

https://dspace.org/

Pregnancy in adolecents attending a paediatric HIV clinic in South Africa

Dennis, Tanya

2016
http://hdl.handle.net/10539/22579

Downloaded from a DSpace repository. https://dspace.org/

PREGNANCY IN ADOLESCENTS ATTENDING A PAEDIATRIC HIV CLINIC IN SOUTH AFRICA

A DESCRIPTION OF PATIENT PROFILE AND EXPERIENCE

TANYA DENNIS

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Medicine in the Department of Paediatrics

Johannesburg 2016

Declaration

I, Tanya Dennis, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in the branch of Paediatrics, in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

.....

24 October 2016

Dedication

To the remarkable women I had the privilege of meeting while conducting this research – your strength is something to behold.

Acknowledgements

My supervisors, Karl Technau and Jennifer Watermeyer – your wisdom, patience and kindness were everything I could have asked for.

Sister Lucia Thomas – for your endless offers of assistance beyond the call of duty.

My mother, Maureen Dennis, and sister, Tracey Toefy – for editing and your advice.

I thank you all for your time and support in this endeavour.

Abstract

Background

Pregnancy amongst adolescents with HIV acquired perinatally is a relatively new occurrence that will grow in frequency as this population matures.

Aim

This study describes the population of HIV infected adolescents in care at a paediatric HIV clinic who have had pregnancies, including the immunological and virological status on admission to the clinic. I describe the treatment exposure and response. To gain an alternative understanding of this population, an account of their lived experience is given.

Methods

A sequential mixed methods approach was used in which a database and record review was completed for all patients who had been pregnant while in care at the clinic (n=17). Thereafter, three individual semi-structured interviews were conducted with members of the study population and analysed using thematic analysis.

Results

Two subgroups within this population emerged: one with clear perinatal infection and one with high-risk exposure for horizontal transmission or an HIV negative mother. On admission to the clinic (mean age 10,9 years) the median CD4 count was 210 cells/µL (13%) with a median HIV VL was 4,2 log copies per ml. Forty-seven per cent (n=8) had AIDS defining criteria at presentation. All patients in the study achieved immune recovery and virological suppression during the course of treatment. Pregnancy outcomes included 16 live births, 5 terminations of pregnancy

and one miscarriage. All but one infant were HIV uninfected at the 6 week HIV PCR test. There were high rates of psychiatric co-morbidity, sexual assault and psychosocial concerns within this population. Study participants were found to cope with their diagnoses well once disclosed to, though disclosure to their sexual partners is an area of concern as it is frequently delayed until after childbirth. The HIV education received does not adequately address the risks of onward HIV transmission to sexual partners, as well as the risk to the individual of HIV re-infection or acquiring other sexually transmitted infections. All participants perceived a need for support and guidance within the community, and wanted to serve their communities in health-related careers. One interview participant had planned her first pregnancy, insufficient data is available from records to determine whether other pregnancies were planned or not.

Conclusion

The risk of HIV transmission to offspring is low. Early disclosure of HIV status to adolescents as well as more comprehensive HIV education would serve to improve risk of HIV transmission at an individual level. These adolescents require support in identifying and safely managing the challenges associated with HIV infection. Their reproductive health needs must be addressed to facilitate a healthy and normal life into adulthood. At a community level effort is required to improve safety and poverty levels, which contribute to and exacerbate this entity of adolescent pregnancy in this population.

Table of Contents

Declaration	ii
Dedication	iii
Acknowledgements	iv
Abstract	v
List of figures	viii
List of tables	ix
List of abbreviations	x
Chapter 1 Introduction	1
Chapter 2 Objectives and methods	8
Chapter 3 Results	18
Chapter 4 Discussion	38
Chapter 5 Limitations and implications for practice and research	50
Chapter 6 Conclusion	54
Chapter 7 References	56
Addendum A Interview guideline	60
Addendum B HREC (medical) Clearance certificate	63
Addendum C Participant information sheet and consent form	64

List of Figures

Figure 2.1	Origin of population sample	10
Figure 3.1	Modes of transmission of HIV	18
Figure 3.2	Pregnancy outcomes	24
Figure 3.3	Graphic representations of individual patient data	25-26
Figure 3.4	Primary caregiver	27
Figure 3.5	Infant HIV PCR results	30

List of Tables

Table 1.1	South African ART eligibility criteria national policy revisions	3
Table 2.1	Demographic data of sample population	11
Table 3.1	Clinical data (mean) for perinatal transmission patients and high risk exposure patients at presentation to clinic	20
Table 3.2	Clinical data at presentation and WHO clinical and immunological staging	20
Table 3.3	ART data (mean data in years of life)	22
Table 3.4	Total ART exposures	22
Table 3.5	Psychiatric co-morbidities	28
Table 3.6	Themes extracted from qualitative data	31

List of Abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CD4	Cluster of Differentiation 4 cell
DNA	Deoxyribonucleic acid
ELISA	Enzyme-linked immunosorbent assay
HCW	Health care worker
HIV	Human Immunodeficiency Virus
HPV	Human Papilloma Virus
IQR	Interquartile range
IUCD	Intrauterine Contraceptive Device
MDD	Major Depressive Disorder
PCR	Polymerase Chain Reaction
PHIVA	Perinatally acquired HIV infection
PMTCT	Prevention of Mother to Child Transmission
REDCap	Research Electronic Data Capture
STI	Sexually transmitted infection
TOP	Termination of pregnancy
TB	Tuberculosis
VL	Viral load
WHO	World Health Organisation

Chapter 1 Introduction

As the Human Immunodeficiency Virus (HIV) pandemic matures into a chronic disease, the children who were infected as in the perinatal period are maturing into a unique subset within the HIV infected population. Prior to the availability of antiretroviral therapy (ART) these children were not expected to survive childhood.[1] Now they are surviving to adolescence and adulthood, with the hope of leading "normal" lives.[2] The challenges of management of their specific needs are becoming ever more apparent, including concerns about treatment adherence, adolescent sexuality and disorganised social environments.[3]

This study focuses on female adolescents who were perinatally infected with HIV and experienced a pregnancy, in order to gain an understanding of this small, but growing population and their experiences of growing up with HIV, pregnancy and child rearing during adolescence.

Natural history of perinatal HIV infection

Prior to the availability of ART the diagnosis of HIV was associated with very high mortality for children who contracted the virus in utero, at birth or through breastfeeding. Without effective prevention of mother-to-child transmission (PMTCT) strategies, HIV transmission rates are in the region of 25 to 35%.[4] The South African guidelines on PMTCT have been revised for 2015, with the aim of eradicating HIV transmission from mother-to-child (less than 2% transmission).[5] Current transmission rates in South Africa are less than 5%. Prior to the introduction of ART

research conducted in a South African setting shows that AIDS-defining diagnoses were present within the first 12 months of life in 44% of HIV infected infants.[6] Signs and symptoms of this included generalised lymphadenopathy, failure to thrive, pneumonia and diarrhoea. More specific findings for HIV infection were oral candidiasis and chronic parotitis. Mortality rates for infants perinatally infected with HIV were 25% by one year of age, and 45% by two years without the use of ART. This increases to 62% by five years.[7]

The introduction of ART changed the prognosis for these HIV infected children dramatically improving their survival through childhood, to adolescence and beyond. The majority of children with HIV infection are perinatally infected, usually intrapartum or in the post-natal period through breastfeeding.[8] Fewer children are infected thereafter, either through sexual assault, early sexual debut or blood transfusions that have been inadequately screened.

History of ART in South Africa

ART was introduced as national policy in South Africa in April 2004,[9] though private funding allowed for the use of ART in select centres prior to this.[10] The first national guideline allowed for ART in children who met strict medical criteria as well as psychosocial considerations outlined in table 1.1. PMTCT programmes were also initiated at this time. The ART guidelines were modified in 2010,[11] 2013[12] and 2015[13] becoming progressively more inclusive of patients with less advanced HIV infection.

Table 1.1 South African ART eligibility criteria national policy revisions

	2004	2010	2013	2015
Age	-	All <1 year	All <5 years	All <5 years
Admissions	>2 per year *or* One admission for >4 weeks	-	-	-
WHO stage*	II or III	III or IV (1-15 years)	III or IV (5-15 years)	III or IV (5-15 years)
CD4	<20% (under 18 months) *or* <15% (over 18 months)	< 25% *or* <750 cells/µL (1-5 years) *or* <350 cells/µL (5-15 years)	< 350 cells/µL (5-15 years)	<500 cells/µL
Psychosocial factors§	Yes	No	No	Yes
Fast tracking	-	< 1 year MDR or XDR TB WHO Stage IV	<1 years MDR or XDR TB WHO Stage IV CD4 <15% or <200 cells/µL	

Source: South African National ART guidelines for infants and children, (Department of Health, 2004), South African National ART guidelines for infants and children, (Department of Health, 2010), South African National ART guidelines for infants and children, (Department of Health, 2013)

*WHO staging for children was revised in September 2005 to include four stages instead of three.

TB – Tuberculosis, MDR – Multi-drug resistant TB, XDR – Extensively drug resistant TB, WHO – World Health Organisation

§ Includes having an identified caregiver responsible for administration of medication to the child, disclosure to another caregiver in the household who could assist with child's ART, promoting treatment of caregiver by ensuring same-site treatment or referring appropriately

PMTCT in South Africa

The PMTCT guideline in South Africa has undergone numerous revisions since its inception as a pilot project in 2000. The current guideline, implemented in 2015, is in accordance with the World Health Organisation (WHO) option B+, where all pregnant and breastfeeding women are eligible for ART regardless of gestation and

CD4 count. All HIV exposed infants have an HIV polymerase chain reaction (PCR) done at birth and 10 weeks, and nevirapine syrup is prescribed for six weeks. The duration of the infant's prophylaxis may vary according to maternal treatment duration prior to delivery. In cases of suspected maternal treatment failure, zidovudine may be added to the infant's prophylaxis.[13]

Adjustments in the adolescent period

The WHO defines adolescence as the period from 10 to 19 years of age.[14] It is associated with various physical and psychological changes, as the individual transitions from childhood to adulthood. Physical and sexual development is rapid in this life stage and along with this there is the need to develop skills that will serve them in adulthood. Adolescents undertake more social and economic responsibility as they move towards independence. At this time, social pressures outside the home are very influential and experimentation with high-risk behaviours occurs frequently.[14] The exploration of sexuality occurs naturally in this stage of development,[15] placing adolescents at increased risk of sexually transmitted infections, including HIV. They are particularly vulnerable as they are not yet capable of fully understanding the consequences of their actions.

Adolescent pregnancy in South Africa

Though the incidence of adolescent pregnancy in South Africa is decreasing, the fertility rates in adolescents aged 15 to 19 years is still high, with 30% of adolescents reporting having ever been pregnant.[16] The majority of these pregnancies are unplanned and unwanted.[17] Cultural aspects play an important role in maintaining

the current adolescent fertility rate, as discussing matters of sexuality is inappropriate in many traditional South African homes. As such the majority of adolescents rely on school sexual education programmes and information from peers when confronted with sexuality, contraception and HIV prevention. Further contributing factors to high pregnancy rates in this population include poverty, difficulty accessing health services for family planning or termination of pregnancy, unhelpful attitudes of clinic staff, gender inequality and high levels of gender-based violence.[17] Early child bearing often has a negative social impact on the young mothers, as only one third complete their secondary school after having a baby, thus perpetuating the cycle of poverty.[16] Child support grants are provided for South African children living in poverty. At present this amount is R330 per child per month,[18] which may ease some of the financial burdens experienced in these households but many rely on additional support, such as old age pensions, as this amount cannot support the needs of the child and family completely. A study on pregnant women in the same hospital as the clinic under study suggested that the CSG be extended to the antenatal period so as to allow improved nutrition and access to health facilities during the pregnancy, thereby ensuring a healthier pregnancy.[19]

Sexual and reproductive health care needs of adolescents with HIV

Adolescents living with HIV have particular needs regarding their sexual and reproductive health. These adolescents have the desire to go through the normal processes of adolescence and adulthood, including having families.[2, 20] This involves vigilance on their part in protecting their own health as well as that of their partner.

Dual methods of contraception should be encouraged for personal protection, including use of condoms at every sexual encounter to avoid transmission of HIV and contraction of other sexually transmitted infections. To further reduce the risk of HIV transmission adolescents should be adherent to ART.[21]

Differences in Perinatally HIV Infected Adolescents (PHIVA) to adolescents with horizontal HIV infection

There are differences between adolescents with perinatally acquired HIV infection and those who contracted HIV later in life, mostly related to the former having lived with a chronic illness all their lives. Adolescents with perinatally acquired HIV infection have greater duration of ART exposure, with greater risk of virological resistance. Therefore treatment regimens may be more complex, with limited alternative options in these individuals. Treatment adherence issues arise, due in part to the prolonged period of taking medication and the natural tendencies of adolescents to question and assert their developing autonomous spirits into all aspects of their lives, including their health.[22]

The experience of perinatal transmission is different to that of having acquired HIV infection through sexual assault or abuse. The former group, if not orphaned, are likely to have others in the household who require regular follow up at clinics and medication. Those in the latter group may be the sole member of the household who is HIV infected. A qualitative study on adolescents with HIV infection showed that knowing that they were not the only one with HIV in the home was viewed as a positive factor, as children did not feel alone or different in their family context.[2]

PHIVA have been shown to delay engaging in sexual activity as they have more knowledge about HIV. They also have a higher incidence of substance abuse, shown in a multicentre study in the United States of America (USA).[23] Though not fully generalizable to the South African population, this provides interesting insights into possible trends that may emerge in these adolescents.

Aims

To my knowledge no research has been undertaken on this subset of the HIV infected population in South Africa, therefore a descriptive study was undertaken to add to what is known from other settings. The aim of this study was to understand the population of adolescents with perinatally acquired HIV infection who have carried a pregnancy to term during adolescence, through an objective description of the population profile and a qualitative exploration of their lived experiences. This was done by means of an audit of the relevant population with regard to the history of their HIV infection, treatment experience and their pregnancy. This data was supplemented by data from interviews with some members of this population (n=3) so as to access information that was not available in the record review. I intend to identify areas that may be addressed by clinic staff to better support those who are pregnant or have had babies and prevent further unwanted adolescent pregnancies.

Chapter 2 Objectives and Methods

The objectives of this study are:

2.1 To describe the population of HIV infected adolescents attending the chosen clinic who have been pregnant, in terms of

- Age at diagnosis of HIV infection
- Treatment experience
    - Duration on ART at time of delivery
    - Requirement for second line regimen
    - Requirement for third line regimen
- Age at onset of pregnancy
- Treatment adherence
- Pregnancy outcomes
    - Live births
    - Termination of pregnancy
    - Miscarriages
- Social support structure
- Disclosure
    - To adolescent
    - To partner

2.2 To describe infant outcomes of the above-mentioned population, in terms of

- Infant HIV PCR results at 6 weeks
- Mode of delivery
- Birth weight

- Gestational age

2.3 To understand elements of adolescent pregnancy young motherhood given the background of longstanding HIV infection.

Research Design

This study adopted a sequential mixed methods approach. Given the small population it was thought valuable to investigate the participants in multiple facets of their lives. This approach has been shown to increase comprehensiveness of findings, expand the dimensions of the topic under study and increase methodological rigour.[24] Quantitative data were collected by record review and accessing the clinic's database. Thereafter, qualitative data were collected through individual semi-structured interviews with patients who met the criteria discussed below. A sequential approach ensured that those who met the slightly stricter inclusion criteria for the interviews could be identified during the record review. A reflective field journal was kept throughout the data collection process as an additional element of qualitative data collection.

Setting

The paediatric HIV clinic at which this study was conducted is situated within a tertiary hospital in Coronationville, Johannesburg, South Africa. Under Apartheid law this was classified as a Coloured area, and the population consisted of approximately 60% Black African and 38% Coloured people recorded during Census 2011.[25] These subgroups of the South African population are historically more impoverished and have higher rates of adolescent pregnancy[17] and HIV infection relative to the White

population group. Other challenges experienced by the community serviced by this clinic include unemployment, poor infrastructure and basic service delivery, substance abuse and gangsterism.

The paediatric HIV clinic was established in 1994 and currently cares for 1700 children who are living with HIV, from birth to adolescence. ART has been provided to children since 2002 by private funding and by government provision since 2004 in accordance with South African National Guidelines.[9] More than 3500 HIV-infected children have accessed care at the clinic since its inception.

Selection of study population

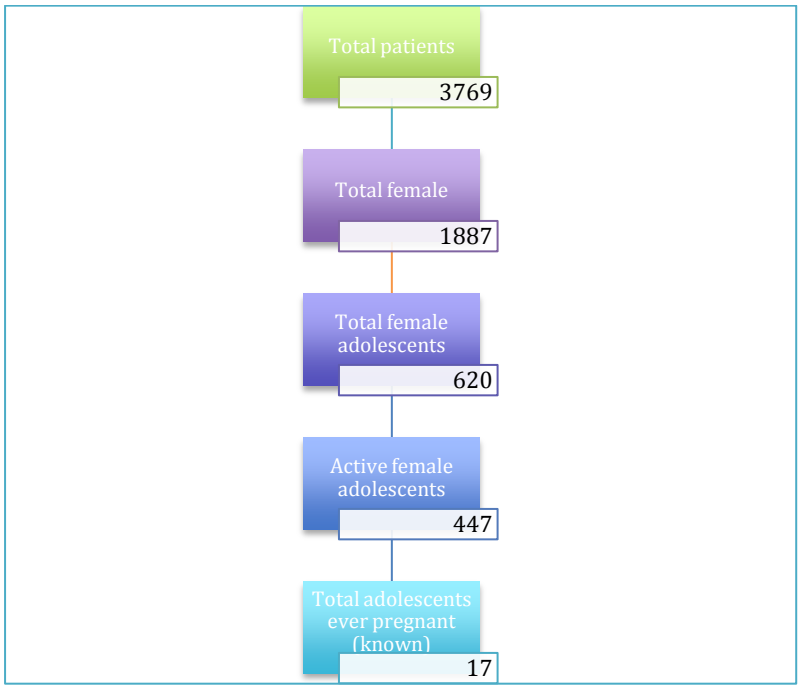

Figure 2.1 Origin of sample population

The population was identified using a register kept at the clinic including every adolescent who was known to have fallen pregnant while in care at the clinic (n=17). They were contacted telephonically to arrange a date and time for the interview. All

adolescents who were treated at this clinic were included in the sample, including those who had been infected with HIV perinatally as well as outside of the perinatal period.

Table 2.1 Demographic data of sample population

	Age at first clinic visit (years)	Age at pregnancy (years)	Race	Gravidity and parity
A	13	17	Black	G1 P1
B	11	17	Black	G1 P1
C	6	17	Black	G1 P1
D	11	17	Black	G1 P1
E	10	17	Black	G3 P? M1
F	9	18	Black	G2 P?
G	13	16	Coloured	G1 P1
H	8	16	Black	G1 P1
I	16	16	Black	G1 P1
J	10	19	Black	G1 P1
K	14	14	Black	G2 P1 T1
L	11	18	Black	G1 P1
M	15	16	Coloured	G1 P1
N	13	19	Black	G1 P0 T1
O	11	16	Coloured	G1 P0 T1
P	6	16	Black	G1 P0 T1
Q	4	16	Coloured	G1 P0 T1

G – gravidity, P – parity, M – miscarriage, T – termination of pregnancy

Data collection

The clinic database was used to extract data relevant to the study. This included:

- Age at diagnosis of HIV
- Records of CD4 counts and HIV viral loads
- Information regarding treatment, including dates of commencement, regimen changes and the drugs given
- Dates of clinic visits (actual and scheduled)

A record review was conducted for each patient eligible for inclusion. Information extracted included:

- Comments on treatment adherence
- Comments on social factors (caregiver, schooling, etc.)
- Comments on disclosure
- Comments on pregnancy
- Infant data

All cases of pregnancy in adolescents were included, with outcomes including keeping the baby and termination of pregnancy. There were no cases where the infant was given up for adoption.

Data regarding infant outcomes were taken from maternal files, the baby's own clinic files where applicable and the REDCap (Research Electronic Data Capture) database of infants born to HIV infected mothers at the hospital where the clinic is situated. REDCap is an electronic data capture tools hosted at the University of the Witwatersrand. REDCap is a secure, web-based application designed to support data capture for research studies.[22] The REDCap database is administrated by the clinic staff.

Data on patients' CD4 counts and co-morbid illnesses was taken from the database or records and used to extrapolate the clinical and immunological stage of illness, according to the WHO clinical staging and immunological classification published in

2007.[26] Advanced HIV was reported in accordance with the WHO criteria for diagnosis of advanced HIV (including AIDS).[26]

Data were recorded on a Microsoft Excel spreadsheet, as well as a Microsoft Word document tabulating pertinent information for each patient.

Interviews

In order to supplement information gained from the database and record review, due to the small sample size, patients who met the criteria set for the interview component of the study were identified and contacted telephonically by a Sister in the clinic, to arrange a meeting with the researcher. To maintain a sense of confidentiality, a professional nurse who was familiar with each of the potential participants contacted patients telephonically, as the clinic staff expressed concern regarding an unacquainted researcher contacting respondents at the outset.

Eligibility criteria for interview included the following:

1. 18 years or older, and
2. Had delivered their baby more than one year prior to the date of the interview, to allow time for the acute stress of being a new mother to have adequately settled.

These patients were contacted to invite them to participate in the study (n=7). Patients younger than 18 years of age were excluded, as caregiver consent would possibly be difficult to obtain. Those who had delivered their baby within one year

were excluded for the preservation of emotional state, as it was thought that the stress of recent delivery and new motherhood may be worsened by the exploration of the experience. This decision was taken based on the clinical and ethical experience of the clinic staff and previous researchers at the same site. Patients who had terminated their pregnancies were not invited to the interviews, as these data would not meet the specified objectives.

Three semi-structured interviews were conducted, using an interview guideline, comprising open- and closed-ended questions (addendum A). Each interview lasted approximately 30 minutes. One of the potential candidates was out of the country and thus not available for the interview. Three further potential candidates were not contactable telephonically. Individual interviews were conducted in a private room in English and digitally recorded, and subsequently transcribed by the researcher. A reflective field journal was kept to record observations and relevant findings.

Participants were first asked to describe their initial HIV clinic visit. I then asked how and when their HIV status had been disclosed to them. Thereafter their social situation was explored, including some detail on the relationship with the father of their child or children. Disclosure to their sexual partner(s) was explored specifically. Details of their methods of family planning, antenatal care, labour and delivery were sought, as well as the details of the baby's health and the impact of being a young mother on their day-to-day lives. Finally, suggestions for improvements in the service provided by the paediatric HIV clinic were requested from each participant. These data were specifically probed to supplement what was documented in records

and to cover all areas pertinent to the objectives. Though these topics were covered in all interviews, the order varied so as to allow the train of thought of participants to flow.

Data analysis

Data obtained from the record reviews were checked against the database where possible to ensure accuracy of information. Basic descriptive statistical methods were used in analysis of the data, calculating mean or median values and p-values for relevant parameters using Microsoft Excel.

The interview data was analysed using principles of thematic analysis.[27] Interviews were reread multiple times to identify ideas that were repeated across interviews in the data set as well as pertinent issues that arose in single interviews. Thereafter, recurrent ideas were merged into themes, which were then coded. Major themes were distinct and encapsulated the thoughts expressed by participants and no subthemes emerged during analysis. Themes across the interviews were triangulated with the quantitative data obtained from the record reviews.

Rigour

To improve the quality of the data obtained, reflective journaling was done after each interview, member checking done in interviews two and three, and peer debriefing after collection of the qualitative data set.[28]

Reliability and validity

To ensure reliability, comparison with other studies on this population was done and all data is reported, including findings that may not be in keeping with previous research. Validity of data was ensured by triangulation with data collected in the record reviews and database extraction.

Ethical considerations

Ethical clearance was granted from the University of the Witwatersrand Human Research Ethics Committee (Medical) (addendum B) and permission was obtained from the clinic for use of the database and patient records. Most patients or caregivers (where patients are minors) attending the clinic sign a data sharing consent form, which allows use of their records for research purposes. All patients included in the study had signed this consent.

Each interview participant was informed about the nature of the study, their role in the study, confidentiality and their option to refuse participation in the study. The participants were also made aware that the researcher was not affiliated to the clinic. Each interview participant was given an information sheet with details of the study, and asked to sign informed consent prior to commencing the interview (addendum C). The consent forms are securely stored with the researcher. Interview participants who agreed to an interview on a day other than their planned follow up date were reimbursed for their travel expenses, using the adolescent fund of the clinic.

To ensure confidentiality each patient was assigned a code, which was used rather than the individual's names on all documentation. The code and name associations were kept in a secure document, accessible only to the researcher.

Chapter 3 Results

The analysis of data for quantitative and qualitative components of the study is presented below, largely sequentially though triangulation allowed for integration of the datasets, which will be incorporated where relevant.

3.1 Modes of transmission

Patients treated at the clinic are generally believed to have acquired HIV in the perinatal period. On review of their records, however, several patients were found to have had an event in childhood that was high-risk for HIV transmission (sexual assault or sexual abuse, n=5), or have repeated documentation that their mother was HIV negative, n=1. The study population has been subdivided into those with clear perinatal infection and those who have likely non-vertical transmission, i.e. high-risk event for HIV transmission, those whose mothers were HIV negative or behaviourally acquired HIV infection (early sexual debut, n=1) (see Figure 3.1).

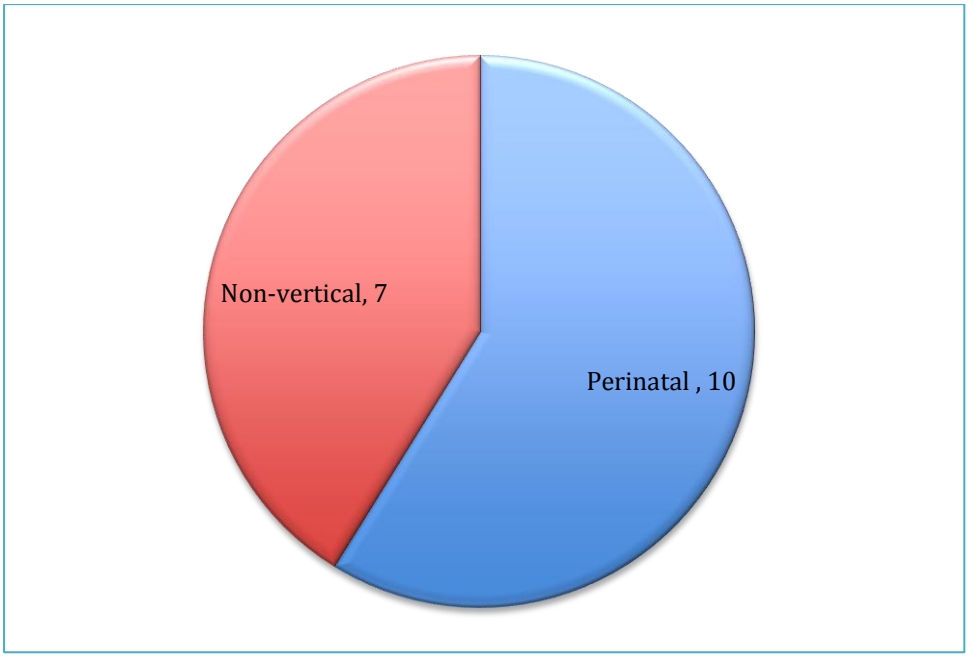

Fig 3.1 Modes of transmission of HIV

3.2 Initial presentation for HIV care

The median age at presentation to the clinic was 10,9 years (IQR 9,1-13,3 years). One patient presented at 4 years of age, four patients between the ages of five and nine years, 10 patients presented between 10 and 14 years, with two presenting at 15 years or older (one had been referred from another treatment centre where she had been treated for nine years). Those who were clearly perinatally infected had presented 4,1 years earlier than those in the (non-vertical) high-risk group (see Table 3.1). T-test analysis showed p=0,012 for age of presentation.

The study population had a median CD4 count of 210 cells/µL (range 2-1120 cells/µL) at presentation. Those presenting between the ages of 5 and 9 years had the lowest median CD4 count percentage of 7,6% (range 0,5-20%). The subgroup aged 10 to 14 years presented with the highest median CD4 percentage of 14,2% (range 0,2-46,6%) (see table 3.2). This discrepancy may be accounted for by the different modes of HIV transmission in the population, with higher CD4 percentage at presentation in those who had acquired HIV after the perinatal period and subsequently presented later.

The HIV viral load median value was 4,2 log copies/ml (IQR 3,8-4,9 log copies/ml) at the time of first presentation to the paediatric HIV clinic. The highest HIV VL log was found in patients aged 5 to 9 years with median of 5,5 log copies/ml (IQR 4,9-5,9 log copies/ml). Those aged between 10 and 14 years had the lowest HIV VL at presentation, with a median value of 3,8 log copies/ml (IQR 3,5-4,8 log copies/ml) (see table 3.2).

Eight patients (47%) had advanced HIV at presentation by WHO clinical staging, with three (18,8%) meeting criteria for AIDS. By WHO immunological classification 11 (68,8%) patients met AIDS defining criteria with 13 (81,2%) presenting with advanced HIV. During the course of their treatment every patient achieved immunological recovery and virological suppression.

Table 3.1 Clinical data for perinatal transmission patients (n=10) and high-risk exposure group (n=7) at presentation to clinic

	Mean age (years)	**Median CD4 cells/µL**	**Median CD4 %**	**Median HIV VL**	**Median HIV VL log copies/ml**
Vertical	9,6	154	10	115438	4,4
High-risk	12,7	251	15,6	14551	4,2

T-test for all variables in this table do not reach statistical significance aside from age (p=0,012).

Table 3.2 Clinical data at presentation and WHO Clinical and Immunological Staging

Age	**Median CD4 cells/µL (%)**	**Median HIV VL Log Copies/ml**	**WHO Clinical Stage**		**WHO Immunological Stage**	
All (n=17)	210 (13)	4,4	1 2 3 4 N/R	5 3 5 3 1	1 2 3 4 N/R	2 1 2 8 -
<5 years (n=1)	201 (11,6)	4,2	1 2 3 4	- - 1 -	1 2 3 4	- - - 1
5-9 years (n=5)	405,5 (7,6)	5,5	1 2 3 4 N/R	- - 2 2 1	1 2 3 4 N/R	1 - - 4 -
10-14 years (n=10)	186,5 (14,2)	3,8	1 2 3 4	4 3 2 1	1 2 3 4	1 1 1 7
15+ years (n=1)	313 (13,3)	3,9	1 2 3 4	1 - - -	1 2 3 4	- - 1 -

N/R – No record

3.3 Treatment experience

ART was initiated within three months of the first visit to the clinic in 10 of 17 patients. One patient was initiated on ART four months after her first visit. The other patients (n=6) had ART delayed by 12 months or more. The mean time to starting ART was 10,3 months, however, for the group who were not initiated within the first four months, the mean time to initiation of ART was 25,2 months. Included in the group of delayed initiation is one patient who had commenced dual therapy ART (April 2000) for 10 months, after which therapy was stopped. Triple therapy ART was commenced more than four years later in May 2004.

Six of 17 (35,3%) patients required regimen change to second line treatment (Didanosine, Zidovudine or Tenofovir and Lopinivir/Ritonavir). The mean duration on first line ART was 4,7 years for these patients. One patient had been on lamivudine monotherapy at the time of conception of her baby, and had been referred to the clinic for third line treatment from another treatment centre where third line ART was not available. Upon admission at the clinic, at 34 weeks gestations, she was initiated on Darunavir, Ritonavir and Emtricitabine/Tenofovir.

The study population had been on ART for a mean time of 5 years prior to pregnancy (Table 3.3). Their drug exposure during that time, as well as total exposure to ART beyond the pregnancy is tabulated (Table 3.4).

Table 3.3 ART data (mean data in years of life)

	Age at initiation of ART	**Total duration of ART**	**Duration on ART at pregnancy**
All	11,8	6,9	5
Perinatal	10,3	8,4	6,6
Non-vertical	14	4,7	2,7

Table 3.4 Total ART exposure

ART drugs before pregnancy		**ART drugs ever taken**	
Drugs	Patients	Drugs	Patients
0	1	0	-
1	-	1	-
2	-	2	-
3	5	3	3
4	5	4	-
5	2	5	6
6	4	6	7
7	-	7	-
8	-	8	-
9	-	9	1

Seven of 13 (53,8%) patients started on a regimen containing Stavudine developed lipodystrophy, requiring a single drug change (from Stavudine to Abacavir or Tenofovir) at a time of virological suppression, maintaining triple therapy with two of the original three drugs. Of the six patients not changed, four were changed from first line treatment to second line, including Lopinavir/Ritonavir, Didanosine and Zidovudine.

For the purpose of this study, surrogate markers for adherence were used to indicate treatment adherence. The HIV viral load and missed clinic appointments were the markers used to infer treatment non-adherence. Eight of 17 patients had an interruption of treatment for three months or longer, based on missed clinic appointments. Of these patients, seven had defaulted follow up on two or more occasions. Reasons cited upon returning to the clinic included forgetting the

appointment, not having enough money to come to the clinic and having other commitments, e.g. a funeral to attend.

It was often recorded that patients who had missed their dose at a specific time were not aware that it could and should be taken at a later time. This was frequently a subject of adherence counselling. Informing patients that missed doses could be taken a few hours later instead of being omitted completely improved adherence for a few patients (by subjective scoring given by counsellors).

3.4 Patient health details at the time of pregnancy

Most patients had one HIV VL done during the course of the pregnancy. Six of 17 patients were virologically suppressed at the time of pregnancy or TOP, with a median HIV VL of 2,3 log copies/ml (IQR 0-4 log copies/ml) at the time of the first pregnancy.

The mean age of the first pregnancy was 16,8 years (range 14-19 years) at the time of delivery. Of the patients who had a TOP the mean age was 16,4 years (range 15-19 years) at the time of procedure.

3.5 Pregnancy outcomes

Seventeen patients experienced at least one pregnancy while in care at the clinic. Five patients had a second pregnancy, including one who had a third while in attendance at the paediatric HIV clinic, resulting in a total of 22 pregnancies. The pregnancy outcomes for these patients are detailed in figure 3.2. There were no

known incidences of miscarriage only, although one patient had a miscarriage with a subsequent pregnancy resulting in a live birth.

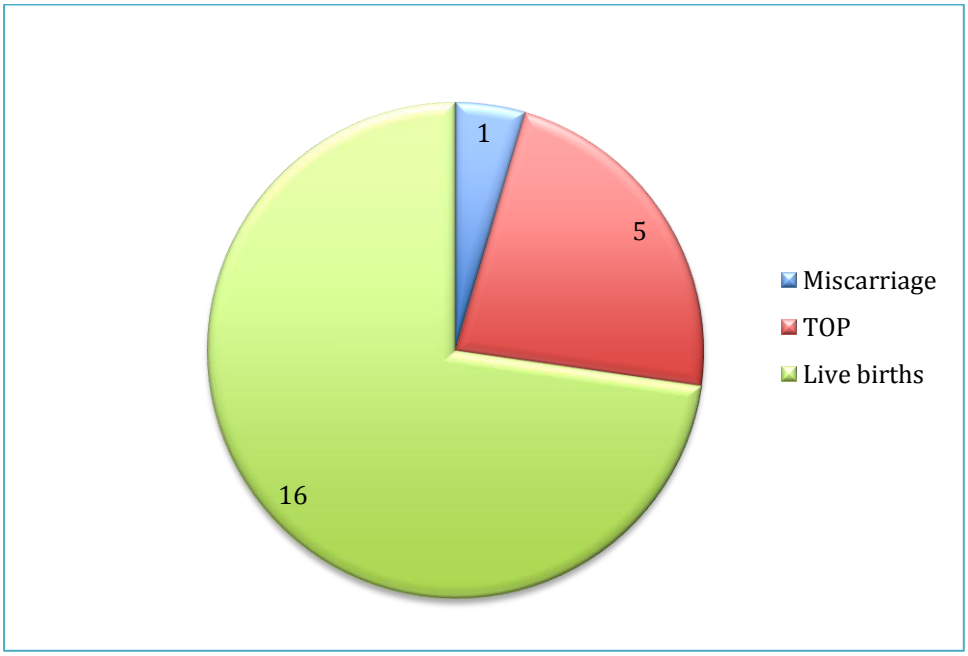

Fig 3.2 Pregnancy outcomes

3.6 Individual patient descriptions

Data for each member of the study population is documented graphically below (Fig 3.3). Included is the trend for HIV VL on a logarithmic scale, CD4 percentage, date at initiation of ART, date of changing to second or third line treatment where applicable and the timing of pregnancy or TOP.

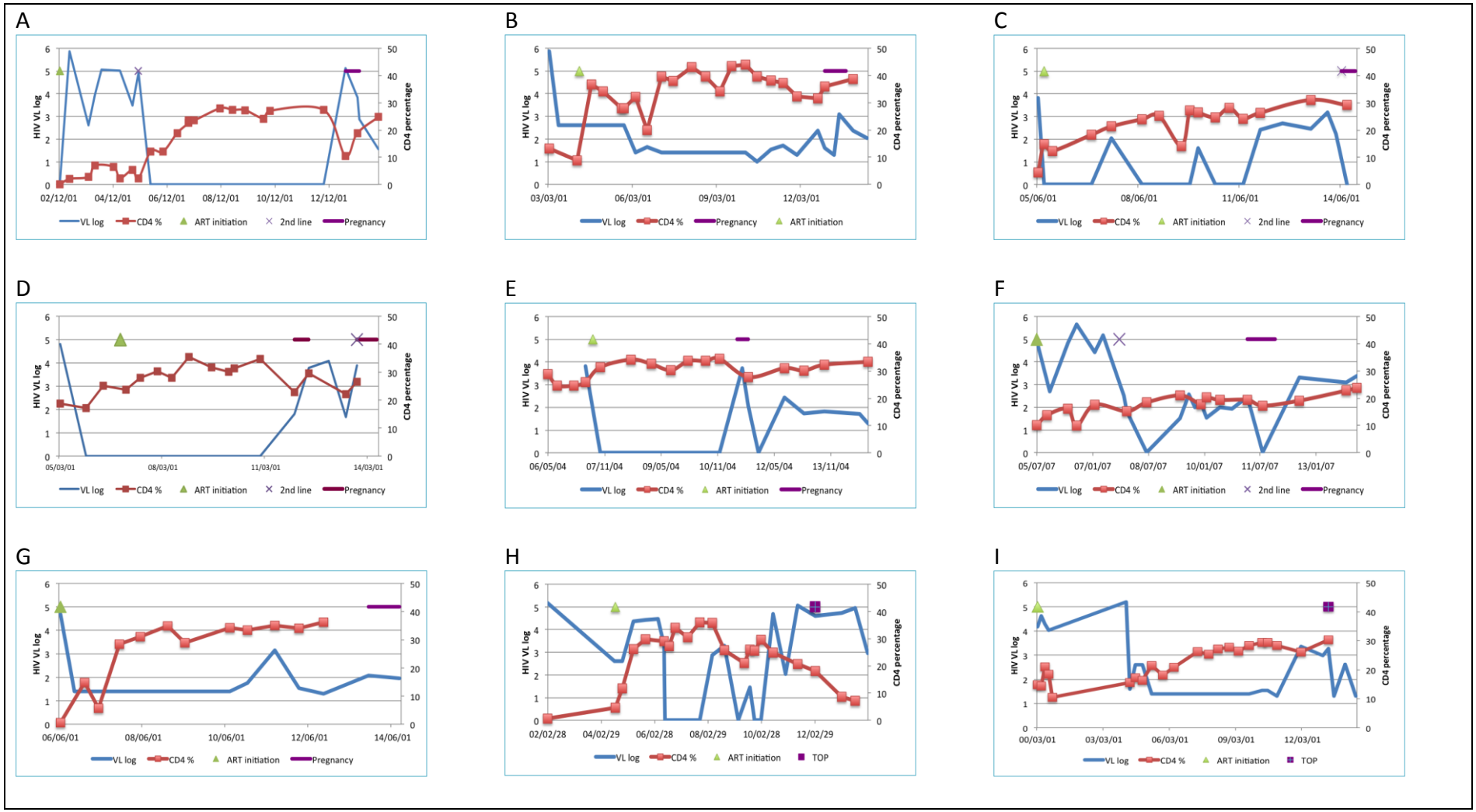

Fig 3.3 Graphic representation of individual patient data
All dates are presented in yy/mm/dd format

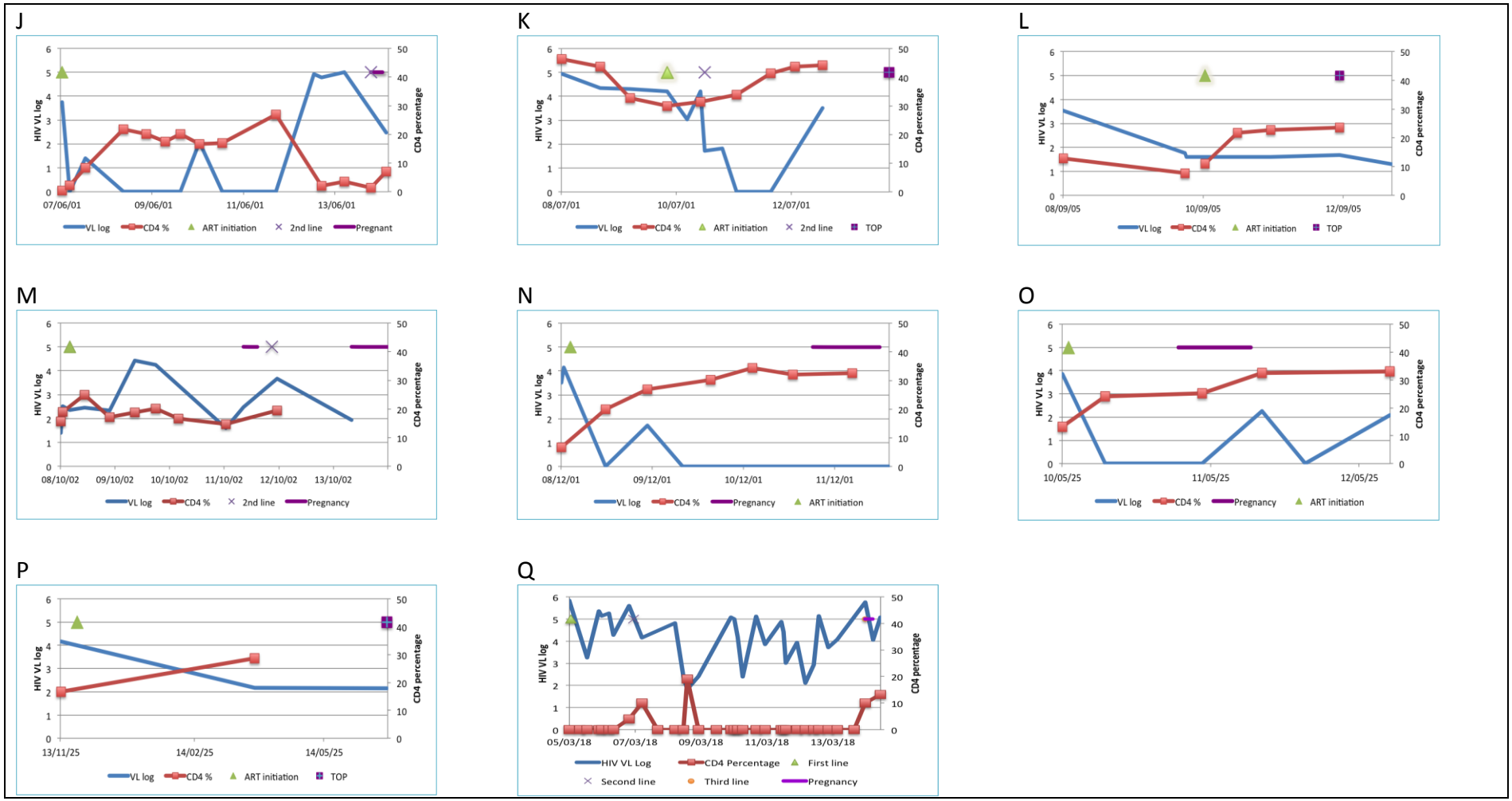

Fig 3.3 Graphic representation of individual patient data continued

All dates are presented in yy/mm/dd format

3.7 Social structure

No patients in the sample population had both of their parents as their primary caregiver. Six of 17 (35,2%) patients were cared for by their mothers, three (17,6%) were cared for by their grandmother and a further three (17,6%) by an aunt. One patient moved between her parents repeatedly and another one moved between her grandmother and aunt. In one case, the patient moved between an uncle and aunt. Two patients were placed in a children's care facility, having been removed from their homes after reports of abuse (Fig3.4).

In ten patients' records there is clear and recurrent documentation about concerns within the home environment. Examples of this include instability of the primary caregiver, reports of physical abuse, food insecurity and caregivers withholding ART. These findings are in keeping with the context of the population, where an impoverished background, high rates of substance abuse as well as physical and sexual abuse are prevalent.

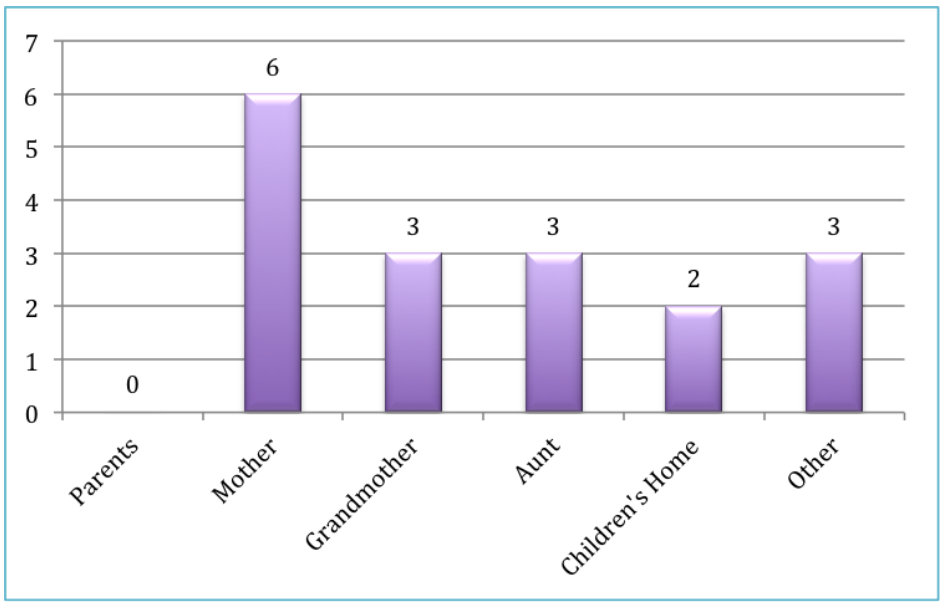

Fig 3.4 Primary Caregiver

3.8 Psychiatric co-morbidities

Seven of 17 patients had co-morbid psychiatric diagnoses documented, with referral to psychology and/or psychiatry services as deemed necessary (table 3.5)

Table 3.5 Psychiatric co-morbidities

Suicide/parasuicide	3*
Major depressive episode	3*
Borderline traits	1
Schizophrenia	1

*One patient with co-morbid MDD and suicidal attempt

3.9 Disclosure of HIV status to patient

Age of disclosure of HIV status to patient was erratically recorded within patient records. Where clear records were kept (n=8), the mean age of disclosure was 12,8 years. Three patients had been told of their status as HIV infected prior to their first visit to the clinic. One patient was not aware of her status at 16 years of age, but the age of disclosure was not subsequently documented. In one record there was documentation about disclosure at age 11 years, but a subsequent record 2 years later indicated that the patient was unaware of her HIV status.

3.10 Disclosure of HIV status to partner

Regarding disclosure of HIV status to the sexual partner, there is erratic documentation once again. In nine (52,9%) records there was no mention of this. Four (23,5%) records indicate that disclosure to the partner was done post-natally. A further three (17,6%) records state that disclosure was not done to the partner. Only one (5,9%) record reflects that disclosure was done, but the timing of this was not stated.

3.11 Family planning

The injectable contraceptive was the primary method used by the sample population, with seven patients using either Depo Provera (n=6) or Nur Isterate (n=1). Two patients were recorded to use condoms as an additional means of family planning. One patient used only condoms. One patient was reported using no contraceptive method (recorded in the post-natal period). One patient used the combined oral contraceptive pill and a consideration for the intrauterine contraceptive device (IUCD or "loop") was documented in two patient records, though there was no subsequent comment on whether the procedures were completed. There was no record of contraceptive choice in six patient records.

3.12 Sexual assault and abuse

Though not clearly detailed in the records, sexual abuse was documented in two patient records. Three further patients had been raped, with notes suggesting that this event was linked to that patient contracting HIV. Two of patients were removed from the home to a different caregiver or to a place of safety. The third had not told her mother about the rape and no support or counselling was offered until the diagnosis of HIV infection was made.

3.13 Infant outcomes

Data regarding the infants born to the study population was poorly recorded in the patient files. From the records present, all infants were born alive and survived to have an HIV PCR test at six weeks (Fig 3.5).

One HIV PCR result was not traceable and one infant had a positive HIV PCR result done in the first week of life. This infant was born to the only patient who had not had any ART during pregnancy (information regarding ART during delivery was not available). This patient was likely to have acquired HIV infection in the months prior to conception or during pregnancy, rather than in her own perinatal period. All other infants (n=13) were HIV PCR negative at six weeks, with two confirmed with an HIV ELISA at 18 months.

Additional data on six of the 15 live births are available. Three caesarean sections were performed (indications not available). The other three deliveries were by normal vaginal delivery. Five of the six infants were born at term (37 completed weeks or more), with one born at 36 weeks. The mean birth weight was 2791g (range 2370-3270g). One baby had a birth weight less than 2500g and is thus classified as low birth weight.

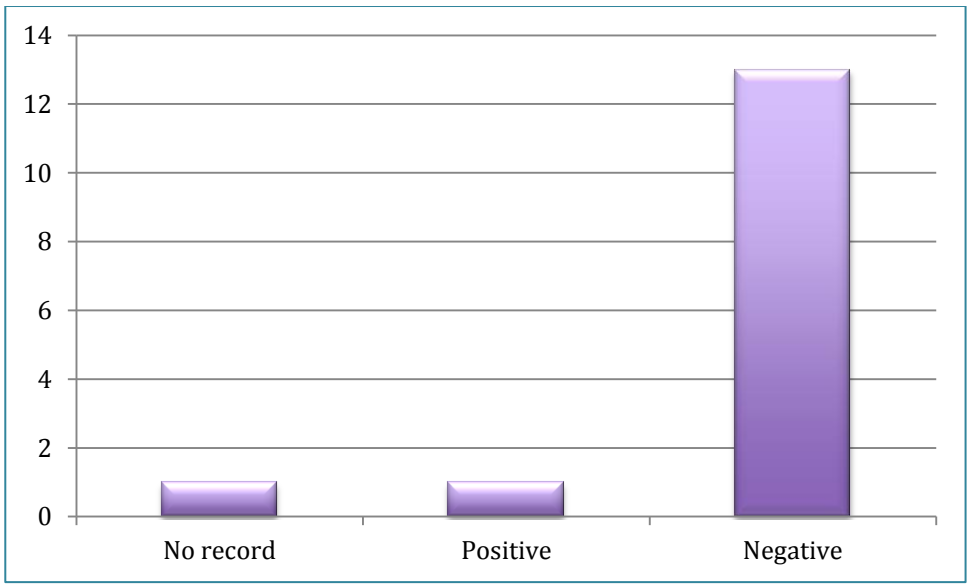

Fig 3.5 Infant HIV PCR results

3.14 Interview (qualitative) outcomes

The qualitative data is presented in accordance with themes that emerged during analysis of the dataset (table 3.6). Prominent or recurrent ideas, as well as important aspects of single interviews that informed the research question about the lived experience of the HIV infected adolescents were identified and are discussed below.

Table 3.6 Themes extracted from qualitative data

Disclosure of HIV status	Giving back
Caregivers of HIV infected children	Planned pregnancies
Knowledge and education on HIV	Lack of trust and confidence in health facilities
Sexual assault	Source of HIV infection

Disclosure of HIV status

None of the participants was willing to openly discuss her HIV status with anyone outside of her immediate family or close friendship circle. Only one had disclosed her status to two of her friends, who responded with support. It was stated repeatedly that HIV remains their "secret" and only those closest people to each participant were disclosed to.

In Thandi's* case the close circle of disclosure did not extend to her sexual partner, who was still not aware of her status as HIV infected after five years in the relationship. Busisiwe* had disclosed her status prior to onset of sexual activity, and Patricia* disclosed months after their child was born. The two who had disclosed mentioned that their partners were supportive thereafter in reminding them to take their medication. However, Busisiwe expressed that in moments of anger her

partner used her HIV status in criticism of her during arguments. “He used to swear me with it [HIV], but I understand…”

Patricia (aged 20 years) expressed the desire to have known her HIV status earlier. She had been told that she was on medication for allergies, though she recalls having been told by her grandparents that they could not look after her “because she was going to die” prior to her first visit at the clinic. Busisiwe had been told her HIV status before her first clinic visit. Thandi figured out her status after being exposed to HIV education at high school. She said, “it was in Grade 9 they were teaching us [about HIV] and then… oh, okay.” In the context of her interview it was clear this indicated her understanding and acceptance of her HIV infection.

Though the stigma of HIV in the community plays a big role in non-disclosure, a lack of knowledge of the risks may also contribute to delayed disclosure to partners. Patricia was not aware that HIV was transmissible through sexual contact at the onset of sexual activity. She said, “that time I didn’t know, I didn’t have that much information.” Thandi stated that she only found out during her first pregnancy that HIV was transmissible to her sexual partner. However, the link between lack of knowledge of transmission of HIV and non-disclosure was not explored and would require further research to establish whether this is contributory.

Caregivers of HIV infected children

Patricia moved from her grandparent’s home to her aunt’s when her HIV status was disclosed to them, as their experience of HIV infection was synonymous with death.

They had already suffered this with the death of Patricia's biological parents. She said, "they chased me away because they say I'm going to die". Busisiwe was primarily cared for by her aunt during her childhood and early adolescence. She experienced much difficulty as the only one with HIV infection in the home, and was treated differently: "She treat me badly, she wasn't treating me like [her] child". Busisiwe left her aunt's home as soon as another option presented itself, electing to move in with her boyfriend, the father of her children, while she was still a teenager. Her mother had abandoned her and subsequently passed away due to HIV related complications (though Busisiwe was not perinatally infected with HIV according to her as well as her medical records). Busisiwe and Thandi both mentioned food insecurity as reasons for leaving home, one to her boyfriend and one between her parents who were not co-habiting.

Knowledge and education on HIV

All respondents indicated that the HIV education that they were given from sources such as high school and radio aided in the acceptance of their illness. As mentioned earlier, through these education modalities one respondent identified herself as HIV infected, though this means of disclosure may be problematic for many. Learning about how common HIV infection was in the community seemed to make them feel better about their diagnosis. It did not, however, aid in allaying stigma around HIV. Education from the clinic was not spontaneously mentioned, but on enquiry it was agreed that valuable information was provided. One respondent mentioned that at each appointment she was given an opportunity to ask questions to improve her understanding of HIV.

Though the respondents were aware of the sexually transmitted nature of HIV as well as the potential to transmit the virus to their infants in pregnancy or through breastfeeding, some expressed that they did not know this before they fell pregnant. One respondent was not aware that mixing bottle- and breast-feeding increased the risk of HIV transmission, as she had only been told "the baby can get sick". Though each respondent said that they always used barrier contraception, the evidence of pregnancy indicates that this is at best true only some of the time.

Sexual assault

Thandi and Busisiwe had been sexually assaulted. Thandi had not told anyone about the experience, including her mother who is HIV negative. She mentioned that she "thinks this is how she got HIV". There is no further comment on this in her clinic record. Busisiwe had been told that she had been infected with HIV as a result of this assault. The incident led to a pregnancy, which was subsequently miscarried. She had been the victim of a robbery while walking down the street in the months prior to the interview. Her fear of being raped again was so great that she was hospitalised with post-traumatic stress disorder for three months thereafter. She was receiving ongoing psychological support and was treated with anti-depressant medication at the time of the interview.

"Giving back"

Each of the young women interviewed had chosen or intended to pursue careers that would allow them to help others who may find themselves in similar positions. Thandi said, "I've experienced so many challenges and (…) there are a lot of kids who

need help. So if I can help somebody, that will make me happy." One intends to study nursing, one social work and the other is currently working as a Community Health Worker. There was great maturity shown by these young women who recognise an opportunity to be of service to others in sharing the experience gained by their trying childhoods. This quality is perhaps an opportunity for the clinic to bring in these individuals to enhance the counselling and education aspects of the service offered.

Planned pregnancies

Of the six pregnancies experienced by the participants, five resulted in the birth of healthy infants. Busisiwe had planned her first baby because her partner frequently asked her why she was not falling pregnant, with the implication that there was something wrong with her related to her HIV infection. She recalls him saying, "Why [are] you not getting a baby? I have 3 years now, you [are] not getting a baby… Why?" She had not told him that she had been using the injectable contraceptive, which she then stopped in order to fall pregnant. Pressure from partners to bear children is a well-recognised entity in the South African context, as is the value placed on being a mother.[20] This story indirectly tells of the (lack of) use of barrier contraception in this couple.

Busisiwe suggested that the paediatric clinic offer the injectable contraceptive to young girls in attendance, along with their other treatment so as to avoid them falling pregnant and allowing the opportunity to complete schooling first.

Lack of trust and confidence in other health care services

All of the young women interviewed expressed a lack of trust in other health care facilities. One stated that she "didn't trust them with her secret". Each one was extremely pleased with the care received at the paediatric HIV clinic and despite being old enough to be transferred to an adult facility, they all preferred to continue their care in the paediatric clinic. This finding is consistent with previous research done in this clinic in 2013 on factors contributing to successful care in a clinic context. One point highlighted is the good relationship and communication between clinic staff and the patients.[29] This was re-iterated by Busisiwe, who named one doctor repeatedly in the positive and supportive role he had played in her life, saying "he was the good doctor, [he] always give me (…) good advice".

Source of infection: "It's alright to get HIV from your mother, not from the other person"

The idea of vertical transmission of HIV being more acceptable than horizontal transmission was expressed in all three interviews. Only one of the respondents was vertically infected and indicated she was very comfortable with her diagnosis. One of the respondents who had been sexually assaulted expressed some shame in being HIV infected, though after further probing she stated that she had subsequently accepted her diagnosis.

The interviews allowed an insight into the personal context of a few young ladies living with HIV infection regarding how they deal with their illness and its management, their partners, children and communities. It demonstrates the

successes achieved in this population, but also highlights the difficulties in their lives to date and going forward.

* denotes use of pseudonym

Chapter 4 Discussion

Notable findings of this study include the large number of patients who were not perinatally infected with HIV, and had instead either been exposed to a high risk event such as sexual assault or have repeated documentation of an HIV uninfected mother, with no indication of the source of HIV infection. An encouraging finding is the dramatic improvement in health status noted objectively by the recovery of CD4 counts and the suppression of HIV viral load as a measure of response to ART. Each participant had a health status sufficient to conceive a pregnancy, with most going on to deliver healthy infants, or electively terminating the pregnancy with no adverse health outcomes to the individuals. Many members of the study population (n=7) had co-morbid psychiatric illnesses, which mirrors what is known about these adolescents from studies done in higher income settings. Notably, the family structure of these adolescents was not traditional in the sense of being raised by two parents, though was very much in keeping with the norms of South African society, where the primary caregiver is often a single mother, aunt or grandmother.

Adolescent pregnancy in HIV infected patients (perinatal or early horizontal) is a phenomenon that will become more prevalent as this population matures into the adolescent phase of life. They are surviving to adolescence and beyond, with their health restored and as such feel like ‘normal’ teenagers, an idea that was repeated by the interviewed participants.

The HIV infected adolescents in this paediatric HIV clinic are a growing population with unique health needs. A constant consideration for the underlying HIV infection must be maintained in all aspects of their lives. However, the contrast from other chronic illnesses is the nature of transmission of HIV. As it is sexually and vertically transmitted, the affected can infect their sexual partners and children. Though the study population mostly contracted HIV in circumstances outside of their control, the consequence of infection remains theirs to bear. This extended into multiple areas of their lives. Due to the sexually transmissible nature of HIV as well as the risk of vertical transmission there is a weight of responsibility upon each individual regarding their sexual encounters. This may impact upon their decisions regarding childbearing, in the face of cultural expectations regarding the role of the woman in society as a wife and mother. The responsibility is felt only if the relevant individuals have adequate knowledge of the spread of HIV and the methods of preventing this.

In the interviews two participants expressed that they were unaware that they could transmit HIV to their sexual partners and as such did not perceive the need to disclose her HIV status prior to the onset of sexual activity. As such education in adolescents could be better directed as a tool in the prevention of HIV transmission. Knowledge of routes of HIV transmission and means of preventing transmission may lead to behaviour modification in terms of high risk sexual behaviour and improved use of barrier contraception methods. These adolescents have each lived through a period of severe ill health due to HIV infection and recovered to a point of relative wellness with ART. This experience should be drawn upon in impressing upon them and their peers the benefits of treatment adherence. Education is a key tool in

allowing the adolescents to gradually take charge of their illness and their lives. The detail included in this should be dynamic, as new concerns or patterns are noted, e.g. discussing taking ART as soon as possible after a missed dose rather than skipping it entirely. This should ideally be done with the support of caregivers and health care workers at the clinic. Where such knowledge is poor or incomplete, and opportunities to educate this population are missed, a great disservice is done to them as individuals as well as to the wider community. Unfortunately the latter scenario is ubiquitous, where emphasis is placed on the clinical features of HIV as a disease and the social implications are not given due consideration. Knowledge about HIV is essential in empowering to individuals to take charge of their own state of health, as well as that of their partners and offspring by extension.

Mode of transmission

An unexpected finding of this study was the number of patients who had apparently been infected with HIV outside of the perinatal period. Further investigation is needed with a larger sample size in order to identify whether this finding is representative of the greater HIV infected population in attendance at this clinic or whether it was a spurious result. A study from the University of Port Harcourt in Nigeria looked at this incidence of non-vertical transmission of HIV in children, finding that 11,5% of children were infected in a non-vertical manner.[30] To fully investigate this, data on early sexual debut, sexual assault/abuse and history of blood transfusions, operations, sharing of contaminated sharp objects and other high-risk events must be identified in cases of discordant mother and child pairs.

The large number of sexually abused patients in this small sample is indicative of communities that are unsafe and the protection of children is suboptimal. This concern requires attention at a community, provincial and national level, in order to provide better social support for children living in these communities.

Recovery from advanced HIV

The majority of patients in this sample were found to have advanced HIV on clinical and/or immunological criteria at the time of admission to the clinic. With treatment all members of the study population improved, achieving virological suppression and immunological recovery. One concerning finding is how few (n=6) remained virologically suppressed at the time of pregnancy despite all being in care, which speaks to poor adherence to ART. Further evidence of physical recovery is in the ability of the body to conceive and to support a pregnancy, which would not be possible in a state of severe ill health. In the early years of the HIV epidemic ART was not available and many children did not survive beyond childhood.[1] A few years later with the advances made in this field the idea of childbearing in this HIV infected population has presented itself as a very real untouched area that needs to be addressed to ensure holistic health for the affected adolescents.

The idea that these children would not survive was one that was carried in the community, as portrayed in Patricia's case where her grandparents chose not to look after her because they feared she would die. The consideration of their grandchild surviving was outside the paradigm of their experience, as was common prior to the

introduction of ART. Now a new paradigm is being established, where survival is the norm and all aspects of 'normal' life are possible.

Social circumstances

Studies conducted in various settings of perinatally acquired HIV infection, or on HIV acquired at a young age (less than 10 years) indicate that concerning social circumstances are common, up to 67% in a study from Ireland and the UK.[31] Though these circumstances are not detailed and are likely to differ significantly from those faced in the South African population, a cause for concern was documented in a majority of the study participants. Fathers were notably absent from the lives of most of the study population, a finding that is in keeping with what is known about the community feeding the clinic as well as in the greater South African context.[32] Two interview respondents mentioned food insecurity at home as a reason for moving away from home or moving between various homes, ultimately to the home of their boyfriends. Once again, dedication to improving the social circumstances of children living in poverty would benefit the affected population in many ways, including a possible delay in seeking out partners who would serve as providers.

Psychiatric co-morbidities

Many patients in this sample had psychiatric conditions, a finding that is in keeping with others conducted in similar populations in the United Kingdom[31] as well as studies of HIV infected youths in New York when compared to their uninfected counterparts.[33] Co-morbid mental illness impacts negatively on feelings of well being, and in turn on the ability to adequately care for their children and themselves.

It adds to the number of clinic appointments as well as to the pill burden in these patients. Though numbers are in keeping with international literature, the incidence of mental illness in these patients is likely underestimated. Poor maternal mental health is known to affect the health of her infant if not adequately addressed, with increased incidences of developmental problems as well as many physical illnesses.[34]

Disclosure and stigma

A great concern regarding stigma is its impact upon treatment adherence. Patients frequently reported that not taking their medication was related to fear that being seen taking medication would force an untimely disclosure. This correlates with findings published in 2009 in research relating to challenges of transitioning patients from a paediatric to an adult HIV clinic.[3] Many records had revealed that the reason for treatment non-adherence was for fear of being seen taking medication by other people. Overcrowded spaces within the home, an indicator of poverty, contributed as there was no private space where medication could be stored and taken. A study from Cambodia showed that the risk of perceived stigma decreased with social support in some form and increased with poverty.[35] Though not specifically documented in this population, studies have shown that children anticipate or have experienced negative consequences of disclosure, and therefore are very careful about disclosing only to those whom they trust to "keep the secret".[2, 36] This finding regarding stigma was echoed in the data, though not specifically in relation to treatment adherence.

The recommendation by the WHO is that all adolescents are fully aware of their HIV infected status by 12 years of age, with staged and age-appropriate disclosure done from early childhood.[37] Delayed disclosure of HIV status to the infected patient is associated with poorer outcomes in the adolescent population, with regard to treatment adherence and mental health concerns. Early disclosure of HIV status to this population is recommended as something of a public health measure, as education on the risk of transmission needs to be conveyed prior to sexual debut.[38-42] The benefit of disclosure to children and adolescents is in the potential for reducing onward infection.[41] The crucial factor in reducing onward HIV infection is disclosure of HIV status to the patient.

Data on disclosure were not reliably recorded with frequent discrepancies with recorded age of disclosure and subsequent notes regarding a need for disclosure to the patient. This indicates a lack of adequate emphasis on this issue. Difficulties with disclosure relate to uncertainty as to who will do the disclosure, i.e. the health care worker or the caregiver.[42, 43] Caregivers often feel anxiety about disclosing their own status to their children for fear of stigmatisation, out of guilt and fear that the child will not be secretive about the diagnosis.[43] In aiding this, HCWs should be trained in how best to facilitate staged disclosure in conjunction with caregivers.[40]

Though there is data missing from the records, the rate of disclosure to partners was worryingly low, which may be a function of lack of knowledge, personal responsibility and fear of stigmatisation. The adolescents in the interview group indicated that they were content with the level of education around HIV that they

had received, but it did not translate into the action required to attempt to prevent transmission of HIV to their sexual partners. Less than a third of participants had disclosed their HIV status to their partner/s, usually only after the delivery of the infant. A European study found that half of HIV infected adolescents disclosed their HIV status to their partners.[31] An Indian study of a similar population reported 100% disclosure to partners.[39] The reasons for this discrepancy are purely speculative; it would appear that cultural norms differ markedly from the Indian to the South African context as the majority of the adolescents in the Indian study were married.

Sexual and Reproductive health

The American College of Obstetricians and Gynecologists' Committee on Adolescent Health Care state the following: "Adolescents who are infected with HIV should receive counselling and care that allows them to realize their sexual and reproductive goals while maximizing their personal health and minimizing the risk of unintended pregnancy, acquisition of new STI's, and transmission of infection to partners or offspring."[15] Sexually active HIV infected adolescents should be educated on the benefits of dual contraception. Unwanted pregnancies, STI's and HIV re-infection are associated with unprotected sexual intercourse. Screening for these as well as regular pap smears and Human Papilloma Virus (HPV) vaccine administration should be considered as part of holistic care for this population.

Many patients were found to be pregnant during their second trimester and were referred to antenatal clinic from the paediatric HIV clinic at that relatively late stage. Counselling on the symptoms of pregnancy and advice on seeking pregnancy testing

with any change in their menstrual pattern needs to be regularly incorporated into education sessions with the adolescent HIV infected population. This also implies that TOP's, if desired, could be offered and arranged within the first trimester, which is associated with fewer complications than procedures performed later.[15]

Research from Canada has shown that HIV infected adolescents begin their sexual lives with anxiety related to fear of rejection by their partner.[44] These adolescents should be encouraged to have a positive outlook on their sexuality with due consideration for the responsibility associated with this.[36] This would enable HIV infected adolescents to lead "normal" lives, a desire expressed by young HIV infected people in a study done at a paediatric HIV clinic in Cape Town.[2]

Speaking further to the need for improved emphasis on reproductive health, nearly 30% of the young women had more than one pregnancy, the majority of which were unplanned. This despite their opportunities for education on HIV-related matters being greater than average and having had regular access to a health care facility. This finding was corroborated by similar studies, where repeat pregnancy rates were almost 25% in the first year.[31] The challenge for HIV practitioners is to enable HIV infected adolescents to safely negotiate sexual relationships and have families of their own. There are many opportunities for improvements and interventions at this level.

Infant outcomes

The infant outcomes in this sample are very encouraging, showing that despite incomplete virological suppression at the time of pregnancy in the majority (64,7%) ART still dramatically reduces the rate of HIV transmission from mother to child. This finding was in keeping with multiple studies of this population in many settings, concluding that the risk of HIV transmission to the infant is low.[31, 38, 45] The evidence is further supported by the one case of HIV transmission to the infant, where the infected adolescent was likely to have been recently infected and was treatment-naïve at the time of delivery. The mode of delivery of this infant was not documented. This patient commenced ART with her infant once his HIV infected status was confirmed and he achieved virological suppression on ART. There was no documentation regarding post-natal use of nevirapine as PMTCT in the infant after delivery.

Adolescent pregnancies are known to have higher complication rates as well as complications in the neonatal period.[31] Based on known information regarding the deliveries and infants (birth weights and six week HIV PCR results) the inference is made that there were no complications during delivery or in the neonatal period. The small sample size and poor documentation of relevant information are limitations with regard to this finding. As such ability to draw reliable conclusions is limited.

Lived experience of this population

The opportunity to explore a few of the young women's experiences and difficulties proved extremely beneficial as an adjunct to quantitative data collection. Though the number of interviews was small, the data extracted from these encounters was rich and interfaced well with data collected via quantitative methods. It highlighted the need for clinicians to individually address the concerns of each patient, as they have many requirements in terms of education about HIV, troubling social matters and family planning. The perspective gained by including the interview component was valuable in terms of data as well as in terms of deepening the understanding of the experience of healthcare for the participants. Future mixed methods research in this area would be immensely useful as much value was gained in exploring questions with participants that arose while reviewing records. Thus rather than speculating the reasons or relying only on quantitative data, answers were provided by the members of the population.

It was clear from the interviews that this paediatric clinic provides an excellent service with firm relationships formed between patients and HCWs. This echoes findings of previous research done in the same clinic.[29] Many of the patients in this population fall outside of the paediatric/adolescent category, but choose to remain in care at this facility as the experiences at other health care facilities have not lived up to the standard to which they have become accustomed.

Record keeping

Clinical records, though well organised through the use of a preprinted clerking sheet, were often lacking in information or necessary follow up of previous concerns. Documentation on matters around sexuality and contraception was limited. Clinic doctors did indicate that these topics were frequently discussed with adolescents, though often limited to visits where caregivers were not present. Particular issues, such as social difficulties and disclosure to the index patient, were poorly documented in follow up notes in patient records. Additional detail that should routinely be contained in patient records include:

- Detail on counselling about various issues, including social concerns, sexual activity and the use of or need for contraception
- More extensive records on disclosure of HIV status to the adolescent

A useful addition to the clerking sheet regarding specific non-medical issues to address at the follow up visit, e.g. disclosure, social concerns and need for counselling or further interventions, onset of sexual activity and need for contraception in adolescents. Specific prompting of non-medical issues may encourage an improvement in record keeping in this area.

Chapter 5 Limitations and Implications for Practice and Research

Limitations

The small sample size is recognised as a limitation of this study, restricting the statistical analysis that may be beneficial in further understanding this population. However, the sample is by nature restricted as the population is maturing. Information presented is thus largely descriptive. It is reassuring that studies on the perinatal HIV infected population in India,[39] the USA,[38] Italy[46] as well as Ireland and the UK[31, 45] had similar findings. No known studies have explored the lived experiences via a qualitative study of this population.

Another limitation is that only adolescents who were known to have had a pregnancy were included in this study. Instances of miscarriages or TOPs without the clinic being informed could not be included as the identification of these cases was outside the scope of this study.

Implications for practice

The role of the health care worker in the paediatric HIV clinic needs to adapt in order to meet the diverse needs of this adolescent population. Though involved in a paediatric service, the ability to advise on family planning methods is becoming essential. Further to this imparting a sense of the need for barrier contraceptive methods in addition to another form so as to protect the sexual partner from HIV infection, but also to protect the HIV infected population from re-infection and other STI's.

The clinic staff should be aware of the risk of adolescent pregnancy in each patient encounter and encourage methods of protection against this as well as the risk of transmitting the disease to their sexual partners and infants. Discussions on reproductive health should start early, so that patients are well equipped to make informed decisions when they are faced with the prospect of sexual activity or a romantic relationship. The importance of treatment adherence should be stressed, as it is essential to achieve virological suppression, which is key in protecting partners and babies from acquiring HIV infection. Disclosure to the adolescents is essential if education is to be relevant and internalised by individuals. Issues around disclosure to the patient as well as the sexual partners more intensely is a priority area to be addressed. In addition to this, the manner in which sexual assault in children and adolescents at the clinic are managed may need attention, as counselling and support was not routinely documented to have been provided. This may be an omission in documentation rather than an actual deficiency in care provided. As such an improvement in record keeping, possibly through a review of the current clerking sheet, is vital.

To specifically address the needs of the population under study, the high number of social concerns (food insecurity, caregiver instability, sexual assault prevalent in the community) should be assessed as part of management for each patient at every clinic visit, with referral to social work, psychologists or other allied health professionals as required. Financial difficulty could be addressed by ensuring that patients who qualify are in receipt of the Child Support Grant.

These patients should be followed closely as rates of repeat pregnancy are high, and family planning options discussed and arrangements made for appropriate referral to reproductive health care services as necessary. The infants form an interesting cohort who should be followed to ensure that their HIV status is confirmed at 18 months and beyond.

Adolescents with HIV infection should be supported through the initiation of romantic and sexual relationships in an environment that is non-judgemental and friendly. The opportunity to discuss new challenges may provide significant benefit to the adolescents as well as their offspring, should they fall pregnant.[47] As these adolescents have been attending the same clinic for many years from a young age, there may be some awkwardness in discussing reproductive health. This as clinic staff indicated that the role they play may be seen as 'parental', which may not allow for the recognition and appropriate management of the adolescent life stage because of familiarity. As discussed earlier the role of the HCW must go beyond what is currently the norm in order to address these issues for the benefit of the adolescent.

<u>Implications for future research</u>

- Assess the number of patients in attendance at the clinic that were infected with HIV via a non-vertical route, and the frequency of these routes.
- An anonymous questionnaire-based study or focus groups of the general adolescent population in the community on their knowledge of routes of transmission of HIV and sexual health – in order to establish the knowledge

base of the population and identify where further education must be targeted.

- Research on this population in other South African Paediatric HIV centres would be beneficial in establishing comprehensive guidelines applicable to multiple centres.
- Explore the attitudes of male and female adolescents at the clinic towards sexuality and their expectations and concerns as they face their reproductive years.

Chapter 6 Conclusion

The overwhelming sense in reflecting on the data was the ideal of normality, which was afforded to the study population by ART and the compassionate presence of the paediatric HIV clinic. Though there is scope for improvement in practical aspects of management and education, the care for patients and concerns for their well being was evident and confirmed by interviewed participants.

That adolescent pregnancy has become a concern in the perinatally infected HIV population indicates great success in the field to date. It has revealed opportunities for much exploration and research, to offer these adolescents the best life possible. A dynamic approach in the management of HIV infected children is vital to achieve the goal of HIV eradication worldwide.

HIV infection has become a chronic, manageable disease with the improved availability of ART. Though this bears similarities to other chronic illnesses faced by adolescents, it is distinct in its transmissible nature. As such it requires more responsibility and maturity from the infected adolescents than non-communicable diseases, as only they can control the prevention of transmission. To do this efficiently they need education about the disease and support at home as well as by health care workers whom they trust. This paediatric HIV treatment clinic provides some of the education, but may be lacking in the re-enforcement of the knowledge gained. The HCWs at the clinic play an excellent supportive role for the patients in their care.

The intricacy of each patient's experiences was highlighted by the inclusion of the qualitative component of this study. While the database and record review data informs the clinician on clinical aspects of these patients, the question of their experience has added valuable insights into their world.

As studies done on similar cohorts show similar results regarding treatment adherence and unplanned pregnancies,[31, 45] effecting behaviour change is essential in achieving improvement in individual patient care.

Chapter 7 References

1. Hazra R, Siberry GK, Mofenson LM. Growing Up with HIV: Children, Adolescents and Young Adults with Perinatally Acquired HIV Infection. Annu Rev Med. 2010;61:169-85.
2. Li RJ, Jaspan HB, O'Brien V, Rabie H, Cotton MF, Nattrass N. Positive futures: a qualitative study on the needs of adolescents on antiretroviral therapy in South Africa. AIDS Care. 2010;22(6):751-8.
3. Vijayan T, Benin AL, Wagner K, Romano S, Andiman WA. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. AIDS Care. 2009;21(10):1222-9.
4. Woldesenbet S, Goga A, Jackson DJ, group ftSEs. The South African Programme to Prevent Mother-to-Child Transmission of HIV (PMTCT): Evaluation of Systems for Early Infant Diagnosis in Primary Health Care Facilities in South Africa: Report on Results of a Situational Assessment, 2010. South African Medical Research Council. 2012.
5. Bhardwaj S, Barron P, Pillay Y, Treger-Slavin L, Robinson P, Goga A, et al. Eliminataion of mother-to-child transmission of HIV in South Africa: Rapid scale-up using quality improvement. SAMJ [Internet]. 2014; 104(3 Suppl 1):[239-43 pp.].
6. Bobat R, Moodley D, Coutsoudis A, Coovadia H, Gouws E. The early natural history of vertically transmitted HIV-1 infection in African children from Durban, South Africa. Annals of Tropical Paediatrics. 1998;18(3):187-96.
7. Spira R, Lepage P, Msellati P, Van de Perre P, Leroy V, Sionon A, et al. Natural History of Human Immunodeficiency Virus Type 1 Infection in Children: A Five-Year Prospective Study in Rwanda. Pediatrics. 1999;105(5).
8. Gillespie SL. Epidemiology of paediatric HIV infection. In: UpToDate, Paul ME, editors. Pediatric HIV Infection. Waltham, MA.2015.
9. National Department of Health. The South African National Antiretroviral Treatment Guidelines 2004 [13 December 2014]. Available from: http://southafrica.usembassy.gov/media/2004-doh-art-guidelines.pdf.
10. Boulle A, Bock P, Osler M, Cohen K, Channing L, Hilderbrand K, et al. Antiretroviral therapy and early mortality in South Africa. Bulletin of the World Health Organisation. 2008:657-736.
11. National Department of Health. The South African National Treatment Guidelines 2010. Available from: http://apps.who.int/medicinedocs/documents/s19153en/s19153en.pdf.
12. National Department of Health. The South African Antiretroviral Treatment Guidelines 2013 [cited 20 January 2015]. Available from: http://www.kznhealth.gov.za/medicine/2013_art_guidelines.pdf.
13. National Consolidated Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults. In: National Department of Health, editor. Pretoria: Department of Health; 2014.
14. World Health Organization. Adolescent development [20 January 2015]. Available from: http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/.

15. Committee Opinion No. 572: Reproductive health care for adolescents with human immunodeficiency virus. Obstetrics and gynecology. 2013;122(3):721-6.
16. Willan S. A review of teenage pregnancy in South Africa - Experiences of schooling, and knowledge and access to sexual & reproductive health services. Partners in Sexual Health [Internet]. 2013 [cited 3 Feb 2015]. Available from: http://www.rmchsa.org/wp-content/uploads/2013/08/Teenage-Pregnancy-in-South-Africa-2013.pdf.
17. Mkhwanazi N. Understanding teenage pregnancy in a post-apartheid South African township. Culture, health & sexuality. 2010;12(4):347-58.
18. South African Social Security Agency. Child support grant 2014 [updated 28 October 2014]. Available from: http://www.gov.za/services/child-care-social-benefits/child-support-grant.
19. Scorgie F, Blaauw D, Dooms T, Coovadia A, Black V, Chersich M. "I get hungry all the time": experiences of poverty and pregnancy in an urban healthcare setting in South Africa. Globalization and health. 2015;11:37.
20. Sofolahan Y, Airhihenbuwa CO. Cultural Expectations and Reproductive Desires: Experiences of South African Women Living with HIV/AIDS (WLHA). Health Care Women International. 2013;34(3-4):263-80.
21. Croucher AP, Jose S, McDonald S, Foster C, Fidler S. Sexual and reproductive health in a UK cohort of young adults perinatally infected with HIV. Sexually transmitted infections. 2013;89(5):392-4.
22. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap): A metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42(2):377-81.
23. Koenig LJ, Nesheim S, Abramowitz S. Adolescents with perinatally acquired HIV: emerging behavioral and health needs for long-term survivors. Current opinion in obstetrics & gynecology. 2011;23(5):321-7.
24. Chow MY, Quine S, Li M. The benefits of using a mixed methods approach--quantitative with qualitative--to identify client satisfaction and unmet needs in an HIV healthcare centre. AIDS Care. 2010;22(4):491-8.
25. Statistics South Africa. Census 2011 Census in Brief. Pretoria: Statistics South Africa; 2012.
26. World Health Organization. WHO Case Definitions of HIV for Surveillance and Revised Clinical Staging and Immunological Classification of HIV-related Disease in Adults and Children. Geneva: WHO Press; 2006.
27. Braun V, Clarke V. Using Thematic Analysis in Psychology. Qualitative Research in Psychology. 2006;3:77-101.
28. Long T, Johnson M. Rigour, reliability and validity in qualitative research. Clinical effectiveness in nursing. 2000;4(1):30-7.
29. Watermeyer J. "This clinic is number one": a qualitative study of factors that contribute toward "successful" care at a South African Pediatric HIV/AIDS clinic. Evaluation & the health professions. 2012;35(3):360-79.
30. Ugwu RO, Eneh AU. Nonvertical (Horizontal) Route of HIV Transmission in Children. J Acquir Immune Defic Syndr. 2014;65(3):e128-e30.
31. Kenny J, Williams B, Prime K, Tookey P, Foster C. Pregnancy outcomes in adolescents in the UK and Ireland growing up with HIV. HIV medicine. 2012;13(5):304-8.

32. Nduna M, Sikweyiya Y. Silence in Young Womens' Narratives of Absent and Unknown Fathers from Mpumalanga Province, South Africa. Journal of Child and Family Studies. 2015;24(2):536-45.
33. Mellins CA, Brackis-Cott E, Leu CS, Elkington KS, Dolezal C, Wiznia A, et al. Rates and Types of Psychiatric Disorders in Perinatally Human Immunodeficiency Virus-Infected Youth and Seroreverters. 2009;50(9):1131-8.
34. World Health Organization, Department of Mental Health and Substance Abuse. Maternal Mental Health and Child Health and Development in Low and Middle Income Countries: Report of the meeting held in Geneva, Switzerland, 30 January-1 February. Geneva: World Health Organisation, 2008.
35. Barennes H, Tat S, Reinharz D, Vibol U. Perceived stigma by children on antiretroviral treatment in Cambodia. BMC Pediatr. 2014;14(1):300.
36. Fielden SJ, Sheckter L, Chapman GE, Alimenti A, Forbes JC, Sheps S, et al. Growing up: perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. AIDS Care. 2006;18(8):1050-3.
37. World Health Organization. Guideline on HIV Disclosure Counseeling for Children Up To 12 Years of Age Geneva: WHO Press; 2011 [cited 2015 15 January]. Available from: http://whqlibdoc.who.int/publications/2011/9789241502863_eng.pdf.
38. Zorrilla C, Febo I, Ortiz I, Orengo JC, Miranda S. Pregnancy in perinatally HIV-infected adolescents and young adults--Puerto Rico, 2002. MMWR Morbidity and mortality weekly report. 2003;52(8):149-51.
39. Chibber R, Khurranna A. Birth outcomes in perinatally HIV-infected adolescents and young adults in Manipur, India: a new frontier. Archives of gynecology and obstetrics. 2005;271(2):127-31.
40. O'Malley G, Beima-Sofie K, Feris L, Shepard-Perry M, Hamunime N, John-Stewart G, et al. "If I Take My Medicine, I Will Be Strong: " Evaluation of a Pediatric HIV Disclosure Intervention in Namibia. J Acquir Immune Defic Syndr. 2015;68(1):e1-e7.
41. Evangeli M, Foster C. Who, then what? The need for interventions to help young people with perinatally acquired HIV disclose their HIV status to others. AIDS (London, England). 2014;28 Suppl 3:S343-6.
42. Vaz LME, Eng E, Maman S, Tshikandu T, Behets F. Telling Children They Have HIV: Lessons Learned from Findings of a Qualitative Study in Sub-Saharan Africa. AIDS patient care and STDs. 2010;24(4):247-56.
43. Kenu E, Obo-Akwa A, Nuamah GB, Brefo A, Sam M, Lartey M. Knowledge and Disclosure of HIV Status among Adolescents and Young Adults Attending an Adolescent HIV Clinic inAccra, Ghana. BMC Research. 2014;7.
44. Fernet M, Wong K, Richard ME, Otis J, Levy JJ, Lapointe N, et al. Romantic relationships and sexual activities of the first generation of youth living with HIV since birth. AIDS Care. 2011;23(4):393-400.
45. Thorne C, Townsend CL, Peckham CS, Newell ML, Tookey PA. Pregnancies in young women with vertically acquired HIV infection in Europe. AIDS (London, England). 2007;21(18):2552-6.
46. Calitri C, Gabiano C, Galli L, Chiappini E, Giaquinto C, Buffolano W, et al. The second generation of HIV-1 vertically exposed infants: a case series from the Italian Register for paediatric HIV infection. BMC infectious diseases. 2014;14:277.

47. Berg A. Infant-parent psychotherapy at primary care level: establishment of a service. South African medical journal = Suid-Afrikaanse tydskrif vir geneeskunde. 2012;102(6):582-4.

Addendum A: Interview guideline

Expanded Interview guideline for Interviewer

Thank you for agreeing to talk to me today. Just to remind you that everything we talk about is private and nobody at the clinic will know what you've told me, good or bad. I am recording this interview so that I can refer to it later. If you feel uncomfortable with any questions and don't want to answer please tell me. We will move on, or stop if you prefer. If you have any questions for me please feel free to ask.

Can you tell me about the time you started coming to this clinic?	
It can be very difficult for doctors and caregivers to tell a child that she is HIV positive. • Who first told you that you had HIV? • How did you feel when you found out that you have HIV? • How were you when you found out? • How do you feel now about your HIV status?	
Tell me about your home and your family • Who do you live with? • Tell me about your parents • Who was the main person looking after you when you grew up? • Did you have to look after any of	

your brothers and sisters?		
Talking about HIV to your partner can be very difficult. Did your partner/the baby's father know about your HIV status?	Yes	No
Do you know your partner's HIV status before you fell pregnant?	Yes	No
Did you have any problems during your pregnancy?	Yes	No
Tell me about your baby • Did you have a boy or a girl? • Did you breastfeed the baby? If yes, for how long? • Did he/she have an HIV test? • What was the result? • Did you have to give the baby any medication when he/she was born? • Did you manage to give the medication every day?		
Having a baby while you're young can be very hard and can change your life very quickly. Did you plan to have a baby at this stage of your life?	Yes	No
There are ways of preventing pregnancy and protecting yourself from other infections that can be passed on through sex. • Do you know of this and where to get it?	Yes	No

• Did you have any difficulty getting family planning or using it?		
Would you have liked help or information from Empilweni clinic before your pregnancy?	Yes	No
	If so, please explain	
Would you have liked help or information from Empilweni clinic during your pregnancy?	Yes	No
	If so, please explain	
Would you have liked help or information from Empilweni clinic after your pregnancy?	Yes	No
	If so, please explain	
Did you feel supported by Empilweni clinic staff during/after your pregnancy?	Yes	No
	If so, please explain	
Would you have liked more or different types of help during or after your pregnancy?	Yes	No
	If so, please explain	

Addendum B: HREC (medical) Clearance certificate

M140731

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140731

NAME: (Principal Investigator)	Dr Tanya Dennis
DEPARTMENT:	Department of Paediatrics Rahima Moosa Mother & Child Hospital
PROJECT TITLE:	Pregnancy in Adolescents with Perinatally Acquired Human Immunodeficiency Virus- A Description of Patient Profile and Experience in a Paediatric HIV Clinic in South Africa
DATE CONSIDERED:	25/07/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Karl Technau
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 25/07/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature M140731Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Addendum C: Participant information sheet and consent form

Participant Information sheet:

Pregnancy in adolescents with perinatally acquired HIV infection

Good day

My name is Tanya Dennis and I am doing research at Empilweni clinic at Rahima Moosa Mother and Child Hospital on being a young mother living with HIV. This research study is being done for my MMed degree at the University of the Witwatersrand. Research is the process of gathering information on specific topics to answer questions and in this study we would like to learn about your experience of having to live with HIV since you were a child as well as of having a baby while you were young.

I am doing this research to understand the challenges you experienced to be able to help other young girls in your situations in the future. Many young girls in South Africa have babies when they may not be completely ready to be a mother and for the responsibility that comes with looking after a baby. For young mothers who got HIV at an early age there is even more responsibility for themselves, their partners and their babies.

I would like to invite you to take part in this research study. If you agree to participate, it will involve a private interview with you and me on one of your clinic follow up dates. In the interview we will talk about things like your feelings about having got HIV when you were born and about what help or information you would have liked to have before you fell pregnant and when the baby was born. If you feel uncomfortable about answering any questions during the interview you do not have to answer. The interview will last about 30 minutes, but we can be shorter or longer depending on how you feel and what you want to tell us.

I would like to make an audio recording of the interview if you are comfortable with this. The audio recording is to make sure that when I report on what you have told me it is right and that I don't forget any important information. All information that we discuss will be kept private. The interview will take place at Rahima Moosa Mother and Child Hospital, close to where your usual clinic appointments are but not in the clinic or with any of the other adolescents or staff members of the clinic being present. All the young mothers at the HIV clinic will be asked to join in the study, if they are 18 years or older.

The interview might make you emotional or upset if you had a difficult time when you fell pregnant or when the baby was born. If this happens and you would like to talk to someone about it, I will arrange for you to meet with a psychologist or social

worker at the hospital to help you cope with whatever problems come up and I will also be there to help you take any steps of this kind.

Participating is completely voluntary and if you do not wish to participate it is not a problem at all, your decision will be respected and it will not affect your care in the clinic in any way. If you decide to do the interview and later decide that you don't want to, that is completely fine. Taking part or not taking part will not change the way you are treated at the Empilweni clinic. It is important that you know that there will not be any payment for joining in this study. If we are not able to do the interview on your clinic follow up date we will ask you to come to the clinic on another day, and in that case the cost of your transport will be covered.

I will make sure that no one aside from the people involved in the study knows what information you have given to us; it will be kept private. Any information about you will only have a code instead of your name to know whose it is. The audio recordings will be safely stored for between 2 and 6 years depending on whether the study is published or not, as this is required of me in doing this study by the Health Professions Council of South Africa. Your information will not be shared with anyone or used by anyone other than myself.

You can discuss anything on this information sheet with your family, partner or friends. If you have any questions about this study please contact me, and I will be happy to answer any questions about this research (0798739981). My supervisors can also be contacted for any further information: Dr K Technau (011 470 9421 during office hours) and Dr J Watermeyer (011 717 4578 during office hours).

If you would like to speak to someone else about this study, please contact Ms Anisa Keshav of the Wits Human Research Ethics Committee on 011 717 1234 or Anisa.Keshav@wits.ac.za

Thank you

Tanya Dennis

0798739981

tanyadennis37@gmail.com

Consent form

I understand what this study is about and have had all my questions answered.
I understand that taking part in this study is my choice and that if I decide not to, it will not cause any problems with the treatment I will receive at this hospital.
I understand that my interview will be audio recorded and I agree to this.
I understand that there is no payment if I decide to participate.

All information in this study is confidential and only the people involved in the study will have access to it. Nobody outside the clinic will have access to my name or identity at any time.

I have been given a copy of the information sheet and the consent form, which I have read, or its contents explained to me through an interpreter. I have had all my questions and concerns answered to my satisfaction by the clinic staff. I understand that I may refuse to participate in this study or withdraw at any stage without giving a reason for doing so and this will in no way influence the way I am treated in the clinic.

I, _____, agree / do not agree (delete appropriate) to be part of the Pregnancy in Adolescents with Perinatally Acquired HIV Study, for the study team to report the findings without my identity.

Client's signature: .....
Client's name: .....
Date: .....
Witness signature: .....
Witness name: .....