MENTAL HEALTH OF MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Chevon Blumberg

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfillment of the requirements for the degree of
Master of Science in Medicine in Child Health (Neurodevelopment)

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DECLARATION

I, Chevon Blumberg, declare that this research is my own work. It is being submitted for the degree of Master of Science in Medicine in Child Health (Neurodevelopment) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signature _____

On this _____ day of _____

To my parents, Michael and Glenda Blumberg, who have sacrificed so much in their lives, in order to ensure that their children would never need to sacrifice anything

ABSTRACT

CONTEXT: Autism Spectrum Disorder (ASD) may have an impact on maternal mental health. Maternal mental health may also be influenced by the socio-economic variables of single parenthood, and lack of income.

AIM OF STUDY: The aim of the study was to compare the mental health of mothers of children with ASD, with a control group. The total group was divided using the socio-economic variables of single parenthood and lack of income in order to compare the impact of these variables on maternal mental health.

DESIGN, SETTING AND PARTICIPANTS: A cross-sectional study design was used for descriptive and comparative purposes. Data was collected from mothers of children with either ASD or asthma, who functioned as the control group, who were patients at a hospital in Johannesburg, South Africa.

METHODS: 101 mothers of children who were patients at the hospital were assessed. Participants were administered a demographic data questionnaire, and a standardised questionnaire for assessing symptoms of depression, anxiety and stress (Depression, Anxiety, Stress Scale- DASS).

RESULTS: There was no significant difference between the two groups of mothers on socio-economic variables ($p>0.05$), with the exception of government grant receipt ($p=0.01$). Although there was a trend for higher scores in the ASD group, this study found no significant difference in the mental health status of mothers of children with ASD when compared to the control group. Similarly, no significant difference was found in the mental

health status between mothers who were in a relationship, when compared to mothers who were not in a relationship ($p>0.05$). A significant difference was found between mothers who received an income and those who did not, on all three subscales of depression, anxiety and stress ($p<0.05$). These differences were more pronounced in the ASD group, with these mothers scoring consistently higher than the control group.

CONCLUSION: ASD was not shown to have a significant impact on maternal mental health, when compared to a control group. Single mothers were not shown to experience significantly more psychological distress than those mothers who were in a relationship. Lack of income was shown to significantly increase the symptoms of depression, anxiety and stress in mothers participating in this study. This impact was more pronounced in those mothers who had children living with ASD.

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All the mothers who care and take responsibility for their children

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ABBREVIATIONS

ASD	Autism Spectrum Disorder
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital
DASS	Depression Anxiety Stress Scale
DASS21	Depression Anxiety Stress Scale 21-item
DDQ	Demographic Data Questionnaire
DSM	Diagnostic and Statistical Manual of Mental Disorders
HIV	Human Immunodeficiency Virus

CHAPTER 1

INTRODUCTION

1.1 Background

The World Health Organisation defines mental health as a ‘state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.’ (p1) (1)

Mothers experience many challenges and stresses while rearing a child, even under the most optimal circumstances. When caring for a child with a disability, these challenges are intensified by the increased demands on resources, such as time, money and parental availability. (2) The experience of raising a child with a disability increases the risks for poor maternal mental health. (2)

Published literature has shown that Autism Spectrum Disorder (ASD), in particular, has a negative impact on parenting mental health, with increased rates of depression, anxiety and stress. (3-6)

Autism Spectrum Disorder (ASD) is defined as a developmental disorder in which there is pervasive and sustained impairment in several areas of development, including reciprocal social interaction and communication, as well as the presence of particular behaviours, interests and activities. (7)

Poverty and single parenthood, (8) impact further on maternal mental well-being. (9,10) Mothers who are single receive less social support, increasing their risk for psychological stress and poor mental health. (9) Published literature has consistently reported a positive association between poor mental health and poverty. This association is particularly true for women. (10)

Poor maternal mental health has an impact not only on maternal functioning, but also on the functioning and development of her child. (11) Children's early development relies on the health and well-being of their parents or care-givers. (11) Therefore, parental psychological distress is an important factor to consider in the treatment of all children, but in particular, those with developmental disorders. (3)

1.2 Aim, Objectives and Hypotheses

1.2.1 Aim of the Study

The aim of this study is to assess the mental health of mothers of children living with Autism Spectrum Disorder.

1.2.2 Study Objectives

1 To assess the presence of symptoms of depression, anxiety, and stress in mothers of children with ASD, and compare the prevalence of these symptoms to a control group. In this study, mothers of children with asthma have been chosen as the control group. Asthma was chosen as the diagnosis for the control group because of the reversible, episodic nature of the condition, and the potential for normal inter-episodic health. However, the condition, like ASD, requires regular clinic visits, administration of medication, and possible intermittent hospitalisations. It is therefore reasoned that any differences found cannot merely be attributed to logistical and administrative issues.

2 To identify single motherhood as being associated with the presence of symptoms of depression, anxiety or stress in mothers of children with ASD.

3 To identify unemployment as being associated with the presence of symptoms of depression, anxiety or stress in mothers of children with ASD.

1.2.3 Hypotheses

This research tested the following hypotheses:

1) Mothers of children with ASD experience symptoms of depression, anxiety and stress to a greater extent than mothers of children with asthma.
2) Single parenthood is a risk factor for the development of depression, anxiety and stress in mothers of children with ASD, and mothers of children with asthma.
3) Unemployment is a risk factor for the development of depression, anxiety and stress in mothers of children with ASD, and mothers of children with asthma.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter will provide a description of ASD and discuss the impact of the condition on maternal mental health. The current socio-economic climate of the South African child and family will be explored, and the impact of various factors on maternal mental health will be discussed. The implications of poor maternal mental health as pertaining to childhood development will be described, and the challenges of accessing mental health care will be presented. The necessity for holistic childcare will also be presented.
This chapter concludes with a description of the aim, objectives and hypotheses of the study.

2.2 Impact of Childhood Disability on Maternal Mental Health

Caring for a child with a disability has been associated with poor emotional and physical health in caregivers. (12) Mothers of children with developmental disabilities are at increased risk of depression compared to mothers of typically developing children. (13) Caregivers who experience the most

distress are those who spend the most number of hours in caregiving tasks, expend more of their own money on expenses arising from the care of the disabled child, require more help from support services, and care for children who are older or of higher complexity. Levels of distress are often related to child behaviour and caregiving demands. (12)

Of particular interest in this study is the impact of Autism Spectrum Disorder on maternal mental health.

2.3 Autism Spectrum Disorder

In 1943 Leo Kanner (14) published a paper describing a group of children 'whose condition differs so markedly and uniquely from anything reported so far, that each case merits… a detailed consideration of its fascinating peculiarities.' (14)(p217) He concluded that 'these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handcaps.'(14)(p250)
The condition he described was to become known as Autism Spectrum Disorder (ASD).

ASD is characterised by pervasive and sustained impairment in several areas of development including reciprocal social interaction and social verbal and nonverbal communication, as well as the presence of restricted, repetitive and stereotyped patterns of behavior, interests or activities. (7) These symptoms

present in early childhood and significantly limit or impair functioning in social, occupational, or other important areas of functioning. The impairments cannot be solely explained by intellectual disability, and exceed difficulties expected on the basis of developmental level. (7) The disorder is termed a spectrum disorder, as manifestations of the disorder vary significantly depending on the severity of the condition, developmental level and chronological age. (7)

The condition presents in the first years of life, and is often associated with some degree of cognitive impairment. Children with ASD can have normal or superior intelligence, but the majority present with below average intelligence. (15)

Many individuals with ASD have language deficits ranging from complete lack of speech, to language delay, poor comprehension, echoed speech (echolalia), and overly literal use of language. Even if the individual has intact language skills, the use of language for reciprocal social communication is impaired. (7)

Social-emotional reciprocity is defined as the ability to engage with others and share thoughts and feelings. Children with ASD show an obvious deficit in this reciprocal interaction, with little or no initiation of social interaction, limited sharing of emotions, and reduced or absent imitation of others' behaviour. If language exists it is often one-sided, lacking in social reciprocity, and used to make a request or to label, rather than to comment, share feelings, or engage in conversation. (7)

Deficits in non-verbal communication are manifested by absent, reduced or atypical use of eye contact, gestures, facial expressions, body orientation, or speech intonation. One of the earliest features noticeable in children with ASD is impaired joint attention. This is manifested by a lack of pointing, showing, or presenting objects of interest to others, or failure to follow someone else's pointing or eye gaze. (7)

Young children with ASD manifest deficits in social relationships with a lack of shared social and imaginative play, and, later, insistence on playing by very fixed rules. There may be a preference for solitary activities, or for interacting with much younger or older individuals. (7)

The restricted patterns of behaviour, interests or activities of individuals with ASD include simple motor stereotypies (e.g. hand flapping), repetitive use of objects (e.g. lining up toys), and repetitive speech (e.g. echolalia). Children with ASD may display excessive adherence to routine, and extreme resistance to change, as well as highly restricted and fixated interests of abnormal intensity or focus. They may also present with hyper- or hypo-reactivity to sensory input, manifesting as extreme responses to specific stimuli, including sounds, textures, smells, lights and movements, resulting in extreme reactions or rituals. (7)

The prevalence of ASD varies between geographical regions and across epidemiological studies, with a global mean prevalence of 62/10 000, which translates into one child out of every 160. (16) There are no prevalence

estimates available from any African or other low-income countries, (16) and accurate South African national autism statistics are not available. (17) However, despite variability, there is no evidence to support differences in prevalence by geographic region, nor is there evidence of a strong impact of ethnic, cultural or socio-economic factors. (16) In the South African province of the Western Cape, 10 children per week are diagnosed with ASD at Red Cross Children's Hospital, Lentegeur and Tygerberg Hospitals combined. (17)

It has been noted that ASDs are the fastest growing paediatric developmental disorder (18), and some well-controlled studies have reported rates that are two to three times higher than the accepted 1 in 160 children. (16) It is unclear if this increase reflects an expansion of the diagnostic criteria of ASD in the DSM-IV or DSM-V, increased awareness and knowledge of the disorder, differences in study methodology, or a true increase in the frequency of ASD. (7)

Published literature has consistently shown that ASD has a negative impact on parental mental wellbeing, with increased rates of stress, depression and anxiety, when compared to parents of typically developing children, and parents of children with other developmental disorders, or intellectual disability. (3-6,19)

Giallo et al (6) found that when compared with mothers of typically developing children, mothers of children with ASD experience significantly higher levels of fatigue. Factors associated with increased fatigue include poor maternal sleep quality, increased need for social support, and poor quality of physical activity.

Fatigue is significantly related to other aspects of wellbeing, including stress, anxiety and depression, and lower parenting efficacy and satisfaction.

Raising a child with ASD places huge strain on families, often due to competing personal, family and social commitments. (20) The impact is multidimensional, involving the personal sphere but also extending into the wider community, with negative experiences of discrimination, ultimately leading to social withdrawal and isolation. (20) Parents struggle to manage relationships with spouses, other children, and extended family members due to the increased attention required for their child, (20) thus increasing social stressors and limiting access to external social support.

Mothers of children with ASD report an increased number of life stress experiences (e.g. moving, changing employment), and daily difficulties (e.g. cleaning up, difficulty finding care for their children), compared to mothers of typically developing children. (4) The impaired social relatedness characteristic of ASD can be very emotionally painful for mothers. (3) Unusual, aggressive or destructive behaviours can lead to difficulties in public situations, especially when observed by uninformed people. (3) Children with ASD may also have impaired daily living skills (eg. washing, dressing, toileting), requiring increased parental care-giving responsibilities. (3) In addition, families need to change schedules and routines, set aside time to access therapeutic services, and bear the financial costs of transporting the child to and from these services. (21) Aside from the considerable health care costs for a child with ASD, research has shown that the financial impact is far more profound, with mothers of children with ASD earning less and working less than mothers of children with other or no health limitations.(22)

2.4 The South African Context

In the South African context, the challenges of child-care are often complicated by a disadvantaged socio-economic environment. (8)
A study by the South African Institute of Race Relations, showed that the 'typical' South African child is raised by their mother, in a single-parent household. (8) Mothers who are single receive less social and financial support, and are therefore at a greater risk for psychological stress and poor mental health. (9) Holborn and Eddy (8) also showed that most South African children live in households with unemployed adults. Parental unemployment places a family at risk for poverty and deprivation. This in turn affects parental mental health as well as childhood development. Literature from low- and middle-income countries has shown a relatively consistent trend in which poor mental health, including depression and anxiety, is associated with poverty, particularly among women. (10) In developing countries, it is estimated that more than 200 million children under 5 years do not fulfill their potential as a result of poverty, malnutrition, poor health, deficient care, and unstimulating home environments. This detrimentally affects their cognitive, motor and social-emotional development. (23) Poverty and socio-cultural context affects children's development by exposing them to psychosocial risks that cause changes in brain structure and function, thus impacting behavior. (24)
Research has shown that poor children experience more behavioural and emotional difficulties than non-poor children, with elevated levels of depressive and anxiety symptoms. There is a strong link between poverty and

conduct problems, as well as academic failure. Poor children are more likely to be affected by substance abuse, teen pregnancy, juvenile crime and premature termination of education, than those children who are not affected by poverty. (25)

Growing up in poverty greatly increases the probability that a child will be exposed to environments and experiences that will negatively impact his or her well-being, thereby increasing the risk of more adverse developmental outcomes. Poverty during early childhood may be more damaging than if experienced at a later stage, particularly regarding eventual academic achievement. The dual risk of poverty experienced simultaneously in the family and in the surrounding neighbourhood further increases young children's vulnerability to adverse consequences. (11)

2.5 Impact of Poor Maternal Mental Health on Child Development

Poor maternal mental health has an impact not only on maternal functioning, but also on the functioning and development of her child, (11) thereby contributing to inter-generational disadvantage that accumulates throughout the life span. (26) Poor caregiver mental health is associated with greater child disability, more extensive child behavior problems, poor child temperament, and specific cognitive (27) and sensory deficits. (2)

Shonkoff et al (11) have shown that there is much incontrovertible scientific evidence for the significance of developmental impacts of early experiences, caregiving relationships, and environmental threats on childhood development. Practically all aspects of early human development, from the brain's developing circuitry (28) to the child's capacity for empathy (29), are affected by the child's environment and experiences. (11) These effects are cumulative, beginning early in the prenatal period and extending throughout early childhood. (11) Parents and other regular caregivers are "active ingredients" in the child's environment during the period of early childhood. (11)

Research on early childhood development has highlighted that the parenting role, as well as general caregiving relationships, is the primary influence on children's development. (30) Schore (31,32), has indicated that the attachment relationship is indeed a major organiser in the development of brain neurobiological systems, including processing of emotion, modulation of stress, and self-regulation; and Zeanah (33) has described the infant-caregiver relationship as the most important experience in the development of the young child. Similarly, Ziabreva et al (34) have indicated that the mother functions as a regulator of the socio-emotional environment during early stages of postnatal development contributing to the development of the infants capacity for affect regulation.

Children thrive in the context of close and reliable relationships that provide love, nurturance, attachment security, responsive interaction, and encouragement for exploration. (11) A lack of positive relationships, inadequate supervision, and poverty of the parent-child experience (30) is

strongly associated with poor child outcomes, resulting in an increased risk for behavioural and emotional problems. (30)

Three parenting factors have been reported as being consistently linked to the competent expression of young children's cognitive and social-emotional abilities: cognitive stimulation; care-giver sensitivity and responsiveness; and care-giver affect (emotional warmth). (11) Poor maternal mental health affects the ability of mothers to express nurturing qualities necessary for optimal childhood development, with depressed mothers being less affectively positive, less energetic and less effortful when interacting with their child. (35) Children's early development depends heavily on the health and well-being of their parents or care-givers. Unfortunately, a significant number of young children are exposed daily to untreated mental health problems in their families. (11) This often coincides with recurrent family violence, as well as the psychological fallout from living in an impoverished and violent neighborhood. These cumulative risk factors impose heavy burdens on early childhood development. (11)

Estimates of depression in women with children range from 10% to 42%, with few of these women either identified or treated. (36) The reported prevalence of diagnosed major depressive disorder in low-income South African mothers is 34,7%.(37) This prevalence was based on research conducted on mothers in the postpartum period, thus excluding mothers not presenting during this period, as well as those not seeking healthcare. It is clear that maternal depressive symptoms are not transient(36) therefore the prevalence is likely

to be higher than this reported figure. It is also important to note that the persistence of symptoms further increases the effect on children's health. (27) Cooper et al (37) found that mothers with depression were less sensitive when interacting with their children, and that these infants were less positively engaged with their mothers. Evidence suggests that depressive episodes interfere with the affective maternal state, influencing the quality of the bond between mother and child. (21)

Maternal depression is recognised to have a broad influence on child health and well-being. Children of mothers who are depressed, or who have depressive symptoms, are at increased risk, at different stages of life, for developmental delay, behavioral problems, depression, (38) and repeated unintentional injuries (39). Child abuse has also been linked to maternal depression. (40)

Maternal depressive symptoms have negative effects on the use of routine infant health services and preventive child health measures, (41,42) and are associated with an increased inclination to utilise health care services unnecessarily, (38,42) as well as recurrent hospitilisations.(12)

2.6 Limited Access to Mental Health Care Services

Neuropsychiatric disorders contribute an estimated 14% to the global burden of disease. (43) Mental health care can be directly linked to the United Nation's Millenium Development Goals of reduction of child mortality, and improvement of maternal health, yet services remain insufficient. (44) A large discrepancy exists between mental health needs and the provision of mental

health services, this is especially true in Africa. (45) In South Africa, problems affecting the adequate provision of mental health services include: mental health institutions being in disrepair; shortages of mental health professionals; undeveloped community and rehabilitation services; and a lack of sufficient specialist mental health services, such as child and adolescent units. (44)
Access to mental health care services and parental health promotion may also be limited by personal barriers. Lack of time, lack of respite hours, lack of qualified alternative care providers for the child, and low prioritisation of the need may influence health-seeking behaviour. (12)
Pertaining to ASD specifically, research performed by Nyoni and Serpell (46) in Zambia showed that despite the recommendation that within 6 weeks of diagnosis with ASD children should receive access to intervention, there are no preschools in Zambia that cater for children with ASD, and very few services offer speech therapy. In South Africa, with just 9 schools in the whole of the country specialised in teaching children with ASD, an estimated 135 000 children are not receiving the education that they need. (17)

2.7 Holistic Child Care

The World Health Organization defines health as a ‘state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’. (1)(p1)
The main aims in the treatment of children with chronic disorders is, as far as possible, to treat the condition, decrease or avoid complications, and ensure the fulfillment of the child’s maximal developmental potential through helping

the child to acquire new skills and improve existing abilities. (47) Collaboration of health care-workers together with parents of the disabled child is at the core of management. (47) Parental psychological distress is an important factor to consider in the holistic care of children with developmental disorders. (3) However, maternal depression is often not addressed. (13) Health care workers need to be aware of the psychological status and quality of life of mothers when formulating treatment plans and making decisions. (47) Paediatricians can play an important role in identifying mothers with mental health risks, as they are often the most frequent point of contact that mothers have with a health care professional. (41)

2.8 Conclusion

Maternal mental health can be negatively affected by the challenges of caring for a child with a disability. This in turn can negatively impact child development. Mothers of children with ASD experience more stress than that experienced by mothers of typically developing children, or mothers of children with other developmental disorders. This stress is exacerbated in single-parent households, where mothers typically receive less social support. The mental health risks are further compounded in the context of unemployment and limited resources.

Although there is a recent emergence of research on autism from developing countries, the focus is often on the characteristics and presentation of these children. (48,49) There is a need for research to assess the experience of the caregivers of children with ASD, as this is an integral part of management.

CHAPTER 3

METHODS AND MATERIALS

3.1 Introduction

This chapter presents the methodology used in performing the study, and includes the study design, population and sampling methods, and the procedure of the study. It also describes in detail the measurement tools utilised.

3.2 Study Design

This was a non-equivalent, cross-sectional study, used for descriptive and comparative purposes. (50) A cross-sectional study is defined by the selection of a sample of individuals from a previously defined population. Information regarding both the exposure and outcome of interest is obtained simultaneously from this sample, at a single point in time.(51)

3.3 Study Population and Sampling

This study took place between June 2012 and April 2013, at the Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) Paediatric

Neurodevelopmental Clinic (area 297) and Paediatric Asthma Clinic (area 284). The population consisted of mothers of children who are patients at CMJAH. The sample included 51 mothers of children with ASD, who are patients of the Neurodevelopmental Clinic, as well as 50 mothers of children with asthma, who are patients of the Asthma Clinic.

3.3.1 The Control Group

In this study the control group is comprised of mothers of children with asthma. Asthma is defined as a chronic condition characterised by episodes of reversible airway narrowing, accompanied by coughing, wheezing, and dyspnoea. (15) The prevalence of asthma in South African children is between 6 and 12 percent. (15)

Despite being categorised as a chronic condition, in between acute episodes the child living with asthma may experience normal health.

Studies have shown that actual asthma status is not causally related to the mother's symptoms of depression, and is not associated with poor maternal mental health. (52,53) Therefore, mothers of children with asthma were chosen as the control group, as a proxy for mothers of typically developing children without a diagnosis, as they were an accessible population.

However, as in the treatment of most chronic conditions, asthma requires maintenance through regular specialist appointments, medications, and might require emergency treatment at a health facility during an acute episode. For this reason, this group of mothers was felt to be comparable to those of children with ASD, as both mothers are required to cope with the financial and time constraints of having a child who requires specialised care.

3.3.2 Sampling

Cross-sectional studies require the use of randomised sampling, to avoid the distortion of results by selection bias. (51) However, in this study, convenience sampling was used. (50) Convenience samples are composed of individuals from an easily accessible population, as they present in a central place. (54) Convenience sampling is the least costly to the researcher, in terms of time, effort and money; It is also the least rigorous of the sampling techniques, potentially yielding poor quality data. (55) In order to decrease this innate bias, attempts were made to limit threats to internal validity. (50) Mothers who were attending routine clinic visits were invited to volunteer to take part in the study. All participants who volunteered completed all of the questionnaires. Data were excluded from the analysis according to the inclusion and exclusion criteria, in order to decrease factors that might introduce extraneous risks for poor mental health.

3.3.3 Inclusion and Exclusion Criteria

The following criteria were used for admission of participants to the study:

3.3.3.1 Inclusion Criteria

Mothers who presented with the following were included in the study:

- A child who has a diagnosis of ASD or asthma
- Age 18-50 years
- South African citizenship
- Negative or unknown HIV status
- Proficiency in English as a first or second language

Children who presented with the following were included in the study:

- Age 1-10 years
- Previous diagnosis of ASD or asthma by a neurodevelopmental paediatrician/ paediatrician

3.3.3.2 Exclusion Criteria

Mothers who presented with the following were excluded from the study:

- Non-state/non-government hospital patients
- Not living with their child
- Previous psychiatric diagnosis
- Use of prescribed psycho-active medication
- Diagnosis of a chronic illness or physical/mental disability
- More than one child with a physical/mental disability
- Pregnant at the time of interview
- Illiterate

Children who presented with the following were excluded from the study:

- Comorbid chronic medical illness
- Acute illness at the time of the interview

Fathers and other caregivers/relatives were also excluded.

3.4 Outcome Measures

The questionnaires used included the Demographic Data Questionnaire (DDQ) and the Depression Anxiety Stress Scale (DASS).

3.4.1 Demographic Data Questionnaire (Appendix 1)

The Demographic Data Questionnaire (DDQ) was designed to extract information pertinent to the inclusion and exclusion criteria, and details used in the final analysis of the information elicited from the study.

The demographic data includes: age, race, relationship status, employment status, grant reception, indicators of social support (family and friends), HIV status, medical and psychiatric status of the mother, citizenship, relationship to the child, health status of the child.

3.4.2 DASS Questionnaire and Scoring Template (Appendix 2)

The Depression, Anxiety, and Stress Scale (DASS) developed by Lovibond and Lovibond (56) (1995) is a well-researched and widely accepted self-report clinical assessment, which has been found to be a reliable and valid measure of the constructs it was intended to assess. (57-59) The DASS is comprised of a 42-item or 21-item self-report questionnaire, which yields three 14-item or 7-item subscales respectively, that measure levels of depression, anxiety, and stress. (56) Participants rate the extent to which they have experienced each symptom over the past week, on a 4-point Likert scale. (56)

The Depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The Anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The Stress scale is sensitive to levels of chronic non-specific arousal. It assesses difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient. (56)

Scores for the Depression, Anxiety and Stress scales are each determined by

summing the scores for the relevant set of seven of the 21 items. (56) A high score on each subscale indicates poor psychological health. (60)
Internal consistency of the DASS subscales has been shown to be high, with Cronbach's alphas of 0.94, 0.88, and 0.93 for depression, anxiety, and stress respectively. Factor analysis found a three-factor solution in the DASS, which corresponds well with the three subscales, namely depression, anxiety and stress. Construct validity is supported by moderately high correlations of the DASS with indices of convergent validity (0.65 and 0.75), and lower correlations of the DASS with indices of divergent validity (range -0.22 to 0.07). Criterion validity is supported by reported statistically significant differences in DASS scores between two diagnostic groups. (61)

The DASS has been used in a range of developing countries, including Iran (62), Malaysia (63), Nigeria (64) and Peru (65). The DASS has also been used successfully in Sub-Saharan African research. (66) Although studies using the DASS have been carried out in South Africa, most have been of small cohorts, and have not been published in peer-reviewed literature. (67,68)

There are several published studies showing that the DASS 21-item questionnaire (DASS21) has the same factor structure as the full DASS, and that it yields similar results. Although it has only half the number of questions, it has coverage of all subscales within each scale. (56) In general, the full DASS is often preferable for clinical work, and the DASS21 is often best for research purposes. (56) For purposes of time management, this study used

the DASS21. Due to the standardised nature of the tool, all the questions were asked in their original form, without any alteration.

3.5 Procedure

Mothers attending the Neurodevelopmental and Asthma clinics were issued with an information sheet (Appendix 3) explaining the purpose and content of the study. Once they had agreed to participate in the study, they were issued with an informed consent form (Appendix 4) to read and sign. The investigator was available to answer all questions related to the informed consent form. Participants were then taken to a private room to complete the DDQ and DASS questionnaire. Questionnaires were completed in the presence of the investigator when possible.

After completion, the DDQ and DASS were collected. There was a short debriefing, and the participants were asked if they needed any psychological support as a result of having completed the questionnaire.

The services of a social worker were sought for mothers indicating the need for additional support. A social worker was used, in preference to those of a psychologist, as there is a permanent staff social worker on the ward. The possibility of such referrals was discussed with the ward social worker, prior to commencement of the study. She was fully aware of the study, and able to provide counseling.

After completion, participants were offered refreshments and thanked for their participation in the study.

3.5.1 Distress Protocol

In keeping with ethical requirements to deal with possible research induced distress, the following distress protocol was designed:

In the event of a participant becoming distressed, the following procedure was in place to be followed:

- The participant will be taken to a private room and counseling will be offered to her by the ward social worker.
- If following counseling by the social worker there is concern that the participant requires further immediate or long term intervention and/or medication, the participant will be referred to the psychologist at the Child, Adolescent and Family Unit, or the Psychiatry Out Patient Department, or the psychiatry registrar in casualty at the Charlotte Maxeke Johannesburg Academic Hospital.
- The researcher will take responsibility to ensure that the participant is correctly referred, and the outcome of the referral will be followed.

The distress protocol was approved by the Human Research Ethics Committee.

3.6 Ethics

Ethical clearance for the study was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand: Clearance certificate M120218. (Appendix 5)

3.7 Statistical Analysis

Descriptive statistics were used to report on frequency and percentage of the demographic variables. The groups were compared on socio-demographic variables using the Chi-square test for independence. In cases where small cell sizes were responsible for violations of the Chi-square test assumptions, categories were combined meaningfully.
Frequency distributions of socio-demographic characteristics of study participants were examined and compared between the two groups.

Although the categorised DASS scores lack the variance of the underlying continuous scores, these scores represent clinically relevant classifications. Therefore the categorised data, and not the continuous data, were analysed. The Chi-square test of independence was conducted on these categorised DASS scores.
Due to sample size, for analysis purposes, depression, anxiety and stress scores were divided into three categories: ‘normal’, ‘mild and moderate’, and ‘severe and extremely severe’.

In order to assess the psychometric adequacy of the scales, reliability and validity were examined. Cronbach’s alphas were calculated for each of the DASS subscales in order to evaluate the internal consistency. To examine construct validity of the DASS in terms of convergent and discriminant validity, exploratory factor analysis using principle component analysis with Varimax rotation was performed, and the number of factors was determined by

Keiser's criterion of eigenvalues greater than one. The strength of the inter-item correlation matrix was assessed for suitability for factor analysis based on the significance of Bartlett's test of sphericity.

To test the hypotheses, Chi-square tests of association were used to examine the relation between the categorised DASS scores and the identified socio-demographic variables (marital status and employment status), using a 5% level of significance. When the assumption of expected frequency in any cell of the contingency table was less than five, the Fisher's exact p-values are reported. In all instances, there was very little difference between the Chi-square and Fisher's exact analyses, and no meaningful difference in the significance of the two p-values.

All data analyses were performed using STATISTICA (69) and STATA (70) data analysis software system.

CHAPTER 4

RESULTS

4.1 Introduction

This chapter presents the findings of the research.

A detailed description of the socio-demographic variables of the participants will be presented. These variables will then be compared between the asthma and ASD groups.

Thereafter, the DASS properties are presented in terms of their summary statistics, reliability and factorial validity. Confirmation of the adequacy of the psychometric properties of these scales is important prior to testing hypotheses based upon them.

Finally, the hypotheses of the study are tested in the following sequence:

The levels of depression, anxiety and stress on the categorised DASS scores of the two groups of mothers are analysed and compared (Hypothesis 1)

The effect of single parenthood on DASS scores are evaluated (Hypothesis 2)

The effect of unemployment on DASS scores are evaluated (Hypothesis 3)

4.2 Study Population

A total of 131 participants completed the questionnaires, with 68 in the asthma group, and 63 in the ASD group.
After consideration of the inclusion and exclusion criteria, 30 participants (22,9%) were excluded. Therefore, the total number of participants analysed was 101, with 50 in the asthma group, and 51 in the ASD group.

None of the participants reported any research induced emotional distress, and therefore counseling was not required.

4.3 Socio-Demographic Variables

The socio-demographic variables of the asthma and ASD groups were compared using the Chi-square test for independence. Within the variables, groups were combined meaningfully for analysis purposes.
The asthma and ASD groups did not differ significantly in terms of: age of mother, age of child, racial composition, marital status, and income, using a 5% level of significance. The groups did, however, differ significantly ($p=0.01$) on the percentage of mothers receiving a child government grant. (See Table 4.1)

It is important to note that data was collected that was not analysed in this study (marital living arrangements, family contact, friend contact). However,

for purposes of completeness, the groups were compared on these variables, and no significant differences were found (p=0.21, p=0.5, p=1.0 respectively).

4.3.1 Age

The mean age of the mothers in the two groups was not significantly different (p=0.19). The mean age of the asthma mothers was 34.7 years (SD = 6.9 years), and the mean age of the ASD mothers was 36.4 years (SD = 6.3 years). The mean ages of the children in the two groups were also not significantly different (p=0.96). The mean ages of the asthma and ASD children were 6.2 years in both groups (SD = 2.7 and 2.3 years respectively).

4.3.2 Race

The majority of mothers in both the asthma and ASD groups were Black (88.0% and 96.1% respectively), with smaller percentages of White (4.0% and 0% respectively), Indian (6.0% and 1.9% respectively) and Coloured (2.0% and 1.9% respectively) participants.

For analysis purposes, the race category was divided into Black and other (White, Indian, and Coloured combined). The asthma and ASD groups did not differ significantly on this variable (p=0.13).

4.3.3 Marital Status

Mothers in both asthma and ASD groups were categorised as married (38.0% and 45.1% respectively), single (28.0% and 35.3% respectively), in a relationship (24.0% and 17.6% respectively), widowed (4.0% and 0% respectively), and divorced (6.0% and 1.9% respectively).

For analysis purposes, the marital status category of ‘in a relationship’ was combined with ‘married’ to form a ‘relationship’ category, and the categories of ‘widowed’, ‘divorced’ and ‘single’ were combined to form a ‘no relationship’ category. The asthma and ASD groups did not differ significantly on this variable (p=0.76).

4.3.4 Income Status

More than half of mothers in both asthma and ASD groups earned no personal income (53.1% and 60.8% respectively). The remainder of the mothers in the ASD and asthma groups received an income as follows: salary (42.9% and 31.4% respectively) and informal income (4.1% and 7.8% respectively). One participant in the asthma group did not provide information, for this question only, and therefore the denominator for this variable is 100. For analysis purposes, the income categories of ‘salary’ and ‘informal income’ were combined to form an ‘income’ category, compared to a ‘no income’ category for those who were unemployed and did not receive any informal income. The asthma and ASD groups did not differ significantly on this variable (p=0.27).

4.3.5 Government Child Support Grants

This is the only variable that revealed a statistically significant difference between the groups (p=0.01).

In total, 42.6% of mothers did receive a grant: asthma group (30.0%), ASD group (54.9%).

TABLE 4.1 Comparison of socio-demographic variables of ASD and asthma groups

Socio-demographic Variables	Groups	Asthma n (%)*	ASD n (%)*	Chi-square Test ** (p=)
Race	Black	44 (88.0)	49 (96.1)	0.16**
	Other	6 (12.0)	2 (3.9)	
Marital Status	Relationship	31 (62.0)	32 (62.7)	0.94
	No Relationship	19 (38.0)	19 (37.3)	
Income Status	Income	23 (46.9)	20 (39.2)	0.44
	No Income	26 (53.1)	31 (60.8)	
Government Grant	Yes	15 (30.0)	28 (54.9)	**0.01** ᵀ
	No	35 (70.0)	23 (45.1)	

*Percentages are column percentages per variable

**When the assumption of expected frequency in any cell of the contingency table was less than five, the Fisher's exact p-values are reported

ᵀ Significant p-values are high-lighted in bold

4.4 DASS Statistics

Prior to testing the hypotheses of the research based on the DASS, it is necessary to present summary statistics of the scales in terms of central tendency, variability and shape, and to assess the adequacy of the scales' psychometric properties of reliability and validity.

4.4.1 Summary statistics

Detailed summary statistics are supplied for the total group of participants in Table 4.2. The mean and its 95% confidence interval, as well as standard deviation and range are shown for the two groups and total group, for all 3 scales.

The DASS scores are not comparable to each other in their raw score form, as shown by the clinical cut-offs presented in Table 4.3. Therefore, they are presented in a more comparable grouped categorised form in Table 4.4.

For analysis purposes, depression, anxiety and stress scores were divided into three categories: 'normal', 'mild and moderate', and 'severe and extremely severe'.

TABLE 4.2 Summary statistics for continuous DASS scales

DASS scale	Group	Mean (95% CI)	SD	Range
Depression	Asthma	10.6 (8.1-13.1)	8.7	0-34
	Autism	15.7 (12.3-19.1)	12.1	0-38
	Total	13.2 (11-15.3)	10.8	0-38
Anxiety	Asthma	10.5 (7.9-13.1)	9.2	0-38
	Autism	12.4 (10.1-14.7)	8.1	0-34
	Total	11.5 (9.8-13.2)	8.7	0-38
Stress	Asthma	14.8 (12.3-17.2)	8.5	0-36
	Autism	18.1 (15.3-20.8)	9.8	0-38
	Total	16.4 (14.6-18.3)	9.3	0-38

TABLE 4.3 DASS Clinical Categories

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

TABLE 4.4 Summary Statistics for grouped categorised DASS scores

DASS Scale	Group	Normal n (%)	Mild/ Moderate n (%)	Severe/ Extremely Severe n (%)
Depression	Asthma	28 (56.0)	13 (26.0)	9 (18.0)
	ASD	19 (37.3)	17 (33.3)	15 (29.4)
	Total	47 (46.5)	30 (29.7)	24 (23.8)
Anxiety	Asthma	23 (46.0)	13 (26.0)	14 (28.0)
	ASD	14 (27.4)	21 (41.2)	16 (31.4)
	Total	37 (36.6)	34 (33.7)	30 (29.7)
Stress	Asthma	27 (54.0)	16 (32.0)	7 (14.0)
	ASD	21 (41.2)	17 (33.3)	13 (25.5)
	Total	48 (47.5)	33 (32.6)	20 (19.8)

4.4.2 Reliability

The DASS scales showed satisfactory reliability with Cronbach Alpha values of 0.83, 0.73, and 0.75 for depression, anxiety and stress respectively. The respective average inter-item correlations of the scales were similarly satisfactory with values of 0.41, 0.29 and 0.30.

4.4.3 Construct Validity

In an attempt to validate the constructs measured by the DASS in the context of South African mothers of children with ASD and asthma, factor analysis using principle component analysis with Varimax rotation was performed on the total sample responses to examine the scales' construct validity in terms of convergent and discriminant validity. The inter-item correlation matrix was sufficiently strong for factor analysis to be conducted based on the significant Bartlett's test of sphericity and the high value of .83 for the KMO measure of sampling adequacy.

According to the criterion of convergent validity, the three sets of seven items measuring depression, anxiety and stress respectively were expected to have high factor loadings on separate factors; and according to the criterion of discriminant validity, each item was expected to load highly on a single factor only.

Although, according to Kaiser's criterion, three factors with eigenvalues greater than one explaining 50% of total score variance were retained for interpretation, contrary to expectation the factor loadings of the three sets of seven items did not all load highly on separate factors. While this finding showed the scales to have questionable convergent validity, for each scale, four of the seven items did load highly on the same factor. Examples of this on the Depression sub-scale include the items:

-'I couldn't seem to experience any positive feeling at all'

-'I found it difficult to work up the initiative to do things'

-'I felt I wasn't worth much as a person'

-'I felt that life was meaningless'

(See Appendix 2 to correlate DASS statement numbers with actual statements). Only three items from each scale had relatively high loadings on more than a single factor. (See Table 4.5)

There was thus some evidence, although weak, for the construct validity of the scale. As the factor analysis was based on a relatively small sample size of 101 cases, and in order for the study results to be comparable with those of other DASS researchers, the three subscales of the DASS were considered in their original form.

TABLE 4.5 Factor loadings (principle component analysis)

DASS Scale	DASS Statements	Factor 1	Factor 2	Factor 3
DEPRESSION	3	0.68	0.16	0.17
	5	0.55	0.03	0.36
	10	0.44	0.08	0.50
	13	0.39	-0.02	0.59
	16	0.33	0.11	0.73
	17	0.63	0.10	0.28
	21	0.72	0.18	0.25
ANXIETY	2	-0.03	0.58	0.24
	4	0.41	0.59	-0.14
	7	-0.04	0.79	0.18
	9	0.18	0.43	0.55
	15	0.18	0.09	0.63
	19	0.41	0.49	0.14
	20	0.58	0.43	0.15
STRESS	1	0.00	0.14	0.64
	6	0.53	-0.04	0.20
	8	0.16	0.66	0.10
	11	0.20	0.31	0.68
	12	0.42	0.34	0.42
	14	0.38	-0.02	0.59
	18	0.67	-0.04	0.33
Explained Variance		3.99	2.68	3.85
Proportion of total variance explained		0.19	0.13	0.18

It has been suggested that most existing self-report scales for anxiety and depression predominantly measure the common factor of negative affectivity (NA), (71) therefore making it difficult to distinguish between these two constructs empirically. (71) NA is described as the experience of subjective distress and unpleasurable engagement. (71)

However, each sub-scale has also been shown to tap into the more general dimension of psychological distress or NA, (71) resulting in questionable ability of the DASS to discriminate adequately between the constructs it is purported to measure. (72) In keeping with this finding, a study performed on a large non-clinical sample showed that a greater percentage of items within each dimension (depression, anxiety and stress) had a stronger association with the general dimension of distress (NA) than with the domain-specific dimension, and that conversely, this general distress factor accounted for a greater percentage of variance than the domain-specific factors. The study also showed that the items did not contribute uniquely to the specific domains, and that four or more of the items in each subscale were not identified as specific to any group dimension. (73) This was also the finding in this study, as 3 of the items for each subscale did not load highly on the same factor, resulting in reduced construct validity.

Research has also suggested that cross-cultural applicability of the DASS may be limited, as the constructs the scales were designed to assess may vary across different population groups. (74)

4.5 Tests of Hypotheses

The following section of the results presents tests of the three hypotheses of the study.

4.5.1 Test of Hypothesis 1

Hypothesis 1: Mothers of children with ASD experience symptoms of depression, anxiety and stress to a greater extent than mothers of children with asthma.

The results of this study do not support this hypothesis.

In order for ‘having a child with ASD’ to be a risk factor for the development of depression, anxiety and stress in mothers of children with ASD, the DASS scores should be significantly higher for these mothers when compared to mothers of children with asthma.

The Chi-square test of independence conducted on the categorised depression ($p=0.15$), anxiety ($p=.12$) and stress ($p=0.28$) scores for the asthma and ASD groups provided a non-significant result for all three subscales ($p>0.05$). (See Table 4.6)

TABLE 4.6: Chi-square test comparing ASD and asthma groups on DASS Scale for all subscales

DASS Scale	Group	Normal n (%)*	Mild/ Moderate n (%)*	Severe/ Extremely Severe n (%)*	Chi-Square Test (p=)
Depression	Asthma	28 (56.0)	13 (26.0)	9 (18.0)	
	ASD	19 (37.3)	17 **(33.3)^**	15 **(29.4)^**	0.15
Anxiety	Asthma	23 (46.0)	13 (26.0)	14 (28.0)	
	ASD	14 (27.4)	21 **(41.2)^**	16 **(31.4)^**	0.12
Stress	Asthma	27 (54.0)	16 (32.0)	7 (14.0)	
	ASD	21 (41.2)	17 **(33.3)^**	13 **(25.5)^**	0.28

*Percentages are row percentages per group

^The higher inter-group non-normal scores (percentages) for each DASS grouped category have been high-lighted in bold

4.5.1.1 Conclusion

There was no significant difference found between the asthma and ASD groups when using the categorised DASS scores for depression, anxiety and stress.

Despite the results showing a difference in scores for all three subscales between the two groups, with the ASD group showing consistently higher

scores for depression, anxiety and stress, this difference was not found to be significant. Therefore, it can be said that despite a trend in the hypothesised direction, Hypothesis 1 was not upheld in this study.

Therefore, the differences between the conditions of their children have not been shown to have a significant impact on the mental health of these mothers.

4.5.2 Test of Hypothesis 2

Hypothesis 2: Single parenthood is a risk factor for the development of depression, anxiety and stress in mothers of children with ASD.

The results of this study do not support this hypothesis.

In order for single parenthood to be a risk factor for the development of depression, anxiety and stress in mothers of children with ASD, the DASS scores should be significantly higher for the mothers who are not in a relationship compared to those who are in a relationship. The marital status categories of 'in a relationship' and 'married' were combined to form a 'relationship' category, and the categories of 'widowed', 'divorced' and 'single' were combined into a 'no relationship' category.

Although there is a trend towards higher scores (particularly for the Stress subscale) for those mothers not in a relationship, there was no significant difference ($p>0.05$) between those mothers who were in a relationship compared to those who were not in a relationship. (See Table 4.7)

Interestingly, despite non-significance, in the ASD group there was consistently a higher percentage of mothers who garnered 'severe and

extremely severe' scores on all three subscales, when compared to mothers of children with asthma.

TABLE 4.7: Chi-square test comparing mothers in a relationship with those not in a relationship, for each group separately (asthma and ASD) and the total group

			VARIABLE		
DASS Scale	Group	DASS grouped category*	Relationship n (%)**	No Relationship n (%)**	Chi- square test*** (p=)
Depression	Asthma	Normal	18 (58.1)	10 (52.6)	
		Mild-Mod	9 **(29.0)^**	4 (21.1)	0.53***
		Sev-ESev	4 (12.9)	5 **(26.3)^**	
	ASD	Normal	12 (37.5)	7 (36.8)	
		Mild-Mod	12 **(37.5)^**	5 (26.3)	0.60
		Sev-ESev	8 (25.0)	7 **(36.8)^**	
	Total	Normal	30 (47.6)	17 (44.7)	
		Mild-Mod	21 **(33.3)^**	9 (23.7)	0.31
		Sev-ESev	12 (19.1)	12 **(31.6)^**	
Anxiety	Asthma	Normal	13 (41.9)	10 (52.6)	
		Mild-Mod	10 **(32.3)^**	3 (15.8)	0.49***
		Sev-ESev	8 (25.8)	6 **(31.6)^**	
	ASD	Normal	9 (28.1)	5 (26.3)	
		Mild-Mod	13 (40.6)	8 **(42.1)^**	0.99
		Sev-ESev	10 (31.3)	6 **(31.6)^**	
	Total	Normal	22 (34.9)	15 (39.5)	
		Mild-Mod	23 **(39.5)^**	11 (28.9)	p=.74
		Sev-ESev	18 (28.6)	12 **(31.6)^**	
Stress	Asthma	Normal	18 (58.1)	9 (47.4)	
		Mild-Mod	9 (29.0)	7 **(36.8)^**	p=.72***
		Sev-ESev	4 (12.9)	3 **(15.8)^**	
	ASD	Normal	16 (50.0)	5 (26.3)	
		Mild-Mod	9 (28.1)	8 **(42.1)^**	0.25
		Sev-ESev	7 (21.9)	6 **(31.6)^**	
	Total	Normal	34 (53.9)	14 (36.8)	
		Mild-Mod	18 (28.6)	15 **(39.5)^**	0.25
		Sev-ESev	11 (17.5)	9 **(23.7)^**	

*(Normal)= Normal; (Mild-Mod)= Mild-Moderate; (Sev-ESev)= Severe-Extremely Severe

** Percentages are column percentages per group

^ The higher non-normal scores (percentages), per grouped category, have been high-lighted in bold

***When the assumption of expected frequency in any cell of the contingency table was less than five, the Fisher's exact p-values are reported.

4.5.2.1 Conclusion

Hypothesis 2 was not upheld in this study. Despite a trend showing higher scores for those who are single, there was no significant difference between those mothers who were in a relationship compared to those who were not in a relationship.

Therefore, in this study, single parenthood has not been shown to be a risk factor for the development of depression, anxiety and stress in mothers of children with ASD or asthma.

4.5.3 Test of Hypothesis 3

Hypothesis 3: Unemployment is a risk factor for the development of depression, anxiety and stress in mothers of children with ASD.

The results of this study support this hypothesis for depression and anxiety. In order for unemployment to be a risk factor for the development of depression, anxiety and stress in mothers of children with ASD, the DASS scores should be significantly higher for the mothers who are unemployed compared to those who are employed or earning an income.

For analysis purposes, the income categories of ‘salary’ and ‘informal income’ were combined to form an ‘income’ category, compared to a ‘no income’ category.

Although government grant receipt can be considered a form of income, there was a statistically significant difference between the two groups for this variable. Therefore, it was not included in analysis.

The Chi-square test of association conducted on the comparison of the ‘income’ with the ‘no income’ group revealed significantly higher DASS scores for the ‘no income’ group ($p<0.05$) for all three subscales, for the total group (See Table 4.8). On the Depression sub-scale, there was no significant result per group, but the total group yielded a significant result. On the Anxiety and Stress subscales, the ASD group yielded significant results on both subscales, while the asthma group in isolation did not. Even when groups did not achieve significant results, scores consistently trended in the hypothesised direction throughout.

TABLE 4.8: Chi-square test comparing mothers with an income with those without an income, for each group separately (asthma and ASD) and the total group

		VARIABLE			
DASS Scale	Group	DASS grouped category*	Income n (%)**	No Income n (%)**	Chi- square test *** (p=)
Depression	Asthma	Normal	16 (69.6)	12 (46.1)	
		Mild-Mod	5 (21.7)	7 **(26.9)^**	0.19***
		Sev-ESev	2 (8.7)	7 **(26.9)^**	
	ASD	Normal	11 (57.9)	8 (25.8)	
		Mild-Mod	6 (35.3)	11 **(35.5)^**	0.08***
		Sev-ESev	3 (20.0)	12 **(38.7)^**	
	Total	Normal	27 (62.8)	20 (35.1)	
		Mild-Mod	11 (25.6)	18 **(31.6)^**	**0.01** ¶
		Sev-ESev	5 (11.6)	19 **(33.3)^**	
Anxiety	Asthma	Normal	14 (60.9)	9 (34.6)	
		Mild-Mod	4 (17.4)	9 **(34.6)^**	0.22 ***
		Sev-ESev	5 (21.7)	8 **(30.8)^**	
	ASD	Normal	10 (50.0)	4 (12.9)	
		Mild-Mod	8 (40.0)	13 **(41.9)^**	**0.005** *** ¶
		Sev-ESev	2 (10.0)	14 **(45.2)^**	
	Total	Normal	24 (55.8)	13 (22.8)	
		Mild-Mod	12 (27.9)	22 **(38.6)^**	**0.002** ¶
		Sev-ESev	7 (16.3)	22 **(38.6)^**	
Stress	Asthma	Normal	14 (60.9)	13 (50.0)	
		Mild-Mod	7 (30.4)	8 **(30.8)^**	0.62 ***
		Sev-ESev	2 (8.7)	5 **(19.2)^**	
	ASD	Normal	13 (65.0)	8 (25.8)	
		Mild-Mod	3 (15.0)	14 **(45.2)^**	**0.02** ***¶
		Sev-ESev	4 (20.0)	9 **(29.0)^**	
	Total	Normal	27 (62.8)	21 (36.8)	
		Mild-Mod	10 (23.3)	22 **(38.6)^**	**0.04** ¶
		Sev-ESev	6 (13.9)	14 **(24.6)^**	

*(Normal)= Normal; (Mild-Mod)= Mild-Moderate; (Sev-ESev)= Severe-Extremely Severe

** Percentages are column percentages per group

^ The higher non-normal scores (percentages), per grouped category, have

been high-lighted in bold

*** When the assumption of expected frequency in any cell of the contingency table was less than five, the Fisher's exact p-values are reported

$^{\pi}$ Significant p-values are high-lighted in bold

4.5.3.1 Conclusion

Hypothesis 3 was upheld in this study.

There is a statistically significant difference between the mothers who were earning an income and those who had no income, for all three of the categories of depression, anxiety and stress. The mothers of children with ASD experienced the impact of not having an income to a greater extent than the mothers of children with asthma.

CHAPTER 5

DISCUSSION

5.1 Effect of ASD on Maternal Mental Health

Hypothesis 1 in this study states that mothers of children with ASD experience symptoms of depression, anxiety and stress to a greater extent than the control group, mothers of children with asthma. The findings of this study were surprising, as they do not support this statement, nor published literature. The hypothesis is therefore rejected.

Research has shown that parents of children with ASD experience higher levels of stress, anxiety and depression when compared to parents of children with other disorders, or parents of typically developing children. (75,76) This study has not shown a significant difference between the mental health of mothers of children with ASD, when compared to mothers of children with asthma.

Despite the overwhelming evidence showing the deleterious impact of ASD on the mental health of mothers of these children, there is some literature that reports that despite the context of high stress, mothers of children with ASD show remarkable strengths in the parent–child relationship, social support, and stability of the household. (77) And in contrast to the wide body of evidence, there is research that does not corroborate findings in the literature

that these caregivers are more vulnerable to developing psychological difficulties. (21) Some parents have reported positive parenting experiences in raising a child with ASD. (78) There are also longitudinal studies that suggest that many mothers of children with ASD have shown increased well-being over time.(79)

The findings of this study may be due to instrument factors, and problems with cross-cultural applicability. (74) However, they may also be due to factors related to the population enrolled in the study.

Studies examining the caregiving burden suffered by parents of a severely mentally ill child have concentrated primarily on white American mothers and fathers. (80) Despite the wide range of cultures in which ASD has been reported, there is a surprising lack of knowledge about the condition within differing cultural contexts. (81) Although the number of studies examining the family impact of a child with ASD are increasing, most research has had limited inclusion of families from diverse socio-economic backgrounds. (79) In this study, 92% of participants were black, and less than 2% were white, with no white mothers in the ASD group.

Previous research has noted that although African American caregivers typically have lower incomes, are less well educated, in poorer health, more likely to be widowed at earlier ages, and care for more impaired relatives than their white counterparts, they consistently report lower levels of caregiving burden, grief, depression, anger, hostility, and higher levels of caregiver satisfaction. (82) Included among the theories that have been examined for the possible reasons underlying this resilience, is the protective role of cultural

traditions. These include family and community involvement, social support, participation in church activities, extended family systems, family reciprocity, and mutual assistance. (82) Caregiving is typically not the sole responsibility of one individual.(80)

Research has proposed that black mothers and fathers use methods of dealing with their child's severe mental illness that do not negate their own feelings of self-worth, demonstrating an almost pragmatic readiness towards caring for a psychiatrically disabled child. This does not minimise the pain parents experience as a result of their child's mental illness, but instead shows an acceptance of the illness as a problem like any other in life, to be managed accordingly. (80) Picket et al (80) have also suggested that black mothers and fathers are able to adjust their expectations according to their child's psychiatric disability, whereas white parents appear to be unable to accommodate themselves to the child's loss of future success. (80)

It is acknowledged that the current study has not separated out the effects of socio-economic status, cultural practices, and race, and can therefore make no comment in this regard. These findings need to be investigated further with additional research, which may offer valuable insights into the findings of the current study.

An extensive literature search for studies regarding the mental health of black mothers of disabled children in Africa revealed no published literature directly pertaining to this topic.

Another factor to consider is that research has shown that among mothers of children with ASD, African American mothers with lower levels of education

reported significantly lower levels of negative impact on mental health than African American mothers with higher levels of education and white mothers for all levels of education, (79) possibly due to differences in levels of expectation. These expectations may be correlated with levels of socio-economic status and educational attainment. The current study did not assess education of the participants.

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The present study is based upon the literature-supported assumption that mothers of children with asthma have normal mental health status, comparable to that of the general population. However, the results of this study were only compared, and not analysed for clinical significance, and therefore no comment can be made on the actual mental health status of the participants.

Therefore, although it can be stated that the mental health of mothers of children with ASD is comparable to that of mothers of children with asthma, it cannot be stated that it is normative relative to that of the general population. Conversely, it is possible that both groups experience equivalent mental ill health, as a result of other shared factors, such as socio-economic disadvantage.

5.2 Effect of Single Parenthood on Maternal Mental Health

Hypothesis 2 in this study states that single parenthood is a risk factor for the development of depression, anxiety and stress in mothers of children with

ASD, and mothers of children with asthma. The findings of this study do not support this statement, and therefore the hypothesis is rejected.

Single mothers experience higher rates of physical and mental health difficulties when compared to partnered mothers. (83) The economic and social conditions associated with single motherhood frequently result in various stressors resulting in elevated levels of psychological distress. (84) Single mothers also report higher rates of stress and anxiety,(85)and twice the incidence of depression. (86)

Despite substantial evidence to suggest that single mothers experience more mental health problems than those who are married, (85) literature examining the difficulties of single mothers, show variable results regarding their mental health characteristics. (87) The manner in which single-mother status, independent of financial status, affects the risk of mental health morbidity is poorly understood. (87) The traditional approach of comparing single mothers with married mothers may perpetuate negative stereotypes about single mothers, as there is considerable heterogeneity among single mothers, and marked individual differences in coping abilities. (83)

A study in Ontario, Canada, based on provincial health survey data, showed generally increased prevalence rates for all adverse mental health outcomes for single mothers, but few that were statistically significant. (87) This study shows similar results with a trend towards higher scores for those mothers who are single, but with no significant differences. The Canadian study also showed that single mothers were significantly more likely to have had major

depression in the past year or ever, but their rates of dysthymia were not significantly higher than mothers who were married. (87) This study excluded mothers with a psychiatric history, and therefore these mothers would have been excluded.

It has been suggested that the different pathways leading to single motherhood are associated with differential mental health outcomes. (88) Previously-married mothers were shown to experience a significantly higher burden of mental illness when compared to currently-married mothers, as well as mothers who were never married. (88) Better mental health outcomes have also been shown for widows, compared with divorced or separated mothers. (88) Therefore, it is important to disaggregate the group of single mothers in any study. (88) Although this study made use of separate categories for single motherhood, due to sample size, it was necessary to combine these categories into one group for analysis purposes. For the ASD and asthma groups, 80% and 70% respectively, of mothers were married, single or widowed, compared to 2% and 6% respectively, who were divorced. Therefore, there was only a small percentage of the sample that was previously married. Unfortunately, this study did not include a category for separated mothers.

It is important to note that research has shown that married mothers of children with ASD experience low levels of marital satisfaction, which is associated with higher maternal negative affect. (89) This may serve to explain the lack of significant difference between the two relationship categories in this study, for the ASD group.

5.3 Effect of Unemployment on Maternal Mental Health

Hypothesis 3 in this study states that unemployment is a risk factor for the development of depression, anxiety and stress in mothers of children with ASD, and mothers of children with asthma. The findings of this study support this hypothesis.

In this study, income was used as a proxy for financial status.

Although the results of this study show elevated symptoms in all 3 categories of depression, anxiety and stress, for unemployed mothers in both groups, the vast majority of the literature discusses the connection between socio-economic status and maternal mental health in the specific context of depression.

Rates of depression differ by social circumstances, with higher rates found amongst disadvantaged groups, (86) particularly low-income women. (36) A large body of psychological research has shown that a major psycho-social risk factor for depression is exposure to stressors that cannot be adequately managed with existing resources. (90) Cross-cultural studies of depression show that social disadvantage is a key factor in depression, including factors such as unemployment and housing difficulties. (86) This has been a consistent finding in studies throughout the world, including the United Kingdom, Pakistan, Zimbabwe, Uganda and Australia. (86)

A study performed in Mexico to assess the effects of a conditional cash transfer poverty reduction programme, showed clinically meaningful improvements in maternal mental health, particularly depressive symptoms

and stress levels, as an indirect result of the programme. (90) Their study design allowed for stronger causal inference than observational studies linking poverty and depression. (90)

An important consideration when discussing economic disadvantage and poor mental health, is that lower income is also linked to reduced access to, inadequate, and lower quality treatment. (91)

The association found in this study, between lack of income and poor maternal mental health, applied to both groups of mothers, but the difference in symptoms between those mothers receiving an income, and the mothers who did not, was greatest for mothers of children with ASD.

The reasons for this finding need to be explored. Possible reasons may include the innate difficulties of ASD: the common accompaniment of extremely disruptive antisocial behaviour (92), no one 'best option' for treatment, uncertain predictors of prognosis, and under-provision of resources. (93) The diagnosis is particularly difficult for parents of children with ASD, with some parents describing the process as eliciting feelings of shame, guilt and self-pity. (93) The process of receiving an accurate diagnosis, and the initiation of appropriate treatment is often a long, frustrating and often expensive experience. (92) Comparatively late diagnosis, often with a significant delay between parent's initial concern and final diagnosis, combined with lack of clarity of diagnosis, especially for children with more subtle behaviours, contribute to the stress experienced. (93) Another important contributor to the psychological difficulties experienced by these parents is the question of aetiology. There is much controversy and debate

surrounding the cause of ASD, and multiple theories abound. (93) In Bruno Bettelheim's 1967 book, *The Empty Fortress: Infantile Autism and the Birth of the Self,* (94) Leo Kanner's (14) initial proposal that the infant's relationship with a 'refrigerator mother' was the cause of ASD, was further elaborated upon. The theory became widely accepted in popular as well as in some professional circles, and despite overwhelming evidence disproving his theory there are those who still accept this explanation. (95) There are also differing cultural beliefs regarding the acquisition of the condition. A study performed in Ghana showed that ASD is sometimes seen as a contagious illness transmissible from one child to another, or as possession by evil spirits or ancestors. (96) In South Korea, the cultural belief is that ASD is punishment for the family's previous sins, the mother's neglect of the child, or the affliction of wicked ghosts. (97)

As a result of all these factors, the majority of parents of children with ASD experience stigmatisation, with mothers more likely than fathers to experience avoidance, hostile staring and rude comments from others. (92) Gray (92) has argued that the often normal physical appearance of these children can make their breaches of normal social behaviour even more stigmatising for their parents, leading to feelings of shame and humiliation, as well as exclusion from normal social activities.

It can be reasoned that these factors may be compounded when combined with the considerable financial resources required for the holistic management of the child with ASD (22), and the negative impact of unemployment on maternal mental health (36). This may serve as an explanation for the findings of this study.

Mental health problems in children and maternal depression are conditions that commonly co-exist in families. Mothers' well-being is often negatively influenced by difficulties experienced in the care of a child with mental health problems. (98)

A lack of resources has been associated with higher levels of depression among caregivers of children with mental health problems, with higher rates of maternal depression existing among low-income families. (98) Similar to the findings of this study, a study in the US assessing depression in mothers of children with mental health problems found that with respect to demographic variables, only income was related to depressive symptoms, with mothers who reported significantly lower incomes experiencing more depressive symptoms. (98) A study performed in Turkey assessing the levels of stress, depression and anxiety of parents of disabled children also found financial problems to be the most important factor affecting psychological well-being of these parents. (99) The results of a study performed in India assessing depression in mothers of children with ASD, showed that mothers who were unemployed had significantly greater scores of depression when compared with employed mothers. (100)

Although the relationship between mental health and socioeconomic conditions is quite complex, it has been found that low-income families are relatively more isolated from their communities, have fewer social support resources, and have greater difficulty accessing child care and mental health services. Therefore, socio-economic disadvantage may influence maternal

depression because of fewer support resources available to these mothers. (98)

5.4 Limitations of Study

1. Patients using English as a second language were included in this study. Although it would have been ideal to only include a population of first-language English speakers, due to the fact that the tool being used is in English, it was not feasible given the population studied. It was also not possible to translate the standardised tool. This may have introduced bias if questions were not correctly understood. This limitation is acknowledged.
2. Due to the nature of caring for a child with ASD, the investigator was often required to be more involved with these mothers, compared to those of the asthma group. In most cases, mothers in the ASD group needed to be actively involved in containing their children. Therefore, the investigator was always present to assist these mothers, and was often requested to help with form completion. This complication was not predicted. Despite attempts to reassure the participants, it is acknowledged that this may have introduced observer bias.
3. The population studied was composed of a variety of socio-economic levels. The questionnaire did not include a formal measure of socio-economic status, and it was presumed that patients who were attending a government hospital clinic, and were not private patients, could be matched for socio-economic status.

4. The Demographic Data Questionnaire included a question on the receipt of a government grant. However the question was not clearly defined, and should have included details on the type of grant being received, for example child care grant or care dependency grant.
5. The study did not utilise diagnostic tools in order to verify either the diagnosis of ASD or asthma of the children whose mothers participated in the study. It assumed that the diagnosis given by the respective paediatric professionals was correct. The possibility of an incorrect diagnosis in either group is acknowledged.
6. The study did not include details of severity of either asthma or ASD. However, one can reasonably assume a range of severities in both groups.
7. This study has excluded mothers with a previous history of mental illness in an attempt to make the groups more equivalent. Therefore, by definition, this study has excluded those mothers who would have presented with more severe symptoms of mental ill health, if previously diagnosed. This may skew the data towards less severe symptoms, making the data less generalisable.
8. The DSM criteria for fulfilling the conditions of a disorder, including Major Depressive Disorder and Generalised Anxiety Disorder, require that the symptoms of the condition cause ‘clinically significant distress or impairment in social, occupational, or other important areas of functioning’. (7) This study utilised convenience sampling of an accessible population. Therefore, it is important to consider that those mothers who are most affected by debilitating mental illness might be

incapacitated and unable to attend routine clinic visits for their children. Therefore, there may be a population of mothers who are not accessing health care for themselves or their children, and were not represented in this study. This may skew the data towards less severe symptoms, making the data less generalisable.

9. The DASS has not been validated for a South African population. As the DASS has not been standardised for the defined population of this study, it is acknowledged that cultural factors and language differences may have introduced bias, affecting construct validity of the scales in this study.

5.5 Recommendations for Future Research

Due to financial constraints, this study was purely comparative, and did not analyse the clinical significance of the DASS scores for each group. Therefore, no comment can be made on the absolute mental health status of either group, and no comparison can be made to the general population. Future research should investigate this topic for clinical applicability, and contextualisation within the general population.

Future research focusing on delineating the financial status of the mothers involved would be beneficial. This study used employment status as a proxy for financial status. It would be important to investigate if employment in itself is protective for these mothers, or if financial status is the important factor. Further research investigating this topic utilising a larger sample size is also recommended.

CHAPTER 6

CONCLUSION

The main aim of this study was to assess the presence of symptoms of depression, anxiety, and stress in mothers of children with ASD, and compare the prevalence of these symptoms to a control group; to identify whether single motherhood is associated with the presence of symptoms of depression, anxiety or stress in mothers of children with ASD, and mothers of children with asthma; and to identify whether lack of income is associated with the presence of symptoms of depression, anxiety or stress in mothers of children with ASD, and mothers of children with asthma.
Information was gathered using a demographic data questionnaire and a standardised tool, the Depression Anxiety Stress Scales, to assess the symptoms of depression, anxiety and stress.

The conclusions are summarised below:

- Mothers of children with ASD did not experience symptoms of depression, anxiety and stress to a greater degree than mothers of the control group. This was a surprising finding, as it is contrary to the majority of the large body of research showing that mothers of children with ASD experience mental health difficulties.
- Mothers not in a relationship did not report an increase in the symptoms of depression, anxiety and stress, when compared to

mothers in a relationship. The literature shows conflicting results in this area, with the pathways leading to single motherhood possibly being more important than the actual state of single parenthood.

- Lack of income was associated with a significant increase in the symptoms of depression, anxiety and stress in both mothers of children with ASD and mothers in the control group. This increase was more pronounced for those mothers in the ASD group. This finding is in keeping with the literature, which shows that financial status has a large impact on mental health status.

The findings of this study show that for the population studied, having a child with ASD does not have a significant impact on maternal mental health, when compared to mothers of children with asthma. Similarly, single motherhood is not associated with an increase in poor mental health, relative to those mothers in a relationship. Lack of income was shown to have a significant impact on maternal mental health, with mothers not receiving an income experiencing higher symptoms of depression, anxiety and stress, when compared to those mothers who did have a form of income.

Maternal mental health is an important factor to consider when treating children with neurodevelopmental disorders, as it has consequences for the holistic and effective treatment of these children.

CHAPTER 7

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APPENDICES

DEMOGRAPHIC DATA QUESTIONNAIRE

Please fill in or circle the correct answer:

1) Please complete the following information about yourself:

- Age: _____

- Race: _____

Are you currently married, involved in a relationship, single, divorced or widowed?	Married		Single
	In a relationship		Divorced
	Widowed		Other
If you are married or in a relationship, do you live with your partner?	Yes		No
Do you have family near to where you live?	Yes		No
If YES, are you in contact with them?	All the time	Sometimes	Never
Do you have friends near to where you live?	Yes		No
If YES, are you in contact with them?	All the time	Sometimes	Never
Do you yourself have an income?	Y		N

If YES, what is the source of your income?	Monthly salary (employment/ self-employment)		Informal income
Do you receive a government grant for your child?	Y		N
Do you have another child with a chronic illness/disability?	Y		N
What is your HIV status?	Positive	Negative	Unknown
Have you ever been diagnosed by a medical doctor as having a psychiatric illness (eg. anxiety, depression, schizophrenia)?	Y		N
Do you take any psychiatric medication (for the above mentioned psychiatric illness)?	Y		N
Do you have a chronic illness/ disability?	Y		N
Are you pregnant?	Y		N
Are you a South African citizen?	Y		N
Are you a government patient (I.e. not a private patient on medical aid/ paying private rates)?	Y		N
Are you the biological mother of the child attending the clinic?	Y		N
Do you live with your child?	Y		N

2) Please complete the following information about your child:

What is your child's current age? _____

What is your child's diagnosis (as diagnosed/confirmed by a paediatrician at the Charlotte Maxeke Johannesburg Academic Hospital)?	Autism	Asthma
Does your child have any other diagnosed chronic illnesses/disabilities?	Y	N
Is your child currently medically well (i.e. No flu/gastro)?	Y	N

THANK YOU for completing this questionnaire

DASS21

Name: *Date:*

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0 1 2 3
2	I was aware of dryness of my mouth	0 1 2 3
3	I couldn't seem to experience any positive feeling at all	0 1 2 3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0 1 2 3
5	I found it difficult to work up the initiative to do things	0 1 2 3
6	I tended to over-react to situations	0 1 2 3
7	I experienced trembling (eg, in the hands)	0 1 2 3
8	I felt that I was using a lot of nervous energy	0 1 2 3
9	I was worried about situations in which I might panic and make a fool of myself	0 1 2 3
10	I felt that I had nothing to look forward to	0 1 2 3
11	I found myself getting agitated	0 1 2 3
12	I found it difficult to relax	0 1 2 3

13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

DASS Scoring Template

	S	
	A	
	D	
	A	
	D	
	S	
	A	
	S	
	A	
	D	
	S	
	S	
	D	
	S	
	A	
	D	
	D	
	S	
	A	
	A	
	D	

INFORMATION SHEET

Dear Mother,

My name is Dr Chevon Blumberg.
I am currently doing research in order to complete a Masters degree in Neurodevelopmental Child Health.

The title of my research paper is:
Mental Health of Mothers of Children with Autism Spectrum Disorder

The aim of my study is to see whether or not mothers of children with a disability or chronic illness experience problems with mental health (such as stress, anxiety and feelings of depression).

All of the information is completely ANONYMOUS (your name will NOT be put on any of the forms).

If you choose to take part, you will need to complete 3 forms:
1) Consent Form (saying that you agree to take part in the study)
2) Demographic Data Sheet (personal information)
3) Depression Anxiety Stress Scales (to see how you are currently feeling)

It should take approximately 30 minutes to complete all the forms.

Once you have finished, you will be offered a small snack.

PLEASE NOTE that there will be no compensation (money or otherwise) for participating in this study, and the answers you give about how you are feeling will NOT be discussed with a mental health professional (such as a social worker, psychologist, or psychiatrist). There will be no personal benefit to you for taking part in this study.
However, if there are any feelings or problems that you would like to discuss, as a result of the questions you have answered, a qualified social worker will be available to talk to you.

You do NOT have to take part in this study. If you choose not to take part, this will not in any way affect the service provided for your child.

If you have any queries regarding this research project, please contact me on 083 564 7832. If you have any problems or complaints, please contact Prof Peter Cleaton-Jones or administrator, Anisa Keshav, on 011 717 1234.

Thank you for your time.

Sincerely,

Dr Chevon Blumberg

CONSENT FORM

YES, I agree to participate in this study.

- The reason for the study has been explained to me clearly
- I understand that I don't have to participate if I don't want to, and that I can change my mind at any point without repercussions
- I have been given the opportunity to ask any questions that I might have
- I understand that my participation in this study is confidential, and that my name will not appear on any of my personal information

Participant Signature: _____

Date: _____