct interviews with women who are HIV-positive
- Conduct interviews within 45 to 60 minutes, with audio taping of interview to verify the findings by the supervisor and independent coder.

The name and dignity of each participant will be presented by observing the following ethical standards throughout the research process

- Voluntary participation and freedom to withdraw without a penalty
- Informed consent
- Names of participants and their communities will not be mentioned during discussions
- Raw materials will be kept under lock and key to ensure confidentiality
- Information related to the interviews will only be accessible to my supervisor and the independent coder.
- Field notes will be destroyed and audio tapes will be erased as soon as possible, and the summary of the research study will be made available to participants if they wish.

Their participation in this study will benefit other pregnant women who are HIV-positive. The guidelines will be beneficial to others who experienced similar problems.

Thank You

Malindi FC

Researcher:

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ANNEXURE V

INTERVIEW TRANSCRIPT: REPRESENTATIVE SAMPLE 1

TRANSLATED FROM TSHIVENDA TO ENGLISH TO DEMOSTRATE HOW THE EXPERIENCES OF PREGNANT WOMEN LIVING WITH HIV/AIDS WERE ANALYZED

Key: Researcher=R, Participant=P

R: Good morning!

P Good morning!

R: What are your experiences of being pregnant while you are living with HIV/ AIDS?

P: I have accepted my status, but I am worried about my health, especially delivery because my hemoglobin (Hb) is too low. I am afraid that I may die during delivery and nobody will take care of my children.

R: Are you on iron preparation?

P: Yes and I am also eating beet root, fanta grape, fruits and vegetables.

R: Can you tell me more about your fears?

P: I am afraid because nurses told me that my Hb is too low and I realize that if I have little blood in my body maybe when I give birth I will bleed and die and I heard that most of the pregnant women who are living with HIV/AIDS when they deliver they got worse and die. I am afraid to die (participant looks down and cried) this disease is not good when you are pregnant I should have used contraceptives. If I knew that this man will make me pregnant.

R: Tell me more about how you became pregnant?

P: I think this man has purposefully ruptured the condom, I was not worried because I knew that we are using condom. Maybe I should have used contraceptives to make sure. This pregnancy wouldn't have happened, is putting my life in danger. I am angry with him.

R: Have you disclosed your status to him?

P: Yes

R: How is the relationship between you and your partner after you disclosed your positive status?

P: I was diagnosed in December 2007. After I disclosed my status, he first rejected me, he was no longer coming to visit me as he is a married man, but all my children belong to him. He also stopped giving me money for maintenance, but he only gives me money for few months. He didn't even want to see me, he used to call the children to collect money by the roadside, he will stop the taxi driver to give money to my children, but after some few months he stopped to support me and the children. It is like the maintenance officers are being paid bribe because each time I inquire about the money they just tell me to come next week, eventually I stopped to go to the maintenance offices, is too expensive because I am not working I rely on my mother's pension and child grant.

R: Since you were not on good terms with your partner, what happens now that you are pregnant and living with HIV/AIDS?

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P: When he found out that he is also ill he came and apologized, we were getting along well until I told him that I am pregnant. He no longer comes and visits me. He have stopped to support me financially, he no longer care about the children, as for me he no longer answers my calls. I am really suffering with this pregnancy, my health and my children. It is really hard.

(Participant looks down and keeps quiet for ± 3 minutes.

He is ignoring me. He don't love me any longer. He wants to divorce me. I am not legally married to him, but he is the only man that I ever loved. He gave me his children and left me to suffer alone while he and his wife and children are enjoying themselves and now that I am sick no man will ever love me again. Hey, (she breaths heavily) this thing is very painful. I don't know if I will make it, I am so weak I am afraid that (Pause) I may die, I am so much afraid.

R: Who is supporting you financially?

P: My mother is a pensioner. We survive with her pension money and child's grant and it is too little, with this up and down, nurses told me to eat good food and to avoid stress, how can I eat good food with little money I got from my mother and one's child's grant, as for stress how can I avoid stress with lot of problems. I am sick and not working, the owner of this pregnancy is not taking care of me. Hey, I don't know what to do. I am thinking of going back to maintenance office, but it is waste of time, they don't help, instead I will just go up and down with no help. My eldest daughter is at the secondary level, she also needs transport money and money to buy food at school, but is difficult. My children are also suffering, my last born child is better because they are given food at school, but she also need money to buy sweets and Simba chips at school. (Participant pauses). This life is very difficult, maybe it's better if I die, but my mother is too old to take care of my children. If I have somebody to help me, but no, there is nobody to help me.

R: Can you tell me more about your financial problems?

P: Hey (vhonnese) is difficult. I really don't know what to do. If you have time just come and see where I stay. If it wasn't the house of RDP we will now be staying in the open space, our huts have fallen down due to heavy rains and I don't have a brother who can help us. My only young sister is married, but things are no well with her because her husband is not working, but doing peace job. With money there is no support. I wish if I was working.

R: Have you disclosed your status to your mother and the children?

P: Yes and my mother and children support me. They don't segregate me, we use same utensils (mmeanga a vhannengwi) my children also loves me. I think they are the only people who are helping me to survive. It's better when there is somebody who loves you.

R: Have you disclosed your status to your relatives and neighbours and how are they treating you?

P: Since I got ill, I was so thin and very ill, I did disclose my HIV-positive status to my relative and some of my neighbours. Now that I have disclosed my status, my relatives no longer come to visit us, they no longer involve us, in their things. It's so painful to be rejected by your own relatives, but I heard that one of my relative is telling other people that I have AIDS and I will die. They also said they cannot visit as they are afraid to get the disease from me. When you are living with HIV/AIDS people change, they no longer regard me as a relative, to them I am as good as a dead woman. If I happen to go to their meetings I can see them talking and I know that they are talking about me. Nobody wants to talk to me like they used to be. That is why I no longer attend family and relatives meetings. One of my relatives also suggested that now that I am pregnant and so thin is better if I

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rest at home, but she says it politely, but I know she fee[illegible] me.

R: What about the neighbours?

P: My neighbours. Hey, life is so difficult in this village. They talk about me behind my back. They also laugh at me especially when I went to the spaza shop to buy bread they stand in their yard just to look at me, after that they will, call each other and laugh at me (Muthu u do to fanathumtungavhunzhulumba - one will die with pregnancy because of running around with other women's husband) when they prepare food for funerals they prohibited me from helping with cooking. At a certain funeral one lady asked me to stop peeling vegetables - she said (Haivhasongoshuma.hafhuvha a vhonalaurivhamatungunivhukuma -don't trouble yourself , we are so many who will work, it's clear that you are not well). These days I no longer bother myself when there is a funeral or Imbizo don't go there because I know people are talking about me, and some are laughing at me. Others are feeling shame of me.

R: Can you tell me more?

P: My children are also facing problems. My elder daughter came home crying saying that our neighbor's child told her that your mother is dying from AIDS (Vhonnese) - Nurse it's difficult to be HIV/AIDS positive while you are pregnant. I no longer have many friends, those who spread gossips. I don't know what to do (Thidivhiurindotshinya mini Mudzimuni ,athinamunnazwangamara a thifhufhifhufhinavhannavhavhanwevhasadzivhasinavhanna).(I don't krow what have I done to God, I don't have a husband, but I don't move around with other women's husbands.). He promised to marry me after my first child, but failed and again he said he will build a house for me, but he also failed. I wish to go to another village where nobody knows me, maybe it will be better.

R: How is your relationship with nurses at the clinic?

P: Nurses are the ones who are encouraging me, they are polite, is like they are also living with HIV/AIDS they don't reject me, they are not afraid to touch me. They teach us about how to take care of our unborn babies and our own health. I am also attending support group. It's good to be with the people who are having the same problem you are having, the same problem you are going through. We also cook and eat, share our experiences. I really want to be with that group. If everybody was like them it will be easier to live with HIV/AIDS while you are pregnant.

R: Do you still have anything to say?

P: Sometimes I feel tired of this pregnancy and disease. Sometimes I wish if this is a dream. Nothing in this life ever prepared me to take this problem. Maybe I have sinned. I really don't know? Maybe it's true that I am being punished because I took somebody's husband. This is really pairful. Maybe I should have aborted this pregnancy, I hate this man. He is the one who caused everything. (u nambilummbi) (hehas an ugly heart). I don't care about this man if he want to divorce me he may do so I am only worried about my health and the well-being of my children.

R: Do you still have more to tell me?

P: I no longer have anything to tell you, I think I have told you everything from my heart unless you still have other questions.

R: No, I think I have asked everything I wanted to know. Thank you so much for the information, but if I still need more information I will contact you again otherwise you gave the answers the way I wanted them. Thank you again.

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ANNEXURE VI

INTERVIEW TRANSCRIPT: REPRESENTATIVE SAMPLE 2

TRANSLATED FROM TSHIVENDA TO ENGLISH TO DEMOSTRATE HOW THE EXPERIENCES OF PREGNANT WOMEN LIVING WITH HIV/AIDS WERE ANALYZED

Key: Researcher=R, Participant=P

R: Good morning!

P Good morning!

R: Can you tell me about your experiences of living with HIV while you are pregnant?

P: To tell you the truth I was not prepared to be pregnant now, because I was diagnosed during my last pregnancy. My husband is also HIV-positive, we were taught not to have another child as it is dangerous to my health and my husband. We are on ARV, I am also an ambassador of an HIV/AIDS group that is educating people about prevention of HIV/AIDS. Our support group is usually invited to other clinics to encourage others to disclose their HIV-positive status.

R: What happens to you now that you are pregnant and you know more about HIV/AIDS and pregnancy?

P: (Crying bitterly; the researcher gave her water to drink and a tissue to wipe away the tears)

I … I was using inject able contraception and my husband was using condom one night as we were having sex I realize that he has removec the condom and he released himself inside me. When I asked him why he was doing that he was so angry and he started to beat me up. From that day onwards he was no longer using the condom, and each time I asked him to use condom he beats me up (Participant took off the T shirt and on her back there was a lot of black scars). He uses black swine to beat me if I refused to sex without condom). My husband become more violent like I was bitten every night and he threatened to kill me. He told me that he bought some tablets from an Ethiopian man and he knows that even if I use contraceptive I will be pregnant and if I abort his baby he will kill me. (She cried again). It was too much and one day when he went to his work place I took my children and go back to my parents. When he comes back from work he followed me to my parent's house and he wanted to kill me. I ran away and report to case to the police at our nearest Site light. I was so scared I was facing death and the following day we went to Thohoyandou police station, the police wanted to put him in jail, but I told the police that I only need a protection order because I was afraid that if they lock him in jail he will kill me for that as he have already told me that if I report him I must know that when he come back from jail he will kill me. I was so scared (she cried).

R: Can you tell me more about your experiences?

P: After few days I collapsed and was taken to the hospital by Emergency Medical Services (EMS). I spend almost 3 months at the hospital, for the first 2 and half months I was helpless. I couldn't wake up. I was being bathed and fed by nurses. They told me after I recovered that I was unable to recognize people. I was so helpless. I wanted to die. I was no longer interested in living I am so young with so many children, now I am expecting child number five and I am weak and I have lost a lot of weight. Nurse look at me, my CD4 cells are low, they are now 116 and before pregnancy I was so well and happy. This man wants to kill me purposefully, because at

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the clinic we were told that if I become pregnant again I may die: now I know that he deliberately wants to kill me. (Houlamunna o ntshinyelavhumatshelozwino u khoutodoummbulaha) That man has ruined my future now he wants to kill me. He is so cruel.

R: Hmmm continue.

P: Now that I stay with my parents when we meet on the road he no longer talk to me if I greet him he keeps quiet. It's obvious that he no longer loves me.

R: Who is supporting you financially?

P: I depend on children's grants. The money is not enough. I am struggling because nobody is helping me financially and I have to travel to the hospital for follow-up and also ANC visits at the clinic. I have many children the grant is not enough. I am so wasted and tired, I am no longer able to do piece job. I am really struggling. I don't even know where I will get money to buy clothes for the coming baby. My mother is a widower, and she is not yet receiving old age grant. She depends on collecting and selling woods. We are so poor and my mother is having many children, we are nine in the family and only five children are adults, otherwise she still have four kids to support plus my four children, it's very difficult.

R: Ehh …

P: We have threerondavels, my mother, I and the children are using one rondavel and the other rondavel is used by my brothers and the other rondavel is used as a kitchen, we are really running short of accommodation. I am also afraid that if it may start to rain we will have no place to stay as our rondavels have scant thatch roofing.

R: Is your husband supporting the children?

P: Not at all but he is working as a security guard. I cannot ask him to help me because he told me that now that I get money for children's grant and I don't give him I must not claim maintenance and he vows that if I happen to report him for maintenance he will kill me and the children so because of that I cannot report him. I will struggle alone. When I recover after delivery I will search for a job.

R: Hmmm

P: I can work as a domestic worker. I am a fast learner: I can work anything, anywhere.

R: How is the relationship with your relatives and family members?

P: My relationship with the family is good because I have disclosed my status and the nurses at the clinic are encouraging family members and relatives not to discriminate me. They are supportive and sometimes they help financial.

R: What about your neighbours?

P: As I have already said that I am an ambassador of HIV/AIDS and people living with HIV/AIDS, even my neighbor knows about it and they are supportive. They even come and ask questions if they are suspecting that one of their family members or relatives is sick. My neighbours don't discriminate me.

R: What about your in-laws?

P: My mother-in-law is so supportive, she even counsels me. She also told me that I must not worry as she knows that her son (my husband) will calm down and she will take me home and the children.

R: Hmmm

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P: The nurses are so supportive. If it wasn't for the care I received at the hospital, I don't think I will be alive today.

R: Do you still have more information to tell me?

P: No. I think I have told you everything, unless you have another question.

R: Thank you, I think you gave me enough information. I will call you again if I have any questions or if I need clarity. Thank you.

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ANNEXURE VII

LETTER FROM SCIENTIFIC AND MEDICAL EDITOR

FACULTY OF NATURAL SCIENCES
DEPARTMENT OF MEDICAL BIOSCIENCES

the faculty of Science

Donavon C. Hiss, PhD (Medicine)
University of the Western Cape
Private Bag X17
Bellville 7535
South Africa

Tel: +27 (0) 21 959 2834
Fax: +27 (0) 21 959 1663
E-mail: dhiss@uwc.ac.za

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To Whom it May Concern

This serves to confirm that I have edited the language, spelling, grammar and style of the MCur dissertation by **Malindi Fhulufhedzani Constance: EXPERIENCES OF PREGNANT WOMEN LIVING WITH HIV/AIDS AT VHEMBE DISTRICT IN THE LIMPOPO PROVINCE.**

Sincerely Yours

Donavon C. Hiss
SCIENTIFIC AND MEDICAL EDITOR
Ph.D. (Medicine), Dip. Freelance Journalism, Dip. Creative Writing

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