

Living with Attention Deficit Hyperactivity Disorder (ADHD)

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Contents

Chapter One: Introduction	1
Section One: Review of research into ADHD	3
Features of ADHD	3
History of the ADHD concept	8
Section One Summary	10
Section Two: Models of ADHD	10
Biological models	11
Sociological models	15
Psychological models	21
Section Two Summary	25
Section Three: Research into the individual experiences of ADHD	25
Summary and Rationale for current study	36
Chapter Two: Method	38
Overview	38
Recruitment	38
Response Rates	39
Participant Details	39
Data collection	40
Ethical Approval	44
Analysis of Data	44
Summary	50
Chapter Three: Results	52
Overview	52
Core Category One: Difference	54
Parents' experience of difference	54
Delayed	55
Disorganised	57
Disruptive	60
Dangerous	63
Concern about difference	64
Children's experience of difference	65
Effects of being different	66
Noticing	69
Summary	71
Core Category Two: Blame	72
Mother blame	72
Child blame	77
Respite from blame	78

Core Category Three: Battles	79
Parents' battles with partners	80
Battles with teachers	83
Battles with families	87
Battles with children	89
Battles with professionals	91
Children's external battles: bullying	93
Parents' internal battles: Ritalin	96
Children's internal battle: Ritalin	101
Summary	105
 Core Category Four: Adjusting	 105
Parents' adjustment	106
Children's adjustment	110
Results section summary	112
 Chapter Four: Discussion	 113
Overview of results	113
Parents' understanding of ADHD	116
'Trouble from day one'	117
Description of difference	118
Use of medication	119
Children's understanding of difference	121
Discussion of biological view	122
ADHD as a biological disorder	122
Dominance and power in medicine	124
Mothers' psychological distress	125
Summary	127
 Sociological views of ADHD	 128
Blame	128
Battles	130
Discussion of the sociological view	131
Poor parenting	131
Diagnosis <i>du jour</i>	133
Integration of biological and sociological views	134
Overview	137
 Clinical implications	 138
Research implications	140
Methodological issues	142
The sample	143
Data collection	144
Data analysis	146
Reflections on the research process	150
Conclusion	152
 References	 153

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Abstract

Much of the extensive body of research into ADHD has concentrated on understanding the aetiology of the disorder. Additional research has focused on issues of diagnosis and assessment, and treatment interventions. However, despite the wealth of research into ADHD, little is known about the individual experiences of those directly affected by the disorder. The aim of this study was to investigate issues of importance for children with ADHD and their parents, with the aim of contributing to the small but growing body of knowledge about the experiences of those affected by the disorder. Nine boys, aged between eight and eleven years, their mothers and one father agreed to participate in the study. In-depth interviews, following a semi-structured format, were held with each participant. Interviews were transcribed verbatim and analysed using a grounded theory approach. Data analysis revealed the importance of three core categories for both children and adults: difference, battles and adjusting. For adults alone, a fourth core category of blame emerged as important. These categories were developed into a theoretical model around the issue of understanding ADHD, in which parents reported that their views of ADHD as a biological condition differed from others' sociological views of the condition. These issues were discussed in terms of the origins of parents' and children's perceptions of these differing views. Clinical implications included (1) the need to integrate biological and sociological explanations if blame and battles are to be avoided; (2) the need for clear and unambiguous explanations about the nature and causes of ADHD. Research implications included the need for further research into the processes of diagnosing ADHD, and the need for further research into fathers' understanding of the condition.

Chapter One

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most widely researched childhood psychiatric conditions (Richters, Arnold, Jensen, Abikoff, Conners et al., 1995). Much of the research into the condition has concentrated on understanding its nature and causes, and has revealed that children diagnosed with ADHD suffer from a variety of difficulties in behaviour, learning and social relationships. Additional research into the diagnostic criteria and features of ADHD, co-morbid disorders, and the efficacy of psychostimulant medication has led to the development of a widespread assumption that ADHD is as a discrete, biologically-based, psychiatric disorder (e.g., BPS, 1996; DSM-IV, 1996). However, research into psychosocial and environmental factors involved in the expression of ADHD has also been undertaken, in which the influence of factors such as parenting styles, attachment and cultural expectations of children has been explored. This research suggests that there are a number of difficulties in assuming that ADHD is a purely biological condition.

Although a large amount of research into ADHD has been undertaken, certain areas of research remain neglected. For example, the everyday experiences of children affected by the condition and their parents have been ignored in the scientific literature, with only one published study (Kendall, 1998), and one unpublished study (Byram, 1999), known to this author. These studies found that understanding ADHD was one of the most important issues for parents, as well as adjusting to and accepting their children's strengths and difficulties. In addition, experiences such as disruption and blame emerged as important issues. A key aim of the present study is to assess whether these

issues are common to other children with ADHD and their families, and, if so, to explore further how they come about and how they impact on parents and children. In addition, the study aims to assess whether other, previously unidentified, issues relating to the experiences of children with ADHD and their parents are important. For example, little is known about parents' and children's understanding of ADHD, which, given the many different aetiological models and the vast amount of research in the area, may have important implications for how they make sense of the disorder, how they adjust to the diagnosis, and how they manage the difficulties it creates.

There are a number of reasons why further research of this kind is important. Firstly, the dearth of qualitative research in this area suggests that there are many experiences of children with ADHD and their parents that have yet to be explored. Secondly, from the two existing qualitative studies, quite different experiences were noted as important. Further research is required to assess whether these findings are consistent with the experiences of other parents, and whether they contribute to a growing body of information about children with ADHD and their parents, or whether these experiences were specific to the group interviewed. Thirdly, further research involving families of different social backgrounds and children of different ages will be useful for assessing the generalisability of the results. Fourthly, understanding how children and their families are affected by the condition is important for predicting how services should be organized and what resources will be needed. As the frequency with which ADHD is diagnosed increases, the workload of clinicians working in the field will also increase, and the necessity for specific and practical interventions highlighted.

The present study aims to provide an account of the experiences of children with ADHD and their parents. The introduction is divided into three sections. Section One describes the features of ADHD and the history of the ADHD concept. Section Two outlines current conceptualisations of the disorder, including biological, sociological and psychological explanations. Section Three reviews the limited amount of research into parents' and children's experiences of ADHD, and highlights areas which have yet to be explored.

Section One: Review of research into ADHD

Features of ADHD

In mainstream medical and clinical literature, the Diagnostic and Statistical Manual (DSM-IV, APA, 1996) provides criteria for the assessment and diagnosis of ADHD. DSM-IV considers ADHD to be a 'persistent pattern of inattention and/or impulsivity that is more frequent and severe than typically observed in individuals of a comparable level of development'. Based on field trials (Lahey, Applegate, McBurnett, Biederman, Greenhill et al., 1994), three sub-types of ADHD are distinguished: hyperactive-impulsive, inattentive and combined. Features of the hyperactive-impulsive subtype include difficulties regulating behaviour; for example, children are described as being constantly 'on the go', are considered to act impulsively, and are unable to tolerate frustration. These children are often seen moving quickly from one task to another with little apparent enjoyment, often call out answers to questions without waiting their turn, and are often restless and fidgety in social situations and activities.

The inattentive subtype is used to describe children whose primary difficulties are those of attention and concentration. These children are described as having difficulty sustaining attention on one task, and seem easily distracted by competing stimuli. In school this may manifest itself in difficulties focusing on academic work, and at home children have difficulty listening when spoken to and are often reluctant to finish chores. The combined type is used to describe those children who display symptoms of both types of behaviour. DSM-IV includes a fourth category, ADHD not otherwise specified, for those children whose symptoms have an identifiable, known origin, such as head trauma or illness. As with all psychiatric conditions, DSM-IV stipulates that the severity of symptoms must be such that they cause clinically significant distress or impairment. In addition, the symptoms of ADHD must be present before the age of seven, indicating the developmental nature of the condition. See Table One for DSM-IV criteria for ADHD.

According to DSM-IV, approximately 3-5% of the childhood population suffers from ADHD. However, using ICD-10 (WHO, 1990) criteria, this figure decreases to approximately 1% of the childhood population (Hinshaw, 1994). This difference may be accounted for by the more stringent criteria used by ICD-10, for example the fact that both significant inattention and hyperactivity must be observed for a diagnosis of Hyperkinetic Disorder (ICD-10 equivalent to ADHD) to be made. Gender differences have been well documented, and current estimates suggest that boys are more likely to be affected than girls at a ratio of 3:1 (Szatmari, Offord, & Boyle, 1989b).

ADHD is often accompanied by impairments in intellectual, behavioural, and emotional development. Children diagnosed with ADHD are likely to score 7 to 15 points lower

on standardised intellectual assessments than control groups or their siblings (Faraone, Biederman, Lehman, Keenan, Norman, et al., 1993). It is likely that these figures are influenced by the behavioural symptoms of the disorder, so they may not represent real differences in intelligence (Barkley, 1998). Regardless of ability, it is known that children with ADHD typically perform poorly in the classroom, and that this poor performance is highly correlated with the severity of behavioural symptoms. ADHD children have difficulties with reading, spelling, mathematics and reading comprehension. Many require additional assistance in the classroom (Barkley, DuPaul & McMurray, 1990).

Table 1.DSM-IV Criteria for ADHD

- A. Either (1) or (2):
- (1) six (or more) of the following symptoms of inattention have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:
- Inattention
- (a) often fails to give close attention to details or makes careless mistakes in schoolwork, work or activities
 - (b) often has difficulty sustaining attention in tasks or play activities
 - (c) often does not seem to listen when spoken to directly
 - (d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions)
 - (e) often has difficulty organising tasks and activities
 - (f) often avoids, dislikes, or is reluctant to engage in tasks that requires sustained mental effort (such as schoolwork or homework)
 - (g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books)
 - (h) is often easily distracted by extraneous stimuli
 - (i) is often forgetful in daily activities
- (2) six (or more) of the following symptoms of hyperactivity-impulsivity have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level
- Hyperactivity
- (a) often fidgets with hands or feet or squirms in seat
 - (b) often leaves seat in classroom or in other situations in which remaining seated is expected
 - (c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
 - (d) often has difficulty playing or engaging in leisure activities quietly
 - (e) is often 'on the go' or often acts as if 'driven by a motor'
 - (f) often talks excessively
- Impulsivity
- (g) often blurts out answers before the questions have been completed
 - (h) often has difficulty awaiting turn
 - (i) often interrupts or intrudes on others (e.g., butts into conversations or games)
- B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before the age of 7 years
- C. Some impairments from the symptoms is present in two or more settings (e.g., at school/work and at home)
- D. Clear evidence of clinically significant impairment in social, academic or occupational functioning
- E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder, and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

High co-morbidity exists between ADHD and other forms of psychiatric disorder. It has been suggested that up to 44% of children with a diagnosis of ADHD may have at least one other psychiatric diagnosis, 32% may have two others, and 11% may have at least three other disorders (Szatmari, Offord, & Boyle, 1989a). The most common co-morbid disorders are anxiety and depression, which are often associated with a history of greater family and personal stress and greater parental symptoms of mood disturbance (e.g., Biederman, Newcorn, & Sprich, 1991). Oppositional Defiant Disorder (ODD) and Conduct Disorder (CD) are also commonly diagnosed among children with ADHD (e.g., Barkley, Fischer, Edelbrock & Smallish, 1990). It has been suggested that between 50-70% of ADHD children meet criteria for ODD (Barkley, DuPaul & Murray, 1990), and between 40-50% of ADHD children meet criteria for CD (Szatmari, Boyle & Offord, 1989a).

A recent review of the literature suggests that psychostimulant medication is the most effective form of pharmacotherapy for the treatment of ADHD (Spencer, Biederman, Wilens, Harding, O'Donnell et al., 1996). This review indicated that psychostimulant medication improves much of the behaviour of children with ADHD, as well as improving self-esteem, cognition, and social and family functioning in 70% of the children who take it. However, the review also suggested that more research is needed to establish whether other forms of medication could have similar efficacy, and whether co-morbid features associated with ADHD could benefit from similar interventions. In addition, the review highlighted the need for more research into the efficacy of combined treatments involving medication and psychosocial interventions.

History of the ADHD concept

A review of the development of the ADHD construct is important for highlighting the changes in conceptualisation and understanding of the disorder that have occurred.

This is necessary for understanding some of the contemporary debates in the field of ADHD, such as the many varied theories of ADHD outlined below.

The features of what is now known as ADHD were first described by Still in 1902. Still (cited in Barkley, 1998) noted that characteristics such as aggression, defiance, resistance to discipline, excessive emotionality, volitional inhibition and 'defects in moral control' co-occurred in groups of children whom he described as having 'Minimal Brain Damage'. As with ADHD criteria today, these symptoms were noted more frequently in boys, often arose in children younger than 8 years, and were typically found in children whose biological relatives were prone to psychiatric disorders.

Still's hypothesis of an association between these behavioural characteristics and residual brain damage was strengthened by an encephalitis epidemic in the USA in 1917. Of those children who survived the outbreak, many were left with significant behavioural and cognitive impairments. These included impaired attention, impulsivity, and difficulties regulating activity levels, which resulted in disruptive behaviour. The clear link between these characteristics and the encephalitis epidemic led to the study of other brain injuries such as birth trauma, epilepsy, head injury and other infections (see Barkley, 1998). Behavioural studies of primates with frontal lobe lesions provided further evidence of a brain-behaviour link (e.g., Blau, 1936, cited in Barkley, 1998).

The success of pharmacological therapy (particularly amphetamines) for the treatment of disruptive behaviour was used to suggest more specifically that neurological mechanisms were underlying the behavioural symptoms (e.g., Bradley, 1937, cited in Barkley, 1998).

These findings shifted the emphasis from brain damage *per se*, and focused more on the symptoms of a disorder. This resulted in the concept of the 'hyperactive child' (Chess, 1960, cited in Barkley, 1998), which separated the syndrome of hyperactivity from the concept of a brain syndrome. It was now recognised that hyperactivity could arise with or without organic pathology and, in 1968, Hyperkinetic Reaction of Childhood was first introduced in the Diagnostic and Statistical Manual (DSM-II). Following its inclusion in the DSM, research into the disorder multiplied. By the 1970s, the defining features included hyperactivity, impulsivity, short attention span, low frustration tolerance, distractibility and aggression. The plethora of research in the 1970s was matched in the 1980s, and emphasis was placed on attempts to develop specific diagnostic criteria.

The 1980s were also marked by the reconceptualisation of Hyperkinetic Reaction of Childhood as Attention Deficit Disorder (ADD), which emphasised the features of inattention and impulsivity rather than hyperactivity. ADD was now sub-typed in DSM on the basis of the presence or absence of hyperactivity. However, research continued to assess the validity of these subtypes, and this approach was later abandoned in favour of combining all the symptoms into one list (DSM-III-R) under the label of ADHD.

The 1990s again saw significant developments in the field of ADHD. These included increases in the use of neuroimaging methods and genetic studies to assist in understanding the aetiology of the disorder (e.g., Zametkin, Nordahl, Gross, King, Semple et al., 1990), research of adults with ADHD (e.g., Mannuzza, Gittelman-Klein, Bessler, Malloy, & LaPadulta, 1993), and a re-introduction of sub-typing within the disorder. The term ADHD has remained unchanged, although the diagnosis currently includes reference to whether the disorder is predominantly inattentive, predominantly hyperactive-impulsive or combined.

Section One Summary

Section One has outlined the features of the disorder and explored the history of the ADHD concept. This section has demonstrated the many changes in conceptualization of ADHD that have occurred, and how these have led to the current widespread understanding of the disorder. In the following section, the impact of these changes on the development of theoretical models of ADHD will be discussed.

Section Two: Models of ADHD

Many different explanations for the causes of ADHD have been proposed. These theories range from genetic, neurological and physiological anomalies, to theories suggesting that ADHD is a social construction and an epiphenomenon. It is important to outline these theories because, although not previously researched, it is possible that these different conceptualisations of the disorder play an important role in how ADHD is experienced by parents and children. Presented below is a brief résumé of each theory, highlighting the salient issues.

Biological models

A genetic contribution to ADHD has long been postulated (Rutter, MacDonald, LeCoutier, Harrington, Bolton et al., 1990). One of the earliest twin studies was undertaken by Goodman and Stevenson (1989), who found concordance rates for ADHD of 51% in monozygotic twins and 33% in dizygotic twins. Family aggregation studies have suggested that ADHD symptoms occur more frequently in close family members of an individual with ADHD (e.g., Biederman, Faraone, Keenan, Benjamin, Krifcher et al., 1992). Adoption studies imply that this family link is genetic rather than environmental (e.g., Barkley, 1990).

Genes relating to the dopamine system have been of primary interest mainly because of the efficacy of pharmacological agents which act primarily on the dopamine (DA) systems. Two genetic components associated with dopamine function have been specifically linked to hyperactivity: the D4 dopamine receptor (DRD4) and the dopamine transporter gene (DAT1) (see Rutter, Silberg, O'Connor & Simonoff, 1999). Swanson, Sunahara, Kennedy, Regino, Fineberg et al. (1998) found that children with ADHD were more likely to have the 7 or 8 variants of a DRD4 allele than controls, although this finding has not been replicated elsewhere (e.g., Rowe, Stever, Giedinghagen, Gard, Cleveland et al., 1998).

Genetic models of ADHD have been strengthened by studies indicating an association between general resistance to the thyroid hormone (GRTH, a rare autosomal disorder) and ADHD, particularly the hyperactive-impulsive sub-type. Hauser, Zametkin, Martinez, Vitiello, Matochik et al. (1993) found that rates of the hyperactive-impulsive sub-type were significantly higher among families with thyroid resistance than among

families without. The link with ADHD was strengthened by the finding that thyroid hormone levels correlated with symptoms of hyperactivity (Hauser, Soler, Brucker-Davis & Weintraub, 1997).

Advances in neuroimaging techniques have been used to assess the theory that ADHD occurs as a result of neurological damage. MRI scans have revealed a wide range of structural anomalies. For example, the cerebral hemispheres, the globus pallidus, the genu, the splenium, the rostrum and the rostral body have been found to be smaller in children with ADHD, and some studies have suggested that the left caudate is smaller than the right in children with ADHD (see Filipek, 1999).

PET scans have revealed metabolic anomalies. Zametkin et al. (1990) and Cantwell (1994) found that adults with ADHD had lower cerebral glucose metabolism in the premotor cortex and in the superior prefrontal cortex than non-ADHD adults. Ernst, Liebenauer, King, Fitzgerald, Cohen et al. (1994) found that female adolescents with ADHD had reduced glucose metabolism, although no differences were found in younger children.

Before considering alternative models, it is important to highlight some of the criticisms levelled at these biological models, and indeed the definition of ADHD as a discrete biologically based disorder as outlined above. Firstly, the situational variability in the behaviour of children labelled with ADHD suggests that the behavioural symptoms are amenable to environmental contingencies. For example, the primary symptoms of ADHD have been found to show significant fluctuations across settings and caregivers (e.g., Zentall, 1985). ADHD children have been found to be more

compliant and less disruptive when with their fathers (Tallmadge & Barkley, 1983), and to have fewer behavioural problems when in novel or unfamiliar surroundings (Barkley, 1977). Attentional deficits seem particularly amenable to immediate reinforcement or punishment. Speculation has also been raised about ADHD children who have particular difficulty doing chores and concentrating on homework, but who are able to concentrate when playing computer games or watching television (Zentall, 1985).

Secondly, prevalence rates vary according to the classification system used, the population studied, the geographical location of that population and the degree of agreement required between parents, teachers and professionals for a diagnosis (Lambert, Sandoval & Sassone, 1978). When ICD-10 is used, for example, far fewer children are diagnosed with the disorder. Prevalence rates also differ from one country to another (e.g., Germany and the USA; Baumegeartel, Wolraich & Dietrich, 1995), thus indicating a potential role for social and cultural factors in the diagnosis of the disorder.

Thirdly, despite the wealth of literature in the area, no unique, specific biological markers for the disorder have been found (Silberg, Rutter, Meyer, Maes, Hewitt et al., 1996). In addition, in none of the neuroimaging studies have the brains of children with ADHD been considered to be clinically abnormal (Hynd and Hooper, 1995), and sample sizes have often been small. Finally, a unidirectional theory of cause and effect should be treated with caution, as changes in behaviour may result in changes in neurochemistry, rather than representing altered neurochemistry (Christie, Lieper, Chessells & Vargha-Khadem, 1995).

Fourthly, as stated earlier, the main form of treatment for ADHD is the use of psychostimulant medication. Although the review by Spencer et al. outlined above indicated that 70% of individuals benefit from taking psychostimulant medication, the remaining 30% are known to suffer from a variety of side-effects. For example, Fitzpatrick, Klorman, Brumaghim & Borgstedt (1992) found that children reported sleep problems, reduced appetite, weight loss, irritability, stomachaches and headaches. In addition, despite some short-term improvements in behaviour and concentration, long-term advantages are less apparent. Weber, Frankenberger & Heilman (1992) found that after one to two years of treatment, Ritalin was not associated with improvements in academic achievement, and Landau & Moore (1991) found no long-term improvements in social interactions.

Finally, with each revision of the diagnostic criteria, a larger cohort of children is found to be above the threshold for diagnosis. For example, changing from DSM-III to DSM-III-R more than doubled the number of children (from the same population) diagnosed with the disorder and changing from DSM-III-R to DSM-IV increased the prevalence by a further two-thirds. It has been suggested that the criteria could now be applied to the majority of children with behavioural or academic problems (Baumgaertel et al., 1995). The large number of children labelled with ADHD questions the accuracy of current diagnostic criteria, and contemporary conceptualizations of normality and abnormality.

The many inconsistencies in the medical perspective of ADHD have led to the development of alternative understandings of the disorder. Outlined below are ideas generated from social and psychological theories.

Sociological models

Sociological models highlight the importance of social, cultural and political factors in the development of disorders such as ADHD. These models vary widely in their understanding of 'psychiatric' conditions, from assuming social causes to looking at the social construction of the condition itself. These models are outlined below, and specific implications for ADHD are considered.

Social causation theories argue that the aetiology of conditions such as ADHD lies in social rather than biological factors. A number of studies have looked at the social correlates of ADHD, including social class, infant-mother attachment, mother's age, the presence of parental psychiatric disorder and parenting style. Some studies have suggested that ADHD occurs more commonly in children from families of lower social class, although this finding is not specific to ADHD, and it is unlikely that social class *per se* is a causal factor (e.g., Szatmari, 1992). Attachment style has been linked with many forms of behaviour problems, and some studies have suggested that attachment and hyperactivity may be specifically linked. For example, Sanson, Smart, Prior & Oberklaid (1993) suggest that ADHD may be the result of a failure of the mother to regulate the child's attention and arousal.

The presence of psychiatric disorders in the parents of children with ADHD has been used to suggest a genetic link between these conditions (Faraone & Biederman, 1997; cited in Barkley, 1998), although it is equally likely that the difficulties these parents experience managing their own condition and raising a child may impact on the child's development. In terms of parenting style, parents of children with ADHD are known to be less responsive, more negative and directive and less rewarding of their

children's behaviour (Danforth, Barkley & Stokes, 1991). Parents are also noted to be acrimonious in their interactions with their sons (Buhrmester, Compas, Christensen, Gonzalez & Hinshaw, 1992), and it has been suggested that hyperactive behaviour is the result of poor parental management of children and an overstimulating approach to caring for and managing the child (Carlson, Jacobvitz & Sroufe, 1995).

As indicated above, one of the problems with social causation theory is that correlations between social factors and ADHD do not necessarily imply causation. Although there may be links between social factors and ADHD, it is unlikely that these characteristics caused the disorder. Indeed, it is possible that the direction of effects is reversed, so that instead of parenting style causing ADHD, the symptoms of ADHD evoke a certain way of responding from parents. Alternatively, a third factor may affect both variables. However, it is likely that the social characteristics outlined above exert an influence on the expression of the disorder, and the ways in which the disorder is perceived and managed.

Social constructionist theories highlight the view that reality is not self-evident and waiting to be discovered, but rather that it is the product of human activity. Influenced by writers such as Foucault (1965), social constructionists argue that mental illness is merely an epiphenomenon, created by the use of language and symbols related to power. This approach thereby questions the factual status of mental illness and analyses the ways in which mental illness is created, emphasising the influence of social, cultural and economic factors on conceptualisations of normality and abnormality.

Coppock (1997) discusses the application of social constructionist ideas to childhood disorders. She emphasises how conceptualisations of normality and abnormality are often grounded in professional discourses emanating from psychology and psychiatry, particularly the theories of Bowlby (1951) and Winnicott (1957). Coppock believes that the emphasis on the importance of early mother-child experiences and the potentially harmful effects on children who are deprived of this have contributed to contemporary understandings of normal and abnormal behaviour.

Schrag and Divoky (1976) were amongst the first researchers to develop social constructionist ideas of ADHD. Their work polarised the opinions of those interested in ADHD into two identifiable schools of thought, one which viewed ADHD as a primarily medical disorder with secondary social implications (the 'reductionist' view) and the other which viewed ADHD as a means of social control, and arising as the result of social discrimination and political oppression (the 'idealist' view). Schrag and Divoky argued that the label of ADHD was simply a form of child control. They stated that the rapid rise in similar 'syndromes' was a reflection of society's increasing intolerance towards children who were 'different' from a supposed norm. They challenged this approach and argued that ADHD along with many other new 'syndromes' (e.g., Conduct Disorder) had little validation in science or medicine.

Block (1977) also suggested that ADHD was culturally created. He stated that the increasing demands of an industrial culture (such as high achievement and accelerated output) were effectively pathologising children who were unable to meet these demands. Children would have been able to avoid these demands before compulsory education, but since the increase in educational demands on these children, difficulties

in this area have been highlighted. Similarly, Jensen, Mrazek, Knapp, Steinberg, Pfeffer et al. (1997) have suggested that ADHD should be considered a disorder of adaptation. These researchers have taken an evolutionary approach to understanding ADHD, arguing that the characteristics of the disorder could be viewed as adaptive responses to the child's environment. Jensen et al. link the different symptoms of ADHD with strategies needed in hunter-gatherer environments, for example, linking hyperactivity with exploration of the environment for threats and opportunities, and attentional processes with scanning and shifting attention rapidly, necessary for the detection of threats. Although Jensen et al. recognise that this perspective may not explain the presence of ADHD in all children, they stress that the presence of the disorder in 3-5% of the population indicates that there may be some selection forces which convey some advantages to some ADHD characteristics.

More recently, Timimi (2000) has attempted to explain how the medical discourse on ADHD has become so dominant. He states that increasing expectations on the medical profession to have a scientific understanding of disruptive behaviour has led to the overuse of the ADHD label. These expectations are rooted in growing cultural anxieties (parental, professional and governmental) about children's development, and have led to the expectation that a diagnosis of a disorder necessarily implies a cure. Timimi argues that these expectations have led to changes in perceptions about responsibility for change, to such an extent that responsibility has come to lie increasingly with professionals rather than the family. Timimi also discusses how the clinical improvement of children taking psychostimulant medication has been a powerful reinforcer of the ADHD construct, because the positive effects are interpreted as confirming the physical cause of the disorder. However, he believes that

the over-prescription of medication is likely to be harmful because of its effects on children's beliefs about their ability to regulate their own behaviour without medication.

Finally, a book recently published by DeGrandpre, entitled 'Ritalin Nation' (2000) proposes an alternative understanding of ADHD. DeGrandpre reflects on the work of Schrag and Divoky, and Block, by suggesting that ADHD is culturally created. He states that the many technological advances that have taken place in society over the last decade, such as the use of the internet and mobile telephones, have led to the development of a 'rapid-fire culture', in which there is an expectation of speed, a demand of efficiency and a general increase in the tempo of life. These changes have had two effects on the development of children: (1) children have become 'addicted' to the sensory stimulation they receive from this rapid-fire culture; and (2) a 'culture of neglect' has emerged around child rearing. Both of these factors have contributed to the development of ADHD.

Central to DeGrandpre's understanding of ADHD is that the condition represents an addiction to stimulation. By this he means that children have become so familiar with the rapid stimulation they receive from the internet, television and video games that they have become addicted to this stimulation, and unable to cope with a slower pace of life. DeGrandpre uses one of the common criticisms of the biological theories of ADHD to support his model. He states that children are often restless, anxious and hyperactive when doing tasks which have little inherent stimulation, such as homework or household chores. However, children are calmer and more able to concentrate when they are completing tasks which have stimulating properties, such as watching

television or playing computer games. DeGrandpre also suggests that Ritalin has proved to be so effective and popular because it provides exactly the kind of stimulation that these children are seeking.

In addition to the sensory addiction, DeGrandpre suggests that the technological changes occurring in society have impacted on the core structures of the family and community, which children need for stability and security. DeGrandpre describes these effects in terms of a 'culture of neglect'. By this he means that the demands and expectations of society have given rise to an overall increase in work and stress and a conflicted sense of life priorities. Rather than parents perceiving their main role as one of providing children with a secure and stable home life, DeGrandpre suggests that parents have become pre-occupied with material wealth and financial security which has led to them spending more time at work and less time at home. This has two main effects on children; firstly, children are increasingly coming to rely on technology for entertainment, which exacerbates their sensory addictions; and secondly, children have fewer opportunities for learning to regulate their own emotional state.

DeGrandpre therefore argues that the current rapid-fire culture has led to changes in child rearing practices and priorities. In terms of ADHD, DeGrandpre suggests that because children are not given opportunities to stimulate their own minds and organise their own behaviour, they are not developing the internal structures and mechanisms of self-organisation and self-control. In addition, they are spending more time in passive light entertainment and less time in activities that require them to be calm and quiet, and so are not having adequate opportunities for learning these skills. Rather than blaming parents or teachers for this 'culture of neglect', DeGrandpre argues that these

institutions are shaped by larger cultural and economic forces, such as the devaluing of the role of housewife and mother, and the increased status of career women. He suggests that the way forward and away from simply diagnosing children with ADHD would involve a huge shift in priorities within cultures, with the emphasis changing from material wealth and possessions to emotional health and psychological well-being.

Sociological perspectives provide a useful addition to the medical perspectives of ADHD, by highlighting the contribution of social factors to childhood disorders, and questioning current conceptualisations of 'disorder'. The final perspective considered here is one derived from psychological theories of cognition and behaviour.

Psychological models

Psychological models have examined both cognitive and behavioural aspects of ADHD and have proposed alternatives to the medical and sociological accounts of ADHD outlined above. Cognitive models of ADHD implicate dysfunctional cognitive processes in the aetiology of the disorder. A number of different cognitive theories have been proposed including (1) the inattention hypothesis, (Douglas, 1983); (2) the over-activity hypothesis, (Schacher, 1991); (3) the impulsivity hypothesis (Barkley, 1994); and (4) the rule-following deficit hypothesis (Barkley, 1981). More recently, Barkley (1998) has attempted to synthesise the information presented in these models and create a model which incorporates many of these aspects, which he calls the behavioural inhibition model.

The inattention hypothesis argues that difficulties sustaining attention on a single task, and screening out other distracting stimuli, are the core features underpinning the symptoms of impulsivity and over-activity characteristic of ADHD (Douglas, 1983).

This theory predicts that children with ADHD perform at an equivalent level to children without ADHD at the start of a task, but that over time their difficulties sustaining attention mean that they become error prone. Their problems sustaining attention lead them to change their focus of attention frequently, which then manifests itself in excessive impulsivity and over-activity. However, this theory of sustained attention does not easily account for why some children with ADHD have immediate selective attention problems (e.g., Taylor, 1994), and why some children show over-activity while asleep (e.g., Hinshaw, 1994).

The over-activity hypothesis argues that the core deficit underpinning ADHD is a problem of inhibiting motor activity (e.g., Schacher, 1991). This theory is supported by evidence indicating that hyperactivity is a symptom unique to children with ADHD, and that hyperactivity correlates highly with many indices of attentional problems (Hinshaw, 1994). The impulsivity hypothesis states that the central problem in ADHD is with cognitive and behavioural impulsivity or disinhibition (e.g., Barkley, 1994).

According to this theory, children with ADHD have difficulty completing academic tasks requiring high levels of sustained attention because they are cognitively impulsive, and they have difficulty in social situations because they are behaviourally impulsive (e.g., Hinshaw, 1996). Neuropsychological evidence supports the assumption that children with ADHD do indeed have difficulties withholding responses over time (e.g., Pennington and Ozonoff, 1996). However, other studies have shown

that this impulsiveness can be reduced when certain environmental contingencies are in place (e.g., Sonuga-Barke, Houlberg & Hall, 1994).

The rule-following deficit model was initially proposed by Barkley (1981) and states that the central problem of children with ADHD is their difficulty following rules. This difficulty is due to an inability to use inner speech as a discriminative stimulus to cue particular responses. There is extensive evidence suggesting developmental language delay in children with ADHD, and there is some support for the delay in the development of internal speech in children with ADHD (e.g., Berk and Potts, 1991).

The theories outlined above have been criticised by Barkley (1998) for lacking a clear understanding of the cognitive processes involved in each of the hypotheses. Barkley attempts to synthesise the suggestions above into his behavioural inhibition model. In this model, Barkley emphasises the importance of behavioural inhibition as the key deficit in ADHD. Behavioural inhibition refers to three connected processes: (1) inhibiting the initial prepotent response to an event; (2) stopping an ongoing response or response pattern, thereby permitting a delay in the decision to respond or continue responding; and (3) protecting this period of delay and the self-directed responses that occur within it from disruption by competing events and responses (Barkley, 1998).

These three processes necessary for behavioural inhibition rely on four components of executive function: (1) non-verbal working memory, which is the capacity to mentally maintain internally represented information in order that it can be used to control a subsequent response; (2) internalisation of speech, which is thought to provide a means for reflection and description, during which the individual covertly labels, describes and

verbally contemplates the nature of an event before responding to it; (3) the self-regulation of affect, motivation and/or arousal, which is the process of becoming aware of one's own emotional responses and using these responses to persist in goal-directed action when no external rewards are available; and (4) reconstitution, which is the process of analysing a behavioural sequence so that it is broken into units, and then synthesising the units to form novel behaviours and sequences of behaviours from previously-learned responses. These four processes are thought to share a common purpose: that of internalising behaviour in order to anticipate future change in the environment. Most importantly, these functions are interactive and interreliant and must act in concert in order to produce normal human self-regulation. Barkley states that these processes probably develop in a phase- or stage-like way during early child development, with non-verbal working memory developing first.

Barkley states that the four executive functions outlined above come to control the actions of the behavioural programming and execution systems across child development, giving behaviour both a more deliberate, reasoned and dispassionate nature and also a more purposive, intentional and future-oriented one. The executive functions produce observable effects on behavioural responding and motor control. In particular, the result of this internal regulation of behaviour is that both sensory and motor behaviour that is unrelated to the goal and its internally represented behavioural structures become minimised and even suppressed during task- or goal-directed activities. ADHD is thought to arise when these executive functions are unable to control behavioural responding because of deficits in the behavioural inhibition system.

Cognitive models of ADHD have been useful for addressing the possible processes involved in the expression of the disorder. However, one criticism of these models is that they do not address all of the factors involved in ADHD. For example, although Barkley links ADHD with behavioural inhibition and executive functions, he does not address why it is that behavioural inhibition is deficient in children with ADHD. Similarly, other cognitive models have suggested different mechanisms to be the central deficit in ADHD, but have not explored how these particular deficits link with biological markers. Further research in this area is clearly needed.

Section Two: Summary

Section Two has presented an overview of the different aetiological models of ADHD. Biological, sociological and psychological explanations have been proposed, each of which has strengths and weaknesses. This section highlights the huge amount of interest in the condition that exists, and the plethora of research this interest has stimulated. However, as discussed in the following section, little is known about how these different conceptualisations are understood by those affected by the disorder.

Section Three: Research into the individual experiences of ADHD

Two studies have focused on the individual perceptions and experiences of parents and children with ADHD. It is not clear why so few studies in this area have been undertaken, although it can be hypothesised that the growing professional, parental and societal anxiety about the condition have led to a pre-occupation with establishing its causes and the most effective forms of treatment. This appears to have led to a

neglect of other important areas for research, including the effect of the condition on those most seriously affected: children with ADHD and their parents.

The two studies in the area to date are those of Kendall (1998, 1999) and Byram (1999). These studies have revealed a number of important issues related to ADHD, and identified a number of areas where further research is required. These studies are described below.

Kendall's (1998) research examined how parents of children with ADHD experienced, adapted and coped with the disorder. She conducted 109 interviews (both individual and family interviews) with 15 mothers and 10 fathers to elicit this information.

Individual interviews focused on what it was like to live with ADHD or with an ADHD family member, and how parents thought their family functioned in relation to the ADHD. Family interviews were also conducted to elicit data on how the family as a unit interacted and shared experiences. These interviews started with each member being asked to describe ADHD in their own words and then to describe what it was like to be in the family.

Using a grounded theory approach, Kendall identified the central experience of these families as 'outlasting disruption'. Families reported that living with a child with ADHD was chaotic, conflictual and exhausting and that the primary task was to survive these difficulties. Many types of disruptive behaviour were identified, including aggression, out-of-control hyperactivity, emotional and social immaturity, academic underachievement and learning problems, family conflicts, negative peer interactions, and isolation and rejection from the extended family. The primary pattern of disruption

involved the ADHD child doing something that required attention, although occasionally other siblings initiated the disruption by mimicking the behaviour. In addition, it was noted that the way in which the family responded to the disruption often exacerbated the problem (e.g., yelling at the child; excusing the behaviour). The primary task for parents became 'just getting through it'.

Kendall also found that regaining control over their lives was an important goal for parents. Parents passed through three processes to achieve this goal before they could engage in the process of 'reinvesting': 'making sense', 'recasting biography' and 'relinquishing the good ending'.

The process of 'making sense' highlighted the importance to parents of differentiating 'normal' behaviour from ADHD-related behaviour. Many parents wanted more definitive information about ADHD, and struggled to understand what was really going on with their child. The process of 'making sense' involved four sub-processes: 'sinking in', 'believing', 'wearing out' and 'transferring responsibility'.

'Sinking in' describes the process of parents noticing that their child was different, seeking medical assistance to understand this difference, and the sense of relief engendered by the diagnosis. 'Believing' describes the sense of sadness experienced by many parents when they received the diagnosis, the rush to find out more about ADHD to ensure that their children would achieve normal developmental goals, and the frustration parents experienced about the lack of understanding of ADHD.

'Wearing out' was characterised by periods when family life seemed to be going smoothly, but was then 'thrown off balance' by a particular incident and feelings of

hopelessness, anxiety and exhaustion followed. 'Transferring responsibility' was a process characterised by parents relinquishing the belief that normalisation was possible, and eventually believing that they needed to step back and let their children take responsibility for themselves.

The process of 'recasting biography' highlighted the way in which parents became more introspective, examining their own sense of self. This process also consisted of four sub-processes: 'remembering', in which parents identified with the struggles experienced by their children, often by remembering times from their own childhood when they were punished or misunderstood; 'grieving', which included sadness about their child's lack of friends, guilt at not being able to do more for their child and having 'caused' their child's difficulties, and concern at the effects the ADHD had on their other children, such as the loss of normal family life; 'individuating' which describes the difficulties mothers felt separating from their sons for fear of their son's vulnerability; and finally 'restoring self' which describes the process whereby, having passed through the above three stages, parents were finally able to feel relatively comfortable with themselves as parents and individuals.

The process of 'relinquishing the good ending' was the process of letting go of the belief that their child would grow up to be 'just like everyone else'. This process consisted of three sub-processes: 'deintegrating stigma', which describes the fact that although many parents felt stigmatised by having a child with a diagnostic label and taking medication, parents who believed in the medical model were able to separate from these stigmatising beliefs; 'gaining perspective' which involved changing old beliefs and being open to looking at things differently; and 'letting go of the anticipated

normal child', which describes the fact that the variability in the children's behaviour, (e.g., children being able to behave 'normally' sometimes), initially caused parents to believe that their children might outgrow their difficulties although over time parents began to realise that this variability was more predictive of continued disruption.

Having passed through these three processes, parents were able engage in the process of reinvesting in their child with ADHD, their families, their other children, their marriages and themselves. Parents decided that it was less important to improve their children's opportunities than to connect with their children as themselves. As children became older, parents were able to recognise their own limits and transfer the majority of the responsibility for their children to the children themselves.

The findings from this study indicate that parenting a child with ADHD is a long and arduous process. Although studies using quantitative methods have shown this to be the case (e.g., Lewis-Abney, 1993), the qualitative approach enabled a full exploration of these difficulties and revealed the depth of parents' despair. These processes contributed to the depth of understanding about the difficulties experienced by families of children with ADHD, and enabled concrete and specific suggestions for clinical intervention to be developed (see Kendall, 1998). The practice within qualitative research of returning to participants with the results of a study, and asking participants to comment on results, provided validation for the findings and ensured they related specifically to the individual experiences of the participants.

Kendall's (1999) study described the experiences of the siblings in the same families.

Kendall again used grounded theory to generate a rich description of these

experiences. The interviews and diary entries of 13 siblings were included in the research (7 boys and 6 girls, with a mean age of 11 years). Diary entries included daily events, highlighting difficult times and times when things seemed to be going well. Analysis of the data revealed three major categories: disruption, the effects of disruption, and managing disruption. Similarities were found between the parental experiences outlined above, and the sibling experiences presented here.

The core category of disruption, caused by the symptoms and behavioural manifestations of ADHD was considered by siblings to be the most significant problem. Siblings described family life as chaotic, conflictual, unpredictable and exhausting, and stated that living with an ADHD child meant never knowing what was coming next. Seven types of disruptive behaviours were identified: hyperactivity, aggression, emotional immaturity, family conflicts, academic and learning difficulties, poor peer relationships and difficulties with extended family relationships. The child with ADHD was consistently considered to be the source of the majority of these disruptions, which were more pronounced in families where the ADHD child was an adolescent, and where the ADHD child used high amounts of aggression.

Disruptive behaviours had three salient effects on siblings: 'victimisation', which describes the experience of being victimised by the ADHD child by acts such as physical violence and verbal aggression, and being victimised by parents who often overlooked their difficulties; 'caretaking' which describes the fact that parents expected siblings to take care of, play with and supervise their ADHD brother, as well as help him with homework, resolve conflicts with neighbours, organise play and stop

their brother from acting impulsively; and ‘sorrow and loss’ which describes siblings’ feelings of anxiety and sadness at not being able to do things ‘like other children’.

Children managed the disruption in two ways: ‘retaliatory aggression’ which describes patterns of aggression from the sibling in response to the child with ADHD; and ‘avoidance and accommodation’ which describes siblings who became resigned to their situations and learnt to either conform to the needs of the child with ADHD, or to avoid the child with ADHD. Kendall also notes that seven of the siblings in her study met DSM-IV criteria for either a depressive or an anxiety disorder, suggesting that the psychological effects of ADHD may be quite profound.

Kendall’s studies therefore revealed that disruption was a core feature of family life for the parents and siblings of children with ADHD. Kendall also revealed ways in which families attempted to manage the disruption, and how parents and siblings tried to adjust to the child’s strengths and difficulties. However, Kendall’s study has a number of limitations. Firstly, the study was undertaken in the United States, and so generalizations to families of children with ADHD in the United Kingdom should be undertaken with caution. Epidemiological studies of ADHD suggest that prevalence rates vary cross-culturally, and prevalence rates in the US are known to be higher than in the UK (e.g., Velez, Johnson & Cohen, 1989). This might indicate that children in the US are simply diagnosed more frequently, or it may indicate that the level of disturbance of children in the US is greater than in the UK. If the latter is correct, this might have implications for whether one would expect similar levels of distress and disruption in UK families.

Secondly, Kendall's study was undertaken with a group of 15 families, all of which were of middle to upper-middle socio-economic status, and 14 of which were Caucasian. All parents were described as being well-educated on ADHD, and all were knowledgeable about the medication and behavioural techniques available to them. In addition, some parents were professionals working with children with the condition, and others were described as 'experts', having themselves run support groups or written articles on ADHD. Whether the experiences of families from different social backgrounds, ethnic groups and with different intellectual ability differ from those described above is open to further study.

Thirdly, although Kendall looked extensively at the experiences of parents and siblings of children with ADHD, she did not undertake individual interviews with the children with ADHD themselves. Little is known, therefore, about the perceptions of the children with ADHD, or the effects of the disruption on children's own psychological development and well-being. From the behavioural descriptions of the children given by parents and siblings, it seems likely that these children will have been profoundly affected by their condition, both in terms of the nature of their relationships with others, and the extent to which they were able to control and regulate their own behaviour. In addition, the fact that parents and siblings perceived the child with ADHD to be the cause of huge family disruption and conflict is likely to have had a negative impact on children's own well-being. If the issue of disruption emerges in other research studies, the impact of this on the child with ADHD certainly requires exploration.

Byram (1999) undertook a similar study in which grounded theory was used to examine children's and parents' experiences of ADHD. Data were collected from interviews with 11 boys and their parents. Byram found that children's core construct was one of behavioural control. This construct was developed from children's reports of the importance for them of controlling their behaviour. Byram described how, prior to diagnosis, children had been described as naughty and, since diagnosis and since taking medication, children no longer felt naughty, although believed that they should be controlling their behaviour more effectively.

This variable of behavioural control was mediated by internal and external mechanisms. In terms of internal mechanisms, some children commented that they were unable to restrain themselves if confronted by another child, indicating a belief that they had a deficit in an internal control mechanism, although other children commented that they had some internal control over behaviour and 'worked together' with their medication to control their behaviour. In terms of external mechanisms, many children attributed complete control of their good behaviour to their medication, although occasionally these children could ignore the positive effects of their medication and continue with the naughty behaviour. These children also commented that other children attributed control of their good behaviour to their medication.

Byram also found that children used a number of strategies to enable them to manage their behaviour. These included avoiding certain situations, trying to work hard in class, and using relaxation techniques, such as guided imagery. Children reported that these strategies, along with the use of medication, had a beneficial effect on their behaviour by making them calmer.

In terms of the adult interviews, Byram identified the core construct as ‘explanation seeking’. Two factors contributed to the process of explanation seeking: the perception of having a difficult child, and parental feelings of inadequacy. In terms of the former, many of the children in Byram’s sample were perceived as having been difficult to manage from birth, both because they needed a great deal of parental supervision, and because they were generally non-compliant and aggressive. Parental feelings of inadequacy arose as the result of these difficulties and as parents came to realize that their management strategies were ineffective. These two processes led parents to attribute responsibility for their child’s behaviour to themselves, although they also believed that teachers were not managing their children effectively, and that there could be a medical explanation for their sons’ behaviour. The resulting ADHD diagnoses enabled parents to feel more competent about their parenting skills, and many commented that the diagnosis had changed the way they understood their sons’ behaviour, and subsequently the quality of their relationship with their sons improved. Byram also found, prior to diagnosis, that some parents had experienced feelings of blame from professionals for their sons’ difficulties, but that this feeling dissipated once the diagnosis of ADHD had been made.

As with Kendall’s study, Byram’s study has a number of limitations. Firstly, although Byram’s study examined children’s experiences of ADHD, it is felt that some of the issues revealed could have been discussed further. For example, the issue of behavioural control could have been elaborated upon by, for instance, exploring the reasons for children’s need for control, and issues around why children felt unable to control their behaviour. Similarly, the effects of being labelled ‘naughty’ and the

reasons behind why children no longer felt naughty after their diagnoses were not fully addressed.

Secondly, a number of issues emerged from the adult interviews which could also have been explored further. For example, Byram briefly reported that parents experienced blame from professionals for their children having ADHD, which apparently dissipated after the diagnosis of ADHD was made. Anecdotal clinical evidence suggests that blame may be an important experience for parents of children with ADHD, and so it is suggested here that this issue of blame could have been explored further. For example, the mechanisms through which blame arises, in which contexts blame occurs, and what effects blame has could usefully be discussed. Similarly, understanding how parents make sense of blame and manage blame would be useful for thinking about how to help others parents who are also feeling blamed. The experience of blame in ADHD is an area of particular interest to clinicians, particularly as the diagnosis is made with some degree of subjectivity, and is of interest to this researcher. If blame emerges as an issue in this study, these types of questions will be addressed.

Thirdly, Byram's study involved a relatively small sample of children and so findings should be extrapolated with caution. In addition, the experiences of children this age (7-8 years) may differ from children of other ages or developmental stages. Further research with a different group of children, and with children of different ages will be useful for assessing how far the findings from this particular study can be generalized to other children with ADHD.

Summary and Rationale for present study

Taken together, the studies of Kendall and Byram have explored some of the important issues central to the experiences of children with ADHD, their parents and their siblings. The findings from these studies indicate the difficulties of living with a child with ADHD. These include the disruption to family life caused by the ADHD and the desire to seek explanations for the disruption. These studies have also differed from those outlined in previous sections because they have shown how qualitative methodology can be used both to derive rich descriptions of the lives of those affected by ADHD, and to reveal important issues which have yet to be researched.

However, the studies also indicate a number of areas in which further research is required. For example, the impact of the many different conceptualisations of ADHD outlined in Section Two has yet to be explored, and may be important for understanding how parents and children adjust to, and make sense of, the disorder. Similarly, development of some of the themes outlined in these studies, such as blame, is necessary for a more detailed understanding of the experiences of these children and their parents. Finally, studies of children of different ages and families of different demographic characteristics will be useful for assessing the generalisability of the findings outlined above. Further research may also reveal previously unidentified issues of importance.

There are four clear aims to the current research project:

- To assess whether the findings from the two qualitative studies in the area can be generalized to other groups of parents and children, who may differ in terms of age, socio-economic status and geographical location
- To assess whether the experiences described in the previous two studies can be elaborated upon, developed and clarified
- To assess whether other, previously unidentified, experiences emerge as important for other children with ADHD and their parents
- To contribute to the growing body of knowledge about the everyday experiences of children with ADHD and their parents.

In order to achieve these aims, a number of specific research questions have been developed.

(1) What are the everyday experiences of children with ADHD and their parents?

Do the issues of disruption, behavioural control and explanation-seeking occur in other families affected by the condition and, if so, how do other parents and children manage these difficulties? How do parents make sense of the different conceptualizations of ADHD?

(2) Do previously unidentified issues emerge as important for other families? For

example, is blame a key issue for parents of children with ADHD and, if so, how does this arise, what form does it take and what effect does this have on children and parents?

(3) What are the clinical implications of these issues for working with families

affected by ADHD?

Chapter Two

Method

Overview

This chapter focuses on the methodological issues involved in the study, including (1) the way in which participants were recruited to the study; (2) how data were collected, transcribed and analysed, and (3) the importance of considering a number of practical, ethical and moral issues particularly when interviewing children.

Recruitment

Access to the database of children given a diagnosis of ADHD within the past two years was obtained from the Child Development Centre (CDC) in Luton, Bedfordshire, with permission from the Head of the Community Paediatric Service. Because of the large number of children on the database (n=270), families were selected if they met the following criteria: (1) the child with ADHD was male; (2) the child with ADHD was aged between nine and eleven years; and (3) the family of the child lived in Dunstable. These criteria were selected because of the high incidence of boys with ADHD, and the likelihood that between the ages of nine and eleven the difficulties of managing ADHD would be most apparent. In addition, families living in Dunstable were selected for ease of access to the interview site.

Families were sent a letter inviting them to participate in the study (see Appendix I). Letters included a covering note from the Community Paediatrician, explaining that their names had been obtained from the database held at the CDC (see Appendix II). Letters presented a brief outline of the study's aims, and how families would

participate. Parents were asked to complete a response slip, stating whether or not they would be interested in finding out about the study. Stamped addressed envelopes were provided.

Response Rates

Of the initial batch of ten letters, a response was received from three families, all of whom were interested in participating in the study. A month later, a letter was sent to the remaining seven families, reminding them of the study (see Appendix III). From this second batch of letters, three replies were received and of these, two families were interested in participating. A second batch of ten letters was sent four months later. From these letters, four families responded that they were interested in participating in the study.

Following confirmation of interest, families were contacted by telephone and the study aims were outlined again. All parents agreed to attend an initial meeting, at which they were asked to complete a consent form (see Appendix IV) and had the opportunity to ask questions. At this meeting, arrangements for the research interviews were made. All meetings were held at the Child and Family Consultation Clinic in Dunstable. All families consented to the study.

Participant details

A total of nine mothers, one father and nine boys sons (total $n = 19$) were interviewed. One child refused an individual interview, but made comments about ADHD during his mother's interview which were later included in the data analysis (child 8). The mean age of the mothers was 36 years (range 29 to 40 years). Parents' occupational class

was classified using the Standard Occupational Classification (Office of Population Census and Surveys, 2000), as follows: I Managers and Senior Officials (0%); II Professional Occupations (20%); III Associate Professional and Technical Occupations (10%); IV Administrative and Secretarial Occupations (10%); V Skilled Trades Occupations (0%); VI Personal Service Occupations (30%); VII Sales and Customer Service Occupations (30%).

The mean age of the boys was nine years nine months (range eight years nine months to eleven years seven months). All children met ICD-10 criteria for Hyperkinetic disorder (equivalent to DSM-IV criteria for ADHD). Eight children were in local mainstream education, one child attended a Special School. Three children had a Statement of Special Educational Needs. In addition to their ADHD diagnosis, one boy had an additional diagnosis of Asperger's syndrome, and two boys had additional diagnoses of both Asperger's syndrome and dyspraxia. Two boys were also described by their parents as having mild learning difficulties.

Data collection

Individual, semi-structured interviews were held with each parent and child from July 2000 to March 2001. Interviews ranged in duration from 30 to 90 minutes.

Participants were asked to wear a clip-on microphone and each interview was recorded by audiotape. All interviews were transcribed verbatim by the researcher. The structure of the interviews followed an open format, in which themes raised by the participants were picked up on by the researcher and explored further. A semi-structured interview schedule was developed prior to interviews, and can be viewed in Appendix V.

Prior to data collection, guidelines relating to interviewing children (e.g., Lewis and Lindsay, 2000) were considered. These guidelines address a number of important practical, ethical and moral issues, such as (1) how to ensure that children do not feel pressurised from parents or researchers to participate in research studies; (2) how to ensure that children fully understand their role in a research study; (3) how to alleviate anxiety relating to the interview process; and (4) how to minimise the effects of any developmental difficulties (e.g., cognitive, linguistic, social or behavioural difficulties) the child may have. Lewis and Lindsay highlight the need to give full consideration to these issues in order to ensure informed consent, and the fact that such consideration will also enhance the amount of information given by the children, and increase the reliability of this information.

The child interviews were conducted with these considerations in mind. A simplified explanation of the research was provided through an information sheet (see Appendix VI). Children were also provided with a verbal explanation of the study, and were told clearly that they did not have to answer any questions or participate in the study if they did not wish to do so. Children were then asked whether there was anything about the study that they did not understand, and whether they had any questions about the study. All children felt that they knew enough information to participate in the study and were willing to do so.

The importance of building rapport with children in order to put them at ease and hence facilitate more open communication was acknowledged, and children's interviews began with some 'getting to know you' questions. Other attempts to reduce anxiety included asking children if they would like their parents to stay with them in

the interview room, allowing children a break in the interview if they wished to see their parent, and ensuring that the interview room was child-friendly (e.g., that toys were available).

In terms of difficulties with concentration and attention, children were asked during the interview whether they would like a break, and they had opportunities to play with the toys in the room and have a drink. Parents were asked whether they felt it would be better to interview the child on two occasions, although no parent felt this would be necessary. In addition, the researcher observed the child throughout the interview for verbal and non-verbal signs that the child was becoming bored, tired, distressed or uncomfortable, and responded to such signs by asking the child if they would like to

stop the interview, take a break or change the topic of conversation.

In terms of addressing the issue of interviewing children with social or learning

difficulties, where possible simplified language was used, and children's understanding of various questions was verified by phrasing the question in a different way, or by returning to it later during the interview. Particular attention was paid to the difficulties children with a dual diagnosis of ADHD and Asperger's syndrome might have answering questions about feelings and emotions (Attwood, 1998). Creative ways of eliciting information from children (such as making up stories) were used when it was felt the child was finding it difficult to talk about their experiences.

Three other important ethical issues were addressed. These were (1) the possibility that children would be uncomfortable or saddened by talking about the negative aspects of ADHD; (2) how to respond to families who were either in need of professional help in

managing their child with ADHD, or who specifically requested help from the researcher; and (3) the issue of confidentiality, and specifically how to respond if children made allegations of (or reference to) abuse or neglect.

It was decided that, if a child became upset during an interview, he would be encouraged to share his upset with his parents. This process would be facilitated by the researcher and the child would be encouraged to do so whilst still at the Child and Family Consultation Clinic, and in the presence of the interviewer if the child requested. If necessary, the interviewer could then think with the parents about how best to help the child resolve the difficulty (e.g., by suggesting that parents contact the child's school). The need for this provision did not arise.

For families who seemed to have particular difficulties coping with the ADHD symptoms, it was decided that the interviewer would suggest to the parents that they ask their GP for a referral to the Child and Family Consultation Service, and that this would also be suggested if parents asked for specific advice. This situation arose in four of the families interviewed, and each was recommended to ask their GP for a referral to Child and Family. Two of these families were already on the waiting list for Child and Family services.

In terms of confidentiality, and the issue of children making reference to abuse or neglect, it was decided that children would be told at the start of the interview that the content of the interview was confidential, unless something discussed caused the researcher to be seriously concerned for the child's welfare, in which case the researcher would have to discuss the concern with a colleague, although she would not

do so without informing the child first. None of the children in the study made comments which gave rise to concern.

The importance of avoiding acquiescence in children, and the issue of the power imbalance in the researcher-child relationship were also considered. Open-ended questions were felt to be an important means of avoiding acquiescence, and the power imbalance was addressed by ensuring that children felt comfortable in the surroundings, felt able to refuse to answer questions they were uncomfortable with, and ask questions about the research.

Ethical Approval

Ethical approval was obtained from the South Bedfordshire Local Research Ethics Committee (see Appendix VII).

Analysis of data

The transcripts were analysed using a grounded theory approach (Strauss and Corbin, 1998b). Grounded theory is a method of qualitative data analysis, which is based on a phenomenological approach to understanding human experience. This means that it highlights the importance of subjective perceptions, perspectives and assumptions, and aims to use individual reports to generate new theories and ways of understanding phenomena. Grounded theory aims to develop new theories by understanding the meaning people hold in relation to specific events or experiences. The emphasis is therefore placed on the participants' own accounts of social and psychological events which are used to develop theories around particular issues (Pidgeon, 1996).

Alongside grounded theory, a number of different types of qualitative research exist, including Interpretative Phenomenological Analysis (IPA, Smith, 1995). IPA is based on the same philosophical foundations (i.e., phenomenology) as grounded theory and hence highlights the importance of understanding meaning and examining individual experiences, attitudes and assumptions in depth. However, there are a small number of subtle differences between the two approaches.

Firstly, IPA highlights the importance of the researcher's own assumptions and perspectives in influencing the collection and interpretation of data, suggesting that the researcher's own attitudes and assumptions will invariably impact on the research process, and that this can be used to usefully guide the themes and categories developed. Researchers are therefore encouraged to be reflexive in the research process, and use their own knowledge and perceptions about a certain phenomenon to guide their data collection and analysis. Grounded theorists also highlight the importance of the researcher acknowledging his or her own perspective, but suggest that it is possible and preferable to 'bracket' or 'put to one side' their own assumptions and beliefs, so that the theory developed is based solely on the reports of the participants and is not clouded by their own beliefs about a phenomenon. Grounded theory therefore highlights the necessity of grounding the emerging theory in data (i.e., giving specific examples), and ensuring that these examples have not been overtly influenced by the researcher's own beliefs or assumptions. Although practitioners using grounded theory acknowledge that this is sometimes difficult to achieve, and that invariably their own experiences will impact on the area of study to some extent, in general there is an attempt to act as a 'tabula rasa' and to ensure that any theory

developed emerges from the participant's accounts of the phenomena, rather than the interaction of researcher and participant.

Secondly, and perhaps as a result of this difference, IPA does not attempt to create a new theory about a particular phenomenon, instead suggesting that although new understandings pertaining to certain issues emerge through research, the small number of participants and the reflexive process between researcher and participant mean that it is not possible to make an objective statement about the presence of a new 'theory'. Grounded theory, however, argues that it is possible to make a theory from individual accounts, providing that the theory is grounded in examples (i.e., verbatim reports given by participants), and that the researcher has been able to successfully 'bracket' his or her experiences.

Grounded theory was chosen as a method of data analysis for this piece of research. There are a number of reasons why the researcher chose grounded theory over IPA, and these include (1) the fact that the two previous qualitative studies in the area had used grounded theory indicated that this method lent itself well to the study of ADHD; (2) the researcher felt that the approach of starting the interviews as a 'tabula rasa', and attempting to 'bracket' her own assumptions would enable her to be more objective when listening to the interviews; and (3) the belief held by the researcher that to generate a theory from participants' responses would be more meaningful for the participants and indeed more clinically useful.

As with IPA, grounded theory provides clear guidelines for data analysis, which is undertaken in three clear stages: open coding, axial coding, and final

conceptualization. This process is detailed below, along with Elliott et al's (1999) guidelines for good practice in qualitative research, which were used to ensure the reliability and validity of the data.

Stage one: labelling/open coding

The process of data analysis starts with 'open coding'. This is the line-by-line labelling of the text with a word, concept or category used to describe the main theme or content of each line. These labels can simply be a repeat of a word used by the participant (e.g., participant talks about her 'nightmare' experience in labour, which is coded as 'nightmare'), or can be a brief description of what the participant is referring to (e.g., participant comment of 'I never really noticed' is coded as 'not noticing'). As recommended by Strauss and Corbin, the labels used by the coder resembled those of the participant as closely as possible.

As the number of labels increases, labels that appear to represent the same issue are categorised together. Often, these categories are clearly identifiable by the particular word or description used in the labelling process. For example, many participants talked about how difficult their child's behaviour was to manage, using words such as nightmare and horrendous, and so the category of 'nightmare experience' emerged. As the number of participants increases, and the number of categories rises, consideration is given to underlying concepts that emerge across participants. This process searches for the more abstract meaning to the concept, and this abstract meaning is reflected in the concept's name. For example, the category of 'nightmare experience' was conceptualised as a process of constant disruption.

Stage two: axial coding

The process of axial coding involves relating the categories developed in the open coding stage to sub-categories, such as looking for different manifestations of the category and considering how these manifestations can be understood in relation to sub-categories, such as home environment. For example, one of the key variables that emerged from the adult interviews was 'disruption'. This variable was further sub-categorised into the types of disruption, the effects of disruption (on home life, school life and the relationship that mothers had with their husbands and other children), and ways of managing the disruption.

Stage three: final conceptualisation

The final conceptualisation requires that the axial codes and their derivatives are linked in such a way that a core category, or categories emerge. Much of the variation in the behaviour described in the interviews should be explained by these core categories (Benton, 1992). A number of criteria have been identified to determine whether a category should be considered a core category: (1) the category should be central to the theory; (2) the category should account for a large percentage of variation in behaviour; (3) the category should appear frequently in the data; (4) the category should be clearly related to the majority of other categories; and (5) the core category should have clear implications for more general theories (Strauss, 1987). In this study, three core categories for both adults and children emerged, and an additional core category for adults alone emerged. Most of the interview material presented was included under one of these category headings.

Stage four: Guidelines of good practice in qualitative research

The final stage of the process of qualitative analysis is to ensure that the previous processes have been undertaken in ways that ensure the reliability and validity of the data. Elliott et al. (1999) have produced a number of guidelines for best practice in qualitative research, as outlined below. Further discussion of these issues can be found in chapter four.

Firstly, Elliott et al. recommend that the researcher should state his or her own interests and assumptions about a subject matter before attempting to analyse any data. This process is described as ‘owning one’s perspective’, and is important for establishing whether the values of the researcher have influenced the description and labelling of the categories identified or the theory developed

Secondly, Elliott et al. suggest that the researcher ‘situates the sample’. This refers to the importance of describing the research participants and their life circumstances so that it is possible to assess how far the findings from one study can be extrapolated to other populations and situations. This process is often undertaken by collecting general demographic information about the children and families involved in a study, and also more specific information relating to the subject matter (e.g., whether children with a diagnosis of ADHD are currently taking medication).

Thirdly, Elliott et al. highlight the importance of grounding the emerging theory in examples. This process ensures that the existing theory has been developed from the participants’ accounts of their experiences, rather than simply being the ideas of the researcher. These examples may include quotes relating to different concepts and

categories from the open or axial stages of coding, as well as examples of the final theory (see chapter three for quotes relating to the theory developed).

Fourthly, Elliott et al. suggest that credibility checks are undertaken. This refers to the process of checking the data to ensure that the categories yielded and the theory developed resemble the experiences of the participants. This can be achieved by having multiple people analyse the data.

Fifthly, Elliott et al. highlight the importance of 'coherence'. By this, they are referring to the importance of the data fitting together into an integrated theory, rather than simply being a list of concepts or categories. They suggest that this process is aided by the use of diagrams with feedback loops depicting relationships among categories. The process of moving from individual categories and themes to an integrated theory is outlined in chapter three.

Finally, the ultimate credibility check is undertaken by assessing whether the data resonate with the readers of the theory. This means that both readers and reviewers should feel that the theories described reflect their own experience of the subject matter (for example, of working with families of children with ADHD). Theories which describe very different experiences to those of the readers and reviewers, are likely to be questioned for their reliability.

Summary

This chapter has presented information about both the recruitment of participants to the study and the ways in which the data were collected and analysed, as well as the

practical and ethical issues relating to interviewing children. The following chapter outlines the results of the grounded theory analysis.

Chapter Three

Results

Overview

This study examined the everyday experiences of children with ADHD and their parents. This chapter describes these experiences by outlining the themes extracted from the interviews, and the theoretical model that has developed as a result. The grounded theory analysis of both parents' and children's reports led to the development of four core categories: Difference, Blame, Battles and Adjusting.

Central to the theory developed was the category of Battles, which described the many different ways in which children with ADHD and their parents struggled with everyday life. Some of these battles involved other people, and have been described as external, whilst others involved a psychological dilemma, and have been described as internal. These battles were linked with the two categories of difference and blame. Parents described many ways in which they perceived their sons to be different, and discussed how these differences led to many confrontations and arguments occurring between them, their sons and others involved in their sons' lives. Children described how their differences led them into emotional and physical battles with other children. Parents also discussed how they felt blamed for the difficulties their sons were experiencing, and how this blame often resulted in battles occurring between themselves and others. The final category, Adjusting, describes how parents and children attempted to adapt to these battles.

The theoretical issue central to each of these categories is the issue of how ADHD is understood and conceptualised. It is clear from the descriptions given by parents, and the model into which these descriptions have been developed, that parents and children understood ADHD to be a biological or medical disorder. However, parents also considered that professionals, family members and the general public thought that ADHD was caused by environmental and parenting factors. These differences in conceptualisation of ADHD clearly link together the four core categories by having a direct impact on the battles that parents and children experienced, and through their influences on parents' and children's perceptions of difference and experience of blame. The different theoretical models outlined in the introduction have therefore emerged as important factors influencing the experiences of children affected by the disorder and their parents.

A detailed description of the emergence of this understanding is presented below.

Examples are drawn from the data to illustrate the four categories. Throughout this description, links with the underlying theoretical framework of understanding ADHD will be made. Direct quotes from specific participants are referred to by identification codes (e.g., (3) for participant 3; where an (a) is added to the code, a child's comment is indicated).

Category One: Difference

‘He was trouble from day one’ (3)

The first category to emerge from the data was the category of difference. This category described the sense of difference that all parents had about their children, as well as the sense children had of themselves as being different. This category was made up of three components. The first component describes the ways in which parents viewed their children as different, and includes descriptions such as the child being disorganised and delayed, and their behaviour being disruptive and dangerous. The second component describes children’s views of themselves as different, and includes beliefs about themselves as being silly and annoying. This component also describes the effects these beliefs have on children’s psychological well-being. The third component describes how parents came to notice that their children were different. For some parents this occurred on ‘day one’; for others the differences were not noticed by parents until someone else pointed them out. Implicit in each of these components is that these differences evoked tension and frustration in parents and children, and created many episodes of disagreement and distress. In addition, these perceptions of difference highlight the dominance of mothers’ views that these differences represented a biological disorder present in their sons from early infancy, and indeed suggest that this view is also held by the children themselves.

Parents’ experience of difference

Parents described a number of ways in which they viewed their sons as different, including descriptions of their sons as delayed, disorganised, disruptive and dangerous. These descriptions indicated that parents had concerns both about their children’s

behaviour and their children's general development. Parents also discussed their concerns about the effects of these differences, in particular the impact these differences might have on their sons' futures.

Delayed

Parents described a number of behaviours that suggested their sons were delayed. These included soiling and wetting, indicative of a developmental delay; and frequent crying and attention seeking, indicative of social or emotional delay. Although social and emotional difficulties are common in children with ADHD, wetting and soiling are not. However, these children also had additional diagnoses of Asperger's syndrome, which might account for this difficulty more readily than a diagnosis of ADHD *per se*.

Two children in the study were described as frequently wetting or soiling themselves, both at home and school. One mother described how this behaviour occurred in cycles, whereby the child had a period of being dry, followed by a period of being wet and soiled, each lasting approximately one month. This mother attributed this cycle to stress. The second parent, however, did not link the wetting and soiling with specific times, although she commented that her child was often incontinent at night, when he suffered with severe nightmares. For these two parents, an additional difficulty arose when they tried to ensure their sons were clean. Often the two boys would refuse to have a bath, and even if they did so they were often unable to wash themselves properly.

'He tends to soil himself or he'll wet his bed but he won't tell me. He can't wash himself even though he's nearly ten and he soils in the bath' (7)

Parents also had to cope with their children being deeply ashamed of their actions, which often meant that they tried to hide soiled sheets or clothes. Parents would then need to hunt around their children's rooms for soiled clothes and sheets. An additional difficulty was that the two children were often too ashamed or embarrassed to tell anyone at school. This meant that they occasionally came home from school very soiled.

'He'll hide his pants or pyjamas in the night, or he'll wet his bed but he won't tell me. If he tells me I can sort him out but he hides things' (7)

Both of the parents affected by this problem had sought medical advice. This clearly indicated that mothers believed there to be some innate biological or medical reason for their sons' delay. However, both mothers were told that there was no biological reason for these difficulties, and that the wetting and soiling was the result of emotional problems. It was suggested that mothers punish their children in order to reduce the likelihood of the behaviour reoccurring. Neither of the two mothers accepted this suggestion, both instead believing that this difficulty was part of their sons' Asperger's diagnosis.

Although parents did not explicitly say so, it was felt that one mother was also ashamed of her sons' difficulties. This mother described her son as looking like a 'nerd' when he ran into the school gates at the start of the day.

'I would have tears nearly every day because the way he used to run was so uncoordinated he would come into that 'nerd' category' (7)

These developmental delays prompted some parents to claim Disability Living Allowance. All of the parents in the study were entitled to this money (between £100-£200 per month) and to additional services. Parents had mixed views about the legitimacy of them claiming these benefits, however. Some felt that their difficulties did not justify claiming the money and so did not do so. Other parents claimed the money, but experienced guilt about doing so because they felt that they did not really deserve it.

‘As a carer you can get £100-£200 a month but we think that’s not right. All right we might wash more clothes for him than the other kids but apart from that it doesn’t cost us money’ (6)

‘The money helps but I felt awful when I got it’ (2)

Disorganised

Many parents also described their sons as disorganised. This disorganisation was particularly evident when parents were trying to get their children ready for school. The children in the sample were often reluctant to switch off the television in the morning, and then tried to get ready for school in a haphazard fashion. Parents reported that children would often find that they had left clothing at school (e.g., shoes) or that they had lost clothing that they needed for the day (e.g., PE clothes). In addition, parents would often be presented with torn clothes or missing buttons shortly before leaving the house. Children also needed reminding to wash themselves and clean their teeth. This disorganisation led to last-minute battles to get ready for school and be out of the house on time. Some children never appeared to be fully ready for school,

and even as they were getting into the car would run back into the house to collect something.

‘He’s got no organisation whatsoever. It’s 8.15 and he’s still sitting in his pyjamas in front of the telly, and then he might remember that he’s ripped his trousers five minutes before he goes to school. (2)

‘When it’s time to go to school he disappears ’cos he wants to get something to take to school with him. He’s been up for an hour and should have done it ages ago, but he leaves it to the last minute when everyone is waiting’ (6)

‘No matter how early he’s up we’d be late for school’ (7)

On returning home from school, the children in the sample also had difficulty remembering to put clothes in the wash basket, and would often leave their clothes in a pile on the floor. They would often leave homework books at school or had forgotten to write down what homework they had. Although some of these behaviours might be considered ‘typical’ for most children of this age, the parents in this study considered their sons to be more impaired in these areas than their other children at this age.

‘He’s just got his head in the clouds, he doesn’t put his clothes in the linen bin and the reminder is there constantly’ (1)

‘He brings home homework and you say ‘what have you got to do’ and he says ‘I dunno’ (4)

This disorganisation was also clear when parents and children went out socially.

Parents reported that holidays were particularly difficult because the children would be bombarded with new and exciting information and activities, which made it very difficult for them to concentrate on one thing at a time. Parents reported that often children would get lost on the beach or at adventure playgrounds, because they were not listening or attending to parents' instructions.

'We went to Euro Disney and I swore I would never ever take them anywhere again 'cos we spent the whole day looking for him' (2)

'We went bowling and he kept disappearing' (5)

Interestingly, although parents reported that holidays and activities were difficult because of their child's disorganisation, many parents also commented that their children were much calmer on holiday. It seems that the dangerous and disruptive behaviours outlined below dissipated to a great extent, and children were more relaxed. Parents attributed this change in behaviour to the fact that children had more stimulation on holidays, suggesting that they were drawing on the biological theory of ADHD which suggests that the disorder is due to under-arousal of certain neurotransmitters.

'They spend the two weeks in the water and they are an absolute pleasure, absolutely great 'cos they've done all that they wanted to' (2)

Disruptive

Parents also described their children as disruptive. Parents reported that children often argued and fought with their siblings, interrupted parents and adult conversations and were perceived as disruptive in school by teachers. Parents also felt that their children's behaviour had a disruptive impact on their own marital relationship. These descriptions highlight the pervasive nature of the boys' difficulties, and the impact these difficulties had on all areas of the boys' lives.

Relationships between children with ADHD and their siblings were often difficult. Parents perceived their ADHD child to be the cause of these difficulties, as they would often attempt to disrupt their siblings' games and to interfere when siblings had friends to play. The cause of this difficulty was considered to be a lack of social understanding, and this was not limited to children with dual diagnoses. The effect of this disruption on siblings was also experienced at school, when siblings often became involved in their brother's fights or the bullying that occurred. Sibling relationships were therefore relatively split, between those siblings who constantly argued with each other, and those who looked after one another.

'They constantly wind each other up, arguments and fights non stop' (2)

'S [brother] is having to look after him and say "look, that's my brother" and he just says he hasn't got any friends and he's finding it very hard' (1)

The children with ADHD were also considered to have a disruptive impact on parents' relationships with friends. Many parents commented that they had lost friends who could not cope with their sons' behaviour. Some parents were unconcerned by this,

and had made new friends with parents of other children with ADHD. However, other parents resented losing friends, and wished that friends had been more tolerant. One mother reported being ostracised by other mothers at her sons' school because of the reputation her son had gained as a troublemaker.

'I don't even bother trying to explain to people. I just think you either accept us or you don't' (2)

'My friends have stopped coming round because S is literally sitting on their heads and jumping on the settee or if they've got drinks in their hand, they haven't got drinks for long, so we have lost quite a few friends' (8)

Parents also reported that their children's behaviour had a disruptive impact on their close relationships. Many parents felt that the disruption affected the quality of their marital relationships, as well as their relationships with family members. Although most parents in the sample were married, mothers talked about fears that their marriages would not survive the disruption. This fear had become a reality for two mothers, who linked the disruption with their marital separations. Some mothers specifically told their sons about the effect their disruptive behaviour was having on their relationships, in order to try to encourage their sons to improve their behaviour.

'We were always at loggerheads over how we should deal with the problem'
(9)

'A [husband] left us last summer because the stress on the family is so bad' (7)

‘S [child with ADHD] knew that he was putting a toll on our marriage because we were arguing all the time’ (8)

Parents also reported that their sons’ teachers considered their sons to be disruptive during school time. Parents stated that teachers complained that their children could not sit still in class and attend to lessons, and instead would often wander around the room and interrupt other children. The children were also reported to do ‘silly’ things during lessons, such as acting out and playing the fool. Parents reported that there were a number of similar children in their sons’ classes, and that the disruption in the classroom was not simply the result of their sons’ behaviour, as teachers perceived it to be. Parents also discussed the impact of this disruptive behaviour on their sons’ learning.

‘School finds him a problem. He’s disruptive. He can’t sit still. His teacher tries hard with him but there’s another four children in the class in the same situation. He can’t concentrate, so no concentration, no learning’ (2)

‘He didn’t know how to behave in a classroom. If he knew an answer he would just call it out, he monopolised the group and if children didn’t listen to him he would just down talk everyone else’ (4)

These reports of children being disruptive suggest that parents and teachers understand the child’s behaviour in different ways. For example, parents seemed to be more tolerant of the behaviour and appeared to feel that they are unable to change it. Parents

reported that teachers also witnessed the disruption, but had different expectations of the child, believing that the child could change and behave in a less disruptive way.

Dangerous

Finally, parents described many aspects of their sons' behaviour as dangerous.

Dangerous behaviours included leaving the house alone at night, running along the roof tops of houses, climbing into electricity boxes, hanging out of windows, playing with knives and setting fire to furniture. These dangerous behaviours were frightening for parents to witness, and resulted in many parents worrying about whether their sons would turn to crime or delinquency in the future. Some wondered how their sons were still alive, whilst others feared that their sons were on a road to delinquency that would ultimately lead to something more catastrophic.

‘We’ve found them in the most dangerous situations, like at home we’ve got some flats and they are up on the roof tiles belting it along’ (2)

‘One day they found him trying to climb through the skylight at school. He does the most dangerous things. He climbed into an electricity box with 1000 volts. How he is alive today is beyond me’ (10)

The fear engendered by these behaviours led many parents to believe that they could not let their children out of their sight. In addition, parents attempted to make their houses as safe as possible for their children, indicating a belief that children were unable to control this behaviour.

‘You don’t know what he’s doing so I don’t leave him alone. I’ve removed all the dangers downstairs’ (10)

Concern about difference

Having discussed the ways in which parents considered their sons to be different, parents went on to detail their concerns about the impact of these differences, with particular reference made to concerns for the future. One mother feared that her son would not be able to live independently, although this concern may reflect the additional learning difficulties experienced by her son rather than a concern about ADHD *per se*. Some parents worried about whether their sons would be able to gain employment and, if so, what type of employment. For parents with higher academic qualifications, a particular concern was whether their children would be able to obtain employment that reflected their intellectual ability. Parents also worried that their sons would drop out of school early and turn to crime or delinquency. This fear seemed to have arisen from talking to other parents at support groups, and from reading the literature on ADHD. Regardless of the nature of the concern, all parents predicted that their sons would continue to suffer from difficulties regulating and controlling their behaviour.

‘I don’t know how the hell he’ll cope in the future. It worries me’ (1)

‘It’s a worry ’cos they are the sort of children that are led’ (2)

Children's experiences of difference

Children outlined a number of ways in which they felt themselves to be different. These reports were particularly interesting because two children explicitly stated that they considered themselves to have an innate biological condition, which they felt caused them to behave in ways that were different from others. Many children reported that they were bullied because of these differences.

In terms of behaviour, children identified a number of behaviours which they felt made them different. Children described themselves as silly, annoying and naughty, as well as having too much energy. Some of the comments made about their behaviours seemed to be linked with adults' perceptions of their difference. For example, one boy stated that he 'got out of hand', indicating that he defined his difference in terms of those who were looking after him.

'Sometimes I have a bit too much energy' (5)

'I annoy my brother and sister' (8)

In addition to the behavioural descriptions, two children described their difficulties in terms of neurology. Both of these children had additional diagnoses of Asperger's syndrome, and so their understanding of their difference might reflect the organic nature of this condition. One child stated that he had a friend with ADHD who had brain damage, and that this made him do 'annoying things', such as speaking in a high-pitched tone. The other child discussed the link between the behavioural symptoms of ADHD and the frontal lobes of the brain.

‘People have brain damage and they can say “what are you doing?” [speaks in whiny voice] like that. A boy down my road he’s always doing it and it’s annoying’ (1a)

‘The bits connected to the frontal lobes are not developed. There’s one boy and he’s got ADHD and he shouts when you can just talk normally and he carries on talking about things. He’s sort of got more ADHD [than me]’ (4a)

Interestingly, it emerged during the course of the interviews that these two children were referring to each other. Rather than thinking about their own differences, these children seemed to be comparing themselves with one another. Both boys appeared to experience each other as more impaired, which might reflect their own difficulties in accepting their difference.

Effects of being different

Many children also discussed how their differences affected them. For some children, being different meant that they did not have any friends, which resulted in them feeling lonely and miserable. Other children were physically and emotionally bullied because they were different. Name-calling and physical attacks were a common occurrence for some of these children, and these were sometimes so severe that the child had to be removed from school. Children therefore fought physical and emotional battles because of their difference. Presented below is a summary of the effects of bullying as they relate specifically to the child being different. Parents’ comments are also included.

Two children reported that they felt lonely because they were different. One child reported that he had no friends and so nobody to pair up with for group work and teamwork. When asked why he thought he did not have any friends, he stated that it was because he was not good at physical activities, and because he was clever. This boy's mother, however, stated that he was not popular because he was often wet and soiled at school. The second child stated that for some time he had felt lonely at school because he had been the only child with ADHD. This loneliness dissipated, however, when another child with a diagnosis of ADHD joined this boy at his school.

‘Whenever we do group things at school no one wants to be with me’ (4a)

‘There’s this other boy and he has ADD and I felt like I wasn’t alone now, like I had a friend; ’cos before I was the only one in the school who had ADD and I was lonely’ (3a)

Many children talked about name-calling, verbal taunts and being teased. The verbal bullying occurred frequently, with children being called a variety of names, some of which were clearly linked with biological conceptualizations of disorders, such as being ‘mental’. Children were also bullied because they took tablets.

‘At my other school I just used to get beaten up. They were saying “ha ha you’ve got to go to a mental school”, just being horrible’ (3a)

‘Everyone keeps on calling me names like mental, lunatic, crazy or unstoppable’ (3a)

‘They keep calling me peanut brain’ (10a)

Physical bullying was also common.

‘He got me by the jaw and turned my head right round and it was hurting’ (3a)

Parents validated the link between being different and being bullied by highlighting bullying that occurred because of the developmental delays experienced by their children, and also bullying that occurred because of their children’s learning difficulties.

One parent stated that she understood why her son was bullied, and that she sympathised with children who sat next to him when he was wet and soiled. Another mother made a specific link between her son being called names and his learning difficulties.

‘He was doing nasty things like calling S a spasticated kid because S was finding things hard in school’ (8)

Children therefore described the ways in which they felt different in terms of behaviours, and in terms of organic factors. They also discussed how being different resulted in battles with other children. Parents validated their experiences of being bullied and attempted to understand why their children were bullied, which they too linked with their child being different.

Noticing

The final sub-category of the difference variable was 'noticing'. Noticing that their children were different occurred at different times of the parents in the study, and was an issue that many parents talked about. Many parents had noticed that their child was different in infancy, although the differences noted at this time were obviously not the same as those they talked about at the time of interview. Mothers also talked about additional difficulties they, as parents, experienced at this time. Others parents did not notice that their child had difficulties at all, until they were pointed out by someone else. This sub-category of noticing suggests that parents were drawing on biological arguments about the nature of their sons' difficulties, by highlighting the fact that they had noticed these difficulties whilst their sons were infants.

Of the mothers who felt their sons had been different from birth, many described ways in which as babies and toddlers they had been different. Mothers reported that their children had been difficult to feed and that they had experienced difficulties getting them off to sleep. As toddlers, these children were reported to be disruptive at playgroup and nursery, and to have difficulty mixing with other children. One mother described her son as 'trouble from day one', indicating her recollection of the difficulties she experienced with her son from early on.

'I had trouble with D from day one. As soon as I put him in the cot he'd be up like a shot, and at nine months he threw himself out. He never slept until he was four-and-a-half' (3)

These recollections of their sons' early development led some mothers to comment on how difficult this time had been. Many mothers commented that they had suffered from post-natal depression, and other described the experience as distressing and exhausting. Many commented also on additional stresses they experienced at the time, such as the death of their own mothers, the lack of support they received from husbands, and the birth of a second child. Although mothers did not make specific links with their children's current difficulties, it is possible that mothers were linking their own personal difficulties at this time with their sons' difficulties in order to try to make sense of them more fully.

'I fell pregnant when he was about six months with my second child and I had no backup from my husband for years, and my mother died' (1)

'The first four years were an absolute nightmare' (2)

'I suffered from post-natal depression. It was horrendous' (3)

For other parents, infancy was not a time when they were concerned for their children. Indeed, two parents felt that their sons were intellectually advanced for their age as toddlers, and had looked forward to their sons starting school to have this belief confirmed. It was not until teachers or health professionals pointed out the difficulties their sons were experiencing, that they became fully aware of the differences. These two mothers both reported feeling ashamed and guilty that they had not identified their sons' difficulties earlier.

‘We knew he was bright and I thought “he’s going to be really good at school” and I waited for the teachers to say “oh what an absolute star” and it didn’t happen, and instead the teacher said “we have concerns about him” ’ (4)

‘I felt ashamed that I hadn’t noticed that I had a child with a disability’ (7)

Summary

The first category to emerge from the data was one of difference. Parents talked about the many ways in which they felt their sons were different, which have been labelled here under the headings of disorganised, dangerous, delayed and disruptive. Children also perceived themselves as different, and described the ways in which they behaved and their own neurological processes as indicative of this. Parents also discussed how they came to notice these differences, which for some was very early, and possibly linked with other problems mothers were experiencing at the time. For others, however, these problems were not identified until teachers or health professionals pointed them out. These differences clearly contributed to a number of battles that occurred between parents and their children, and between the children in the group and peers at school. Parents’ perceptions that these differences were pervasive, chronic, and had been present from infancy has been used to suggest that they believed these differences to be biological in origin.

Category Two: Blame

'You blame yourself' (7)

The second category to emerge from the data was the category of blame. Blame played a clear role in the battles parents experienced, although was not reported by children. Parents reported that blame was directed at them from a variety of sources, including family members, teachers and the general public. Many parents also blamed themselves for their sons' difficulties, and many mothers blamed their sons' fathers for their difficulties. Some attributions of blame were also made to the children in the study. Parents reported that they experienced some respite from blame when they received a diagnosis of ADHD, but this respite was often short-lived. The experience of being blamed by others for their sons' difficulties has been used to suggest the emergence of a more sociological understanding of ADHD, in which factors such as poor parenting were considered to have caused the difficulties these children were experiencing. Mothers resented this assumption, and highlighted the role of genetic factors in causing ADHD when they discussed the link between their sons' difficulties and the difficulties experienced by their sons' fathers. Again, clear links are evident between this experience of blame and the central category of battles.

Mother blame

Mothers felt that they were being blamed for their sons' difficulties by a number of people. These included their sons' teachers, their own family and by the general public.

Mothers reported that teachers made specific attributions of blame towards them.

Mothers felt that often teachers believed that the difficulties their sons experienced

were related to bad parenting, rather than a biological disorder. Teachers and schools were generally thought to be resistant to the diagnosis of disorders such as ADHD, and many mothers commented that their children had been the first in the school to be diagnosed, which meant that they came across a great deal of scepticism. Mothers met teachers who specifically indicated that they thought ADHD was the fault of poor parenting. This resulted in some mothers questioning their own judgement.

‘It was like “there’s no such thing as ADHD, these kids are just really unruly whose parents have got no idea about parenting, it’s their fault” ’ (2)

‘All I thought was there's something wrong here and I know it's not me, no matter what the school was saying’ (3)

The mothers interviewed also reported being blamed by their wider family. Many mothers reported that their extended family (particularly mothers-in-law) felt that their sons simply needed some firm discipline, and that the battles arose from inconsistent parenting rather than any inherent or unexplained difference in the child. Mothers found themselves trying to convince their families, arguing that their other children did not have similar difficulties and so the differences could not simply be the result of parenting difficulties. Many mothers commented that they felt their families were basing their opinions on television documentaries in which parents clearly had difficulty managing their children’s behaviour. Specific attributions of blame are presented below.

‘My mother-in-law said “do something about him, smack him and he’ll be fine”
, (1)

‘D’s family think we’re atrocious parents and I think my sister does. They just
think it’s us not disciplining them’ (2)

Many mothers experienced the blame from family members as more damaging and stressful than from teachers, and invested a great deal of time and effort trying to persuade their families that they were not to blame. For some mothers, this proved to be successful, as their family came to review its understanding of ADHD and eventually became quite supportive. Others, however, remained sceptical and unsupportive.

‘She’s accepted it now because she knows someone with ADHD. She’s quite supportive’ (1)

Although mothers felt blamed by teachers and their families, the greatest experience of blame came from the general public. Mothers talked about avoiding going into public places, such as supermarkets and buses, with their children because they would be stared at, and they would hear people commenting about their children and their parenting. This made many mothers feel very angry, and ashamed of their children, and some mothers would walk away and pretend that their child was not with them. Other mothers felt obliged to explain to people that their son had ADHD, although they often resented doing so. Mothers also found themselves in a double bind, whereby if they

punished their child in public they would be criticised for being abusive, but if they failed to do so they would be criticised for being too lenient.

‘If I hold him he wriggles out and that just makes the situation worse and if you ignore it people just look at you and go “look at that woman ignoring what he is doing”. So you never win either way’ (10)

These difficult experiences resulted in many mothers wishing for greater social acceptance of their sons’ difficulties. Many considered ADHD to be a ‘hidden disability’, which they perceived as being more difficult to cope with than a physical disability because of the lack of public acceptance. Whether parents of children with physical disabilities would agree with this seems questionable though. However, many parents felt there would be greater acceptance if their child had an obvious disability, such as Down’s syndrome.

‘With other disabilities like Down’s syndrome you can look at the child and know that there’s something wrong but obviously K looks like a normal boy so when he’s playing up you get this “can’t you control that child?” ’ (9)

‘A lot of people don’t understand and because there isn’t a physical disability it makes it harder’ (10)

Despite the difficulties of being blamed, mothers themselves were also aware that they too blamed other mothers with ‘naughty’ children. Mothers commented that they found themselves judging others if they were in the supermarket, or if they were

watching documentaries on television. Mothers considered their own judging as human nature, even though they knew how difficult it was being judged. This judging of others also indicated that some mothers were drawing on these sociological models of ADHD too.

‘I see children like it [misbehaving] and I think “little brats”. That’s just human nature. So I can see why society looks at them like that’ (2)

‘People read the papers and watch the news and they see these programmes about dysfunctional families and it gives all of us a bad name. Even I watch those programmes and think “well why has the mother done that and not this”’ (7)

It is clear that mothers felt blamed by teachers, their family and the general public. In addition (or possibly as a result of this) mothers blamed themselves for their sons’ difficulties. Mothers asked themselves many questions about how they might have contributed to their sons’ difficulties, for example, questioning their own parenting skills, whether they went back to work too early or had two children too closely together, or whether something genetic had been passed from themselves to their sons.

‘Why have I had this child? What have I done? Did I have two children too close together? Did I go back to work [too early]? Where does it come from? Is it a bit of me?’ (1)

‘You blame yourself. You think it’s something you’ve done that’s made your child like this’ (7)

In addition to blaming themselves, all the mothers blamed their husbands for their sons’ difficulties, believing that there were strong similarities between their sons’ behaviour and their husbands’ behaviour as a child. Parents linked their sons’ absent-mindedness, unruly and dangerous behaviour, their disorganisation and their difficulties interacting with others, with their husbands’ own behaviour and, in doing so, were clearly considering the genetic components of ADHD. In support of this link, the one father in the study also wondered whether he had contributed to his sons’ difficulties, stating that there were similarities in his behaviour as a child and his son’s current difficulties.

‘They say it’s hereditary, and I do wonder if my husband had it ’cos he’s the same. He can’t sit still anywhere and concentrate’ (3)

‘I was a naughty boy’ [as a child] (6)

Child blame

Very few parents blamed their children for the difficulties they were experiencing. However, one mother made some statements which clearly did blame her son for his difficulties. This mother discussed the effect that her son had on her relationships with her other children, and with her husband, as well as on herself emotionally.

‘It was getting us down and S knew that he was putting a toll on our marriage because we were arguing all the time. I had to give my job up to be at home with S, and he was basically putting the family upside down. It’s hard on his brother and sister because we have to work round what S wants. I stay at home with him but I feel like I’m not doing stuff with the other two. The oldest one misses out and he gets quite down really. He is a big strain on our family and sometimes we say “why can’t we have a normal family life?” We understand S comes first and we’ve told our other two children that S’s needs come first’ (8)

Although this mother was not being hostile when blaming her child, these attributions of blame may have affected her son’s understanding of his condition. For example, when describing ADHD, this child made reference to other people, stating that he annoyed other people. This might indicate a feeling of being blamed or responsible for his actions, although it is not possible to be certain about this.

Respite from blame

Some parents commented that once they had received the ADHD diagnosis, they experienced a lessening of blame. In particular, mothers seemed to feel that the diagnosis reduced the amount of blame they should attribute to themselves and their parenting practices, despite the fact that others remained sceptical about the validity of the diagnosis.

‘I felt happy because there was an excuse for the behaviour. It wasn’t me’ (1)

‘For somebody to say “it’s okay, you haven’t been doing it wrong, there’s actually something wrong here”, it was relief’ (4)

However, this respite from blame was only temporary, as many mothers soon found themselves trying to ‘convince’ others about the nature and causes of their sons’ difficulties.

Category Three: ‘Battles’

‘Everything is a battle field’ (10)

The third category to emerge from the data was battles. Parents and children fought many battles; some of these involved other people, and have been described as external, whilst others involved some kind of psychological dilemma, and have been described as internal. External battles for parents included a battle to get others to agree with mothers’ views on the origins of their sons’ difficulties, fought with partners, teachers, and family members; and battles that occurred between parents and their sons as parents attempted to change their sons’ behaviour. External battles for children included those that arose through bullying other children, or being bullied by others. Internal battles for parents included an emotional battle in which they tried to assess whether the advantages of taking Ritalin outweighed the risks. Internal battles for children included a battle to be good without medication. These internal battles were considered particularly difficult because of the ‘double binds’ with which they were often associated. The underlying difficulty within each of these battles seemed to be the competing views about the nature of ADHD.

Parents' battles: external

Perhaps the clearest examples of battles arising from differences in understanding of ADHD came from the parents' reports of their interactions with others. It is clear from their descriptions that mothers felt they were battling to gain recognition and respect from their partners, family members and their sons' teachers for their sons' differences. This battle for recognition and respect appeared to represent mothers' frustration that others were not in agreement with them about the nature and causes of their sons' difficulties: mothers reported that whilst they attempted to convince others that their sons' difficulties were biological in origin, those around them appeared to prefer a more sociological understanding.

Battles with partners

Mothers' primary battle seemed to be with their partners. Many mothers perceived their partners to be unsupportive, and many felt that their partners dismissed their concerns about their child's well-being. Rather than finding this reassuring, mothers specifically suggested that their husbands were wrong, and battled with their husbands to get them to see things their way.

'My husband would not talk to me at all and it caused me to have almost a breakdown' (7)

'I had no backup from my husband for years. He didn't want to believe that there was anything wrong' (1)

Mothers had a number of explanations for why fathers could not see the difficulties in the same way as they did, believing that fathers could not accept that their son might have a disability. This placed an additional burden on mothers, as they both attempted to manage and understand their sons' difference, as well as help their husbands come to terms with the difficulties. One explanation given by a mother was that the difficulties were related to gender issues. This mother stated that she felt it was harder for a man to accept a disability in his son because fathers had greater expectations of their sons. She then went on to say that her husband could not 'even play football' with his son because of his difficulties. However, this seemed to be an exaggeration, as when the child was interviewed it was clear he enjoyed playing football. Instead, it is possible that this mother experienced her son as more physically disabled than he was.

'I had the task of trying to convince my husband. I have heard that for a man's son to have a disability is worse than his daughter because you have more expectations of a son' (7)

Not all mothers experienced their husbands as unsupportive, however. Mothers reported that some fathers could see the difficulties their sons were experiencing, and supported mothers' beliefs about their causes. Interestingly, though, no fathers took the lead on this issue, perhaps indicating that this was considered the work of the mother as primary care giver. It was also interesting to note that only one father participated in the study, which may indicate that mothers were more concerned about their sons' differences, and more interested in finding out about the condition and current research in the area. It may also indicate that they were primarily responsible for understanding their sons.

‘We had been talking all along. I did more of the reading than him because it’s more my field. I’d read and say “listen to this love” and he’d say “that’s it, that’s J” ’ (4)

One possible explanation for mothers battling to gain fathers’ recognition was that fathers genuinely did not agree with mothers’ views that their sons had a medical disorder. Rather than not acknowledging the difference, as many mothers perceived, fathers may simply have felt that mothers were over-anxious, or that sons’ differences were the result of social factors. The one father who participated in the study indicated that he felt this to be the case, suggesting that his wife was more anxious than he was about his son, and that he saw similarities in his son’s behaviour to his own as a child. This father also directly questioned whether ADHD was a valid diagnosis, or whether it was simply a label given to children who misbehaved occasionally. He also wondered whether he himself would be given an ADHD diagnosis if he were growing up now.

‘I was a bit of a naughty boy when I was a kid and you think if you were brought up nowadays would you be prescribed Ritalin?’ (6)

This father’s concerns about the validity of ADHD seemed to be exacerbated by the fact that his son behaved differently with him. This father reported that his son was calmer and better behaved when he was around, and that he had not witnessed all of the difficulties his wife reported. He attributed the differences in his son’s behaviour to the fact that he was stricter with him, and implying that he felt there was a social element to his son’s behaviour.

‘I’m a little stricter than she is and she lets him get away with things where as I will be a bit firmer’ (6)

Without having the views of additional fathers, it is not possible to assess whether the battles mothers experienced ‘convincing’ fathers of their sons’ differences were due to fathers having different conceptualisations of these difficulties, or whether fathers genuinely did not witness them. Whether certain factors affected fathers’ ability to perceive these differences, as suggested by mothers, cannot therefore be ascertained.

The difficulties recognising and accepting the differences led some battles to end in separation or divorce. Mothers reported that these separations often occurred after long-running battles between themselves and their husbands over their sons. These battles included disagreements over whether the child should be allowed to take medication, whether mothers were being consistent and firm enough with their children, and whether fathers were simply refusing to acknowledge their children’s difficulties.

‘In the end I was prepared to pack M’s bags and mine and leave because A [husband] would not recognise or admit to any of this’ (7)

Battles with teachers

Parents fought battles with teachers over a number of issues. Parents reported that they battled with teachers who were inconsistent with their punishments, and more punishing of their children than other children. Parents also battled with teachers who

expected parents to manage their sons' behaviour during school time, often telephoning parents at home and asking them to come into school; and with teachers whom they felt wanted their child excluded from school. Often these battles were verbal battles, in which parents and teachers shouted at each other. Sometimes these battles had a direct effect on mothers' decisions to move their child from that school. Although not all mothers were experiencing current difficulties with their sons' teachers, many had experienced difficulties in the past. A final battle fought between parents and teachers was one of respecting their child's diagnosis: parents resented teachers refuting a diagnosis of ADHD and telling parents there was nothing wrong with their child, indicating clearly a different understanding of the disorder.

Reports that teachers were more punishing towards the children in the study came from a number of parents. These parents acknowledged that their children could be naughty at times, but felt that they had become scapegoats for other children's misbehaviour. They also felt that teachers were 'on the look-out' for misbehaviour in their sons, and were quick to notice minor transgressions in their sons' behaviour, which would probably go unnoticed in other children. Parents also felt that teachers were more punitive towards their sons. There was a feeling of unfairness behind many of the parents' accounts.

'I mean he lifted a girl's skirt up and school never told us about it, but they had us in for him saying something silly. Where's the comparison? D does something innocent and we were called in' (3)

Parents also battled over the issue of teachers calling them at home or at work, and expecting them to go into school to manage their child's behaviour. This particularly affected two parents, both of whom had different ways of managing the situation. The first mother often refused to go into school, and instead argued with teachers on the telephone, suggesting that they try different methods of teaching her son. The second reported that she often sat at home expecting the school to ring her. She felt she had no option but to then go and collect her son, who had already been excluded a number of times.

‘School kept phoning me at work and I said “listen don’t phone me up at work, he’s in school with you so deal with him. If you can’t then you shouldn’t be a teacher” ’ (2)

‘It’s driving me to distraction constantly waiting for the phone to ring and the school complaining about K, and it got to the point where every time the phone rang I would be like “oh no” ’ (9)

The second mother had not entered into a verbal confrontation with her son's teachers until shortly before the interview. However, at a school meeting just prior to the interview, she and one of the teachers had engaged in a verbal confrontation. This confrontation had centred on the issue of the teacher feeling that the parents were not doing enough to change this child's behaviour. Despite the nature of the confrontation, it seemed that it had been successful in some ways because since it had occurred, the teacher had become more understanding.

‘Mrs B says “I am not at all happy with K’s parents thinking that it is okay to go around treating people like this”, and I just said “how dare you sit there and say that I condone his, I’ve had enough, I am leaving”, and I just got up and walked out. And since then she has been really good’ (9)

Some parents clearly believed that the teachers at their sons’ schools wanted their sons permanently excluded. This seemed to particularly be the case in a Catholic school, which one mother described as being very strict. Two children had been given temporary exclusions and parents reported that the tone of some of the conversations they had with the teachers indicated the way the teachers were thinking.

‘I said to my husband “I reckon they want him out”’ (3)

The battles between parents and teachers, along with the bullying described below, led many parents to consider moving their child to another school. Some parents had decided to do so because they felt their son was not getting the support he needed, others simply felt that there was too much bad feeling between themselves and the school for their child to stay there. Of those parents who did move their children from one school to another, all were happier with their current schools. Comments from the children themselves indicated that they too were glad to have changed schools, and that they had also experienced difficulties with their teachers.

‘I used to get shouted at a lot. This teacher who I didn’t like, she kept on dragging me about and throwing me about. She kept sending me to the head teacher. I like my new school better’ (8a)

Finally, mothers also battled with teachers over the issue of the diagnosis of ADHD and the prescription of Ritalin. Some mothers reported that teachers were openly sceptical about the validity of the diagnosis, and felt that their sons did not need to take Ritalin. One mother reported that a teacher had told her that there was nothing wrong with her child. This had made this mother so angry that she had decided to take her child off medication in order for the teacher to see how different he would be. She was outraged when the teacher told her that his behaviour was just the same.

‘His class teacher kept saying “there’s nothing wrong with him he’s fine”. So I thought “right you cow, I’ll show you”, and I took him off it. And she said there was no difference, no difference at all’ (7)

Battles with families

In addition to their battles with their partners and sons’ teachers, parents fought battles with family members. These battles were mainly fought over the issue of the validity of the ADHD diagnosis. Many parents reported that their own parents, and parents-in-law were sceptical about the diagnosis, and simply believed that their child needed some firm discipline. Mothers reported that family members were also critical of mothers allowing their sons to take psychostimulant medication. This battle therefore seemed to be one of convincing family members of the legitimacy of the diagnosis, and the necessity for medication.

‘My parents don’t like him being on the Ritalin. I’m always getting these newspaper cuttings about Ritalin and the side-effects’ (3)

‘My mother-in-law basically said “well he’s a naughty little boy, do something about him, smack him and he’ll be fine” ’ (1)

For some parents, the fact that their families did not share their understanding of ADHD caused considerable distress. Some mothers went into detailed descriptions with their families as to what ADHD was, but still felt their families were unsupportive. One mother arranged for her son to have a brain scan in order to ‘prove’ he had ADHD. This is interesting because it reflects this mother’s belief that ADHD can be demonstrated by a scan, which is in fact incorrect. It is also interesting to note that the scan was unsuccessful in persuading this mother’s family about ADHD. The comment outlined below indicates that this mother-in-law felt that ADHD was related to parenting difficulties.

‘We’ve had brain scans now and she still won’t have it. When we decided he did need the Ritalin there was something in the paper about bad parenting and she brought it round to show me and I nearly went for her’ (7)

It is also interesting to note that many of the intra-family battles took place between mothers and their mothers-in-law. The comments made by mothers suggest that mothers-in-law were similar to their husbands in not perceiving their grandchildren to have any inherent difficulties.

Battles with children

The final external battle fought by parents was a battle between themselves and their sons. Although this battle did not specifically relate to the issue of understanding ADHD, it was important because it reflected parents' desire for their sons to behave better. Many parents talked about the constant battles they had with their sons, as they attempted to make their sons conform to their own standards of behaviour. Some parents acknowledged that these battles could end in physical violence between themselves and their children, although parents discussed mainly verbal battles. Some parents reported that they sometimes worried about their child's safety during these times, and they feared they would hurt their children. For some mothers, these battles were so severe that at times they wished they had not had their children. Interestingly, the children themselves did not comment on these battles during their interviews.

The battles between parents and children often arose when children were not complying with parents' wishes. For example, the behaviours described in the previous category (difference) often led to battles, such as when children refused to get ready for school or refused to get into the bath. Similarly, parents reported battles occurring when their children were disrupting their siblings, or when their children refused to take their medication. Many mothers described some degree of physical contact occurring during the battles.

'He was kicking the back door, then I dragged him upstairs and I put him in his room' (3)

Some mothers were frightened by the amount of physical contact that occurred during these battles. Mothers reported pushing their children out of the front door and locking it behind them, locking them in their rooms, and one mother described how she had once tied her son to a chair. These mothers were understandably anxious about telling the researcher about these incidents, and indeed anxious that their sons would also talk about these incidents during the interviews.

‘You could end up really hurting them sometimes’ (3)

‘When you talk to him I will be worrying that he’s going to say “do you know my Mum smacks me sometimes” ’ (4)

Mothers reported that after a battle, they often felt that they had been too punitive with their sons, and often hated themselves for punishing their children. There also seemed to be a great deal of shame around these battles for mothers, as mothers often felt they should not have become so angry. The external battle with the child therefore became an internal battle, as parents tried to understand how and why they were behaving in certain ways.

‘I’m angry and frustrated and I feel guilty about how I respond to my son, but I can’t stop it at the time’ (4)

‘I’ve ended up where I’ve hated myself. I’ve smacked him, and I’ve hated myself for what I’ve done’ (3)

As a result of the battles between parents and children, many parents sought professional support. Some parents requested involvement from social services, whilst others were seen at the local Child and Family Consultation Service. Some parents openly expressed the depths of despair they experienced because of the battles, and commented on how fearful they were that they would harm their children. Fortunately, professionals had already acknowledged this despair and two of these families were receiving support from the Child and Family Consultation Service.

‘I said to my health visitor “if you don’t come and get this baby away from me I’m going to put a pillow over his head and smother him” ’ (2)

‘I just said “I need help, I can’t cope with them”. Otherwise they would have been battered children’ (2)

Battles with professionals

The final battle parents fought was one with professionals. Some parents found professionals unsympathetic and even patronising. Often mothers entered into battles in which they tried to convince professionals there was something ‘wrong’ with their child. Others found professionals helpful and supportive, particularly professionals who gave a quick and straightforward diagnosis of ADHD, which seemed to fit with mothers’ own understanding of their child. The main battle with professionals, however, arose when parents had a diagnosis of ADHD that was made by one professional refuted by another. This happened for two of the families in the study.

‘We did see a family psychiatrist who basically told us S was a very healthy little boy and there was no problem whatsoever’ (8)

‘We ended up coming here to Child and Family and being told more or less that there was nothing wrong with him’ (9)

These experiences engendered feelings of blame in these two families, as discussed previously. Parents also felt confused about their sons’ diagnoses. Eventually this situation was resolved when parents returned to their original paediatrician, who reinstated the diagnosis of ADHD. This satisfied the parents’ concerns, although it did not address the issue of the difficulty of making diagnoses of ADHD, or indeed the conflicting views held by professionals about these boys’ difficulties, as well as the effects that being blamed by professionals might have had on parents.

‘We thought we’d been misled, and it’s us that needed to deal with it, it’s our fault and we just had a naughty child’ (8)

‘I was just confused’ (9)

Other parents also battled with professionals, although over different issues. One mother was dissatisfied with the diagnosis given by the initial paediatrician she saw, and so took her son for numerous second opinions. It seemed that each professional she saw gave her a different diagnosis, until her son had four diagnoses: ADHD, Asperger’s syndrome, dyspraxia, and learning difficulties. This mother was quite pragmatic about these diagnoses, acknowledging that there was overlap in symptoms

and that differentiation of the disorders was complex. However, she also battled with her GP whom she felt had little knowledge or understanding of, or interest in, her son's conditions. Eventually she bought her GP a book so that he could be better informed. This whole process led this mother to express the following belief, indicating that she too was questioning the validity of some diagnoses.

'I think what diagnosis you get depends on where you live' (7)

Children's external battles: bullying

Children also fought a number of external battles, most of which occurred around bullying. Children reported that other children bullied them, and that they also got involved in a number of fights as they retaliated to the bullying. Some children were forced to move schools because the bullying became so intense.

Children reported that they were bullied in a number of ways, such as by being called names such as 'mental', 'spastic', 'mad', 'insane', 'crazy', and 'peanut brain'. Children commented that both children in school, and their own siblings called them these names. It seems that the children who were bullying the boys in the study recognised an association between ADHD and mental illness, as these labels have clear links with psychiatric conditions. In addition, the boys in the sample linked these names with the fact that they took medication, stating that the bullies understood taking medication to mean that they were indeed 'mad'. This may suggest that the bullies also considered ADHD to be a biological condition. Many children also commented that they were taunted because they took medication. This resulted in children being reluctant to take

medication at school, and in some cases directly contributed to them stopping their medication. Alternatively, many children tried to keep the fact that they took medication a secret.

‘The bully says “why do you take tablets?” but I didn’t tell him ’cos he would take the micky out of me’ (8a)

‘I don’t tell my friends [that I take tablets] ’cos they will take the micky, tell everyone else and call me a peanut brain’ (9a)

Children also discussed other aspects of bullying, such as physical bullying (described as being ‘beaten up’), being teased and being threatened. These children often felt hounded by other children, and felt they could not avoid the bullies even if they told their parents and teachers. This seems to reflect a belief that these children were not safe anywhere, and that they could not be protected from the bullies. As a result, many children described school as a place of unhappiness.

‘At my other school I just used to get beaten up. They were saying “ha ha you’ve got to go to a mental school”, just being horrible. There was this boy that kept on picking on me and calling me names’ (3a)

‘I had to always bring this chocolate bar for this boy in this gang and if I didn’t he would beat me up’ (8a)

In order to escape the bullying, many children attempted to find places of safety and refuge. This meant staying indoors during break times, or going to the library.

However, these places were not always safe, as sometimes children would be bullied in these areas. One child spoke specifically of the emotional distress that this created.

‘I usually go to the library, and once some boys even followed me there. They wouldn’t go away and I can’t get away from them anywhere. Except at weekends or when I get home, I’m always safe’ (1a)

For some children, the only way to escape the bullying was to move schools. Two children were known to have moved schools because of bullying, although only one child mentioned this during his interview. This child stated that he had not told his friends at his new school about why he had moved there, possibly because he feared further bullying.

‘My friends keep on saying “why did you come to the school” but I didn’t tell them. I just don’t want to tell them’ (8a)

In addition to the experience of being bullied, some children also talked about getting into fights and calling other children names. Although we cannot be sure that these children were perceived as bullies, it is possible that a cycle of bullying around these children had emerged, in which some children with ADHD were both bullied by other children and engaged in bullying of others themselves.

‘I don’t get picked on but sometimes people start fights with me and if I don’t like them I beat them up’ (2a)

‘I told them “don’t call me that or you know what I’ll do, I’ll beat you up” ’
(9a)

‘People just make my angry so I go and punch them ’cos one time there’s this boy that got me so angry I punched him on his nose and his nose started bleeding’ (10a)

Bullying therefore emerged as the core issue at the heart of the battles experienced by the boys in the sample. Although not the key issue discussed in relation to bullying, it seems that other boys also held views about the biological nature of ADHD, and linked this with their understanding of the boys’ differences. As outlined earlier, the children did not discuss the battles that took place between themselves and their parents or their siblings, although clearly for parents these were a concern.

Parents’ internal battle: Ritalin

Alongside the external battles, parents also fought an internal battle over the issue of Ritalin. This battle was thought to reflect a more significant battle over ADHD, in which biological and sociological views of the disorder were represented. All parents reported that they experienced huge relief when their sons were diagnosed with ADHD because this confirmed their perceptions of their sons’ difficulties. Many parents were also keen to try their sons on Ritalin and marvelled at the dramatic effects it had on

their children. However, parents were also aware of the side-effects of the medication, and this created a double bind for them as they attempted to weigh up the benefits of the medication with the costs. This was a difficult decision for parents, and resulted in some parents deciding to take their child off Ritalin regardless of the negative effects this would have on their behaviour, whilst others struggled with the possibility of side-effects, but felt they could not take their child off the medication, both for the child's sake, and for their own.

On receiving the diagnosis, many mothers expressed relief that they finally had an answer to their questions. Mothers felt the diagnosis was an explanation for their sons' difficulties, and that it indicated a discrete biological cause. The external battles mothers had experienced in their attempts to gain recognition for their sons' difficulties seemed now to have been worthwhile.

'It was a relief actually to know that he had a label. He had a condition' (5)

'Relief. It wasn't fear and panic because I had done so much reading and I knew what it was' (4)

All parents in the study felt that Ritalin significantly improved their sons' behaviour. Parents reported that children were calmer, more communicative and more pleasant on Ritalin, and that they were more sociable with other children. Ritalin had also improved children's concentration and attention, and therefore they were learning more in school. Interestingly, many parents were particularly pleased with the effects of Ritalin on their children's handwriting, which they felt to have improved within

twenty minutes of their child taking the medication. This was interesting because it is not something commonly reported by parents of children with ADHD, but seemed to have occurred in three of the children involved in this study.

‘You definitely notice the difference when he’s not on the tablet. He’s more controlled and he doesn’t get so agitated all the time’ (6)

‘He went on the Ritalin and it was unbelievable’ (7)

Parents were therefore initially both relieved at the diagnosis and pleased with the effects of the medication. During the immediate post-diagnosis period, very few parents questioned the validity of the diagnosis. However, after experiencing scepticism and blame from their families and professionals, some parents began to question their understanding of ADHD, and hence whether their sons should be taking Ritalin. These concerns were exacerbated by other concerns about the possible side-effects of the medication, of which a number were reported. For example, parents were concerned about the effects of Ritalin on children’s appetite, as many children were noted to have lost their appetite since being on the medication. Some mothers also felt that their sons’ personality changed so considerably on Ritalin that it was like having a different child. For example, children were reported to have become withdrawn and depressed. One mother worried about a possible link between Ritalin and schizophrenia, a theory learnt from her sister-in-law who worked overseas, and presumably based on the involvement of dopamine in the two conditions. One mother talked about Ritalin being a Class A drug, and wondered about the long term

implications of taking this medication. Four parents expressed these concerns by asking the researcher specific questions.

‘Is there any research on long-term side-effects? They say “give him a couple of weeks off” and I think “but why, if it’s safe?” I wonder about long-term effects because it hasn’t been around that long’ (6)

The nub of the internal battle fought by parents at this stage was deciding whether the benefits of Ritalin, in terms of improvement in behaviour, outweighed the costs. This was a decision often made between mothers and their partners, indicating that by this time partners had become more involved in the decision making. Generally, however, mothers seemed to have the casting vote on whether or not the child remained on Ritalin. Mothers also involved their sons in this decision, and sons’ desire to come off the Ritalin was often an important factor in the decision. All families experienced this dilemma, and three families decided to take their child off medication. For one mother, this decision arose after a particularly distressing incident, in which she had been frightened by the difference in her son on Ritalin.

‘I was horrified, he just sat and hung his head and so I took him off it. It was brilliant but I can’t use him as a guinea pig. I can’t sacrifice his life just for him to be an ‘A’ grade student’ (2)

‘We took him off the Ritalin ’cos he didn’t like being on the Ritalin and the tablets dulled his senses. He was better on them but then any child given Ritalin would be able to concentrate more’ (7)

The remaining six families felt that the Ritalin was sufficiently beneficial for their child to be taking it. Some families eased their own anxiety about this by ensuring that their sons remained on a low dose and that the side-effects were carefully monitored. Other families expressed concern but felt they could not live without Ritalin. This raised the possibility that parents had become psychologically dependent on the effects of Ritalin themselves. These parents specifically indicated that they felt they could not live with their child without the Ritalin, and in two cases, this had resulted in children taking increasingly large doses of the drug. Two boys were taking 4-5 tablets per day, and one family had been recommended by a medical doctor to give the first dose before the child got out of bed. Parents often felt guilty and concerned about the increase in the amount of Ritalin their sons were taking, but felt they had no alternative. The comment made by parent (8) specifically indicates this belief.

‘I know that I couldn’t live without Ritalin. He takes 4 or 5 a day’ (10)

‘I just feel a bit guilty giving it but I have to have it to cope’ (1)

‘We know he can’t come off it’ (8)

One parent expressed the issue of reliance on medication in a particularly cogent manner. During the course of the interview, it was noted that her son had changed from being lively and animated to quiet, withdrawn and reluctant to communicate. When asked by the researcher how she accounted for this change, this mother said that she had given her son a Ritalin tablet before coming into the interview. The change in her son’s behaviour was worrying for the researcher to witness, and indicated that this

mother felt unable to tolerate the interview without her son taking Ritalin, although this child had been able to sit quietly and contribute to the discussion prior to the Ritalin taking effect.

‘He had a tablet outside. We couldn’t cope with it much longer. So he is just winding down now. He will be quiet and it’s hard to get anything out of him.

It’s wicked but it’s nice. We don’t agree with them, but what can we do?’ (8)

The most significant internal battle fought by parents was therefore the issue of whether the advantages of Ritalin outweighed the disadvantages. This was exacerbated by the corresponding argument about whether their children really needed the medication. The answer to this question was often made by mothers, many of whom were not happy giving their children medication. Those with greater anxiety about the effects eventually took their child off the medication, but it was felt that some parents were themselves ‘addicted’ to the effects, and therefore could not live without Ritalin.

Children’s internal battle: Ritalin

Children also fought an internal battle over Ritalin. Many children believed that Ritalin helped them control their behaviour, and was therefore good. However, children were also aware of the side-effects of the medication. An internal battle therefore arose for children who wanted to be good, but who did not like taking Ritalin.

Children varied in their understanding of why they took Ritalin. Many understood that the role of Ritalin was to change their behaviour. For example, children stated that Ritalin was to stop them fiddling around, to calm their behaviour, to stop them being

silly or to keep themselves 'under'. In addition, some neurological explanations were offered, such as Ritalin 'making fake connections' in the brain. All of these explanations were linked with a 'deficit' model, in which Ritalin was perceived as making up for something the child lacked naturally, for example, control of their own behaviour.

'They [the tablets] are so that in school I won't fiddle around and everything'

(2a)

'It develops the connectors to the frontal lobes so that it's fully connecting and then after about 4 hours it dissolves' (4a)

In addition to these explanations, some children specifically thought that Ritalin had the effect of making them 'good'. These children described how before they took Ritalin, they were bad, but that once they took Ritalin, they were good. Not only do these comments suggest that these children believed themselves to be bad without Ritalin, but they also suggest that, for some children, being good was dependent on taking Ritalin.

'When I wasn't taking them I was bad. When I was taking them I was good but when I stopped taking them I got bad again' (2a)

'The tablets help me be good. [Can you be good without them?] No' (9a)

When asked whether they felt Ritalin worked, all children felt that it did work 'sometimes'. They gave examples of times when the Ritalin had clearly worked straight away, but also examples of times when they felt the Ritalin had not been useful. One child linked the tablets not working with his brother annoying him. Others reported that they could sometimes control the effects of the tablets.

'I think they are helping me. They keep me a bit cool' (1a)

'Sometimes [they work] but sometimes they don't really. When my brother annoys me it won't work' (8a)

Children therefore perceived Ritalin to be useful in helping them be good most of the time. However, two dilemmas arose here. Firstly, some children wanted to be good without the medication, but felt they could not be so. Secondly, children did not like taking medication, which they described as having two main side-effects: physical side-effects and emotional side-effects.

In terms of wanting to be good without medication, one child expressed this dilemma succinctly. He stated that he often told himself that he should be good without Ritalin, and that he got upset with himself when he was not able to do so. He wanted to be good so that he could please his parents and his teachers, and also because his mother had stated that, if he was good, she would consider taking him off his medication. This child had very strong beliefs about not being able to be good without medication, as described below.

‘I know I can’t be good so I just think of the idea of just taking them and then one day it might just get rid of all my badness and make me good again’ (3a)

‘I feel upset about myself going on the tablets ’cos I was thinking “I shouldn’t be on these tablets, I should be good without these tablets. I try to be good for my Mum and Dad and then they might think about taking me off the tablets” ’
(3a)

Many children succinctly described the side-effects of the medication. Physical and emotional side-effects were reported. The physical side-effects included the fact that the tablets tasted horrible and made children feel sick, as well as giving the child chest pain and headaches and making the child feel tired. Emotional side-effects included the anxiety, loneliness and isolation which resulted from the bullying. Often these side-effects made children want to stop taking the medication, which some were allowed to do. Others, however, were felt to need the medication too much for them to be able to stop taking it. Parents rather than children often made these decisions.

The internal battle for children was therefore one of relying on medication to be good and to help children control their behaviour, versus not wanting to take medication because of the side-effects. For most children this dilemma was resolved by parents either deciding that the child should come off the medication, or feeling that they could not cope without the medication. Children therefore seemed to have little power in this decision-making process, which may have exacerbated their difficulties with the issue.

Summary

The parents and children in the study fought both external and internal battles. Many of these battles were related to the issue of whether ADHD were a true biological disorder. Parents battled with many people about their sons' difficulties, and children fought mainly with other children. Medication emerged as a key issue over which children and adults fought internal battles, during which it appeared that parents themselves acknowledged the limitations of the treatment recommended by the biological models of ADHD.

Category Four: Adjusting

Many parents talked about how they attempted to come to terms with their sons' differences, their own battles and the experience of blame. Children also talked about ways in which they attempted to adjust to, and manage the effects of their differences. For many parents, this process of adjusting began with an acknowledgement of the emotional distress engendered by the difficulties they were experiencing, which included acknowledging the sadness and loss they experienced. Parents then outlined particular cognitive and behavioural strategies they used for managing their difficulties, which included (1) seeking professional help for themselves; (2) looking for the positive aspects of their sons' behaviour and personality; (3) comparing themselves with people whom they perceived to be in a more difficult position; and (4) using specific management techniques. For children, the main adjustment strategy seemed to be one of taking control: many children perceived themselves as able to control their behaviour, the effects of their medication, and the people around them.

Parents' adjustment

Many mothers talked about the profound effects of their difficulties on their own psychological well-being. Some mothers commented that they were currently suffering from depression, which they specifically linked with their sons' difficulties. Some mothers had also suffered from depression in the past, and four mothers had been diagnosed with post-natal depression shortly after the birth of their sons. In addition, mothers suffered from a variety of other mental health problems, such as anxiety, weight gain, sleepless nights, suicidal thoughts and beliefs that they were going mad. Guilt and self-blame were also common.

‘I’m putting on weight because I am eating for the wrong reasons, and I am eating because I’m angry and frustrated and we were looking at this business of me feeling guilty about how I respond to my son’ (4)

For some parents, feeling suicidal was the nadir of their experiences. Three mothers acknowledged having felt suicidal in the past, and two revealed that they had become aware of suicidal thoughts whilst driving, which is often thought to indicate serious intent. In addition to feeling suicidal, some mothers began to question their own sanity. For example, some mothers questioned whether others saw the same differences in their sons, or whether they were imagining them. In addition, the blame experienced by some parents led them to question their own judgement. These experiences seemed particularly pronounced for a few mothers who seemed to hold quite rigidly to the more biological views of the disorder.

‘I’ve been suicidal at times. I have actually thought of ways to kill myself’ (7)

‘I wanted to put the car into a wall and just lay down and die’ (3)

‘I just thought it was me, that I was completely off my trolley, that I was just stupid’ (1)

Some parents also talked about the sense of sadness and loss they experienced when their sons were diagnosed with ADHD. One parent likened the experience to a bereavement, another parent commented on how she felt she had lost a ‘normal child’ and how she wished that her son had a brain tumour rather than his current difficulties, because a brain tumour could be operated on and removed. Three parents discussed how they believed ADHD to be a hidden disability, suggestions comparisons with other medical conditions.

‘It was a bereavement. You had just lost the child you thought you had. You had just been told that your son has got a disability’ (7)

‘You want a cure. I used to think “maybe it’s going to be a brain haemorrhage, a nice benign one, or a nice brain tumour, that we can operate and then he’ll be fine” ’ (1)

‘I lost my sister who was handicapped and I totally miss her and can’t accept that she’s gone. She had my constant attention. Anniversaries and birthdays knock you for six’ (8)

Parents sought help for themselves in dealing with these difficulties. Many parents spoke to their GP about their difficulties, and some saw counsellors and psychologists. Four were currently taking anti-depressant medication. Some mothers had been surprised and shocked when they were told they were suffering with depression, and initially refuted the diagnosis, not wanting to believe that they were depressed. Gradually, however, parents came to accept more fully the effects of their difficulties, and after a period of time on anti-depressants, some felt that they could not live without them.

'I'm now on anti-depressants all the time' (7)

'It was helpful to have my own counselling' (7)

'I went to the GP and he said I had severe depression. I'm on Prozac and they are helping. I didn't want to go to counselling because I am going to have to deal with everything anyway' (8)

As well as seeking help for themselves, some parents used strategies such as looking for the positive aspects to their sons' behaviour and personality, and comparing themselves with others whom they perceived to be in a more difficult position. In terms of looking for the positive aspects of their sons' behaviour, parents described how their children related well to adults and younger children, and how they were often generous and kind-hearted. Some parents also commented on their child's academic strengths.

'He's very bright. He's got an amazing brain and an amazing memory' (5)

‘He’s got a heart of gold, very generous, very friendly (6)

‘He’s a nice little boy and he seems to get on well with helpers’ (1)

Alongside looking for the positive aspects of their sons, parents also looked at the positive aspects of their situations. In doing so, some parents compared themselves with parents of children with more severe disabilities, although parents clearly differed in their views on whether physical handicaps were more difficult to manage than emotional ones. Parents also compared themselves with friends who had received little support from professionals such as social services and teachers.

‘I’ve been really lucky because I had a friend who went four years in front of J [at school]. She hit all the barriers but she’s paved the way for me’ (2)

‘It could be a lot worse. He could be physically handicapped’ (6)

Parents also developed specific behavioural strategies for managing the difficulties they experienced with their children. These included avoiding certain people, places or situations; telling their children in advance of changes to a daily routine (used by parents of children with both Asperger’s syndrome and ADHD, and with pure ADHD); ‘playing down’ important social occasions such as Christmas; and being firm and consistent with boundaries and punishments.

'It's important to work out solutions. You just work out what's going to be easy' (1)

'I've started to make them pay for damage to other people's property' (2)

'I play down hype' (10)

Children's adjustment

Children also talked about the ways in which they attempted to adjust to their experiences. For many, control emerged as an important adjustment strategy. Children talked about controlling their symptoms of ADHD, controlling the effects of their medication, and, to some extent, feeling that they had control over others. Parents also felt that children could control some aspects of their behaviour, suggesting that they were drawing on more sociological frameworks.

Many children felt they had some control over their ADHD symptoms. This was clear from the way that children described their behaviour, with many children stating that the symptoms of ADHD only occurred occasionally, and that most of the time they could control these behaviours. Some children made specific reference to the fact that they could control their symptoms, and described how they would choose to 'go hyperactive' when they were bored. One child described how he chose not to 'go hyperactive' in other people's houses because it was rude to do so, and because it did not feel as comfortable as when he was at home.

‘[When] I’m enjoying myself, I don’t go that hyperactive. When you’re bored and you want some fun you think “I’ll be hyperactive”. I don’t go hyperactive in other people’s houses ’cos it’s rude. The place where it’s more comfortable to do it is my house’ (2a)

Some children also felt they could control the effects of their medication. These children believed that the medication only worked if they allowed it to do so, and that they could exert some power over the effects of the Ritalin. This made children believe that they did not need the medication, and that they could control their behaviour without it. This idea differed from the experience described earlier, in which children felt they could not be good without their medication. Instead, this latter group of children felt that they were in control of the effects of their medication, and the issue of being good without the medication was not discussed.

‘They are to keep me under but I don’t need them’ (1a)

In terms of controlling others, it seems that many of the children in the study exerted considerable control over their families. Although the children did not talk about this themselves, many parents described ways in which their sons seemed to dominate and control family life. For example, mothers reported being unable to do many of their own chores and hobbies because their children needed constant supervision. Parents also talked about the knock-on effect this had on siblings, whose needs were often overlooked. One mother reported that her son was constantly by her side, and did not let her go to the toilet or have a bath without him being present. Other children seemed also to exert control over their teachers, particularly when they were being disobedient

or disruptive and refusing to listen to teachers' demands or request. From these examples it is clear that the control shown by children in these situations was perceived as unhelpful. However, in terms of an adjustment strategy, controlling the environment may have been a useful way for these children to compensate for the lack control they appeared to have over their psychological and emotional lives.

Result Section Summary

This section has described the central experiences of children living with ADHD and their parents. The central difficulty appeared to be reconciling the different views about the causes of ADHD. 'Battles' arose as the key feature of everyday life for the participants in this study, and this was felt to reflect this difficulty with competing views. Two additional categories, difference and blame, emerged as important categories and seemed to reflect parents' beliefs that whilst they considered ADHD to be biological, others did not. The category of adjusting represented how some parents and children attempted to adapt to their situation.

Chapter Four

Discussion

The aim of this study was to explore the everyday experiences of children with ADHD and their parents. Only two previous studies had been published in this area, and so this research was important for assessing whether the results from these studies could be generalised to other populations and indeed whether other, previously unidentified, issues emerged as important. This study found that for both children and their parents, three key categories emerged as important: difference, battles, and adjusting; and, for parents alone, an additional category of blame emerged as significant. In this section, these categories will be linked into a theoretical discussion about how ADHD is understood and conceptualised. It is clear that, according to parents, their views of ADHD as a biological or medical disorder differed widely from those of professionals, family members and the general public, whom parents felt viewed the condition as mediated by environmental and parenting difficulties. These differing views formed the basis of the theory developed around these four categories. This section will also discuss the implications of these findings for clinicians working with people affected by the disorder.

Overview of results

Four core categories emerged from the data. The first category, difference, referred to four aspects of behaviour which parents described as different in their sons. These behaviours have been described as disorganised, disruptive, dangerous and delayed. Concern about these differences led parents to fear for their sons' futures, and to feel

that they could not let their children out of their sight. Parents also discussed how they came to notice the differences, which for some occurred during infancy, but for others did not happen until some time later. Children also felt that they were different and described ways in which they behaved differently from other children, and the effects these differences had on them.

The second category, blame, was reported by many parents in the study, although children did not report feeling blamed. Parents reported feeling blamed for their sons' difficulties by many people, including their families, their sons' teachers, professionals and the general public. This experience of blame led many parents to try to persuade others of the validity of the ADHD diagnosis. In addition, many parents started to blame themselves and their partners for their sons' difficulties. Some parents also blamed their children for the disruption to family life the ADHD was causing.

The third category, battles, describes the main difficulty experienced by parents of children with ADHD. Battles were also a problem for the children themselves. External and internal battles were fought. External battles involved other people, and included parents' battles with family members, their sons' teachers and their sons themselves, and children's battles with bullies at school. Internal battles involved an emotional dilemma, and for parents this included a dilemma about whether the improvements noted in their children's behaviour after Ritalin outweighed their concern about the possible side-effects of this medication. Some parents resolved this internal battle by taking their child off Ritalin. For children, an internal battle arose over whether they could be good without Ritalin, and whether the physical and psychological side-effects of the medication outweighed its benefits.

Finally, adjusting emerged as the fourth category central to the experience of parents and children. Parents used a variety of strategies for this process. The first stage of adjusting was described as the process of parents acknowledging the emotional distress that ADHD engendered, such as feelings of depression and anxiety. Mothers often then sought support for themselves from their GP or from counsellors or psychologists, and some were taking anti-depressants. Other strategies included looking for the positive aspects of their son's personality, comparing themselves with others whom they perceived to be worse off, and developing specific management techniques, such as playing down big occasions. For children, control emerged as an important adjustment strategy. Children believed that they could control their behaviour and indeed the effects of their medication, a belief that was felt to arise as a compensation for a feeling of lack of control over other aspects of their lives.

The central discussion point presented here is the issue of the difference between parents' views of their sons' difficulties and parents' reports of the views held by the wider public. This section will discuss parent' views that their sons had a biological disorder, and compare this with their views that society felt their sons simply needed some firm discipline. These two views will be presented separately, and will include hypotheses about how each group came to these conclusions. Although the sociological views of others are presented and discussed, it is acknowledged that this view is based on parents' and children's perceptions, and that without specific research involving family and professionals, it is not possible to be sure that others did indeed hold this competing framework for understanding the condition. The final section of the discussion will address the possibility that some parents were able to integrate the

two competing views, and discuss how clinical interventions may be focused towards achieving this goal.

Before proceeding with this discussion, it is important that the researcher acknowledges her own position in relation to this issue. The competing views about the causes of ADHD were discussed in the introduction, and the view that ADHD may not be a purely biological condition resonates with the researcher's own experience of ADHD. The researcher believes that, although a 'pure' condition of ADHD may exist, many of the diagnoses of ADHD made in current practice are probably a result of a mix of biological and sociological factors. This view has been highlighted by this piece of research, in which parents have reported idiosyncratic diagnostic procedures and professional challenges to a diagnosis of ADHD. The researcher's own clinical experience has also influenced the belief that parents who are able to hold more than one view of ADHD in mind may find the clinical suggestions made for management of ADHD symptoms more helpful than those who hold a purely biological understanding of the disorder.

Parents' understanding of ADHD

Much of the evidence presented by parents indicated that they felt there was a biological reason for their sons' behavioural difficulties. This included the following: (1) parents reported that their sons had been difficult from birth; (2) parents reported that their sons displayed many different behaviours which they believed were consistent with a medical diagnosis; and (3) parents reported that the medication their sons took was extremely effective. Children too believed there to be a biological basis to their behaviour. The links between these factors and the biological understanding of ADHD

are outlined below, before a discussion of the reasons for parents holding these views is presented.

'Trouble from day one'

One of the first possible indicators that parents felt their sons' behaviour had a biological origin came at the start of the interviews, when parents discussed how they had noticed these differences. Many parents reported that they had noticed differences in their sons when they were very young, describing them as 'trouble from day one'. Parents gave descriptions of how their sons had been difficult from birth, for example describing how they had been difficult to settle, constantly restless and seeking attention, and unable to establish regular patterns of feeding and sleeping. Mothers reported that this time had been very stressful for them, and indeed it had resulted in four of them suffering from post-natal depression.

Because of these difficulties, many mothers sought help and advice from their health visitors. Some mothers found the advice given useful, but others continued to have difficulties managing their children. Two mothers reported that their children had been taken to specialist nurseries because mothers felt unable to cope with them. As the children in the sample grew older, it was clear that concerns about their behaviour and development continued. As toddlers these children were reported to have difficulties interacting with other children, to be destructive when playing and to suffer from nightmares. When they started school, teachers reported that they were constantly 'on the go', socially or emotionally immature, restless and fidgety.

The perception of difference from infancy is the first indication that the mothers in the sample were drawing on medical frameworks for understanding their children's behaviour. Although some mothers also discussed their own emotional difficulties at the time of their children's births, such as the lack of social support they received and the fact that they suffered from post-natal depression, these experiences were not integrated into mothers' understandings of their sons' current difficulties. Rather, it was suggested that the difficulties parents experienced at this time were probably exacerbated by their sons' innate behavioural problems. The fact that mothers sought help and advice from medical professionals at this time, such as health visitors, their GPs and their sons' school doctors also suggests that they believed that there may be something innately wrong with their child.

Descriptions of difference

Mothers' descriptions of their sons' difficulties also reflected a biological understanding of these problems. Some differences were clearly typical of ADHD, and consistent with Kendall's core category of 'disruption', such as behaviour which was disorganised and disruptive. However, other differences described by both parents and children in the study were not typical of ADHD, but were consistent with other medical diagnoses.

For example, many parents discussed at great length a variety of behaviours which they considered to be typical of their sons' difficulties. One mother described how, in the previous week alone, her son had flooded the bathroom, cut his head with a knife, climbed into an electricity box and set fire to a sofa. Although these behaviours clearly gave cause for concern, they were not indicative of ADHD *per se*. However, they may

be consistent with a diagnosis of Conduct Disorder, which although linked with social and parenting factors, is also believed to be biologically based. Other parents reported similar behaviours, such as playing with knives and running away from home, which parents believed to be beyond the child's control, as indicated by comments about increasing doses of Ritalin as their sons' behaviour became less manageable.

In addition, two parents described how their sons suffered from incontinence, and were often wet or soiled during the day. These parents discussed how they had sought a medical reason for their sons' bladder and bowel problems, but that they had been told that it was not part of a medical condition, and that they should try behavioural techniques to alleviate it. Neither of these parents believed that this problem was emotional in nature, as the doctors had suggested, and both considered it to be part of their sons' diagnosis of Asperger's syndrome.

It seems possible that parents' discussion of the many ways in which their sons were different was linked to their understanding of ADHD as biological, particularly as parents commented on the chronic, persistent nature of the difficulties, and discussed how they believed them to be beyond the child's control. The one father in the study suggested he knew of other families with children with ADHD, and that for them the diagnosis of ADHD had become a panacea for all of the behaviour problems their children displayed.

Use of medication

The use of medication for changing the behaviour of the children in the sample also refers to parents' belief in the biological nature of the condition. All parents initially

gave their children medication, and all parents commented that the medication had significant effects on their sons' behaviour.

Some parents clearly considered that the medication their sons were taking had a dramatic effect on their behaviour. A few of these parents described how they could not live without Ritalin because it made their children so much more manageable.

These parents appeared to believe that medication was the only method of changing their sons' behaviour, indicating that they did not feel the behaviour could be modified by any social or environmental changes.

However, whilst talking about the effects of medication, some parents were clearly confused about the effects of the medication. For example, some parents commented that the medication did not seem to help the behaviours for which it was meant, such as improving social skills. Similarly, some parents reported that the medication improved aspects of their sons' behaviour which they had not predicted, such as changing their handwriting.

The fact that some parents clearly indicated that they could not live without the medication suggests that parents viewed the biological basis of ADHD as very important. Although this issue only affected a small number of parents, two families were felt to be 'addicted' to the effects of medication. This dependence sometimes seemed to be exacerbated by professionals, who often increased the dose of medication as children became tolerant to its effects, which may have reinforced this understanding of the disorder. This resulted in some children taking four or five Ritalin tablets per day, which raises the additional concern that children may have been experiencing side-

effects to the medication. Indeed, the behaviour and social interaction of one child who was given a dose of Ritalin prior to coming into the interview was noted to alter significantly as the effects of the drug were experienced. The mother justified this change by commenting that she was much more able to manage her child's behaviour when her child was on the medication.

Finally, although all children had taken Ritalin at some time, a number of children were not taking it at the time of interview. Parents reported that this was because of the side-effects they had noted in their sons, such as their sons becoming withdrawn and depressed whilst taking the medication. Although this does not necessarily challenge parents' views about the nature of ADHD, it might suggest that parents were responding to the concerns about Ritalin which their families had displayed.

Children's discussion of difference

Children's discussion of difference also described how they believed there to be a biological cause for their behaviour. This is perhaps unsurprising, given that their parents believed this to be the case. Two children specifically discussed how 'brain damage' sometimes led other children to behave in certain ways, and one child suggested that there was something wrong with the frontal lobes of his brain. Although these two children did not refer to this issue in relation to themselves, instead choosing to discuss these differences by referring to each other, each clearly linked the irritating behaviours of the other to a biological condition.

Children also described how they were bullied at school because they took tablets. The names that these children were called by other children, such as 'crazy', 'lunatic', and

‘mad’, also indicate that their peers at school associated their behavioural difficulties with other disorders for which a biological basis is often considered. One boy reported that his peers and siblings called him ‘peanut brain’, which again clearly indicates that brain-related factors are thought to contribute to his behaviour. Another child commented that his peers had told him that he would have to go to a ‘loony bin’ because he took medication.

There was therefore a link for these children between their behavioural difficulties, the fact that they took medication, and the perception that they had a biological disorder. Whether this link would have been so strong if the children were not taking medication is unknown. It is possible that peers were referring to the fact that children took medication, rather than that their behaviour was different, when they made these comments. Further research of this issue may reveal some interesting ideas.

Discussion of biological view

There is therefore a great deal of evidence which suggests that parents’ and children’s understanding of ADHD is influenced by biological theories. There are a number of reasons why these ideas might have developed, which will be discussed in terms of (1) ADHD as a biological disorder, (2) dominance and power in medicine; and (3) mothers’ psychological distress.

ADHD as biological disorder

There is a vast amount of research suggesting that ADHD is indeed a disorder with a biological basis. As outlined in the introduction, studies have suggested that ADHD is related to a variety of neurological or neurochemical abnormalities, many of which may

be genetically mediated. Although no one particular marker for the disorder has been identified, it is clear that a great amount of research has been undertaken looking for this, and that many clinicians and researchers in the field believe this to exist. The fact that children diagnosed with ADHD show a positive response to psychostimulant medication has been used to support this biological understanding by highlighting the likelihood that the central deficit in the disorder is one of the neurotransmitter dopamine.

This belief about ADHD is now widespread in mainstream medical practice, as well as being common to a range of professionals working with children, such as other health professionals and education services. This understanding of ADHD has also been spread by the media, and there have been many documentaries and television programmes supporting this link. These programmes often detail the difficulties of parenting a child with ADHD and highlight the role of Ritalin as the key element in any treatment program, thus further disseminating this belief. Although behaviour modification is also recommended by practitioners in the field, other forms of psychological intervention, such as family therapy, are often discouraged as not fitting with this medical understanding, and some television documentaries have been actively hostile towards the suggestion that family therapy would be beneficial.

It is therefore unsurprising that this perspective has been so pervasive in influencing parents' views of the disorder. Indeed, it is perhaps more surprising that parents were so strongly criticised by teachers and family members for considering their sons' difficulties in this way. A discussion of how the medical profession has come to consider ADHD in this way is described below.

Dominance and power in medicine

It is perhaps unsurprising that parents accepted the medical explanation of their sons' difficulties given the dominance and power of medical practitioners in Western Culture. Although in mental health services a gradual assimilation of ideas from sociological and psychological frameworks is apparent, in general, the assessment and treatment of problems such as ADHD continues to occur from a predominantly medical viewpoint. Even non-medically trained practitioners, such as psychologists and psychotherapists, are influenced by these ideas, as represented by the widespread use of medically based diagnostic labels, and classification systems such as DSM-IV and ICD-10.

In addition, the influence of the medical view of ADHD may be so widespread because, on the surface, ADHD is a clear, straightforward and unambiguous diagnosis. According to DSM-IV, there are a number of discrete behavioural patterns which represent the disorder, which, providing they cannot be accounted for by any other diagnosis and providing they cause significant distress and impairment, can be assumed to be indicative of the ADHD condition. However, diagnosing disorders such as ADHD is clearly not this straightforward, and the lack of clear diagnostic markers makes the issue particularly difficult. The fact that many children in this sample were given dual diagnoses testifies to this difficulty, and suggests the overlap between symptoms of ADHD and other disorders. Although, on the surface a diagnosis of ADHD may appear to be reliable, in fact it is often highly subjective. However, parents did not seem to be aware of this, as indicated by their belief that ADHD could be reliably diagnosed with a blood test and treated effectively with drugs.

The information given to parents, by professionals, about ADHD is also likely to have affected their understanding of the condition. The reliability of this information may be questionable. For example, despite the fact that no one particular scan can identify ADHD, one parent had managed to persuade a private medical doctor to take a scan of her son's brain, in order to 'prove' that her son did have ADHD. It seems that this professional was mistaken in his or her belief about the validity of using scans for diagnosis, and the fact that the scan was taken may have reinforced the myth that ADHD could be diagnosed in this way. Other parents also reported being told information about ADHD which is inaccurate. For example, one family was told that their son might have ADHD or Asperger's syndrome, and that the way to differentiate the two was to assess his response to Ritalin. Here again, the professional is inaccurately assuming that response to medication is an effective way of identifying ADHD. Similarly, another mother reported that her son had been diagnosed on the basis of a blood test. Finally, two families were told to simply increase the dose of their sons' medication when it stopped working. These boys were currently taking four to five tablets of Ritalin per day. This view of treating ADHD is clearly linked with a biological understanding of the disorder.

Mothers' psychological distress

Although this hypothesis is speculative, it is also possible that mothers' anxiety and psychological distress for their sons' well-being contributed to their understanding of the difficulties as being biological in origin. It is clear from the comments made by mothers that many were experiencing deep psychological distress, including feeling suicidal and believing that they were going mad, which they attributed to the difficulties they were experiencing with their sons. This distress was exacerbated by

parents' perceptions that others, for example family and friends, did not view these difficulties in the same way, and mothers clearly felt unsupported in their battles to gain a medical diagnosis for their sons' difficulties. The psychological distress might have contributed to their understanding of ADHD by (1) making them resistant to any suggestion that parenting factors were also involved; (2) increasing their need to find a biological cause; and (3) exonerating them from blame.

It is likely that the deep emotional distress experienced by mothers around the time of diagnosis may have affected how they assimilated information about the disorder. For example, whether professionals considered ADHD to be purely biological or not, it is possible that some parenting issues were involved in the difficulties many parents were experiencing. Ideally, this would have been addressed with parents when given the diagnosis. However, it is possible that professionals avoided this discussion, either because they did not think it necessary, or because they did not feel parents would be responsive to this suggestion. Discussion of parenting difficulties can be difficult because of the experience of blame it can evoke. In order to avoid the difficulties inherent in this process, therefore, it may have been easier for the person making the diagnosis to simply focus on the biological elements of the disorder.

Similarly, it is possible that the diagnosis of ADHD may also have been made in order to pacify parents' concerns, or may reflect a feeling of exhaustion by professionals.

Many of the mothers appeared to be on a 'crusade' to get a medical diagnosis, and one mother specifically took her son to five different professionals in order that he would be given the 'correct' diagnosis. What actually happened in this case was that the boy was given a number of different diagnoses by different professionals, so that he

eventually had diagnoses of ADHD, Asperger's syndrome, dyspraxia and learning difficulties. It therefore seems possible that some of the diagnoses she was given were simply the result of her persistence and curiosity, rather than the fact that any one disorder particularly described her son's difficulties. The suggestion here is that some professionals may be making diagnoses in order to pacify angry or anxious parents, although it must be stressed that this suggestion is speculative. This issue highlights the importance of research into the diagnostic process.

Finally, the view that their sons' difficulties were biological in origin may also have been influential because it exonerated mothers from blame. Many mothers reported that, prior to diagnosis, they had experienced blame for their sons' problems from many people. All parents commented that getting the diagnosis had been a relief, and many specifically stated that the relief was linked with the fact that it meant they were not incorrect in their beliefs about their sons. Mothers reported that they experienced the diagnosis as concurring with their own beliefs about the causes of their sons' difficulties, which meant that the responsibility for these difficulties was not attributed to themselves.

Summary

This section has outlined parents' understandings of ADHD. Parents seemed to favour the biological theories of the disorder, as indicated by their discussions about noticing these differences from birth, describing the many ways in which their sons were different, and the efficacy of medication. Children also appeared to concur with this view, suggesting that biological factors caused them to behave in certain ways. This biological understanding has been discussed in terms of three factors: (1) ADHD as a

biological disorder; (2) dominance and power in medicine; and (3) mothers' psychological distress. In the following section, society's understanding of ADHD will be reviewed.

Sociological views of ADHD.

It is clear from the interview material that mothers believed the battles and the blame they experienced to be linked to other peoples' beliefs that parents were responsible for their sons' difficulties. This section will review mother's evidence for this belief, and suggestions will be made about why others might view ADHD in this way. Again, it is important to stipulate that this discussion centres on mothers' perceptions of others' views, and that further research is necessary to understand whether others did view ADHD in this way and, if so, what the reasons for this view were.

Blame

One of the key experiences of the parents in the study was the issue of blame, which was reported by all mothers in the sample. Blame was problematic because parents believed it to be a rejection of their views on the biological causes of their sons' difficulties. Parents reported being blamed by a number of people, including their sons' teachers, health professionals, family members and the general public. Mothers reported that they were often told there was nothing wrong with their children, and that they simply needed some firm boundary setting.

Teachers were considered to be particularly resistant to the biological models of ADHD, and parents commented that teachers often explicitly stated that their sons' difficulties were the result of mothers' incompetence. This is interesting in view of the

fact that teachers too were having difficulty managing these children, although this finding may be explained by the fact that teachers had the option to blame mothers, whilst mothers had no-one else to blame. Mothers-in-law were also likely to blame parents, suggesting that they should simply smack their children in order to improve their behaviour. Mothers reported that the greatest problem with blame, however, came from the general public, who frequently made comments to them about them needing to control their children more effectively. Parents responded to these comments by discussing the issue of ADHD being a 'hidden disability'. Here they compared ADHD with other forms of disability which were clearly visible, such as Down's Syndrome, and suggested that one reason for the lack of social acceptance for ADHD was that it could not be so clearly seen as a disability. The fact that mothers considered ADHD to be a disability also has important implications for understanding their views of the disorder, and use of this term may represent an attempt to medicalise the condition.

Parents also felt blamed by some health professionals. Although all of the children had been given a diagnosis of ADHD by a medical doctor, it was clear that there was some disagreement between various medical doctors about whether these boys' difficulties were genuinely due to a biological disorder or whether parenting factors were the primary cause. Some professionals refuted existing diagnoses of ADHD, and told parents that there was nothing biologically wrong with their child. Parents found these comments confusing, and the two families affected by this situation returned to their original doctor and had the diagnosis reinstated.

Battles

The battles fought between parents and others were also thought to reflect the issue of understanding ADHD. For example, parents fought battles with their partners, family members and health professionals over the validity of the ADHD concept.

Some parents reported battles occurring between themselves and their husbands about their children's difficulties. Most mothers felt that their husbands could see the differences they were discussing, but that they did not share mothers' understanding of the differences. Many mothers commented that fathers simply felt the behaviour was part of normal development for a young boy, thus suggesting a developmental model of understanding. Some support for this proposal came from the one father in the study, who clearly endorsed this belief by stating that he believed his son's difficulties were linked with parenting factors. For example, this father suggested that his son behaved differently when he was around, and that the difficulties his wife experienced could be because she was too 'soft' with him. Although it is not possible to assess whether other fathers also considered their sons' difficulties to be the result of parenting issues, this is certainly a point worthy of further research, particularly as these different viewpoints may well have contributed to the marital separations and divorces reported by some parents.

The battles parents fought with teachers also seemed to be linked with different models of ADHD. Many parents seemed to have difficult relationships with their sons' teachers, whom they believed to be stricter with their sons, expecting them to behave in a way that parents felt was unrealistic. For example, one mother reported that her son's teacher telephoned her at work and asked her to come to school and take control

of her child. This mother suggested to the teacher that her son had a disorder which made him behave in an unruly manner, and that the teacher should be more understanding of this. This discussion may have reflected two competing views on the nature of this boy's difficulties. A second mother described how her son's teacher had suggested that her son did not need to take Ritalin because there was nothing biologically wrong with him, clearly reflecting a difference in opinion concerning the reasons for the boy's difficulties.

Discussion of sociological views

The experience of blame, and the battles that ensued as a result of the blame, were reported by mothers to indicate their difficulties in gaining acceptance for their views of their sons' difficulties. Rather than acknowledging that the boys in the sample had a biological disorder, parents felt that other people thought the ADHD was simply the result of bad parenting. A number of reasons for why others might have considered this view are presented below, and include (1) the possibility that ADHD was indeed related to poor parenting; and (2) ADHD as the 'diagnosis *du jour*'.

Poor parenting

In terms of the views held by many people that parenting difficulties were responsible for ADHD, it was clear from talking to these parents that some of them were experiencing great difficulty setting boundaries and being consistent with their children. For example, some parents reported that their children would take chocolate bars off the shelves in supermarkets and eat them, or push trolleys down shopping aisles and into people. Because these actions were felt by both these parents and their sons to be under the child's control, behavioural principles of punishment and reinforcement

should have been effective in alleviating this kind of behaviour if they were in fact controllable. Similarly, the situational variability in the behaviours of many children, for example the fact that mothers reported that children generally behaved much better when they were with their fathers, would suggest that the views held by many people about possible the link between parenting difficulties and children's behaviour may have been correct.

Although the parents in the study did not report problems with setting boundaries for their children, it is possible that other significant adults in the child's life did believe this to be the case. For example, of the nine mothers in the study, five reported that their mothers-in-law were critical of their child-rearing practices, and directly suggested that these practices accounted for their sons' difficulties. Similarly, the fact that some teachers suggested to parents that they should take their children off medication because their behaviour could be modified and improved without it suggests this view.

However, the suggestion that ADHD is simply a disorder of bad parenting is certainly not a useful clinical hypothesis. This idea is clearly likely to alienate parents from help, and establish resistance to further intervention. Many parents attending services for help with managing their children will simply feel blamed if this idea is raised as a significant issue. Instead, alternative ways of understanding ADHD are needed (see the section on clinical implications below).

'Diagnosis *du jour*'

Hinton and Wolpert (2000) have described how ADHD has become a 'Diagnosis *du jour*'. They suggest that the problem with the diagnosis, and the fact that parents feel blamed by it, is that the label is simply a description for a group of behaviours, rather than a means for understanding the causes of the condition. The fact that the term is widely used to describe many children with a wide array of behavioural difficulties also serves to raise questions about the nature of the disorder. Although it is assumed that the biological basis for the disorder is clear, as outlined earlier, this is not the case. This has led to a great deal of scepticism about the condition, and whilst attempts to understand its causes continue, it is possible that parents in the meantime are looked upon as being to blame.

It is also possible that the emergence of more sociological models of ADHD may be influenced by a natural social trend away from biological explanations for human difficulties. The influences of social constructionist ideas on different types of mental health difficulties in adulthood, such as schizophrenia, has clearly become more widespread in the past ten years. This movement has criticised the dominance of the medical perspective for both its reductionist and linear approach to understanding complex human experiences, and for not truly examining the many factors involved in the expression of 'disorder', including the social factors influencing conceptualisations of normality *per se*. These ideas are as applicable to childhood disorders as they are to those affecting adults, and theories of ADHD seem to resonate with this view.

Although a discussion of social trends is beyond the scope of this study, it is perhaps timely to mention the possible influence of the James Bulger murder case on these theories (see Coppock, 1997). In writing their reports on the boys responsible for the

death of James Bulger, psychiatrists commented on the emotional and social deprivation that these boys had experienced. Rather than being linked with a discrete disorder, this crime was considered the result of neglect, poverty and exposure to violence, considered to reflect both a failure of parenting and a failure of society at large to meet the needs of these boys. This case therefore highlighted how abnormal behaviour could be accounted for by social factors, and did not necessarily suggest the presence of an innate disease model of causation, thereby presenting alternatives to traditional medical approaches which may have influenced current conceptualisations of 'abnormal' behaviour.

Integration of biological and sociological views

The theory outlined here suggests that parents were concerned about the discrepancy between their views about ADHD, and the views they perceived others to hold, and that this issue was at the heart of the battles they encountered. From the interview material looking at adjusting, it also seems likely that whilst some parents rigorously held on to their belief in the biological basis of the disorder, others were clearly more able to assimilate ideas from both views. Evidence that suggests an assimilation of views includes: (1) the internal battles over Ritalin; (2) parents' questions about the diagnosis; (3) parents' questions about the causes of the disorder; (4) children's experiences; and (5) parents' self-blame.

The internal battle over Ritalin appeared to reflect parents' difficulties reconciling the two competing views of ADHD. For example, all of the parents commented on the improvements noted in their sons' behaviour on Ritalin. These included improvements in concentration and attention, as well as in general behaviour and social interactions.

However, parents were also very concerned about the negative effects of the medication, which included depression and withdrawal. In addition, parents were acutely aware that their families, their sons' teachers, and some professionals were not in favour of their sons taking the medication. Some professionals, particularly GPs, refused to give repeat prescriptions of the drug, and one parent was refused Ritalin by two medical doctors before a third agreed to prescribe. These views about the safety and necessity of Ritalin may have influenced parents' views about giving it. It is suggested that this concern about the competing views on ADHD was reflected in parents' decisions to take their children off medication, although further research is required to investigate fully whether this was so.

Parents' questioning of the diagnosis was also thought to reflect a concern about their biological beliefs about the disorder. Although not all parents asked the researcher her views on the disorder, some were clearly interested to know her views and also had their own questions about the validity of the concept. For example, one mother specifically asked the researcher whether she 'believed in' the disorder, whilst another parent wondered why there were so many children diagnosed with the disorder at present, and where these children had been ten or twenty years ago. The one father in the study clearly expressed scepticism about the validity of the disorder, suggesting that it was simply a means of describing certain children who behaved in certain ways, rather than being a truly biological condition. Perhaps it is surprising that this father had not decided to take his child off medication, although he clearly had concerns about the value of giving it to his son.

It was also observed that, despite the fact that parents had received a diagnosis of ADHD which accounted for their sons' difficulties, many parents continued to ruminate about, and discuss, the many ways in which their sons were different. It appeared that for these parents, the diagnosis of ADHD served as a useful description for their difficulties, but did not address parents' need to fully understand the condition. Repeated discussions of the different behaviours may therefore represent parents' attempts to understand the condition, in light of the competing views about its aetiology.

As outlined under the adjusting category, many children in the sample felt that they could control their behaviour. This is important because it may reflect the fact that these children were also able to integrate sociological views of ADHD with the biological views. The fact that children reported they could control their symptoms of ADHD suggests that they may believe that ADHD is not simply a biological disorder over which they have no control. One child reported that he chose to 'go hyperactive' when he was bored, and that he would choose certain places in which to go hyperactive. Other children reported that they behaved in certain ways because it was fun, whilst others clearly understood the implications of what they were doing, and indeed had often planned a certain behaviour in advance. The idea that this may represent an alternative view of ADHD from a purely biological one is supported by other comments made by the children, one of whom stated that he 'didn't know' that he had ADHD, because he felt that he was normal, whilst another stated that he did not need the medication because he could manage his own behaviour without it.

Finally, it is suggested that the comments made by parents in which they blamed themselves for their sons' difficulties also indicated that they were assimilating biological with sociological views of their sons' difficulties. This self-blame seemed to occur after parents had experienced being blamed by others, and included parents commenting both about social factors which might contribute to their sons' problems, such as whether they went back to work too early, and indeed about biological factors, such as whether rogue genes had been transmitted from themselves or their partners to their sons.

This section has been used to suggest that some parents were gradually starting to integrate biological with sociological understandings of the disorder. The integration of the perspectives for some appears to have been useful for moving towards an acceptance of their sons' difficulties. Some parents appear to have been forced into this position from the competing views about ADHD, whilst others may well have been considering these views since diagnosis. However, some parents were firmly adhering to the biological understanding of the disorder, and the parents in this position seemed to have the most difficulty managing their children's behaviour. For example, the two families considered to be particularly 'stuck' in the biological framework were those for whom Ritalin was considered the only solution to their sons' difficulties, and who clearly were dependent on the effects of this medication.

Overview

This section has discussed the competing views about the nature and causes of ADHD. In the following sections, the clinical implications of these findings will be addressed, as well as implications for further research and links with previous studies in the area.

Finally, a section on the process of interviews and the development of this theoretical model will be presented, in which the researcher will reflect on her experiences of the research process.

Clinical implications

Two particular clinical implications are addressed here. These include: (1) the need to help parents understand the different views of ADHD, in order to minimise the experience of blame and the battles; and (2) the need to develop consistency between professionals about the nature of ADHD.

In order to enhance parents' understanding of others' views it is suggested that, when making the diagnosis, clinicians should ensure that an open and honest discussion about the nature and causes of ADHD is held. This may help parents both understand the condition and understand where the scepticism that exists about it has arisen. Some of the parents in the study would probably have benefited from such a discussion at the time of diagnosis, rather than holding this discussion with the researcher some time after the diagnosis had been made. Included in this discussion should be the issue of Ritalin, and it is suggested that this should be offered as a form of treatment in conjunction with, and not instead of, behaviour therapy. Parents' understanding of others' views of ADHD might also benefit from them being given information about the effects of Ritalin on people both with and without a diagnosis of ADHD. The experience of blame may be minimised if this discussion also raises the issue of the diagnosis being a label and a description, but not a cause of the condition.

Given that parents have already experienced many battles over this issue, and will be very wary about the issue of blame, any discussion about ADHD should be undertaken in a sensitive and respectful manner. Family therapy or parenting skills classes are likely to reinforce the issue of blame, and so are not likely to be experienced as helpful. However, it might be more helpful for parents to meet other parents affected by the disorder, and discuss the competing views about ADHD with other parents, as well as with clinicians in the field. This would serve to avoid attributions of blame being experienced from professionals, and may enable enhancement of integration of ideas about ADHD.

One way of achieving this aim for the participants in the present study could be through a group meeting held between the researcher and the parents involved in this study. The meeting could be convened to discuss the results of the study, and parents could be asked to give feedback on whether the data resonated with their experiences. This would both provide parents with exposure to alternative views, and enable a discussion about ways in which services could be improved to meet their needs.

In addition, the need for consistency between professionals is highlighted. Many of the difficulties parents experienced seemed to be related to their belief that professionals were inconsistent in their diagnosing of the disorder, and that professionals themselves disagreed about the nature of the condition and whether their sons met criteria for the disorder. This exacerbated parents' difficulties because it evoked feelings of blame and led to battles between themselves and professionals. It is therefore suggested that some clear guidelines about diagnosing ADHD are drawn up, and disseminated between professionals working with children affected by the condition. It is also recommended

that multi-disciplinary assessments of ADHD are made, so that the understanding of each child's difficulties is shared between health and education services, and is consistent with parents' views of their sons' difficulties.

Research implications

Some of the categories revealed in this study linked well with the findings from previous studies. However, the overall theory developed is an advance on those outlined by Kendall and Byram.

A number of issues reported by Kendall and Byram were replicated in this study. For example, Byram's finding that for children 'control' was an important issue was replicated here, as indeed was the suggestion in Byram's study about blame. Kendall's study focused on the issue of disruption, which has also been found to be central in this study, in terms of the battles parents and children experienced and the effects of the difference. There is now a growing body of knowledge about the experiences of children with ADHD and their parents. For example, the fact that children from two different populations and of different ages have commented on being able to control aspects of their behaviour suggests that other children with ADHD may also feel able to do so, although without further research into this, it is not possible to say whether this is simply a perception, or whether this is in fact true. Similarly, disruption is obviously a key experience for these parents and their children, which is perhaps unsurprising given the nature of the condition. Outlined below are a number of suggestions for further research.

A number of areas for further research are indicated, such as (1) research into whether the diagnostic process affects parents' understanding of the condition; (2) research into factors influencing fathers' understanding of ADHD; (3) research into factors affecting how parents integrate the two views; and (4) research into whether the competing views affected parents' decision to take their sons off medication.

Further research into the diagnostic process, perhaps involving the professionals making the diagnosis, might enable greater understanding of how parents formed their views about the biological basis of the disorder. This research might usefully reveal whether professionals are influenced or affected by parents' distress in making their diagnosis, as well as addressing whether the information about ADHD given to parents is indeed accurate. Of particular interest would be the explanations given by professionals about the nature and causes of ADHD, and their descriptions about the efficacy of psychostimulant medication.

Research into fathers' understanding of ADHD would be useful for addressing whether the sociological models discussed by the one father in this study were replicated elsewhere. If so, this interesting gender divide could be usefully explored by considering issues such as whether fathers' experience of blame is different to mothers' and, if so, whether this is linked with their status in society, or the amount of time they spend with their children. In addition, whether fathers' involvement in the diagnostic process influences their understanding of ADHD is a further area of interest. Initially, though, replication of fathers' sociological understanding of ADHD is necessary.

Understanding how some families manage to integrate competing views about ADHD, whilst others have difficulty moving away from a purely biological model is another important area for further research. Whether certain intrinsic factors affect families' ability to integrate competing views is unknown, but may be important for identifying how to help families come to a more balanced view of the condition. For example, factors such as locus of control, pre-existing beliefs about mental health, or experience of children with behaviour problems might influence these beliefs, and could be usefully explored.

Finally, the issue of whether parents' decision to take their sons off medication is representative of changing views on ADHD is worthy of further research. Indeed, whether their perceptions and concerns about Ritalin influence their beliefs about the disorder is another interesting point. These suggestions highlight the need for further qualitative research in this area. This research study has demonstrated how qualitative research can be used to reveal both interesting and new findings, and to enable adults and children to generate rich descriptions of their experiences. Further research of this type could usefully explore these other areas of importance.

Methodological issues

It is important to address a number of methodological limitations to the study. These will be considered in terms of the sample, data collection and data analysis.

The sample

A number of issues will be discussed in terms of the sample. These include (1) the demographic characteristics of the parents; (2) the issue of non-respondents; (3) the additional diagnoses held by some children; and (4) the lack of paternal reports.

The key issue to be discussed in terms of the sample concerns the issue of how representative it was of the general population. This is an important issue because it may affect how far the results from this study can be generalised to other families affected by ADHD. From demographic data collected at the time of interview, it emerged that all mothers were white, and that 70% of mothers were social class IV and below. Although it is well known that ADHD affects families from predominantly white working class backgrounds (see chapter one), it is important to note that this sample may not be reflective of the views held by parents from different social and ethnic backgrounds. Care should therefore be taken when generalising from the population studied, and further research involving families from different backgrounds is indicated.

In addition, it is important to recognise that the nine families who agreed to participate in the study constituted only half of the families who were invited to attend. This raises the possibility that those who did participate were a select group who were already interested in understanding ADHD, or who wanted to share particular experiences they had found traumatic. Obviously it is not possible to assess why other families did not participate, although it is possible that non-participation reflected a lack of concern about the differing views of ADHD or good adjustment to the condition. Again this indicates that care should be taken when generalising from the results of the study.

It is also important to recognise that many of the children involved in the study did not have a pure diagnosis of ADHD. Some children had at least one additional diagnosis, whilst others had two or even three additional diagnoses. Although co-morbid disorders are common amongst children with ADHD (see chapter one), it is important to consider that some of the experiences reported by the children may be related to these co-morbid disorders. For example, some of the name calling that children and parents reported may have been related to learning difficulties rather than ADHD. Further research involving children with a pure diagnosis of ADHD would be useful for assessing the impact of the diagnosis of ADHD *per se*.

Finally, it is important to recognise that only one father participated in the study. Although common themes and experiences emerged from the interviews with the nine mothers, it is not possible to assess whether fathers would have reported similar experiences, or whether other issues are more important for fathers of children with ADHD. Further research with fathers is necessary to develop a fuller picture of parents' experiences of living with ADHD.

Data collection

It is also important to reflect on the process of collecting data, and the difficulties that arose during this process. Three particular issues will be addressed (1) the difficulty obtaining information from children; (2) parents' concerns about the researcher's views of ADHD; and (3) parents' experiences of other professionals and expectations of the researcher.

One of the most significant difficulties of the data collection process was obtaining information from children. This was particularly difficult when the children had additional diagnoses of Asperger's syndrome or learning difficulties. Some of these children provided very short, one-word, answers to questions which made it difficult to develop a theory from their responses. Although on one occasion a story was used to elicit more information, the researcher was aware that this process might affect the reliability of the information given, and so did not want to use this method repeatedly. Instead, attempts were made to phrase questions in different ways, and to ask children to elaborate on their answers. One possible explanation for this difficulty was that some children had been given a dose of Ritalin prior to the start of the interview, and this was known to have been the case for one child. These difficulties highlight the need for more creative methods for eliciting information from children which, whilst allowing flexibility in responses, can also be standardised and measured reliably. Researchers might also consider whether they interview children prior to taking Ritalin, or interview children who are not currently taking medication.

A second difficulty of the data collection process was the issue of ensuring engagement and rapport with parents whose views of ADHD differed from those of the researcher. For example, some parents believed that the only method of treating ADHD was with medication, and questioned the researcher's belief that behavioural measures could also be useful. The researcher responded to this issue by highlighting her interest in parents' own views about why they might feel behavioural management was ineffective, rather than entering into a debate about whose views were more accurate. This issue highlighted the controversy about the nature of ADHD and stressed the

importance for researchers to be able to accommodate many potentially competing views about the condition.

A final difficulty of the data collection process was the issue of ensuring that participants genuinely felt that they were able to report their own experiences honestly, without feeling judged or blamed for the difficulties they were having. For example, some parents expressed concern that what they were saying might have caused the researcher to be concerned for the safety of their child. Others reported that they were concerned their children would say things during the interview which might reflect badly on them as parents. The researcher attempted to overcome this difficulty by highlighting the importance of parents giving their own accounts of their difficulties, without trying to conceal information which could be important. The researcher also suggested that if parents were concerned about their actions or behaviours, it might be helpful to discuss these concerns and receive advice and support from the Child and Family service if necessary.

Data analysis

Finally, it is important to highlight difficulties with the process of data analysis. A number of 'good practices', based on Elliott et al.'s (1999) guidelines for qualitative research, and Yardley's (2000) characteristics of good qualitative research, were used to guide this process but inevitably it was not always possible to overcome some difficulties.

Firstly, Elliott et al. recommend that the researcher should state his or her own interests and assumptions about a subject matter before attempting to analyse any data.

This process is described as ‘owning one’s perspective’, and is important for establishing whether the values of the researcher have influenced the description and labelling of the categories identified or the theory developed. The researcher included a section on her experiences of ADHD, in particular her understanding of the different models of ADHD, in the discussion section, once this issue had emerged as important. This section enabled readers to understand the researcher’s own views on this topic, and so be able to evaluate her interpretation of the data, and any possible alternatives to her interpretation.

Secondly, Elliott et al. suggest that the researcher ‘situates the sample’. This refers to the importance of describing the research participants and their life circumstances so that it is possible to assess how far the findings from one study can be extrapolated to other populations and situations. Characteristics of the sample were presented in chapter two, and the issue of generalising from this population to others was discussed in this section.

Thirdly, Elliott et al. highlight the importance of grounding the emerging theory in examples. This process ensures that the existing theory has been developed from the participants’ accounts of their experiences, rather than simply being the ideas of the researcher. These examples may include quotes relating to different concepts and categories from the open or axial stages of coding, as well as examples of the final theory. This process aims to achieve what Yardley has termed ‘transparency’, so that each aspect of the process of theory development can be analysed by the readers. Attempts were made to achieve transparency in this project by providing many

examples of quotes from parents and children to support the categories that emerged from the data.

Fourthly, Elliott et al. suggest that credibility checks are undertaken. This refers to the process of checking the data to ensure that the categories yielded and the theory developed resemble the experiences of the participants. This can be achieved by having multiple people analyse the data. In this study, two clinical psychologists provided credibility checks. These individuals were given a number of transcripts to read, and were asked to code the transcripts in the ways outlined above (i.e. open and axial coding). A discussion was then held between the researcher and the checker relating to the theory developed.

Fifthly, Elliott et al. highlight the importance of ‘coherence’. By this, they are referring to the importance of the data fitting together into an integrated theory, rather than simply being a list of concepts or categories. They suggest that this process is aided by the use of diagrams with feedback loops depicting relationships among categories. The process of moving from individual categories and themes to an integrated theory was outlined in chapter three.

Finally, the ultimate check is undertaken by assessing whether the data resonate with the readers of the theory. This means that both readers and reviewers should feel that the theories described reflect their own experience of the subject matter (for example, of working with families of children with ADHD). Theories which describe very different experiences to those of the readers and reviewers, are likely to be questioned for their reliability. This issue was addressed by discussing the categories and theory

developed with a team of mental health professionals including a psychiatrist and clinical psychologist at the Child and Family Consultation Clinic where the research interviews were held.

Although these checks were used to ensure the quality of the theory developed, it is also recognised that a number of alternative methods exist, which were not used in this study. These include the use of a 'paper trail' (Smith, 1996), which involves checking that a coherent chain of argument runs from the initial raw data to the final list of themes. A person familiar with the research, but obviously not the researcher, undertakes this process. In addition, data checks can also be undertaken through returning to participants and presenting them with the findings from the study. This is known as testimonial validity (Barker et al., 1998) and aims to assess whether the participants feel that the theory has accurately reflected their experiences. Although at the time of writing this report it has not been possible to achieve this aim, the researcher plans to use this method before submitting the report for publication.

In addition, it is felt that some of the methods recommended by Elliot et al. (1999) and Yardley (2000) could have been used more fully. For example, Yardley (2000) recommends 'rigour' when collecting data. By this, she means that the data collection and analysis should be thorough and complete. This is similar to the term 'saturation' which is used in grounded theory to indicate that the researcher has received enough information to have reached a point at which no further new information is likely to be revealed. Although the researcher felt that 'saturation' had been achieved from the adult interviews, it is acknowledged that this was difficult to achieve from the children's interviews, because of the difficulties outlined above. This raises the

question of how complete the data collected from the children's reports were. This is a limitation of the present study.

Reflections on the research process

A number of issues were reflected on during the course of the interviews and data analysis. These reflections were used to develop the theoretical model, and included both my own emotional reactions to the content of the sessions, and the notes I made after the interviews concerning particularly salient discussion points.

One of the first feelings I became aware of was one of frustration with parents who seemed unable to accept their sons' difficulties and the diagnosis of ADHD. Many parents seemed preoccupied with discussing the minutiae of their sons' difficulties, which included discussing many incidents in which their behaviour had been 'bad'. Although this was useful in helping me understand the nature of the boys' difficulties, at times it seemed that the different episodes were dominating the interview, and that no space for discussion of other issues, such as how this affected mothers, was given. However, this feeling was useful as it enabled me to reflect on how parents understood the diagnosis they had been given. This reflection enabled me to consider that the diagnosis *per se* may not have enabled parents to be fully reconciled with their sons' difficulties because it represented a description rather than a cause. This realisation then enabled me to think more widely about how this impacted on parents' experiences, and enabled me to understand more fully why the issue of blame was so frequently reported.

Another useful observation which contributed to the development of the theory was the fact that some mothers were anxious about what I thought about ADHD, whether I agreed with the diagnosis their sons had been given, and what my views on the validity of the disorder were. Although this question required some sensitivity in answering, particularly as I believe that social and biological elements are important in ADHD, I did hold a conversation with some parents about my views of ADHD. The fact that some parents asked these questions indicated to me an awareness that the condition was not viewed by everyone as being biological, and helped develop my understanding of the different views about ADHD which parents believed others to hold.

Another useful observation from the interview process was the realisation that parents were concerned about what I would think of them and their sons' difficulties. For example, some parents stated that they were concerned about telling me about the incidents in which they struggled to manage their sons' behaviour (described under 'battles with children'). I was pleased that mothers did in fact discuss this information as it was useful clinically and testified to the effectiveness of the reassurances I gave. In addition, the expression of these concerns also highlighted for me the difficult relationships that had built up between some of these families and professionals, and the fact that parents expected professionals to misunderstand their difficulties.

Finally, the content of the interviews also alerted me to the sense of sadness and loss experienced by some families. Although I had predicted a lot of anger from families, I had not predicted that sadness would also be an important emotion. This was particularly important as it alerted me to the fact that parents understood ADHD to be

a disability, which fitted well with their understanding of the medical basis for the disorder. The view of ADHD was not one that I had come across before, and yet was strongly held by the parents in the study.

Conclusion

This study looked at the everyday experiences of children with ADHD and their parents. Only two previous studies in the area have been published, which revealed that issues of disruption and behavioural control were particularly important. A grounded theory approach was used to develop a theory around parents' and children's views of the different conceptualisations of ADHD held by themselves, their family members, professionals and the general public. This theory was discussed in terms of the origins of the different views about ADHD, and the benefits for parents who were able to integrate the views more fully. Clinical implications included the benefits for some parents of being able to assimilate biological and sociological views of the disorder. Research implications included the need for further understanding of how parents and children developed these particular views. This research revealed some useful, original findings which will contribute to the growing body of knowledge around understanding parents' and children's experiences of ADHD.

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Appendix I:
Letter of invitation

Family Consultation Clinic
Dunstable Health Centre
Priory Gardens
Dunstable
LU6 3SU

Date as postmark

Dear

At the Family Consultation Clinic we are undertaking a study of children with Attention Deficit Hyperactivity Disorder (ADHD) and their parents. We are interested in finding out how ADHD affects parents and children, how parents and children cope with the disorder, and what feelings about the disorder they have. Very little research has been done in this area, and it is important that we listen to families' experiences in order to form ideas about how best to help them.

The study involves meeting parents and children on two occasions, firstly to provide information about the study, and secondly to talk about what it is like to have, or live with someone who has ADHD. Parents and children will have the opportunity to ask questions before the start of each meeting, and consent will be obtained from both. Each interview will start with some general 'getting to know you' questions, which for children may involve talking about their family, friends and school.

The meetings will last for approximately 50 minutes for parents and approximately 30 minutes for children. We understand that some children may find it difficult to concentrate for this long, and will adapt the length of interview according to your child's needs. The interviews will usually take place at the Family Consultation Clinic in Dunstable, although it may also be possible to meet families in Luton. A waiting area would be provided for parents and siblings when children are being interviewed. The meetings would be tape recorded so that the information can be looked at in more detail afterwards. However, all information given during the meetings will be confidential and the tapes will be destroyed once the study is complete.

Participation in this research is entirely voluntary and your treatment from the Edwin Lobo Centre will not be affected whether you choose to enter the study or not.

Should you agree to participate and then change your mind, you are free to opt out at any point.

If you feel that you would be interested in participating in this study, please complete the enclosed slip and return to me in the envelope provided. I will then contact you by phone and explain a little more about the study, and we would then arrange a time for a meeting. Please feel free to ask questions at any point.

Yours sincerely,

Alexandra Harborne, Clinical Psychologist in training
supervised by Miranda Wolpert, Consultant Clinical Child Psychologist, Bedfordshire
and Luton Community NHS Trust and Linda Clare, Lecturer in Clinical Psychology,
University College London.

Please fill out the slip below and return in the stamped addressed envelope

Name of parent : _____

Name of child with ADHD: _____

Date of birth of child with ADHD: _____

Telephone contact number: _____

- Yes I would be interested in finding out more about the study
- No I would not be interested in finding out more about the study

Thank you

Appendix II:
Covering letter

Liverpool Road Health Centre
9 Mersey Place
Luton LU1 1HH
Tel: 01582 708100 Fax: 01582 708101

Date as postmark

Dear Parent

There is currently a research study of children with ADHD taking place in Luton and Dunstable. The study is organised by Alexandra Harborne, Clinical Psychologist in training, and Miranda Wolpert, Consultant Clinical Child Psychologist, and is based at the Family Consultation Clinic in Dunstable.

The study is called 'Living with Attention Deficit Hyperactivity Disorder (ADHD)' and its aim is to find out what it is like to have ADHD, or to be a parent of a child with ADHD. The researchers hope to talk to parents and children directly, and are particularly interested in how families cope with the disorder.

I have been asked by the study organisers to forward details of the study to parents of children who have attended the Edwin Lobo Centre. The researchers are keen to hear from anyone who would like to be involved in the study.

Yours sincerely,



Dr Pauline Hey

Community Consultant Paediatrician.

**Appendix III:
Reminder letter**

**Family Consultation Clinic
Dunstable Health Centre
Priory Gardens
Dunstable
LU6 3SU**

Date as postmark

Dear Parents

You may remember receiving a letter from the Family Consultation Clinic concerning a research project looking at family experiences of Attention Deficit Hyperactivity Disorder (ADHD). This letter is simply a reminder to those parents interested in taking part.

The study involves meeting parents and/or children on two occasions and having a short discussion about what it is like to parent a child with ADHD or to be a child with ADHD. Interviews are held at times convenient to parents and the content of the interviews is kept confidential.

Although this letter is a reminder, participation in the study remains voluntary, and your decision will not affect any treatment you have from either the Edwin Lobo Centre or the Family Consultation Service now or in the future. If you would like to take part, please complete the slip below and return in the envelope provided. If we do not hear from you, we will assume that you do not wish to participate in the study.

Yours faithfully

Alexandra Harborne

Clinical Psychologist in training, working with Miranda Wolpert, Consultant Clinical Child Psychologist, Bedfordshire and Luton Community NHS Trust

Appendix IV:
Consent form

Consent form
for the study 'Living with ADHD'

Part A: To be completed by the investigator

I confirm that I have explained this study both orally and in writing to the participant. I am satisfied that his person is now in a position to make an informed decision about participation.

Part B: To be completed by the participant

Please answer the following questions:

Have you read the patient information sheet? Yes/No

Have you had the opportunity to ask questions and discuss the study? Yes/No

Have you received and understood the answers to your questions? Yes/No

Do you need further information about the study? Yes/No
(if so, please indicate to the researcher)

Do you agree to the interview being tape recorded? Yes/No

Do you understand that you are free to withdraw from the study at any time without having to give a reason for doing so? Yes/No

Do you agree to participating in the study? Yes/No

If you have answered yes to each of these questions, please complete the following information:

Name: _____

Signature: _____

Today's date: _____

Researcher's signature and date: _____

Appendix V:
Semi-structured interview questions

Parents:

Can you tell me what it is like to have a child with ADHD?

How does ADHD affect you emotionally?

How does ADHD affect you practically?

What are the difficulties of parenting a child with ADHD?

What are the strengths of parenting a child with ADHD?

How does ADHD affect your relationships?

Children:

General icebreakers:

Can you tell me something about yourself? Prompt: Who is in your family? Who are your friends? What do you like/dislike about school?

What do you think ADHD means?

What's it like to have ADHD? (good and bad things)

How does ADHD affect you?

What do other people think about ADHD?

How does ADHD affect your relationships?

How do you manage to cope with ADHD?

Appendix VI:
Information sheets

Information Sheet
for parents participating in the study
‘Living with ADHD’.

This information sheet is provided for parents who are interested in taking part in the study ‘Living with ADHD’. The aim of this sheet is to ensure that parents understand (1) why the research is taking place; and (2) what role they will play in the research. It is necessary that you read this information sheet before you agree to participate in the study. Please feel free to ask any questions about anything that you do not understand.

Why is this research important?

ADHD is one of the most common childhood behaviour problems. There has been lots of research into ADHD, but very little of this research has involved talking directly to children with ADHD and their families. We feel that talking to children and families directly is the best way of finding out about their experiences. This information is important for helping us think about ways of helping people who are affected by ADHD.

We know from previous research that ADHD affects everyone in the family: parents, siblings, and, of course, children with ADHD themselves. We are interested specifically in what it is like to live with ADHD, for example, what the particular stresses are and how families adapt and cope with the disorder.

What would your role be?

You will probably be reading this information sheet on your first visit to the Child and Family Clinic. Participating in the study would involve meeting with you one more time. These meetings would involve talking about what it is like to be a parent of a child with ADHD. The meetings would be tape recorded so that the information can be looked at in more detail afterwards. However, all information given during the meetings would be confidential and tapes would be wiped once the study is complete.

These meetings would take place separately (i.e. individual meetings for parent/s and children) and on separate days, so that the researcher has time in between meetings to think about what has been discussed. The meetings are confidential, however, and we would not share what you discuss in the meeting with your child. The meetings would take place at the Child and Family Clinic in Dunstable.

Please note that you are under no obligation to participate in this study. Participation is entirely voluntary. Also, if you choose to participate and later change your mind, you are free to leave the study at any time without having to explain why.

General issues

This research is being co-ordinated by Alexandra Harborne, Clinical Psychologist in training at University College London. The research team also consists of Dr Miranda Wolpert, Consultant Clinical Child Psychologist, Bedfordshire and Luton Community NHS Trust, and Linda Clare, Lecturer in Clinical Psychology, University College London.

The research forms part of the requirements for the Doctoral training in Clinical Psychology at University College London, and has received ethical approval from the South Bedfordshire Local Research Ethics Committee.

If you are happy with the information provided here, you will be given a consent form to complete.

Information Sheet
for children participating in the study
'Living with ADHD'

This information sheet is for children who have heard about our study of children with ADHD. The study is called 'Living with ADHD'. This sheet explains (1) why we are doing the study; and (2) how you would be involved in the study. We need you to read this information sheet before you say that you would like to join in with the study. You can ask any questions about the study at any time.

Why are we doing this study?

We know that lots of children find it very difficult to cope with having ADHD. Some children say that they are picked on at school, and some children find it difficult to make friends. We would like to find out about what living with ADHD is like for you.

We also know that some children don't seem that bothered by their ADHD. We would like to know a bit more about this. For example if ADHD does not bother you so much, what helps you cope with having ADHD?

This information will be helpful for other children who have ADHD.

What would we want you to do?

If you would like to talk to us about ADHD, we would set up a time for another meeting. This meeting would last for about half an hour and would happen here at the Child and Family Clinic in Dunstable. There will be toys in the room for you to play with whilst you are talking to us. We will also have a tape recorder in the room with us, so that we can record what we are both saying. After our meeting, I will listen to our recordings, but no one else will be able to listen to what you have said.

Please remember that you do not have to join in with this study if you do not want to. If you have any worries about joining in, please speak to us today or to your parent.

Thank you