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A pilot study evaluating depression in mothers with children diagnosed with Down syndrome in state healthcare.

Melissa Swanepoel

(595974)

A research report (in the format of a “submissible” paper) submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree Master of Science in Medicine (Genetic Counselling).

Johannesburg, 2017

Declaration

I, **Melissa Swanepoel**, declare that this research report (in the format of a "submissible" paper) is my own, unaided work. It is being submitted for the Degree of Master of Science in Medicine (Genetic Counselling) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



(signature of candidate)

16th day of November in 2017 in Johannesburg

Contribution of the candidate to the paper

Declaration: Student's contribution to article(s) and agreement of co-author(s)

I, Melissa Swanepoel, student number 595974, declare that this Research Report is my own work and that I contributed significantly towards research findings presented in the paper intended for publication below.

Signature of Student  **Date** 16/11/2017

Name of Primary Supervisor: Ms Tabitha Haw

Signature of Primary Supervisor  **Date** 16/11/2017

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of her Research Report. In cases where the student is not the 1st author of a published article, the primary supervisor must explain (under comments) why the student is entitled to use the paper for his/her degree purposes.

Article Title: A pilot study evaluating depression in mothers with children diagnosed with Down syndrome in state healthcare.

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Comments by primary supervisor:

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This research report is dedicated to my loving and supportive parents, Mercia and Gerhardus Swanepoel, and partner, Frederick Johannes Clasen.

Presentations arising from this research project

1. 8th Cross-Faculty Postgraduate Symposium-25 October 2017-School of Public Health Auditorium; University of the Witwatersrand (Poster Presentation).
2. Division of Human Genetics Departmental Seminar-08 November 2017-National Health Laboratory Service Braamfontein (Oral Presentation).

Abstract

Parenting a child who has an intellectual disability has been shown to increase the risk for developing depression. The purpose of this study was to screen for depression in mothers with a child diagnosed with Down syndrome in state health care in Johannesburg, and to identify associated sociodemographic variables. The Edinburgh Postnatal Depression Scale (EPDS) was used to assess depression in participants along with a 10-item sociodemographic questionnaire, administered to 30 biological mothers of children postnatally diagnosed with Down syndrome. Eight mothers (26.7%) screened positive for depression with an EPDS score of 13 or greater. A statistically significant association was found between an HIV positive status and mothers who had an EPDS score of 13 or greater (p = 0.01). No significant association between a positive screening score for depression and various other sociodemographic factors were identified. Mothers with children diagnosed with Down syndrome, may be vulnerable towards developing depression.

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"For I know the plans I have for you," declares the Lord, "Plans to prosper you and not to harm you, plans to give you hope and a future." Jeremiah 29:11

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A pilot study evaluating depression in mothers with children diagnosed with Down syndrome in state healthcare.

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The authors declare that there is no conflict of interest.

Abstract

Background: Parenting a child who has an intellectual disability has been shown to increase the risk for developing depression. The purpose of this study was to screen for depression and to determine if there is an association between depressive symptoms and certain sociodemographic factors in mothers with a child diagnosed with Down syndrome in state health care facilities in Johannesburg.

Methods: The study included 30 biological mothers of children between the ages of six months and three years who were postnatally diagnosed with Down syndrome. The Edinburgh Postnatal Depression Scale (EPDS) was used to assess depression in participants. A 10-item sociodemographic questionnaire was concurrently administered. Data analysis was conducted using descriptive and correlational analysis.

Results: The 30 mothers had a mean EPDS score of 9.1 (SD =5.89) with scores ranging between 0 and 26. Eight mothers (26.7%) screened positive for depression with an EPDS score of 13 or greater. A statistically significant association was found between an HIV positive status and mothers who had an EPDS score of 13 or greater ($p = 0.01$). No significant association between depression and various other sociodemographic factors were identified.

Conclusion: Mothers with children diagnosed with Down syndrome, may be vulnerable towards developing depression. A significant association was found between a positive HIV status and symptoms of depression, in mothers with children diagnosed with Down syndrome. This study indicates the need for further investigations assessing the causes and exacerbating factors resulting in postnatal depression in mothers with a child diagnosed with Down syndrome.

Keywords: Down syndrome, postnatal depression, Edinburgh Postnatal Depression Scale, maternal depression, Trisomy 21, intellectual disability

Introduction

Down syndrome and its incidence in South Africa

Down syndrome, also known as Trisomy 21, is a genetic condition which occurs when there is an extra partial or complete copy of chromosome 21 (Bull, 2011). Non-disjunction (the failure of segregation of homologous chromosomes during cell division) accounts for 95.0% of cases of Down syndrome and it occurs more frequently in women of advanced maternal age. The remainder of Down syndrome cases are explained by mechanisms of chromosome translocation or mosaicism (Bull, 2011).

Children with Down syndrome have intellectual disability, are short in stature, hypotonic and have distinctive facial features (Bull, 2011). They are also at risk of multiple other medical complications including congenital cardiac defects which often need to be corrected surgically (Bull, 2011).

Down syndrome is one of the most commonly seen syndromes in genetic clinics across the world (Sheets *et al.*, 2011). Approximately one in 500 live births in South Africa are diagnosed with Down syndrome (Christianson *et al*., 2006; Willoughby *et al.*, 2016).

Postnatal depression risk factors and its effect on the child

Postnatal depression is a common mental health issue worldwide, however, data from South Africa suggests the prevalence estimates are higher than those reported in other countries (Kathree *et al.*, 2014). Postnatal depression occurs predominantly within the first three months after birth. The duration of postnatal depression is variable, with many women reportedly still being affected between three to six months after onset but sometimes, up to three or four years after onset (Hewitt & Gilbody, 2009). Risk factors associated with developing postnatal depression include, a prior history or family history of mental illness, partner conflict, poor social support, obstetric complications and low socioeconomic status (Huang & Mathers, 2001; Patel *et al*., 2002).

Maternal depression can result in neglect and can impede cognitive development in an infant as a result of reduced responsiveness from the mother (Kathree *et al.*, 2014). It has also been shown to adversely affect parents' ability to function and to establish positive relationships with children, however, depression is often treatable. Identifying and treating depression in mothers can have a lasting positive outcome not only for the mother but also for other family

members (Cuijpers *et al.*, 2014).

Risk for depression in parents of children with Down syndrome

Parenting a child who has an intellectual disability, increases the risk for developing depression, due to the emotional, financial and psychological strain caused by the challenges new parents are confronted with daily (Olsson & Hwang, 2001; Habib *et al*., 2015). When compared to children without disabilities, families of children diagnosed with Down syndrome report that there is less family involvement in social activities and more financial strain, caretaking responsibilities and time demands for educational activities (Padeliadu, 1998; Most *et al.*, 2006; Povee *et al.*, 2012).

Several international studies have assessed maternal well-being of mothers and families with children diagnosed with Down syndrome. These families often report social responsiveness, language development and minimal behavioural problems as factors which have a positive effect on family functioning and decrease stress experienced by mothers following a diagnosis of Down syndrome (Padeliadu, 1998; Most *et al.*, 2006; Povee *et al.*, 2012). A North American study reported that families with children with Down syndrome show remarkable resilience, stating that lower levels of stress is also experienced when families have psychosocial support and are well resourced (Van Riper, 2007). In support of this finding, a study conducted in Switzerland identified that lower education levels, lack of income and partner conflict, greatly contributed to the extent of hopelessness that mothers with children with Down syndrome experienced. The authors emphasized the importance of psychosocial and socioeconomic support offered to mothers (Yildirim & Yildirim, 2010).

Maternal depression studies conducted in South Africa

A literature search conducted using various databases such as PubMed, Google Scholar, SABINET, SA-e-Publications and Wiley Online Library during January 2017 revealed that no study has assessed symptoms of depression in South Africa, in women who have a child with Down syndrome. Combined keywords used to conduct this literature search included: ‘parenting challenges in Down syndrome’, ‘postnatal depression after Down syndrome diagnosis’, ‘maternal depression and Down syndrome South Africa’, ‘intellectually disabled child and postnatal depression South Africa’ and ‘South Africa postnatal depression’ revealed that no study has investigated the variables of interest. However, at least three studies have highlighted that depression in mothers in South Africa is a significant cause for concern

(Ramchandani *et al.*, 2009; Manikkam & Burns, 2012; Stellenberg & Abrahams, 2015). A recent study which screened for the prevalence of postnatal depression in mothers, in a rural community using the Edinburgh Postnatal Depression Scale (EPDS) and the Beck Depression Inventory (BDI) in South Africa, showed that 50.3% of the sample screened positive for depression (Stellenberg & Abrahams, 2015). A cohort study conducted in Soweto, Johannesburg, identified exposure to crime, poverty and partner conflict as the highest correlating social stressors which increases the risk for developing postnatal depression in mothers (Ramchandani *et al.*, 2009). A similar study which assessed general antenatal depression rates and associated risk factors in the Kwa-Zulu Natal province of South Africa, showed that 38.5% of recruited mothers were suffering from depression. Causative risk factors associated with depression in this study included predicted adverse neonatal outcomes, single marital status, unplanned pregnancy, and a human immunodeficiency virus (HIV) positive status (Manikkam & Burns, 2012).

The above-mentioned studies indicate that further research to identify causes of increased maternal depression should be pursued and supports policy development to screen women antenatally as well as postnatally for depression (Manikkam & Burns, 2012; Stellenberg & Abrahams, 2015). The purpose of this study was to screen for depression in mothers with a child diagnosed with Down syndrome in state health care facilities in Johannesburg. Furthermore, we aimed to determine whether certain sociodemographic factors were positively associated with cognitive and affective symptoms of depressive illness.

Methods

Participants

The study included 30 biological mothers of children between the ages of six months and three years who had been diagnosed with Down syndrome postnatally. The mothers were recruited from the Down Syndrome Support Group and specialist clinics at tertiary hospitals in Johannesburg using convenience sampling. Specialist clinics included the Genetic Counselling, Cardiology, Developmental and Endocrine Clinics. All mothers were proficient or had reasonable proficiency in English. There was no participation bias, as none of the mothers identified for the study, declined to take part in the study.

Procedures

Quantitative data was collected from May to July 2017. A pilot study design was chosen to evaluate the need and feasibility for a large-scale study. The two questionnaires, namely the Edinburgh Postnatal Depression Scale (EPDS) and a 10-item sociodemographic questionnaire, were administered to each participant by the principal investigator. Written informed consent was obtained from mothers who were willing to participate.

The principal investigator assisted with uncertainties regarding the questions and ensured completeness of questionnaires. Upon completion of the EPDS, the principal investigator immediately evaluated the score, enquired further about feelings of depression and risk of self-harm where necessary. All participants who scored 13 or greater on the EPDS questionnaire, and mothers who voluntarily expressed a need for psychological counselling, were referred to psychology services at the respective hospital.

Questionnaires

Edinburgh Postnatal Depression Scale (EPDS)

The EPDS was used to screen for depression in participants (Cox *et al.*, 1987). The EPDS is a 10-item self-report screening measure which aims to identify symptoms of depression experienced in the previous seven days. All questions have four possible answers which are scored as 0, 1, 2, or 3 and indicates severity of the symptom. The initial validation of the scale suggested a threshold score of 12 or 13 to be used as an indicator of major depression. It was specifically designed to detect depression in the postnatal period and does not primarily focus on somatic symptoms but rather on the identification of affective and cognitive symptoms (Cox *et al*., 1987). The time and duration of symptoms identified in mothers was not collected, therefore, no distinction was made between postnatal depression and other depressive illnesses.

The EPDS was chosen because it was previously validated in the Gauteng Province of South Africa, at Rahima Mother and Child Hospital and it was validated against the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* criteria for screening for depression (American Psychiatric Association, 1994; Lawrie *et al.*, 1998). The scale was shown to have sensitivity of 80.0%, specificity of 76.6% and does not have to be administered by a healthcare practitioner specifically trained in psychiatry and is therefore a valid screening tool for depression in South Africa (Lawrie *et al*., 1998; Manikkam & Burns, 2012).

Sociodemographic Questionnaire

The sociodemographic questionnaire administered to participants consisted of self-report items based on factors found to be significant in a previous study, namely: age of mother, number of children, highest level of education, employment status, source of household income, relationship status and HIV status (Manikkam & Burns, 2012). Questions regarding race, social support received from family and friends, age of child at diagnosis and current age of child diagnosed with Down syndrome were also included.

Ethics

Ethical clearance was obtained from the Human Research Ethics (Medical) Committee at The University of the Witwatersrand (Ethics Reference: M170259). Institutional and departmental approval was obtained from the tertiary hospitals.

Data Analysis

The data was analyzed using GraphPad QuickCalcs and STATA Data Analysis and Statistical Software (Graphpad.com, 2017; Stata.com, 2017). These freely available software programmes were used to conduct descriptive and correlational analysis of collected data. Data were organized per measures of central tendency (mean and median) and dispersion analysis was used to determine the range and standard deviation of the collected data. A Shapiro Wilk Test was used to assess the normality of continuous variables.

Categorical variables were presented as frequencies and percentages. The relationship between categorical variables and the number of screen positive depressed mothers (EPDS score of 13 or higher) and screen negative depressed mothers (EPDS score below 13) were analyzed individually, using two-tailed Fisher's exact tests and a Chi-square test. The continuous variables (age of mothers, age of child at diagnosis, current age of the child and the number of children), were studied individually against the variables mean depression score, using a t-test, for normally distributed data and a Mann-Whitney U test for non-normally distributed data. These independent calculations aimed to establish and support whether a statistically significant relationship exists between a positive depression screening test score and identified sociodemographic factors. A two-tailed p-value of < 0.05 was considered statistically significant.

Results

Sociodemographic characteristics of mothers and children

The ages of the 30 mothers of children with Down syndrome ranged from 25 to 46 years. Table 1 shows the sociodemographic profile of mothers of children with Down syndrome. A majority of the mothers (86.7%; n=26) were of black African ancestry, with four mothers (13.3%) being of mixed ancestry. A high percentage of mothers (70.0%; n=21) were in a relationship. The number of children ranged between one and eight with the median number of children being three. At the time of data collection, the children with Down syndrome were between six months and three years of age. The median age of diagnosis was three days, but ranged from one day to one year after birth.

Six mothers (20.0%) had completed tertiary education in the form of a degree or diploma. Eleven mothers (36.7%) reported that completion of secondary schooling was their highest qualification and thirteen mothers (43.3%) had not completed primary and/or secondary schooling.

Most of the mothers (60.0%; n=18) were not working with 23.3% (n=7) being unemployed and 36.7% (n=11) choosing to be stay-at-home mothers. Twelve mothers (40.0%) reported that they received weekly wages or monthly salaries. Many mothers had more than one source of income consisting of other primary or concurrent sources of income which included unemployment benefits (10.0%; n=3), receiving money from family support (43.3%; n=13) or a monthly disability government social grant (60.0%; n=18) which are provided to indigent families. All stay-at-home mothers were dependent on receiving a disability government social grant. Twenty-one mothers (70.0%) felt that they had sufficient social support from family and friends.

Twenty mothers (66.7%) disclosed their HIV negative status, eight (26.7%) were HIV positive and two mothers (6.7%) disclosed that they did not currently know their HIV status.

Outcome of the Edinburgh Postnatal Depression Scale

The 30 mothers had a mean EPDS score of 9.1 (SD =5.89) with scores ranging between 0 and 26. Eight mothers (26.7%) had an EPDS score above the screening cut-off of 13. Ten mothers (33.3%) were referred to see a psychologist because two women who had EPDS scores of 10 and 12 respectively, asked for a referral to psychology services.

Comparison of sociodemographic factors and a positive screening score for depression

Along with the sociodemographic profile of mothers of children with Down syndrome, Table 1 also illustrates the outcomes of the two-tailed Fisher's exact tests and Chi-square test calculated for the categorical variables and the categories of the number of mothers who had an EPDS score below 13 and those who had an EPDS score of 13 or greater. No statistical significance was found for race ($p = 1.00$), relationship status ($p = 1.00$), level of education ($p = 0.47$), employment status ($p = 0.42$) or social support ($p = 1.00$) and a positive screening score for depression. A statistically significant association was found between an HIV positive status and mothers who had an EPDS score of 13 or greater ($p = 0.01$).

Table 2 shows the outcomes of the independent t-test and Mann-Whitney U tests calculated for continuous variables for mothers who had an EPDS score below 13 and those who had an EPDS score of 13 or greater. The current mean age of the children with Down syndrome, of mothers with a significant EPDS score was one year and five months (CI: 5.22-12.26) and no statistical significance was found ($p = 0.40$). The median age of mothers who had an EPDS score of 13 or greater was 38 years (IQR: 29.50-42.00). The age of mothers was not found to have a significant effect on the EPDS score obtained ($p = 0.42$). The median age of children at diagnosis, of mothers who had an EPDS score of 13 or greater was two days old (IQR: 1.00-53.23) and did not have a significant effect on the EPDS score obtained ($p = 0.73$). The number of children of the mothers who had screened positive for depression, had a median number of three children (IQR: 1.00-4.00). The number of children was not associated with depression ($p = 0.65$).

Table 1. Comparison of characteristics of mothers and a positive depression screening score

Categories	Frequency	Frequency of ≥ 13 EPDS score[1]	Mean EPDS score[1] (SD[2])	F exact test *p-value*
Race				**1.00**
Black	26 (86.7%)	7 (26.9%)	9.38 (5.93)	
Mixed Ancestry	4(13.3%)	1 (25.0%)	7.25 (6.08)	
Relationship Status				**1.00**
Single	9 (30.0%)	2 (22.2%)	7.67 (6.26)	
Married/Partner	21 (70.0%)	6 (28.6%)	9.71 (5.77)	
Highest Level of Education[4]				**0.47[4]**
Some Primary/Secondary Schooling	13 (43.3%)	2 (15.4%)	7.62 (4.09)	
Completed Secondary Schooling	11 (36.7%)	4 (36.4%)	10.82 (6.88)	
Tertiary Degree/Diploma	6 (20.0%)	2 (33.3%)	9.17 (7.36)	
Employment Status				**0.42**
Employed (Full-time/Part-time)	12 (40.0%)	2 (16.7%)	8.42 (5.30)	
Unemployed/Stay-at-home mother	18 (60.0%)	6 (33.3%)	9.56 (6.36)	
HIV Status[3]				**0.01**
Positive	8 (26.7%)	5 (62.5%)	13.13 (6.51)	
Negative	20 (66.7%)	2 (10.0%)	7.30 (4.91)	
Social Support[3]				**1.00**
Yes	21 (70.0%)	5 (23.8%)	8.57 (5.33)	
No	5 (16.7%)	1 (20.0%)	10.60 (9.10)	

[1]EPDS score: Score on Edinburgh Postnatal Depression Scale

[2]SD: Standard Deviation

[3]Mothers who indicated 'Unknown HIV Status' and/or 'Sometimes Social Support' excluded therefore mothers do not total 30

[4] Chi-square test used due to 3x2 contingency table

Table 2. EPDS scores of mothers and their children diagnosed with Down syndrome and factors relating to their age or their child

t-test						
Variable	**Sample Mean**	**Mean (EPDS[1] score < 13)**	**Mean (EPDS[1] score ≥ 13)**	**SD[2] (EPDS[1] score ≥ 13)**	**t-value**	***p*-value**
Current Age of Child (Months)	19.83	20.77	17.25	9.84	0.88	0.40
Mann-Whitney U test						
Variables	**Sample Median**	**Median (EPDS[1] score <13)**	**Median (EPDS[1] score ≥ 13)**	**IQR[3] (EPDS[1] score ≥ 13)**	**U-value**	***p*-value**
Age of Mother (Years)	40.00	40.50	38.00	29.50-42.00	105.50	0.42
Age of Child at Diagnosis (Days)	3.00	4.00	2.00	1.00-53.23	95.50	0.73
Number of Children	3.00	3.00	3.00	1.00-4.00	98.00	0.65

[1]EPDS: Edinburgh Postnatal Depression Scale

[2]SD: Standard Deviation

[3]IQR: Interquartile Range

Discussion

Sociodemographic circumstances of South African state healthcare patients

South Africa is a developing country where great disparity exists between state and privatised healthcare (Kromberg *et al.*, 2013). Communicable and non-communicable disease has greatly burdened the state healthcare system, as it serves the majority of South Africa's impoverished and middle-income population groups (Mayosi *et al.*, 2009). Maternal mental health is often neglected in the state healthcare system of South Africa, as the burden of disease such as diabetes, tuberculosis, HIV, cancer and cardiovascular disease fails to decline (Mayosi *et al.*, 2009; Honikman *et al.*, 2012). With few or no screening for maternal mental health issues in antenatal clinics, many women with mental health issues remain untreated (Honikman *et al.*, 2012).

Social welfare is the sole source of income for many mothers attending state healthcare in

South Africa (Kathree *et al.*, 2014). From our analysis, 60.0% of our sample was receiving a state funded disability grant, which is granted to those who earn below a certain level of income. Of the mothers screened, 43.3% had not completed their schooling. Being uneducated in an economy where jobs are scarce can be devastating and can further reduce prospects and hope for a better future (Kathree *et al.*, 2014). A lack of income has directly been linked to a perception of hopelessness in parents of children with Down syndrome, which in turn increases the risk of developing depression (Yildirim & Yildirim, 2010). Of the unemployed mothers in our sample, 33.3% screened positive for depression.

Contextualisation of depression rates identified in the study participants

Although estimates are variable, postnatal depression is believed to affect between 13-19% of all women in developed countries with higher prevalence estimates for developing countries such as Brazil (Abuchaim *et al.*, 2016). High rates of maternal depression have previously been documented in South African women whilst in the United States of America, a 19.2% prevalence rate of postnatal depression has previously been described (Gavin *et al.*, 2005; Rochat *et al.*, 2006; Manikkam & Burns, 2012; Stellenberg & Abrahams, 2015). The analysis of data from this study showed that eight mothers (26.7%) screened positive for depression whilst ten mothers (33.3%) were referred to psychology services for further evaluation. The results of general antenatal depression rates, however, from the Kwa-Zulu Natal population (38.5%) and general postnatal depression rates in a rural community in South Africa (50.3%), are higher than the percentage of depression screen positive mothers identified in this study (Manikkam & Burns, 2012; Stellenberg & Abrahams, 2015). Similarly, a high rate of postnatal depression (39.0%) was identified in a study of women in the rural area of Khayelitsha, South Africa. The factors attributed to this high rate included unemployment, exposure to crime, a lack of support from partners and largely an HIV positive status (Hartley *et al.*, 2011; Lund *et al.*, 2014).

Variation in sample population screening methodology and sociodemographic background in mothers with or without a child diagnosed with Down syndrome makes comparisons between studies very challenging. The percentage of symptomatic depression identified in this study, however, is high when compared to the 10.0% national prevalence of depression described in the general population of South Africa in 2009 (Herman *et al.*, 2009). These results indicate that mothers in our sample are vulnerable and at risk for developing symptoms of depression which may go unnoticed.

HIV status and risks for developing depression

We found a significant association between an HIV positive status and a positive depression screening score in mothers of children diagnosed with Down syndrome ($p = 0.01$). HIV and depression has previously been found to be positively associated (Wouters *et al*., 2016).

Factors previously found to be causative of depression in HIV positive individuals include stigmatization, social discrimination, fears regarding the future impact on their family, poverty, lack of support, loss of loved ones and the inevitability of death (Andersen & Seedat, 2009). In HIV-epidemic rural areas of South Africa, various studies, have indicated a prevalence of depression symptoms of between 30.0-50.0% of women attending antenatal clinics (Rochat *et al.*, 2006; Rochat *et al.*, 2013; Manikkam & Burns, 2012).

Public health education efforts have decreased stigmatization surrounding a positive HIV status, yet it remains one of the most stigmatized conditions globally. Such stigmatization results in shame, internalized guilt, and results in depression, regardless of other personal or sociodemographic factors (Simbayi *et al.*, 2007). In Kwa-Zulu Natal it had been reported that many pregnant mothers were gravely concerned about possible discrimination in healthcare facilities, for themselves or their unborn child due to being HIV positive, with some even admitting that this prevented them from attending clinic appointments. This study highlighted the importance of screening HIV positive pregnant women for depression in order to ensure adherence to antiretroviral treatment and attendance at antenatal clinics (Rochat *et al.*, 2006). It is uncertain how having a child with Down syndrome impacts on the risk of developing depression in HIV positive mothers.

Perception of social support and its effect on maternal well-being

Perceived social support has been described as a protective factor against developing depression in individuals with a chronic medical condition, however very few studies have explored the association of social support and depression in communities with a high HIV incidence (Casale *et al.*, 2015). In this study sample, only five mothers (16.7%) felt they had no social support from family or friends, of which only one mother was HIV positive and had an EPDS score above 13.

In South Africa, most state patients have limited socioeconomic and psychosocial support resources (Manikkam & Burns, 2012). However, 70.0% of mothers in the study felt that they had adequate social support. Such a high level of perceived social support may be associated

with less depressive symptoms. Although a high percentage of mothers with depressive symptoms were identified, a sampling bias may have resulted in a lower percentage than exists or the recruitment of only mothers with high-functioning depressive symptoms. The utilization of clinic services has been shown to be decreased in many mothers who suffer from depression as these mothers may be less responsive to their child's needs and less proactive in preventative medical management (Minkovitz *et al.*, 2005; Balbierz *et al.*, 2015). Many severely depressed mothers may not have been identified due to reduced tendency to attend regular clinic appointments. Therefore, the percentage of mothers who screened positive for depression may be higher than 26.7%. Mothers were recruited from specialist clinics or attended the Down Syndrome Support Group where mothers may gain social support. Speaking to other mothers of children with Down syndrome and being able to share mutual feelings and lived experiences can modulate stress and reduce guilt and sadness mothers experience in their unique situation. (Wei *et al.*, 2012). Future research including mothers who do not attend specialist clinics or the Down Syndrome Support Group, would allow for more reliable conclusions about perceived social support in communities in South Africa.

Limitations of the study

A larger sample size would have increased statistical power in comparisons between sociodemographic variables and the EPDS scores obtained. This would have allowed for the possible identification of associations between more variables and a positive depression screening score. A comparison group was not included due to lack of time available to conduct the study. Having a comparison group of mothers with children without Down syndrome and with similar sociodemographic characteristics, would have allowed for accurate comparison between two groups which would have allowed us to determine if mothers of children diagnosed with Down syndrome in state healthcare have increased rates of depression.

Although the EPDS scale is one of the most widely recognised and implemented postnatal depression screening measures, it has been reported to more reliably detect postnatal depression in women with symptoms of anhedonia and anxious affect instead of psychomotor retardation symptoms (Guedeney *et al.*, 2000). Use of a universal cut-off score has been cautioned against, as differences in cultures and languages may lead to great variability in the sensitivity and specificity of the EPDS scale score (Kozinszky & Dudas, 2015). It is possible

that these limitations may have resulted in some false negative scores.

Conclusion

Symptoms of depression were identified in eight mothers (26.7%) whilst ten mothers (33.3%) were referred to psychology services for further assessment. Considering that a significant under ascertainment due to selection bias may have obscured our findings, mothers with children diagnosed with Down syndrome may be vulnerable towards developing depression. Healthcare professionals should be aware that mothers of children with Down syndrome are at increased risk of developing depression and should therefore routinely screen and refer them for appropriate treatment and support. A significant association was found between a positive HIV status and symptoms of depression, in mothers with children diagnosed with Down syndrome ($p = 0.01$). Previous studies have also shown a strong association between HIV status and depression (Rochat *et al.*, 2006; Rochat *et al*., 2013; Simbayi *et al.*, 2007; Andersen & Seedat, 2009; Lund *et al.*, 2014; Casale *et al.*, 2015; Wouters *et al.*, 2016). No significant association between depression and various other sociodemographic factors were identified however, this may be due to our small sample size. Future studies with a larger number of participants could provide more accurate information with regards to the association of various sociodemographic variables and depression. A longitudinal study, in which depressive symptoms are evaluated at birth, six months and one-year post birth, would be useful to assess the increase or decrease of the severity of depressive symptoms in mothers. Research indicates the need for further investigations assessing the causes and exacerbating factors resulting in postnatal depression in mothers with a child diagnosed with Down syndrome.

Reference List

Abuchaim, E. de S. V., Caldeira, N. T., Di Lucca, M. M., Varela, M. & Silva, I. A. (2016) 'Postpartum depression and maternal self-efficacy for breastfeeding: prevalence and association', *Acta Paulista de Enfermagem*, 29(6), pp. 664–670.

American Psychiatric Association (1994) *Diagnostic and statistical manual of mental disorders, (DSM-IV)*.

Andersen, L. S. & Seedat, S. (2009) 'Mental health services for HIV / AIDS patients are long overdue', *South African Medical Journal*, 99(11), p. 2009.

Balbierz, A., Bodnar-Deren, S.,Wang, J. J. & Howell, E. A.. (2015) 'Maternal Depressive Symptoms and Parenting Practices 3-Months Postpartum', *Maternal and Child Health Journal*. Springer US, 19(6), pp. 1212–1219.

Bull, M. J. (2011) 'Health Supervision for Children With Down Syndrome', *Pediatrics*, 128(2), pp. 393–406.

Casale, M., Wild, L., Cluver, L. & Kuo, C. (2015) 'Social support as a protective factor for depression among women caring for children in HIV-endemic South Africa', *Journal of behavioral medicine*, 38(1), pp. 17–27.

Christianson, A., Howson, C. P. & Modell, B. (2006) *Global Report on Birth Defects, March of Dimes Birth Defects Foundation*. Available at: http://www.marchofdimes.org/materials/global-report-on-birth-defects-the-hidden-toll-of-dying-and-disabled-children-executive-summary.pdf.

Cox, J. L., Holden, J. M. & Sagovsky, R. (1987) 'Detection of postnatal depression. Development of the 10-item Edinburgh Postnatal Depression Scale.', *The British Journal of Psychiatry*, 150(6), pp. 782–786.

Cuijpers, P., Weitz, E., Karyotaki, E., Garber, J. & Andersson, G. (2014) 'The effects of psychological treatment of maternal depression on children and parental functioning: a meta-analysis', *European Child and Adolescent Psychiatry*, 24(2), pp. 237–245.

Gavin, N. I., Gaynes, B. N., Lohr, K. N., Meltzer-Brody, S., Gartlehner, G. & Swinson, T. (2005) 'Perinatal depression: a systematic review of prevalence and incidence', *Obstetrics and gynecology*. United States, 106(5 Pt 1), pp. 1071–1083.

Graphpad.com (2017) *GraphPad Software*. Available at: https://www.graphpad.com/quickcalcs/

(Accessed: 24 July 2017).

Guedeney, N., Fermanian, J., Guelfi, J. D., Kumar, R. C. (2000) 'The Edinburgh Postnatal Depression Scale (EPDS) and the detection of major depressive disorders in early postpartum: some concerns about false negatives', *Journal of Affective Disorders*, 61(1), pp. 107–112.

Habib, H. A., Jameel, S. & Fazal, S. (2015) 'Psychological distress of parents of children with Down syndrome', *Science International*, 27(4), pp. 3797–3800.

Hartley, M., Tomlinson, M., Greco, E., Comulada, W. S., Stewart, J., le Roux, I. *et al.* (2011) 'Depressed mood in pregnancy: prevalence and correlates in two Cape Town peri-urban settlements', *Reproductive health*. BioMed Central Ltd, 8(1), p. 9.

Herman, A. A., Stein, D. J., Seedat, S., Heeringa, S. G., Moomal, H., Williams, D. R. (2009) 'The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders', *South African Medical Journal*, 99(5), pp. 339–344.

Hewitt, C. E. & Gilbody, S. M. (2009) 'Is it clinically and cost effective to screen for postnatal depression: A systematic review of controlled clinical trials and economic evidence', *BJOG: An International Journal of Obstetrics and Gynaecology*, 116(8), pp. 1019–1027.

Honikman, S., van Heyningen, T., Field, S., Baron, E. & Tomlinson, M. (2012) 'Stepped Care for Maternal Mental Health : A Case Study of the Perinatal Mental Health Project in South Africa', *PLoS Medicine*, 9(5).

Huang, Y. C. & Mathers, N. (2001) 'Postnatal depression - Biological or cultural? A comparative study of postnatal women in the UK and Taiwan', *Journal of Advanced Nursing*, 33(3), pp. 279–287.

Kathree, T., Selohilwe. O. M., Bhana, A. & Petersen, I. (2014) 'Perceptions of postnatal depression and health care needs in a South African sample: the "mental" in maternal health care', *BioMed Central Women's Health*, 14(140), pp. 1–11.

Kozinszky, Z. & Dudas, R. B. (2015) 'Validation studies of the Edinburgh Postnatal Depression Scale for the antenatal period', *Journal of Affective Disorders*. Elsevier, 176(2015), pp. 95–105.

Kromberg, J. G. R., Sizer, E. B. & Christianson, A. L. (2013) 'Genetic services and testing in South Africa', *Journal of Community Genetics*, 4, pp. 413–423.

Lawrie, T. A., Hofmyer, G. J., de Jager, M., Berk, M. (1998) 'Validation of the Edinburgh Postnatal Depression Scale on a cohort of South African women', *South African Medical Journal*,

88(10), pp. 1340–1344.

Lund, C., Schneider, M., Davies, T., Nyatsanza, M., Honikman, S., Bhana, A., *et al.* (2014) 'Task sharing of a psychological intervention for maternal depression in Khayelitsha, South Africa: study protocol for a randomized controlled trial.', *Trials Journal*, 15.

Manikkam, L. & Burns, J K. (2012) 'Antenatal depression and its risk factors : An urban prevalence study in KwaZulu-Natal.', *South African Medical Journal*, 102(12), pp. 940–944.

Mayosi, B. M., Flisher, A. J., Lalloo, U. G., Sitas, F., Tollman, S. M. & Bradshaw, D. (2009) 'Health in South Africa 4 The burden of non-communicable diseases in South Africa', *The Lancet*. Elsevier Ltd, 374(9693), pp. 934–947.

Minkovitz, C. S., Strobino, D., Scharfstein, D., Hou, W., Miller, T., Mistry, K. B., *et al.* (2005) 'Maternal depressive symptoms and children's receipt of health care in the first 3 years of life', *Pediatrics*. United States, 115(2), pp. 306–314.

Most, D. E., Fidler, D J., Laforce-Booth, C. & Kelly, J. (2006) 'Stress trajectories in mothers of young children with Down syndrome', *Journal of Intellectual Disability Research*, 50(Pt 7), pp. 501–14.

Olsson, M. B. & Hwang, C. P. (2001) 'Depression in mothers and fathers of children with intellectual disability', *Journal of Intellectual Disability Research*, 45(6), pp. 535–543.

Padeliadu, S. (1998) 'Time demands and experienced stress in Greek mothers of children with Down's syndrome', *Journal of Intellectual Disability Research*, 42(2), pp. 144–153.

Patel, V., Rodrigues, M. & De Souza, N. (2002) 'Gender, poverty, and postnatal depression: A study of mothers in Goa, India', *American Journal of Psychiatry*, 159(1), pp. 43–47.

Povee, K., Roberts, L., Bourke, J. & Leonard, H. (2012) 'Family functioning in families with a child with Down syndrome: A mixed methods approach', *Journal of Intellectual Disability Research*, 56(10), pp. 961–973.

Ramchandani, P. G., Richter, L. M., Stein, A. & Norris, S. A. (2009) 'Predictors of postnatal depression in an urban South African cohort', *Journal of affective disorders*. Netherlands, 113(3), pp. 279–284.

Van Riper, M. (2007) 'Families of Children with Down Syndrome: Responding to "A Change in Plans" with Resilience', *Journal of Pediatric Nursing*, 22(2), pp. 116–128.

Rochat, T. J., Richter, L. M., Doll, H. A., Buthelezi, N. P., Tomkins, A. & Stein, A. (2006) 'Depression among pregnant rural South African women undergoing HIV testing', *Journal of*

the American Medical Association, 295(12), pp. 1376–1378.

Rochat, T. J., Tomlinson, M., Newell, M. L. & Stein, A. (2013) 'Detection of antenatal depression in rural HIV-affected populations with short and ultrashort versions of the Edinburgh Postnatal Depression Scale (EPDS)', *Archives of Women's Mental Health*, 16(5), pp. 401–410.

Sheets, K. B., Crissman, B. G., Feist, C. D., Sell, S. L., Johnson, L. R., Donahue, K. C., *et al.* (2011) 'Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: Recommendations of the National Society of Genetic Counselors', *Journal of Genetic Counseling*, 20(5), pp. 432–441.

Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N. & Mqeketo, A. (2007) 'Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa', *Social Science and Medicine*, 64(9), pp. 1823–1831.

Stata.com (2017) *Data Analysis and Statistical Software | Stata*. Available at: http://www.stata.com/ (Accessed: 19 July 2017).

Stellenberg, E. L. & Abrahams, J. M. (2015) 'Prevalence of and factors influencing postnatal depression in a rural community in South Africa', *African Journal Of Primary Health Care And Family Medicine*, 1(7), pp. 1–8.

Wei, Y. S., Chu, H., Chen, C. H., Hsueh, Y. J., Chang, Y. S., Chang, L. I., *et al.* (2012) 'Support groups for caregivers of intellectually disabled family members: Effects on physical-psychological health and social support', *Journal of Clinical Nursing*, 21(11–12), pp. 1666–1677.

Willoughby, M., Aldous, C., Patrick, M., Kavonic, S. & Christianson, A. (2016) 'Delay and poor diagnosis of Down syndrome in KwaZulu-Natal, South Africa: A retrospective review of postnatal cytogenetic testing', *South African Medical Journal*, 106(6), pp. 626–629.

Wouters, E., Masquillier, C. & le Roux Booysen, F. (2016) 'The Importance of the Family: A Longitudinal Study of the Predictors of Depression in HIV Patients in South Africa', *AIDS and Behavior*. Springer US, 20(8), pp. 1591–1602.

Yildirim, A. & Yildirim, M. S. (2010) 'Hopelessness of mothers who have children with Down syndrome', *Genetic counseling (Geneva, Switzerland)*. Switzerland, 21(4), pp. 375–380.

Appendix A. Approved research protocol with appendices

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24 August 2017
Person No: 595974
TAA

Miss M Swanepoel
Po Box 21639
Helderkruin
Roodepoort
1733
South Africa

Dear Miss Swanepoel

Master of Science in Medicine: Change of title of research

I am pleased to inform you that the following change in the title of your Research Report for the degree of **Master of Science in Medicine** has been approved:

From:	**A pilot study evaluating depression in mothers with infants diagnosed with Down syndrome in state healthcare**
To:	**A pilot study evaluating depression in mothers with children diagnosed with Down syndrome in state healthcare**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

UNIVERSITY OF THE
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06 April 2017
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Miss M Swanepoel
Po Box 21639
Helderkruin
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Dear Miss Swanepoel

Master of Science in Medicine: Approval of Title

We have pleasure in advising that your proposal entitled *A pilot study evaluating depression in mothers with infants diagnosed with Down syndrome in state healthcare* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

CANDIDATE'S SURNAME:	FIRST NAME/S:	STUDENT NUMBER:
Swanepoel	Melissa	595974

CURRENT QUALIFICATIONS: BA Psychology; BSoc. Psychology Honours

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DEGREE FOR WHICH PROTOCOL IS BEING SUBMITTED: MSc. Med Genetic Counselling

PART-TIME OR FULL-TIME: Full-Time

FIRST REGISTERED FOR THIS DEGREE:	TERM : January	YEAR: 2016

DEPARTMENT: Division of Human Genetics; School of Pathology

TITLE OF PROPOSED RESEARCH:

A pilot study evaluating depression in mothers with infants diagnosed with Down syndrome in state healthcare.

CANDIDATE'S SIGNATURE: 	DATE: 27 January 2017

SUPERVISOR #1'S NAME: Tabitha Haw

% OF SUPERVISION TO BE PROVIDED BY SUPERVISOR #1: 100%

SUPERVISOR #1'S QUALIFICATIONS: BSc (Hons) , Msc (Med) Genetic Counselling

SUPERVISOR #1'S DEPARTMENT: Division of Human Genetics; School of Pathology, Faculty of Health Sciences

SUPERVISOR #1'S ADDRESS / TEL / **E-MAIL**: tabitha.haw@nhls.ac.za

SUPERVISOR #2'S NAME: n/a

% OF SUPERVISION TO BE PROVIDED BY SUPERVISOR #2: n/a

SUPERVISOR #2'S QUALIFICATIONS: n/a

SUPERVISOR #2'S DEPARTMENT: n/a

SUPERVISOR #2'S ADDRESS / TEL / **E-MAIL**: n/a

SYNOPSIS OF RESEARCH:

The aim of this pilot study is to evaluate depression experienced and associated risk factors for developing depression, in mothers with infants diagnosed with Down syndrome in state healthcare in Johannesburg. Individuals with Down syndrome are intellectually disabled, short in stature and have distinctive facial features amongst other congenital abnormalities (Sheets et al. 2011). The unanticipated news of a diagnosis of Down syndrome may evoke strong emotions of anxiety and sadness in mothers (Skotko 2005).The proposed study objectives includes to evaluate the presence of maternal depression in mothers who have an infant diagnosed with Down syndrome and to determine which sociodemographic factors are correlated with increased risk for developing maternal depression in mothers who have an infant diagnosed with Down syndrome.

Women attending the Down syndrome support group, the Developmental Clinic or a follow-up genetic counselling session at Charlotte Maxeke Johannesburg Academic Hospital and/or Chris Hani Baragwanath Academic Hospital, will be asked to voluntarily participate in the study by completion of a sociodemographic questionnaire and the Edinburgh Postnatal Depression Scale. This study will aim to recruit 30-40 respondents. This pilot study will be conducted quantitatively, using both descriptive and correlational research designs. We will compare results, to a study of postnatal depression levels in the Western Cape (Stellenberg & Abrahams 2015), to determine whether depression levels are significantly increased in women who have an infant diagnosed with Down syndrome. The correlational design aims to establish whether a relationship between the particular sociodemographic factors and depression amongst mothers exists.

ETHICS PENDING: Ⓨ ETHICS APPROVED: Ψ (circle appropriate symbol)	IF Y SUPPLY ETHICS CLEARANCE No:

SIGNATURE OF SUPERVISOR/S:	TSHaw	

1. A pilot study evaluating depression in mothers with infants diagnosed with Down syndrome in state healthcare.

Student: Ms. Melissa Swanepoel | 595974 | MSc.Med Genetic Counselling

Supervisor: Ms. Tabitha Haw | MSc.Med Genetic Counselling | Genetic Counsellor

2. Introduction

Down syndrome is one of the most commonly seen syndromes in genetic clinics in South Africa and elsewhere in the world with a birth prevalence of approximately one per 500 live births in South Africa (Sheets et al. 2011; Willoughby et al. 2016). The unanticipated news of a postnatal diagnosis of Down syndrome may evoke strong emotions of anxiety and sadness in mothers (Skotko 2005). Knowing that a child is developmentally and intellectually delayed greatly increases the risk for parents to develop depression (Habib et al. 2015).

2.1 Down syndrome

Individuals with Down syndrome are intellectually disabled, short in stature and have distinctive facial features (Sheets et al. 2011). Congenital abnormalities occurring with this syndrome often include cardiac abnormalities which may need to be corrected surgically (Glasson et al. 2002).

2.2 Psychological impact of a Down syndrome diagnosis

Parenting a child who has profound developmental delay drastically increases risks for developing depression due to the emotional, financial and psychological strain caused by the challenges parents are confronted with on a daily basis (Habib et al. 2015; Olsson & Hwang 2001). Studies describe parents experiencing anger, sorrow, and excessive anxiety amongst other distressing emotions upon hearing the news that their baby has Down syndrome (Skotko & Capone 2009).

A study in mothers with infants with Down syndrome in Malaysia reported that parenting stress was significantly increased in mothers with depression. Negative maternal

psychological wellbeing was one of the identified risk factors for mothers experiencing increased parenting stress (Norizan & Shamsuddin 2010). Similarly, a Swiss study identified that education level, socioeconomic income and partner conflict greatly contributed to the extent of hopelessness that mothers with children with Down syndrome experience, emphasizing the importance of psychosocial support being offered to mothers (Yildirim & Yildirim 2010).

2.3 Risk factors associated with developing depression

Depression is defined as a mental state in which an individual experiences emotions of sadness, despair, lowered self-esteem, agitation and withdraws from other people (Sadock & Sadock 2014).

A study by Manikkam and Burns (2012), assessing antenatal depression rates and associated risk factors in the Kwa-Zulu Natal population revealed that 149 of 387 (38.5%) participants were identified as suffering from depression. Identified risk factors associated with the cause of the depression included predicted adverse neonatal outcomes, single marital status, unplanned pregnancy, and HIV positive status (Manikkam et al. 2012).

Stellenberg and Abrahams (2015) conducted a similar study to determine the prevalence of, and factors which, influence postnatal depression in a rural community in South Africa. A sample of 159 women was screened for depression using the Edinburgh Postnatal Depression Scale (EPDS) and the Beck Depression Inventory (BDI). Of the sample, 50.3% were identified as suffering from postnatal depression (Stellenberg & Abrahams 2015).

Antenatal risk factors which may increase the risk for developing postnatal depression was identified in a cohort study in Soweto during 2009. The two most highly correlated risk factors identified included social stressors such as exposure to crime and poverty as well as partner conflict (Ramchandani et al. 2009).

The above mentioned studies concluded that further research in causes of increased maternal depression should be pursued and supports policy development to screen women antenatally as well as postnatally for depression. (Manikkam et al. 2012; Stellenberg & Abrahams 2015).

2.3 Genetic Counselling for families with a child diagnosed with Down syndrome

2.3.1 Genetic Counselling

Genetic Counselling is defined by the National Society of Genetic Counsellors (NSGC) as a process of assisting and educating people in their understanding of the medical implications of genetic disease as well as helping people to adapt psychologically through the provision of counselling support (Resta et al. 2006).

2.3.2 Genetic Counselling clinics in South Africa

Following a diagnosis of Down syndrome, it is recommended that a genetic counsellor see the parent/s and allow individuals the space to openly deal with the many emotions and questions that they may be faced with (Skotko & Capone 2009). Medical complications, intellectual and developmental delay, life expectancy, future risks, resources, support groups and many more topics should be discussed with the patient, to ensure patients are well-informed about the condition and what their new baby's future may look like (Sheets et al. 2011).

A Brazillian pilot study concluded that 96.7% of mothers felt that genetic counselling was beneficial to their situation and that it proved to be a valuable source of psychological support. Such results emphasize the benefits and importance of referring mothers to genetic counselling when a diagnosis of Down syndrome is made in an infant (Ricardo et al. 2013).

2.4 Research questions, aim and justification of the proposed study

2.4.1 Research Questions

1. Are women who have an infant with Down syndrome, attending state healthcare in the Johannesburg region depressed?

2. Are the sociodemographic factors measured, correlated with depression experienced by mothers with an infant with Down syndrome?

2.4.2 Research Aim

The aim of this study is to evaluate depression experienced and associated risk factors for developing depression, in mothers with infants diagnosed with Down syndrome in state healthcare in Johannesburg.

2.4.3 Hypothesis

Mothers with infants diagnosed with Down syndrome in state healthcare in the Johannesburg region suffer from depression.

2.4.4 Justification of proposed study

There are currently no studies assessing depression levels in South Africa in women who have a child with Down syndrome. Maternal depression is believed to adversely affect parents' ability to function and to establish positive relationships with children however, depression is often treatable. Identifying and treating depression in mothers can have a lasting positive outcome not only for the mother as an individual but also for family members (Cuijpers et al. 2014).

A comparison of depression levels detected in mothers who have an infant diagnosed with Down syndrome in this study, to studies identified in the literature of postnatal depression detected in women, both those with children with Down syndrome in other countries and those who have normal children but live in South Africa will be done (Manikkam et al. 2012; Norizan & Shamsuddin 2010; Ramchandani et al. 2009; Ricardo et al. 2013; Stellenberg & Abrahams 2015; Yildirim & Yildirim 2010). Concurrently assessing sociodemographic risk

factors identified by Manikkam and Burns (2012), will allow us to gain insight into which factors may be associated with the development of depression (Manikkam et al. 2012).

3. Study Objectives

- To evaluate the presence of maternal depression in mothers who have an infant diagnosed with Down syndrome.
- To compare the percentage of depression detected in mothers with an infant diagnosed with Down syndrome to the percentage detected in previous published studies of postnatal depression in other samples, population groups and/or countries.
- Determine which sociodemographic factors are correlated with increased risk for developing maternal depression in mothers who have an infant diagnosed with Down syndrome.

4. Methods

4.1 Site of study and respondent characteristics

Women attending the Down Syndrome Support Group, the Developmental Clinic or a follow-up genetic counselling session at Charlotte Maxeke Johannesburg Academic Hospital or Chris Hani Baragwanath Academic Hospital will be asked to voluntarily participate in the study by completion of a questionnaire.

4.1.1 Inclusion Criteria:

- Respondent must be a female seeking state healthcare support and services.
- Respondent must have a biological child, between the ages of 3 months to 2 years, diagnosed with Down syndrome.
- Respondent should have completed at least one genetic counselling session prior to completing the questionnaire or should be attending a Down Syndrome Support Group or the Developmental Clinic.
- Mothers must be between the ages of 18-50 years old.

4.1.2 Exclusion Criteria:

- Mothers who cannot complete the questionnaire without the assistance of a translator (low level of English proficiency required for sociodemographic section of questionnaire).
- Mothers who had a child diagnosed with Down syndrome who has passed away.
- Mothers attending their first Genetic Counselling session.

4.1.3 Sampling and sampling size

Nonprobability sampling techniques will be used as participants will be identified based on convenience, availability, and willingness to participate in the study. This pilot study will aim to recruit 30-40 respondents from the following clinics at Chris Hani Baragwanath Academic Hospital (CHBAH) and/or at Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) for a period of 3 months. The following estimated number of respondents has been indicated:

CHBAH:

Genetic Counselling Clinic: Approximately 5 patients per month-15 patients (3 months)

Developmental Clinic: Uncertain (bookings not made based on diagnosis)

CMJAH:

Down syndrome Support Group: Approximately 6 individuals

Developmental Clinic: Approximately 10 patients per month-20 patients (2 months)

Total Estimated Number: Approximately 41 respondents

4.2 Study design

This pilot study will be conducted quantitatively, using both descriptive and correlational research designs. We will compare results to previous published studies assessing postnatal depression in women with or without a child with Down syndrome (Manikkam et al. 2012; Norizan & Shamsuddin 2010; Ramchandani et al. 2009; Ricardo et al. 2013; Stellenberg & Abrahams 2015; Yildirim & Yildirim 2010). This will help determine whether depression

levels are significantly increased in women who have an infant diagnosed with Down syndrome or not, and whether the situation in South Africa differs to other countries. The correlational design aims to establish whether a relationship between the particular sociodemographic factors and depression amongst mothers exists (Gravetter & Forzano 2012).

This study is a non-experimental study as no variables are intrinsically manipulated or controlled for. Voluntary participation will be explained to individuals and the reason for the study will be made known to respondents

4.3 Method

The Edinburgh Postnatal Depression Scale (EPDS) is a 10-item self-report screening test which will be used in the questionnaire to detect the presence of depression (Cox et al. 1987). The scale has a total score range of 0-30 and each item is scored on a 4-point scale. The scale focuses on cognitive and affective symptoms of depression during the past 7 days. Scores equal to or above 13 will be used as a cut-off score for an indication of depression. The EPDS has been validated in South Africa at Rahima Moosa Mother and Child Hospital. During the validation of the scale it was translated into six different African languages and validated against the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) criteria for diagnosing depression. The study concluded that the scale has a sensitivity of 80% a specificity of 76.6%, can be used from birth until 36 months post birth and is thus a valid screening tool in South Africa (Lawrie et al. 1998; Manikkam et al. 2012).

During the administration of the scale, respondents will also be required to complete a 10-item socio-demographic questionnaire (see Appendix Two).

4.3.1 Data Collection

Informed consent forms will be provided along with each questionnaire and the nature of the study will be explained using an information document (see Appendix Two). Confidentiality

and anonymity of respondents participating will be ensured through assignment of a unique respondent number to each questionnaire instead of making use of personal names, surnames, or hospital numbers. Contact details will be obtained on the signed consent form where the unique respondent number will be noted and kept separately from the questionnaires. The researcher will be present during the administration and completion of the scale and the questionnaire in the event that the respondent requires assistance.

Questionnaires will be administered and collected by the researcher after a Down Syndrome Support Group session, Developmental Clinic session and/or after the completion of a follow-up genetic counselling session. Questionnaires will be administered in English; however, the Edinburgh scale may be completed in an African language the respondent feels most proficient in. Respondents will need approximately 10-15 minutes or less, to complete the questionnaire and scale.

Response score to the scale will be evaluated immediately upon collection, in the event that immediate referral offer to Psychology Department should be made. Immediate evaluation of the respondents' score on the EPDS will allow the detection of significant levels of depression or risk of self-harm for which immediate intervention will be offered. Immediate intervention will be offered through explaining to the respondent that the scale indicates significant reason for concern about their welfare and that it is important to address this issue immediately. This information is included in the information document given to the respondent (see Appendix Two). In this scenario, the supervisor, who is an HPCSA registered genetic counsellor will be contacted to provide immediate counselling and assistance at the hospital. A family member may be contacted, with permission of the patient, to liaise with the researcher, genetic counsellor, the respondent and the psychologist in arranging, attending and following up a psychology referral. In the event that the respondent affirms the intention

to cause self-harm, the respondent will be referred to the Casualty Ward and the casualty officer will be alerted of the concern.

4.3.2 Limitations and confounding variables

Limitations of the study include the lack of a control group and therefore published studies are being used for comparison purposes. The research design will have low internal validity as extraneous and confounding variables are not controlled for. Volunteer bias and participant characteristics may threaten external validity. Disclosing that a psychology referral will be offered or recommended if significant depression levels are identified and/or risk for self-harm is detected, has the potential to make mothers wary of participating in the study and/or cause them to answer the questionnaire dishonestly (Gravetter & Forzano 2012).

5. Data Analysis

Data obtained from the EPDS scale will be summarized using descriptive statistical methods. These include organizing data per measures of central tendency (mean, median and mode) and using dispersion analysis to determine the range, standard deviation and variance of the collected data. Single sample hypothesis testing of the mean will be used to test whether mothers who received a postnatal diagnosis of Down syndrome have higher depression levels than expected. Organizing and summarizing data in this manner can be used to determine whether mothers in this study had higher levels of depression than mothers in a postnatal depression study through use of a t-test calculation (Coolican 2009).

In order to determine which interrelated sociodemographic variables are most significant in predicting depression in women who have an infant diagnosed with Down syndrome, a multiple regression analysis calculation will be used to account for the correlation between interrelated variables such as, for example, unemployment and monthly income. This method of analysis will provide insight into whether a relationship exists between linked variables

and levels of depression experienced (Gravetter & Forzano 2012). Multiple regression analysis will be done using freely available online tools and the assistance of a statistician, employed by the University of the Witwatersrand will be sought.

6. Ethics

No ethical issues have been identified however, if questionnaire results are indicative of depression, it is the duty of the researcher to refer the respondent for further psychological assessment. In the event that risk for self harm is identified on the scale, immediate referral to the Psychology Department will be made and/or immediate intervention through counselling will be made. Respondents will be referred to the Psychology Department at Charlotte Maxeke Johannesburg Academic Hospital and to the Psychiatry department at Chris Hani Baragwanath Academic Hospital. Written permission to refer respondents has been obtained from Dr. Zama Radebe at Charlotte Maxeke Johannesburg Academic Hospital and from Dr. Jasmin Koorverjee at Chris Hani Baragwanath Academic Hospital.

Ethical approval has been applied for and will be obtained from the Human Research Ethics Committee at the University of the Witwatersrand. Institutional approval will be obtained from Charlotte Maxeke Academic Hospital, Chris Hani Baragwanath Academic Hospital and from the Down Syndrome Association of South Africa support groups as well as from the Developmental and Genetic Counselling Clinics prior to commencement of research (see Appendix Three).

7. Timing

Study will commence on approval from the Human Research Ethics Committee at the University of the Witwatersrand.

	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov
Literature Review and Protocol Design												

Internal Protocol Assessment												
Ethics Application												
Protocol Assessment												
Collecting Data												
Data Analysis												
Writing up- research report												
Writing up- paper												

8. Funding

No funding is required for conducting the study. Respondents will be invited to participate voluntarily whilst at the hospital and/or whilst at the support group. The EPDS scale is freely available and thus no purchase is necessary. Statistical analysis will be done using freely available software. Travel expenses and printing costs will be paid through use of the National Research Foundation Block Grant fund awarded for the duration of the postgraduate degree.

Expenses:	**Estimated Amount**
Travelling costs to clinics from NHLS weekly (based on estimated data collection period of 12 weeks, twice per week)	2.9km to CMJAH + 15.5km to CHBAH= 18.4km 18.4km x 24 =43 296 km 43 296km/ 82.4 c/km = **R525,44**
Printing costs of approximately 60 questionnaires, consisting of 3 pages each and 60 consent forms, consisting of 2 pages each (Prices estimated from Wits student Rates)	300 pages x R 0.39 = **R117.00**
	Total: R 642.44.

9. Problems

Individual unwillingness to participate or a sudden decrease in the number of infants being referred to Genetic Counselling Clinics, Developmental Clinics and/or to Support Groups will dramatically decrease the statistical validity of the study.

10. References

Coolican, H., 2009. Research Methods and Statistics in Psychology. , p.703.

Cox, J.L., Holden, J.M. & Sagovsky, R., 1987. Detection of postnatal depression. Development of the 10-item Edinburgh Postnatal Depression Scale. *The British Journal of Psychiatry*, 150(6), p.782 LP-786.

Cuijpers, P. et al., 2014. The effects of psychological treatment of maternal depression on children and parental functioning: a meta-analysis. *European Child and Adolescent Psychiatry*, 24(2), pp.237–245.

Glasson, E.J. et al., 2002. The changing survival profile of people with Down's syndrome: implications for genetic counselling. *Clinical genetics*, 62(5), pp.390–393.

Gravetter, F. & Forzano, L.-A., 2012. *Research Methods for The Behavioral Sciences, 4th Edition*,

Habib, H.A., Jameel, S. & Fazal, S., 2015. Psychological distress of parents of children with Down syndrome. , 27(4), pp.3797–3800.

Lawrie, T.. et al., 1998. Validation of the Edinburgh Postnatal Depression Scale on a cohort of South African women. *South African Medical Journal*, 88(10), pp.1340–1344.

Manikkam, L. et al., 2012. Antenatal depression and its risk factors: An urban prevalence study in KwaZulu-Natal. , 102(12), pp.940–944.

Norizan, A. & Shamsuddin, K., 2010. Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, 54(11), pp.992–1003.

Olsson, M.B. & Hwang, C.P., 2001. Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45(6), pp.535–543.

Ramchandani, P.G. et al., 2009. Predictors of postnatal depression in an urban South African cohort. *Journal of affective disorders*, 113(3), pp.279–284.

Resta, R. et al., 2006. A New Definition of Genetic Counseling : National Society of Genetic Counselors ' Task Force Report The National Society of Genetic Counselors ' Definition Task Force: , 15(2).

Ricardo, M. et al., 2013. Effects of a Genetic Counseling Model on Mothers of Children with Down Syndrome: A Brazilian Pilot Study. , pp.784–794.

Sadock, B.J. & Sadock, V.A., 2014. Kaplan and Sadock's Synopsis of Psychiatry: Behavioural Sciences/Clinical Psychiatry. In *Kaplan and Sadock's Synopsis of Psychiatry: Behavioural Sciences/Clinical Psychiatry*. pp. 1–45.

Sheets, K.B. et al., 2011. Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling*, 20(5), pp.432–441.

Skotko, B. Capone, G. Kishnani, P., 2009. Postnatal Diagnosis of Down Syndrome: Synthesis of the Evidence on How Best to Deliver the News.

Skotko, B., 2005. Mothers of children with Down syndrome reflect on their postnatal support. *Pediatrics*, 115(1), pp.64–77.

Stellenberg, E.L. & Abrahams, J.M., 2015. Prevalence of and factors influencing postnatal depression in a rural community in South Africa. *Afr J Prm Health Care Fam Med*, 1(7), pp.1–8.

Willoughby, M. et al., 2016. Delay and poor diagnosis of Down syndrome in KwaZulu-Natal, South Africa: A retrospective review of postnatal cytogenetic testing. *South African Medical Journal*, 106(6), pp.626–629.

Yildirim, A. & Yildirim, M.S., 2010. Hopelessness of mothers who have children with Down syndrome. *Genetic counseling (Geneva, Switzerland)*, 21(4), pp.375–380.

Appendix One:

i. Plagiarism Declaration
ii. Statement of Principles for Postgraduate Supervision
iii. Recommendation for appointment of supervisor(s) of research report

Appendix Two:

i. Information Document
ii. Informed Consent Form
iii. Sociodemographic Questionnaire
iv. Edinburgh Postnatal Depression Scale

Appendix Three: Hospital Permission Letters

i. CEO-Chris Hani Baragwanath Academic Hospital
ii. CEO-Charlotte Maxeke Johannesburg Academic Hospital

Appendix One:

i. Plagiarism Declaration
ii. Statement of Principles for Postgraduate Supervision
iii. Recommendation for appointment of supervisor(s) of research report

Faculty of Health Sciences, Postgraduate Office
Phillip V Tobias Building, 2nd Floor
Cnr York & Princess of Wales Terrace, Parktown 2193
Tel: (011) 717 2745 | Fax: (011) 717 2119
Email: Mathoto.senamela@wits.ac.za

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Melissa Swanepoel (Student number: 595974) am a student

registered for the degree of MSc. Med Genetic Counselling in the academic year 2017.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature:  Date: 26 January 2017

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG | FACULTY OF HEALTH SCIENCES

STATEMENT OF PRINCIPLES FOR POSTGRADUATE SUPERVISION

IN A CONTEXT OF ACADEMIC FREEDOM AND WITHIN A FRAMEWORK OF INDIVIDUAL AUTONOMY AND THE PURSUIT OF KNOWLEDGE THIS STATEMENT IS WRITTEN IN THE BELIEF THAT THERE IS A RECIPROCAL RELATIONSHIP AND MUTUAL ACCOUNTABILITY BETWEEN SUPERVISOR AND STUDENT.

THE SUPERVISOR AND THE STUDENT:

1. Will establish agreed roles and clear processes to be maintained by both parties. In the case of join supervision everybody's role needs to be clarified.
2. Will meet regularly and as frequent as is reasonable to ensure steady progress towards the completion of the proposal, research report, or dissertation or thesis. This time varies but the normal minimum requirement for face-to-face contact spread across each year of registration is: 10 contact hours for an Honours project, 15 contact hours for a Masters by a research report and 24 contact hours for a Masters by dissertation and a PhD.
3. Will keep appointments, be punctual and respond timeously to messages.
4. Will keep one another informed of any planned vacations or absences as well as changes in his/her personal circumstances that might impact on the work schedule. Unplanned absences or delays should be discussed as soon as possible and arrangements should be made, to catch up lost time.
5. Will ensure that research on animal or human subjects is concluded according to the procedures and the requirements of the relevant University Ethics committee.
6. Will together complete progress reports on the research project, as requested by each Faculty Graduate Studies Committee.

THE SUPERVISOR

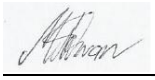
1. Undertakes to provide guidance for the student's research project in relation to the design and scope of the project, the relevant literature and information sources, research methods of data analysis.
2. Has a responsibility to be accessible to the students.
3. Will be prepared for the meeting with student. This includes being up to date on the latest work in his/her area of expertise.
4. Will expect written work as jointly agreed, and will return that work with constructive criticism within a timeframe (a suggestion of 2-4 weeks) jointly agreed at the outset of the research.
5. Will provide advice that can help the student to improve his/her writing. This may include referrals for language training and academic writing. The supervisor will provide guidance on technical aspects of writing such as referencing as well as on the discipline specific requirements. Detailed correction of drafts and instruction in aspects of language and style are not the responsibility of the supervisor.

6. Will support the student in the production of a research report, dissertation or thesis. Provision should be allowed for adequate, mutually respectful, discussion around recommendations made.
7. Will assist with the construction of a written time schedule, which outlines the expected completion dates of successive stages of the work.
8. Will ensure the student has the opportunity to present work at postgraduate/staff seminars/national/international conferences as appropriate.
9. Will assist with the publication of research articles appropriate.
10. Will discuss the ownership of research conducted by the student in accordance with the University guidelines and rules on intellectual property, co-authorship and copyright.
11. Will ensure that the research is conducted in accordance with the University's policy on plagiarism.
12. Will ensure that the student is made aware in writing of the inadequacy of progress and/or of any work where the standard is below par. Acceptability will be according to criteria previously supplied to the student.
13. Has a duty to refuse to allow the submission of sub-standard work for examination, regardless of the circumstances. If the student chooses to submit without the consent of the supervisor, then this should be clearly recorded and the appropriate procedures followed.

THE STUDENT

1. Undertakes to work independently under the guidance of the supervisor. This includes reading widely to ensure that the literature pertinent to his/her chosen topic has been identified and consulted.
2. Is obliged to make appointments to see the supervisor and will arrange meeting times well in advance.
3. Will think carefully about how to get maximum benefit from these contact sessions by planning what s/he wants in these sessions.
4. Should submit written work for discussion with the supervisor well in advance of a scheduled meeting. The kind and frequency of written work should be agreed with the supervisor at the outset of the research.
5. Written work that is submitted should be relatively free from basic spelling mistakes, incorrect punctuation and grammatical errors. Responsibility for the accuracy of language, the overall structure and coherence of the final research report, dissertation or thesis rests with the student.
6. Undertakes to heed the advice given by the supervisor and to engage in discussion around suggestions made. Ultimately the student has to take responsibility for the quality and presentation of the work.
7. Should strive, within reasonable bounds, to maintain a focus on his/her research area and to work within the agreed time schedule.
8. Will prepare material for presentations at seminars and conferences.
9. Undertakes to submit papers for publication.
10. Agrees to honour agreements about ownership of the research and in accordance with the University's guidelines and rules in relation to co-authorship, copyright and intellectual property.
11. Will ensure that the work contains no instances of plagiarism and that all citations are properly referenced and that the list of references is accurate, complete and consistent.
12. Agrees to work in accordance with the criteria of acceptability as supplied by the supervisor.
13. Undertakes not to place the supervisor under undue pressure to submit work for examination until the supervisor is satisfied that it has reached an acceptable level of quality. We confirm that we have read and understood this statement and agree to be guided by its principles for as long as we continue to work together.

Please note: The University and Faculty endorse the **Singapore Statement** on research integrity. The principles of the Singapore Statement include honesty, accountability, professionalism and stewardship. Our responsibilities as researchers (i.e. both as students and supervisors) are as pledged in the Singapore Declaration: the assurance of appropriate "data integrity, data sharing, record keeping, authorship, publication, peer review, conflict of interest, reporting misconduct and irresponsible research, communicating with the public, complying with regulations, education, and social responsibilities (World Conference on Research Integrity, 2010)". These principles and responsibilities are important in training our postgraduate students and in promoting global research integrity. Ref: Resnik, DB and Shamoo AE (2011). The Singapore Statement on Research Integrity. Account Res. 18:71-75.

Name of student: Melissa Swanepoel Student's signature: 

Name of Supervisor: Ms Tabitha Haw Supervisor's signature: 

Name of Co-Supervisor: n/a Co-Supervisor's signature: n/a

The broad area of study is: Depression in mothers with infants diagnosed with Down syndrome in state healthcare.

Provisional submission date is: 31 August 2017 Degree: MSc. Med. Genetic Counselling

School: School of Pathology , Division of Human Genetics Faculty: Health Sciences

Date: 27 January 2017

Specific agreement pertaining to: ownership and joint publication, funding, may be attached and signed.

GRIEVANCE PROCEDURES: It should be acknowledged that during the course of the research that both students and supervisors can feel aggrieved. In this event, these should be dealt with as swiftly as possible by the parties involved and, if necessary, the Postgraduate Coordinators and Committees. There is, in addition, a University Grievance Policy to help guide deliberations.

Postgraduate Office, Faculty of Health Sciences
Wits Medical School, 7 York Road, PARKTOWN, 2193, Johannesburg • Tel: (011) 717 2000 • Fax: (011) 717 2119

APPOINTMENT OF SUPERVISOR/S OF RESEARCH REPORT, DISSERTATION OR THESIS

Motivation / Reason for Appointment: Tabitha Haw is a genetic counsellor in the Division of Human Genetics where Melissa is completing her MSc(Med) training and is therefore qualified and available to supervise her in completing the research aspect of her degree.

Recommendation of Division / Department / School:

___Supported

Student Surname and Initials: Swanepoel M Student Number: 595974

Degree: MSc. Med Genetic Counselling Div / Dept / School: Division of Human Genetics, School of Pathology

Title: Depression in mothers with infants diagnosed with Down syndrome in state healthcare.

Supervisor 1: Tabitha Haw

Supervisor Qualifications: BSc (Hons); MSc (Med) Genetic Counselling

Supervisor Department: Division of Human Genetics

Supervisor Telephone: 011 489 9233 E-mail: tabitha.haw@nhls.ac.za

Supervisor 2: N/A

Supervisor Qualifications:

Supervisor Department:

Supervisor Telephone: E-mail:

Student Signature: **Supervisor 1** Signature: TSHaw

Supervisor 2 Signature:

RECOMMENDATION BY HEAD OF DIVISION / DEPARTMENT / SCHOOL:

Krause A 28/01/2017

(Surname and Initials) (Signature) (Date)

APPROVAL BY ASSESSOR GROUP:

Appendix Two:

i. Information Document
ii. Informed Consent Form
iii. Sociodemographic Questionnaire
iv. Edinburgh Postnatal Depression Scale

Information Document

Good day,

Introduction: My name is Melissa Swanepoel and I am a Genetic Counselling Masters student from the University of the Witwatersrand. I am conducting a study, for research purposes, to learn if mothers who have children with Down syndrome, experience sadness, which may lead to depression. The title of my research study is *"A pilot study evaluating depression in mothers with infants diagnosed with Down syndrome in state healthcare"*.

Invitation to participate: You are invited to take part in this research study. If you choose to participate in this study, you will need to answer two questionnaires, which will take approximately 10-15 minutes to complete. The questionnaires will be administered to 30-40 mothers who have infants between the ages of 3 months and 2 years, who have been diagnosed with Down syndrome.

- The first questionnaire consists of 10 questions about your age, marital status, residence as well as other details about your social and living environment.
- The second questionnaire is a 10-question scale called the Edinburgh Postnatal Depression Scale. This scale will assess how you have been feeling in the past seven days and indicates if you are experiencing depression or not.

Risks: There is a potential risk that an emotional response may be evoked. If depression is indicated on the questionnaire, a referral to a psychologist at the hospital will be offered to you. If immediate support is required, a registered genetic counsellor, Tabitha Haw (011 489 9233), will be asked to come and see you while you are still at the clinic, at no expense to you.

Benefits: By choosing to participate we will be able to better understand how mothers with children diagnosed with Down syndrome feel. This study could also help to identify if you may have depression, to enable us to refer you for support to assist you.

Participation is voluntary: You have the right to withdraw from this study at any time. If you choose to withdraw from the study, all information that you provide will be destroyed and excluded from the final results analysis. Not taking part in the study or withdrawing from the study will not affect your child's or your care in the hospital or at the support group in any way.

Confidentiality: If you choose to take part in the study, the information that you provide will be kept strictly confidential. Absolute confidentiality cannot be guaranteed as your personal information may be disclosed if required by law and/or if risk of self-harm is indicated. Results of the study may be published in a relevant accredited journal; however, all personal identifying information will be withheld from publication.

Contact Details: You are encouraged to ask questions or raise concerns at any time about the nature of the study or the methods that I am using. Please contact me at any time. My email address is melissa.swanepoel@nhls.ac.za and my telephone number is 011 489 9239.

You can also contact the Human Research Ethics Committee if you have concerns. Contact the chairperson, peter.cleaton-jones@wits.ac.za or administrators, Zanele Ndlovu, Rhulani Mkansi, Lebo Moeng on 011-717-1252/2700/1234/2656 or email: hrec-medical.researchoffice@wits.ac.za.

Consent Form

I hereby grant permission to the researcher, Melissa Swanepoel, from the University of the Witwatersrand and the National Health Laboratory to utilize my demographic data and my results from the Edinburgh Postnatal Depression scale without identifying personal information for research and publication purposes. I acknowledge that I have read, accept and have received a copy of the information document. I understand that efforts will be made to keep my personal information confidential and anonymous although absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law and/or if significant depression levels are indicated, a referral to a psychologist will be offered to me.

Name: _____

Surname: _____

Contact Number 1: _____

Contact Number 2: _____

Age of child at diagnosis: _____

Respondent Number: (for use on questionnaire) ☐

Date Signature of respondent

Date Signature of researcher

NATIONAL HEALTH LABORATORY SERVICE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

Sociodemographic Questionnaire

Respondent Identification Number: ☐ _____ Date: _____

Please complete the following questions by marking the appropriate box and/or answering appropriately where specified.

Question 1: Current age: _____

Question 2: Race:

☐ Black
☐ White
☐ Indian
☐ Mixed ancestry
☐ Other (please specify: _____)

Question 3: Marital /Relationship Status:

☐ Single
☐ Married
☐ Divorced
☐ Separated

Question 4: Highest Level of Education Status:

☐ No formal education
☐ Primary Education (Grade 1-7)
☐ Secondary Education (Grade 8 and higher)
☐ National Matric Certificate
☐ Tertiary Education (Degree or Diploma)

Question 5: Employment Status:

☐ Full time employed
☐ Part time employed
☐ Self-employed
☐ Stay-at-home mother

(Please specify prior/current occupation :_____)

☐ Unemployed (seeking work)

Question 6: Main source of financial income or support:

- ☐ My income (wages or salary)
- ☐ Family support (including child support)
- ☐ Unemployment benefits
- ☐ Workman's compensation
- ☐ Disability grant

Question 7: HIV status:

- ☐ Positive status
- ☐ Negative status
- ☐ Unknown status

Question 8: Number of children:

- ☐ 1 child
- ☐ 2 children
- ☐ 3 children
- ☐ 4 or more children (please specify number of children: _____)

Question 9: Age of child diagnosed with Down syndrome: _____

Question 10: Social support from family and/or friends:

- ☐ Yes
- ☐ No
- ☐ Sometimes

Edinburgh Postnatal Depression Scale (EPDS)

Respondent Identification Number: ☐ Total Score: ☐

Please mark one box that describes best how you have felt in the past 7 days.

1. I have been able to laugh and see the funny side of things:
- ☐ As much as I always could
- ☐ Not quite as much now
- ☐ Definitely not so much now
- ☐ Not at all

2. I have looked forward with enjoyment to things:
- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

3. I have blamed myself unnecessarily when things went wrong:
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ Not very often
- ☐ No,never

4. I have been anxious or worried for no good reason:
- ☐ No,not at all
- ☐ Hardly ever
- ☐ Yes, sometimes
- ☐ Yes, very often

5. I have felt scared or panicky for no very good reason:
- ☐ Yes, quite a lot
- ☐ Yes, sometimes
- ☐ No, not much
- ☐ No, not at all

6. Things have been getting on top of me:
- ☐ Yes, most of the time I haven't been able to cope at all
- ☐ Yes, sometimes I haven't been coping as well as usual
- ☐ No, most of the time I have coped quite well
- ☐ No, I have been coping as well as ever

7. I have been so unhappy that I have had difficulty sleeping:
- ☐ Yes, most of the time
- ☐ Yes, quite often
- ☐ Not very often
- ☐ No, not at all

8. I have felt sad or miserable:
- ☐ Yes, most of the time
- ☐ Yes, quite often
- ☐ Not very often
- ☐ No, not at all

9. I have been so unhappy that I have been crying:
- ☐ Yes, most of the time
- ☐ Yes, quite often
- ☐ Only occasionally
- ☐ No, never

10. The thought of harming myself has occurred to me:
- ☐ Yes, quite often
- ☐ Sometimes
- ☐ Hardly ever
- ☐ Never

Administered/Reviewed by _____ Date _____

Source: Cox, J.L., Holden, J.M., and Sagovsky, R. 1987. Detection of postnatal depression: Development of the 10-item Edinburgh Postnatal Depression Scale. British Journal of Psychiatry 150:782-786.

NATIONAL HEALTH LABORATORY SERVICE
UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
FACULTY OF HEALTH SCIENCES

Appendix Three: Hospital Permission Letters

i. CEO-Chris Hani Baragwanath Academic Hospital
ii. CEO-Charlotte Maxeke Johannesburg Academic Hospital

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 13 Feb 2017

TITLE OF PROJECT: A pilot study evaluating depression in mothers with infants diagnosed with Down Syndrome in state healthcare

UNIVERSITY: Witwatersrand

Principal Investigator: M Swanepoel

Department: Human Genetics

Supervisor (If relevant): T Haw

Permission Head Department (where research conducted): Yes

Date of start of proposed study: Feb 2017
Date of completion of data collection: Dec 2019

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Human Research Ethics Committee of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 13 February 2017

.....
Approved/Not Approved
Hospital Management
Date: 15/2/17

GAUTENG PROVINCE

HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Mr. J. Maepa
Office of the Clinical Director
Tell: (011): 488-3365
Email:Johannes.maepa@gauteng.gov.za
02 May 2017

Dear Miss Melissa Swanepoel

STUDY TITLE: A Pilot Study Evaluating Depression in Mothers with Infants Diagnosed with Down syndrome in State Healthcare.

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic Hospital will not anyway incur or inherit costs as result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the HOD and Unit Manager or sister in charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Supported / ~~not supported~~

Dr. M.I. Mofokeng
Clinical Director
DATE: 2/05/2017

Approved/not approved

Ms Q. Bogoshi
Chief Executive Officer
Date: 04.05.2017

Appendix B. Ethics clearance certificate

R14/49 Miss Melissa Swanepoel

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M170259

NAME: (Principal Investigator)	Miss Melissa Swanepoel
DEPARTMENT:	Human Genetics, School of Pathology NHLS Genetic Counselling Clinics The Down Syndrome Association (Gauteng)
PROJECT TITLE:	A Pilot Study Evaluating Depression in Mothers with Infants Diagnosed with Down syndrome in State Healthcare
DATE CONSIDERED:	24/02/2017
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Ms Tabitha Haw
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	07/04/2017

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in February and will therefore be due in the month of February each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date 10-04-2017

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C. Turn-it-in report

595974:Research_article_final_for_turnitin.docx

ORIGINALITY REPORT

4%	2%	3%	1%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Seth, Sunaina, Andrew Lewis, Richard Saffery, Martha Lappas, and Megan Galbally. "Maternal Prenatal Mental Health and Placental 11β-HSD2 Gene Expression: Initial Findings from the Mercy Pregnancy and Emotional Wellbeing Study", International Journal of Molecular Sciences, 2015. Publication	1%
2	Giakoumaki, O., K. Vasilaki, L. Lili, M. Skouroliakou, and G. Liosis. "The role of maternal anxiety in the early postpartum period: screening for anxiety and depressive symptomatology in Greece", Journal of Psychosomatic Obstetrics & Gynecology, 2009. Publication	<1%
3	etheses.bham.ac.uk Internet Source	<1%
4	www.biomedcentral.com Internet Source	<1%
5	www.jove.com	

	Internet Source	<1%
6	clinicaltrials.gov Internet Source	<1%
7	doaj.org Internet Source	<1%
8	Örün, Emel; Yalçın, S. Songül; Aykut, Osman; Orhan, Günnur; Koç-Morgil, Göksel; Yurdakök, Kadriye and Uzun, Ramazan. "Mercury exposure via breast-milk in infants from a suburban area of Ankara, Turkey", Turkish Journal of Pediatrics, 2012. Publication	<1%
9	Submitted to University of Ulster Student Paper	<1%
10	repub.eur.nl Internet Source	<1%
11	espace.curtin.edu.au Internet Source	<1%
12	Andrew D. Carothers, Lynne Murray. "Estimating psychiatric morbidity by logistic regression: application to post-natal depression in a community sample", Psychological Medicine, 2009 Publication	<1%

Appendix D. “Journal of Intellectual Disability Research” Author guidelines

Journal of Intellectual Disability Research

© John Wiley & Sons Ltd



Edited By: Chris Oliver; Mental Health Edition Editors: Craig Melville and André Strydom

Impact Factor: 1.99

ISI Journal Citation Reports © Ranking: 2016: 4/38 (Education Special); 10/70 (Rehabilitation (Social Science))

Online ISSN: 1365-2788

Author Guidelines

Thank you for your interest in *Journal of Intellectual Disability Research.* Please read the complete Author Guidelines carefully prior to submission, including the section on copyright.

Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Content of Author Guidelines:
1. Editorial and Content Considerations
2. Ethical Guidelines
3. Manuscript Types Accepted
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Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: *Life Course Perspectives on Adulthood and Old Age* (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

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