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**“Everything just turned up to maximum volume ...
everything turned up a notch ...”**

**The sibling experience of living with Attention
Deficit Hyperactivity Disorder**

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**Submitted in the fulfilment of the requirements for
the Degree of MSc (Med Sci)**

University of Glasgow

Section of Psychological Medicine

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Abstract

Sibling relationships between children and their brothers and sisters with Attention Deficit Hyperactivity Disorder (ADHD) have been studied infrequently. This study is the first to examine the experiences of a British sample of siblings and mothers of children with ADHD. Semi-structured interviews were conducted with 17 siblings and 15 mothers. Standardised questionnaire measures completed by mothers and teachers revealed that the children with ADHD were experiencing considerable behavioural and emotional difficulties, however, the siblings' difficulties were in line with those expected in a community sample. Mothers reported experiencing high levels of depression and parenting stress. Qualitative analysis of the interview responses revealed that maternal perceptions of conflict in the sibling relationship were similar to those of the siblings, and both reported that aggression initiated by the child with ADHD was a significant part of the sibling relationship. Siblings perceived their sibling relationship as different to those of their friends in terms of the severity and persistence of this aggression. Siblings described managing this aggressive behaviour with retaliatory aggression, requests for paternal intervention, avoidance and accommodation. The majority of siblings considered mothers a source of emotional and practical support. Findings suggest that mothers of children with ADHD should be supported to identify and manage sibling conflict and to recognise and seek help for psychological difficulties they, the sibling, or the child with ADHD might be experiencing.

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Definitions

ADHD: Attention Deficit Hyperactivity Disorder

CAMHS: Child and Adolescent Mental Health Service

DSM-IV: Diagnostic and Statistical Manual

ICD-10: International Classification of Diseases

HKD: Hyperkinetic Disorder

ODD: Oppositional Defiant Disorder

PACS: Parental Account of Childhood Symptoms

POP: Pre-School Overactivity Programme

PSE: Present State Examination

PSI/SF: Parenting Stress Index: Short Form

SDQ: Strengths and Difficulties Questionnaire

1 Introduction

1.1 Attention Deficit Hyperactivity Disorder

The core symptoms of Attention Deficit Hyperactivity Disorder (ADHD) are hyperactivity, impulsivity and inattention and constitute one of the most common disorders affecting children and adolescents (Meltzer et al, 2000). These behaviours occur to some extent in all of us at times, but the difference between ADHD and normal behaviour is the severity and persistence of the problem and the degree of impairment that results. Attention Deficit Hyperactivity Disorder is the term used to describe these symptoms in the Diagnostic and Statistical Manual (DSM-IV) (American Psychiatric Association, 1994) whilst in the International Classification of Diseases (ICD-10) (World Health, 1992) these symptoms are referred to as Hyperkinetic Disorder. Both classifications have similar criteria for the identification of inattention, impulsive and hyperactive symptoms (Schachar & Tannock, 2002) but differ in terms of symptom severity and pervasiveness (Barton et al, 2001) with ICD-10 being the more demanding criteria (Thompson et al, 2004). In this thesis the term ADHD will be used to encompass both diagnostic labels.

The consequences of ADHD for children, their families and for society can be very serious. Children with ADHD can develop poor self-esteem, emotional and social problems and their educational attainment may be severely impaired (Barkley, 1998). In addition, comorbid aggressive, oppositional and defiant behaviours shown by the child with ADHD may place additional stress on family members (Podolski & Nigg, 2001). Living with a child with ADHD may be particularly challenging for families because of the misconception that ADHD is a result of poor parenting (Lewis-Abney, 1993). The negative impact of ADHD on the child itself and their parents has been extensively researched but the impact on siblings needs to be explored (Johnston & Mash, 2001), particularly from the siblings' perspective (Kendall, 1999). To date no research has been carried out examining the siblings' perspective of living with a child with ADHD in a British sample.

In order to review the literature on siblings of children with ADHD, a search of the abstract sources PsychInfo, Medline, British Nursing Index and Cumulative Index to Nursing and Allied Health Literature was carried out for published papers and unpublished PhD theses containing the keywords ADHD/hyperactivity paired with family/families or sibling(s)/brother(s)/sister(s) from 1982 onwards. The references of published literature reviews on families and ADHD were also examined.

1.1.1 Diagnostic criteria

ADHD is characterised by the three core symptoms of inattention, hyperactivity and impulsivity. According to the Diagnostic and Statistical Manual (DSM-IV) (American Psychiatric Association, 1994) in order to meet diagnostic criteria:

“six or more symptoms of inattention or hyperactivity-impulsivity must have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level, some of the hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years, some impairment from the symptoms is present in two or more settings, there is clear evidence of clinically significant impairment in social or academic functioning, the symptoms are not better accounted for by any other mental disorder.”

ADHD is one of one of the most commonly diagnosed psychiatric disorders in children and adolescents, with an estimated prevalence of two to five percent in the United Kingdom (Meltzer et al, 2000) and four to six percent in America (American Psychiatric Association, 2000). This difference is thought to be due to the more demanding diagnostic criteria used in United Kingdom (Schachar & Tannock, 2002). Boys are three times more likely to have ADHD than girls and are six to nine times more likely to be referred to a clinic (Barkley, 1998). Girls are more likely to have symptoms of inattention, but less likely to have comorbid conditions such as disruptive behaviour problems, learning difficulties and social dysfunction (Biederman et al, 2002).

1.1.2 Characteristics

Research has found that children with ADHD are:

“impaired in their relationships with others, their school performance, and competence in extra-curricular activities.” (Szatmari, Offord, & Boyle, 1989)

ADHD is associated with a range of current and long-term impairments (Barkley, 1998). Hyperactive and impulsive behaviours may include: fidgeting, having trouble playing quietly, interrupting others and always being “on the go”. Symptoms of inattention may include: being disorganised, being forgetful and easily distracted and finding it difficult to sustain attention in tasks or activities. These symptoms present in different ways over time (Schachar et al, 2002). Pre-school children with ADHD exhibit motor restlessness and reduced play intensity. Associated problems include developmental deficits, oppositional defiant behaviour and problems of social adaptation. Primary school aged children exhibit

distractibility, motor restlessness, impulsive and restless behaviour. Associated problems include specific learning disorders, repetition of classes in school, aggressive behaviour, low self-esteem, comorbid psychiatric diagnosis like conduct disorder and anxiety, rejection by peers and impaired family relationships. Adolescents show difficulty in planning and organisation. Associated problems include aggressive anti-social and delinquent behaviour, alcohol and drug problems, emotional problems and accidents. ADHD can persist into adulthood and this can be associated with other mental disorders, anti-social behaviour/delinquency and lack of achievement in academic and professional activities. Barkley (1990) reports that no single factor has been found useful in predicting adolescent outcomes of ADHD children; rather several predictor variables have been associated with positive adolescent outcomes including:

"higher levels of family socio-economic status, higher general levels of intelligence, milder ADHD symptoms in early childhood, well adjusted parents and stable family environment, and low incidence of child aggression."

1.1.3 Comorbidity

The diagnosis of ADHD conveys a significant risk for other coexisting psychiatric disorders. A general population sample of 409 Swedish children aged seven years old with ADHD found that 87% had one or more, 67% at least two, and 33% had at least three comorbid diagnoses. Sixty percent of these children with ADHD had Oppositional Defiant Disorder, 7% had Autistic spectrum disorders and 13% had special educational needs (Kadesjo & Gillberg, 2001). In an American clinical sample of 140 girls and 140 boys with ADHD aged between six and 17 years old, 66% of boys and 36% of girls had behaviour disorders, and 36% of boys and 27% of girls had mood disorders (Biederman et al, 2002). Kadesjo et al (2001) conclude that:

"pure ADHD was rare even in a general population sample ... studies reporting on ADHD cases without comorbidity probably refer to highly atypical samples."

1.1.4 Heritability

ADHD has a strong genetic component (Hechtman, 1996; Johnston & Mash, 2001). Biederman et al (1995) found that in a "sample of 84 parents with childhood onset of ADHD, 57% of their children also had ADHD" and siblings have a two to three times greater risk of ADHD than siblings of controls (Faraone & Biederman, 1994).

1.1.5 Treatment

Psychostimulants (c.g. methylphenidate, dextroamphetamine) are the preferred treatment for the core symptoms of ADHD if they are causing significant impairment (Barton et al, 2001) and have been found to improve family functioning (Barkley, 1989). Behavioural therapy for the child and their family, and educational strategies have been found to be useful in the management of comorbidities (Barton et al, 2001). Research has found that treatment of parental ADHD is essential for compliance in medication management of childhood ADHD (Jerome, 1995) and a prerequisite for success of psychosocial interventions (Sonuga-Barke, Daley, & Thompson, 2002). Hechtman (1996) suggests that diagnosing and treating all family members is important for better long-term outcomes for the whole family.

1.1.6 Summary

Mash & Johnston (1983b) suggest:

"the stressful, demanding and intrusive nature of the child's ADHD characteristics are likely to evoke negative reactions from other family member and to exert a disruptive influence on family relationships and the psychological functioning of the parents."

Research has highlighted the importance of examining the impact of ADHD not only in terms of the psychological functioning of the child itself but also the impact of ADHD on relationships within the family, particularly between the child with ADHD and their mothers.

1.2 Sibling relationships

The research into siblings of children with ADHD is limited. Early research simply used the siblings of children with ADHD to evaluate the genetic basis of ADHD or as a control or comparison group for their brothers with ADHD (Hechtman, 1996). However, extensive research in non-clinical samples has found that sibling relationships have been described as being "emotionally ambivalent" – that a typical sibling relation will include warmth as well as conflict (Deater-Deckard, Dunn, & Lussier, 2002). In particular, brothers have been found to be more antagonistic and conflicted and less warm and supportive than sisters (Dunn et al, 1999) and more conflict is found in opposite-sex pairs than same-sex pairs (Epkins & Dedmon, 1999). Activity levels of the siblings have an impact on levels of

conflict and warmth in the relationship. Conflict is greatest when both siblings are high in energy and when the older sibling has higher levels (Stoneman & Brody, 1993). Brody (1998) summarises that children who have hostile sibling relationships which lack warmth tend to show psychological difficulties. All these factors need to be taken into account when examining the research on sibling relationships in special populations and, as there is little information about families with a child suffering specifically from ADHD, the literature on sibling relationships in families with a chronically ill child is discussed first.

1.2.1 Siblings of chronically ill children

Siblings of chronically ill children have been found to suffer from greater emotional and behavioural problems than control children, but often these adjustment problems are not severe (Dunn, 1992). McHale & Gamble (1989) found that although siblings of children with physical disabilities often have higher scores within the normal range for behavioural and psychological problems, these scores are still below the clinical cut-off. Although the findings of research examining siblings of children with chronic physical conditions are inconclusive, this area of research has important implications for sibling relationships in families where there is a child with ADHD, in particular the characteristics of the sibling pair, caretaking by the sibling, siblings' knowledge of the illness and social support for the sibling.

The nature and extent of the problems experienced by siblings are related to characteristics of the ill child. Siblings have been found to do best when the ill child does not display aggressive behaviour (McHale & Harris, 1992). Fisman et al (1996) found that having a warm sibling relationship that is low in conflict can be a protective factor against externalising problems.

Siblings of learning disabled children spend more time in caregiving activities than control siblings, with brothers and sisters of these children spending equal amounts of time caregiving. Siblings with a heavy caretaking burden are more likely to experience emotional and behavioural difficulties (McHale et al, 1989).

A study examining the siblings of children with a chronic illness or a developmental disability found that improved siblings' knowledge about the illness/condition improved sibling well-being (Williams et al, 2002). Sharpe and Rossiter (2002) carried out a meta-analysis of research on siblings of children with a chronic illness and concluded that siblings found information sessions and support groups useful.

Research has suggested that high levels of emotional social support from family and friends appears to play a protective role in the psychological adjustment of siblings of children with chronic illness (Barrera, Fleming, & Khan, 2004; Kaminsky & Dcwey, 2002). In addition, siblings benefit from the peer support of other siblings of chronically ill children (Court, Kearney, & Rogers, 2003).

1.2.2 Siblings in families in which a child has ADHD

Only recently has research into families of children with ADHD examined the siblings' perceptions of the sibling relationship. The majority of this research has focused on mothers' perceptions of sibling interaction and observed mother-child interactions. Fathers' perspectives of the sibling relationship have been examined but not described separately from those of the mothers (Kendall, 1998). Where research has been carried out with fathers and mothers of children with ADHD almost no differences have been found between the two parents in terms of parental self-esteem, perceptions of parenting behaviour and family affective functioning (Phares & Compas, 1992). Although fathers have an important role to play in the family, as mothers are generally the main caregiver, they will be the focus of this literature review and this thesis.

1.2.2.1 Interaction between the child with ADHD and their sibling

Mash & Johnson et al (1983b) observed 23 boys with ADHD (mean age six and a half years) and their siblings and a control group of boys and their siblings, matched in terms of gender and ordinal position of the sibling. Sibling interaction was observed during unstructured play without the mother present and during a task activity where the mother was present but not interactive. The siblings of children with ADHD suffered more aggression and conflict from their brothers than the siblings of the control children. The children with ADHD and their siblings both engaged in conflict and negative behaviour, with few behavioural differences between the children. Aggression between the child with ADHD and their sibling was not related to sex or ordinal position of the sibling, but younger children with ADHD were more negative than the older children with ADHD during the supervised task. Stormont-Spurgin & Zentall (1995) suggest that aggressive behaviour in preschool boys with ADHD appears to be supported by the behaviour of siblings. Aggressive preschool boys with ADHD were more likely to have siblings who retaliated to their physical or verbal aggression with physical or verbal aggression. Mothers' questionnaire ratings of the severity of the ADHD behaviour were positively

associated with conflict in the relationship with the child with ADHD and the sibling (Smith et al, 2002).

Everett & Everett (2001), two family therapists writing from the perspective of case reports on families of children with ADHD, have suggested that the sibling's experience of living with a child with ADHD changes over time. During the infant and toddler years the sibling becomes aware of the "differentness" of child with ADHD. As the sibling moves into the preschool years, the sibling starts to experience early conflicts, rivalry and jealousy and reduced time from parent. During the early primary school years, the sibling expresses anger and argumentativeness which leads to rejection and isolation. During the later primary school years the sibling feels alienation and withdrawal of affect from the child with ADHD and family. Physical confrontations with the child with ADHD start to occur during this stage. Then during the secondary school years, the sibling expresses acting-out behaviours and/or emotional reactivity and physical withdrawals from the family. Everett et al (2001) believe that the assessment and treatment of ADHD needs to be carried out in the family context and that clinicians need to evaluate the impact of ADHD not only the affected young person, but also the impact on their parents and siblings.

1.2.2.2 Mothers' perceptions of the sibling relationship

The management of sibling conflict is frequently reported as a problem and source of stress for mothers of children with ADHD (Barkley, 1981; Mash et al, 1983b). Stone (1999) found that mothers of boys with ADHD aged seven to 11 year old reported that siblings aged nine to 14 year old show more resentment and less warmth/closeness, less intimate relationships, and more quarrelling between siblings compared to control families. However, the siblings of the children with ADHD did not report less satisfaction with how they got on with their brother with ADHD. Whereas, Doran (1997) found that mothers and siblings aged six to 26 years old described the sibling relationship in similar terms, with both mothers and siblings describing aggression and conflict as a significant part of the sibling relationship. This highlights the importance of using reports from both the sibling and the mother when examining sibling relationships.

1.2.2.3 Siblings' perceptions of their relationship with the child with ADHD

In order to fully understand the impact of ADHD on siblings, research needs to examine the views of siblings rather than relying on adults' views of ADHD, in particular the views of mothers or clinicians (Kendall, 1997). Qualitative research methods are increasingly

being used to examine the perspectives of children and are starting to be published in peer-reviewed journals. Kendall highlighted the importance of using qualitative methods to understand how children and families experience ADHD (Kendall, 1997) and was the first to examine the nature of the relationship between the child with ADHD and their siblings from the siblings' perspective (Kendall, 1999).

Kendall carried out individual and family interviews with five older and eight younger siblings (seven brothers, six sisters) of ten boys with ADHD (Kendall, 1999). The siblings had a mean age of 11 years and the boys with ADHD had a mean age of ten years. The majority of the families were middle to upper middle class and described by the author as "high functioning and well educated." Families were recruited via posters in schools, adverts in a university newsletter or flyers handed out at ADHD support groups. The sample was described as a "schools based sample" so no details were given about whether the children with ADHD were taking medication or seeing a clinician. The families were experiencing considerable psychiatric comorbidity according to self-report and psychiatric and medical histories provided by the parents. Eight of the mothers had one or more comorbid conditions: eight with depression, one with bipolar disorder and three with diagnosed or suspected ADHD. Ten of the siblings (77%) had been diagnosed with psychiatric conditions: three with ODD, four with depression, two with anxiety, and one with anxiety and depression. Five of the children with ADHD also had a diagnosis of ODD.

Kendall (1999) concluded that these siblings viewed their family life as "chaotic, conflictual and exhausting" and the aggressive behaviour of the child with ADHD was central to this. Siblings who seemed most negatively affected by the disruption lived with an adolescent with ADHD, a parent with ADHD or suffered from high amounts of aggression from the adolescent with ADHD. The age of the child with ADHD did not influence levels of aggression; the younger boys with ADHD were as aggressive as the older boys. However, there was a gender difference in that boys with ADHD were more aggressive to brothers than sisters. The amounts of aggression varied between families, with six of the 13 siblings reporting being subjected to severe forms of aggression. However, all siblings described feeling victimised by the aggression behaviour of their brother with ADHD and did not see it as being part of "normal" sibling rivalry, although they reported that many of their parents did. Ten of the siblings described using strategies of avoidance and accommodation to manage the disruptive behaviour by the child with ADHD, while only three siblings described responding with retaliatory aggression.

Kendall (1999) described these siblings as being "severely and negatively affected by their ADHD brother." All of the siblings said their parents expected them to "befriend, supervise and care" for their brothers with ADHD and only two younger sisters regarded this as a positive role. The rest described being in the difficult position of being expected to take care of their brother with ADHD while being a target of his aggressive behaviour. Siblings described feeling anxious, worried and sad because they could not have a "normal" family life.

Two other unpublished qualitative studies examining the experience of siblings of children with ADHD were identified (Doran, 1997; Singer, 1997). Singer (1997) interviewed eight siblings (four sisters, four brothers) aged eight to 12.5 years old who were two to three and a half years younger than their brother with ADHD. Conflict was a significant theme of these sibling relationships, with siblings perceiving their family as being different compared to others because of the increased levels of aggression in their own families. Siblings expressed anger at the behaviour of the child with ADHD but described managing conflict by parental intervention rather than retaliatory aggression.

Doran (1997) interviewed eight older and younger siblings (five sisters, three brothers) who were aged six to 26 years of four female and three male young people with ADHD aged between 14 and 21 years old. The mothers of these children were also interviewed and it was found that their descriptions of the relationship between the sibling and the child with ADHD that were relatively consistent with the siblings' descriptions. All the siblings described their homes as places of stress and expressed feelings of anger and depression. Siblings retaliated with aggression when the child with ADHD behaved aggressively toward them, but this was often considered unhelpful which resulted in siblings using passive responses such as lowering their expectations and disengaging from the child with ADHD.

These three studies examining siblings' perceptions of living with a child with ADHD found that conflict was a significant theme, however, the siblings' management strategies, maternal perceptions of the sibling relationship and the negative psychological effects on the sibling varied (Doran, 1997; Kendall, 1999; Singer, 1997). Although the literature on sibling relationships would suggest that the incidents of aggression between siblings may not be unique to families with a child with ADHD, it is the intensity and frequency with which they occur that differentiates them from non-case sibling behaviour (Doran, 1997). Each of these studies gives one possible account of the experience of siblings of children with ADHD and although generalisation was not the main aim of these studies, caution

needs to be taken when applying these findings to samples other than those of high-income American families who attend ADHD support groups. There is a need for research in the British context.

1.2.2.4 Summary

Children with ADHD have been found to be experiencing considerable psychological difficulties, and living in a family with a child with ADHD has a significant negative impact on sibling relationships. Siblings have been found to have difficult and conflicted relationships with the child with ADHD.

1.3 Characteristics of families in which a child has ADHD

Children with ADHD and their siblings have been found to have difficulties interacting. Relationship difficulties have also been found to occur between the children with ADHD and their mothers, according to mothers' reports of the relationship, as well as observation of the mother-child interaction. Research into the impact of living with a child with ADHD has primarily focused on the parents, in particular mothers. Only recently has research evaluated the psychosocial adjustment of these siblings. In addition, in families where the child has ADHD there is a high likelihood that other family members will also have ADHD (Faraone et al, 1994).

1.3.1 Interaction between children with ADHD and their mothers

Compared to parents of control children, mothers of children with ADHD aged three to five years old were more likely to display negative behaviour toward their children, such as being more directive and less socially interactive, while the children with ADHD were less compliant and exhibited more problem behaviour such as disobeying established rules and having a tantrum (DuPaul et al, 2001). Parents of boys aged seven to 14 years old with ADHD have been found have a more punitive-authoritative style compared to matched control families (Hechtman, 1981). This finding was maintained when these families were followed up ten years later (Hechtman, 1996).

Mothers have also been found to have greater difficulties interacting with their child with ADHD than other children in the family (Smith et al, 2002; Tarver-Behring et al, 1985). Tarver-Behring et al (1985) observed the mother-child interactions of 16 boys with ADHD aged four to 12 years old and their siblings. The mothers carried out 20 minutes of free

play then 20 minutes of a task situation with each child individually. The child with ADHD spent more time engaged in behaviour that conflicted with maternal requests than the sibling, in both the free play and structured tasks. Mothers completed a questionnaire examining home behaviour problems of both children which revealed that the boys with ADHD showed more problematic behaviour than the sibling. Smith et al (2002) found that mothers and their sons with ADHD aged between seven and 13 years old had more conflicted relationships than mothers and younger siblings aged six to 12 years old as rated by mothers. In addition, mothers' questionnaire ratings of the severity of the ADHD behaviour were positively associated with conflict in the ADHD child-mother relationships.

1.3.2 Psychological functioning of mothers of children with ADHD

Mothers of children with ADHD have significantly higher rates of depression and anxiety than mothers of children without ADHD (Cunningham, Benness, & Siegel, 1988; Faraone et al, 1995). Higher rates of parental psychological problems have been found among parents of children with comorbid ADHD and conduct disorder or oppositional defiant disorder, than ADHD alone, however, parents of children with ADHD only were still more distressed than controls (Anastopoulous, Guevremont, & Shelton, 1992). Child defiance, not hyperactivity, has been found to correlate with negative family functioning (Taylor et al, 1986). In addition, parents of children with ADHD have a high risk of having a diagnosis of ADHD themselves (Faraone & Biederman, 1997). Thompson et al (2004) found that 26% of mothers of children with ADHD in a British clinical sample were assessed as having underlying ADHD.

1.3.3 Parenting stress of mothers of children with ADHD

Parents of children with ADHD experience higher rates of stress in their parenting roles compared to parents of non-ADHD children (Cunningham et al, 1988) and clinic-referred children without ADHD (Mash & Johnston, 1983a). Increased parenting stress is associated with symptom severity and aggressive behaviour of the child with ADHD (Anastopoulous et al, 1992).

Kendall (1999) suggests that parents of children with ADHD may be experiencing additional stresses over and above those due to dealing with a temperamentally difficult child, because of the perception of the condition:

"ADHD has not yet been accepted by society as a biological condition and, as a result, ADHD children and their families suffer social consequences and stigma."

In particular, ADHD may be perceived as a result of the child being poorly parented rather than due to parents being overwhelmed by the nature of the disorder (Lewis-Abney, 1993).

1.3.4 Psychological functioning of siblings of children with ADHD

Siblings of children with ADHD appear to be at risk for psychological difficulties.

Hechtman (1996) reviewed the early literature on siblings of children with ADHD and found that adult siblings were functioning better than their adult brothers with ADHD but less well than controls in measures of anti-social outcomes and alcohol problems and had higher rates of hyperactivity and depressive-anxiety symptoms.

Research examining the current functioning of siblings of children with ADHD has found that they have an increased risk for psychopathology. A higher prevalence of behaviour, mood and anxiety disorders have been found in siblings of children with ADHD compared to control children (Samudra & Cantwell, 1999). Faraone et al (1993) carried out psychiatric and intellectual assessments on 174 siblings (mean age ten and a half years) of boys with ADHD and 129 siblings of control boys. The siblings of children with ADHD were found to have increased intellectual impairment and school difficulties. This sample was followed up four years later and half of the siblings of children with ADHD were still experiencing academic problems.

Siblings of children with ADHD have also been found to have higher rates of ADHD than controls (Faraone et al, 1996). A British sample found that 15% of the clinic-referred children with ADHD had siblings with suspected ADHD according to a clinical interview with the mothers (Thompson et al, 2004). The high risk of siblings having ADHD themselves needs to be taken into account when examining sibling relationships in families of children with ADHD. However, it has been suggested by several authors that the diagnosis of ADHD is often overlooked in siblings and although treating the whole family is recommended, this is often not carried out in practice (Hankin, 2001; Kendall, 1999).

1.3.5 Summary

Living with a child with ADHD has a considerable negative impact on maternal mental health and mother-child interaction. Unsurprisingly, siblings have also been found to be experiencing difficulties in psychological functioning and their relationship with the child with ADHD. However, it is unclear from this research whether siblings are having difficulties due to living with a child with ADHD, because they have undiagnosed ADHD or due to other difficulties.

Many of these studies examining the impact of ADHD on siblings have used quantitative research methods and relied on mothers', teachers' and clinicians' perceptions of the functioning of the sibling (Smith et al, 2002). Few studies have interviewed and assessed siblings themselves (Faraone et al, 1996) and only one published study has used a qualitative approach (Kendall, 1999).

Mothers' perceptions of conflict in the sibling relationship also need to be examined alongside the siblings' perceptions. (Kendall, 1999). The literature on sibling relationships in non-ADHD families has suggested that mothers and siblings view the sibling relationship differently, with siblings perceiving more conflict and less co-operation in the relationship compared to their mothers (Graham-Berman, 1994). The limited findings from families of children with ADHD have been mixed in this respect. Kendal (1999) found a difference in siblings' and mothers' perspectives of conflict in the sibling relationship, with mothers reporting lower levels of aggression while Doran (1999) found that mothers and siblings described the sibling relationship in similar terms, with both mothers and siblings describing aggression and conflict as a significant part of the sibling relationship. Mothers' perceptions of conflict are important to examine as mothers can act as advocates for the siblings of children with ADHD and can seek help for the sibling if they are experiencing difficulties.

Research in this field needs to use standardised questionnaire measures to clearly describe the psychological functioning of the child with ADHD. The heterogeneity of outcomes for the children with ADHD (Biederman et al, 1995) has led to research examining the impact of ADHD on families being criticised for not accounting for the presence of conduct problems (Frick, 1999) and for not reporting the severity of ADHD symptoms and co-morbidity (Johnston & Mash, 2001). It is also important to use standardised questionnaire measures to describe the psychological functioning of parents and siblings in order to be

able to examine whether living with a child with ADHD has a negative impact on family members.

Finally, the literature examining the psychological functioning of siblings of other chronically ill children has identified the benefits of social support and siblings being knowledgeable about the condition. It is important to examine whether siblings of children with ADHD are supported in dealing with a potentially difficult sibling relationship. However, these factors have not yet been examined in a sample of siblings of children with ADHD.

1.4 Conclusions

Despite the large amount of research on ADHD, research on the impact of ADHD on relationships between siblings is still scant. The limited research into living with a child with ADHD suggests a considerable negative impact on the sibling. Extant research has made exclusive use of North American samples so there is a need to examine the experience of a British sample of siblings of children with ADHD. Few studies have used qualitative approaches to examine siblings' descriptions of the relationship with the child with ADHD and how maternal perceptions of conflict in the sibling relationship compare with siblings' accounts. In addition the psychological functioning of siblings and mothers, as well as the child with ADHD, need to be described using standardised questionnaire measures.

2 Methodology

The literature review revealed the need for further investigation into siblings' accounts of living with a brother or sister with ADHD along with a description of the psychological functioning of these families.

2.1 Aims and objectives of this study

The main aim of this study was to examine the experience of siblings of children with ADHD in a British context.

The specific objectives of the study were:

- To examine the siblings' descriptions of their relationship with their brother or sister with ADHD.
- To examine the siblings' perceptions of other sibling relationships.
- To examine the siblings' perceptions of social support.
- To examine the siblings' beliefs about ADHD.
- To examine the mothers' and siblings' descriptions of conflict in the sibling relationship.
- To describe the psychological functioning of the siblings and the children with ADHD using standardised questionnaire measures completed by mothers and teachers.
- To describe the psychological functioning of the mothers of the children with ADHD using semi-structured interview and standardised questionnaire measures completed by mothers.

2.2 Choice of methodology

This study examined sibling relationships in a British clinical sample of children with ADHD using a qualitative approach. This approach enabled a detailed exploration of individual accounts about the experience of being a sibling of a child with ADHD.

Qualitative methods give individuals the opportunity to explain their views, beliefs and attitudes in their own words (Holloway & Wheeler, 1996). Qualitative methods have several advantages over quantitative methods including being "a way of accessing 'private accounts' of social reality, which may not be revealed in questionnaire surveys" (Streubert & Carpenter, 1999) and providing "a view of reality that is important to the study participants, rather than the researcher" (Green & Thorogood, 1998).

Qualitative data can be generated in a number of ways including in-depth interviews, focus groups, passive and participant observation (Greenhalgh & Taylor, 1997). Semi-structured interviews are increasingly being used to examine the perspectives of children (Buston et al, 1998) and are an effective way to elicit individual accounts of being a sibling of a child with ADHD (Kendall, 1999). The flexible nature of semi-structured interviews have been found to elicit information that goes beyond the researchers' hypotheses which is useful when a topic, like this one, is relatively unresearched (Buston et al, 1998). Focus groups were felt to be an unsuitable means of generating these data as they examine how views are constructed socially rather than the view of the individual, which was the main interest of this study. In addition, it was felt that the sibling and their family might regard the subject of sibling relationships as a personal issue unsuitable for group discussion. Due to the time and resource constraints imposed on this study, it was decided that observing sibling interaction in either the home or laboratory setting was not a feasible option.

Quantitative data were collected in order to obtain a description of the psychological functioning of these families in relation to general population norms and clinical cut off points. Mothers completed standardised questionnaire measures and semi-structured interviews examining their current functioning. Mothers also completed standardised questionnaire measures examining the functioning of the child with ADHD and the sibling. Teachers of the children were asked to complete standardised questionnaire measures on the child with ADHD and the sibling in order to determine the existence of behavioural and emotional problems in more than one setting.

2.3 Ethical approval and informed consent

Prior to participant recruitment the research protocol was approved by the local NHS research ethics committee. Once written permission to contact the family had been received from the child's CAMHS clinician or General Practitioner, mothers were contacted by telephone and asked to participate in the present investigation if they fulfilled inclusion criteria. If it was not possible to contact the mothers by telephone then they were

sent a letter giving a brief outline of the study and asking them to "opt in" should they wish to be involved in the study. Information sheets and consent forms were sent to the mothers prior to the interview (see Appendix 1 to 4). Informed consent was obtained in writing from the mothers and the sibling (see Appendix 3 and 4). All participants gave consent for the interview to be recorded by mini-disc. The child with ADHD gave signed consent for the author to speak to their mother and sibling. Consent was also obtained from the mother, the sibling and the child with ADHD to send questionnaires to the children's teachers. Permission to contact teachers, via their head teacher, was given by the appropriate Education Board.

Before starting the interview, families were told that if they presented with a disorder which was not being treated then this would be discussed with them and arrangements made for referral to the appropriate mental health service.

2.4 Recruitment

This was a pragmatic sample of siblings of a British clinical sample of children with ADHD. The child with ADHD had been referred to the University Department of Child and Adolescent Psychiatry based in the Royal Hospital for Sick Children, Glasgow when they were between the ages of three and five years old. At that time these children presented with developmentally inappropriate levels of overactivity, inattention and impulsivity and some also presented with comorbid disruptive behaviour problems. The children with ADHD and their mothers took part in the Pre-School Overactivity Programme (POP), a ten-week parent training and group child behaviour programme. Sixty families (47 subjects, 13 controls) were followed up a year after completion of the programme (Barton, 2002). At the time of the programme, children aged under-five with suspected ADHD were routinely referred to this clinic; therefore the sample is likely to be representative of a clinic sample.

2.4.1 Inclusion criteria

In order to be included in the current study, the child who had attended the programme had to have a current diagnosis of ADHD and a sibling aged eight years or older living in the family home. At the time of the study all of the children with ADHD had active symptoms of the disorder and scored above the cut-off for clinical caseness for ADHD according to the mothers' responses to the Conners' Rating Scale (Conners, 1997).

2.4.2 Exclusion criteria

The only exclusion was that the child was taking part in another research project. Children with comorbidities were not excluded in view of the fact that such difficulties are frequently associated with ADHD (Kadesjo et al, 2001).

2.5 Data collection

Data collection took place between July 2003 and May 2004. Mothers were given the choice of being interviewed at home or in the Child and Adolescent Psychiatry Clinic based in the Royal Hospital for Sick Children, Glasgow. Thirteen mothers and siblings were interviewed at home and four mothers and siblings were interviewed at the hospital. The author interviewed all the mothers and all but one of the siblings; an Assistant Psychologist interviewed this sibling.

2.5.1.1 Interview technique

Mothers were contacted by telephone in order to discuss the study. If mothers were happy to take part, an appointment was made for the author to meet with the mother. Before the interview commenced, the purpose of the study was explained again and mothers were encouraged to ask questions before the consent forms were signed. Permission was given by the mothers for the interview to be recorded by a mini-disc recorder and microphone. Mothers completed a semi-structured interview then standardised questionnaire measures were administered to the mother. At the end of the interview mothers were given the opportunity to discuss any issues that had been raised during the interview or completion of the questionnaires.

An appointment for the author to meet with the sibling was arranged with the mother. It was agreed that mother would tell the sibling that this meeting had been arranged but it was the sibling's choice whether they wanted to be interviewed. When the author arrived at the family home, mothers would introduce the author to the sibling and stay in the room while the author discussed the study with the sibling. The author read the information sheet and consent form to the sibling before encouraging the sibling to ask any questions. The consent form was signed by the sibling in the presence of their mother. Mothers were very helpful in arranging the interview so that the sibling could have some privacy: often mothers would suggest the sibling and author went into a room away from the rest of the family and some mothers arranged the interview for a time when the child with ADHD

was out of the house. The author told siblings that their conversation would not be discussed with their mother or the child with ADHD, and that the family could not be identified in the write up of the research. Mothers and siblings were told that only the author would listen to the interview and that the author was the only person to have access to the names and addresses of the families taking part in the study and these details were kept in a password protected computer database.

Permission was given by the siblings for the interview to be recorded using a mini-disc recorder and a microphone. This technology was often used to build up a rapport with the siblings, as the author would often ask them to help set up and test the equipment. Each interview started with the author saying:

I'd like to ask you some questions about how you are feeling and how you are getting on at home and at school. I'm interested in your own ideas and feelings so there are no right or wrong answers. What you tell me is private so I won't tell anyone about what we talk about. But if you tell me something that makes me worried about your safety, like somebody was hurting you, then I would have to tell someone. However, I would always tell you first that I was going to talk about it to other people. Is that ok?

The interview started with general questions about their family to encourage the siblings to speak freely. The questions then became more specific to examine issues relating to living with a child with ADHD. These more sensitive questions were intended to be raised later on in the interview but some siblings freely introduced them in the early stages of the interview.

The interview technique used in this study was based on good practice for interviewing children suggested by various authors (Backett-Milburn, Cunningham-Burley, & Davis, 2003; Davis, 1998; Faux, Walsh, & Deatrick, 1988; Harden et al, 2000). The author made the child feel comfortable by starting off the interview with informal conversation to establish a rapport. Open questions were used initially then more focused questions were asked. Children were given as much time as they needed to answer questions and were always asked to give examples if their responses were unclear. Children were told they could take breaks whenever they wanted, they could stop the interview at any time without giving a reason and they did not have to answer any question if they did not to. The terminology used by the family to describe ADHD was established from the mother prior to the interview and the interview questions were altered accordingly, for example, some siblings used the term "Hyperactive" and others did not know that their brother had a diagnosis of ADHD. At the end of the interview siblings were given the opportunity to ask

questions. The author also spent several minutes debriefing the siblings to ensure they had not been upset by any of the interview questions.

Both the interviews with the mothers and siblings addressed some potentially sensitive issues and some questions were not fully probed where the interviewee appeared to be upset or distracted.

2.6 Quantitative Component: Standardised Questionnaires

Mothers completed standardised questionnaire measures in the presence of the author after they had been interviewed. Permission to contact the teachers was given by all of the mothers, siblings and children with ADHD. Questionnaires were sent to the teachers along with a pre-paid addressed envelope. Teachers were sent a reminder letter if they had not returned the questionnaire within two weeks. The measures used are shown in Table 1. In addition, the mother was asked to describe the current living circumstances of the family including who was living in the family home, employment details of the mother, and if applicable live-in partners.

Domain	Measure	Source of information
Psychological functioning of the child with ADHD	Strengths and Difficulties Questionnaire	Mother Teacher
Psychological functioning of the sibling	Strengths and Difficulties Questionnaire	Mother Teacher
Psychological functioning of the mother	Questions from the Present State Examination Conners' Adult ADHD Rating Scale Parenting Stress Index	Mother

Table 1 - Summary of quantitative measures

2.6.1 Psychological functioning of the child with ADHD and the sibling

2.6.1.1 Strengths and Difficulties Questionnaire

The presence of behavioural or emotional problems in the children with ADHD and siblings aged eight to 16 years old was assessed with the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997; Goodman, Meltzer, & Bailey, 1998).

Questionnaires were completed to the mothers and sent to the current teacher of children

with ADHD and the siblings. The parent and teacher versions of the SDQ contain 25 items which are divided into five scales: emotional symptoms, conduct problems, hyperactivity, peer relationship problems and prosocial behaviour. Items are added together to generate a total difficulties score. The SDQ discriminates well between psychiatric and non-psychiatric samples. Each scale on the SDQ has a cut-off point above which the child is classified as showing abnormal behaviour, with ten percent of children in a community sample expected to obtain a score above cut-off.

2.6.2 Psychological functioning of the mother

2.6.2.1 Present State Examination

Maternal depression was assessed using the questions on depression from the Present State Examination (PSE) (Wing, 1974).

2.6.2.2 Parenting Stress Index

The short form of the Parenting Stress Index (PSI/SF) (Albidin, 1995), a standardised assessment of stress associated with parenting, was administered to the mothers to produce a total parenting stress score as well as subscale scores for parental distress, parent-child dysfunctional interaction, and difficulty with the child with ADHD, with higher scores reflecting greater parenting stress.

2.6.2.3 Conners' Adult ADHD Rating Scale

The Conners' Adult ADHD Rating Scale (CAARS) (Conners, Erhardt, & Sparrow, 1994) is a 66-item rating scale that contains the DSM-IV symptoms for ADHD and includes the subscales: inattention/memory problems, hyperactivity/restlessness, impulsivity/emotional lability, problems with self-concept and total ADHD symptoms.

2.6.3 Quantitative Data Analysis

The questionnaire data provided a description of the emotional and behavioural functioning of the child with ADHD, the sibling and the mother at the time of the interview. A categorical analysis was carried out to examine the proportions of the participants classified as scoring above the cut-off for clinical caseness using cut-off points recommended by the author of each questionnaire. The data was managed using an Excel database.

2.7 Qualitative component: Semi-structured interviews

2.7.1 Siblings' semi-structured interview

Siblings completed a semi-structured interview which was developed from the literature and objectives of the study. Open-ended questions were used to explore the siblings' views on living in their family (see Appendix 5). The interview was based on a schedule of key questions and themes. The main area of enquiry in the study was siblings' perceptions of aggressive behaviour by the child with ADHD and the emotional impact of living with a child with ADHD which has been explored previously in North American samples (Doran, 1997; Kendall, 1999). Other questions examined mothers' and siblings' perceptions of the sibling relationship and the availability of support for the sibling, areas which have been identified by previous research as areas for further investigation (Kendall, 1999). Siblings' perceptions of their friends' siblings relationships, their beliefs about ADHD and their perceptions of social support were also examined. Prior to the start of the project, the interview schedule was piloted with psychologists, psychiatrists, teachers and researchers working in a Specialist Clinical Academic Service for ADHD.

Semi-structured interviews are only partially prepared in advance so that the interviewer largely improvises their responses to the interviewee (Wengraf, 2001). The interview schedule is an aide-mémoire for the interviewer so that all questions and themes are examined in all of the interviews (Mason, 2002). The order of questions is flexible to allow the interviewer to alter the sequence of the questions during the interview. In this study the questions were also adapted to the sibling's age and level of understanding of ADHD. Any new themes that were raised by the siblings were noted on the interview schedule and were included in subsequent interviews.

2.7.2 Mothers' semi-structured interview

Mothers completed the Parental Account of Children's Symptoms (Taylor et al, 1986) (see Appendix 6). This semi-structured interview schedule includes a short series of questions asking mothers to briefly describe conflict in the relationship between the child with ADHD and their brother/sister in the last week.

2.7.3 Qualitative data analysis

2.7.3.1 Management of interview data

The interviews with the siblings and the mothers were recorded using a mini-disc recorder and microphone. In order to maintain anonymity all interviewees were assigned an identify number. The interview mini-discs, interview schedules and questionnaires were labelled with the interviewee's identification number and kept in a locked filing cabinet. Consent forms were stored separately.

The recordings were transcribed in full and all identifying information was removed. During transcription punctuation was added in a way which attempted to report the actual words of the siblings and mothers as accurately as possible: (-) was used to indicate short pauses in speech, (...) was inserted if an irrelevant sentence was removed from the middle of a paragraph, [] was used to identify explanations for the reader. The transcripts were read through whilst listening to the recordings to ensure that each transcript was accurate. Although transcribing the interviews was a time consuming process, it was an opportunity to become familiar with the data and to make notes of potential themes for analysis. The software package Atlas.ti was used to manage the data (Muhr & Fricse, 2004). Quotes were labelled with the identification number assigned to each interviewee.

2.7.3.2 Identification of themes

The transcriptions of the interviews were content analysed to identify themes (Pope & Ziebland, 2000). Qualitative analysis is an iterative process which involves reading and rereading the transcripts in order to:

"to identify persistent words, phrases, themes or concepts within the data so that underlying patterns can be identified and analysed" (Morse & Field, 1996).

The data was broken down to develop a coding schedule of main themes and sub-categories. The transcripts were coded for themes that emerged from the data, for example, siblings using parental intervention as a management strategy, in addition to the "a priori" themes which came from the literature or the questions derived from the objectives of the study, for example, siblings using retaliatory aggression, avoidance and accommodation as management strategies (Kendall, 1999).

Each transcript was coded into as many codes as necessary, so that it was possible for one sentence to have more than one assigned code, or that two or three sentences combined to form one code. When a new theme was noted, data from all transcripts were re-examined to check for other instances of the theme. The passages where each theme occurred were coded then all of these passages were examined side by side to consider shared meanings across all transcripts, as well as in context of the original transcript.

A synopsis of the main themes coded in each interview was made to enable comparisons to be made between interviews and to identify the characteristics of the respondents which were associated with particular views. Once all the transcripts had been coded, the sections of the data that were alike or related were identified and grouped together under broad headings. These main themes across all transcripts were described, patterns across transcripts identified and explanations for the relations between themes developed. The data was checked for negative instances, i.e. cases that contradicted the majority view (Mason, 2002)

2.7.3.3 Co-scoring of the transcriptions

In order to check the coding scheme developed by the author, a sample of the transcripts were coded by an expert qualitative researcher. Both coders agreed upon a coding frame and this was applied to the transcript of each interview. In addition, a Child and Adolescent Psychiatrist reviewed the findings.

3 Findings

The quantitative findings include a description of the sample as a whole and the current psychological functioning of the families according to the questionnaire measures completed by the mothers and teachers.

The qualitative findings include the six major themes from the interviews with the siblings. In addition, the mothers' descriptions of conflict within sibling relationships will be examined alongside the siblings' descriptions.

3.1 Sampling strategy

At follow up 39 of the children who attended the POP group had a current diagnosis of ADHD, however, eight families were not eligible to take part in the study: five were taking part in another research project and three families did not have an eligible sibling in the household. Of the 31 eligible families, permission to contact three families was refused by their clinician and six families could not be contacted by telephone and did not respond to the recruitment letter. Seven (22%) families declined to take part. In total 15 families (48%) were followed up (see Figure 1).

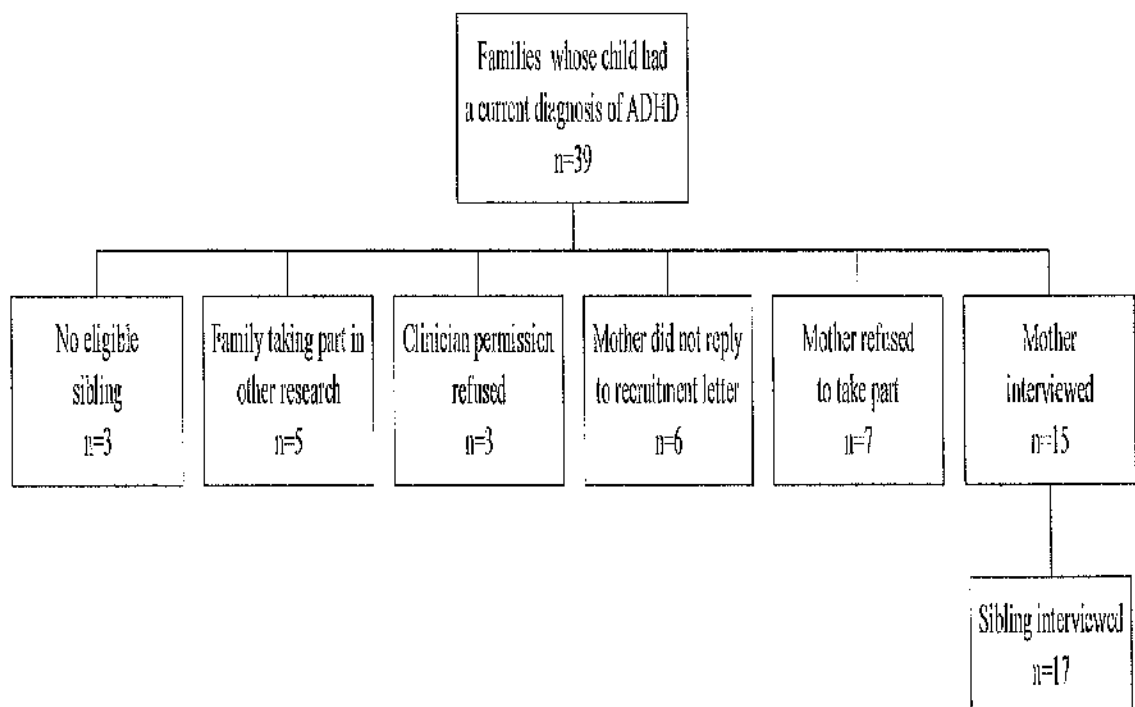


Figure 1 – Recruitment of families in the study

3.2 The socioemotional development of the child with ADHD

This was a clinical sample of children with ADHD who had attended a treatment group when they were aged between three and five years old because they reached diagnostic criteria for ADHD. At follow-up the children with ADHD were aged between 11 and 14 years old (median age 13 years). Ten of the children (nine boys and one girl) were receiving treatment for the symptoms of ADHD from Child and Adolescent Mental Health Services (CAMHS) (see Figure 2). Seven of these children had an additional diagnosis: one boy had Learning Difficulties and was attending a school for children with Moderate Learning Difficulties, two boys had Autism and were receiving regular residential care at a school for children with Moderate Learning/Communication Difficulties, one boy had Dyslexia and one boy had Asperger's Syndrome, both were attending mainstream school, one boy was having Emotional Difficulties and one girl was in part-time Social Services care because of family breakdown. Eight of these children were taking medication for the symptoms of ADHD. Of the five children who were not currently attending a CAMHS clinic none were taking medication for the symptoms of ADHD and only one boy had an additional diagnosis of Learning Difficulties and was attending a school for children with Moderate Learning Difficulties.

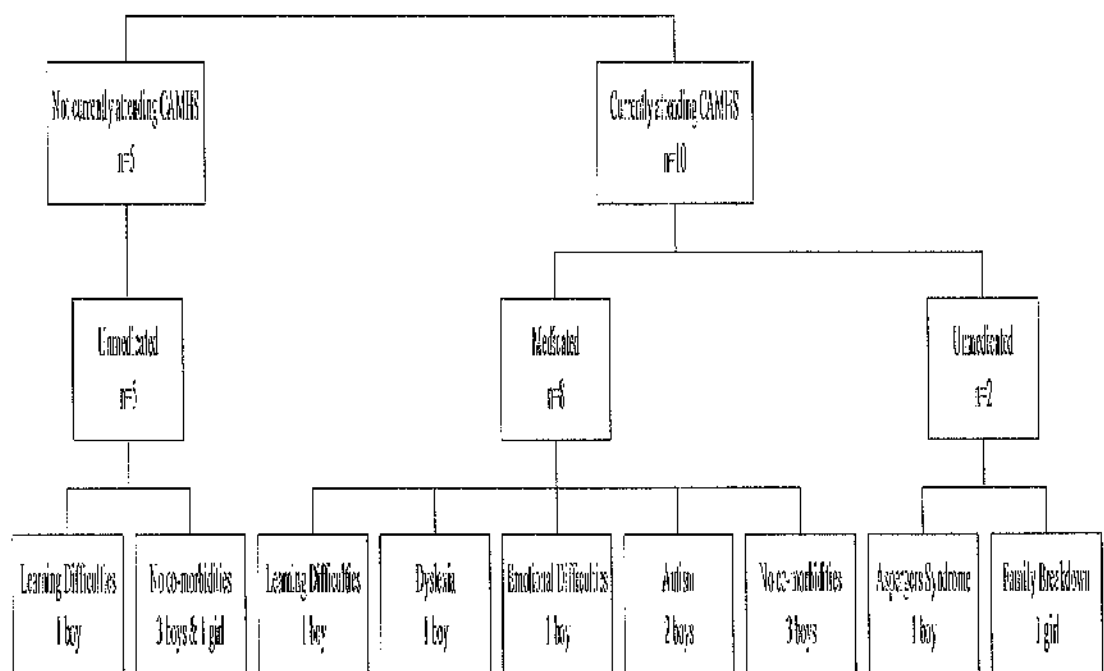


Figure 2 – Description of the diagnosed comorbidities of the children with ADHD

3.3 Participants

Fifteen biological mothers and 17 siblings took part in the study. The siblings were aged between eight and 20 years old (median age 14 years). Seven of the siblings were attending primary school, seven were attending secondary school, two were attending college and one was undertaking an apprenticeship. Ten (59%) of the siblings were older (seven sisters, three brothers) than the child with ADHD and seven siblings were younger (five sisters, two brothers) (see Figure 2). Twelve of the sibling pairs were opposite sex, four were male and one was female. Eleven (65%) of the sibling pairs contained siblings whose ages fell within zero to four years of one another. Two families had two siblings who took part in the study: one boy had an older brother and older sister, and one boy had two older sisters. None of the siblings had a current diagnosis of ADHD or any other condition or were currently receiving treatment from a CAMHS clinician. However, one sibling had previously attended a CAMHS clinic for emotional/concentration problems. The sample of ten children with ADHD who were currently attending a CAMHS clinic had 11 siblings (six older, five younger) and the sample of five children with ADHD who were not currently attending a CAMHS clinic had six siblings (four older siblings, two younger siblings).

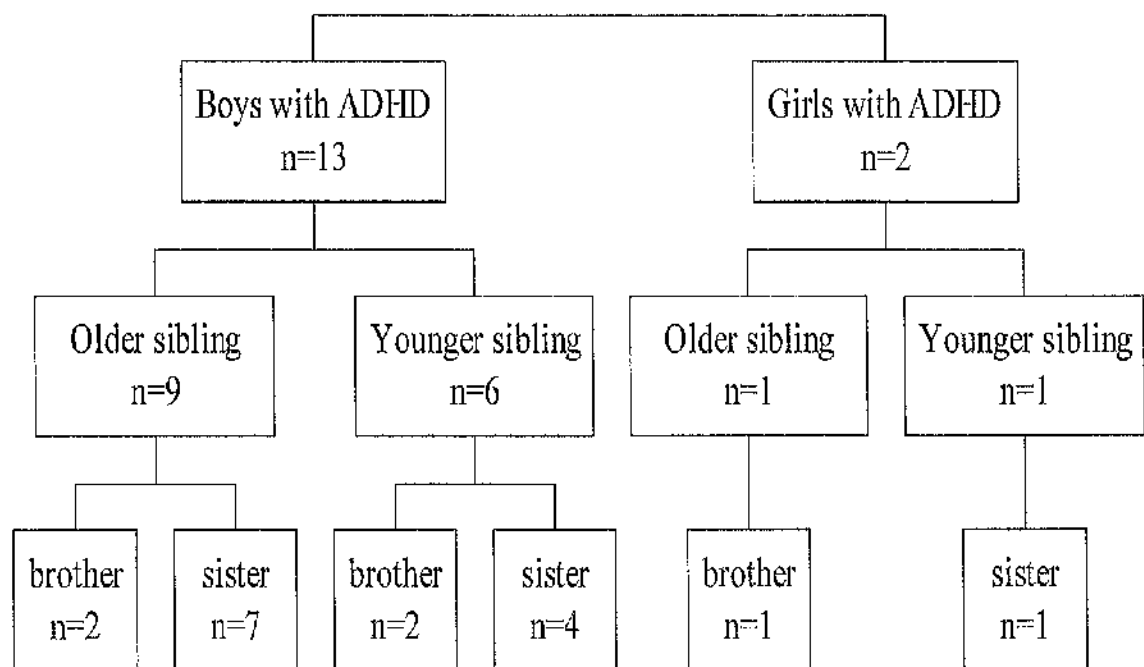


Figure 3 - Description of the siblings

All the families were White British. Ten families had both biological parents living in the home, three families were headed by a single-mother and two families were headed by a mother and a stepfather. Eight of the families had a total of two children, four families had three children, two families had four children (including one family which included two step-children) and one family had five children. Mothers were aged between 31 and 45 years old (median 40 years). In four of the families at least one parent had a higher technical occupation. The remaining 11 families were of lower socio-economic status, including six who were receiving Income Support. None of the families were members of an ADHD support group.

3.4 Quantitative Findings

3.4.1 Psychological functioning of the child with ADHD

The scores on questionnaire measures were analysed to establish the severity of the child's ADHD symptoms and the presence of behavioural and emotional difficulties in the home and school environment. The levels of difficulties experienced by the child with ADHD did not appear to be affected by ordinal position or gender. Although the children in the group who were currently attending a CAMHS clinic were experiencing a higher incidence of comorbidities than the group who were not, the levels of hyperactive symptoms were similar between the two groups. According to the mothers' responses, many of the children with ADHD were having considerable difficulties in addition to those caused by the symptoms of hyperactivity and any diagnosed comorbidity. Teacher reports identified fewer, but still a considerable level of problem behaviour.

3.4.1.1 Mothers' reports on the child with ADHD

All mothers completed the parents' version of the Strengths and Difficulties Questionnaire (SDQ). As can be seen in Table 2, 73% of the children with ADHD fell into the abnormal category on the total difficulties scale. Seventy three percent of the total sample fell into the abnormal category on the hyperactivity subscale, 27% on the prosocial behaviour subscale, 60% on the peer problems subscale, 60% on the conduct problems subscale and 40% emotional problems subscale.

3.4.1.2 Teachers' reports on the child with ADHD

All the teachers of children with ADHD completed the teachers' version of the Strengths and Difficulties Questionnaire. As can be seen in Table 2, 60% of the children with ADHD fell into the abnormal category on the total difficulties subscale. Sixty percent fell into the abnormal category on the hyperactivity subscale, 47% on the prosocial behaviour subscale, 33% on the peer problems subscale, 40% on the conduct problems subscale and 26% on the emotional problems subscale.

	Mothers' Reports n = 15	Teachers' reports n = 15
Measure	% in clinical range	% in clinical range
SDQ: Total Difficulties	73	60
SDQ: Hyperactivity	73	60
SDQ: Prosocial Behaviour	27	47
SDQ: Peer Problems	60	33
SDQ: Conduct Problems	60	40
SDQ: Emotional Problems	40	26

Table 2 – Mother and teacher ratings of the children with ADHD on the SDQ

3.4.2 Psychological functioning of the siblings

The siblings showed lower levels of emotional and behavioural difficulties according to the mothers and teachers compared to their brothers and sisters with ADHD. Although data on the psychological functioning of four siblings was not collected because they were too old for the measures, it could be assumed that they were doing well as all of these siblings were in higher education or working and were not attending psychiatric services. The siblings as a group were experiencing a similar level of difficulties that would be expected by children in a community sample. Two siblings were experiencing problems across the range of difficulties according to the mothers' reports, and these difficulties were confirmed by the teachers' reports, however, the remaining siblings obtained scores that were within the normal range.

3.4.2.1 Mothers reports on the siblings

Thirteen siblings were within the age range for their mothers to complete the Strengths and Difficulties Questionnaire. As can be seen in Table 3, 15% of the siblings fell into the abnormal category on the total difficulties subscale. Eight percent fell into the abnormal category on the hyperactivity subscale, 8% on the prosocial behaviour subscale, 15% on the peer problems subscale, 23% on the conduct problems subscale and 15% on the emotional symptoms subscale.

3.4.2.2 Teachers' reports on the siblings

Strengths and Difficulties Questionnaires were sent to the teachers of the 13 siblings who were aged eight to 16 years old and 12 questionnaires were returned (92% response rate). As can be seen in Table 3, 17% of siblings fell into the abnormal category on the total difficulties subscale. Fourteen percent of the siblings fell into the abnormal categories on the hyperactivity subscale, 17% on the prosocial behaviour subscale, 8% on the peer problems subscale, 8% on the conduct problems subscale and 25% on the emotional problems subscale.

	Mothers' Reports n = 14	Teachers' reports n = 12
Measure	% in clinical range	% in clinical range
SDQ: Total Difficulties	15	17
SDQ: Hyperactivity	8	14
SDQ: Prosocial Behaviour	8	17
SDQ: Peer Problems	15	8
SDQ: Conduct Problems	23	8
SDQ: Emotional Problems	15	25

Table 3— Mother and teacher ratings of the siblings on the SDQ

3.4.3 Psychological functioning of the mothers

The mothers were exhibiting considerable psychiatric morbidity. Fourteen mothers completed the Parenting Stress Index (PSI) and 93% obtained scores on Total Stress score in the clinical range which indicates that mothers were experiencing their relationship with

the child with ADHD as stressful. Thirteen mothers completed the Conners' Adult ADHD Rating Scale and 23% obtained scores within the clinical range on the ADHD Total Symptoms subscale suggesting they were suffering from ADHD. In addition, 14 mothers answered questions from the Present State Examination and 57% obtained scores that indicated low mood.

3.4.4 Summary of quantitative findings

There were three main findings from the questionnaire data completed by mothers and teachers. Firstly, both mothers and teachers described the children with ADHD as having considerable emotional and behavioural difficulties. Secondly, only two siblings were described by mothers and teachers as having emotional and behavioural difficulties, while the remaining siblings were within normal range. Thirdly, mothers reported that they themselves were experiencing considerable psychiatric morbidity.

3.5 Qualitative findings

All the siblings agreed to be interviewed and the interviews lasted between ten and 30 minutes. Six major themes were identified. The first theme was entitled "Siblings' descriptions of the sibling relationship" and included two sub-categories: negative interaction between siblings and positive interaction between siblings. The second theme was entitled "Siblings' management strategies" and included three sub-categories: parental intervention, retaliatory aggression, avoidance and accommodation. The third theme was entitled "Siblings' perceptions of other sibling relationships" and included three sub-categories: no differences in the sibling relationship, differences due to aggression in the sibling relationship and differences due to poor social relationships of the child with ADHD. The fourth theme was entitled "Siblings' emotional reactions to living with a child with ADHD" and included two sub-categories: anger and sadness. The fifth theme was entitled "Support for the sibling" and included three sub-categories: support within the family, support outwith the family and professional support. The sixth, and final theme, was entitled "Siblings' understanding of ADHD". In addition, the mothers' perceptions of conflict in the sibling relationship were described then examined alongside the siblings' perceptions.

The themes generated were interdependent in nature and cannot be viewed as being mutually exclusive. The themes described were on a continuum, with some siblings experiencing more difficulties than others.

3.5.1 Siblings' descriptions of the sibling relationship

When siblings talked about their relationship with the child with ADHD, two categories emerged: negative and positive interaction. Siblings spoke about the issue of negative interaction in greatest length and with greater frequency than any other issue in this study. While the focus of the siblings' discussions was the conflict in their relationship, the majority of siblings also described positive aspects of the relationship.

3.5.1.1 Negative interaction between siblings

All siblings described feeling annoyed by the behaviour of the child with ADHD and gave examples of teasing and arguing with the child with ADHD. Siblings talked about their lives being disrupted by behaviour of the child with ADHD in a variety of ways and with varying degrees of intensity. While this sibling rivalry was common in all of the families, the aggressive behaviour started by the child with ADHD varied greatly in intensity between sibling pairs. Only one sibling did not describe any aggression in the relationship, while all the other siblings described their brother or sister with ADHD carrying out a range of verbally aggressive behaviour and overt physical aggression. Verbal aggression by the child with ADHD included calling the sibling names, shouting and swearing. Overt physical aggression by the child with ADHD toward the sibling included pulling their hair, putting their hands round their neck, jumping on top of them, kicking, scratching, hitting, slapping and biting. Reactions to this aggressive behaviour varied greatly from individual to individual.

Older siblings described low levels of aggression between themselves and the child with ADHD:

"It's never really like a proper fight - it's sort of playful fighting ... it's just like a wee slap."

20 year old sister of a 12 year old boy with ADHD (Id15)

For the siblings who were not getting physically hurt, the behaviour of the child with ADHD was seen as more of an annoyance rather than a significant problem:

"There's not much to get upset about, he just gets on your nerves."

15 year old sister of 12 year old boy with ADHD (Id14)

These siblings either described having a good relationship with the child with ADHD or if they had a poor relationship with the child with ADHD they described keeping out of the way of each other.

The other ten siblings, three older siblings and all of the seven younger siblings described more severe incidences of aggressive behaviour which they did not regard as being part of a "typical sibling relationship":

"Once I was fighting with him and he pulled a knife to me."

15 year old sister of 13 year old boy with ADHD (Id13)

"She strangled me and pulled my hair and kicked me ... she hits you and bites you on your toes. She's like an animal."

11 year old sister of 13 year old girl with ADHD (Id12)

In the majority of incidences the sibling would be described as coming out worse in terms of getting hurt physically by the child with ADHD. This is understandable given that most of the children with ADHD were older and physically stronger; in addition the majority of these siblings were female:

"He has pulled a big chunk out of my head which was quite sore ... he has given me a few bruises on my leg."

15 year old sister of 13 year old boy with ADHD (Id16)

However, one younger brother and one older sister described incidences of aggression which resulted in the child with ADHD getting hurt as well as themselves:

"Like hitting him when he's annoying me - I always take it too far ... I like hit him, kick him too hard ... took my trousers out of my drawer and the zip hit him on the eye ... I meant it because he was annoying me."

8 year old brother of a 13 year old boy with ADHD (Id9)

Both these siblings scored highly on the SDQ for conduct problems.

The siblings who were most negatively affected by this aggressive behaviour were three younger sisters. They had concerns for their safety in relation to this aggressive behaviour and said they were afraid the aggression might escalate out of their control:

"Sometimes it's kinda scary because when he goes mad he'll end up coming in and he might hurt you or something ... he might strangle me."

10 year old sister of 14 boy with ADHD (Id11)

All the children with ADHD were aged between 11 and 14 years old and the levels of aggressive behaviour exhibited by the child with ADHD did not differ with age. However, the ordinal position of siblings did appear to have an influence. Younger siblings describing receiving more severe levels of aggression from the child with ADHD and aggression was more likely to escalate when the sibling was younger than the child with ADHD. Siblings with the greatest age gap between them and the child with ADHD and siblings who were already in their late teens, appeared to receive less aggression and when aggression did occur appeared not to retaliate with aggression:

"We do [quarrel and fight] but not very often ... we used to when we were younger ... but I've grown up a bit and realised I shouldnay [shouldn't] because he's got an illness and when I was younger I didnay [did not] know so I just fought with him. We did fight ... we punished each other ... we don't do anything like that anymore."

16 year old sister of a 13 year old boy with ADHD (Id1)

Although there were only two girls with ADHD, gender of the child with ADHD did not appear to be a factor in the expression of aggressive behaviour. Both the girls with ADHD were described by their mothers as having conduct problems, and their siblings and mothers described them being aggressive toward their siblings. In addition, the siblings of both these girls with ADHD fought back. Boys with ADHD were equally aggressive towards their sisters as brothers. However, it did appear that gender was an important factor in the experience of the siblings. While siblings of either gender were as likely to retaliate, younger girls appears to be more frightened of their older siblings' aggression and these were most negatively affected by the aggression.

3.5.1.2 Positive interaction between siblings

Despite the considerable disruption caused by the behaviour of the child with ADHD, the majority of siblings also described positive aspects of their relationship with the child with ADHD. The children with ADHD were described as being a source of support against parents, someone to play with and a source of comfort:

"If you want something say like your mum says "You're not going there" and he'll stick up [for me] and say "Just let her go."

15 year old sister of a 12 year old boy with ADHD (Id14)

"If ... none of your pals want to go out ... you can go out with your wee brother."

16 year old sister of a 13 year old boy with ADHD (Id13)

"He takes care of you like if something went wrong. When my gerbil died and I was crying and he came in to me and gave me a hug and said he felt sorry for me."

10 year old sister of a 14 year old boy with ADHD (Id11)

3.5.2 Siblings' management strategies

Siblings used a variety of strategies to manage the behaviour of the child with ADHD. Strategies included trying to avoid conflict by asking for help and involving the parents or trying to ignore or avoid the child with ADHD. However, these strategies did not appear to contain the situation and all siblings ended up retaliating with aggression to various degrees.

3.5.2.1 Parental intervention

All siblings said that they asked for help from their parents or that their parents intervened when problematic situations arose with the child with ADHD. Mothers, rather than fathers were most likely to be described as intervening even when two parents were living in the house:

"[An argument] just keeps going on until my ma comes in and stops it."

18 year old brother of a 13 year old girl with ADHD (Id10)

"Sometimes I get annoyed with it [the child with ADHD] and I shout "Mum, get a grip of him."

16 year old sister of a 13 year old boy with ADHD (Id1)

The siblings described their parents using a variety of strategies. Some parents were described attempting to intervene in a calm, effective manner while others described their parents as having their own difficulties dealing with the behaviour of the child with ADHD. However, siblings described only two instances of physical punishment by parents; once toward a sibling and once toward the child with ADHD. The most commonly mentioned parental intervention was the separation of the children once the aggression had started. This often involved excluding the child with ADHD, who was usually regarded by parents as starting the aggression. In some cases, however, parents punished the siblings as well, regardless of who had started the aggression:

"He pulls my hair and I'll punch him back then my mum will come up and start shouting at the two of us and the two of us will get sent into our rooms."

10 year old sister of a 14 year old boy with ADHD (Id11)

One sibling described following her mother's example of avoidance:

"My mum just walks away and doesn't listen to him and that's what I do ... I just walk away into my room and just listen to my music."

10 year old sister of 14 year old boy with ADHD (Id11)

The majority of siblings appeared happy with their parents' intervention. However, three siblings were critical of their mother's intervention. These siblings felt that their mothers had no control over the child with ADHD and that the child with ADHD was inadequately punished for their aggressive behaviour:

"We were out playing ...she strangled me and pulled my hair and kicked me and then I had to go home and she went "Aye, you go away greeting [crying]" ... she gets grounded for a day ... then gets allowed back out again."

11 year old sister of a 13 year old girl with ADHD (Id12)

"My mum and dad cannay [can not] stop my brother ... one time my mum and dad says "[Child with ADHD] go to your room" and he says "No" and I walked in and said "Go to your room" and he says "Right [ok] then."

14 year old sister of a 13 year old boy with ADIID (IdP16)

These siblings described their mothers as having a difficult and conflicted relationship with the child with ADHD. The children with ADIID in these families were 13 or 14 years old and were not taking medication even though they had significant symptoms of ADHD plus other comorbidities. Although these mothers' mental health varied, all these mothers were not working due to significant physical health problems.

Maternal advice on managing the behaviour of the child with ADHD varied according the ordinal position of the sibling. Younger siblings were advised to retaliate when the child with ADIID was behaving aggressively toward them, whereas older siblings were told not to fight back. The three younger sisters who were receiving considerable aggression from the child with ADHD were told by their mothers "to hit back." However, these siblings considered this strategy as a last resort as it led to an escalation of aggression by the child with ADIID. In additional, all these siblings had described worrying about being physically hurt by the child with ADHD:

"My mum keeps saying when he hits me I need to hit him back so sometimes I do that because my mum tells me."

8 year old sister of 11 year old boy with ADHD (Id6)

When asked if this helped, the sibling said:

"No, because then he hits me back harder but then I'll go and tell my mum and she just says "I'll give [get] him into trouble."

3.5.2.2 Retaliatory aggression

Siblings also said they used retaliatory aggression to manage the aggressive behaviour of the child with ADHD. For some siblings fighting back was considered the most successful strategy for managing aggressive behaviour by the child with ADHD "because that's what he needs sometimes" and for some siblings it was the only strategy that appeared successful:

"If I got rough back with him then he would finally stop ... if I don't get rough back with him then it will just keep going on and on and on ... that's the only way to stop him."

8 year old sister of 13 year old boy with ADHD (Id2)

However, others considered retaliatory aggression as a last resort:

"He'd start to hit me and I'll have to hit him back and if I hit him back, he'll start to hit me harder."

8 year old brother of a 13 year old boy with ADHD (Id5)

Younger siblings said they tried to avoid retaliation because of fears of getting hurt or that this would just continue the aggression. Older siblings tried to avoid retaliation because they were more likely to try reasoning with the child with ADHD or because they believed "the child with ADHD could not help their behaviour" or because they had been told by their parents "not to fight back."

3.5.2.3 Avoidance and accommodation

A minority of siblings described responding to the intrusive, annoying and aggressive behaviour of the child with ADHD by avoidance and accommodation. Strategies included ignoring the child with ADHD or taking themselves away from the child with ADHD:

"You just learn to ignore him and he'll just leave it."

15 year old sister of a 13 year old boy with ADHD (Id13)

"I think I'd just stay out of his way for a good while ... go out with my pals and just keep my mind off him and just try to stay out of his way."

16 year old sister of a 13 year old boy with ADHD (Id1)

Several siblings summed up their attitude of accommodation by saying said they were "used" to the behaviour by the child with ADHD and had learnt that the best way to deal with it was not react to it:

"I think you just get used to it because he has been like that since he was dead [very] young ... you just get used to it because most of the time he's like that."

15 year old sister of a 12 year old boy with ADHD (IdP14)

Avoidance also included avoidance of retaliatory aggression if physically keeping out of the way of the child with ADHD was not possible. Several older siblings described having the emotional maturity to realise that not fighting back contained the aggressive behaviour by the child with ADHD:

"Normally he'd pull my hair ... punch me and that ... I don't like hitting him because he's got problems ... I just like to get him off me and walk away."

15 year old sister of a 13 year old boy with ADHD (Id13)

The siblings eldest in age acknowledged that they had the capacity to defuse the situation as well having a part to play in the maintenance of the aggressive behaviour of the child with ADHD:

"Sometimes when she hits me and if I know I'm wrong - like I've done something to annoy her, I'll just let it go."

18 year old brother of a 13 year old girl with ADHD (Id10)

3.5.3 Siblings' perceptions of other sibling relationships

As sibling conflict is common in non-case families, it was important to put these descriptions of sibling relationships in families with a child with ADHD in context with other sibling relationships. Siblings were asked whether they felt their life was different to their friends in order to examine how siblings felt their sibling relationship compared to others. Many of the siblings talked about how the behaviour of the child with ADHD had a negative impact on their lives.

3.5.3.1 No differences in the sibling relationship

Only three siblings said their relationship was similar to their friends and that arguments and fights were about "normal things that every brother and sister has fights about":

"My friend [and] her wee [younger] brother they still argue and bicker - it's exactly the same really. If you ever go round to their house it's exactly the same."

20 year old sister of a 12 year old boy with ADHD (Id15)

3.5.3.2 Differences due to aggression in the sibling relationship

In general, siblings mentioned differences in their sibling relationship in terms of the aggressive behaviour by the child with ADHD as being more severe and persistent than the experience of their friends:

"Their brothers don't break their doors and put holes in their walls."

15 year old sister of 13 year old boy with ADHD (Id13)

"They [older sisters] don't hit them [younger sisters] or bully them. They just kinda get on."

11 year old sister of 13 year old girl with ADHD (Id12)

3.5.3.3 Differences due to poor social relationships of the child with ADHD

However, a few siblings did not identify differences in the levels of aggression in the sibling relationship but perceived differences in terms of looking after the child with ADHD. These siblings described having to play with, befriend and supervise the child with ADHD and only one sibling viewed this as positively:

"I'd probably get asked to help out a bit more ... like baby-sit quite a bit. It doesn't really bother me because we just watch a movie or play a game or read a comic or something."

16 year old brother of a 13 year old boy with ADHD (Id4)

The other siblings appeared more ambivalent about these responsibilities. Although the siblings were sympathetic toward the difficulties the children with ADHD was having with

their social relationships, the siblings were aware that looking after the child with ADHD was having a negative impact on their own peer relationships:

"I play with him because he doesn't [does not] really have friends ... if I want to go out to play with one of my friends then I'd be leaving [child with ADHD] out so I just go and play with [child with ADHD]."

10 year old sister of a 14 year old boy with ADHD (Id11)

"I've stuck up for him a lot of times. People in the street used to bully him and I used to have to go out and argue with them ... and then I would get their big sisters on [after] me."

16 year old sister of a 13 year old boy with ADHD (Id1)

"Most people can have their pals round ... people can stay for dinner but here they can't because there is him ... you've got somebody staying and then he's upstairs in your room. He hates being left out ... the next morning he's up at crack of dawn ... to see you and just be dead annoying."

15 year old sister of a 12 year old boy with ADHD (Id14)

3.5.4 Siblings' emotional reactions to living with ADHD

All siblings described being angry and frustrated by behaviour of the child with ADHD, with some siblings also described feelings of sadness. The intensity of these feelings were closely related to the siblings' descriptions of high levels of conflict in the relationship.

3.5.4.1 Anger

Most siblings described feeling angry, frustrated and annoyed because of the disturbance caused by the behaviour of the child with ADHD.

"I don't want to live with her ... I just want to kill her or get a knife or something ... just go "Yeah she's dead."

11 year old sister of a 13 year old girl with ADHD (Id12)

For many of these siblings this anger led to retaliatory aggression:

"He was coming along hitting me and I just couldn't stand it ... I was kicking him, punching him."

8 year old brother of a 13 year old boy with ADHD (Id9)

Several older siblings described their frustration at wanting to hit back, but knowing that they knew they should not:

"You can end up greeting [crying] ... because you've a pure temper inside you and my Mum telling me not to hit him ... because he's wee [younger] but sometimes you just pure want to kill him now and then. ... It's no [not] like being upset, it's pure anger. I just greet [cry] because my Ma says not to hit him ... but I wish I could hit him because that's what he needs sometimes."

15 year old sister of a 12 year old boy with ADHD (Id14)

3.5.4.2 Sadness

For some siblings this anger was also mixed with feelings of sadness. These siblings were younger sisters who were experiencing considerable levels of aggression and described feeling scared that they were going to get serious hurt by their brothers:

"I feel angry and sad because when he is shouting at me I try to stop ... and quite sad because I can't stop, then again inside another side I'm really angry with him ... for like starting off [fighting] with me just because I went in his room at the wrong time and that."

8 year old sister of 13 year old brother with ADHD (Id2)

3.5.5 Support for the sibling

Given the strong emotions described by the siblings in relation to the behaviour of the child with ADHD, it was important to examine whom the siblings could turn to for support. All the siblings named someone they could turn to when they had a problem or they were upset. Family members, both inside and outside of the home were the main sources of support. Older siblings were also likely to consider friends as sources of support.

3.5.5.1 Support for the sibling within the family

The majority of siblings said their mothers, or their mothers and fathers were a source of comfort and practical support when they had any problems or worries about anything, including the behaviour of the child with ADHD:

"[I'd] go to my mum - she'd ask me and I'd tell her and she'd do something about it."

11 year old sister of a 13 year old girl with ADHD (Jd12)

However, three older sisters who were adolescents did not view their parents as a source of support and did not talk to them about their problems. Instead these siblings said they talked to family members outside of the home: an aunt, an elder sister and a cousin. These girls also described their parents' management of the aggressive behaviour child with ADHD as ineffectual:

"Because they say like they cannay [can't] help it because of his disability and all that. "We cannay stop [him] ... it just his problem" ... I prefer talking to somebody else who doesn't stay in the house."

16 year old sister of a 13 year old boy with ADHD (Id1)

Although several siblings who lived in families with more than two children mentioned that their non-ADHD sibling was a source of support they did not regard the child with ADHD as a source of support. Only one sibling in the whole sample mentioned getting support from the child with ADHD.

3.5.5.2 Support for the sibling outwith the family

Some siblings said they had support outside of the family and the main source of this support was from friends:

"He was a pest [annoying] last night. We [my friends] all talk about that because everybody has stuff like that."

15 year old sister of a 12 year old boy with ADHD (Id14)

3.5.5.3 Professional support for the sibling

All the children with ADHD had attended a CAMHS clinic as preschoolers and many of them were still attending, so siblings viewed medical professionals as their family's primary source of support. Many talked about medication for the child with ADHD helping the family but only a few siblings mentioned professional intervention in the form of teaching the family behaviour management. Although some of the children were receiving considerable educational support few siblings regarded schools or teachers as a source of professional support for their family.

Several siblings mentioned that they would welcome professional support extended to include themselves. Older siblings reflected back on their experiences and mentioned the need for more information about the condition:

"When I got told about ADHD I never really knew a lot about it so I think that they [professionals] should give more information about what it's like and stuff to deal with it and that because I never really found out then [at the time of diagnosis]."

15 year old sister of a 13 year old boy with ADHD (Id13)

"Rather than just explain it to the parents ... I think it would be more useful [if] somebody outside of the family [explained ADHD to the sibling] because a lot of kids don't listen to much of what their parents are talking about."

20 year old sister of a 12 year old boy with ADHD (IdP15)

Siblings expressed interest in meeting other siblings and gave reasons such as wanting to find out how other siblings "cope with things" or "deal with" the child with ADHD. The majority of these siblings were enthusiastic about the idea of meeting other siblings in a group setting:

"Then I know I wouldn't be the odd one out."

11 year old sister of 13 year old girl with ADHD (Id12)

Some siblings thought going to a group would an opportunity to meet new friends and also suggested that the children with ADHD would also benefit from this opportunity to make friends. A couple of siblings did not like the idea of going to a group because they "didn't really like going to things like that" and "because I think it's between your family, not between other people". These were both older siblings who described freely discussing problems with the child with ADHD with their mothers.

3.5.6 Siblings' understanding of ADHD

Siblings described the behaviour of the child with ADHD in terms of the clinical picture of ADHD with reference to the child with ADHD being "hyper all the time", "having a lot of energy", "being unable to stay still for very long" and "not being able to pay attention for something very long."

The siblings' descriptions of the child with ADHD was summarized by this older sister:

"He has a bit more energy than needed really. Everything just turned up to maximum volume ... everything turned up a notch."

20 year old sister of a 12 year old boy with ADHD (Id15)

However, the terms "ADHD", "Attention Deficit Hyperactivity Disorder" and "Hyperactivity" were not part of every siblings' vocabulary. Only thirteen of the siblings had previously heard of this terminology and realised that it was the name of their brother's or sister's diagnosis. The siblings of four of the children who were not currently attending CAMHS Services had a less medical understanding: two younger siblings were unaware of their brothers' diagnosis and two older siblings believed the behaviour of the child with ADHD was due to an allergy to food or drink:

"The Doctor says 'cos [child with ADHD] is allergic to orange ... if he takes orange he pure goes mental ... one time my big sister gave him an orange and he pure flew for everybody ... he nearly stabbed one of my friends with a knife."

14 year old sister of a 13 year old boy with ADHD (Id16)

The siblings of the children with ADHD who were taking medication (and the sibling of the child who had previously taken medication) all described ADHD as a "disability" or a "condition." Several of these siblings talked about the child with ADHD going to a clinic and the benefits of medication:

"Ritalin ... is that not to reverse the effect of hyperactivity? To calm him down."

16 year old brother of a 13 year old boy with ADHD (Id4)

None of these siblings described the medication having any negative effects on the child with ADHD; however, one sibling mentioned that the child with ADHD only took medication during school hours so the family did not benefit from the improvement in his behaviour:

"He goes for Ritalin ... to calm him down ... to calm him down for during school ... it's only in school so they get the pure [very] easy life out of it and then he comes home and we've got to put up with it."

15 year old sister of a 12 year old boy with ADHD (Id14)

The siblings' understanding of ADHD did have a limited impact on their management of the behaviour of the child with ADHD, several older sisters with a good understanding of ADHD said they tried not to fight with their brother because they knew he had an "illness" or had "problems."

3.5.7 Mothers' descriptions of the sibling relationship

Nine mothers said that the aggressive behaviour of the child with ADHD was a major concern, with two mothers saying they were particularly concerned because this aggression was directed toward the sibling. Mothers' and siblings' descriptions of high levels of aggression between the siblings in the semi-structure interviews was reflected in high scores on the conduct disorder scale on the mothers' questionnaire measure.

3.5.7.1 Mothers' descriptions of conflict in the sibling relationship

Mothers described aggression being started by the child with ADHD, then the aggression escalating when the sibling retaliated:

"She will shove at him and he'll hit her because she's shoving him ... she generally does start it."

Mother of a 13 year old girl with ADHD and 17 year old boy (Id27)

Mothers were aware of the differences in the force of the aggression displayed by the child with ADHD and the sibling:

"If he does fight and punch her she will [fight back]. She'll threaten him first, keep threatening and eventually if he keeps pushing her she will hit him back. But her hitting is different ... she will give him a wee [little] tap whereas he will give her a full force punch."

Mother of a 12 year old boy with ADHD and a 15 year old girl (Id31)

However, mothers were aware of that some of the siblings' had a part in aggressive behaviour and that aggressive behaviour not always started by the child with ADHD.

Six mothers described how they tried to manage the aggressive behaviour in the relationship by keeping the siblings apart and intervening during arguments before it escalated into aggression:

"In saying they fight ... they don't get long enough to fight because the minute I know ... I know when they are going to start ... I'm right in there. This is not on."

Mother of an 11 year old boy with ADHD and a 8 year old girl (Id23)

3.5.7.2 Mothers' and siblings' descriptions of sibling conflict

Both siblings and mothers were asked to describe examples of aggression in the previous week. The majority of mothers and siblings described these incidences of conflict between the child with ADHD and their brother/sister in similar terms:

"Physically fighting - no, they don't do a lot of that. As I say the odd time if he is out on the street with friends he'll walk by and swipe her ... maybe a slap on arm but not really hard but she'd be more embarrassed than hurt ... if it did get physical I would intervene ... I'd intervene because [child with ADHD] can be quite physical."

Mother of Id14 (Id31)

"He just like slaps you ... it's not on your face or anything ... it's on your arms and legs. ... sometimes it's just like a wee thing [Mum and Dad] are like "Sort it out" ... but if it gets worse and worse like she'll tell him to shut up and me to shut up as well and then she'll either send the two of us up to our room or have us in here [in the sitting room]."

15 year old sister of a 12 year old brother with ADHD (Id14)

However, two mother-sibling pairs differed in their opinions of the sibling relationship, with both mothers underestimating the amount of aggression started by the child with ADHD. Both these children with ADHD had an additional diagnosis of learning difficulties and the mothers were experiencing significant levels of parenting stress, although these mothers were not depressed:

"They don't really fight - quarrel because [child with ADHD] doesn't really bother too much ... he's just away in his own wee world."

Mother of Id5 (Id22)

"When we are playing a game of fighting he takes it too far ... he jumps on me ... when I'm trying to get out he always grabs me back in ... he'd start to hit me and I'll have to hit him back and if I hit him back, he'll start to hit me harder."

8 year old boy of a 13 year old boy with ADHD (Id5)

One mother described the relationship between the child with ADHD and his sister as a typical sibling relationship, whereas this sibling did not feel that about the relationship:

"Calling each other names ... the usual brother and sister."

Mother of Id13 (Id30)

"Sometimes wee brothers can be in your room ... but not when they've got a knife to you and breaking your door."

15 year old sister of a 13 year old boy with ADHD (Id13)

Overall mothers were sympathetic towards the aggressive behaviour suffered by the sibling and attempted to intervene. However, the mothers of two younger siblings appeared less sympathetic towards the sibling. Both these mothers were experiencing significant parental stress and depression. These mothers were aware of the aggressive behaviour of the child with ADHD toward the sibling but believed that the siblings had a role to play in maintaining and over-reporting this behaviour:

"[Sibling] is one of they wee lassies if you pull her hair she'll greet [cry] - you know she's very kind of 'Oh no, he done that to me. He done that to me.' But she gives as good as she gets, don't get me wrong."

Mother of an 11 year old boy with ADHD and a 8 year old girl (Id23)

3.5.8 Summary of qualitative findings

There were six main findings from the qualitative interviews with the siblings. Firstly, although many siblings did describe their relationship with the child with ADHD in positive terms, the majority also described the relationship in negative terms, with a particular focus on the aggressive behaviour by the child with ADHD. Secondly, siblings described managing this negative behaviour by the child with ADHD with parental intervention, retaliatory aggression, avoidance and accommodation. Thirdly, although some siblings described no differences in their sibling relationship compared to their friends', others described differences in the levels of the aggression behaviour and the poor social relationships of the child with ADHD. Fourthly, siblings described their emotional reactions to living with a child with ADHD in terms of anger and sadness. Fifthly, siblings described receiving support from within the family, outwith the family and from professionals. Finally, there was a variety of levels of understanding of ADHD amongst

siblings. In addition, mothers' and siblings' descriptions of the sibling relationship were examined alongside each other and the majority of pairs were found to hold similar views.

3.5.9 Summary of findings

The objective of this study was to obtain a deeper understanding of the experiences of a sample of British siblings of children with ADHD. The siblings in this sample appeared to welcome the opportunity to talk about their family life and spoke freely about the negative and positive aspects of their relationship with the child with ADHD. Aggressive behaviour by the child with ADHD was a significant concern for a number of these siblings, however, as a group these siblings appeared to have good psychological functioning and had developed successful strategies to manage difficulties in their sibling relationship.

4 Discussion

4.1 Overview

The data provide one set of perspectives of siblings' relationships in a British clinical sample of children with ADHD. The use of qualitative methods offered an opportunity to examine the interactions and meanings that siblings of children with ADHD give to their sibling relationship. All the siblings who were invited to meet with the author agreed to be interviewed. Siblings appeared to welcome the opportunity to share their thoughts on family life and to talk about these experiences using the flexible format of a semi-structured interview.

The findings of this study confirm previous research that found aggressive behaviour started by the child with ADHD was a significant problem in the sibling relationship (Doran, 1997; Kendall, 1999; Singer, 1997). Siblings in this study described the aggressive behaviour by the child with ADHD causing feelings of anger, with only a minority describing feelings of sadness. Siblings were fighting back rather than feeling victimised by the aggression, and involving their parents in the management of aggressive behaviour by the child with ADHD. Siblings did not describe high levels of maternal expectations for caretaking of the child with ADHD.

As expected from previous research, the children with ADHD and the mothers were experiencing significant psychiatric morbidity. Some of the families were dealing with a child with ADHD with comorbid conditions which had been diagnosed and were being treated, while the questionnaire data revealed that many of the children with ADHD had significant levels of previously unidentified difficulties. The behaviour of the child with ADHD varied greatly across the sample, and so did the impact of this behaviour on the sibling and the family as a whole. However, siblings had similar levels of difficulties to that which would be expected in a community sample (Goodman et al, 2000).

This study used a purposive sample of children with ADHD. They were a clinical sample of preschoolers with ADHD but at follow up, not all the children with ADHD were currently being seen by a CAMHS clinician. However, there were no differences between these children and those who were not receiving treatment from a CAMHS clinician in terms of severity of ADHD symptoms or emotional and behavioural difficulties identified by the questionnaire measures completed by mother and teachers.

4.2 Psychological functioning of the families

In line with previous research both the children with ADHD and the mothers showed significant psychiatric morbidity (Johnston et al, 2001). The poor ratings on the standardised questionnaire measures for the child with ADHD were similar to those reported for a previous British clinical sample (Thompson et al, 2004). This would suggest that this sample were reasonably representative of a clinical sample of children with ADHD. This sample of families would score poorly on Barkley's predictor variables for positive outcomes for adolescents with ADHD (Barkley, 1990). As well as severe symptoms of ADHD, these children were exhibiting considerable comorbid conduct disorder and high levels of emotional symptoms. Mothers were experiencing high levels of parenting stress, depression and ADHD symptoms.

The psychological functioning of the siblings aged eight to 16 years old was in line with general population norms (Goodman et al, 2000). Ten percent of children in a general population sample in this age range would be expected to have some mental health difficulties, and it was found that two siblings were experiencing high levels of difficulties with symptoms of ADHD and emotional symptoms which were not being treated. This sample of siblings had a much lower rate of difficulties compared to previous samples (Kendall, 1999). The similarities of mothers' and siblings' perceptions of the sibling relationship and the emotional support siblings described receiving from parents and others could perhaps explain why there were doing better than the majority of the previous published literature would suggest. In addition, caretaking of the child with ADHD was not an issue for these siblings unlike previous samples (Kendall, 1999). The high levels of overt conflict between the siblings in this sample might explain why mothers were not asking the siblings to help with looking after the child with ADHD. This could act as a protective factor in maintaining good sibling mental health but could add to the mothers' burden and their high levels of parental stress and depression.

Mothers rated the psychological functioning of the child with ADHD more poorly than teachers. Teachers were asked to complete the questionnaire in order to confirm the existence of problems in more than one setting. Children with ADHD respond to structured environments which school is likely to offer, and so are highly likely to be experiencing fewer difficulties in such an environment (Schachar et al, 2002). In addition, several of the children who were attending schools for pupils with social and emotional behavioural difficulties which provide a very high level of structure and a high ratio of adults to

children, including one to one interaction. Several of the children were only taking stimulant medication during school hours so parents and siblings were not likely to be experiencing the benefits of medication on behaviour. Finally, children with ADHD are likely to exhibit difficult behaviour in their home environment, as they are more likely feel safest there. Mothers and teachers also appeared to disagree on their assessment of the siblings' psychological functioning, however, on closer examination of the data it appears that both mothers and teachers recognised that two children were having particular problems across the range of symptoms.

4.3 Conflict in the sibling relationship

Siblings and mothers described conflict as a significant theme in the majority of sibling relationships which is consistent with the limited previous research in this area (Doran, 1997; Kendall, 1999; Singer, 1997). Gender did not appear to make a difference to levels of aggression by the children with ADHD. Although the sample only included two girls with ADHD, these girls with ADHD were equally aggressive as the boys toward their siblings. Both girls and boys with ADHD showed similar levels of aggression towards their sisters as their brothers, and both male and female siblings were equally aggressive. Although the children with ADHD were equally aggressive to older and younger siblings, conflict in the sibling relationship appeared to be more problematic for younger siblings in this sample; in particular younger female siblings. This is the pattern that would be expected from non-case families where higher levels of conflict are found in opposite sex pairs (Epkins et al, 1999) but in this study the levels of aggression seemed to be of a greater order of magnitude, precipitating the researcher to encourage discussion of these siblings concerns with their mother. The severity and intensity of aggressive behaviour of three boys with ADHD described by their sisters concerned the researcher. These issues were discussed with the sibling, who then talked to their mother about these concerns in the presence of the researcher.

The children with ADHD in this sample showed levels of considerable comorbid conduct disorders according to mother and teacher questionnaire reports and this was reflected in the siblings' and mothers' descriptions of conflict in the sibling relationship. This confirms the previous findings that more severe behavioural symptoms of ADHD are associated with more problematic family relationships, and that mothers' questionnaire ratings of the severity of the ADHD behaviour are positively associated with conflict in the ADHD child-mother relationships, as well as their relationship with their younger siblings (Smith

et al, 2002). Taylor et al (1986) found that it was the defiant behaviour of the child with ADHD rather than their hyperactivity that caused the mothers the greatest problems. This appears to be consistent with siblings' perceptions of their relationship with the child with ADHD.

4.4 Mothers' and siblings' descriptions of the sibling relationship

It was important to examine the mothers' descriptions of conflict in the sibling relationship in a family with a child with ADHD to see if they reflect the siblings' description. Mothers having an accurate perception of the sibling relationship is important because they are more likely to have contact with professionals and be in the position to seek help for the sibling if they are experiencing problems.

The majority of mothers and siblings described the conflict in the sibling relationship in similar terms. Mothers and siblings both recognised when the behaviour by the child with ADHD was not part of "normal" sibling rivalry, whereas previous research found that this was not recognised by mothers (Kendall, 1999). This maternal recognition of conflict, particularly their recognition that the child with ADHD usually initiated it, would often cause mothers to seek help.

Several mothers in the present study spontaneously mentioned difficulties in the sibling relationship and described this issue as their biggest concern regarding the behaviour of the child with ADHD. Compared to Kendall's sample this insight could be due to the differences between the two samples of mothers and the children with ADHD (Kendall, 1999). The mothers in the current study had lower rates of maternal depression and ADHD and had attended a parent training programme when the child with ADHD was a pre-schooler. Some of the children in the current study were attending a clinic so mothers may have been receiving support in dealing with conflict in the sibling relationship. Finally, this sample included a larger number of older siblings who might be more likely to tell their mother about difficulties in their relationship with the child with ADHD and if aggression was occurring.

4.5 Siblings' perceptions of other sibling relationships

It was important to look at these sibling relationships in the context of "non-ADHD" sibling relationships and examine siblings' perceptions of these relationships. The majority of siblings did perceive differences in their relationship with the child with ADHD compared to the sibling relationship of their friends', particularly in relation to the frequency and intensity of aggressive behaviour by the child with ADHD. Mash et al (1983b) found that siblings of children with ADHD suffer more aggression and conflict from their brothers than siblings of control children. Several siblings also described having to look after the child with ADHD and although these responsibilities were considered to be a source of disruption for the sibling they did not appear to be a cause of great concern or impact on the siblings' psychological functioning. Siblings of chronically ill children with a heavy caretaking burden have been found to experience greater emotional and behavioural difficulties (McHale et al, 1989).

4.6 Management of conflict

Consistent with previous research the majority of siblings in this study described using parental intervention as a management technique (Kendall, 1999; Singer, 1997). Seeking the help of parents, in particular mothers, was found to be effective for the majority of the siblings. Mothers were described as getting involved once aggressive behaviour had started between the children, but few mothers were described using strategies to avoid the aggression starting, such as keeping the children apart. Some siblings also described using their own techniques such as avoidance and accommodation, which is in line with previous research (Doran, 1997; Kendall, 1999). The children with ADHD were equally aggressive to older and younger siblings but older siblings were less likely to describe fighting back. Several children with ADHD scored highly for conduct problems but were not described as being aggressive toward their sibling. Their behaviour was managed by the sibling avoiding conflict or by the mothers intervening in the argument before it became aggressive.

Aggressive behaviour by the child with ADHD resulted in a high level of retaliatory aggression by the sibling. Previous research that found both the child with ADHD and their sibling engaged in conflict and negative behaviour, and that it was hard to distinguish between the behaviour of the two children (Mash et al, 1983b). However, siblings in the current study reported much higher levels of retaliatory aggression than the siblings in

Kendall's work (Kendall, 1999). The increase in levels of retaliation in the current study could be due to differences in gender of the sibling pairs, with a higher number of male-female sibling pairs in the current study. In non-case families opposite-sex pairs have been found to have a more conflicted relationship than same-sex pairs (Epkins et al, 1999).

The families in this sample were also from a lower socio-economic group than Kendall's sample (Kendall, 1999). Hankin (1999) found that low socio-economic status increases stress in families with ADHD which could explain the higher levels of aggressive behaviour exhibited by the siblings and the high levels of maternal psychopathology. Several siblings reported that their mothers had suggested the use of retaliatory aggression to manage the behaviour of the child with ADHD. It was unclear whether the mothers thought this was appropriate behaviour for the children or whether it was a "last resort" strategy if mothers could not think of any other way to manage this aggression. Although aggression between siblings appears to be accepted by mothers, parental use of aggression to manage the behaviour of the child with ADHD was reportedly rare. Parental aggression was described by two siblings, once toward the sibling and once toward the child with ADHD. It is interesting to speculate whether these differences from middle-class American samples evidence class or cultural differences in parents' tolerance of sibling conflict.

Three younger sisters said they were afraid the aggression in their sibling relationship might escalate and they would get hurt. These findings suggest that their mothers were not dealing with the conflict to the siblings' satisfaction and that perhaps these mothers might need help in dealing with the conflict between these siblings. Mash et al (1983) suggest that parent training needs to focus on the management of sibling relationships rather than simply the individual children. Studies have suggested that siblings relationships were helped by the professional support received by their mothers (Doran, 1997; Moore, 1995; Singer, 1997). Mothers receiving help with their poor mental health and high levels of parenting stress could lead to an improvement in management of the aggression between the child with ADHD and their sibling.

4.7 Emotional reactions to living with a child with ADHD

Siblings described their feelings about the behaviour of the child with ADHD in terms of anger, with three siblings mentioned sadness in addition to feelings of annoyance. Kendall (1999) found that the majority of her sample of siblings described feeling anxious, worried, sad and victimised and were experiencing much greater levels of psychiatric morbidity. Getting angry and fighting back appeared to help the siblings in this study cope with the

aggressive and disruptive behaviour of the child with ADHD. However, by fighting back, the siblings might be maintaining the poor behaviour of the child with ADHD, and perhaps adding to the burden on the family. Whalen et al (1999) suggest that:

"the fact that some siblings display relatively high rates of dysfunctional behaviour has consequences for children with ADHD, to the extent that the siblings' actions help maintain abrasive interaction patterns and almost certainly have a negative impact on the quality of family life."

Although the siblings had learnt to behave aggressively at home, they did not appear to be behaving aggressively toward other children outside of the home as they were not generally described as having problems with their peers according to the questionnaires completed by mothers and teachers.

These findings confirm suggestions that services for these families need to be increased, in particular the need for mental health services for all members of the family (Hankin, 2001) and that research needs to evaluate outcomes of a family centred approach to ADHD treatment (Kendall, 1998).

4.8 Support for the siblings

All siblings had someone they viewed as a source of emotional support; in most cases this was their mother. Friends and family members outside of the house were also seen as a source of support. Siblings also gave examples of the value of professional support; in particular they mentioned medication for the child with ADHD. Two siblings also mentioned professional support in the form of behavioural management techniques as helpful for their families. The majority of siblings said they would value professional support for themselves and the child with ADHD. Many siblings said they would like to meet other siblings of children with ADHD and some siblings said they would like to attend a support group. Although the value of providing this sort of support for siblings of children with ADHD has not been examined, support groups for siblings of chronically ill children have found them to be beneficial (Court et al, 2003). Siblings also thought the child with ADHD would benefit from attending a support group. Research has found that support groups for teenagers with ADHD are helpful. Participants were found to enjoy taking part in group discussion and exercises to improve conflict resolution and communication skills. At two year follow up, parents reported there had been improvements in the children's behaviour and compliance with community rules (Timmer, 1995).

4.9 Siblings' understanding of ADHD

All siblings described the behaviour of the child with ADHD in relation to the clinical picture of ADHD. However, understanding of ADHD varied greatly across the sample depending on the age of the sibling and whether the child with ADHD was currently being attending a CAMHS clinic. Several older siblings mentioned the importance of being given information about the condition in order to be able to cope with the behaviour of the child with ADHD. Providing this support for siblings of children with ADHD has not been examined but children with mentally ill siblings have been found to benefit from psycho-social interventions to improve their knowledge of the condition and to develop their life skills for coping in their family (Pitman & Matthey, 2004). These findings suggest that siblings believed in the medicalisation of the behaviour of the child with ADHD which appeared to be reinforced by the child's involvement with CAMHS. Given that ADHD is not a universally accepted diagnosis, there is a tension between further medicalisation of the behavioural problems of the child with ADHD by suggesting professional support for their siblings.

4.10 Critique of the method

In quantitative research credibility of the data is established using the criteria of validity and reliability. These measures are inappropriate for qualitative research and alternative means to assess the credibility of this data have been suggested (Barbour, 2001; Greenhalgh et al, 1997; Malterud, 2001; Mays & Pope, 2000). This section will discuss the attempts that were made to meet these standards including providing a detailed description of sampling, data collection and analysis, examining the transferability of the data and acknowledging the interviewer's influence.

4.10.1 Data collection and analysis

Qualitative research takes an interactive approach which involves:

"altering the research methods and the hypothesis as the study progresses, in the light of information gleaned along the way." (Greenhalgh et al, 1997)

The interview schedule was not formally piloted with the first few siblings in order to reflect on any difficulties before modifying the schedule accordingly and using this version for the remaining interviews. However, attempts were made to maintain the flexible

reflexivity of the qualitative approach throughout the process of data collection and analysis. The interview schedule was piloted with a group of professionals working with children with ADHD and their families. Conducting the interviews was an iterative process with the author reflecting on the approach throughout the data collection period. The author reflected on each interview once it had taken place to identify strengths and difficulties of the interview schedule and interview technique. The scheduling of the interviews gave the author the opportunity to reflect on each interview before conducting the next interview. After each interview the author had the time to listen to the recording of the interview several times during the process of typing and checking the transcription. Initial difficulties in getting the siblings to talk, in particular the younger siblings, led to minor modifications in the interview technique rather than the interview schedule. In an attempt to get the children talking more freely the author increased the amount of time spent trying to establish a rapport with the child. This including spending a greater amount of time getting to know the child, for example, finding out about what they liked doing before starting the interview. Also as way of an introduction and giving a reason for carrying out the interview with the sibling, the author shared that she was a sister so she thought it was very important to speak to siblings in a family.

The data was collected in a systematic way using semi-structured interviews with the mothers and siblings. Semi-structured interviews keep the focus of the questions on the key issues but allow a degree of flexibility in the interview so that the researcher and interviewee can develop unexpected themes (Mason, 2002). The use of a qualitative interview with siblings provided a valuable insight into the siblings' perceptions of living with a child with ADHD. All of the siblings spoke freely during the interview and none appeared upset about discussing their experiences. Siblings appeared to welcome the opportunity to give their views on life at home. The semi-structured interviews used were flexible enough to allow siblings to suggest their own priorities, for example, the use of parental intervention as a management strategy of the child with ADHD emerged from the data.

Semi-structured interviews were selected for this study because they have found to be an effective way to elicit individual accounts of being a sibling of a child with ADHD (Doran, 1997; Kendall, 1999; Singer, 1997). Previous research with siblings of children with ADHD has used interview methods exclusively and other qualitative methods such as observation and focus groups have yet to be used with these participants. Due to the time and resource constraints imposed on this study, it was decided that observing sibling interaction was not a feasible option. Research observations of the sibling pair in a laboratory setting might not

provide a more accurate picture of the incidences of aggression behaviour as children with ADHD have been found to behave better in "novel and highly structured situations" (Schachar et al, 2002).

In order to collect the best data from the siblings, the interview technique used was based on good practice for interviewing children suggested by various authors (Backett-Milburn et al, 2003; Davis, 1998; Faux et al, 1988; Harden et al, 2000). However, semi-structured interviews create an artificial discussion on the topic and other methods could have been used to encourage full engagement by the younger/less articulate siblings. For example, the Draw and Write Technique which gathers qualitative data in the form of pictures and comments by asking children to draw a series of pictures and label them in response to a series of questions (Wetton et al, 1998).

In establishing credibility of the data collection, triangulation of data sources is important (Mays et al, 2000). In this study triangulation of perspective was achieved by collecting data on the mothers' and siblings' perceptions of conflict in the sibling relationship and comparing the results from both data sources. The collection of qualitative and quantitative data achieved triangulation of methods. The qualitative findings were reflected in the results of the quantitative data, for example, the children with ADHD who were rated highly by mothers and teachers on the emotional and behavioural difficulties questionnaires were generally also the children perceived by siblings and mothers to show more aggression.

Although this study focused on the siblings' perceptions of living with a child with ADHD, mothers' perceptions on these sibling relationships were an essential part of the study. As discussed in the Methodology section, only a small part of the interview with the mother specifically focused on sibling relationships and even though all available data from the interview was used, this data was limited. Although this resulted in a partial exploration of the perceptions of the mothers, this data did indicate that this was an important subject for future research.

Mothers were given the choice of the location of the sibling interview, which resulted in some of the siblings being interviewed in the clinic and other siblings being interviewed at home. As mothers rather than siblings decided the location, this might have had an impact on the engagement of the sibling during the interview. Siblings might have been glad of the privacy that being interviewed out of the home gave them. On the other hand, they might have felt less comfortable in the unknown surrounding of the clinic.

Participant feedback and a follow up interview were not carried out during this project. Although this can be a validity check, it can also be criticised for producing another set of potentially conflicting data as interviewees have their own individual concerns whereas the researcher attempts to provide an overview (Mays et al, 2000).

Although this study aimed to examine siblings' perceptions of their relationships with the child with ADHD it would have been interesting to also examine the perceptions of the children with ADHD themselves and of fathers. Unfortunately time constraints did not allow for these other family members to be interviewed.

4.10.2 *Transferability of data*

Transferability of data refers to "the probability that study findings have meaning to other in similar situations" (Streubert et al, 1999). Many aspects of the experiences described by the families in this study are likely to be common to all families of children with ADHD, however, some of the ways these families related will be different due to different influences, for example, the children with ADHD in this study were a clinical sample. Although the results only give one account of the phenomenon and may not be generalisable, the theory that is generated may be (Brown & Lloyd, 2001). The aim of qualitative research is to improve understanding of a topic, rather than generalise results to a whole population (Holloway et al, 1996). With this in mind, attempts were made to describe the sample using standardised questionnaire measures so that a coherent explanation of the phenomenon under study could be given (Miles & Huberman, 1994).

This was a pragmatic sample of siblings due to time constraints of carrying out a Masters project and the availability of participants. The main issues that came out of the interviews have been reported in this thesis but data saturation was not reached because the siblings introduced other issues that could not be pursued in this study. Given that the sample covered a broad age range and the semi-structured interview used was flexible enough to allow the interviewees to suggest their own priorities, it is not surprising that all the issues raised could not be explored more fully.

The sample was likely to be a representative clinical sample of children with ADHD as all the children with ADHD had active symptoms of the disorder and scored above the cut-off for clinical caseness for ADHD according to the mothers' responses to the Conners' Rating Scale (Conners, 1997) at the time of the study. Attempts were made to clearly describe the sample so that there is the potential for the findings to be applied to other samples with

similar demographic and psychological profiles. The families in this sample had all attended a parenting programme when their children were pre-schoolers and these families were found to be doing better than the control families at one year follow up (Barton, 2003). Mothers could be using the skills that they learnt in the programme to manage the conflict in the sibling relationship so it must be taken into account that these families might be still doing better than a random sample of ADHD families. However, this does not seem to be the case when the psychological functioning of these families was compared to the norms in the literature (Thompson et al, 2004).

Using a follow up sample could have a possible bias toward recruiting the children with fewer problems because clinicians acted as gatekeepers to the sample. Reason for refusing permission to follow up certain families was not given but one could be speculate that families who did not take part in the research would be experiencing more difficulties. However, the families who were followed up were experiencing considerable difficulties so are likely to be a reasonably representative sample of the initial families.

This sample was mixed in terms of the child with ADHD currently seeing a CAMHS clinician or not but there was no difference in terms severity of ADHD symptoms and comorbidities between these two samples. The majority of the families whose child was not currently seeing a CAMHS clinician were also having considerable difficulties with the child with ADHD and were receiving help from other sources, including Social Work and Education.

4.10.3 Interviewer influences

The researcher has influence in relation to what they bring to the design of the study:

"in terms of pre-existing theoretical positions and how their presence affects the research process" (Brown et al, 2001).

The author carrying out this study developed an interest in siblings of children with ADHD from working with children with ADHD and their mothers. This contrasts to a number of the American researchers carrying out qualitative research that have a personal background in ADHD (for example, mothers of children with ADHD or siblings of children with ADHD). Both group of researchers bring different perspectives and influences to the research agenda, and it is not suggested that one is better than another.

Although the author was sympathetic to the siblings and the potential difficulties in their home lives, the author attempted not to take the side of the sibling or the child with ADHD and unduly influence the interviews. As a sibling herself, the author felt empathy with some of the siblings but was aware of these feelings and reflected on them after each interview.

Even though it was explained to the participants that the author did not come from a service that could offer support, the mothers' previous experience of taking part in research with this department involved being part of treatment group and having the support of psychiatrists, nurses and teachers. It is possible that mothers may have exaggerated their child's difficulties in the erroneous view that this would encourage the author to provide help. The author was often asked for advice but could only suggest to mothers that they went to their General Practitioner for help. However, a positive aspect of the mothers and siblings taking part in these interviews was that several mothers were encouraged to seek help from professional services.

Qualitative interviews gave a further knowledge into the experience of these siblings that would have been gained with questionnaire methods. The participants had an influence on the research agenda as any new themes they raised were introduced into the next interview. This method was able to elicit information that had not been described in previous research, for example, siblings initiating aggressive behaviour, and that went beyond the author's hypotheses, for example, the use of parental intervention as a management strategy.

4.11 Implications for future research

Study participants were selected based on being able and interested in expressing their experiences of living with ADHD. A replication of this study using theoretical sampling to obtain a wider ranging sample, for example, sampling for siblings of girls with ADHD or using a smaller age range of siblings, could add credibility to the findings.

It is hard to separate whether siblings of children with ADHD are experiencing difficulties due to the nature of ADHD in their sibling or because of maternal influences such as depression, parenting stress or maternal ADHD. Parenting stress was examined in relation to the mothers' perceptions of her relationship with the child with ADHD and not in relation to perceptions of her relationship with the sibling. This study focused on the relationship between the child with ADHD and their sibling but did not examine sibling-

mother relationships. Mother-sibling relationships in families with children with ADHD need to be further examined.

The influence of fathers was not specifically examined in this study, although they appear to play a part in the management of the child with ADHD. This support needs to be examined, both in terms of the support given to siblings and to mothers. An examination of the full complexity of family relationships (including the father) will be a task for future research.

Siblings expressed an interest in receiving more information about ADHD, in meeting other siblings of children with ADHD and attending a support group. Siblings also expressed views that the children with ADHD themselves could benefit from these interventions. Further research could develop these ideas, perhaps using focus groups with siblings to design interventions and testing such interventions in randomised controlled trials.

4.12 Implications for clinical practice

This research found that the severity of the child's ADHD symptoms and the incidence of conduct problems are related to higher levels of aggression within the sibling relationship. This study confirms the views of several authors (Everett et al, 2001; Kendall, 1999) that ADHD is a family affair and that all family members need to be taken into account.

Assessment of the whole family is recommended as siblings may themselves have considerable difficulties, which get lost in the families' difficulties. Ideally, clinicians should interview the whole family including siblings and treat other family members as necessary. However, if this is not possible then clinicians need to ask mothers about sibling relationships, in particular aggression between siblings. This research found that mothers and siblings had very similar views on the negative aspects of the sibling relationship and therefore mothers in these families could have a greater role as advocates for the siblings. Difficulties in the sibling relationship were reflected in mothers' and teachers' accounts of the child with ADHD having comorbid conduct problems. Questionnaires could be routinely used to collect this useful information.

Even though their intervention was not always successful, mothers played an important role in the management of aggression between siblings. Mothers recognise aggression in the sibling relationship but need to be supported in developing more effective intervention strategies. As mothers are seen as a source of support for siblings, mothers need to be

supported themselves. Mothers also need to be routinely screened for emotional problems such as depression, parenting stress and for ADHD.

Siblings were keen to take part in the research and many welcomed the opportunity to express their views. Several talked about the need for information and how siblings should be given the opportunity to talk to a professional about ADHD. Several siblings expressed an interest in meeting other siblings of children with ADHD. While some siblings were interested in a support group for themselves, as well as for the child with ADHD. These groups have been found to be helpful to siblings of children with other chronic conditions (Lobato & Kao, 2002). There is a need to offer this kind of support for both children with ADHD and their siblings.

4.13 Summary of discussion

ADHD is one of the most common psychiatric disorders in the UK and has been found to have a significant negative impact on the child itself and their parents. This study attempted to examine the siblings' and mothers' perceptions of the sibling relationships within families with an ADHD child in a British clinical sample.

This study has found that living with a child with ADHD appears to have a significant impact on siblings. This impact is not necessarily in terms of significant emotional and behavioural difficulties measured by standardised questionnaires measures, in fact the siblings appear to be doing much better than expected. However, talking to the siblings revealed that they were experiencing considerable levels of aggressive behaviour from the child with ADHD. Siblings attempted to manage this conflict with help from their parents and by avoiding the child with ADHD, but many siblings found retaliatory aggression the most successful strategy. It may be that retaliatory aggression minimises the psychological impact on siblings, while maintaining aggression in the family.

Mothers showed insight into the difficulties that the siblings were having with the child with ADHD and in many cases wanted to be advocates for the siblings. The impact of ADHD in the family needs to be actively explored by clinicians and the psychological functioning of siblings examined. Mothers need to be helped to be a source of support for siblings in the home, including a routine examination of their own psychological difficulties.

5 Appendices

Appendix 1 Mothers' Information Sheet

Follow up of mothers and children involved in the Pre-School Overactivity Programme

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Some years ago you and your child attended the Pre-School Overactivity Programme (POP) at the Department of Child and Adolescent Psychiatry, Yorkhill Hospital. You may remember that we were trying to find out whether these treatment groups were helpful to families. We would like to see you and your child again to find out how things have turned out for you and your family since the group ended. If you have other children living in your household (including step children) we would also like to interview the brother or sister closest in age to the child who attended POP.

Why have I been chosen?

All the mothers and children who attended the POP are being invited to take part in this study. We hope to study approximately 60 families.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part will not affect the standard of care you or your child receives.

What will happen if we agree to take part?

We would like to visit you and your child at home. We will ask you to fill in some questionnaires about your child's behaviour at home and school and then ask you some more detailed questions about how you and your family are getting on. Your child will be asked some questions about how they are getting on at home and school and to complete some questionnaires. With your permission we would like to audio-tape your interview and the interview with your child. The visit should take approximately one and a half hours and you will be given breaks as you need them. We would like to write to your child's teacher(s) to ask them to complete a questionnaire about how your child is/are getting on. We would also like to look at your child's case files to see how they have been getting along and to see how things were for you both when you attended POP. All information which is collected as part of the study will be kept private.

What do we have to do?

Neither you nor your child need to do anything different or special because you are taking part in this study. If your child is taking medication then they should continue taking it as normal.

What are the side effects of taking part?

There are no side effects for either you or your child from completing our interview or questionnaires.

What are the possible disadvantages and risks of taking part?

The one disadvantage is the time spent being interviewed and completing the questionnaires.

What are the possible benefits of taking part?

While there is no direct benefit to you or your child from taking part in this study, we hope that this study will help us find out more about the long term effectiveness of the POP and how ADHD affects families, which might help others in the future.

What if new information becomes available?

Sometimes during the course of a research project, new information about the condition that is being studied becomes available. If this happens, your research doctor will tell you about it and discuss with you whether you want to continue in the study. If you decide to continue in the study you will be asked to sign a new consent form updated with this new information.

What happens when the research study stops?

Your child will continue to be seen by their doctor or General Practitioner.

What if something goes wrong?

If you have any concerns about how you, your child, or another family, is treated during the course of this study, please let us know and we will try to help. In addition, you can make a formal complaint to Yorkhill NHS Trust or the University of Glasgow in the usual way.

Will our taking part in our study be kept confidential?

All information that is collected about you and your child during the course of the research will be kept strictly confidential. Study records will be kept safe in our department, and only study staff will have access to them. We will ask your permission to disclose any relevant information you give us to your child's General Practitioner and/or other clinician as appropriate.

What will happen to the results of the research study?

We hope to present our findings at academic meetings, and publish the results of this study in an academic journal as soon as possible after the end of the study. Please contact us if you would like a copy of the published results. We will ensure that no member of your family can be identified in any report.

Who is organising and funding the research?

The study will be based within the Department of Child and Adolescent Psychiatry, Yorkhill NHS Trust. The research is being supported by Yorkhill NHS Trust and the University of Glasgow.

Who has reviewed this study?

This study has been reviewed by Yorkhill Research Ethics.

Contact for Further Information

If you would like more information about this study, please contact:

Amanda Burston
Research Assistant
Child and Adolescent Psychiatry
Glasgow University
Caledonia House
Yorkhill Hospital
Glasgow G3 8SJ
Telephone: 0141 201 0217

or

Dr Helen Minnis
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Glasgow University
Caledonia House
Yorkhill Hospital
Glasgow G3 8SJ
Telephone: 0141 201 0223/8

If you decide to participate in this study, you will be given a copy of this information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.

16 February 2003

Appendix 2 Siblings' Information Sheet

Follow up of mothers and children involved in the Pre-School Overactivity Programme

You are being invited to take part in a research study. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the study about?

A few years ago your Mum and your brother or sister came to a group called the Pre-School Overactivity Programme (POP) at the Department of Child and Adolescent Psychiatry, Yorkhill Hospital. We would like to see you, your Mum and your brother or sister to find out how things have turned out for your family since the group ended.

Why have I been chosen?

All the mums and children who took part in POP are being asked to take part in this study. We would also like to meet the brothers and sisters of these families. We hope to see 60 families.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you can change your mind at any time, without having to tell us why. If you do decide to "pull out", you will still get any help you need from your clinic or your General Practitioner.

What will happen to me if I take part?

We would meet with you, your Mum and your brother or sister and ask you to fill out some questionnaires and answer some questions about how you are feeling and how you are getting on at home and school. This should take about one and a half hours but you can take breaks when you need them. While you are doing this, your mum will fill out some questionnaires and answers some questions about how she is feeling and how you are getting on at home and school. We would like your brother or a sister to fill out some questionnaires about how they are feeling and how you are getting on at home. If you agree we would like to tape record what you say so we can listen to it again later to make sure we have got what you said. All the information which is collected as part of this study will be kept private. You will not need to do any special blood tests or other medical tests for this study.

What do I have to do?

You do not need to do anything different or special because you are taking part in this study. If you are taking any medication then you should take it as usual.

What are the side effects of taking part?

There are no side effects from being interviewed.

What are the possible disadvantages and risks of taking part?

The one disadvantage is time spent being interviewed.

Can taking part help me?

This study will not help you but we hope that this study will help us find out more about whether the POP was helpful, which might help others in the future.

What if new information becomes available?

Sometimes while a study is going on doctors learn new things about a problem or condition. If this happens, we will tell you about it and discuss with you if you want to carry on in the study or if it is best that you stop. If you do carry on, we will ask you to sign a new consent form.

What happens when the research study stops?

The doctors you see at the clinic or your General Practitioner will still take care of you.

What if something goes wrong?

If you are worried or upset about the way you are treated during this study, please tell your parent, carer or another adult you trust. They can help you complain and stop the problem.

Who will get to know about me and my problems?

All information that we collect about you and your family will be kept safe in the hospital. We will always ask you if it is OK before we tell anyone else about your problems.

What will happen with the information that you find out in the study?

Once the study is finished, we will write a report so that other doctors can learn from it. If you like, we can also let you and your family know what we have found out. We will not put your name in the report and we will make sure that nobody will be able to tell anything about you or your family from the report we write.

Who is running the study?

The project is being run by doctors from Yorkhill Hospital in Glasgow.

Who has checked over this study?

Yorkhill Research Ethics committee has checked this study. This is a group of people with lots of different jobs, who try to make sure that children and their families are not hurt by helping with research.

Contact for Further Information

If you would like more information about this study, please contact:

Amanda Burston
Research Assistant
Child and Adolescent Psychiatry
Glasgow University
Caledonia House
Yorkhill Hospital
Glasgow G3 8SJ
Telephone: 0141 201 0217

or

Dr Helen Minnis
Senior Lecturer
Child and Adolescent Psychiatry
Glasgow University
Caledonia House
Yorkhill Hospital
Glasgow G3 8SJ
Telephone: 0141 201 0223/8

If you decide to take part in this study, you will be given a copy of this information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.

16 February 2003

Appendix 3 Mothers' Consent Form

Follow up of mothers and children involved in the Pre-School Overactivity Programme

Please tick box

1. I confirm that I have read and understood the information sheet (16/02/03) for the above study and have had the opportunity to ask questions. ☐
2. I agree to my interview being tape recorded and understand that this information is confidential and that no identifying information will be used. ☐
3. I understand that my participation and the participation of my child(ren) is voluntary and that we are free to withdraw at any time without giving any reason, without our medical care or legal rights being affected. ☐
4. I agree to take part in the above study. I give permission for my child () to take part in the above study. ☐
5. I understand that sections of my child's () medical notes may be looked at by responsible individuals from this study where it is relevant to my taking part in research. I give permission for these individuals to have access to my child's () records. ☐
6. I agree that a questionnaire will be sent to my child ()'s teacher. ☐
7. I give permission for my child () to take part in the above study. ☐
8. I agree that a questionnaire will be sent to my child ()'s teacher. ☐

Name of parent

Date

Signature

Name of person taking consent
(if different from researcher)

Date

Signature

Witness

Date

Signature

Appendix 4 Siblings' Consent Form

Follow up of mothers and children involved in the Pre-School Overactivity Programme

Please tick box

1. I have read and understood the information sheet and asked the questions that I wanted to. ☐
2. I know I can stop the study at any time. ☐
3. I agree that my mum can be asked questions about me. ☐
4. I agree that my brother/sister can be asked questions about me. ☐
5. I agree to the interview being tape recorded and understand that this information will not be shared with anyone else and that nobody will be able to tell anything about me or my family from this information. ☐
6. I agree that a questionnaire can be sent to my teacher. ☐
7. I agree to take part in the above study. ☐

Name of sibling

Date

Signature

Name of person taking consent
(if different from researcher)

Date

Signature

Witness

Date

Signature

Appendix 5 Siblings' semi-structured interview

Introduction

Everyone lives in different kinds of family. Who lives in your family?

Tell me about your family. How does everyone get on?

Living with brother/sister

What is it like living with your brother/sister?

What are the best parts? What are the worse parts?

All brothers and sisters fight sometimes. What about quarrels and fights with your brother/sister? How often has that happened in the last week?

Is that how often it usually happens?

Perceptions of other sibling relationships

Do you have any friends with a younger/older brother/sister?

Do you think your life is different from theirs? In what way?

Beliefs about ADHD

Why does your brother/sister come to the clinic/hospital to see the doctor?

What is ADHD/ Hyperactivity?

What is it like living with a brother/sister with ADHD?

What helps you and your family manage your brother/sister's ADHD?

What do you tell other people about your brother/sister's ADHD?

Social support

Do you know any other children who have a brother or sister with ADHD? If yes, tell me about that. If no, would you like to? Why?

Does your family go to a group for families with an ADHD child? If yes, tell me about it. If no, would you like to? Why?

What do you do when have a problem or you are upset?

What or who helps you the most?

Is there any other help you'd like?

What do you think parents, teachers, doctors and other "professionals" could do for brothers and sisters of children with ADHD?

Closure

Is there anything else you want to talk about or that you think is important for me to know?

Appendix 6 Mothers' semi-structured interview

What about quarrels and fights between (child with ADHD) and (sibling)?

Do the children tend to quarrel a lot?

Over what sort of things, for example?

Do they tease each other?

Who comes out worse?

Do they fight?

What happens in the fights?

Does someone usually get hurt?

Or do things get broken?

In the last week have they done anything like that?

Questions from the Parental Account of Children's Symptoms (Taylor et al 1986)

6 References

- Albidin, R. R. 1995, *Parenting Stress Index Manual*, Third edn, Pediatric Psychology Press, Charlottesville, VA.
- American Psychiatric Association 2000, *Diagnostic and Statistical Manual of Mental Disorders*, Fourth edn, American Psychiatric Association, Washington DC.
- Anastopoulous, A. D., Guevremont, D. C., & Shelton, T. L. 1992, "Parenting Stress Among Families of Children with Attention Deficit Hyperactivity", *Journal of Abnormal Child Psychology*, vol. 20, pp. 503-520.
- Backett-Milburn, K., Cunningham-Burley, S., & Davis, J. 2003, "Contrasting lives, contrasting views? Understanding of health inequalities from children in differing social circumstances", *Social Science & Medicine*, vol. 57, pp. 613-623.
- Barbour, R. S. 2001, "Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?", *British Medical Journal*, vol. 322, pp. 1115-1117.
- Barkley, R. A. 1981, *Hyperactive Children; A handbook for diagnosis and treatment* Guilford Press., New York.
- Barkley, R. A. 1989, "Hyperactive girls and boys: stimulant drug effects on mother-child interactions", *Journal of Child Psychology & Psychiatry & Allied Disciplines*, vol. 30, pp. 379-390.
- Barkley, R. A. 1990, *Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment* Guilford Press., New York.
- Barkley, R. A. 1998, *Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment (2nd ed.)*, Second edn, The Guilford Press, New York.
- Barrera, M., Fleming, C. F., & Khan, F. S. 2004, "The role of emotional social support in the psychological adjustment of siblings of children with cancer", *Child: Care, Health & Development*, vol. 30, no. 2, pp. 103-111.
- Barton, J. 2002, *The effect of modifying maternal expressed emotion on outcome of preschool hyperactivity*.
- Barton, J., Aitken, K., Butler, S., Habour, R., Johnstone, R., Eunson, P., Nairn, M., Nasir, J., Norton, B., Puckering, C., Robb, C., Steer, C., & Stone, D. 2001, *Attention Deficit and Hyperkinetic Disorder in Children and Young People*, A national clinical guide. Scotland: Scottish Intercollegiate Guidelines Network.
- Biederman, J., Mick, E., Faraone, S. V., Braaten, F., Doyal, A., Spencer, T., Wilens, E., Frazier, E., & Johnson, M. A. 2002, "Influence of Gender on Attention Deficit Hyperactivity Disorder in Children Referred to a Psychiatric Clinic", *The American Journal of Psychiatry*, vol. 159, pp. 36-42.
- Biederman, J., Milberger, S., Faraone, S. V., Kiely, K., Guite, J., Mick, E., Ablon, S., Warburton, R., Reed, E., & Davis, S. G. 1995, "Impact of Adversity on Functioning and Comorbidity in Children with Attention-Deficit Hyperactivity Disorder", *American Academy of Child and Adolescent Psychiatry*, vol. 34, no. 11, pp. 1495-1503.

- Brody, G. H. 1998, "Sibling relationship quality: Its causes and consequences", *Annual Review of Psychology*, vol. 49, pp. 1-24.
- Brown, C. & Lloyd, K. 2001, "Qualitative methods in psychiatric research", *Advances in Psychiatric Treatment*, vol. 7, pp. 350-356.
- Buston, K., Parry-Jones, W., Bogan, A., & Wood, S. 1998, "Qualitative research", *British Journal of Psychiatry*, vol. 172, no. 197, p. 199.
- Conners, C. K. 1997, *Conners' Parents Rating Scale, Technical Manual* Multi-Health Systems Inc., Toronto.
- Conners, C. K., Erhardt, D., & Sparrow, F. 1994, *Conners' Adult ADHD Rating Scales, Technical Manual* Multi-Health Systems Inc., Toronto.
- Court, D., Kearney, S., & Rogers, A. Attention Deficit: living in a sick sibling's shadow. *YoungMinds Magazine* 63, 14-16. 2003.
Ref Type: Magazine Article
- Cunningham, C. E., Benness, B. B., & Siegel, L. S. 1988, "Family Functioning, Time Allocation, and Parental Depression in the Families of Normal and ADHD Children.", *Journal of Clinical Child Psychology*, vol. 17, no. 2, pp. 169-177.
- Davis, J. M. 1998, "Understanding The Meanings of Children: A Reflexive Process", *Children & Society*, vol. 12, pp. 325-335.
- Deater-Deckard, K., Dunn, J., & Lussier, G. 2002, "Sibling Relationships and Social-emotional Adjustment in Different Family Contexts", *Social Development*, vol. 11, no. 4, pp. 571-590.
- Doran, S. F. 1997, *Siblings of teens and young adults with Attention-Deficit Hyperactivity Disorder: A qualitative study*.
- Dunn, J. 1992, "Sisters and Brothers: Current Issues in Developmental Research," in *Children's Sibling Relationships: Development and Clinical Issues*, F. Boer & J. Dunn, eds., pp. 11-13.
- Dunn, J., Deater-Deckard, K., Pickering, K., & Golding, J. 1999, "Siblings, parents and partners: Family relationships within a longitudinal community study", *Journal of Child Psychology and Psychiatry*, vol. 40, pp. 1025-1037.
- DuPaul, G. J., McGoey, K. E., Eckert, T. L., & Vanbrakel, J. 2001, "Preschool Children With Attention-Deficit/Hyperactivity Disorder: Impairments in Behavioral, Social, and School Functioning", *Journal of the American Academy of Child & Adolescent Psychiatry*, vol. 40, no. 5, pp. 508-515.
- Epkins, C. C. & Dedmon, A. M. 1999, "An Initial Look at Sibling Reports on Children's Behavior: Comparisons with Children's Self-Reports and Relations with Siblings' Self-Reports and Sibling Relationships", *Journal of Abnormal Child Psychology*, vol. 27, no. 5, pp. 371-381.
- Everett, C. A. & Everett, S. V. 2001, "Assessing ADHD in the Intergenerational Family System," in *Family Therapy for ADHD: Treating Children, Adolescents, and Adult*, Guilford Press, pp. 97-163.

- Faraone, S. V. & Biederman, J. 1994, "Is attention deficit hyperactivity disorder familial?", *Harvard Review of Psychiatry* no. 1, pp. 271-287.
- Faraone, S. V., Biederman, J., Chen, W. J., Milberger, S., Warburton, R., & Tsuang, M. T. 1995, "Genetic Heterogeneity in Attention-Deficit Hyperactivity Disorder (ADHD): Gender, Psychiatric Comorbidity, and Maternal ADHD", *Journal of Abnormal Psychology*, vol. 104, no. 2, pp. 334-345.
- Faraone, S. V., Biederman, J., Lehman, B. K., Spencer, T., Norman, D., Seidman, L. J., Kraus, I., Perrin, J., Chen, W. J., & Tsuang, M. T. 1993, "Intellectual Performance and School Failure in Children With Attention Deficit Hyperactivity Disorder and in Their Siblings", *Journal of Abnormal Psychology*, vol. 102, no. 4, pp. 616-623.
- Faraone, S. V., Biederman, J., Mennin, D., Gershon, J., & Tsuang, M. T. 1996, "A Prospective Four-Year Follow-up Study of Children at Risk for ADHD: Psychiatric, Neuropsychological, and Psychosocial Outcome", *Journal of American Academy of Child and Adolescent Psychiatry*, vol. 35, no. 11, pp. 1449-1459.
- Faux, S. A., Walsh, M., & Deatrick, J. A. 1988, "Intensive Interviewing with Children and Adolescents", *Western Journal of Nursing Research*, vol. 10, no. 2, pp. 180-194.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. 1996, "Risk and Protective Factors Affecting the Adjustment of Siblings of Children with Chronic Disabilities", *Journal of American Academy of Child and Adolescent Psychiatry*, vol. 35, no. 11, pp. 1532-1541.
- Frick, P. J. 1999, "Family Dysfunction and the Disruptive Behavior Disorders", *Advances in Clinical Child Psychology*, vol. 16, pp. 203-226.
- Goodman, R. 1997, "The Strengths and Difficulties Questionnaire: A Research Note.", *Journal of Child Psychology and Psychiatry*, vol. 38, pp. 581-586.
- Goodman, R., Ford, T., Simmons, H., Gatward, R., & Meltzer, H. 2000, "Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample", *The British Journal of Psychiatry*, vol. 177, pp. 534-539.
- Goodman, R., Meltzer, H., & Bailey, V. 1998, "The Strengths and Difficulties Questionnaire: A pilot study on the validity of the self-report version", *European Child and Adolescent Psychiatry*, vol. 7, pp. 125-130.
- Graham-Berman, S. A. 1994, "The Assessment of Childhood Sibling Relationships: Varying Perspectives on Cooperation and Conflict", *Journal of Genetic Psychology*, vol. 155, no. 4, pp. 457-470.
- Green, J. & Thorogood, N. 1998, *Analysing Health Policy: A Sociological Approach* Addison Wesley Longman Limited, London.
- Greenhalgh, T. & Taylor, R. 1997, "How to read a paper: Papers that go beyond numbers (qualitative research)", *British Medical Journal*, vol. 315, pp. 740-743.
- Hankin, C. S. 2001, "ADHD and Its Impact on the Family", *Drug Benefit Trends*, vol. 13, pp. 15-16.
- Harden, J., Scott, S., Backett-Milburn, K., & Jackson, S. 2000, "Can't Talk, Won't Talk?: Methodological Issues in Researching Children", *Sociological Research Online*, vol. 5, no. 2.

- Hechtman, L. 1981, "Families of Hyperactives," in *Research in Community and Mental Health*, R. G. Simmons, ed., JAI Press Inc., Greenwich, Connecticut, pp. 275-294.
- Hechtman, L. 1996, "Families of Children with Attention Deficit Hyperactivity Disorder: A Review", *Canadian Journal of Psychiatry*, vol. 41, pp. 350-360.
- Holloway, I. & Wheeler, S. 1996, *Qualitative research for nurses* Blackwell Science, UK; Oxford.
- Jerome, L. 1995, "Teacher and parent influences on medication compliance", *Journal of Child and Adolescent Psychopharmacology*, vol. 5, pp. 85-86.
- Johnston, C. & Mash, E. J. 2001, "Families of Children With Attention-Deficit/Hyperactivity Disorder: Review and Recommendations for Future Research", *Clinical Child and Family Psychology Review*, vol. 4, no. 5, pp. 183-207.
- Kadesjo, B. & Gillberg, C. 2001, "The comorbidity of AD/HD in the general population of Swedish school-age children", *Journal of Child Psychology & Psychiatry & Allied Disciplines*, vol. 42, no. 4, pp. 487-492.
- Kaminsky, L. & Dewey, D. 2002, "Psychosocial adjustment in siblings of children with autism", *Journal of Child Psychology and Psychiatry*, vol. 43, no. 2, pp. 225-232.
- Kendall, J. 1997, "The use of qualitative methods in the study of wellness in children with attention deficit hyperactivity disorder", *Journal of Child Psychology and Psychiatric Nursing*, vol. 10, no. 4, pp. 27-39.
- Kendall, J. 1998, "Outlasting Disruption: The process of reinvestment in families with ADHD children", *Qualitative Health Research*, vol. 8, no. 6.
- Kendall, J. 1999, "Sibling Accounts of Attention Deficit Hyperactivity Disorder (ADHD)", *Family Process*, vol. 38, pp. 117-136.
- Lewis-Abney, K. 1993, "Correlates of family functioning when a child has Attention Deficit Disorder", *Issues on Comprehensive Pediatric Nursing*, vol. 16, pp. 175-190.
- Lobato, D. J. & Kao, B. T. 2002, "Integrated Sibling-Parent Group Intervention to Improve Sibling Knowledge and Adjustment to Chronic Illness and Disability", *Journal of Pediatric Psychology*, vol. 27, no. 8, pp. 711-716.
- Malterud, K. 2001, "Qualitative research: standards, challenges, and guidelines", *The Lancet*, vol. 358, pp. 483-488.
- Mash, E. J. & Johnston, C. 1983a, "Parental perceptions of child behaviour problems, parenting self esteem, and mother's reported stress in younger and older hyperactive and normal children", *Journal of Consulting and Clinical Psychology*, vol. 51, pp. 86-99.
- Mash, E. J. & Johnston, C. 1983b, "Sibling Interactions of Hyperactive and Normal Children and Their Relationship to Reports of Maternal Stress and Self-Esteem", *Journal of Clinical Child Psychology*, vol. 12, no. 1, pp. 91-99.
- Mason, J. 2002, *Qualitative Researching*, 2nd Edition edn, Sage Publications Ltd, London.
- Mays, N. & Pope, C. 2000, "Assessing Qualitative Research", *British Medical Journal*, vol. 7226, no. 320, pp. 50-52.

- McHale, S. M. & Gamble, W. C. 1989, "Sibling Relationships of Children With Disabled and Nondisabled Brothers and Sisters.", *Developmental Psychology*, vol. 25, pp. 421-429.
- McHale, S. M. & Harris, V. S. 1992, "Children's Experiences With Disabled and Nondisabled Siblings: Links With Personal Adjustment and Relationship Evaluations," in *Children's Sibling Relationships: Development and Clinical Issues.*, F. Boer & J. Dunn, eds., pp. 83-100.
- Meltzer, H., Gatward, R., Goodman, R., & Ford, T. 2000, *Mental Health of Children and Adolescents in Great Britain* Stationery Office Books, London.
- Miles, M. B. & Huberman, A. M. 1994, *Qualitative data analysis : an expanded sourcebook*, 2nd edn, Sage, Thousand Oaks, CA.
- Moore, A. M. 1995, *Characteristics of siblings of children diagnosed with Attention-Deficit/Hyperactivity Disorder.*
- Morse, J. A. & Field, P. A. 1996, *Nursing Research The application of qualitative approaches*, 2nd edn, Stanley Thornes Ltd, Padstow.
- Muhr, T. & Friese, S. 2004, *User's Manual for Atlas.ti 5.0*, 2nd edn.
- Phares, V. & Compas, B. E. 1992, "The Role of Fathers in Child and Adolescent Psychopathology: Make Room for Daddy", *Psychological Bulletin*, vol. 111, pp. 387-412.
- Pitman, E. & Matthey, S. 2004, "The SMILES Program: A Group Program for Children With Mentally Ill Parents or Siblings", *American Journal of Orthopsychiatry*, vol. 74, no. 3, pp. 383-388.
- Podolski, C. & Nigg, J. T. 2001, "Parent Stress and Coping in Relation to Child ADHD Severity and Associated Child Disruptive Behavior Problems.", *Journal of Clinical Child Psychology*, vol. 30, no. 4, pp. 503-514.
- Pope, C. & Ziebland, S. 2000, "Analysing Qualitative Data", *British Medical Journal*, vol. 320, no. 7227, pp. 114-117.
- Samudra, K. & Cantwell, D. P. 1999, "Risk Factors for Attention-Deficit/Hyperactivity Disorder," in *Handbook of Disruptive Behavior Disorders*, H. C. Quay & A. E. Hogan, eds., Kluwer Academic/Plenum Publishers, New York, pp. 199-220.
- Schachar, R. & Tannock, R. 2002, "Syndromes of Hyperactivity and Attention Deficit," in *Child and Adolescent Psychiatry*, Fourth edn, M. Rutter & E. Taylor, eds., Blackwell Publishing Company, Oxford, pp. 399-418.
- Sharpe, D. & Rossiter, L. 2002, "Siblings of Children With a Chronic Illness: A Meta-Analysis", *Journal of Pediatric Psychology*, vol. 27, no. 8, pp. 699-710.
- Singer, B. 1997, *The Psychological Experience of Siblings of Children with ADHD.*
- Smith, A. J., Brown, R. T., Bunke, V., Blount, R. I., & Christophersen, E. 2002, "Psychosocial adjustment and peer competence of siblings of children with Attention-Deficit/Hyperactivity Disorder", *Journal of Attention Disorders*, vol. 5, no. 3, pp. 165-177.
- Sonuga-Barke, E. J., Daley, D., & Thompson, M. 2002, "Does Maternal ADHD Reduce the Effectiveness of Parent Training for Preschool Children's ADHD?", *Journal of American Academy of Child and Adolescent Psychiatry*, vol. 41, no. 6, pp. 696-702.

- Stoneman, Z. & Brody, G. H. 1993, "Sibling Temperaments, Conflict, Warmth, and Role Asymmetry", *Child Development*, vol. 64, pp. 1786-1800.
- Stormont-Spurgin, M. & Zentall, S. S. 1995, "Contributing Factors in the Manifestation of Aggression in Preschoolers with Hyperactivity", *Journal of Child Psychology and Psychiatry and Allied Disciplines*, vol. 36, no. 3, pp. 491-509.
- Streubert, H. J. & Carpenter, D. R. 1999, *Qualitative Research in Nursing: Advancing the Humanistic Imperative*, 2nd edn, Lippincott, Williams & Wilkins, Philadelphia.
- Szatmari, P., Offord, D. R., & Boyle, M. H. 1989, "Correlates, Associated Impairments and Patterns of Service Utilization of Children with Attention Deficit Disorder: Findings from the Ontario Child Health Study", *Journal of Child Psychology and Psychiatry*, vol. 30, no. 2, pp. 205-217.
- Tarver-Behring, S., Russell, M. A., Barkley, R. A., & Karlsson, J. 1985, "The mother-child interactions of hyperactive boys and their normal siblings", *American Journal of Orthopsychiatry*, vol. 55, no. 2, pp. 202-209.
- Taylor, E., Schachar, R., Thorley, G., & Wieselberg, M. 1986, "Conduct disorder and hyperactivity: Separation of hyperactivity and antisocial conduct disorder in British child psychiatric patients", *British Journal of Psychiatry*, vol. 149, pp. 760-777.
- Thompson, M. J., Brooke, X. M., West, C. A., Johnson, H. R., Bumby, E. J., Brodrick, P., Pepe, G., Laver-Bradbury, C., & Scott, N. 2004, "Profiles, co-morbidity and their relationship to treatment of 191 children with AD/HD and their families", *European Child and Adolescent Psychiatry*, vol. 13, no. 4, pp. 234-242.
- Timmer, D. F. 1995, "Group support for teenagers with Attention Deficit Hyperactivity Disorder", *Social Work in Education*, vol. 17, no. 3, pp. 194-199.
- Wengraf, T. 2001, *Qualitative Research Interviewing* Sage Publications Ltd, London.
- Wetton, N. & McCoy, M. 1998, *Confidence to learn*, Health Board for Scotland, Edinburgh.
- Whalen, C. K. & Henker, B. 1999, "The Child with Attention-Deficit/Hyperactivity Disorder in Family Contexts," in *Handbook of Disruptive Behavior Disorders*, H. C. Quay & A. E. Hogan, eds., Kluwer Academic/ Plenum Publishers, New York, pp. 139-153.
- Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., Hafeman, C., Liebergen, A., Leuenberg, K., Setter, R. K., Ridder, L., Curry, H., Barnard, M., & Sanders, S. 2002, "Interrelationships Among Variables Affecting Well Siblings and Mothers in Families of Children With a Chronic Illness or Disability", *Journal of Behavioural Medicine*, vol. 25, no. 5, pp. 411-424.

