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The severity of depressive symptoms in the mothers of paediatric oncology patients

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Declaration

I, Dr Juanita Subrayadoo, declare that this research report is my own work. It is being submitted for the degree of MMED Psychiatry at the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signature.. 

The day of August 5th, 2022

Dedication

"I sustain myself with the love of family" - Maya Angelou.

This study is dedicated to my stronghold: My family.

My mother, Savy and my other mothers, Priscilla, Shirley, and Dhaya

My late father, Vishnu and my other fathers, the late Manikum, Reginald, Paul and Johnny

*My brothers and sisters, Tracen, Yvonne, Lennard, Cassandra, Prenton, Carolyn, and
Kamal.*

And lastly, my dear Ari, Zeke, Yahir and Ethan.

Presentations and Publications

This study has been presented on the 22nd of June 2022, at the Witwatersrand department of psychiatry's annual research day.

Abstract

Introduction

The task of caring for a child with cancer can be taxing and is often associated with varying degrees of depressive symptoms. This study aimed to explore the socio-demographic data and perceived levels of depression of mothers of paediatric oncology patients at Chris Hani Baragwanath Academic Hospital (CHBAH), Soweto, Paediatric Outpatient Department.

Methods

This cross-sectional study was undertaken from 01/09/2020 until 28/02/2021. After consenting to participation, the mothers completed a survey that included socio-demographic data related to the mother and her child and the Hamilton depression scale.

Results

A total of 75 mothers of paediatric oncology patients at CHBAH participated in this study.

Significantly, 50 (66.7%) of the women were considered depressed (>7 score) on the Hamilton depression scale scores. Significantly more women suffered from mild depression in the study sample ($\chi^2=35.85$, $df=2$, $p<0.001$).

Younger and unmarried mothers were more likely to be depressed. However, the level of education, employment and income levels were not significantly different between the depressed and non-depressed mothers.

Conclusion

Most of the mothers who participated in this study experienced mild depression. This study provides further evidence for the need of early psychiatric and social intervention in mothers and families of children with cancer.

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*Proverbs 3:6- In all your ways acknowledge Him,
And He will make your paths straight*

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List of abbreviations

CHBAH	Chris Hani Baragwanath Academic Hospital
CEO	Chief executive officer
DSM-5	Diagnostic and Statistical Manual of Mental Disorders -5
HREC	Human Resources Ethics Committee
OPD	Outpatient department
SACCSG	South African Children's Cancer Study Group
SACTR	South African Children's Tumor Registry
SADAG	South African Depression and Anxiety Group
WHO	World Health Organization
HADS	Hamilton Depression Scale

Chapter 1: Introduction

Approximately 600 - 700 new cases of childhood malignancies have been reported yearly for the last 25 years to the South African Children's Tumor Registry (SACTR) (Stefan and Stones, 2012). However, survival rates for cancer in childhood in South Africa are low compared with international data (Stones et al., 2014).

According to the South African Children's Cancer Study Group (SACCSG) registry statistics, leukaemia, lymphoma, brain tumours, neuroblastomas or Wilms tumours and soft tissue sarcomas were the most frequently diagnosed childhood cancers in South Africa in the period between 2009 to 2013 (South African Children's Cancer Study Group, n.d.; CANSA, n.d.; Stones et al., 2014).

The SACTR was developed by and forms part of the SACCSG. The SACCSG provides a platform for the ongoing dialogue regarding paediatric cancer. (South African Children's Cancer Study Group, n.d.)

The SACCSG started the SACTR with aim to record the impact of childhood cancer on a nationwide level. The registry is considered one of the major sources of data regarding malignancy in children. This information is gathered by various South African paediatric hospitals. It includes child-specific details such as sociodemographic particulars, malignancy characteristics, management plan, results thereof and, annual reviews. (South African Children's Cancer Study Group, n.d.; Stefan and Stones, 2012).

Parents and caregivers of paediatric oncology patients endure a great deal of emotional, physical and financial distress. Caregivers are often responsible for various duties that can be perturbing, time-consuming, and effortful. Such duties may involve assisting with basic and instrumental activities of daily living. This includes providing financial, emotional,

informational and appraisal support; organising transportation for regular treatments; assisting with mobility and monitoring the general health status of the oncology patient. In addition, the vital task of taking care of and parenting a potentially terminally ill child is profoundly taxing and can be associated with depressive features (Sullivan and Miller, 2015).

The depressive features of such caregivers may go unnoticed as they are often overshadowed by the clinicians' preoccupation with the medically unwell patient (Ghufran et al., 2014).

Bonner et al. (2006) found that parents who experienced higher levels of guilt and worry also had difficulty dealing with their complicated caregiver duties. These difficulties include making decisions regarding initiating or terminating treatment and handling their child's clinical complications. Such parents feel anxious about adequately tackling such tasks involving their frail child.

Bonner et al. (2006) further stipulated those parents who had high levels of unresolved sorrow and anger also reported other negative effects. Such as feelings of grief, a sense of loss, had ongoing rumination and added distress regarding their unwell child.

There is very little research on depression in mothers of oncology patients in South Africa (Naidoo et al., 2016).

There is a great need for further studies to be done in order to understand better and assist mothers. Such mothers may need more help to cope better with the demanding and arduous circumstances at hand (Greenberg and Meadows, 1991; Maurice-Stam et al., 2007; Vrijmoet-Wiersma et al., 2008).

Chapter 2: Literature Review

2.1 Depression Rates in South Africa and globally

Globally, more than 264 million people suffer from depression. Depression is a prime source of disability. The occurrence of depression is on the increase worldwide. When depression becomes enduring and of moderate to high levels, it can lead to significant impairment in major areas of functionality and may even result in suicide. Approximately 700 000 people commit suicide annually. As of 2019, suicide is the fourth leading cause of death in people aged 15-29 years globally (WHO, 2021).

According to statistics released from the South African Depression and Anxiety Group (SADAG, 2017), at least 20 % of South Africans may encounter depression once in their life. According to a WHO publication done in 2017, it was found that the prevalence rates of depression can differ with age. The occurrence of depression can climax in greater than 7.5% of females aged between 55-74 years and greater than 5.5% of males. It is also possible for children and adolescents younger than 15 to be affected by depression. However, the rates are lower compared to adults (WHO, 2017).

Tomlinson et al. (2009) and Stein et al. (2008) found the lifetime prevalence of depression in South Africa to be 9.7% and 9.8%, respectively. These studies also had findings suggesting that depression was markedly increased in females compared to their male counterparts.

Tomlinson et al. (2009) further stipulates that depression was higher in people with a lesser educational standing. This study estimated that more than 90% of the participants who reported depression also reported overall role impairment. It was also noted that women were more prone to difficulties in domestic functioning than men and that depression also resulted in difficulties in carrying out usual activities. Lastly, Tomlinson's findings suggested that

South Africa has higher levels of depression than Nigeria but lower levels of depression than the United States of America.

Two studies done in a rural South African village near Cape Town showed differing overall rates of depression. I.e., 27% (Rumble et al., 1994) and 18% (Rumble et al., 1996). In respective to the studies done by Rumble et al. (1994) and Rumble et al. (1996), the term depression refers to the combination of the following diagnoses: “major depression”, “depressive neurosis”, “major depression or depressive neurosis”. Rumble et al. (1996) suggested that higher prevalence rates could be due to the relevant rater’s experience in mental health. This factor may affect the scores given by the raters after administering the instrument in question to the participants.

Gillis et al. (1991) did a study in an urban area and found the prevalence rate of depression to be 25.2%. Cooper et al. (1999), who conducted a study in Khayelitsha, a location adjacent to an urban area, found the prevalence rate of post-natal depression to be 34.7 %.

Stein et al. (2008) suggested that the high prevalence of psychiatric disorders can be due to aggravating factors specific to South Africa that are not seen in other developing countries. These factors include a history of racism and political discord, increased gender discrimination, crime and poor socioeconomic standing. South Africa's history has resulted in differing socioeconomic positions related to racial groups. This history has thus contributed to the inequalities in social determinants of health often observed in the country (Stein et al., 2008). The resultant socioeconomic superiority afforded to some can be considered advantageous and protective against psychiatric disorders.

There is successful medical care for depression; roughly 80- 90 % of patients have favourable outcomes due to such treatment (WHO, 2021). Depressive disorders may largely negatively influence South Africa, impeding the economy's wealth, productivity, and growth (SADAG,

2017). The impact of depression also adds significantly to the worldwide burden of disease (WHO, 2021).

2.2 Depression in parents of paediatric oncology patients

There is literature focusing on the emotional and psychological signs of stress, including anxiety and depression, in parents of children with cancer (Vrijmoet-Wiersma et al., 2008).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM–5), depressive symptoms include depressed mood, loss of interest or pleasure in daily activities, feelings of hopelessness, worthlessness, inappropriate guilt, tearfulness, unintentional weight loss or weight gain, changes in appetite, insomnia or hypersomnia, psychomotor agitation or retardation, feeling restless, fatigue or loss of energy, poor concentration, thoughts of death, suicidality with or without a plan, or a suicide attempt (American Psychiatric Association, 2013).

Sloper (2000) found that 51% of mothers and 40% of fathers of patients with paediatric cancer had elevated levels of emotional stress at 6 and 18 months after the child was diagnosed with cancer.

Kostak and Avci (2013) reported that in their study, 18.2% of mothers of paediatric cancer patients displayed moderate depression whilst 36.4% displayed severe depression.

In addition to this Kostak and Avci (2013) reported that 4.5% of fathers of paediatric cancer patients exhibited moderate depression whilst 25.0% exhibited severe depression.

The parents in question can develop depressive symptoms during the course of their child's illness, from the time of diagnosis (Vrijmoet-Wiersma et al., 2008). If parents experience moderate to severe levels of depressive symptoms from the beginning of the timeline, then it

is possible that the depressive features can continue throughout the course of their child's illness and even years after finishing treatment (Norberg et al., 2003; Vrijmoet-Wiersma et al., 2008). Such an affliction can be experienced up to 5 years after the diagnosis was made (Wijnberg-Williams., 2006a).

Studies showed that mothers were at higher risk of experiencing depressive symptoms, especially after receiving confirmation of the ominous illness diagnosis and after commencement of treatment. (Wijnberg-Williams et al., 2006a; Dolgin et al., 2007; Vrijmoet-Wiersma et al., 2008).

The cancer diagnosis in children and the ferocity of medical interventions can overwhelm such parents. These feelings can result in poor functionality in the parental role and can tamper with their child's capacity to endure such medical treatments (Manne et al., 1996; Steele et al., 2004).

Manne et al. (1996) suggested a possibility of depressive symptoms being present prior to the child's diagnosis; however, this is difficult to measure.

Vrijmoet-Wiersma et al. (2008) proposed that low moods may disrupt the quality of relations between the family members, decision-making abilities (specifically medically related), and adherence to clinic review dates. Klassen et al. (2011) described various problems such as parents having sleeping issues, feelings of social detachment, and shifting roles. Klassen et al. (2011) further noted that substance use was also used as a coping strategy.

Optimistic and cheerful personalities may be associated with better physical health and decreased depressive symptoms (Kostak and Avci, 2013). Furthermore, optimistic parents may have a greater ability to adjust to stressors, i.e., when faced with a cancer diagnosis in their child (Fayed et al., 2011; Kostak and Avci, 2013).

This psychological impact of cancer in a child may result in long term emotional disturbances that may have a catastrophic effect on the entire family, especially the parents (Vrijmoet-Wiersma., 2008).

2.3 Gender differences

Worldwide, females have a greater possibility of incurring depression than men. WHO (2017) stated that depression affects 5.1 % of females and approximately 3.6 % of males globally (WHO, 2017). In South Africa in keeping with the global trend, women are twice as likely to be affected by depression than men (SADAG, 2017).

There are differences in severity of depressive symptoms between mothers and fathers of a child with cancer. Some studies have found that mothers have more depressive and anxiety features than fathers (Wijnberg-Williams et al., 2006; Vrijmoet-Wiersma et al., 2008; Kostak and Avci, 2013; Al-Maliki et al., 2016). However, other studies found no significant difference (Frank et al., 2001; Norberg and Boman, 2008).

The difference in severity may be because females are more expressive with regards to airing their difficulties, and report high degrees of distress compared to males (fathers) and perhaps have different reporting styles (Greenberg and Meadows, 1991; Sloper, 2000; Wijnberg-Williams et al., 2006a; Vrijmoet-Wiersma et al., 2008; Al-Maliki et al., 2016).

Sloper (2000) suggested that it is uncertain if the gender differences are due to parents having contrasting ways of dealing with stressful matters (i.e., when a child is diagnosed with cancer) rather than due to dissimilarities in gender in the general population.

In addition, cultural and financial constraints may result in the fathers working most of the time, leaving the mothers solely to tend to the sick child. It is assumed that children are more attached to their mothers than fathers, hence mothers being more affected emotionally. The

mothers may generally feel overwhelmed with multitasking emotionally-taxing tasks such as looking after themselves, their ill child and managing the household. It is due to the increase in duty, added strain coupled with such mothers getting little rest and time off, that make them more likely to have depressive features (Norberg and Boman, 2007; Kostak and Avci, 2013; Ghufran et al., 2014; Al-Maliki et al., 2016).

Ghufran et al. (2014) proposed that the higher levels of depression in mothers are due to their use of online facilities and researching the child's diagnosis, finding unfiltered and mixed distressing information.

There are contrasting results regarding the level of education and the occurrence of depression. For example, some studies suggest that women who have higher levels of schooling experience less depressive symptoms (Kholasehzadeh et al., 2014; Al-Maliki et al., 2016), while another study by Kostak and Avci (2013) found that there is no such correlation.

Furthermore, it has been suggested that mothers who have several children to take care of may have an additional strain, impairing coping mechanisms, thus worsening depression symptoms (Ghufran et al., 2014). However, this finding is inconsistent, as Kostak and Avci (2013) found that the number of children in the family did not have an impact on depressive symptoms.

2.4 Risk factors

Parents of children with cancer are at risk for developing psychiatric symptoms, which can persevere. Therefore, it is vital to identify such risk factors timeously to best benefit the parents and prevent further negative psychological repercussions (Vrijmoet-Wiersma et al., 2008).

Socioeconomic standing can be a possible risk factor. Other components adding to the distress can be a financial burden, worrying about the general welfare of the family and stressful evolution of roles (Iqbal and Siddiqui, 2002). There are confounding findings regarding the relationship between income and occurrence of depressive symptoms, family functionality and mental well being. Some studies favour a correlation (Kostak and Avci, 2013; Kholasehzadeh et al., 2014; Al-Maliki et al., 2016), while a study done by Erkan and Kaplan (2009) show that there is no significant correlation. But realistically, it is perhaps difficult for poorer families to afford the costly medical care associated with the disease at hand (Al-Maliki et al., 2016).

Apart from socioeconomic status, other risk factors that could initiate and sustain such symptoms include previously experienced trauma, poor communal support and increasing caregiver burden (Vrijmoet-Wiersma et al., 2008).

There has not been much evidence suggesting a correlation between the occurrence of depression and profession as well as ages of parents, age, sex or sort of cancer of the child, or phase in the disease progression (Iqbal and Siddiqui, 2002; Kostak and Avci, 2013; Kholasehzadeh et al., 2014; Al-Maliki et al., 2016).

Barrera et al. (2004) found that added pressure, issues pertaining to the child's behaviour, conjugal and financial discord forecasted depressive symptoms.

It is essential to identify parents with a history of mental health issues as they are perhaps vulnerable and susceptible to coping poorly when faced with the devastating news of a child being diagnosed with cancer (Vrijmoet-Wiersma et al., 2008).

Having a grasp on possible risk factors may assist health care professionals and parents in recognising and preventing such menacing symptoms from advancing further past the

expected response to getting devastating news of a potentially terminal illness (Vrijmoet-Wiersma et al., 2008).

2.5 Coping

Maternal coping ability in relation to a potentially fatal cancer diagnosis is crucial in terms of the emergence of depressive symptoms.

Norberg et al. (2005) suggested that in parents of children with cancer and parents with children that do not have cancer: the presence of active problem-focused behaviours (increase in purposeful behaviour) rather than evasive and passive behaviours, were affiliated with fewer symptoms of depression. However, uncertainty about their child's illness and its consequences and treatment can make the parents feel like they do not adequately grasp the situation (Khatun et al., 2016).

Perceived, impaired social support from family, friends, partners, and medical professionals (nurses) can negatively impact coping (Khatun et al., 2016). Familial support can soften the distress incurred by parents of oncology patients. Mothers, who frequent the hospital, also obtain a considerable amount of support from fellow parents. However, due to fathers possibly spending less time in health facilities, attributed to work responsibilities as sole breadwinners, they are often not as exposed to the same sources of support as mothers (Sloper, 2000; Wijnberg-Williams et al., 2006b; Al-Maliki et al., 2016).

Although that may be the case, working may be beneficial and protective against depression for fathers. This is due to fathers being exposed to additional support at work and from extended family (outside the basic family unit) (Norberg and Boman, 2007; Kostak and Avci, 2013; Al-Maliki et al., 2016). Evidence also shows that fathers obtain support from friends of the same gender and externally from work colleagues whilst mothers tend to lean more on

close family and friends with a substantial amount of support from the partner (Sloper, 2000; Wijnberg-Williams et al., 2006b; Tuna et al., 2012). However, as mothers may spend a great deal of time on hospital premises, fathers who do not mirror this may find that such spousal support is lacking (Sloper, 2000).

Superior family cohesiveness has been found to positively impact the mental state of mothers and the functioning of the family. Such mothers experienced more favourable emotions and less feelings of isolation and perturbation (Maurice-Stam et al., 2007).

Social support appears to play a vital function in parental support and can be identified as a positive factor in bettering coping. Health care professionals who interact directly with parents of children with cancer can identify situations where support is lacking and take the appropriate steps to assist such parents (Kostak and Avci, 2013).

2.6 Possible outcomes of children with depressed mothers

Distress in parents can be directly linked to distress in children. It has been found that children of depressed mothers show a diverse array of internal and external features, considerably more so than children of mothers who are not depressed. However, it was stipulated that distressed parents tended to report their child having more distress than usual (Brennan et al., 2002; Robinson et al., 2007).

Parents who experienced moderate to severe depression expressed that their child had considerably more distress than parents who experienced mild or diminishing depression (Manne et al., 1995; Manne et al., 1996; Steele et al., 2004). There is a significant relationship between depression in parents and behavioural issues in children (Manne et al., 1995; Manne et al., 1996). Steel et al. (2004) found that at 22-24 weeks after diagnosis, mothers who were deemed to have high distress described their children as having more

somatic distress than those mothers who were deemed to have moderate or low distress. Steel et al. (2004) stipulated that at first, such mothers were unbiased when it came to the occurrence of unavoidable treatment-induced physical adverse effects, however as treatment continued, they reacted with heightened emotion to these treatment outcomes.

Increased amounts of anxiety and depression in parents are associated with a poorer quality of life for their children. (Roddenberry and Renk, 2008; Irwanto et al., 2020).

Bernard-Bonnin (2004) stated that there was a difference in outcomes of children whose mothers were depressed compared to children whose mothers were not. Infants of mothers who displayed depression are more vulnerable to forming attachment difficulties (insecure attachment) and poorly regulated attention and arousal. Toddlers or preschoolers of mothers who displayed depression are more vulnerable to forming inadequate self-restraint, internalising and externalising issues, problems with cognitive development, and problems in social communication regarding their parents and other children. Children, who attended school, and adolescents of parents who display depression, are more vulnerable to developing poor adaptive functioning and mental disorders. These mental disorders may encompass anxiety disorders, mood disorders, conduct disorders, Attention deficit and hyperactivity disorder, and learning difficulties (Bernard-Bonnin, 2004).

Depressive symptoms in parents may have a negative impact on their perception of the diagnosis and further treatments. This negative impact may influence their child's psychological and behavioural states (Kostak and Avci, 2013; Ghufuran et al., 2014).

2.7 The Hamilton Depression Rating Scale

The Hamilton Depression rating scale is a 17-item questionnaire administered by health professionals. It is used to determine the degree of depression by asking about symptoms

related to depression; this includes mood features, neurovegetative, neurocognitive and physical features, including psychomotor activity. It also determines the degree of severity of depressive symptoms (Hamilton, 1960).

The Hamilton Rating Scale for Depression is a valuable tool as it has been extensively used in research and in medical fields to measure the severity of depression. It can be thought of as the gold standard (Rohan et al., 2017).

Bagby et al. (2004) found that the scale had adequate reliability and validity.

This rating scale allows for the following to be assessed:

- Mood features include the presence of a depressed mood (i.e., sadness, hopelessness, helplessness, worthlessness).
- Time spent and enthusiasm regarding work and pleasurable activities.
- Social withdrawal.
- Decrease in libido.
- Changes in appetite.
- Changes in eating.
- Changes in weight.
- Greater disposition for carbohydrates.
- Changes in sleeping pattern (insomnia or hypersomnia).
- Somatic symptoms.
- Presence of fatigue.
- Guilty feelings.

- Suicidal thoughts.
- Feelings and physical symptoms of anxiety.
- Increasing deliberations about one's state of health.
- Slowing or changes of thoughts, speech and psychomotor activity.
- Insight into illness. (Hamilton, 1960; Rohan et al., 2016).

The scoring is as follows: 0–7: normal, 8–16: mild depression, 17–22: moderate depression and scores over 24 are indicative of severe depression (Hamilton, 1960).

2.8 Justification

The data in South Africa regarding depression in mothers of paediatric oncology patients is substantially deficient. Early diagnosis and management of depression will assist in decreasing the long-term harmful consequences in such mothers. It would be beneficial to examine the prevalence and severity of depression in this group of individuals in order to improve overall awareness and understanding.

2.9 Hypothesis

This study hypothesises that mothers of children being treated for oncology-related pathology will experience more significant levels of depressive features than the general population.

2.10 Aim

This study aims to determine if there is a greater occurrence of depression in mothers of paediatric oncology patients (in comparison to the whole population) due to their child being

diagnosed with cancer and, if present, to determine the severity and related features of the depression.

2.11 Study objectives

2.11.1 To determine the occurrence of depression in mothers of paediatric oncology patients compared to the whole population.

2.11.2 To determine the severity of depression, if present, in mothers of paediatric oncology patients.

2.11.3 To describe the demographic profile of these mothers, including the level of education, age, marital status, occupation, number of children and monthly income in Rands, and child factors, including the type of oncological illness, age and gender.

2.11.4 To compare the demographic profile of mothers, and associated child factors, between the mothers with depression (scores >7 on the HADS) and without depression (scores 0-7 on the HADS).

Chapter 3: Methodology

3.1 Study design:

This is a cross-sectional study undertaken using a survey (Appendix 2) and the Hamilton depression scale (Appendix 3).

3.2 Population and sampling

Mothers whose children are patients at the paediatric oncology outpatient department in Chris Hani Baragwanath Academic Hospital (CHBAH) participated in this study from 01/09/2020 until 28/02/2021. The participants were specifically mothers of children diagnosed with cancer. The study site was the paediatric oncology outpatient department at CHBAH.

Convenience, voluntary response sampling was used in this study.

The study had the following inclusion and exclusion criteria:

Inclusion criteria

- A participant must be a mother of a child with cancer.
- The mother must have a child with cancer who is less than 18 years of age.
- The child may have any cancer.
- Cancer must have been diagnosed at least two months prior to participation but within a year of participation in the study.

The child (and accompanying mother) must be following up at the CHBAH paediatric oncology department.

Exclusion criteria

- Mothers who have a premorbid mental illness, diagnosed by a doctor prior to their child being diagnosed with cancer, and/ or are taking treatment for mental illness.
- Mothers with pre-existing medical pathology that may impact the mother's mood.
- Mothers with neurological conditions.

3.3 Data collection

Mothers of paediatric oncology patients accompanying their child for review and treatment at the CHBAH outpatient's department were identified to participate in the study. The participants were given an information letter and further clarification if needed (Appendix 1). Thereafter, informed consent was sought by the investigator (Dr J Subrayadoo). The Hamilton depression scale (Appendix 3) was also administered. In addition to this, the following information about the research participants was collected: age, the highest level of education, marital status, occupation, number of children, monthly income in Rands, gender and type of oncological illness of child (Appendix 2). Interviews were conducted in English. Permission to conduct this research was granted by the CEO of the hospital before the research was carried out (Appendix 5).

3.4 Data analyses

The data was captured in Microsoft Excel™. All statistical analyses were conducted using R software (R version 3.4.2; <https://www.r-project.org>). Tests are two-tailed probability values, and statistical significance is accepted when $\alpha \leq 0.05$. Data are presented in tables or figures,

as appropriate. Continuous variables are reported as mean \pm standard deviation, and categorical variables as frequency and percentages.

The data set for this study was generated using continuous scores (0 to >24) obtained from the Hamilton depression scale and categories of normal or different levels of depression. The continuous scores were assessed for departures from normality using the Shapiro-Wilk test and visualised using Q-Q plots. As indicated below, since these scores were non-normal (i.e., heteroscedastic), and others were categorical, non-parametric analyses were used.

The frequency distribution of Hamilton scale scores was plotted to determine whether the mothers of oncology children suffered from depression. The mothers were then grouped into those having normal scores (score of 0-7) and those having depressed scores (score >7) based on the Hamilton depression scale. Next, a chi-squared contingency analysis was used to analyse whether the occurrence of depression within the study group differed from chance. Similarly, a chi-squared contingency analysis was used to analyse whether the number of mothers classified as having a score that showed no depression (0-7), mild (8-16), moderate (17-22) and severe (>24) depression, using the Hamilton depression scale, differed by chance.

For each socio-demographic variable in this study, chi-squared contingency tests were used to analyse whether the frequency of mothers for the component (e.g., married vs not married) of a category differed by chance. To analyse the demographic profile and associated child factors of the mothers who have depression (>7 scores) with those of non-depressed mothers (0-7 scores), Pearson's chi-squared analyses (with Yates correction) and Fisher's exact tests (and odds ratio, as appropriate) were used for categorical variables and Mann-Whitney U tests for continuous variables.

The relationship between these socio-demographic variables and depression score on the Hamilton scale were analysed using Mann-Whitney U or Kruskal Wallis tests and Spearman rank correlations.

3.5 Sample sizes

From an assessment of Z scores of expected frequencies, a sample size of 200 patients will detect statistical significance between the depression scales at the 5% level. Realistically, statistical significance can be expected with a minimum sample of 75 patients (the lowest number recommended) if all patients assessed have some level of depression.

3.6 Ethics

The Human Research Ethics Committee (HREC) of the University of the Witwatersrand unconditionally approved the study before collecting data (Appendix 6). Permission to accomplish the research was also obtained from the Chief Executive Officer of the CHBAH (Appendix 5). Furthermore, the University of the Witwatersrand assessor group approved the research protocol before the study was commenced (Appendix 7).

Informed consent was obtained from all participants involved (Appendix 1). All participants remained anonymous in order to maintain confidentiality about their personal information.

The research procedure did not involve any invasive methods.

Participants were readily given information regarding the study and were allowed to make an informed decision. They were not unduly persuaded into doing this study. Participants were given leeway to remove themselves from the study at any particular time. Study participation did not result in any advantage for the patient, and refusal to participate did not

prejudice the patient or parent in any manner. No financial or other reward was offered for participation.

In the event of a participant showing evidence of depression, or if she found the questionnaire distressing, the participant was referred to Mrs Najeebah Noorbhai, a clinical Psychologist based at CHBAH. Mrs Noorbhai had agreed to assess the participant further and/ or provide counselling if required. Depending on the severity of the depression and assessment outcome, Mrs Noorbhai then took the necessary actions regarding further intervention. In addition to this, depending on the severity, the investigator managed the situation if possible or liaised with the Psychiatry Department of CHBAH to assist. The mother was also referred to her local clinic, if appropriate. A letter detailing the investigator's concerns and the patient's particulars was completed and used as the referral method to Mrs Noorbhai and/ or the appropriate Hospital/Local clinic if warranted (Appendix 4). The contact details of Mrs Noorbhai were made readily available to the participant and appeared on the information and consent letter (Appendix 1).

Chapter 4: Results

4.1 The frequency distribution of Hamilton depression scale scores

A total of 75 mothers of oncology children at CHBAH were surveyed in this study. The frequency distribution of Hamilton depression scale scores showed that most women scored between 2 and 16 (Figure 1), indicating absent to mild depression. Of the 75 women, 50 (66.7%) were considered as depressed (>7 score), and 25 (33.3%) were considered as having a normal mood (0-7 scores) on the Hamilton depression scale scores. This comparison was statistically significant ($\chi^2=8.33$, $df=1$, $p=0.003$). Significantly more women suffered from mild depression in the study sample ($\chi^2=35.85$, $df=2$, $p<0.001$), as opposed to moderate and severe depression. Of the depressed women, 41(54,7%) were considered to be suffering from mild depression, 7 (9.3%) with moderate depression and 2 (2.7%) with severe depression.

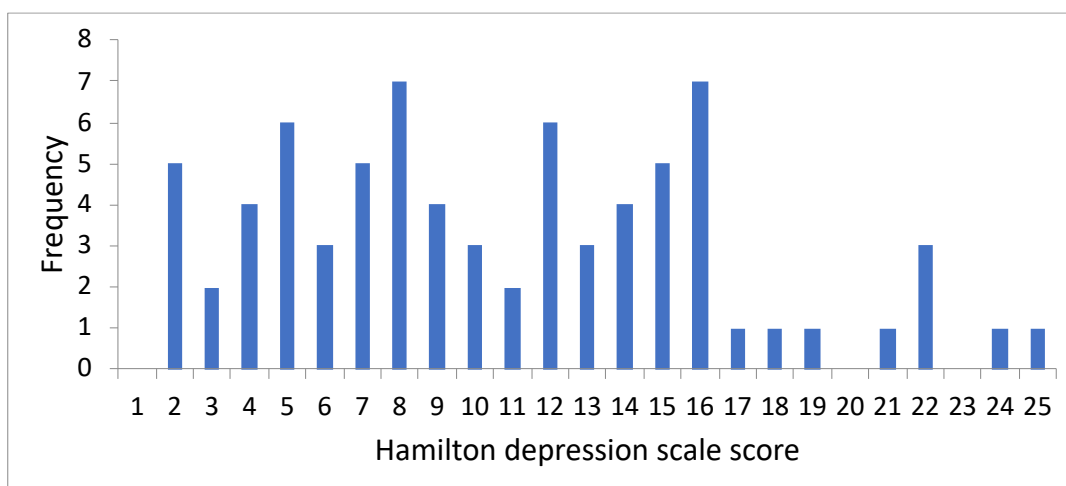


Figure 4.1. The frequency distribution of Hamilton depression scale scores in 75 mothers

4.2 Socio-demographic variables

Table 4.1. Socio-demographic variables of 75 mothers of paediatric oncology patients.

(Statistics in bold are significant.)

Variable	Component	Frequency (percentage)	Statistics
Education	<Grade 10	n= 21 (28%)	($\chi^2=29.84$, df=2, p<0.001)
	>=Grade 10	n= 46 (61.3%)	
	Tertiary	n= 8 (10.7%)	
Occupation	Employed	n= 13 (17.3%)	($\chi^2=32.01$, df=1, p<0.001)
	No formal employment	n= 62 (82.6%)	
Marital status	Married	n= 52 (69.3%)	($\chi^2=11.21$, df=1, p=0.001)
	Not married	n= 23 (30.7%)	
Monthly income	<=R999	n= 43 (57.3%)	($\chi^2=47.39$, df=3, p=0.001)
	R1000-R7000	n= 26 (35.7%)	
	R15000-R19000	n= 3 (4.0%)	
	R8000-R14000	n= 3 (4.0%)	
Age of child	<=1	n= 8 (10.7%)	($\chi^2=30.65$, df=3, p=0.001)
	2-6	n= 40 (53.3%)	
	7-11	n= 16 (21.3%)	
	12-18	n= 11 (14.7%)	
Gender of child	Female	n= 35 (46.7%)	($\chi^2=0.33$, df=1, p=0.563)
	Male	n= 40 (53.3%)	

The average age of the mothers in the study was 34.7 (\pm 7.3) years, and they had 2.9 (\pm 1.5) children on average. Table 1 provides other the socio-demographic variables recorded in this

study. Significantly, most mothers (72%) had completed Grade 10 or higher schooling, most had no formal employment (82.6%), and most (69.3%) were married (Table 1). Significantly, most mothers (57.3%) earned less than R1000 per month. The mothers had between two and six children. However, the gender difference was not significant (Table 1).

4.3 The number of children with different oncological illnesses at CHBAH

Table 4.2. The number of children with different oncological illnesses at CHBAH

Illness	Number of children
Acute lymphoblastic leukaemia	1
Acute Myeloid leukaemia	12
Acute promyelocytic leukaemia	1
Anaplastic large cell lymphoma	1
Chronic Lymphocytic leukaemia	2
Craniopharyngioma	1
Diffuse large B-cell lymphoma	1
Ewing's Sarcoma	3
Germ cell tumour	2
Haemangioma	1
Hepatoblastoma	1
Hodgkin's lymphoma	3
Malignant rhabdoid tumour of the kidney	1
Medulloblastoma	1
Melanotic neuroectodermal tumour	1
Nasopharyngeal carcinoma	1
Neuroblastoma	4
Non- Hodgkin's Lymphoma	2
Osteoblastic sarcoma	1
Osteogenic sarcoma	1
Osteosarcoma of right distal femur	1
Parotid and glottic haemangioma	1
Pineal gland tumour	1
Posterior fossa pilocytic astrocytoma	2
Pre B cell acute lymphoblastic leukaemia	8
Retinoblastoma	1
Rhabdomyosarcoma	2
Sacroccygeal yolk sac tumour	2
T-cell acute lymphoblastic leukaemia	1
Vaginal Yolk Sac Tumour	1
Wilms Tumour	14

Table 2 shows the number of children by oncological illnesses in this study. There were 31 different illnesses, with one child each for 19 (61%) of the illnesses. Most children had Wilms Tumours followed by Acute Myeloid Leukemia.

Comparisons between the mothers' socio-demographic profile and their normal or depressed states based on the Hamilton score scales are considered in Figures 2- 17.

4.4 The age distribution of mothers with normal and depressed HADS scores

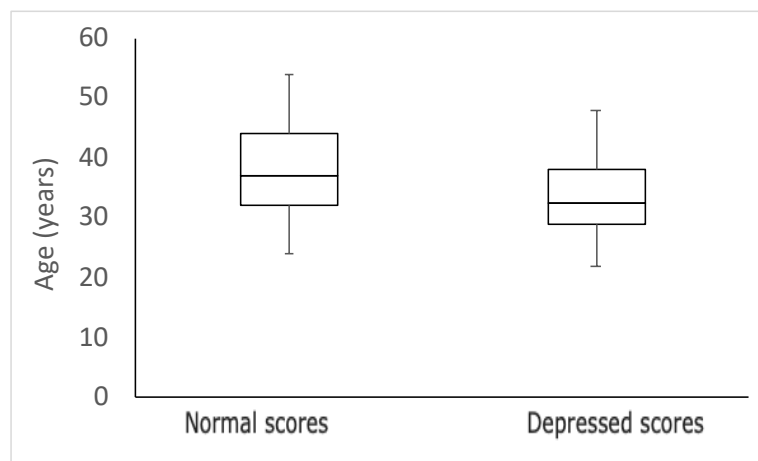


Figure 4.2. The age distribution of mothers with normal (0-7) and depressed (>7) HADS scores

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

Older mothers were significantly more likely to have normal scores than younger mothers (Mann-Whitney U = 848.5, n1 = 50, n2 = 25, p=0.012; Figure 2).

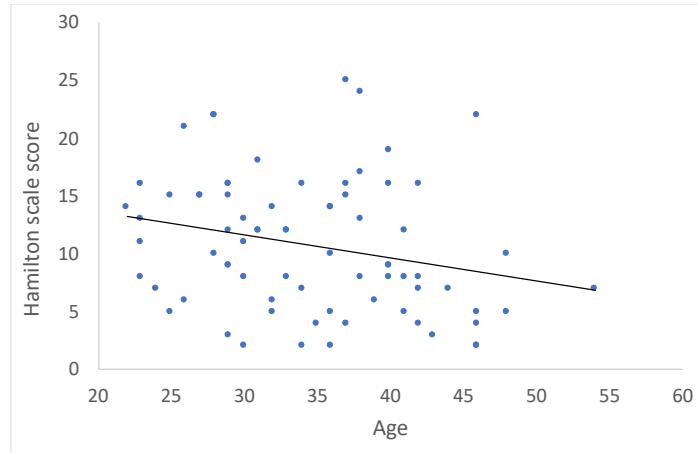


Figure 4.3. The relationship between the age of the mother and their HADS scores

(A trend line is included since the relationship was significant (see text)).

The Hamilton scale scores correlated negatively with mothers' age (Spearman rank $r = -0.28$, $p = 0.016$; Figure 3). Thus, it appears that age is a predictor of coping in the mothers in this study.

4.5 The level of education of mothers with normal and depressed HADS scores

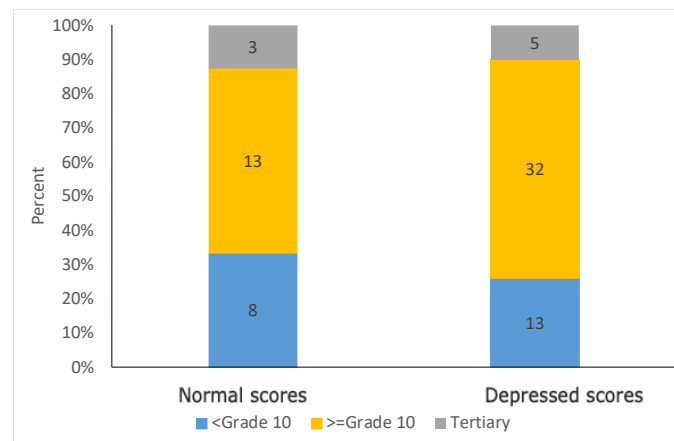


Figure 4.4. The level of education of mothers with normal (0-7) and depressed (>7) HADS scores

(The number of patients is shown within the bars, and the percentage on the y- axis refers to the percent of the total of each column).

The distribution of education levels did not differ significantly from chance (the null model) in mothers with normal and depression state scores ($\chi^2=0.66$, $df=2$, $p=0.719$; Figure 4).

However, a greater percentage of mothers in both groups finished grade 10 or higher (Figure 4).

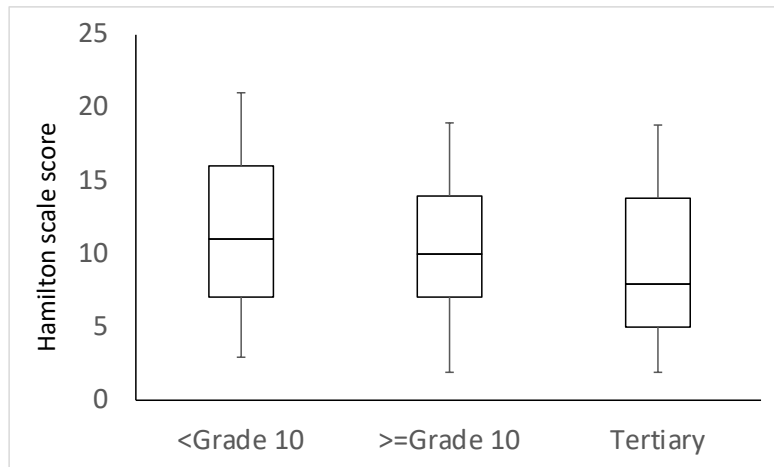


Figure 4.5. The Hamilton scale scores of mothers in relation to the level of education

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

There was no significant difference between education levels and Hamilton scale scores (Kruskal-Wallis $\chi^2 = 0.68$, $df = 2$, $p\text{-value} = 0.713$; Figure 5).

4.6 The employment status of mothers with normal and depressed HADS scores

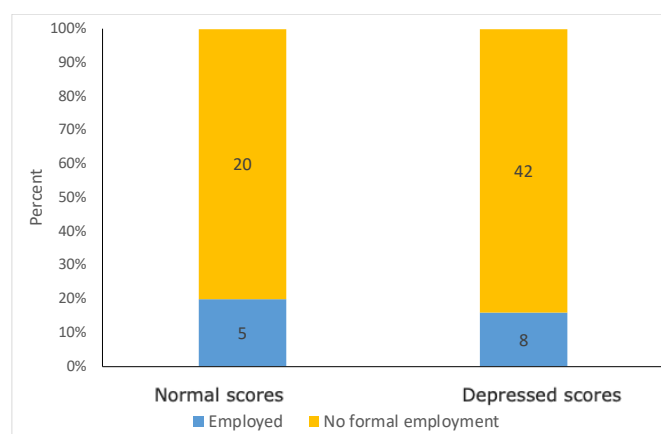


Figure 4.6. The employment status of mothers with normal (0-7) and depressed (>7) HADS scores

(The number of patients is shown within the bars, and the percentage on the y- axis refers to the percent of the total of each column).

The employment status distribution did not differ significantly from chance in mothers with normal and depression state scores (Fisher's exact test: $p=0.750$; Figure 6). However, a significant percentage of mothers in both groups had no formal employment (Figure 6).

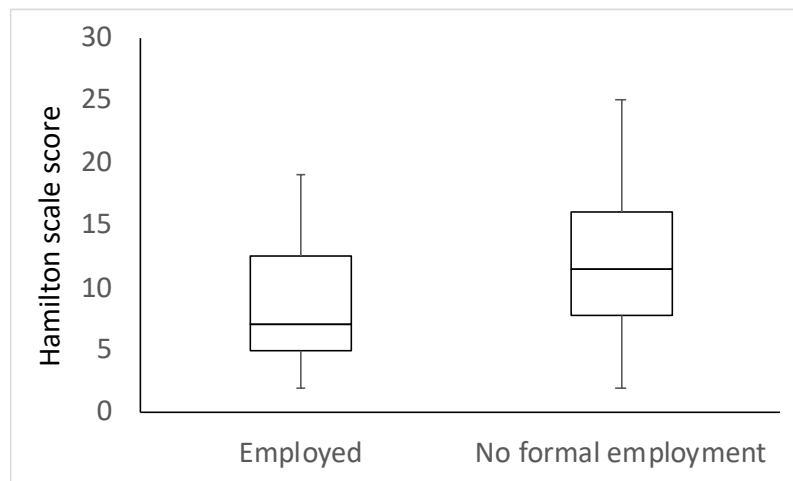


Figure 4.7. The Hamilton scale scores of mothers in relation to employment status

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

The Hamilton scale scores did not differ significantly between mothers employed or those who did not have any formal employment (Mann-Whitney $U = 348.5$, $n_1 = 13$, $n_2 = 62$, $p=0.445$; Figure 7).

4.7 The marital status of mothers who had normal or depressed HADS scores

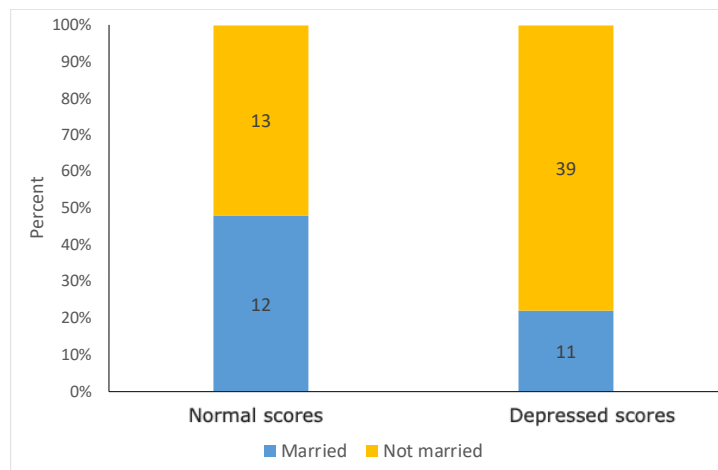


Figure 4.8. The marital status of mothers who had normal (0-7) or depressed (>7) HADS scores

(The number of patients is shown within the bars, and the percentage on the y-axis refers to the percent of the total of each column).

Comparing mothers' marital status with normal and depression state scores indicated that a significantly higher proportion of unmarried mothers were depressed than the proportion of married mothers (Fisher's exact test = 0.033; Figure 8). For example, unmarried mothers were 3.2 times more likely to be depressed than married mothers (Figure 8).

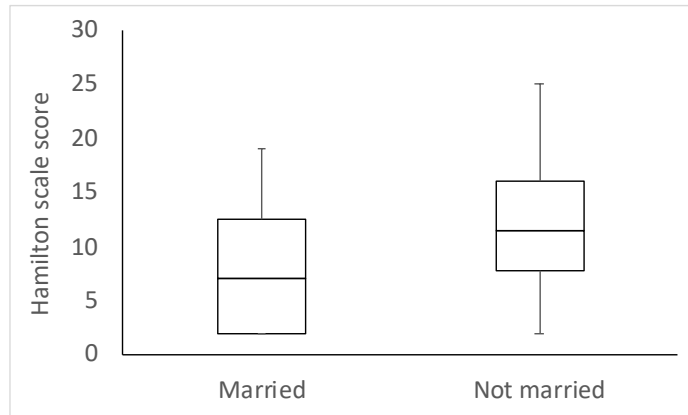


Figure 4.9. The Hamilton scale scores of mothers in relation to marital status

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

Mothers that were married tended to have lower Hamilton scale scores than those that were not married (Mann-Whitney $U = 428.5$, $n_1 = 23$, $n_2 = 52$, $p=0.052$; Figure 9).

4.8 The number of children of mothers with normal and depressed HADS scores

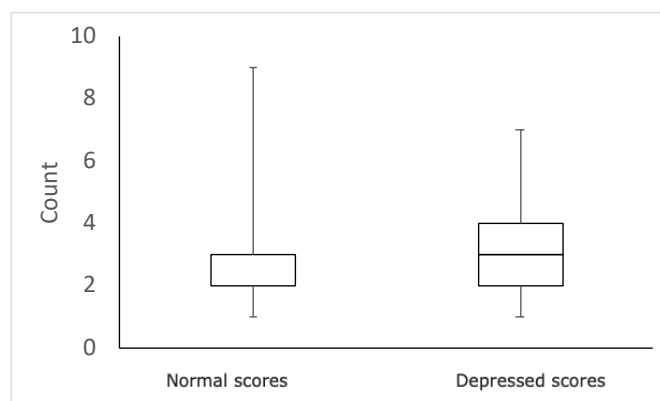


Figure 4.10. The number of children of mothers with normal (0-7) and depressed (>7) HADS scores

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

There was no significant difference in the number of children of mothers with normal and depressed states (Mann-Whitney U = 689, $n_1 = 50$, $n_2 = 25$, $p=0.285$; Figure 10).

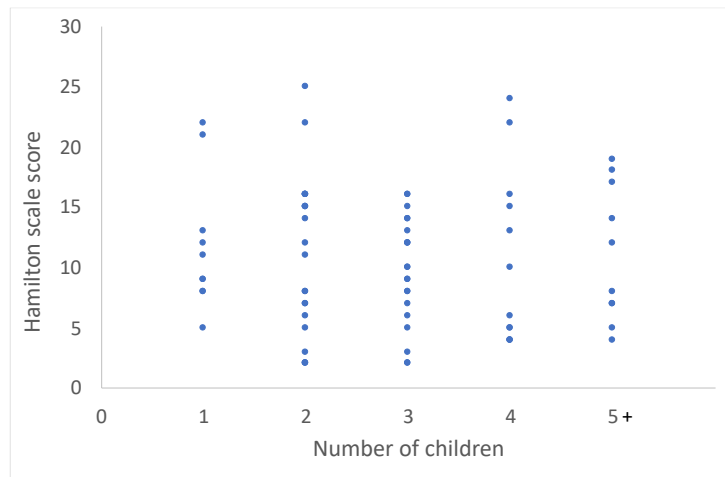


Figure 4.11. The relationship between the number of children and their mother’s HADS score

There was no correlation between the Hamilton scale scores and the number of children in the family (Spearman rank $r = -0.05$, $p = 0.650$; Figure 11).

4.9 The income level of mothers who had normal or depressed HADS scores

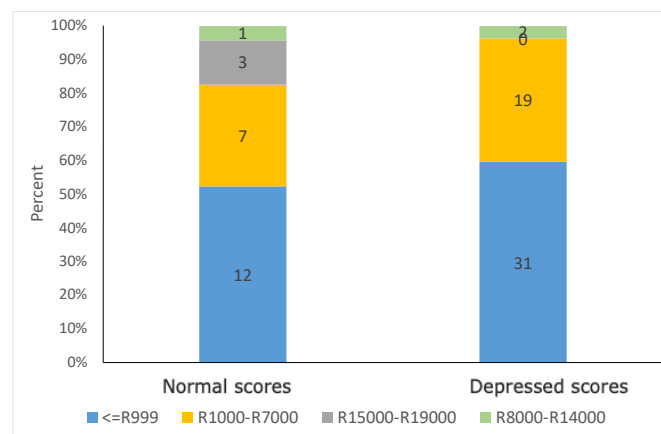


Figure 4.12. The income level of mothers who had normal (0-7) or depressed (>7) HADS scores

(The number of patients is shown within the bars, and the percentage on the y- axis refers to the percent of the total of each column).

The distribution of income levels did not differ significantly from chance in mothers with normal and depression state scores ($\chi^2=7.12$, $df=3$, $p=0.068$; Figure 12). However, most mothers in both groups earned less than R1000 per month (Figure 12).

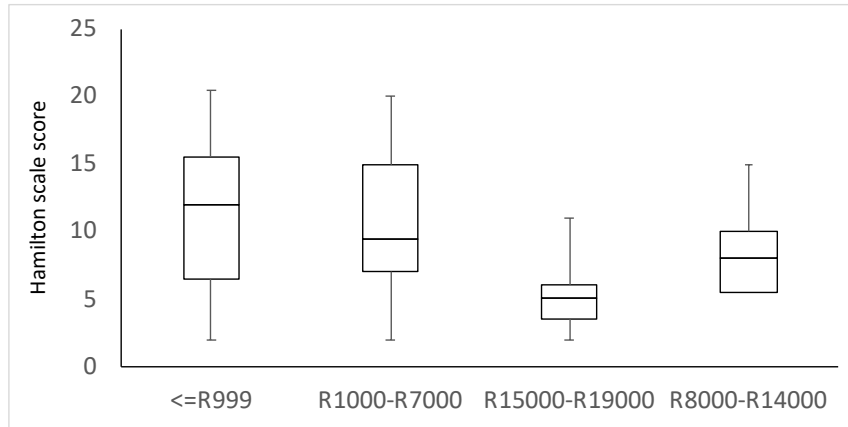


Figure 4.13. The Hamilton scale scores of mothers in relation to monthly income

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

There was no significant difference between monthly income levels and Hamilton scale scores (Kruskal-Wallis $\chi^2 = 5.26$, $df = 3$, $p\text{-value} = 0.154$; Figure 13).

4.10 The children's gender distribution of mothers with normal and depressed HADS scores

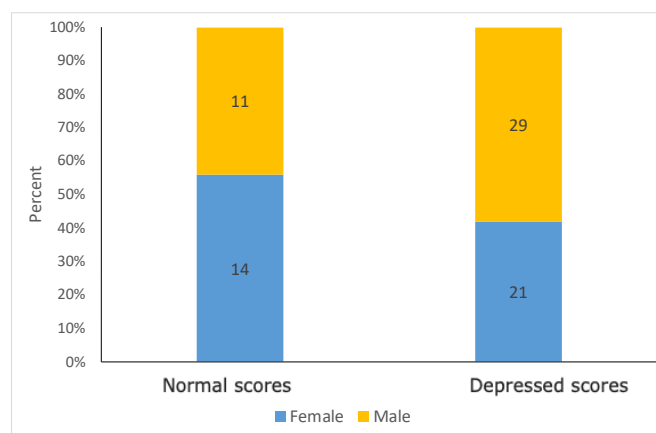


Figure 4.14. The children's gender distribution of mothers with normal (0-7) and depressed (>7) HADS scores.

(The number of patients is shown within the bars, and the percentage on the y- axis refers to the percent of the total of each column).

The distribution of the gender of the children did not differ significantly from chance in mothers with normal and depression state scores (Fisher's exact test: $p=0.328$; Figure 14). A similar percentage of female and male children were recorded for normal and depressed mothers (Figure 14).

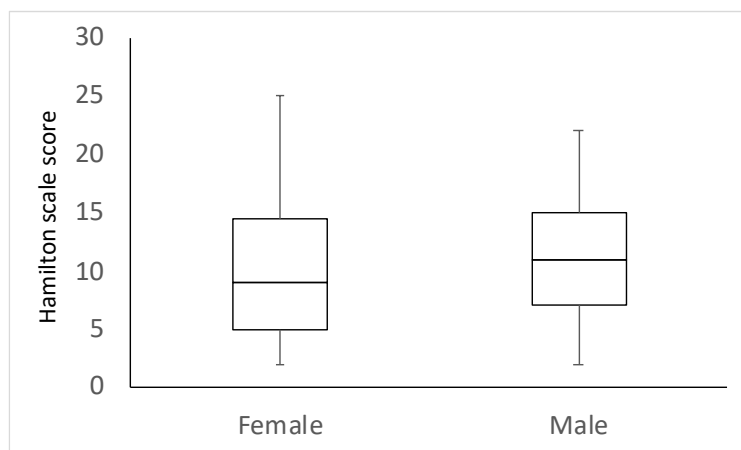


Figure 4.15. The Hamilton scale scores of mothers in relation to child gender

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

There was no significant difference in the Hamilton scale scores and the gender of the children (Mann-Whitney $U = 8631.5$, $n_1 = 35$, $n_2 = 40$, $p=0.469$; Figure 15).

4.11 The age distribution of the children of mothers with normal and depressed HADS scores

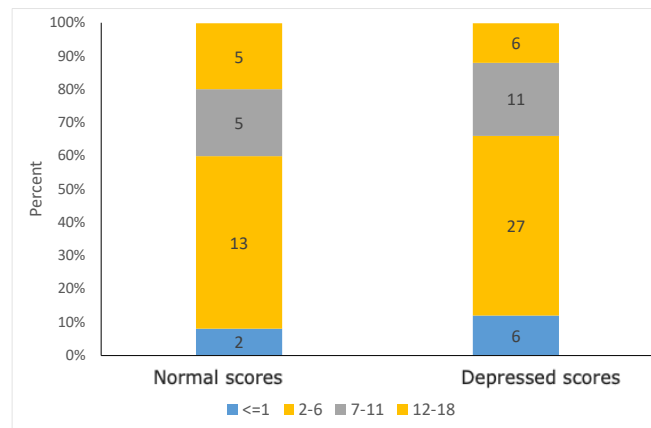


Figure 4.16. The age distribution of the children of mothers with normal (0-7) and depressed (>7) HADS scores

(The number of patients is shown within the bars, and the percentage on the y- axis refers to the percent of the total of each column).

The distribution of age classes of children did not differ significantly from chance in mothers with normal and depression state scores ($\chi^2=1.02$, $df=3$, $p=0.796$; Figure 16). Nevertheless, more mothers in both groups had children aged between 2-6 (Figure 16).

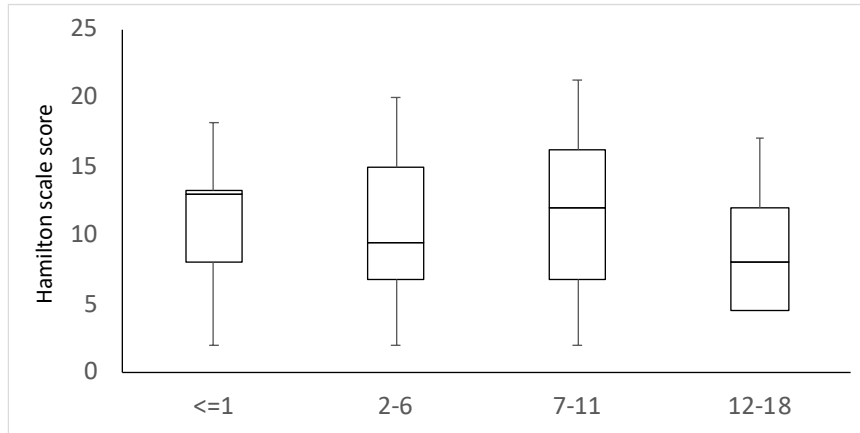


Figure 4.17. The Hamilton scale scores of mothers in relation to the age of the child

(Horizontal bar is the median, box shows first and third interquartile, and whiskers are minimum and maximum scores).

There was no significant difference between age classes of the children and Hamilton scale scores (Kruskal-Wallis $\chi^2 = 1.93$, $df = 3$, $p\text{-value} = 0.587$; Figure 17).

Chapter 5: Discussion

5.1 Demographic characteristics

The mothers in the study had a mean age of 34.7 years of age and had a mean of 2.9 children. It was also found that significantly more mothers had completed Grade 10 or higher schooling; were married; earned less than R1000 per month or had no formal employment; had 2 to 6 children and lastly, the sex ratio of children did not differ in relation to maternal HADS scores.

5.1.1 Age of mothers

This study found that younger mothers were significantly more likely to have HADS scores that indicated depression.

Similarly, Tomlinson et al. (2009) found that the mean age of onset for depression in women is around 26 years old.

Leach et al. (2008) stated that unstable relationships and relational conflict might negatively influence the emotional state of younger women to a greater extent. Leach et al. (2008) further stipulated that these variations between age groups are best explained by their differing psychosocial circumstances instead of factors unique to age.

The patient sample comes from Soweto, where the socioeconomic conditions are generally, but not exclusively, very poor.

Jorm et al. (2000) identified that maturity in age is linked to improved emotional regulation and psychological resistance in response to distressing events.

Perhaps the older women who participated in this study had developed better coping skills throughout the years than the younger mothers. Consequently, their experience in facing

previous hardships may have better prepared them emotionally to face the struggles of having a child with cancer.

However, it is possible that older mothers, as a defense mechanism, learn to minimise depressive symptoms, thus appearing not to be depressed. It could also be postulated that such mothers belong to a generation less exposed to mental wellness information.

5.1.2 Education levels of mothers

In this current study, the distribution of education levels did not differ significantly in mothers with normal and depression state scores. This finding was in keeping with Erkan and Kaplan (2009) and Kostak and Avcı (2013).

However, in contrast, Tomlinson et al. (2009) found that the prevalence of major depression was more pronounced in participants with a decreased level of average education. More specifically, he found that persons who had primary level education (Grade 1-7), compared to persons with more schooling, had a greater likelihood of having higher levels of depression.

Despite the findings in this study, previous research shows that higher levels of education and the resultant components may prove to be a protective factor. Such associated components may include variations in individuals coping skills in response to stress and variations in tension levels related to career (Bjelland et al., 2008).

It is also speculated that higher levels of education may positively affect an individual's overall mental and physical health (Mirowsky, and Ross, 2017).

However, in this study, the educational levels did not differ in mothers with depression versus mothers with no depression. This observation could possibly be attributed to the small sample size and lack of significant variation in the level of education.

The other possible explanation is that mothers with higher education also may take on the sole duty of being primary caregivers. This may result in an inability to utilise their educational attainments in a fulfilling way, leading to frustration and lack of career prospects. Furthermore, even though their educational attainment is thought to grant them access to better resources, they may not be in a position to utilise these resources.

In South Africa, having a better education level does not necessarily equate to having more employment opportunities or a more stable financial status. This is because the job market in South Africa can be viewed as significantly competitive, with the unemployment rate being 32,6% (in the first quarter of 2021) as per South Africa's Quarter Labour Force Survey (QLFS) released mid-2021 (Statistics South Africa, 2021). Therefore, the mothers in this study may not be able to use their higher level of education to gain a better socioeconomic standing and miss out on the protection they may afford.

5.1.3 Marital status of mothers

This study compared mothers' marital status with normal state scores and mothers with depression state scores. These findings showed that a significantly greater proportion of unmarried mothers were depressed than married mothers.

Similarly, Dolgin et al. (2007) found that single mothers seemed to be included in the group of mothers experiencing moderate to high levels of stress, as they were inclined to show decreased problem-solving skills, and in terms of personality structure, displayed neuroticism.

Statistics South Africa released the 2019 General Household Survey results in 2020. This survey revealed that women led 41,8% of South African households. This survey also found that 42,0% of South African children lived with their mothers (Statistics South Africa, 2020).

Single mothers can be considered a vulnerable group, with an increased propensity towards developing elevated depression and anxiety symptoms (Mullins et al., 2010).

Mullins et al. (2010) proposed that single mothers of children with chronic illness face a multitude of challenges. Single-parent households can be linked with poor social support. As mentioned earlier, they can be emotionally overwhelmed as they are usually solely tasked with caring for a chronically sick child. The burden is worsened by having the responsibility of taking care of other children. The presence of another parent often proves to ease this emotional strain. In addition to this psychological burden, single mothers often have limited funds and find themselves being the only breadwinner (Mullins et al., 2010).

Mullins et al. (2010) continue to suggest that essentially lower socioeconomic status puts single mothers more in jeopardy of parental distress.

Although Mullins and colleagues (2010) make an important point on single mother households, it is also essential to note that comparing married vs unmarried mothers is somewhat reductionistic since the mother may be getting excellent support elsewhere.

A conglomeration of certain factors may contribute to prolonged socioeconomic, emotional and bodily health issues in single mothers of paediatric cancer patients. These factors include monetary, occupational, and caregiver pressures, and previous exposure to trauma (Granek et al., 2014). Therefore, it can be said that the single mothers who participated in this study certainly faced many hardships, thus putting them at a significant disadvantage in terms of their mental well-being.

5.1.4 Income levels of mothers

This study found that the distribution of income levels did not differ significantly from chance in mothers with normal and depression state scores. This could be because most of the mothers interviewed earned less than R1000 per month (57.3%). Thus, the sample primarily included lower-wage earners. This, however, is a function of the small sample size.

Iqbal and Siddiqui (2002) and Erkan and Kaplan (2009) showed similar findings regarding income and its relation to depressive symptoms in mothers of paediatric oncology patients.

However, it is important to note that other studies had contrasting findings (Kostak and Avci, 2013; Al-Maliki et al., 2016), as depression is more common in the poorer population (Kessler et al., 2003).

The costly course of the clinical management of childhood cancer can cause further stress to an already struggling low-income family (Al-Maliki et al., 2016).

A publication by Statistics South Africa (2017) called “Poverty Trends in South Africa” stated that black African women and minor children were especially at risk of falling into poverty (Statistics South Africa, 2017).

The Statistics South Africa (2017) report also found that women were more impoverished than men. Women accounted for approximately 52,7 % of the total impoverished population, while males only accounted for 47,3%. In addition, there was an increase in the number of women living below the upper-bound poverty line, from 54.9 %, in 2011 to 57,2% in 2015 (Statistics South Africa, 2017).

Bona et al. (2014) suggested that indigent parents of children with advanced cancer, compared to richer ones, were at risk of experiencing excessive revenue deficits. Such parents were often forced to redistribute their money to the medical needs of the sick child.

As a result, they would have to do without some essential necessities to afford the bare minimum needed to sustain the family. Subsequently, this affects the child's well-being.

Having limited funds may prove to be an obstacle in coordinating events needed to access health care establishments.

A possible explanation of the finding of no significant difference in terms of income level in this study, could be because this study was conducted at a public healthcare facility, with relatively minor costs involved to those in the lower income bands i.e., majority of the patients.

Depression in parents, as a result of their child having cancer, may have a negative impact on their capacity to continue working and deal with the increasing financial burden (Bona et al., 2014).

5.2. Levels of depression

In this study, by far, a higher number of mothers had HADS scores in keeping with depression than had normal scores. Again, this finding is in keeping with other literature (Iqbal and Siddiqui, 2002; Erkan and Kaplan, 2009; Al-Maliki et al., 2016).

Strained caregivers (of patients with cancer) are at risk of incurring a worsening fiscal status, emotional and physical health issues; poor immunity; and sleep disruptions (Northouse et al., 2012). These factors will have an impact on their mental health.

It is not surprising to find that most of the mothers following up at the CHBAH paediatric oncology outpatient department found themselves struggling with depression.

This study was conducted during the 2nd wave of the Covid-19 pandemic. Paediatric cancer patients can be deemed high risk due to significant co-morbidity. Due to lockdown

restrictions such paediatric patients and their caregivers may have had restricted access to facilities and possible postponing and/or defaulting treatment. Therefore, the impact of the Covid-19 pandemic on oncology services could have caused significant distress to the caregivers and paediatric cancer patients.

However, in the current study specifically, significantly more women suffered from mild than severe depression. These levels of depression were also seen in other international studies (Ghufran et al., 2014; Kholasehzadeh et al., 2014). Unfortunately, this could not be corroborated for the local population as there is limited existing data related to the topic at hand.

Mild depression may result in more outpatient clinic visits and negatively influence the quality of life (Cuijpers et al., 2004). In addition, the functional disability, poor work productivity and unemployment can be associated with higher levels of depression (Kessler et al., 1997; Cuijpers et al., 2004; Birnbaum et al., 2010). However, whilst mild depression may not result in such severe consequences, it can still be correlated with difficulties in occupational and social functioning (Kessler et al., 1997; WHO, 2020). It can also be argued that mild depression is linked to acute and chronic role inefficiencies (Kessler et al., 1997).

The finding of more mothers in this study displaying mild depression scores rather than moderate or severe depression scores is possibly due to them prioritising their child's needs over their own. The enormity of their child's illness may force them to monopolise most of their energy on their child's, instead of own, health. Thus, they become preoccupied with the child's well-being and, as a result, do not leave much room to process and deal with their own emotional struggles. Perhaps this may lead to them under-reporting symptomatology.

It is also possible that the women in this study who displayed mild depression had more extended family support. Social support has been identified as a protective element against

depression and other psychiatric complications, particularly women caring for chronically unwell children (Casale et al., 2015). It has also been suggested that social support improves help-seeking practices in depressed women (Gagné et al., 2014). Thus, this extended support could have protected the women from developing more severe forms of depression.

Smith et al. (2013) found that women make better use of mental health care services.

Perhaps, in conjunction with free health care being available, the possible increased pursuit of psychiatric services could explain the findings of more minor rather than major depressive symptoms since these may have been managed in the past.

Women who had pre- morbid mental illness were excluded from this study, this may also explain the finding of lower symptom severity.

It is also plausible that some of the women in this study may have sought basic counselling and perhaps psychological support, therefore placing themselves in better mental health.

The presence of mild depression may increase the chances of progression into more severe forms of depression. Thus, it is vital that more focus be given to this level of depression to prevent further complications (Kessler et al., 1997; Cuijpers et al., 2004).

5.3 The strengths of the study

The topic in question has minimally been researched in Africa, let alone South Africa.

Moreover, this study highlights the emotional challenges of mothers of children with cancer.

It is imperative that more effort be put into offering psychological and social support to such families. The data was collected from a tertiary level hospital in Soweto, which offers an exclusive perspective on this population.

5.4 The limitations of the study

There have been several limitations that were identified in this study. The study sample was relatively small. Therefore, the results may not be an accurate representation of the population. Further, the self-reporting questionnaires are subject to self-report bias, thus affecting the data in the study. Other aspects that may influence depression levels were not deliberated, such as sources of support. It has been noted that poor social support can be a risk factor for depression (Vrijmoet-Wiersma et al., 2008; Khatun et al., 2016). Therefore, further exploration may have offered vital information on the contributing factors to the depressive symptoms. The severity of the child's disease was also not included in this study. However, other studies have found that it has a negative impact on the mother's mental state (Rosenberg et al., 2013; Sultan et al., 2016). Perhaps, in order to broaden the understanding of maternal coping, it would have been of value to compare the severity of the child's disease with maternal depression levels. First, however, the method used for quantifying severity would have to be determined.

Perhaps a future approach could, for example include mothers of current in-patients (as an arbitrary metric of illness severity at the time) vs those who are currently more stable and able to be managed on an out-patient basis.

Major depression can occur concurrently with a range of medical, psychiatric, and substance use diseases (Freeman and Joska, 2013). In this study, these co-morbidities may have also impacted the mothers' psychological state. Perhaps enquiring more about such factors may have enlightened the topic.

So-called skip generation households make up 4.5 % of all households. Also, approximately 14.4% of children in South Africa are orphaned (Statistics South Africa, 2020). Therefore, it

may have been helpful to have included primary caregivers other than mothers concerning the local context,

5.5. Recommendations

- More wide-reaching studies are recommended in South Africa. Larger sample sizes at various sites may help find significant associations between levels of depression and other parameters.
- Early detection and intervention of depression may assist mothers in improving their mental health and, as a result, may benefit their children.
- For example, promoting mental health literacy and early psychoeducation on prevention of further mental health issues (i.e., progression into major depression with the concomitant functional impairment) may play a significant role in interventional strategies.
- In the form of psychotherapy, counselling or groups, professional support should be available to the mother and her family from the beginning of the child's treatment onwards.
- Intervention should be a collaborative effort, including social services, oncologists and the multidisciplinary psychiatric team. Therefore, broadening the support offered to the mother and her family.
- There is a great need for future qualitative/ phenomenological research to be done on this subject.

Chapter 6: Conclusion

The majority of the mothers who participated in this study experienced mild depression. The results showed that a significantly higher proportion of unmarried and young mothers were depressed.

The findings of this study provide evidence that can be used to motivate for the provision of early psychological and social intervention for the mother and her family.

Unaddressed depression in the mothers may have multiple adverse repercussions. This may include negative interpersonal, occupational and socioeconomic effects that involve the quality of life of herself, her sick child and her family, which ultimately impacts the outcome for the child with cancer. Therefore, evidence of the significant rates of maternal depression should be considered in the overall treatment strategy for paediatric oncology patients.

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Appendix 1: Information letter and consent

Dear Parent,

Good Day

My name is Dr Juanita Subrayadoo; I am a Psychiatry Registrar at Witwatersrand University Psychiatry Division. I am doing a research project on mothers of children with cancer; I am trying to find out if such mothers suffer from depression. My supervisor is a specialist psychiatrist, Dr W Friedlander.

This research project is intended to help us understand the impact of cancer on mothers and in the future identify mothers that need further support.

I invite you to participate in my study. If you choose to participate, you will be asked some specific questions related to depression. I also will require certain information about you, such as your level of education, age, marital status, occupation, number of children and monthly income in Rands and about your child, the type of oncological illness, age, gender of the child,

Your answers will be documented, but your name, your child's name, and personally- identifying details will not be recorded so that the information is completely confidential. You will remain anonymous at all times.

This study is completely voluntary; you may decide to remove yourself from participation at any given time. If you decide to participate or not, this will not negatively impact you or your child. You will not directly benefit from participating in the study, and you will not be given any financial reimbursement for your participation.

This study has been approved by the Human Research Ethics Committee of the University of the Witwatersrand and by the hospital. If you have any concerns about how the study is being conducted, please contact the Chairperson of this Committee, Professor Clement Penny, who may be contacted on telephone number 011 717 2301 or by e-mail at Clement.Penny@wits.ac.za.

By signing this document, you are consenting to participate in the study. You are free to withdraw from participation at any given time.

If you feel depressed or find the questionnaire distress-provoking, I will gladly refer you to Mrs Noorbhai and/or to the nearest hospital/clinic. She is a psychologist at Chris Hani Baragwanath Hospital and will provide you with further assistance. Please feel free to contact her if need be.

Her details are as follows:

Mrs Najeebah Noorbhai

Contact number: 011 933 8891/8839

The principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

Please do not hesitate to ask any further questions or any additional information regarding this study.

Thank you for participating!

Kind Regards

Dr J Subrayadoo
0794922661

Dr W Friedlander
Wendy.Friedlander@wits.ac.za

Consent

I _____ consent to participate in the study: *The severity of depressive symptoms in the mothers of paediatric oncology patients.*

I have been well informed about the study, and I understand the goals of this study.

I have been given and understand the information regarding the study and have been given a chance to ask questions.

I understand that I will remain anonymous, and confidentiality will be maintained.

I am aware that I will not receive any form of financial compensation for my participation in this study.

I am aware that I can decide to remove myself from participating in this study, and I understand that I will not be negatively affected if I do so.

Name

Surname	
Date	
Signature	
Witness	
Date	

Appendix 2: Data collection sheet

Participant data collection sheet

Tick where applicable

Age

Highest level of education

No formal	Primary school level	High/Secondary school level	Tertiary level

Occupation

No formal employment	Full-time employment	Part-time employment

Marital status

Single	Divorced	Married	Widow	In a Relationship but not married

Monthly income

< = R999	R1000- R7000	R8000-R14 000	R15 000- R19 000	> R20 000

Number of children

--

Age of patient (child) in years

<= 1	2- 6	7-11	12- 16	17-18

Gender of child

Male	Female

Type of illness

--

Appendix 3: Hamilton Rating Scale for Depression

Patient Name: _____

Date: _____

Hamilton Rating Scale for Depression (17-items)

Instructions: For each item select the "cue" which best characterizes the patient during the past week.

1. **Depressed Mood**
(sadness, hopeless, helpless, worthless)
 - 0 Absent
 - 1 These feeling states indicated only on questioning
 - 2 These feeling states spontaneously reported verbally
 - 3 Communicates feeling states nonverbally, i.e., through facial expression, posture, voice and tendency to weep
 - 4 Patient reports VIRTUALLY ONLY these feeling states in his spontaneous verbal and nonverbal communication
2. **Feelings of Guilt**
 - 0 Absent
 - 1 Self-reproach, feels he has let people down
 - 2 Ideas of guilt or rumination over past errors or sinful deeds
 - 3 Present illness is a punishment. Delusions of guilt
 - 4 Hears accusatory or denunciatory voices and/or experiences threatening visual hallucinations
3. **Suicide**
 - 0 Absent
 - 1 Feels life is not worth living
 - 2 Wishes he were dead or any thoughts of possible death to self
 - 3 Suicide ideas or gesture
 - 4 Attempts at suicide (any serious attempt rates 4)
4. **Insomnia - Early**
 - 0 No difficulty falling asleep
 - 1 Complains of occasional difficulty falling asleep i.e., more than ½ hour
 - 2 Complains of nightly difficulty falling asleep
5. **Insomnia - Middle**
 - 0 No difficulty
 - 1 Patient complains of being restless and disturbed during the night
 - 2 Waking during the night – any getting out of bed rates 2 (except for purposes of voiding)
6. **Insomnia - Late**
 - 0 No difficulty
 - 1 Waking in early hours of the morning but goes back to sleep
 - 2 Unable to fall asleep again if gets out of bed
7. **Work and Activities**
 - 0 No difficulty
 - 1 Thoughts and feelings of incapacity, fatigue or weakness related to activities; work or hobbies
 - 2 Loss of interest in activity; hobbies or work – either directly reported by patient, or indirect in listlessness, indecision and vacillation (feels he has to push self to work or activities)
 - 3 Decrease in actual time spent in activities or decrease in productivity. In hospital, rate 3 if patient does not spend at least three hours a day in activities (hospital job or hobbies) exclusive of ward chores.
 - 4 Stopped working because of present illness. In hospital, rate 4 if patient engages in no activities except ward chores, or if patient fails to perform ward chores unassisted.
8. **Retardation**
(slowness of thought and speech; impaired ability to concentrate; decreased motor activity)
 - 0 Normal speech and thought
 - 1 Slight retardation at interview
 - 2 Obvious retardation at interview
 - 3 Interview difficult
 - 4 Complete stupor
9. **Agitation**
 - 0 None
 - 1 "Playing with" hand, hair, etc.
 - 2 Hand-wringing, nail-biting, biting of lips
10. **Anxiety - Psychic**
 - 0 No difficulty
 - 1 Subjective tension and irritability
 - 2 Worrying about minor matters
 - 3 Apprehensive attitude apparent in face or speech
 - 4 Fears expressed without questioning
11. **Anxiety - Somatic**
 - 0 Absent Physiological concomitants of anxiety such as:
 - 1 Mild Gastrointestinal - dry mouth, wind, indigestion,
 - 2 Moderate diarrhea, cramps, belching
 - 3 Severe Cardiovascular – palpitations, headaches
 - 4 Incapacitating Respiratory - hyperventilation, sighing
Urinary frequency
Sweating
12. **Somatic Symptoms - Gastrointestinal**
 - 0 None
 - 1 Loss of appetite but eating without staff encouragement. Heavy feelings in abdomen.
 - 2 Difficulty eating without staff urging. Requests or requires laxatives or medications for bowels or medication for G.I. symptoms.
13. **Somatic Symptoms - General**
 - 0 None
 - 1 Heaviness in limbs, back or head, backaches, headache, muscle aches, loss of energy and fatigability
 - 2 Any clear-cut symptom rates 2
14. **Genital Symptoms**
 - 0 Absent 0 Not ascertained
 - 1 Mild Symptoms such as: loss of libido,
 - 2 Severe menstrual disturbances
15. **Hypochondriasis**
 - 0 Not present
 - 1 Self-absorption (bodily)
 - 2 Preoccupation with health
 - 3 Frequent complaints, requests for help, etc.
 - 4 Hypochondriacal delusions
16. **Loss of Weight**
 - A. When Rating by History:
 - 0 No weight loss
 - 1 Probable weight loss associated with present illness
 - 2 Definite (according to patient) weight loss
 - B. On Weekly Ratings by Ward Psychiatrist, When Actual Changes are Measured:
 - 0 Less than 1 lb. weight loss in week
 - 1 Greater than 1 lb. weight loss in week
 - 2 Greater than 2 lb. weight loss in week
17. **Insight**
 - 0 Acknowledges being depressed and ill
 - 1 Acknowledges illness but attributes cause to bad food, climate, overwork, virus, need for rest, etc.
 - 2 Denies being ill at all

Total Score:

Appendix 4: Referral letter

To _____

Date _____

Dear Colleague

RE: Research project conducted by Dr J Subrayadoo, regarding depression on mothers of paediatric oncology patients, at Chris Hani Baragwanath Academic Hospital (Paediatric oncology OPD).

I am kindly requesting your assistance, as I would like to refer a participant in my study for further evaluation and management.

Her details are as follows:

Miss/Mrs/Ms _____ Age (in years) _____

The results of the Hamilton depression rating scale administered on the above mentioned has shown that she displays the following levels of depression:

Mild Moderate Severe Very severe

Additional comments: _____

My recommendations: _____

Kind Regards

Dr J Subrayadoo (MBChB WSU)

juanitasuu@gmail.com

Appendix 5: Permission to conduct research from the CEO of CHBAH



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 20th May 2020

TITLE OF PROJECT:

The severity of depressive symptoms in the mothers of paediatric oncology patients.

UNIVERSITY: Witswatersrand

Principal Investigator: Dr J Subrayadoo

Department: Psychiatry

Supervisor : Dr W Friedlander

Permission Head Department (where research conducted): Yes

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

- **Permission having been granted by the Committee for Research on Human Subjects 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: 20/5/2020

.....
Approved/Not Approved
Hospital Management
Date: 22/5/2020

Received By: J Subrayadoo
Date: 26/05/2020

Appendix 6: HREC clearance certificate



R14/49 Dr J Subrayadoo

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M200563

NAME: Dr J Subrayadoo
(Principal Investigator)

DEPARTMENT: School of Clinical Medicine
Department of Psychiatry
Medical School
University

PROJECT TITLE: The severity of depressive symptoms in the mothers of
paediatric oncology patients

DATE CONSIDERED: 2020/05/29

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Dr W Friedlander

APPROVED BY: 
Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 2020/08/12

This clearance certificate is valid for 5 years from the 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 on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
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 submit details to the Committee. **I agree to submit a yearly progress report.** When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **May** and will therefore reports and re-certification will be due early in the month of **May** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

Appendix 7: Assessor group approval

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG



20th May 2020

RE: RESEARCH PROTOCOL

TITLE: The severity of depressive symptoms in the mothers of paediatric oncology patients.

This serves to confirm that the research protocol of Dr Juanita Subrayadoo (student number 070298) has been revised according to the assessor group recommendations, and approved by the supervisor Dr W Friedlander. The protocol was assessed by a group chaired by Prof C Smith.

A handwritten signature in blue ink, appearing to be "U Subramaney", written over a horizontal dashed line.

Professor U Subramaney

Academic HOD

Department of Psychiatry

Appendix 8: Turnitin Report

Juanita Subrayadoo turn it in 27:02:2022-1.docx

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