

CHILDREN WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER
NEEDS AND EXPERIENCES OF PARENTS/CAREGIVERS RECEIVING
SERVICES FROM A PUBLIC SECTOR HOSPITAL

BY

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Submitted in fulfillment of the academic requirements for the degree of MASTER OF SOCIAL WORK in the School of Social Work and Community Development, Faculty of Humanities, Development and Social Sciences, University of KwaZulu-Natal.

DECLARATION

Submitted in fulfilment of the requirements for the degree of Master of Social
Work, in the Graduate Programme in

Social Work and Community Development, University of KwaZulu-Natal,
South Africa.

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. I confirm that an external editor was not used. It is being submitted for the degree of Master of Social Work in the Faculty of Humanities, Development and Social Sciences, University of KwaZulu-Natal, 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

The focus of this study was the exploration of parents and caregivers experiences of raising children with ADHD and their experiences of services at a public sector hospital. There is a paucity of scholarly studies conducted on this topic in South Africa. The context of the study is the public sector hospital where the researcher is employed as a social worker. Through her interactions with the parents and caregivers of ADHD affected children she became aware of the challenges that they were exposed to and this prompted her to undertake the study.

This was a qualitative study and a purposive sample was used. Semi-structured interviews were conducted with 21 participants and one focus group was conducted as a method of triangulation, with six participants. This study was guided by two theoretical frameworks, namely the bio-psychosocial and ecosystems approaches.

The main conclusions drawn from the findings of the study were that many participants experienced a lack of support from their families and from the hospital. Participants did not have sufficient knowledge of the comprehensive treatment plan available in the management of ADHD. Health care professionals failed to engage in mutual decision making with participants, related to ADHD treatment and they neglected to address the concerns of participants regarding their children. A further finding was that the referral process to allied health professionals was inconsistent. Participants also experienced difficulties with the hospital administrative processes.

Based on the findings, the recommendations include the need for more comprehensive support which includes medical and psychosocial support for participants. The limited knowledge base of participants with regard to the nature, causes and the use of medication for ADHD should be addressed by the health care providers. This could be achieved through participant education on the disorder at the initial stages of diagnosis. ADHD should be managed in a more collaborative and co-ordinated manner at the health care facility through an actively interdependent team.

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CHAPTER ONE

CONTEXTUAL FRAMEWORK OF STUDY

1.1 INTRODUCTION

Attention deficit hyperactivity disorder (ADHD) is a behavioural condition, predominantly diagnosed in childhood (Snyman & Truter, 2010). The essential features are developmentally inappropriate levels of inattention, impulsivity and motor activity, (American Psychiatric Association, 1994). Attention deficit hyperactivity disorder is not a benign disorder. This then implies that ADHD is an “active” disorder that causes devastating problems for the individual diagnosed with it (Venter, 2006). These problems interfere with social relationships in all spheres of the individual’s life. Children with ADHD experience severe and chronic impairment in daily functioning, including academic problems, disruptive behaviour and problematic relationships with parents, teachers and peers (Venter, 2006). As the problematic nature of the disorder suggests, increased caretaking demands exist for parents of children with ADHD (Neff, 2008).

ADHD and disruptive behaviour disorders are among the most common reasons for referrals of children to mental health services (Kazdin et al, 1990 cited in Mcleary, 2002:285). It is the most common child psychiatric disorder in Europe and the United States of America affecting between 3 to 10 percent of primary school children (Meyer, 2004). Research conducted by Snyman and Truter (2010) suggests that ADHD is the most prevalent child psychiatric disorder in South Africa. They found that statistics from a South African study conducted on ADHD shows that it predominates in boys (3:1 male: female ratio). This impression is however changing with the emergence of a group described to have attention deficit disorder without hyperactivity, where girls outnumber boys (Venter, 2006). The Attention Deficit Hyperactivity Support Group of South Africa (ADHASA) estimated in 2004 that 10 percent of all South African children may have characteristics associated with ADHD (Snyman & Truter, 2010). However, very little is known about ADHD on the African continent (Meyer, 2004).

This chapter provides an overview of the background to the study, the significance of the study, the main aim, objectives and key questions of the study. Included are the theoretical frameworks which guide the study.

1.2 Description of the problem and rationale

As noted in the introduction there has been limited research on ADHD on the African continent (Meyer, 2004). According to Snyman and Truter (2010) the same is true of South Africa as there is little published information on the incidence, treatment and management of ADHD. Research on ADHD in South Africa has either been conducted with private practitioners or at community clinics. There is no evidence of ADHD studies conducted at public hospitals in KwaZulu- Natal.

The paediatric department at the public, district regional hospital under study runs an ADHD clinic as one of its specialized services. Over the last few years a growing number of children have been diagnosed with the disorder and prescribed medication for its treatment. In 2008, 610 children with ADHD were treated at the clinic as compared to 720 in 2009 (statistics from the paediatric clinic). This increase in the number of children being managed for ADHD is significant.

I am a social work manager at the hospital in KwaZulu-Natal. As a health care professional at the hospital, I address the psychosocial needs of children diagnosed with ADHD, together with their parents or caregivers who are referred for services. Generally parents and caregivers are referred for social work services when there is treatment non-compliance. My preliminary investigation into non-compliance with ADHD treatment revealed several underlying problems experienced by parents and caregivers of ADHD affected children which underscored the need for a study of this nature.

In discussions with parents and caregivers an overwhelming number indicated dissatisfaction with services relating to their children's diagnosis and treatment of ADHD. Subsequent discussions with the paediatric professional nurses highlighted the need to identify problems experienced by parents and caregivers. The abovementioned discussions necessitated a study of this nature.

A further rationale for the study was that parents and caregivers expressed through their interactions with the social worker, psychologist and occupational therapist how isolated they felt in their battle with the disorder. It was apparent that they were not coping with their ADHD affected children. I felt that this study would provide pertinent information on parent support structures or the lack thereof.

The ADHD clinic at the hospital has been operational for many years. This is the first time that a topic of this nature is being researched at the hospital under study. It will therefore provide valuable information to health care professionals in their management of the disorder.

1.3 Main aim of research

The main aim of the research was to explore the needs and experiences of parents/caregivers whose children have been diagnosed with ADHD.

1.4 Research objectives

The research objectives were:

- To determine the needs of parents/caregivers of children diagnosed with ADHD.
- To explore parents/caregivers experiences of services received at the hospital.
- To identify parents/caregivers recommendations for future services at the hospital.

1.5 Key questions

The research questions were as follows:

- What are the needs of parents/caregivers with children diagnosed with ADHD?
- What are parents/caregivers experiences of services provided at the hospital?
- What are parents/caregivers recommendations for future services at the public sector hospital?

1.6 Significance of study

The results of the study would assist in the development of policies and protocols in the management of ADHD. Further, the findings could potentially identify the type of support structures parents/caregivers would find beneficial to them. This study would be fundamental in the formulation of effective ADHD parent training programs and other

intervention programs designed for use by health care professionals for the effective management of ADHD in children in receipt of services from the public sector.

Although the study has been undertaken at a selected public hospital the findings would be useful to health care professionals within public sector hospitals that provide a similar service. Research undertaken in this field has focused mainly on the medical management of the disorder. There has been limited research conducted in South Africa from a social work perspective. This study would add value to paediatric social work practice as it would assist in the psychosocial management of the disorder.

1.7 Theoretical framework

The two theories that provide a framework and guide this study are the bio-psychosocial approach and the ecosystems approach.

1.7.1 Bio-psychosocial approach

The bio-psychosocial approach is a comprehensive health care approach in its ability to deal with current problems, predict mental and physical health problems and supply a sound scientific basis for health promotion (Vanker et al, 1990). Within this approach human functioning is viewed as an interaction of biological, psychological and social factors (Schlebusch, 1990). This approach emphasizes that each person is comprised of systems which in turn are part of external systems (Schlebusch, 1990). This means that "while individuals are composed of molecules, cells and organs, this being their biological structure, they also belong to families, communities, cultures, nature and the world" (Schlebusch, 1990:15).

The biological, psychological and social structures of each individual are interdependent. ADHD may be considered primarily a biological disorder because of neurobiological and genetic associations. However its aetiologies have also been associated with psychological and social factors and the interplay of all 3 factors (Sagvolden et al, 2005). The psychological sphere relates to the structure and processes of the mind and the social functions relate to structure and processes of the society in which the person lives (Schlebusch, 1990). ADHD results from, and is continuously modified by the dynamic context of individual predispositions and interpersonal surroundings (Sagvolden et al, 2005). This disorder affects more than one system in an individual (Schlebusch, 1990).

Hence, the disruption of family equilibrium, stressful events, the child's temperament and environmental factors are some of the factors of the psychosocial construct of the disorder. The individual with ADHD must be viewed as a whole as the biological, psychological and social constructs of the disorder are closely interrelated. These constructs, in the context of this study, are discussed below:

Biological construct

The parent/caregiver after receiving their child's diagnosis needs to understand the nature and causes of the disorder and the treatment regime required for the management of the child. This would result in improved therapeutic benefit due to patient adherence.

Psychological construct

The aim is to understand how parents/caregivers respond to the child's condition. For optimal upbringing the family has to adapt to the child's special needs by taking into account the implications of the child's challenging behaviour and adjust their expectations and demands accordingly. At this level, the impact of the child's ADHD diagnosis on emotional health, participants' levels of stress and self esteem issues were explored.

Social Level

The impact of the child's condition on relationships such as the spousal relationship, extended family, peers, school and with the health care workers at the hospital was explored.

The bio-psychosocial approach was suited to this study as it allowed for holistic understanding of the experiences of parents and caregivers with their ADHD affected children.

The ecosystems theory is discussed below.

1.7.2 Ecosystems theory

Ecosystems theory, which is based on systems theory, highlights how interconnected society is, embedded in various social systems (Rothery, 2001). The key concept of the ecosystems theory is that "all people or groups of people in a system share a reciprocal

influence on one another” (Rothery, 2001:70). The reciprocal relationship shows that individuals change and are changed by the environment. In order to function well in society, people must maintain a good fit with their environment (Wakefield, 1996). The ecosystems approach was considered for this study because of its emphasis on the “person in environment”. According to Kotkin and Fine (2003) quality of life for parents and caregivers depends in part on how they attempt to cope with their children’s disorder. If there is adequate support offered by the various social systems to parents and caregivers in the management of their children’s disorder then there would be a “goodness of fit “with the environment.

Bronfenbrenner’s ecosystems model, presents an ideal theoretical framework for this study, as it enhances the understanding of the ADHD affected child as well as the parent/caregiver by taking their larger environmental context into account. For equilibrium to be reached at the different levels, interaction between the levels must occur on a fairly regular basis (Bronfenbrenner, 1994). In the following paragraphs the different levels of the ecosystems theory, in the context of this study, is discussed.

Microsystem

The microsystem refers to an individual’s immediate surrounding. At this level Bronfenbrenner (cited in Berk, 2000:28) speaks of all relationships being bi-directional, that is, adult behaviour affects children’s behaviour and adults are also affected by children’s characteristics. An example to illustrate this relationship is that of a friendly, attentive child who is likely to evoke positive and patient reactions from parents whereas a distractible child as in the case of an ADHD child is likely to receive restriction and punishment. Parent-child interactions are at the centre of the micro-system therefore it follows that participants play a crucial role at this level. The family is a very important part of the micro system and they have to have an understanding of the child’s diagnosis.

Mesosystem

This is the second level of Bronfenbrenner’s model and it encompasses connections between microsystems (Berk, 2000). Such systems in the case of the ADHD child would involve the school, the home, the extended family, the neighbourhood and the health facility. At this level it is important to explore the relationships between participants and the different social systems that play a part in the lives of ADHD affected children. If

there is equilibrium at this level then there is “goodness of fit” between the micro and meso levels. Parent-child and caregiver-child relationships are each likely to support development, when links in the form of visits and exchange of information, are built between home and child care setting (Berk, 2000).

Exosystem

The exosystem refers to social settings that do not contain children but affect their experiences in immediate settings (Berk, 2000). In the case of the ADHD affected child this system would include parents/caregivers employers and their workplace where leave policies are discussed for hospital appointments. It is important for this structure to be flexible and supportive. Included also at this level would be some of the infrastructure that parents/caregivers depend on such as transport. Parents/caregivers have to bring their children for early appointments to the hospital therefore they require that this infrastructure is available and reliable. Non –government organisations such as the Attention Deficit Hyperactivity Association of Southern Africa which are meant to assist parents/caregivers by providing a supportive role also form part of this exo-system. If this system fails or is in disharmony then this could have a negative impact for both parent and the child.

Macrosystem

This is the outermost level in Bronfenbenners’ model. It consists of cultural values, laws, customs, and resources. The priority that the macro system gives to children’s needs affects the support they receive at the inner levels of the environment. With ADHD it is important that at a macro level government and non-governmental organizations lobby for more support resources to be established within communities and which can be easily accessed by the community. Policies and protocols needs to be continuously reviewed and updated by the government departments responsible for the management and treatment of ADHD.

The subsystems outlined above, served to guide the researcher in carefully identifying the areas in which deficit and dysfunction may have occurred in the management of the ADHD child and the parental relationships thereof.

1.8 Definition of terms and abbreviations

ADHASA- Attention Deficit Hyperactivity support group of South Africa (Picton, 2005)

Attention Deficit Hyperactivity Disorder (ADHD) - a behavioural disorder of attention and impulse control with specific DSM-IV criteria. It is a developmental disorder that appears in childhood and may continue through to adulthood (Barkley, 2000).

Caregiver- Any person other than the parent or guardian who factually cares for the child (No 38 of 2005: Children's Act, 2005).

CD- conduct disorder

CNS- Central Nervous System

Dopamine-This is a neurotransmitter found in the brain. Neurotransmitters are released to tell your brain what to do. Dopamine in particular helps initiate and control movement, energy and alertness (Brock, 2009).

DSM-IV- Diagnostic and Statistical Manual of Mental Disorders

EFA- Essential Fatty Acid

Methylphenidate (Ritalin) - A central nervous system stimulant used in the pharmacotherapy of ADHD (Bester, 2006)

Multimodal-It is a treatment approach to ADHD that involves medical, educational and behavioural interventions. It consists of parent and child education about diagnosis and treatment, behaviour management techniques, medication and school programming and supports (Venter, 2006).

ODD- oppositional defiant disorder

Parent- the biological mother or father of a child (<http://en.wikipedia.org/wiki/parent>)

PET- Positron Emission Tomography- A non invasive brain scan

1.9 Structure of the dissertation

The dissertation comprises of six chapters:

Chapter one

This chapter contains an introduction and background to the study, the significance of the study, the main aim, objectives and key questions of the study. Incorporated in this chapter are the theoretical frameworks which guide the study.

Chapter two

This chapter consists of the literature review. This includes an overview of ADHD, the history of the disorder, the aetiology and epidemiology of ADHD. Also discussed in this chapter is the diagnosis of the disorder, the pharmacological aspects, alternate treatments, roles of health care workers and the effects of the disorder on parents/caregivers.

Chapter three

This chapter details how the research was conducted, the research design, research paradigm, sampling method, data collection tools and analyses are discussed.

Chapters Four & Five

These chapters provide an analysis and discussion of the results of the study.

Chapter six

The conclusions and recommendations of the study are discussed.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter provides a review of the literature with respect to the history and definition of ADHD, the aetiology of the disorder, the diagnosis and differential diagnosis and other co-morbid conditions. Included in the chapter are alternate views and treatment of ADHD, in particular, the multi modal approach to management of ADHD within public sector hospitals. The main section in this chapter focuses on parental stress, care demands and the use of support services from a public sector hospital. The biological and psychosocial constructs of the disorder are also discussed.

2.2 History of attention deficit hyperactivity disorder

ADHD was first described in 1902 by George Still as the “lack of moral control among children without noted physical impairment” (Rowland *et al*, 2002:162). The early origins of ADHD have been linked to the encephalitis epidemic of 1917-1918, whereby children who survived the infection experienced subsequent problems such as hyperactivity, personality changes and learning difficulties (Rowland *et al*, 2002). The disorder has been identified in the literature for many years under a variety of terms. From 1940 through 1960, the condition was identified as minimal brain damage or minimal brain dysfunction and its aetiology was attributed to damage in the brain such as a head injury, infection or toxic damage (Kidd, 2000). In the 1960s the condition was referred to as “hyperactivity” or “poor impulse control” with no mention of any underlying organic damage (Kidd, 2000: 403).

In 1980, the “hyperactivity” symptom had taken on a “more diagnostic significance” and the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (Third Edition, DSM-III) listed the term “Hyperactivity” as hyperkinetic reaction of childhood (Kidd, 2000:403). This term “Hyperactivity” evolved through “hyperkinetic syndrome”, “hyperactive child syndrome” to “attention deficit disorder”, either with hyperactivity or without (Kidd, 2000:403). By 1987, there was a shift in focus from the hyperactive symptom of this disorder to symptoms of inattention and impulsivity. Research on the disorder continued to progress and the three major

diagnostic clusters were further refined until 1994 when The Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM 1V) officially termed the disorder, Attention Deficit Hyperactivity Disorder or ADHD, with 3 subtypes (Kidd, 2000). The past 100 years has seen the disorder come under scrutiny from many researchers in the field of child and behavioural development, but ADHD still remains a “highly variable, complex and imprecisely” defined condition (Green & Chee, 2004:2).

2.3 Definition and Diagnosis of ADHD

The term ADHD is commonly used by lay people, support groups and by professionals (Bester, 2006). ADHD is characterised by pervasive and impairing symptoms of inattention, hyperactivity and impulsivity according to DSM-1V (Polanczyk et al, 2007). It is one of the most common psychiatric disorders that cause distress in the lives of both children and adults, as well as the lives of all other role players involved with these children (Lowe, 2009). The symptoms of childhood ADHD affect cognitive, academic, behavioural, emotional, social and developmental functioning (Rader *et al*, 2009). ADHD is the most commonly diagnosed neurodevelopmental disorder in children and adolescents (Rader *et al*, 2009)

The current Diagnostic and Statistical Manual of Mental Health Disorders (4th edition-revised (2000) specifies three subtypes of ADHD:

- predominantly inattentive subtype
- predominantly hyperactive/impulsive subtype
- or combined subtype

The inattentive subtype described in the DSM-1V –TR (2000) diagnostic criteria for ADHD requires 6 or more symptoms of inattention to have persisted for at least six months. According to the diagnostic criteria, inattention includes the child failing to give close attention to details, making careless mistakes and experiencing difficulty sustaining attention in tasks or play activities (DSM-1V-TR, 2000). In addition they experience problems following through on instructions, organising tasks and with listening when spoken to directly. Researchers, Green and Chee (1997) comment that it is these behaviours that children with ADHD present with that parents find bothersome and emotionally stressful.

The sub-type described in the diagnostic manual (DSM-1V-TR, 2000) are the hyperactive/impulsive behaviours. There must be 6 or more symptoms of hyperactivity-impulsivity to have persisted for at least six months to a degree that is maladaptive and inconsistent with the child's developmental level for the child to be diagnosed with ADHD. Children with ADHD have poor impulse control and are often getting themselves into trouble. They act before they think with no thought given to the repercussions of their actions. Other symptoms that present in the child with ADHD are that they are accident prone, they talk excessively, fidget with hands or feet and often have difficulties playing or engaging in leisure activities (Green & Chee, 2004).

The hyperactive/impulsive child is the greatest challenge to a teacher and this child is often found in the principal's office because of his/her behaviour in the classroom (Green and Chee, 1997). Children with the hyperactivity/impulsivity sub-type may exhibit behaviour such as blurting out answers, interrupts or intrudes on others and has difficulty waiting his/her turn. The third subtype of ADHD is a combination of symptoms of the inattentive and the hyperactive/impulsive subtypes.

The diagnosis of ADHD usually occurs when the child is about six or seven years old and this coincides with the child starting school (Saddock & Saddock, 2009). According to Saddock and Saddock (2009) there are some hyperactive/ impulsive or inattentive symptoms that result in impairment which are present before age 7 years. For ADHD diagnosis, impairment from the symptoms is usually present in two or more settings such as the home environment and at school. There must be clear evidence of clinically significant impairment in social, academic or occupational functioning (Saddock & Saddock, 2009).

According to Saddock and Saddock (2009) the principal signs of hyperactivity and impulsivity are based on a detailed prenatal history of a child's early developmental patterns along with direct observation of the child, especially in situations that require attention. These authors add that hyperactivity may be more severe in some situations and less marked in others and it may be less obvious in pleasant structured activities such as sport.

Saddock and Saddock (2009) state that children who have hyperactivity as a predominant feature are more likely to be referred for treatment than are children with primary symptoms of attention deficit. From a biological perspective a “child’s history may give clues to prenatal (including genetic), natal, and post natal factors that may have affected the central nervous system structure or function” (Saddock & Saddock, 2009:1225). The rate of a child’s development, the deviations in development and parental reactions to significant or stressful behavioural changes should be ascertained, as they may help clinicians determine the degree to which parents have contributed or reacted to a child’s inefficiencies and dysfunctions (Saddock & Saddock, 2009).

The ecosystems approach which underpins this study explores the manner in which the different levels affect and are affected by each other. In terms of diagnosis the school which forms the meso level has an integral role to play in the assessment of a child suspected of having ADHD. The school history and teachers’ reports are important in evaluating whether a child’s difficulties in learning and school behaviour are primarily due to the child’s attitudinal or maturational problems or to poor self image because of felt inadequacies (Saddock and Saddock, 2009).

The parent, siblings and extended family who are found within the micro and meso levels also contribute to the diagnostic process by describing their interactions and observations of the child in the home and social environment (Green and Chee, 2004). The manner in which a child relates to siblings, to peers, to adults, and to free and structured activities gives valuable diagnostic clues to the presence of ADHD and helps identify the complications of the disorder. Collaboration between the school, the parent and the health care provider does not presently exist. Health care workers may not necessarily have the time in busy public health facilities to render holistic care in this regard and it thus remains a neglected area in terms of ADHD diagnosis (DeMarle & Ernthausen, 2003).

The bio-psychosocial approach which guides this study focuses on the importance of understanding the biological constructs of this disorder. A neurological examination is necessary when diagnosing ADHD as it may reveal “visual, motor, perceptual, or auditory discriminatory immaturity or impairments without overt signs of visual or auditory acuity disorders” (Saddock & Saddock, 2009:1225). These authors add that an important aspect of diagnosing ADHD is the use of an electroencephalogram test (EEG)

to recognise the child with frequent “bilaterally synchronous discharges resulting in short absence spells”. The child with an unrecognized temporal lobe seizure focus can have secondary behaviour disorder. In these instances, several features of ADHD are often present (Saddock & Saddock, 2009:1226). Venter (2006), in his study contradicts the value of an EEG in diagnosing ADHD by stating that an EEG plays no part in the diagnosis or prognosis of ADHD.

According to Venter (2006), an accurate diagnosis of ADHD will include an adequate history and subsequent collateral information from various sources. The more thorough the history taking and the more members of the team are involved in providing additional data, the more likely the diagnosis will be correct. There is no single defining test used in diagnosing ADHD.

The overall approach to diagnosis may involve the following according to Goldman *et al* (1998).

- A comprehensive interview with the child’s adult caregivers.
- A mental status examination of the child.
- A medical evaluation for general health and neurologic status.
- A cognitive assessment of ability and achievement.
- Use of ADHD-focused parent and teacher rating scales.
- School reports and other adjunctive evaluations if necessary (speech, language assessment, etc) depending on clinical findings.

Whilst Venter (2006) views history taking from various sources to be integral to diagnosing ADHD in children, Goldman (1998) advocates for the bio-psychosocial approach to diagnosis. This entails the mental and physical examination of the child as well as the psychosocial assessment to be conducted in all spheres of the child’s life. Both researchers stress the importance of collaboration with educators as an essential ingredient to the diagnosis process; however there is little evidence to support this statement.

A gap exists in service delivery relating to the diagnosis of neurological disorders within South African public hospitals, as there is a gross shortage of qualified neurologists

(<http://www.doh.gov.za>). The type of services advocated for by researchers in the field of ADHD is therefore not being provided to children with ADHD. The public health system is currently overburdened with chronically ill patients and is in a crisis with the shortage of skilled medical professionals; therefore the time taken to diagnose the child with ADHD would be limited as this condition would not be considered as priority in a crisis oriented paediatric clinic (Cullinen, 2006).

The following sub-section will focus on the differential diagnosis and co-morbid conditions to ADHD.

2.3.1 Differential diagnosis and co-morbidity

When there are a number of conditions that appear a lot like ADHD but are not ADHD it is known as a differential diagnosis (Saddock & Saddock, 2009). A differential diagnosis of ADHD may be made by the health care professional as the behaviour of a child with ADHD could be mistaken for another similar psychological disorder. Co-morbidity may be defined as two conditions that occur together in the same individual (Saddock & Saddock, 2009). To make a diagnosis of ADHD before the age of 3 years is difficult because of the overlapping features of a normally immature nervous system and the emerging signs of visual-motor-perceptual impairments frequently seen in ADHD (Saddock & Saddock, 2009).

Shokane and Rataemane's (2004) findings are similar to Saddock and Saddock (2009) in that they note that there are a myriad of disorders that mimic ADHD. This then poses a great challenge for medical practitioners in their evaluation of the child. The presence of ADHD greatly increases the coexistence of associated or co-morbid conditions (Green & Chee, 2004: 53). Studies of children with ADHD consistently document higher rates of co-morbidity with other psychiatric conditions, including disruptive behavioural disorders, depression, other mood disorders, anxiety disorders, tic disorders etc. The incidence of co-morbidity ranges from 50 to 90 percent (Shokane & Rataemane, 2004). The existence of an additional disorder dramatically affects the prognosis, treatment and health care delivery decisions. Correctly identifying ADHD is complicated by a high prevalence of co-morbid disorders or the presence of conditions that can be confused with ADHD (Shokane & Rataemane, 2004). These co-morbidities present extra challenges to parents, educators and to health care providers as they are so often easily

confused or misdiagnosed as ADHD. The most frequently occurring co-morbid conditions are briefly discussed below:

2.3.1.1 Oppositional defiant disorder

According to Venter (2006), Oppositional Defiant Disorder (ODD) is one of the conditions most frequently associated with ADHD (Bester, 2006:47). It is claimed that 40 percent of ADHD children are also ODD (Green & Chee, 2004:54). Children who are diagnosed with ODD are often rebellious, lose their tempers, refuse to obey adults and argue. These children do not accept blame and usually blame others for their mistakes.

2.3.1.2 Conduct disorder

Conduct Disorder (CD) is a much more serious behavioural problem than ODD (Bester, 2006:47). The media often wrongly diagnoses CD behaviour as ADHD. The behaviours of conduct disorder (CD) include “lying, cheating, stealing, threatening, cruelty, violating the rights of others, destruction of property and inflicting pain” (Green & Chee, 2004: 56). When CD is associated with ADHD it usually starts young, with a severe presentation of ODD before the features of CD first come through between the age of seven and ten years. The factors that increase the risk of CD are “marital discord, hostile-critical parenting, and probably the poor early treatment of ADHD” (Green & Chee, 2004:57).

2.3.1.3 Tics and Tourette syndrome

There is a higher incidence of minor twitches and involuntary movements occurring in those diagnosed with ADHD than with the general population (Green & Chee, 2004). Tics refer to involuntary twitches, usually around the eyes or face, but sometimes a clearing of the throat, movement of the neck or shrug of a shoulder. The most extreme form of tic disorder, Tourette syndrome, involves throat noises, other major involuntary movements and occasionally the uttering of inappropriate words (Green & Chee, 2004: 59). Tic and Tourette syndrome rarely causes any significant problem in behaviour, learning or emotional well-being, however the same cannot be said for the presence of ADHD which can cause great disadvantage in all these areas (Green & Chee, 2004: 59).

2.3.1.4 *The clumsy child*

Difficulties with co-ordination, motor functioning, written work and late neurological maturity are all commonly associated with ADHD (Green & Chee, 2004). When ADHD and co-morbid clumsiness coexist, therapists tend to see the motor problems in the child and term this the 'Clumsy Child Syndrome' (Green & Chee, 2004).

2.3.1.5 *Anxiety disorders*

ADHD has also been associated with anxiety disorders. Anxiety symptoms are generally expressed in four domains, these are the cognitive, affective, physical and behavioural (Spencer *et al*, 2007). The cognitive elements may range from "rumination and vigilant apprehension to catastrophic thinking" whilst behavioural features may include agitation, tantrums, attention seeking and overdependence (Spencer *et al*, 2007: 638). It is estimated from epidemiological studies on ADHD that anxiety disorders range from 25 to 34 percent in children (Furman, 2005). However, the anxiety seen in children with ADHD seems to be related more to poor emotion control than to fear and panic (Barkley, 2002).

2.3.1.6 *Learning problems*

Handicaps in reading and spelling abilities are often manifested in children with ADHD. They also experience problems with computation (Bester, 2006). Findings from a study conducted on cognitive performance using children with ADHD and a control group showed poor performance by the ADHD group on standard measures of intelligence and achievement as opposed to the control group (Spencer *et al*, 2007). However research conducted by Chan (2007) showed the overall intelligence of children with ADHD to be normal. Various studies also show that children with ADHD perform more poorly in school, repeat grades and require more tutoring than non ADHD children. In response to poor academic performance by learners with special needs, the South African Department of Education has prioritized the needs of learners with ADHD in the Education White Paper 6 on Special Needs Education (2001). This document pays particular attention to the role of educators in identifying and teaching learners who may have barriers to learning.

At a micro level, parents of children with ADHD are often not able to accept that their children have a learning disorder and this results in them having unrealistic expectations

of their children. At a meso level, educators experience problems within the classroom as these children are often described as “lazy” or “slow” and tend to demand more of the teacher’s attention than the average child.

2.3.1.7 Substance abuse disorders

Data obtained from studies indicates that children with ADHD are at an increased risk for smoking cigarettes and abusing substances (Faraone & Wilens, 2003). These authors add that there has been persistent fear that the use of stimulants to treat ADHD has a potential for abuse. However, the study which examined the association between pharmacotherapy and substance abuse dispelled the hypothesis that stimulant drugs used in the treatment of ADHD induced substance abuse, rather they confirm that stimulant treatment appears to reduce the risk for substance abuse disorders (Faraone & Wilens, 2003). Recent research suggests that ADHD children disproportionately become involved with cigarettes, alcohol and then drugs (Spencer *et al*, 2007). These researchers added that these individuals tend to maintain their addiction longer compared with their non ADHD peers.

2.3.1.8 Depression

Depression occurs in children with ADHD at a significantly higher rate than in children without ADHD (Daviss, 2008). Depressive disorders may emerge several years after the onset of ADHD and may be attributed to environmental difficulties associated with chronic ADHD. The ADHD affected child with depression is “moody, preoccupied, sad and withdrawn and often shows stress by becoming more irritable and annoying” (Green & Chee, 2004:58). Other signs and symptoms of the depression include physiologic disturbances such as changes in appetite and weight, altered sleep patterns, fatigue, psychomotor abilities, feelings of guilt and worthlessness (Spencer *et al*, 2007). Some of the associated features of depression in children include school difficulties, school refusal, withdrawal, somatic complaints, negativism, aggression and antisocial behaviour (Spencer *et al*, 2007). Many children with ADHD have secondary depression in reaction to their continuing frustration over their failure to learn and their consequent low self esteem. This condition must be distinguished from a primary depressive disorder (Saddock & Saddock, 2009:1227).

According to Green and Chee (2004) the failure to see the association between ADHD and the above co-morbid conditions remains one of the most frequent causes of

misunderstanding and incorrect treatment. The co-morbid conditions can be viewed from a bio-psychosocial paradigm where these conditions occur as a result of biological factors in the child but the manner in which these conditions present themselves affects the child's psychological and social sphere. The family unit and the child's school environment play a significant role in this area of co-morbidities as it is imperative that they are supportive instead of punitive in their responses to the child's behaviour (Green and Chee, 2004).

A discussion on the epidemiology and prevalence of the disorder follows in the next section.

2.4 Epidemiology and prevalence of ADHD

ADHD is a behavioural disorder that affects up to 1 in 20 children in the USA (Faraone *et al*, 2003). There are as many as four million children that carry this diagnosis in the USA, which is responsible for 30 to 50 percent of referrals to mental health services (Kidd, 2000). The predominance of American research into this disorder over the past 40 years has led to the impression that ADHD is largely an American disorder and is much less prevalent elsewhere. Contrary to this view, research conducted in non –United States populations found that the prevalence of this behavioural disorder in many countries is in the same range as that in the USA (Faraone *et al*, 2003). Results from a recent meta analysis on prevalence rates revealed that “South American countries have the highest prevalence (11,8 percent) of school-age children with the disorder and European countries have the lowest prevalence, 4,6 percent” (Singh, 2008). In South Africa at least 3 to 6 percent of the school aged population may have ADHD (Snyman & Truter, 2010). However, little published information exists about the incidence, treatment and care of ADHD in South Africa (Snyman & Truter, 2010). The lack of available South African statistics makes it difficult to compare with other countries. According to the Attention Deficit Hyperactivity Support Group in Southern Africa (ADHASA), between 8 to 10 percent of the South African population have ADHD (Picton, 2005).

According to Polanczyk *et al* (2007) the reasons for variability with the prevalence rates have not been completely understood however demographics and geographics seem to play an important role. Kidd (2000) found that ADHD affects 3 to 6 percent of the school age population from diverse cultures and geographical regions. This view is supported by Faraone *et al* (2003) who suggests that ADHD is a behavioural disorder common to

children of many different races and societies' worldwide. Literature shows that ADHD is diagnosed three to nine times more often in boys than in girls in South Africa (Snyman & Truter, 2010). The reason for this difference is that many girls with ADHD may be overlooked because their symptoms may not be as flagrant as that of boys (Chan, 2007). Green and Chee (2004:157) comment that the reason many girls remain undiagnosed is that by nature they tend to be less disruptive but they "suffer" more silently than males. However Venter (2006) argues that there is a shift with girls now being diagnosed more often than in the past.

ADHD may persist into adolescence in about 85 percent of patients and into adulthood in about 31 percent of patients which confirms that ADHD is a developmental disorder (Venter, 2006). According to Barkley (2006) children with ADHD face greater adversity in their adult lives than non-ADHD children. It is recognised that ADHD is a chronic condition that will persist over the lifespan.

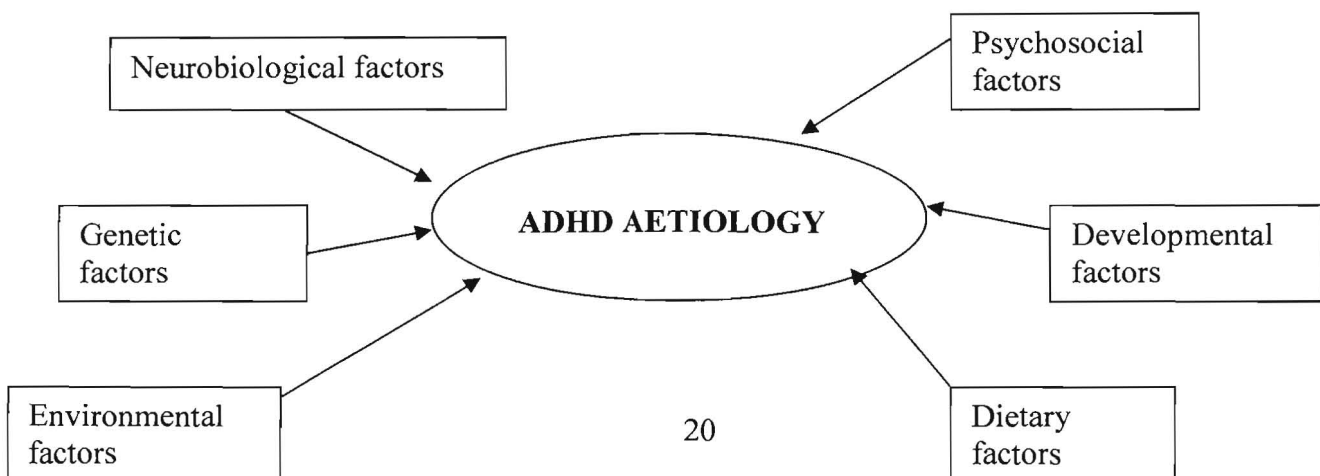
In the following discussion, the aetiology of the disorder is discussed.

2.5 Aetiology of ADHD

The aetiology of ADHD is disputed, but current research suggests that no single aetiological process is involved (Brock, 2009) The exact cause of ADHD remains undetermined but emerging evidence suggests a host of contributing factors such as genetic and hereditary factors, neurobiological conditions and pathologies, nutritional factors and deficiencies and environmental influences to be the contributing factors to ADHD (Madrona, 2003). The aetiology of ADHD can be viewed from a bio-psychosocial perspective (Starcher, 2002). The figure below depicts the bio-psychosocial model of ADHD related to the aetiology of the disorder.

Figure 2.1(adapted from Starcher, 2002)

The bio-psychosocial aspects of ADHD aetiology



2.5.1 Genetic factors of ADHD

There is strong evidence that genetics plays a powerful aetiological role in ADHD which suggests a biological basis for ADHD. Evidence in support of this comes from a variety of studies on the following subject matter, family, twin, adoption, genome and candidate gene search studies.

2.5.1.1 Family studies

“A genetic component to ADHD is strongly suggested because ADHD clusters in families” (Rowland *et al*, 2002: 166). A study conducted by Biederman (1992, cited in Rowland *et al*, 2002) reported that 34 to 40 percent of subjects from a clinic referred sample had a family history of ADHD as compared to 8 percent of the control group. Children share 50 percent of their genes with each parent therefore for genetics to play a vital role in the aetiology of ADHD it must run in families (Brock, 2009). Researchers Green and Chee (2004), claim that children with ADHD usually have a close relative with a similar problem. Thus a family history of ADHD is an important variable to consider when diagnosing the disorder.

2.5.1.2 Twin and sibling studies

Green and Chee (2004) in their research, showed evidence in identical twin studies where if one twin has ADHD, there is an almost 90 percent chance that the other will also have this problem. Twin studies suggest that concordance for hyperactivity is greater among monozygotic twins than dizygotic twins (Brock, 2009). Barkley's (2006, cited in Brock 2009), twin study suggested the average heritability of ADHD to be at least 80 to 90 percent. The risk to siblings or non-identical twins is approximately 32 percent (Madrona, 2003). Studies done by Saddock & Saddock (2009) indicate that siblings of hyperactive children have about twice the risk of having the disorder as those in the general population.

2.5.1.3 Adoption studies

Early adoption studies focused on ADHD confirmed that the biological relatives of children who were hyperactive were more likely to have hyperactivity than the adopted relatives of these children (Brock, 2009). Madrona (2003) and Saddock and Saddock (2009) strongly support the view that it is genetics and not the environment that is a cause of ADHD.

2.5.1.4 Genome search and candidate gene search studies

Two approaches are used to evaluate the genetic aetiology of ADHD: Firstly, the genome scan which examines all chromosomal locations without guessing which genes underlie ADHD. Within ADHD affected families, DNA sequences along different chromosomes are examined for slight differences in order to find differences which are consistently found among family members who have ADHD (Biederman, 2005). By determining how close the differences or polymorphisms, unique to the ADHD family members are to a specific gene, it could be linked to that gene (Biederman, 2005). ADHD genes could then be located within that chromosome region (Brock, 2009). It was beyond the scope of this study to go into further detail on this subject.

Family, twin and adoption studies offer persuasive evidence that ADHD is a heritable disorder whilst genome and candidate gene studies suggest that the explanation of ADHD is quite complex.

2.5.2 Developmental factors

A variety of developmental factors have been associated with an increased risk for ADHD. These include pre, peri and post-natal complications, toxins and brain injury (Brock, 2009). Studies conducted by Saddock and Saddock (2009) report that prenatal exposure to winter infections during the first trimester may contribute to the emergence of ADHD symptoms in some susceptible children. It has been speculated that some children affected by ADHD suffered subtle damage to the central nervous system (CNS) and brain development during their foetal and perinatal periods. The “hypothesized brain damage may potentially be associated with circulatory, toxic, metabolic, mechanical, or physical insult to the brain during early infancy caused by infection, inflammation and trauma” (Saddock & Saddock, 2009: 2556).

Pregnancy and delivery complications (ie. toxemia, eclampsia, poor maternal health, maternal age, foetal post maturity, duration of labour, foetal distress, low birth weight, antepartum hemorrhage) are predisposing factors for ADHD (Biederman, 2005). Brock (2009) and Biederman (2005) found that a variety of pregnancy, birth and neonatal complications have been associated with a predisposition to ADHD. They listed foetal distress, forceps delivery and young maternal age to be added as predisposing factors to ADHD in children. Studies document that maternal smoking, alcohol exposure during

pregnancy and low birth weight are additional independent risk factors for ADHD (Biederman, 2005).

2.5.3 Neurobiology of ADHD

Modern brain monitoring techniques have established that ADHD is organically a brain dysfunction and that behavioural abnormalities are the result of developmental brain pathologies (Kidd, 2000; Brock, 2002). Neurochemical and neurophysiological research methods have been used to understand the neurobiology of ADHD. Neurochemical and neurophysical factors are discussed below.

2.5.3.1 Neurochemical factors

Many neurotransmitters have been associated with ADHD symptoms. The neurotransmitters dopamine and norepinephrine have been implicated in the pathophysiology of ADHD (Rader *et al*, 2009). According to Biederman (2005), although there are several inconsistencies with studies done in this area, it can be hypothesized that deficits in frontal lobe function and the connections between the frontal lobe and key sub cortical regions underlie this disorder. Damage to the frontal lobe has been associated with symptoms evidenced in ADHD. The importance is that the frontal areas of the brain are thought to be involved in the processes of attention, executive functions and motor functions (Biederman, 2005). In ADHD these areas show less activity and may also be relatively smaller. According to Saddock and Saddock (2009) although many neurotransmitters have been associated with ADHD symptoms, overall there is no evidence which implicates a single neurotransmitter in the development of ADHD.

2.5.3.2 Neurophysiological factors

Saddock and Saddock (2009) in their ADHD study found that the human brain normally undergoes major growth spurts at several ages: 3 to 10 months, 2 to 4 years, 6 to 8 years, 10 to 12 years and 14 to 16 years. There are some children who have a maturational delay in the sequence and may present with symptoms of ADHD. Studies conducted by these researchers using subjects with ADHD and a control group indicate no consistent findings regarding computed tomographic (CT) head scans with children. However, Saddock and Saddock (2009) state that using the positron emission tomography (PET) scan showed lower cerebral blood flow and metabolic rates in the frontal lobe areas of children with ADHD than with the control group. They explain the theory that supposes

that the frontal lobes in children with ADHD are not adequately performing their inhibitory mechanism on lower structures, this effect leading to disinhibition.

There is convincing evidence that ADHD is associated with significant differences in brain development, this includes overall brain size, and specific prefrontal, striatal and cerebella differences (Biederman, 2005). The prefrontal cortex which is situated near the front of the frontal lobes, and is thought to be responsible for executive functioning, has been found to be significantly smaller among children with ADHD (Spencer *et al*, 2007).

2.5.4 Psychosocial factors

Several studies have suggested that the severity of ADHD is associated with family stressors and other psychosocial variables (Brock, 2009). Saddock and Saddock (2009) cite stressful events, disruption of family equilibrium and other anxiety inducing factors as factors that contribute to the initiation or perpetuation of ADHD. They add further that predisposing factors may include the child's temperament, genetic-familial factors and the demands of society to adhere to a routinized way of behaving and performing.

In a study conducted by Biederman *et al*, (cited in Brock 2009), they had implemented the "Rutters Adversity Indicators" such as severe marital discord, low social class, large family size, paternal criminality and maternal mental disorder. The findings of Biederman *et al* (cited in Brock, 2009) were that the risk of ADHD increased as the number of adversity factors increased. Pressman (cited in Brock, 2009) concludes that there are strong links between impairment in children with ADHD and family environment. Findings from more recent studies reveal that chronic family conflict, decreased family cohesion and exposure to parental psychopathology, particularly maternal, were more common in ADHD families compared to control families (Brock, 2009). There appears to be no relationship to socio economic status as a predisposing factor to ADHD (Saddock & Saddock, 2009).

It can be concluded that the severity of symptoms in ADHD patients may be related to the stress and social adversity experienced among families of children with the disorder. Psychosocial factors may not be the exact cause of ADHD but it clearly affects the clinical presentation of this disorder.

2.5.5 Dietary factors

There are a number of divergent views and convictions about the effect of eating habits on ADHD. Diet therapy to treat ADHD was first made famous by Dr Benjamin Feingold in 1973 (Bendelius, 2003). The Feingold theory proposed that salicylates, artificial food colours and artificial flavours caused ADHD and that a diet free of these substances would dramatically decrease hyperactivity (Bendelius, 2003). Research in this area is still being conducted to confirm or refute this theory. Another commonly held belief is that ADHD symptoms stem from the ingestion of refined sugar; however this aetiological explanation has also received much criticism because despite its persistent popularity, it has fared poorly in carefully controlled studies (Anastopoulos & Barkley, 1998). Contrary findings by Green and Chee (2004) suggest some parents do see changes with diet but these are only with one or two clearly identified foods such as chocolate, cola, some cordials and some artificial colourings and flavourants. Dietary studies conducted by Holford & Burne (2006) reveals that hyperactive children eat more sugar than other children. A study conducted on 265 hyperactive children found that more than three quarters displayed abnormal glucose tolerance, meaning that their bodies were less able to handle sugar intake and maintain balanced blood sugar levels (Holford & Burne, 2006).

Additional research on nutrition indicates that a deficiency of Essential Fatty Acids (EFAs), namely Omega 3 and Omega 6 seem to aggravate neurological and other symptoms of ADHD (Picton, 2005). ADHD has been associated with the deficiency in the breakdown of the Essential Fatty Acids. It is notable that children diagnosed with ADHD also have symptoms of essential fatty acid deficiency, such as excessive thirst, dry skin, eczema and asthma (Holford & Burne, 2006). It can be concluded that hyperactive children have a deficiency of EFAs either due to an inability to absorb EFAs adequately from the gastrointestinal tract or because their requirements are higher than that of other children (Picton, 2005). Professionals in the field of dietary management agree that diet is not the cause of ADHD but it does exacerbate the condition.

2.5.6 Environmental toxins

There has been suggestive evidence that environmental toxins such as lead have been linked to the aetiology of ADHD (Rowland *et al*, 2002). Rice *et al* (1996, cited in Rowland *et al*, 2002), reported from their study that animals injected with lead are far more aggressive, more distracted by irrelevant stimuli and were less able to inhibit

inappropriate responses. Children exposed to lead are often left with “permanent neurological sequelae” that include attention deficits (Kidd, 2000:412). Lead is damaging to cognition and behaviour in children and could cause both developmental delay and mental retardation (Kidd, 2000). Given the pessimistic data of the environmental toxins, children with ADHD should be screened for heavy metal load, either where prior exposure is established or where other ADHD risk factors have been ruled out.

In the following section, the pharmacological aspects to the management of ADHD will be discussed.

2.6 Pharmacological aspects of treatment

The use of stimulant medication for treating ADHD is not new, as it was first shown to be effective in 1937 for treating disruptive behaviour in children (Venter, 2006). It was however not widely used until the late 1950s when Methylphenidate (Ritalin) was first introduced (Green & Chee, 2004). According to Green and Chee (2004) stimulants have been used for more than fifty years although the exact mechanism of action is still unknown. The use of stimulants is the mainstay of the medical management of children with ADHD in South Africa and methylphenidate also remains the drug of choice for the pharmacological management of ADHD in South Africa (Truter, 2005).

Methylphenidate is a central nervous system stimulant and shares many of the pharmacological effects of amphetamines (Wright, 1997). The active constituent of Ritalin is methylphenidate hydrochloride and Ritalin’s scheduling status is schedule 6 (Bester, 2006). Numerous studies have shown the efficacy of Methylphenidate (Ritalin) in reducing the core symptoms of ADHD which are inattention, hyperactivity and impulsivity. Stimulant drugs result in immediate and often dramatic improvement in behaviour. Despite the efficacy of Ritalin in suppressing the symptoms of ADHD, the use of such a powerful drug to control children’s behaviour and increase compliance has caused considerable apprehension for parents of these children (Wright, 1997).

The growing use of the stimulant Ritalin for the treatment of ADHD has generated worldwide debate both in the media and in the medical community. The apparent dichotomy that exists with the use of Ritalin is that on the one hand it is promoted as effective in the management of ADHD but on the other, it is criticized as a problematic

drug of abuse (Evans *et al*, 2004). Recently the extensive use or overuse of Ritalin has been a widely publicised concern and the prescribing patterns of Ritalin have also resulted in public health concerns about the frequency and appropriateness with which this stimulant is prescribed by medical practitioners to children (Truter, 2009).

Stimulants like Ritalin improve the ADHD affected individual's ability to block irrelevant thoughts and impulses. There are two theories according to Taylor (1997, cited in Bester, 2006: 126) as to how Ritalin works. The first theory suggests that Ritalin acts chemically like dopamine and therefore acts in the brain as a synthetic addition to dopamine in the brain. The second theory is that the stimulant (Ritalin) helps release already formed neurotransmitters like dopamine and noradrenalin and that it cannot influence the generation of neurotransmitters.

Ritalin, which is available on prescription in South Africa, comes in different forms. Bester (2006:124-125) lists them as follows:

- Ritalin: The “normal” Ritalin which has an efficacy period of about 4 hours. This should not be recommended for school going children as it has a short efficacy period.
- Ritalin SR 20(Slow Release): The absorption of methylphenidate in SR20 is slower than conventional Ritalin and it has an efficacy period of 8 hours. Ritalin slow release may be recommended for school going children as it would prevent them from taking their midday dosage at school.
- Ritalin LA 20, Ritalin LA 30, Ritalin LA 40(Long Acting): With the Ritalin LA, half of the methylphenidate in the capsule is absorbed immediately and the other half in the modified release capsules is only absorbed about four hours later. The Ritalin LA capsule basically contains two doses of methylphenidate that is administered as one dosage but is absorbed at different times. As a result there are two plasma concentration peaks, separated by about 4 hours. Ritalin LA would benefit school going children as it is long acting.

In the following sub-section the use of an alternate drug is discussed.

2.6.1 Concerta

This drug has been available in South Africa since 2005. It represents a new dosage formulation of methylphenidate and it works much the same way as Ritalin (Venter, 2006). The rationale for developing Concerta was for once a day dosing. Bester (2006:128) states that the advantages of using Concerta are as follows:

- Only one daily dosage is required
- Lengthened efficacy rate (twelve hours)
- The possibilities of abuse are less

This medication is still very new in South Africa and is not readily available for dispensing at public hospitals (Bester, 2006:128).

2.6.2 Side effects of methylphenidate

Resistance by parents' and caregivers to the use of psychotropic drugs in the management of ADHD persists mainly because of the reputed side effects. Venter (2006) reports the following side effects of methylphenidate:

- Anorexia and weight loss- A loss of appetite is quite common. Loss of appetite was reported in 13 to 60 percent of ADHD paediatric patients and parents worry about growth reduction resulting from this loss of appetite (Meijer *et al*, 2009). This is usually the case with thinner patients. Anorexia decreases after two to three weeks of treatment.
- Insomnia and Nervousness- Researchers found that the most common side effects are sleep deprivation and anxiety. This normally occurs during the initial stages of treatment. This side effect may be controlled by reducing the dosage or by skipping the afternoon dose.
- Growth Suppression- Methylphenidate has been reported to delay growth in children with ADHD. Fortunately these growth delays associated with Methylphenidate appear to be short lived and reversible.
- Dysphoria- refers to a state of being sensitive to criticism and subject to tears. Barkley, McMurray, Edelbrock and Robbins (1990) found that 49 percent of their ADHD cohorts were prone to crying, 72 percent were irritable, 58 percent were anxious and 43 percent presented with sadness.
- Cardiac Symptoms-children using Methylphenidate may complain of mild palpitations and there may be mild elevations in blood pressure and cardiac rate.

- Drug Abuse- many parents fear that children receiving Methylphenidate may become addicted. This fear arises from the fact that Methylphenidate binds the dopamine transport protein similar to the way cocaine does, however Methylphenidate has a lower potential for abuse. Studies concluded that Methylphenidate is a mild stimulant and that stimulant therapy does not promote drug abuse in children. The responsible provision of Methylphenidate therapy should not lead to abuse or addiction problems. Contrary studies indicate that the stimulant, Methylphenidate may protect children against later drug abuse.
- Headaches, impaired vision, dizziness and dyskinesia (inability to perform voluntary movements) are side effects which may manifest but are not common. The same could be said for side effects such as convulsions, muscle cramps, fits, toxic psychosis and depression. These side effects are resolved upon discontinuation of the drug.

While the value of stimulant medication for the treatment of ADHD in school-aged children is well established, there is a substantial minority of parents who have reservations about its use (Sonuga-Barke *et al*, 2006). In a New York/Montreal multimodal treatment study of 7 to 9 year old children with ADHD, 25 percent of the parents who enquired about the study indicated an unwillingness to consider medication treatment for their child. Another significant study on the use of methylphenidate found a substantial proportion of potential cases that could not be included because of strong antimedication concerns. Parents cited reasons that included unknown long- term effects of stimulant treatment in children and a desire for non-pharmacological treatment (Sonuga-Barke *et al*, 2006). According to Green and Chee (2004), it has been shown conclusively that stimulants work in the short term; however the long term effects still remain unknown. These authors add that there have been reported improvements in 70 to 90 per cent of children with ADHD.

Despite the wealth of information advocating the benefits and effectiveness of pharmacotherapy of ADHD in children, especially Ritalin, not all parents are convinced about this treatment option. The widespread mounting controversy over the widespread use of Ritalin and the possible life threatening effects from its long- term use make it imperative that alternate modalities be implemented for ADHD management. In view of parents' reluctance to administer medication, the development of effective non-

pharmacological therapies for treating paediatric ADHD is a major public health priority. Psychosocial approaches, however are currently not recommended as stand –alone, frontline treatments for ADHD, instead they are a component in a multimodal strategy that targets the broader range of behavioural and emotional problems that frequently accompany the disorder.

The conventional management of ADHD involves a multimodal approach which includes individual and family education, counselling, behaviour therapy, school remediation, diet and medication (Picton, 2005). In the next section psychosocial interventions are discussed and the use of multidisciplinary and interdisciplinary teams in the management of ADHD.

2.7 Psychosocial interventions

A range of psychosocial interventions are discussed below. These include behavioural approaches, cognitive behaviour therapy, parent training programs, parent support groups, parent and family therapy and parent education.

2.7.1 Behavioural approaches

Behavioural approaches represent a broad set of specific interventions that have a common goal of modifying the physical and social environment to alter or change behaviour (AAP, 2001). Behavioural approaches are used in the treatment of ADHD to provide structure for the child and to reinforce appropriate behaviour. In treating ADHD by implementing behavioural interventions, the ecosystems approach is emphasized as parents as well as a wide range of professionals, such as psychologists, school personnel, primary care physicians, occupational therapists and social workers are involved at different levels in the treatment process. These levels would include the child and the parents who are treated at a micro level and at a meso level, the interactions between the therapists and educators regarding the child's inattentiveness at school. Behavioural treatments are most effective when they are conducted in the child's natural environment. These interventions are usually carried out in the home or at school. One justification for using behaviour modification techniques for ADHD is the argument that, since referral of children for ADHD in part rests on the social distress they have created for their caregivers, an intervention that attempts to change the interaction between children and their caregivers should be useful (Barkley, 2002).

Pelham *et al* (cited in Sadag, <http://www.sadag.co.za>.) found in their 25 studies the effectiveness of behaviour therapy with ADHD affected children. By contrast they found no studies demonstrating the effectiveness of individual or play therapy. Behaviour treatments can be divided into two broad categories, namely: Clinical behaviour therapy and direct contingency management (Sadag, <http://www.sadag.co.za>).

Clinical behaviour therapy is usually conducted by a mental health professional such as a psychologist or a social worker in an out patient setting. Clinical behaviour therapy involves training in problem solving and social skills. Parents of ADHD children are confronted on a daily basis with difficult situations relating to their child's disorder, hence training in problem solving would enhance their parenting skills. The contingency management program uses approaches such as positive reinforcement, time outs, response cost and token economy as behaviour modification strategies with ADHD children. These approaches are designed to use direct teaching and reinforcement strategies for positive behaviours and direct consequences for inappropriate behaviour (Barkley, 2000).

These interventions are encouraged for parents to use as it discourages the use of physical punishment. Although the use of behavioural strategies holds promise and allows the ADHD affected child to develop their strengths, other research indicates that behavioural interventions are effective but to a lesser degree than treatment with psychostimulants (Jadad *et al*, 1999). Behaviour therapy has been found to be effective only when it is implemented and maintained (US, Department of Education, 2003). Although behavioural management programs have been shown to enhance the academic performance and behaviour of children with ADHD, follow-up and maintenance of the treatment is often lacking (US, Department of Education, 2003). The benefits of behaviour therapy were seen in 2001 when researchers, Connors *et al* (2001, cited in Sadag, <http://www.sadag.co.za>) indicated that behavioural treatment was an appropriate first level treatment for children with milder ADHD and when families prefer psychosocial treatment as opposed to medication. Within the public sector hospitals social workers use the behaviour modification method of behaviour therapy with parents of children with ADHD (Dept of Health, Social Work: 15/2004) Parents are taught to encourage good behaviour with rewards and withdraw privileges or punish for the undesired behaviours displayed.

2.7.2 Cognitive behaviour therapy

Cognitive behaviour therapy interventions are designed to assist in the management of inattention, to improve academic performance, to build social skills and to reduce disruptive behaviour. The effects of the intervention is evaluated on an ongoing basis and follow up evaluations are conducted to ensure that behaviour change is being maintained and transferred to the various contexts of the child's life (Alexander & Edwards, 2009). The goal is to produce an observable change that is clinically significant. In individual cognitive behaviour therapy, therapists such as social workers or psychologists work with children themselves. Children are taught to regulate their own behaviour through self control strategies such as self-monitoring, self-instructional training, problem solving, cognitive rehearsal, self reinforcement and self evaluation (Alexander & Edwards, 2009). Thus, in implementing this form of psychotherapy, its benefits include an increase in attention span, an increase in self-esteem, effective communication with the various role players in the child's life, effective parenting skills and a decrease in the impulsive and aggressive behaviours in the child, thereby creating an equilibrium within the micro and the meso systems in the ADHD child's life (Moore, 2003).

The process of the child adapting to new, more accepting behaviours, results in more harmonious relationships in the child's life. More widely used cognitive behaviour interventions are those that target the teacher, the parent or other caregivers and who are seen as the main change agents. These change agents are trained to implement contingency management programmes in the everyday context of the child's life both at school and at home. The current behavioural approaches contain elements that are clearly cognitive in form therefore there is no clear distinction between behavioural therapy and cognitive behaviour therapy.

2.7.3 Parent training programs

Behavioural parent training (BPT) is one of the empirically supported psychosocial treatments for ADHD. Over many years and in many studies, BPT has been documented to improve both child ADHD behaviour and maladaptive parenting behaviour (Chronis *et al*, 2004). BPT has also been significant in showing benefits in domains such as parenting stress and child classroom behaviour. The inattentive, hyperactive and impulsive behaviours that characterize ADHD often lead to impairment in the parent-child

relationship and contribute to increased stress among parents of children with the disorder. Researchers found mothers of hyperactive ADHD children less likely to respond positively to their children's social interaction, solitary play activities, and compliance to on-task behaviour, instead the mothers display a more controlling and intrusive interaction style as compared to mothers of non-ADHD children (Johnson & Reader, 2002). Existing evidence seems consistent with the notion that the negative behaviours of children with ADHD can elicit negative parenting behaviour (Johnson & Reader, 2002). According to Barkley (1998, cited in Johnson & Reader, 2002), a disruption in positive parenting seems to lead to increases in negative child behaviours, which in turn may further increase parent stress levels. This evidence is in keeping with Bronfenbrenner's ecosystems theory, where he speaks of all relationships being bi-directional at a micro level (Berk, 2000). Thus, the child's behaviour influences the parent and parents' behaviour would influence the child.

Given the stress levels of parents, over time parents may develop maladaptive and counterproductive parenting strategies to deal with the problems. It follows that effective treatment for ADHD must include working directly with parents to modify their parenting behaviours to increase positive outcomes with their children (Chronis *et al*, 2004). Effectively modifying poor parenting practices is crucial, as poor parenting is one of the more robust predictors of negative long-term outcomes in children with behaviour problems. Parent training has a successful history as being one of the most effective ways to change parenting and therefore treat ADHD (Pelham *et al*, 1998).

Social workers or psychologists are key role players in the management of ADHD and are part of the multi-disciplinary team of professionals responsible for providing parents with behaviour modification techniques that are based on the social learning principle. Parents are taught to identify and manipulate the antecedents and consequences of child behaviour, target and monitor problematic behaviours, reward prosocial behaviour through praise, positive attention, tangible rewards and decrease unwanted behaviour through planned ignoring, time out and other non physical discipline techniques. Although the empirical evidence supports the use of BPT in addressing multiple issues faced by parents and caregivers of children with ADHD, not all parents benefit from BPT equally. A review conducted by Miller and Prinz (1990, cited in Chronis *et al*, 2004), reported the non optimal use of BPT in situations such as single parenthood, multiple environmental stressors such as low socioeconomic status, parental adjustment factors such as marital

discord and inappropriate parental expectations regarding parental involvement and child improvement during BPT.

2.7.4 Parent support groups

Parenting support is any intervention for parents aimed at reducing risks and promoting protective factors for their children, in relation to their social, physical and emotional well-being (Moran *et al*, 2004). Bronfenbrenner's ecosystems perspective provides a framework for understanding how factors that impinge on parents and children nest together within a hierarchy of different levels; socio-cultural (macro-system), community (meso system); family (micro system) and the individual. These levels also describe a "pathway of influence moving from the distal (social and community factors) to more proximal (family and individual factors), reminding us that parenting does not take place in a vacuum, but within a complex web of interacting, interdependent factors" (Moran *et al*, 2004). Building on this model it shows us that parents and children influence each other in an ecological and bi-directional way (Moran *et al*, 2004).

It is difficult to parent ADHD affected children as specific parenting skills need to be developed to match their special needs (Moore, 2003). The general public can never understand why an ADHD affected child should be so different and difficult and invariably blame the parents (Picton, 2005). Parents of ADHD affected children are usually emotionally stretched to the limit, exhausted and feeling guilty (Picton, 2005). Support groups are one of the most effective forms of treatment for parents with ADHD affected children (Moore, 2003). It is often a relief to parents when they discover that they are not in a unique situation in dealing with their ADHD affected children and they learn that there are many children like their own (Picton, 2005).

Support groups are helpful for parents in assisting them to discard their feelings of guilt and inadequacy. Moore (2003) and Picton (2005) share similar views on the benefits of support groups which include parents having the opportunity to share experiences with each other, groups provide information as well as emotional support and parents receive feedback from their shared experiences and are able to be effective care-givers. Through the use of support groups parents can relate to the frustrations experienced by others and empathise. These meetings have a therapeutic and cathartic effect on the individuals that attend (Moore, 2003).

In South Africa, the support group that has been founded for parents is the Attention Deficit Hyperactivity Support Group of Southern Africa (ADHASA), which has its national office in Johannesburg and branches throughout the different provinces (www.adhasa.co.za). However, support groups of this nature are centrally situated and cannot be easily accessed by communities that live in the lower socio economic suburbs. It is then the task of the hospital social worker or psychologist who within their scope of practice may facilitate such a group within the hospital setting.

2.7.5 Parent and family therapy

Family therapy is defined as, “any psychotherapeutic endeavour that explicitly focuses on altering the interactions between or among family members and seeks to improve the functioning of the family as a unit, or its subsystems, and or the functioning of the individual members of the family” (Cottrell & Boston, 2002). Parents and families influence their children’s development in many areas, their cognitive and academic skills, speech and language ability, behaviour and social competence. Families also have an opportunity to help with additional challenges faced by children with emotional and behavioural difficulties. When a person in a family has a serious problem or difficulty, that problem often acts as a stressor on the whole family. That ‘it’s everybody’s problem’ is especially true for families of children with ADHD. Harpin (2005) concluded in his study that ADHD indeed impacts not only the child but also on parents, causing disturbances to family and marital functioning. The family context of a child with ADHD is critically important in understanding the child. The parent-child interactions in a family of a child with ADHD have been shown to be inherently more negative and stressful for all family members than the typical interactions in other families (Barkley, 2000).

Family oriented therapy, whether used as the primary treatment or in combination with other treatments, such as medication, behavioural management programs, cognitive behaviour therapy or other modalities has been successful in treating a range of behavioural, academic and psychiatric disorders in children (www.aboutourkids.org). While there is a wealth of outcome research showing that family therapy works in treating behavioural and psychiatric disorders in children, there are also increasing challenges from public and private mental health bodies to demonstrate an evidence base for the approach (Larner, 2004). According to Cottrell and Boston (2002), family therapy is not high on the

preferred treatment list for mental health services in relation to ADHD. This view was also supported by Nathan and Gorman (1998 cited in Larner, 2004) who in their influential guide to psychosocial treatments, reported the dominance of cognitive –behavioural therapies. Researcher’s reviews found that family therapy is not perceived widely as a major treatment of choice for ADHD and is at risk of being replaced by other evidence based techniques and approaches (Larner, 2004).

Within the public hospital setting, family therapy is not widely used for several reasons. Firstly, it is most often the mother who attends the clinic with her child. The fathers very rarely attend hospital with their child due to their work commitments (Bester, 2006). Secondly, family therapy is time consuming and would require the therapist to spend a lot of time with one family. In a public hospital, with the high patient load and a shortage of staff it is impossible to provide this type of therapy with all families of ADHD children (Cullinen, 2005).

2.7.6 Parental Education

Parents of children with ADHD are often lacking critical information about the chronic nature of the disorder. They are usually bombarded with all sorts of conflicting and often incorrect information on their children’s condition from well meaning friends as well as professionals who hold strong opinions but don’t understand ADHD fully (Green and Chee, 1997). Experts in the field of ADHD advocate providing information on the disorder as part of the treatment for families of children of ADHD. This intervention would correct misperceptions about ADHD and diminish negative feelings that may accompany misperception (Mcleary, 2002). Research indicates conflicting findings about the relationship between knowledge about ADHD and willingness to pursue treatments for ADHD (Mcleary, 2002). In a study conducted in the United States and presented at the American Academy of Child and Adolescent Psychiatry, the results showed that 60 percent of parents were not aware that ADHD can persist into adulthood and believed that dietary manipulation would improve ADHD symptoms and were therefore reluctant to start their children on stimulant medication (Ananzi Health, <http://www.ananzihealth.co.za>).

A similar study conducted at the Mount Saint Vincent University published in the Canadian Journal of Psychiatry, found that parent’s knowledge of ADHD and opinions of treatment played a significant role in whether they are willing to consider treatment for

the child with ADHD. The study further highlighted that providing information to parents regarding ADHD and offering them treatment options could have a favourable impact on treatment enrolment and therefore treatment adherence (<http://www.ananzihealth.co.za>). “A moderate negative correlation between mother’s knowledge of ADHD and perceived parenting competence” suggests that providing information about ADHD may improve mothers’ confidence (Mcleary, 2002:290). Increasing parents’ knowledge base on ADHD may indicate positive effects on parent-child conflict, child behaviour and adjustment, family functioning and parent mood (Mcleary, 2002).

2.8 Integrated multimodal approach to ADHD

The treatment and management of ADHD in children is best viewed from a bio-psychosocial approach, where a combination of stimulant medication and psychosocial approaches ensures success in treating the disorder. Because no one intervention is maximally effective, literature supports a multimodal approach (Hazelwood *et al*, 2002). A review of literature indicates that ADHD represents a syndrome in which many mind-body subsystems are involved, therefore one can understand why both, pharmacological and non pharmacological interventions is required for optimal treatment of ADHD (Starcher,2002).

The National Institute of Mental Health (NIMH) and six academic research sites have undertaken a major study for ADHD on treatment efficacy in the United States and Canada (Pelham et al, 1999). This study, known as the multimodal treatment study for children with ADHD occurred over a 14 month period, using 579 subjects (Pelham et al, 1999). Pelham, the primary researcher described the four treatments they offered for ADHD: behavioural treatment, medication management, combined treatment (medication & behaviour treatment) and a community comparison control group. The results yielded from the study showed that both medical management and the combined treatments were superior to behaviour management alone and the community sample (Pelham et al, 1999, cited Starcher, 2002). Parents need to be educated about the benefits of medication as it is indeed effective, but it can be more effective if it is supplemented by a behavioural program designed to teach children with ADHD to stay focused on tasks and to control their impulsivity, and by parent training designed to help parents understand and manage the behaviour of their ADHD child (Cosser, 2005).

Within the hospital setting in South Africa, the first line of treatment is the use of stimulant medication (Truter & Snyman, 2009). Doctors prescribe Ritalin to children with ADHD at the first consultation as this was the treatment of choice by doctors (Venter & Linde, 2003). Referrals are sometimes made to the other professionals allied to medicine only if parents report that stimulant medication is not effective or if parents are reluctant to administer stimulant medication. The treatment of ADHD can only be successful if a holistic approach is used by involving all members of the hospital team who provide services to this category of patients.

While genetic studies and response to psychostimulant medication provide strong evidence for biological vulnerabilities associated with ADHD, an integrated bio-psycho-social approach to diagnosis and management of the disorder is advocated (Halasz & Vance, 2002). According to the KwaZulu-Natal treatment protocols for mental disorders (2007), the recommendation for the management of ADHD at public hospitals should be a combination of stimulant medication and psychosocial treatment for both parent and child.

ADHD is by definition a pervasive disorder that touches every aspect of the child's life. Children affected with ADHD have a high incidence of other associated difficulties which includes cognitive disabilities, problems of motor control, conduct and emotional disorders as well as social interactional difficulties. These children have a disorder that not only constitutes a personal handicap but is notable in causing secondary dysfunction in the child's educational, family and social domains (Keen *et al*, 1997). This pervasiveness usually results in a multidisciplinary team approach to the management of the disorder. In treating children with ADHD, the aim is to maximise the child's cognitive, emotional, behavioural and interpersonal development. To achieve this, an integrated multimodal bio-psycho-social approach to treatment must be adhered to by service providers of these children. Further, the psychosocial approach is also implemented to alleviate parental stress that is inevitable in the family of an ADHD child. The multimodal approach which is strongly advocated focuses on medication, behavioural interventions, school based support including remedial strategies, family and individual support, educational interventions and dietary modifications.

2.9 Effects of ADHD on parents

As noted in section 2.3 above, children with ADHD present with a temperamental constellation of high activity, short attention span and impulsiveness which is consistent with the DSM 1V-TR (2000) diagnosis of the disorder (Polanczyk *et al*, 2007). These children are prone to developing disruptive behaviours and often ignore parental requests and refuse to comply with the rules and regulations parents set. “The excessive, demanding, intrusive and generally high-intensity behaviour of children with ADHD as well as their clear impairment in self control elicit greater efforts at direction, help, supervision and monitoring by parents” (Barkley,2000). Thus the role of a parent with an ADHD child far exceeds the demands of what parents of children without ADHD need to do. The strain of raising an ADHD child affects many areas of parental functioning. The discussion that follows shows areas in which ADHD has caused familial dysfunction.

2.9.1 Parental stress

ADHD is a chronic and debilitating disorder affecting a significant number of individuals throughout their childhood and beyond. Based on the ecosystems model which stresses interrelatedness at the various levels of the individual’s functioning, the negative impact of the disorder extends beyond the affected individual to his or her family (Tripp, 2005). Of significance is that parents of children with ADHD very often experience considerable stress in their parenting roles (Anastoupoulos *et al*, 1992). The increased caretaking demands that children with ADHD impose on their parents would suggest that stress does emanate directly from these children’s disorder (Johnson &Reader, 2002).

The stress experienced by parents of children with ADHD does not result solely from dealing with symptoms of inattention, impulsivity and activity level but also from other demands placed on parents as a result of the child’s problem behaviours (Johnson & Reader, 2002). The following stressors represent only a few commonly reported by parents or caregivers. “Parents of children with ADHD must often deal with repeated phone calls from teachers regarding their child’s misbehaviour, they often have to “explain” their child’s behaviour to other parents, they are often restricted socially due to their inability to get someone to care for their children, they often miss work to attend their child’s ADHD clinic appointment and they worry incessantly about the possibility of an accidental injury to their child as a result of his/her behaviour”(Johnson & Reader, 2002).

Researchers emphasize the role of everyday parenting events as sources of caretaker stress. Crnic and Acevedo (1995 cited in Johnson & Reader, 2002) highlight “daily parenting hassles”, and describe them as routine care giving and childrearing responsibilities that parents may, in the form of chronic demands, find irritating, frustrating, annoying and distressing. High levels of daily parenting hassles have been shown to relate to lower life satisfaction, more negative mood and increased maternal distress (Johnson & Reader, 2002). It would seem that the concept of daily parenting stress is of importance in understanding the functioning of families of children with ADHD, as parents of children with this disorder often have to deal with problematic behaviours at much higher rates and at higher levels of intensity than is usually found in normal families (Johnson & Reader, 2002). The degree of parenting stress is determined by parent factors, child factors and social environment factors and the co-dependence of these factors highlights its congruence with the ecosystems model (Mcleary, 2002). The parent factors would be health, depression, a sense of competence, personality and psychopathology. The child factors would include adaptability, acceptability, mood, hyperactivity and reinforcing the parent; and the social environmental factors are parent role restrictions, spousal relationship and social support. Parent-child conflict has an impact on the child, the environment and the parent (Mcleary, 2002)

2.9.2 Parent/ADHD-Child interactions

Understanding parent-child interactions in families of children with ADHD is important for two reasons. Firstly, the potential role family functioning plays in long term prognosis of children with ADHD and secondly, the association of negative child behaviour and parent child interactions with parental adjustment in this ADHD population (Tripp *et al*, 2006). Elevated levels of parenting stress are associated with disruptions to the parent-child relationship, parenting practices and disruptions in parent psychological functioning (Tripp, 2005).

Parenting stress is generally understood to arise from characteristics of the parent, the child and the environment, and the interactions among these factors which highlight the ecosystems perspective when viewing parental stress (Tripp, 2005). Mash and Johnson (1990) agree that parenting a child with ADHD is a highly complex task, in which an interplay among parent, child and environmental factors influences parent-child interactions and child outcomes. Research conducted by Cunningham and Barkley (cited

in Johnson & Reader, 2002) found mothers of hyperactive children to be less likely to respond positively to their child's social interactions, their solitary play activities and their compliance on task behaviours. These researchers found mothers to display a more controlling and intrusive interaction style as compared to mothers of non ADHD children. Researchers reported that mothers of children with ADHD were more depressed, socially isolated and restricted in their parental roles than the mothers of typically developing children (Gupta, 2007). In addition these mothers had less attachment to their children and felt less competent in dealing with them (Gupta, 2007). Mothers of ADHD children reported greater psychological distress and perceived less support from their families than did mothers of children without ADHD (Lowe *et al*, 2008).

According to Mash and Johnson (1990), in most families with hyperactive children, the behaviours of hyperactive children drive the negative and control oriented experience of the ADHD affected child's behaviour. Hence it could be deduced that the negative behaviours of children with ADHD can elicit negative parenting behaviour (Mash & Johnson, 1990). The disruption in positive parenting seems to lead to increases in negative child behaviours which in turn may further increase parent stress levels. This results in a coercive cycle in which parent and child reciprocally elicit negative behaviours from each other, leading to adverse impacts on parent and child functioning (Read & Johnson, 2002). According to Mash and Johnson (cited in Gupta, 2007) with hyperactive children, parenting stress derived largely from the child's behavioural problems and was not due to parental incompetence.

Researchers have noted the impact of the absence of the father figure in the lives of ADHD affected children. There are many reasons for the father's unspoken concerns about his ADHD affected child. These would include feelings of personal failure, weakness, disappointment in their sons and in themselves and concern over their own potential pathology (Singh, 2003). On a positive note, fathers being silent about their child's ADHD diagnosis and treatment may be related to them trying to preserve the marital relationship by not voicing their scepticism about diagnosis and medication. They also attempt to maintain harmony and protect their relationships and interactions with their children (Singh, 2003). Research has shown that fathers are also not keen to discuss their child's diagnosis and drug treatment with friends or family outside the home (Singh,

2003), thus not having the opportunity to unburden themselves of their concerns. Although both fathers and mothers display distress over their children's aggressive and hyperactive behaviours, mothers also display distress over the inattentive behaviours of ADHD, whereas fathers do not. This could be attributed to the fact that fathers parent differently to mothers (Singh, 2003). Tallmadge and Barkley (cited in Singh, 2003) reported that boys with ADHD are better behaved with their fathers than with their mothers. Further research found that fathers' appraisals of their children's behaviour were less severe than mother's appraisals, indicating that fathers may experience their ADHD affected children differently to mothers (Mcleary, 2002). Hinshaw (cited in Singh, 2003) found that a more authoritarian fathering style may be related to a more positive behavioural outcome in children.

Studies have revealed that parents of children with ADHD often react to high child rearing stressors by engaging in inappropriate or less than optimal parenting. These parents frequently give attention to overactive and impulsive behaviour. They give more verbal direction, repeated commands, verbal reprimands and correction than parents of children without ADHD. These parents are less rewarding and responsive than the parents without the ADHD child (Lowe, Danforth & Brooks, 2008). Parents of children with ADHD are found to have lower self confidence and less warmth and involvement with their children than parents of non ADHD children. They also tend to use physical discipline significantly more (Lowe, Danforth & Brooks, 2008).

2.9.3 Parental Depression

Parents of children with ADHD report higher depression than those without ADHD (Cunningham, 2007). Parental depression like other psychiatric disorders is linked to poor child outcomes. While genetic factors do play an important role in depression, the link between parental psychiatric disorders and childhood adjustment appears to be also mediated by poor parenting (Cunningham, 2007). Parents with depression or other psychiatric disorders spend less time and show less affection to their ADHD children, provide poorer supervision, use harsher punishment, inconsistently reinforce rules and argue with partners about child management issues (Cunningham, 2007). Studies reveal that mothers of children with ADHD experience higher levels of depressive symptomatology than do mothers of comparative children. In addition, parental

depression has also been shown to predict family discord and behaviour problems in children with ADHD (Chi & Hinshaw, 2002). If a parent is depressed, with distorted perceptions and cognitions and with difficulties in communication, he or she may have problems with objective evaluations of child behaviour. This would appear to increase the likelihood of conflictual and negative parent-child interactions.

Alcohol consumption has been found to be elevated in parents of children with ADHD and several studies have found increased levels of marital discord and strained interpersonal relationships in ADHD families (Johnson & Reader, 2002). Researchers have also found a positive relationship between high levels of difficult child behaviour with maternal anxiety and depression, feelings of being restricted in the parenting role, a decreased sense of parenting competence, poorer parent-child attachment, and a more negative relationship with spouse and increased levels of family related stress (Johnson & Reader, 2002).

2.9.4 Marital Breakdown

Research has shown that more marriages ended in divorce when the parents had a child diagnosed with ADHD (Grohol, 2009). Marital conflict and poor marital adjustment are common in families of children with ADHD (Cunningham, 2007). Fathers of young children with ADHD are more likely to find their marriages under stress (<http://www.greatdad.com>). In a study conducted at the State University of New York-Buffalo, researchers found that from a sample of 280 families in which a child had been diagnosed with ADHD, 23 per cent of these parents had ended their marriage by the time the child turned eight (<http://www.greatdad.com>). According to Pelham (cited in Grohol, 2009), the stress of raising a child with ADHD leads to marital dissatisfaction and divorce. Some of the reasons for parental conflict are that the mother is often the main caretaker of the child and is left to make important decisions relating to the ADHD child on her own. This leads to her experiencing psychological distress as she has little support from family members including the child's father (Lowe *et al*, 2008). When the task of raising an ADHD child is not shared by both parents, it creates an enormous burden on the primary caregiver and invariably results in the irretrievable breakdown of the marriage.

Research findings suggest that special child care demands faced by parents of children with disabilities can cause significant stress for the parents and significant disruption in family relationships (Floyd & Gallagher, 1997). These demands persist throughout childhood and require continuous adaptation by the parents to both ongoing stressors and frequent crises. When families are able to cope well with special childcare demands they may be able to enhance social and cognitive adjustment for the child, and may also avoid distress and disruption for other family members (Floyd & Gallagher, 1997). The key to successful adaptation lies in the ability of families to access appropriate support services that helps families to cope with child's needs and to reduce the ADHD related problems for the child and family (Floyd & Gallagher, 1997).

In the next section the use of multidisciplinary and interdisciplinary teams will be discussed.

2.10 The use of multidisciplinary and interdisciplinary teams

Multidisciplinary team approaches utilise the skills and experience from different disciplines, with each discipline approaching the patient from their own perspective (Jessup, 2007). This approach involves separate individual consultations which usually occur in a "one-stop-shop" fashion with all consultations occurring in a single day (Jessup, 2007). Children with ADHD have a high incidence of other associated difficulties and very often this results in different professionals being asked to help to manage the disorder (Keen et al, 1997). At a public hospital, the various professionals who make up the multidisciplinary team for the management of the ADHD child are the paediatrician, professional nurse, psychologist, social worker, occupational therapist, pharmacist and dietician. It is common for multidisciplinary teams to meet regularly, in the absence of the patient to "case conference" findings and discuss future directions for the patient's care. The benefit of multidisciplinary teams is that they provide more knowledge and experience than disciplines operating in isolation (Jessup, 2007). However, a critical review of the multidisciplinary team concept found that it was not the most cost effective method and that the challenge was to find more evidence based approaches which focused on improving patient care (Jessup, 2007).

ADHD is managed by many health care workers at a hospital. Because it is a bio-psychosocial phenomenon, it challenges conventional styles of working and presents new

opportunities, in this instance the interdisciplinary approach is the preferred intervention to the multidisciplinary approach (Keen *et al*, 1997; Jessup, 2007). An interdisciplinary team consists of practitioners from different professions who share a common patient population and common patient care goals and have responsibility for complementary tasks. This team is actively interdependent with an established means of ongoing communication among team members and with patient and families to ensure that various aspects of patients' health care needs are integrated and addressed. That is, the patient-history taking, assessment, diagnosis, intervention and short and long term management goals are conducted by the team, together with the patient. The patient and family are involved in any discussions regarding their condition or prognosis and the plans about their care (Jessup, 2007). This approach is patient centred and does not rely only on the case notes presented by the different disciplines.

A common understanding and holistic view of all aspects of the patients care ensues, thereby ensuring that the bio-psychosocial component to treatment of the disorder is promoted and adhered to. The advantages of the interdisciplinary team approach are that it is a patient-centred approach, which is both time saving and cost effective. It also prevents the parents from duplicating information to the various professionals they may encounter. This integrated approach ensures that the biological system (in the case of ADHD, this would refer to the neurological functioning and pharmacological use), the psychological system (how ADHD affects the child's self esteem, the effects on behaviour, personality and emotions) and the social system (how ADHD affects the child's familial, environmental and cultural factors) are in a state of balance with each other. The multi and inter-disciplinary approaches serve to comprehensively address the context in which an ADHD diagnosis has been made.

2.11 The role of the different team members who provide support services

This section focuses on the various role-players within the public hospital system that are involved in providing services to the children with ADHD and their parents and caregivers.

2.11.1 The role of medical practitioners

The assessment of ADHD may be conducted by a neurologist or paediatrician. In the initial assessment, history taking is conducted with the parents of the child. The questions include the health of the parent (before conception and present), details of the pregnancy, birth problems, childhood trauma or any information which the parent finds significant (Picton, 2005). A family history of medical conditions and behavioural changes in the child is also taken into account. The medical doctor also views other systems in the child's life such as the school system as important in giving evidence about the child's classroom behaviour and learning ability. This is in keeping with the DSM IV criteria for ADHD that states that behaviour must occur across multiple settings (Leslie, 2002). The medical practitioner must also rule out other conditions that mimic ADHD. The AAP, Clinical Practice guidelines on ADHD with school aged children (2001) stress that an important aspect of the medical practitioners' role is to provide knowledge and information to parents about the condition in an effort to reduce parental stress and promote treatment adherence.

In a busy state hospital outpatient facility, the aforementioned scenario seldom exists. Medical officers or paediatricians might not have the time or the expertise to diagnose and treat ADHD (Vania *et al*, 1997). Parents complain about overly brief assessments and hasty decisions by the doctor to offer medication (Charach *et al*, 2006). According to Fogelman & Kahan (2007) most experts agreed that the primary care physicians and paediatricians can handle the straightforward cases of ADHD but would have to refer complicated cases to a paediatric neurologist. Not all out patient clinics will have a neurologist or paediatrician on duty all day, given the staff shortage in the department of health. In South Africa 1.8 million children need to be treated by a specialist in paediatric neurology or in child development; however there are only 11 full - time and 5 part-time specialists based in government practice attempting to provide this service (Dept of Health, 2003). In KwaZulu-Natal (Durban), only King Edward hospital and Inkosi Albert Luthuli hospital has one full time and two part time paediatric neurologists (Dept of Health, 2003). According to Fogelman and Kahan (2007) child neurologists may be the only specialists capable of managing patients who have ADHD with associated disorders. In the hospital under study, there is no neurologist available and referrals for the complicated cases of ADHD are referred to Inkosi Albert Luthuli Hospital which has a long waiting list. Very often out patient clinics are managed by medical officers and intern doctors, both having very little knowledge in this specialised field of practice

(Perrin, 1999). This view by Perrin (1999) is supported by Lowe (2009), who reported that doctors have very limited undergraduate training, in core psychiatric conditions especially ADHD.

2.11.2 The role of professional nurses

Nurses are active participants in all aspects of management of the child with ADHD. Nurses co-ordinate services and serve as a liaison between health and educational professionals directly involved in the child's therapy program. Nurses provide support and guidance to children and families during the difficult period of the child growing up with a disabling condition (Hockenberry *et al*, 2006). Nursing management begins with an explanation to the parents and the child about the diagnosis, including the nature of the problem and the practitioner's concept of the underlying central nervous system basis for the disorder. Another role that the nurse plays is one of educator as parents of ADHD children need information about the prognosis and an understanding of the treatment plan (Hockenberry *et al*, 2006).

A common complaint of parents of ADHD children is that professional nurses do not listen to what they have to say about their children (Hockenberry *et al*, 2006). The reason for this could be attributed to the fact that these nurses have patient ratios that make it impossible to provide quality care. Hospitals, patients and nurses in South Africa need to be aware of the fact that having many patients per nurse degrades hospital care (Nurse shortage in South Africa, 2009). The situation at the out patient paediatric clinic at the hospital under study is that there is at most times only one professional nurse who manages all children coming in for treatment for various chronic conditions, ADHD being one of them.

2.11.3 The role of occupational therapists

The primary goal of the occupational therapist is to enable children to participate in the activities of everyday life. Occupational therapy has proved successful in treating perceptual learning problems as well as lowering the activity levels of such children and in improving their ability to concentrate (Chu & Reynolds, 2007). The occupational therapist has much to offer children with ADHD in facilitating engagement in meaningful tasks and successful participation in different occupations such as activities of daily living, education, play, leisure and social participation (Chu & Reynolds, 2007). This

assessment of task performance is conducted using a battery of tests such as perceptual motor tests, a school functional assessment as well as the schools assessment of motor and process skills (Chu & Reynolds, 2007).

Occupational therapists strive for a collaborative relationship with parents and appreciate that the child with ADHD is part of an interactive family system. Occupational therapists working with children with special needs are part of the formal social support system and are in a position to encourage the family's efforts to network among friends, family members and parent groups (Chu & Reynolds, 2007). These authors add that the family centred approach used by the occupational therapist recognises that each family is unique; that the family is the constant in the child's life and that parents are the experts on the child's ability and needs. Therapists work collaboratively with parents to make informed decisions about the services and supports available, and to empower and enable them in the whole intervention process (Chu & Reynolds, 2007)

A similar treatment protocol is being used in the hospital under study. The children are assessed and treated using formal tests such as the VMI Beery, Development test of visual perceptual skills DTVP 2, Ayres clinical observations and Durrell writing speed test (Occupational Therapy, 08/2006). Included in the occupational therapy treatment package at the hospital under study are intensive home programs for parents to conduct as well as teacher assessments on the cognitive ability of children. The challenge for parents and children who receive occupational therapy support is that treatment is rendered to children only until the children are 8 years old (Dept of Health, Occupational Therapy: 08/2006). Thereafter they are referred to the Psychological Guidance and Special Education service (PGSES) which falls under the auspices of the Department of Education. The reason for this management strategy is that once children with ADHD starts school the responsibility to provide psychological and developmental services lies with the Department of Education.

2.11.4 The role of psychologists

Parents and carers of ADHD children seem most to want someone to talk to, with a listening ear, empathetic and supportive (Evans *et al*, 1997). Psychology is a way of addressing problems by talking them through with someone who, whilst supportive, is not directly involved in the situation (Occupational Therapy, ND). The role of the psychologist in treating paediatric ADHD is two fold, in that the needs of the child as

well as the parent is taken into consideration. Parenting a child with ADHD is incredibly challenging and stressful (Barkley, 2000). Many parents of children with ADHD have experienced shame and humiliation at the hands of educators, family and professionals involved with their children. Mothers of children with ADHD express lower levels of parenting self esteem and experience markedly more depression, self-blame and social isolation than mothers without ADHD children (Barkley, 2000). Parents need to invest in self care and this could be achieved by attending psychotherapy sessions with the psychologist.

Psychologists are trained not only to evaluate psychological problems in children but also to give psychological, learning or neuropsychological tests that can help pinpoint the type of learning or behavioural problem a child has (Barkley, 2000). All children who are believed to have ADHD should be given a standard intelligence test, followed by specialised assessments in reading, writing, spelling, maths and language. Unfortunately, for most this situation remains an ideal but not a reality because of limited resources (Green & Chee, 1997). This situation parallels that of the hospital under study as there is a gross shortage of both material and human resources within the department of psychology with just one full time psychologist, a community service psychologist and an intern psychologist (communication with Human Resource department, accessed: 23/08/2010).

Educational psychologists have a powerful role to play in evaluating and developing strategies for managing the behaviour of learners who have ADHD. The strategies used by psychologists in managing ADHD children involve individual sessions with the child, parent support and parent skills sessions, social skills dyad (2 children with a therapist) and formal psychological assessment to assist with diagnosis (Occupational Therapy, ND) The protocols used by most psychologists are made up of many subtests and ADHD children often produce a characteristic pattern of sub scores. The task for the educational psychologist is to help others understand the complexities involved in the ADHD symptomatology (Connor *et al*, 1997).

Within the public hospitals of KwaZulu-Natal, clinical psychologists are the only specialised field of psychologist employed by the Department of Health in conjunction with the Department of Behavioural Medicine at the Nelson Mandela School of Medicine

(Dept of behavioural medicine, ND). The department of behavioural medicine's clinical psychology services in the Province of KwaZulu-Natal focuses on the interaction between behavioural medicine, clinical health psychology, medicine and psychiatry (Dept of behavioural medicine, ND). The clinical psychologist's role is to provide psychotherapy and counselling services to ADHD children and their families but they do not provide the battery of tests for the assessment of ADHD for school aged children as this is the responsibility and role of the educational psychologist. Children with ADHD are referred to the Department of Education, Psychological Support Services for an educational psychologist evaluation. The recommendation in the Education White Paper 6 on Special Needs Education stresses the importance and advocates for the role of the psychologist and social workers in providing support to school aged children with special needs (D.O.E, 2001). Du Tooit (2005) argues that the South African Education policy on LSEN does acknowledge that a well established education support service is imperative for inclusive education to be successfully implemented, yet this policy fails to describe the role of the educational psychologist within this support service.

One of the challenges facing the recipients of psychological services is that there is a shortage of services. Within the department of health, psychological services have been fragmented resulting in inadequate service delivery especially to learners with special needs (LSEN) (DuTooit, 2005). Psychological services, both clinical and educational, form an integral part of the integrated approach to managing ADHD in children.

2.11.5. The role of hospital social workers

“Social Work is the bridge linking the individual client being served to the environment” (Dzieglelewski, 2009:17). The “person in environment” or “person in situation” concept has been the cornerstone of the social work profession. For optimal functioning of any individual or family, the social worker must have a holistic understanding of the person's support and environmental system (Dzieglelewski, 2009). One of the concepts that differentiate social workers from other professionals is the inclusion of the “person in environment” perspective that enables social workers to understand their clients or patients within a bio-psychosocial and spiritual framework (Dzieglelewski, 2009). Medical social work is a sub-discipline of social work, also known as hospital social work. The social worker is part of an integrated team based in a hospital whose task it is to assess, plan and support patients and families to cope with emotional, economic, social

and environmental problems (Family Health Teams, 2005). In managing ADHD the role of the social worker in the team is to provide the psychosocial perspective to complement the biomedical perspective provided by medical doctors and nurses, thus ensuring that the bio-psychosocial model to treatment is adhered to (Family Health Teams, 2005).

The social work profession is often involved with patients who have been diagnosed with ADHD and their families. ADHD symptoms can intrude dramatically into a family's experience affecting not only the child but all members of the family (Everett & Everett, 1999). For this reason the social worker uses the ecosystems perspective to guide her in her assessment of the child with ADHD, his/her family, the home environment, other significant relationships and the school environment. The family system must make accommodations for the symptomatic ADHD individual in order to maintain the family's stability and equilibrium. The necessary accommodations by the family system are often extensive and affect all family members' roles such as the parents, spouses, siblings and grandparents (Everett & Everett, 1999). The hospital social worker, in conducting the evaluation for children in the context of each individual's family milieu offers one of the most effective means of assessing the impact of ADHD. In working with parents of ADHD children, the goals of the medical social worker is to restore, maintain and enhance emotional and social functioning by mobilizing strengths, supporting coping capacities, modifying ineffective patterns of relating and behaving (Family Health Teams, 2005). Their responsibilities include linking parents to resources, alleviating environmental stressors and providing psychosocial education related to wellness and subjective wellbeing (Family Health Teams, 2005).

Although social work historically endorses the bio-psychosocial perspective, the one criticism is that the biological component is often missing from theory, practice and education (Dorfman, Meyer & Morgan, 2004). This impacts on hospital social workers as they often feel inadequate in addressing certain concerns of parents as they lack knowledge on the biological component of the disease model. A challenge to social workers managing ADHD and other psychiatric conditions is that social workers are not well versed in the neurochemical processes involved or the biological risk factors in psychosocial disorders (Dorfman et al, 2004).

Most health care professionals agree that the physician or paediatrician generally leads the health and mental health care team, yet the social worker spends most quality clinical time with the patient. Therefore social workers are expected to have some degree of understanding of medication as it relates to the diagnostic criteria usage and they are the first team members who would recognize patients' concerns related to medication. This concern is very evident with parents of ADHD affected children as they have ambivalent feelings about medicating their children and find it stressful and overwhelming to take the decision to use stimulant medication (Barkley, 2000). Due to the therapeutic relationship and the trust and rapport social workers develop with families of ADHD children, social workers are in a unique position to help ensure medication compliance (Dzieglewski, 2009).

An ability to understand and appreciate the patient's total situation makes the social worker an available team member who is often called upon to assist other professionals in understanding the psychosocial dynamics of the individual (Dzieglewski, 2009).

2.11.6 The role of the dietician

Dieticians are health care professionals, who apply their unique body of knowledge and expertise to support people in understanding and applying the principles of healthy eating throughout the entire lifecycle. The dietician contributes towards the health and well-being of patients and clients and therefore is considered to play a role in the multidisciplinary/interdisciplinary team in patient care. Their role is to identify nutritional needs and translate evidence-based practice into practical guidelines and intervention for individuals to make more informed decisions about food choices and lifestyle behaviour (Mackenzie, 2008). As members of an interdisciplinary team, dieticians can contribute to health promotion and illness prevention strategies, and develop specialized nutrition therapy and rehabilitation/support strategies to address specific nutrition-related illnesses (Family Health Teams, 2005).

Many parents look for drug free therapy as their first line of choice in managing their ADHD children; therefore they find comfort in knowing that a dietician may help with the behaviour change in their children through diet manipulation. According to Holford and Burne (2006), children and adults with ADHD often have one or more nutritional imbalances, that once corrected can dramatically improve their energy, focus,

concentration and behaviour. However research conducted by Green and Chee (2004) suggests that diet has a smaller part to play in the treatment of ADHD. These researchers add that diet never causes ADHD, though in a minority of ADHD affected children, certain foods may make their behaviour more active and possibly more irritable (Green & Chee, 2004). There seems to be little evidence that diet directly affects attention, impulsivity or insatiability (Barkley, 2000).

The role of the dietician in managing ADHD could be to assist parents in recognizing foods that may exacerbate the behaviour, such as fizzy drinks or cola. Dieticians also assist in developing nutritional plans based on the individual child's needs. Included in diet management would be individual and parent counselling, conducting nutritional and weight assessments, conducting patient and parent workshops and seminars. The dietician is part of the integrated approach to care with ADHD children and parents, therefore they play a collaborative role in working with paediatricians on medication monitoring plans as they relate to nutrition (Family Health Teams, 2005).

A challenge that parents find with diet therapy is that the work of the dietician has a slow and long-term effect, thus results are not seen immediately. It is difficult for those who are unaware of the effects to acknowledge the worth of therapy (Mackenzie, 2008). A further challenge is with compliance to therapy as parents find it difficult to restrict children from avoiding certain foods (Green and Chee, 1997). The treatment of ADHD through the means of diet manipulation has had many controversial viewpoints. It could be concluded though that diet does have a small part to play in managing ADHD than the popular mythology might suggest.

The different team members as noted above are part of the meso level in this ecosystem and they play an integral role in the management of ADHD in children who are receiving services from a hospital. There must be strong interrelations between the meso level and the micro level to ensure a good "person in environment fit", ie there must be good communication by the various allied professionals to ensure efficient and effective services are rendered to the individual with ADHD and their parents/caregivers.

Interdisciplinary or multidisciplinary care is an integrative approach between groups of professionals including the patient and family. It is becoming more common in acute care

hospital settings and public health clinics as professionals understand that patient care is not a single person's responsibility but a conjoint one (NASW,2003). Within public hospitals all role players in the multidisciplinary team are available to assist in the management of ADHD children and their parents, however, the challenges arise from the poorly implemented referral systems. Policies and protocols need to be revised and implemented for processes to occur in a more uniform and consistent manner. A multidisciplinary or interdisciplinary team approach to the management of ADHD ensures that the disorder is holistically treated within the bio-psychosocial perspective.

In the following section Batho Pele principles will be discussed. These principles are fundamental to this study as they focus on effective service delivery at public hospitals.

2.12 Batho Pele Principles

The South African government in an attempt to redress past inequalities and discrimination introduced the concept of Batho Pele in 1997 which means "Putting People First" in (Batho Pele Handbook, ND). The government's objective was to provide a framework for the transformation of public service delivery. Batho Pele is an initiative of the government to get public servants to be service oriented, to strive for excellence in service delivery and to commit to continuous service delivery improvement. It is supposed to be a transparent mechanism that allows patients to hold public servants accountable for the types of service they deliver (Batho Pele Handbook, ND). There are eleven principles of Batho Pele which focuses on effective service provision.

In order to meet the needs of parents and caregivers efficiently and to provide quality services to individuals with ADHD and their families, it is imperative for health care workers to employ the principles of Batho Pele, that is "Putting people first". It is essential that these guiding principles that are the cornerstone to effective service delivery are complied with by the different disciplines that provide services to patients and their parents or caregivers. Effective service oriented departments are those that consult with their patients, maintain open relations with them and monitor the patients needs and expectations as well as their levels of satisfaction. The principles of Batho Pele if adhered to ensures that the concerns of the participants and their needs are the heart of all key decisions, actions and communications in the state hospital.

Conclusion

The literature discussed in this chapter reveals the challenges that individuals with ADHD and their families are exposed to in their everyday lives. The complexity of the disorder presents further challenges to parents/caregivers, educators as well as health care providers who at the different levels of the ecosystem are instrumental in the well-being of these children identified with ADHD. It is evident from this literature study that although the public health system renders a service to children with ADHD, research has pointed to the apparent gaps in the service that needs to be addressed.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter the research methodology and the research process are discussed. It includes discussions of the research approach, the research design, sampling strategy, and the methods of data analysis. The chapter concludes with descriptions of the reliability and validity of the research as well as the ethical considerations and limitations to the study.

3.2 The research approach

Since the aim of this study was to understand the needs of parents and caregivers raising children with ADHD and their experiences of services at a public sector hospital, a qualitative research paradigm was used. According to Babbie and Mouton (2001:53), qualitative research “attempts to study human action from the insiders’ perspective”. When using this approach the primary goal is to describe and understand human behaviour rather than explain and predict it. The focus is on “thick” descriptions and “understanding of actions and events” (Babbie & Mouton, 2001: 270).

There are different types of qualitative approaches. De Vos (2005:269) discusses the five different approaches which are biography, phenomenology, grounded theory, ethnography and case study. According to Leedy (2001, cited in De Vos et al, 2005: 264), “a phenomenological study is a general description of the phenomenon as seen through the eyes of people who have experienced it first hand”. Van Rooyen *et al* (2010:2) define phenomenology as a qualitative approach which “seeks to understand the lived experiences of individuals”. They further state that it aims to answer the question, “What is it like to have a certain experience” (Van Rooyen et al, 2010:2). The focus of this study was on discovering and understanding the lived experiences of parents and caregivers of children with ADHD, and their experiences with the hospital under study. As with other types of qualitative research approaches, phenomenology “seeks a thick description” of responses from participants.

In using a qualitative approach it was possible to explore in-depth the needs and experiences of parents/caregivers raising their children with ADHD and the challenges

they encountered in their daily lives. Rich information was extracted from participants through interviews with them. Qualitative research also aims to gain a holistic understanding of the phenomena under study. This qualitative approach was useful at surfacing deep issues and making voices heard. In the current study, parents and caregivers were for the first time given an opportunity to vent their emotions and have their needs heard. The emphasis in this type of qualitative research is to gain understanding of participants' essential "truths", that is the essence of the lived experiences (Byrne, 2001).

This qualitative approach was considered appropriate as the focus was on obtaining descriptive experiences of how parents and caregivers experienced ADHD. Through the use of this approach, thick descriptions of parents and caregivers perceptions, attitudes and feelings were attained and interpreted.

3.3 Research Design

A combination of exploratory and descriptive research designs within the qualitative research paradigm was used. Exploratory and descriptive designs were considered appropriate for this study because this was the first time that a study of this nature was being conducted at a public hospital in KwaZulu-Natal. According to De Vos (2005:134) by using exploratory research, the researcher "gains insight into a situation, phenomenon, community or individual". Hence in this study I explored parental experiences of their ADHD affected children within a local context where research was limited. The exploratory nature of this study was also focused on ascertaining parents' and caregivers' perceptions of the services provided to their ADHD children at a public hospital in an attempt to address the gaps that may exist in state health care.

According to Babbie and Mouton (2001: 80) "qualitative studies aim primarily at description". They add that descriptive studies provide an in-depth description of an individual, social event or group. Descriptive research allows the researcher to observe and then describe what he/she has observed (Babbie & Mouton, 2001). For this study the descriptive approach was used as well as it took into account parents' experiences of their ADHD affected child within the hospital setting, thereby adding a richer and deeper meaning to the phenomena being studied.

3.4 Sampling Strategy

In this study, a non-probability, purposive sampling method was used. Babbie (2007) points out that purposive sampling is a type of non-probability sampling in which the units to be observed are selected on the basis of the researcher's judgment about which ones will be the most useful or representative. In purposive sampling a particular case is chosen because it illustrates some feature or process that is of interest for a particular study (De Vos et al, 2005).

The first criteria for inclusion in this study related to the ages of children diagnosed with ADHD and receiving services from the paediatrics clinic. Although the clinic provides services to children from birth to 12 years old, Ritalin medication is only prescribed from 6 years onwards (discussion with paediatric professional nurse: 26/09/10). Children above 12 years old are in receipt of services from the medical out-patient clinic at the hospital. Since participants' experiences with Ritalin was an important component of the study it was decided to include children between 6 and 12 years.

The second criteria for inclusion were children in receipt of services from the paediatric clinic for more than one year. Denzin and Lincoln (2000, cited in Strydom and Delpont, 2005:328) state that qualitative researchers seek out individuals, groups and settings where specific processes being studied are most likely to occur. This enables the researcher to understand all aspects of the topic under study.

In this study, individual interviews as well as one focus group discussion were conducted. I am a social worker at the hospital under study and through my involvement with the paediatric clinic was able to select participants for the study. I shared close liaisons with the paediatric sister and other paediatric support staff at the clinic. It was through this mutual relationship that the task of selecting a sample was also made easier as the staff at the clinic had a designated area for parents/caregivers of children with ADHD to sit. The sample for the interviews was drawn from the parent population that attended the paediatric ADHD clinic with their children on a Tuesday or Thursday which were specific ADHD clinic days. The process of selecting the sample involved the paediatric sister at the clinic identifying parents / caregivers of children with ADHD. She then informed me of their attendance at the clinic. On these ADHD clinic days I introduced myself to the group of parents/caregivers and explained to them my purpose at

the clinic. I also explained to parents/caregivers that their decision to participate in the study was voluntary. I then recruited volunteers to participate in the study and scheduled specific times with them for the interview.

Purposive sampling continued until saturation was reached. For the individual interview a sample size of 21 parents/ caregivers was selected. In this sample, 16 participants were mothers, 2 participants were fathers, 2 were caregivers who were the grandmothers and there was 1 couple (mother and father).

For the focus group a sample size of 6 parents was selected. The focus group included 5 mothers and 1 grandmother. The 6 participants were purposively selected from the group of 21 participants. The selection of participants for the focus group stemmed from the individual interviews. Participants with differing views or those that expressed strong views on issues such as medication usage or their experiences at the hospital were considered for the focus group discussion. The selection of focus group participants was also done through voluntary participation. Since the parents or caregivers responsible for their children's caretaking responsibilities were predominantly mothers, the sample comprised predominantly of female participants. The sample also included parents/caregivers of different ages in the focus group.

3.5 The Setting for the interviews

An office in the paediatric clinic at the hospital under study was used as the setting for the semi-structured interviews. Prior arrangements for the use of this venue were made with the paediatric professional nurse at the clinic. I used this venue as I thought that participants would be familiar with it and therefore would find it non-threatening. It was also easy for participants to access within this large institution. I used a doctor's room that was not being occupied and ensured that there were no interruptions during the one to one interview process.

For the focus group discussion I used a larger venue that accommodated the six participants. A social work office within the hospital was used as this was a larger and more comfortable venue. The seating arrangements had to be considered for better interaction and involvement amongst participants. Both the one to one interviews and the

focus group discussion were conducted in an environment which was quiet, comfortable and provided privacy to the participants in the study (De Vos et al, 2005).

3.6 Data collection instruments

This study used two methods of data collection, which were the semi-structured in-depth interviews and a focus group discussion. I used semi-structured interviews as it was an informal, interactive process that utilized open-ended questions. It allowed participants to give detailed accounts of their caregiving experiences with their children and about the service provider. Furthermore, as this was a qualitative study it was considered appropriate to use a semi-structured interview in order to gain a detailed picture of the participants' experiences (Greef, 2001). According to Terre Blanche and Kelly (2002) interviewing gives the researcher an opportunity to get to know the participants quite intimately so the researcher can really understand how they think and feel. A semi-structured interview guide with open ended questions was used (see Appendix A). I also made use of probes in eliciting more detail.

My professional background as a medical social worker assisted in the research process as I employed the skills of interviewing with ease and was able to establish rapport and engage with participants in an attempt to make them comfortable during the interview process. I was able to get detailed, rich and "thick" responses from participants through the use of open ended questions and probes. The information obtained was in-depth as I was able to get participants to elaborate on a response through the use of probes. The semi-structured interview which was an hour long was conducted with parents/caregivers alone. Their children were supervised by other social workers at the hospital who engaged them in play activities.

The second method of data collection used in the study was the use of a focus group which was used as a supplementary source of data. The focus group in this study was used to understand the everyday experiences of participants with their ADHD affected children and their experiences of the services provided by the public hospital. De Vos et al (2005:299) mention that "focus groups are group interviews". Focus groups assist with better understanding of how individuals think or feel about a given issue. In the focus group used in this study, the six participants chosen shared a common problem in that they all had children diagnosed with ADHD. An interview guide (See Appendix C) was

used and participants shared their feelings, concerns, experiences and desires with the group, with the realization that they were not alone in this problem.

In this study the focus group was used to engage participants in discussions on issues they felt strongly about and which emerged from the individual interviews. Through the use of a semi-structured guide (see Appendix C) more detailed discussions about aspects such as Ritalin usage, long waiting times and the lack of adequate support were explored further. As the facilitator to this focus group I encouraged participants to communicate by exploring reasons for particular viewpoints and by probing participants for in-depth responses.

The researcher used focus groups as a method of triangulation to extract more in-depth and detailed information about contentious issues that parents/caregivers may have commented on in the individual interviews. Creswell (1994:17 cited in De Vos et al, 2005:361) explains triangulation as follows, “the concept of triangulation is based on the assumption that any bias inherent in a particular data source, investigator and method would be neutralised when used in conjunction with other data sources, investigators and methods”. In this study, any bias that might have arisen from the one to one interviews would be neutralised by the focus group discussion. In this qualitative research the advantage of using triangulation was that it would enhance the validity and reliability of the study.

3.7 Data Analysis

Data analysis in qualitative studies involves “capturing the richness of themes emerging from participants talk” (DeVos, 2005: 287). The author adds that it is a process that brings order, structure and meaning to collected data. In this study each participant’s responses was tape recorded and transcribed. The recordings were transcribed immediately after each interview so that the content of the interviews were still fresh in my memory and I could record non-verbal responses as well as my impressions. Each transcript was numbered, in order to protect the identity of participants and to uphold the principle of confidentiality. The same process was done for the focus group discussion where the responses were recorded and transcribed. In order to verify the accuracy of the transcribing process for the individual interviews and the focus group discussion, I

replayed the audio recorder several times to ensure that the transcriptions were accurately captured. Thereafter, I engaged in analysing the transcripts of participants.

Through reading the transcripts several times, I had immersed myself in the details in order to get an overall sense of the data and made notes of significant issues. I wrote memos in the margins of the transcripts of the key ideas and concepts. This process was a time consuming process as it was important that the information captured was accurate. Significant statements from each participant's transcriptions were extracted. Major themes and sub-themes were highlighted by colour coding data that was similar. Thereafter, I formulated tables and divided the information into sections with the different themes and sub-themes that emerged from the data. This also included a critical analysis of the data by searching for explanations for the data and reasons why the explanation provided is the most plausible. The final phase involved writing the research report and the presentation of the findings of the study. This was done through a critical analysis of the themes and sub- themes and the interpretation of the data. I interpreted the themes and sub-themes, by using participants' direct quotes. At this stage reference was made to the literature in chapter 2 and to the theoretical frameworks to search for supporting information or to make comparisons. I attempted to draw conclusions from the data presented by the participants.

In terms of reflexivity I was aware of my own perceptions and ideas on the topic and the possible impact my own biases could have on the study. . According to De Vos (2005: 363) "reflexivity is the ability to formulate an integrated understanding of ones own cognitive world, especially understanding ones influence or role in a set of human relations". As a social worker working at the hospital under study, I also acknowledged that my role at the hospital as a social worker may create a hierarchical relationship. I reassured participants that their responses would not affect the treatment received from the hospital and that confidentiality will be maintained.

3.8 Validity and Reliability

The validity and reliability of the data analysed will be discussed under the following headings.

According to Guba and Lincoln (cited in Babbie and Mouton, 2001:276), the key criterion or principle of good qualitative research is found in the notion of trustworthiness. These authors state further that a qualitative study cannot be called transferable unless it is credible, and it cannot be deemed credible unless it is dependable. Guba and Lincoln (cited in Babbie and Mouton, 2001:276) state that certain concepts are relevant in order to ensure trustworthiness during the research process. For this research study the researcher considered Guba and Lincoln's concepts as follows:

3.8.1. *Credibility*- "Credibility is the alternative to internal validity, in which the goal is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described" (De Vos, 2005: 346). Credibility was achieved through developing trust with participants and making them feel comfortable. They were able to discuss their concerns and did not feel threatened by the interview process. Credibility for this study was also enhanced through the method of triangulation whereby information was collected from different data sources, ie through the use of semi-structured interviews and a focus group. For this study, credibility was built by using the procedure of 'referential adequacy', that is the method used to document the findings was through audio recordings and transcripts which gave exact accounts of participants experiences. Discussions of the transcripts with my supervisor and peer reviews with medical professionals at the hospital also ensured credibility of the study.

3.8.2. *Transferability*-refers to whether the findings can be applied to other contexts and settings. Therefore the research method is documented so that it can be applied to other similar studies. Guba and Lincoln (cited in Babbie and Mouton, 2001:277) mention 'thick description' as a strategy for transferability. For this study this strategy was used as I collected descriptions of data with sufficient detail and precision about the experiences of parents and caregivers with children with ADHD.

3.8.3 *Dependability*- According to De Vos (2005: 346) "dependability is the alternative to reliability". The study must be able to provide the researcher with evidence that if it were to be repeated with the same or similar respondents in a similar context, its findings would be similar. In this study, I provided an audit trail by describing clearly the research methods used.

3.8.4 *Confirmability*- According to De Vos (2005:347) “confirmability captures the concept of objectivity.” The findings of the study must be the focus of the enquiry and not reflect the biases of the researcher. It is important to know if the findings from this study could be confirmed by another. The focus is on whether the data is able to confirm the general findings and lead to the implications (De Vos, 2005).

3.9 **Ethical Considerations**

Researchers are ethically obliged to ensure that the research is undertaken in a responsible manner and that the research was conducted with honesty and integrity. The following ethical considerations were taken into account in this study.

- Informed consent was obtained from participants for their participation in this study and they were informed of the purpose of this study.
- Consent from the hospital was attained to carry out this study.
- Ethical clearance was received from the University of KwaZulu-Natal.
- The researcher also ensured that the identity of the minor child was protected by guaranteeing anonymity of the interviews.
- The researcher ensured that confidentiality was maintained during and after the research process.
- Participation in the research was voluntary and the participants incurred no penalty for refusal to participate.
- The participants were not subjected to any physical, mental distress or harm in the research process.
- Appropriate referral services were made available for those participants who required it during and after the interview process although none of the participants required such services.
- The researcher acknowledged all participants in the research.
- The researcher used her skills as a social worker to deal with those participants who became emotional during the interview process.

3.10 **Limitations to the study**

In planning the study I was aware that the responses of parents/caregivers could be guarded given my employment at the hospital. In order to address these concerns participants were assured that non-participation did not jeopardise their access to treatment. I reassured participants that the interviews would be confidential.

The sample in this study included predominantly Indian participants although this study was aimed at all racial and ethnic groups. Thus the findings are not reflective of all ethnic groups and cultures. An explanation for this limitation is that the geographical location of the hospital under study is in a predominantly Indian area. The schools that refer their children for assessments are also predominantly from the same geographical location as the hospital. The area of coverage for the hospital extends to the inner and outer west areas. Not many children are identified and referred for an ADHD assessment by the schools situated in the black townships in these areas. Therefore this study was not representative of all population groups.

I had difficulties in obtaining information for the literature study which was South African based, as most of the literature studies were American or from other countries abroad.

Another limitation to the study was that two participants did not give in-depth information or detailed descriptions of their experiences as they had difficulty in expressing themselves. These were participants who also had low education levels and this also affected the quality of their responses.

Conclusion

This chapter focused on the methodology of the study. It reflected that the study was a qualitative study and the designs used were exploratory and descriptive. The sample comprised of 21 parents/caregivers for the individual interviews and 6 participants for the focus group discussion. The two data collection methods used were semi-structured interviews and a focus group. The aspects of validity and reliability were also considered. Finally, discussion centred on the ethical considerations and limitations of the study.

The findings of the study are presented in chapters 4 and 5

CHAPTER 4

**PARTICIPANTS' EXPERIENCES AND REACTIONS TO
THEIR CHILDREN'S ADHD DIAGNOSIS**

4.1 INTRODUCTION

The aim of this study was to explore the needs and experiences of participants raising children with ADHD, who access services from a public sector hospital. This study focused on the experiences of 16 mothers, 2 caregivers, 2 fathers and 1 couple whose children had been diagnosed with ADHD.

The analysis and discussion of participants' responses are presented in chapters 4 and 5. In chapter 4 the demographic profile of participants is provided together with their experiences and reactions relating to their children's ADHD diagnosis and treatment. The findings on participants knowledge of ADHD and psychostimulant medication is also presented in this chapter. In chapter 5 participants experiences of service provision from the hospital under study are presented. Participants' recommendations for future services are also discussed. The findings for both chapters are analysed within the context of the ecosystems theory and the bio-psychosocial approach.

4.2 Short Profile of Participants

Participant 1

Participant 1 is a 44 year old mother who lives with her husband and two children. She is a housewife and her husband is the sole breadwinner in the home. The family reside in the Chatsworth area. Both spouses completed matric. This participant has been bringing her son to hospital for the past 6 years. He is now 10 years old. The problem that she experiences is that her husband is still in denial and will not accept their son's ADHD diagnosis. She related that whilst she had support from the extended family she had little support from her husband. She expressed several concerns regarding the hospital's management of her son's disorder.

Participant 2

Participant 2 is a 40 year old mother with 2 children. Her son with ADHD is 11 years old and was diagnosed with ADHD when he was in grade 1. Participant 2 lives separately

from her husband due to marital problems. The father resides in Gauteng. Participant 2 is experiencing grave difficulties with raising her children especially her son who is diagnosed with ADHD. She has limited support from family members. She is employed but is struggling financially. She mentioned that she would like to receive support services from the hospital.

Participant 3

Participant 3 is a 37 year old father who brings in his eight year old son for his monthly treatment to the ADHD clinic. His son was diagnosed with ADHD in grade 1. This participant and his spouse are employed and enjoy a comfortable home environment. They are financially stable. He has a tertiary level education. He vented his frustration over the lack of communication between the doctor and himself over his child's ADHD management. Participant 3 is dissatisfied with the services provided to children with ADHD at the hospital under study.

Participant 4

Participant 4 is a 41 year old single parent of one child. Her son with ADHD is eight years old and was diagnosed with the disorder when he was five years. This participant is employed but her financial status is poor. She has a matric level of education but displayed little knowledge of the disorder. She lives in an extended family situation but stated that she does not have much family support. She expressed her dissatisfaction with the administrative processes of the hospital system.

Participant 5

This participant is 40 years old with 3 children. Her 6 year old daughter was recently diagnosed with ADHD. The participant and her husband are unemployed. This participant's husband is a psychiatric patient and is in receipt of a disability grant. The family are living under very poor socioeconomic conditions. The father is a substance abuser and the family are exposed to volatile outbursts from him. The child is also being managed at the hospital for epilepsy. The family are unstable and are burdened by the social problems that plague them.

Participant 6

Participant 6 is a 55 year old grandmother and caregiver to her eight year old grandchild who has ADHD. The child was diagnosed with ADHD at six years old. The child's parents are divorced and his mother is in a relationship where her partner will not accept the child. The child is being raised by his paternal grandparents since birth. The grandmother expressed her love for the child but admitted that she cannot cope with his ADHD disorder. She has a primary school level of education and her knowledge of the disorder is limited. She has many challenges facing her relating to the child's ADHD disorder and difficulties with the school is one of them. The grandmother has support from her husband who also shares the caretaking responsibilities of the child.

Participant 7

Participant 7 is a 57 year old housewife and mother to an 11 year old son with ADHD. The child was diagnosed with ADHD when he was in grade R. She has a very supportive husband and the family system is very stable. Her concerns relate to her child's academic performance, his behaviour, his inability to get along with peers and his inability to read. She has expressed her satisfaction with the treatment received from the medical staff but would prefer more interaction with the allied medical professionals.

Participant 8

Participants 8 are a couple who had an 11 year old son who received treatment for ADHD from the hospital. The child was diagnosed with ADHD in grade 1. The family lives within a nuclear family system. The mother of the child is a housewife and the father is employed on a casual basis. These parents are not happy about the child taking Ritalin. They would also like to see the hospital playing a more supportive role to parents who come in with their ADHD children. They expressed dissatisfaction with the services offered to ADHD children and their parents.

Participant 9

Participant 9 is a 23 year old single mother. She is employed and is the sole breadwinner in her home. She and her two children live with her family. Her son who has been diagnosed with ADHD is 6 years old and she has a 3 year old daughter. Her son has no contact with his father. The mother mentioned that her son has been ill since birth. She

expressed concerns regarding Ritalin usage. She felt that more support services should be introduced to parents at the hospital.

Participant 10

Participant 10 is a 26 year old single mother of two children, aged 2 and 7. Her 7 year old son was diagnosed with ADHD in grade 1. Her husband is in an extra marital relationship and has left the marital home. Both parents are unemployed. The child does not share a relationship with his father. This participant is in receipt of a child support grant and this is her only source of income. She lives with her parents but the relationship is a very strained one. She has no external support. Financially, participant 10 is struggling. She cannot cope with her son who has ADHD and finds her life to be really difficult at this stage. She mentioned that she would benefit from support offered at the hospital.

Participant 11

Participant 11 is a 38 year old housewife with 2 children. Her husband is employed and they are financially stable. Her older daughter is 16 years old and her son who has ADHD is 6 years old. Her son has been attending the paediatric clinic at the hospital under study since he was 4 years old. She stated that her son's disruptive behaviour has caused much marital tension in their home and that she does not get much support from her husband.

Participant 12

Participant 12 is a 26 year old mother who is separated from her husband. She is employed and lives with her extended family. Her only son is 8 years old. They have no contact with the biological father. She has little support from family. Her child was diagnosed with ADHD when he was in preschool. She mentioned that her son is struggling at school and her greatest challenge is finding him a school that caters to his educational needs. The participant desperately seeks support services to have better skills to cope with her son.

Participant 13

Participant 13 is 51 years old and has 3 sons, of which the youngest is his 7 year old son who has ADHD. The child is in grade 1. The participant and his wife are employed. He reported that his son was first referred to the paediatric clinic for epilepsy. He was later diagnosed with ADHD. The participant is presently experiencing many problems with his

son's school. The family are seeking assistance from social welfare services. The parents are also not coping with the child's disruptive and aggressive behaviour.

Participant 14

Participant 14 is a 36 year old single mother with one son who is 6 years old and in grade 1. The son was diagnosed with ADHD when he was 4 years old. The participant is employed and is responsible for all her son's needs. She lives with friends who she claims are like family to her. They are her only source of support and assist with the caretaking demands of her son. She has no contact with her son's father or with her family. She is very reluctant to administer the Ritalin to her son. She also would like more exposure to the health care workers who provide support at the hospital.

Participant 15

Participant 15 is a 33 year old mother with 2 children. She is separated from her husband but they are currently trying to reconcile. Her 12 year old son has ADHD and has been living with his grandparents. Her son's ADHD was identified by his school when he was 6 years old. His ADHD diagnosis was met with a lot of resistance from the family including the grandparents therefore this participant claims she has no family support. According to her a more stable family environment may see a positive change in her son's behaviour. She has many concerns about her son's future.

Participant 16

Participant 16 is a 68 year old grandmother and caregiver to two siblings, who are both diagnosed with ADHD. The children are a 7 year old boy and an 8 year old girl. Their mother had abandoned the children 3 years ago. Their father works away from home. Both these siblings were diagnosed with ADHD after presenting with disruptive behaviour both at home and at school. The grandmother is a pensioner and receives a child support grant for the children. Financially, she struggles to maintain these children. She has many concerns about their future care. This grandmother has no support from the family.

Participant 17

Participant 17 is 36 years old and has two sons, aged 6 and 14. The 6 year old son is diagnosed with ADHD. Her older son also has a concentration problem. The participant

and her husband have tertiary qualifications. They are financially stable and enjoy a good quality of family life. The participant has sound knowledge of the disorder as she previously worked for a paediatrician. She spoke of her difficulties in raising her son and her concerns about him using Ritalin. She is also not happy with the administrative processes at the paediatric clinic and dispensary.

Participant 18

This 32 year old mother is married and has two children. She is unemployed. She is presently experiencing marital problems. Her son is 9 years old and has ADHD. He was diagnosed with the disorder at age 6. He attended mainstream school but could not cope. Subsequently he has been moved to a school for children with special needs. The participant has support from her parents. She is in receipt of social work services from the hospital. She mentioned having concerns about her son's future. She also values support services from the hospital in view of his disorder.

Participant 19

This participant is 42 years old and has 3 children. Her 8 year old son with ADHD is the youngest and only son. He was diagnosed with ADHD when he was 6 years old. The reputed father abandoned the family many years ago. The mother is unemployed and receives child support for her son. Her two older daughters aged 20 and 22 work and help her to support the family. She is financially unstable.

Participant 20

This participant is 36 years old and is married with 2 children. She lives with her in laws. Both the participant and her husband are unemployed. This mother mentioned that her son does not display any behavioural problems; but he is unable to concentrate. He is 12 years old but was diagnosed with ADHD at 3 years old. The participant mentioned that her son could not cope at a mainstream school. He therefore attends a school that has a LSEN (Learners with Special Educational Needs) class. She indicated that she would like more support from the team at the hospital.

Participant 21

Participant 21 is 27 years old with two children. She is a housewife and her husband is employed. Her daughter, who is now 7 years old, has been diagnosed with ADHD in

grade 1. The participant was also referred to the local child welfare with regards to the child's disruptive behaviour. She mentioned that her husband was in denial and he still remains ashamed of having a child with a disorder. The participant does experience problems at the hospital with the administrative processes and lack of communication between doctor and parent.

4.3 Demographic profile of participants

A summary of the demographic information of participants is provided in the table below:

Table 4.1: Demographic data

Participant	Relationship to child	Age of participant	Education level	Family circumstances	Age of child	Gender of child
1	Mother	44	Matric	Nuclear family	10	Male
2	Mother	40	Matric	Separated	11	Male
3	Father	37	Tertiary	Nuclear family	8	Male
4	Mother	41	Matric	Single parent	8	Male
5	Mother	40	Std 7	Nuclear family	6	Female
6	Grandmother	55	Std 4	Extended family	8	Male
7	Mother	57	Std 8	Nuclear family	11	Male
8	Mother&Father	39 & 40	Std 8(both)	Nuclear family	11	Male
9	Mother	23	Std 7	Single parent	6	Male
10	Mother	38	Std 9	Single parent	7	Male
11	Mother	38	Std 6	Nuclear family	6	Male
12	Mother	26	Matric	Single parent	8	Male
13	Father	51	Std 5	Nuclear family	6	Male
14	Mother	36	Matric	Single parent	6	Male
15	Mother	33	Matric	Separated	12	Male
16	Grandmother	68	Std 6	Extended family	7 & 8	Male & female
17	Mother	36	Tertiary	Nuclear family	7	Male
18	Mother	32	Std 7	Separated	9	Male
19	Mother	42	Std 8	Single parent	8	Male
20	Mother	36	12	Extended family	12	Male
21	Mother	27	Std 8	Nuclear family	7	Female

4.3.1 Participant Description

The participants in this study included 16 mothers, 2 fathers, 1 couple and 2 caregivers who were grandmothers. As can be seen the majority of participants were mothers or grandmothers. Two fathers stated that they brought their children in for treatment as work commitments prevented their wives from doing so. The couple mentioned that although they shared some of the caretaking responsibilities for their child, the mother was

responsible for assuming a more dominant role with the caretaking responsibilities of her son. According to Bester (2006), it is usually mothers who are most involved with their children and are responsible for daily tasks as opposed to fathers who are conditioned to be the “breadwinners” to the family. Fathers believe that it is the mother’s duty to care for the child and to discipline them and they therefore do not provide the daily hands-on support to them (Bester, 2006). This finding by Bester is relevant to the study as many participants reported that their husbands did not play an active role in helping to care for their children with ADHD.

The ages of participants in the study varied with many of them being in the 30 to 40 age range. Four participants were over 50 years and three were below 30 years. The age of participants is significant as the findings revealed that the older participants had more difficulties in coping with the children with ADHD and they felt that their caretaking tasks were onerous

4.3.2 Educational Level

Table 4.1 depicts the educational level of participants. With regards to their educational levels, 47 percent of participants started secondary school but did not complete matric, followed by 33 percent who completed matric. On either extreme, 10 percent of the participants had tertiary level and primary school education. Participants with lower levels of education displayed poor to no knowledge of ADHD. Those participants with a tertiary level education did acknowledge having good insight into the disorder. In the context of this study the educational level of participants was significant as it had direct implications on participants’ understanding of the nature and causes of the disorder and the management of their children. It was important to know participants’ educational levels as it helped the researcher ascertain if the terminology used by the health care professionals was at a level of participants understanding. As will be shown later in the chapter their level of understanding had direct implications on acceptance of pharmacological therapy which is the first line of treatment used at public hospitals.

4.3.3 Family Circumstances

Table 4.1 shows that of the 21 participants, only 12 were in a marital relationship with both spouses living together. The remaining 9 participants raised their children without the support of a spouse as a result of either death, a failed relationship or through marital

breakdown. The two grandparents were raising their grandchildren as a result of the children's parents failed marriages. The natural mothers in both cases had abandoned their children.

Research has shown that ADHD is a causative factor in marital breakdown and that parents of children with ADHD report less marital satisfaction than parents without an ADHD affected child (Wymbs *et al*, 2008). When a family has a child with ADHD added to the regular marital pressures, such as financial and job-related concerns, the marriage endures a tremendous strain (Sullivan, 2008). Barkley (1990) found that both the stress of raising a child with ADHD and the greater risk for personal emotional problems in the parents can greatly strain a marriage or relationship. Barkley (1990) followed a large number of families of children with ADHD over an eight-year period. He found that these parents were three times more likely to have separated or divorced than families of children without ADHD. According to Barkley (1990) marital breakdown occurs for a number of reasons such as differences in parenting styles, disagreement over the use of medication and when the responsibility of caring for the ADHD child is not shared. These authors add that as a result of the mother's preoccupation with her ADHD affected child, she tends to neglect her marriage. In this study there were a significant number of participants who experienced strain and stress in their relationships which has resulted in the relationship irreversibly breaking down.

4.3.4 Age and gender of children

The ages of the children in this study ranged from six to twelve years old. Most of the children in this study were diagnosed with ADHD either at preschool or when they entered grade one. This finding from the study is in keeping with AAP guidelines (2001) which states that ADHD is usually diagnosed at school going age which is around six or seven years depending on the child. There were some children in this study who were diagnosed with the disorder prior to going to school as the symptoms presented in early childhood.

In this study 19 of the children diagnosed with ADHD were male children and the remaining 3 children were female. There were 22 children diagnosed with ADHD as one participant was the caregiver to two siblings with ADHD. The findings are in line with Green and Chee (1997) and Venter (2006) who found that ADHD occurs in the ratio 3:1

with the occurrence in boys outnumbering girls. These researchers add that many girls remain undiagnosed as by nature girls tend to be less disruptive than boys therefore ADHD goes unnoticed in girls.

4.3.5 Employment

Forty eight percent of the participants in this study mentioned that they were employed, which includes both those in full time employment and in casual employment. Thirty eight percent were unemployed whilst fourteen percent of the participants were in receipt of a state grant.

The significantly high number of participants who were employed mentioned that bringing in their children to hospital did affect their work day routine. Comments like *"We lose out on an entire day at work"* or *"It's difficult for me because I have to take leave from work"* highlight the difficulties working participant's experience. They complained about the long administrative processes that are time consuming and affects them returning to work on the same day. According to Matza *et al* (2005), ADHD does place an economic burden on parents and affects parents' employment because they may often miss work in order to meet with teachers or take their children to appointments with physicians or mental health professionals

It is also important to recognize that those participants who were unemployed or in receipt of a state grant were only able to afford treatment from a public facility. Further the cost of medication as well as specialised services are more affordable and accessible to participants in the study as they pay a minimal hospital fee as compared to the high private rates.

4.4 Diagnosis of ADHD

Participants' experiences relating to their children's ADHD diagnosis is discussed in this section.

Table 4.2 Diagnosis of ADHD: Overview of themes and sub-themes

Themes	Sub-themes
Referral sources	Schools Parents/caregivers Allied health professionals Private health practitioners Community clinics
Participants' reaction to diagnosis	Anger Denial Depression Self-blame Secrecy Relief
Participants' concerns regarding diagnosis	Future Implications Lack of cognitive and motor skills Aetiology of ADHD Concern over substance Abuse
Family members' reaction to diagnosis	Adverse Concern with diagnosis Supportive
Explanation of diagnosis to child	Non-disclosure of diagnosis Disclosure and explanation

4.4.1 Referral Sources

Participants cited the school to be the most common referral source for the identification of ADHD. Other referral sources included the participants themselves who could not cope with the disruptive behaviour, allied health professionals who the child may have been referred to for delayed milestones and private health practitioners whom parents initially may have taken their child to.

4.4.1.1 Schools

In this study 9 out of the 21 participants mentioned that the school was responsible for referring the child for an ADHD assessment. Participants' statements such as "*He could not concentrate*", "*He had to repeat the grade*", "*He could not cope with the level of work*", revealed the problems experienced at school and the need for educators to refer children for assessments.

Teachers are usually the first to notice if a child is coping or not in the classroom (Sax & Kautz, 2003). This view is supported by Barkley (2000) who states that teachers are the first and foremost to identify learners with ADHD. According to the statutory

requirement for government schools the age for enrolment is either 6 or 7 years for grade 1. According to the DSM 1V- TR (2000), the onset of ADHD symptoms occurs when a child is 6 or 7 years old. At this time the child is in school and may present with behaviours that are consistent with ADHD, the prominent behaviours being inattentiveness and impulsivity. It is these symptoms that draws the teachers attention to identify the child with a learning or behavioural disorder. According to Green and Chee (1997: 5), teachers of children with ADHD complain that the child is “distractible, disruptive and needs one-to-one supervision”. All children with ADHD do not present with the same symptoms therefore it makes the teacher’s task difficult in identifying a child with the disorder (Green & Chee, 2004).

Teachers observe that ADHD presents in different ways (Green and Chee, 2004). The hyperactive-impulsive, poor self-monitoring behaviours result in the child rushing his work, slow to settle down in class, fidgets all the time and hands in poor quality work. Attention deficit learning problems affect listening skills, organisation of the work, short term memory and distractibility (Green & Chee, 1997). It is for these reasons that educators make referrals for the child to have an assessment. At this meso level, educators need to be equipped to identify children with ADHD in the classroom. Within the South African school context, with the grossly imbalanced teacher-learner ratios, the task of identifying children with ADHD makes the educator’s task even more difficult.

4.4.1.2 Parents/caregivers

Parents usually have a gut feeling when something is wrong with their child and know when they need to get help (Picton, 2005). In this study four participants suspected that there could be problems with their children as they presented with unusual behaviour either at home or at school. This prompted them to seek professional help as they realized that the child’s problems exceeded the capacity of the family to solve. As one mother stated “*He used to do funny things like climbing up the gate and not listening, very hyper*”. Many parents notice on their own that their child seem to behave differently from others and this is the reason for referral to their family doctor or any mental health professional (Barkley, 2000).

4.4.1.3 Allied health professionals

Many professionals are involved in diagnosing ADHD in children. In this study three of the participants mentioned that the speech therapist or audiologist was the first person to make the referral to the paediatrician after suspecting that the child may have ADHD. Responses from parents such as *“He was 3 years old and could not speak”* or *“He started speaking late and could not pronounce words”* were reasons they provided for taking the child to a speech therapist and or audiologist.

Children with ADHD frequently present with difficulties performing tasks that challenge the central auditory nervous system. Researchers have demonstrated that preschoolers with speech language delays are more likely to be diagnosed as having ADHD as well (Keller, 1992). There appears to be a close relationship between language disturbances and difficulties with sustained attention, impulsivity and distractibility (Keller, 1992).

Two of the participants reported referrals from the psychologist to the paediatric doctor for their children’s ADHD assessment. These children were initially referred to the psychologist for management of the behavioural disorders. A clinical psychologist might function on a one-to-one basis with a child or in a group session. He/she may employ the use of psychotherapy or behavioural therapy in their management of the ADHD child. (<http://www.netdoctor.co.uk>).

4.4.1.4 *Private Health Practitioners*

Two participants initially sought the services from their private doctors. The doctors then referred them to psychologists for an assessment. Owing to the high cost of private medical facilities these participants were forced to seek services in the public health sector for their children. The general practitioner often forms the first point of contact for help and support when parents/caregivers suspect there is a problem with their child.

4.3.1.5 *Community clinics*

Two of the participants were referred with their children from the local clinics in their areas. A mother reported the following:

“I took him to the clinic as I was having a problem with him at home. He used to keep on getting hurt because he was so hyper. He climbs up high places; he jumps from wardrobes onto beds. The sister at the clinic observed his behaviour and referred him to hospital”.

The municipal clinic which offers primary care services to both adults and children shares a relationship with the state hospitals. Referrals are made via the clinic to the hospital closest to the individual if management of the illness or disorder is not successful at a primary level. These local government clinics are managed by a primary health care team which is led by the medical doctor and professional nurse.

The main findings related to this theme on diagnosis were that the school was the main referral source, followed closely by participants requesting services. According to the AAP guidelines (2001), it is usually at around age seven when children are first diagnosed with the disorder and this correlates with children starting their first year of school at this age. According to Bester (2006), teachers usually pick up when a child has concentration problems or is disruptive in class. Hill and Van Haren (2005), mention that even some preschoolers may be detected with ADHD by their class teachers. It can be concluded that since parents/caregivers and teachers spend the most amount of time with children, they are bound to notice unusual behaviour or problems. It is therefore imperative for teachers to be knowledgeable on the bio-psychosocial components of ADHD as they spend the most amount of time with children each day and this would enable them to identify children with the disorder.

In terms of the "Education White Paper 6 on Special Needs Education" (2005) (discussed in chapter 2), it is recommended that educators receive training to identify and manage children with special education needs. This recommendation must be heeded so that children such as those with ADHD are not lost amongst the large numbers of learners allocated to classes. Furthermore, educators must become familiar with the disorder as they play an integral role in informing parents and caregivers when they detect dysfunctional behaviour in their children.

This theme explored the various referral sources that exist within the ADHD affected child's social network and the value that they have played with regards to the ADHD diagnosis. These referral sources are found within the micro and meso layer of this ecosystem and it is evident that there was equilibrium between these layers as children were identified and appropriately referred to the hospital under study for further assessment. In the next section participants reactions to diagnosis is discussed.

4.4.2. Participants' reaction to diagnosis

Of the 21 participants interviewed, 18 participants reacted negatively to their children's diagnosis of ADHD. The remaining 3 participants felt a sense of relief knowing their children's condition. According to Barkley (2000) parents' emotional reactions to information about ADHD are an important part of their adjustment to the child's disorder. Parents go through a range of emotions before there is acceptance of the disorder. The following sub-themes show the range of emotions that participants in this study experienced.

4.4.2.1 Anger

The majority of participants in this study reported initial feelings of anger after being given their child's ADHD diagnosis. One participant expressed her emotion as follows:

"I was so angry with God. Why my child?" and another parent's comment was *"I was so angry with myself for not seeing this earlier"*.

As can be seen from the responses, one participant revealed that she felt angry with herself for not discovering her child's disorder sooner whilst the other participant directed her anger on a more spiritual level as she felt that "God" has failed her. The anger that is directed against oneself is often in the form of guilt. According to Martin (1998), parents also display anger towards outside resources and may make disparaging comments against the sources of help in their children's lives such as the paediatrician or class teacher. In this study, participants expressed anger towards educators as they felt that they got no support from this meso layer. They were angry with the manner in which educators addressed their children's ADHD problem with them. As will be shown, participants also expressed their anger towards the hospital doctors as they felt that the doctors were hasty in making the diagnosis of ADHD without concrete tests being conducted. It is evident that there was disequilibrium within the meso layer as they failed to provide adequate support to participants relating to the diagnosis of their children.

4.4.2.2 Denial

"I was in denial, I did not want to accept that he has a problem" and *"I did not want to acknowledge my child's problem"* were some of the reactions that participants expressed in their discussion with the researcher. Five of the participants in the study expressed that they were in denial when they were given their children's diagnosis of ADHD. They

refused to accept the diagnosis. There were other participants who complained that their spouses refused to offer any support to them as they did not want to accept their children's diagnosis. The following were some of the comments:

"My husband does not want to acknowledge the child's problem up until today. He feels that the child does not need medication and he is just naughty. This was now my battle"

"My husband was also in denial. He felt that there was nothing wrong with the child. He said that he was just being a child".

"Her father at first did not want to talk about it. He was in denial. He felt ashamed".

These responses demonstrate that participants had to deal with the diagnosis on their own as their spouses refused to believe that their children were diagnosed with ADHD. According to Martin (1998) denial is often the first reaction to the discovery of ADHD. Barkley (2000) supports Martin's finding by stating that some parents initially engage in denial of the diagnosis. Parents hold on to the view that nothing could be so wrong with their child that can not be corrected by behaviour management methods.

4.4.2.3 Depression

Some participants in this study acknowledged that after receiving their child's diagnosis they went through a stage of depression. Parents expressed the following reactions *"I was crying because I was upset. I never experienced something like this before"* or *"We were initially depressed"*.

Parents of children with ADHD, especially those with co-morbid oppositional defiant disorder and conduct disorder are frequently more depressed than those parents with children without ADHD (Barkley, 1998). Greater levels of psychopathology and psychiatric disorders have been found in parents of children with ADHD (Barkley, 1998). In addition, parental depression has also been shown to predict family discord and behaviour problems in children with ADHD. If a parent is depressed, with distorted perceptions and cognitions and with difficulties in communication, she/he may have problems with objective evaluations of child behaviour, which would appear to increase the likelihood of negative parent-child interactions (Chi & Hinshaw, 2002). Researchers, Chi and Hinshaw (2002) reveal that mothers of children with ADHD experience higher levels of depression than do mothers of comparison children. This could be attributed to mothers spending the most amount of time with caretaking duties

of their ADHD child. In this study 19 out of the 21 participants were mothers who were the primary caregivers to their children.

Participants who experienced feeling depressed were often left feeling very isolated. Participants expressed feeling alone in this problem and reported not having sufficient family support. In most instances it was the mothers who were left to carry the burden of their child's diagnosis. This feeling of isolation was especially experienced by some of the single parents in this study who said the following:

"I did not get any support. Because my son is so disruptive, we are often shunned".

"My brothers don't communicate with me. My family does not bother about us".

"For me as a single mother, I am always judged. My family offer little support but are too quick to criticise the way I bring my child up".

From these participants' responses it can be concluded that there was little extended family support offered to them. In addition, single parents often carry a heavier burden, with financial responsibilities, work commitments and added to that the lack of spousal support in raising an ADHD child.

According to Barkley (2000) many parents end up socially isolated as friends, relatives, and neighbours try to avoid contact with the family. Peters and Jackson's (2008) findings found that mothers experienced minimal practical support from family or the community and often people were reluctant to offer child care help or involve these mothers with their children in activities. This form of isolation was attributed to the child's challenging behaviours. It can be concluded that the micro and meso layers in this ecosystem were in disequilibrium as there was little to no support offered at both the levels in the study.

4.4.2.4 Self-blame

Three of the participants in this study felt they were responsible for the child's ADHD diagnosis. Participants' responses such as *"I felt I was to blame"* and *"I try to go back and see where I went wrong"* highlight the amount of guilt parents experience as they attribute the disorder to something that could have been as a result of an omission or neglect, by them as parents. According to Shah (2010) the worst part of the whole ADHD dilemma is that most parents feel they are being blamed for the child's ADHD and

inevitably assume this blame. Parents often question themselves as to whose fault it is that their child has ADHD. This can be seen in the following response, *“My first response was, what have I done? I wanted to know how he got this way. Did we do this to him?”* In this study the findings reveal that many participants were ignorant of the aetiology of the disorder. They therefore assumed that their children’s ADHD was as a result of their wrong doing.

Bester (2006) states that one of the first reactions of a mother when her child is diagnosed with ADHD is that she experiences guilty feelings. It feels like an accusation against her, as if her parenting skills or lack thereof is being criticized. This view was further highlighted by researchers, Peters and Jackson (2008) who in their study found that mothers of children with ADHD suffer emotional stress because of self-blame, perceived blame from others (family members and teachers) and lack of family support.

4.4.2.5 Secrecy

In the present study some parents mentioned that they had not disclosed their child’s disorder to the extended family. The following responses from participants emerged.

“I did not tell anyone”.

“I don’t tell anybody he take the tablet. I feel so bad for him”.

Reasons that were cited were that family would not understand, and that they as parents were still coming to terms with the disorder. According to Peters and Jackson, (2008), there is so much negative stigma surrounding the disorder that parents choose not to disclose for fear of the child being stigmatised. They also found that parents sometimes attribute the behavioural difficulties to conditions that they perceive to be less stigmatising. Another reason for non-disclosure is that parenting skills come under constant scrutiny from family and friends (Barkley, 2000).

4.4.2.6 Relief

Three participants in this study revealed that they were relieved when given the child’s diagnosis. Two of the participants were the caregivers in this study. Responses such as the following showed parents’ relief:

“I was happy to know what was wrong with him”.

“I didn’t feel bad; this could be a way in helping them”.

"I felt a bit relieved because now I knew what was wrong".

The participants whose responses are noted above were older and according to them they experienced difficulty in coping with the children's disruptive behaviours. Therefore not knowing what was wrong with the child was a source of stress to them. The participants were willing to accept the diagnosis as it now provided the explanation that they had been desperately searching for. Prior to the diagnosis they perceived these children as being very naughty or presenting with severe behavioural problems. According to Barkley (2000: 141), "these families welcome relief from the burden of uncertainty and often of guilt as well". The participants in the study now had peace of mind after being given the child's diagnosis.

An analysis of this theme showed that participants experienced a range of emotions and feelings regarding their children's ADHD diagnosis. According to Barkley (2000), it is not uncommon for parents to go through an array of emotions before finally accepting the diagnosis. The manner in which they dealt with this diagnosis depended on the type of support they received from the micro and meso systems in this study. Responses from participants showed that some of them had strong support from family and friends whilst with other participants they struggled and had to deal with this diagnosis on their own. In this study it was mainly the mothers' who received their children's diagnosis, and mentioned their difficulties in eliciting support from their spouses and families. The findings reveal that some of the spouses were reluctant to accept the diagnosis and held onto the belief that there was "nothing wrong" with their children; therefore they offered no support to their wives who received the primary diagnosis. The two caregivers who were the grandmothers also received the primary diagnosis for their grandchildren. The grandmothers' reaction was that of relief as they now had an explanation for the children's behaviour. It can be concluded that in this study it was mainly the mothers who had to bear the burden of their children's disorder with very little external support.

The next sub-theme focuses on participants' concerns regarding diagnosis.

4.4.3 Participants' concerns regarding diagnosis

Almost all the participants in this study had concerns about their children's ADHD diagnosis. Participants' ubiquitous concerns pertained to the implications their children's

ADHD diagnosis held for the future. Participants in the study were particularly apprehensive about the educational needs of the child. Some participants expressed concern about the lack of cognitive and motor skills that their children presented with. Another primary concern of participants focused on the aetiology of the ADHD. A minority of participants' trepidations lay with their inability to cope with their children's disruptive behaviours as well as ADHD being associated with later substance abuse. The following emerging themes will be the focus of discussion.

4.4.3.1 Future Implications

Six participants showed concern about their children's future and the implications of the disorder into their adulthood. Some of their concerns focused on the following:

"Like if my child grows up, will he find a job? Is he going to get married? I wonder whether he will have kids. Would he be like a normal human being?"

"I am worried as to how it would affect his body. Will he get a job when he grows bigger?"

"I worry about what he is going to do about his future. I know it won't be academic. He likes electrical. He also likes cooking".

The above responses indicate that participants had not been educated on the disorder and were unaware of the prognosis of ADHD. They expressed a lack of knowledge on the long term effects of the disorder. The two ideas that present in this paragraph are the participants' lack of education and participants' concerns regarding their children's future. Participants were particularly concerned whether their children would be accepted into the job market or whether they would continue to be reliant on their parents. The response from one participant showed that she was concerned that her child could only engage in practical tasks. Since ADHD is a developmental disorder it pervades from infancy, into childhood, adolescence and finally into adulthood. It persists throughout the lifespan for most individuals who are diagnosed in childhood (Teeter, 1998).

Participants in the study have well founded concerns as the core symptoms of ADHD makes it extremely difficult for adults to adjust to structure, demands and the challenge of work and interpersonal relationships (Teeter, 1998). Green and Chee (2004) expand on Teeter's view by stating that adults with ADHD have the same difficulties as children as the school problems now become work problems. Parents' concerns were valid as Green

and Chee (2004) add that adults with ADHD perform below the level of competence in their jobs, have difficulty in finding and keeping jobs and are unable to perform at an intellectual level required for the job. These authors also state that adults with ADHD are unable to maintain social relationships. The primary features of the disorder (as discussed in chapter 2) interfere with work productivity, behavioural adjustments and psychosocial interactions (Teeter, 1998).

4.4.3.2 Lack of cognitive and motor skills

Six participants described feeling a sense of hopelessness at their children's poor cognitive and motor skills. One participant's reaction was as follows:

"His schoolwork is very bad. If he can read and write he would be able to get on in this world". This participant struggles with her child as he repeatedly fails his grade.

"He cannot put pen to paper. He can verbalise anything but has difficulty reading and writing".

Some participants pointed out their children's difficulties with motor skills. One participant made the following statement:

"He also cannot tie his lace. Simple tasks are hard for him".

This participant raised an earlier concern that her child was 12 years old but was still functioning at a grade 4 level. It can be concluded that his ADHD has resulted in these developmental delays and hence has affected both his cognitive and motor abilities.

Children with ADHD are already disadvantaged by their problems of attention, memory and executive control. In addition to the ADHD many children also have specific learning or motor disabilities. The most common areas of cognitive weakness are reading, spelling, mathematics and language (Green & Chee, 1997). In the current study, reading and writing feature as the prominent learning disabilities. Writing features as both a motor and cognitive skill.

Research conducted by Fliers et al (2009) on motor abilities of children with ADHD found that these children presented with difficulties in dressing, tying shoelaces, writing and sporting abilities. Participants were aware that this has severe implications for their children as it further reduces their social participation and places them at a disadvantage.

4.4.3.3 Aetiology of ADHD

Participants in this study expressed the need to know the cause of their children's ADHD diagnosis. Some of the reasons for wanting to know were to exempt themselves from the feelings of self blame. Some of the comments were:

"Firstly, I like to find out if we as parents faulted in any way for him to have this condition. Also how did he develop ADHD? He was fine from birth until 3 years old. What have we done wrong with him?"

"How did she get it? Why did it happen to her? Have I done something wrong?"

Participants' responses could be linked to researchers DeMarle and Ernhausen's (2003:304) findings, which reinforces the reactions of participants in this study, by stating that "although they may not ask, parents often have questions about the aetiology of ADHD". Participants in this study indicated that they want to know the nature and causes of the disorder as well as the total treatment regimen for their children in order to help them cope better with their children. Participants expressed a sense of disappointment as this important information was not divulged to them by the health care workers at the hospital. Findings from this study showed that participants were riddled with guilt as they felt that their children's ADHD diagnosis was attributed to some fault of their own. In analysis of this sub-theme it can be concluded that some participants have no knowledge on the nature and causes of their children's disorder and that this has been an area overlooked by the health care team in the initial stages of diagnosis of the disorder.

4.4.3.4 Concern over substance abuse

Two participants were concerned about their children becoming substance abusers as they became older. These participants commented that their primary concern was that their children would be addicted to prescription drugs. Both participants were aware of the potency of the medication prescribed for their children as they had read some literature on the psychostimulant drug, Ritalin. According to Holford and Burne (2006) Ritalin can cause an addiction in a similar way as cocaine does, by promoting levels of dopamine. This view is shared by Goldman et al (1998) who in their article state that those with ADHD are at an increased risk of developing a substance use disorder. They add that Ritalin may be the drug abused by individuals diagnosed with ADHD or it may be the entry point to other types of drug abuse. However, Faraone and Wilens (2003) refute the view of a positive relationship between ADHD psychostimulants and later

substance abuse. Their theory postulates that the pharmacotherapy of ADHD does not increase the risk for subsequent substance use disorders; rather it has a protective effect on later substance abuse. Thus, from a bio-psychosocial perspective, pharmacotherapy is used to address the biological needs of the affected children.

In conclusion of this theme, the overall picture presented by the majority of the participants was that they perceived their children's diagnosis of ADHD negatively. Further, there were many important but unanswered questions that plagued them. It is evident that participants were faced with many obstacles in their path to seeking holistic treatment for their ADHD affected children. It can be concluded that participants at the micro systemic level were being affected by the meso level in this ecosystems model, thereby creating dissatisfaction. The lack of adequate support for participants upon diagnosis of their children and failure by the health care workers to provide information on the disorder at the initial stages of diagnosis implies that there was disequilibrium between the two levels. The findings also show that participants were concerned about the bio-psychosocial functioning of their children as their main concerns lay with the outcome of their children's ADHD for the future.

The next theme explores family members' reactions to the children's ADHD diagnosis.

4.4.4 Family members' reaction to diagnosis

As noted earlier, support systems are an important aspect when coping with children with ADHD. The role of the family as a support network is central to ADHD management. Participants in this study reported both positive and negative experiences with family members relating to their reaction of their children's ADHD diagnosis. Immediate families' responses were also noted in this section. Extended family members form part of the micro or meso layer depending on whether they share the same living environment with the child or not; such as grandparents, uncles, aunts and cousins. In this study they were reported to have either played a supportive role upon receiving the child's diagnosis or they were critical and punitive in their responses toward the child and parent. The following sub-themes emerged.

4.4.4.1 Adverse Reactions

Ten participants reported negative attitudes from extended family relating to their children's ADHD diagnosis. Comments from participants regarding their families' reactions were as follows:

"One of my sisters really gets on my case but I ignore her. She is always passing insults"

"Family insult and pass remarks" and *"Some don't want to go near him and mock him"*.

Participants in a study conducted by Peters and Jackson (2008) disclosed that they became accustomed to a multitude of criticisms from family because of their children's behaviour. They were also subjected to scrutiny and being negatively judged by family (Peters & Jackson, 2008). Some participants in this study were exposed to the similar adverse and unpleasant comments from family. In this study, some participants felt that family judged them negatively on their parenting style, use of discipline and on their decision to comply with the treatment regime to use pharmacological treatment for the ADHD disorder.

4.4.4.2 Concern with diagnosis

There were a significant number of participants in this study who got no support at all from family. Instead they received criticism for taking certain decisions regarding their children's diagnosis. These participants who received no support found caretaking tasks of their ADHD child even more stressful. Some participants reported that some family members demonstrated support if they were allowed in joint decision making with them regarding the ADHD diagnosis.

Some participants reported that family often encouraged them to get a second opinion in order to confirm the child's disorder. Reasons for a second opinion included that family were often not happy with the thought of a child being given Ritalin, or that they did not want the child to carry a label of ADHD as they felt this would be an embarrassment to the family. Participants in this study reported that family members criticized them for administering Ritalin to their children and insisted that the participant get another medical opinion on these children. Furthermore, families also request a second opinion because they hold on to the hope that no serious medical condition is found with the child. These well meaning relatives therefore suggest that parents either take their children for a second evaluation or that they reconsider the use of medication. In this study, some participants also felt that their families were ashamed of having a child in their home with

ADHD. One participant expressed the following *"It hurts us when my in laws treat my son differently to the other children in the family. They lock him outside the house and don't allow him in"*, and other participants mentioned the following:

"For his grandparents, it was difficult to understand his condition. Even for his father, there was a lot of talking to get him to understand. The grandparents felt he was just lazy, they did not want him to have ADHD"

"The family all advised us to see a specialist"

"My family is very angry about him taking Ritalin. My sisters do not want him to continue taking Ritalin. I sometimes don't know what to do because who do I listen to".

The findings from the study show that the immediate, as well as, the extended family members especially grandparents were concerned upon receiving the diagnosis of their grandchildren. The manner with which they reacted to the diagnosis also reveals that they do not understand the condition. In this study the two extreme reactions from grandparents were that they either ignored the child or they refused to acknowledge that the child was diagnosed with the disorder.

Parents are often overwhelmed by the reactions of the extended family to their children's diagnosis and find the suggestion of a second evaluation even more stressful. In this study participants felt that if extended family members provided the support to them upon receiving the diagnosis, it would help with better coping strategies for the family as a whole. An analysis of this sub-theme reveals that there was disequilibrium at the micro and meso layers of this ecosystem. Participants' responses show that they felt confused and uncertain about the management of their children as the reactions from the family led to ambivalent feelings about medication usage and the diagnosis made.

4.4.4.3 Supportive

Ten participants in this study did receive support from extended family members such as their parents, siblings or in-laws. The responses below highlight the support they received:

"My parents and sisters offered a lot of support and this is what made it easier"

"My sisters were very supportive. They were very concerned and worried".

"My parents were very supportive. They helped me in whichever way they could"

The support offered was in the form of their role in child care, provision of financial support, emotional support and in some instances the provision of shelter. Families also expressed concern for the child, especially relating to the use of Ritalin. According to Barkley (2000: 105), "children with ADHD do not exist in a vacuum", they occupy certain specific places within various systems which is in keeping with the ecosystems model which guides this study. The most significant of these systems is the family. Knowing the role that families play and how they impact on the child with the disorder is the key instrument to better management of the child (Barkley, 2000). Extended family support especially grandparents are a wealth of knowledge and experience that parents with ADHD affected children could draw upon (Hill & Van Haren, 2005). A key finding is that when a parent had support from the extended family this impacted positively on their coping mechanisms with the child as they did not feel alone with this problem.

Families can choose to be supportive by showing empathy, being sympathetic or by being proactive. In this study families showed sympathy as a form of showing support by being overprotective towards the child, by being over compassionate and to an extent "pitying" the child by spoiling him/her. Participants mentioned the following reactions from family members

"It was more sympathy I should say. They felt sorry for him" and *"My parents were crying, even up to now they don't like me shouting at him"*.

Extended family members, especially grandparents are often accused of spoiling children with ADHD. According to Hill and Van Haren (2005) it is sometimes difficult for a person from the older generation to understand an ADHD affected child's behaviour and they tend to feel sorry for the child or are inconsistent in applying discipline. Children who are pitied for having the disorder begin to feel inadequate (Martin, 1998). The author adds that feelings of sympathy which encroaches on overprotection does not allow the child to grow and develop, instead it keeps the child immature and delays growth.

It can be concluded from the findings of this sub-theme that family networks play an integral part in the lives of ADHD affected children and their parents or caregivers. In this study it is apparent that many family members failed to provide the support that was needed for effective family functioning surrounding the disorder. It can be concluded from the responses that grandparents may not have the knowledge of the disorder therefore they found this diagnosis overwhelming and reacted adversely. There were

some participants who responded that family showed concern and support. If there is disequilibrium at this micro or meso layer it will negatively impact on the participant and the child. The interrelations between these two systems must be strong for it to be effective.

The theme that follows focuses on disclosure of ADHD to the child.

4.4.5 Explanation of diagnosis to child

Disclosure of the disorder to the child is an important aspect in the management of ADHD. Only eleven participants in this study informed their children of their diagnosis. Participants reported that although this information was given, the nature of illness was ineffectively communicated to the child as they were uncertain of the nature and causes of ADHD. The remaining ten participants chose to withhold diagnosis from the children.

4.4.5.1 Non disclosure of diagnosis to child

Ten participants did not disclose the ADHD diagnosis to the child. Participants either did not know how to explain the disorder or they felt that there was no need for the child to know. Participants felt that by withholding the diagnosis they enjoyed the comfort of protecting the child. According to researchers Nadeau and Quinn (2004) many parents are concerned about labelling their child with ADHD. They feel that by telling the child his/her diagnosis, the child is then left to carry this stigma. These researchers add that parents don't know where to start or exactly what to say to their ADHD children once the diagnosis has been made, yet they stress that not telling the child can have negative consequences as well. Six of the ten participants in the study did not disclose to the child his/her ADHD diagnosis as they felt that the child was too young to understand what this meant. Some of the participants' responses were as follows:

"I have not explained anything to him. He is not at an age where he can understand."

"We did not tell him anything, he would not understand. He is too young."

"I did not tell him anything about his condition. I don't know what to tell him."

"I don't tell him anything because he is small. He wont understand."

The age category for the purposes of this study was children between the ages 6-12 years old. This would hence account for children in the preschool years up to primary school learners who are in grade seven. The responses of participants show that some felt that

their children were too young to receive this diagnosis of ADHD. Participants also face this dilemma of non disclosure due to the negative image that the general public holds about the disorder (Nadeau & Quinn, 2004). The above responses show that the issue of disclosure was not discussed by health care workers.

4.4.5.2 Disclosure and explanation

Eleven participants in this study discussed the ADHD diagnosis with their children. These participants mentioned that they felt that their children had to know their medical condition as it involved a lifestyle change for these children. The following were some of the participants' responses:

"We told him that he must stop eating sweets or drinking coke".

"We did tell him that he does have a problem".

"She knows that she has a problem and that she has to take medication".

"I told them that I would have to control their eating of sugary food and that they were eating too much junk food".

Some participants' explanations to their children about their diagnosis focused on their present diet as being one of the causes of the disorder. Other participants felt that their children were old enough to understand their medical condition. Some of these children who were given their ADHD diagnosis were the older children in this study, whose ages ranged from nine years to twelve years old and had a fair level of understanding of what was happening to them. It is interesting to note that the participants who disclosed the diagnosis to their children were participants who had higher education levels, that being matric or tertiary education. This could be a possible explanation for these participants having a better understanding of the aetiology of the disorder.

Nadeau and Quinn (2004) stress the importance of informing children of their diagnosis in a realistic and constructive way. Information on the disorder can be tailored according to the age of the child and explained on a level that the child can understand. Nadeau and Quinn (2004) state that one of the dangers of growing up with undisclosed ADHD is low self esteem, the result of a lifetime of criticism and being embarrassed about not being able to keep up with others academically but not understanding why this is so.

From the participants responses on this sub-theme it is evident that parents require more information on how to disclose to children their diagnosis of ADHD. The findings reveal that many participants did not disclose the diagnosis to the children as they did not know what information to give. Furthermore participants with young children who have just started formal schooling had difficulty determining the level of their children's understanding and to the amount of information they should be exposed to. Of importance is the need to ensure that the child understands the nature of the disorder and the importance of complying with treatment.

4.5 Participants' knowledge of ADHD

This section focuses on the participants' knowledge of ADHD. The following themes and sub-themes emerged.

Table 4.3 Participants' knowledge of ADHD: Overview of Themes and Sub-themes

Themes	Sub – themes
Participants' understanding of ADHD	Lack of information Hearsay information Misunderstanding of ADHD Sufficient level of insight
Participants' reaction to medication	Lack of knowledge Fear of using medication Benefits of medication
Participants' knowledge of dietary needs	Adverse effect of Ritalin Misconceptions regarding diet in ADHD Use of vitamin supplements

4.5.1 Participants' understanding of ADHD

In this study participants displayed varying degrees of understanding of ADHD. It varied from a large proportion of participants not having any understanding at all to a minority group that had some insight into the nature of the disorder. The sub-themes that emerged are discussed below.

4.5.1.1 Lack of information

Nineteen participants in the individual interviews mentioned that they had little to no knowledge about the disorder. From the focus group 3 participants mentioned that the first time they heard of the disorder was at the initial diagnosis at the paediatric clinic at

the hospital under study. They had no prior information on ADHD. These were responses from participants regarding their knowledge base of ADHD.

"I got my information from my sister's laptop. None of the information I like. Everything was so bad, like a child dying after 7 years."

"We got the information on our own".

"I have no knowledge about ADHD. No one to explain it to us".

"No, I don't know anything about it. First time you telling me ADHD. I know he is hyper".

"I did hear about ADHD but not too much information. I never thought that I would ever need to know. These children are a handful".

"I don't know much. I would like to know more".

"I tell you honestly that I don't know much. This is all new to me although it is now going two years".

"We don't really understand much. We get our information from parents with similar children".

"I have vague knowledge of ADHD".

"For me too, it was my first experience with something like this. My other child is so fine, so how can this one be so abnormal. I never knew there was something like this. It is so sad".

The above responses have a critical implication for participants in their management of their children's disorder. As a result of the lack of information on ADHD participants are ill-informed on the disorder and therefore are unable to manage the disorder effectively. Participants' lack of information on the disorder has resulted in some believing that the disorder is pathological and that their children are not functioning as normal individuals. The use of terminology such as "abnormal" to describe a child is likely to impact on the psyche of the child.

From participants responses it is evident that they were frustrated with not being given information on the disorder. For one participant, it was the first time that she had heard the term ADHD. Participants complained that there was little effort made by medical staff at the hospital to explain the exact nature and cause of the disorder. Some participants sought their own information and had their own interpretations of the

disorder, sometimes with detrimental effects such as participants believing that ADHD could result in death.

Literature also reveals that parents and caregivers of children with ADHD are often lacking critical information about the chronicity of the condition. In support of the findings in this study that parents' lack understanding of ADHD, the findings from a survey conducted with parents of ADHD children in the USA in 2006 showed that there was an urgent need for family education about ADHD in order to dispel the myths that parents in the study assumed (<http://medical.bizcommunity.com>). A similar study conducted at the Mount Saint Vincent University found that if parents were provided with information regarding ADHD prior to offering them treatment options it could have a favourable impact on treatment enrolment thereby enhancing treatment adherence (<http://medical.bizcommunity.com>). Both these studies are significant as it demonstrates the value of parental knowledge in the effective management of the disorder.

Of significance to parents level of understanding is the amount of information sharing that medical professionals engage in with parents at public hospitals. In a busy state facility, doctors may not have the necessary time to spend with the parent or caregiver to review the nature and causes of ADHD (DeMarle & Ernhausen, 2003). Furthermore the participants' level of understanding could also be positively correlated with their level of education.

4.5.1.2 Hearsay information

Some participants revealed that they got their information from other parents attending the clinic, from family members or from people within their communities. The most common source of hearsay information in this study was from parents who had children who were also diagnosed with the condition. The following were parents' responses around this sub-theme:

"We get our information from parents with similar children".

"Parents at the clinic sit and talk".

"My sister did some research on ADHD from the internet and it said something about death".

"I heard from other relatives. My husband's nephew is ADHD. It seems to run in the family".

Participants meet at the ADHD clinic every month and have to wait for long periods before being attended to. They have become familiar with each other and often share their experiences with one another. Through this informal meeting, a lot of information sharing occurs.

One participant mentioned receiving her information from her sister who had retrieved information from the internet. This was alarming and devastating for the participant as the information given to her associated ADHD with death. According to DeMarle and Ernhausen (2003) information from the web may sometimes be controversial, unfounded or factually wrong. However, they add that there are a large number of factually correct, updated resources available which parents could benefit from. According to Green and Chee (1997) parents are frequently given copious amounts of information on ADHD from well meaning friends or family, however this often leaves the parent feeling confused and overwhelmed with not knowing whose information to consider. Parents in their search to want to know more about their children's' condition in an attempt to reduce their feelings of guilt and blame will accept any information provided to them (Barkley, 2000).

4.5.1.3 Misunderstanding of ADHD

Four of the participants in the study demonstrated a misunderstanding of their child's disorder. Their responses were as follows:

"He is not like a normal child and needs special attention"

"It is a sickness where he can't do anything at all"

"His brain is working faster than the rest of us. He gets bored easily"

"From a medical point I know that they are hyperactive and can't sit still but from a mother's point of view I think they are just children and need more attention"

These participants' responses showed clearly that they did not have a good understanding of their children's disorder. Some of them felt that their children were completely disabled or "abnormal". As shown in the previous sub-theme in 4.5.1.1 the lack of information resulted in participants believing that their children's condition being pathological. The above responses were from mothers who showed sympathy towards their children for the ADHD diagnosis. Statements from participants such as *"He is not*

like a normal child’ or “*He can’t do anything at all*”, emphasizes the extent to which this disorder is misunderstood by participants.

Critics argue that parents are often misinformed about ADHD because they are often influenced by public perception of ADHD which is full of myths, misconceptions and misunderstandings of the disorder (<http://medical.bizcommunity.com>). Participants’ misunderstanding of the disorder became a hindrance when doctors provided them with the treatment plan for their children. As a result of not being adequately informed of the disorder participants were ambivalent about commencing treatment. Some of the participants’ misunderstanding of the disorder led them to believe that the disorder was a lot more severe than it actually is.

A study by Ghanizadeh (2007) with 119 participants found that knowledge about ADHD was relatively low. The findings of this study support the view that many parents are not aware or educated on the aetiology of ADHD. The participants’ misunderstandings in the current study could be attributed to low education levels of the participants as well as insufficient information provided to participants by the attending medical personnel at the clinic.

4.5.1.4 Sufficient level of insight

In this study there was only one participant from the individual interviews and one participant from the focus group discussion who revealed that they had sufficient insight on ADHD. The one participant cited her previous work experience as the reason for her familiarity on this disorder. A contributing factor to her obtaining adequate knowledge on ADHD is possibly her tertiary level of education in an allied medical field. The other participant received information from her private doctor. A study conducted by Corkum et al (1999) on parental knowledge on ADHD found that improvements in parental knowledge would be the first step to improving adherence to treatment and that parental knowledge plays a significant role in the families’ decision to seek help for the ADHD child.

4.5.2 Participants’ reaction to medication

The sub themes discussed below reveal participants’ reactions to the use of ADHD medication. The reactions of participants were largely adverse. There was only a small

minority of participants that saw the benefits of psychostimulant medication in the treatment of their children. The following sub-themes are discussed:

4.5.2.1 Lack of knowledge

A large proportion of the respondents in this study demonstrated a lack of knowledge on the use of psychostimulant drugs for the treatment of children with ADHD. The following responses were provided by participants.

“Not much knowledge, but we have heard from people who do give their children Ritalin, what it is about”.

“No, Not too much knowledge, but we don’t like giving the Ritalin because of all the negative publicity on it”.

“I read a leaflet that comes with the medication and that is all the information I have”.

The above responses from participants revealed that participants had insufficient knowledge on ADHD medication. It can be concluded that doctors at the clinic within the hospital have neglected to provide participants with adequate information on the use of Ritalin. One participant also revealed that she had stopped the medication as a result of not being informed of the benefits and side effects of the medication. She felt that it was the responsibility of the hospital to inform the parent of medication use.

In a study conducted in Johannesburg with 23 mothers on the use of Ritalin in treating their ADHD children, researchers Wright and Van Staden (2005) found that 12 of these mothers were reluctant to use the stimulant Ritalin because they lacked knowledge on the benefits of the drug. Similarly in the current study eighty percent of the participants were mothers and their negative reaction to the use of Ritalin stemmed from the lack of education on the drug. Participants in this study displayed an equal lack of education regarding Ritalin, however they continued to administer the drug as they entrusted the wellbeing of the child with ADHD to the health professional. Both fathers in this study preferred alternatives to Ritalin as they were witness to some of the adverse effects of Ritalin on their children.

4.5.2.2 Fear of using medication

The fears that participants revealed in this study on the use of psycho-stimulant medication were as follows:

"I read the leaflet that comes with the medication and yes it worries me because it had death written on the pamphlet".

"I have little knowledge on Ritalin. I was scared the first time to give it to him because people say so much negative things about it".

"Everything is so bad, like a child dying after taking it for 7 years. It is so addictive".

Participants' fears in this study were consistent with the study conducted by Charach et al (2006) who explored parents' views on stimulant medication. Their findings were that their subjects expressed fear about the safety of using medication in treating ADHD and that the decision to use medication was difficult because participants were afraid they were rendering their children drug dependant. Added to this were negative media portrayals of Ritalin use which complicated the decisions for parents. Participants in the study were apprehensive about the use of Ritalin as a result of their ignorance of the drug. These participants were also exposed to controversial information which further exacerbated their fears.

From the responses of participants in the current study, it can be concluded that medical professionals at the hospital under study failed to address the participants' fears and that these participants were sceptical about the use of stimulant medication. Some participants were also affected by media reports of the negative effects of Ritalin.

The fear expressed by participants stemmed from concerns on the side effects of Ritalin and the long term use of this drug. Some of the responses which displayed concern were as follows:

"It concerns me a lot. As a parent I don't like seeing my child taking medication all the time. Is the medication going to affect him in the long run? I spoke to the doctor today and told her that I consumed alcohol in my pregnancy. I thought this may have affected him with this condition".

"I need to know what the side effects are. What I noticed was that my child becomes reserved for a couple of hours. The fact that they say it causes harm is a worry".

"The Ritalin is not long lasting and the hospital does not give Concerta. The doctors say that Concerta is better than Ritalin. It has less side effects than Ritalin and is long lasting".

"It concerns me as to how long he would be on Ritalin and what it would do to him. Would it affect his kidney?"

“As soon as he takes the medication he does not want to eat. He refuses to eat food”.

“Is it having an effect on his body, sometimes he does not have an appetite”.

As noted above, participants in the study raised several concerns about the use of Ritalin. Some participants were emotional as they described their children’s side effects. Their primary concern was the danger that Ritalin poses over a period of time. It is apparent from their responses that there was little education or counselling provided to them by the service provider prior to their children being prescribed a scheduled drug. The most pressing concern for most of these participants was the harsh side effects of the drug. As discussed in Chapter 2, the number of side effects when using the stimulant Ritalin is extensive and alarming. A common concern noted by parents is the refusal of the child to eat. According to Bester (2006) most side effects do disappear after the adjustment period but the loss of appetite is often the most long lasting side effect. This highlights the validity of parents’ concerns on this issue.

One participant commented that the service provider fails to consider other forms of stimulant medication with fewer contra indications. The process involved in changing over to a new prescription drug involves a long process which would entail revising protocols and tenders on the public sector’s essential drug list.

Some participants raised their concern over the effects of prolonged use of the drug. This view is supported by Bester (2006) who mentions that the long term effects of Ritalin include concerns over organ damage.

The concerns raised by participants in this study are in line with what researchers Sonuga-Bark *et al* (2006) found in their study on non-pharmacological interventions. Their findings suggested that fifty five percent of parents in their study with school aged children on ADHD medication reported initial hesitation to use Ritalin due to concerns over side effects and negative press reports. Clinical reports from this study by Sonuga-Bark *et al* (2006) showed that the younger the child, the greater was parents’ resistance to use medication. An opposing view shared by Goldman *et al* (1998) claims that the adverse effects from Ritalin are generally mild, short lived and responsive to dosing or timing adjustments.

Universally parents want to do what is best for their children. However with children with ADHD there is a lot of hype about the adverse effects of medication usage and parents/caregivers are concerned about their children taking a scheduled drug everyday. Further stigmatization by family and friends over the parent's decision to comply with pharmacological treatment leaves parents/caregivers in a state of complete confusion (Charach *et al*, 2006).

4.5.2.3 Benefits of medication

A few participants in the study had positive experiences with their children using Ritalin. They reflected on the following experiences:

"The medication is helping him, it takes time but I can't rush. It does not work overnight. I feel relieved that there is some form of help for my child".

"Well, I know it is a schedule 6 drug. It has to be taken at a certain time. I know it helps him".

"I think it really helps him. It keeps him quiet".

"There is nothing that worries me. It is peaceful. I like it when he takes the tablets, otherwise headache for me. Now I don't scream and shout, you can come ask my neighbours".

The above participants described feeling a sense of relief after administering Ritalin. Participants who saw the benefits of Ritalin had children who presented with disruptive behaviour, and in some instances violent behaviour was noted. These participants enjoyed this newfound peace and tranquillity within their homes. Participants in the study who had positive experiences with the drug were in the older age category and this could account for them not coping with hyperactive and aggressive behaviour of the children. Both the participants who were the caregivers to the children and who were in the above age 50 category did share some concerns about the drug but overall they found Ritalin to be useful as it had a calming effect on the children.

The responses from these participants were not unique to this study. A study conducted by Wright (1997), on parents' perceptions of Ritalin found that their response to Ritalin was overwhelmingly positive. Similar to this study, parents in Wright's (1997) study reported that children were calmer and that concentration was better. Furthermore, the aggressive behaviour had diminished. According to Evans *et al* (2004) Ritalin has been

effective in reducing the core symptoms of ADHD which is inattention, hyperactivity and impulsivity. They add that parents are accepting of treatment as it facilitates improvements in relationships with peers, teachers and parents, thereby ensuring that their children's psychosocial needs are being met.

In summary, participants in the study had ambivalent feelings about the use of Ritalin. The large majority of participants were reluctant to administer Ritalin to their children whilst a small number of participants saw the benefits to this psycho-stimulant drug. Discussions with participants in the focus group revealed that although caregivers had concerns over the use of Ritalin, they largely saw the advantages of their children taking Ritalin. These participants' responses highlighted that they found some solace with their children taking Ritalin as there were noted improvements in their behaviour and concentration in class. Thus, from a bio-psychosocial perspective, the use of Ritalin ensured that the biological, psychological and social needs were attended to. Furthermore, biologically, the use of Ritalin would ensure that the dopamine levels in the brain of these affected children would be regulated, thereby improving the concentration, hyperactivity levels and impulsivity of these children. As stated previously, participants concerns about Ritalin use, stemmed from the negative publicity around the use of this psychotropic drug. It can be concluded that participants' lack of knowledge contributed to their dilemma about using Ritalin on their children with ADHD.

4.5.3 Participants' knowledge of dietary needs

The majority of participants expressed that they were not given specific dietary guidelines for their children to follow. Some participants complained that the only advice given to them was to prevent their children from eating "junk food" which comprised of chips, chocolate, fizzy drinks and processed food. Twelve participants were not provided with any dietary advice whilst a small minority of participants were provided with comprehensive advice which included a dietary pamphlet. Some participants were asked to exclude certain foods from their child's diet. The following sub- themes emerged:

4.5.3.1 Adverse effect of Ritalin

One participant mentioned that she noticed a decline in the child's appetite upon taking Ritalin. She said the following:

"Nothing at all was told to me, but her appetite is so poor when she takes the Ritalin".

A similar response was given by another participant who shared her concern with the researcher.

“The doctor has not referred me to the dietician. He was healthy before, now he has nothing on him. When he takes Ritalin he does not eat”.

Another response from the participant was that her child now has an eating disorder after commencing with Ritalin treatment.

Participants were not informed by the doctor that one of the side effects of the drug was a decrease in appetite. This was one of the most frequent concerns expressed by participants. Participants in the study were concerned because their children refused to eat breakfast prior to going to school. According to Wright (1997) parents reported that the most common side effect their children experienced was the loss of appetite. Bester (2006) concurred with this finding as she found the loss of appetite is often the most long-lasting side effect.

4.5.3.3 Misconceptions regarding diet in ADHD

A popular view held by parents, some professionals and the general public is that the intake of sugar causes ADHD (Barkley, 2000: 75). In the current study participants reported that medical professionals advised along similar lines:

“I should cut down giving him sweets and chocolates

“They advised me not to give him sugar”

“The doctor told me not to give him clover items. No sweets or chocolates. Nothing with sugar must be given to him”.

Participants who brought their children to the clinic mentioned that the doctor often told them that it was the child's diet that contributed to the disruptive behaviours these children exhibited. Doctors at the clinic frowned upon a diet high in fat or sugar. Some parents were provided with information relating to their child's diet, where they had to make certain exclusions with regards to the types of food their children were exposed to. The one participant in the study was curious as to why Clover branded foods were eliminated from the child's diet. This participant was probably advised not to give her child dairy products and the example used by the health care worker could perhaps have been the product label “Clover”. This response indicates that the participant did not understand the advice of the health care worker. Participants were not offered any in-

depth explanation for reasons why their children should refrain from specific food. Participants were hastily told by medical professionals that sugar and “junk food” results in ADHD.

Research conducted to prove the hypothesis that sugar causes ADHD have generally proven negative (Barkley, 2000). Research conducted by Holford and Burne (2006) refute studies which show a negative correlation between sugar and ADHD. Their study of 265 hyperactive children found that more than three quarters displayed abnormal glucose tolerance, meaning that their bodies were less able to handle sugar intake and maintain balanced blood sugar levels.

4.5.3.4 Use of Vitamins supplements

There was one participant in the study was advised to supplement her child’s diet with vitamins. She mentioned the following:

“I have been giving him multivitamins. I have been buying everything. The hospital did give vitamin B but my child did not take it because it was too big and it had a funny smell. The doctor prescribed Cod liver oil but I used to buy it from Clicks. It is very expensive to look after a child with this condition”.

Although this participant was given a prescription for vitamins, this was not provided by the hospital in this study. Participants attending the public hospital do so because they cannot afford private hospital rates. Before recommending the use of supplements for their children, doctors must ensure that it is available at the hospital pharmacy. Not all participants in the study were informed about giving their children vitamin supplements. Thus doctors must ensure that there is consistency with the treatment regimen for all ADHD children.

According to Bester (2006) the use of vitamins in relieving the symptoms of ADHD is advocated. She adds that Omega 3 and Omega 6 supplements are being marketed with the claim that they reduce the symptoms of ADHD. Other nutritional experts offer the view that ADHD sufferers need higher levels of essential fatty acids. Therefore doctors within public hospitals need to realize the value of vitamin supplements in the management of the child with ADHD.

In analysing this sub-theme it is evident that participants recognized the benefit of dietary advice as an adjunct to the treatment regime for their ADHD children. However, the service of the dietician was not easily accessible to participants as the process of referral was not consistent for all participants. This had an impact on participants as they were not equipped with sufficient knowledge on the dietary requirements for their ADHD children.

Conclusion

In conclusion of this chapter it is evident from participants' responses that they were bereft of essential information pertaining to their children's' disorder. They therefore experienced ambivalence with certain aspects in the management of their ADHD affected children, more specifically being the use of pharmacological treatment. Furthermore, it is clear that the bio-psychosocial approach to care was not discussed with participants by the health care team at the hospital at the initial stages of their children's ADHD diagnosis and treatment. Participants' concerns relating to pharmacological use further highlight the neglect by the health care providers at this public facility in providing a holistic bio-psychosocial approach to the management of ADHD in their affected children.

The findings also reveal that participants lacked support from immediate and extended family which further exacerbated and heightened their levels of stress. It can be concluded from an eco-systems perspective that both the micro and the meso layers in this study were in complete disequilibrium. The findings reveal that there was "no goodness of fit" between participants and their environment.

The next chapter focuses on participants' experiences of service provision at the hospital under study.

CHAPTER FIVE
PARTICIPANTS' EXPERIENCES OF SERVICE PROVISION

5.1 INTRODUCTION

Included in this chapter are participants' responses on their interactions with allied medical professionals and the type of support they received at the hospital. The chapter concludes with recommendations by participants for an improved service delivery at the hospital under study.

5.2 Service Delivery

Participants' experiences with the service provider were explored when bringing in their ADHD affected children to the public hospital under study. The researcher identified gaps in the provision of services to children with ADHD and the participants. The table below shows the themes and sub-themes that emerged.

Table 5.1: Service Delivery: Overview of themes and sub-themes

Themes	Sub-themes
Information on ADHD received from the hospital	Insufficient information Information on psychostimulant medication
Experiences when attending hospital with children	Difficulties controlling children in the outpatient clinic Long waiting times Challenges with hospital processes
Contacts with health care workers	Occupational therapists Psychologists Speech therapists and Audiologists Social workers Dieticians
Experiences of service provision	Lack of communication Discriminatory behaviour of health care workers Inadequate care due to busy clinic Positive experiences
Treatment plan	Inadequate communication pertaining to the use of Ritalin Parental compliance with treatment Acceptance of treatment

5.2.1 Information on ADHD received from the hospital

Participants were asked about the information they were given by health care workers at the hospital on their children's ADHD disorder. Their responses are discussed under the following sub-themes.

5.2.1.1 Insufficient information

Some participants revealed that they did not get information on ADHD from the health care workers at the hospital. They mentioned receiving ADHD information from other parents, and the media. Two of the parents' mentioned the following:

"We got nothing and that is what is so disappointing. We speak to other parents to get our information".

"Nothing from the hospital. The information was from other parents".

Other responses were as follows:

"I got information on ADHD from watching Oprah and reading the You magazine".

"No information was given from the clinic. We should be given a talk, at least at the first visit".

"It is important to be given material to read when your child is diagnosed with ADHD".

"The doctors and nurses should at least give us some pamphlets"

Many participants expressed their disappointment with health care workers at the hospital for not taking the initiative to provide them with information on the nature and cause of the disorder. Participants were left to seek their own prognosis on their children's condition as it was not clearly explained to them by hospital staff. As a result of health care workers not providing sufficient information, participants resorted to obtaining information from other sources. Sources of information included multi-media sources as well as other parents/caregivers who attended the ADHD clinic with their children. The inherent problem with this is that the information they received was left to their subjective interpretations and in certain instances it resulted in misinterpretation or misunderstanding of the disorder.

Some of the participants said that they were not provided with any literature from the hospital on ADHD. They felt that providing information to parents on the disorder was an important part of the treatment process. This would assist them in better understanding

their children's behaviour. Their responses also highlight that an important area regarding the provision of information on the disorder was being neglected by health care workers within the hospital. These participants felt that information should be given to them at least at the initial stages of their children being diagnosed. According to Hockenberry et al (2006), nurses have an important role to play in educating the child with ADHD and the parent on the disorder. They add that nursing management begins with an explanation to parents and the child about diagnosis. The participants in this study were not provided with this information from this vital source.

According to DeMarle and Ernthausen (2003) a parents' ability to cope with a child with ADHD is affected by the information given and the listening ability of the physician. They add that equally as important as accurate diagnosis and treatment is the ability to provide family members with clear and concise information that leads to an understanding of the disorder.

As mentioned previously, the reason nurses and doctors may not be able to provide sufficient information is that there are gross shortages of scarce skills professionals within the health sector. It can be concluded that there are too few health care workers to meet the needs of a busy clinic and imparting health information or education is viewed as a luxury at busy state hospitals.

5.2.1.2 Information on psychostimulant medication

A frequent complaint of the majority of the participants was that little to no information was provided to them on the use of the psychostimulant drug, Ritalin. This lack of knowledge on Ritalin can be seen in participants' responses below:

"I am starting to give her the medication from today, but I don't know where to start or how to give the medication".

"We give him the medication but we don't know how it helps. It does not seem to help because my son complains about headaches and I see funny twitches in his face"

Participants indicated that they had limited knowledge of Ritalin and their main concern was that the health care workers at the hospital did not inform them of the side effects of the drug. According to some participants their children's reaction to Ritalin was so severe that it resulted in non adherence to treatment.

Participants criticized the health care team at the hospital for their lack of accountability to parents in providing drug education and advice. Participants' fears were heightened from the negative publicity Ritalin received through the public and media. The findings of DeMarle and Ernthausen (2003) show that there are a number of myths and misconceptions about medication and pharmacologic management of ADHD and that parents are often in a quandary over whether or not to medicate. However, they add that doctors or other health care workers within the clinical environment can put into context for the concerned participant the primary goal of Ritalin and the specific target symptoms for which the medication is being prescribed.

In summary, it can be assumed that the lack of knowledge by parents on psychostimulant use can result in poor outcomes for their children with ADHD in terms of treatment compliance. At a micro level it is imperative that parents be educated on their children's disorder. It is essential for them to be aware of the nature and causes of the disorder as well as the use of pharmacological treatment for better management of their children. It can be concluded that at a meso level health care workers have neglected an important aspect in the management of the ADHD child, by not providing information to participants on the nature and causes of the disorder.

5.2.2. Experiences at the hospital

Participants shared their encounters of a typical visit to the hospital when accompanying their children for their ADHD clinic appointment. Only a minority of parents verbalised positive encounters whilst a large proportion of parents expressed experiencing immense stress during their hospital visit. The sub-themes below illustrate participants' experiences with their children.

5.2.2.1 Difficulties controlling children in the outpatient clinic.

The majority of participants in the study described their hospital visit with their children as challenging and arduous. They reported this experience as being a source of stress to their already stressful lives. Participants articulated the following responses which illustrated their stressful encounters at the hospital on the day of bringing in the child for the clinic appointment.

"It is horrible because I cannot control her. She demands for things and I have no money. She does not leave me in peace. I am also a heart patient and if I sit she runs off. I cannot run after her. We also wait a long time in the hospital".

"It is dreadful. When I come in with my child I cannot control him. He knows it is not his routine day and refuses to take his medication. He runs outside and talks to everyone. Everybody in POPD knows when he is there. It is so embarrassing".

"He is a child who cannot sit quietly. To have to sit with him and to wait for the chart and to have patience with him is not easy. It takes its toll on parents to have to sit all day with a hyperactive child."

The responses of participants highlights the stressors they experience in the caretaking demands of their children when bringing them to the hospital. It is evident from their responses that they were unable to cope with their children during these visits and that it resulted in heightened parental distress. Children are hyperactive and have difficulty waiting and following processes for long periods. They therefore become disruptive and cause anguish to participants.

Participants' inability to cope was as a result of their children's restlessness and disruptiveness which are typical ADHD behaviours as noted in chapter 2. With a child diagnosed with ADHD, routine, structure and consistency play an important role for the child to function effectively with daily tasks. Therefore their day at the clinic is an unpredictable day for them and sets their equilibrium off balance, thereby intensifying parental stress (Green and Chee, 1997).

5.2.2.2 Long waiting times

Some participants reported unfavourable waiting times. The following responses were heard from participants:

"It is a long day. Dispensary is very long. We have to wait in long queues for our charts and we sometimes miss the doctor's appointment time. It does get frustrating because these children should be given priority".

"The day is very long, from the time we wait for the charts to the time we receive medication and this is tiring for the children".

"It takes so long before we get to see the doctor for a few minutes"

"Every month we have the same waiting problem at the clinic. We hear the same excuses about staff shortages".

"We have to wait so long just to sign for one medicine".

Participants said that waiting to be attended to by the health care provider was prolonged and they found it unacceptable. Participants complained that the longest and most tiring wait was at the dispensary. It was at this service point that children became restless and disruptive which resulted in parents' agitation. Cullinen (2006) mentions that waiting times especially for children and the elderly are indicators of the overburdened public health system. She adds that these two categories of patients are "crowded out" of hospitals by people who are critically ill and in need of more care. There was a perception by participants that one of the reasons for the prolonged wait for treatment was the insufficient staff complement at the hospital. This view is supported by Cullinen (2006) who found that approximately one-third of health posts throughout South African public hospitals were vacant and that some institutions are functioning with less than half the required staff. The hospital under study shares a similar problem in that not all critical posts are filled resulting in service delivery being hindered. In this study the impact of this is clearly seen with parents' elevated levels of frustrations.

5.2.2.3 Challenges with hospital processes

Many participants expressed dissatisfaction with the processes at the hospital under study. The inconvenient administrative processes such as obtaining the medical outpatient chart and waiting to sign for acceptance of the scheduled drug were high on the list of parents' frustrations at the hospital. The majority of participants complained bitterly about their prolonged wait at the dispensary. Some participants objected to the bureaucratic practices that hospital processes followed, such as the ADHD clinic being only opened until a certain time and the inflexible manner with which Ritalin was dispensed. Furthermore, participants faced conflicting situations where appointments were scheduled for their children at a specific time but they were not able to adhere to these time frames because of the laborious administrative tasks that were a pre-requisite to receiving treatment. Participants' dissatisfaction is narrated hereunder:

"My day here is very miserable. When you come here, taking out the chart is difficult. As for the medication, that takes forever to receive. We have to keep on going to the counter. It is a nightmare to bring my son to hospital".

"Only to get your chart out it becomes a problem. For me it is difficult because I got to see to both children and to get here by 7am is difficult to get the chart. I used to get to the clinic at only 8am and this used to be a problem with the sisters in the clinic".

“The appointments are all made on different days for him. I don’t bring him on one day so that he can see all the doctors. I haven’t got money to come so many days. Why they don’t make me come one day?”

“I had an experience where I had to sit and wait an hour for his chart, then I got a shouting from the POPD clinic because I was not there at 7am. It is very difficult because we are taking public transport and when we get here we have a long wait. The nurses at the clinic are fine. When we go to pharmacy it is terrible. I post the chart sometimes at 8:30 and only get it at 11:30. For children with ADHD it is absolutely terrible because the medication wears off. My child is all over the place and the dispensary is full”.

The above quotes give detailed accounts of participants’ experiences with hospital processes. They described the hospital processes as tedious, time consuming, inconsistent and stressful for themselves as well as their ADHD children. The most common complaint that participants had was about the long delay to obtain their children’s medical charts. The wait to see the doctor was an equally tedious and tiresome process which further agitated the participants and their children. Due to Ritalin being a scheduled substance, which requires a specialist authorised prescription, there was a further delay at the pharmacy before this item could be dispensed. It can be concluded that these hospital processes added to the stress that participants were already predisposed to.

In the following section participants’ interactions with the allied medical professionals are discussed.

5.2.3 Contacts with allied health care workers

Participants’ interactions with other allied health care workers at the hospital under study were explored. Some participants stated that they had in-depth sessions with allied professionals whilst other participants were not familiar with these support service providers. In the context of this study, allied health professionals form the meso level of the different systems in this ecosystem. These professionals need to work together for this system to maintain equilibrium. Participants’ responses relating to their interactions with allied health professionals are discussed below.

5.2.3.1 Occupational therapists

All participants with children diagnosed with ADHD and who are below the age of eight years are referred to the occupational therapist. Majority of the participants had favourable comments about their interactions with the occupational therapy department. The following comments could be heard from parents:

“The OT benefits my child the most because he learns to concentrate there”.

“The OT has benefited my son but this was stopped when he turned 8. I feel this service should continue because he showed a lot of improvement here”.

“Our experiences with the occupational therapist have been positive. The OT has been of a great help to my son.

“He benefited from occupational therapy but we feel he should have been kept longer on the program”.

“The occupational therapist does activities with him. He is not naughty there”.

The responses from participants on the benefits of occupational therapy were overwhelmingly positive. Parents saw the advantages of their children entering the occupational therapy program. Parents satisfaction with this service stemmed from them observing their child engaged in an activity which is usually not a normal practice. These findings are in line with those of Green and Chee (1997). They found that participants had positive reactions with occupational therapy because of the marked improvement in a child's motor skills and coordination.

Some participants however discussed their disappointment with having this service terminated once their children turned 8 years old. According to the internal policy document of the occupational therapy department, services are only offered to children with learning disorders until 8 years of age (Dept of Health, Occupational Therapy: 08/2006). The assumption is that the department of education would continue to render services, however participants indicated that their children did not receive occupational therapy services from the department of education.

5.2.3.2 Psychologists

Seven participants had exposure to the clinical psychologist at the hospital under study. There were two participants who initially had contact with a private educational psychologist but terminated services because of the high cost factor. Some participants in the study stated that they were persistent in their request for an educational psychology

assessment for their children in order to correctly place the child at school. The requests from participants for assessments were as a result of educators recommending that their children with ADHD be assessed for the special needs class. However, the services of an educational psychologist are not available within the public health sector as it is the responsibility of the department of education as indicated in the White Paper on Special Needs Education (2001). The public hospital under study has only a registered clinical psychologist available who has been providing psychosocial counselling to children with ADHD and the participants. Again, these services are similar to occupational therapy because the services are limited to children eight years old and below.

These were the responses from participants who had contact with the psychologist:

"The psychologist listens to us parents and we can talk".

"From all the services, she (child) communicates the most with the psychologist. This helps her".

"Psychology at this point in time will be good. I will have an avenue to vent my frustrations. It will be good for him too. Both of us need therapy, in fact all 3 of us need to see a psychologist".

"I think my child benefits from OT and psychological services. Here he is free to explain himself."

Participants who had been referred to the psychologist noticed the positive changes in their children upon receiving psychological help. They indicated feeling relief at having someone listen to them without being judgemental. Some participants added that they would like to be referred to a psychologist as they felt that it would help them cope better with the presenting behavioural problems. Participants who were still on a waiting list were eager to enter into therapy or psychological management of their problems.

The challenge with this service at the hospital under study is the gross shortage of full time psychologists; therefore participants had to wait a while for an available appointment to see the psychologist. It is evident that the referral process has also been inconsistent in that some participants were in therapy with their children whilst others knew nothing of the service. A child with ADHD is referred to the psychologist if the attending doctor assesses that there is no improvement in the child's behaviour or attention span with medication alone. A referral is also done if the parent/caregiver communicates to the staff at the clinic their difficulties in coping with their children. The referral process is not uniform for all children with ADHD. According to Chronis *et al*

(2004) the value of psychological services could be observed in parent training groups or in child behaviour therapy which are known to result in improvements in domains such as parental stress and behavioural adjustments in children.

5.2.3.3 Speech Therapists and Audiologists

A minority of participants had exposure to this service as the speech therapist and audiologist were responsible for the early detection of speech and auditory problems in their children. One participant had requested speech therapy services as her child had difficulty reading, more specifically with word recognition. Although other participants in the study found a similar problem with their children they were not referred to the allied professional for further help in this area. This oversight cannot be explained or excused as medical staff at the clinic are familiar with the network of services available at the hospital under study. Green and Chee (1997) noted that parents need to engage a speech therapist to improve their children's language abilities, reading skills and their overall comprehension. As one parent in the study said *"If my child can only read and write I know then that he will get on in this world"*. This statement has strong implications in that it highlights parents concerns about the children's lack of cognitive abilities and their silent cry for help for a better future for their children. It can be concluded that health care providers have neglected to recognize the cognitive deficits in children with ADHD and have failed to refer them appropriately to allied health professionals.

5.2.3.4 Social Workers

Only two participants in the study had been referred for social work services. Other participants expressed the need to be referred to the social worker as they were aware of the benefits to this service. Participants said the following:

"My child is benefiting from OT and we have also had assistance from the social workers".

"We are seeing the social worker for marital therapy".

The responses from participants requesting a referral to social workers can be seen below:

"There should be support services for children with his condition. If there is someone who can speak to him alone like a psychologist or a social worker, he may open up".

“I want to see a social worker for a grant for her”.

“We need to be referred to a social worker because we are having housing problems”.

Social workers provide psychosocial evaluations for children with ADHD and their families thereby ensuring that the bio-psychosocial approach to care is being adhered to. Social workers explore the child’s social networks to ensure that there is a “goodness of fit” with the child and his or her environment. If the “goodness of fit” does not exist then it is the social workers role to ensure that the child adapts to his environment or that the environment is changed to suit the child.

The two participants mentioned above reported receiving services from social workers which included counselling services as well as behaviour modification therapy for their children. There were some participants whose view on the role of the social worker was purely for the processing of grant applications. Some participants requested to be referred to a social worker as they wanted someone to share their problems with. The referral to the social worker is done only upon request from the participant or if the doctor, through the process of history taking identifies underlying social problems in the home. Social workers through their training have developed the skills to listen, empathize, establish rapport and have a non judgemental attitude, all of which is put to practice when working with children with ADHD and their parents. As noted with other allied professionals, the referral procedure is yet again inconsistent.

5.2.3.5 Dietician

Participants in the study expressed their desire to seek dietary advice from the hospital dietician. This desire is as a result of their children refusing to eat or requesting a diet which is unhealthy or not recommended by the doctor. Participants in this study were at both ends of the continuum as they experienced extremes in either gross weight loss or weight gain with their children. However, the number of participants with children who had lost a lot of weight outweighed the number who experienced weight gain. Participants felt that seeing a professional in this specialized field would help clear certain discrepancies for them. The following responses reveal this need:

“I was supposed to see a dietician but I have not seen one as yet. The appointments are far ahead”.

“Nothing at all was told to me, I am now not sure what he can and can’t eat”.

“They were supposed to refer us to the dietician and psychologist but this has still not been done”.

“They never tell me about the diet. But hey this child, he likes sweets and chips. He cry for me to buy KFC”.

The challenge which participants were faced with was that not all were referred for dietetic services. Further, the hospital under study at the time when the research was being conducted had only one dietician to service the needs of both the in-patient population as well as the out-patient clinics. Therefore participants had a long wait before being given an appointment with the dietician.

Although participants see the importance of receiving dietary advice for their children as fundamental to the management of the disorder, there are many controversies over the relationship between diet and ADHD (Bendelius, 2003). According to Green and Chee (1997) diet has a small part to play in the treatment of ADHD. These researchers add that diet never causes ADHD as the aetiology of ADHD still remains inconclusive. Contrary views are expressed by Picton (2005) and Holford and Burne (2006) who state that the omission of certain foods from the child's diet does reduce the trio of symptoms experienced by an ADHD child. The findings show that there were only a few participants who had formal referrals to the dietician. However, there was an overwhelming request by the majority of the participants to seek the services of the hospital dietician. The primary concern of participants was the irregular eating patterns of their children and considerable decrease in appetite, following psychostimulant use. The challenge that faces the hospital under study is the shortage of human resources within this field. The dietetic services are mainly provided to in-patients because of staff shortages therefore ADHD affected children are all not given a dietetic appointment. The focus is on critically ill patients until the staffing issues are improved. Participants referred to this allied professional would have to endure a long wait for their scheduled appointment.

Allied health professionals provide a supportive role within the hospital. The responses from participants reveals that with some allied health professionals there was equilibrium between the micro system (parent and child) and the meso system (allied health professionals). If there is optimal functioning at a meso level that is if these allied

professionals are offering the support they are supposed to then it has positive outcomes at the micro level. In this instance it would result in a satisfied parent of a child with ADHD. However, in this study, it is evident from the responses that the micro system is being affected by inconsistencies within the meso layer, thereby resulting in participants experiencing the services provided as inadequate. The lack of consistency with the referral process to allied professionals is hindering effective service delivery to participants. Allied health services appear to be fragmented at the meso level in this study.

Participants' experiences of services provided to them and their children with ADHD will be discussed as the next sub-theme.

5.2.4 Experiences of service provision

Participants descriptions of the services provided to them will be discussed under the following sub-themes.

5.2.4.1 Lack of communication

When participants were questioned on the type of support they received from the hospital regarding their children's diagnosis and treatment many of them complained about the lack of communication between them and the medical and nursing staff. Responses from parents to illustrate this complaint were as follows:

"It's not the support we would like. They just prescribe medication. We have requested several tests to be done but it has fallen on deaf ears"

"Up until now, not much support. They don't do proper tests here for children"

"The doctors don't have the time to tell you much about the child's condition"

"We have requested for an urgent EEG to be done on him but this has fallen on deaf ears, I am prepared to go privately if I have to"

"I feel that my husband should have been included in the discussions. If this was given priority, my husband would have accepted the child's condition. The doctors have lacked in this area for involving all family members"

Participants felt that the doctors and nurses at the clinic do not listen to their needs as parents. Participants also verbalised a need for more communication regarding objective testing prior to the diagnosis of ADHD being made. There was a general feeling that their

concerns were overlooked by the healthcare workers and that effective communication was replaced by a hasty prescription for Ritalin.

According to the AAP (2001) guidelines, the clinician or paediatric doctor must work within a collaborative care model whereby doctors are required to partner with parents in order to reach their target treatment outcomes. The AAP guidelines (2001) suggests that the doctor also has an important role to play in presenting evidence based information regarding ADHD to families and helping families develop a long term plan for success with their child (Leslie, 2002).

The conclusion that could be drawn is that participants would like conclusive evidence to show that their child has ADHD rather than medical professionals taking a subjective history from parents and thereafter prescribing psychotropic medication. Participants would experience a greater degree of confidence in their children's ADHD diagnosis if it were supported in a more scientific manner. Their acceptance of Ritalin as a treatment modality would be easier if concrete evidence could be provided to warrant its use.

There were also a significant number of participants who articulated that they did not benefit from the services offered to them by the health care workers at the hospital under study. Their dissatisfaction could be attributed to the level of care provided by the health care workers at the hospital. Many participants felt that health care workers failed to address their concerns regarding their children. These concerns related to some participants' requests for family education on the disorder, more spousal involvement at the initial stages of diagnosis as well as mutual decision making between parent/caregiver and the health care workers. A possible reason for health care workers not being able to address participants' concerns is lack of both human and material resources that are currently challenging public hospitals (Cullinan, 2006).

5.2.4.2 Discriminatory behaviour of health care workers

Some participants in the study reported that some medical personnel displayed a judgemental attitude towards them. This was particularly noted by those participants who were single parents and who already felt stigmatised by their single status. Their responses were as follows:

"I don't think that all the experiences here are good. Some nurses and doctors lash out at parents. Sometimes, I feel this way because we are single parents".

"The services are okay. The psychologist listens to us parents and we can talk. The doctors and nurses are too critical of us as parents".

"The staff at the hospital has no way of talking to us parents. We also have problems and we don't need to be shouted at. If only my medical aid paid for the treatment I would not have to come, but I am forced to. I am the sole breadwinner in my house".

"The doctors and nurses really judge you. There is not too much of support".

As noted above some participants complained that some health care providers had a disapproving view of them in their caretaking ability of their children with ADHD. Some parents in the study were offended by the manner with which professionals related to them. Participants felt marginalised by medical professionals in that professionals refuse to consider parental opinions on treatment for their children and hastily proceed to administer psychostimulant drugs. Some participants lack support structures to help them cope and are thus sensitive to disparaging comments or attitudes levelled against them. According to Barkley (2000), parents are subjected to blame for their children's ADHD condition, even by professionals.

Participants felt that some professionals blamed them for their children's disruptive behaviour and felt that that it was as a result of poor parenting skills. According to Martin (1998) often when doctors and therapists involved in making recommendations for ADHD suggest that parents go for therapy; parents feel that they are being blamed by the doctor for the children's disorder. Participants in the study felt that these professionals failed to consider parents' stresses and that they need to understand that parents carry a heavy burden of having a child with ADHD. It is under these difficult circumstances that they attempt to succeed at parenting. In summary of this sub-theme it can be concluded that the service providers who form the meso level of the ecosystems model are not providing an effective service delivery and this and appears to be affecting participants who play a vital role in the micro system

5.2.4.3 Inadequate care due to busy clinic

There were five participants in the study who felt that medical professionals made hasty decisions regarding their children's ADHD treatment as a result of the high demands

placed on them at the clinic. According to participants the clinic is always busy and is full with all types of ill children. Doctors and nurses are always attending to the high patient load of critically ill children and therefore tend to spend less time with the not so serious cases. The following responses were noted by parents:

"The team at the hospital are busy but they attend to our most pressing needs. We must know that this is not like private".

"The doctors don't have the time to tell you much about the child's condition".

"The doctors are too busy to listen to us. The clinic is always full when we come".

"The waiting period at the doctor is long, yet we just spend a few minutes with them. At that time you can't really tell them or ask any questions you really want to. They don't give parents the time".

"We feel that the doctor can spend a bit more time with the child. The doctor spends too little time with the child. When we tell them any problem they just increase the dosage. They don't spend time".

The responses from participants showed that they would have preferred more time allocation by medical professionals with respect to their children's disorder. Some parents recognized the strain these professionals were exposed to and realized that it was not possible at a state facility to demand this quality of service from medical professionals. DeMarle and Ernhausen's (2003), found that fourteen percent of paediatricians believed that seeing patients with ADHD disrupted their schedules and thirty nine percent of paediatricians reported that the time requirement was the biggest challenge in caring for children with ADHD in their practice.

It can be concluded from participants' responses that majority of them reported that medical professionals within the public sector hospitals do not allocate time in their busy schedules to give parents with children diagnosed with ADHD the type of management and treatment plan they desire and which is recommended according to the AAP guidelines (2001).

5.2.4.4 Positive experiences

A few participants had positive experiences with health care workers. Their experiences can be seen in the following quotes:

“With the doctors it is a good experience because I got good treatment. Our experiences with the occupational therapist as well have been positive”.

“The treatment is okay. But I only go to the doctor and the OT for him. We don’t go to the psychologist or anybody else”.

“It is a very good service. I think my child benefits from OT and psychological services. Here he is free to explain himself. No one judges him”.

“The doctors try their best to help. They listen to me. But we would like to see more of the psychologist and social worker”.

These participants were satisfied with the level of care provided to their children. It is interesting to note that some of these participants who shared their positive experiences were from the lower income category and had no alternate means to accessing medical care. They therefore valued the services provided to their children. These participants could also see the benefits of the services provided as it reflected in their children’s behaviour and development. Other participants who also expressed satisfaction with the services provided were those who enjoyed the benefits of referral to the allied professionals. These professionals played a support role to ADHD affected children. The perception was that the allied professionals provided the support that the doctors sometimes may not have the time to provide. There appeared to be a good rapport established between the allied professionals and participants in those instances where participants had exposure to allied health workers. According to Marincowitz (2004), it is important for health care workers to have at least the following personal values and skills which foster a good relationship with patients and their families: humility, empathic listening, unconditional positive regard and their awareness of their position of power and the ability to value even the poor.

In summary of this theme, there was a mixture of responses from participants. A few participants expressed positive experiences whilst the majority experienced negative responses. In view of the majority of participants’ experiences being negative, it is evident that there appears to be an imbalance between the needs of parents and the ability of the hospital environment to meet and support such needs. Therefore it can be concluded that there is no “goodness of fit” between participants and the environment from which they seek medical treatment for their children diagnosed with ADHD.

5.2.5 Treatment plan

The participants in both the individual interviews and the focus group discussion strongly criticised medical staff for failing to provide them with sufficient information regarding the treatment plan for their children's ADHD. Almost all the participants lacked information on the duration of treatment of their children. Participants were also irate as they were not involved in decisions relating to treatment. The following sub-themes emerged from the data:

5.2.5.1 Inadequate communication pertaining to the use of Ritalin

As noted above, participants in this study complained that there was poor communication between medical professionals at the clinic and themselves. They were especially concerned about the duration of treatment as this was not conveyed to them. There was no prior discussion with them regarding the initiation of treatment or dosage requirements of the child and this lack of mutual communication presented a dilemma. The following responses were from participants:

"There is no consulting with parents. We can't even ask questions because we are so rushed at the clinic. They say there is no staff. We want an alternative to Ritalin. We want to be included in these decisions".

"Parents are not included in any decisions. These doctors don't consider us. They think we are stupid and have no rights. I stopped the medication on my own and give it when I want to. I halve the dosage because my son is like a zombie when he takes it. They must give us Concerta".

"We need to know for how much longer he has to be on it. He is on the treatment for 2 years already".

The above responses reflect that participants felt slighted by the lack of consideration given to them by medical staff. They indicated their desire to be included in mutual decision making prior to medication prescription. One of the possible reasons for the lack of effective communication between doctor and parent is the gross shortage of medical personnel within the public sector. The current doctors and nurses rendering the service are not able to cope with the high patient load. A second reason for this ineffective communication could be as a result of insufficiently trained doctors in the field of neurology. As discussed in chapter 2, there is a shortage of trained specialists in the field of paediatric neurology.

Participants' responses are in line with DeMarle and Ernthausen (2003) findings. They reported that most practitioners do not have the necessary time to spend with a family to review the nature and causes of ADHD and the treatment regime for the disorder. They add that without time physicians can inadvertently reinforce the parents' misconceptions of the disorder and fail to address their fears. It is evident from participants' responses that within the micro and meso systems there appears to be an imbalance. The poor communication channels between medical staff and parents make both these systems very fragile.

5.2.5.2 Parental compliance with treatment

Five participants reported that they had terminated medication dosage with their children after observing the negative side effects of the drug. Some participants chose to terminate medication after receiving negative feedback on the drug. Participants also stopped giving their children medication to ease their own fears about Ritalin use. Some of these participants terminated medication use without any consultation with the doctor. Participants mentioned that when they informed the attending doctor of ineffectiveness of the drug, instead of considering an alternate option, there was an incremental dosage adjustment. This led to participants' dissatisfaction.

It can be concluded from these participants' reactions that their children's Ritalin prescription schedules are not reviewed often enough and not in a manner which takes cognisance of the psychosocial aspects of ADHD. Furthermore, parents are hesitant about using this psychostimulant drug because of their lack of knowledge as discussed in 5.2.1.3. According to Goldman et al (1998) children on psychostimulant medication should be re-evaluated periodically for dosage adjustments or a change in medication.

5.2.5.3 Acceptance of treatment

Three participants in the study were happy to accept treatment for their children's ADHD and mentioned their relief at finally finding some type of help for their children. These parents felt that if the medication was helping the child then there was no reason for further concern. They were of the opinion that the doctor's decision was final and therefore did not oppose treatment initiation. Although there was no consultation with these parents regarding the treatment plan, these parents were not opposed to the child being on treatment as they saw the advantage of the psychostimulant drug. Prior to taking

Ritalin, these mothers and caregivers complained that the disruptive behaviour of the child made it impossible for them to cope with. Participants' positive attitude towards the treatment plan is discussed below:

"As long as I give the medication he is okay. Otherwise our lives are hell. He is violent and even hits".

"I feel relieved that there is some form of help for my child"

"He cannot be controlled without medication".

Participants in the study who were optimistic about the treatment for their children felt that it was in the best interest of the child to initiate and continue treatment. Furthermore it can be noted that participants who shared this favourable view were in the older age category which included the grandmothers and therefore it can be assumed that the treatment regime also helped to ease their burden of stress.

The need for a collaborative approach to include the school system is discussed in the following section. Participants in this study criticized the health care professionals for failing to liaise with their children's educators on their children's disorder. There were some participants who stressed that this was an important area as in this study educators were the most common referral source and would be able to provide valuable and objective information regarding the child diagnosed with ADHD, therefore the need for a collaborative effort between both these institutions.

5.3 Perception of school support

Participants views on the support received from educators and other school personnel has been one of the most contentious issues in this study. The school which forms part of the meso layer in this ecosystem has come under scrutiny by many participants in this study. The following theme and sub- themes emerged.

Table 5.2 Perception of school support: Overview of themes and sub-themes

Theme	Sub –themes
School support and involvement	Refusal to administer Ritalin Level of support received from teachers Repeated school failure

5.3.1 School Support and involvement

At least half of the participants in this study expressed that the school personnel are reluctant to accommodate children with an ADHD diagnosis. Regardless of the new dispensation on inclusive education which stresses the importance of including learners with special needs, the education system is failing to address the needs of ADHD learners adequately. Participants cited problems with educators' coping skills, schools lack of accountability with the pharmacology aspects of the disorder and the lack of special classes within mainstream schools. There were only 8 participants who had positive experiences with their children's school.

5.3.1.1 Refusal to administer Ritalin

Participants in this study reported one of their challenges with the schools attended by their children was the refusal by school personnel to administer the psychostimulant medication. One caregiver mentioned the following difficulty: *"The school does not want to give him his medication and asked me to come in everyday to give his midday dose of medication"*. Another father's complaint was as follows: *"The teachers don't want to give my child the Ritalin in class."*

The issue of administering Ritalin has come under controversy recently with educators and school principals expressing reluctance to administer medication for the learner with ADHD. Children who are prescribed stimulant medication often need to take their medication during the middle of the day, as the effects will usually wear off after 4-5 hours. This means that many children need to take this medication during school hours. If medication is not taken at school the pupils' behaviour may become more challenging and the pupil's ability to engage in lessons will be affected (www.drugsscope.org.uk).

According to the policy changes with the South African Department of Education, it has positive implications for the ADHD learner (Bester, 2006). This was not evident in this study as some of the responses from participants indicated that educators were reluctant to administer the midday dosage of Ritalin to the ADHD affected learner. The new inclusive policy implies that adaptations are made with regard to the level of support for learners with special learning needs. In terms of Education White Paper 6 on Special Needs Education (2001), which is an inclusive policy document, a comprehensive support system which includes educational psychologists, social workers and trained

educators in the field of special needs in children has been developed to support learners who experience learning difficulties. This White Paper mentions that schools are now required to accommodate learners with special learning needs and must make provisions for them within the school.

Some participants in the study did not enjoy such support from their children's present schools as educators were hesitant or refused to be accountable for the pharmacotherapy of children.

5.3.1.2 Level of support received from teachers

Responses from participants in this study indicated that there were those who received support from teachers whilst a significant number of them received no support at all. Nine participants in this study reported teacher complaints about their children's behaviour in the classroom. Participants made the following comments relating to support received from the school.

"When he was in grade R, the teacher always complained to my wife. The school gave us lots of problems. They did not understand at all".

"They have not played much of a role. They complain his work is bad. He talks too much".

"They don't give much support. I gave them his tablet to give to him but they refuse to give it to him. They say it is not their job. In school when he walks out the class they don't worry about him. For this reason I stopped him from school".

Unfortunately many educators are uninformed about ADHD or have not been exposed to the new developments in relation to the disorder and its management thereof (Barkley, 2000). This has serious implications for the learner as the educator is not adequately equipped to handle the ADHD learner with special learning needs. The other challenge that educators face is that in the new dispensation educators are often overworked and stressed. They have large classes and the inclusion of learners with ADHD makes teaching an even more difficult task (Bester, 2006).

Bester (2006) also suggests that through educator training workshops, educators should be trained to deal with and recognize the ADHD learner. Educators also have the responsibility to provide collateral information to doctors on the child's behaviour in the

classroom. It is essentially the educator who makes the first referral for help for the ADHD child.

Participants in this study also shared positive experiences with educators. These were some of the positive responses from participants:

“The school played a role in that they brought in the educational psychologist to evaluate him”.

“His class teacher has been very supportive”.

“Mrs Moodley has been very supportive. She insisted that the child must be in a special school. The principal was also supportive”.

It is also the role of educators to ensure that parents are empowered with information on the management of the ADHD learner.

5.3.1.3 Repeated school failure

Almost all the participants in the study mentioned experiencing problems with their child's school. Participants reported that their children did not cope with the pace of work in class, experienced problems with reading and writing, lack of concentration and disruptive behaviour in the class. Participants were concerned that their children had to repeat grades at school. Their concerns also centred on the lack of special classes within the mainstream school that would focus on the children's learning needs and cater to their pace of learning. Some of the participants' responses are noted below:

“He was performing very bad, he had to repeat grade R”;

“I worry because he is going to be 14 years old and still in grade 4”

“There is no place at the special school and only a few schools have the LSEN classes. There too there is no place”.

“I am getting worried because he is 12 years old and is now doing grade 4 work. I worry when the time comes for him to go to high school. Where would he go to”.

“The school picked up that he was hyper and has poor concentration. They are always sending home complaints because the teacher cannot cope with him in class. He is so disruptive, he cannot care about his work and he daydreams and is in his own world. I think he will be better off in a special class”

“They kept on getting him to repeat the year. Now they have come up with a solution to send him to a school with children like him. These schools don't have place but he is on a waiting list. There are so few schools that cater for these children. He simply cannot cope in mainstream school”.

An analysis of participants' responses indicated that they experienced several challenges with their children's school placement, educators' complaints of poor academic performance accompanied by displays of disruptive behaviours by the ADHD learners in the classroom

Educators in their assessment of the child will observe that the quality of work that the child with ADHD produces is usually below standard and that they usually disrupt the whole class (Bester, 2006). Educators are expected to have knowledge of the diagnostic criteria of ADHD as mentioned in chapter 2 in order to identify the learner with ADHD in the classroom. They may refer a child with repeated school failure to the Department of Education's support program for an educational psychology assessment. Certain public schools in KwaZulu-Natal have been identified to meet the needs of learners with special education needs as there are special classes set aside for these children with learning challenges.

In certain instances a recommendation was made by the school educators to have the child referred to a special school which would accommodate the child's learning disability. Despite the comprehensive support program that has been developed to support learners which consists of psychologists, social workers, teaching support and school management specialists only some schools within the province have accessed it successfully and have a Learners with Special Education Needs (LSEN) class (DOE,2001). Further difficulties lie in accessing psychological support from the Department of Education. Participants in this study complained of long waiting times for their children to be granted an appointment with the support staff for their assessments for LSEN class placement. The current mainstream education system would appear to disadvantage the learner with special education needs as there appears to be a shortage of resources in this area of need.

5.4 Future Recommendations from Participants

The following themes and sub-themes emerged as participants recommendations.

Table 5.3 Future Recommendations: Overview of themes and sub-themes

Themes	Sub-themes
Support Services	Parent support groups Counselling Parent education Collaboration with department of education
Improved Service	Continuation of occupational rehabilitation Prioritizing children Address staff shortages Change dispensing practices Address current referral system Alternative to Ritalin

5.4.1 Support Services

“Whether parents can perform effectively in their child-rearing roles with the family depends upon the role demands, stresses, and support emanating from community settings. The availability of supportive settings is, in turn a function of their existence and frequency in a given culture or sub-culture” (Brofenbrenner, 1979 cited in Shelton & Barkley, 1992:520).

The above quotation suggests that if parental stresses are not addressed effectively it detracts from the participants’ ability to effectively manage their children’s ADHD disorder. It also highlights the ecosystems perspective which emphasizes the importance of the meso system, which includes supportive settings for participants in this study, which if present and effective will create harmony at the micro and meso levels. The sub-themes of this theme are discussed below:

5.4.1.1 Parent Support Groups

Participants from the individual interviews as well as some participants from the focus group discussion stressed the lack of support services available to them at the hospital and recommended that this area of need should be explored further. There was an overwhelming positive response from participants for parent support groups to be formed at the hospital. They expressed the need for formal support groups as they currently engaged in casual discussions with each other on the day of their appointments. These were participants’ responses:

“Please, they must do something for parents, like support groups. There also must be more time spent with parents. Involve both parents so it makes home life better”.

"We want support. Counselling will be a big benefit".

"Why is there no support for parents?"

"A support group for parents because all parents sit and wait for a long time. We discuss our issues with each other. We relate to one another".

"As I said, support groups are lacking and more and more parents are coming into the clinic".

"A support group for parents would be nice. We go through so much. It would be nice to see if other parents are in the same boat as us".

"Please start support groups for parents. I go through so much of stress I can't take it anymore".

"Support groups for both parents and children of ADHD should be run at the hospital. I cannot cope with him. Financially I am not managing with the two children on a child support grant. I live with family and this is difficult because they call my child names. I act out my frustrations. I welcome any support I get".

"Support groups for parents after hours or on weekends must be introduced. Parents can interact with each other because we have similar problems".

Participants requested support from health care professionals as many participants felt that this was an area of neglect at the hospital. Most of the participants in this study were mothers and were responsible for most of the caretaking responsibilities of their children and expressed that there were many demands that were placed on them. This view was supported by Bester (2006) who discussed the daily pressures mothers were exposed to. Some participants also had little support from the extended family and therefore look forward to any form of support offered to them. There was also a suggestion by participants that both parents become involved in the management of their children so that they can cope better with the child in the home.

In analysing participants' responses, it is evident that they viewed the support group as a means to alleviating their stress. Parents face significant stress when their children are diagnosed with ADHD. Empowering parents and caregivers by providing a facilitative social system helps to enhance their competence in coping with their ADHD children (Adesida & Foreman, 1999). Participants perceived benefits of a support group included emotional support in sharing their experiences with raising an ADHD child, a reduction in feelings of isolation and an increase in their knowledge base on the disorder through the sharing of information amongst participants. The findings by Shelton and Barkley

(1992) are in line with participants' perceptions as they reiterate that support groups facilitate important social networks and provide an opportunity for parents to listen and share in a non-judgemental atmosphere that can lessen the isolation and frustration that many parents experience.

5.4.1.2 Counselling

Some participants in this study suggested that counselling services is an area of support that is missing from the hospital but is needed by them in order to cope with the impact of raising their ADHD children. Parents made the following suggestions:

"Get dads into counselling. More counselling is required for fathers".

"Counselling for parents and children would be nice. We only see the doctor".

"We want support. Counselling will be a big benefit"

"Fathers must also be involved in counselling because they do not understand the child's condition. Family support groups would be nice. We want to know how to deal with our children without screaming and hitting".

In analysing participants' responses it is evident that their children's diagnosis of ADHD is a major crisis in their lives and that the sudden need to adapt is forced upon parents, therefore the urgent plea for psychosocial intervention. Counselling is the provision of psychological and social help, implemented simultaneously with physical care, but directed at the whole family (Davis, 2002). Hence, by providing counselling to parents and caregivers and to their children with ADHD, the psychosocial aspects to management of the disorder are adhered to. Many mothers in this study suggested that counselling services should be offered to their spouses as their spouses often had little understanding of their children's disorder. According to Bester (2006:57) "fathers' support is essential even if it is only emotional support". These findings suggest that parents and caregivers require help to cope with their children with ADHD and through counselling they hope to achieve greater parenting satisfaction, an increase in ADHD knowledge, improved adherence to treatment regimes and less psychosocial distress. It is also predetermined that within the hospital environment it would be the task of the social worker or the psychologist to undertake these therapeutic counselling sessions with participants and their children, in order to ensure that their psychosocial needs are being addressed, as this is a vital ingredient to the well-being of ADHD children and their parents or caregivers.

The conclusion drawn was that participants assume that this communicative and listening process will have therapeutic benefit in helping them cope with the disorder.

5.4.1.3 Parent education

Participants expressed that parent education was an aspect that was ignored by the health care providers attending to ADHD children. Many participants in the study verbalised the need for educative programs to be hosted within the hospital setting. Participants requested that this area be given priority as it was neglected by health care providers. Some of the participants' responses were as follows:

"We need more information on ADHD. Pamphlets need to be given to parents. Talks should be done at the clinic".

"When our children were put on Ritalin it was not explained to us what is the disease. They should at least have a talk to parents before the children start treatment. Lots of parents don't really know what it is all about".

"Have more literature for parents. The psychologist and social worker can have more programs for parents and children. We are frustrated and stressed, we need to learn coping skills. We also want more coping skills and parenting programs"

These responses show that participants are not satisfied with the present level of care provided to their ADHD children and themselves. The overall theme for participants is *"We want to know more so that we can help our children"*. They would like to be better equipped with information on ADHD to better manage their children's disorder. The findings also reveal that participants are disappointed with the manner in which health care providers are addressing this disorder with them. Participants feel that this area of parent education is often neglected by professionals, yet it is parents themselves who have to take responsibility for carrying out most of the treatments for their ADHD children with limited skill and knowledge. Researchers, Corkum *et al* (1999) found that parental knowledge of ADHD correlated with the acceptability of interventions, and stimulant medication was viewed more favourably with an increase in parents' knowledge of the disorder. Therefore participants in this study recommended that health care providers at the public hospital prioritize parent education through the medium of parenting programs, added literature on the disorder and through educative talks at the paediatric clinic.

According to Shelton and Barkley (1992), the most important goal to parenting programs is to increase parental knowledge and understanding of ADHD. They comment that an added advantage of parenting programs is to provide parents with coping skills, which leads to happier and less stressful lives for parents and their children with ADHD.

5.4.1.4 Collaboration with department of education

There was a recommendation from a proportion of participants that the medical personnel should liaise with the school so that they could better advocate on behalf of the ADHD child to elicit educators support. Issues relating to disruptive behaviour in class, poor concentration, assessing the appropriate placement of the child as well as pharmacological management of the child's needs have to be communicated with the school. Participants' responses were as follows:

"They have not communicated with the school. The doctor or nurse should at least telephone the class teacher. They can motivate for a special class".

"There has been no contact with his school".

"The doctors need to speak to the teachers to get the full picture. I keep reminding them but they don't listen when I talk"

"I battle to get him to do his schoolwork. I am always being called to school. The teachers have complaints; they cannot control him or get him to do his work. I feel them at school lack an understanding of this type of child".

Participants expressed the need for healthcare workers to communicate with educators about their children's ADHD as the disorder clearly had the most impact on their children's schooling. They felt that if there was communication between these two institutions then there would be better understanding and management of the disorder. Research conducted by Steer (2005) concurs with these parents' views as he adds that dialogue and regular contact with schools by medical personnel is pivotal for the management of ADHD in ensuring that performance and behaviour in school are optimised.

Steer (2005) states that health care providers can contribute positively to school review meetings, not only to exchange views and information but also to inform educators and other school personnel involved with the child on knowledge of the disorder and its management thereof. Findings from this study conclude that this type of liaising is certainly not occurring. It can also be assumed that such liaising would be the task of the

social worker or psychologist as the parent or caregiver spends the most amount of time with these professionals and most of the networking with other referral sources is conducted by either of these professionals. In conducting the psychosocial assessments, the social worker would have to explore all spheres of the child's life which includes the school; thereby ensuring that all levels in this ecosystem is in equilibrium.

In analysing this theme, the findings are clear that parents require added support because their own coping mechanisms are fragile. In caring for an ADHD child in a context where there is a lack of resources for these children and their parents it is not unusual to find these parents stressed and burdened by their newfound responsibilities. Further analysis shows that the meso system which in this study is the extended family, the school and the health care providers, is in a state of disequilibrium as there is failure to provide the type of support envisioned to do, thereby negatively impacting on the micro system, which is the ADHD child and the parent or caregiver.

5.4.2 Improved Services

The overall responses of participants in the study were that the current services needed improvement. They requested that improvement in the following areas needs to be considered. Continuation of occupational rehabilitation, prioritization of ADHD affected children before others in the queue, addressing staff shortages, changing dispensing practices, alternatives to Ritalin and addressing the current referral system.

5.4.2.1 Continuation of occupational rehabilitation

Participants who have had exposure to occupational therapy services and have terminated services due to their children's age have come out in strong support for such services to be continued for a longer period of time. Four participants expressed their reactions as follows:

"The occupational therapy services are only until eight years old. More time is needed here or until the child is older".

"He was referred to the OT but stopped when he was eight years old. I did check with the doctor last month to see if he could go back but she said that the program stops at eight years old".

"He benefited from OT but we feel he should be kept longer on the program".

“Why can't the OT services and psych services extend beyond eight years of age? We can't afford private services”.

From the above participants responses, it is evident that they had positive experiences with the occupational therapist and are disappointed that these services are not being extended to cater to their children's needs. As noted earlier, participants enjoyed the experiences of their children engaging with the occupational therapist as this is one area which allowed free expression of the child through activities. These findings suggest that parents find relief when their children participate in activities which allow and teach them to be “normal”, such as engaging in motor activities(writing and tying of shoelace) and coordination through the medium of play(kicking or catching a ball). They also find benefit with services whereby both parent and child are involved in interacting with the therapist. This view is supported by Marincowitz (2004), who stresses the importance of mutual participation in the health worker-patient relationship. Parents also wish for a continuation of service as they are not able to afford private therapy for their ADHD children.

5.4.2.2 Prioritizing children

Eight out of the twenty one participants requested that children should be given priority at the hospital and therefore should not be made to wait for long periods for their treatment.

Some participants shared the following views:

“Think about the children and make them a priority. Try to lessen waiting times especially with this category of child”.

“Ask them to meet our needs first and to think about our children. They must be prioritized”.

“For these children a different method should be used when coming to hospital. The present system is hopeless. We don't expect private treatment but we don't want to sit here the whole day”.

“When I sit here I see that these children are so restless. We don't carry medication with us. With this type of child we still have to wait our turns. Priority should be given to these children”.

Many participants revealed that they could not cope with their children for the long periods of time they had to wait in hospital for either their children's medication or the doctors' appointment. In analysing parents and caregivers responses on this subject it was evident that parents and caregivers were frustrated by the long processes their children

had to endure. Participants' feelings were that this category of patient by the nature of their illness (as described in chapter 2), were irritable, fidgety and disruptive, and needed to be attended to quickly and without unnecessary delay. The need for prioritising children also stems from these children causing heightened levels of stress for their parents as they present with behaviours that embarrass parents in the presence of other parents and health care workers. In summary, it is evident that participants experience difficulties with their children on their hospital appointment dates and therefore look forward to this concern being addressed by the health care provider.

5.4.2.3 Address staff shortage

Four participants felt that the shortage of staff resulted in poor service being provided to their ADHD children. These were some of the responses of participants:

"Staff shortages must be addressed. That will help to get through faster, we hope".

"The hospital must get more staff. It is such a busy hospital but we hear the same excuses every month".

"The changes should be the waiting times and more staff".

"More staff needs to be allocated to attend to children's concerns".

The participants recommended that there was a dire need to address the staff shortages at the hospital, especially at the paediatric clinic which provides the treatment to their children with ADHD. They felt that they were exposed to the same situation at every clinic visit. Participants also perceived the shortage of health care workers to be the reason for their long delays at the hospital. This view bears out findings in Cullinen's (2005) report which revealed that public hospitals are presently in a state of crisis with the shortage of scarce skilled staff. The challenge therefore is how to improve services given these constraints.

5.4.2.4 Change dispensing practices

Many participants from the individual interviews as well as the focus group discussion suggested that the manner in which Ritalin was dispensed to their children needs to be reviewed.

"Why are adults and children mixed at dispensary? Children should be given priority".

"Medication should be given at the clinic".

"If medication could be given once in 3 months it would ease the burden of coming to hospital".

"Dispensing Ritalin in POPD would solve the problems .We don't have to wait too long then".

"Separate facilities should be made for adults and children receiving medication"

Participants recommended that Ritalin should be dispensed at the paediatric clinic since there is a dedicated specialised ADHD clinic at the hospital. They complained that the wait for medication at dispensary was time consuming and tiring for both participants and their children. Further analysis of participants' responses showed that participants felt that a change in the dispensing practice would reduce the extended waiting times at hospital. This would ensure that the service met out to their children is efficient and prompt than the present service delivery to participants.

5.4.2.5 Alternatives to Ritalin

The majority of participants in the study recommended an alternative to Ritalin. These were the comments made by participants:

"Doctors only prescribe medication. Other alternatives must be explored first before prescribing Ritalin. Doctors must conduct the relevant tests to prove ADHD in the child".

"They must try other methods to help these children. The Ritalin is useless. It only makes him sick and very thin".

"We would like to know if there are other alternatives. We would like to stop the medication because when we see him we want to cry".

"But, can't they give him anything else, instead of Ritalin".

Participants felt strongly that doctors needed to consider other options first before prescribing Ritalin. Many participants were not comfortable giving their children Ritalin as the side effects were extensive and the overall negative publicity on this drug added to their uncertainties of its benefits, as discussed in the earlier theme in 4.5.2.3. Participants' recommendations for alternatives arose from the lack of evidence based diagnosis on the disorder. They complained that medication was being prescribed without any tests being conducted on their children. It is evident from participants' recommendations that they were reluctant to put their children onto Ritalin and expressed their dissatisfaction with Ritalin being used as first line treatment for the disorder. They therefore felt that other

options needed to be explored before the prescription of this psychostimulant drug. All of these responses also point to the need for more communication between participants and doctors.

5.4.2.6 Address current referral system

There were many participants who expressed that they had no exposure to the allied health professionals at the hospital. These participants requested that they have more contact with professionals who offered support services such as the social worker and psychologist. Participants had the following to say:

“We have not had contact with other professional staff”.

“We only see the doctor; we don’t get to see the other people you are talking about. Only some parents talk of seeing the social worker”.

“We would like to see a social worker in the future”.

“Maybe a social worker can help to counsel him”.

“We want to see the psychologist and the social worker”.

It is evident from participants’ responses that not all participants are referred to all the support allied services that provide a service to children with ADHD. Some participants expressed having no contact with allied health services at the hospital. They however noted that they would benefit from these services if they are referred in the future. It would appear that the referral process to allied services is inconsistent and needs to be addressed so that participants and their children may benefit from this bio-psychosocial approach to care.

This section focused on participants’ recommendations for future care of their children with ADHD at the hospital under study. In terms of the ecosystems perspective which focuses on the degree of “person in environment fit”, and the reciprocal exchanges between people and environments, it is clear that in this study there is instability with this “person in environment fit” as participants revealed that they did not get the full support from all role players at the hospital under study.

Conclusion

In this study the gap in service delivery experienced by participants is clearly evident from the responses that the participants provided to the researcher. It can be concluded that services are fragmented and this is impeding effective service delivery. The findings are clear that there is disequilibrium between the micro and meso level in this ecosystem. This is as a result poor communication between role players within the two levels. The findings of the study were largely in agreement with available literature that had been reviewed. The study has potentially identified numerous shortfalls in the present level of care available to ADHD affected children at the institution under study. In the next chapter the conclusions and recommendations of the study will be discussed.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

This chapter provides a summary of the main findings and conclusions and includes recommendations based on the research findings. The main aim of the research was to explore the needs and experiences of participants whose children have been diagnosed with ADHD and who received services from the public hospital under study. This was a qualitative study with 21 participants included in the sample. Semi-structured interviews were conducted with the 21 participants and one focus group was conducted as a method of triangulation, with six participants. The aim of this study served to address the following objectives:

- To determine the needs and experiences of parents or caregivers of children diagnosed with ADHD
- To explore parents or caregivers experiences of services received at the hospital
- To identify parents or caregivers recommendations for future services at the hospital.

This qualitative study used an explorative-descriptive design. The focus was on obtaining “thick descriptions” from participants of their needs and experiences. The ‘lived’ experiences of participants with their ADHD affected children were explored through this qualitative study. The theoretical framework that guided the study was the bio-psychosocial and ecosystems theory.

6.2 Summary of main findings

In this section a summary of the main findings and conclusions of the research are presented. The main findings are aligned to the aims and objectives of the study.

6.2.1 Referral sources

The findings from the study showed that participants’ first experience of their children’s disorder was with the referral source. In this study, of the 21 participants 9 reported that their children were identified and referred for an ADHD assessment by teachers. This is significant because teachers spend the greatest amount of time with children and are

therefore able to identify problem behaviour. In relation to the bio-psychosocial theory it can be seen that the educator identified unusual behaviour of the child within this social context and made an appropriate referral for an ADHD assessment. There are possibly a number of children who go undiagnosed as the present public education system is facing challenges with high learner-educator ratios. To accurately identify children with ADHD the educator must have knowledge of the disorder. It can be concluded that there is an urgent need for teachers to be educated on ADHD as they play an important role in the initial stages of diagnosis of the disorder.

There were a range of referral sources other than the school that existed within the ADHD affected child's social network that played an invaluable role in the diagnosis of the disorder. The findings showed that the remaining 12 participants were identified by referral sources which included the participants themselves, allied health professionals, private practitioners and community clinics which are found within the micro and meso layers of this ecosystem. Although some of these referral sources had minimal contact with the children, it is important to note that they were able to identify the signs and symptoms of behaviour associated with ADHD. The community clinics, private practitioners and allied health professional are an important resource within the community as they are able to recognize children with problems. There appears to be a "goodness of fit" between children identified with ADHD and their social network within the environment as these sources were able to pick up the dysfunctional behaviour that presented in these children.

6.2.2 *Participants' reaction to diagnosis*

Participants experienced a range of emotions relating to their children's diagnosis. These reactions ranged from anger to relief. It was noted that participants with higher levels of education had a greater level of acceptance of the ADHD diagnosis. A possible reason is that they had a better understanding of the nature of the disorder. In addition, both the grandmothers in the study accepted the diagnosis and were relieved as there was an explanation for the children's behaviour. The findings also showed that there were some participants who coped better with their children's disorder as they had more family support and more spousal support; therefore there was acceptance of the diagnosis. It would seem that those participants who were unable to manage appropriately with the disorder lacked adequate family support, had limited spousal support and therefore were

unable to cope with their children's diagnosis. It can be concluded that the manner with which participants react to an ADHD diagnosis is also dependant on the type of support they receive from the immediate and extended families.

Most of the participants in this study were mothers and the findings showed that they experienced tremendous stress as the main caretakers of their children diagnosed with ADHD. A large proportion of these participants were single mothers and their reactions to their children's diagnosis were largely adverse. These adverse reactions were as a result of the emotional stressors of the disorder that challenge these participants as well as the accompanying financial stressors. The overall picture presented by the majority of the participants was that they perceived their children's diagnosis of ADHD negatively.

6.2.3 *Participants' concerns regarding diagnosis*

Most of the participants had concerns about their children's diagnosis. Their primary concern focused on the future implications for the children diagnosed with the disorder. These concerns included their academic capabilities, future employment opportunities, relationship issues and their ability to successfully progress in the different spheres of their development. Other concerns centered on the lack of motor and cognitive skills and substance abuse later in adulthood. Participants were particularly apprehensive about the use of psycho stimulant medication because of the notable negative side effects as well as the negative media publicity on pharmacological use. The findings show that the main concerns expressed by some participants were the future prognosis for their children.

6.2.4 *Family members' reaction to diagnosis*

There were mixed reactions from family members which ranged from adverse to supportive reactions. The adverse reactions from some family members included negative remarks about the child, criticism levelled against the participants for complying with the prescribed treatment and insults aimed at both participant and the child. The findings showed that there were some family members who were concerned about the diagnosis yet their concerns were not perceived as being supportive by the participants. A possible reason for this perception is that family members communicated their concerns in a negative and critical manner that offended the participants.

There were a significant number of participants who received support from the immediate and extended family. The support offered assisted the participant in coping with the ADHD affected child. It was evident from some participants' responses that the extended family which forms the meso layer was not functioning optimally and had negatively impacted on the micro level. An explanation for this is that participants felt hurt by negative comments or actions made towards them or their children by family members. Participants expected the extended family to play an integral part in their children's diagnosis and treatment, however this proved ineffective in some cases as participants did not receive the elicited response from family. It can therefore be concluded that there is disequilibrium between the meso layer and the micro layer in this study.

6.2.5 *Explanation of diagnosis to child*

Only eleven participants informed their children of their ADHD diagnosis. It was interesting to note that the participants who did disclose the ADHD diagnosis to their children were those who had higher education levels. They probably had a better understanding of the aetiology of ADHD and communicated this better to their children. The findings also showed that those children who were given the diagnosis were in the older age range and therefore had a fair understanding of what was happening.

The remaining ten participants did not disclose the diagnosis to the children as they did not know what information to give. A conclusion that can be made based on the responses from participants is that they require more information on how to disclose to their children their ADHD diagnosis and that the issue of disclosure was not discussed by the health care workers.

6.2.6 *Participants knowledge of ADHD*

Participants were faced with many unmet needs which were obstacles in their path to seeking holistic treatment for their children with ADHD. The most pressing need of participants was their need to know more about their children's condition. Participants' lack of knowledge and understanding of their children's disorder was a theme that prevailed throughout this study. It was evident that participants lack of knowledge of the nature, causes and treatment of ADHD was a critical area of concern for participants and had impacted on the bio-psychosocial functioning of their ADHD affected children. From a bio-psychosocial perspective, it was clear that parents and caregivers were not aware of

the comprehensive treatment regime for ADHD. The findings reveal that this lack of knowledge resulted in the disorder being misunderstood by some participants. It can be concluded that the health care team at the hospital under study, which forms the meso layer failed to discuss the bio-psychosocial management of their children's disorder at the initial stages of diagnosis. Therefore there was no "goodness of fit" between the participants and their environment.

6.2.7 *Participants' reaction to medication*

It was found that participants in this study had legitimate concerns over the use of the psychostimulant medication Ritalin, which was the first line treatment for their ADHD affected children. The responses from participants in this study towards Ritalin use were largely adverse. Participants' reactions ranged from fear to concern over the use of Ritalin. Furthermore, the participants expressed concern over their lack of knowledge of this psychostimulant drug. Some participants from the focus group revealed that although they had concerns over the use of Ritalin, there were noted improvements in their children's behaviour and concentration. It can be concluded that participants' lack of knowledge as well as the negative media publicity contributed to their dilemma about using Ritalin. These concerns were not addressed by the health care professionals at the hospital under study.

6.2.8 *Information on ADHD received from the hospital*

A key finding was that participants were disappointed with health care workers at the hospital for not taking the initiative to provide them with sufficient information on the nature and causes of the disorder. The role of the multidisciplinary team is to ensure that the bio-psychosocial needs of participants and their children with ADHD were being addressed. The findings show that there is a lack of communication on the disorder between the various professionals and the participants. Doctors and nurses are the initial service providers that participants come into contact with in the treatment of their ADHD affected children and it is their role to educate and inform parents/caregivers on the nature, causes and treatment of their children's disorder. However, the findings showed that this area required strengthening as there were gaps to effective communication between the doctors/nurses and participants. An explanation for this gap in service delivery could probably be as a result of the shortage of skilled professionals in the public facility and the overburdened public health system which prioritizes the critically ill

patient. Therefore with the focus of attention being primarily clinical, the aspect of education is a forgotten entity. It can be concluded that the paucity of information on ADHD and on psychostimulant medication remains an area of need for participants.

6.2.9 *Contacts with allied health care workers*

This study also explored the interactions between participants and other allied workers at the hospital. In the context of this study, the allied professionals who form the meso layer of this ecosystem were found to be inconsistent in the manner with which they delivered services to the participants. The only allied health discipline that was found to provide consistent and regular care were occupational therapists as participants expressed overwhelming positive feedback on this service provider. Their only challenge with this service was that services were discontinued once the child reached eight years of age.

Many gaps in the provision of services by the allied health care workers were identified in this study. The allied professionals were responsible for providing a support role for participants with respect to their psychosocial needs. These services include the social worker and psychologist who are primarily responsible for ensuring that the psychosocial needs of participants and their children were being attended to. Participants' responses showed that they were desperately searching for psychosocial comfort in the form of counselling and therapy. In addition, participants also identified that another area of need that remained unaddressed was the services of the dietitian; as most participants were of the view that diet was a cause of their children's disorder.

The lack of adequate support from this meso layer clearly has shown to have a negative impact on the micro layer in this ecosystem. A conclusion can be reached that the allied health services are fragmented and that each discipline works in isolation to the other and this therefore takes away the team concept to the provision of support services for the participants with ADHD affected children. Thus, the findings from this study implies that the relationship between the biological factors, psychological factors and social factors needed to be urgently addressed by the allied health professionals for equilibrium to be attained at this level.

6.2.10 *Participants' experiences when attending hospital with their children*

An objective of this study was to explore participants' experiences at the hospital when receiving treatment and other services. Most participants' vivid descriptions of their experiences at the hospital revealed that these experiences were a major source of stress to the participants. The hospital's administrative processes proved to be arduous, time consuming and inconsistent. There was a level of dissatisfaction by participants with certain service points such as the dispensary and the card office. The other challenges that participants faced were long waiting times owing to the shortage of human resources and therefore the prioritizing of the more critical cases within the clinic. Participants expressed that they did not receive the kind of support they would have liked to receive from the hospital. They cited the lack of communication, lack of referrals to allied professionals and the judgmental attitude of health care workers as contributing factors to this unsupportive meso layer. It can be concluded that the hospital which forms the meso level in this ecosystemic model is currently providing an ineffective and fragmented service thereby compromising patient care.

It is evident that the government's policy of "Batho Pele " (as discussed in chapter 2) which focuses on "putting people first" and on service delivery priorities was not being upheld by the hospital under study. The findings also show that there was a small minority of participants who appreciated and were satisfied with the level of care provided to them by the service providers. A possible reason for their satisfaction with services is that they only accessed the public health services as they could not afford private health care. Overall, there appears to be an imbalance between the needs of the parents/caregivers and the ability of the hospital environment to meet and support such needs. Therefore it can be concluded that there is no "goodness of fit" between participants and the environment from which they seek medical treatment for their ADHD affected children.

6.2.11 *Participants' experiences with schools*

Participants' responses indicated that they experienced several challenges with their children's school relating to their poor academic performance and displays of disruptive behaviours in the classroom. Participants were also faced with the challenge of seeking out schools that catered to their children's special learning needs. This posed a problem as participants were unable to access psychological services for their children in order for them to be accurately placed in a special needs class. The findings showed that

participants saw the need for a collaborative relationship between the school and the health care team at the hospital as they felt that the needs of their children will be attended to more promptly if there was effective communication between these two institutions. Participants expressed that if the relationship between the two institutions were strengthened then it would help to address problems that participants complained of such as the educators poor coping skills with the children diagnosed with ADHD, the schools lack of accountability with pharmacological aspects, for example the reluctance to administer Ritalin during school hours and the lack of special classes (LSEN classes, as previously discussed in chapter 5) within mainstream schools. The findings from this study showed that participants desperately wanted this triadic relationship between the school, the health care workers and the parent as they felt that their children's needs would be adequately taken care of if this type of interrelatedness occurred. It can be concluded that if this relationship was strengthened it would result in better management and understanding of the disorder.

6.2.12 Support Services

Another objective of this study was to determine participants' recommendations for future services at the hospital for their ADHD affected children. Participants' recommendations focused on two important areas which were support services and an overall improved service delivery by the health care provider. There were useful suggestions made by some participants who requested that the issue of support services must be prioritized as it was a sorely neglected area. These participants more specifically made suggestions for the introduction of support groups to help alleviate their stress, as this form of support network was non existent for parents and caregivers as well as for their children. Another form of support that participants perceived would be beneficial was therapeutic family counselling. Parent and caregiver education was also high on the list of participants' recommendations for future services as this would enable them to better manage their children's disorder.

Another aspect of support that a large proportion of participants requested for was support from their children's school. Their suggestion was for the health care provider to collaborate with school personnel so that there was mutual sharing of information between these two institutions regarding better management and understanding of the disorder.

6.2.13 Improved Service Delivery

Participants' responses revealed the need for an improved service delivery as they identified gaps in the current provision of services at the hospital under study. Participants in the study requested improvements in six areas of service provision.

- Continuation of occupational rehabilitation

Some participants requested that the present age criteria for receiving occupational therapy services be revisited. These participants requested that their children continue with therapy beyond eight years of age.

- Prioritizing children

Some participants strongly recommended that children with ADHD should be given priority treatment as they were unable to cope with the long waiting times at the hospital. This suggestion was as a result of participants experiencing the stress of managing their children whilst following the prolonged hospital procedures on their treatment days.

- Address the staff shortages

Four participants recommended the need to address the staff shortages at the hospital. These participants perceived an improved service delivery by addressing this issue of human resources

- Changing dispensing practices

The recommendation for the service provider to change the current dispensing system of Ritalin was strongly proposed by the majority of the participants who found that this service point was a stumbling block to efficient service provision. Participants felt strongly that Ritalin should be dispensed at the ADHD clinic by the attending doctor instead of the current practice where it is dispensed at the hospital pharmacy. The intention is to decrease patient waiting times.

- **Alternative to Ritalin**

The view of many participants was that other options must be considered first, before Ritalin was prescribed as a first line treatment. Participants requested that the drug Concerta be considered as they perceived it had fewer side effects than Ritalin.

- **Address the current referral system to allied professionals**

The request to be referred to all allied professionals who offer a support service was a firm recommendation. Participants viewed themselves as being at a disadvantage with the current services as they had little or no exposure with the allied health service providers.

A conclusion drawn was that these future recommendations by participants would ensure that the participants and their ADHD affected children will benefit from a more holistic bio-psychosocial approach to the management of the disorder.

6.3 Recommendations arising from the study

The following recommendations are based on the findings of this study.

6.3.1 *The need for support*

Participants of ADHD affected children need support especially after receiving their children's diagnosis. The reactions that participants experience is profound and therefore the level of support offered to them must be made available to them. Through a uniform referral system participants must be referred for psychosocial support. This can be achieved by getting the health care workers such as social workers and psychologists to provide counselling services to the participants as well as to spouses and significant family members. It is imperative for fathers to be included in these sessions as they play a vital role at the micro level. They form the closest support nest to mothers who are the main caregivers. A recommendation for family therapy as a means of support will be advantageous for all members of the family unit who are significant in the child's life. The intensity of participants' emotions must be recognized and needs to be supported during the diagnosis stage of the disorder.

6.3.2 *Alternatives to Ritalin*

An overwhelming majority of participants in this study had negative feelings and experiences about the use of Ritalin as a first line treatment for ADHD. On the basis of information emerging from this study there were suggestions for less controversial alternatives to be implemented before the prescription of Ritalin. It is important to implement a multi modal approach to treating ADHD which encompasses the bio-psychosocial approach to care. This includes the use of pharmacotherapy as well as behavioural management techniques such as behaviour modification. This proposed dual therapy ensures that the biological needs as well as the psychosocial well being of the ADHD affected child is adequately addressed. Further, participants' fears of using psychostimulants such as Ritalin are alleviated once other alternatives are offered as first line treatment for their children

6.3.3 *Parent and caregiver knowledge*

As noted in the study, the lack of knowledge on ADHD was one of the primary concerns of participants that prevailed throughout the study. For participants to ensure that there is holistic bio-psychosocial functioning of their children, knowledge and understanding of the disorder by the parent or caregiver is an essential component. Therefore, one of the main recommendations is for health care workers to engage in detailed discussions with parents at the onset of diagnosis and treatment of the disorder. It is essential for participants to be educated on the nature and causes of their children's disorder as this has an impact on the way in which they deal with and react to their children's diagnosis. It is important to have strong interrelatedness between the meso and the micro layers.

6.3.4 *Referrals to the allied health professions*

The referral to allied health professionals needs strengthening. Allied health professionals must have policies and protocols stipulated for the referral procedure. It is imperative for doctors at the clinic to uniformly refer participants with their children to support services at the hospital. Allied health professionals also need to be sensitive to the needs of participants and therefore need to take the time to address parent and caregiver concerns. As noted in the study, participants saw the benefit to receiving services from the social worker, psychologist, and the dietician. The role of the social worker and the psychologist are seen as crucial components in addressing the psychosocial needs of

parents/caregivers. It is therefore recommended that standardized processes and procedures be established by each discipline in collaboration with each other.

6.3.5 *Interdisciplinary team approach*

It is imperative for health care workers to work together with participants and their children. This approach focuses on team work and effective communication between team members in the interest of the patient and their families. This in turn would reduce parent and caregiver anxiety. The interdisciplinary approach is recommended as it is patient centered. The strength of this approach lies with the team being actively interdependent. The “team” concept must be strongly advocated as the current system is very inconsistent and fragmented, yet there is the availability of professionals from all disciplines. If proper systems are put into place the interdisciplinary approach would work well in the hospital environment for several reasons. Firstly, appointments with the health care professional are scheduled on one day, therefore it is a cost effective approach for participants. The team can collaborate with each other and through a well communicated referral system patients can benefit from all the services offered to them. Through the hospitals policy and protocol committee, professionals from each discipline can discuss relevant policies or protocols pertinent to the management of the disorder and reach consensus for effective and efficient service delivery to these patients. Evidence of an effective team approach can be seen with the current Child Abuse Committee that is hosted every month at the hospital with the relevant role players. Similarly, the team concept can again be used at the ADHD clinic. Thus the inter disciplinary team approach must be promoted for future service delivery as this approach embraces the bio-psychosocial approach which focuses on the wellness of the body and mind systems in the ADHD affected child.

6.3.6 *Collaboration with educators*

Since the concern of many participants was that their children experienced difficulties in school and that educators’ knowledge and skills needed to be improved for better management of the disorder in the classroom, there were recommendations for more collaboration between health care workers and the school. The social worker can play a key role in liaising between the educator and the health care facility as he/she will play a facilitative role in this dyadic relationship. It is important for both these institutions to discuss the needs of the child and to further include the parent/caregiver. This triadic

relationship will yield a better outcome for children with ADHD. Educators must be aware of the symptoms of ADHD and the treatment regime so they as well are active participants in the management of the disorder. Likewise, health care workers, especially social workers or psychologists need to involve themselves with the child's school to ensure that there is optimal psychological and social functioning at this level. Collaboration at this meso layer ensures equilibrium at a micro level as well. It must also be a collaborative effort at a macro level where policies and protocols are developed with consultation between the Department of Health and the Department of Education on the management of this disorder by both the institutions.

6.3.7 Improved hospital administrative processes

Participants in this study were hopeful that the outcome of the study would serve to inform policy changes at the state hospital in terms of quality assurance pertaining to waiting times, dispensing practices, scheduling of appointments and prioritizing of children with ADHD. The findings from the study indicated that participants recommended that Ritalin be dispensed at the ADHD clinic instead of the hospital pharmacy. This would help in decreasing the waiting time. This study also recommends that appointments with the different allied health professionals be scheduled for the same day as it is cost effective for the participant. The recommendation for an improved service was for children with ADHD to be prioritized at the paediatric clinic as this would also reduce the waiting times for the participants. Other suggestions for an improved service include addressing the human resource component at the hospital as this is the key to effective and efficient service delivery. These improvements would alleviate the stress and tension participants currently experience with the long hospital processes.

6.3.8 Parent and Caregiver support groups

The one area of support that participants in this study requested for was the establishment of support groups for themselves. The research findings indicate that there is an urgent appeal by participants for health care workers at the hospital under study to pursue this request for the commencement of support groups. The formation of such support groups should have its needs dictated by the parents and caregivers of children with ADHD. Such support groups may be informal but facilitated by a social worker or psychologist and in addition it could serve a therapeutic function to participants. Through mutual

sharing of experiences, participants are not left feeling alienated and there is comfort in knowing that others are in the same situation.

6.3.9 *Parent education programs*

The hospital needs to become involved in parent and caregiver education programs. Bearing in mind the literacy levels of participants, these education programs need to occur on a regular basis at the paediatric clinic. An awareness drive on ADHD can be promoted around the national ADHD awareness day which is on 14 September every year. Through pamphlet distribution, poster displays and arranging for experts in the field of ADHD to present talks at the paediatric clinic, awareness can be created for parents and caregivers to benefit from. Community awareness can be created at community clinics, schools, and through media coverage.

6.3.10 *Upholding Batho Pele principles*

In order to meet the needs of parents and caregivers efficiently and to provide quality services to affected individuals and their families, it is imperative for health care workers to employ the principles of Batho Pele, that is "Putting people first". It is essential that these guiding principles that are the cornerstone to effective service delivery are complied with by the different disciplines that provide services to patients, their parents or caregivers. Effective service oriented departments are those that consult with their patients, maintain open relations with them and monitor the patients needs and expectations as well as their levels of satisfaction. The principles of Batho Pele if upheld ensures that the concerns of the participants and their needs are the heart of all key decisions, actions and communications in the state hospital. It is strongly recommended that services providers within the state facility apply all eleven principles (as discussed in chapter 2) of Batho Pele as the benefits of these principles accrue both to the hospital facility and more importantly to the benefactors of the service.

6.3.11 *Recommendations for future research*

The study has highlighted the need for further research to be carried out pertaining to the knowledge and attitudes of health care professionals in the comprehensive management of ADHD. It would also be of interest to conduct a comparative study between private and public sector patients to evaluate the outcomes in respect of ADHD management.

Conclusion

In this final chapter, the main conclusions were presented and from the analysis of participants' discussions, recommendations were extracted. It can be concluded that participants did not receive the support they required from health care workers at the state hospital and this intensified their stress. Further, the various layers of the ecosystem in this study were in disequilibrium as there was no "goodness of fit" between participants and the hospital environment. The bio-psychosocial approach has not been effectively implemented in this study as the emphasis is on biological and pharmacological and not the psychosocial factors. In order to address the gaps in service provision and to uphold the "Batho Pele principles it is imperative for policy makers at a meso and macro level to take cognizance of the recommendations of this study.

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Appendix A

Semi-Structured Interview

Participant Details

Age

Marital Status

Relationship to child

Educational level

Employment

Significant others living in the home

Children's Details

Age

Gender

Diagnosis

- Who referred your child referred to the hospital?
- What was your reaction when you were given your child's diagnosis of ADHD?
- What were some of the family member's reactions to the diagnosis
- What role has the school played with regards to your child's referral and diagnosis?
- Could you describe what information/services/support you received from the hospital at the time of diagnosis?
- What were some of your concerns regarding the ADHD diagnosis

Parental Knowledge of ADHD

- What do you understand about the condition ADHD?
- Can you describe your experience regarding the use of prescribed medication?
- What concerns do you have about the medication prescribed?
- What have you been told about the treatment plan for your child?
- What have you been told about your child's dietary needs?

Service Delivery

- What information have you been given about ADHD?
- What was/ is your experience when you visit the hospital with your child?
- What are your experiences of services provided by the doctor/ social worker/psychologist/dietitian/ occupational therapist/speech therapist / audiologist?
- Which services do you feel most benefit your child?
- What concerns do you have with regards to the services offered to you and your child at the hospital?

Future Recommendations for service delivery

- What suggestions do you have for the hospital to ensure better services for participants bringing in their children with ADHD?
- In addition to the current services provided to you by the doctor/social worker/psychologist/occupational therapist/audiologist/speech therapist/dietician, how else could these professionals assist you?
- What type of support would you like to receive from the hospital in respect of your child?
- What changes do you think needs to be made to improve on the current services provided to parents/caregivers of children with ADHD?

Appendix B

Letter of informed consent- Participant

Title of Research: Children with Attention Deficit Hyperactivity Disorder: Needs And Experiences Of Parents/Caregivers Receiving Services At A Public Hospital.

I, ----- hereby consent to participate in an hour long interview, in the above mentioned study. I acknowledge that I have been informed of the purpose of the study. I understand that any information provided in the interview will remain strictly confidential and I will remain anonymous in any publication of the research findings. I declare that my participation in this study is of a voluntary nature, and that I am free to withdraw from the study without any negative consequences, should I wish to do so. I consent to a tape recorder being used to tape the interview so that the researcher can focus on the interview process.

Signature of participant

Date

Appendix C

Focus Group Discussion: Themes which were explored:

- Reactions to diagnosis of ADHD.
- Knowledge on ADHD and the use of psychostimulant medication.
- Challenges in raising a child with ADHD.
- Support received from health care professionals at the hospital.
- Support received from the family.
- Involvement of school personnel.
- Involvement of participants in the treatment process.
- Recommendations for an improved service.