Depression scores in a cohort of HIV positive women followed from diagnosis during pregnancy to eighteen months postpartum

By Jennifer Dianne Makin

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Declaration

I hereby declare that this dissertation presented to the University of Pretoria for the Masters of Science in Clinical Epidemiology is my own work and has not been presented previously to any other tertiary institution for any degree.

Abstract

Depression scores in a cohort of HIV positive women followed from diagnosis in pregnancy to eighteen months postpartum.

Student: Jennifer Dianne Makin

Supervisor: Professor P Rheeder

Supervisor: Dr T Kershaw

Department: Faculty of Health Sciences

                    Clinical Epidemiology

Degree   MSc (Clinical Epidemiology)

Background Depression has been found in the literature to be a major problem in people living with HIV/AIDS. Not only does this impact on their daily functioning but has been shown to have negative HIV related outcomes, and result in poorer adherence to antiretroviral medication. The population under study was pregnant at the time of diagnosis. It would seem likely that their risk for depression would be greater than even a general HIV infected population, because of the pregnancy and the fact that they might have concerns around the health and future of the unborn infant. There are a limited number of studies looking at levels of depression over time and possible determinants of this depression even in a general HIV infected population. It was thus felt necessary to establish levels of depression and to establish if there were any factors associated with changes over time in this pregnant population.

Method Two hundred and ninety three women were recruited at antenatal clinics in Tshwane from June 2003 and December 2004. They were interviewed at approximately 28 weeks gestational age and were followed for 18 months after the birth. Data included socio demographic variables, a "self efficacy score", past history of violence, disclosure, CD4 count and

knowledge score. Psychological variables included measures of stigma, social support, self esteem and coping. Depression was measured using a modified CES-D (Center for Epidemiological Studies Depression Score) Repeated measures mixed linear analysis was used to assess if there were changes in depression scores over time and if there were factors associated with these changes.

Results Two hundred and twenty four women were included in the mixed linear analysis. The mean age of the women was 26.5 years (standard deviation -5.1). Seventy six percent (152) were single with a partner. Seventy six percent (171) had some form of secondary education and 14% (32) had some form of tertiary education. Sixty percent (135) lived in a brick house and 35% (79) had running water in the house. Twenty nine percent (64) had a per capita income below the poverty line.

The prevalence of borderline depression (CES-D scores above 12) for this group of women at baseline was 45%. There were significant changes in depression scores over time. This was not a linear relationship (significant quadratic time to interview term p=0.008). This was evidenced by the fall off in scores at 3-9 months followed by a subsequent rise. The factors associated with higher depression scores overall were lower active coping (p=0.004), higher avoidant coping (p=0.003), higher internalised stigma (p=0.001), higher housing scores (0.026), lower self–esteem (0.002), a history of violence (p<0.0001) and having no partner (p=0.005). No factors were associated with changes over time.

Conclusion There are significant changes in depression scores over time in this cohort of women Depression scores while falling after the birth of the child as in other cohorts, start to rise again. Although there are no specific factors associated with these changes, overall women who have a history of violence, who have no partner, who live in better housing circumstances, who have poor self esteem, who have high levels of internalized stigma and make use of negative coping strategies are more likely to be depressed. Women who make use of active coping strategies are less likely to be depressed. There are a large number of women at baseline who have scores considered to be diagnostic of borderline depression and because of the

potential negative consequences to the woman and child, an intervention aimed at addressing the above issues should be devised. This should start in the antenatal period and carry on beyond this time.

Abstrak

Depressie tellings in 'n kohort van MIV positiewe vroue nagevolg vanaf diagnose tydens swangerskap tot en met agtien maande na geboorte.

Student:	Jennifer Dianne Makin
Supervisor:	Professor P Rheeder
Supervisor:	Dr T Kershaw
Departement:	Fakulteit van Gesondheid Wetenskappe
	Kliniese Epidemiologie
Graad:	MSc (Kliniese Epidemiologie)

Agtergrond In die literatuur is gevind dat depressie 'n ernstige probleem is vir mense wat met MIV/VIGS saamleef. Nie alleen word hul daaglikse funksionering daardeur geïmpakteer nie, maar dui dit ook op negatiewe MIV verbandhoudende uitkomste en 'n minder getroue gebruik van antiretrovirale medikasie. Die populasie in die studie was swanger tydens hul diagnose. Die verwagting is dat hul risiko vir depressie moontlik groter behoort te wees as die algemene MIV geïnfekteerde populasie, hoofsaaklik omrede hul swangerskap en die feit dat hulle miskien bekommerd mag wees oor die gesondheid en toekoms van hul ongebore kind. Daar is 'n beperkte aantal studies wat die vlakke van depressie oor 'n tydperk navolg asook studies wat kyk na die moontlike determinante vir depressie in selfs 'n groter algemene MIV geïnfekteerde populasie. Om die rede is die noodsaaklikheid geïdentifiseer om vlakke van depressie te bepaal en te bepaal of daar enige faktore geassosieer kan word met veranderinge oor tyd in hierdie swanger populasie.

Metode Twee-honderd-drie-en-negentig vrouens is gewerf by voorgeboorte klinieke in Tshwane tussen Junie 2003 en Desember 2004. Hulle onderhoude het plaasgevind op ongeveer die 28ste week van swangerskap en

hulle is weer opgevolg 18 maande na geboorte. Die ingeslote data sluit sosiodemografiese veranderlikes in, 'n 'self bekwaamheid telling', vorige geskiedenis van geweld, bekendmaking van MIV status, CD4 tellings en verstaan van die tellings. Sielkundige veranderlikes wat ingesluit is, is stigma-, sosiale ondersteuning-, selfwaarde en hantering skale. Depressie is gemeet deur gebruik te maak van 'n gemodifiseerde CES-D (Center for Epidemiological Studies Depression Score). Herhaalde gemengde liniêre analise meting is gebruik om te assesseer of daar veranderinge in depressie tellings oor tyd was en of daar faktore geassosieër is met die veranderinge.

Resultate Twee honderd vier en twintig vroue is ingesluit in die gemengde liniêre analise. Die gemiddelde ouderdom vir die vrouens was 26.5 jaar (standaard afwyking-5.1). Ses-en-sewentig persent (152) was ongetroud met 'n maat. Ses-en-sewentig persent (171) het 'n tipe vorm van sekondêre opleiding gehad en 14% (32) het 'n vorm van tersiêre opleiding gehad. Sestig persent (135) het in 'n baksteenhuis gebly en 35% (79) het lopende water in die huis gehad. Nege-en-twintig persent (64) het 'n per capita inkomste onder die broodlyn gehad.

Die voorkoms van grenslyn depressie (CES-D tellings hoër as 12) vir die groep vroue met die begin van die studie was 45%. Daar is betekenisvolle veranderinge in die depressie tellings oor tyd. Hierdie was nie 'n liniêre verwantskap nie (betekenisvol kwadratiese tyd tot onderhoud termyn p=0.0008). Hierdie is aangedui deur die vermindering van tellings op 3-9 maande gevolg deur 'n verhoging van tellings. Die faktore geassosieer met die hoër depressie tellings was in geheel laer aktiewe hantering (p=0.004), hoër vermydende hantering (p=0.003), hoër geïnternaliseerde stigma (p=0.001), hoër behuising tellings (p=0.026), laer selfwaarde (p=0.002), 'n geskiedenis van geweld (p<0.0001) en nie 'n lewensmaat te hê nie (p=0.005). Geen faktore is geassosieer met veranderinge oor tyd nie.

Gevolgtrekking Daar is betekenisvolle veranderinge in depressie tellings oor tyd in hierdie kohort van vroue. Terwyl die depressie tellings daal na geboorte van die kind soos in ander kohorte, begin dit weer te verhoog

daarna. Alhoewel daar geen spesifieke faktore geassossieer kan word met die veranderinge nie, blyk dat vroue wie 'n geskiedenis van geweld het, geen lewensmaat het, wie in beter verblyf omstandighede woon, wie 'n swak selfbeeld het, wie hoë vlakke van geïnternaliseerde stigma het en wie gebruik maak van negatiewe hantering strategieë meer geneig is om depressief te wees. Vrouens wat gebruik maak van aktiewe hantering strategieë is minder geneig om depressief te wees. Daar is 'n groot hoeveelheid vrouens met aanvang tellings toon wat oorweeg kan word om diagnosties te wees van grenslyn depressie. As gevolg van die potensiële negatiewe gevolge vir die vrou en kind, moet 'n intervensie ontwikkel word wat die bogenoemde probleme sal aanspreek. Die intervensie moet 'n aanvang neem in die voorgeboortelike periode en voortgaan daarna.

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Chapter 1

Literature Review

Introduction

Depression is a major mental health disorder. It is associated with disability and poor quality of life for the individual and high costs for society as a whole. In 2000 depression was found to be the fourth most common cause of global disease burden and in fact, it is predicted by the World Health Organization, that by 2020, depression will become the second most common cause of disease burden [1, 2].

It is a disorder characterised by feelings of constant sadness, loss of interest or pleasure in life, guilt feelings, low self esteem, disturbed sleep and appetite, inability to concentrate, lack of energy and suicidal ideation [3,4,5]. Terms that are used synonymously with depression are the following: - major depressive disorder, major depression, unipolar depression, unipolar disorder, or clinical depression [6,7]. In this literature review, I will refer to three other "presentations" of depression that, while having similar symptomatology, as described above, differ in terms of timing, perception and severity. These conditions are dysthymic disorder, postpartum depression and adjustment disorder. Dysthymic disorder, also known as dysthymia, is characterized by similar symptoms, which have been present for two years or more, which are less severe and less disabling than the depression described above [7]. Post partum depression encompasses the same symptomatology, but occurs within one month of delivery [8]. Adjustment disorder differs from depression in that the affected person can identify an external causative factor or event and is able to feel pleasure normally if distracted from thoughts of this event. People that are affected with adjustment disorder tend not to feel diminished self esteem and are able to separate themselves from the event causing their distress [5]. The literature included in this review does not attempt to distinguish between adjustment disorder and depression.

Depression in general

Diagnosis and screening

The diagnosis of depression is most often made by using the criteria found in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV-TR) produced by the American Psychiatric Association or the International Statistical Classification of Diseases and Related Health Problems produced by the World Heath Organization [8,9]. Rating scales are also used as part of the DSM-IV and measure the overall severity of illness, these being, the Global Assessment of Functioning Scale and the Social and Occupational Functioning Assessment Scale [8].

Several other rating scales are used in research or as screening tools to detect depression; the main purpose of these scales is not to diagnose depression but to establish the presence and severity of symptoms of depression. In this literature review use has been made of multiple scales. Most of the scales have cut off scores above which a diagnosis of depression is considered likely.

Prevalence

It is estimated that 121 million people worldwide are affected by depression [4], 20% of the population will have an episode of depression at some time during their lives [3,9]. There is very little literature on the prevalence of depression in South Africa. A study in rural KwaZulu-Natal found the weighted prevalence for general anxiety and depressive disorders to be 24% (depressive disorders-20%, and anxiety disorder-4 %) which compares with rates of 31% in a sample of found in Zimbabwe by Abas and Broadhead [11,17]. Kleintjies et al., derived estimates of the overall adult prevalence of 25% of mental disorders in the population of the western Cape, by means of consensus informed by a systematic literature review. The prevalence rates for both depression and dysthymia were estimated to be 15% [12].

Associated factors

Many factors are associated with the development of depression. Most experts believe that both biological and psychosocial factors play a role in causing depression, often described as the "biopsychosocial model" [7]. Associated factors tend to overlap and interact so the causes depend on the individual's circumstances. Genetic predisposition, early childhood experiences, a history of a psychiatric disorder, psychosocial factors, coexisting disease and "neurobiological" factors have all been implicated in the development of depression [10,13].

- Twin studies have shown that there is a 60% risk of one twin developing recurrent depression if the other has the condition, indicating a genetic link [14].

- Early childhood loss of a mother, but more particularly, inadequate parental care has been shown to predispose a person to the development of depression [10]. It has also been shown that the children of women who are depressed are themselves more likely to be depressed [15].

- Psychosocial factors that appear to be of importance in the development of depression are poor socio-economic status, being single, perceived level of social support and exposure to stressful life events [17]. Stress and depression can form a vicious cycle, which can be broken by social support, support from the partner and by a sense of belonging [1].

- Neuroendocrine, neurochemical and pathological changes have been found in patients with depression. Stress has an effect on the hypothalamic-pituitary-adrenal axis (HPAA), which has been shown to be different in those with depression. These changes are that of hypercortolism and adrenal hyperplasia. Raised levels of cortisol have been found in animal models to be associated with neuronal damage within the hippocampus, also demonstrated in some depressed patients. Treatment with anti-glucocorticoid drugs has shown good effect in those patients with hypercortolism, lending support to the idea that HPAA dysfunction plays a role in some

patients. It is also postulated that depression may be due to monoamine deficiency and support has been lent to this theory by neuroimaging techniques that have shown decreased dopamine release in the striatum of depressed patients. Neuro-imaging techniques demonstrate atrophy in brain structures in people with depression, particularly the hippocampus, as mentioned previously, and in the fronto-striatal area [10].

- Depression is twice as likely to affect women as men and is most likely to occur in the childbearing years from 15 to 44 [2]. In 2000 depression was second to HIV infection as a cause of years lost to disability in South African women [2]. Worldwide it is the leading cause of disease-related disability in women [15]. The gender differences emerge at puberty [15]. A number of theories have been put forward as to why there is a gender difference, these include women approaching problems in a more "ruminative" way; increased numbers of women working has led to a redefining of women's role; more women are single parents and have to deal with issues of poverty; and the demands of multiple roles [15]. In South Africa where women for the most part live in a patriarchal society, they are more exposed to factors which are potentially "depressogenic" such as lower education levels and the associated lower wages if they are employed, poverty, discrimination, violence, HIV infection, unwanted pregnancies, childbirth, single parenthood, childcare and other caring roles [2].

Depression in the antenatal and postpartum periods

Antenatal depression

Pregnancy and the postpartum period are times in a woman's life where there are large hormonal, physical and potential changes in a woman's social circumstances, which may make her vulnerable to the development of depression [16].

Prevalence

Prevalence rates in the literature from other parts of the world range from 10-25% [16,18-23]. Bennett et al reviewed 40 studies and found the prevalence rates of depression in the first trimester were similar to those of non-pregnant women but then increased to almost double in the second trimester and remained at this level during the third trimester [16]. Rochat et al, found in a group of pregnant woman waiting to undergo HIV testing, a rate of 41%, in KwaZulu, Natal [24]. This is however a biased sample as many of these women were possibly anticipating an HIV positive diagnosis and were thus more likely to be depressed.

Associated factors

A summary of factors that appear to be associated with antenatal depression are listed in Table 1 and 1a using the classification system of Ryan and Milis [25].

Table 1. Factors associated with antenatal depression
Biological factors

Biological factors	Reference
1. Familial psychiatric history	25,26
2. Premenstrual dysphoric syndrome	25
3. Previous mood disorders	25,27
4. Previous postpartum depression	25

Table 1a. Factors associated with antenatal depression
Psychosocial factors

Psychosocial factors	Reference
Holding negative self beliefs	28
Dissatisfaction with level of perceived social support received from others resulting in the use of avoidant coping strategies	29, 26
Worries about the health of the future infant	20
History of childhood abuse	25
Low level of education	25, 20, 19
Younger age	25
Not being married	25, 20
Marital conflict	20. 25
Unemployed, lower occupational status	25
Low family income	19
Stressful life events	25, 20
Higher parity	25
History of previous abortion	19
Unplanned/unwanted pregnancy	20, 25
History of some form of violence	25
Substance abuse and smoking	25

Consequences of antenatal depression

Antenatal depression may have negative consequences for the mother and her foetus/ infant. Lindgren et al, found that antenatal depression was a significant predictor of poor maternal-foetal attachment, which begins during pregnancy. This in turn predicted poor health behaviour on the part of the mother [22]. This is borne out by Patel et al, who, in study, in South East Asia, found depression is associated with poor antenatal clinic attendance and risk taking behaviour such as smoking and unhealthy eating [30]. Clearly this can have consequences for the health of the mother and foetus. In an evidence-based review by Alder et al, elevated levels of depressive symptomatology were found to be associated with increased numbers of pregnancy symptoms experienced by the women, increased preterm labour, increased requirements for pain relief in labour and an increased number of obstetric complications [31]. It appears that the effects of antenatal depression may not just be confined to the antenatal intrapartum and postpartum periods but may have long-term consequences for the child. Luoma et al., found that antenatal depression was a very strong predictor of emotional problems in a group of 8 to 9 year old children as detected by the Child Behaviour Checklist [32].

Postnatal depression

Prevalence

Antenatal depression is the strongest predictor of postpartum depression. Several studies have shown that almost half of the women who are depressed in postpartum period were also depressed in the antenatal period (44%-54%) [18, 33]. The prevalence of postpartum depression appears to vary greatly from site to site. Figures from developed countries indicate a rate of 10-15% but in a review of the literature by Halbreich et al, where 143 studies from 40 countries were identified, the prevalence ranged from 0 to 60 % [34]. Potential reasons for this variation are biological differences, socio-economic differences, how mental health is viewed in different communities, the possible stigma associated with poor mental health, differences in how symptoms are reported and possible cross-cultural differences [34]. It must be noted that this applies to depression at all stages.

As relates to postpartum depression in South Africa, a study done by Cooper et al, found a rate of 35% in a group of 147 women in Khayelitsha in Cape Town who had delivered two months earlier [23]. This is similar to a study done in women of low socio-economic status in Montreal by Segun et al [35].

It is interesting to note that while it is assumed that the postpartum period is a time of high risk for the development of depression, several studies have shown that rates of depression may be higher antenatally and may fall after birth, or, that there is no difference between the postpartum and antenatal periods [20,36-38].Eberhard-Gran et al, in a study on 416 women in Norway, did not find a significant difference in prevalence between the first four months postpartum and the three trimesters of pregnancy, or the rest of the first postnatal year [39].The duration of postpartum depression also seems to vary from study to study with some authors finding that postpartum depression had remitted by 4 –12 months [40]. Others found that 14% still had symptoms at 1-year postpartum and others found that more women were depressed at 9 months postpartum than at 3 months [21,41].

Associated factors

A summary of factors that are associated with postpartum depression are shown in Tables 2 and 2a. As can be seen many of the associated factors are similar to those associated with antenatal depression.

Table 2. Factors associated with postpartum depression
Biological factors

Biological factors	Ref
Previous history of depression	18, 27, 21, 26, 32, 42 30
Family history	26
Maternal personality characteristics Nervous, shy, worry	26
Low self esteem	21,42
Physical health	32
Previous psychiatric history	26, 21

Table 2a. Factors associated with postpartum depression
Psychosocial factors

Psychosocial factors	Ref
Stressful life events	27, 21, 42 43
Obstetric complications pre-eclampsia preterm labour Caesarean section, instrumental delivery	26
Social support particularly from partner	21,23, 26, 27, 30, 39
Lower income resulting in a lower sense of control over life	26,27,30
Lower occupational status	27
Early parental divorce	27
Conflicting interpersonal relationships especially marital	21, 27, 42 44
Unemployment	21
Low education	21, 26
Polygamy	45
Multiparity	45
Smoking	45
Single status	21, 43, 46
Unplanned pregnancy	21, 43, 46
Infant temperament	21, 32, 42
Child care stress	21
Bottle feeding	46
Prenatal anxiety	42
Female gender of infant	47
Maternity blues	42
Maternal ill health	32

A hypothesis that postpartum depression is not necessarily a unique entity that occurs because of childbirth but just occurs incidentally after this time is supported by the following: -:

1. The most significant predictor of postnatal depression is depression in the antenatal period and many of the associated factors in both periods are similar [18, 33].

2. In some longitudinal studies there is no increase in depression postpartum [20,36-39].

Consequences of postpartum depression

Postpartum depression, as with antenatal depression has a number of negative outcomes, for example, poor maternal-infant bonding [18]. It has been found that depressed women give less and poorer quality of stimulation to their infants, they are slower to respond to their infants and the actual response is decreased [30]. This possibly explains why postnatal depression is associated with long-term behavioural and cognitive problems in children [27, 30]. In a study in Khayelitsha, mother-child interactions in those who were depressed were characterised by maternal insensitivity and infant disengagement when compared to a non-depressed group [23]. A study in Jamaica demonstrated that depressed mood, low self-esteem, inadequate parenting and an inability to provide a suitably stimulating environment for the child is associated with undernutrition in children from 9 to 30 months [48]. In studies in India and Pakistan, maternal mental distress was found to be a risk factor for malnutrition in the 6 to 12 month age group (adjusted odds ratio ranged from 2.3- 7.4) [30]. Depression may also affect the woman's ability to perform her daily activities and affect relationships with those around her [18]. These women are also at risk for recurrence of the depression [21].

Depression and HIV

Prevalence of HIV/AIDS

In the 2007 UNAIDS report it was estimated that 33.2 million people are infected with HIV, 15.4 million of these are women and 2.5 million are children. Worldwide the prevalence of HIV is 5 % but in southern Africa this is more than 15%. Sixty one percent of individuals affected in sub-Saharan Africa are women [49]. Women in the childbearing years are most affected. In 2005 in South Africa, it was found that there was a HIV prevalence of 9.4% in the 15-19 year age group, 23.9% in the 20-24 year age group and this peaked in the 25 to 29 year age group at 33.3% [50]. In the 2005 South African sero-prevalence survey performed in antenatal clinics in the public sector, the rate was found to be 30%. This dropped to

29% in 2006 [50] There are thus a large number of women who are affected by HIV and thus potentially vulnerable to depression.

Prevalence of HIV related depression

Depression in HIV-infected people has been shown in many studies to be significant with reported prevalence rates varying from 0-71% [50,52-60]. Potential reasons for this wide variation are: the different populations studied; the settings in which the studies were performed; and the methods used to make the diagnosis of depression [51]. Lower rates of depression tended to be found in white, mainly homosexual male cohorts and higher rates of depression in heterosexual cohorts with differing ethnic and socio-economic backgrounds [52]. As noted previously, there are a number of instruments used to measure both depression and its symptomatology.

Several studies have shown rates not dissimilar to those associated with other chronic diseases [53, 54]. Ciesla and Roberts, in a metanalysis of 10 studies found that the rate of depression in HIV-infected individuals was almost twice that of comparative HIV-negative individuals [55]. The HIV Epidemiologic Research Study (including 1310 HIV infected and non-infected women) found that the women did not differ with regard to depressive symptomatology or negative life events [53]. This suggests that in the early stages of HIV disease, the socio-demographic factors were more likely to predict depressive symptoms than HIV infection itself. A second study including 170 men found that the one- year prevalence rate for depression was 37% in HIV-infected men compared to 15% in the HIV-uninfected men and although the former study was looking at severity of symptomatology and the latter at rates of depression, this does tend to illustrate the differences between populations, in this case - men and women [56].

Studies from South Africa have shown high rates of depression in HIV-infected individuals. Shisana et al., in the 2005 found that 41.8% of HIV infected individuals were depressed compared to 29% of the general

population [50]. Olley et al., found in a group of 149 HIV infected men and women attending an infectious diseases clinic at Tygerberg Hospital, that 34% were depressed [57]. Leickness et al., found similar rates of 30% in a study in Cape Town involving 1663 HIV positive men and women [58]. Several studies have shown that HIV infected women tend to be at greater risk for the development of depression than HIV infected men [56, 57, 59, 60]. Rates given vary from 30-75%.

Depression diagnosis in HIV infected individuals

The diagnosis of depression in the face of HIV infection can present a challenge. Asche et al., compared depression screening of HIV infected individuals with what was recorded in their medical records and found that, in only 45% of those who had depression as detected by the screening had the diagnosis made and recorded [61]. A possible reason for this under-diagnosis is the tendency for the healthcare provider to "normalise" the condition, seeing it as the expected reaction to the condition. [62]

Depression in an HIV infected individual can be seen as either primary or secondary. Primary depression can be seen as being due to so-called major depression, and other psychiatric disorders e.g. bipolar disorder and adjustment disorder. Secondary depression might be the result of HIV encephalopathy, other central nervous system infections, medication effects e.g. Isoniazid and Efavirenz, substance abuse and Hepatitis C invasion [62,63]. Symptoms, such as weight loss, fatigue, neurocognitive changes e.g. memory impairment, a reduced ability to concentrate and motor retardation may be seen in both primary and secondary depression making the diagnosis difficult [62].

Associated factors

Factors associated with depression or levels of depressive symptomatology in HIV infected people are shown in Table 3

Table 3. Factors associated with depression or levels of depressive symptomatology in HIV infected individuals

Study	Comment	Ref	Measure	Type of study
Perceived social support	Includes men and women	60	CES-D	Cross sectional
Illicit drug use, stress diagnosis by the attending physician, being in a relationship was protective.	Includes men and women	64	Inventory to diagnose depression	Cross sectional
Perceived stress, social isolation, avoidant coping, positive partner support	Includes pregnant women	65	CES-D	Cross sectional
"Escape avoidance coping", less social support, more life stressors, "less planful problem solving"	Includes women	59	CES-D	Cross sectional
Perceived level of support determines the type of coping style, low support =high avoidant coping and this affects depression symptomatology, HIV symptom burden	Includes men and women	62	CES-D	Longitudinal
Social conflict, perceived social integration	Includes women	67	CES-D	Cross sectional
Personality style, past psychiatric history, stressful psychosocial situation	Includes men and women	68	Beck Depression Inventory	Cross sectional
Older person, female, white	Includes men and women	69	Depression Minimum Data Set	Cross sectional
No longer being in a relationship with the previous partner venting coping mechanism	Includes postpartum women	53	CES-D	Cross sectional
Low socio-economic status, illicit drug use, high risk sexual behaviours	Includes women	53	CES-D	Cross sectional
Previous psychiatric history, poor support, recent diagnosis of HIV, recent diagnosis of AIDS	Includes men	56	DSM-III	Longitudinal
Internalised stigma	Includes men and women	58	CES-D	Cross sectional
Low CD4 count, no income female gender, Age >50	Includes men and women	69	CES-D	Cross sectional
Illness, fear of death, poverty, social isolation as a result of stigma– outcome chronic sorrow	Includes men and women	70	CES-D	Cross sectional
Stigma	Includes men and women	53	CES-D	Cross sectional
Female gender and negative life events	Includes men and women	53	Mini International Neuropsychiatric Interview	Cross sectional

Many of the factors in the table are not specific to HIV/AIDS but probably accentuated by the disease.

Depression over time

As can be seen, most of these studies are cross sectional, which poses a problem, as the risk of depression varies over time and it is to be supposed that there are factors that are associated with changes over time. In the few longitudinal studies, results are mixed as to whether depression levels or symptoms increase, decrease or remain constant over time. In a longitudinal study of 765 HIV- positive women who were followed for 5 years, it was found that the levels of depressive symptoms were high at baseline and although there was a decrease of approximately 2 points on the CES- D scale over 5 years it can be said that levels remained relatively constant over this time. Partner conflict, whether it be of a violent nature or not was associated with depression and it was associated with changes in depression symptoms over time [71]. In another study comparing HIV infected and HIV negative men who were not depressed or anxious at the time of entry to the study, Atkinson et al., found over a 2 year period, that 26% of HIV infected men had developed depression compared to 23% of HIV negative men. A history of major depression or of lifetime psychiatric co-morbidity (2 or more psychiatric conditions) predicted a subsequent major depressive episode. Those who had symptomatic HIV disease at baseline were more likely to develop depression [72]. Olley et al, found in South Africa, that in a group of 65 patients recently diagnosed as HIV positive, 15% of patients were depressed at baseline but by 6 months, 55% of these patients were no longer depressed. Eight percent of the patients who were not depressed at baseline were depressed at 6 months. Depression at 6 months was significantly associated with problems in the patient's work, social or family environment [73]. Guring et al., followed a group of 221 HIV infected women and 129 HIV negative women for 6 months, to assess the relationship of socioeconomic status and chronic burden (defined as "ongoing difficulties in major social roles"). They found that HIV status and ethnicity were associated with depression at each time point but not with

changes over time. Chronic burden and low socioeconomic status were significantly associated with changes in depression. Guring et al, felt that this was possibly due to the fact that sero-positivity increases the possibility of developing depression in its own right, it also increases the burdens that these women already face. HIV infected women who experienced higher levels of chronic burden had larger increases in levels of depression. [74]. No mention was made in this article as to changes in depression score over time. Gibbie, in a 2 year follow up study in Australia of HIV infected individuals found a decrease in depression symptoms and related this to the use of highly active antiretroviral therapy [75].

Consequences of depression in HIV disease

Depression and high levels of depressive symptoms are associated with a number of negative outcomes. Chronic depressive symptoms have been shown to affect the quality of life of HIV infected individuals. In a study by Tate et al., it was found that 80% of the 45 HIV infected individuals had decreased quality of life as measured by all aspects of the Shortform 36 form [76]. One of the contributing factors to this impaired quality of life may have been fatigue, which is associated with both sleep dysfunction and depression [77]. In a study assessing the quality of life in 82 American HIV infected women, Cowdery et al., found that even in asymptomatic women Quality of Life Scores (MOS-SF) were below that of the general population and similar populations with other chronic diseases. The mental health score, which forms part of the total sore was relatively low (59/100) and was thus a potential contributor to these low scores [78].

Chronic depression has been shown to be a potential risk factor for increased morbidity and mortality. Leserman in a recent review article of 20 longitudinal studies on HIV disease progression found "consistent and substantial evidence" that depression, stressful events and trauma affect progression as measured by increases in viral load, decreases in CD4 counts, accelerated clinical decline and increased mortality [79]. Chronic depression is also associated with poor adherence to medication which can have

consequences in terms of the patient's health, may result in earlier death, and the development of drug resistant strains of the virus [33,80,81,82]. Chronic depression may also be associated with sexual risk taking behaviours a finding that applies to both HIV infected and negative groups [77,83]. This clearly has implications for the spread of the disease.

A woman who is diagnosed as being HIV-infected during pregnancy is potentially, much more vulnerable to the development of depression, than a women who is diagnosed at a different time, as she has to deal with the additional concerns about her unborn infant [84]. This is illustrated in a study by Kwalombata in Zambia where 40 women who has discovered their status during pregnancy were questioned regarding the presence of depressive symptomatology and suicidal thoughts. All of these women felt they were harming the foetus, and had thought about terminating the pregnancy, 95% experienced depressive symptoms and 100% had continual suicidal thoughts [85].

Motivation for the study

If an HIV infected pregnant woman does become depressed there are potential consequences in the antenatal, intrapartum and postnatal periods as described previously, in addition to the consequences of simply being HIV positive. As already mentioned there are very few studies that look at the changes in depression over time and what predicts these changes especially in women who learn of their diagnosis during pregnancy. In a country where mental health services are poor, and where there are large numbers of women diagnosed during pregnancy it was felt important to assess the magnitude of the problem in Tshwane and establish if there are associated factors that could be addressed by some form of intervention.

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Chapter 2

Aims and Methods

This is a sub-study of the larger longitudinal study (Serithi Project) where HIV-positive pregnant women who were diagnosed during pregnancy were followed for twenty-four months postpartum to establish factors impacting on the women's infant feeding choices. For this sub-study, data were obtained from interviews conducted at approximately four weeks after diagnosis and then, at 3 months, 9 months and eighteen months postpartum. Data were collected on certain demographic, psychosocial and medical variables at each interview. The outcome of interest was the scores obtained from the data collected for the Center for Epidemiologic Studies Depression Scale (CES-D), which measures the severity of women's depressive symptoms. By making use of mixed linear modelling the changes in depression scores from pregnancy to eighteen months postpartum and possible associated factors were assessed.

Aims of the Study

1. To establish the severity of depressive symptoms in a cohort of HIV positive pregnant women followed over time.
2. To determine what factors are associated with these depressive symptoms and, if these vary over time.

It was hypothesised that socio-economic factors, violence, self-esteem, the woman's ability to make her own decisions as measured by a so-called "self efficacy" score and coping ability would affect depression scores overall and that stigma, disclosure, and negative life events might be associated with changes over time.

Study design

Longitudinal study.

The Serithi Project was an NIH funded study that was run under the auspices of the MRC Unit for Maternal and Infant Health Care Strategies. It was set up in October 2002 to attempt to understand the role of stigma and its effect on the women's infant feeding choices and disclosure in women newly diagnosed as HIV positive during pregnancy. This is a sub-study utilising the CES-D score used to measure the severity of women's depressive symptoms.

Setting

Women were recruited from three antenatal clinics in Atteridgeville and one in Mamelodi (Tshwane). Recruitment took place from June 2003 to December 2004.

Patient selection

Inclusion Criteria

1. Pregnant women who tested HIV positive during the current pregnancy who consented to be part of the study at the four clinics involved in the study.

Exclusion Criteria

1. Women less than 15 years old.

2. Women testing HIV- positive prior to the current pregnancy.

3, Women who indicated they were likely to move away from Tshwane during the study period.

Measurements

See Appendix 1 for a copy of the interview.

Development of the questionnaire

The research team consisted of members of the Departments of Psychology from Yale University and the University of Pretoria, members of the Departments of Sociology, Obstetrics and Gynaecology – University of Pretoria, members of the MRC Unit for Maternal and Infant Health Care Strategies - University of Pretoria, a member of the Immunology Clinic at

Kalafong Hospital and a member of the Paediatrics Department and Center for International Research on AIDS (CIRA) - Yale University.

Initially focus groups were held with healthcare workers from Kalafong Hospital and members of the Atteridgeville community to identify themes that needed to be addressed in the questionnaire. Making use of this information, information from the literature and extensive consultation with all the members of the research team, the questionnaire was compiled and covered the following themes: -

1. Medical

    - Pregnancies past & present
    - Contraception history
    - Feeding intentions
    - Staging of HIV disease.

2. Demographic information
3. Family relationships

    - Partners background
    - Woman's work and financial status
    - Woman's ability to make decisions in the household (self efficacy)

4. Personal experience of HIV testing and diagnosis
5. Experiences around disclosure
6. Stigma
7. Experience of violence
8. Social support
9. Knowledge of HIV/AIDS
10. Self-esteem
11. Depression
12. Coping.

The three month, nine month, and eighteen month interviews were similar to the baseline interview but also included specific questions on change in the women's living, marital, employment and financial situation. There was a

staging examination of the mother at each interview. The post-partum interviews all included questions on infant feeding and the infant was examined at these points.

Dried blood spot PCR testing to determine the infant's HIV status was done at 3 days, six weeks and at 3 months postpartum.
CD4 counts were done in pregnancy and at 3months.

Members of the African Languages Department, at the University of South Africa, translated this interview into Afrikaans, Sepedi, Tswana and Zulu. It was then piloted by members of the interview team, using 30 pregnant women at the same clinics as the main study, to determine if it was understandable, whether it was too lengthy and whether the three / four point scales were easy for the women to interpret. Using the information gleaned from these pilot interviews the questionnaire was adjusted.

Research assistant training and quality control

Prior to the start of the study all the research assistants underwent a training course that consisted of sessions providing information on HIV/ AIDS, interviewing skills, basic information on how to do research and the importance of meticulous data collection and sessions devoted to the administration of the questionnaire itself. Those research assistants (midwives) who were to do the medical examinations were instructed on how to perform a staging examination. Senior researchers from both Yale and Pretoria Universities conducted these sessions. The training sessions on the questionnaire were repeated on two further occasions during the study. In the initial phases of the study one of the senior researchers with a knowledge of the interview languages sat in on a number of the interviews conducted by each research assistant to assess their competence. Problem issues were then brought to the research assistant's attention. If, at entry of the data, any problems were detected this was brought to the attention of the respective research assistant and she/he was requested to adjust as necessary.

Voluntary counselling and testing (VCT) counsellors

The VCT counsellors that assisted in the recruitment of these women were given training on the purpose of this research and the process of recruitment. Although they had received training in all aspects of counselling, once they were assigned to a clinic by the local authority, it was felt that this was not necessarily adequate, so they received additional information on HIV/AIDS and all aspects of prevention of mother to child transmission relevant to counselling of a pregnant woman. The Serithi Project paid the counsellors a small monthly stipend for the duration of the recruitment phase.

Process

Pregnant women who attended the antenatal clinics were informed in group sessions, about the possibility of undergoing HIV testing. If they chose to undergo testing, they were counselled by a VCT counsellor regarding the test and then, if they agreed, testing was performed by a VCT nursing sister. The woman was then referred back to the counsellor with the result for post-test counselling. This is standard procedure at the clinics for all patients undergoing testing. It was at this point that the woman was informed of the Serithi Project and if interested, was asked for her contact details and given an appointment to speak to a research assistant. Where possible this was made for four weeks after the testing, this was not always practical as it depended on the gestational age at which the woman tested. The woman was phoned prior to the appointment and asked if she was still interested in the project. If she was, she was asked to come to the relevant building in the clinic on the specific day.

At the appointment, the research assistant provided the woman with more detailed information about the project and, if she agreed to participate, written informed consent was obtained. The baseline interview (which lasted approximately an hour) was then administered. An appointment card with Serithi contact numbers was issued to the women and she was requested to phone, once the baby was born or to come to the clinic on the specific day when the Serithi team was visiting the particular clinic (as close to the date of birth as possible). The women and the neonate were either

seen at the clinic or if possible a research assistant would visit the woman in the hospital after the birth. A short questionnaire, as previously mentioned, was administered, the PCR test performed on the neonate and appointments were then scheduled for all subsequent interviews and written in the woman's appointment card.

Prior to each interview the woman was phoned to remind her of her upcoming appointment. If the woman did not attend her appointment she was again phoned. If a woman did not have access to a telephone and did not attend her appointment, or was not contactable by phone either, a research assistant or a VCT counsellor visited her at her home. The woman was informed that this would happen, should she not attend her appointments, as part of the informed consent.

Women were given money for transport at each visit.

Any medical or social problems found at any of the visits were referred to the relevant persons or institutions.

Data management

A user-friendly database was created, making use of MS Access 2000 database (Microsoft Corp., Redmond, WA) for input of all the data. There were two people responsible for data entry, the author and a research assistant with experience of data entry. In order to ensure accuracy of data entry, periodic checks of the data entered into the database, were performed. The data were exported to Excel, checked for any obvious errors, edited and then exported to SPSS for Windows Version 16 (SPSS Inc, Chicago, IL, USA) for analysis.

Data Analysis

Variables

Independent and dependant variables used in the analysis are shown in Table 1. Time varying covariates are those variables that were likely to change and were assessed at each interview ("Y"=yes, "N"=no).

Table 1: Variables included in the analysis

Independent variables (explanatory variables)	Time varying covariate
Socio-demographics of the woman	N
• Age	N
• Schooling (none secondary tertiary)	N
• Marital status	Y
• Housing and amenities (housing score)*	Y
Woman's position in the family relating to decisions and financial status	
• Self efficacy score*	Y
• Woman's employment	Y
• Partner employment	Y
• Financial support from partner	Y
• Per capita income	Y
Questions regarding disclosure	
• Disclosure status	Y
Assessment of levels of stigma *	
• Internalised	Y
• Attributed	Y
History of previous violence *	N
• Emotional	
• Financial	
• Physical	
• Sexual	
Support score positive*	
• Practical support	Y
• Emotional support	Y
• Affirmational support	Y
Support score negative	Y
Knowledge score*	N
Self esteem score *	Y
Coping Active *	Y
Coping avoidant	Y
CD4 count	Y
Life events**	Y

- *Scales/ scores discussed in next section
- **Scales/Scores and other measure requiring explanation

Explanation of scales/scores

Housing score (Score 0-5)

Five questions were asked regarding the type of materials the house was made of, the source of water, and the type of toilet facility, whether there was electricity in the house and whether there was a fridge in the house. A score of "1" was assigned for each of the following: - if the house was built of bricks or cement, there was running water inside the house, there was a flushing toilet, the house had electricity and there was a fridge.

Self-efficacy score (Score 0-7)

Members of the research team developed this score. Seven questions were asked about who in the household, made decisions regarding the purchasing of food, the way money was spent, decisions about the woman's health, the infant's health, whether to have another infant, sex and contraception. If the woman made the decision or it was made jointly with others in the household, a score of "1" was assigned for each item. Internal consistency was adequate (alpha=.62).

Stigma scale (Attributed 0-12. Internalised 0-12)

From the work in this project, two scales were developed to measure the "internalised" stigma this being the stigma the woman feels within herself and the "attributed" stigma this being the stigma that the woman attributes to others [1]. Results showed adequate internal consistency for internalised (alpha=.70) and attributed stigma (alpha=.77).

Social Support (Positive 0-27, Negative 0-9)

This was measured by making use of the Multidimensional Social Support Inventory (MSSI) a scale developed by Bauman and Weiss [2]. This was adapted to create a 9-item scale, which assessed affirmational, emotional and practical support providing the positive support scale. For each item the woman was asked if she received support and if so how much support she received. This ranged from a '3' if she received all the support she needed to '1' if she received a small amount. There were 3 questions included under

each type of support giving a total of nine questions. Results showed good internal consistency (alpha= 0.87).

Negative support included 3 questions on the negative aspects of support such as be treated like a child, getting too much unwanted advice and that people were too protective. This was scored as a '3' if this happened as all of the time and as '1'if this happened occasionally.

Results showed an adequate internal consistency (alpha=0.60).

Self-esteem (0-40)

This was measured by making use of the Rosenberg Self-Esteem Scale, which consists of 10 statements related to overall feelings of self-worth or self-acceptance. The items are answered on a four-point scale ranging from "strongly agree" to "strongly disagree." [3] The item "I wish I could have more respect for myself" gave a negative inter-item correlation and was excluded. The score for each participant was adjusted to make the possible range from 0-40, so comparisons could be made to population values and other samples. Results showed adequate internal consistency (alpha=.75).

Coping

The Brief Cope scale is a 28- item scale made up of 14 subscales with two items in each subscale [4]. This was adapted by including 15 of the original items. Minor wording changes were made to ensure comprehension. Nine items were added to make the measure more HIV-specific. An exploratory factor analysis was performed and identified two factors-active and avoidant. Two separate scales were then created namely active and avoidant coping. The active coping scale consisted of 13 items (0-39) and the avoidant coping scale consisted of 8 items (0-24). All items were measured on a three- point scale related to how often they made use of that particular strategy.

Results for the active coping scale showed an adequate internal consistency (alpha=0.75). The avoidant coping scale had poor internal consistency (alpha=0.54).

Violence **

Information on the subject's past experience of violence (emotional, physical and sexual abuse, and financial withholding) was obtained using questions from a survey of women's experience of violence in South Africa. [5]. In initial analyses the experience of multiple different types of violence appeared to be more important than the experience of any single category of violence. To avoid complexity in the analyses, those who had experienced two or more different types of violence were compared with those who had experienced less than two types.

Life events**

As negative life events are mentioned in the literature as being important predictors of depression it was decided to retrospectively attempt to develop a life events score that was more HIV-specific then existing scores [10]. The following table indicates the data on changes in a women's life that might be considered as negative or stressful. Some of this information was collected routinely at all follow up visits but other information was offered voluntarily by the women in response to the question – "How have things changed in your life?" All responses to this question were coded as either as positive or negative. In order to assess whether it was reasonable to assume that some of the events was stressful, several scales and articles covering the topic were used as guidelines.

1. The Social Readjustment Rating Scale, which is an 87- item scale where each item is assigned a score. This scale covers health, work, and home, family, personal, social and financial related life events. [6]

2. Other authors have used a few items from established life events scales [7, 8, 9].

3. Moore et al created an index of severe life events covering lack of money, no safe place to live, being physically attacked or raped, having children taken away, break-up of a relationship with a partner and death of a person close to them. This was then categorised into no events 1-2 events and > 3 events. [10].

It was thus decided to create a score by assigning "1" to each of the events the woman had experienced

Life events were only taken into consideration in this analysis after the preliminary analyses were completed. As mentioned above some of the events were routinely asked about for example, changes in financial status but some were not. It was assumed, that if the women had experienced severe negative life events, that they would mention these in the interviews, however it is possible that not all those women who had experienced negative life events, would have reported them and thus this would be a potentially biased measure. It was thus decided to include this score, in an exploratory sub-analysis, to assess if there was any impact on the depression scores. The following table shows the data that was used to create the score

Table 2: Data used to develop Life events Score

Data collected at 3 months, 9 months & 18 months and in the interim periods
• Changes in residence –if she indicated this was a negative event
• Financial status deteriorating
• Changes in marital status – divorce, breakup
• Changes in employment status- loss of employment
• Changes in partner employment- loss of employment
• Illness admission to hospital
• Baby HIV positive
• Baby illness
• Baby death
• Death of spouse
• Death of family member*
• Difficulty in relationships*
• Experience of stigma

* Not routinely asked

Depression score (**Dependant/outcome variable)** (0-60). This is measured using the Center for Epidemiological Studies Depression Scale (CES-D). This scale was developed to measure depressive symptoms in adults within the general population. It is a 20- item scale, which assesses depressed mood, somatic symptoms, interpersonal problems and lack of positive affect. For each item there is a four-point scale (0-3) based on the frequency of occurrence of a particular symptom in the previous week. (0-60) [11].

The measure has been shown to have a high internal consistency, which remains relatively constant across different populations and scores correlates relatively well with other measures of depression. A score of 16 or more has been used to classify persons as depressed. Other cut-off points have been suggested [11,12]. Sensitivity ranged from 80 to 90% and specificity from 70-80%, when compared to the DSM-III classification of a major depressive episode [13].

A study done by Kalichman et al to look at the overlapping of somatic items with symptoms experienced by HIV positive individuals, established that if the full scale was used in symptomatic individuals, there was a significant over-diagnosis of depression compared to that when a modified score excluding the somatic items was used [14]. As we are dealing with, not only HIV positive individuals, but pregnant women where symptoms of pregnancy may also include somatic symptoms, the modified scale was used. Results indicate a good internal consistency (alpha=0.88) As the number of items in the score is less the cut off point for borderline depression for the purposes of this study was proportionally lowered to 12.

Sample size

There were two phases to the Serithi trial. The first phase was to collect baseline data on feeding practices and factors affecting the practices. Phase 2 was the intervention phase. The intention was to compare the two to assess the effect of the intervention. The initial sample size was calculated based on the rate of unsafe feeding practices. It was thought that the rate in the pre-intervention group would be 20% and that in order for the difference between the two groups to be clinically significant the rate would have to drop to 10%. (α =0.05, β =0.8)The sample size was estimated to be 180 in each cohort. A total of 293 were actually recruited as the rates of breastfeeding were lower than anticipated for Phase 1. A sample size calculation was not performed for this sub-study. All the participants from the Serithi trial who had more than one interview were included. There is not very much written on sample size in the literature on MLA. Simulation studies suggest that the 150 individuals (groups) with 5 observations each

would give adequate statistical power [19]. In this study with the majority of individuals having 4 observations each, one must assume that the sample size is adequate.

Statistical analysis

SPSS 16$^®$ was used for data analysis.

A. Descriptive statistics

Descriptive statistics were used to describe the population at baseline. In the case of categorical date frequencies and percentages were used. Means and standard deviations were used to describe continuous data. Medians and ranges were used to describe data not following a normal distribution.

B. Differences between those attending one interview and those attending more

In order to establish if there were any significant differences between those attending more than 1 interview and those lost to follow-up after attending the baseline interview the two groups were compared in terms of the variables described previously. Chi squared tests were used for categorical data and where expected values were found to be less than 5, Fischer's Exact test was used. Student t tests or where appropriate, one-way analysis of variance (ANOVA) was used for continuous data. Non-parametric tests in the form of the Mann Whitney U test was used in the case of data that was not normally distributed e.g. per capita income. A p value of <0.05 was considered to be statistically significant

C. Mixed linear analysis. (MLA)

The depression scores at each time point for each subject are repeated measures and thus require the use of some form of repeated measures model as it is likely that measurements taken at different times are not independent. The decision to use MLA was based on the following:

    a. Not all the participants had interviews at all the time points.

b. Not all the participants attended the interviews at exactly the prescribed time.

c. Not all the information collected at the time points was complete.

These three factors militate against the use the general linear model repeated measures procedure but can be accommodated in the mixed model procedure [15]

- The mixed model procedure also allows for the use of a large number of covariance structures [16 17].

- MLA allows the inclusion of only the interactions that are of interest whereas GLM requires that all interactions of within subjects and between subjects' effects be included in the model [16].

- All the depression measurements from 1 participant are considered as a group. The level 1 model describes the data for 1 participant and the level 2 model describes the differences between participants. The participants are considered to be random factors [16].

- Time can be treated as a fixed or random effect [18].

- Time varying covariates can be included in the model. [16].

Assumptions

1. It is assumed that the measurements on one participant are independent of the measurements on the other participants and that they have the same covariance structure [19].

2. It is assumed that the dependant variable follows a normal distribution but it must be noted that for large sample sizes it is assumed that the estimates based on the Restricted maximum likelihood and maximum likelihood algorithms may be presumed to "exhibit asymptotic normality" [19].

Other assumptions

The missing data from each interview was 'produced' in a random fashion.

Procedure

1. All those study participants (69, 24 %) who only attended the baseline interview were excluded from the analysis.
   One hundred and eighty nine (84.4%) of the remaining participants had more than 2 interviews.

2. Despite the fact that the sample was large it was thought advisable to assess the depression score for normality using normal probability plots at all 4 time points. From these plots it appeared that some form of transformation was required. The depression score was transformed in 2 ways namely by square rooting the score and by log transformation. It appeared that the square root transformation was the better transformation procedure when visualising the Q-Q plots.

3. The data format required for this analysis is one row per person per measurement time, i.e. in this analysis there are four rows per person to take into account the measurements taken at four different interviews. This conversion was performed in SPSS.

4. Two approaches can be used in repeated measures:-
   - the random coefficients model. Here one can assess by how much the slopes and intercepts vary among individuals (Slopes and intercepts are treated as random effects). One can also assess whether the average slope and intercept differ from 0, i.e. (across participants) so the slope and intercept are also treated as fixed effects in the model. If a random factor is included in an analysis, a covariance structure is imposed on the data – the so-called G matrix, which describes the error-covariance structure of the data [16].
   - Should the slope and intercept not vary between individuals, the repeated measures model can be used – here one specifies the R matrix – this will then describe the error- covariance

structure of the data. Should there be random factors in the data set, the R and G matrices can both be specified in the repeated measures model however, in this data set there are no other random factors [16].

5. In order to establish which independent variables were associated with depression, independent variables thought to be of interest, were entered into a random coefficients model one at a time. If the variable had an associated p value of less than 0.25, it was entered into the full model [20].

6. Interactions of the independent variables with time were assessed for significance. This was to assess if changes in depression over time could be related to a specific independent variable. If these were found to be significant ($p<0.05$), these were entered into the full model.

7. Interactions between independent variables that were thought to be theoretically feasible were also assessed for significance ($p<0.05$) and entered into the model.

8. To obtain the most parsimonious model a backward stepwise procedure was then followed after including the independent variables and the interactions of those variables with time and interactions between independent variable. Variables with p values >0.25 were removed one at a time and the effect of removal assessed by the Likelihood ratio test. If, this was >0.05 the independent variable was removed.

9. As the type of covariance structure used has an impact on the standard error of the estimate for the fixed effects and thus the significance level for the independent variables models making use of different covariance structures was assessed making use of the Likelihood ratio test [16].

10. Q-Q plot of the residuals to determine if these are normally distributed.

Exploratory analysis life events score (reliability and factor analysis

1. In order to determine if the life events scale was internally consistent, use was made of the Cronbach alpha coefficient. A value of >0.7 is considered to be optimal to determine if the scale is reliable [21,22].

From the analysis, the item- total correlations are also obtained. If there are any below .3 one may consider removing this item from the scale.

2. Factor analysis was used to attempt to reduce and refine the items that were initially considered to be important in the development of the scale. The following steps were followed [22].

   - Determining if the items were suitable for factor analysis based on the data. This depends on the size of the sample. There should be 5-10 subjects per item in the scale. This criterion is met as there are 13 items and between 224 and 131 subjects (interview 1 to interview 4). It also depends on the inter-item correlations, if there are only a few inter-item correlations above the 0.3, this tends to suggest that this data does not lend itself to factor analysis. A significant Bartlett's test of sphericity (p<0.05) would suggest that the data lends itself to factor analysis

   - Principal components extraction. The number of factors that best describe the underlying data was determined by means of a scree plot

   - To attempt to interpret the factors obtained by means of the scree plot, Varimax rotation was performed to determine which items loaded on which factor.

Time Schedule

Recruitment of women began in July 2003. Recruitment was completed by December 2004. The last follow-up interview was conducted at 18 months in May 2007

Ethical Aspects

The original protocol was approved by Faculty of Health Sciences Research Ethics Committee, University of Pretoria, South Africa (Protocol number 209(a)) and the Human Investigation Committee of Yale University School of Medicine, USA.

Women were required to give written informed consent before entering the study. See Appendix 2.

All data files had names and other identifying information removed once the data had been entered into the computer database. A list of names and addresses were kept under lock and key away from the data files.

There was no identifying information in the database being used and other than the author and the research assistant entering the data, no one had access to the data.

Special ethical issues

The fact that women were phoned prior to an upcoming appointment posed a potential problem if she shared the use of a phone with someone else. Many of these women had not disclosed their status so, in order not to put the woman in a difficult position, they were asked, if they did not answer the phone themselves, how the research assistants should introduce themselves, so that the woman would know it was the Serithi Team phoning and a notation made in the research file.

The same consideration applied when a member of the team visited them at home if they had not attended an appointment and were not contactable by phone.

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Chapter 3

Results

Description of population

Four hundred and thirty eight HIV infected women were approached to be part of the study. A total of 293 (62%) women were enrolled from June 2003 to December 2004 and took part in the baseline interview. A total of 198 (68%) women attended the second interview at 3 months, 175 (60%) attended the 9-month interview, and 166 (57%) attended the 18-month interview. Sixty- nine women attended only the baseline interview. These women were excluded from the analysis because at least two measurements (baseline and one other) are recommended [1]. The total cohort consists thus of 224 HIV positive women (76% of the original cohort). See Table 1 for breakdown of interviews.

Table 1. Attendance at Interviews

1 Interview (baseline)	2 Interviews	3 Interviews	4 Interviews
N=69 (excluded)	Baseline + 3 months N=23	Baseline+ 3months+9months N=30	N=131
	Baseline + 9months N=5	Baseline+3months+18months N=14	
	Baseline + 18months N=7	Baseline+9months+18months N=14	

N=number

Table 2 shows the socio-demographic characteristics of the women at the baseline interview.

Table 2. Socio-demographic characteristics (baseline interview)

Variable	
Clinic where womenrecruited N (%)	
• Atteridgeville	26(11)
• Saulsville	61(27)
• Phomelong	97(43)
• Mamelodi	110(49)
Age [mean(sd)]	26.5(5.1)
Home language N (%)	
• Sepedi	93(41.5)
• Setswana	38(17.0)
• Izizulu	34(15.2)
• Others (Isixhoza, Zitsonga Sesothu,Tshvenda, Siswati, Isindebele)	59(26.3)
Marital status N %)	
• Married	43 (19.1)
• Single with partner	152(67.9)
• No partner	29(12.9)
Participant's education level N (%)	
• None/primary	21(9.3)
• Some form of secondary	171(76.3)
• Some form of tertiary	32(14.3)
Partner's education level N (%)	195 (only those with partners)
• None/primary	15(7.6)
• Some form of secondary	129(66.2)
• Some form of tertiary	35(17.9)
• Unknown	16 (8.3)
Housing N %)	
• Made of concrete or bricks	135(60.3)
• Running water indoors	79(35.3)
• Flushing toilet	165(73.7)
• Electricity	186(83)
• Fridge	152(67.9)
Housing score [mean (sd)]	3.2(1.7).
Occupant's of house [median]	4
Staying with N (%)	
• partner	98(43.8)
• other relatives	181(80.8)
• person's unrelated	7 (3.1)
Household income monthly per-capita [median]	R320
Below poverty line <R200 N (%)	64(28.6)
Regular income employment N (%)	
• participant	52(23.2)
• partner	151(67.4)
Partner providing financial support N (%)	160(71.4)
Accessing grants N (%)	78(34.8)

N=Number
*sd=standard deviation

The majority of women were recruited from the greater Atteridgeville area (57%). As can be seen from the above table the women had an average age of 27, were mainly single but had a partner. The majority had some form of secondary education, as did the partners. Most lived in brick houses, did not have running water inside, but had a flushing toilet, electricity and a fridge. There were approximately 4 living in the house and these were in most cases, the woman's relatives. Only 44% of women were living with their partners. For 29% of women, the household income was below the poverty line. Only 23 % of women were employed but the majority of partners were employed (67%). The majority of partners (71%) were providing the women with some form of material support. Thirty five percent of households were accessing some form of government aid in the form of a grant.

The medical and other characteristics are shown in Table 3.

Table 3. Other characteristics

Variable	
Parity[median]	1
Gestational age at baseline interview [mean (sd)]	27.6(7.0)
Clinical Stage 1 [N (%)]	215(97.3)
Stage 2	6(2.7)
CD4 [mean (sd*)]	433 (232.5)
• <200 [N(%])	27 (12.2)
Experiences of past violence N (%)	
• Emotional	55(24.6)
• Financial withholding /control	36(16.1)
• Physical	26(11.6)
• Sexual	12(5.4)
Two or more types of violence	49(21.9)
Interval since HIV test done N (%)	
• <1 week	63(28.1)
• 1-4 weeks	94(42.0)
• >4 weeks	67(29.9)
Discussed testing with partner N (%)	68(30.4)
Partner tested N (%)	52(23.2)
Partner positive N (%)	12(23)
Know someone with HIV N (%)	89(39.7)
• Family	44(19.6)
• Close contact	65(29.0)
Disclosure N (%)	138(61.6)
• Partner	102(45.5)
• Others	72(32.1)

The majority of these women were clinically well and expecting a second child. It must be noted however that the clinical staging was found to be difficult by some of the research assistants. Therefore, CD4 count (as categorized by < 200) was used as the primary indicator of disease status. Twenty two percent had experienced 2 or more types of violence. At the time of the first interview the majority of women (71%) had known their diagnosis for more than 1 week with only 30% having known it for more than 1 month. The minority of women (30%) had discussed the possibility of testing for HIV with their partner prior to doing so. Only 23% of women were aware that their partners had tested. Of these only 23% had indicated that they were positive. Forty percent of women knew someone who was HIV positive. Sixty two percent of women had disclosed to someone by the time of the first interview.

Table 4 shows the score on the different scales measuring the psychological characteristics and level of knowledge of these women.

Table 4. Psychological variables and knowledge

Variable	Mean (sd)	Scale/score total
Self-efficacy score	4.3(1.8)	7
Internalised stigma	4.5(2.6)	12
Attributed stigma	9.9(2.4)	12
Social support		
• Positive	22.7(7.7)	27
• Negative	1.9(2.3)	9
Knowledge	11.0(1.9)	15
Self-esteem	31.5(3.9)	40
Coping		
• Active	31.3(3.9)	39
• Avoidant	16.2(2.7)	24
Outcome variable CESD Depression scale (excluding somatic items)	**12.2(8.8)**	**60**

It is interesting to note that the levels of stigma that women attribute to others is very high compared to their own levels of internalised stigma (9.9 vs. 4.5). The mean value of the depression score is above that of the cutoff point for borderline depression.

Differences between those attending only baseline and those coming for two or more interviews

Sixty-nine women attended only the baseline interview. In order to establish if this group was different to the group included in the analysis, comparisons were made between the two groups with regard to all of the variables mentioned above. Four of these women were excluded from this group as they died before they could attend the three-month interview (65 women remaining). Table 5 shows the differences that were significant.

Table 5. Differences between those attending only the baseline interview and those attending two or more interviews

Variable	1 interview N=65	> 1 interview N=224	P value
Stay with someone else when child born N (%)	20(30.7)	44 (19.6)	0.03
Housing score [mean (sd)]	2.06(1.7)	3.2(1.7)	<0.001
Share home with partner N (%)	38(58.5)	97(43.5)	0.03
Share home with relatives N (%)	45(69.2)	181(80.8)	0.04
Total no of people in the house [median]	2	4	0.04
Accessing grants N (%)	14 (21.5)	78(34.8)	
Know someone who is HIV positive (family and close contacts) N (%)	16(24.6)	89(39.9)	0.02
Clinic N (%) - Phomelong - Atteridgeville - Saulsville - Mamelodi	26(40.0) 7(10.8) 19(29.2) 13(20.0)	69(30.8) 18(8.1) 41(18.3) 96(42.9)	<0.001

The women who only attended the baseline interview were more likely to be going to stay with someone else after the birth of the child, were more likely to be living in zinc houses where there was no running water inside the house, the toilet facility was likely to be a pit or bucket latrine, and where there was no electricity or fridge (all the factors included in the housing score were significantly associated with attendance at only the baseline interview). Phomelong clinic had the highest number of women who only came for the baseline interview- 26(40.0%). This is a clinic that serves a

large informal settlement where people who move in from rural areas, may initially settle. The women have possibly come into the area to be with their partners for the birth of the child and to receive antenatal care in the Tshwane. This would potentially explain why they are more likely to be staying with their partners, less likely to be staying with relatives and more likely to be going to live with others after the birth of the infant. There was no significant difference in depression scores between the two groups. The fact that there are a number of differences between the two groups in terms of some of the factors considered to be potential predictors of outcome and the fact that they comprised 24% of the original cohort may have an impact of the generalisability of the study.

Changes over time

The variables mentioned in this section are those that were considered as possible predictors of depression scores The following variables were treated as time-invariant - age, knowing someone who was HIV-infected, level of education, violence and HIV-related knowledge.
The following table shows the variables that were treated as time-variant and the values for each variable at the different interviews. While these values do not represent the whole sample as not all women attended each interview, they do give some idea about possible trends over time.

Table 6. Possible trends over time.

Variable	Baseline N=224	3 months N=198	9 months N=175	18 months N=166
Categorical N (%)				
Marital status				
1. Married	43 (19.2)	40(20.2)	39(21.7)	40(24.2)
2. Single living with partner	58(25.9)	45(22.7)	41(22.8)	30(18.2)
3. Single not living with partner	94(42.0)	79(39.9)	60(33.3)	60(36.4)
4. No partner	29(12.9)	34(17.2)	40(22.2)	35(21.2)
Share home with outsiders	7(3)	12(6)	10(6)	7(4)
Share home with relatives	181(80.8)	163(85.3)	154(86.0)	134(80.7)
Women working	68(29.5)	65(32.8)	66(36.7)	77(46.4)
Partner providing support	160(72)	143(73)	114(66.7)	114(70)
Percapita income above poverty line	159(71)	134(69.1)	124(69.3)	116(70.7)
Disclosure	138(62)	160(81)	179(84.4)	166(91)
CD4>=200 *MD	169(87.6) 31	166(86) 5	141(87.6) 19	149(90) 0
Antiretroviral medication	0(0)	0(0)	19(10.6)	23(13.9)
Continuous variable Mean (sd) / Median (range)				
Median per capita income	320(0-3000)	325(0-3000	300(0-2500)	333(13-2000
Housing score	3.2(1.7)	3.2(1.6)	2.7(1.4)	2.8(1.3)
Self efficacy score	4.3(1.8)	4.7(1.7)	5.0(1.7)	5.4(1.4)
Internalised stigma	4.5(2.6)	3.9(2.3)	3.3(2.3)	3.3(2.6)
Attributed stigma	9.9(2.4)	9.3(2.7)	9.4(2.7)	9.1(3.1)
Positive support	18.6(6.4)	19.4(5.8)	19.9(5.3)	19.6(4.9)
Negative support	1.9(2.3)	1.9(2.3)	1.6(2.0)	2.6(2.5)
Self-esteem	31.5(4.0)	32.5(3.9)	32.0(3.4)	34.3(3.9)
Active coping	31.3(4.0)	32.7(4.1)	33.6(3.3)	33.3(4.0)
Avoidant coping	16.2(2.7)	15.6(2.8)	14.6(2.3)	14.0(2.1)

*MD=missing data

More women have no partners at 9 and 18 months than at baseline, more women are working, more women have disclosed and more women are using antiretroviral medication. The self-efficacy score is higher as is the positive support, negative support, self-esteem and active coping scores. The internalised stigma score is lower as is the negative coping score.

Depression scores over time

The following table shows the mean values of the depression score at each interview for all women attending a particular interview, in the second row are the mean values for only the women attending all four interviews.

Table 7. Changes in CES-D score over time.

Scores Mean(sd)	Baseline N=224	3 months N=198	9months N=175	18months N=166	P value
Scores at each interview	12.2(8.8)	7.3(7.7)	8.8(9.4)	11.1(10.7)	
Scores of only women attending all 4 interviews (N=131)	12.4(9.1)	7.5(7.8)	8.9(9.4)	10.6(10.4)	0.000

Table 8. Borderline depression at each interview

Borderline depression CESD>12	Baseline N=224	3 months N=198	9 months N=175	18 months N=166
N(%)	100(45)	42(21)	46(26)	64(39)
CESD>16 N(%)	64(29)	29(15)	41(23)	47(28)

As can be seen there is a trend towards a drop in scores at 3 months followed by a gradual rise in scores at the subsequent interviews (Figure1). The p value using General Linear Repeated Procedures model suggesting that the are significant differences in depression scores between interviews. It is important to note that while the depression scores in the two situations seem to follow the same trends, the GLM procedure requires there to be data at each time point, so there is a resultant reduction in numbers in the analysis from 224 to 131.The mixed linear procedure can deal with unbalanced data so has the advantages in this case [2,3]. It must also be noted that the standard deviations shown above are large relative to the mean suggesting that depression scores are not normally distributed.

Figure 1. Mean values each interview vs. mean values of women attending all interviews
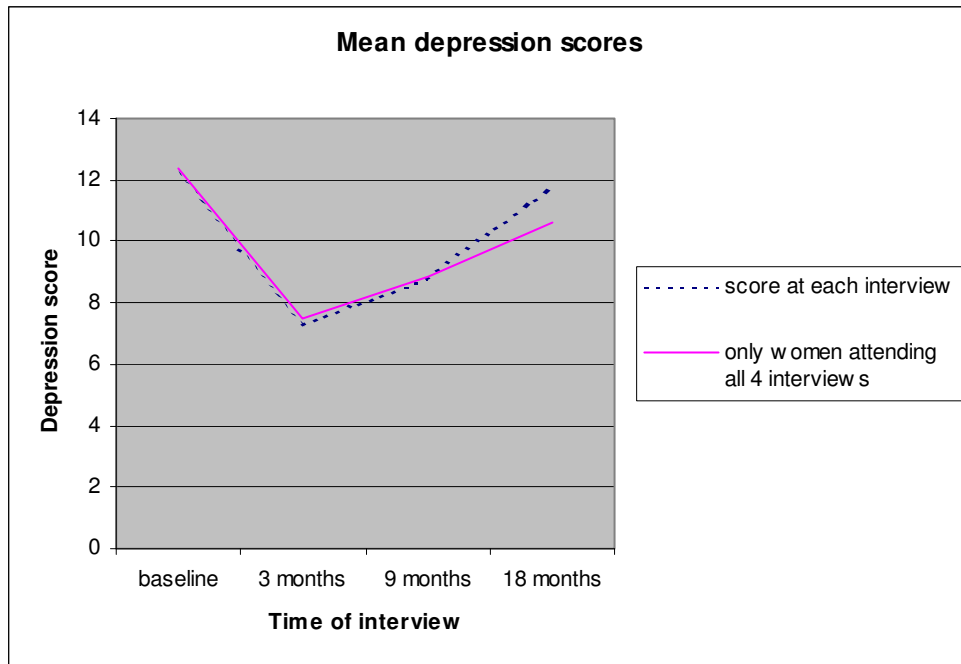
The line drawn between the score at each interview (blue) is broken because these are not necessarily the same women attending each interview

Mixed linear analysis

Procedure

1. Assessing normality of the data.

Figures 2 a-d show frequency distributions of the depression scores at each time point.

Figure 2a. Depression score at baseline

Histogram

for interview time = baseline

Mean =12.19
Std. Dev. =8.831
N =224
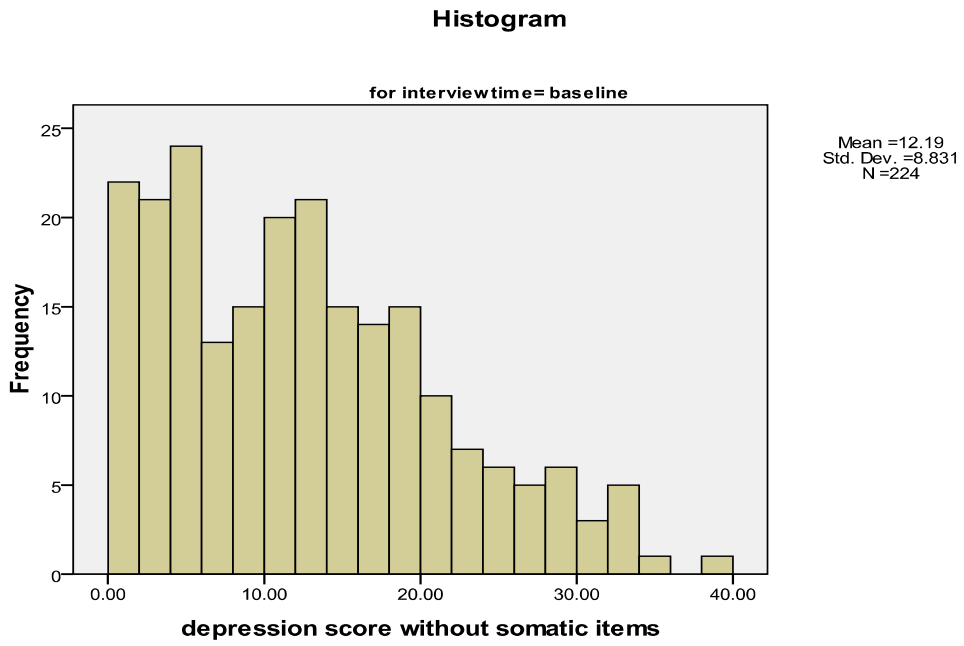
Figure 2b. Depression score at 3 months

Histogram

for interview time = 3month

Mean =7.28
Std. Dev. =7.674
N =197
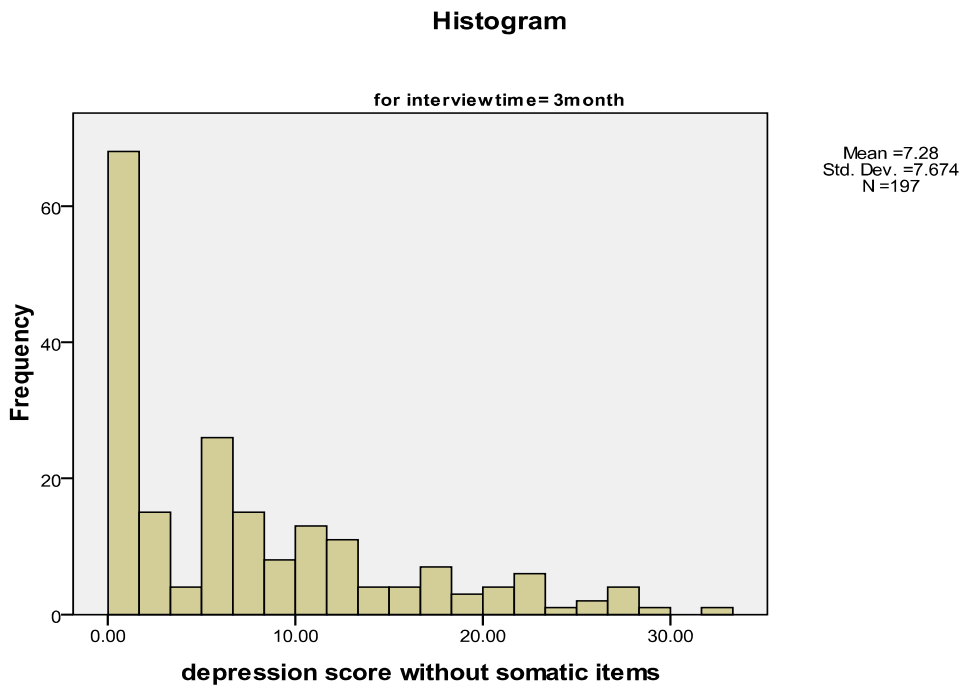
Figure 2c. Depression score at 9 months

Histogram

for interview time= 9 month

Mean =8.83
Std. Dev. =9.431
N =178
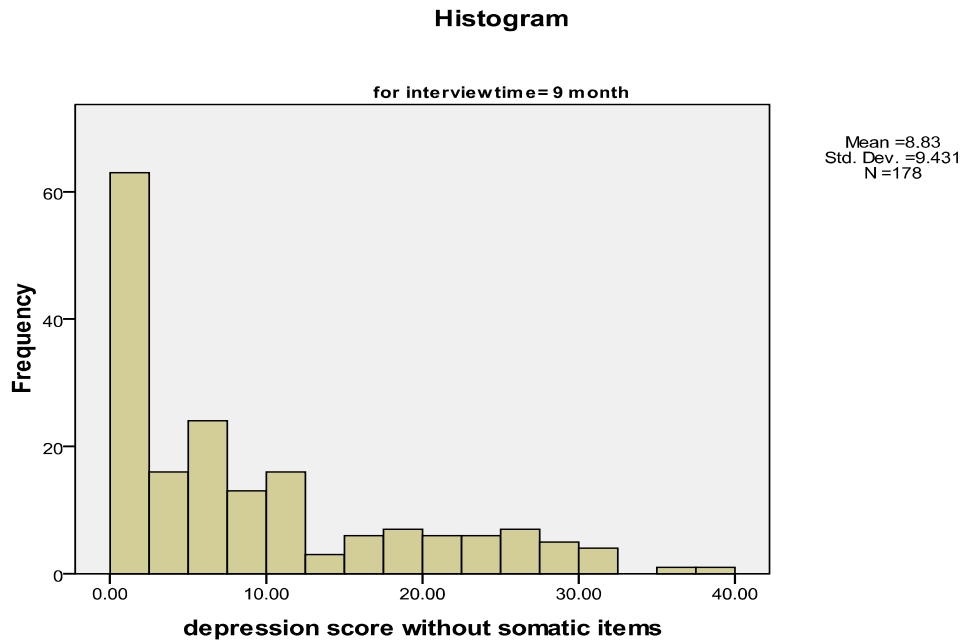
Figure 2d. Depression score at 18 months

Histogram

for interview time= 18month

Mean =11.09
Std. Dev. =10.649
N =166
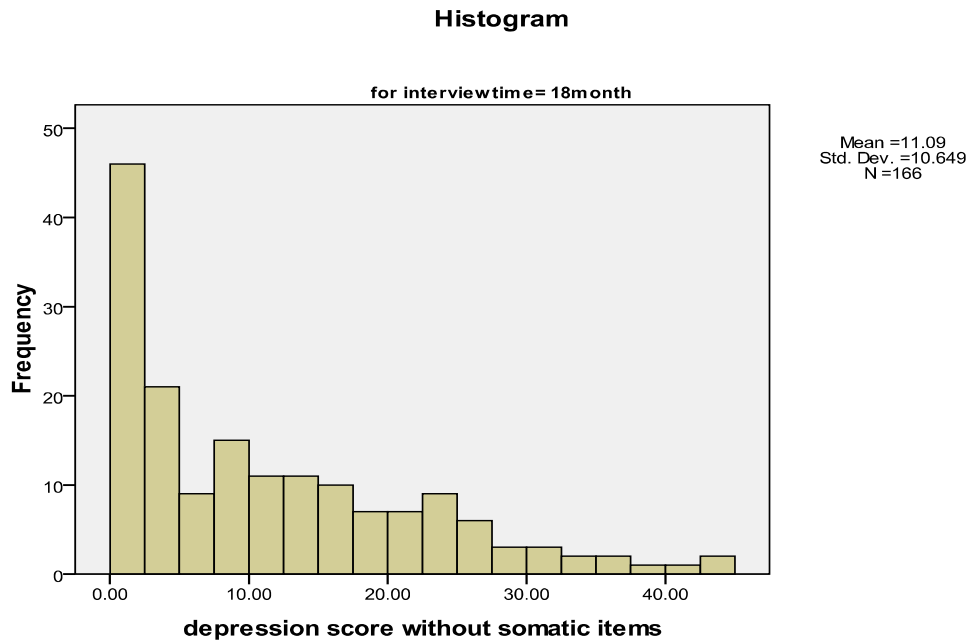
These histograms indicate that the score is positively skewed.

Figures 3a-d show q-q plots of the same scores.

Figure3a. Depression score at baseline

Normal Q-Q Plot of depression score without somatic items

for interview time= baseline
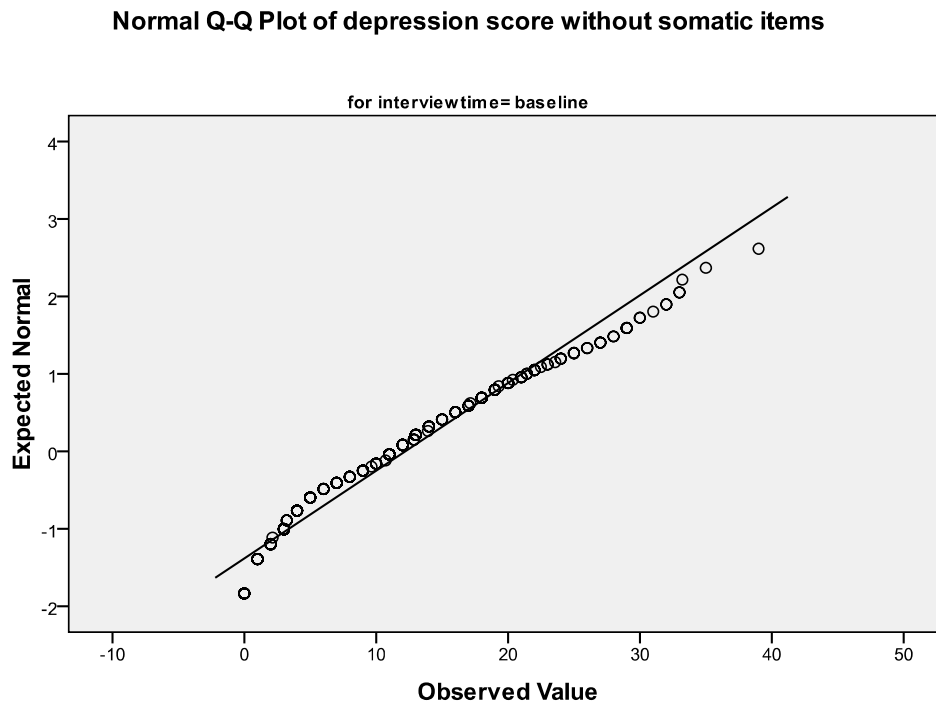
Figure 3b. Depression score at 3 months

Normal Q-Q Plot of depression score without somatic items

for interview time= 3month
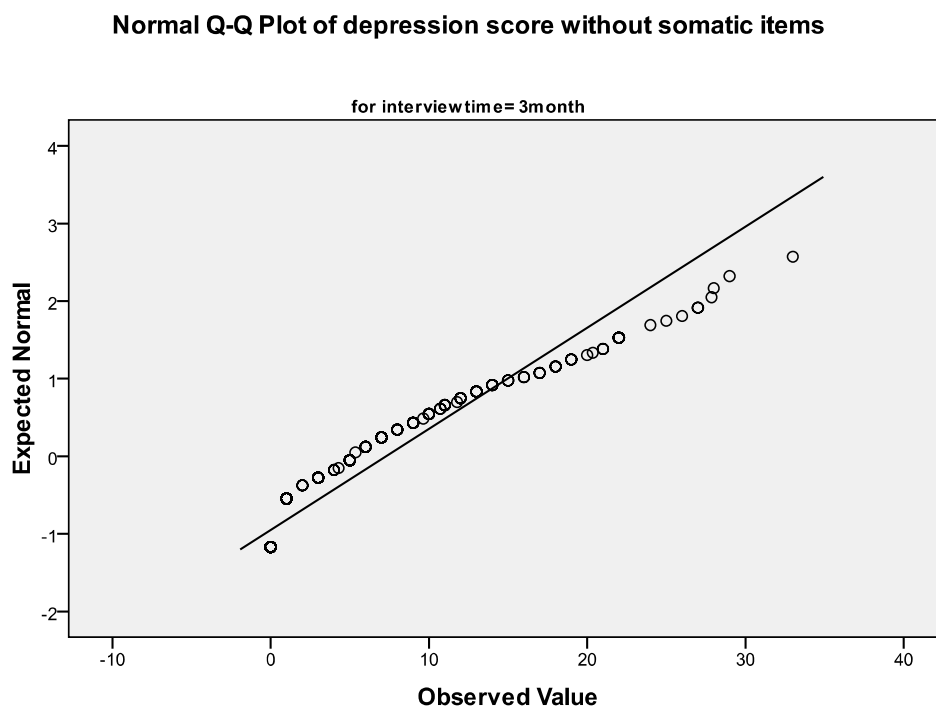
Figure 3c. Depression score at 9 months
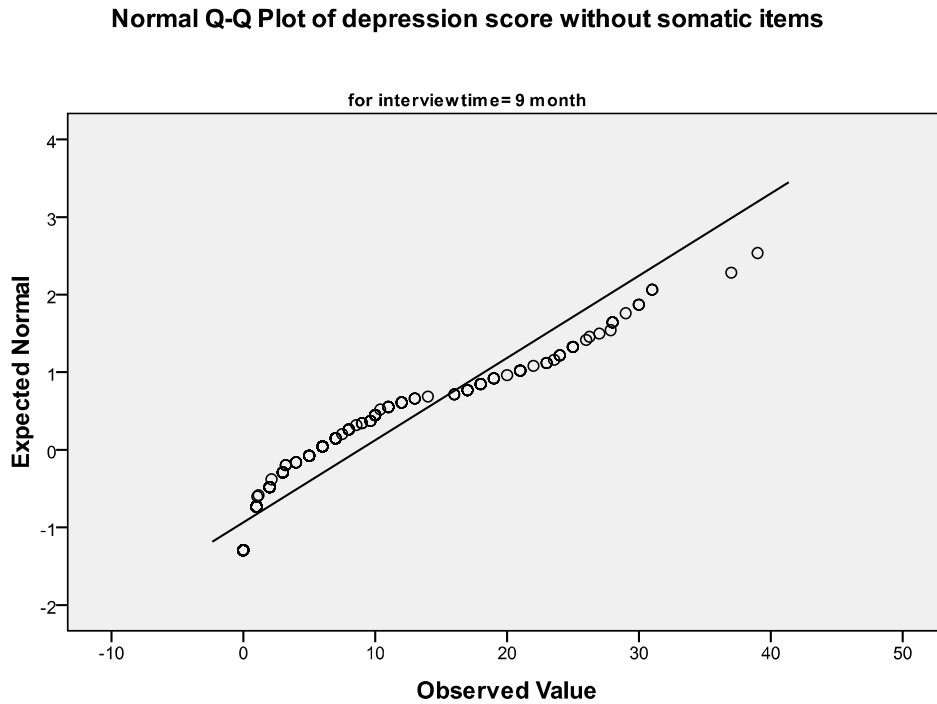
Figure 3d. Depression score at 18 months
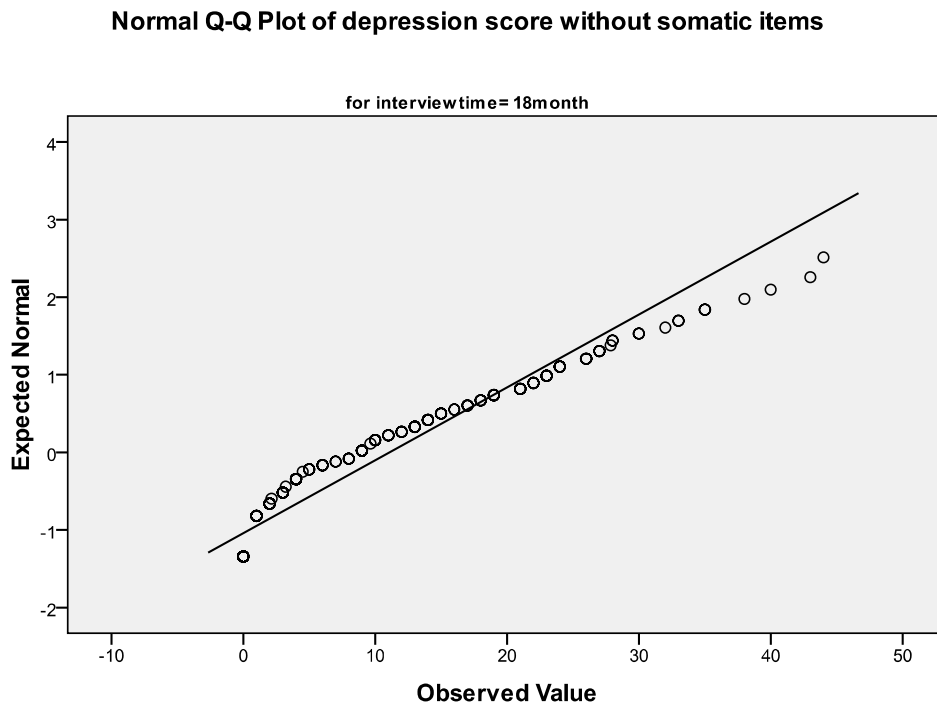
The histograms and Q-Q plots tend to suggest that some form of transformation of the scores should be performed. Square root and

lognormal transformations were performed. The transformation that most improved the data fit to that of a normal distribution was the square root transformation. This is in keeping with Tabachnik and Fidell who suggest that the transformation most suited for positively skewed data is the square root transformation [4]. This was performed by adding 1 to the depression score and square-rooting the result. Figures 4a-d show the resultant Q-Q plots.

Figure 4a. Square root depression score at baseline

Normal Q-Q Plot of sqrtdepsompl1
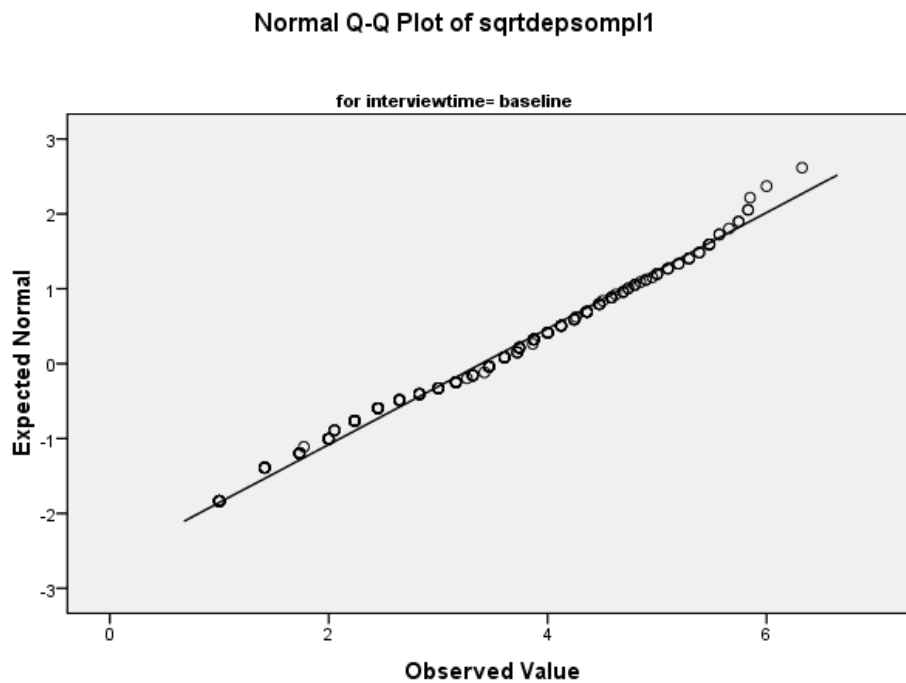
Figure 4b. Square root depression score at 3 months
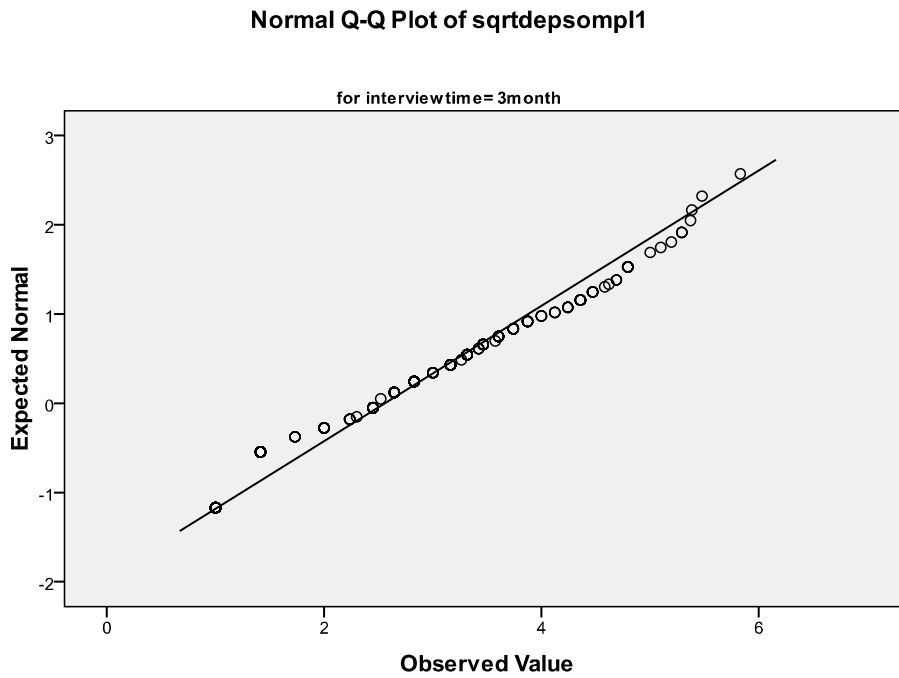
Figure 4c. Square root depression score at 9 months
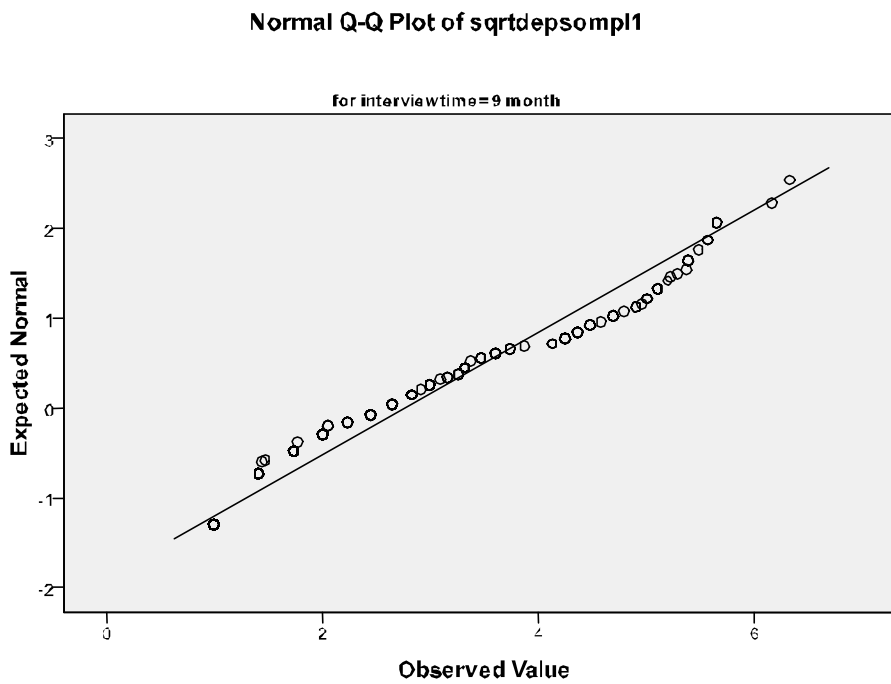
Figure 4d. Square root depression score at 18months

Normal Q-Q Plot of sqrtdepsompl1

for interview time= 18month
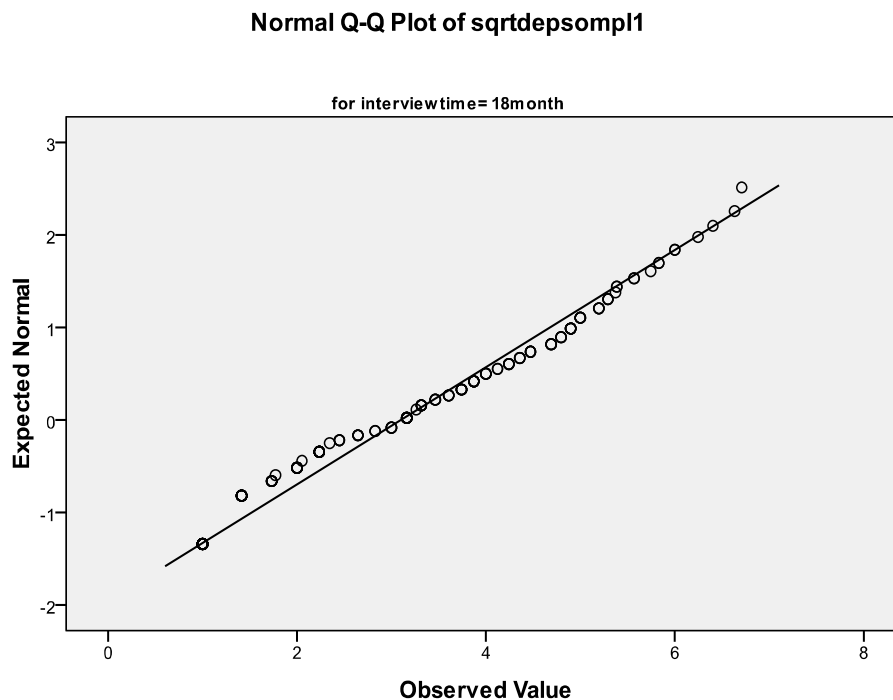
As can be seen from the Q-Q plots there has been some improvement as in all four plots there is a closer approximation to the line.

At all four time points there were a number of outliers. These were examined and any incorrect values adjusted. The remaining outliers were examined for their impact on the mean by assessing the difference between the 5% trimmed mean and the total mean [5]. See Table 9.

Table 9. Transformed scores and effect of outliers

Interview time	Total mean Square root CESD	5% trimmed mean Square root CESD
Baseline	3.39	3.39
3 months	2.56	2.49
9 months	2.76	2.70
18 months	3.10	3.04

The effect on the mean is relatively small and it was decided to retain the outliers in the analysis

2. Selection of predictors to include in the model

Potential predictors were included in a simple random intercept model with the CES-D depression score as the outcome variable, one at a time. Those with a p value less than 0.25 were then to be included in a full model [6]. These were variables that were to be treated as fixed effects in the proposed model.

One time- related variable was included in the model. This was a continuous variable that was computed by taking the date of an interview (3 months, 9 months, 18 months) from that of the baseline interview. This variable takes into account the fact that women did not have interviews at the same gestational age and then may have attended the interviews at different times to those specified namely 3 months, 9 months and 18 months after the birth of the baby. As it is possible that time to interview would not be linearly related to outcome, a quadratic term (time to interview*time to interview) was included in the model. The time variable was to be treated as both a fixed and random factor in the analysis.

Table 10 shows the variables that were found to have a p value below 0.25 and includes the time related variables.

Table 10. Variables to include in the model

Parameter	Estimate	Std. Error	P value	95% CI	
				Lower	Upper
Married living with partner	-.194	.196	.321	-.580	.190
Married not living with partner	.010	.493	.983	-.962	.982
Single living with partner	-.055	.186	.767	-.421	.311
Single not living with partner	-.408	.162	.012	-.727	-.089
No partner	0^a	0	.	.	.
Partner support	.211	.131	.108	-.046	.469
Violence <2	-.597	.139	<.0001	-.872	-.321
Internalised stigma	.133	.020	<.0001	.093	.174
Attributed stigma	.053	.019	.005	.016	.091
Positive support	-.031	.009	.001	-.050	-.013
Negative support	.072	.022	.002	.027	.118
Self-esteem	-.080	.013	<.0001	-.106	-.054
Active coping	-.077	.013	<.0001	-.104	-.051
Avoidant coping	.100	.019	<.0001	.063	.138
Housing score	.051	.039	.191	-.025	.128
Knowledge	-.109	.034	.002	-.177	-.042
No disclosure	.202	.134	.133	-.061	.466
Time to interview	-.102	.019	<.0001	-.140	-.065
Time to interview^2	.004	.001	<.0001	.002	.006
Active coping * Time to interview	.011	.005	.043	.0003	.022
Active coping * Time to interview	-.001	.0002	.022	-.001	-8.99E-5

a- reference category
*- Interaction term
2- Quadratic interaction term

Interactions, that were considered important between fixed effects were entered into a random intercept model and assessed for significance (p<0.05). The interactions considered were the following :-

> **Marital status** * (Internalised stigma, attributed stigma, positive support, negative support, self- esteem, active coping, avoidant coping.)

> **Disclosure** * (Active coping, avoidant coping, self-esteem , positive support, negative support)

> **Partner support** * (Positive support, negative support, active coping, avoidant coping, self-esteem).

No interactions that were readily interpretable were found to be significant. Interactions of the fixed effects with time to interview and the quadratic term were also assessed for significance to establish if there were factors that might predict changes over time. These are also shown in the above table.

3. Selection of the model

In order to establish if a random coefficients model was appropriate the time to interview variable was entered into a model as a random and a fixed factor along with a random intercept. This represents the rate of change in square root depression scores This would thus assess if women differ at the outset in terms of the outcome variable (intercept) and in the rate of change in the outcome variable depression (slope). The covariance structure (imposed because of random effects) that was chosen was "unstructured". This is a general covariance matrix that tends to be used in random effects models. It assumes that within one individual that there is no pattern in how depression changes over time. It requires, however the computing of a large number of parameters The following table, Table 13 shows the covariance parameters and associated p values which suggest that this is not an appropriate model as the random intercept UN(1,1) is significantly different from 0 but the time to interview (namely random slope) is not (UN(2,2) i.e. women did not differ in the rate of change in the square root depression score.

Table 11. Estimates of covariance parameters

Parameter		Estimate	Std. Error	Wald Z	P value	95% CI	
						Lower	Upper
Residual		1.47	.113	12.96	.000	1.270	1.719
Intercept + basetotime [subject = WomanID]	UN (1,1)	.381	.147	2.58	.010	.178	.814
	UN (2,1)	-.002	.010	-.265	.791	-.023	.018
	UN (2,2)	.002	.001	1.90	.057	.001	.005

A random intercept only model was then run with all the fixed effects shown in Table 10. Table 12 shows the results from the full model.

Table 12. Random intercept model –estimates of fixed effects

Parameter	Estimate	Std. Error	P value	95% CI	
				Lower	Upper
Intercept	5.757	.937	<.0001	3.917	7.597
Time to interview	-.377	.180	.037	-.732	-.022
Time to interview^2	.020	.008	.019	.003	.038
Violence <2]	-.459	.129	<.0001	-.715	-.204
Violence>1	0^a	0	.	.	.
No partner support	-.126	.157	.423	-.436	.183
Partner support	0^a	0	.	.	.
Negative support	.020	.022	.348	-.022	.064
No disclosure	-.158	.132	.230	-.418	.100
Disclosure	0^a	0	.	.	.
Married	-.419	.224	.062	-.859	.021
Single living with partner	-.302	.208	.147	-.712	.106
Single not living with partner	-.596	.184	.001	-.958	-.234
No partner	0^a	0	.	.	.
Active coping	-.058	.021	.006	-.101	-.016
Active coping * Time to interview	.008	.005	.123	-.002	.019
Active coping * Time to interview^2	-.0004	.0002	.081	-.001	5.858E-5
Internalised stigma	.082	.022	<.0001	.038	.127
Attributed stigma	.027	.019	.156	-.010	.064
Positive support	.004	.009	.672	-.014	.023
Self-esteem	-.045	.014	.001	-.072	-.017
Avoidant coping	.060	.020	.004	.019	.101
Housing score	.081	.036	.026	.010	.153
Knowledge	-.031	.032	.328	-.094	.031

^{a} reference category

In order to achieve a more parsimonious model, a stepwise process was used to eliminate variables that did not significantly contribute to the model. To do this the model with the fixed effect was compared with the model without the fixed effect (nested model) making use of the log likelihood ratio test. For fixed effects one uses the difference in the –2 Log likelihood statistic (which assesses goodness of fit of a model) between the larger model and smaller model in a Chi squared test with degrees of freedom equal to the difference in the number of parameters between the larger and smaller models A non significant p value indicates that the fixed effect can be dropped [2]. Table 13 shows the results from the final model The

problem with using the random intercept model is the fact that one can only use the identity covariance structure.

Table 13.Final Random intercepts model estimates of fixed effects

Parameter	Estimate	Std. Error	P value	95% CIl	
				Lower	Upper
Intercept	5.428	.851	.000	3.756	7.101
Time to interview	-.419	.179	.020	-.771	-.067
Time to interview^2	.023	.008	.008	.006	.040
Violence<2	-.473	.129	<.0001	-.727	-.218
Violence>1	0^a	0	.	.	.
Married	-.266	.175	.129	-.611	.077
Single living with partner	-.208	.172	.227	-.548	.130
Single not living with partner	-.523	.152	.001	-.822	-.223
No partner	0^a	0	.	.	.
Active coping	-.057	.020	.006	-.098	-.016
Activecoping * time to interview	.009	.005	.071	-.001	.020
Activecoping * time to interview^2	-.0005	.0002	.042	-.001	-2.102E-5
Internalised stigma	.090	.021	<.0001	.048	.132
Self-esteem	-.043	.014	.002	-.071	-.016
Avoidant coping	.062	.020	.002	.022	.103
Housing score	.087	.036	.017	.015	.159

^{a} reference category

The other approach is to make use of the repeated measures option where one can directly specify the residual covariance matrix in this case the "R" matrix. This takes into account the fact that repeated measures on one woman are possibly correlated. Random effects can also be included in the model. Here one would specify a separate residual covariance matrix "G" as is the case in a model including random effects as previously described [2] This was not done in the following model as attempting to run such a model resulted in non- convergence despite changing the number of iterations and step- halvings. "Time to interview" was treated as a fixed effect and "interview" defined the repeated measures. Table 14 shows the fixed effects and associated p values after running the full model with all the fixed effects listed in Table 10.

Table 14: Tests of Fixed effects (full repeated measures model)

Variable/source	P value
Intercept	.000
Time to interview	.059
Time to interview*time to interview	.032
Active coping	.005
Active coping*interview time	.192
Active coping * interview time^2	.133
Knowledge	.273
Internalised stigma	.000
Attributed stigma	.100
Negative support	.021
Self-esteem	.001
Avoidant coping	.001
Marital status	.013
Partner support	.021
Housing score	.033
Positive support	.801
Disclosure	.076
Violence	.001

Table 15 shows the final model after removal of non- significant fixed
effects

Table 15. Estimates of the fixed effects after removal of non-significant fixed effects

Parameter	Estimate	Std. Error	P value	95% CI	
				Lower	Upper
Intercept	4.874	.700	.000	3.498	6.250
Interview time	-.095	.186	.000	-.132	-.059
Interview time interview time	.005	.0008	.000	.003	.007
Violence <2	-.461	.125	.000	-.708	-.213
Violence>=2	0[a]	0	.	.	.
Married*	-.176	.172	.306	-.515	.162
Single living with partner*	-.220	.169	.195	-.554	.113
Single not living with* partner	-.471	.150	.002	-.767	-.176
No partner*	0[a]	0	.	.	.
Active coping	-.041	.013	.002	-.068	-.015
Internalised stigma	.087	.020	.000	.046	.127
Self-esteem	-.046	.013	.001	-.073	-.020
Avoidant coping	.072	.019	.000	.034	.111
Housing score.	.076	.034	.028	.008	.145

[a] -reference category
* – marital status
CI-confidence intervals

4. Choosing an appropriate covariance structure

The covariance structure that was used to model the repeated effects was "unstructured". As the choice of covariance structure may have an effect on the standard error of the parameter estimates and thus the level of significance of the tests it is necessary to check that the covariance structure is appropriate for the data [2,7,8]. Table 16 shows the residual covariance matrix (unstructured) but it is not clear if there is any pattern in this. While the variances from time 3 and 4 appear similar, that of time 0 and 1 appears somewhat different namely 1.4 compared to 1.6, 1.9, and 1.9 for 3 months, 9 months and 18 months respectively. It was thus decided to compare several structures.

Table 16. Residual variance matrix (R) Unstructured

	Baseline interview	3 months	9 months	18 months
Baseline interview	1.399	.193	.447	-.272
3 months	.193	1.599	.328	.217
9 months	.447	.338	1.852	.355
18 months	-.272	.217	.355	1.850

This is done by comparing the goodness of fit statistics (Information Criteria) of each model with a different covariance structure. The –2 Restricted Log Likelihood value is appropriate for simpler models and the modified Akaike Information Criteria (AIC) and the Schwarz Bayesian Criterion (BIC) tend to be used to assess more complicated models. BIC takes into account most "strenuously" the number of parameters estimated so should be the criteria used to compare models. As there are many different covariance structures to choose from Singer and Willett recommend the following which they have found to be useful in longitudinal research [9] They are:-

- Unstructured (UN).
- Compound symmetric (CS).
- Heterogeneous compound symmetric (CSH).
- Autoregressive. (AR1).
- Heterogeneous autoregressive (ARH1).
- Toeplitz.

The latter 3 models can however not be used with this data set as the time between interviews is not equal.

The following, which are in the repeated measures procedure in SPSS were also run to find the appropriate structure:-

- Ante-dependence First order (AD1).
- Diagonal (Diag).
- Factor analytic first order(FA1).
- Scaled identity (Identity).

The model was also run using Huyn Feldt and Factor Analytic First Order Heterogenous covariance structures but the Hessian matrix in both cases was not positive so the validity of the results could not be guaranteed.

The models were run using the restricted maximum likelihood method as the goodness of fit statistics then reflect the covariance structure aspect of the model [2,7,9]. Table 17 shows the different covariance structures, the number of parameters estimated, the BIC values

Table 17. Information Criteria and number of parameters estimated

	UN	CS	CSH	AD1	Diag	FA1	Identity
BIC	2435.1	2389.1	2404.0	2419.1	2428,9	2402.8	2400.5
No of parameters	22	14	17	19	16	17	13

The compound symmetry covariance structure performs the best in terms of BIC and has a smaller number of parameters to estimate than all the other structures with the exception of the identity structure where 17 parameters are estimated. In this structure there is a constant variance and there is no correlation between any elements. It was decided to use the model with the compound symmetry structure where it is assumed that the correlation between the measurements close in time, should be the same as those further apart in time. There is very little difference between the various models with different covariance structures. Table 18 shows the final model and estimates.

Table 18. Fixed effects estimates - final repeated measures model (Compound symmetry)

Parameter	Estimate	Std. Error	P value	95% CI	
				Lower	Upper
Intercept	4.99	.734	<.0001	3.55	6.43
Interview time	-.094	.020	<.0001	-.135	-.054
Interview time * Interview time	.005	.001	<.0001	.003	.007
Violence<2	-.478	.131	<.0001	-.736	-.219
Violence>=2	0[a]	0	.	.	.
Married	-.258	.177	.147	-.608	.091
Single living with partner	-.205	.175	.242	-.550	.139
Single not living with partner	-.503	.154	.001	-.807	-.200
No partner	0[a]	0	.	.	.
Active coping	-.040	.014	.004	-.068	-.013
Internalised stigma	.091	.021	. <.0001	.049	.134
Self-esteem	-.046	.014	.001	-.073	-.018
Avoidant coping	.062	.020	.003	.022	.103
Housing score	.082	.036	.026	.009	.154

[a] -reference category

The interpretation of the regression coefficients is approached in 2 ways - the between subjects and within subjects interpretations [10].

There is a significant decrease in square root depression score of 0.094 with every unit (month) away from interview within each woman but women 1 month apart in terms of interview time would also have a 0.094 difference in the square root depression score. This however is not a linear relationship as evidenced by the significant quadratic term. Figure 5 shows this relationship. At approximately 3 months there is an increase in the score of 0.005 (quadratic term).

There is an increase in square root depression score if more than 1 type of violence has been experienced. This, is a time invariant variable so only the between women relationship can be described.

Those who do have not have a partner have significantly higher scores than those who are single but not living with their partner. This amounts to a difference of 0.503 points. The same applies to a woman who was single but had a partner with whom she was not living, who then lost the partner – her score would rise by 0.503 points.

For every unit increase within one subject in active coping score there is a decrease in the square root of the depression score of 0.040points. The between subjects interpretation would be that for every unit difference between women in active coping score, there is a is a decrease in depression score of 0.040.

The square root depression score increases by 0.09 points for a unit increase in the internalised stigma score and a 0.06 increase for every unit in the avoidant coping score. If these levels changed within a women from interview to interview there would be a consequent change in the square root depression score. If there was a difference between women of 1 unit of either internalised stigma or avoidant coping there would be a difference between the women of 0.09 and 0.06 points in the square root depression score.

The decrease in score is 0.046 points for a unit increase in the self esteem score. Women with higher housing scores have higher levels of depression. A unit increase in housing score results in a 0.08- point increase in the square root depression score.

Figure 5 illustrates the estimated square root depression scores at each interview. These values were obtained by averaging the predicted values generated for each data point per interview.

Figure 5. Square root depression scores over time
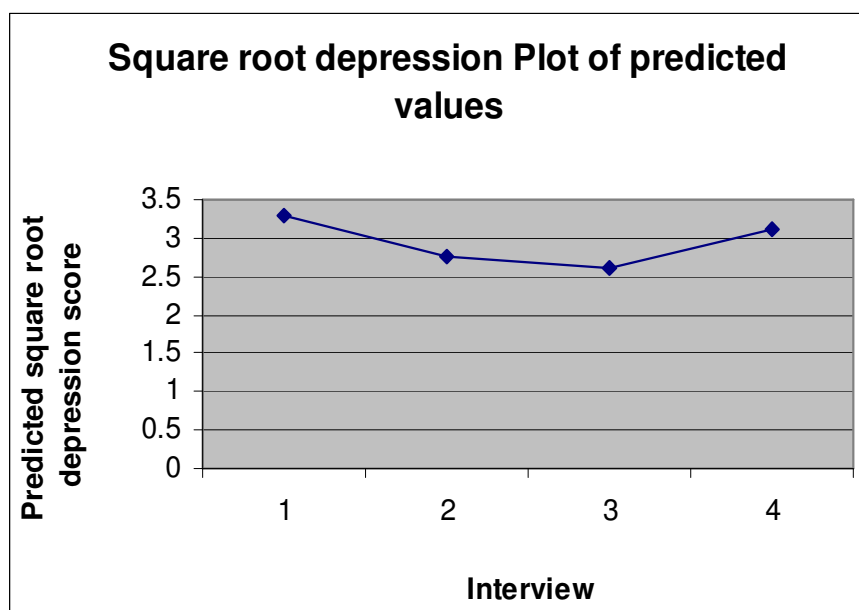
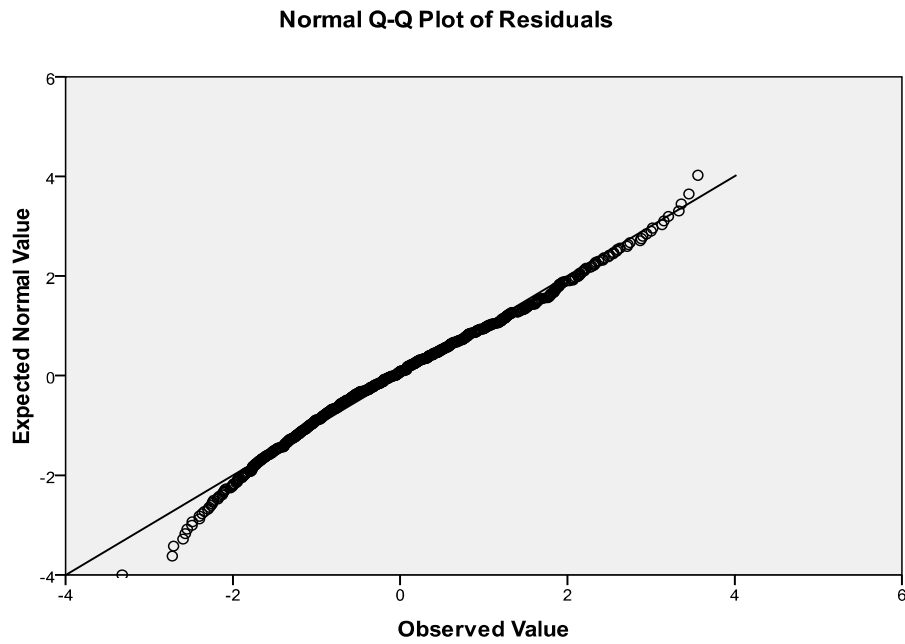## 5. Diagnostic tests for the final model

It is recommended that a Q-Q plot of the residuals is generated in order to assess whether the residuals follow a normal distribution [10]
Figure 6 illustrates this plot

Figure 6 Q-Q plot of the residuals (square root depression score).

Normal Q-Q Plot of Residuals

Visual inspection of this plot suggest that the residuals follow a normal distribution

Exploratory analysis (reliability of life events score and factor analysis)

It must be noted that the development of the above score was not a primary aim of this study. It was done because it was clear from the literature that negative life events were a significant contributor to depression levels. This was an exploratory analysis to establish if a score could be developed that was "HIV-specific".

Table 19 illustrates the mean values of the various items of the life events score at each interview.

Table 19. Life events score mean values.

	3months N=198	9 months N=175	18 months N=166
Mean score (sd)	1.308(0.96)	1.56(1.02)	1.59 (1.11)
Individual Items N (%)			
• Admission to hospital	1(0.5)	6(3.6)	5(2.8)
• Loss of partner employment	3(1.5)	11(6.1)	4(2.4)
• Employment change	5(3%0	1(0.6)	3(1.5)
• Residence change (bad)	32(16.2)	27(15)	30(18.1)
• Marital status change (not widowed)	16(8.1)	9(5)	7(4.2)
• HIV positive baby	21(10.6)	18(10)	15(9.0)
• Baby ill			
• Baby death	2(1%)	29(15.9)	10(6)
• Partner ill	6(3)	11(4.9)	10(6
• Partner death	1.(0.5)	1(0.6)	0(0)
• Family death	0(0)	1(0.6)	2(1.2)
• Experience of enacted stigma	0(0)	5(2.2)	1(0.6)
	35(17.7)	37(21)	45(27.3)
• Conflict with others	1(0.5)	10(5.6)	7(4.2)

All of these variables are dichotomous so the variability is smaller than had it been a scale that went for example from 1-3. As can be seen in some cases no events have occurred so these variables will be excluded from a reliability analysis. As one wishes to have a score that will work across all three time periods, a way to deal with this is to combine variables The following variables were combined partner death, partner illness and family

death into a variable "illness or death in close family". Reliability analysis
of the scores at the three interviews is shown in Table 20

Table 20. Life Events Score: Reliability analysis.

	3 month interview (11 items)	9month interview (11 items)	18month interview (11 items)
Mean (sd)	0.613(0.843)	0.91(1.01)	0.865(0.92
Cronbach alpha	0.239	0.237	0.165
Items with an item-total correlation of >0.4	0	0	0

As can be seen the reliability of all the scores is poor, and all of the items do
not correlate well with the total scores

Principal components analysis results are shown in Table.21 (Rotation
method Varimax with Kaiser Normalisation) [4,5]. The items in this score
do not lend themselves to factor analysis as the correlation between all items
is low. No correlation exceeded 0.3. Bartletts test of sphericity was non
significant also indicating that factor analysis is inappropriate. The
following is thus only shown for completeness.

Table 21. Life Events Score: Principal Components analysis

	3 months	9 months	18months
No of factors identified (Scree plot)	2	2	2
Factor 1	Loss of partner employment HIV positive baby Baby ill Baby die	Employment change Bad residence change Marital status change Conflict	Conflict HIV positive baby Bad residence change
Factor 2	Bad residence change Marital status change Enacted stigma	Loss of partner employment Illness or death in family	Employment change Enacted stigma
Items not loading on either factor	Admission to hospital Illness/death in family Woman employment change Conflict	Admission to hospital Baby death Baby ill Enacted stigma	Illness/death in family Admission to hospital Baby ill Baby die Marital status change Partner employment change

While there appear to be 2 factors (scree plot) in each score the factors loading on each in the different time periods are different.

Correlation with depression score for each time period is shown in Table.22

Table 22. Life Events Score: Correlation with Square root depression score.

	Negative life events 3 mnths	Negative life events 9 mnths	Negative life events 18mnths
Square root depression 3 mnths	0.168 p=0.018		
Square root depression 9mnths	0.009 p=NS	0.03 p=NS	
Square root depression 18 mnths	0.011 p=NS	0.088 p=NS	0.088 p=0.022

There is poor correlation between the square root depression score and the negative life events score.

Summary

1. There are significant changes in depression scores over time. The significant quadratic interview time term suggests that this is not a linear relationship. This can be seen in the fall off in scores at 3-9 months followed by a subsequent rise.

2. The factors associated with overall depression scores are active coping, avoidant coping, internalised stigma, housing score, self -esteem and violence and marital status.

3. The negative life events score overall has poor reliability and is poorly correlated with the depression score. It is not useful in predicting the square root depression score. No further analyses were performed using this score. This score has only been mentioned in this dissertation for the sake of completeness as it was included in the protocol for this study.

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Chapter 4

Discussion, Limitations, Conclusions and Recommendations

Discussion

This was a study performed to determine if there were changes in depression scores over an eighteen- month period in a population of women who were diagnosed as being HIV-infected during pregnancy and to establish if there were associated psychosocial factors. The women were part of the Prevention of Mother to Child Transmission Programme that was introduced to the clinics in Tshwane at the time the study started.

This was a unique population, as not only, were the participants pregnant at the start of the study, they had also only recently discovered their HIV status. Many of these women already had, many of the factors that are mentioned in the literature as being associated with high depression scores, at the start of the study [1,2]. They were female of childbearing age and single parents, (most had one child already). Most of the women were unemployed and had a low median per capita income; in a significant proportion of cases, this was below the poverty line. A significant proportion of the women had experienced some form of violence. In addition to these factors, the women learnt of their HIV infection during pregnancy when it is believed that women are more susceptible to the development of depression [3]. Receiving this information itself could be considered as a trigger for the onset of depression [4]. This cohort of women can be seen as a population where everyone had experienced a negative life event namely learning of their HIV positive status [5,6,7]. As a consequence of this they would have to deal with issues such the possibility of the unborn foetus being infected, disclosure and the potential consequences of disclosure such as stigma, separation from the partner and subsequent loss of support and social isolation all factors associated with high levels of depressive symptomatology in populations, who are HIV positive [8,9,10.11].

Depression scores over time

The mean depression score as measured by the CES-D score changed significantly over time, starting at a mean level of just over 12 considered in this study to be borderline depression at the baseline interview. Forty seven percent of women in the cohort had a score of 12 and above in the group at this interview, some 1- 4 weeks after diagnosis. This is in keeping with what is found in the literature on depression in the antenatal period but also in keeping with what has been found in the literature on depression in HIV infected women [12-19]. In the group that attended the 3-month interview there was as much as s 5-point difference when compared to those attending the baseline interview. Twenty one percent of these women had a level above 12. In the group attending the nine-month interview there was a small increase in the scores of about 1.5 points and an associated rise in the number of women having scores above 12 (26%). This was continued at 18 months with a rise in the number of women having scores above 12(39%). The pattern was similar in the group in attending all 4 interviews. Mixed linear analysis found that the depression scores continued to fall after the 3-month interview but had risen by 18 months and did not reach the same level seen at baseline.

These findings were similar to those of a second study undertaken by the same group on a similar cohort of pregnant women (unpublished data). In this study women who took part in a structured support group intervention were compared to those who did not wish to take part. In both groups there was a fall in depression scores at 3- months, (in fact the fall was larger in those not receiving the intervention). This was followed by a rise in the scores by 9 months when follow up the women ended. Milan and colleagues in their study involving pregnant and non pregnant adolescents found a similar decline in "emotional distress" at 3 months followed by a rise by 9 months postpartum [12]. It is assumed that the postpartum period a time when women are more vulnerable to experiencing depressive symptoms. but as indicated by Eberhard Gran et al in a study found that depression scores in the first four months after delivery were not higher than levels measured

during all the trimesters of the pregnancy [20]. In a longitudinal study by Heron and England most cases of so-called postpartum depression were preceded by antenatal depression. Further there was a mean decrease in symptoms of depression from pregnancy to the postpartum period similar to what was found in this study. They suggest that there are some specific concerns of pregnant women before delivery that make them vulnerable to depression antenatally such as the possibility of there being something wrong with the unborn foetus which would be resolved by having a normal infant [21]. This would be reflected by a fall the depression symptoms. This would be even more so the case in HIV infected women where there is a very real possibility that the infant could be infected. Another explanation is that not only is this a time, where there is intense bonding to that infant, but also a time when both the mother and child may receive a large amount of attention from friends and family because of the birth of the infant. This might contribute to the women feeling less depressed.

As antenatal depression is the most important predictor of postnatal depression it would thus be expected that this group of women would have high depression scores in the postnatal period [4]. This is not the case and they follow same pattern as seen in other cohorts of pregnant women [12,20,22]. In the current study a comparison with a non- infected group of pregnant women would have been useful to determine if the diagnosis of HIV is simply another burden that an already disadvantaged population have to bear [3].

Of concern is the fall off in depressive symptomatology is not sustained after 9 months and there is a rise in symptomatology and by the 18 month interview almost forty percent of women have levels above 12. There does not appear to be consistent picture in the literature as to what happens to depressive symptomatology in the long term. Gibbie in a study in Australia showed a decrease in symptomatology over time but this study included both men and women [24]. Milan found in the 5-year study of a large cohort of HIV infected women that depressive symptomatology decreased over

time but this decrease was small and levels remained relatively constant throughout the 5 years [2].

Factors associated with depression scores

In this study there were no significant interactions between any independent factors included in the mixed linear analysis and the time to interview variable i.e. no factors were associated with changes in depression scores over time. However, overall it was found that higher depression scores were associated with being single, a higher housing score, a higher level of internalised stigma, lower active coping scores, higher negative coping scores and a history of violence.

Single status appears to be associated with depression in general, antepartum and postpartum depression and in depression associated with being HIV positive [29,6,11]. Having a stable partner can have a moderating effect on depression symptomatology. Low level of self-esteem was found to be associated with higher depression scores. This has been found to be the case in studies looking at factors associated with antenatal and postpartum depression [30,4,6,28]. Lower level of active coping and the use of avoidant coping strategies were also mentioned in the literature as being associated with increased depression symptomatology [31-33,11] and certainly plays a very important role in the levels of depressive symptomatology experienced by the women in the current study. Internalised stigma was also found to be significantly associated with higher depression scores in the literature [10,9]. In a study in Cape Town by Leickness and collegues internalised stigma accounted for 5% more of the variability in depressions scores than other factors such as social support thus is an important factor related to the level of the depression score [9].

Violence has been shown to be associated with changes in depression scores in HIV positive women over time in 5- year study by Milan [12]. In the present study it was shown to be associated with depression overall but its

effect over time could not be assessed as it was treated as a time-invariant variable.

A factor that was not found to be significantly associated with lower depression scores, that is mentioned in several studies was that of positive support [31-34,17]. The mean levels varied from 18.6 to 19.9 (total 27) in this study, which would indicate that the women felt moderately supported and this did not change markedly over the 18-month period. This difference between this study and the literature is difficult to explain but may be simply related to different populations studied.

Negative life events are recorded in the literature as being associated with depression [29,32,35]. An attempt was made to retrospectively create a life events score that was HIV specific. This score had a poor reliability and was not associated with depression scores in an exploratory analysis. More work is needed to develop such a score. HIV infected women are more likely to be exposed to negative life events than their HIV negative counterparts because of their HIV infection and its associated consequences such as the death of a partner and possible infection of the infant with HIV. It would be useful to have a score that could potentially assess the effect of negative life events on women.

An unexpected finding, which is not supported in the literature is women with a higher housing score have higher depression scores The housing score is an indirect measure of socio-economic status and a low score would reflect low socio-economic status. The other factor that reflects socio-economic status that were measured in this study was monthly percapita income This was not found to be significantly associated with the depression score. Low socio-economic status is a factor found in the literature to be associated with depression [8,10,35]. It is difficult to give an explanation for this finding.

Other factors that were initially postulated to be important overall and not found to be significant were disclosure, self-efficacy and socio-economic factors.

Limitations

On the initial recruitment only 62% of pregnant women approached agreed to participate in the study. Those that declined to participate may have been different to those participating thus potentially affecting the external validity of the study. There is no way of assessing whether this was in fact the case as no data was collected on these women.

Of the 293 women recruited to the study, 69 (23%) attended the baseline interview only and were lost to further follow-up. These women are different from those attending two or more interviews. One of the factors where they differed from those attending more than one interview were found to be significantly associated with depression scores namely housing score Their scores were significantly lower than those attending more than 1 interview. Exclusion of this group could potentially have an impact on the external validity of the study. It must be noted that their depression score although lower, was not significantly different between the 2 groups.

There was no control group so drawing any conclusion regarding whether HIV infected women are more depressed than their HIV negative counterparts was not possible. Depression has negative health consequences particularly for HIV infected women and needs to be treated whether they are more depressed than their HIV negative counterparts or not.

Conclusions

HIV infected pregnant women had a high level of depressive symptomatology, this declined markedly after birth but gradually returned close to but not to baseline levels. The pattern was similar to that seen in

other cohorts of pregnant women. Factors that were associated with high levels of depression symptomatology were low active coping, use of avoidant coping strategies, high internalised stigma scores, low self esteem scores, a higher housing score, a history of violence and having no partner.

Recommendations

Screening for those women likely to become depressed should take place in the antenatal period; preferably a short while after the diagnosis has been made and conveyed to the woman. Screening should include detecting women with low self-esteem, high internalised stigma, poor coping skills and a history of violence. Support services in the form of support groups or individual counselling should be offered to these women and this should be on an ongoing basis.

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Appendix 1

Questionnaire

SERITHI PROJECT

PREGNANT WOMAN QUESTIONNAIRE
1ˢᵗ VISIT:

IDENTIFICATION

CLINIC:

TOWNSHIP:

PATIENT'S FULL NAME:

PATIENT REGISTRATION NUMBER:

PATIENT'S DATE OF BIRTH

INTERVIEW

DATE IN FULL: DD   /MM/YY

INTERVIEWER'S NAME:

MEDICAL EXAMINER

LANGUAGE

LANGUAGE OF INTERVIEW:

HOME LANGUAGE OF RESPONDENT:

LANGUAGE CODES

1 ENGLISH	5 IsiXhosa	9 ziTSONGA
2 sePEDI	6 isiZULU	10 isiNDEBELE
3 seTSWANA	7 seSOTHO	11 seSWATI
4 AFRIKAANS	8 tshiVENDA	

MEDICAL QUESTIONNAIRE

> First I want to ask you a few questions about your health and about your previous pregnancies and then about this pregnancy

M4. How many of your children were born alive?

☐

M3. How many living children do you have now?

☐

M4.1 IF DIED **what were the causes?**

	CAUSE OF DEATH	AGE
CHILD 1		
CHILD 2		
CHILD 3		
CHILD 4		

M5.0 Were you using contraception before this pregnancy? **IF NO SKIP TO 5.5**

YES	1
NO	0

M5.1.**IF YES** what were you using?

NA	99
CONDOMS	1
INJECTION	2
PILL	3
OTHERS - SPECIFY	4

M5.2. Were you using this method on a regular basis?

YES	1
NO	2

M5.3. Why did you stop?

DIDN'T STOP – METHOD FAILED	1
METHOD OUT OF STOCK AT THE CLINIC	2
PARTNER SAID MUST STOP	3
WANTED BABY	4
CONTRACEPTION GAVE SIDE EFFECTS	5
OTHER – SPECIFY	6
FORGOT	7

M5.4. Would you say this was a planned pregnancy?

YES	1
NO	0

3

M5.5 Did you at any stage think of terminating the pregnancy?

YES	1
NO	0

M5.6   **IF**   **YES,**
why_____
_____
_____
_____
_____

M6.6 Have you ever received treatment from a traditional healer for your HIV?

YES	1
NO	0

Now I wish to ask you some questions on how you intend to feed the baby once it is born

F1. Once your baby is born will you be looking after the baby? **IF YES SKIP TO 2**

YES	1
NO	0

F1.1 IF NO who will be looking after the baby?_____

F1.2   Where   do   they   stay?
_____

F3. What method of feeding your baby would you like to use after the baby is born?

BREAST	1
FORMULA	2
OTHER	3
SPECIFY	

F4. Why would you like to use this method?

IT IS BEST FOR THE BABY'S HEALTH	1
A HEALTHCARE WORKER TOLD ME I MUST USE THIS METHOD	2
IT IS THE ONE I CAN AFFORD	3
IT IS THE TRADITIONAL METHOD	4
IT IS THE ONE I HAVE USED BEFORE	5
MY MOTHER/MOTHER IN LAW /HUSBAND SAYS I MUST USE THIS METHOD	6
OTHER –SPECIFY	7

F5.0 What method do you think you will cope with at home

BREAST	1
FORMULA	2
OTHER – SPECIFY	3

THE FOLLOWING QUESTIONS MUST BE ASKED OF <u>ALL PATIENTS</u>

IF BREASTFEEDING ASK THE FOLLOWING QUESTIONS BUT ADD THE FOLLOWING SENTENCE

"IF YOU DECIDED AT SOME STAGE TO FORMULA FEED……….….."

F5.1 Are there things that would make it difficult to formula feed?

YES	1
NO	0

F5.2 IF YES what makes it
difficult?_____

_____

_____

_____

F5.3 Infant formula costs R300-R400 per month. Are you able to pay for infant formula?

YES	1
NO	0

F5.4 Would someone be able to pay for it for you if necessary?

YES	1
NO	0

I now wish to ask you some questions about your medical history

---

H1. In the past 5 years have you been admitted to hospital?

YES	1
NO	0

H3. Have you had a chest infection or a persistent and recurrent cough?
IF NO SKIP TO H4.

YES	1
NO	0

H3.1 What were you told was the cause of your cough?

TB	1
PNEUMONIA	2
PCP	
OTHER-SPECIFY	

H8. Have you lost a lot of weight in the 6 months before this pregnancy?

YES	1
NO	0

SPECIAL INVESTIGATIONS

S1. RPR

+ve	1
-ve	0

S1.1. Hb

>10	1
<10	0

S1.2 LMP

S1.3 SFM **(cms)**

S1.4. Gestational age according to early sonar

S1.5. Gestational Age

S1.6 EDD

S4. Date of HIV test

E2			YES	NO
1. Skin	1. Acne	Face		
		Back		
	2. Herpes Zoster	Current		
		Scar		
	3. Dermatitis	Non specific		
		Seborrhoeic		
	4. Kaposi Sarcoma			
	5. Nail fungal infections			
2. Mouth	1. Oral candidiasis	White		
		Red		
		hypertrophic		
		periorbital		
	2. Oral hairy leukoplakia			
	3. Oral ulceration			
	4. Gingivitis			
3. Lymph Nodes	1. Small			
	2. Large			
	3. Matted			
4. CNS	1. Appropriate			
	2. Inappropriate			
	3. Peripheral Neuropathy			
5. Chest	1. Dyspnoea			
	2. Tachypnoea			
	3. Cough	Dry		
		Productive		
6. CVS	1. Normal			
	2. Tachycardia			
	3. Other			
7. GIT	1. HSM			
	2. Ascites			
	3. Diffusely tender			
8.	1. Oedema			
	2. Clubbing			
9.	1. Loss of weight			
	2. Cachexia			
STAGE				

CD4 COUNT

TAKEN	1
NO	2

E3.0. Any new problems (medical)_____
_____
_____
_____
_____

E3.1. Action taken_____
_____
_____
_____
_____

SECTION A: DEMOGRAPHIC INFORMATION

Thanks for being willing to talk to us. We need to understand your experiences to enable us to develop ways of helping people who are in similar situations to you. First I am going to ask you some questions about yourself, so that I can understand who you are and know a little bit about your background.

A2. How old were you on your last birthday?   (Age in completed years)

A4. Have you ever attended school?

YES	1
NO	0

IF NO THEN MARK "NA"

Are you currently attending school?

YES	1
NO	0
NA	99

A5. What is the highest level of education you have attained?

PRIMARY	1
SECONDARY	2
TERTIARY	3
NA	99

If PRIMARY OR SECONDARY

What standard/Grade did you reach

GRADE	
STANDARD	

A6. Which race group do you consider yourself?

BLACK	1
WHITE	2
COLOURED	3
INDIAN	4
OTHER, SPECIFY	5

A7. Are you at this moment?

SINGLE	1
MARRIED(civil or traditional)	2
SEPARATED	6

IF MARRIED:

A7.1 Are you living with your husband?

YES	1
NO	2

IF NO
A7.2 Where does your husband live……………………………………..?

IF SINGLE:

LIVING WITH PARTNER	7
HAVE A PARTNER NOT LIVING TOGETHER	8
SINGLE WITHOUT A PARTNER	9
NA	10

If MARRIED fill in NA

IF "8" THEN

A7.2 Where does your partner live…………………………………..?

A8. Is your current partner/husband the father of your child?

YES	1
NO	0
NA	99

SHOULD YOU FIND DIFFICULTY IN FILLING IN THE ABOVE TABLES PLEASE WRITE DOWN WHAT THE|PATIENT HAS SAID AND WE CAN CATAGORISE IT AT A LATER STAGE

Now I would like to ask you about the household in which you usually live.

A9. What is the main source of drinking water in your household?

PIPED WATER INSIDE HOUSE	1
PIPED WATER INSIDE THE YARD	2
PUBLIC TAP	3
OTHER, SPECIFY	4

A10. What kind of toilet facility do you use at home?

FLUSHING	1
BUCKET LATRINE	2
PIT LATRINE	3
NO TOILET FACILITY	4

A11. Can you describe the main material of the outside walls of your home?

PLASTIC/ CARDBOARD	1
MUD	2
MUD AND CEMENT	3
CORRUGATED IRON/ ZINC	4
PREFAB	5
BRICK/ CEMENT BLOCKS	6
WOOD	7
OTHER, SPECIFY	8

Now I would like some information about the people you share your home with.

A15. What whom do you share your home?

PERSON	No	Code
PARTNER		1
PARENT		2
DAUGHTER		3
SON		4
PARENT-IN-LAW		5
SON-IN-LAW		6
DAUGHTER-IN-LAW		7
GRANDCHILD		8
BORTHER/SISTER		9
OTHER RELATIVES		10
NOT RELATED		11
GRANDPARENTS		12
TOTAL		

A16. What are the ages of the children that you support?

Relationship to Mother (e.g. son, daughter, nephew etc.)	Age of the child

10

SECTION B: HUSBAND'S BACKGROUND AND WOMAN'S WORK
Now I am going to ask you a few questions about your work and husband's/partner's background.

B1. Are you currently working for money? (INCLUDING SELF EMPLOYMENT)

YES	1
NO	0

B1.1 IF YES: What kind of work do you do?

_____

B1.2. Do you get a regular income from this work?

YES	1
NO	0
NA	99

IF NO PARTNER FILL IN "NA"

B2. Has your current husband/partner ever attended school?

YES	1
NO	0
DON'T KNOW	2
NA	99

B2.1 IF YES: What is the highest level of education attained?

PRIMARY	1
SECONDARY	2
TERTIARY	3
DON'T KNOW	4
NA	99

B3. Does your current husband/partner currently work? (INCLUDING SELF EMPLOYMENT)

YES	1
NO	0
NA	99

B3.1. IF YES: What kind of work does yourpartner/ husband do? _____

B3.2. Does he get a regular income from this work?

YES	1
NO	0
DON'T KNOW	2
NA	99

B4. Within the last six months has your husband/partner provided money you need for food, rent, and bills?

YES	1
NO	0
NA	99

B5. What are the other sources of income in your household?

OLD AGE PENSION / GOVERNMENT	1
PENSION FROM WORK/RETIREMENT BENEFITS	2
DISABILITY GRANT /.GOVERNMENT	3
COMPENSATION FUND (INJURY / ILLNESS AT WORK)	4
STATE MAINTENANCE GRANT/R CHILD SUPPORT GRANT	5
PRIVATE MAINTENANCE PARENT/ FORMER /PARTNER	6
CARE DEPENDENCY (SINGLE CARE) GRANT	7
FOSTER CARE GRANT	8
UNEMPLOYMENT INSURANCE FUND	9
REMITTANCE/FINANCIAL SUPPORT PEOPLE NOT IN HOUSEHOLD	10
GRATUITIES/OTHER LUMP SUM	11
OTHER SOURCES (SPECIFY)	12
NO OTHER SOURCES OF INCOME	13

B6. After deductions about how much money comes into your household each month   R _____

PROBE FOR ESTIMATE IF NOT SURE

B7.   How many people live on this income?

All families are different and in each family different people make the decisions. I am now going to ask you a few questions about who has the final say about decisions in your family.

B8.   Who in your household decides on what food to buy?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
OTHER, SPECIFY	4

B9.   Who in your household has the final say on how money is spent?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
OTHER, SPECIFY	4

B11.   If your child were sick, who in your household would have the final say, if a decision needed to be made about treatment?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
OTHER, SPECIFY	4

B12. Who in your household has the final say on whether to have another child?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
NA	5
OTHER, SPECIFY	4

B13. Who in your household do you think will have the final say about which method to use to feed your baby?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
OTHER, SPECIFY	4

B14. Partner do not always agree on everything, tell me between you and your partner who has the final say in decisions to do with sex?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
OTHER, SPECIFY	4

B15. Who has the final say about whether to use contraception?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
NA	4

B15.1 Who has the final say about whether to use a condom?

RESPONDENT	1
HUSBAND/ PARTNER	2
JOINTLY	3
NA	4

B15.2 How often do you use a condom?

ALWAYS	1
MOST OF THE TIME	2
SOME OF THE TIME	3
NEVER	4
NOT APPLICABLE	5

B15.3 Have you been sexually active during the last 6 months

YES	1
NO	0

SECTION C: HIV+ PERSONAL EXPERIENCE

It is very important for us to understand how it feels when someone first finds out they are HIV positive and how they react to the news. This is so that in the future we can give better support to people who have this experience. The next few questions will deal with this.

C1. When was the **FIRST** time you tested positive for HIV?

Was it in this pregnancy or before this pregnancy?

THIS PREGNANCY	1
BEFORE THIS PREGNANCY	2

C2. **IF BEFORE THIS PREGNANCY:** Approximately how long ago was it?

YEARS	
MONTHS	

IF THIS PREGNANCY THEN MARK "NA" FOR C3.

C3. Why did you go for a test at that time**?**

PREGNANT	1
SCARED I HAD HIV	2
HUSBAND/ PARTNER TESTED POSITIVE	3
I WAS ILL	4
RAPE	5
OTHER, SPECIFY	6
NA	99

C4. **IF THIS PREGNANCY:** Why did you get tested for HIV this time?

IF DID NOT TEST DURING THIS PREGNANCY AT ALL MARK "NA"

PREGNANT	1
SCARED I HAD HIV	2
HUSBAND/ PARTNER TESTED POSITIVE	3
I WAS ILL	4
RAPE	5
OTHER, SPECIFY	6
NA	7

C5. What was your first reaction when you first found you were HIV positive?

C6. How have your feelings changed since then, or are they just the same?

How have they changed?

JUST THE SAME	1
CHANGED, SPECIFY BELOW	2

14

C7.   Before you had the test did you discuss it with your partner (THE PARTNER THAT SHE HAS/HAD AT THE TIME OF GOING TO HAVE THE TEST)

IF THIS IS DIFFICULT TO FILL IN PLEASE WRITE A COMMENT HERE

YES	1
NO	0
NA	99

IF NO FOR C7 THEN MARK "NA"

C8.   Did he want you to get tested?

YES	1
NO	0
NA	99

C9.   Has your **current partner** ever had an HIV test?

IF NO CURRENT PARTNER FILL IN "NA"

YES	1
NO	2
NA	99

C10.   Do you know if it was positive or negative?

POSITIVE	1
NEGATIVE	2
DON'T KNOW	3
NA	99

C10.1 Did you see the results or did a counsellor tell you

YES	1
NO	0
NA	99

C11. Does anyone else in your family have HIV or has any family member passed away because of HIV/AIDS?

YES	1
NO	0
DON'T KNOW	3

C11.1 IF YES: Who is this person?

EX-PARTNER / EX-HUSBAND		1
SON		2
DAUGHTER		3
SON-IN-LAW		4
DAUGHTER-IN-LAW		5
GRANDCHILD		6
PARENT		7
PARENT-IN-LAW		8
BROTHER/SISTER		9
OTHER RELATIVES		10

C12. Other than your family is there anyone with whom you have frequent contact that has HIV?

YES	1
NO	0
DON'T KNOW	3

SECTION D: EXPERIENCE OF HIV DISCLOSURE

We know it is very hard to talk to other people about having HIV and some people find it too difficult to talk to anyone about it at all. We do not say there is a right or wrong decision We just want to understand the decision you have made regarding disclosure.

D1. Have you told anybody about your HIV status?

If "YES", continue with TABLE 1 & TABLE 2
If 'NO", skip to TABLE 2 (D3)

YES	1
NO	0

D2. **TABLE 1: Disclosure table**

Who was it that you told? first, second etc.	Why was it that you wanted to disclose to this person?	What was this person's reaction?	Overall, do you consider it a good or bad thing that you disclosed to this person? Good Bad	
1)				
2)				
3)				
4)				
5)				

PROMPT, BEFORE YOU FINISH COMPLETING DISCLOSURE SHEET: "IS THERE ANYONE ELSE YOU HAVE TOLD ABOUT THE HIV?"

D3. "NOT TOLD": FOR THOSE WHO HAVE TOLD NO ONE, ASK: C) AND D) RELATING THE ANSWERS TO THE PERSONS LISTED IN COLUMN A OF D3.

"TOLD": FOR THOSE WHO HAVE TOLD SOMEONE, ASK: A), B), C) AND D).

TABLE 2:

a. You did not mention……? (ASK ABOUT ALL NOT MENTIONED)	b. Have you ever disclosed to this person?		c. Why did you not disclose to this person?	d. Do you think he/she might already know/ suspect?	
	YES	NO		YES	NO
PARTNER	1	0		1	0
YOUR PARENTS	1	0		1	0
YOUR IN-LAWS **(IF SINGLE DO NOT ASK)**	1	0		1	0
OTHER FAMILY MEMBERS?	1	0		1	0
FRIENDS	1	0		1	0
PEOPLE AT WORK	1	0		1	0
OTHER PEOPLE IN THE COMMUNITY	1	0		1	0

IF DISCLOSED DO D4 ONLY

IF NO DISCLOSURE DO D6 ONLY

D4. Many people are afraid to disclose their HIV status. What made you different and gave you the courage to disclose?

_____
_____
_____

D6. If you do want to disclose in the future what do you think would make it easier for you?

_____
_____
_____
_____

SECTION E: STIGMA RELATED RESPONSES

We know that different people have very different feelings and reactions to HIV and we want to get a better understanding of these feelings. The next few questions are about how you feel about HIV and how you think other people react to HIV.

E1

The following is a list of statements that people with HIV have made about themselves. For each statement, please let me know the answer est to the way you feel about yourself. Let me know if you strongly agree, agree, disagree or strongly disagree (pointing at words) with the OW CARD)

PERSONAL VIEW	STRON	AGREE	DISAGREE	STRONG DISAGREE	DK/ NO ANS
1. When people know I have HIV I feel uncomfortable around them					
2. I feel ashamed that I have HIV					
3. I must have done something to deserve getting HIV					
4.If I drank from a tap and people knew I had HIV they would not drink from the same tap					
5. Most employers would not employ me because I am HIV+					
6.Although I have HIV I am a person who deserves as respect as anyone else much					
7. I feel that it is my fault that I got HIV					
8.People are right to be afraid of me because I have HIV					
9.Because of my HIV I feel I am less attractive to others					
10 I have a lot to teach people about life through having HIV					
11. I feel it is completely safe for me to handle other people's children					
12. I deserve a lot of praise for coping with HIV					
13. I would understand if people rejected my friendship because I'm HIV+					
14. My neighbours would not like me living next door if they knew I had HIV					
15. I think less of myself because I have HIV					
16. I think my getting HIV was just a matter of bad luck					
17. I feel that I am bewitched because I have HIV					
18. If I was in public or private transport and someone knew I had HIV they would not sit next to me					
19. Even though I have HIV I don't believe I am different from anyone else					
20. Getting HIV is a punishment for bad behaviour					

E4	The general public has a wide range of beliefs about people who have AIDS or HIV. I am going to read a list of some of these beliefs and attitudes and I want you to let me know what you think **most people** in your community believe. Let me know if you strongly agree, agree, disagree, or strongly disagree that most people think like this. (SHOW CARD)

COMMUNITY VIEW	STRONG AGREE	AGREE	DISAGREE	STRONG DISAGREE	DK/ NO ANS
1. Most people think that getting HIV is a punishment for bad behaviour					
2. Most people think that someone with HIV is no different from anyone else					
3. Most people would not sit next to someone with HIV in public or private transport					
4. Most people feel that some people with HIV are bewitched					
5. Most people think that having HIV is just a matter of bad luck					
6. Most people think less of someone because they have HIV					
7. Most people would not like someone with HIV to be living next door.					
8. Most people would reject the friendship of someone with HIV					
9. Most people feel that a person with HIV deserves a lot of praise for the way that they cope with the disease					
10. Most people feel that it is safe for a person with HIV to look after somebody else's children					
11. Most people think that people with HIV can teach us a lot about life					
12. Most people would not be attracted to a person with HIV					
13. Most people are afraid to be around people with HIV					
14. Most people feel that if you have HIV it is your own fault					
15. Most people feel that people with HIV deserve as much respect as anyone else					
16. Most employers would not hire someone with HIV to work for them					
17. Most people would not drink from a tap if a person with HIV had just drunk from it					
18. Most people believe that if you have HIV you must have done something to deserve it					
19. Most people believe that someone with HIV should be ashamed of themselves.					
20. Most people feel uncomfortable around people with HIV					

E5

I am now going to go through a list of things that some women have experienced because they have HIV.

Please let me know whether you have experienced this and, if so, whether it was a little or a lot. (SHOW CARD)

SKIP E5 E6 E7 E8 IF THE CLIENT HAS NOT DISCLOSED

ENACTED OR EXPERIENCED COMMUNITY STIGMA	NO EXPERIENCE	LITTLE EXPERIENCE	LOTS EXPERIENCE	DK/ NO ANS
1. I have lost friends because I'm HIV+				
2. I have felt hurt by how people have reacted to learning about my HIV				
3. People have avoided touching me because of my HIV				
4. People don't want me around their children because of my HIV				
5. People act as though it is my fault I am HIV+				
6. People don't want me to come to their houses because I am HIV+				
7. I have been shouted at because I am HIV +				
8. I have been called bad names because I am HIV+				
9. I have been hit or physically hurt because I am HIV+				
10. People have threatened to kill me because I am HIV+				

E6

My ex-husband/ ex-partner left me because I am HIV +

YES	1
NO	0

E7

Have you had any other experiences than those mentioned where people have discriminated against you or treated you badly because of your HIV (IF "NO" GO TO F1)

YES	1
NO	0

E8

I know this might be difficult for you, but could you please describe these experiences for me.(ONLY RELATES TO E7)

_____

_____

_____

_____

SECTION F QUESTIONS ON TREATMENT AND EXPERIENCES IN THE HOUSEHOLD

> **I am now going to ask you some questions about your experiences in the household**

F1. Have you **ever** experienced problems with household members regarding financial matters

YES	1
NO	0

PROBE IF NECESSARY
1. Money taken without consent
2. Prevented from getting access to food
3. Control taken over money without permission
4. Forced to ask for food etc from others
5. Prevented from earning an income

F2. Have you **ever** experienced problems with household members regarding emotional relations?

YES	1
NO	0

PROBE IF NECESSARY
1. Household member threatened to harm you physically (or family) or threatened with eviction
2. Degraded or belittled by household member
3. Restricted your contact with people of your choice
4. Household member called you crazy or bewitched
5. Household member threatened to commit suicide because of you

F3 Have you **ever** experienced problems with household members regarding your physical safety

YES	1
NO	0

PROBE IF NECESSARY
1. Household member has hurt you by slapping, hitting, punching, kicking you
2. Household member has hurt you by throwing harmful objects at you
3. Household member has used a knife or any other weapon on you
4. Household member has tried to choke strangle or suffocate you
5. Household member has burnt you

F4. Have **ever** experienced problems with household members regarding sexual relations

YES	1
NO	0

PROBE IF NECESSARY
1. Household member has forced you to have sex with someone else
2. Household member has kissed or touched you sexually against your will
3. Household member has forced you to have sex in exchange for food money goods etc against your will
4. Household member has forcefully tried to have sex with you against your will
5. Household member has forced you to have a child /fall pregnant against your will
6.

F5	We know the situations are very challenging, how do you try and cope with the situations you have mentioned above ? (ONLY VIOLENCE) _____ _____ _____ _____

F6. In a desperate situation,outside of your household have you ever been in the position where you had to have sex with someone in order to obtain money, food, shelter & safety

YES	1
NO	0

COMMENTS_____
_____
_____
_____
_____

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SECTION G: SOCIAL SUPPORT

> The amount of support people get from others around them can be important to people with HIV. In the next few questions we want to get an understanding of how much support you get from others.
>
> **PRACTICAL SUPPORT**
>
> First, I will ask you about people who are available to provide the practical, everyday kinds of things people sometimes want from each other. Feel free to mention anyone you want as often as you want, including people who live with you. I do not need the names of these people only their relationship to you.

G1	If you were ill and had to stay in bed for days, is there someone who would take care of you? **IF YES:** Who is this person/persons?……………………….…… ……………………………………………………………………	YES	1	
		NO	0	
		IF NO (Skip to G2)		
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3	
		QUITE A LOT (SOME)	2	
		ONLY A LITTLE	1	

G2	If you needed money for food would there someone to help you? **IF YES:** Who is this person/persons?……………………….…… ……………………………………………………………………	YES	1	
		NO	0	
		IF NO (Skip to G3)		
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3	
		QUITE A LOT (SOME)	2	
		ONLY A LITTLE	1	

G3	Is there someone who would help you in an emergency even if they had to go out of their way? **IF YES:** Who is this person……………………………………….. ………………………………………………………………..	YES	1	
		NO	0	
		IF NO (Skip to G4)		
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3	
		QUITE A LOT (SOME)	2	
		ONLY A LITTLE	1	

EMOTIONAL SUPPORT

Now I want to ask you about who provides you with emotional types of support. Feel free to mention anyone you want as often as you want.

G4	Is there someone you could talk to about things that have been troubling you? **IF YES:** Who is this person/persons?…………………………… ………………………………………………………………………	YES	1	
		NO	0	
		IF NO (Skip to G5)		
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3	
		QUITE A LOT (SOME)	2	
		ONLY A LITTLE	1	

G5	Is there someone who really understands you, and what your life is like? **IF YES:** Who is this person/persons?……………………………….. ………………………………………………………………………	YES	1	
		NO	0	
		IF NO (Skip to G6)		
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3	
		QUITE A LOT (SOME)	2	
		ONLY A LITTLE	1	

G6	If you were going through a tough time, would you have someone to talk to? **IF YES:** Who is this person/persons?……………………………… ………………………………………………………………………	YES	1	
		NO	0	
		IF NO (Skip to G7)		
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3	
		QUITE A LOT (SOME)	2	
		ONLY A LITTLE	1	

AFFIRMATIONAL SUPPORT

Next, I want to ask about people who value you as a person, or who show that they respect you.

G7	If you were feeling low about yourself, or felt that you couldn't do anything right, is there someone who has faith in you? ((PROMPT –Is there someone who encourages you?) **IF YES:** Who is this person/persons**?**……………………………… ………………………………………………………………………………	YES	1
		NO	0
		IF NO (Skip to G8)	
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3
		QUITE A LOT (SOME)	2
		ONLY A LITTLE	1

G8	Is there someone who accepts you as you are, both your bad points and your good points? **IF YES:** Who is this person/persons**?**……………………………… ………………………………………………………………………………	YES	1
		NO	0
		IF NO (Skip to G9)	
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3
		QUITE A LOT (SOME)	2
		ONLY A LITTLE	1

G9	Is there anyone who lets you know that they respect who you are and how you think and act? **IF YES:** Who is this person/persons?……………………………… ………………………………………………………………………………	YES	1
		NO	0
		IF NO (Skip to G10)	
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3
		QUITE A LOT (SOME)	2
		ONLY A LITTLE	1

	HIV SUPPORT
	Now I want to ask you about people who provide you with support related to being HIV+.

G10	If you had a decision to make about the HIV, is there someone you could talk to who would give you good advice? **IF YES:** Who is this person/persons?……………………………. ………………………………………………………………………	YES	1
		NO	0
		IF NO (Skip to G11)	
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3
		QUITE A LOT (SOME)	2
		ONLY A LITTLE	1
G11	If you had to be hospitalized for a few days because of your HIV is there someone who would care for your child(ren)? **IF YES:** Who is this person/persons?…………………………… ………………………………………………………………………	YES	1
		NO	0
		IF NO (Skip to G12)	
	How much of this type of support would there be if you needed it?	AS MUCH AS I NEED (A LOT)	3
		QUITE A LOT (SOME)	2
		ONLY A LITTLE	1
G12	Is there someone who knows about your HIV and who really understands what you're going through? **IF YES:** Who is this person/persons**?**…………………………… ………………………………………………………………………	YES	1
		NO	0
		IF NO (Skip to G13)	
	How much of this type of support would there be if you needed it?	AS M UCH AS I NEED(A LOT)	3
		QUITE A LOT (SOME)	2
		ONLY A LITTLE	1

G 12.1 Do you have a friend who you meet with regularly whom is HIV+?

YES	1
NO	0

G12.2 Do you participate in an HIV support group?

YES	1
NO	0

NEGATIVE SUPPORT
Now I want to ask you about some negative and unwanted support that you have been given by family and friends.

G13	Are there any people in your circle of family and friends who are domineering, who try to tell you what to do or want to run your life for you? IF YES: **Who is this person/persons?…………………………** How often does this happen?	YES	1
		NO	0
		IF NO(Skip to G14)	
		All the time	3
		Some-times	2
		Occasionally	**3**

G14	Are there any people in your circle of family and friends who try to protect you too much or treat you like a child? IF YES: Who is this person/persons?…………………………… How often does this happen?	YES	1
		NO	0
		IF NO(Skip to G15)	
		All the time	3
		Some-times	2
		Occasionally	1

G15	Are there people in your circle of family and friends who give you too much unwanted advice? IF YES: Who is this person/persons?………………………………………… How often does this happen?	YES	1
		NO	0
		IF NO (Skip to G16)	
		All the time	3
		Some-times	2
		Occasionally	1

G16	Are there people in your circle of family and friends who didn't offer to help or support you when you thought they should? IF YES: Who is this person/persons?…………………………………………… How often does this happen?	YES	1
		NO	0
		IF NO(Skip to G17)	
		All the time	1
		Some-times	2
		Occasionally	**3**

G17	Is there anyone who would prevent you or make it difficult for you to get treatment for HIV or related conditions?		
		YES	1
		NO	0
G18	**IF YES:** Who is this person?………………………………………….…… Why do you think they are preventing you from getting treatment for HIV? _____		

SECTION H: KNOWLEDGE ABOUT HIV/AIDS

	Next I am going to ask you a few questions about what you know about HIV/AIDS.			
H2	Now please answer whether the following statements are true or false.	TRUE 1	FALSE 0	DK 99
	1. A person can get HIV from drinking from the same glass as someone with HIV/AIDS			
	2. A person can get HIV by not using condoms during sexual intercourse			
	3. A person can get HIV by touching an HIV+ person's blood if they have a small cut on the hand			
	4. A person can get HIV by being bitten by a mosquito or similar insect			
	5. The HIV test can remain negative for many months after someone becomes infected with HIV.			
	6. A medical person e.g. doctor/nurse can tell if the baby has HIV by just looking at the baby.			
	7. A person can have HIV for many years without becoming ill with AIDS			
	8. When someone gets HIV they always lose weight very quickly			
	9. Following a healthy lifestyle can to help someone with HIV stay healthy			
	10. Some babies born to pregnant women with HIV will get HIV			
	11. If a pregnant woman with HIV takes the AIDS medicine before her baby is born, she will not get sick from HIV			
	12. If a woman with HIV takes an "AIDS" medicine before that baby is born it is less likely that the baby will get HIV			
	13. All babies born to women with HIV who take the "AIDS" medicine will not get HIV			
	14. All babies being breast fed by women with HIV will get HIV			
	15. All babies born to pregnant women with HIV will get HIV			

	It can be a very emotional time having a baby. I am now going to ask you about how you are feeling about yourself right now. (SHOW CARD)			
I1	SELF ESTEEM? remove	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
	1. I think I am no good at all				
	2. I feel I have a number of good qualities				
	3. I can do things as well as most other people				
	4. I do not have much to be proud about				
	5. I feel useless at times				
	6. I am as good as other people				
	8. I think I am a failure				
	9. I have a positive attitude toward myself				
	10. In general I am satisfied with myself				

Having HIV can cause all sorts of emotions. For each statement, how often have you felt of behaved this way DURING THE PAST WEEK? (SHOW CARD)					

I2	DEPRESSION	RARELY OR NONE OF THE TIME (LESS THAN 1 DAY)	SOME OR LITTLE OF THE TIME (1-2 DAYS	OCCASIONALLY OR A MODERATE AMOUNT OF THE TIME (3-4 DAYS)	MOST OR ALL OF THE TIME (5-7 DAYS)
	1. I was bothered by things that usually don't bother me				
	2. I did not feel like eating; my appetite was poor				
	3. I felt that I could not shake off the blues even with the help of my family				
	4. I felt that I was just as good as other people				
	5. I had trouble keeping my mind on what I was doing				
	6. I felt depressed				
	7. I felt that everything I did was an effort				
	8. I felt hopeful about the future				
	9. I thought my life had been a failure				
	10. I felt fearful				
	11. My sleep was restless				
	12. I was happy				
	13. I talked less than usual				
	14. I felt lonely				
	15. People were unfriendly				
	16. I enjoyed life				
	17.I had crying spells				
	18.I felt sad				
	19. I felt that people disliked me				
	20.I could not get going				

Now I would like you to select from the statements below the one that best describes how you try and cope with daily situations that confront you. (SHOW CARD)			

I3	COPING	MOST OF THE TIME	SOME OF THE TIME	ALMOST NEVER
	1. I take responsibility to protect my and other people's health			
	2. I try to fight this virus by keeping fit and eating in a healthy way			
	3. I learn to live with HIV			
	4. I accept that I have HIV and that this cannot be changed			
	5. I try to get as much information as I can about HIV			
	6. I talk to someone with similar experience to find out how best to handle the situation			
	7. I use my time to educate others to stay healthy			
	8. I support other people with HIV			
	9. I am inspired to make the most of the rest of my life			
	10. I refuse to believe that it has happened to me			

	MOST OF THE TIME	SOME OF THE TIME	ALMOST NEVER
11.I can cope as long as people do not know my status			
12. I talk to someone who can help me			
13. I get comfort and understanding from people			
14. I look for something good in what is happening			
15. This situation helped me to change my life for the better			
16. I seek comfort in my religion or spiritual beliefs			
17. I keep myself busy to take my mind off HIV			
18. I try not to think about the situation I am in			
19. I get upset and fight with other people			
20. I talk to let my unpleasant feelings escape			
21. I use alcohol or drugs to help me get through it			
22. I wish I could escape from this situation			
23. There is nothing I can do to make me feel better			
24. I do not feel in control of my health			

I4
On a scale of 1 to 10 how would you rate the way you are coping?

I5. Now that more clinics are going to be providing treatment for HIV/AIDS how do you think this will affect your disclosure of your status? Will it make it easier.

YES	1
N0	0

I6 Why do you think this?_____
_____
_____
_____
_____
_____

PLEASE NOTE DOWN ANY SOCIAL PROBLEMS THAT THE PATIENT HAS BROUGHT TO YOUR ATTENTION AND ANY ACTION TAKEN TO SOLVE THE PROBLEMS

_____
_____
_____
_____

Thank you very much for answering all these questions. The information you have given will go a long way towards helping other women who are HIV+. In order for us to contact you again to remind you about your future appointments please could provide us with the following information. If we do phone you and do not speak to you personally we will leave a message for you to contact us at Serithi. We will not give any other information to the person

Patient address	Address of person who can contact patient	Address of person who can contact patient
Tel no.	**Tel no**	
	Relationship to patient	**Relationship to patient**

Appendix 2

Consent Form

PREGNANT WOMAN QUESTIONNAIRE
28 Weeks: 1ˢᵗ Visit

PATIENT INFORMATION LEAFLET AND INFORMED CONSENT

Study title   Understanding HIV-related stigma and its effect on choices of infant feeding and disclosure of status.

Introduction

You are invited to volunteer in this study. This information leaflet will help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions please do not hesitate to ask a member of the project staff. You should not agree to take part unless you are completely happy about your participation and all the procedures involved.

Purpose of the research

HIV now affects many people in South Africa. One of the aims of the Serithi project is to assist and empower women to cope with their HIV status and to make informed choices. The project is being conducted by the University of Pretoria in partnership with Yale University and supported by the staff at the clinic you are attending now. You have been chosen or approached to participate in this study because you are pregnant and have HIV infection and therefore we would like to invite you to join a support group for HIV positive individuals, where you will receive information, learn new skills and share experiences. You may also have the opportunity to join an income-generation group (or a skills development initiative that may lead to income generation).

This study will also provide us with important information about experiences of HIV positive women, and the number of babies that are becoming infected with HIV and how this relates to how they are fed.

The information gained from you and others will be used to develop a support program for other HIV-positive pregnant women in the future. We hope that this program will help HIV positive women to be more able to speak to others about their diagnosis and choose a safe way of feeding their babies. We further hope that this programme will empower women to take responsibility for their own health and that of their babies.

Description of what to expect in this study

If you agree to participate in this study, you would be involved from the time of your pregnancy and after the birth of your baby. If the baby is not staying with you, and thus not able to bring your baby for the follow-up visits to this clinic, you will not be able to enter onto this trial. Following is a description of the different parts of the study:

Interviews: We will ask you to participate in one interview when you are pregnant. At this visit we will do a physical examination. You will be asked to bring your baby back to the clinic within three days of birth. At this time you will be asked a few questions about your health and that of the baby. A second interview will be conducted when your baby is 6 weeks old. There will be a third interview when your baby is three months old. The fourth interview will be conducted when your baby is six months old. The fifth when your baby is nine months old and the sixth when the baby is twelve months old. The first of these interviews will take about 2 hours. The second interview will take about an hour and will include questions about your health and your baby's health, the method you are using to feed your baby, and whether you have been able to talk to others about the HIV. The third interview will take about 2 hours and will include similar questions. Subsequent interviews will last about an hour.

Information from medical records: We will collect information about your baby's birth from your medical record and the medical record of your baby. We will also collect information about your baby's growth and any illnesses that might occur during the time you and your baby are involved in the study.

Blood tests from you: At the first interview we will take blood from you for a CD4 count. This will enable us to stage and monitor your disease. At six weeks after delivery we will take bloods to assess and monitor your CD4+ count and nutritional status, in particular we are interested in finding out if you are getting enough nutrients from your

diet. This information will be obtained through analysis of your blood. At six and twelve months after the birth of your baby, we will repeat all these blood tests.

Blood tests from your baby: To find out whether or not your baby has HIV infection, blood tests will be done at different times - the first will be just after your baby is born, and the other times will be when you come to the clinic for your baby's regular visits when your baby is 6 weeks and 3 months old. For some babies a fourth test may be required at 6 months. These blood tests are done by pricking your baby's heel or finger and using blotting paper to take a small amount of blood.

What are my rights as a participant this study?

You participation in this trial is entirely voluntary and you can refuse to participate or stop at any time without giving any reason. If you decide not to participate or withdraw from the study this will not affect the care you receive or your relationship with the doctors and nurses who provide care for you and your baby. If you do participate in the study, you can leave blank or refuse to answer any questions that you don't want to answer.

Risk regarding confidentiality

The only risks to you and your baby in this study relate to confidentiality of information.

All information obtained during the course of this study is strictly confidential. Any scientific reports using data from this study will not include information that identifies you as a subject in this study.

Once information is collected, your name will be removed and it will be identified by a code number only. The list of names and code numbers will be kept in a locked cabinet to which only the researchers will have access to. Whenever we need to contact you or meet with you for a follow-up visit, this will be described as a routine health care visit and there will be no mention to anyone about the HIV infection.

We consider it important that if the blood tests show that your baby has HIV infection this information should be given to the medical staff caring

for your baby so that they can provide the best care available. This, however, will only be done with your written permission and if you do not wish this to happen, no information will be provided.

Benefits

This study is unlikely to benefit you personally, except it will provide information about whether or not your child is infected. Finding out early on that your child is not infected will provide you with relief. If, unfortunately, your child is infected, then finding this out early could help make sure that your child gets the most appropriate medical care that is available. Further, by monitoring your CD4+ count and nutritional status, we will be able to refer you for medical assistance at the clinic you are attending or to the Immunology clinic at Kalafong Hospital.

This study is expected to help us in the future develop more effective programs for pregnant women who are HIV positive.

Insurance and financial arrangements

You will not be paid to participate in this study, however, you will receive some money in compensation for out-of-pocket and/or travel expenses for each of the interviews. The amount will be discussed with you by the Serithi Project Staff.

Has this study received ethical approval?

This study has been approved by the Health Sciences Ethics Committee of the University of Pretoria. This study is in accordance with the Declaration of Helsinki (last update: October 2000), which deals with the recommendations guiding doctors in biomedical research involving human/subjects.

Informed consent

I hereby confirm that I have been informed by the investigator, …………………………………. about the nature, conduct, risks and benefits of the study, protocol number 209(a) and (b) /2002. I have also

read (or have had someone read to me) the above information regarding this study. I am aware that the results of this study, including personal details regarding my age, the month of my baby's birth, and the diagnosis, will be anonymously processed into a report. I may, at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Name of subject _____ **(Please print)**

Subject's signature_____ **Date _____**

I, …………………………………. herewith confirm that the above patient has been informed fully about the nature, conduct, and risks of the above study.

Investigator's name_____ **(Please print)**

Investigator's signature _____ **Date _____**

If you have any further questions about this study or if you have a problem, you can call the Serithi offices, at 012-373-1077. If you have a question about your rights as a participant, you can call the University of Pretoria Health Sciences Ethics Committee at 012-339-8612.

ICB NUMBER	00 00 2235
FWA	00 00 2567