

*An exploratory study investigating the experiences of parents coping
with children who are being treated for Attention
Deficit/Hyperactivity Disorder (ADHD)*

By

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DECLARATION

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. This dissertation is being submitted for the degree of Master in Social Science (Clinical Psychology), in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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ABSTRACT

Aim: To explore parents' experiences when caring for a child with Attention Deficit/Hyperactivity Disorder (ADHD). The coping mechanisms employed by the parents in such a situation were also investigated.

Objectives: To gain an understanding of the parents' experiences when their child has ADHD. The factors affecting these experiences include dealing with their child's behaviours, receiving an ADHD diagnosis, deciding on treatment and coping resources.

Research Design: Through a qualitative, phenomenological approach, this study is characterized by an interpretative style with the aim of facilitating an in-depth exploration of the participants' experiences.

Subjects: A non-probability, purposive sample was used. The sample consisted of 12 parents. The only requirements for the sample were:

1. The participant must be the primary caretaker of a child who has been diagnosed with ADHD and is being treated for ADHD.
2. The participant's child must be 18 years old or younger.

Data Collection: Semi-structured, in-depth interviews were used as an instrument for collecting the required data and were devised in order to appropriately address the objectives of this study.

Data Analysis: The transcripts were analyzed thematically using Interpretative Phenomenological Analysis (IPA) in order to identify relevant and common parental experiences. Lazarus and Folkman's Transactional Theory of Stress (TTS) and Coping was utilized as a conceptual framework to help make sense of the emergent themes.

Results: Participants in the present study displayed increased levels of stress and frustration when caring for a child with ADHD. The child's difficult behaviours frequently induced a sense of incompetence in the parents and a desire to use physical punishment on the child. The participants employed various methods of coping in order to adapt to their child's disorder. Such efforts included modifying daily routines and utilizing social support. Most of these coping efforts helped to diminish stress and anxiety and improved parent-child relationships.

TABLE OF CONTENTS

<u>CONTENTS</u>	<u>PAGE NO.</u>
Declaration	ii
Acknowledgements	iii
Abstract	iv
CHAPTER ONE: Introduction	
1.1 Introduction	1
1.2 Background to the Present Study	1
1.3 Rationale and Aim of the Present Study	2
1.4 A Current View of Attention Deficit/Hyperactivity Disorder	3
1.4.1 A Description of ADHD Taxonomy	3
i) Inattention	4
ii) Hyperactivity	4
iii) Impulsivity	4
1.5 ADHD Prevalence in South Africa	4
CHAPTER TWO: Literature Review	
2.1 Introduction	6
2.2 Determinants of Parent Stress in General	6
2.3 Parent Response to a Child with a Disability	7
2.3.1 Parent Adaptation and Coping	8
2.4 Parental Experience Specifically Related to a Child with ADHD	9
2.4.1 The Parent Experience and Child Behaviours associated with ADHD	9
i) Discipline	10
ii) Socialisation and Isolation	11
iii) The Working Parent	12
2.4.2 Factors Affecting the Help-seeking Process	13
i) Parental Ambivalence and Health Professional Opinions	14
ii) Media Influence and Parent Misconceptions surrounding ADHD	15
2.4.3 Parents' Experiences Relating to their Child's ADHD Diagnosis	16
i) Parents Questioning the Reasons for their Child's ADHD	18
2.4.4 Factors Affecting Parents' Decisions Regarding Treatment	19

2.4.5 Strategies for Coping with a Child’s ADHD	22
i) Maladaptive Parent Coping Efforts	22
ii) Adaptive Parent Coping Efforts	23
(a) Social Support	24
(b) Religion and Hope	25
2.5 Conclusion	26
CHAPTER THREE: Conceptual Framework	
3.1 Introduction	27
3.2 Historical Development of the Theory of Stress and Coping	27
3.2.1 Stress	27
3.2.2 Coping	28
3.3 Current Models of Stress and Coping	28
3.3.1 The Parenting Stress Model	29
3.3.2 The Double-ABCX Model of Stress and Coping	30
3.3.3 The Transactional Model of Stress, Appraisal and Coping	31
3.4 A Discussion of Stress According to Lazarus and Folkman	31
3.4.1 Mediating Processes	32
i) Cognitive Appraisal	32
(a) Primary Cognitive Appraisal	32
(b) Secondary Cognitive Appraisal	33
(c) Cognitive Reappraisal	33
ii) Emotion	34
iii) Coping	34
(a) Emotion-focused Coping	35
(b) Problem-focused Coping	35
3.4.2 Antecedent Variables	36
i) Person factors	36
ii) Situation factors	37
3.4.3 Adaptational Outcomes	37
3.5 Limitations of the Model of Stress, Appraisal and Coping	37
3.6 Conclusion	38
3.7 Flow Chart	

CHAPTER FOUR: Methodology

4.1 Introduction	39
4.2 The Present Study	39
4.3 Conceptual Framework	39
4.4 The Researcher's Role	40
4.5 The Research Site	40
4.6 The Sampling Strategy	41
4.6.1 Age, Gender, Race	42
4.7 The Data Collection Strategy	43
4.7.1 The Individual Interview	43
4.7.2 Devising the Interview Schedule	44
4.8 Data Analysis	44
4.8.1 Stage One: Reading and Rereading	45
4.8.2 Stage Two: Identifying Themes	45
4.8.3 Stage Three: Listing Themes	45
4.8.4 Stage Four: Summary Table	46
4.9 Ethical Considerations	47
4.10 Conclusion	47

CHAPTER FIVE: Results and Discussion

5.1 Introduction	48
5.2 Experiences Instigating Help-seeking Prior to Diagnosis	48
5.2.1 The Impact of Child Problem Behaviours	48
i) Parents Description of their Daily Hassles	49
ii) Parents' Feelings of Frustration	50
iii) Conflict in the Parents' Familial Relationships	51
(a) The Impact of Sibling Rivalry	52
iv) Parents Doubting their Parenting Competency	53
v) Parental Difficulties in Public Situations	54
5.2.2 Parents Recognizing the Need to Seek Help	55
i) Parents Comparing their Child with Other Children	55
ii) Parent Response to Teacher Input	57

iii) Seeking Different Opinions Prior to Diagnosis	58
5.3 Experiences Surrounding Formal Diagnosis and Treatment	59
5.3.1 Parents Response to their Child’s Diagnosis	60
i) Reactions to the ADHD Diagnosis	60
ii) Parents and Self-Blame	62
iii) Parents Interactions with Health Professionals	63
5.3.2 Parents Seeking Help after Diagnosis	66
i) Parents Seeking a Second Opinion	66
ii) Parents Seeking their own Information about Treatment	67
5.3.3 Parents Making Decisions Regarding Treatment	68
i) Parents Seeking Support when Making Decisions Regarding Treatment	68
ii) Parents’ Thoughts Regarding their Child’s Medication	70
iii) Parents Making the Choice to use Alternate Treatment Options	72
5.4 Acceptance, Adaptation and Coping	73
5.4.1 Parent Adaptation	74
i) Parents Creating Structure	74
ii) Parents Getting Involved	75
iii) Social Support as a Coping Resource	77
5.4.2 Outcomes for Parents	79
i) Parents Continue to Face Daily Hassles	79
ii) Parents Express Future Concerns	81
ii) Parents Hope and Optimism	82
5.5 Conclusion	83

CHAPTER SIX: Implications, Limitations and Recommendations

6.1 Introduction	84
6.2 Theoretical Implications	84
6.3 Clinical Implications	84
6.4 Limitations of the Present Study	88

REFERENCES	x
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APPENDICES

Appendix A	Letter to Principals of Research Site	xxii
Appendix B	Consent by Principal to use of Research Site	xxiii
Appendix C	Letter to Participant Requesting Permission to Interview	xxiv
Appendix D	Participant Consent Form	xxv
Appendix E	Interview Schedule	xxvi
Appendix F	Transcript of Interview: Participant 2	xxvii
Appendix G	Letter of Ethical Clearance	xxxiii

CHAPTER ONE

INTRODUCTION

1.1 Introduction

Children with Attention Deficit/Hyperactivity Disorder (ADHD) display significant attention and behavioural problems. These behaviours are noticeably more severe, disruptive and unruly than the conduct of their peers. Of particular interest to mental health professionals and parent support groups, is the impact that such problematic behaviours have on parents. However, qualitative research that focuses on how parents experience and cope with their children's ADHD seems limited. The present study thus seeks to explore the experiences and coping mechanisms that are adopted by parents whose children have been diagnosed with ADHD. This introductory chapter will present the background to the present study by delineating the contextual framework within which these parental experiences are shaped. Additionally, a brief outline of the predominant ADHD behaviours is described as a basis for exploring the circumstances influencing the parental experiences. An overview of the rationale and aim of the present study will also be stated.

1.2 Background to the Present Study

ADHD is a common neuropsychiatric disorder diagnosed in 3-7% of school-age children and is characterized by a number of problematic behaviours (Barzman, Fieler & Sallee, 2004; National Institute of Health Consensus Statement, 1998).

Conceptualizing and generating a definitive description of ADHD has posed a challenge for mental health professionals over the last several decades. This continues to affect the diagnosis and treatment of this disorder (DeMarle, Denk & Erntshausen, 2003; Hallowell & Ratey, 1995; Rafalovich, 2001). To confound the matter further, there are a plethora of theories that attempt to provide different explanations for the condition. Amongst these are theories that have put emphasis on the association between ADHD and the family environment. In this context, the genesis of this disorder is often associated with dysfunction within the family (Barzman et al., 2004). As a result of these different theories, a new interest in parent's experiences when caring for a child with ADHD has begun to emerge.

As early as 1845 behavioural features, similar to those categorised as ADHD today, were described by Dr Heinrich Hoffman as being as a result of poor parenting methods in his book "The Story of Fidgety

Philip” (Austin, Reiss & Burgdorf, 2007). Then, in 1902 the features of ADHD were cited as being as a result of genetic dysfunction when Sir George F. Still, published a series of 12 lectures describing problematic behaviours in children. As a result, the first clinical description of ADHD emerged as “Morbid Defect of Moral Control”. Subsequent terms used to describe ADHD included Encephalitis Lethargica, Minimal Brain Dysfunction, Hyperkinetic Syndrome, Atypical Development and Attention Deficit Disorder to name a few (Austin et al., 2007; Rafalovich, 2001). Contending theories conceptualising ADHD as environmentally-based and as a result of poor parenting, re-emerged in 1960. At the time this was supported by the American Psychiatric Association and the features of ADHD were renamed “Hyperkinetic Reaction of Childhood” (Austin et al., 2007). Much of the twentieth century has not been free from theoretical views maintaining that psychiatric disorders in the child are as a result of “faulty” parenting (Hinshaw, 2005). Various theoretical opinions of ADHD, and how best to treat this disorder, continue to be presented by mental health authorities. This contributes to parental stress and uncertainty (Jackson & Peters, 2008). Further discussion of the effects of these theoretical opinions will be elaborated on in Chapter 2.

Sensationalised reporting by the media has at times reinforced misconceptions about ADHD amongst the general public. Such misconceptions include an exaggeration of the negative effects of pharmacological intervention and a belief system that holds that parenting and family environment are sometimes the main cause of ADHD (Dosreis & Myers, 2008; Hallowell & Ratey, 1995; Jackson & Peters, 2008).

Scharer (2002) suggests that the lack of theoretical clarity surrounding the nature of ADHD, as well as the difficult child behaviours characteristic of this disorder, tends to result in an increase in parents’ stress levels and a decrease in their sense of competence as parents. In addition, the capacity of the medical fraternity to provide parents with appropriate support and accurate information about their child’s ADHD appears to influence the parents’ experiences in accepting, understanding and coping with the impact of ADHD.

1.3 Rationale and Aim of the Present Study

Whilst there is considerable literature on the subject of ADHD and the experiences of children diagnosed with this disorder, there seems to be limited qualitative research on parents’ experiences when caring for a child with ADHD. Yet, a child with ADHD depends on his/her family and more specifically his/her parents, as a primary source of support (Bussing, Koro-Ljungberg, Gary, Mason & Garvan, 2005;

Hastings, 2002; McDonald, Donner & Poertner, 1992). Increased levels of stress experienced by parents when caring for these children may affect their ability to cope. Consequently, the parents' decision-making processes, help-seeking efforts, the manner in which the parents interact with their children and the manner in which parents implement the recommended treatment options could be impaired. Such difficulties experienced by parents, may directly and indirectly affect their overall well-being, their children's treatment process and the family environment (Hastings, 2002; McKee, Harvey, Danforth, Ulaszek & Friedman, 2004; Podolski & Nigg, 2001). It seems fair to assume that with such a potential impact, understanding parents' experiences when caring for a child with ADHD is essential.

The present study thus aims to investigate and confirm the experiences of parents as alluded to in the opening statements presented above. In addition to this, parents' coping mechanisms when dealing with a child with an ADHD diagnosis will be explored. Further, it is an unfortunate well known fact that within the South African context, specialised paediatric services are limited and where available, they are characterised by a lack of proper assessment and observations in diagnostics and treatment. In addition to this, there is also an observed limited multidisciplinary focus. Furthermore, the majority of South African schools are dealing with an under-resourced educational system with a poor teacher-student ratio, frequently leading to out-of-control classroom environments. Consequently, teachers feel enormous pressure and find themselves wanting their students to be medicated during class in order to maintain some control. Through the analysis of the accumulated data, the product of the present study could enhance the existing psychological perspectives on ADHD. The information gained from this study may therefore assist in developing multidisciplinary, family-centred mental health intervention strategies, including empowering teachers with knowledge of ADHD and improving parent-teacher relationships. Such strategies could also be aimed at engendering positive outcomes, alleviating parental anxieties, fulfilling parental needs and improving parent-child relationships as a whole.

1.4 A Current View of Attention Deficit/Hyperactivity Disorder

In order to explore parent experiences in the present study, an understanding of the characteristic behaviours of ADHD is necessary. This section will focus briefly on the currently utilised definition of ADHD, with particular reference to children.

1.4.1 A Description of ADHD Taxonomy

In the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000), ADHD is defined as a mental disorder with a distinct taxonomy. The essential features of ADHD are a persistent pattern of problem behaviours characterised by inattention, hyperactivity and impulsivity. However, children may not always exhibit inattentive symptoms simultaneously with hyperactive-impulsive symptoms. This has resulted in there being three ADHD subtypes appropriately categorised as: ADHD, Predominantly Inattentive Type; ADHD, Predominantly Hyperactive-Impulsive Type and; ADHD, Combined Type.

i) Inattention

In general, symptoms of inattention in children include failure to give close attention to details and making careless mistakes, whether the mistakes are in schoolwork or other activities (APA, 2000). Difficulty in sustaining attention to tasks for a period of time, being disorganised, difficulty in following through on instructions, as well as being easily distracted by extraneous stimuli, exhibiting forgetfulness and not seeming to listen when directly spoken to are also frequently exhibited symptoms of inattention (Hansell & Damour, 2005).

ii) Hyperactivity

Children exhibiting hyperactive symptoms tend to find it difficult to relax and appear as if they are always “on the go” (Hansell & Damour, 2005). Hyperactivity manifests as frequent fidgeting, difficulty remaining seated when expected to do so, excessive talking, a sense of restlessness and excessive climbing and running about in situations in which it is inappropriate (Hansell & Damour, 2005).

iii) Impulsivity

Symptoms of impulsivity include behaviours such as impatience, blurting out answers prematurely, difficulty in delaying responses and not waiting one’s turn (Hansell & Damour, 2005). Children with symptoms of impulsivity tend to interrupt or bother others in games and conversations, initiate conversations at inappropriate times, clown around and engage in dangerous activities without consideration of the possible consequences (APA, 2000).

According to Podolski and Nigg (2001), difficult child behaviours such as inattention, hyperactivity and impulsivity as described above are likely to increase parent levels of stress.

1.5 ADHD Prevalence in South Africa

The present study investigates the experiences of South African parents. It is noteworthy that, to date, studies on ADHD in South Africa are limited. When evaluating the present study, it is relevant to take note that the number of children diagnosed with ADHD has been reported to vary in prevalence among different cultural populations and appears to be more highly diagnosed in western populations (APA, 2000). Scheffler, Hinshaw, Modrek and Levine (2007) claim that between 2003 and 2005 North America has experienced an 8 times greater consumption of methylphenidate (Ritalin) than developing countries. These findings suggest that western countries could have a greater prevalence of ADHD. However, research conducted by Polanczyk and Rohde (as cited in Moffitt & Melchior, 2007) revealed that there is a 5.2% - 6% average ADHD prevalence rate worldwide and the prevalence rates between different countries are relatively uniform.

Similarly, Aase, Meyer and Sagvolden (2006) conducted a study comparing ADHD prevalence in South Africa to the disorder's prevalence in western countries. These researchers posited that if ADHD is a neurobehavioural disorder, and not just a social construct predominantly recognized in western countries, ADHD prevalence should therefore be replicated in non-western populations as well. In their study of children in South Africa, these researchers successfully replicated the results of studies performed in western countries. The prevalence of ADHD was reported to be at an average of 5.5% and thus just as high in South Africa across all population groups, as in western populations.

It would appear therefore, that although the present study was conducted in South Africa, the relevance of the findings would be valid in relation to other studies conducted in various parts of the world amongst different population groups.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter is a review of literature relating to the parent's experience when caring for a child with ADHD. Issues discussed in the previous chapter will be expanded upon. In reviewing the literature surrounding this topic, it emerged that stress is a predominant feature when parenting under these circumstances. Levels of stress, coping with and adapting to these circumstances are reportedly mediated by factors such as the determining aspects of the child's disorder, parental characteristics and situational factors (Maes, Broekman, Dosen & Nauts, 2003). The concepts of stress, coping and adaptation will be elaborated on in chapter three, where there is an in depth presentation of the chosen theoretical framework.

2.2 Determinants of Parent Stress in General

According to Abidin (1992), stress is a significant concept affecting parental experiences. Lazarus and Folkman (1984) claim that stress is not experienced uniformly by individuals- even when individuals are confronted with the same situation. As will be discussed further in the following chapter, these variations in stress reactions may be from the manner in which the individuals appraise the situation, the efficacy of their chosen coping strategies and the personal and environmental resources available to them. In light of the focus of the present study, attention has been briefly directed towards determining which factors may influence variations of *parent* stress levels in general. In a review of study findings, factors most commonly touched on were parent characteristics and child characteristics (Abidin, 1992; Abidin & Wilfong, 1989; Webster-Stratton, 1990). Parent characteristics were described as parent physical health, psychopathology and parent belief systems. Child characteristics were described as the child's temperament, mood, adaptability and physical and psychological health. Other factors included in study findings were environmental factors such as employment problems, financial difficulties, marital discord

and daily hassles (Abidin, 1992; Webster-Stratton, 1990). The influence these factors appear to have on the parental experience, as related to levels of stress, is also determined by the coping resources available to the parent. Such resources include, material resources, social support and the parent's personal skills and competencies (Abidin, 1992). The severity of parent stress appears to influence parent functioning and the manner in which the parent interacts with the child. Abidin (1992) asserts that the higher the level of stress experienced by a parent, the more dysfunctional the parent's behaviours will be. Consequently, the parental experience may be more negative.

2.3 Parent Response to a Child with a Disability

The role of parents and the act of parenting are areas of interest that are under constant research. As discussed above, there are several factors that can mediate levels of parent stress in general. More specifically, and in relation to the present study, a factor that will be elaborated on is the child health characteristic. Caring for children is a complex task, but when a child has a disability, this adds to the complexity of parenting and is almost always challenging (McDonald et al., 1992).

In a review of disability literature relating to parents, the concept of *disability* is frequently interchanged with terms such as impairment, physically or mentally challenged, handicapped or developmentally delayed. Jones and Passey (2003) point out that disability is also viewed differently by different cultural and societal groups. The most commonly studied disabilities, in relation to their effect on parents, are Autism, Down's Syndrome, learning and behavioural disorders, and physical disabilities (Jones & Passey, 2003). Studies have shown that parents who are caring for a child with a disability tend to experience higher levels of stress and higher financial and emotional demands, compared with parents of children without a disability (Benzies, Harrison, & Magill-Evans, 2004; DeMarle et al., 2003; Hastings, 2002; Maes et al., 2003; Maniadaki, Sonuga-Barke, Kakouros & Karaba, 2005; McKee et al., 2004; Podolski & Nigg, 2001; Sanders, Mazzucchelli & Studman, 2004; Scharer, 2002; Trollvik & Severinsson, 2004). In studies exploring parent-child interactions, the most commonly reported pattern of interaction causing stress was from child to parent (Fischer, 1990). This could indicate that the more severe the child's disability, the more stressed the parent becomes.

According to Ong-Dean (2005) and Thompson (cited in Pritzlaff, 2001), when parents first receive a diagnosis of a disability affecting their child, they can initially experience feelings of shock, denial, guilt, self-blame, fear and anger. Ong-Dean (2005) describes parent self-blame as a common occurrence.

Parents have expressed feeling like a failure for having a “damaged” child and they express feeling guilty that their inherent faults have been passed on to their child. A sense of disappointment and sadness is reported by these parents, in knowing that their child is not “normal” and may never experience a “normal” childhood (Ong-Dean, 2005). A child’s disability diagnosis is often unexpected. This creates a crisis event where parents report feeling uncertain about what to do next (Ong-Dean, 2005). In addition, following such a diagnosis, parents are faced with making immediate decisions about treatment for which they are often unprepared. Parents have reported feeling out of their depth when they are expected to understand unfamiliar medical terms and concepts (Abidin & Wilfong, 1989; Ong-Dean, 2005; Scharer, 2002). They may not have prior knowledge of their child’s disability and proposed treatment, which can result in them experiencing difficulty in voicing their concerns effectively and asking the appropriate questions of the mental health professional. This can hinder the parent’s ability to obtain accurate and relevant information, which can increase parental stress (Scharer, 2002; Walker, 2000).

The permanent nature of a disability frequently leaves parents feeling overwhelmed by the prospect of the long-term task of parenting a child with special needs (Jones & Passey, 2003). Following diagnosis, a new level of family organization and balance is sometimes required. Caring for a child with a disability often results in the need for additional equipment, or home modifications, as well as the need for more time and patience from the parent. Parents are confronted with the task of having to change daily routines, having to change their role as a parent and change their expectations of the child with special needs (Jones & Passey, 2003).

2.3.1 Parent Adaptation and Coping

Parents differ in their coping response. How parents appraise the situation, and the meaning they give to their child’s disability, can result in the use of either maladaptive or adaptive coping strategies (Jones & Passey, 2003). Scharer (2002) and Trollvik and Severinsson (2004) posit that increased levels of parent stress could hinder the parent’s judgement of the child’s disability. When a parent’s stress reaction persists, the parent’s sense of helplessness and anxiety is exacerbated and subsequently the child’s situation might be perceived as being more serious than it really is. This perception may impair the parent’s ability to manage the stressor in a constructive manner. Maladaptive coping efforts can be characterised by focusing on the problems and the child’s limitations, viewing the need for the use of social support as a personal weakness and blaming others for the child’s disability. However, Jones and Passey (2003) assert that despite increased levels of stress, parents can cope well and adapt effectively to

such situations. Studies have shown that the use of mediating factors like seeking social support such as family support, and developing an alliance with health professionals, schools and other parents in similar situations, has assisted in reducing stress for these parents (Kerr & McIntosh, 2000; Pritzlaff, 2001). Other examples of the mediating factors in the reduction of parent stress when caring for a child with a disability are aspects such as parent self-belief, especially in the control they may have over the situation. A sense of competence in their parenting role, their control over the treatment decision-making process, seeking their own information about their child's disability, and their locus of control, have also been shown to mediate parent levels of stress (Jones & Passey, 2003; Pritzlaff, 2001).

2.4 Parental Experience Specifically Related to a Child with ADHD

Gupta (2007) conducted a study examining how different child disabilities affected levels of parent stress. Interestingly, the findings revealed that in a study of children with ADHD, asthma, HIV/AIDS and developmental disabilities, the parents of children with ADHD reported higher total levels of stress than the parents of children with chronic medical disorders. The parents who were caring for the children with ADHD expressed that because of their child's problematic behaviours, the parents felt more depressed, more socially isolated and more restricted in their parenting roles than the other parents participating in the study. Also, the parents of the children with ADHD expressed feeling less competent in dealing with their children. These difficulties experienced by parents in such a situation, will be elaborated on in the following sections of this chapter. As previously mentioned, a parent's experience when caring for a child with ADHD is shaped by several factors, which can mediate the parent's level of stress and coping efforts.

2.4.1 The Parent Experience and Child Behaviours associated with ADHD

ADHD can be a markedly impairing disorder affecting the child's academic, familial and social adjustment. Disrupted spousal, parent-child and sibling relationships are common in families of children with ADHD. These can persist as a chronic strain on the family environment, increase parent stress and negatively affect the parents' quality of life (Lange, Sheerin, Carr, Dooley, Barton, Marshall, Mulligan, Lawlor, Belton & Doyle, 2005; Webster-Stratton, 1990). There can be considerable variability in how parents appraise and respond to their child's disability, thus not all parents will respond to their child's ADHD behaviours in the same manner (Baker, Blacher & Olsson, 2005; Kashdan, Jacob, Pelham, Lang, Hoza, Blumenthal & Gnagy, 2004). Further, it should be mentioned here that parental responsibilities continue to be gendered in nature with most studies reporting that the

traditional role of mothers as the primary caregivers is still common (Kashdan, Pelham, Lang, Hoza, Jacob, Jennings, Blumenthal & Gnagy, 2002; Malacrida, 2001; Mash & Johnston, 1990; Rashley, 2005; Walker, 2000). Johnston (1996) claims that many studies show that mothers experience higher parenting stress than fathers, which may be indicative of fathers being less involved with childrearing than mothers. Mothers also tend to be more reactive to their child's problematic behaviours than fathers, possibly because of these higher stress levels (Johnston, 1996; Webster-Stratton, 1990).

Children with ADHD tend to exhibit problematic behaviours that may often appear to be willful. Distractibility, a low frustration tolerance, temper outbursts, bossiness and stubbornness, as well as being argumentative, less compliant, overly active and forgetful are characteristic of ADHD (APA, 2000; McCluskey & Blahy, 2004). Amongst others, such difficult behaviours frequently provoke family discord and negative parent-child interactions. Parents express feeling overwhelmed and frustrated by these problematic behaviours and have described their parent-child relationships as conflictual and regularly fuelled with resentment and antagonism (McCluskey & Blahy, 2004). A parent's sense of competence in handling the child's difficult behaviours is decreased as the child frequently does not comply with parent demands (Johnson & Reader, 2002; McLaughlin & Harrison, 2006). Consequently, parents report feeling less confident in their role as a parent, which contributes to their feelings of distress.

Non-compliance is common amongst children diagnosed with ADHD, usually because the child is unable to attend to directives issued by the parent or because the child has difficulty calming down. In a study conducted by Johnson and Reader (2002), parents report that normal daily routines become daily hassles, which are significantly more annoying and frustrating than is usual. Trying to get their inattentive and hyperactive child to comply with commands and perform regular tasks such as sitting down to finish meals, taking a bath, initiate and follow through on school homework, and get ready for bed, frequently results in conflicts that can last for several hours (Johnson & Reader, 2002). According to Montgomery (2005), these stressful altercations between parent and child often result in the other family members disengaging from the conflict, leaving one parent to discipline the child alone. This tends to leave the parent feeling unsupported by the rest of the family and can increase levels of stress in the parent, whilst simultaneously provoking a more negative parental affect towards the child.

Montgomery (2005) discussed another factor that could influence the family dynamics and increase parental stress. Studies proving ADHD to be a heritable disorder indicate that there is a likelihood that a child with ADHD may also have a sibling or a parent with ADHD. Parents with ADHD may struggle to implement and maintain structure and organization, which can contribute to a chaotic family environment.

i) Discipline

McKee et al. (2004) posit that when parents are experiencing increased levels of stress, they are more likely to exhibit negative parent behaviours such as overly permissive or conversely, authoritarian disciplining methods. Studies conducted by Johnston and Ohan (2005) and McKee et al. (2004) revealed that parents in such a situation tend to utilize more directives, demands and physical punishment than parents of children without ADHD. In addition, these parents were found to display more disapproval of the child, withhold attention and exhibit a decrease in parental warmth and positive involvement with the child. Such parenting behaviours are referred to as maladaptive forms of coping and will be elaborated on further when discussing the coping methods employed by parents in section 2.4.5. Hastings (2002) and Johnson and Reader (2002) hypothesize a coercive cycle whereby the child's difficult behaviours result in increased parental stress, which leads to negative parental behaviour. Negative parental behaviours tend to result in dysfunctional parent-child interactions, which appear to exacerbate the child's problem behaviours, which subsequently intensify the parent's existing level of stress. It was noted that the majority of the studies on parenting stress and ADHD focused primarily on children with symptoms of hyperactivity and impulsivity. However there are some studies that have shown that children with symptoms of inattention have also been linked with increased levels of stress in parents (Bondy & Mash, 1999; Johnston, 1996). Studies conducted by Benzies et al. (2004), Chronis, Chacko, Fabiano, Wymbs and Pelham (2004) and Hastings (2002), revealed findings that disagreements over the most appropriate child-rearing practices commonly occur between parents faced with disciplining a child with ADHD. Amongst other factors such as financial concerns, family support, and making treatment decisions, child-rearing disagreements regularly provoked marital discord. Webster-Stratton (1990) found that disagreements over child-rearing practices did not always stop with the child with ADHD, but also involved the child's siblings. Parents reported increased distress when sibling rivalry occurred in their families, because they expressed feeling concerned about whether they were treating and disciplining all their children fairly. Parents worried that they might be

making excuses for their child's ADHD behaviours, thus appearing to be taking sides (Webster-Stratton, 1990).

ii) Socialisation and Isolation

As a result of a child's unruly behaviours, parents report that including their child in certain activities outside the home is sometimes difficult (McCluskey & Blahy, 2004; Webster-Stratton, 1990). For example, repeatedly trying to discipline their child to remain seated while travelling or while watching a movie, and not to wonder off alone in shopping centers or pull products off the shop shelves, can be challenging and frustrating. Some parents express feeling humiliated in public places when their child's hyperactive and impulsive behaviours are obviously boisterous, disruptive and noticeably different from other children. Parents report concern that their child's problematic behaviours irritate and annoy others, which results in the parents feeling self-conscious about their inability to control the child's behaviours (McCluskey & Blahy, 2004).

McCluskey and Blahy (2004) further report that child problematic behaviours frequently result in children with ADHD and their parents being alienated from their social circles. According to these researchers, a child with ADHD struggles to study, maintain peer relationships and connect to "normal" childhood experiences. Their ADHD-related behaviours tend to put strain on their interactions during classroom hours; the initiation and maintenance of their friendships and their relationships with their friends' parents. Sometimes other parents, who may not understand ADHD, choose not to have the child with ADHD associating with their children or attending their children's social functions. Consequently, the parents of the child with ADHD are also left out of these social occasions, putting strain on their own adult friendships (McCluskey & Blahy, 2004). Lacking social support from friends generates feelings of isolation and insecurity in the parent, and is claimed to be a factor that can negatively affect parents' quality of life, decrease their self-confidence and increase their level of stress (Scharer, 2005). In addition, parents report increased distress at seeing their child's rejection by others and the fact that their child is missing out on "normal" childhood experiences with other children (Fischer, 1990).

iii) The Working Parent

Rosenzweig, Brennan and Ogilvie (2002), bring to our attention the effect of caring for a child with ADHD on a working parent. It is estimated that up to 15% of employed parents care for children with a disability. According to Rosenzweig et al. (2002), studies have revealed that the ease of fit between a

parent's work and home has an effect on personal relationships and marital and parental role quality. Without a flexible, work-family fit, many parents have reported having to work in lower-level forms of employment, with less work hours and less income, so that they can care for their child (Brennan, Rosenzweig, Ogilvie, Wuest & Shindo, 2007; Rosenzweig et al., 2002). Finding appropriate child care support for a child with behavioural problems can be difficult as childcare workers may be reluctant to care for a child with a disability. Working parents in such a situation report higher levels of work stress, diminished concentration at work and increased work interruptions from home and school calls to deal with problems involving their child (Brennan et al., 2007; Rosenzweig et al., 2002). Taking into account the above, balancing work responsibilities, financial implications and care-giving can become overwhelming and stressful for the parent.

2.4.2 Factors Affecting the Help-seeking Process

Maniadaki, Sonuga-Barke, Kakouros and Karaba (2006) propose that a parent's individual belief system and characteristics need to be considered in order to understand the parent experiences associated with seeking help for their child. The process of help-seeking appears to depend on the child's behaviour being appraised as problematic and stressful by the parent. According to Bussing, Gary, Mills and Garvan (2003), each parent's personal "threshold" for tolerating difficult behaviour will determine whether a child's behaviour is found to be problematic. Bussing et al. (2003) assert that parental "thresholds" for tolerating child problem behaviours can vary from individual to individual and across cultural and ethnic groups. These authors state that "thresholds" are determined by each parent's belief system. Belief systems form the basis for each parent's explanatory model, which can govern their subjective understandings of mental illness. According to Kleinman (1978), an individual's explanatory model is socially and culturally constructed from previously acquired knowledge and experience, and it is used to subjectively interpret situations.

Ethnic studies performed by Bussing et al., (2003) revealed that Caucasians were more likely to seek help for their child's problematic behaviours than other ethnic groups. In terms of ADHD, Caucasians exhibited more concern for their child's behaviours as being a possible disability, rather than a variation of "normal" child behaviours. Caucasian parents were thus, more likely to seek professional help for their child than other ethnic groups. These parent reactions to child problematic behaviours may have been related to varying antecedent factors such as the previously acquired knowledge of ADHD and beliefs

surrounding the cause of ADHD behaviours. It was noted in the review of literature, that the parent's explanatory models frequently played an important role in their thoughts and decision-making regarding their child's problem behaviours. The influence of the parents' explanatory models seems to be a factor throughout the respective literature review. With regards to a South African context, Meyer, Eilertsen, Sundet, Tshifularo and Sagvolden (2004) assert that the differences between ethnic groups' understandings of ADHD may be as a result of lack of access to knowledge and resources and the fact that most of the research that is conducted is not performed in the sample population's own language.

It should also be mentioned, that the age of the child displaying difficult behaviours may initiate different help-seeking reactions in parents. Studies performed on younger, pre-school-age children with ADHD revealed that parents suspended their child's referral to a doctor, because they did not perceive their child's behaviour as problematic (Baker et al., 2005; Maniadaki et al., 2006). The parents felt they were would either get used to the behaviour or they could handle the behaviour competently.

According to Fischer (1990), parental help-seeking behaviours appear to occur more frequently when the child is older and beginning formal schooling. Generally speaking, more children with symptoms of ADHD are first identified in their early schooling years when there is the opportunity to compare their behaviour and performance with that of their classmates (Hansell & Damour, 2005). Teachers are thus beginning to play a significant role in identifying problematic behaviours and developmental delays in the child, which could be the beginning of the assessment process for the child. Interestingly, however, Montgomery (2005) asserts that some parents tend to become defensive as they may not understand the teacher's comments about their child. Such misunderstandings could create a communication breakdown between the child's parents and the child's teachers. This reaction by parents could be out of a fear of being labeled as "bad" parents. Similarly, in a study performed by Malacrida (2001), it was found that because of this fear, there is evidence that many parents, especially mothers, feel that their parenting came under negative scrutiny by teachers. Malacrida (2001) revealed that when a child was displaying problematic behaviours in the classroom, or other public places, the mothers heard, both directly and indirectly, that their mothering was questionable and the child's home life was believed to be problematic. Mothers then tended to exhibit a resistance towards the teachers after being told by teachers that their child may have a disability. Some women tended to become aggressive and rude towards their child's teachers and there appeared to be an effort to restate the truth, as if the mothers were feeling like they were being judged inappropriately by the teachers. According to most of the

mothers, they felt that they were being examined and judged in the public and professional eye, because their children did not behave “normally”.

i) Parental Ambivalence and Health Professional Opinions

Parents have frequently expressed feeling overwhelmed, anxious and uncertain when facing the prospect of their child being diagnosed with ADHD (McCluskey & Blahy, 2004). During the help-seeking process, parents may experience a sense of ambivalence as they vacillate between denying and admitting that their child may have this disorder. Parental ambivalence in such a situation may stem from the lack of confirmed evidence standardising the nature of ADHD, its aetiology and treatment, which affects parents’ beliefs about ADHD. Mental health authorities have voiced varying and diverse theoretical opinions about ADHD in particular, which tends to promote parental uncertainties and anxiety regarding seeking help for their child’s behavioural problems.

For example, both neurobiological and psychodynamic perspectives have been applied in an attempt to understand the features of ADHD (Faraone, 2005; Rafalovich, 2001). The neurobiological perspective, associates ADHD with an organic, biological aetiology, which has been given considerable legitimacy over time. In contrast, the psychodynamic perspective hypothesises ADHD aetiology as being a child’s behavioural reaction to difficulties encountered with the parents, school or community (Rafalovich, 2001). Armstrong (1997) and Breeding and Baughman (2001) take the psychodynamic perspective further by claiming that ADHD is simply a manner of labelling inappropriate child behaviours that are a child’s reaction to poor parenting methods, an overall lack of motivation and laziness and, schooling systems that are boring and ill-equipped to handle their pupils. Breeding and Baughman (2001) make the claim that ADHD is not a valid mental disorder and parents should be resistant to their child being labelled in this way. According to Faraone (2005), psychodynamic theories should not be dismissed, but too much emphasis placed on environment-based perspectives can result in parent misconceptions and increased occurrences of parents being defensive and also blaming themselves for their child’s problems. As seen above, such diverse standpoints on the part of the health professionals can undermine parents’ trust of health professionals, further intensifying their confusion and impeding their help-seeking efforts for their child.

ii) Media Influence and Parent Misconceptions surrounding ADHD

As discussed earlier, parent belief systems are an aspect that affects help-seeking behaviours (Maniadaki et al., 2006). Beliefs held by parents about ADHD can be influenced by previous exposure to information about ADHD from sources such as the health professionals mentioned above, and information from the internet and the media. The media can influence the public's attitudes and perceptions about a topic because it functions as the mediator communicating scientific and academic thought to the public (Guttman & Salmon, 2004; Hinshaw, 2005). Link and Phelan (2006) and Scharer (2002) state that through the media, mental disorders continue to be frequently misperceived as negative and abnormal, thus stigmatising those who are diagnosed. Being diagnosed with a mental disorder can generate insecurity, shame and self-blame amongst those affected. More specifically, Barzman et al. (2004) posit that the media often misrepresent facts about ADHD, which results in misconceptions surrounding the disorder. The authors identified such misconceptions as: ADHD does not exist; ADHD disappears by adulthood so it is just a case of dealing with the problem behaviours until the child grows up; ADHD can be prevented by various social remedies; ADHD can be prevented by better schools; ADHD is caused by "faulty" parenting and; ADHD can be prevented and/or "cured" by better and stricter parenting. Holding such flawed and negative beliefs about the aetiology, treatment and characteristics of ADHD, can hinder parents in seeking help for their child. Further, these misconceptions may also inhibit parents from disclosing their child's behavioural disturbances to others, for fear of being blamed for causing their child's mental disorder (Barzman et al., 2004; Hinshaw, 2005; Rafalovich, 2001). This barrier could restrict positive development and cohesiveness of the family unit, whilst simultaneously exacerbating a chaotic family environment and increasing levels of parent stress (Barzman et al., 2004; Faraone, 2005; Guttman & Salmon, 2004; Hinshaw, 2005).

2.4.3 Parents' Experiences Relating to their Child's ADHD Diagnosis

Arriving at a diagnosis of ADHD may be a long and drawn out process for many parents. On one hand parents may be anxious to find out what is troubling their child, whilst on the other hand, the parents may be just as anxious not to have to deal with a definitive diagnosis (McCluskey & Blahy, 2004). A thorough assessment process prior to diagnosis is vital as many children may present with symptoms of ADHD, but they may not have the disorder (Concannon & Yang, 2005; Magyary & Brandt, 2002; Sadock & Sadock, 2003; Venter, 2006). Venter (2006) asserts that up to 50% of children diagnosed with ADHD exhibit symptoms of other childhood disorders such as Disruptive Behaviour Disorders and Learning Disorders. The co-occurrence of secondary anxiety and/or depression is also common and may be a reaction to difficulties the child experiences in social and academic settings. Consequently, parents

may find themselves being referred to more than one health professional such as child psychologists, occupational therapists and general practitioners in an attempt to establish the reasons for their child's behavioural disturbances. This extensive process may contribute to parents experiencing confusion, a sense of uncertainty, fear and frustration, and an increase in their levels of stress and anxiety.

Diagnosing a child with ADHD may come as a shock to the child's parents, especially if the child's behaviour has not been willingly recognised by the parents as problematic. Taylor, O'Donoghue and Houghton (2006) state that prior to diagnosis, many parents hold a media-generated, stereotyped image of a child with ADHD "bouncing off walls" and being out of control, which may not correspond with their own child's behaviours. An ADHD diagnosis could be appraised as a time of crisis for the child's parents and family (DeMarle et al., 2003; Scharer, 2002). The parents' realisation that their child has a mental disorder may generate anxiety, fear and increased levels of stress (Scharer, 2002). According to DeMarle et al. (2003) and Taylor et al. (2006), parents may initially respond to the diagnosis by denying the child's disability. Taylor et al. (2006) report that when parents are in denial, they often turn to "doctor shopping", because they do not have confidence in the initial ADHD diagnosis and feel other professional opinions are necessary. Parents may also experience feelings of grief, anger and disappointment. Taylor et al. (2006), further state that parents often grieve over the loss of their child's "normal" status, whilst simultaneously becoming angry with the doctor for diagnosing their child with a disorder. A child's ADHD diagnosis could be frightening for parents, as this could be seen as a manner of "labelling" the child as "abnormal" and therefore, making the child more vulnerable in social settings (Hinshaw, 2005; Link & Phelan, 2006; Malacrida, 2001). The stigma surrounding mental disorders can generate concern for parents when confronted with their child's diagnosis (Hinshaw, 2005). According to Scharer (2002), some parents are concerned that they may be labelled by others as "bad" parents with "poor" parenting skills, when their child is diagnosed with a behavioural disorder. Also Taylor et al. (2006) report on findings where following a diagnosis, one parent may accept the diagnosis, but the spouse may not. Such a situation can generate conflict between the parents of the child, resulting in heightened anxiety and increased parent stress.

Alternatively, many parents express remorse at not having acted sooner in their help-seeking efforts (Taylor et al., 2006). An ADHD diagnosis may be viewed as a relief for some parents who recognise that their child is experiencing difficulties (Angermeyer & Matschinger, 2003; Ong-Dean, 2005). Ong-Dean (2005) asserts that diagnosing a child with mental disorder such as ADHD, could be a manner of

clarifying that the child is not “lazy” or “naughty”, thus reassuring the parents that they are not parents with dysfunctional disciplining skills. According to Angermeyer and Matschinger (2003) diagnosing a child from a clinical point of view provides a point of reference for the health professional, the child and the child’s parents. As a result, uncertainty can be replaced with understanding and relief. Upon diagnosis some parents have reported a sense of being able to move forward with the help of treatment and professional advice and support (Scharer, 2002).

On a different note, Venter (2006) maintains that if parents do not feel fully involved in the diagnostic process and they feel the process has not been thorough enough, the parents may feel dissatisfied with and distrustful of the diagnosis outcome. In several studies, parents have reported that they have either not had prior knowledge, or been given enough knowledge, to ask appropriate questions regarding ADHD (Anastopoulos, Guevremont, Shelton & DuPaul, 1992; DeMarle et al., 2003; Malacrida, 2001; McCluskey & Blahy, 2004; Ong-Dean, 2005; Popper, 2002). Scharer (2002) and DeMarle et al. (2003) assert that a vast number of parents whose children are being treated for a mental disorder, express feeling alienated from the mental health fraternity because of a lack of emotional and informational support from the health professionals. It follows then that this could result in health professionals failing to address the parents’ anxieties, concerns and misconceptions about their child’s ADHD. Venter (2006) recommends that parents are fully involved in the diagnostic process, as they could use this time to gain informational support from the health professional, which could help to allay some of the parents’ fears and anxieties associated with handling their child’s ADHD diagnosis and making informed treatment decisions thereafter.

i) Parents Questioning the Reasons for their Child’s ADHD

In an attempt to understand the reason for their child’s ADHD, parents may well question the aetiology of the disorder. In this situation, parents will again turn to their own explanatory model in order to make sense of the cause of their child’s disorder. As mentioned previously, parents are confronted with varying perspectives on the cause of ADHD, which can leave parents feeling perplexed and experiencing difficulty in understanding and accepting their child’s diagnosis (DeMarle et al., 2003). According to these researchers, parents have frequently expressed feeling guilty about their child’s problems and tend to blame themselves for their child’s disorder. As previously mentioned, both biological and environmental factors have been attributed to the cause of ADHD. According to Faraone and Doyle (2001), there is a sufficient amount of evidence supporting the speculation that ADHD is a multifactorial

disorder caused by an interaction between genes and environmental factors. Nevertheless, a limited understanding of these factors can influence how parents interpret their situation, as well as how they react towards their child with ADHD (Barzman et al., 2004).

Numerous studies have revealed that environmental and genetic factors influence the development of ADHD, but genetic factors have been established as having a greater proportion of influence in the cause of ADHD (Hansell & Damour, 2005; Yeh, Morley & Hall, 2004). Recent molecular genetic studies support the involvement of particular genes in ADHD, indicating that heredity factors may play a key role in the development of this disorder (Faraone, 2005). Yeh et al. (2004) suggest that upon understanding that the child's ADHD is based on genetic factors, parents may experience relief that their child's problem behaviours are not as a result of bad parenting. On the other hand, Ong-Dean (2005) noted that some parents hope that the disorder is a consequence of bad parenting, because parenting methods can be "changed" and then the child can be "fixed". Both Ong-Dean (2005) and Yeh et al. (2004) also point out that parents may be tempted to overindulge the child out of guilt for passing on their undesirable genetic traits, or conversely, treat the child as a scapegoat associated with their feelings of guilt. Furthermore, parents may also lower their expectations of their child's educational achievements and social relationships.

Also, prenatal exposure to infections, trauma and inflammation, may cause subtle damage to the foetal brain and the central nervous system, thus possibly increasing the risk of ADHD (Cnattingius, 2004; Sadock & Sadock, 2003; Venter, 2006). Mothers can at times exhibit feelings of remorse and self-blame, where they feel that they may have had some responsibility for their child's impairment prior to birth (Hansell & Damour, 2005).

When discussing environmental factors as the possible cause of ADHD, Hansell and Damour (2005) assert that issues such as disruption of family equilibrium, stressful psychological events and other anxiety-inducing factors could contribute to the emergence of ADHD. For example, children experiencing emotional distress or prolonged emotional deprivation, tend to display symptoms of inattention and hyperactivity. Sadock and Sadock (2003) and Segal (2001) reflect on related studies which show that ADHD symptoms may emerge when parents regularly overwhelm a child or are unable to help a child develop skills for emotional and behavioural self-regulation. Findings such as these have

frequently resulted in parents blaming themselves for their child's behavioural problems (Austin et al., 2007; Segal, 2001).

2.4.4 Factors Affecting Parents' Decisions Regarding Treatment

A review of literature indicates that varying opinions about ADHD have resulted in there being the development of an array of intervention strategies aimed at treating ADHD (Dopfner, Rothenberger & Sonuga-Barke, 2004). According to Venter (2006), parents of children with ADHD, commonly feel overwhelmed and confused by the diverse treatment options offered for their child. To briefly elaborate, ADHD requires a multimodal treatment approach, which generally entails a combination of modalities such as education about the disorder, medication and psychosocial management.

Currently, pharmacological intervention has proven to be effective and safe in the management of ADHD (Popper, 2002; Sadock & Sadock, 2003; White & Rouge, 2002). The most frequently prescribed medication for ADHD is methylphenidate (Ritalin, Ritalin-SR, Concerta and Metadate). Studies have shown that approximately 75% of children treated with methylphenidate have displayed significant improvement in their school-based productivity (Popper, 2002; Venter, 2006). However, adverse side-effects such as insomnia, headache, dysphoria, mild cardiac palpitations and decreased appetite are known to exist. Methylphenidate is also reported to exacerbate symptoms of Tourette's syndrome, epilepsy and anxiety and it may cause stunting of growth (Venter, 2006).

Psychosocial interventions for treating ADHD include, psychotherapeutic training for parents of children with ADHD; the implementation of behavioural interventions at home and at school and; child social skills training (Venter, 2006).

By implementing a multimodal treatment regime, the child's learning becomes more effective and the child's ability to relate socially to others improves. These improvements appear to not only elevate the child's self-esteem and confidence, but that of the parent's as well. As a result, parent stress is also reduced (Barzman et al., 2004; Chronis et al., 2004). Parent training programs have shown to improve parent outcomes by assisting in alleviating parent stress, improving parent-child interactions and decreasing family dysfunction (Anastopoulos, Shelton, DuPaul & Guevremont, 2004; Chronis et al., 2004). Findings from a study conducted by McKee et al. (2004) reveal that parent training programs

can reduce negative parenting methods, but not all parents experience the same outcomes from parent training programs. This may be due to other factors not related to their child.

According to Bussing et al. (2005), parent explanatory models also extend to their beliefs about the efficacy of the different interventions available to treat ADHD. Jackson, Cheater and Reid (2008) posit that the parent's treatment decisions are based on relevant information and the parent's personal values and beliefs. These authors state that receiving professional support in order to make informed decisions is key to successful intervention programs. This is achieved by supporting parents in helping them to gain the relevant information and assisting them in clarifying their beliefs underlying the treatment decisions they are intending to make. Further, Kerr and McIntosh (2000) recognize that receiving support from friends and more specifically, family when making decisions about treatment has been found to increase parents' confidence in their decision-making efforts, by validating their choices and reducing their anxiety.

Jackson and Peters (2008) claim that some parents continue to feel uncertain about the validity of their child's ADHD diagnosis, which results in them displaying resistance to making decisions about the treatment options offered for their child. Also, the existence of divergent opinions on treatments for ADHD can affect parents' decisions. A study conducted by Venter, Van der Linde and Joubert (2004) revealed that 45% of 489 psychiatrists and paediatricians found parents of children with ADHD to be difficult in consultations and resistant to treatment options. Parents tended to feel that they had no control in such a situation as they were pushed into making decisions about treatment options that they were uncertain about. In Malacrida's (2001) study, mothers who were resistant to treatment options, such as refusing to medicate their child, claimed that they were accused of being negligent and in denial of their child's disability. Jackson and Peters (2008) claim that parents can be subject to criticism whether they choose to medicate their child or not. There is a degree of stigma associated with treating children with "drugs". Parents are sometimes criticized for medicating their child to "benefit the carer rather than the child", whilst on the other hand, when parents choose not to medicate, they are accused of being in denial.

With regards to medication, parents can have highly ambivalent attitudes towards this treatment option. Such ambivalence stems from parent concerns about the adverse side-effects of medication, as discussed above, and frequently generates parent anxiety and resistance to this method of intervention

(Popper, 2002; Venter, 2006; White & Rouge, 2002). According to McNeal, Roberts and Barone (2000), medication side-effects can increase barriers to parents adhering to treatment programs. Similarly, McKee et al. (2004), confirm that many parents prefer to implement behaviour programs rather than utilize medication because of a concern about the long-term side-effects of the medications available. In addition, financial demands associated with medicating children for ADHD can generate increased stress for the parents. Kazdin and Whitley (2003) found that when parents perceive barriers to conventional treatment, they are more likely to turn to alternate forms of treatment for their child's disorder. In a study conducted by Johnston, Seipp, Hommersen, Hoza and Fine (2005), over half of the 73 parents participating in the study used alternative treatment for their child. The parents claimed they preferred the "naturalness" of the treatment and they all felt that their sense of control over their child's treatment process was enhanced.

Stimulant medication is however, used by many parents with positive results. Studies have revealed that stimulant medication treatment can have a positive effect on the child, and consequently, on the parent-child relationship (Chronis, Pelham, Gnagy, Roberts, & Aronoff, 2003; Kazdin & Whitley, 2003; Popper, 2002; Venter, 2006). Frequently, child compliance improves with the use of medication. This tends to bring about a reduction in parent stress and a stronger sense of control in parents over their child's problem behaviours, allowing parents to view the situation in a more positive light, with potential for personal growth (Kazdin & Whitley, 2003). As a consequence, the parents may be more committed to being involved in, and maintaining their child's treatment intervention.

2.4.5 Strategies for Coping with a Child's ADHD

Having a child with ADHD creates a crisis situation for which parents often feel unprepared. A diagnosis such as this may disrupt the family system and leave parents feeling as if they have little control over their family lives (Pritzlaff, 2001). Parents are forced to adjust to the situation by utilising cognitive and behavioural efforts to cope with the demands they may be experiencing. Such efforts depend on factors such as the parent's belief system, their interpretation of the crisis event, their sources of support, available resources and family structure.

According to Johnston and Ohan (2005), the interpretative meaning a parent attributes to their child's ADHD diagnosis can guide the parent's emotional and behavioural efforts to cope with the child. Not all forms of coping are effective, and the coping strategies employed by parents can vary from parent to parent. In a review of literature detailing the capacity to parent a child diagnosed with ADHD, both maladaptive and adaptive forms of parent coping were identified.

Optimism and pessimism are two of several parent characteristics shown to mediate parent stress levels. A parent's level of optimism or pessimism has been shown to influence how a parent appraises an event. A parent's positive or negative expectation of an outcome will affect the coping strategies employed by the parent to manage the situation (Baker et al., 2005). Optimists tend to have a favourable outlook on life and believe in good outcomes. Conversely pessimists have a negative outlook on life, which has been shown to increase their psychological vulnerability to higher levels of stress. Baker et al. (2005) posit that if an event is initially deemed a crisis, which is generally negative in nature, optimistic parents are more likely to reappraise the event in a positive manner and find meaning and growth in the stressful experience. Parents with high levels of pessimism generally find difficulty in adapting to stressful events and tend to display more negative emotions and behaviours in reaction to these events.

i) Maladaptive Parent Coping Efforts

In reviewing literature pertaining to how parents cope with caring for a child diagnosed with ADHD, many parents did display more negative emotional reactions to their situation. In addition some of these parents exhibited a greater use of dysfunctional parenting methods (Jones & Passey, 2003; McKee et al., 2004; Podolski & Nigg, 2001). These parents tended to view themselves as victims. They felt the world was unfair and blamed others for their situation. The parents focused predominantly on their own limitations and expressed that they felt like "failures", claiming that there was nothing they could do about the situation (Jones & Passey, 2003; Mash & Johnston, 1990). The parents presented negative attributes to the child's problem behaviours, claiming that the difficult behaviours were intentional and uncontrollable (Mash & Johnston, 1990). The child's weaknesses were also focused on instead of the child's strengths. Parents reported lowered expectations of their child's ability to achieve in life and tended to interpret any achievements reached by the child as luck. Because some parents removed themselves from public situations as a result of feeling embarrassed about their child's behaviours, parents were left feeling socially isolated and depressed (McLaughlin & Harrison, 2006). Other parents distanced themselves from their child in an attempt to avoid dealing with the difficulties associated with

caring for a child with ADHD (Jones & Passey, 2003). Instead of diminishing the parent's stress however, these efforts to cope were maladaptive and usually resulted in even more stress (Jones & Passey, 2003; McKee et al., 2004; Podolski & Nigg, 2001).

Permissive and authoritarian parenting methods were mentioned earlier in this chapter. Parents attempting to manage children with difficult ADHD behaviours and reduce their own levels of stress, have frequently been shown to utilise these parenting methods (Jones & Passey, 2003). According to McKee et al. (2004), both these forms of parenting are dysfunctional and maladaptive forms of coping. Permissive parenting refers to parental tendencies to make few demands of their child, to not enforce rules, to be inconsistent in their disciplining and to give in to the child's difficult or coercive behaviours. Authoritarian parenting, on the other hand, refers to punitive, overly harsh and hostile forms of disciplining (McKee et al., 2004). When parent coping is maladaptive, the parent-child relationship can become aggravated and strained. Kazdin and Whitley (2003) claim that when a parent is in such an intense and critical situation, the parent may feel threatened by the worsening situation and experience a poor sense of competence in their parenting role. This decreases the likelihood of the parent implementing or complying with required treatment programs that could potentially assist with reducing stress in both the child and the parents.

ii) Adaptive Parent Coping Efforts

Parents who were more optimistic tended to positively reframe their child's diagnosis (Baker et al., 2005). Jones and Passey (2003) found that parents' optimism, and parents' beliefs that the child's problem behaviours did not control their lives, were factors highly correlated with lower levels of parent stress. It was mentioned earlier that receiving an ADHD diagnosis for their child can initially come as a shock to parents and create a sense of loss of control. Jackson et al. (2008) found that some parents expressed a desire to be actively involved in their child's treatment interventions and the decision-making processes that are required. In this way, parents report regaining a sense of control and stability in their lives, as well as reducing their levels of stress (Jackson et al. 2008). Parents who react in this way are said to employ active coping efforts that are more positive and adaptive.

Seeking their own informational support about their child's ADHD through sources such as the internet, health professionals and relevant books, appeared to assist parents in participating more willingly in the child's treatment regime. Parents reported feeling more at ease and in control during consultations with

their child's health professionals and teachers (Johnston et al., 2005; Podolski & Nigg, 2001). This also allowed parents to voice their questions about their child's disorder, thus giving rise to feelings of being in control of any decision-making processes regarding the child. In addition, the parents utilised what they had learned to implement structure and routine at home, which further enhanced the parents' sense of control and increased their sense of competence (Segal, 2001). Segal (2001) found that this form of "structuring" reduced levels of parent stress and improved parent-child interactions. Parent's involvement can also include building an alliance with their child's teachers and doctors. If there is a breakdown in communication and cooperation in this alliance, it can be stressful for the parent, and engender feelings of inadequacy, isolation, frustration and anger (Magyary & Brandt, 2002; Montgomery, 2005; Vanderbleek, 2004).

(a) Social Support

Building an alliance with health professionals and teachers is a form of formal social support frequently documented in parent literature. Scharer (2005) asserts that parents caring for a child with a disability report a significant need for both formal and informal social support. According to this author, there is a clear causal relationship between a lack of social support and an increase in levels of parental stress. Webster-Stratton (1990) describes social support as the availability of meaningful relationships that provide nurturance and a sense of security and connectedness to others. Such support can be gained from individuals, groups or institutions (Scharer, 2005).

Formal social support is described as support gained from health professionals, care centres and group intervention programs. According to Ruffolo, Kuhn and Evans (2005), seeking support and utilising support groups can improve an individual's quality of life and decrease stress and strain. Support groups are beneficial because they combine information about the disorder, teach problem-solving skills, communication skills and coping skills. Social support can also assist parents in their emotion-focused coping efforts through reframing their child's diagnosis in a positive manner (Ruffolo et al., 2005).

Parents report that they value the opportunity to talk to other parents in a similar situation to their own (Jackson et al., 2008). Informal social support is referred to as support from family and friends; church organisations and parent-groups made up of parents in similar situations. Like formal support, informal social support can be used to provide emotional support, informational support, material support and appraisal support (Scharer, 2005). Being available to listen and offer care and sympathy is referred to as

emotional support. Informational support is the transmission of knowledge to another, or guidance on how to obtain that knowledge. Material support includes aspects such as financial assistance, or assisting with daily tasks that make it easier for the parent to cope with the child. Appraisal support is viewed as a manner of providing feedback and affirmation to the individual in need. Social support allows for the expression of positive and negative feelings between people and most importantly, social support alleviates feelings of being isolated (Ruffolo et al., 2005). When individuals do utilise social support, they display an increase in their level of self-efficacy, thus positively affecting their coping efforts and adaptation to a situation (Scharer, 2005).

(b) Religion and Hope

Religion is shown to be a correlate affecting psychosocial adjustment and coping. Using religion to cope may be especially strong amongst those confronted with a disability in the family (Seigel, Anderman & Schrimshaw, 2001). Religion is often used to find meaning in stressful events. When parents feel as if they are not in control of the situation, they may turn to religion as a source of hope. Religion can help sustain a parent's hope regarding prospects for improvements or recovery in the future. In addition, religious institutions can offer emotional support, practical assistance and charity to parents experiencing a stressful situation. However, studies have shown that utilising religion as a form of coping can sometimes be used in a maladaptive manner by the parent. In such circumstances, religious beliefs could become pathological in that it may begin to have a negative impact on the parent's health, their character and their personal adjustment to the new situation with their child. For instance, parents who display doubts about their beliefs, may believe that they are being punished or not worthy of help. They may also use their religious beliefs negatively to reinforce self-condemnation and feelings of guilt, which can affect their capacity to adapt positively to their situation.

Kashdan et al. (2002) introduce hope as a factor that, like optimism, may give the parent a sense of control in their ability to obtain their goals and sustain the desired positive outcome. Parental hope is commonly shown to reduce stress in the hope of obtaining child compliance, maintaining positive relationships with the child and sustaining balance in the multiple parental roles. Studies showing parents who have claimed to utilise hope as a coping mechanism when caring for their child with ADHD, have revealed that these parents tend to be less vulnerable to psychological stress and less likely to utilise ineffective coping strategies. Findings show a strong relation between hope and the adaptive individual. Parents with hope also displayed pro-social parenting behaviour, characterised by displays of warmth,

nurturing and intimacy. Hope was also correlated with active problem-solving coping. Hope appears to be a significant predictor in optimistic attributions.

2.5 Conclusion

Increased levels of stress are commonly experienced by parents who are caring for a child with ADHD. This appears to be true particularly prior to diagnosis and the implementation of treatment. This chapter has illustrated a number of factors such as difficult child behaviours, complex social interactions with family, teachers and health professionals and misconceptions obtained from the media, all of which affect the parent experience. In order to obtain a reduction in levels of stress, parents are forced to cope and adapt to their circumstances.

CHAPTER THREE

Conceptual Framework

3.1 Introduction

This chapter provides a theoretical framework for understanding concepts such as stress, appraisal, coping and adaptation. These concepts have been briefly introduced in chapter two. The current chapter will thus provide a brief historical account of the development of these concepts, followed by an in-depth review of more recent theories relating to stress and coping.

3.2 Historical Development of the Theory of Stress and Coping

Commonly utilised as colloquial terms, *stress* and *coping* are concepts that have been redefined over several centuries and continue to be studied to this day. A brief description of formally articulated positions on the historical revisions of stress and coping will be presented. This may assist in developing the reader's perception of these concepts and, simultaneously, highlight the significance of these revisions in relation to the present study.

3.2.1 Stress

The concept of *stress* has been extensively discussed in the field of health care. According to Lazarus and Folkman (1984), the term *stress* was used as early as the 14th century to mean hardship and affliction. Then in the 19th century, stress was conceived as a basis for ill health within the field of medicine. In 1932, Walter Cannon considered stress to be a disturbance of an individual's homeostasis under particular conditions (Lazarus & Folkman, 1984; Mitchell, 2006). Cannon suggested the fight or flight model, asserting that external threats elicited physiological changes characterised by increased activity rates and arousal. By the late 1950's, Hans Selye developed the General Adaptation Syndrome (GAD) (Lazarus & Folkman, 1984; Mitchell, 2006; Ogden, 2000). Selye suggested that stress was not an environmental demand but was instead a set of physiological reactions to a stressor. His three-stage model of stress comprised stages of alarm, resistance and exhaustion. Both Cannon and Selye's models were limited because the models were based on a stimulus-response framework, positing that the individual's reactions to the external stressor are automatic. The individual was perceived as passive and there was no consideration for psychological factors, which might influence the individual's coping efforts (Mitchell, 2006; Ogden, 2000).

Later, Sigmund Freud began using stress to explain psychopathology, but the term *anxiety* was utilised instead of the term *stress*. Freud suggested that anxiety triggered defence mechanisms and unsatisfactory efforts to manage and reduce the anxiety, which resulted in maladaptive symptom patterns (Lazarus & Folkman, 1984). The underlying implication of Freud's suggestion was that psychopathology was the

product of anxiety, or stress – a dominant view formulated in 20th century. In the field of medicine, Harold Wolff attempted to define stress as a “dynamic state” (Lazarus & Folkman, 1984). Stress was conceptualised as being an ongoing relationship between the stressor and the individual, where interactions and feedback occurred. According to Lazarus and Folkman (1984), Wolff’s conceptualisation was important, as it assisted with conceptualising the management of stress, which is currently termed *coping*.

3.2.2 Coping

Since the 1960’s the concept of *coping* has been viewed as a vital aspect influencing the individual’s ability to adapt to stress (Ogden, 2000). Coping was derived from an animal model and a psychoanalytic ego psychology model, which are both traditional, but separate literatures. The animal model posits that coping consists of learned behavioural responses used to neutralise external stressors. The psychoanalytic model views cognition as more important than learned behaviour and posits that coping is an individual style characterised by flexible thoughts and acts that work to reduce stress (Lazarus & Folkman, 1984; Ogden, 2000). Both of these traditional approaches are limited because they treat coping as a trait or style; the models lack clarity in distinguishing whether the responses to stress are automatic or effortful; there is confusion between the process of coping and the outcome of coping and finally; the models tend to equate coping with mastery, and yet not all stressful circumstances are problems needing to be mastered (Lazarus & Folkman, 1984; Ogden, 2000). With limitations such as these, more recent, alternative theories attempting to conceptualise and measure stress and coping were developed and will be discussed further.

3.3 Current Models of Stress and Coping

The theoretical revisions discussed above have had important implications for the psychological analysis of stress and coping in the latter half of the 20th century. A review of literature revealed several more recently developed theories which are potentially relevant to the present study. The following models have been proposed: the parent stress model developed by Abidin (Abidin, 1992; Abidin & Wilfong, 1989); the Double-ABCX model reformulated by McCubbin and Patterson (cited in Baker et al., 2005; Jones & Passey, 2003; McDonald et al., 1992) and; a transactional model of stress, appraisal and coping developed by Lazarus and Folkman (1984), (also cited in McDonald et al., 1992).

A discussion of all three models follows for the purposes of comparison. However, it will be seen that the first two of the abovementioned models have been found limited for the present study, whilst Lazarus and Folkman's transactional model has been chosen as a more applicable theory for understanding parental experiences when caring for a child diagnosed with ADHD.

3.3.1 The Parenting Stress Model

The Parent Stress Index (PSI) is one of the more widely used indices of parenting stress. It has assisted in providing a useful and influential guide in the field of parent stress theory and research (McCleary, 2002; Walker, 2000). According to Abidin (1992), higher levels of parenting stress can result in dysfunctional parenting, which can influence the outcome for the child. The PSI model recognizes that parenting is a complex task and that there is an interaction between child, parent and environmental factors.

Delineated in the PSI, a parent's degree of stress can be determined by the nature of a stressor (Abidin, 1992; cited in McCleary, 2002). Abidin (1992) demonstrates this by incorporating sociological, behavioural and personality factors into the PSI model. A *stressor* can be multi-dimensional in nature and can derive from three predominant sources. In the first instance, a stressor could be in the characteristics of the child, such as the child's potential to adapt to a situation, the child's temperament or the child's level of hyperactivity. Secondly, a stressor could be in the form of the parent's characteristics, such as the parent's personality, sense of competence, psychopathology or attachment to the child. Thirdly, a stressor could be in the form of situational life stress, such as social support, divorce, death of a family member or changing jobs (Abidin, 1992; Abidin & Wilfong, 1989). The interaction of these above-mentioned characteristics can result in parenting stress. Abidin (1992) acknowledges that parents' cognitions and beliefs are key factors in the process of experiencing stress in that, the subjective interpretation of the event is viewed as being equally important as the objective event (Anastopoulos et al., 1992; Walker, 2000). Hence, when confronted with the same situation, one parent may experience the situation as stressful, whilst another parent may not view the situation as stressful.

Several other researchers have generated similar parenting stress models (Mash & Johnston, 1990; Vitanza & Guarnaccia, 1999; Webster-Stratton, 1990). Initially, parenting stress models might appear to be the most appropriate models to utilize in the conceptualization of the parenting experiences in the present study. However, upon closer examination this parent stress model does exhibit shortcomings. The parent stress model is limited because it appears to lack clarity in defining the concepts of parent stress

and that of parent-child conflict (Anastopoulos et al., 1992; McCleary, 2002). The model is complicated in that there are many characteristic components to consider and determining the relative importance of these parent and child characteristics as potential stressors, is not possible. Lastly, the PSI model focuses primarily on how parents become stressed and how this can negatively affect the outcome for the child. Other aspects such as parenting outcomes and how parents cope in such situations are not considered. These limitations render this parent stress model unsuitable for the present study.

3.3.2 The Double-ABCX Model of Stress and Coping

Unlike the parenting stress model, Hill's ABCX model primarily focuses on the family as a whole and has dominated family research since its development in 1949 and through its reformulations in the 1980s (cited in McDonald et al., 1992). This model has been applied to families with children who have disabilities, as well as to studies relating to parental stress (Baker et al., 2005; Jones & Passey, 2003; McDonald et al., 1992). Although there have been further expansions on this model, the most notable reformulation, which will be discussed, is the Double-ABCX model developed by McCubbin and Patterson in 1982 (cited in McDonald et al., 1992).

In the initial formulation of the ABCX model, A is the stressor event, B is the family's resources and, C is how the family defines the stressor event. A, B and C interact to produce X, which is the family crisis. Thus, the initial ABCX model introduced the concept of defining the stressor and the resources utilised by the family. Whilst Hill accounted for the pre-crisis factors, McCubbin and Patterson (cited in McDonald et al., 1992) introduced the concept of *adaptation* as a post-crisis factor in their Double-ABCX model of stress and coping. The authors also contributed to the ABCX model by labelling the interaction between A, B and C as *coping*. Thus, the essence of this model is that a parent's ability to cope with a stressful situation is determined by the interaction of the stressor event, subsequent life stressors, family resources, parental perceptions and coping strategies (Jones & Passey, 2003). The outcome of this interaction is family adjustment and adaptation, which can range from severe crisis or *maladaptation*, to successful adaptation or *bonadaptation* (Jones & Passey, 2003). McCubbin and Patterson (cited in McDonald et al., 1992) also view stress and the changes resulting from the stress as an ongoing process, because the family not only experiences the original stressor event, but also an accumulation of demands as the process unfolds. The demands can be the stress from the original stressor event; stress resulting from the changes in the family's life and; stress resulting from the family's attempts to deal with the problem.

The Double ABCX model of family stress and coping is frequently used to conceptualise families in distress. However, this model is limited for the present study because it does not clearly distinguish between the central constructs of adjustment and adaptation, nor does it clearly define these constructs. Also there is no clarification of which behaviours are a response to stress and which behaviours are an outcome of the adaptation process. Lastly, the model fails to separate cognitive processes from behaviours, which is a fundamental variable needed when attempting to understand the subjective experiences of the parents in the present study.

3.3.3 The Transactional Model of Stress, Appraisal and Coping

Lazarus and Folkman's (1984) transactional model of stress, appraisal and coping holds similarities with the Double-ABCX model discussed above. However, the transactional model does not specifically apply to families, but rather focuses on the individual. Lazarus and Folkman (1984) approach the concept of stress and coping from an individual person perspective, with particular interest in *why* and *how* psychological stress is not experienced uniformly by different individuals.

Derived from cognitive theory, this model centers on the cognitive aspects of stress and coping and provides greater conceptual clarity than the models discussed above. The transactional model of stress and coping can simultaneously encompass the various emotional, cognitive and behavioural components of parental experiences explored in the present study. The role of *emotion* is not discussed in the Double-ABCX model of stress and coping. Furthermore, in a review of previous studies, the transactional model has proven to be a useful framework for conceptualizing the daily experiences parents have when caring for a child with a disability (Eisengart, Singer, Fulton & Baley, 2003; McCleary, 2002; McKee et al., 2004; Trollvik & Severinsson, 2004; Vitanza & Guarnaccia, 1999). This model is therefore applicable to the present study, as it is a framework which may be used to develop an understanding of the potentially stressful impact of parenting a child with ADHD.

3.4 A Discussion of Stress According to Lazarus and Folkman

In Lazarus and Folkman's model of stress, appraisal and coping (1984), the authors agree that extreme environmental conditions could result in stress for nearly everyone, but state that as a stressor becomes more of a milder and ambiguous daily hassle, so there is a greater variation in individual responses. These researchers argue that stress is not part of either, a stimulus, a response or an outcome, but rather

stress is a general concept consisting of different variables and processes. Defining stress had to include both the nature of the environmental encounter and the varying characteristics of the respective individual. The term *stress* is thus defined as "...a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.19). That is, the relationship between the individual and the environment is viewed as reciprocal and bidirectional. The reasons for different stress reactions in different individuals were put down to two critical processes believed to mediate the person-environment relationship. These mediating processes are *cognitive appraisal* and *coping*. Emotion is also included in this process. A flowchart of this model is provided at the end of this chapter.

3.4.1 Mediating Processes

Lazarus and Folkman (1984) have developed a model that is transactional in nature and is comprised of interactions occurring between antecedent variables, mediating processes and adaptational outcomes. According to these authors, *cognitive appraisal* is phenomenological because it is the individual's subjective interpretation of the transaction occurring between him/herself and the environment.

i) Cognitive Appraisal

Cognitive appraisal is defined as "an evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful" (Lazarus & Folkman, 1984, p.19). Here, the individual subjectively evaluates the significance of the encounter and attempts to give meaning to the encounter in relation to his or her well-being. Lazarus and Folkman (1984) have defined three basic forms of cognitive appraisal: primary appraisal; secondary appraisal and; reappraisal.

(a) Primary Cognitive Appraisal

There are three kinds of primary appraisal: irrelevant appraisal, benign-positive appraisal, or stressful appraisal. If an individual's encounter with the environment has no implication for the individual's well-being and nothing is to be lost or gained from the encounter, then the encounter is cognitively appraised as *irrelevant*. If an individual's encounter with the environment will result in a positive outcome and enhance the individual's well-being, then a *benign-positive* appraisal of the encounter will occur and emotions such as joy and peacefulness may manifest. Lastly, there are stressful appraisals which are separated into three types namely harm/loss; threat and; challenge. A *harm/loss* stressful appraisal is

when damage in the form of illness, injury or loss of self-esteem has already been sustained by the individual in a situation. A *threat* stressful appraisal occurs when harm or loss has not yet taken place but is anticipated, which allows for the individual to anticipate the future, plan for it and work through difficulties in advance. A *challenge* stressful appraisal is like a threat appraisal because it also calls for anticipatory planning. However, unlike a threat appraisal which focuses on the potential for harm, a challenge appraisal focuses on the potential for gain and personal growth in an encounter. Emotions such as eagerness and excitement may then manifest. Lazarus and Folkman (1984) also note that threat and challenge appraisals can occur simultaneously. For instance, in light of the focus of the present study, receiving an ADHD diagnosis is an encounter that may initially be appraised by the parent as a crisis and a threat. The parent may feel unprepared as the sudden demands of this crisis encounter could appear to threaten the well-being of the parent and his/her child. Later, however, following reassurance, new informational support and the promise of effective interventions, the threat of the diagnosis may be appraised by the parent as more of a challenge, where potential for gain and growth of the parent's well-being is anticipated.

(b) Secondary Cognitive Appraisal

Lazarus & Folkman (1984) posit that secondary appraisal is a further form of cognitive appraisal. In a threat or challenge situation, the individual uses secondary appraisal to evaluate what can be done to manage a situation. The process of secondary appraisal is used to determine what coping options are available. The *outcome expectancy* of the chosen coping options is evaluated by the individual to determine if the options will accomplish the task. The individual will also evaluate the likelihood that he/she can implement the coping options effectively, which is referred to as *efficacy expectation* (Lazarus & Folkman, 1984). Primary appraisals are thus mirrored by secondary appraisals and they interact with each other in determining the level of stress and the strength and quality of the emotional reaction. To illustrate, if a parent perceives his/her coping resources as insufficient, such as a lack of knowledge to understand the child's diagnosis, and the parent believes his/her coping efforts are ineffective, this could result in an increase in levels of stress for the parent.

(c) Cognitive Reappraisal

The last form of cognitive appraisal is reappraisal. Reappraisal refers to when the individual's initial cognitive appraisal of a situation changes because of new information received from the environment. This can increase or decrease pressure on the individual (Lazarus & Folkman, 1984; Trollvik &

Severinsson, 2004). A review of literature revealed that once receiving informational, emotional and social support from informal and formal sources, many parents displayed a positive transformation in the way they viewed their child's ADHD diagnosis (Jones & Passey, 2003). In this case, the parents reappraised their situations through methods of cognitive reframing.

ii) Emotion

Lazarus and Folkman (1984) include emotion as an important component of the mediating processes. These authors state that emotions can arise from the individual's appraisal of a situation. When the individual appraises the significance of the encounter, the appraisal becomes the cognitive basis for the emotional reaction. Studies focusing on parents' reactions to their child's ADHD, showed that parents often exhibited negative emotions ranging from frustration, shock, fear, anger and disappointment upon appraising their situation (Podolski & Nigg, 2001). Frequently, these emotions would then fuel the parents' initial behavioural reactions, such as using impulsive physical punishment, shouting at the health professional or attempts at avoiding the situation altogether. According to Lazarus and Folkman (1984), emotions can influence the individual's reappraisal of the situation and how the individual copes. Although, it should be noted that causality is bidirectional in the mediating process, so cognition does not always precede emotion and vice versa.

iii) Coping

Coping, is another major mediating process which Lazarus and Folkman define as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus and Folkman, 1984, p.141). Whilst both the Double-ABCX and the transactional model of stress, appraisal and coping address the construct of coping, Lazarus and Folkman's transactional model takes this further by proposing that coping requires conscious effort and is not automatic (McDonald et al., 1992). Subsequently, unlike the Double-ABCX model, because the transactional model views coping as a cognitive and behavioural effort to manage an encounter, the transactional model also avoids confounding coping function with outcome and mastery. In addition, the definition of coping implies that this process is determined by cognitive appraisal. According to Lazarus and Folkman (1984), *coping function* refers to the purpose a strategy serves, whilst *outcome* refers to the effect a strategy has. There are two functions of coping, namely *emotion-focused* coping and *problem-focused* coping.

(a) Emotion-focused Coping

Emotion-focused coping is when coping strategies are directed at regulating the individual's emotional response to the encounter. For instance, in attempting to reduce stress, a parent might employ strategies such as avoidance, distancing, positive thinking, meditating or venting anger. Lazarus and Folkman (1984) assert that sometimes emotion-focused coping can result in the problem being construed in an alternative manner, which is similar to reappraisal of a situation. However, not all forms of emotion-focused coping are reappraisals.

(b) Problem-focused Coping

The second coping function is problem-focused coping. This is a form of coping that is directed at managing or altering the problem. Problem-focused coping is similar to problem-solving, except that problem-focused coping has two strategies, namely one that is focused on the environment and one that is focused on the self (Lazarus & Folkman, 1984). Coping that focuses on the environment includes strategies such as altering environmental barriers or altering resources and procedures. "Structuring" and developing daily routines, as discussed by Segal (2001), would be an example of this method of coping, which is employed by parents to gain a sense of control over their situation and reduce their levels of stress. Coping that focuses on the self includes strategies directed at cognitive changes, such as shifting levels of aspiration, developing new standards or learning new skills and procedures. When parents research their own information about their child's ADHD, they may learn new skills and procedures to care for their child. According to Lazarus and Folkman (1984) emotion-focused coping and problem-focused coping influence each other by either facilitating or impeding each other.

Lazarus and Folkman posit that the way in which an individual will cope is largely determined by the resources available and the constraints inhibiting the use of those resources. Certain personal and environmental constraints, such as internalised cultural values and beliefs and a finite amount of resources, could work against the utilization of resources. Constraints and coping resources that are not relevant to the problem can increase the individual's levels of stress. Coping resources can vary from one individual to the next, however, predominant categories exist: health and energy; positive beliefs; problem-solving skills; social skills; social support and; material resources, such as finances and information.

It was mentioned earlier that Lazarus and Folkman's transactional model comprises antecedent variables, mediating processes and adaptational outcomes. In order to gain a comprehensive understanding of the central mediating processes of stress as discussed above, the antecedent variables and adaptational outcomes will also be identified.

3.4.2 Antecedent Variables

Antecedent variables in the person-situation relationship are divided into two categories, namely *person factors* and *situation factors*. These variables are important determinants influencing cognitive appraisals (cited in McDonald et al., 1992).

i) Person Factors

The two most important person factors are commitments and beliefs. *Commitments* refer to the choices, goals and values that the individual does not want to abandon (Lazarus & Folkman, 1984). Commitments underlie the choices that the individual makes and commitments determine what is at stake in a specific stressful encounter. That is, commitments can guide the individual into or away from situations, which could benefit or harm the individual's well-being. Moreover, the greater the strength of the individual's commitment, the greater the threat of the encounter and the more vulnerable the individual will be to psychological stress. But the greater the individual's commitment, the higher the motivation the individual may feel in attempting to ward off a threat by utilising greater the coping efforts. To illustrate, many parents may become highly stressed when their child's health professional strongly recommends medication to treat the ADHD. This increased stress may be due to these parents holding values of anti-medication for children, which they do not want to abandon. In this case, the parent is confronted with conflicting feelings and could feel threatened.

Another person factor is the individual's *beliefs*, which are culturally or personally-formed cognitive configurations (cited in McDonald et al., 1992). An individual's beliefs are pre-existing perceptions about reality. Beliefs about personal control over an encounter have to do with feelings of confidence and competence. When discussing control, the subject of internal and external locus of control should be mentioned. *Internal locus of control* refers to the individual's belief that an event is dependent on his or her own behaviour, whereas an *external locus of control* refers to the individual's belief that the event is not dependent on his or her behaviour, but rather the event is dependent on luck, fate or powerful others.

According to Lazarus and Folkman (1984), beliefs and commitments work together with situation factors in influencing the process of cognitive appraisal.

ii) Situation Factors

Situation factors are identified characteristics of the encounter itself, such as *novelty*, *predictability*, *event uncertainty* and *ambiguity*. Lazarus and Folkman (1984) state that it is rare for an encounter to be totally *novel*, because usually the individual has some form of knowledge of the encounter, which will influence the individual's appraisal. A novel encounter can be stressful if there is knowledge of a similar encounter being threatening or harmful to an individual's well-being. To elaborate in relation to the present study, a parent may hold misconceptions about the child's diagnosis and treatment options, which could influence the parent's perception of the new situation as threatening. In addition, although there may be knowledge of the encounter, there may be inadequate knowledge of coping efforts, which could also increase the level of stress.

The second characteristic is *predictability*, which implies that the individual can discern whether something harmful is about to happen. Predictability may allow for control over the environment and for feedback from the transaction with the environment about what can or cannot be done about the encounter (Lazarus & Folkman, 1984). Unpredictability has shown to increase the level of stress in an individual (cited in McDonald et al., 1992). A third characteristic is *event uncertainty*, which refers to how knowing the likelihood of an encounter occurring will influence the individual's appraisal of a situation and the individual's level of stress. Lastly, when the information that is needed for the appraisal is unclear or insufficient, the situation is *ambiguous*, which can intensify the individual's sense of threat because ambiguity limits the individual's sense of control.

3.4.3 Adaptational Outcomes

The importance of appraisal and coping efforts is how they affect short- and long-term adaptational outcomes. Lazarus and Folkman (1984) identify short-term outcomes as being the individual's immediate positive and negative emotional response to the stressor, quality of outcome of the stressor and, somatic changes and acute illness. Thereafter, three basic, long-term forms of adaptational outcomes are identified namely: functioning at work or social living; morale or life satisfaction and; overall somatic

health. It is noteworthy that these long-term outcomes are not viewed as direct products of coping, but derive from the effects of coping on the short-term outcomes.

3.5 Limitations of the Model of Stress, Appraisal and Coping

A theory employed in a study is not always directly related to the study's subject matter. Although Lazarus and Folkman's Model of stress, coping and appraisal is one of the more appropriate theories that can be applied to the present study, this particular model does not specifically focus on families with children with disabilities. In lacking a narrowly defined focus, this could be considered a shortcoming. In addition, like many other models, the respective model is not entirely well-articulated, in that there appears to be a relative lack of conceptual clarity in certain areas. In particular, whilst Lazarus and Folkman (1984) have been successful in separating coping from adaptational outcomes, the authors seemed to have failed to clearly distinguish *coping* from *cognitive appraisal* as unique concepts, in that *cognitive efforts* have been included in the definition of coping and yet cognitive appraisals are a form of cognitive efforts. Furthermore, according to McCleary (2002) and McDonald et al. (1992), the direct and indirect relationships between antecedent factors, processes and effects are not altogether well-articulated, which may be problematic. Lastly, the concept of stress has been variously described as a cause or an effect and in Lazarus and Folkman's model, stress is defined as a process, but this is not entirely elaborated on. Different perspectives and conceptual ambiguities such as these and the ones mentioned above do characterise this field of research. However, such indistinctness could be viewed as a shortcoming of this particular model.

3.6 Conclusion

Different children present with different challenges for their parents. However, the presence of a child disability adds an additional complexity. Stress, appraisal of challenging situations, coping and adaptation are processes possibly experienced by parents who are caring for a child with a disability, such as ADHD. With the aim of generating an understanding of these processes in order to apply them to the present study, these constructs have been explored and described using different models of stress and coping. Whilst Lazarus and Folkman's model of stress, coping and appraisal does not narrowly focus on parent stress, the model's comprehensive nature of all concepts including outcomes, allows for a more thorough exploration of individual parental experiences when caring for a child with ADHD.

CHAPTER FOUR

RESEARCH METHODOLOGY

4.1 Introduction

In this chapter, the nature of the present study is introduced. The strategies employed to guide participant sampling, data collection and data analysis are described. Attention is also turned to ethical considerations.

4.2 The Present Study

The present study was designed to invite parents to share their experiences when caring for a child with ADHD. The research was concerned with gaining an enhanced understanding of the participants' subjective interpretations of their experiences. In order to formulate a holistic illustration of the various dynamics characterising the experiences of these parents, the present study is qualitative in nature. Qualitative research is concerned with meaning and holds the underlying assumption that reality is subjective to the individual (Terre Blanche & Durrheim, 1999). In light of this, each participant was encouraged to express their own understanding of ADHD, their perceived levels of stress, their manner of coping and their thoughts and emotions throughout the process of their child's diagnosis and treatment.

4.3 Conceptual Framework

In chapter three, the concept of cognitive appraisal was described as a predominant mediating factor in determining an individual's level of stress and coping efforts. Because cognitive appraisal rests on the individual's subjective interpretation of an event, the present study utilises a phenomenological approach. Formulated by Husserl (cited in Willig, 2001) in the early twentieth century, phenomenology is concerned with how the world is experienced by human beings. A phenomenological perspective asserts

that the world is understood through the individual's own understandings, perceptions and experiences of it. Kvale (cited in Willig, 2001, p52) states that phenomenology, "...studies the subjects' perspectives of the world; attempts to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings".

The phenomenological approach and its respective method of Interpretative Phenomenological Analysis are viewed as being similar in its methods to grounded theory. However, there remains a crucial difference. Grounded theory aims to identify, explain and theorise about social processes and attempts to provide a reason for *why* a phenomenon occurs. On the other hand, phenomenology does not aim to describe *why* a phenomenon occurs, but rather it aims to describe *what* the phenomenon is according to the meanings that individuals apply to it (Lemon & Taylor, 1997; Willig, 2001). To elaborate in terms of the present study, the phenomenological approach is concerned with describing and documenting the parents' accounts of their own thoughts, beliefs and feelings about caring for a child who has ADHD.

4.4 The Researcher's Role

In a qualitative study, the researcher interacts and collaborates with the research participants. By entering the world of the participants, the researcher acts as an instrument for gathering information about the participants' experiences and then analyzing and interpreting the study data (Marshall & Rossman, 2006). In the present study, the role of the researcher was primarily that of an interviewer. The researcher was responsible for organizing mutually convenient interview schedules with the participants. The researcher also had to ensure that the participants were educated on the aim of the study, as well as the level of interaction expected of the participants during the interviews. According to Marshall and Rossman (2006), in order to protect the participants' privacy, it is essential that the researcher follows ethical guidelines. Prior to the interviews, the researcher distributed letters of informed consent to the parents for signature. During the interviews, the researcher should also pay close attention to social cues from participants, which could be signs of discomfort (Marshall & Rossman, 2006). The researcher was aware that her own demeanor during the interviews could influence the manner in which the participants answered interview questions and interacted with the researcher. Lastly, because the research involved the participants giving their time, the researcher showed appreciation of this and reciprocated by attempting to be a good listener and provide any informal feedback needed by the participants.

4.5 The Research Site

According to Marshall and Rossman (2006), the researcher should choose a site for conducting the research which facilitates easy access to the participants. There should also be a high probability that the necessary subject material of interest to the researcher is available. In addition, the quality of the data and the credibility of the study must be assured.

The initial site selected was a public secondary school that was established less than 20 years ago, with the aim of offering an inclusive education system to the families in the surrounding community. This school was one of the first schools in South Africa to welcome a child diagnosed with Down's Syndrome into their mainstream program. As a result of this policy, the school has a wide cross section of pupils, with and without learning difficulties. This was of assistance in the purposive selection of the study participants. However, it was later decided to avoid a sample that would be entirely influenced by the same school environment. More than one school was therefore contacted with the aim of approaching potential participants whose children were attending different schools in different areas. The study participants were given the choice as to what site they preferred to be interviewed at, which interestingly resulted in many of the participants showing preference to being interviewed in their own homes. The participants were allowed to negotiate the most convenient times for their interviews. Many felt that it was easier to be interviewed during the midmorning when their children were already at school and they were alone at home.

4.6 The Sampling Strategy

A non-probability, purposive sampling strategy was used in the present study, because the nature of the study is qualitative and small-scale with the intention of obtaining information-rich cases reflecting the participants' experiences. According to Willig (2001), when using Interpretative Phenomenological Analysis (which is utilised in the present study), data collection is usually done through purposive sampling, whereby the participants are selected according to criteria that is relevant to the research being conducted. Similarly, Kvale (1996) posits that purposive sampling allows the researcher to identify the characteristics of a sample that will provide the researcher with the most valuable information. A result of this method of sample selection is homogeneity - in view of the fact that the selected participants all share similar experiences, which they then describe to the researcher (Neuman, 1997; Willig, 2001). In light of this, and based on the specific aims and requirements of the present study, it appeared most appropriate to approach parents who were caring for a child who had received a formal diagnosis of ADHD by a health professional.

In order to locate parents with children diagnosed with ADHD, school psychologists were approached and briefed on the study. The school psychologists were believed to be the most likely involved with the children who were clinically diagnosed with ADHD and therefore, in contact with the children’s parents. For reasons of confidentiality, it was felt to be more appropriate that the child’s psychologist approach the parent about participating in the present study, rather than an unknown researcher. It was felt that this method of approach would also facilitate the participants’ decision to take part in the present study.

For the purpose of sample selection in the present study, a “parent” was defined as the primary caretaker. Thus in relation to the child, the parent could be a biological parent, a grandparent, a step-parent or an adoptive parent. The psychologists were informed that upon choosing the parents for the present study, there were no restrictions with regards to the parents’ gender, level of income and education. In addition, parents of all racial groups were approached to take part in the present study. The only specific requirements for this study’s sample were:

- a) The participant must be a primary caretaker of a child who has been diagnosed with ADHD and is being treated for ADHD.
- b) The participant’s child must be 18 years old or younger.

4.6.1 Age, Gender, Race

The sampling frame consisted of 12 parents. Eleven of the parents were females and one was male. All of the parents were Caucasian. During the time of the present study interviews, the participants’ children were between the ages of 6-18 years old and still under the parents’ guardianship. Three of the participants reported having more than one child diagnosed with ADHD.

INTERVIEW	PARENT PARTICIPANT	ADHD CHILD’S GENDER	CHILD’S CURRENT AGE
1	Mother	Male	18 yrs
2	Mother	Male	18 yrs
3	Mother	Male	11 yrs
4*	Mother	Female	11 yrs
		Male	7 yrs
5*	Mother	Female	18 yrs
		Male	14 yrs
6	Mother	Male	16 yrs

7*	Mother	Male	14 yrs
		Male	16 yrs
8	Father & Mother	Female	8 yrs
9	Mother	Male	10 yrs
10	Mother	Male	7 yrs
11	Mother	Male	11 yrs

Table 1: Details of Study Sample

* Parents with more than one child being treated for ADHD

4.7 The Data Collection Strategy

Because the present study has a smaller sample size, questions initially arose regarding whether the data collection strategy should be in the form of individual interviews or focus groups. Focus groups may appear to more efficient, in that the researcher is able to interview several individual's simultaneously and overall results can thus be obtained in a reasonably short amount of time. However, there are several features relating to focus groups that were of concern. According to Sherraden (2001), a focus group impedes upon the participants' ability to choose when and where to meet with the researcher, as one specific time and place has to be allocated in order to conduct a focus group. Furthermore, within focus groups, there is the possibility of experiencing the effects of conformity. As the group establishes itself, so the pressure for a participant to conform to the group's norms is increased. Subsequently, the participants may be less likely to express their own opinions that are divergent from the rest of the group, but which may also be just as important to the present study (Sherraden, 2001). A participant may feel insecure in disclosing their personal experiences in front of several others and thus, be less likely to express an interest in participating in the present research (Ingham & Stone, 2005). Taking the above factors into account, an individual interview strategy was considered to be the best way of achieving a comprehensive understanding of each of the participants' emotions, behaviours and thoughts.

4.7.1 The Individual Interview

Semi-structured, in-depth interview schedules were devised as an instrument for collecting the required data (see appendix E). The beginning of the interview was characterised by short, specific questions in order to gather relevant details about the participant and the participant's child. These questions were also incorporated to allow for the development of rapport between the researcher and the participant. This enabled the participant to relax and speak more freely about his/her experiences as the interview

session progressed. The parents who participated in the study were then encouraged to communicate their experiences, as well as issues such as their understanding of ADHD, their perceived levels of stress, their manner of coping and their thoughts and emotions throughout the process of their child's diagnosis and treatment. The initial interview questions were preceded by open-ended questions that were unstructured and non-directive, with the sole purpose of providing the participants with the opportunity to share their personal experiences. In doing this, it enabled the researcher to gain more of an inside perspective into the parental experiences of living with a child who is diagnosed with ADHD. During the interview, more focused questions were introduced and utilised merely with the aim of probing and encouraging the participants to elaborate further.

At the end of each session, the participants were given the option of adding or deleting information. Each parent participated in one interview, with the exception of a husband and wife who chose to participate in one interview together. The interviews were approximately one hour in duration and they were audio taped and transcribed verbatim thereafter (see appendix F).

4.7.2 Devising the Interview Schedule

The open-ended questions incorporated in the interview schedule were developed on the basis of a review of literature, which has brought to light several factors that appear to shape a parent's experience of caring for a child with ADHD. Citations that were prominent in the relevant literature included:

- Parents experience increased levels of stress in response to their child's problem behaviours (McCluskey & Blahy, 2004).
- Parents experience a sense of alienation from the social arena because of general misconceptions about ADHD (Scharer, 2002).
- Parents experience a sense of alienation from the mental health arena because of a lack of emotional and academic support from health practitioners (Scharer, 2002).
- Medicating a child for his/her mental disorder remains a questionable issue for many (Armstrong, 1997).
- There is a perceived need for health practitioners to recognise and act on the needs of parents in these situations (Scharer, 2002).
- Parents frequently feel they are to blame for their child's disorder (Dopfner et al., 2004).
- Shock, distress, anxiety and frustration are common emotions that parents of children with mental disorders will experience (McCluskey & Blahy, 2004).

- Parents implement various support systems in order to cope with caring for their child with ADHD (Podolski & Nigg, 2001).

4.8 Data Analysis

As was mentioned earlier, this study utilised a phenomenological approach which was aimed at exploring and describing the lived, subjective experiences of the participants. Thus, in keeping with the tenets of this phenomenological design, Interpretative Phenomenological Analysis (IPA) was selected as a method of analysis. Noteworthy is that IPA accepts that in attempting to capture the quality of the participant's experience, it is nevertheless, impossible to gain direct or complete access to the participant's world (Willig, 2001). This particular form of analysis recognises that the participants' experiences that are being explored will also have the researcher's own worldview implicated in them. The implication of this is that the production of the present study's analysis is actually the researcher's own interpretation of the participants' experiences. IPA utilises a series of steps, which were employed in the analysis of the data collected. According to Smith (cited in Willig, 1997), these steps assist the researcher in identifying themes and commonalities both within each participant's account and between all the participants' accounts. Thereafter, all of the themes can be integrated into meaningful groups and interpreted.

The steps of IPA were performed on each transcript and only after stage four had been completed for each transcript, did the integration of all the cases commence. To elaborate, the stages of data analysis were as follows:

4.8.1. Stage One: Reading and Rereading

In working with transcripts generated from semi-structured interviews, Smith, Jarman and Osborn (1999), state that the initial stage of IPA is characterised by reading and rereading the transcripts. In conjunction with the reading, the researcher drew up wide-ranging unfocused notes comprising reflections or observations that emerged during the reading process. That is, in becoming intimate with the participants' experiences, the researcher's notes began to include preliminary interpretations, comments on language, questions, associations and descriptive labels and so on. According to Willig (2001), note-taking is common and is generally the researcher's manner of documenting issues that may have arisen upon the researcher's initial encounter with the content of the transcripts.

4.8.2 Stage Two: Identifying Themes

The second phase of analysis involved the process of identifying and labelling themes that emerged from the data. According to Smith et al. (1999) and Willig (2001), it is important to note that labelling the themes captures the essence of what is represented in the transcripts. Willig (2001) further states that psychological terminology can be used to label the emergent themes. Once the themes have been labelled, the analysis of the data involved establishing a form of order by looking for connections between the emerging themes. The researcher found that some themes could be clustered together, whilst others were found to be either subordinate or deviant from the original focus of the study.

4.8.3 Stage Three: Listing Themes

The third stage of data analysis involved an attempt to list all the emergent themes identified in stage two in a logical order. In listing these themes, the researcher began to think about them in relation to one another, whilst simultaneously developing new labels for each theme cluster that was beginning to form. Several of the emergent themes were not anticipated and as these varying themes emerged, the researcher was forced to re-evaluate the focus of the present study. At this point in the analysis certain anticipated themes were discarded as they could not be sufficiently supported because of a lack of evidence in the transcripts. Smith et al. (1999), state that it is fundamental that the researcher takes care that each theme is represented verbatim in the transcript, so that they still makes sense in relation to the transcripts. It is also recommended that identifiers such as, page numbers and line numbers, should be given to the varying themes in order to make it easier to identify them within the transcripts.

4.8.4 Stage Four: Summary Table

The final stage of data analysis entailed the production of a summary table that included the identified themes arranged in their respective clusters, along with the relevant quotations from the transcripts that illustrated each theme. The summary table contained the themes which characterised the essential quality of the participants' experiences being explored. According to Willig (2001, p.56), "the summary table should reflect the meanings that structure the participant's account rather than the researcher's expectations of what constitutes an acceptable number of clusters and themes".

As mentioned previously, the four stages of analysis were performed on each individual account. After drawing up summary tables for each participant's account, the researcher then attempted to integrate all of the themes included in the summary tables into a list of master themes. This process was performed to separate the emergent master themes from the non-essential themes. According to Willig (2001), the

generation of the master themes from a study is for the purpose of gaining a more generalised understanding of the phenomenon being explored. The master themes should ultimately lead the researcher to be able to understand and reflect upon the essence of the phenomenon itself.

It should be mentioned that unlike other versions of phenomenological analysis, such as Lemon and Taylor's phenomenological analysis (1997), Smith's IPA is a new and developing approach, allowing the researcher more freedom in analysing and interpreting the reported data (Willig, 2001). Lemon and Taylor's phenomenological analysis (1997) requires the researcher *bracket*, or *suspend*, any preconceptions or biases regarding the phenomenon being explored. IPA, on the other hand, accepts that this is impossible. The researcher works by interpreting the participant's accounts, with the knowledge that his/her own worldview is influencing the interpretation.

4.9 Ethical Considerations

The Ethics Review Committee of the University of KwaZulu-Natal, South Africa approved and granted ethical clearance for the present study (see appendix H). In order to conduct the present study, consent forms were distributed to the principals of the selection sites asking permission for the use of the school premises (see appendix A & B). This was to ensure a site if any of the parents would prefer to meet there for the interviews. Once the parents had been approached by the school psychologists and briefed on the study's purpose, consent forms were also distributed to each of the parents who agreed to participate in the interviews (see appendix C & D). Amongst other issues of importance, the participant consent forms were composed of information regarding the purpose of the present study, as well as full, non-technical and clear explanations of what an interview would entail. The consent forms also highlighted that the interviews would be audio recorded and all references to the names of the participants, their children or any health professionals would be removed, thus reassuring the participants that they would remain anonymous and all information collected would be treated confidentially. For this purpose, the research does not report any personal details of the participants and their families. Participants were also informed that they could withdraw from the interviews at any point. The security of all research records was maintained at all times and the data was securely stored electronically during and after analysis.

4.10 Conclusion

This chapter delineates the methodology applied to the present study and locates the study within a phenomenological framework. The practical details concerning the method of data collection and data analysis were described. The role of the researcher and the ethical principles used to guide the present study were addressed.

CHAPTER FIVE

RESULTS AND DISCUSSION

5.1 Introduction

Caring for a child with ADHD can be a negative experience for parents and is frequently characterized by high levels of stress associated with the child's difficult behaviours. The aim of the present study was to explore and confirm these parental experiences and investigate the coping mechanisms that were employed by parents in such a situation. This chapter presents the results of the interviews with the participants. Each of the results will be followed by analysis and discussion. The analysis of the data revealed a number of dominant themes identified as significant factors in the parents' experiences. These dominant themes fall into *three broad thematic areas* which appear to have been encountered by the parents, namely: Experiences Instigating Help-Seeking prior to Diagnosis; Experiences Surrounding Diagnosis and Treatment and; Acceptance, Adaptation and Coping. Each of these *broad thematic areas* encompass *dominant themes* and *sub-themes*. The various themes, and their respective quotations, may at times seem to be repetitive as it was not always possible to consider one theme as distinct from another. Quotations from the interview transcripts will also be presented in order to elucidate themes identified. The key research findings from the present study are discussed in relation to the study aims and the literature reviewed.

5.2 Experiences Instigating Help-seeking Prior to Diagnosis

The *first broad thematic area*, which emerged as a noticeable phase in parents' experiences, reflected the difficulties that most parents encountered throughout their daily child caring routines. Discussion at this time refers to experiences prior to the child's formal diagnosis. Because of the children's behaviours, parents expressed a general feeling of self-doubt, frustration and even anger towards their children. These emotions preceded parents identifying their children's behaviour as problematic enough to warrant a formal investigation and taking initial steps to seek professional assistance for their child. The following discussion encompasses two dominant themes which emerged in this broad thematic area.

5.2.1 The Impact of Child Problem Behaviours

The focus of the first dominant theme identified is the negative impact child problem behaviours have on parents, and their sense of competence in their role as a parent, when attempting to deal with normal daily routines, discipline, relationships and social activities. Parents described their children's behaviours as difficult to handle and taxing, frequently leaving the parents feeling exhausted at the end of each day. To quote:

"...he just wasn't sleeping. He was climbing walls and windows and burglar guards and escaping out of, climbing through the burglar guards and escaping into the garden, when I wasn't looking, I mean he was a nightmare...I remember those early days saying to (spouse's name), 'all I feel I do from day to day, is damage control and cope'. That's all you do, you don't, you kind of exist" (Parent 2, Mother).

According to Baker et al. (2005), the experience of caring for a child displaying problem behaviours can vary from one parent to the next. In a number of studies, the Parenting Stress Index has been utilized to quantify parent stress, with results showing that levels of parent stress usually increase when a child's behaviours are difficult (Johnson & Reader, 2002). According to these authors, child problem behaviours have been correlated with an escalation of stress related to what parents describe as "daily hassles".

i) Parents Description of their Daily Hassles

Parents participating in the present study reported that their child's difficulties in being compliant, attending to tasks and keeping to daily routines usually resulted in the parents' day-to-day experiences being disjointed, unstructured and chaotic. To quote:

"...um, we wake up and I go wake them up, 15minutes later, after screaming now for 15minutes, I now throw them out the bed because they are still lying there. Um, it takes them I would say on a good half an hour just to put their clothes on, to brush their teeth and comb their hair and come through to the kitchen to eat breakfast. Ja, um, then we get to the kitchen to eat breakfast, and it now sort of dawdles around the kitchen, looking out the window, plays with the dogs, whistles to the bird, thinks about something back in her room, and runs back to the bedroom because she has thought of something and forgotten about breakfast that is waiting for her. So now 10 minutes later the breakfast is now cold, I'm still screaming down the passage, comes running back, breakfast is cold, miserable because breakfast is now cold. Um, so it's very hard, it's very difficult, it's very daunting and then the same in the afternoons with homework. Ah, homework" (Parent 4, Mother).

All of the parents interviewed indicated that having a child with problem behaviours was often overwhelming. Evidence from the findings showed that the demands of trying to exist in such an environment tended to increase the parents' levels of stress and had a negative impact on their quality of life. Congruent with these findings, Lange et al. (2005) showed that such child problem behaviours can persist as a chronic strain on the family environment.

ii) Parents' Feelings of Frustration

In the present study, frustration was the predominant emotion experienced by the parents when dealing with daily routines. Parents stated that they were so frustrated by their child's behaviours and their inability to control their child, that they found themselves experiencing feelings of anger and resentment and sometimes experienced a desire to use physical punishment on their child. To quote:

"But very challenging, I mean, jeez, there were days that I honestly couldn't, I can understand why people batter children. Absolutely. Oh, ja, I mean there were days when I would actually put him in a room or lock myself in another room so that I couldn't go near him, because I would've hit him...But half an hour later he's got you on that edge again, and that was how we lived. He tested the boundaries all the time" (Parent 2, Mother).

And

“I remember being frequently in tears and phoning (spouse) saying, ‘you better come home before I kill this child’” (Parent 7, Mother).

And

“When you look back you see the problems with (the child’s) listening. It was very frustrating for us and if you add (the child’s) strong will to not listening, well then you know it’s hard” (Parent 8, Father).

Parents reported another factor that generated frustration. Their desire to push their child into achieving expected age-appropriate tasks often left the parent feeling frustrated because their child was unable to achieve those tasks. To quote:

“I must say that he is the one that gets screamed at, shouted at...I was actually trying to push him in school, almost in a denial sort of thing to try and help him, like ‘come on my boy, we have got to do this, learn this, know this’ and I would say it repetitively and he just didn’t get it” (Parent 11, Mother).

In their study McCluskey and Blahy (2004) identified frustration as one of the predominant emotions displayed by parents who were often overwhelmed by the problem behaviours exhibited by their child. Further, mothers were identified by Johnston (1996) as being more likely to experience a higher degree of stress resulting from the frustration of dealing with a difficult child, as the traditional role of mothers as the primary caregivers of children still tends to be the norm. Similarly, mothers in the present study stated that they feared losing control and harming their child. More than one mother mentioned needing support and telephoning their spouse in the workplace in order to gain some relief from the stress at home. This said, findings from the present study indicated that a child’s problematic behaviours also impacted on the working life of one or other spouse. These findings are comparable with the findings of Brennan et al. (2007) and Rosenzweig et al. (2002) as outlined in chapter 2. The frustration resulting from such occurrences not only led to conflict in parent-child relationships, but also influenced spousal relationships and extended to broader family interaction.

iii) Conflict in the Parent’s Familial Relationships

Parents reported that their child’s behaviours resulted in a high incidence of marital conflict and sibling rivalry. Disagreements with their spouses over the most appropriate child-rearing practices and how to discipline their child were common. In the present study it was observed that marital conflict was

increased where there was evidence of one parent displaying maladaptive, permissive parenting methods, whilst the spouse exhibited overly authoritarian parenting methods. To quote:

“It causes a problem with me because he (husband) will then punish him and I will get very upset, when the child is in the room and then the child also plays on that and it’s ‘ah, mommy, mommy’ you know, and I want to be there, and I’m a very compassionate and a soft person, so it definitely does create a bit of confusion and tension between the parents” (Parent 3, Mother).

Sometimes, the child was described as the instigator of conflict between the parents. To quote:

“He can get in between two people, like my husband and I, and use that later on against one of you” (Parent 11, Mother).

The parents in the present study described these conflicts as tense and at times confusing, because they were uncertain about how to handle the situation with their child. Such marital disagreements have also been detailed in studies conducted by Benzies et al. (2004), Chronis et al. (2004) and Hastings (2002). As discussed by McKee et al. (2004) in their study, difficult child behaviours can increase parent stress and as a result, the likelihood of dysfunctional parenting practices.

a) The Impact of Sibling Rivalry

An aspect of intra-familial conflict which was discussed repeatedly by parents was the impact of sibling rivalry on the family. Conflict between the child with problematic behaviours and his/her siblings often extended to involving the parents. Participants in the present study reported finding it difficult to discipline all of the children in their family equally. They expressed that they felt concerned when sibling rivalry occurred, because they were afraid of “taking sides” or seeming to be unfair to one of their children. Parents found that the child with behavioural problems frequently required far more discipline than the other children in the family. This led to anxiety when the difficult child accused the parent of being unfair. At other times, parents expressed concern that they might be seen to be favouring the difficult child by allowing him/her more leniency. To quote:

“So I have to be very careful, because I don’t shout at (child’s sibling) as much, purely because he doesn’t do things that aggravate me, whereas with (difficult child), I end up having to shout at him. Ja, its challenging and you do - you feel guilty, because you think you know, I mean (difficult child) will make a comment, being 11 and very, very bright, and he’s on the ball and he’ll say ‘you never shout at my brother, you always shouting at me, you love my brother more than me’” (Parent 3, Mother).

And

“... if I say ‘okay, calm down’, the other one will say ‘but that’s not fair, why do you take his side’ - and now you must deal with this, and it’s very hard. They fight like cat and dog and it’s very difficult to actually say ‘right, you are right and you are wrong so let’s get over it’. You see there’s not always a right and a wrong, because the one that is now wrong can’t understand, why” (Parent 4, Mother).

At times, conflict within the family led to other family members disengaging from the situation. As a result participants expressed feeling anxious and stressed when left to make parenting decisions on their own because of this disengagement by their spouse. To quote:

“The other issue is with siblings, he will get them into trouble. I’m the one who has to question whether I punish him or not, you know it’s like ‘what do I do there?’” (Parent 11, Mother).

The above findings are in line with the findings of Montgomery (2005) who stated that conflict between a parent and child could often result in the other family members disengaging. Disengagement by a parent in circumstances such as these, can be seen as a form of maladaptive, permissive parenting and can exacerbate marital conflict. The manifestation of sibling rivalry described above and its negative impact on familial relationships is congruent with the findings of Webster-Stratton (1990).

High levels of parenting stress resulting from situations such as those described above by the parents, were found by Kashdan et al. (2004) and McKee et al. (2004) to impact on the parents’ ability to apply their parenting skills effectively. These authors found that when parents become anxious about their parenting skills, the result is that they become more critical of the child, and tend then to use negative and maladaptive parenting practices. As a consequence of the conflict that resulted from the situations quoted above, parents in the present study began to question their parental competency. This will be explored as the following sub-theme.

iv) Parents Doubting their Parenting Competency

The participants in the present study displayed anxiety and concern about caring for their child effectively. They appeared to be disappointed in themselves and their parenting skills and displayed a fear of “damaging” their child emotionally. The parents reported doubting their methods of discipline and their competence in all areas of parenting. To quote:

“You feel that you are damaging the child and you think to yourself, ‘oh God, what issues is he going to have to deal with when he’s an adult’ you know? ‘What am I creating here?’ You are always blaming yourself” (Parent 3, Mother).

And

“...now I’m thinking ‘well, what am I doing wrong? Where have I gone wrong? What must I do? Must I start hitting them into submission’, you know, ‘just what am I doing wrong?’ So you very much question your parenting skills” (Parent 4, Mother).

Johnston (1996) revealed that a deterioration in parents’ self-esteem is common when they are caring for a child displaying uncontrollable behaviours. McLaughlin and Harrison (2006) found that parental sense of competence is a central factor in effective parenting. These authors also found that child problematic behaviours could lead to a gradual erosion of the parents’ sense of competence and result in maladaptive parenting. A parent’s lowered sense of competency in their ability to effectively control their child’s behaviours can result in increased levels of parent stress and anxiety. Webster-Stratton (1990) states further that such a lowered sense of competence in the parenting role is related to parents’ feelings of helplessness. These findings were mirrored in the statements made by all of the parents in the present study. An underlying anxiety became evident when the parents reported their concerns about their parenting. Such anxiety could impede the parents’ decision-making regarding the most effective manner of disciplining their child, without exacerbating the child’s problem behaviours. This could lead to further conflict within the parent-child relationship and increased stress for the parent.

v) Parental Difficulties in Public Situations

Many of the parents in the present study reported that they perceived their child’s behaviours as being so disruptive that they deliberately removed themselves from public activities, such as social engagements, going to restaurants and the movies. In essence, parents felt increasingly sensitive to the perceptions and criticisms of others. The parents described their children’s behaviours as being so unruly that they were often difficult to control. Displays of these behaviours in public resulted in parents feeling self-conscious, because they felt that their parenting skills were being scrutinized by others. To quote:

“When you go to a public place or whatever and your child is running riot...and you have to be firm, you have to be constant, you have to do the same thing, so a lot of it is to do with almost like people looking at you and saying, ‘yow, what a bad mother you are’ you know. Ja, ‘you

can't control your child, you can't do this', and so on, although you've put in place all the boundaries...I think as a parent you do kind of feel people looking at you. They look at you as if to say you are not putting in structures for your child, you know your discipline is not good at all" (Parent 5, Mother).

And

"I mean the first movie we did when he was 10 and we left half way through, because by then he was standing on his head and the people behind couldn't see because his legs were flicking up and down" (Parent 2, Mother).

The same applies when one visits other families in their homes. To quote:

"...they sort of like 'gee, that child is revolting and I'm never letting that kid into my house'"
(Parent 7, Mother).

Hinshaw's (2005) concept of "faulty" parenting was evident in the parents' remarks above, in that parents felt that other parents thought their child's disruptive behaviours were a consequence of poor parenting practices. This perception of being publicly scrutinized led parents to voluntarily remove themselves from public situations and social occasions with others. Consequently, some parents found themselves isolated from friends and at times alienated from their social circles, which tended to erode their self-esteem and provoke a sense of despondency in their situation.

From the above sub-themes that have been discussed, it can be seen that a parent's encounters with their child's problematic behaviours can be initially overwhelming, frustrating and confusing, causing the parent to feel insecure. The parents in the present study appraised the situation with their children as being taxing, because they were confronted with stressors such as daily hassles, conflict within their families and isolation from others outside of their immediate family. According to McCleary (2002), when parents appraise their child's behaviours as stressful, they tend to engage in coping efforts to manage their heightened levels of stress. In the present study, it was established that during this initial phase of the parents' experience with their child, they began to utilize coping strategies, which often tended to be maladaptive. These maladaptive coping efforts were characterized by overly permissive or authoritarian disciplining; the use of physical punishment; social isolation as well as avoidance of conflict situations.

5.2.2 Parents Recognizing the Need to Seek Help

The second dominant theme to emerge under this broad thematic area encompassed the beginning stages of help seeking. As their child's behaviours became increasingly disruptive, the parents stated that they began to question the reasons for the difficulties they were experiencing when caring for their child. As conflicts within the family increased, parents began to experience escalating levels of stress and the need to seek help became more imperative. According to Maniadaki et al. (2006), increased family conflict and a corresponding increase in parent stress is closely related to parents initiating help-seeking activities. Significant features noted in the findings of the present study, which influenced the parents' initial help seeking efforts, included beginning to compare their children with peers, listening to teachers' comments and seeking advice from professionals.

i) Parents Comparing their Child with Other Children

In an attempt to understand why their parental experience was so stressful, it was noticed that parents in the present study began to make comparisons between their child and other children. Every parent stated that they felt increasing concern and fear for their child when they started to identify differences between their child's behaviours and that of their peers. To quote:

"You know I look at the other mothers and parents and their kids are sitting calmly, and they take them and they can put them at the Wimpy and, oh no, please, we could never do any of those things...Ja, often you compare to the cousins or the friends and you think, 'ah, you know they must think my child is mad'" (Parent 2, Mother).

And

"We used to always put it down to the fact that he was just being a boy. But when I used to walk through the classroom and be aware that his picture was the one thing at the bottom of the page, all crumpled up and not the big, bold, beautiful one and so I knew that the communication just wasn't happening, something wasn't working here" (Parent 10, Mother).

And

"I mean he wasn't learning like anybody else, he didn't know his nursery rhymes, he couldn't sit still for five minutes" (Parent 11, Mother).

And

"You see like us, we have a gifted child doing matric right now, so we knew that when she was born, that she was so different to him. We just knew that something was not right" (Parent 8, Father).

Some of the parents also experienced personal conflict upon realizing that their child may be experiencing problems. This was evidenced by the fact that when faced with their child's problematic behaviours, the parents stated that even though they knew there may be a problem with their child, they initially tried to avoid facing this possibility. There appeared to be this initial conflict between accepting that there may be a problem and denying the existence of a problem. To quote:

"I knew already beforehand, but you sort of don't want to know and you sort of try to wish it all away...I was actually trying to push him in school, almost in a denial sort of thing" (Parent 11, Mother).

And

"...then my husband was like, 'no he's just being a boy'" (Parent 9, Mother).

Congruent with these findings, Taylor et al. (2006) noted that when the possibility arises that a child may be fundamentally different to other children, parents frequently tend not to accept the possibility initially. Disbelief and defensiveness can underlie feelings of denial in such a case, which could be detrimental for both the child's development and the parent's increased level of stress if ignored. Furthermore, and pertaining to parents comparing their child to others, it is interesting that in a review of previous studies of parental experiences, the studies offered no substantial evidence highlighting parents actively comparing their child to other children prior to diagnosis. Yet, such comparison was reported by every parent in the present study as resulting in the initial indication that their child may be experiencing difficulties.

ii) Parent Response to Teacher Input

Most of the parents in the present study reported that, as their child began formal schooling and their differences became more noticeable, the child's increasingly obvious inability to cope effectively with a day in the classroom led to input from the teachers. To quote:

"...he was just coming home with the most shocking reports. I remember saying 'this is not my child' to the teacher and it was actually her recommendation that I have further assessments done on him" (Parent 7, Mother).

And

"It was recommended by the teacher at school. Also, we just had a gut feeling that something was wrong" (Parent 10, Mother).

Parents expressed mixed reactions to the comments made by the teachers about their child. The majority of parents stated that they felt relieved to have someone with knowledge of the child's behaviour validate their concerns. To quote:

"I knew there was a problem so I was actually quite relieved in some ways that somebody picked up something" (Parent 6, Mother).

There were, however, those parents who responded negatively to teachers pointing out that their child may have a serious problem. The parents found it difficult to accept the teacher's assessment of their child and appeared to interpret these comments as a negative judgment of their parenting skills. To quote:

"I was almost told, but not in the exact words, that he is actually quite stupid, he will never learn to read and write and you know, um, it was very heart-sore, I was very heart-sore. It was very hard to accept the fact that your child is just not coping with work and he's just not conforming" (Parent 4, Mother).

And

"We knew from a very young age before he went into grade one that there was something that needed attention, because while he was in, um, preschool, we were hearing some of the teachers making derogatory comments about the child" (Parent 3, Mother).

Teachers are not formally trained to assess a child for ADHD and they also do not possess formal skills to report their findings to the child's parents. Consequently, teachers' comments frequently tend to come across as unprofessional, tactless and blunt, which may provoke defensiveness and anger in the parent who is already experiencing increased anxiety and fear for their child. The above findings are evidence that the parents felt that the teachers' comments were 'hurtful and judgmental', which is similar to findings documented by Malacrida (2001) and McCluskey and Blahy (2004). These authors reported that due to comments made by teachers, parents sometimes felt that they were being blamed by their child's educators for employing bad parenting practices. As a result, the parents expressed feeling self-conscious, isolated and anxious and uncertain about which step to pursue next.

On the whole however, it was noted in the present study findings that the teacher's comments appeared to have been the catalyst for the parents' first steps towards acknowledging the need for professional help and accepting that their child's behaviour was inappropriate. Graham (2007) has indicated that

teachers generally are the first to suggest to parents the possibility that their child may have ADHD and the need for further assessment. This is probably due to the fact that in a structured formal school environment the child becomes challenged in a number of ways, and their problematic behaviour comes to the fore.

iii) Seeking Different Opinions Prior to Diagnosis

Although some parents in the present study were initially relieved at the teacher's comments regarding their child's difficulties, analysis of the findings indicated that many of parents may have been trying to avoid dealing with a definitive ADHD diagnosis. They therefore elected to look for other explanations for their children's behaviour. This resulted in them visiting a number of different health professionals. These actions may also be indicative of parents not trusting the teacher's comments regarding their child having a potential behavioural disorder that is still highly contested publicly and professionally. The parents embarked on a lengthy assessment process for their child, which included physical and educational assessments. Parents reported that moving from one health professional to the next became a long, anxious and confusing process. To quote:

"...you know they were saying, 'yes, definitely signs of ADHD' and everybody just confirms it and you just get swept along...I think at that stage, you don't know what you are doing, you just literally, that one says go to the next one, and the next says go to the next one, and each time you just go, and you are punch drunk eventually" (Parent 2, Mother).

And

"Immediately after those comments, what we did is we took the child for a physical examination, just to ascertain that the child did not have anything physically wrong with him" (Parent 3, Mother).

And

"We went from teacher to psychologist and then to paediatrician, so it was kind of a chain reaction" (Parent 5, Mother).

Vitanza and Guarnaccia (1999) found that a parent's level of stress is influenced by how challenging or threatening they perceive the child's behaviour to be and the resulting escalation in levels of stress more often than not, leads to the initiation of general help-seeking. Further, Maniadaki et al. (2005) showed that adult beliefs of self-efficacy to manage their child's behaviours are closely related to their beginning to seek referral to health services. A low sense of parental self-efficacy is highly correlated

with help-seeking for the child. As discussed in Chapter 2, Bussing et al. (2003) present the concept of parent “thresholds” and relate this to the individual explanatory model developed by Kleinman (1978). Bussing et al. (2003), found that the process of help-seeking appears to depend on how problematic and therefore, how stressful, the child’s behaviour is appraised to be by the parent. In the present study, for instance, the parent’s “threshold” for handling their child’s problem behaviours would be based on the parent’s explanatory model, which would govern the parent’s beliefs, subjective understandings and responses to their child’s problem behaviours. Furthermore, the parent’s explanatory model would determine the parent’s reactions to comments made by teachers and others, as well as influence the parent’s choices regarding initiating help-seeking efforts that are perceived as appropriate. More often than not, it was noted that in parents comparing their child’s development to that of their peers and receiving input from class teachers and others appeared to have triggered the parents’ search for a formal diagnosis.

5.3 Experiences Surrounding Formal Diagnosis and Treatment

The *second broad thematic area* that emerged illustrates findings pertaining to the phase in the parent’s experience, which is characterized by interactions with health professionals, receiving a formal diagnosis and deciding on treatment. The participants’ cognitive and emotional responses to their child receiving a formal diagnosis of ADHD are detailed. The participants also described their interactions with the health professionals during this time. Following their child’s diagnosis, parents made efforts to gain further professional and informational support about ADHD and the treatment options available. The ensuing discussion consists of three dominant themes which became apparent under this broad thematic area.

5.3.1 Parents Response to their Child’s Diagnosis

The analysis of data pertaining to this dominant theme revealed a mixed parental response. These responses ranged from shock and denial, to relief. Some parents felt guilty and blamed themselves for their child’s difficulties, whilst other parents developed positive alliances with their child’s health professionals. The findings of the present study reflected assertions made by Scharer (2002), as most of the parents initially displayed increased anxiety, fears for their child’s future and heightened levels of stress when they realized that their child had been diagnosed with a mental disorder.

i) Reactions to the ADHD Diagnosis

In the present study, some of the parents viewed their child's diagnosis with relief and believed that it would help with moving forward and assisting their child with his/her difficulties. To quote:

"I felt a bit relieved at first because I thought, 'oh, well, at least we can deal with this now'"
(Parent 1, Mother).

And

"It was actually quite a nice thing now, and the fact that it was now diagnosed and it was called something, so in that sense I was quite relieved, because then we could take it from there, because we now had a name for it and we could work with it" (Parent 4, Mother).

And

"It was like relief really. Confirmation of what we had experienced through the first five years"
(Parent 8, Father).

According to Angermeyer and Matschinger (2003), receiving a formal diagnosis can assist in alleviating any parental uncertainties by promoting a better understanding of the nature of the child's problem behaviours. In essence, parents gain some control as they feel they have something tangible that they can deal with. Consequently, parents may feel they can "move forward" by being able to make informed decisions regarding their child's treatment in order to overcome the problems. This may indirectly lead to a decline in the parent's levels of stress.

In contrast to the above findings however, shock and disbelief appeared to be the most common initial parental response to receiving an ADHD diagnosis. Some parents stated that they were unprepared for the diagnosis and others expressed feeling uncertain about what to do next. To quote:

"But it is still a shock, you know, it is still okay, they've told me this, now what?!" (Parent 5, Mother).

And

"I was quite shocked when he was first diagnosed because you kind of think, you know, the teacher must do their job properly...Why can't you get him to sit still and to do the work or whatever" (Parent 7, Mother).

And

"At the moment when the doctor said to me that my son was ADHD, I actually nearly fell off the chair quite honestly... and then he also said '...and then we will need to medicate it', it was like

someone had just hit me in the stomach. I was like ‘oh, okay, breathe through your nose here’ ...So the label kind of threw me in a different direction” (Parent 9, Mother).

Some parents also expressed disappointment at their child’s ADHD diagnosis. To quote:

“I was disappointed and I was very, very tearful. In fact, when I was told, I just burst into tears” (Parent 3, Mother).

Where one parent accepted the diagnosis, but the spouse did not, conflict occurred. The same was reported by Taylor et al. (2006). Parents in the present study underwent similar experiences and mentioned that it was stressful when others in their family could not accept the diagnosis. To quote:

“...my husband was not too keen. He didn’t want to accept it” (Parent 9, Mother).

Similar to these present study findings, Taylor et al. (2006) found that when a child initially receives an ADHD diagnosis, both parents commonly display feelings of disbelief, followed by anger, disappointment and grief. These authors posited that parents grieved the loss of their child’s “normal” status. At times, the occurrence of one parent accepting the child’s diagnosis more easily than the spouse tended to result in conflict, which sometimes extended to other family members who were also finding difficulty accepting the diagnosis. This would leave the accepting parent feeling isolated and uncertain about how to handle this new situation alone.

According to Scharer (2002), receiving a diagnosis can be viewed as a crisis event. Bearing this in mind, it could be assumed that when parents are confronted with a crisis event or encounter, they may experience increased levels of stress depending on how they understand and appraise the encounter. During this time, parents may evaluate the resources available to them. These include resources such as previous experiential knowledge and support systems, both emotional and financial. Parental stress and anxiety will increase when parents find their resources to be lacking and the encounter can therefore become more threatening. Parents in the present study reported going through a similar evaluation process. They described looking for reasons for their child’s diagnosis, where many of the parents reported feeling that they were somehow to blame for their child’s ADHD.

ii) Parents and Self-Blame

A number of the parents in the present study exhibited conflicting emotions following their child's diagnosis. They found themselves dealing with feelings of self-blame and guilt. Some parents blamed themselves for not having identified the problem behaviours earlier. To quote:

"I felt guilty and I felt terrible that I was a teacher and that I hadn't picked it up myself"
(Parent 6, Mother).

And

"I mean I was a little confused and I blamed it on myself at first because I did want to see it, but I didn't want to see it" (Parent 11, Mother).

Malacrida (2001) observed that mothers more commonly see themselves as the bearers of blame for their child's disorder. Some of the mothers in the present study appeared to exhibit intense self-blame when their child initially received a formal ADHD diagnosis. To quote:

"When I was told about the child being ADHD, I immediately felt guilty, I immediately felt it was my fault because I didn't give the child attention when he was born and when he was an infant, so I wondered whether this could have influenced his condition now...I felt again, that I had failed my own child" (Parent 3, Mother).

In contrast to the above findings, some parents expressed relief at the ADHD diagnosis because they felt that they could now rid themselves of blame for their child's problem behaviours. This opposite view of the crisis encounter led to a reduction in the levels of stress for the parents concerned at this point in their child's development. To quote:

"...it wasn't just our discipline, it was that somebody had now told us that something was wrong, it wasn't just that she was a naughty child and she just didn't listen" (Parent 8, Mother).

In a case such as above, Hinshaw's (2005) concept of "faulty" parenting would fall away, because where parents and others may have initially believed that their poor parenting skills were the reason for their child's problem behaviours, receiving a formal diagnosis may have changed this perspective.

The above findings demonstrate how parents' appraisals of their child's diagnosis tended to determine their levels of stress. The parents who experienced a sense of relief upon receipt of their child's diagnosis exhibited a more relaxed attitude towards the situation and appeared to display less stress than the parents who viewed their child's diagnosis as negative, shocking and disappointing. The

numerous parents who reported self-blame tended to report a correlating increased level of initial stress, as compared to those parents who accepted the diagnosis with a sense of relief and saw it as a way forward for their child. Further, the parents' reactions to their child's diagnosis seemed to extend to their attitude and reactions towards the health professional they were dealing with. However it was observed in the study findings that the manner in which the health professional handled the situation impacted on the parents' reactions and determined their response to the formal diagnosis.

iii) Parents Interactions with Health Professionals

In the present study, a number of parents expressed feeling alienated from the health fraternity. The parents reported that the health professionals they dealt with were dismissive of their need for both emotional and informational support, which heightened their anxiety about their child's diagnosis. To quote:

“One day in the middle of a question, he looked at his watch and said, ‘Sorry, your fifteen minutes are up’. Um, so no, there was no support from him” (Parent 2, Mother).

And

“...when I questioned him about the various side effects like depression and headaches and lack of appetite and all that sort of thing, he was very dismissive of those, which I thought were really relevant...He wasn't very sympathetic in fact” (Parent 1, Mother).

And

“You don't have enough time with them. Usually they are running late and when you are there you can't think of the right questions and because you have to pay to see them, you know that you have like five million questions and you can't get to see them and it's just, that's what I find most difficult” (Parent 6, Mother).

The parents in the present study who were disappointed in the health professional's approach, mentioned that they felt that, along with the lack of empathy from the health professionals, there was a corresponding lack of informational support provided. To quote:

“I also felt that I wasn't getting enough, that it wasn't concrete enough, that they weren't telling me enough, because it just didn't seem like this was going to sort it out...I was confused, irritable, because I don't believe the professional people had informed me well enough on how they arrived at their diagnosis, what the outcome will be and what I can do to support this child through school” (Parent 1, Mother).

And

“...the paediatricians actually need to take a little more time and explain, not only exactly how it works, but also the kind of things that a child like this would be doing so the parents can relate to that, like, ‘ah, yes, that makes sense’ you know” (Parent 5, Mother).

However, several of the parents in the present study did mention that the health professionals that they dealt with were very helpful and understanding in their approach to dealing with them and their child.

To quote:

“You know I don’t think the health professionals let you down. I mean it is quite a huge call to make and I think they err on the side of caution generally, the ones we deal with that is” (Parent 7, Mother).

And

“Ja, and he is very inclusive and he likes us both to be there preferably for the appointments once a quarter and you can just see the whole approach is very, he knows what he is doing. You feel very confident as a parent in what he says” (Parent 8, Father).

And

“...you can move forward now. Of course as well, having (doctor’s name) as a paediatrician has been a great sense of security” (Parent 8, Mother).

Parents who had confidence in their health professional, generally felt that they had received adequate informational support regarding their child’s ADHD diagnosis. To quote:

“Once we had been with him, being an authoritative figure on it, that settled it for me, because when I heard it properly explained and he explains it with diagrams and everything, and what exactly happens in the brain and everything...hearing it from him, I was settled and understood” (Parent 8, Father).

And

“Our GP was very good...and giving us the whole spiel about it. I also don’t remember ever being befuddled, and I think (spouse’s name) was with me and I mean he doesn’t know any of this stuff and I don’t think he ever had to question either what was going on. He understood” (Parent 7, Mother).

Kerr and McIntosh (2000) found that parents caring for a child with a disability insisted that they needed informational support from their child's doctors. In analysing the findings of this phase of the parents' experience, as recounted in the present study, a pattern was noticed, which revealed that where the parents had received adequate informational support from their child's health professionals, they were positive about their experience. Consequently, the parents appeared to develop a relationship wherein they accepted the health professional's diagnosis and trusted the treatment plan offered. Further, those parents who felt that they had not received enough support or information from the health professional they were dealing with reported a more negative experience. They tended to display negative emotions regarding their health professional's dismissive attitude and developed feelings of resentment and anger.

Interestingly, Venter (2006) found that many health professionals viewed diagnosing and treating ADHD as a complex process filled with obstacles, as they found parents to be difficult, and consultations to be time-consuming and disruptive. However, Concannon and Yang (2005) and DeMarle et al. (2003) reported that when health professionals are busy, they frequently do not follow guidelines regarding information gathering from, and informational support to, the parents. These authors claim that this is disappointing as misdiagnosis can occur and parents' questions are not adequately answered, which often reinforces parents' fears, self-blame and misconceptions about ADHD. According to Taylor et al. (2006), dismissive attitudes from health professionals who do not acknowledge the parent's reactions to the new diagnosis, can lead to parents feeling disempowered by making them feel that they are unable to manage their child's health issues. Dosreis and Myers (2008) claim that maintaining a positive alliance with health professionals can prevent disengagement by the parents, reduce treatment dropout and ultimately improve parent and child outcomes.

5.3.2 Parents Seeking Help after Diagnosis

This dominant theme includes parents' reporting the need to seek a second opinion following the diagnosis and the treatment options offered to them. Parents also tended to undertake their own research regarding treatment options, and their reputed outcome efficacy. Taylor et al. (2006) describe the concept of "doctor shopping", which became evident when analysing parent's reactions to their child's diagnosis in the present study. It was interesting to note that whether or not parents had a positive experience with the health professional through the diagnostic process, they still tended to embark on a further process involving seeking a second opinion and seeking their own information

about ADHD and treatment options, before finally accepting the diagnosis and making decisions regarding treatment. To Quote:

“...although you trust the professionals, you know you’ve still got this little thing in your mind, in the back of your mind, but what if you know, if he didn’t tell me everything, what if something does go wrong...” (Parent 4, Mother).

i) Parents Seeking a Second Opinion

Most parents reported not being wholly convinced that their child’s diagnosis was correct. As a result, the parents wanted the reassurance of a second opinion. To quote:

“...I’m now going to contact a clinical psychologist to see if she can offer any more help in terms of, is it actually ADHD, you know. Could there be something else?...I would just like to reassure myself that I have done absolutely everything I can to find out you know, the facts of his condition and whether there could be something else that’s also um, contributing to this” (Parent 3, Mother).

And

“I would say that sometimes I feel confused about it because I’m not one hundred percent sure if ADHD covers what’s really going on in his life and if it’s enough” (Parent 1, Mother).

As discussed in chapter 2, Taylor et al. (2006) describe the concept of “doctor shopping” wherein parents who found difficulty in accepting their child’s definitive ADHD diagnosis, felt compelled to seek further opinions regarding the reason for their child’s problem behaviours. The above quotations illustrate this concept in the present study and also indicate the parents’ disbelief and mistrust in their child’s new diagnosis, which was discussed earlier in this chapter.

ii) Parents Seeking their own Information about Treatment

Participants in the present study stated that following their child’s diagnosis and treatment recommendations by the health professional, they felt it was necessary to follow up on information concerning the most appropriate treatment options for their child. Many parents showed reluctance regarding the use of medication to treat their child’s ADHD. They felt that there was still too much negativity surrounding the use of medication such as Ritalin and they were concerned about the side-effects. To quote:

“I also had a lot of questions about the Ritalin, I didn’t like the reputation it had, and I found it very difficult to get more information on the Ritalin and I was concerned about the side effects” (Parent 1, Mother).

And

“I was very concerned about the drug, I had only really heard the negative aspects of the drugs, for instance um, all the side-effects and all these horror stories that people tell you” (Parent 3, Mother).

And

“I was quite wary about it; you know because of the whole Ritalin thing, it’s got very bad misconceptions about it” (Parent 4, Mother).

And

“There’s a lot of stuff on the internet you know. Also I think that there are so many misunderstandings about ADHD and this person said that, and that person said this, you know, and it can get confusing” (Parent 10, Mother).

And

“There is so much negative nonsense and people sprout off what they don’t know” (Parent 9, Mother).

Parents appeared to experience conflict when they were trying to make a decision about whether it would be beneficial for their child to be treated with medication. Such conflict tended to result in confusion and anxiety for the parents. To quote:

“...you know there is a lot of negative information out there, especially on the internet, there’s a hell of a lot of negative information about medication and it’s hard as a parent who knows nothing about the subject to make decisions after that, because there is all this negativity” (Parent 5, Mother).

And

“...you get different opinions which are, ag there are so many different opinions and also it creates a lot of anxiety because you get confused. You ask yourself am I doing the right thing or aren’t I doing the right thing?, and this person says its right and the other person says it’s wrong” (Parent 3, Mother).

And

“I have such mixed messages; I don’t know anymore, I’m actually sick and tired of ADD, ADHD” (Parent 11, Mother).

These study findings were mirrored by assertions made by Dosreis and Myers (2008) and Jackson and Peters (2008). These authors claim that during the decision-making process, parents are still hesitant to medicate their child. Parents’ reservations about available medication, tends to revolve around media generated misconceptions about psychostimulant treatment for children. Popper (2002) observed that parents still held concerns regarding “poisoning their child’s body” and “chemically controlling” children’s minds and behaviours. This shall be elaborated on further under the following dominant theme.

5.3.3 Parents Making Decisions Regarding Treatment

The final theme encompassed by this broad thematic area pertains to parents making decisions regarding which direction they would like to take when treating their child’s ADHD. These decisions appear to have been affected by the existence of, or lack of support. As has been mentioned, Dosreis and Myers (2008) reports that parent’s decisions on whether or not to use medication to treat their child’s ADHD are at times ambivalent. These authors confirm that the strongest predictor for choosing to use medication is not only the parent’s general attitude towards medication, but also the parent’s level of trust in the health professional.

i) Parents Seeking Support when making Decisions Regarding Treatment

When making decisions during the initial consultations, parents in the present study reported the need for informational and emotional support from their health professionals. In the present study, it was noted that a lack of support sometimes resulted in parents doubting their decisions and becoming angry at the health professionals. To quote:

“I started reading up as much as I could and I did start accessing as much information as I could from various sources and looking at complementary and alternative homeopathic type, um, cures, or not cures, support and when I did that I started receiving more and more information of the negative aspects of Ritalin and it was at that time that I got really quite angry that he had just been shoved on Ritalin without the support and more information...I got more and more angry and disenchanted from the lack of support from the health professionals...the more I asked the more betrayed I felt, because I felt that I should have been

given, as a parent it was my right to be given, a lot more information before I made that choice for him and I hadn't been given the correct information”” (Parent 1, Mother).

And

“I know a lot of people are against it (Ritalin), I mean my mother-in-law thinks I'm absolutely out of my tree” (Parent 10, Mother).

And

“I said to him (spouse) ‘remedial school is the only answer’ and he was adamant that this child was not going to remedial school. I said ‘he’s got to go to remedial school, it’s the only answer’, and he said to me that I must take my child and do what I need to with him, because ‘if you put a child in a dumb class, he is going to stay dumb’... I wasn’t sure, am I doing what is really right, I'm taking him out of a normal school and putting him into a remedial school” (Parent 11, Mother).

Some parents reported that they felt pressured into making decisions to treat their child’s ADHD with medication, which appeared to increase their uncertainty. To quote:

“It made me feel, um, very, um, very insecure. Um...I didn’t know what else to do, because I was surrounded by professional people from the teacher through the GP, through the therapists, telling me that he couldn’t cope without it” (Parent 1, Mother).

And

“I started off negative against Ritalin and then you know, no support, but kind of pressurized by everybody to do this big thing” (Parent 2, Mother).

However, some parents did report feeling supported by the health professional in their decisions to medicate. To quote:

“He explained it very nicely in the sense of keeping it going and how to take it and its effects” (Parent 9, Mother).

When a parent’s own experiential knowledge is incongruent with the health professionals views about treatment, this can make decision-making difficult for the parents (Taylor et al., 2006). Jackson et al. (2008) assert that parents need professional support in order to make informed decisions regarding their child’s treatment. During the initial consultations, parents in the present study for instance, were confronted with the demands of a new encounter. In order to cope with these demands, the parents

required resources such as professional and informational support. Without such formal support during the initial decision-making process, parents experienced a sense of not being in control of their situation with their child, which appeared to increase the parents' stress and anxiety. This was reflected in the findings by McNeal et al. (2000), which revealed that a lack of information about their child's treatment options can result in the parents feeling powerless to control their child's treatment regime.

ii) Parents' Thoughts Regarding their Child's Medication

It was interesting to note that even though the majority of parents in the current study had their children on medication, there were still wide ranging views regarding medicating their child. To quote:

"I want what's best for my child and I'm still not totally convinced that medication is the right way to go...It's a bit of a responsibility to decide for your child. We were disappointed" (Parent 5, Mother).

And

"Well I never liked Ritalin, and I never liked the fact that these kids had to be doped" (Parent 2, Mother).

And

"I don't think the Ritalin addresses their lifetime behaviour. They get to matric, they finish school, and they stop taking Ritalin, now what?!...I didn't want him on it. I made up my mind quite early that I wasn't going to keep him on it for any longer than I absolutely had to" (Parent 1, Mother).

And

"...actually I'm still very anti it. I just think that they've got to learn to cope without it, um, you can't stay on medication forever and ever and ever and ever and he's got to cope as an adult. And I also didn't think that he was that severe that medication was going to make a difference, so I just, I just didn't do it" (Parent 6, Mother).

And

"I think at the bottom of it is always that guilt that you, I feel sorry for them that they have to take a tablet to be able to function and to be able to get through the day so that they having a successful day" (Parent 7, Mother).

Related to these issues, were parents' concerns about medication side-effects and how these were affecting their child. To quote:

“...you still wonder, even though there's been 25, 30 years research on the drug, you still, there's no real proof actually that in 30 years time he's not going to suffer from some type of side effect” (Parent 5, Mother).

And

“Also the eating, they didn't eat on the old Ritalin and I must admit, from a parenting point of view that used to freak me out a bit” (Parent 7, Mother).

In contrast to the above findings, some parents did report that they were convinced that choosing to medicate their child was the most appropriate route to take. Several parents displayed feelings of relief when reporting being satisfied with the effects of the medication on their child. To quote:

“...so I was quite relieved when she was diagnosed, because then I was like ‘right, let's go the Ritalin route and let's try it’, because like I say, by then you can do something about it and be practical” (Parent 4, Mother).

And

“I think it was also like a relief once he was diagnosed and he was on the treatment, because then you start to see the kid is well behaved and he is finishing his work and you get this great feedback from the teacher.” (Parent 7, Mother).

And

“Yes, it was a huge relief with the help of the medication, because he is so much more happier” (Parent 10, Mother).

And

“...once you've gone onto Ritalin and the change in the work, the change in the kid, because suddenly he was achieving, then you suddenly think to yourself...you know, really I was horrible, I should have done it last year” (Parent 2, Mother).

Jackson and Peters (2008) reported finding that medication is frequently the last resort that parents choose. Interestingly, however, a few of the parents who expressed satisfaction with the medication were those who initially expressed concern about medicating their child because of the medication side-effects. Such a change in attitude towards the medication may be due to the transient nature of the side-effects, which was discussed by Venter (2006). This author asserts that although the medications do elicit side-effects in the child, the side-effects are transient and usually discontinue after two weeks. Furthermore, study findings documented by Fischer (1990) revealed that following being treated with

Ritalin, children calmed down to such an extent that there was also a correlating decrease in the parents' level of stress. It seems therefore, that it would help if health professionals were to communicate this factor to parents as it would alleviate some of their concerns. These findings were later reported in other studies, wherein the medication decreased the child's non-compliant, difficult behaviours. As a result, parents displayed less authoritarian behaviours and less negativity towards their children, which helped to improve the parent-child relationship and decrease the parents' levels of stress (Chronis et al., 2003; Johnson & Reader, 2002; Johnston & Mash, 2001; McLaughlin & Harrison, 2006). This may be another reason why the parents in the present study altered how they felt about their child being on medication. The medication's positive effects on their child's problem behaviours extended to the parent-child relationship, consequently decreasing the parents' level of stress. In such circumstances, parents may begin to appraise the situation with their child as less threatening and more of a challenge that could be overcome.

iii) Parents Making the Choice to use Alternate Treatment Options

When exploring the parents' thoughts on treatment options, most of the parents in the present study spoke about their choices to use alternate treatment for their child, rather than using conventional medication. The parents recalled researching and testing the efficacy of the alternate treatments for their child. However, it was observed that a significant number of parents did revert to the use of conventional medication alongside the alternate treatment regime. To quote:

"We didn't start her with Ritalin at first, we actually started her with the IQ when we first found out her diagnosis. You know you always don't want to go the drug route" (Parent 8, Mother).

And

"(spouse's name) been spending his days on the internet. I mean he used to come home quite regularly with this new idea for treatment, like when the Omega 3's were the big buzzword and 'we must get these into the boys' and then the IQ supplements, I mean we did all of that. We looked at the diet and I have made sure that their diet is healthier than maybe it was" (Parent 7, Mother).

A parent also reported that when her child was younger and she was looking for alternate medications, she was confronted with cynicism by others who felt that alternate treatments were not valid. In such cases, it was observed that the reactions of those in the parents' social circle and their families were a

significant influence on whether the parent felt validated and supported in their treatment choices. To quote:

“It was very difficult because it was a few years ago and things have changed a lot in the last 10 years, but then it was very difficult. There wasn’t much around , and what there was around, was pooh-pooed by everybody else, so they didn’t have much validity as far as professionals were concerned, which I think was unfair to the parents and to the children as well” (Parent 1, Mother).

The choice to use alternative treatments may be indicative of parents holding fears of “drugging” their child and the potential negative consequences of long-term drug treatment. Johnston et al., (2005) documented that 50% of 103 parents participating in a study, chose to use alternative treatment instead of conventional medication. According to McKee et al. (2004), parents tend to display preference towards implementing alternative interventions and behaviour modification treatments, rather than use medication because of the potential long term side-effects. In another study, Chen, Seipp and Johnston (2008), found that parents felt behaviour management was a better method of treatment than the use of psychostimulant medication. Jackson and Peters (2008) found that many parents wanted to try alternate treatment options first, but often felt the need to defend their decision about their treatment choices to others. In light of the parents in the present study, the need to defend oneself could lead to feelings of self-doubt and anxiety, further complicating the situation for the parent and increasing the parent’s vulnerability to stress and isolation from others.

5.4 Acceptance, Adaptation and Coping

The *third broad thematic area* that emerged through the data analysis encompasses the manner in which parents began to accept their child’s diagnosis and evaluate and utilize the coping resources available to them. The following discussion comprises two dominant themes detailing another phase of the parent’s experience when caring for a child with ADHD. These themes include parent adaptation and the outcomes of their situation. Parents describe the steps they took to modify their daily lives as an adaptive approach to coping with their child’s ADHD. In addition, the outcomes that parents are faced with regarding caring for their child and how this impinges on their long term experiences as parents are also illustrated.

5.4.1 Parent Adaptation

The first dominant theme in this section discusses the tasks that parents performed in order to adapt to their child's disorder. All the parents in the present study described attempts at adaptation that were predominantly positive and proactive. With the help of both informal and formal support, these parents made efforts to improve their lives and that of their child's. Parents made efforts to restructure their home environments and daily routines, whilst reviewing their methods of discipline for their child. Consequently, the parents' levels of stress appeared to be reduced as treatment interventions began to work, plans and structures were realised, and support structures were put into place. To quote:

"...this is the child that you have and you have to work out different ways of dealing with it"
(Parent 5, Mother).

In line with these findings, Segal's (2001) study produced findings which showed mothers' reports having to "relearn" how to parent their child. The mothers claimed that this was necessary because their children diagnosed with ADHD were so "different" to children without ADHD. DeMarle et al. (2003) and Segal (2001) maintain that upon receiving a diagnosis for their child, the parents invariably are faced with the necessity of adjusting their family organization in order to adapt to this novel situation.

i) Parents Creating Structure

In the present study, parents reported that they felt it was necessary to readjust or reorganize the structure in their homes so as to assist both themselves and their child. It was noticed that the most common form of structuring and readjustment made by the parents appeared to be changes in their methods of discipline to suit the child's needs. To quote:

"...you have to be more structured. I find that people will say 'you run your house like you are in the army', but that's the only way that it works for me and I think that you also tend to maybe do more than you should be doing for them because it's just easier to do it that way" (Parent 7, Mother).

And

"What I find with him is positive reinforcement all the time and that seems to work for him"
(Parent 3, Mother).

And

“Ja, we feel much better with a plan in place” (Parent 8, Mother).

These findings are congruent with those in Segal’s study (2001). The author introduced the concept of “structuring” and presented findings detailing parents’ reports on their attempts to introduce more “structure” into their child’s daily routine. The parents claimed that “structuring” assisted with improving their parent-child relationship, as well as other intra-familial relationships that had become conflict-ridden due to the child’s difficult child behaviors. In light of this study, “structuring” could be considered an adaptive coping mechanism, the implementation of which would lead to a sense of being in control and reduction in the parent’s stress and anxiety.

However, another aspect noted was parents’ mention of their choice to sometimes avoid the situation with their child. To quote:

“When I can’t deal with him, or I need my own space I say, (friend’s name) won’t you actually spend some time with him and she will take him, then he’s not feeling my anxiety, my frustration” (Parent 3, Mother).

And

“...if he gets into trouble, he gets into trouble, I’m not there for him all the time...Homework and all that has always been an absolute nightmare and still is. I mean sometimes I just leave him to do it” (Parent 6, Mother).

As has been evident throughout the findings discussed thus far in this chapter, caring for a child with ADHD can be time-consuming, frustrating and difficult. In their attempt to avoid a situation with their child, parents may feel they would like to spend time alone to regroup their thoughts and replenish their energy before tackling another task with their child. Leaving their child to finish tasks alone, could also be indicative of any underlying parental feelings of frustration and resentment at having such a dependent child who has difficulty achieving age-appropriate tasks alone.

ii) Parents Getting Involved

Following the implementation of treatment, the parents in the present study commented that they felt they coped better with their child’s behaviours when they became more actively involved with monitoring their child’s progress. The parents also continued to research their own information on the subject of ADHD and subsequently, used their newly acquired knowledge to assist them with taking

part in their child's intervention process. Being involved in such a manner appeared to promote parents' sense of being in control over their child's disorder and in their role as a primary caregiver. To quote:

"...I then went ahead and did my own research, because we were battling to get people to help us, um you know...So then decided that well, if nobody could help me, I could help myself. It was one of those scenarios and just, I mean I eventually said to the psychiatrist, 'that is the medication he will go on', which is the one we used...You feel in more control. You feel that when you are going to go into these places, these people aren't going to now say stuff that will go way over your head and you just, eventually you feel so stupid, you just go with whatever they say. I could now challenge them and ask the proper questions and that sort of thing, which forced them to then discuss it on my level" (Parent 2, Mother).

And

"I took the decision that because he didn't take it comfortably, and because there wasn't actually a marked improvement in the classroom, then I thought well, I better find out more about this, so I started reading up and reading about learning disabilities and ADHD and how they affected your life in a learning environment and how it was likely to affect him as he grew, because I come from a family where we don't have anything like that...I started looking at other things like diet, like vitamin support, that kind of thing and a very strict routine" (Parent 1, Mother).

And

"I also went to every parent interview, I made sure that every term I would see the teacher and give my input and hear what they had to say" (Parent 11, Mother).

Taylor et al. (2006) posit that as parents become accustomed to their child's diagnosis, the parents tend to reach a stage where they adopt a more proactive approach to parenting. A feature of involvement most commonly observed in the present study findings was parents choosing to be more actively involved in their child's school activities and with their child's teachers and doctors. Employing proactive parenting methods, such as these, are problem-focused coping strategies that are adaptive and more likely to reduce parent stress and enhance parental competence. Similar to the present study findings were those documented by Segal (2001) who found that parents chose to confront their child's teachers and the health professionals about what they wanted for their child, because in this way, the parents reported that they could constantly "monitor" their child's progress. The concept of

“monitoring” was also described by Griffiths, Norwich and Burden (2004). From their findings, these authors established that parents caring for a child with ADHD felt more in control over their child’s progress and development when they were actively involved in all aspects of their child’s home and school life. Consequently, the parents reported experiencing diminished stress and less chaos on a day-to-day basis.

iii) Social Support as a Coping Resource

In the present study the parents expressed a strong need for ongoing social support, especially informal social support, following their child’s diagnosis and during the implementation of their child’s treatment regime. The parents commented that receiving social support during these times assisted in reducing their sense of isolation and provided them with a space to share their knowledge, thoughts, emotions and concerns. The study findings also revealed that most of the parents who sought informal social support, found solace in sharing with other parents who were experiencing a similar situation to them. To quote:

“...the more you tend to read up on it, and speak to other people about it, especially people who are positive about it, you actually feel better...I’ve got also a very good friend who has also got an ADHD son and it helps you know to sort of know that you are not alone, that there is someone out there like you” (Parent 4, Mother).

And

“As parents we all talk about how, and then you don’t feel so alone, because it’s like ‘ah, my son also can’t organize his life, my son also hasn’t done the assignment’ and we also phone each other” (Parent 6, Mother).

And

“Ja, there was a group of us who always used to chat. You know you don’t feel alone and also they don’t criticize your kid once they know what is going on...there were a couple of us that were friends. One of them was a friend of mine whose child was also diagnosed with ADHD. You know we chatted together, we commiserated together. That was helpful” (Parent 7, Mother).

And

“I think that support when you have a child like this is good because then you know that you are not dealing with this on your own” (Parent 8, Father).

And

“...we have tea and biscuits and then we sit and there might be some crying and sometimes the dads come to hear their side of it” (Parent 11, Mother).

And

“I felt that I liked reassurance, um you know, for instance, ‘no it’s not your fault’, cause every now and then you do doubt yourself...I think that your greatest support systems are your friends and I’m particularly grateful because my friends happen to be people that understand the illness” (Parent 3, Mother).

And

“...you just try and develop a support system within your friends.. If he was now driving me to distraction, then I’d say to them, ‘bring your kids to come and play’, because if there were other kids, he would back off me a bit and he would go to them for an afternoon...I think it’s really good if there are support groups out there for people to belong to. I joined the one at (child’s school) eventually. That was just a group of us mothers that got together and we all had kids that were the same so we understood each other’s kids and if any of us were reading any good books that helped us, we’d pass them on, that sort of thing. It was just nice to speak to somebody else who doesn’t think that your child is an absolute lunatic, because their kids are exactly the same” (Parent 2, Mother).

In line with the above findings regarding informal social support, Kerr and McIntosh (2000) ascertained that when parents are in contact with other parents in a similar situation, they can swap advice for dealing with day-to-day problems that they may encounter with their child. Parent-to-parent support thus helps parents realize that they are not alone and leads to a sense of “togetherness”. According to Lindblad, Holritz-Rasmussen and Sandman (2007), informal support is searched for spontaneously and it is more efficient in reducing parent stress than formal support.

Nevertheless, the aspect of formal social support was introduced by the parents in the present study. It was discussed earlier that the parents sought formal support from their child’s health professionals during the initial consultations once the diagnosis had been made and treatment decisions were to follow. However, the parents claimed that they also continued to seek this formal social support subsequent to the initial consultations. Parents reported that such ongoing support assisted them with effectively handling their child’s treatment interventions, as well as with understanding any changes in their child’s development. To quote:

“...I’m learning through experience rather than knowledge. I think it’s a good way to learn, and also speaking to people that are professionals” (Parent 3, Mother).

And

“...and the school also. They have got um, you know, the OT’s and they provide talks on it for everybody. And they also have a support group that you can go to. Yes and you know, you don’t feel so isolated” (Parent 8, Father).

According to Gupta (2007), the more social support a parent can gather the more the parent’s levels of stress will diminish. In the present study, the parents’ statements about receiving social support highlighted their sense of relief at feeling less isolated and feeling more in control of their situation because of receiving help and support from others. Scharer (2005) and Sepa, Frodi and Ludvigsson (2004), claim that social support for parents caring for a child with ADHD can increase parents sense of competence and induce improved overall psychological wellbeing. Receiving social support is an adaptive coping resource that helps to diminish the gap between resources available and the demands of the situation (Lazarus & Folkman, 1984). McLaughlin and Harrison (2006) and Sepa et al. (2004) both found evidence that when parents have little or no social support, this may lead to a decrease in parental competence and an increase in dysfunctional parenting behaviours, such a poor disciplining methods.

5.4.2 Outcomes for Parents

The second dominant theme of this broad thematic area details parents’ views of their situation as it was at the time of the present study interviews. Throughout the analysis of findings in the present study, it has been observed how parents’ experiences have been mediated by their cognitive appraisals of the situation and the manner in which they choose to cope with the situational demands. As indicated by Lazarus and Folkman (1984), appraisals and coping strategies have an important effect on the outcome of a situation. This said, aspects such as the parents’ social living and their quality of life are analysed as related to their situations presently. When asked about their thoughts regarding their experience as parents at the present time, parents described it as improved, but still taxing. The parents described daily hassles that were still occurring, and mentioned their hopes and concerns about their child’s future.

i) Parents Continue to Face Daily Hassles

Although the parents in the present study had reported that following treatment implementation, they had observed an improvement in their parent-child relationships and a reduction of their child's problematic behaviours, the parents also maintained that they continued to experience daily hassles with their child. The parents showed evidence of feeling frustrated and anxious when providing an evaluation of their current day-to-day experiences, which appeared to continue to negatively impact on their quality of life. To quote:

"...he tends to push you and he still does, I mean he's 18. He pushes me to breaking point"
(Parent 2, Mother).

And

"It's frustrating, because like trying to get him to school in the mornings, even at this stage, is like almost impossible, we are always late. Um, if he remembers his lunch we are lucky...I say, 'what have you got to do and when does it have to be in' or else he will be leaving for school in the morning and he'll say 'ah today our huge science fair thing has got to be in' and I'll be like 'WHAT?'...We have tough times, when he's got a project I've had to help him a lot, because working at home in the afternoons is just not possible, and planning his life is also almost impossible, even now when he's in grade 11. I mean to plan that you've got an assignment due next Friday and it's just a mess" (Parent 6, Mother).

And

"...it is exhausting because you trying to keep the peace all the time...Those have been the frustrations, because you think they are 16 years old, surely there must be some sense of responsibility, but there's none" (Parent 7, Mother).

And

"I think it's an uphill, it's not downhill, it's not a straight road, it's only uphill, always. Always, because you think it's going easy now, and then you hit something and it just turns. You know it will be an easy road, it was going well and then the failing of a test and everything slides. It's almost like um, a catch 22, it's like almost everything full on or everything let go...There's upheavals all the time, you know like had a bad night, the next day we have a bad day" (Parent 11, Mother).

And

"I do feel, still feel quite exhausted, I mean he goes to bed very late...Yes, you get tired, you get drawn out, you get frustrated" (Parent 3, Mother).

Interestingly, a review of literature yielded limited information pertaining to the matter of parents continuing to face daily hassles with their child during the implementation of a treatment intervention. Studies done by Fischer (1990) and Gau (2007) are two of a small number of studies that included such findings in their work. These authors found that even when children are medicated and following a treatment regime, they tend to continue to display problems with their social interaction and communication. Subsequently, and congruent with the present study findings, some of the children's parents reported continuing to experience difficulties at home, a higher sense of incompetence in their parenting role and higher levels of stress and frustration than parents of children without ADHD. Some of these difficulties can wax and wane over time as the child matures and attempts to handle tasks independently, consequently also affecting the parents' levels of stress as well.

ii) Parents Express Future Concerns

When asked about harbouring any concerns about their child's future, several parents did express that they were apprehensive about their child's future achievements and the potentially long-term aspect of ADHD. Particular comments made by the parents revealed that some of their anxieties were not fully allayed. To quote:

"...maybe it's going to be a life-long thing, um then it's sad" (Parent 7, Mother).

And

"But he is going to have a hard road for himself...Another thing is that a further education is my biggest concern for a child like that, because he has got the potential, but it will only be acknowledged or seen once he has found his little field, his little niche" (Parent 11, Mother).

And

"...the only thing that does worry me is that I have heard that if they become sportsmen professionally, they can be drug tested and Ritalin is a banned substance. So that would just be a worry for me" (Parent 10, Mother).

And

"It's just a pity though that he has such a high IQ and it just doesn't show. It's just awful and he just can't apply it and it's so frustrating" (Parent 6, Mother).

And

"...it's not just a quick fix, it's a process that takes a long time" (Parent 8, Father).

A sense of disillusionment appears to underlie these findings, which are also congruent with those found by McDonald et al. (1992). These authors reported that some parents display disillusionment and resentment of the fact that their child's disorder may result in long-term dependence for their child. Consequently, future personal expectations and expectations of the child are forced to be readjusted and may continue to generate anxiety and increased stress. Further, the present study findings revealed parents' concerns about their child's ability to achieve in the future. Such concerns were replicated in studies performed by Malacrida (2001) and Young (2000), who found that parents were apprehensive about their children being at a high risk of antisocial behaviours, drug abuse problems, emotional difficulties, and tertiary education and employment problems when they became adults.

iii) Parents Hope and Optimism

It was found in the present study that some parents appeared to also adjust the manner in which they viewed their child's ADHD in order to assist themselves in coping. The parents displayed that they had changed their attitudes towards their child's diagnosis and they claimed that this had assisted them in coping and caring for their child up till now. To quote:

"...there's something extraordinary about that child and I believe in it from the depth of my heart, that's why I have a lot of hope for him...I try to look at it in a positive light, and I actually do look at it in a positive light...You know the situation is the situation, it's not going to change and I think that at the end of the day its changing how you see it, changing your paradigm, putting on a different set of glasses and seeing things differently, in a positive light and in that way I think that you, as an individual can cope with it better" (Parent 3, Mother).

Maintaining a hopeful and optimistic attitude towards an otherwise potentially stressful situation has been correlated with problem-solving coping that is active and adaptive (Jones & Passey, 2003; Kashdan et al., 2002). Adjusting one's attitude towards a situation is analogous with the concept of cognitive reframing discussed by Jones and Passey (2003). These authors claim that by cognitively reframing a situation, a parent's stress may begin to diminish in severity, as the situation ceases to be viewed by the parents as overwhelming and uncontrollable. Similarly, Podolski and Nigg (2001) found in their study that when parents cognitively reframed their child's ADHD diagnosis in a positive manner, this resulted in parents feeling less frustrated and stressed by the situation.

To elaborate further, cognitive reframing could also be is akin to the concept of cognitive reappraisal which was discussed in chapter 3. The parents may have initially viewed their child's ADHD diagnosis and difficult behaviours as stressful and a crisis situation. However, when the parents found ways to assist themselves in coping with the situation, they also began to cognitively reappraise the situation as more of a challenge than a threat, which helped to reduce their stress. When the situation is perceived as more of a challenge, parents feel improvements can be achieved, consequently leading to potential for positive gain and personal growth.

5.5 Conclusion

By using the method of Interpretative Phenomenological Analysis, patterns and themes have emerged both within, and between each of the transcripts. Commonalities and differences between the parents participating in the present study have been noted. In this chapter, quotations from the transcript analysis were documented under broad thematic areas, dominant themes and sub-themes. Through the data analysis it was observed that when caring for a child with ADHD, parents went through three broad thematic phases: The initial phase encompassing the parents' early interaction with their child portrays their efforts to deal with their child's problematic behaviours and their recognising the need to seek help. This was followed by the period in their child's life when the parents embarked on the process of having their child properly assessed, diagnosed and treated. Finally, there followed a time where parents adjusted to the implications of their child's diagnosis and put coping structures into place.

The research findings documented above have helped to illustrate parents' experiences when caring for a child with ADHD. Several factors have been highlighted by the parents as contributing to their experiences, such as dealing with a difficult child, seeking help, handling the shock of receiving a formal ADHD diagnosis, dealing with health professionals and making decisions regarding treatments that are still highly contested. Whilst it was noted that not all of the parents have endured entirely bad experiences with their child, caring for a child with ADHD was appraised as a taxing experience for most parents. Increased levels of stress, anxiety and frustration were common under such circumstances, however the manner in which the parents chose to cope with their situational demands varied. The study findings brought to light the impact ADHD had on the parents and illustrated every parent's experience as being subjective, different and unique.

CHAPTER SIX

IMPLICATIONS, LIMITATIONS AND RECOMMENDATIONS

6.1 Introduction

This final chapter presents the theoretical and clinical implications drawn from an analysis of the data on which the present study is based. This analysis reveals areas that would benefit from further consideration and research. Limitations of the present study will also be discussed.

6.2 Theoretical Implications

The Transactional Theory of Stress, Appraisal and Coping as formulated by Lazarus and Folkman (1984), proved to be a relevant and useful model when trying to understand the experiences of parents who care for a child with ADHD. In addition to the specified aims of the current study, the researcher also sought to explore the reasons for parents' stress and the coping efforts they employed as conceptualized through the application of the abovementioned theoretical model. The findings of the study confirmed that, as a result of caring for a child with a disorder, parents do experience increased stress and anxiety. In line with the theory used, there were various ways in which parents appraised the crisis events that they encountered during the process of identifying and seeking help for their child's problem behaviours. It was also found that parents held individualised appraisals of their child's ADHD diagnosis and these appraisals were influenced by the explanatory models they applied to their particular life experience. These unique appraisals appeared to determine the severity of stress that the parents experienced and the steps they took thereafter to manage the situation.

6.3 Clinical Implications

The research findings of the present study could contribute to expanding existing perceptions about ADHD and its impact on the parenting role. Identification of factors that shaped the parents' experiences, and the parents' responses to these factors, could assist in gaining a better appreciation of the parents overall experience. The information gained from the findings could also assist in the development of mental health intervention strategies that are more family-centered and orientated towards alleviating parental anxieties, fulfilling parental needs and improving parent-child relationships in general.

Addressing the unique manner in which each parent appraises their child's situation can assist health professionals in the development of more sensitive assessments of parents' sources of stress in such a situation, as well as provide appropriate parental support tailored to each parent's needs. Frequently, the focus of ADHD intervention programs involves only the child with ADHD, wherein effective methods of managing and treating the child's behaviours are implemented. These intervention programs are not targeted at parents per se and yet, the parent's cognitive appraisal of their child's diagnosis, the parent's emotional reaction and sense of competence in the parenting role are all aspects that determine how effectively the child's intervention program is initiated, implemented and followed through. This was one of the dominant issues that emerged from the present study. It would seem that placing a narrow focus on ADHD symptom management only, is likely to be insufficient. DeMarle et al. (2003, p. 108) states that, "the importance of being clear with parents about the exact diagnosis, what causes it and how it can be treated cannot be overstated" and that it is just as important to a successful outcome for the child, for the health professional to acknowledge the impact of the parent's reaction to this new information.

By recognizing these reactions and what it is that parents evaluate as their most important needs, there could be an enhancement in areas such as the parent-professional relationship and the parent's confidence in the implementation of their child's intervention program. This parent support could take the form of formal, individual and professionally structured training and information sessions along with individual therapy, and marital therapy where it is required in addition to existing parent support groups. Parent support groups already appear to be extensively used by parents but seem to fulfil a less formally structured function. Training should include enhancing the parents' understanding of ADHD as a mental health disorder and providing a thorough understanding of the treatment interventions available. Further, the correct and most effective manner of implementing behavioural interventions should also be addressed. A child with special needs requires a great deal of specialised parental participation, so training should include parenting classes that teach specialised parenting skills. The parents would need

to learn how to act rather than react to their child's problem behaviours, by employing skills that are characterised by how to discipline a child with ADHD effectively and consistently. In conflict situations when levels of stress and anxiety are increased, parents would need to learn how to cope with their child's behaviours, and extend those coping skills to teaching the child how to cope in such situations as well.

The importance of positive and adaptive parenting practices is evident. Positive parenting also extends to the necessity for parents to work together as a team when dealing with their child's problem behaviours. However, as the present study findings indicate, marital conflict is a common occurrence in families with children with ADHD. Thus, marital therapy is suggested as another resource that should be utilised to support parents in coping. Initially, seeking marital therapy can assist parents with addressing any unresolved issues within their marital relationship that may be negatively affecting the manner in which they choose to discipline their child. Furthermore, marital therapy can help parents to mutually develop communication patterns that are positive and can support the child through development and in organising his/her life. Finally, attending marital therapy could facilitate parents in coping with the pressure that ADHD may have on their marriage.

Both individual and family therapy could be employed to address any negative emotions and conflict that the parents and the child's siblings may be experiencing. The parents' emotions discussed in the findings, such as disappointment and guilt in their child's diagnosis, self-doubt and a low sense of competence in their parenting role, and anger and frustration towards the child's difficult behaviours, could be dealt with and handled between the parents and a psychologist in these therapy sessions. Parents could use individual therapy to learn how to handle their anger and consequently, learn how to model self-control in conflict situations within the family. Further, family-centred therapy may also address the need for change in the family members' expectations of the child with ADHD.

Interestingly, the study findings revealed no reference to parents' use of religion as a manner of coping with their child. However, in the review of literature, religion was found to be a coping mechanism employed by parents in similar situations. Furthermore, as discussed in chapter 2, religion as a coping mechanism can at times be maladaptive and destructive, negatively impacting a situation and hindering improvement. This said, religion and spirituality are constructs that may require further research to guide

the health professionals attempting to assist parents who utilise this coping mechanism when caring for a child with ADHD.

Through the use of all the therapeutic techniques discussed above, the parents and the child may be able to reach a fair and equitable compromise in the family environment. This might then engender more positive outcomes for both the child and the parent. When parents are properly supported and trained to persist with interventions for their child, they are more likely to persevere and implement the process successfully (Scharer, 2002). As a result, parents could experience an enhanced sense of competence and associated diminished levels of stress and anxiety. A sense of well being can then be established along with an improved quality of life for the parents. Once parents begin to appraise their parenting skills as competent, their view of themselves as successful parents is more likely to be fulfilled.

Another issue that emerged when reviewing the findings of the present study was that most parents began the process of having their child properly diagnosed on the recommendation of a teacher. It is understood that teachers are not trained to diagnose ADHD, or any other disability for that matter. However, from the findings of the present study, they appear to have played a significant role in initiating the process of having a child assessed and diagnosed. From comments made by parents, teachers appeared to base their recommendations on observations of, and comparisons to other children in their classroom. At times, the approach of teachers was not received comfortably by the parents and was reported to be derogatory and scrutinising. It would seem that this is an area that needs addressing. Training teachers to be sensitive when dealing with parents could result in the parents having more trust in the teacher's assessments regarding their child. This could allow for more positive communication and interaction between the teacher and the parent once the child has received a formal diagnosis.

In support of the above viewpoint, De Nijs, Ferdinand, Bruin, Dekker, van Duijn and Verhulst (2004) found that teachers have been shown to be better informants than parents when tasked with reporting on a child's behaviour. It would seem then that training teachers more formally to identify, assess and make recommendations regarding referral of children with behaviour difficulties to a specialist health professional for formal diagnosis would be beneficial to the child. More specifically, and in regard to the present study, this may also benefit the parent who would then have a basis on which to place their trust in the teacher's recommendations.

Another recommendation that one can make on the basis of the findings from the present study was the potential benefit that could be obtained by training teachers to be involved with the child's treatment program whilst at school. ADHD occurs in more than one daily setting (APA, 2000). The greater part of a child's life is spent either at home or in the classroom. It would therefore be of benefit if the teachers were also trained to be involved in the management of the child's treatment. Magyary and Brandt (2002) suggest that communication through a "working partnership" between parents, the school and the health professionals may be a useful way of ensuring a better outcome for the child with an associated reduction of stress for the parent. Parents could benefit from knowing that their child is in a situation where their difficulties are being supported and managed at all times during their day and it might reduce the necessity for parents to attempt to act as a communicator between teaching staff and medical health professionals.

It is understood that recommendations involving the education system in South Africa specifically are likely to be restricted in their implementation because of well-acknowledged limited resources. There is however, currently a move towards a more structured approach to effective educational spending. Where it is possible to implement these recommendations, the benefits may far exceed the additional expenses involved.

6.4 Limitations of the Present Study

The present study highlights factors which have been shown to shape the experiences that parents have when caring for a child with ADHD. However, despite this contribution, the small-scale sample of participants may not be entirely representative of the increasing percentage of the South African population being treated for ADHD. Further, the participants who volunteered for the study were predominantly mothers. Fathers' opinions and experiences were, therefore, not explored in as much detail. The results may also have been influenced by a social desirability bias, where parents might have been tempted to present their experiences in a manner which reflected on them advantageously. As all of the participants in the present study were of one ethnic group, this may have limited the study findings with regard to the influence of cultural differences on the parental experiences. Further, an area worth noting that may have not been clearly defined is the time frame of the children's formal diagnoses. A parent who may have recently received a diagnosis could respond differently to the interview questions, in comparison to a parent who has been dealing with a diagnosis for a longer period of time.

It is acknowledged that the interview schedule itself may have its own shortcomings. Because the formulation of the interview schedule was guided predominantly by the literature reviewed at the time of the study, the capacity to gain novel information from the participants may have been lost. Noteworthy is that utilizing reviewed literature as empirical evidence to guide the development of the interview schedule works to enhance both the validity and the reliability of the present qualitative research. However, in an attempt to overcome the potential restrictions of the interview schedule, the participants were allowed the space to add their own information and thoughts over and above their answers to the open-ended questions asked of them.

The views expressed by the participants are predominantly value-laden, which could result in a restriction of the information being gathered. It should be noted here that interpretive phenomenological analysis utilizes language as a tool for communicating with the participants (Willig, 2001). Thus, it is essential that the role of language is acknowledged, as it plays a fundamental part in the analysis of the transcripts and can affect the study's outcomes. Furthermore, a researcher's understanding of the participant's thoughts and feelings is necessarily influenced by the researcher's own ways of thinking, his/her assumptions and concepts of the world.

Despite the above limitations, it is hoped that the information gained in this exploratory study will contribute to current understanding and awareness of the experiences parents have when coping with a child who has been diagnosed with ADHD. Upon evaluation, these findings may be beneficial when defining future areas of research.

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APPENDICES

Appendix A

The following is a letter addressed to the principals of Site A and Site B requesting their permission to conduct the research interviews with the participants at the respective schools. The letter simultaneously explains the purpose of the study, and what the interviews will entail. Please note that the names and other details have been changed to maintain anonymity of both the schools and the participants.

The Principal, Mr/s X
Site A
P.O. Box XX
DURBAN
4000

April 2009

FAX: (031) ()

Dear Mr/s X

RE: RESEARCH PROJECT AT SITE A

I would like to request permission to use the Site A premises to conduct research interviews with the parents of some of the pupils at your school. The research is aimed at interviewing parents of children who have been diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD) in order to explore the experiences that these parents have had as a result of having been so closely affected by ADHD. There will be an exploration of any anxieties, concerns and suggestions that the parents may have. The project will entail a single hour-long interview with each parent. The interview sessions will be led by myself and will be held under the supervision of my supervisor, N C (Zethu) Memela of the University of KwaZulu-Natal. It is hoped that this research will lead to a greater understanding of such parental experiences, which could possibly enhance this area of development in the field of mental health, as well as assist in the development of mental health programs aimed at addressing and supporting the needs of parents of children diagnosed with ADHD.

Should you require further information about the project, please do not hesitate to contact me on (tel) or (email). In addition, you may also contact my supervisor at the University of KwaZulu-Natal for further information: N C (Zethu) Memela on (031).

Yours sincerely

SHANNON-MAY NEAVES

N C (ZETHU) MEMELA (Research Supervisor)

Appendix B

The following is a consent form which was required to be read and signed by the principal of the respective site in order to consent to the use of his site premises for the purpose of conducting the interviews for this research project.

USE OF SITE CONSENT FORM

I, _____ (full name) hereby confirm that I understand the contents of this document and the nature of the research project surrounding the exploration of the experiences of parents with children who are being treated for Attention Deficit/Hyperactivity Disorder. I hereby consent to the use of (Site A) for the purposes of this research project.

Signature: _____

Date: _____

Appendix C

This letter requests the participation of the parents in the interviews. The letter explains the subject matter that the research project aims to explore and the format that the interviews will take. All names have been changed.

Mr/s XXXX
1 Abrey Place
Kloof
3610

April 2009

Dear Mr/s X

I would like to request your voluntary participation in an interview session for my research project. This research is aimed at exploring parents' experiences when caring for a child who has been diagnosed with, and is being treated for, Attention-Deficit/Hyperactivity Disorder (ADHD). I would like to explore any thoughts, anxieties and concerns that parent's may have regarding their experiences regarding their child's ADHD diagnosis and treatment. There will be one single interview, which will be approximately one hour in duration, and participants are free to withdraw from the research at any time without any negative consequences to themselves. The interview will be audio recorded, but any reference to names and places and other personal details will be changed, in order to maintain anonymity. All data collected will be treated confidentially and with care. The interviews will be led by myself and will be under the supervision of my supervisor, N C Memela of the University of KwaZulu-Natal. It is hoped that this research will lead to a greater understanding of parental experiences when they are so closely affected by ADHD. Research findings could assist in enhancing this developing field of mental health as well as developing more advanced programs that may assist in addressing parental concerns in the future.

Should you require further information about the project, please do not hesitate to contact me on (031) or (email). In addition, you may also contact my supervisor at the University of KwaZulu-Natal for further information: N C (Zethu) Memela on (031).

Yours sincerely

SHANNON-MAY NEAVES

N C (ZETHU) MEMELA
Research Supervisor

Appendix D

The following is a consent form which was read and signed by the participants when agreeing to participate in the research interview.

PARTICIPANT CONSENT FORM

I, _____ (full name) hereby confirm that I understand the contents of this document and the nature of the research project surrounding the exploration of the experiences of parents with children who are being treated for Attention Deficit/Hyperactivity Disorder. I have voluntarily consented to actively participate in this research project. I understand that the interview will be tape-recorded for research purposes and that any personal or identifying details will be treated carefully and confidentiality will be maintained.

I understand that I am at liberty to withdraw from the interview at any time, should I so desire.

Signature: _____

Date: _____

Appendix E

Interview Schedule

Questions

- 1) Is your child a boy or a girl?
- 2) How old was your child when diagnosed with ADHD?
- 3) How old is your child now?
- 4) What grade is your child in?
- 5) How, or by whom, was your child diagnosed? (Teacher, GP etc)
- 6) What treatment regime is your child currently on?
- 7) What do you understand about ADHD?
- 8) At the time of your child's diagnosis, what thoughts were going through your mind and how did you feel?
- 9) Did you feel supported by the health professional through those emotions and thoughts?
- 10) Upon diagnosis, were you provided with any additional information or services that had to do with ADHD? How do you feel about this?
- 11) Did you seek further opinions from other health professionals?
- 12) How much did you know about your child's treatment?
- 13) What were your thoughts about this treatment?
- 14) Did you, or do you, ever feel the need to learn more about your child's disorder?
- 15) Do you have any other support systems, which you utilize?
- 16) Having said all this, can you tell me about your ongoing experience as a parent of a child who is being treated for ADHD?
- 17) Do you have any suggestions that you feel could be offered as possible ways of enhancing and improving a health professional's manner of handling a situation such as your own?
- 18) And lastly, are there any other concerns that you would like to voice regarding anxieties that you may have had, both from the time when your child was first diagnosed and now?

Appendix F

Transcript – Participant 2(P2)

R: **Is your child a boy or a girl?**

P2: *A boy*

R: **How old was your child when he was diagnosed with ADHD?**

P2: *Seven*

R: **How old is your child now?**

P2: *18*

R: **What grade is your child in?**

P2: *Matric*

R: **How, or by whom, was your child diagnosed?**

P2: *A pediatrician*

R: **What treatment regime is your child currently on?**

P2: *Nothing now*

R: **Alright, what was he on before?**

P2: *Ritalin*

R: **What do you understand about ADHD?**

P2: *It's short attention periods, uh, you know, battling to concentrate on anything for any length of time, very scattered thoughts, well in his case anyway. Can be very easily distracted and battles to hold his concentration.*

R: **At the time of your child's diagnosis, what thoughts were going through your mind and how did you feel?**

P2: *Um, you know, I think before he was diagnosed, I knew. I did, I mean, I had fought it the whole of grade one.*

R: **What do you mean by that?**

P2: *The teachers were quite sure that he was that way inclined and I was very anti-medication, so I asked them to work with me. So um, ja, we did a whole year of, you know I would get to the door at the end of school and get a, "Your friend was electrified today, all he managed to do was wash the paint pots". Um, I did query at the time diet. I know diet today; well I believe that diet plays a major part. Well I queried diet then and asked for diets for him, they told me diets*

would make no difference, and I was quite sure there was another way that you could treat the condition and at that stage, and eventually the beginning of grade two, we went onto Ritalin.

R: **Did you feel supported by the health professional through those emotions and thoughts?**

P2: *No, no. I didn't like him at all.*

R: **Ok, how come?**

P2: *Um, he was very pro-diagnosing everybody with ADHD. He was the person the school insisted you used. Um, if you went in there, yes he would weigh the child, measured him, did all the rest. One day in the middle of a question, he looked at his watch and said, "Sorry, your fifteen minutes are up". Um, so no, there was no support from him.*

R: **How did the lack of support make you feel?**

P2: *It was like a sausage factory. These kids just went in, got their Ritalin prescriptions and out and the waiting room was just havoc with all these kids queued up in the waiting room.*

R: **And how did that make you feel upon seeing that?**

P2: *Um, well I never liked Ritalin and I never liked the fact that these kids had to be doped, but you kind of, you kind of pressurized by them and the school and, to just go with it. And I, you know, once you've gone onto Ritalin and the change in the work, the change in the kid, because suddenly he was achieving, then you suddenly think to yourself, shit, you know, really I was horrible, I should have done it last year. Because, with (child's name), you could actually see from page to page, whether he had taken Ritalin that day, the hand writing, everything and I mean for the, he was only on the Ritalin for four years and those four years, he was top of his class. Today he battles to pass, so it's got its pros and cons.*

R: **It must be quite confusing for you, because on one hand you are against the Ritalin and on the other, you are seeing these amazing results from it?**

P2: *Ja. And you know, I also I had a brother who was diagnosed with ADD, you know forty years ago, when they didn't know anything about it and I'd lived with that and my mom having to give him Ritalin and in those days, it was like two tablets a day and he'd walk around like an absolute zombie. Um, it wasn't monitored like it is today, where it's worked out on their weight and stuff like that, there was none of that. Um, and all the trouble she went through with him, so I started off negative against Ritalin and then you know, no support, but kind of pressurized by everybody to do this big thing.*

R: **Upon diagnosis, were you provided with any additional information or services that had to do with ADHD and Ritalin?**

P2: *No.*

R: **Really? How do you feel about this?**

P2: *Well, you know, as I said, he didn't give you any support. When I asked if there were side effects to Ritalin, I was only told, the only side effect there would be was loss of appetite. Ah, now I know there are a lot more side effects to Ritalin but they don't tell you that, even years later when he developed OCD (Obsessive Compulsive Disorder), and through my own research, I found out it was a side effect of Ritalin. Then I went back to the pediatrician and spoke to him about it and he denied that it was a side-effect. Ja, you know, if you going to do that to your child, go in knowing the facts so that you can make an educated decision. Don't give people, you know, he said diet wouldn't help, there were no side effects except, the kid would lose his appetite and that was it.*

R: **Did you seek further opinions from other health professionals?**

P2: *No. Purely because you kind of like swept along and the results come out and the kid's doing better and you think, oh I was just being stupid, you know.*

R: **How much did you know about your child's treatment? You obviously had past experience with the drug from your brother as well?**

P2: *Ja, but when I questioned that they said, "Ah, no no, that's years ago, it's been totally modified since then and adjusted and it's, you know, almost a different drug".*

R: **Okay, and did they try to explain it to you, about how it had been modified?**

P2: *No. "Don't compare it", that was what I got told. They just said that there are thousands of kids on Ritalin and they do fine and you know.*

R: **What were your thoughts about this treatment?**

P2: *You know, if I think back to this, all that time, it was really just, you get caught up in this whole thing, where you start. You know he went to the (local assessment centre), to be assessed initially and then I was sent off to the pediatrician. Um, I lie, not the (local assessment centre), I had him privately assessed by a lady, I think she was (lady's name), and then I didn't want him to go to the (local assessment centre) for like a whole week. I said to her, right you take him for one on one, she had him for two sessions and then from there she said, "Right, we need an occupational therapist". Ja, you know they were saying, "yes, definitely signs of ADHD" and everybody just confirms it and you just get swept along.*

R: **At any time during this did you feel confused and bewildered about this?**

P2: *I don't know. You know I think at that stage, you don't know what you doing, you just literally, that one says go to the next one, and the next says go to the next one, and each time you just go, and you are punch drunk eventually.*

R: **Did you, or do you ever feel the need to learn more about your child's disorder?**

P2: *Well, since then, ja I did. Because I'm quizzy and once he developed side effects, then I then went ahead and did my own research, because we were battling to get people to help us, um you know, when he was diagnosed with OCD. So then I decided that, well, if nobody could help me, I could help myself. It was one of those scenarios and just, I mean I eventually said to the psychiatrist, "That is the medication he will go on", which is the one we used and not the one that they normally used here in South Africa.*

R: **And did you find that researching your own information helped?**

P2: *Oh, ja.*

R: **How did you feel when you felt a more clued up?**

P2: *Ja, you feel in more control. You feel that when you going to go into these places, these people aren't going to now say stuff that will go way over your head and you just, eventually you feel so stupid, you just go with whatever they say. I could now challenge them and ask the proper questions and that sort of thing, which forced them to then discuss it on my level.*

R: **Having said all this, as a parent, can you tell me about your experience of having a child that is being treated for ADHD?**

P2: *Look, I don't think these kids are easy, particularly when they are young, um, because you don't know. It's the blind leading the blind and as a young parent you don't know and you kind of like swept into this whole thing and away you go. I also had both kids very close together, so I was dealing with two of them, 19 months apart, and you know, he just wasn't sleeping. He was climbing walls and windows and burglar guards and escaping out of, climbing through the burglar guards and escaping into the garden, when I wasn't looking, I mean he was a nightmare. But, and I remember those early days saying to (spouse's name), "All I feel I do from day to day, is damage control and cope". That's all you do, you don't, you kind of exist. You don't, you know I look at the other mothers and parents and their kids are sitting calmly, and they take them and they can put them at the Wimpy and, oh, no, please, we could never do any of those things. I mean the first movie we did when he was ten and we left half way through, because by then he was standing on his head and the people behind couldn't see because his legs were flicking up and down.*

R: **So, it's quite disruptive for you as well then?**

P2: *Ja, it is. But because the kids are so busy, you so busy, that at the end of the day, if you actually sit back and think well, what did I do today, it was just trying to stay one step ahead of him and try to cope and predict what he was going to do next.*

R: **So, you must have been physically and emotionally exhausted?**

P2: *Finished. Finished! I was a skinny little runt. But saying that I wouldn't change him for anything. I wouldn't because he's got a personality that comes through, that I look at other children and I think, ah you know, you just sit there. You know, life was always very exciting with (child's name) and then of course, no two days were the same and you know, you just, it was fun.*

R: **So you did have many good times?**

P2: *Oh ja, you know and you just had to keep up with him. But very challenging, I mean, jeez, there were days that I honestly couldn't, I can understand why people batter children. Absolutely. Oh, ja, I mean there were days when I would actually put him in a room or lock myself in a room so that I couldn't go near him, because I would've hit him.*

R: **It also seems to put strain on your mother-child relationship as well.**

P2: *Oh ja, because he tends to push you and he still does, I mean he's 18. He pushes me to breaking point and then he just backs off a little bit and even as a little oke, he'd then crawl onto my lap and put his arms around my neck and say "Ooh, I love you mommy", and then you like, phew and then you take three steps back. But half an hour later he's got you on that edge again and that was how we lived. He tests the boundaries all the time, and still does.*

R: **Do you have any other support systems that you utilize?**

P2: *You just try and develop a support system within your friends. Because I had no family here, um, I had two friends who became a support system for me and you know, if he was now driving me to distraction, then I'd say to them, "Bring your kids to come and play", because if there were other kids, he would back off me a bit and he would go to them for an afternoon, just too.*

R: **Are there any other concerns that you would like to voice regarding anxieties that you may have had, both from the time when your child was first diagnosed and now?**

P2: *I think, I think it's really good if there are support groups out there for people to belong to. I joined the one at (child's school) eventually. That was just a group of us mothers that got together and we all had kids that were the same so we understood each other's kids and if any of us were reading any good books that helped us, we'd pass them on, that sort of thing. It was*

just nice to speak to somebody else who doesn't think that your child is an absolute lunatic, because their kids are exactly the same. Ja, often you compare to the cousins or the friends and you think, "Ah you know they must think my child is mad".

R: Do you have any suggestions that you feel could be offered as possible ways of enhancing and improving a health professional's manner of handling a situation such as your own?

P2: *I really think that the initial consultation needs to be a lot more clear and um, you know, now that we know diet affects and stuff like that, put you on to those sort of things, because I really think a lot of these kids on Ritalin, diet would have sorted them out.*

Appendix G

Letter of Ethical Clearance