Raising an ADHD Child: Relations between parental stress, child functional impairment, and subtype of the disorder

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#### **ABSTRACT**

Families with children that have developmental, neurological or other special care needs, typically experience high levels of stress related to raising those children (Spratt, Saylor, & Marcias, 2007). Empirical studies have shown that parents of children with learning or behavioural problems such as those present in ADHD experience higher stress levels than other parents. Parenting stress can affect not only the parent, but also the child's functioning and the family environment. The aim of this study was to investigate how parents of children with ADHD experience stress, and where this stress might originate. More specifically, I aimed to see whether there are between-group differences in parenting stress levels in children with ADHD – Predominantly Inattentive Type and ADHD – Combined Type. A control group comprised of parents with children that have Autism. Various measures were used to examine parent's subjective stress, depression, quality of life, resources and social support. The results of this study highlight the immense stress these families deal with and will hopefully be the first step for future preventive plans aimed at reducing stress and help families that have ADHD children.

Keywords: Attention-Deficit Hyperactivity Disorder; children; parenting stress; impairment; preventive; South Africa.

Parents who have children with a learning disorder, a developmental disorder, or a psychiatric disorder often experience high levels of stress related to caring for that child and dealing with the implications of the child's disorder for family relationships, finances, and general wellbeing. It is therefore surprising that relatively little research has been conducted on parenting stress levels in families where a child has been diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD). Furthermore, no published studies have investigated whether parents' stressful experiences and stress levels are mediated by the level of functional impairment<sup>1</sup> in the ADHD child, and/or by which subtype of ADHD the child is diagnosed.

Examining the relationship between the functional impairment of the child with ADHD and parenting stress is important because, for example, if a child is severely functionally impaired in the domain of learning, one can assume that the parenting stress will increased due to higher school fees for special education, extra classes or other remedial requirements the child might need. Similarly examining the relationship between the subtype of ADHD and parenting stress is important because the different subtypes result in different problem areas and may cause more stress for the parents.

There is an accepted understanding that the early years of life are critical to the development and growth of an individual. A child's cognitive, emotional, and social capacities can be shaped and formed from an extremely early age. A child's parents and family context plays an important role in this development. If children with behavioural problems such as ADHD are exposed to a family situation that is stressful and their caregivers are unable to provide for all their needs (emotional, social, and cognitive), their behavioural problems are at risk of intensifying, and other emotional disturbances may arise. Abidin (1995) emphasises that parental stress is formed by a combination of child and parent characteristics, the family context and other life stressors. It is important to recognise that caring for a child who has some sort of behavioural problem is difficult for many parents to cope with and if support and resources are inadequate, parents are at risk for increased health problems, depression or feelings of incompetence. Therefore, early identification of potential at-risk families is necessary so that interventions aimed at reducing stress in child-parent systems can be implemented and possibly reduce/prevent future behavioural and emotional problems for both parent and child.

<sup>&</sup>lt;sup>1</sup>Functional impairment is defined here as "specific deficits in multiple domains of functioning developing subsequent to a disorder" (Winters et al., 2005, p. 309).

This study aims to measure parental stress levels, functional impairment and identify the domains from which this stress originates, for parents with children who have ADHD. First, a review of literature describing past research focused on ADHD and parenting stress is discussed. This review serves not only as a summary of the extant literature, but also highlights gaps in the knowledge on the topic.

## **Attention-Deficit/Hyperactivity Disorder (ADHD)**

#### Epidemiology and clinical presentation

ADHD is a syndrome of inattention, hyperactivity and impulsivity. The term is therefore most commonly used to describe individuals who have difficulty sustaining attention, adjusting activity levels, and regulating impulses over various social contexts (Lange et al., 2005). These social contexts may be within the family environment, at school or within peer groups. ADHD is the most commonly diagnosed childhood neurological-behavioural condition, affecting at least 3-7% of school-aged children in Europe and the United States (American Psychiatric Association, 2000). Furthermore, it often continues to affect diagnosed individuals throughout adulthood, with 60% of individuals with ADHD symptoms in childhood continuing to have difficulties in adult life (Harpin, 2005). ADHD is more prevalent amongst boys than girls (Graetz, Sawyer, Hazel, Arney & Baghurst, 2001).

ADHD is as prevalent on the African continent as in Western countries (Meyer, 1998; Meyer et al., 2004). In an epidemiological study Meyer (2005) explored the prevalence rates of ADHD symptoms in South African children to see if cultural differences impacted the prevalence of ADHD. Meyer's (2005) prevalence rates for ADHD resulted in similar findings to studies from the USA and Europe. These data suggest that ADHD is derived from some fundamental neurobiological process.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; APA, 2000), to qualify as true ADHD, problems of inattention, hyperactivity, and/or impulsivity must have been present before 7 years of age and must have been consistent for over 6 months. In practice, such problems are often noticed from a very early age. The problems experienced by children with ADHD are genuinely disruptive to their everyday performance and wellbeing; mere naughtiness at home or not doing well at school cannot result in a diagnosis of ADHD. A complete description of the DSM-IV-TR diagnostic criteria for ADHD is presented in Appendix A.

The DSM-IV-TR also indicates that there are three subtypes of ADHD: Predominantly Hyperactive/Impulsive Type (ADHD-HI), Predominantly Inattentive Type (ADHD-PI) and Combined Type (ADHD-CT). These subtypes manifest themselves in different problem areas and are associated with varying levels of functional impairment (Graetz et al., 2001). For example, a child with the ADHD-PI subtype experiences difficulty with tasks that require focusing and maintaining attention to detail or following instructions. Forgetfulness, being easily distracted and having trouble organising and following instructions are all characteristics of ADHD-PI that disrupt daily activity.

Children with the ADHD-HI subtype are characterised as displaying the following hyperactive behaviour patterns: fidgeting, running about at inappropriate times, talking excessively, and having trouble enjoying leisure activities quietly. Individuals with ADHD-HI also experience problems related to impulsivity that can be manifested as blurting out answers or interrupting conversations. These characteristics affect behaviour in various social settings and are disruptive and inappropriate for the individual's developmental level. Such problems may result in the individual being more at risk of injury or accidents due to impulsive actions. For example, a child may rush across a road without checking for traffic.

Children with the ADHD-CT subtype experience an assortment of traits from both ADHD-PI and ADHD-HI subtypes. Therefore they are more prone to problems rooted in both the ADHD-PI and ADHD-HI subtypes. Research focussing on the validity of the ADHD subtypes found children with ADHD-CT to have more externalizing behaviour problems and functional impairment in social and scholastic domains than ADHD-PI and ADHD-HI children (Graetz et al., 2001).

Clearly, it is important for researchers and clinicians to distinguish between the three subtypes when evaluating family systems, as the behaviours and problems typical of each subtype could affect the child and family differently. Unfortunately, most ADHD research studies have not discriminated between subtypes.

#### **Parental Stress and ADHD**

Parental stress is a complex construct involving behavioural, cognitive and affective components that manifest into a tense child-parent relationship (Kadesjö, Stenlund, Wels, Gillberg, & Hägglöf, 2002). For example, the child's behaviour and the parent's reaction to this behaviour cause negative thoughts and emotions. Stress and poor parent-child interaction increases when the parent tries to deal with the child's behaviour unsuccessfully.

For parents, the challenges that accompany an ADHD child's condition are various: for instance, financial strain might result from expensive medications being prescribed and from special schooling being required if functional impairment is within the realm of learning and academic achievement; social stress might result from trying to gain acceptance, or avoid blame, in a society that stigmatizes any form of abnormal behaviour; relationship stress might result from difficulties associated with imposing a daily routine and discipline on the ADHD child (Austin & Carpenter, 2008). These stressors can result in mental health difficulties for parents. In a family where one of the primary caregivers is morbidly depressed as a consequence of ADHD-related stress and he or she is not able to complete childcare tasks, the children's basic daily needs might be neglected. Clearly, it is of extreme importance that researchers and clinicians recognize and address parental stress as a way to go about developing interventions that might minimize the strain on these families.

Empirical studies investigating parental stress in families of an ADHD child have generally found that parents are extremely stressed, may have difficulty accepting their child's disability, and may experience more difficulties in the marital relationship than in non-ADHD families. Kadesjö et al. (2002) investigated how mothers of children with ADHD perceived their situation and whether these perceptions affected their stress levels. Two groups of mothers of 3-7 year-olds (one group with an ADHD child, n = 131, and the other without an ADHD child, n = 131) filled out self-report questionnaires designed to assess their levels of stress, their evaluation of the child-rearing situation, attributions surrounding child-rearing outcomes, and perceptions and expectations of support and resources.

The researchers found that mothers of ADHD children scored significantly higher than mothers of healthy children on all measures of perceived stress. For example, they tended to experience many more difficulties coping with and accepting their child, and often perceived their child as a burden. Importantly, the authors emphasised that stress may not have been exclusively due to the child's problems or functioning. Situational factors such as education level, financial support and how the mothers perceived their position and resources all need to be taken into account when analysing overall stress.

Gupta (2007), compared differences in parental stress levels between ADHD, children developing disorders (DD) and children with medical conditions. He found that the parents of ADHD and DD children had higher levels of parental stress than parents of children with medical conditions. Spratt et al. (2007) also found that parents of ADHD children experienced significantly higher stress levels than parents of children without ADHD. The authors examined the stress levels of parents of 4-12 year-old children with both

ADHD and learning disabilities (n = 54), intraventricular haemorrhage at birth (n = 70), or neural tube defects (n = 45). The study was designed to examine and compare potential relationships related to parental stress between diverse groups of children with special needs. The results, although not specific to ADHD, indicated that parental stress was related to child dysfunction. The level of child functioning was a significant predictor of total parental stress, accounting for 17% of the variance in total stress scores. Other factors such as availability of resources and support were able to stand alone as significant correlates of total parental stress, accounting for 30% of the variance in those levels. With regard to parents of children with ADHD, stress arose predominantly from internalizing (depressed, low self-esteem) problems the child experienced. In summary, Spratt et al. (2007) highlighted that there is a connection between behaviour problems of the child and elevated stress levels of the parent, especially in conjunction with perceived inadequacy of support and/or resources.

#### Divorce as an Outcome of Parental Stress in ADHD Families

As noted above, parental stress related to the care of an ADHD child can manifest itself in many forms, result from many situations, and affect various facets of family life. It can also result in a higher likelihood of divorce. Wymbs et al. (2008) found that, in a sample of 282 families, 23% of parents with an ADHD-diagnosed child were divorced by that child's 8th birthday. By comparison, in parents matched on socio-demographic factors such as age, education and income, but who did not have a child diagnosed with ADHD, only 13% were divorced by their child's 8th birthday. Additionally, parents of children with ADHD reported less marital satisfaction, more frequent fights, and the use of fewer positive and more negative verbalisations during child-rearing discussions. Importantly, the authors noted that a child's disruptive behavior does not in itself cause marriages to dissolve; such behaviour merely adds to other sources of stress, such as lack of support or resources and financial strain that spark marital conflict.

## Compromised Mental Health as an Outcome of Parental Stress in ADHD Families

Genetic studies have demonstrated that ADHD is heritable (Shah, 2008). According to Thapar, Holmes, Pulton, & Harrington (1999), the mean heritability of ADHD is 0.75, which means that 75% of the etiological contribution is genetic. As a result, parents who have children with ADHD often have symptoms of the disorder themselves. These symptoms obviously have an impact on their mental health as well as their ability to cope with the stress

of caring for a child with ADHD. Surprisingly, however, very few studies have focused on the mental health of parents with an ADHD child.

The few studies that have investigated this relationship have found that the presence of ADHD in a child is associated with increased levels of parental stress as well as parental psychopathology. For instance, Klassen, Miller, and Fine (2004) evaluated the relationship between child quality of life (QoL) and parent mental health in a sample of 165 children referred to an ADHD clinic over a one month period in 2002. Parents of an ADHD child rated their wellbeing as: 15% 'excellent', 33% 'very good', 36% 'good', and 15% 'fair/poor'. Suffering in the areas of emotional stability, behavioural problems, mental health, selfesteem, general health family activities and family cohesion were recorded as being more significant in parents of a child with ADHD than that of parents without a child with ADHD.

Previous literature (e.g., Psychogiou, Daley, Thomas, & Sonuge-Barke, 2008; Spratt et al., 2007) suggests that personal distress (lack of empathy) is associated with negative affect, depression, and anxiety disorders, all of which affect the ability to cope with stress. Psychogiou et al. (2008) explored the relationship between parental psychopathology, parental stress and parenting empathy in mothers with children who have ADHD. Their results confirmed that child conduct problems (e.g., aggression to people or animals, deceitfulness or lying, serious rule violations) were associated with decreased maternal empathy (e.g., lack of responsive, sensitive parenting ability or desire to offer their child comfort and help).

#### RATIONALE FOR RESEARCH AND SPECIFIC AIMS

The review above indicates that parents of ADHD children experience higher stress levels than do parents who do not have children with ADHD. The consequences of these higher stress levels are almost invariably negative, and can often tear a family apart. Although some research on ADHD and parental stress has been conducted, the effects of different subtypes of ADHD on parental stress levels have not been closely examined. Previous studies have also largely ignored different severity levels or functional impairment of ADHD subtypes and their varying effects on parental stress and familial outcomes. The aim of this study, therefore, was to investigate whether, in families with an ADHD child, parental stress levels vary with (a) the particular subtype of ADHD with which the child is diagnosed, and (b) the level of functional impairment/problems present in the child. Furthermore, the research sought to examine (c) whether resources (fiscal, physical, and household) and social support available to parents mediate the relationship between having a child with ADHD and parental

stress, and (d) the relationship between levels of parental stress, symptoms of depression, and overall quality of life.

In other words, this study is the first step in the creation of a theoretical model, based on previous literature, that attempts to concisely conceptualize and capture the bidirectional and unidirectional relationships between the variables mentioned above. That model is presented in Figure 1. Given that this is only the first step in the creation of that model, and given that relatively small numbers of participants have been tested at this stage, it was impossible to test it using path analysis or structural equation modelling; those advanced statistical techniques will be applied in future.

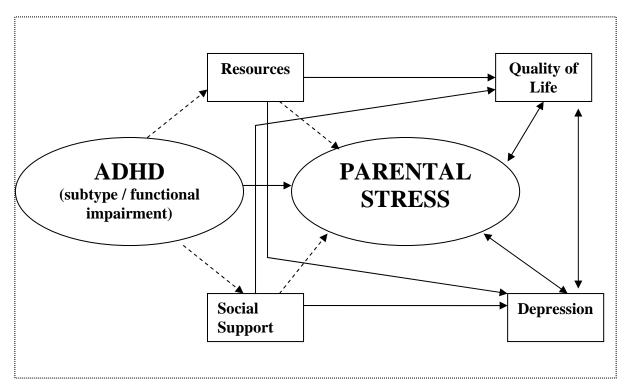


Figure 1. Theoretical model showing the potential relationship between parental stress to ADHD subtype/functional impairment, potential mediators of that relationship, and potential relationships between parental stress, mental health, and overall quality of life.

The value of this research is twofold. Firstly, it raises awareness about the issues and challenges with which parents of ADHD children have to cope. Secondly, it allows effective identification of important stress domains so that parents of ADHD children who seek professional help will receive more effective advice, guidance and support.

#### **METHODS**

## **Research Design**

Following the taxonomy of research types presented by Rosenthal and Rosnow (2008), the current research was of a quasi-experimental, cross-sectional and relational nature. Quantitative measures (semi-structured interviews and self-report questionnaires) were used to collect data.

#### **Participants**

Participants were recruited through the use of posters placed in public areas, such as shopping malls, and psychologists' practice offices advertising the study. Additionally, members of the research team contacted principals and school psychologists at private and remedial schools in the Western Cape and Gauteng to inform them of the study. The majority of the recruitment efforts occurred through internet advertising, however. The Attention Deficit Hyperactivity Support Group of Southern Africa (ADHASA) and a family website focusing on children (Connecting Kids; www.connectingkidz.co.za), promoted the study and advertised the poster in a monthly online newsletter. Various support groups were contacted through these websites. Finally, a group providing advice, information on ADHD developments, and a forum for parents or anyone interested in ADHD, was created on the online social networking site, facebook. These groups advertised the study and provided a platform for interested participants to gather information.

Two distinct groups of participants were recruited. One group (n = 20) consisted of children with ADHD and their parents. This group was further subdivided into children with ADHD-PI and their mothers (n = 10) and children with ADHD-CT and their mothers (n = 10). The second group (n = 10), which served as a control, consisted of children with autism (n = 10) and their mothers. Participants in the latter group were recruited solely through specialized schools and email correspondence.

Previous research has shown that parents of children with autism spectrum disorder (ASD) experience exceptionally high levels of parental stress (e.g., Davis & Carter, 2008; Pisula, 2007). Osborne and Reed (2009) conducted two studies to investigate the relationship between parental stress and the behavioral problems of the child with autism. Their study showed that parental stress was associated with child behavioral problems rather than with the severity of the child's disorder. This study aims to conduct a similar investigation in terms of the ADHD subtypes and the level of child functioning versus their externalizing and

internalizing behavioural problems. It is therefore interesting to use parents of autistic children as a comparison group to parents of ADHD children, as one would expect the stress levels in families with an autistic child to be higher than that of families with an ADHD child.

## Demographic Characteristics of the Sample

Tables 1 and 2 present a complete demographic description of the children and mothers that constituted the final sample. As the tables show, the sample consisted of 30 mothers with children ranging in age from 6 to 18 years (19 males and 11 females). Participants in the three groups were demographically well matched, as illustrated by the results of the analyses of variance (ANOVAs; for continuous variables, such as age) and chi-square analyses (for categorical variables, such as income level) presented in the tables.

With regard to the child participants, Table 1 shows that participants in the ADHD-PI group were slightly older than the ADHD-CT and Autism groups. The ADHD-CT group contained more males, whereas the ADHD-PI group contained more females; this breakdown is in line with knowledge of prevalence rates of these subtypes (Lahey et al., 1994). The two ADHD groups were relatively similar in terms of education, with the majority of the children attending mainstream schools. In contrast, all the children with autism attended a school specifically specialised to provide education suited to individuals with their disorder.

With regard to the mothers, their ages were similar, as was the type of neighbourhood in which the families lived. Income was also reasonably similar.

#### Clinical Characteristics of the Sample

Children with co-morbid psychotic disorders were excluded from participation. The ADHD-PI children displayed more mood and anxiety co-morbid disorders, perhaps due to their tendency toward the kinds of problematic internalizing behaviours (e.g., becoming more withdrawn) that children with this subtype of ADHD typically display. In contrast, the ADHD-CT children displayed more behavioural co-morbid disorders, such as Oppositional Defiance (ODD) and Conduct Disorder (CD), perhaps due to their tendency toward the kinds of problematic externalizing behaviours (e.g., destroying property or personal belongings) children with this subtype of ADHD typically display. For all the participants in the autism group, autism was their primary and only diagnosis.

Table 1 Demographic Characteristics of the Current Sample: Children

Variable	ADHD-CT $(n = 10)$	ADHD-PI $(n = 10)$	Autism $(n = 10)$	$F/\chi^2$	df	р	ESE <sup>a</sup>
Age (years)				1.02	2, 27	0.375	0.01
Range	6-14	7-13	6-18				
Mean (SD)	8.30 (2.36)	10.00 (2.05)	8.60 (3.81)				
Gender					2	0.155	0.35
Males:Females	7:3	4:6	8:2	3.73			
Race					2	0.133	0.37
White:Coloured	10:0	9:1	7:3	4.04			
Education					2	0.117	0.38
Remedial:Specialised:Non-remedial	3:0:7	4:0:6	0:10:0				
Repeated a grade: Never repeated a grade: NA	0:10:0	2:8:0	0:0:10	4.04			
Co-morbid disorders <sup>b</sup>							
Mood:Anxiety:Behavioural:None	0:5:4:3	7:7:4:3	0:0:0:0				

<sup>&</sup>lt;sup>a</sup>Effect size was estimated by  $\omega^2$  in the case of ANOVAs and by Cramer's V in the case of  $\chi^2$  analyses. <sup>b</sup>Some children had comorbid diagnoses.

Table 2 Demographic Characteristics of the Current Sample: Mothers

Variable	ADHD-CT ( <i>n</i> = 10)	ADHD-PI (n = 10)	Autism ( <i>n</i> = 10)	$F/\chi^2$	df	p	ESE <sup>a</sup>
Age (years)				0.29	2, 27	0.752	-0.38
Range	33-42	36-41	35-51				
Mean (SD)	37.30 (3.56)	39.70 (3.37)	42.00 (5.42)				
Neighbourhood				4.07	4	0.396	0.26
Rural: Suburban: Intermediate	1:9:0	0:10:0	0:9:1				
Religion				6.75	8	0.564	0.34
Christian	9	9	7				
Judaism	0	1	1				
Islam	0	0	1				
None	1	0	1				
Marital Status				1.25	2	0.535	0.20
Married:Divorced	9:1	8:2	7:3				
Household Income Level				18.80	18	0.404	0.56
Low	0	1	0				
Low Average	4	2	6				
High Average	3	4	2				
High	3	3	2				

Note: Household income was calculated by dividing household income by the number of household members and defining four income categories per annum, as follows: Low = R 0-125000, Low Average = R126000-275000, High Average = R 276000-375000, High => R 426000.

a Effect size was estimated by  $\omega^2$  in the case of ANOVAs and by Cramer's V in the case of  $\chi^2$  analyses.

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#### **Materials**

Table 3 presents a list of the measures used in the current study, along with the approximate time of administration for each measure. Each instrument is discussed in more detail below.

#### Demographic questionnaire

This instrument (see Appendix B), which was designed for the purposes of the larger study within which this one was nested, was used to gather basic information (e.g., race, income, religion, education, and socio-economic status) about the family being assessed.

Table 3
Instruments Used in the Current Study

Measure	Approximate time for administration (mins)
Demographic questionnaire	5
M.I.N.I Kid	Up to 60
CBCL: Parent Report	5
Parenting Stress Index	20
Family Resource Scale	5
Family Support Scale	5
WHO Quality of Life Questionnaire	5
CES-D	5

*Note:* M.I.N.I Kid = Mini International Neuropsychiatric Interview for Children and Adolescents; CBCL = Child-Behaviour Checklist; CES-D = Center for Epidemiologic Studies-Depression Scale.

#### Child measures

Diagnostic tool. The Mini International Neuropsychiatric Interview for Children and Adolescents (M.I.N.I Kid; English version 5/6; Sheehan, Shytle, & Milo, 1998) was used to assess the presence of DSM-IV-TR Axis I disorders in the child participants. The M.I.N.I Kid provided verification as to whether the child qualified for the study by having either ADHD-CT or ADHD-PI and no co-morbid psychotic disorders. Although evaluation of this version of the measure is still underway, Sheehan et al. (1997), the reliability and validity of the adult version of the M.I.N.I is well established. For example, Sheehan et al. (1997) showed that the instrument had convergent validity with the Structured Clinical Interview for DSM-III-R Patients (SCID-P; Spitzer, Forman, & Nee, 1979) and with the Composite International Diagnostic Interview (CIDI; World Health Organization, 1990) for International Statistical Classification of Disease (ICD-10)

The M.I.N.I Kid has been used successfully in previous studies of child psychiatric disorders (see, e.g., Bastiaens & Dello Stritto, 2005) and has been used in previous studies of South African children by members of our laboratory (Hoppe, 2009; Fischer, 2008).

Functional impairment. The Child-Behaviour Checklist (CBCL; Achenbach & Rescorla, 2001) is a 113-item parent-completed questionnaire that inquires about a variety of child behavioural and emotional domains of functioning. The CBCL includes 20 items that ask the parent to rate their child's competence in the domains of daily activities, social relations, and school performance. The only CBCL subscales used in this study were Total

Competence (used to indicate whether there is a clinically problematic level of competence, e.g., the individual requires special assistance at school or at home to complete what should be age-appropriate activities) and the Externalizing and Internalizing problems subscales. On these subscales, parents rated the extent to which an item applied to their child now or within the past 6 months, using the following scale: 0 (not true); 1 (somewhat or sometimes true); 2 (very true or often true).

The CBCL has been carefully normed and has been widely used in ADHD clinical research (see, e.g., Geller et al., 2004; Spratt et al., 2007) and in previous studies of South African children by a member of our laboratory (Fischer, 2008). Spratt et al. (2007) confirm that the CBCL is one of the strongest available measures of child internalizing and externalizing behaviour problems.

#### Parent measures

Parental stress. The Parenting Stress Index 3rd edition (PSI; Abidin, 1995) is a 120item instrument, suitable for parents of school-aged as well as younger children, used to measure self-perceived parental stress and the relative amount of stress within the parentchild system.

The PSI contains six subscales relating to characteristics of the child, forming what is known as the Child Domain: Adaptability, Mood, Distractibility/Hyperactivity,

Demandingness, Reinforces Parent and Acceptability. There are seven subscales relating to characteristics of the parent, forming what is known as the Parent Domain: Competence,

Isolation, Attachment, Health, Role Restriction, Depression and Spouse. All items are answered on a 5-point Likert-type scale, ranging from 1 (strongly disagree) to 5 (strongly agree). An example of a statement that parents would rate related to child characteristics is:

My child is so active it exhausts me. An example of a statement that parents would rate related to their characteristics is: Being a parent is much harder than I thought. The scores from the individual subscales within each of the Parent and Child Domains yield a stress score specific to that domain for each parent. An overall Total Stress score and Life Stress score can also be derived from this measure. The latter is based on the amount of stress that the parent is experiencing outside of the parent-child relationship, whereas the former is based on the combined total scores from the Child and Parent Domain subscales (Abidin, 1995).

The PSI has been used as a primary measure in several ADHD and parental stress studies (see, e.g., Lange et al., 2005; Spratt et al., 2007; Van der Oord et al., 2006). The PSI

has also been used in a previous study of South African parents by a member of our laboratory (Oosthuizen, 2007). Internal consistency for the 120 items is high and the test-retest reliability on the subscales is substantial; (.63) for the Child Domain, (.91) for the Parent Domain and (.96) for the Total Stress score (Abidin, 1995).

Parental depression. The Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) was used to rate parents' subjective depression. This instrument consists of 20 items relating to mood, and asks individuals to rate depression symptoms over the past 7 days. Items are rated on a 4-point Likert scale ranging from 0 (almost never) to 3 (most of the time or always). A score of 16 or greater is considered clinically depressed. Examples of such questions are, I was bothered by things that usually don't bother me and I felt that people dislike me.

Assessing the effects of the present level of depressive symptomatology is of interest in relation to parental stress. For instance, Van der Oord et al. (2006) used the CES-D to assess the effects of depressive symptomatology as a potential bias in informant agreement on ADHD, ODD and CD symptoms in clinically referred, DSM-IV-diagnosed children with ADHD. Van der Oord et al. (2006) reported good internal consistency (Cronbach's  $\alpha$  .79–.92) for the measure and rated its validity as similar to that of other depression measures.

Resources and support. The Family Resource Scale (FRS; Dunst, Jenkins, & Trivette, 1984) and the Family Support Scale (FFS; Dunst & Leet, 1984) were used to gain information on material resources within the participating families, and social support experienced by the mothers, respectively. The FRS consists of 30 items, each describing a particular resource (e.g., money to buy necessities, dependable transportation, time to be with spouse/friend, money to save); parents are asked to rate the adequacy and availability of these resources to their family. Each item is rated on a scale ranging from 0 (does not apply) to 5 (almost always adequate). The measure has a high internal consistency (.92) and a test-retest reliability of .52 over a period of 2 to 3 months (Spratt et al., 2007).

The FSS consists of 18 items, each describing a possible source of social support (e.g., spouse, friends, doctors); parents are asked to rate the amount of support received from each source. Each item is rated on a scale ranging from 0 (*not available*) to 5 (*extremely helpful*). The measure has an internal consistency of .77, and a test-retest reliability of .91 over a 1-month interval (Spratt et al., 2007).

These measures are important to use in studies of parental stress because often stress is increased by a lack of material resources or social support (Dunst & Leet, 1984). In the case of ADHD, these measures are especially important because the cost of medications and

special schooling can add substantially to parents' financial stress. Furthermore, because there is still social stigma attached to having a child with ADHD, social support is important to parents as a potential buffer against stress.

Quality of life. The WHO Quality of Life Questionnaire (WHO QoL; Gururaj, Bada Math, Reddy, & Chandrashekar, 2008) was used to evaluate parent life satisfaction and wellbeing. The instrument emphasizes the subjective responses of individuals rather than their objective life conditions. Participants report and rate their quality of life in 31 separate domains (e.g., health, love, goals, home). Participants first rate the levels of importance of a domain in their life and then report to what degree they are satisfied with this aspect of their life. The first rating is done on a 3-point scale ranging from 0 (not important) to 3 (extremely important); the second rating is done on a 6-point scale ranging from -3 (very dissatisfied) to +3 (very satisfied). The higher an individual scores on this measure, the more satisfied they are with their life across various domains.

Although this measure has not been used in South African studies on ADHD, it is useful for the current research because it gives a general subjective overview of how the parents view their lives. Analyses of internal consistency, item-total correlations, discriminant validity and construct validity through confirmatory factor analysis indicate that the WHO QoL has good to excellent psychometric properties.

### Procedure

After participants had been recruited and indicated willingness to participate in the study, the researchers scheduled an assessment time and venue that was comfortable for both mother and child. Preferred venues for assessment were at the family's home or in a research laboratory in the UCT Department of Psychology.

Once the mother and child had been informed about their respective roles in the research, the mother was asked to complete the informed consent document (see Appendix C) and the demographic questionnaire. The child was also asked to sign their name on the assent form reading it themselves or having it read to them (see Appendix D). Two researchers were present during the assessments; one worked with the child and the other with the mother. Both parent and child (and thus both researchers) were present for the administration of the M.I.N.I Kid. The child was asked a series of questions and the parent was encouraged to make comments. At this point the mother completed the PSI, CES-D, FSS, FRS, CBCL and WHO QoL questionnaires. The researcher explained each questionnaire to the mother and was available for any queries during the completion of each measure.

When the assessment session was complete, mothers and children an opportunity to ask the researchers any additional questions. One week after participating, the mothers received feedback via email about the information gathered on their child's functioning and the levels of parental stress. The feedback included recommendations relating to psychologists and other mental health professionals, support groups, and other sources of information

#### **RESULTS**

This section is organised around the specific aims presented earlier. First, I will first present the results of between-group comparisons that sought to determine if in families of an ADHD child, parental stress levels vary in relation to the particular subtype of ADHD with which the child has been diagnosed. Second, I will present a correlational analysis examining the relationship between parental stress and the level of functional impairment/problems present in the ADHD child. Third, I will present an analysis that examines the potential mediating effects that family resources and social support may have on stress levels in parents of an ADHD child. Fourth, I will present another correlational analysis, examining the relationship between levels of parental stress, symptoms of depression and overall quality of life in parents of children with ADHD. Finally, I will present data displaying the number of mothers from the current sample whose PSI scores fall within the clinically significant range (i.e., above the 85<sup>th</sup> percentile compared to the instrument's normative sample).

## **Between-Group Comparisons**

Before conducting these comparisons, the assumptions underlying the relevant parametric statistical tests were checked. For some of the distributions, there appeared to be slight violations of the normality assumption, and in a few cases Levene's test suggested that the assumption of homogeneity of variance had been violated. However, because the analysis of variance (ANOVA) design is robust enough to withstand such violations, no modifications were made to the plan to conduct a series on one-way ANOVAs. The aim of the between-group comparisons on the various measures was to determine whether (a) parents of ADHD-CT vs. ADHD-PI children differed in stress levels from each other as well as in comparison to parents of autistic children.

Table 4
Between-Group Comparisons on Outcome Measures Used in the Current Study

	ADHD-CT	ADHD-PI	Autism	· · · · · · · · · · · · · · · · · · ·		
Measure	(n = 10)	(n = 10)	(n = 10)	F	p	ESE $(\omega^2)$
PSI						
<b>Total Stress</b>	261.30 (44.17)	271.30 (51.72)	295.30 (43.28)	1.409	0.252	0.03
Child Domain	126.80 (27.55)	132.10 (24.19)	152.10 (25.84)	2.6549	0.089	0.10
Parent Domain	134.50 (25.73)	139.20 (32.20)	140.00 (26.65)	0.1099	0.896	-0.06
Life Stress	5.20 (5.16)	11.40 (6.72)	17.80 (12.76)	5.07539	0.013*	0.21
FSS	35.20 (11.77)	35.20 (13.36)	37.60 (13.36)	0.1510	0.861	-0.06
FRS	123.50 (15.63)	123.50 (21.28)	105.70 (10.86)	3.886	0.033*	0.16
WHO QoL	31.50 (4.48)	17.00 (20.15)	16.00 (12.40)	3.86441	0.033*	0.16
CES-D	12.50 (7.18)	18.00 (9.60)	17.80 (4.04)	0.9518	0.399	< -0.01

*Note.* PSI = Parenting Stress Index  $-3^{rd}$  edition; FSS = Family Support Scale; FRS = Family Resource Scale; WHO QoL = World Health Organisation Quality of Life; CES-D = Center for Epidemiologic Studies-Depression Scale; CBCL = Child-Behaviour Checklist. For each ANOVA, the degrees of freedom were (2, 27).

Table 4 shows that there were no statistically significant between-group differences in terms of PSI Total Stress, Parent Domain stress scores, and Child Domain stress scores. There were, however, statistically significant between-group differences on the PSI Total Life Stress measure. For this measure, Tukey's HSD post-hoc pairwise comparisons found that mothers of children with autism scored statistically significantly higher than mothers of children with ADHD, t(27) = 17.80, p = .010.

Table 4 also shows that, although there were no statistically significant between-group differences on the measure of depression, there were such differences in terms of perceived quality of life. For this latter measure, Tukey's HSD post-hoc pairwise comparisons found that mothers of children with ADHD-CT scored statistically significantly higher than mothers of children with autism, t(27) = 16.10, p = 0.04.

# Relationship between Functional Impairment in the ADHD Child and Parental Stress, Depression, and Quality of Life

The aim here was to investigate the relationship between the level of functional impairment and the types of problems present in children with ADHD and mothers' stress levels and mental health and well-being (i.e., investigate, to some degree, the far left side of the model depicted in Figure 1). Hence, two subscales of the CBCL (Total Competence and Total Problems) were correlated with the

<sup>\*</sup>*p* < .05

PSI measures. To capture more fine-grained information, and because ADHD-CT and ADHD-PI children typically display behaviour problems in different ways (Graetz et al., 2001), the Total Problems subscale was further separated into Externalizing Problems and Internalizing Problems subscales.

Table 5 shows that ADHD children's CBCL Total Competence scores were not statistically significantly related to any of the stress indexes, but were positively correlated with depressive symptomatology in mothers. The externalizing behaviours of ADHD children were positively correlated with mothers' PSI Total Stress and Child Domain scores. The strongest positive correlations, however, were between internalizing problem behaviours and mothers' depression scores and PSI Parent, Child and Total Stress scores.

## The Protective Effects of Resources and Social Support on Parental Stress

The aim here was to investigate whether high levels of resources and social support could buffer mothers of ADHD children against increasing levels of stress (i.e., to examine the left-middle side of the model depicted in Figure 1). The model explicitly proposes that resources and social support separately mediate the relationship between the functional impairment of the ADHD child and the stress levels experienced by that child's parent(s). Unfortunately, given the small sample sizes currently available, I was not able to satisfy the assumptions underlying mediator variable analyses of the kind originally outlined by Baron and Kenny (1986). For the moment, then, a series of more indirect tests of the propositions will have to suffice.

First, Table 4 shows that there were no statistically significant between-group differences on the FSS: Participants in all three groups had similar perceptions of their level of social support (and, interestingly, all perceived that level of support to be quite low, with mean scores in mid-30s on a 0-90 scale, where higher scores indicate more perceived social support). There were, however, statistically significant between-group differences in perceived adequacy of resources. Tukey's HSD post-hoc pairwise comparisons found only that mothers of children with ADHD-CT scored statistically significantly higher than mothers of children with autism, t(27) = 105.70, p = .04.

Second, Table 5 shows that there were statistically significant negative correlations between FRS scores and PSI Total Stress, Life Stress, and Child Domain scores. In other words, the more resources one has, the less likely one is to experience stress related to external factors and to factors related to the child's behavioural characteristics. Surprisingly, however, the Table also shows that there are no statistically significant correlations of any kind between FSS scores

and parental stress. In other words, the level of social support these mothers report experiencing does not seem to be associated with the levels of stress they reported.

Third, it is of interest to examine whether perceived adequacy of resources and perceived social support have an impact on perceived quality of life, particularly given that we might assume (and this is confirmed in subsequent analyses) that parental stress is negatively correlated with quality of life. As noted above, Table 4 shows that there were statistically significant between-group differences on the WHO QoL measure. Therefore, a series of analyses of covariance (ANCOVAs) were performed to determine whether the between-group difference in perceived quality of life would still be present when controlling for perceived adequacy of resources and social support. When the influence of perceived adequacy of resources was accounted for, the between-groups difference in perceived quality of life was still statistically significant, F(2,26) = 4.65, p = .019. When the influence of perceived social support was accounted for, the between-groups difference in perceived quality of life was still statistically significant, F(2,26) = 4.65, p = .019. When the influence of perceived social support was accounted for, the between-groups difference in perceived quality of life was still statistically significant, F(2,26) = 4.65, P = .002.

In summary, congruent with the model, it appears that resources could be potential buffers between the child with ADHD and the stress levels experienced by parents. However, social support may need to be reconsidered as a potential mediator between the child with ADHD and the stress levels experienced by parents. The differences in perceived quality of life between the mothers in the ADHD and autism groups were statistically significant, even after controlling for differences in resources between the groups. This means that there is some underlying characteristic in the lives of mothers of autistic children over and above resources and support that influence their stress levels.

## Correlations between Parental Stress, Depression, and Quality of Life

The aim here was to examine the relationship between levels of parental stress, symptoms of depression, and overall quality of life (i.e., investigate the far right side of the model depicted in Figure 1). The correlation matrix shown in Table 5 indicates that there were statistically significant correlations, in the expected direction, between the measures of interest. Specifically, depressive symptomatology was significantly positively correlated with all of the parental stress scores, and significantly negatively correlated with quality of life. Furthermore, quality of life was significantly negatively correlated with PSI Total Stress and Parent Domain stress.

Table 5
Correlations between Outcome Measures

	1	2	3	4	5	6	7	8	9	10
1. PSI Total Stress	1.00									
2. PSI Parent Domain Stress	r = .86	1.00								
3. PSI Life Stress	<i>p</i> < .001*** .43	.18	1.00							
5. FSI Life Suess	.43 .061	.18	1.00							
4. Child Domain Stress	.89	.52	.54	1.00						
	.001***	.017*	.014*							
5. CES-D	.80	.57	.47	.81	1.00					
	.001***	.008**	.036*	.001***						
6. FRS	64	28	48	81	69	1.00				
	.001***	.232	.029*	.001***	.001**					
7. FSS	07	.06	23	17	06	.37	1.00			
	.780	.791	.323	.482	.816	.001**				
8. WHO QoL	65	46	38	66	74	.66	.28	1.00		
	.002**	.040*	.103	.002	.001***	.002**	.232			
9. CBCL Total Child Competence	37	20	27	44	35	.59	.33	.36	1.00	
•	.104	.408	.257	.050**	.127	.007**	.159	.118		
10. CBCL Externalizing Problems	.56	.44	.21	.53	.33	-41	.07	06	12	1.00
Ç	.010*	.051	.369	.016*	.150	.074	.746	.977	.610	
11. CBCL Internalizing Problems	.64	.66	.07	.47	.58	21	.15	40	20	-57
S	.002**	.001**	.776	.035*	.007**	.378	.529	.075	.387	.009**

Note. PSI = Parenting Stress Index – 3<sup>rd</sup> edition; FSS = Family Support Scale; FRS = Family Resource Scale; WHO QoL = World Health Organisation Quality of Life; CES-D = Center for Epidemiologic Studies-Depression Scale; CBCL = Child-Behaviour Checklist.

\*p < .05; \*\*p < .01; \*\*\*p < .001

## **Mothers Displaying Clinically Significant Stress Levels**

The PSI manual indicates that a percentile score above the 85 on any of the instrument's major scales or subscales is considered in the clinical range. The manual's author recommends that parents who score in this range be referred for professional assistance (Abidin, 1995).

An examination of the number of mothers from the current sample whose PSI scores fall within this clinically significant range (85<sup>th</sup> percentile) indicates the extent to which these mothers are distressed in their everyday lives. Given the small sample size and the fact that a 'normal' control group was not recruited, Table 6 is an effective way to illustrate the high levels of stress experienced across numerous domains by the mothers in this sample. The majority of this stress appears to emerge from the Child Domain (i.e., from characteristics of the child's behaviour) and can therefore be viewed as a consequence of the child's disorder.

Table 6
Number of Mothers in Clinical Range of Parental Stress

Number of Mothers in Clinical Range of Pa		A DUID DI
	ADHD-CT	ADHD-PI
PSI Scale / Subscale	(n = 10)	(n = 10)
Child Domain		
Distractibility/Hyperactivity	8	8
Adaptability	6	6
Reinforces Parents	6	4
Demandingness	6	7
Mood	6	5
Acceptability	7	9
Total Child Domain	6	8
Parent Domain		
Competence	1	5
Isolation	3	3
Attachment	2	3
Health	4	4
Role Restriction	4	4
Depression	3	4
Spouse	2	4
Total Parent Domain	3	4
Total Stress	5	5
Total Life Stress	1	3

*Note:* Percent in the clinical range for each PSI scale was determined using normative guidelines provided in that scale's manual (Abidin, 1995).

#### DISCUSSION

This is the first study to examine the stress levels of South African parents of children with ADHD. It sought to provide a comprehensive picture of the difficulties that arise when caring for children with ADHD. More specifically, the study had four aims: The first two were to investigate whether, in families of an ADHD child, parental stress levels vary with the particular subtype of ADHD with which the child is diagnosed and/or with the level of functional impairment/problems present in the child. The third aim was to investigate whether resources (fiscal, physical, and household) and social support available to parents mediate the relationship between having a child with ADHD and parental stress. The fourth aim was to examine the relationship between levels of parental stress, symptoms of depression, and overall quality of life.

#### **Between-Group Comparisons**

It is important to look at how characteristics of the child, parent and their environment contribute to parents' stress levels (Johnson & Mash, 2001). For this reason, the theoretical model constructed for the purposes of this study and discussed earlier, is a good way to interpret these between-group differences. The ANOVA that was used to investigate whether, in families of an ADHD child, parental stress levels vary with the particular subtype of ADHD with which the child is diagnosed showed that there were no between-group differences for scores in terms of PSI Total Child Domain stress, PSI Total Parent Domain stress, or PSI Total Stress.

PSI Total Life Stress is defined as external stressors, i.e., stressful events a parent experiences outside of the parent-child relationship (e.g., pregnancy, divorce, debt; Abidin, 1995). On this measure, there was a statistically significant between-group difference, with mothers of children with autism experiencing reporting more Total Life Stress than mothers of children with ADHD. It is difficult to give a definite answer as to what might account for this pattern, as life stress relates to external stressful events that may occur in the mothers' lives and not specifically to problems related to the child. However, some life events (e.g., divorce or debt) may be indirectly related to their child's disorder.

Although there were no between-group differences in terms of parental stress, and small effect sizes associated with the comparisons, an examination of the group means suggests there was a trend for parents of autistic children to have slightly higher stress levels, followed by parents of children with ADHD-PI, and then parents of children with ADHD-CT. This pattern is congruent with that reported by Gupta (1997), who showed that parents of

children with developmental disorders, such as autism, display similar stress levels to parents of children with ADHD.

There were no statistically significant between-group differences in terms of depressive symptomatology as measured by the CES-D. The average scores for the mothers of ADHD-PI and autistic children were, however, in the clinically depressed range, while mothers in the ADHD-CT group, on average, scored below the clinically depressed range. Future studies with larger sample sizes might find it worth looking into the potential impact the subtype of the child's disorder has on depression in mothers of special needs children.

The WHO QoL measure was used to evaluate parents' general perception of their wellbeing. QoL includes parents' perceptions of not only wealth and employment, but also their environment, physical and mental health, education, recreation, and social belonging. There was a statistically significant between-group difference on this measure, with mothers of children with autism perceiving their QoL less positively than mothers of children with ADHD. Previous literature (e.g., Psychogiou, 2008; Spratt et al., 2007) shows that personal distress is associated with negative affect, depression, and anxiety disorders, all of which affect the mothers' ability to cope with stress.

## Relationship between Functional Impairment in the ADHD Child and Parental Stress, Depression, and Quality of Life

This study is one of the first to include an inspection of child functional severity and problems associated with ADHD into an examination of parental stress. In the current sample, there was a significant association between the types of problems the ADHD child displayed and mothers' reported stress levels. More specifically, internalizing characteristics (e.g., the tendency to withdraw from social contact), such as those experienced by children with ADHD-PI, were strongly correlated with mothers' stress and depression. This association may arise because these internalizing behaviours are difficult to recognize and parents may feel incompetent in not being able to assist their children.

Externalizing behaviours (e.g., overt aggression), such as those typically displayed by ADHD-CT children, were significantly associated with the mothers' stress. This association may arise because such behaviours are difficult to manage and can occur at inappropriate times/situations, placing more stress on the parent to control the situation.

The CBCL Total Competence measure, a reflection of the severity of ADHD, was not statistically significantly correlated with the mothers' total stress scores. This finding is in line with research by Osborne and Reed (2008), who found that stress for parents of autistic children was

associated with child behavioral problems (types of problems the child displayed) rather than the severity of autism. CBCL Total Competence was, however, significantly related to parental depression; the more severely impaired the child's functioning, the more depressed the parent. This correlation gives an idea of the possible problem areas/associations that I plan to continue looking at in future, with an increased sample size. The current data call for more inspection into the differing subtypes of ADHD, variations in functional impairment, and their influence on parental stress.

#### The Protective Effects of Resources and Social Support on Parental Stress

The model depicted in Figure 1 proposes that resources and social support separately mediate the relationship between the functional impairment of the ADHD child and the stress levels experienced by that child's parent(s).

In terms of resources, it appears that this conceptualisation may be valid. It appears that resource potentially exhibit a buffering effect between the functional impairment of the ADHD child and the stress levels experienced by the parent. Mothers of ADHD children perceived the adequacy of their resources more positively than the mothers of autistic children. This is congruent with previous research by Kadesjö et al. (2002), who found that situational factors such as material resources need to be examined as potential factors associated with parental stress.

However, whereas previous studies found parents of ADHD children to suffer from a lack of resources, the mothers in the current sample were relatively satisfied with their resources. Referring back to the theoretical model, a possible reason for this is that the availability of resources is acting as a buffer against increasing stress levels.

Social support did not vary significantly for the mothers in the different groups. The mothers do not appear to perceive their social support as adequate in relation to their child's disorder. This confirms previous research by Spratt et al. (2007) who found a lack of perceived social support amongst parents of ADHD children. Clearly this finding highlights the need for research addressing parental stress as these parents are in need of adequate interventions. Referring back to the theoretical model, this data questions the proposed buffering role of social support between the functional impairment of the ADHD child and the parental stress levels. Perhaps, this indicates that in the current sample the social support 'buffer' was not present and therefore mothers were susceptible increased stress.

Furthermore, it is interesting that even though the mothers of autistic children perceived their quality of life and resources as significantly worse and experienced more life stress they did not display statistically significantly higher levels of stress than parents of the ADHD children. Popular conceptions of these disorders may be a possible explanation for the lack of stress significant

differences in these groups. People often expect parents of autistic children to be extremely stressed, whereas parents of ADHD children are often viewed as having a naughty child that merely needs discipline.

## Correlations between Parental Stress, Depression, and Quality of Life

The theoretical model depicted in Figure 1, was designed, in part, to illustrate the potential relationships between parental stress, mental health, and overall quality of life. Consistent with this framework, depressive symptomatology was positively correlated with all of the PSI stress scores, and significantly negatively correlated with the WHO QoL scores. This is expected because if a parent is clinically depressed, they experience many internalizing issues which may make it difficult to fulfil their parenting role, create a tense parent-child relationship and ultimately result in increased stress levels.

QoL scores significantly negatively correlated with PSI Total Stress and Parent Domain stress. This is congruent with the model, as a lower perceived QoL puts the parent at risk for psychological distresses, such as anxiety and emotional disturbances that impact the parent-child relationship and may result in increased stress levels.

The PSI Child and Parent Domain stresses were highly positively correlated with each other and with the PSI Total Stress score. This is evidence for the validity of these PSI measures in the current sample, which is encouraging given my plans to continue using this instrument in future research on parental stress and ADHD in South Africa.

## **Mothers Displaying Clinically Significant Stress Levels**

Table 6 displays the number of mothers from the current sample whose stress scores fall within the clinically significant range (85<sup>th</sup> percentile) on the various PSI scales and subscales. Previous studies (see, e.g., Austin & Carpenter, 2008; Gupta, 2007; Spratt et al., 2007) have shown that parents of ADHD children experience more parental stress than parents of children without ADHD. The current data are similar with those previous findings. Additionally, in the current sample, it is clear that much of the experienced parental stress is associated with the child's disorder itself.

*PSI Child Domain*. Scores in this domain reflect how certain characteristics of the ADHD child make it difficult for parents to fully realize their parenting role (Abidin, 1995). In the case of the current sample, 16 of the 20 mothers of ADHD children indicated that their stress related to the distractibility/hyperactivity of their child was within the clinical range. According to the

PSI manual, high scores on this subscale may be due to the parent lacking energy to keep up with their child or to unreasonable expectations of the parent (Abidin, 1995)

Within the PSI Child Domain, *adaptability* refers to child characteristics such as a child's inability to adjust to changes in different social/physical environments that may increase stress for the parent (Abidin, 1995). Of the mothers with ADHD children, more than half scored in the clinically significant range of stress on this factor. This may be due to the types of problems children with ADHD display which often make it difficult for them to cope in certain domains of life (e.g., school or socially).

Also within the PSI Child Domain, *acceptability* refers to when a child's intellectual and emotional characteristics do not meet the expectations of the parents (Abidin, 1995). With one exception, all mothers of children with ADHD-PI scored within the clinically significant range on this factor. These mothers may have been particularly stressed in this regard because ADHD-PI children typically do not display their problems in an overt manner and may appear to be quiet and well-behaved. Therefore, when the child cannot cope with certain tasks, it may be difficult for the parent to understand; compare this situation with an ADHD-CT child, whose problems are on display in most of his/her actions. This finding is in line with research by Kadesjö et al. (2002), who found that parents with children that have ADHD generally have difficulty accepting their child's disability.

*PSI Parent Domain*. Scores in this domain reflect how certain sources of stress, not directly related to the child, are associated with the parent's functioning and wellbeing. Scores within this Domain were slightly lower than the scores within the Child Domain, showing that it is the child's characteristics (related to their disorder) that are the dominant source of stress for the parents of children with ADHD.

#### **Limitations and Directions for Future Research**

Similar to many studies that have been conducted on parental stress in families with children that have special care needs, the current sample was of a middle-class, suburban background. In a country such as South Africa, it is particularly important to examine culturally and ethnically diverse groups in studies such as this, particularly because parents from lower SES strata will have fewer financial and physical resources, and might have less ready access to health information and health professionals, and so might experience higher levels of stress related to their child's disorder. Future research should try to remedy this shortcoming of the current study by actively recruiting participants and from lower SES neighbourhoods.

In this study, a perceived lack of resources was identified as differing significantly between mothers in the ADHD and autism groups. This dovetails with the previous recommendation in showing that future research needs to carefully investigate the role material resources plays as a mediating factor in parental stress. Future research might do so by including the income of the families as one of the dependent variables.

With regard to expanding and building upon the current study, the general structures set in place will not need to be altered. Unfortunately, due to the small sample sizes, the study had little statistical power and this is something future research should try rectify. Hence, increasing the sample size is of utmost importance to obtain results that might be more statistically valid and significant in relation to the given population. With a larger sample size, one can also employ regression-based path analyses and structural equation modelling (SEM) to properly test theoretical framework conceptualised in Figure 1.

#### Conclusion

This study has provided preliminary steps towards examining and understanding parental stress in parents of ADHD children in South Africa. A better understanding of the factors associated with parental stress and the role the type of ADHD problems have with parental stress will lead to better implementation of family preventative interventions and make the general public more aware of these parents' stressful situations. Further, this study has made a contribution to previous research in the realm of parental stress and ADHD by attempting to examine the subtypes of ADHD separately and by examining the child's functional impairment in relation to parental stress. The theoretical framework for understanding the dynamics of parental stress introduced in this study will form the basis of future research that will make even more of a contribution to the field.

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#### APPENDIX A

#### DSM-IV-TR DIAGNOSTIC CRITERIA FOR ADHD

#### I. Either A or B:

A. Six or more of the following symptoms of *inattention* have been present for at least 6 months to a point that is disruptive and inappropriate for developmental level:

#### Inattention

Often does not give close attention to details or makes careless mistakes in schoolwork, work, or other activities.

- 1. Often has trouble keeping attention on tasks or play activities.
- 2. Often does not seem to listen when spoken to directly.
- 3. Often does not follow instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions).
- 4. Often has trouble organizing activities.
- 5. Often avoids, dislikes, or doesn't want to do things that take a lot of mental effort for a long period of time (such as schoolwork or homework).
- 6. Often loses things needed for tasks and activities (e.g. toys, school assignments, pencils, books, or tools).
- 7. Is often easily distracted.
- 8. Is often forgetful in daily activities.
- B. Six or more of the following symptoms of *hyperactivity-impulsivity* have been present for at least 6 months to an extent that is disruptive and inappropriate for developmental level:

#### Hyperactivity

- 1. Often fidgets with hands or feet or squirms in seat.
- 2. Often gets up from seat when remaining in seat is expected.

- 3. Often runs about or climbs when and where it is not appropriate (adolescents or adults may feel very restless).
- 4. Often has trouble playing or enjoying leisure activities quietly.
- 5. Is often "on the go" or often acts as if "driven by a motor".
- 6. Often talks excessively.

## *Impulsivity*

- 1. Often blurts out answers before questions have been finished.
- 2. Often has trouble waiting one's turn.
- 3. Often interrupts or intrudes on others (e.g., butts into conversations or games).
- II. Some symptoms that cause impairment were present before age 7 years.
- III. Some impairment from the symptoms is present in two or more settings (e.g. at school/work and at home).
- IV. There must be clear evidence of significant impairment in social, school, or work functioning.
- V. The symptoms do not happen only during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder. The symptoms are not better accounted for by another mental disorder (e.g. Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Based on these criteria, three types of ADHD are identified:

- 1. ADHD, Combined Type: if both criteria 1A and 1B are met for the past 6 months
- 2. ADHD, Predominantly Inattentive Type: if criterion 1A is met but criterion 1B is not met for the past six months
- 3. ADHD, Predominantly Hyperactive-Impulsive Type: if Criterion 1B is met but Criterion 1A is not met for the past six months.

## APPENDIX B

## DEMOGRAPHIC QUESTIONNAIRE

1. Child's age:					
1.1. Sex (circle one):	Male	Fer	nale		
2. Primary caregiver's age:					
2.1 Sex (circle one)	Male	Fen	nale		
2.2 Marital status (circle one)	Married	Single	Separated	Divorced	Widowed
3. What is your race or ethnic b	ackground?				
WHITE					
AFRICAN					
COLOURED					
ASIAN					
OTHER: (specify)					
4. Religion:					
5. Home Language:					
5.1. Size of house (indicate the n	umber of ro	oms in th	ne house):		
5.2. Number of people who live	in the house	•			
			<del></del>		
6.					
6.1. What term best describe	es the kind o	f neighbo	ourhood in w	hich you li	ve?
SUBURBAN					
URBAN					
TOWNSHIP					
INTERMEDIATE					
6.2. What is the name of the	neighbourh	ood in wl	nich you live	?	

	0-35000:
	36000-50000:
	76000-125000:
	126000-175000:
	176000-225000:
	226000-275000:
	276000-325000:
	326000-375000:
	376000-425000:
	426000-475000:
	476000-525000:
	> 526000:
EDUCATION LEVEL OF CHILD  8.1. Education (highest grade completed):	
8.2. Has most of your child's schooling been in RURAL	a rural or urban setting (circle one)
8.3. Has he/she repeated any grades? NO	YES

#### APPENDIX C

#### **Consent Form**

You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your mental health and other personal as other information necessary for the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Your participation is entirely voluntary. Before you decide whether or not you want your child and yourself to take part, read the information below and ask questions about anything you do not understand. By participating in this study you will not be penalized or lose any benefits to which you would otherwise be entitled.

<ol> <li>Name of Participant ("Study Subject")</li> </ol>	1.	Name	of Particip	ant ("Study	Subject"
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#### 2. Title of Research Study

Parenting Stress and the Effects of Having a Child with Attention-Deficit/Hyperactivity Disorder

#### 3. Investigators and Telephone Number(s)

Jessica Cheesman Honours Student Department of Psychology University of Cape Town Telephone: 074 133 1899

Kevin G. F. Thomas, Ph.D. Senior Lecturer Department of Psychology University of Cape Town Telephone: 021-650-4608

#### 4. Source of Funding or Other Material Support

None

## 5. What is the purpose of this research study?

The purpose of this research study is to examine and compare the varying levels of parenting stress associated with having a child diagnosed with ADHD compared to Autism. Furthermore this study aims to investigate if the level of functional impairment of a child diagnosed with either ADD/HD has an effect on the level of parenting stress.

#### 6. What will be done if your child/adolescent takes part in this research study?

In this study, you and your child will undergo two interviews that will ask you questions relating to your child's mental health. Both you and your child will undergo the same interview at separate times. In addition, both you and your child will separately complete a questionnaires relating to the impact that your child's ADHD symptoms has had on their lives. You will complete various questionnaires relating to you and your family as well as stress.

Possible locations for the interviews and filling out the questionnaires and completing the interviews are: the University of Cape Town's Department of Psychology or at your home. Each testing session will be individually conducted by a postgraduate psychology student who has been trained in the use of the measures that will be administered, and who is under the supervision of a clinical psychologist.

After the testing session, you will have the opportunity to ask questions and thus learn more about psychological research. However, your child's particular results will not be disclosed.

If you have any questions now or at any time during the study, you may contact the Principal Investigator listed in #3 of this form.

# 7. If you choose to allow your child to participate in this study, how long will he/she be expected to participate in the research?

The study consists of 1 session, which will last for a maximum of 2 hours. If at any time, during the interviews or when filling out the questionnaire, you or your child finds any of the procedures uncomfortable, you are free to discontinue participation without penalty.

### 8. How many children are expected to participate in the research?

30

## 9. What are the possible discomforts and risks?

There are no known risks associated with participation in this study. The only possible discomfort your child may experience is slight fatigue. If he/she becomes tired during either of the interviews or when they are completing the questionnaire, we will take a break. Your child will be allowed to take breaks whenever requested. Your child may feel

slight discomfort with the fact that he/she is taking part in an ADHD study and that people at the venue of the study may know of his/her ADHD diagnosis. However, privacy will be maintained, as best as is possible, in the place where the study is conducted.

If you wish to discuss the information above or any discomforts you or your child may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

## 10a. What are the possible benefits to you and your child/adolescent?

You, your child and family may or may not personally benefit from the research.

#### 10b. What are the possible benefits to others?

The objective is to be able to identify parenting stress and the domain where this stress lies. The areas where their child is most severely functionally impaired will also be identified along with any other factors which contribute to the parenting stress. This will allow for holistic family intervention plans to be developed which focus not only on the child but the parent as well, and aim to reduce stress and create a better living environment for all family members.

#### 11. If you choose to take part in this research study, will it cost you anything?

Participating in this study will not cost you anything.

## 12. Will you receive compensation for taking part in this research study?

There will be no compensation for participation in this study.

## 13a. Can you withdraw your child from this study?

You are free to withdraw your consent and to stop participating in this research study at any time. If you do withdraw your consent, there will be no penalty.

If you have any questions regarding your child's rights as a research participant, and your rights as the individual granting consent for research participation, you may phone the Psychology Department offices at 021-650-3430.

# 13b. If you withdraw your child from this study, can information about you still be used and/or collected?

Information already collected may be used.

# 14. Once personal and performance information is collected, how will it be kept secret (confidential) in order to protect your privacy?

Information collected will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the right to review these research records. These people include the researchers for this study and certain University of Cape Town officials. Your research records will not be released without your permission unless required by law or a court order.

#### 15. What information about your child may be collected, used and shared with others?

The information gathered from your child will be on their mental health status and functional impairments related to ADHD or Autism. If you agree that your child can be in this research study, it is possible that some of the information collected might be copied into a "limited data set" to be used for other research purposes. If so, the limited data set may only include information that does not directly identify you or your child. For example, the limited data set cannot include you or your child/adolescents' name, address, telephone number, ID number, or any other photographs, numbers, codes, or so forth that link you or your child/adolescent to the information in the limited data set.

The results of the research will be presented as part of an Honours research project for the University of Cape Town. Also, the results may be submitted for publication in a peer-reviewed journal. In both instances neither you nor your child will be identified in any way.

#### 16. What should you tell your child?

You may wish to discuss the study with your child to find out or determine whether he/she feels comfortable taking part. Your child should also know that if he/she does choose to participate, he/she can withdraw at any time during the study with no negative consequences

#### 17. How will the researcher(s) benefit from your being in the study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator and others attached to this research project may benefit if the results of this study are presented at scientific meetings or in scientific journals.

#### 18. Signatures

As a representative of this study, I have explained to the parent/guardian of the participant the purpose, the procedures, the possible benefits, and the risks of this research study; and

how the participant's others:	s performance and other data will be c	collected, used, and shared with
Signature of Person	Obtaining Consent and Authorization	Date
risks; and how your impairments and oth received a copy of the	med about this study's purpose, proce child's mental health status and ADH er data will be collected, used and sha his form. You have been given the oppose been told that you can ask other quantum the control of the	D-related functional ared with others. You have portunity to ask questions before
authorize the collect	sent to allow your child to participate ion, use and sharing of your child's mapairments and other data. By signing hts.	ental health status and ADHD-
Signature of Person	Consenting and Authorizing	Date
conducted by our res	w if you would like to be notified of fusearch group: hitial) Yes, I would like to be added to of research projects in which I or my	your research participation
Method of contact:		
Phone number: E-mail address: Mailing address:		

#### APPENDIX D

#### **Assent Form**

**Project Title:** Parenting Stress as an Effect of Having a Child with Attention

Deficit/Hyperactivity Disorder

Principal Investigator: Jessica Cheesman

## Why are you here?

"Your doctors/parents want to tell you about a research study involving children with Attention Deficit/ Hyperactivity (ADHD/ADD).

Research is a special way to learn about something. They want to see if you would like to be in this study. Jessica Cheesman and some other researchers are doing this study."

#### Why is this study being done?

"Your doctors are doing this study because they want to learn more about how ADHD/ADD is affecting children's lives, so that this can provide psychologists and psychiatrists with information that will help them to treat children with ADHD/ADD."

#### What will happen to you if you agree join this study?

"If you take part you will be asked some questions about your feelings and your life. Your mom/dad will also be asked the same questions about you. You and your parents will be asked these questions on two different days. But you will only be asked these questions if you join the study."

"This study won't make you feel better or get well. But the researchers might find out something that will help other children like you later."

#### What if you have any questions?

"If you have questions about the study you can ask them at any time. You can ask now. You can also ask later. You can talk to the researchers or you can talk to someone else. Do you have any questions now?"

## Who will know you are in the study?

"When the study is finished we will tell other researchers, psychiatrists and psychologists what we found out, but we won't tell them your name."

## Do you have to be in the study?

study, you just have to tell us. You can say yes now and chyou."	hange your mind later. It is up	o to
"If you want to be in this study print your name here"		
I want to be in this study		
Signature or Mark of Subject or Legally Authorized Representative	Date	
Signature of Person Obtaining Consent	Date	
Witness to Consent if Subject Unable to Read or Write (Must be different than the person obtaining consent)	Date	

do this. If you don't want to be in this study, you just have to tell us. If you want to be in the

"You don't have to be the study. No one will be mad at you if you don't want to

Signed copies of this consent form must be 1) retained on file by the principal investigator, 2) given to the subject and 3) placed in the subject's medical record (when applicable).