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ADHD Medication Related Attitudes and Behaviours

by

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ABSTRACT

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The aims of this thesis were threefold. First, medication related attitudes and behaviours were identified using in-depth qualitative interviews with parents of children with ADHD. Second, a questionnaire was developed to assess medication related attitudes and behaviours drawing from the data collected in the interview study. Third, the relationships between ADHD related attitudes and behaviours with family factors and cultural factors between the UK and the USA were examined. Parent and child version ADHD Medication Related Attitudes and Behaviours (AMRABs) questionnaires were developed to assess parents' and children's perceptions of the benefits, costs, stigma associated with ADHD medication and whether children resisted taking medication. Parents were also asked about the stigma they experience as parents, how flexible they are in administering medication and how competent they are in administering medication consistently. The questionnaires were piloted in ADHD clinics in the UK and USA, on the internet and through ADHD support groups. The questionnaires were found to have a robust component structure with high internal reliability for each scale. Participants in the UK consistently reported markedly higher levels of child stigma than participants in the USA. The final study examined relationships between the AMRABs subscales and family factors. The results indicated that child conduct problems were associated with resistance to taking medication. Maternal mental health difficulties were associated with maternal perception of the benefits and costs of taking medication, and with resistance to taking medication. Maternal ADHD and poor parenting self-efficacy were associated with difficulties in administering medication consistently. Family cohesion was predictive of child stigma in the USA, and paternal warmth and high maternal criticism were associated with child stigma in both countries. However, the most significant predictor of child stigma was being from the UK. High SES was associated with higher parental stigma. The limitations and potential clinical implications are considered, and avenues for future research discussed.

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Chapter 1
ADHD

Chapter summary

This chapter describes the diagnostic criteria for Attention-Deficit Hyperactivity Disorder (ADHD), associated clinical impairments throughout the lifespan and the impact of ADHD of family functioning. Research literature on the aetiology of ADHD is considered.

1.1 Diagnostic criteria for ADHD

ADHD is the most prevalent developmental disorder, affecting 3-5% of the school-age population and is three times more common in boys than in girls (Barkley, 1990).

The DSM-IV (American Psychiatric Association, 1994) describes ADHD in terms of three core symptoms: inattention, impulsivity and hyperactivity. Children with ADHD display inattentive and hyperactive symptoms that are maladaptive and inconsistent with their developmental level. In order to meet diagnostic criteria for ADHD, these symptoms must cause clinically significant impairments in social, academic or occupational functioning.

1.1.1 Inattention

Inattentive symptoms include failure to give close attention, making careless mistakes in schoolwork, difficulty in sustaining attention in tasks, seeming not to listen when spoken to, not following through on instructions or failure to complete schoolwork/workplace duties, organisational difficulties, losing things (e.g. toys, school assignments), distractibility and forgetfulness.

These symptoms are manifest in a variety of situations. In free play, children with ADHD play with the same toys for shorter durations and frequently shift their attention across various toys (Sonuga-Barke, Daley, Thompson, Laver-Bradbury, & Weeks, 2001). Children with ADHD find it difficult to sustain attention during dull or repetitive tasks such as schoolwork (Zentall, 1985).

1.1.2 Hyperactivity

Hyperactive symptoms include fidgeting with hands or feet, leaving seat during class, running around excessively, difficulties with playing quietly and talking excessively (APA, 1994).

1.1.3 Impulsivity

Impulsive symptoms include blurting out answers, difficulty awaiting turn and interrupting others' conversations and games.

Hyperactive-impulsive behaviours are often a source of irritation for other people, such as teachers, who often find children with ADHD's behaviour disruptive, and may ask them to leave the classroom (Brook, Watemberg, & Geva, 2000).

1.1.4 Categories of ADHD

The DSM-IV distinguishes three diagnostic categories of ADHD:

(i) **ADHD Combined Type:** The child displays at least six of the aforementioned symptoms of inattention and six of the aforementioned symptoms of hyperactivity-impulsivity.

(ii) **ADHD Predominantly Inattentive Type:** The child displays at least six of aforementioned symptoms of inattention, but does not meet diagnostic criteria for ADHD, Combined Type.

(iii) **ADHD Predominantly Hyperactive-Impulsive Type:** The child displays at least six of the aforementioned symptoms of hyperactivity-impulsivity but does not meet diagnostic criteria for ADHD, Combined Type.

1.2. Clinical impairments associated with ADHD across the lifespan

1.2.1 Clinical impairments in preschool

Symptoms of ADHD typically manifest early in life, prior to the age of 7 years (American Psychiatric Association, 1994). As many as 2% of children aged 3 – 5 years in the general population may meet DSM-IV diagnostic criteria for ADHD

(Lavinge, Gibbons, & Chistroffell, 1996; McGee, Partridge, Williams, & Silva, 1991). Preschoolers with ADHD are more likely to experience problems in physical, family, social, educational and psychiatric domains.

1.2.1.1 Physical

Preschoolers with ADHD are more likely to experience motor coordination problems, have accidents and need more medical care than control children (Lahey, Pelham, & Stein, 1998).

1.2.1.2 Family

Preschoolers with ADHD are more likely to be non-compliant towards their parents. Likewise, parents of preschoolers with ADHD are more likely to display negative behaviour towards their children with ADHD (DuPaul, McGoey, Eckert, & VanBrakle, 2001). Parents of preschoolers with ADHD rate their children as being more demanding of parent time, less adaptable to changes in routine and more non-compliant with parental requests than parents of control children (DeWolfe, Byrne, & Bawden, 2000).

1.2.1.3 Social

Preschoolers with ADHD are rated as less socially skilled than control children (DuPaul et al., 2001), engage in more sensori-motor play and less social interaction in group situations (Alessandri, 1992) and are more likely to be aggressive towards their peers (Barkley et al., 2000).

1.2.1.4 Educational

Preschoolers with ADHD show intellectual impairments, developmental deficits and poorer pre-academic skills than preschoolers without ADHD (Gadow & Nolan, 2002; Lahey et al., 1998). It is likely that these deficits may compromise the school readiness of preschoolers who display ADHD symptoms and may make transition from preschool to school particularly challenging.

1.2.1.5 Psychiatric

Children who display ADHD symptoms in their preschool years are more likely to experience pervasive ADHD symptoms into adolescence (McGee et al., 1991; Sonuga-Barke, Thompson, Stevenson, & Viney, 1997). They are more likely to display comorbid disruptive and mood disorders such as oppositional defiance disorder (ODD), conduct disorder (CD) depression and bipolar disorder in later childhood and adolescence (Wilens et al., 2002).

1.2.2 Clinical impairments in childhood

Children with ADHD also display clinical impairments on family, social, educational and psychiatric domains.

1.2.2.1 Family

Children with ADHD are less compliant with parental instructions and display more negative behaviour towards their parents than children of the same age without ADHD (Barkley, Karlsson & Pollard, 1985; Befera & Barkley, 1985). Mothers and fathers of children with ADHD display more commanding behaviour and disapproval and give fewer rewards to their children for prosocial or compliant behaviour than parents of control children in observational studies (Gardner, 1994; Johnston, 1996).

1.2.2.2 Social

Children with ADHD are more likely to experience difficulties and rejection in peer relationships (Stormont, 2000). Girls with ADHD-inattentive type seem particularly at risk from disrupted social relationships. They are more likely than controls to experience rejection from their peers (Gaub and Carlson, 1997). This may be due to higher rates of internalising disorders such as anxiety and depression in the inattentive subtype (Lahey and Carlson, 1991) which can lead to social withdrawal (Zentall, 2005).

However, research suggests that internalising symptoms are not the only cause of peer difficulties in children with ADHD. Hyperactivity at age 6-7 has been associated with difficulties in peer friendships at age 14-16 (Young, Chadwich, Heptinstall, Taylor & Sonuga-Barke, 2005). Additionally, girls with ADHD report higher levels of

dissatisfaction in their relationships with teachers than female controls (Rucklidge and Tannock, 2001).

Children with combined or hyperactive-impulsive type ADHD also have difficulties. Deficits in social skills and self-control lead children with ADHD to interact with other children in an overbearing, unrestrained style characterised by hyperactivity, bossiness and controlling behaviour, which makes them unpopular with their peers (Whalen & Henker, 1992).

Children with predominantly inattentive type ADHD are more likely to be judged by peers as being shy, and children with combined inattentive-hyperactive ADHD are more likely to be judged by peers as being aggressive and starting fights (Hodgens, Cole, & Boldizar, 2000).

1.2.2.3 Educational

Children with ADHD show poorer cognitive skills, lower levels of reading ability and more disruptive and inattentive behaviours at home and at school (McGee et al., 1991). Willcut and Pennington (2000) found that externalising symptoms in boys and internalising symptoms in girls were associated with reading disability. In a large-scale national study, inattentive symptoms were strongly associated with literacy difficulties (Carroll, Maughan, Goodman & Meltzer, 2005).

The association between ADHD and reading disability may explain educational difficulties, at least in part (Hinshaw, 1992; Levy et al., 1996). Willcut and Pennington (2000) found an association between ADHD and reading disability even when controlling for other factors (ODD, CD, aggression and delinquency) that can interfere with children's education. Children with ADHD, both with and without comorbid reading disabilities, show slower and more variable processing speeds and impairments on measures of reading ability and verbal working memory (Willcut et al., 2005). These symptoms jeopardise the chances of children with ADHD to achieve academic success and severity of ADHD symptoms is associated with lower achievement in reading, writing and mathematics (Barry, Lyman, & Klinger, 2002).

Carroll et al., (2005) also found that literacy difficulties were associated with separation and generalised anxiety disorders. This link was not accounted for by

attention levels suggesting that literacy difficulties might constitute a risk factor for the development of anxiety disorders.

In addition, children with ADHD may struggle with the transition from primary to secondary education. Mastering the necessary organisational skills, learning a new timetable, finding their way around a large school building and setting into an independent homework routine presents unique challenges to children with ADHD, who are often forgetful and disorganised (Thompson, Morgan, & Urquhart, 2003).

1.2.2.4 Psychiatric

ADHD is associated with depression and other mood disorders (Biederman et al., 1996; Wozniak et al., 1995). This association has been found in both epidemological studies in the general population (Anderson et al., 1987; Bird et al., 1988) and in clinical studies (Biederman et al., 1990; Jensen et al., 1988). It is estimated that between 15% and 20% of children with ADHD also have a comorbid mood disorder and approximately 25% have a comorbid anxiety disorder (Tannock, 1998). This association seems particularly marked for girls with ADHD (Rucklidge & Tannock, 2001).

However, it has been suggested that the association between ADHD and comorbid mood disorders may be an artifact of overlapping diagnostic criteria. Like children with ADHD, children with depression may struggle to concentrate or may show psychomotor distrubance. Consequently, having one disorder may increase the likelihood of meeting diagnostic criteria for another. Milberger, Biederman, Faraone, Murphy and Tsuang (1995) addressed this issue by examining the number of children with ADHD who met diagnostic criteria for depression even when overlapping symptoms were excluded. They found elevated rates of depression in children with ADHD. Likewise, Biederman, Faraone, Mick, and Lelon (1995) found the same pattern of results in children with depression suggesting genuine comorbidity between the two disorders.

Longitudinal research is unclear as to the association between ADHD and internalising disorders. Weiss, Hechtman, Milroy and Perlman (1985) did not find elevated rates of mood disorders amongst children with ADHD over a five year period. However, it has been argued that Weiss et al. (1995) used insensitive instruments to assess mood disorders (Faraone & Biederman, 1997). Manuzza et al.

(1993) found that the lifetime rate of mood disorder among adults who had been diagnosed as hyperkinetic as children was 23%, which is higher than the 13% lifetime prevaluence in young adult men expected from the general population (Blazer, Kessle, McGonagle & Swartz, 1994). However, Manuzza et al.'s (1993) "normal" control group showed the same elevated levels of mood disorder as the hyperactive group in their study. The results of long term studies need to be interpreted cautiously as sample biases may inflate the rate of comorbidity as people (whether recruited as control or clinical participants) with more severe and comorbid conditions may be more likely to participate in ongoing studies or present in clinical settings (Jensen, Martin & Cantwell, 1997).

1.2.3 Adolescence

Some children who are diagnosed with ADHD in childhood remit quickly. As many as 37% of 7 year old boys diagnosed with ADHD no longer meet diagnostic criteria 9 months later (Taylor, Sandberg, Thorley, & Giles, 1991). However, the majority of children with ADHD are likely to experience continued difficulties. In an 8 year follow-up study, 80% of hyperactive children continued to experience ADHD in adolescence (Barkley, Fischer, Edelbrock, & Smallish, 1990). In a longitudinal study of boys aged 6 to 17 years diagnosed with ADHD, 85% continued to express the disorder four years later (Biederman et al., 1996).

Biederman et al. (1996) also found that familial adversity and psychiatric comorbidity predicted persistence of ADHD. They suggest that this persistence may be linked to familial etiological risk factors such as genetic vulnerability and a family environment characterised by disorganisation and parental psychopathology.

Adolescents with ADHD face particular risks and display high levels of clinical impairments on physical, family, social, educational and psychiatric domains.

1.2.3.1 Physical

1.2.3.1.1 Unhealthy lifestyle behaviour

Adolescents with ADHD are at risk for developing unhealthy lifestyle behaviours. In a time sampling study looking at the everyday lives of adolescents with low, middle and high levels of ADHD symptoms, it was found that even sub-clinical levels of

ADHD symptoms were associated with drinking more fizzy drinks, alcohol consumption and smoking behaviour (Whalen, Jamner, Henker, Delfino, & Lozano, 2002).

ADHD in adolescence is also associated with early initiation of cigarette smoking with adolescents with ADHD being twice as likely to smoke as control children with no psychiatric disorders (Milberger, Biederman, Faraone, Chen, & Jones, 1997). In a large 9-year follow-up study of 177 children with ADHD until they were aged 15 years, 78% children reported using tobacco, alcohol, marijuana or other illicit drug during adolescence, with 51% reporting any tobacco use (Burke, Loeber, & Lahey, 2001). Most studies of ADHD and tobacco use have included many children with comorbid ADHD+CD, which may suggest tobacco use could be a feature of CD rather than ADHD per se. However, Burke et al. (2001) found that ADHD alone accounted for a 2.2 times greater risk of tobacco use than control children, and that children with ADHD+CD were not significantly more likely to smoke than those with ADHD alone. Not only are adolescents and adults with ADHD more likely to smoke, but they are also more likely to experience difficulties such as nicotine withdrawal symptoms if they try to give up (Pomerleau et al., 2003).

1.2.3.1.2 Accidents

Adolescent ADHD is a risk factor for involvement in accidents including bicycle and pedestrian accidents (DiScala, Lescohier, Barthel, & Li, 1998; Liebson, Katustic, Barbaresi, Ransom, & O'Brien, 2001). Adolescents with ADHD are approximately three times more likely than control adolescents to experience motor vehicle crashes and are more likely to sustain injuries from such accidents (Barkley, Murphy, & Kwasnik, 1996). They are also more likely to commit traffic offences such as driving without a license, under influence of alcohol, and not wearing a seatbelt (NadaRaja et al., 1997). Adolescents and young adults with ADHD reported more error, lapse and traffic violation behaviours on a self-report questionnaire about driving behaviours. However, this effect decreases with age and younger drivers with ADHD are more at risk than drivers with ADHD in their 30s and 40s (Reimer et al., 2005).

1.2.3.2 Family

Adolescents with ADHD frequently experience difficult relationships with their parents. Of particular importance is the high comorbidity between ADHD and

disruptive behaviour disorders such as ODD and CD. High levels of hostility have been observed between parents and children with comorbid ADHD and ODD (Fletcher, 1996). Barkley, Anastopoulos, Guevremont and Fletcher (1992) studied parent-adolescent interactions among clinic-referred children with ADHD, ADHD with comorbid ODD and control children. Using both questionnaire and observational methods, they observed significantly higher levels of hostility and conflict in the comorbid group compared to controls, with the ADHD group falling mid-range, not significantly different from either the comorbid group or the controls. Studies of both mother-adolescent and father-adolescent relationships in teenagers with ADHD and ADHD with comorbid ODD have reflected this pattern of results (Edwards et al., 2001; Johnston & Mash, 2001).

1.2.3.3 Social

Adolescents with ADHD experience more social problems such as difficulties in making and maintaining friendships, and are frequently held in low regard by their peer group (Hinshaw, Zupan, Simmel, Nigg, & Melnick, 1997; Taylor, et al. 1996). They are more likely to show antisocial behaviour such as aggression and physical fighting (Steinhausen, Drechsler, Foldenyi, & Brandeis, 2003; Taylor et al., 1996). Additionally, children with comorbid ADHD and anxiety disorders report increased levels of social problems in adolescence (Newcorn et al., 2004).

The negative implications for ADHD on friendships in childhood are well documented. In adolescence, these difficulties extend to romantic and sexual relationships. Children with ADHD tend to have shorter romantic relationships, begin to have sexual intercourse earlier (on average at 15 years of age) and tend to have more sexual partners than their non-ADHD peers. They are less likely to use contraception and are therefore at higher risk for teen pregnancy (42:1 by age 20 years) and sexually transmitted diseases (four times higher risk than control adolescents). Just less than half of the children born to adolescents and young adults with ADHD remain under the custody of their natural parents, with most being raised by grandparents or within the care system (Barkley, 2002).

1.2.3.4 Educational

Adolescents with persistent ADHD experience impaired educational outcomes including academic underperformance in both school and laboratory tests of reading,

writing and mathematics (Barry et al., 2002; Fischer, Barkley, Edelbrock, & Smallish, 1990). They are more likely to repeat grades, be placed in special classes or require individual tuition; be suspended or expelled from school; and have lower than average grades. They are four times more likely to drop out of high school than students without ADHD (Biederman et al., 1996). Of those who enter college education, only about 5% actually graduate (Barkley, 2002).

1.2.3.5 Psychiatric

Children with pervasive ADHD are at risk for comorbid mood disorders (e.g. depression and bipolar disorder) and comorbid disruptive disorders (e.g. ODD and CD) (Biederman, Mick, & Faraone, 1998; Biederman et al., 1998).

It has been found that childhood hyperactivity is a greater predictor of serious conduct problems in adolescence than childhood CD (Taylor, Chadwick, Heptinstall, & Danckaerts, 1996). ADHD overlaps as much as 40-50% with CD (Abikoff & Klein, 1993). This comorbidity gives particular cause for concern as children with ADHD+CD are more likely to engage in behaviours such as property theft, disorderly conduct, assault with fists, carrying a concealed weapon, possession of illegal drugs and use of hard drugs (Barkley, Fischer, Smallish, & Fletcher, 2004). Additionally, 40% of children diagnosed with CD at age-8 go on to experience repeated criminal convictions in adolescence for crimes such as theft, vandalism and assault (Farrington, 1995). CD in childhood is predictive of how much an individual will cost society in the future. Scott, Knapp, Henderson and Maughan (2001) found that by the time they were 28-years old, individuals diagnosed with CD at age-10 cost society an average of £70,019 on services such as crime, extra educational provision, foster and residential care, welfare-benefits and health costs. This compares with an average of £7,423 for controls with no diagnosis of CD.

Although research has not found a direct link between ADHD and substance abuse disorders, children with comorbid ADHD+CD are at increased risk (Barkley et al., 1990; Biederman et al., 1997; Biederman et al., 1995b; Klinteberg, Andersson, Magnusson, & Stattin, 1993). A sharp increase in psychoactive substance abuse is also observed during the transition from adolescence to young adulthood (Biederman et al., 1997).

Adolescents with high levels of comorbidity also show high mortality risk. It has been found that adolescent suicide is strongly associated with bipolar disorder and CD (Brent et al., 1993).

1.2.4 Adult ADHD

Although the DSM-IV (American Psychiatric Association, 1994) classifies ADHD as a childhood disorder, adults may also experience symptoms. Kooij et al. (2005) used confirmatory factor analysis to demonstrate, in adults, the internal validity of the three-factor model of ADHD symptoms (hyperactivity, inattentiveness and impulsivity). These symptoms were associated with higher levels of psychosocial impairments as assessed by the General Health Questionnaire indicating the external validity of adult ADHD. Kooij et al. (2005) estimate the overall prevalence of adult ADHD at between 1.0% and 2.5% in the general population.

1.2.4.1 Persistence of childhood ADHD into adulthood

Studies have reported varying rates of persistence of ADHD symptoms into adulthood. The New York study, which followed up children over 17 years, found that 31% still met diagnostic criteria for ADHD after 9 years, and 8% after 17 years (Gittelman, Mannuzza, Shenker, & Bonagura, 1985; Klein & Mannuzza, 1991). However, more recent research (Barkley, Fischer, Smallish, & Fletcher, 2002) has suggested that these studies may underestimate persistence of ADHD as they relied on self-reports of symptoms: Parental reports yield substantially higher estimates. Barkley et al. (2002) found that 8% of children, who were diagnosed as having ADHD, rated themselves as having ADHD at age 19-25, whereas 66% of parents reported continuing symptoms.

Most adult follow-up studies have focussed on young adulthood with an average age of 20 years (Hansen, Weiss & Last, 1999). Unlike previous studies, Hansen et al. (1999) studied young adults aged 25/26-years with a childhood diagnosis of ADHD and compared them to age matched controls with no psychiatric diagnoses. Although the ADHD group were more likely to have experienced considerable difficulties in adolescence (higher school drop out rate, past legal problems, more likely to have fathered children), by age-25/26, many of these problems had alleviated. Most of the high school dropouts had gone on to attain a GED (a qualification equivalent to a high school diploma) and the rate of young adults in full time employment or

education was almost identical to that of the control group. Both groups reported similar household composition with the majority of both groups being single and living at home. Although slightly more of the ADHD group reported current trouble with the law, the difference did not reach significance. The only difference between the ADHD group and control group was that the ADHD group was more likely to be receiving support from mental health services. All of the children in Hansen's study had received either pharmacological or psychosocial treatment for ADHD as children and it is likely that the willingness of this particular sample to pursue continued treatment contributed to their high levels of adjustment as young adults. However, those adults with persistent ADHD symptoms are at risk for adverse social and psychiatric outcomes.

1.2.4.2 Clinical impairments associated with adult ADHD

Adults with ADHD may experience significant clinical impairments in family, social, academic, occupational and psychiatric domains.

1.2.4.2.1 Family

There is much less research on the impact of ADHD on family relationships in adulthood than in childhood and adolescence. However, early research indicates that adults with ADHD report less marital adjustment and more family dysfunction than adults without ADHD (Eakin et al., 2004).

1.2.4.2.2 Social

Children with ADHD have an increased risk of showing continued deficits in adulthood such as impaired social relationships, low self-esteem, depression, anti-social behaviour and drug abuse. They are also more likely to experience marital breakdowns, have poor work records and more car accidents than adults who have never experienced ADHD (Klein & Mannuzza, 1991; Weiss & Hechtman, 1993; Murphy & Barkley, 1996).

As previously documented, adolescents with ADHD are more likely to engage in juvenile criminality. In a follow up study of adolescents into early adulthood (age 19-25 years), the risk for being a repeat offender is elevated in this group. Adolescents

with ADHD who have engaged in criminal activity are more likely to be arrested and imprisoned in young adulthood (Satterfield & Schelle, 1997).

1.2.4.2.3 Academic/occupational

Parent-report adult ADHD symptoms are strongly associated with life outcomes such as educational achievement and employment outcomes such as job performance and being fired from a job (Biederman et al., 1993; Klein & Mannuzza, 1991; McGough et al., 2005b; Murphy & Barkley, 1996; Weiss & Hechtman, 1993). Clinical experience suggests that adults with ADHD may have continued difficulties in finding a career and in dealing with workplace challenges such as time management, organising a desk and keeping to a schedule (Nadeau, 2005; Nadeau, 1996).

1.2.4.2.4 Psychiatric

Adults with ADHD are also more likely than adults without ADHD to have comorbid psychiatric disorders including anxiety disorders; depression; dysthymia; obsessive compulsive disorder (OCD); substance abuse and dependence; ODD; CD; bipolar disorder; psychosis; and anti-social personality disorders (Biederman et al., 1993; Downey et al., 1997; McGough et al., 2005b; Murphy & Barkley, 1996; Secnik, Swensen, A & Lage 2005; Shekim et al., 1990; Weiss, Hechtman, Milroy, & Perlman, 1985).

1.2.5 Gender differences in ADHD

ADHD is far more commonly diagnosed in boys than in girls (Barkley, 1990). There is relatively little literature on gender differences in ADHD, mainly due to difficulty in recruiting sufficient numbers (Gaub & Carlson, 1997; Gershon, 2002; Graetz, Sawyer & Baghurst, 2005). Community samples and clinical samples have reported different patterns of ADHD behaviour in children with ADHD. The pattern of comorbid disorders in children who present at clinics with ADHD is also different between boys and girls.

1.2.5.1 Community studies

In a community-based sample of children with ADHD, (i.e. children who show high levels of ADHD symptoms, but who have not been referred to clinics), Gaub and

Carlson (1997) found no differences between boys and girls on impulsiveness, academic performance or social functioning with peers. Girls rated lower on hyperactivity and externalising behaviours.

1.2.5.2 Clinical studies

In clinical samples, ADHD presents differently in girls than in boys. In an observational study of classroom behaviour, girls with clinically diagnosed ADHD showed fewer symptoms of interference, aggression and hyperactivity than boys (Abikoff et al., 2002). Girls who are diagnosed with ADHD are less disruptive, but show higher levels of inattention, organisational difficulties and academic problems (Faraone, Biederman, Weber & Russel, 1998; Gershon, 2002). These differences may be due to the relative prevalence of inattentive-type ADHD in girls. However, Graetz, Sawyer and Baghurst (2005) compared boys and girls with combined-type ADHD and found that boys were more impaired on measures of social problems, schoolwork and self-esteem.

1.2.5.3 Gender differences in comorbidity

Studies have found differential patterns of comorbidity between males and females with ADHD. Females show an increased risk for internalising disorders such as anxiety and depression (Rucklidge & Tannock, 2001); and males an increased risk for externalising disorders (Levy, Hay, Bennett & McStephen, 2005). It is suggested that as girls with ADHD are not disruptive in the classroom, they are less likely to be referred to mental health services for ADHD or behavioural difficulties, but may present with depression or anxiety as adolescents or young adults (Quinn, 2005).

1.3 Impact of ADHD on family functioning

The impact of both child and parental ADHD on family functioning is considered.

1.3.1 Impact of child ADHD on family functioning

1.3.1.1 Parental stress

Unsurprisingly, research has consistently shown that parenting a child with ADHD is a source of stress for parents and other family members. Mothers of children with

ADHD report more self blame, more depression and more social isolation than mothers of control children with no psychiatric disorders (Mash & Johnston, 1983a). Similarly, fathers of children with ADHD report more depressive symptoms and perceive their families as less supportive than fathers of control children (Brown & Pacini, 1989). As well as showing higher levels of global stress (Befera & Barkley, 1985), parents of children with ADHD report greater role specific stress. They report lower levels of parenting sense of competence, parenting self-esteem and parenting satisfaction (Beck, Young, & Tarnowski, 1990; Lange et al., 2005; Shelton et al., 1998). They show less adaptive coping styles and are less likely to seek the support of friends and family (DuPaul et al., 2001). Parents of children with ADHD are also more likely to see the causes of their child's ill-behaviour as unstable and are less likely to believe they are able to successfully manage their child's behaviour (Sobol, Ashbourne, Earn, & Cunningham, 1989).

It has been found that increased parenting hassles is associated with increased parental alcohol consumption and parents of children with ADHD are more likely to consume alcohol than parents of control children (Pelham & Lang, 1999; Pelham & Lang, 1993). Parents of children with ADHD show decreased anxiety when they consume alcohol, whereas parents of control children do not, so it may be that parents of children with ADHD use alcohol as a coping strategy (Lang, Pelham, Atkeson, & Murphy, 1999). Lang et al. (1999) observed parents who had consumed alcohol and parents who had not interacting with a child confederate, trained to act as though they had ADHD. Parents who had consumed alcohol showed diminished parenting capacity, paid less attention to the task-at-hand and were less consistent in their control strategies, giving both more commands and showing more "indulgence", letting children off when they did not comply.

1.3.1.2 Parental psychopathology

Higher levels of substance abuse disorders have been found in the parents of children with ADHD relative to control children. Mothers of children with are more likely to exhibit stimulant or cocaine dependence and report higher levels of drinking problems in their children's fathers (Chronis et al., 2003). Higher levels of adversity (chronic conflict, decreased family cohesion and parental psychopathology, particularly, maternal psychopathology) were found in families of children with ADHD compared to control families (Biederman et al., 1995a). Again, indicating that

children with ADHD are at risk for experiencing stressful and dysfunctional family lives.

1.3.2 Impact of parental ADHD on family functioning

1.3.2.1 Parenting

Parents with ADHD face particular challenges. From a clinical perspective, the impulsive and inattentive cognitive style associated with ADHD may lead to a parenting style characterised by inconsistency, reactivity and difficulty in organising daily routines, which in turn may have a negative impact on parents' sense of self-efficacy and self esteem (Weiss, Hechtman, & Weiss, 2000a). It has been found that fathers with ADHD are more likely use authoritarian parenting techniques such as punitive discipline (Arnold, O'Leary, & Edwards, 1997). Maternal ADHD has been associated with difficulties in monitoring children's behaviour and less consistency in disciplining children (Murray & Johnston, 2006). Such parenting techniques have been linked to negative child outcomes such as depression, substance abuse and poor school performance (Leinonen, Solantaus, & Punamaki, 2003).

1.3.2.2 Family stress and psychopathology

In addition to having trouble in parenting their children, parents with ADHD may also experience increased marital stress and breakdown (Klein and Mannuzza, 1991). Parents with ADHD who have children with ADHD are also more likely to have an additional DSM-IV diagnosis such as mood disorder, depression, disruptive personality disorder, and alcohol-abuse or stimulant/cocaine dependence. Their spouses were also more likely to have a psychiatric diagnosis (Minde et al., 2003). Minde et al. (2003) also found an important interaction between parent gender and marital satisfaction. Women married to men with ADHD were more likely to be supportive and willing to compensate for husband's difficulties. Conversely, men married to women with ADHD reported higher levels of distress and marital dissatisfaction and were more critical of their wives.

1.4 Aetiology of ADHD

1.4.1 Neuropsychological perspectives

Two main neuropsychological models will be explored, namely ADHD as a disorder of executive functioning and ADHD as delay aversion.

1.4.1.1 Executive functions and ADHD

Barkley (1998) suggests that the deficits associated with ADHD lie in five domains of executive functioning: working memory; internalisation of speech; self-regulation of affect-motivation-arousal; behaviour analysis and synthesis; and motor control-fluency-syntax. In this model, executive functioning impairments lead to a dysregulation of actions, thoughts and feelings, and a failure to conform to the social and intellectual requirements of situations.

Support for this hypothesis is found in the association between executive functioning deficits and clinical impairments commonly experienced by children with ADHD. For example, the association between working memory deficits and educational impairment, particularly in mathematics and science (Gathercole, Pickering, Knight, & Stegmann, 2004; Gathercole & Pickering, 2000). Barkley (1997) hypothesises that working memory deficits manifest as inattention, disinhibition and forgetfulness in people with ADHD.

Self-regulation deficits may manifest as impulsivity and emotionality as children with ADHD have difficulty in inhibiting initial emotional reactions to events, resulting in impulsive and socially inappropriate responses. Brophy, Taylor and Hughes (2002) found that children rated as disruptive by teachers did poorly on tests of inhibitory control, supporting this hypothesis.

However, children with ADHD are not distinguishable from controls on all executive functioning measures. Several studies have not found a difference between ADHD and controls on the Self Ordered Pointing task, a test of visual working memory (Geurts et al., 2005; Scheres et al., 2004; Wiers et al., 1998). Results for the Tower of London task, which assesses high-level problem solving and strategy planning have been inconsistent. Some studies have not found any differences between ADHD and controls (Houghton et al., 1999; Wiers et al., 1998). Others have found

differences, but these are no longer significant when age, IQ and non-executive functioning demands are controlled (Scheres et al., 2004). Neither do executive functioning deficits distinguish ADHD from other disorders in childhood, in particular higher functioning autism (Sergeant, Geurts, & Oosterlaan, 2002; Pennington & Ozonoff, 1996).

In a recent overview of the research area, Nigg, Willcutt, Doyle and Sonuga-Barke (2005) found that only 50% of children with ADHD score about the 90th percentile on the stop-signal task of inhibitionary control and suggest that it could be possible to define an "executive deficit" etiological subtype of ADHD.

It therefore seems likely that while executive functioning deficits are part of the ADHD phenotype, they are not likely to be the complete picture.

1.4.1.2 The delay aversion hypothesis

Alternative models focus on the motivational basis of ADHD behaviours. In particular, the delay aversion hypothesis (Sonuga-Barke, 2002). This model proposes that ADHD behaviours are a functional expression of an underlying motivational style rather than the result of dysfunctional regulatory systems. Sonuga-Barke (2002) characterises impulsivity as an attempt to escape delay. If delay is unavoidable, children with ADHD will attempt to minimise the subjective experience of delay by creating non-temporal stimuli. This manifests as over-activity (e.g. fidgeting). Such behaviours distract the child's attention away from the task-at-hand and thus can be characterised as inattentive.

There is evidence that children with ADHD have difficulties in waiting, sustaining attention over extended time-periods and are hypersensitive to delay. The choice delay task is a computer-based task where children have to choose between a small reward (few points) and a short delay or a larger reward (more points) and longer delay. Children with ADHD choose the small immediate reward more often than control children. However, this effect only occurs when choosing the small reward reduces the overall delay period (Sonuga-Barke, Taylor, Sembi, & Smith, 1992). Further research has found that children with ADHD's performance on the choice delay task significantly improves with a monetary incentive to choose the long delay, again suggesting that motivation is a key part of ADHD behaviours (Solanto et al.,

2001). This suggests that children with ADHD are able to wait but are motivated to avoid waiting.

1.4.1.3 Executive functioning and delay aversion – neuropsychological heterogeneity in ADHD

Children with ADHD do more poorly than controls both on tests of executive functioning and on tests of delay aversion. In one study examining performance on working memory and delay aversion, it was found that the effect of ADHD on working memory was removed when IQ was controlled for, but not the effect of ADHD on delay aversion, suggesting that delay aversion is a more crucial part of the ADHD profile (Kuntsi, Oosterlaan, & Stevenson, 2001). A recent head-to-head study examining performance in the stop signal task (a measure of inhibitory control) and the choice delay task found that the two pathways were strongly dissociated from each other, but also strongly associated with ADHD. The stop signal task correlated with observational ratings of ADHD behaviours in the lab but not with teacher-ratings of impulsivity, hyperactivity and conduct problems, whereas the choice delay task correlated highly with both. This suggests that delay aversion may be associated with a broader range of ADHD characteristics, whereas inhibition taps a discrete dimension of executive control (Solanto et al., 2001).

In a study of preschool age children with ADHD, 29% displayed both delay aversion and executive function deficit, 27% delay aversion only, 14% executive function deficit only and 29% neither problem (Dalen, Sonuga-Barke & Remmington, 2004). Therefore, Sonuga-Barke (2005) suggests there are multiple neuropsychological pathways, including executive dysfunction and delay aversion, to ADHD.

1.4.2 Biological aetiology

1.4.2.1 Genetics

ADHD is a highly familial disorder and seems to have a strong genetic component (Cook, 1999; Epstein et al., 2000; Faraone & Biederman, 1998). About 50% of parents who have ADHD will have a child with ADHD and about 25% of children with ADHD will have a parent who also has the disorder (Faraone et al., 1998; Faraone & Biederman, 2000). First degree relatives of probands with ADHD are at five times greater risk of having ADHD than normal controls with no family history of ADHD

(Biederman et al., 1992). About 65% of the variance in individual attention differences, 70% of the variance in parent-rated hyperactivity-impulsivity and 83% of the variance in composite ADHD ratings can be accounted for by genetic differences (Gjone, Stevenson, & Sundet, 1996a; Gjone, Stevenson, & Sundet, 1996b; Levy, Hay, McStephen, Wood, & Waldman, 2003; Sherman, Iacono, & McGue, 1997; Silberg et al., 1996). This would suggest that there is a highly heritable, biologically based aetiology underlying ADHD.

There is also considerable evidence for the role of genetics in the development of comorbid disorders. A common genetic influence for ADHD and ODD/CD has been found, suggesting that comorbid ADHD+CD may be representative of a more severe form of the disorder with a strong genetic component (Faraone et al, 1991; Silberg et al., 1996; Thapar, Harrington & McGuffin, 2001; Volk, Neuman & Todd, 2005). Other studies have found unique genetic risks for ADHD, ODD and CD supporting the distinctions between each disorder (Dick et al., 2005). However, these studies have tended to rely on single informant data as to the presence of comorbid ODD or CD. Recent research has found that if both parent and child reports of comorbid symptoms are combined the role of genetic factors is less important than the role of shared environmental factors (Burt et al., 2005; Burt et al., 2001).

1.4.2.2 Neurobiology – dopamine

Two main animal models of ADHD have been used in an attempt to explain the neurobiology that gives rise to ADHD symptomatology, namely the Spontaneously Hypertensive Rat (SHR), and the Dopamine transporter "knockout" mice (DATKO). The neurology of the SHR is characterised by high striatal dopamine turnover and low dopamine release from neurones in the prefrontal cortex suggesting an abnormality of the dopaminergic system. These rats are much less sensitive to reinforcement on fixed-interval training schedules. However, their performance on such learning tasks can be improved by administering stimulant drugs such as those commonly used to treat ADHD in children (Russell, Villiers, Sagvolden, Lamm, & Taljaard, 2003).

The DATKO mice lack the gene coding for a protein that transports dopamine out of the synaptic clefts and into the cytoplasm of dopaminergic neurons and thus show reduced levels of dopamine in the brain. Such mice display high levels of loco-motor activity in open field tasks when compared to normal mice (Giros, Jaber, Jones,

Wightman, & Caron, 1996). These mice also show cognitive deficiencies such as difficulties in radical mazes under win-shift conditions. In these tasks, entry into each arm of the maze is rewarded only once so the mouse must learn not to backtrack on itself. Normal mice learn to solve the maze within five to seven attempts. DATKO mice do not show any notable improvement no matter how many attempts they are given and it is suggested that they have difficulties in spatial learning and in response inhibition. Again, the performance of DATKO mice on such tasks can be improved by administering stimulants similar to those used to treat ADHD. The difficulties of these mice could be seen to parallel Barkley's (1997) hypothesis that the poor attention and disorganised behaviour that characterises ADHD is due to an impairment in inhibiting behavioural responses (Gainetdinov et al., 1999)

Both of these models suggest that the abnormalities underlying ADHD characteristics are located in the dopaminergic system. There is some evidence of genetic abnormalities affecting the dopaminergic system in children with ADHD. For example, the dopamine D4 receptor gene (DRD4) determines the ability of dopamine receptors to bind to dopamine, which in turn determines the impact of dopamine postsynaptic cell activity. An extended version of this gene containing seven repeats of a particular DNA sequence (DRD4 7-r) is associated with hyposensitivity to synaptic dopamine. The DRD4 7-r is over represented in children with ADHD compared to controls (LaHoste et al., 1996). Pharmacological treatment with stimulants, such as methylphenidate and dextroamphetamine has yielded valuable insight into the neurological mechanisms underpinning the disorder. PET scans have found increased levels of dopamine in the striatum of men who had taken methylphenidate compared with men who had taken an inert placebo (Volkow et al., 2001). This suggests that methylphenidate works by blocking the activity of dopamine transporters which remove dopamine once it is released, thereby increasing the amount of dopamine in the synaptic cytoplasm

These abnormalities are consistent with the difficulties in working memory and executive functioning observed in adults with frontal lobe damage, suggesting that the frontal cortex or regions projecting into the frontal cortex may be dysfunctional in children with ADHD. Hence, it is hypothesised that ADHD may be related to abnormalities in the frontosubcortical pathways, i.e. they display cognitive and behavioural dysfunction that looks frontal but may be influenced by subcortical projections on to the frontal cortex (Faraone et al., 1998). These pathways are particularly rich in catecholamines, which may account for the therapeutic benefits of

stimulant medication in ADHD as these drugs increase levels of catecholamines including dopamine and norepinephrine in the synaptic cleft (Zamerkin & Rapoport, 1987).

The dopaminergic system is also implicated in delay and reward mechanisms. The meso-limbic branch of the dopamine system which projects onto the nucleus accumbens plays a primary role in modulating activity within the reward circuit (Sonuga-Barke, 2003). It has been found that rats with damage to the nucleus accumbens show more impulsivity in choosing small immediate rewards over larger delayed rewards (Cardinal, Pennicott, Sugathapala, Robbins, & Everitt, 2001). Administration of amphetamines has been found to increase the value of delayed rewards and decrease impulsive choice in rats (Wade, de Wit, & Richards, 2000). It is therefore likely that dopamine plays a key role in the delay aversion that children with ADHD frequently manifest.

1.4.2.3 Neurobiology – norepinephrine

As described above multiple lines of evidence support a role for dopamine in the aetiology of ADHD both via its influence on executive functioning and delay. Recent research has pointed towards complex interactions between dopamine and other neurotransmitter systems, in particular norepinephrine (Stahl, 2003).

Low concentrations of norepinephrine in the right dorsal and orbital sections of the prefrontal cortex have been associated with ADHD symptoms including concentration difficulties, increased motor activity and a lack of self control (Caballero & Nahata, 2003). As well as affecting the dopamine system, stimulants have been associated with an increase in urinary epinephrine and dextroamphetamine has been found to block the reuptake of norepinephrine. Similarly, clonidine, which is efficacious in reducing disruptive behaviours, has been associated with lower plasma norepinephrine (Elia, 1991).

Norepinephrine reuptake inhibitors (NRIs) such as Atomoxetine have been successfully used in the treatment of ADHD and have consistently been found to decrease levels of ADHD symptoms compared to placebo (Caballero et al., 2003). In an open label study, Atomoxetine was found to produce decreases in ADHD scores in 6-15 year old children with ADHD, and after ten weeks of treatment, 69% of children were rated as having no or minimal symptoms (Buitelaar et al., 2004).

NRIs selectively block presynaptic norepinephrine transporters but do not have an affinity for other noradrenergic transporters including dopamine (Rivas-Vazquez, 2003). However, they have been noted to increase extra-cellular dopamine levels in the prefrontal cortex, while having no impact on the dopamine levels in the striatum or nucleus accumbens, suggesting an important role for the norepinephrine system in the neurobiological roots of ADHD (Bymaster et al., 2002).

1.4.3 Environmental aetiology

1.4.3.1 Family factors

1.4.3.1.1 Family environment

High levels of physical abuse and marital conflict are risk factors for the development of ADHD. Children who grow up in high conflict environments are less likely to learn the conflict resolution and social skills necessary for successful functioning in the home and school environment (Cohen, Adler, Kaplan, Pelcovitz, & Mandel, 2002; Fletcher, Fischer, Barkley & Smallish, 1996). High levels of adversity such as severe marital discord, low socio-economic status, large family size, paternal criminality, maternal mental disorder and foster placement can lead to negative outcomes such as child mental health symptoms (Rutter, 1985). Biederman, Faraone and Monuteaux (2002a) found that low socio-economic status, maternal psychopathology and family conflict increased the risk for ADHD, particularly in male children.

1.4.3.1.2 Parenting style

The style in which children with ADHD are parented may have important implications on their long-term prognosis. Parents of children with ADHD have been found to be more directive, commanding and negative towards their children than parents of control children (Johnston & Mash, 2001) and are more likely to have an authoritarian parenting style (Lange et al., 2005). However, it is unclear whether this is a reaction to the child with ADHD or etiological in the development of psychopathology.

Consistent discipline (following through warnings, giving consistent rewards and consequences for behaviour) and discipline which was not overly harsh (such as

yelling, spanking, saying mean things) have been linked with improved behaviour and academic achievement in school (Hinshaw et al., 2000). Families of hyperactive children show higher levels of poor coping and aggressive discipline (Woodward, Taylor, & Dowdney, 1998), are more likely to suffer from psychopathologies such as depression and adult ADHD (Sonuga-Barke, Daley, & Thompson, 2002), and have higher levels of parenting stress and less adaptive coping styles (DuPaul et al., 2001). Parents who experience anxiety show less parental warmth, less positive involvement and more intrusiveness and negative discipline towards their children with ADHD (Kashdan et al., 2004).

1.4.3.1.3 Parental stress and psychopathology

In a population based study, caregivers who experienced higher stress levels and who had less family support were more likely to seek treatment for ADHD than parents with more social support and lower stress levels (Bussing et al., 2003a). Parents who experience anxiety show less parental warmth, less positive involvement and more intrusiveness and negative discipline towards their children with ADHD (Kashdan et al., 2004).

1.4.3.1.4 Parental ADHD

Parental ADHD may have important consequences for child outcomes. Weiss et al. (2000a) suggest that parents with adult ADHD are likely to have difficulty in supervising their children because of their own attention problems and may also find their child's impulsivity very irritating and consequently be rejecting of their children. Exposure to parental ADHD has been found to predict high levels of family conflict, independent of other psychopathological disorders in the parents or child ADHD status (Biederman, Faraone & Monuteaux, 2002b).

1.4.3.1.5 Impact of family factors on ADHD subtype

Recent evidence has suggested that there may be a relationship between family factors and ADHD subtype. Children with combined type ADHD experience more familial risk factors (low socio economic status, parental psychopathology, marital conflict, history of divorce or separation, high occurrence of stressful life events) than either children with inattentive type ADHD or community controls (Counts et al., 2005).

It remains unclear as to how familial and environmental risk factors contribute to the causal pathways of ADHD. It may be that such factors exacerbate an underlying genetic vulnerability towards inattentiveness, hyperactivity and lack of impulse control.

1.4.3.1.6 Impact of family factors on the development of comorbid disorders

Family factors may play a key role in the development of comorbid disorders such as ODD and CD.

1.4.3.1.6.1 Parental personality

A number of parental personality factors have been associated with the development of antisocial behaviours, and comorbid ODD and CD in children with ADHD. In particular, lower agreeableness, high levels of neuroticism and anxiety, history of substance abuse and higher levels of openness to experience (possibly related to sensation-seeking behaviours such as drug-taking) in the father, and high levels of depression, anxiety, neuroticism and agreeableness and low levels of conscientiousness in the mother were related to more antisocial behaviour (Nigg & Hinshaw, 1998). In a review of over 300 studies examining the relationship between family factors and anti-social behaviour, parenting variables (particularly, poor supervision, rejection of the child and low parental involvement) were the most predictive (Loeber & Stouthamer-Loeber, 1986).

1.4.3.1.6.2 Parental psychopathology

Pfiffner et al., (2005) examined the relationship between parental psychopathology and comorbid ODD and CD in children with ADHD, Paternal (but not maternal) antisocial personality disorder was predictive of CD. However, where paternal anti-social personality disorder was absent, maternal parenting style posed the greatest risk for ODD and CD. In particular, a lack of maternal involvement and high levels of negative discipline were significant risk factors.

1.4.3.1.6.3 Parenting style

Johnston, Murray, Hinshaw, Pelham and Hoza (2002) found that low levels of parental responsiveness and high levels of parental depressive symptoms were associated with behavioural problems such as child defiance. Additionally, depressed parents were more likely to have difficulties with monitoring and responding to child defiance. Seipp & Johnston (2005) replicated the Johnston et al. (2002) study, comparing the parenting practices of parents of children with ADHD, parents of children with comorbid ADHD+ODD and parents of control children. This study suggested that parents of children with ADHD+CD were less responsive, more over reactive and displayed more hostility towards their children than either the parents of children with ADHD or the parents of controls. There were no significant differences between parents of controls and parents of children with ADHD only, suggesting that parenting practices may be important in the development of behavioural problems. However, it is highly likely that oppositional behaviour and parenting practices are reciprocal. Longitudinal studies are necessary to examine the interaction between maternal responsiveness and child temperament in the development of parenting style and child behaviour patterns (Seipp & Johnston, 2005).

Unsurprisingly, high levels of family conflict are found between teens with comorbid ADHD+CD and their mothers and fathers. Teens with ADHD+ CD show high levels of negativity towards their parents and their parents likewise show high levels of negativity and hostility towards their teens. However, parental hostility also contributes to levels of parent-teen conflict beyond the contribution of ADHD and CD severity, suggesting that parent and child factors both contribute to overall familial conflict in families where a child has ADHD+CD (Edwards, Barkley, Laneri, Fletcher, & Metevia, 2001).

1.4.3.2 Gene-environment interaction

It is likely that persistent and comorbid ADHD has strong familial etiological component combining the double impact of both genetic and family environmental factors. Familial difficulties such as maternal psychopathology have been associated with a higher risk for CD and other comorbid disorders, but not with ADHD (Lahey, Russo, Walker, & Paicentini, 1989). Biederman et al (1996) found that children with ADHD from families with high levels of familial adversity were more likely to

experience comorbid disorders and persistent ADHD throughout adolescence and into adulthood. Similarly, children with ADHD who have parents with ADHD are more likely to suffer from a comorbid disorder (Minde et al., 2003).

1.4.3.4 Environmental factors and neurological development

1.4.3.4.1 Acquired brain injury

A number of adverse environmental factors have been associated with the emergence of ADHD symptoms, in particular traumatic brain injury, especially if the ventral putamen is effected (Max et al., 2002). The ventral putamen is a dopamine rich area of the brain, lending support to the hypothesis that ADHD may be associated with abnormalities in the dopaminergic system. Similarly, lesions to the Posner's executive attention network and its orbital frontal connections are associated with ADHD symptoms in children with focal stroke lesions (Max et al., 2005).

1.4.3.4.2 Preterm birth

Preterm birth has been associated with poor attention, behaviour problems and diagnosable ADHD in childhood and adolescence (Bhutta et al., 2002). This has been associated with brain abnormalities such as reduced bilateral caudate volume and corpus-callosum size (Nosarti et al., 2005; Nosarti et al., 2004).

1.4.3.4.3 Maternal smoking during pregnancy

Maternal smoking during pregnancy is also associated with a higher risk for ADHD (Mick, Biederman, Faraone, Sayer, & Kleinman, 2002). It has been suggested that maternal smoking may be related to other familial factors. For example, mothers who smoke are more likely to have ADHD, and as such are more likely to confer a genetic predisposition to ADHD on their children. They are also more likely to drink during pregnancy or abuse other drugs (Mick et al., 2002). Additionally, adversity and other environmental risk factors are more likely when parental ADHD is present (Biederman et al., 1995a).

However, Rodriguez and Bohlin (2005) found that prenatal exposure to maternal smoking was associated with child ADHD at age 7, independent of prenatal parental

stress and socio-demographic variables. Prenatal exposure to nicotine has adverse consequences for neurobiological development, which in turn may lead to impaired cognitive function, particularly in working memory and response inhibition (Fried & Watkinson, 2001). Research into the cognitive impairments of people with ADHD has pointed to particular weaknesses in working memory and response inhibition (Barkley, 1999; Barkley, 1997).

It is likely that such environmental factors are strongly connected to genotype in leading to the development of ADHD symptomatology (Castellanos & Tannock, 2002).

1.4.3.5 Cultural factors

There are large variations in the reported rates of ADHD between countries (Dwivedi & Banhatti, 2005). For example, Taylor and Sandberg (1984) reported that children in America where 20 times more likely than children in the UK to be diagnosed with ADHD. O'Leary, Vivian and Cornaldi (1984) also found that American clinicians were more likely to assess and treat ADHD than Italian clinicians.

Differences between western and non-western cultures are also observed. Mann et al. (1992) compared clinician ratings of hyperactivity in China, Indonesia, Japan and the US and found significantly higher scores for hyperactivity from Chinese and Indonesian clinicians even when all clinicians were using the same scoring criteria. Similarly, boys from Hong Kong are three times more likely to score above the cut-off point on teacher-rated ADHD scales compared to British boys of the same age (Leung, Luk, Ho, & Taylor, 1996). However, when the boys' behaviour was observed and objectively rated by independent observers, the boys from Hong Kong were rated as less hyperactive than their British counterparts (Leung et al., 1996). Similarly, Chinese children diagnosed with ADHD have lower levels of impairment as assessed by parent and teacher-report child behaviour checklist compared to children from the USA (Liu et al., 2000; Li et al., 1989). It is suggested that parents and teachers in non-western cultures are much less tolerant of hyperactive and uncontrolled behaviour than parents and teachers in western cultures.

It seems that deviance is socially constructed and that cultural factors play an important role in determining whether or not a given child is deemed to have ADHD and to be in need of treatment (Taylor, 1998; Timimi & Taylor, 2004).

1.5 Conclusions

ADHD is a disorder characterised by inattention, hyperactivity and impulsivity. Children with ADHD experience considerable functional impairments in education; family and peer relationships; and behaviour and health outcomes. Families of children with ADHD are also at risk for negative outcomes, including parental stress; parental mental health difficulties; negative parenting styles; and comorbid disorders. There is a variety of perspectives as to the aetiology of ADHD. Neuropsychologically, ADHD is a highly heterogeneous condition. ADHD appears to have strong genetic and neuro-chemical components. Environmental factors interact with genetic and biological factors to play a critical role in the development of ADHD. Family factors in particular may be important in the development of comorbid behavioural disorders. The role of cultural expectations and norms is also crucial in determining whether a child's behaviour is deemed impaired and in need of treatment.

The difficulties children with ADHD face in behavioural, educational and social domains necessitate effective treatment. The next chapter will review the current literature on ADHD treatment.

Chapter 2
ADHD Treatment

This chapter reviews the current literature on psychosocial and pharmacological treatments for ADHD. In particular, the Multimodal Treatment Study (MTA), which compares the effectiveness of psychosocial, pharmacological and combined psychosocial and pharmacological treatments, is considered. This chapter explores what factors may be important in predicting successful outcomes to pharmacological treatment.

2.1 Psychosocial treatments

A wide variety of psychosocial inventions have been employed to improve the behaviour and family relationships of children with ADHD. These include interventions with parents, intensive behavioural treatment and cognitive therapy. Psychosocial interventions have less impact on core ADHD symptoms, but may be beneficial in reducing associated behavioural difficulties (Diamond and Josephson, 2005).

2.1.1 Parent interventions

Two main interventions are employed to help parents better manage their children's behaviour: parent training, and parent counselling and support.

Parent training generally takes place in a group setting, aiming to teach standard behavioural techniques such as time out, points systems and contingent attention (Barkley, 1995). These techniques aim to modify the child's behaviour and re-establish positive relationships within the family by providing consistent positive reinforcement and rewards for good behaviour and consistent negative reinforcement for undesirable behaviours (Anastopoulos, Shelton, DuPaul & Guevremont, 1993; Danworth, 1998). In addition to teaching behavioural management techniques, parent training seems to have a therapeutic impact on parents, leading to increased parenting self-esteem and decreased parenting stress, which in turn allows parents to gain increased control over their child's behaviour (Pisterman et al., 1992).

Parent counselling and support gives parents the opportunity to reflect on the parenting process in a supportive setting (Davis & Spurr, 1998).

Of these two interventions, parent training seems to yield the most favourable results (Pelham, Wheeler, & Chronis, 1998). Parent training has been associated with increased parental competence and decreased parent-report behavioural problems, dysfunctional parenting, negative child behaviour and ADHD symptoms in preschool children with comorbid behavioural problems and attention/hyperactivity difficulties compared to pre-treatment and untreated control children (Bor, Sanders & Markie-Dadds, 2002; Pisterman, McGrath, Firestone & Goodman, 1989; Sonuga-Barke et al., 2001). Similarly, parent training has been associated with improved parenting practices and child behaviour in school-aged children with ADHD (Anastopoulos, Shelton, DuPaul & Guevremont, 1993; Dubey, O'Leary & Kaufman, 1983).

Parent training seems particularly effective for younger children, and may eliminate the need for medication in the preschool years (Sonuga-Barke et al., 2001). This is especially important as side effects such as insomnia, decreased appetite, stomach-aches, headaches, dizziness, irritability and crying are more marked in preschool children treated with stimulants than in older children (Handen, Feldman, Lurier, & Murray, 1999).

2.1.2 Behavioural interventions

Behavioural interventions utilise behaviour management specialists to provide consultation to teachers to support effective classroom management and facilitate communication between teachers and parents so that parents can provide consequences and reinforcement for children's behaviour at school in the home environment (Kelley & McCain, 1995). Behavioural interventions have been associated with behavioural improvements at home and at school when compared to no treatment. However, stimulant medication alone (i.e. not combined with behavioural input) is more effective in producing behavioural improvements than behavioural interventions (Pelham et al., 1998).

2.1.3 Cognitive therapy

Cognitive treatments such as encouraging the development of internal speech; verbal self instructions; problem solving strategies; self-monitoring; and self

evaluation and reinforcement have been employed to promote self-controlled behaviour in children with ADHD (Hinshaw & Ehardt, 1991). However controlled studies do not support the efficacy of such cognitive interventions in reducing ADHD symptoms and cognitive therapy combined with medication is less effective than medication alone (Abikoff & Gittelman, 1985).

2.1.4 Family systems interventions

Family systems theory suggests that behavioural difficulties arise when family members fail to communicate effectively (Robin & Foster, 1989). Based on this theory, problem-solving communication skills training (PSCT) provides instructions to both parents and adolescents on problem-solving, positive communication and behavioural contract procedures. PSCT has produced significant decreases in parent-adolescent conflict in families of adolescents with comorbid ADHD+CD (Barkley et al., 2001). Direct comparisons of PSCT and behavioural interventions indicate similar efficaciousness. However, PSCT has a higher drop out rate unless a behaviour management program is implemented simultaneously (Barkley et al., 2001).

2.2 Pharmacological treatment

2.2.1 Stimulant medications

Pharmacological treatment with stimulants is the preferred and recommended front-line treatment for children presenting with ADHD (Spencer et al., 1996). Three main stimulant medications are currently prescribed to children with ADHD: methylphenidate, dextroamphetamine and Adderall (Greenhill et al., 1999; Santosh & Taylor, 2000).

Stimulants work by increasing catecholamines (both dopamine and norepinephrine) in the synaptic cleft by blocking the dopamine and norepinephrine transporters (Solanto, 1998; Zamerkin & Rapoport, 1987). The impact of stimulants on both the dopaminergic and noradrenergic neurotransmitter systems is thought to account for the therapeutic impact of stimulant drugs (Faraone et al., 1998). The effect of stimulants does not vary by age, and sensitisation to therapeutic doses of medication has not been reported (Post, 1990).

The pharmacokinetics of stimulant medications are well understood. They are rapidly absorbed, show low levels of plasma protein binding and are quickly metabolised (Patrick, Mueller, Gualtieri & Breese,1997). Stimulant effects appear within 30 minutes of oral administration, peak after 1-3 hours and disappear within 5 hours (Swanson et al., 1998). This "roller-coaster effect" requires school personnel to assume responsibility for administering medication during the day. This risks increasing the stigma and peer ridicule and the need for teachers and/or school nurses to assume responsibility for administering medication. (Greenhill et al., 1999; Santosh & Taylor, 2000).

2.2.1.1 Sustained-release stimulants

Sustained-release preparations of both methylphenidate and dextroamphetamine are available. Sustained-release medications are released slowly throughout the day and produce a smaller peak concentration than an equivalent standard dose of medication. This relatively slow rise and flat curves of plasma levels reduces the potency of sustained-release medications and higher doses may be necessary to attain equal therapeutic benefits (Fitzpatrick, Klorman, Brumaghim & Borgstedt, 1992; Pelham et al., 1990; Whitehouse, Shah & Palmer, 1980).

The effects of sustained-release medications last for up to 9 hours on laboratory tests of concentration (Greenhill et al., 1999). However, clinicians often find an additional standard dose is required to cover homework and extra-curricular activities in the evening (Santosh & Taylor, 2000). Additionally, as stimulants may decrease appetite, additional care to monitor food intake and weight is necessary on sustained-release medications (Santosh & Taylor, 2000).

Sustained-release medications are also associated with higher adherence (Fine & Worling, 2001; Sanchez et al., 2005) and may be particularly advantageous for children embarrassed by or bullied because of taking medication in school (Santosh & Taylor, 2000).

2.2.1.2 Methylphenidate

Methylphenidate is the most widely prescribed of the stimulant medications and is usually the drug of choice. Usually, children start with a low dose (e.g. 5 mg twice daily) with the dose being adjusted, depending on their response, up to 60mg per

day (Robison, Sclar, Skaer & Galin, 1999). It is recommended that ADHD symptoms, blood pressure, pulse, height, weight, appetite, tics, depression, irritability, lack of spontaneity, withdrawal and rebound behaviour be assessed at 6 monthly intervals after initial titration (Santosh & Taylor, 2000).

Sustained-release formulations of methylphenidate are also available. Research suggests that they are consistently better than placebo at reducing ADHD symptoms (Fitzpatric et al. 1992; Pelham et al., 1990; Pelham et al., 1987). An open-label trial of sustained-release methylphenidate demonstrated its effectiveness and tolerability over 12-months of treatment (Wilens et al., 2003a). The relative advantages and disadvantages of sustained-release methylphenidate are outlined in 2.2.2.

2.2.1.3 Transdermal administration of methylphenidate

More recently, a transdermal system has been designed whereby children wear a transdermal patch that administers methylphenidate via the skin. This system is more effective than placebo in decreasing ADHD symptoms from baseline. Its effect is comparable to those observed in studies of orally administered methylphenidate (Pelham et al., 2005). Although not currently on the market, such a system may be helpful for children who do not like to take medication orally or who respond well to methylphenidate but wish to avoid the necessity of school personnel administering medication.

2.2.1.4 Dextroamphetamine

Dextroamphetamine may be preferred if a child has epilepsy or does not tolerate methylphenidate (Santosh & Taylor, 2000). However, dextroamphetamine carries a higher risk of growth retardation, appetite suppression, compulsive behaviours and has a higher abuse potential than methylphenidate (Gualtierei, Ondrusek & Finley, 1985). Again, sustained-release preparations are available for children who experience rebound effects or for whom frequent administration (every 4 hours) is stigmatising or inconvenient. As with sustained-release preparations of methylphenidate, additional doses may be required for early evening, and it is necessary to monitor children's appetite and weight on the medication (Santosh & Taylor, 2000).

In a double-blind cross-over trial, children showed significant improvements from baseline measures of ADHD symptoms and on the continuous performance task (CPT) while taking methylphenidate and dextroamphetamine. Methylphenidate produced more changes on teacher-ratings of ADHD symptoms than dextroamphetamine. No differences in ADHD symptoms were observed on parent-rating scales or on the CPT. However, children on dextroamphetamine showed slightly more anxiety than children on methylphenidate and parents were more likely to prefer methylphenidate than dextroamphetamine (Efron, Jarman, & Barker, 1997a).

Efron Jarman and Barker (1997b) examined the side effect profiles associated with methylphenidate and dextroamphetamine. The mean number of "side effects" was paradoxically higher before commencing the trial than during the methylphenidate period, but not during the dextroamphetamine period. This suggests that methylphenidate may reduce somatic symptoms associated with ADHD. Appetite suppression was the only side effect that was greater on methylphenidate than at baseline. The mean severity of side effects, particularly emotional symptoms (crying, anxiousness, sadness, unhappiness and nightmares) was greater on dextroamphetamine than on methylphenidate.

2.2.1.5 Adderall

Adderall is a mixture of dextroamphetamine sulphate, dextroamphetamine saccarate, amphetamine sulphate and amphetamine aspartate salts. It was previously marketed as a treatment for obesity but has recently been introduced as a treatment for ADHD (Popper, 1994). It is more potent than methylphenidate, has a longer half-life and is consistently found to be effective and well-tolerated by children with ADHD (Swanson et al., 1998). Studies of Adderall in analog classrooms have documented rapid improvements on behavioural and academic performance measures. These effects are observed within 1.5 hours of administration and dissipate over 5-7 hours. (McCracken et al., 2003; Swanson et al., 1998). Short term trials have demonstrated that one single dose of Adderall is as effective as two daily doses of methylphenidate in reducing both parent and teacher-ratings of ADHD (Manos, Short & Findling, 1999; Pelham et al., 1992). This offers the possibility of once-daily dosing and of managing treatment without involving schools in medication administration. Longer-term studies of Adderall have demonstrated its tolerability and effectiveness over 12 months of treatment (McGough et al., 2005a). Medication regimens with Adderall

have significant potential for tailing medication regimens to best suit the needs of children with ADHD (Santosh & Taylor, 2000).

However, recent reports of 20 fatal myocardial infarctions and 12 strokes occurring in adolescents taking Adderall (Gandhi, Ezeala, Luyen, Tu & Tran, 2005) have led to concern regarding drug safety. Adderall was temporarily withdrawn in Canada in 2005. However, the evidence as to whether or not Adderall was the cause of the sudden death or stroke was inconclusive and Adderall was returned to the Canadian market (Kondro, 2005). Concerns about the safety of Adderall may be alleviated by recent reports suggesting that the effects of Adderall on cardiovascular functioning are minimal and comparable to those of other stimulants such as methylphenidate (Findling et al., 2005; Weisler, 2005)

2.2.2 Norepinephrine reuptake inhibitors (NRIs)

More recently, NRIs such as Atomoxetine have been used to treat ADHD. Atomoxetine is the first non-stimulant medication to be approved as an ADHD treatment. Research suggests that it is well-tolerated and efficacious in reducing ADHD symptoms (Rivas-Vazquez, 2003). Atomoxetine treatment has consistently produced improvements in ADHD symptoms compared to placebo in (Cabellero et al., 2003). It is associated with improvements in social and family functioning (Michelson et al., 2001), and in teacher-rated ADHD symptoms (Weiss et al., 2005).

Initial comparisons between Atomoxetine and methylphenidate over a 10-week period showed similar effects on parent- and investigator-ratings of ADHD symptoms. Both medications were also equally well tolerated (Kratochvil et al., 2002).

At higher doses, Atomoxetine has also been found to reduce symptoms of comorbid disorders including ODD (Newcorn et al., 2005), and depression and anxiety (Kratochvil et al, 2005). Atomoxetine has also been successful at reducing ADHD symptoms in adults (Adler et al., 2005; Michelson et al., 2003).

Unlike stimulants, NRIs do not increase dopamine and norepinephrine in the striatum or the nucleus accumbens (Bymaster et al., 2002). This highly selective effect minimises their abuse potential. NRIs are not controlled substances and do not produce an experience of subjective high. Therefore, they may hold an advantage

over stimulants if clinicians or patients have concerns regarding drug abuse (Rivas-Vazquez, 2003; Wilens, 2004).

Due to a lack of long-term comparative studies between stimulants and NRIs, they are currently only used as second-line treatment for ADHD if the patient does not respond to or tolerate stimulants (Caballero et al., 2003). As the research literature on NRIs is relatively new, and stimulants are generally the front line treatment for ADHD, the remainder of this review focuses on the use of stimulant medication.

2.3 Pharmacological treatment practices

In 1996, 90% of children diagnosed with ADHD in the USA were given a prescription for stimulant medication (Greenhill et al., 1999). However, clinical practice varies from country to country. In North America standard clinical practice is to prescribe stimulants before other treatment avenues are explored, whereas in Europe, including the UK, psychosocial interventions tend to be utilised either prior to or in conjunction with pharmacological treatment (Swanson et al., 1998). Treatment guidelines between Europe and America also differ. In America, it is typical to prescribe stimulants as a frontline treatment. In Europe, medication is usually only prescribed after psychosocial and educational interventions have been attempted (Santosh & Taylor, 2000). Prescription practices also vary. In the UK, stimulant drugs can only be prescribed by a psychiatrist, whereas in America they are widely prescribed in primary care (Bramble, 2003; Wolraich, 2003).

2.4 Potential risks of stimulant medication

2.4.1 Side effects

Despite the widespread popularity of stimulant medications for children with ADHD, there are some pertinent concerns about this avenue of treatment. The majority of children on stimulants experience some side effects including reduced weight gain and growth velocity; cardiovascular side effects; and somatic complaints such as stomach-aches, headaches, dizziness, irritability and crying (Rapport & Moffit 2002).

2.4.1.1 Effect of medication on children's weight and height

Some studies have found reduced weight gain in children with ADHD treated with stimulant medication compared with children with ADHD who are not treated with medication (Klein, Landa, Mattes & Klein, 1988). Similarly, children treated with active methylphenidate have showed reduced weight gain compared with children on an inert placebo in clinical trials (Conners & Taylor, 1980; Schachar, Tannock, Cunningham & Corkum, 1997). Other studies have failed to find any difference in weight between treated and untreated children with ADHD (Spencer et al, 1997; Zeiner et al., 1995). Klein et al. (1988), while finding an initial reduction in weight gain in treated children compared to untreated children with ADHD, failed to find any difference at a two-year follow-up, suggesting effects in weight gain may subside with time.

Studies examining the effect of medication on height have also produced mixed results. Some studies have found reduced height gain in children treated with medication compared to control children (Safer, Allen & Barr, 1972), and lower than expected height gain when taking medication compared to baseline (Mattes & Gittleman, 1983). However, longitudinal studies have found that initial reductions in height gain were no longer significant after follow-up assessment at two-years (Klein & Manuzza, 1988; Satterfield et al., 1979).

2.4.1.2 Cardiovascular side effects

Clinical trials have found increases in heart rate and blood pressure in children treated with methylphenidate compared to children treated with an inert placebo (Tannock, Schachar, Carr & Logan., 1989; Kelly, Rapport & DuPaul, 1988). A recent study assessing 24-hour ambulatory blood pressure and heart rate of children on and off medication found that children showed higher blood pressure and heart rates during the active treatment period than when off-medication. Although children's cardiovascular measures did not fall within a range that would cause clinical concern, this study highlights the possibility of a negative cardiovascular effect of long-term stimulant treatment (Samuels, Franco, Wan & Sorof, 2006).

Other studies have failed to find any difference in cardiovascular measures between children taking medication for ADHD and those taking an inert placebo (Brown, Wynne & Slimmer, 1984; Winsberg et al., 1982). Satterfield et al. (1989) found an

initial increase in heart rate and blood pressure associated with commencement of stimulant treatment. However, this effect dissipated over time. Changes in heart rate and blood pressure associated with stimulant medication are considered minor from a clinical point of view and stimulants are considered to be safe from a cardiovascular perspective (Safer, 1992). Nevertheless, cardiovascular monitoring of heart rate and blood pressure is standard clinical practice. Additionally, the effect of stimulant medication on cardiovascular measures has been found to be dose responsive and can often be alleviated by decreasing the dosage (Kelly, Rapport & DuPaul, 1988).

2.4.1.3 Somatic complaints

Somatic complaints such as reduced appetite, sleep disturbance, dizziness and stomach-aches have been associated with the use of stimulant medication for ADHD (Ahman, 1993; Barkley, 1990; Fine & Johnson, 1993). However, research has produced very mixed results in this area. Some studies have failed to find a difference in somatic complaints between children taking stimulant medication and those on placebo (Buitelaar, van der Gaag, Swaab-Barnveld & Kuiper, 1996; Manos, Sgirt & Findling, 1999). Other studies have found paradoxical results, that is, a decrease in somatic complaints in children taking stimulant medication compared with untreated children. Barkley (1990) studied commonly reported side effects to stimulant medication in a group of 125 children treated with methylphenidate or dextroamphetamine. Parents were given a questionnaire entitled 'Behavioural Questionnaire' in order to disguise the fact that the researchers were asking about side effects. More "side effects" were found at baseline than post-intervention. Only a small number of children (4 out of 125) were unable to tolerate the stimulant prescribed. Similarly, somatic complaints as assessed by teacher-report decrease when children are taking stimulants (DuPaul et al., 1996; Fischer & Newby, 1991). Efron al. (1997b) suggest that methylphenidate and dextroamphetamine are among the safest drugs used to treat child and adolescent behavioural disturbance and that the symptoms often associated with side effects are part of the ADHD phenotype, and consequently, decrease as treatment progresses.

2.4.1.4 Evaluation of the side effects associated with stimulant medication

A number of side effects have been associated with stimulant medication for ADHD. These are usually considered minor from a clinical perspective given the behavioural

and cognitive improvements associated with stimulant treatment (Rapport & Moffit, 2002). Side effects may be reduced by decreasing the dosage and/or taking drug holidays (e.g. not taking medication at weekends) (Martins et al., 2004).

Although side effects are typically mild, a recent clinical trial of a common stimulant (mixed amphetamine salts, Adderall-XR) saw 15% of children drop out due to side effects, most within the first six months of treatment (McGough et al., 2005a). For a sizeable minority of children, side effects are problematic enough to warrant discontinuation of medication. Nevertheless, many children who discontinue one medication find another is more suitable (Elia, Borcherding, Rapoport, & Keysor, 1991).

2.4.1.5 Long-term implications of stimulant medication

Despite the extensive literature supporting the short term safety of stimulant medication for ADHD, much less is known about the longer term implications.

Studies examining animal response (mostly rodents) have suggested that administration of methylphenidate in preadolescence and adolescence may have long term behavioural and neurobiological implications. Bolaños et al. (2003) examined the long term behavioural consequences of chronic administration of methylphenidate during preadolescence and periadolescence in adult rats. Rats exposed to methylphenidate were less responsive to natural rewards (sucrose, novelty stimuli and sex) than control rats. Additionally, rats exposed to methylphenidate were more sensitive to stressful stimuli, showed increased anxiety behaviours and had higher plasma levels of the stress hormone corticosterone. Similarly, Carlezon, Mague and Anderson (2003) studied the behaviour of rats treated with methylphenidate and control rats in a forced-swim paradigm where rats are placed in water from which they cannot escape. Rats treated with methylphenidate showed more immobility, an indication of depression, during this task than control rats. Additionally, methylphenidate-treated rats showed higher levels of locomotor activity than controls.

However, the extrapolation of results from animal studies to humans is complicated for a number of reasons. Animal studies typically use doses of methylphenidate which are far higher than would be prescribed for children with ADHD. Additionally, methylphenidate is usually administered intravenously in animal studies, whereas

therapeutic doses are administered in oral form (Fone & Nutt, 2005; Ricaurte et al., 2005; Vitiello, 2001).

In one of the few studies to study primates rather than rodents, Ricaurte et al. (2005) administered oral form amphetamine similar to that used in the treatment of adult ADHD to nonhuman primates. In this study, changes were observed in the dopamingergic nerve endings in the striatum of nonhuman primates who were treated with amphetamine. However, human studies in this area are limited. Most imaging studies have concentrated on medication naive adults with ADHD. Although it is too early to extrapolate that long-term stimulant treatment might produce neurotoxic effects in humans, Ricaurte et al. (2005) highlight the need for long-term studies of the effect of stimulants on neurological development.

Additionally, Reichart and Nolen (2004) suggested the possibility that stimulants might trigger bipolar disorder in vulnerable children. They suggested that the wide use of stimulants in the USA might account for the higher rate of bipolar disorder in the USA compared to the Netherlands where stimulants are prescribed much less frequently. However, the current evidence for this hypothesis is circumstantial and further research is necessary.

2.4.2 Abuse potential of stimulant medication

There have also been concerns that stimulant medication in childhood may lead to addiction and substance abuse in adult life. However, most of these reports have been in the popular media (Barkley, 2003). Some single cases of intravenous and intranasal abuse of prescribed methylphenidate have been reported in the academic literature (Garland, 1998a; Massello & Carpenter, 1999; Parran & Jasinski, 1991). The overall rate of methylphenidate abuse, as monitored by the American Association of Poison Center's Toxic Exposure Surveillance System, has risen from 17 cases in 1993 to 158 cases in 1999 (Klein-Schwartz & McGrath, 2003). This may reflect the increased medicinal use and prescription of methylphenidate and there is no scientific evidence for widespread abuse in this manner. On the contrary, longitudinal studies consistently associated stimulant treatment in childhood with a reduced risk for later substance abuse (Barkley, 2003; Biederman, Wilens, Mick, Spencer, & Faraone, 1999; Wilens, Faraone, Biederman, & Gunawardene, 2003b).

However, reports of children in schools giving away or selling their medication to peers has given rise to concern that stimulants may be abused by children other than for whom they are prescribed. A USA study reports that although the majority of students prescribed stimulants use the medication as sanctioned, 14.7% of 710 students prescribed stimulants reported having given their medication away, 7.3% reported selling it, 4.3% reported having had it stolen from them and 3% reported being forced to give their medication away (Poulin, 1998). Although research does not point towards an association between stimulant treatment in childhood and substance abuse in adulthood, it is clear that concerns about stimulant abuse are not entirely unwarranted.

2.4.3 Controversy concerning the ethics of stimulant medication

A small minority argue that ADHD should not be characterised as disorder. Breggin (2001) argues that children with ADHD show normal childhood symptoms which probably arise from poor parenting and classroom boredom. Consequently, Breggin argues that pharmacological treatment is both unnecessary and ethically wrong as it suppresses children's autonomous spontaneity. However, Breggin (2001) refers to behaviours such as squirming in the classroom seat and restlessness, neglecting the serious consequences of ADHD as discussed previously (Barry, Lyman and Klinger, 2000; Hodgens, Cole and Boldizar, 2000; Stormont, 2000; Murphy and Barkley, 1996; Biederman et al., 1995; Weiss and Hechtman, 1993; Klein and Mannuzza, 1991).

Genetic studies have found the degree of inheritability of ADHD to be constant across levels of symptomatic severity in twin samples (Gjone et al., 1996). This suggests that ADHD features are inherited in degree, rather than category and that children meeting diagnostic criteria for ADHD are a quantitative extreme of a normally distributed set of characteristics rather than a qualitatively different group (Levy, Hay, McStephen, Wood, & Waldman, 1997). However, this does not mean that treatment is unwarranted as Breggin suggests. People with hypertension or hypercholesterolemia also represent the extreme end of blood pressure and cholesterol level in the population, and yet their condition is considered medically urgent. In much the same way, ADHD symptoms cause distress for the child and their family, treatment is both valid and necessary in order to avert more adverse long term consequences (Faraone & Biederman, 2001).

2.5 Response rate to stimulants

There is some uncertainty as to the rate of positive response to stimulants by children with ADHD. Some have suggested that a variety of stimulants are tried, 96% of children with ADHD show a positive response (Elia et al., 1991). However, this study assessed response using behavioural questionnaires completed by teachers, parents and physicians. Other studies which use uniform performance tasks and incorporate a range of cognitive and behavioural measures have suggested that that the rate of non-response is as high as 15%-30% (Barkley, 1976; Safer & Krager, 1985). In a "review of reviews" which identified 341 review papers, citing a total of 9,000 articles between them, Swanson et al. (1993) estimated that the rate of positive response to stimulants among children with ADHD was approximately 70%.

Non-response to stimulants is particularly common among children with comorbid anxiety. Tannock, Ickowicz and Schachar (1995) found that methylphenidate reduced hyperactivity but not cognitive ability or working memory in children with comorbid ADHD+anxiety. As many as two thirds of children with comorbid ADHD+anxiety do not seem to respond to stimulant treatment (Pliszka, 1989).

2.6 Efficacy of stimulant medication

2.6.1 Effect on core symptoms of ADHD

Stimulant medication is consistently associated with improvements in the core symptoms of ADHD such as decreased hyperactivity and increased attention to tasks (Guervemont, DuPaul, Barkley, 1990). Additionally, when taking medication children are judged to be more consistent in their behaviour and to be exerting more effort into tasks such as playing baseball (Pelham et al., 1990).

2.6.2 Improvement in functional impairments associated with ADHD

2.6.2.1 Academic functioning

Stimulants reduce distractibility and increase self-application on academic tasks (Benedetto-Nasho & Tannock, 1999). Children on a summer treatment programme for ADHD showed more on-task attention, were rated as more calm and less noisy by investigators, and performed better on academic tasks such as arithmetic and

visual letter search whilst taking medication compared with placebo (Tannock, Schachar, Carr, & Logan, 1989; Smith, Pelham, Gnagy, & Yudell, 1998). Similarly, adolescents in a six-week placebo-controlled trial of methylphenidate showed improvements in academic functioning. Adolescents in the medication group displayed improved classroom performance on measures such as note-taking quality, worksheet scores, written language usage, teacher-ratings of on-task and disruptive behaviour and homework-completion compared to the placebo group (Evans et al., 2001).

The above research only considers the effect of stimulant medication over short-term research trials. Improvements in academic functioning have been maintained over two years of treatment with methylphenidate (Hechtman et al., 2004a). Young adults with ADHD who took medication consistently throughout childhood and adolescence also have more academic qualifications than young adults with ADHD who do not (Hechtman, Weiss, & Perlman, 1984).

2.6.2.2 Family relationships

Observational studies examining mother-child interactions with male and female hyperactive children aged 3 – 10 years on and off stimulants, have found that children are more compliant with maternal demands and show less negative behaviour on-stimulants. Similarly, mothers were less demanding and showed less negative behaviour towards the child when the child was on-stimulants. This effect-size was shown to increase with age, suggesting that stimulant medication may help foster improved parent-child relationships (Barkley, 1988; Barkley, Karlsson, Strzelecki, & Murphy, 1984).

The interpretation of these studies is difficult. Children are typically prescribed stimulant medication during school hours and may not be taking medication in the evenings and weekends. Therefore, they may not derive the same benefits from the medication in the home environment. Alternatively, a successful school-day may benefit parent-child relationships because of improvements in child self-esteem and reduced parenting success associated as teachers feedback more positive reports of the child's behaviour and academic performance. Studies have found contradictory findings in this area. Some have reported improved child relationships even while the child is only on medication during school (Brown, Wynne, & Medenis, 1985). Others have found that the benefits of stimulants are limited to the times when the

medication is pharmacologically active (Schachar et al., 1997). Greater improvements in parent-child relationships are noted in children who take stimulants three times daily or who take long-acting preparations (i.e. children for whom the medication is pharmacologically active at home as well as school). However, this may come at a cost, as children are more likely to experience side effects on higher doses of medication (Stein et al., 1996).

Pharmacological treatment may change parental perceptions of child behaviour. In a study of parents of children with ADHD, parents were asked to watch videos of a child who they were told was either on, or not on, medication. When they believed the child was on medication they rated the child's behaviour as more positive overall and viewed the positive behaviour as more stable and enduring over time (Johnston & Leung, 2001).

2.6.2.3 Peer relationships

Methylphenidate is associated with improved peer relationships as rated by teachers (Wilens et al., 2003a). Similarly, children with ADHD who are taking stimulant medication report higher self-esteem and more popularity than children with ADHD who are not taking medication (Frankel, Cantwell, Myatt and Feinberg, 1999).

However, Wilens et al., (2003a) only assessed peer relationships using teacher-ratings of negative peer behaviours such as fighting, bullying other children, intruding on others' games and losing temper. Recent evidence suggests that stimulant medication does not normalise children's peer relationships. Hoza et al. (2005) found that children treated with medication, and children treated with combined medication and intensive psychosocial intervention, did not improve on peer-rated measures of popularity and children remained significantly impaired in peer ratings of peer relationships. Children with ADHD may have continued difficulties in peer relationships and in gaining peer acceptance even when treated with medication and/or intensive psychosocial interventions.

2.6.2.4 Emotional wellbeing

Children with ADHD who take medication report higher levels of self-esteem than children with ADHD who do not take medication (Frankel et al., 1999). Hechtman et al. (2004b) assessed children's levels of depression at baseline and after one-year

and two-years of stimulant treatment. At one year, children reported lower levels depression. This was maintained at two-year follow-up. While it is important to note that the baseline measures of depression were low, this study suggests that the improved academic, social and family functioning that results from stimulant treatment promotes increased happiness and general wellbeing in children with ADHD.

2.6.2.5 Driving performance

Driving performance is a particular concern for older adolescents and young adults with ADHD (Barkley, Murphy, & Kwasnik, 1996; DiScala et al., 1998; Liebson, Katustic, Barbaresi, Ransom, & O'Brien, 2001; NadaRaja et al., 1997; Reimer et al., 2005). Stimulant medication leads to increased attentiveness and decreased distractibility and therefore has a beneficial effect on driving. Older adolescents and adults with ADHD show improved performance on a driving simulator when receiving stimulants than when off-medication (Barkley, Murphy, O'Connell, & Connor, 2005; Cox, Merkel, Penberthy, Kovatchev, & Hankin, 2004).

2.6.3 Long term impact of stimulants

Long-term effects of stimulants have been studied much less than the short-term effects. However, recent research suggests that medication results in an average of 30% reduction in ADHD symptoms, maintained over two years of stimulant treatment (McGough et al., 2005a).

Naturalistic studies have demonstrated substantial benefits of long-term stimulant treatment. Pharmacological treatment patterns vary with some children coming on and going off medication. Charach et al (2004) found that severity of ADHD symptoms was linked with higher levels of medication continuation over five years. Additionally, long-term adherers showed greater reduction in teacher-rated ADHD symptoms than non-adherers. Similarly, Hechtman, et al. (1984) retrospectively followed up children diagnosed as hyperactive between the ages of 6 and 12 years into early adulthood and compared those who had received sustained stimulant treatment with those who did not and with non-hyperactive controls. Both the treated and untreated hyperactives were in more debt, showed less vocational planning, were more likely to fail grades in high school, had lower academic standing and were more likely to be excluded or suspended than controls. Treated and untreated

hyperactives were not different on these measures. However, the untreated group had more car accidents, were less likely to attend junior college and more likely to drop out through lack of interest. Treated hyperactives were also at risk for dropping out of school, but due to poor marks rather than disinterest. Untreated hyperactives were more likely to be in receipt of current psychiatric treatment, more likely to have problems with aggression and had a less positive view of their childhood than those who had been treated. Treated hyperactives showed better job performance as rated by employers and had more social skills. While these results suggest that stimulant treatment does not eliminate work and life difficulties associated with ADHD in early adulthood, it does suggest that stimulants may protect children with ADHD from social ostracism and help to improve self esteem and the development of positive relationships with other people. Use of medication in late adolescence/early adulthood may be helpful for young people with ADHD as they enter further education or employment.

However, the results need to be interpreted cautiously given the naturalistic methods used in the above studies. There may be other factors accounting for the more positive outcomes in children treated with stimulants. For example, children who go on and off medication may come from families who find it difficult to administer medication and attend regular medical appointments (e.g. due to socioeconomic deprivation, high levels of family stress, disorganisation, child refusal as a result of ODD or CD). These family factors may exacerbate children's difficulties and lead to the poorer outcomes found untreated children. Likewise the positive outcomes in the treated group may be an effect of family factors (e.g. parental warmth, conscientiousness, SES, coping, parenting style etc) found in families who are willing and able to maintain long term treatment, administer medication effectively and attend regular medical appointments. Research in psychosocial treatment, suggests that contextual family factors such as high SES, low parenting stress and high family coping predict positive outcomes and may suggest that family factors are more important than treatment in determining outcome (Rostain et al., 1993). This may also be the case for pharmacological treatment, and may account for the positive outcomes of treated children in naturalistic studies.

2.7 Medication, behavioural and combined treatments: The Multi-Modal Treatment Study (MTA)

The MTA aimed to compare the long-term (14 months) effectiveness of pharmacotherapy, intensive behaviour therapy, combined treatment (pharmacotherapy + intensive behaviour therapy) and normal community treatment in 579 children aged 7-9.9 years across six sites in the USA and Canada. Children were randomly assigned to one of four conditions in the MTA

(i) Medication Management, involving monthly appointments with medical staff to give advice about medication and assess compliance through pill counts and saliva measures

(ii) Intensive Behaviour Treatment, including parent, school and child components. The parent component consisted of parenting skills training in both a parenting group and individual sessions. The school component included bi-monthly behaviour management consultations, an aide trained in behaviour management working with the child in the classroom and daily reports of target behaviours given to the parents to follow up the child's good behaviour at school with rewards at home. The child component consisted of a 14-week summer programme aimed at developing the child's academic, behavioural, social, sport and recreational skills.

(iii) Combined treatment, incorporating both medication management and intensive behaviour treatment.

(iv) Normal community care, which involved no special or intensive treatment beyond that normally given to children with ADHD in the community.

The preliminary results of the MTA found that children in all four groups showed improvements in ADHD symptoms over 14 months, but indicated the superiority of medication management over behaviour treatment on parent and teacher-ratings of ADHD symptoms. Combined treatment did not confer any advantages of medication management, but did fare better than behavioural treatment alone in producing decreases in oppositional behaviours, parent-report internalising symptoms and performance in the Weschler reading test (Jensen et al., 1999b). Careful medication management may eliminate the need for intensive behavioural therapy for some

children with ADHD. However, it is important to note that children in the combined treatment group successfully managed on lower doses of medication, so behavioural treatment may allow for dose reduction in medication. It is also notable that 75% of children in the intensive behavioural treatment condition were successfully managed over 14 months without medication, indicating that behavioural treatments were effective, if not as successful as treatment programs involving medication.

Despite these improvements, no treatment condition produced improvements on peer-rated sociometric measures of popularity and children remained significantly impaired on peer relationships (Hoza et al., 2005)

In another dual-site study in New York (USA) and Montreal (Canada), 103 children aged 7-9 years with ADHD with no comorbid conduct or learning difficulties, were randomly assigned to one of three conditions: methylphenidate only; methylphenidate plus intensive psychosocial intervention; or methylphenidate plus attention control treatment. The intensive psychosocial intervention included parent training and counselling, individual academic assistance, remedial reading intervention using phonological techniques, organisational skills training, individual psychotherapy and social skills training. The attention control treatment was designed to account for non-specific treatment effects of the intensive psychosocial intervention such as professional time, extended interactions with peers and parental attention. It aimed to be parallel in content but excluding specific remedial or therapeutic input. For example, instead of attending a social skills training group specifically aimed at targeting and developing social skills, children were put into an activity group with their peers (Klein, Abikoff, Hechtman & Weiss, 2004).

In this study, methylphenidate produced improvements in the children's academic and social functioning and in parenting behaviour compared to baseline. However, combined methylphenidate plus intensive psychosocial intervention did not confer any additional benefits over medication alone (Abikoff et al., 2004b; Hechtman et al., 2004a, Hechtman et al., 2004b). The conclusions of this study suggest that children with ADHD who do not have any comorbid conduct or learning difficulties do not benefit from combining medication with intensive psychosocial intervention, and that psychosocial intervention is unlikely to facilitate medication discontinuation (Abikoff et al, 2004a).

2.8 Factors which effect treatment outcome

Data from the MTA study has been analysed extensively to look for moderators and mediators of treatment effects with the aim of identifying subgroups of children who may derive particular benefit from behavioural intervention or combined treatment. Research has also highlighted a number of factors that may facilitate or hinder successful pharmacological treatment outcomes.

2.8.1 Gender

The MTA found that males fared best in the medication management condition, and that combined treatment did not confer additional benefits. In contrast, combined treatment was better than medication management for girls (Jensen et al., 1999a). This suggests that in order to derive maximum benefit from medication, girls may benefit from additional psychosocial intervention.

2.8.2 Comorbid disorders.

2.8.2.1 Disruptive behaviour disorders

Children with comorbid ODD and CD fared better across all three MTA conditions than in community care. However, they do better on medication management or combined treatment than in behavioural treatment alone. Additionally, children with comorbid ODD/CD showed more behavioural improvements in combined treatment than in medication management (Jensen et al., 2001).

2.8.2.2 Internalising disorders

Behaviour management conferred greater benefits on children with comorbid anxiety than on children with comorbid ODD/CD or no comorbidities. Anxious children did best on combined treatment overall (Jensen et al., 1999a; Jensen, 2001). This suggests that children with comorbid anxiety particularly benefit from having a behavioural/psychological component built into their treatment. This is striking as the MTA behavioural intervention did not specifically target anxiety. It is likely that such children would also benefit from psychological therapy specifically targeting anxiety such as emotional regulation or CBT (Whalen, 2001).

2.8.2.3 Severity of ADHD

Children with more severe ADHD symptoms prior to treatment show an increased response to treatment with methylphenidate (Charach et al., 2004). This response is particularly marked in classroom behaviours but not necessarily academic performance (Denny & Rapport, 1999; Taylor et al., 1987). It may be that children with severe ADHD also have learning difficulties which are unaffected by medication and which hinder their academic performance.

2.8.3 Family factors

The impact of treatment on parenting is well documented (e.g. Barkley et al. 1984, Barkley 1988). Increases in positive parenting and decreases in negative discipline (shouting, corporal punishment, inconsistency) have been reported across all three MTA treatments (Wells et al., 2000). It seems that at least part of the beneficial effect of stimulant treatment is mediated via improved parent-child relationships. Changes in negative discipline have been associated with teacher-report social skills, suggesting that parent-related changes may generalise into other social situations (Hinshaw et al., 2000).

2.8.3.1 Socio Economic Status (SES)

2.8.3.1.1 SES and family context

In the MTA, parents in receipt of public assistance showed a surprising decrease in positive parent-child interactions in the medication management group and fared best in combined treatment (Jensen et al., 1999a). Jensen et al. suggest that medication related improvements in ADHD symptoms allowed parents with more stressors (e.g. parents with low SES) to relax on parenting skills such as behaviour management strategies. This finding is of vital importance because it suggests that children from low SES families may not derive optimal benefit from pharmacological treatment.

2.8.3.1.2 SES and adherence

Prior research has found that parents with low SES may have difficulties in fully engaging in psychosocial treatments (Webster-Stratton, 1985). In the MTA study,

adherence to the behavioural component (over 80% attendance at appointments, not dropping out or refusing treatment) was associated with higher income, education, job status, SES and being a two-parent family. However, there were no differences in adherence in the medication management group. This may be due to the commitment and time necessary to fully participate in the behavioural component. Indeed, adherence to the medication and behavioural components in the combined group was almost identical to adherence in the medication management and behavioural treatment groups, suggesting that treatment in one domain does not impact on adherence in the other (Rieppi et al., 2002).

2.8.3.2 Parental mental health

Parental mental health and parenting style also seem to play a role in successful treatment outcomes. In the MTA trial, maternal depressive symptoms were associated with greater success in the medication management condition but not in the combined or psychosocial treatment conditions (Owens et al., 2003). It may be that behavioural intervention reduced on maternal depression by providing support to parents. Hoza et al. (2000) also found that low maternal self-esteem was associated with poorer treatment response across all three treatment conditions in the MTA. It may be that parents with low-self esteem lack confidence and are more prone to depressive or "helpless thinking" such as described in traditional literature on depression (Abramson, Seligman, & Teasdale, 1978; Seligman, Abramson, Semmel, & von Baeyer, 1979). Parents with depression may not see themselves as able to influence their children's behaviour and may therefore be less likely to take positive action in order to change it (Donovan Levitt & Walsh, 1990; Mash & Johnston, 1983b).

2.8.3.2.1 Parental mental health and family context

Depression and low self-esteem may lead to ineffective parenting (Bugental & Shennum, 1984; Donovan, 1981; Donovan & Leavitt, 1985; Donovan et al., 1990; Dumka et al., 1996; Mash & Johnson, 1983a; Unger & Waudersman, 1985). In turn, this decreases the likelihood of positive treatment response (Hoza et al., 2000). Medication may be less likely to affect the parenting behaviour of depressed parents due to a lack of confidence in their parenting ability, or their beliefs that their situation is unchangeable. Hoza et al. (2000) also suggest that depressed parents may be

less likely to administer medication consistently, especially if faced with child resistance.

2.8.3.2.2 Parental mental health and adherence

Previous research has indicated that people with depression have distorted perceptions and cognitions, and difficulties with communication (McDermut, Haaga & Bilek, 1997). Cognitive distortions increase the likelihood of conflictual and negative parent-child interactions (Richters, 1992). Depressed mothers of children with ADHD self-report higher use of negative discipline with their children, but this is not confirmed by observational data (Chi & Hinshaw, 2002). Depression has also been associated with a negative bias in reporting child behaviour. That is, depressed parents are more likely to over-rate psychopathology in their children (Boyle & Pickles, 1997; Chi & Hinshaw, 2002; Chilcoat & Breslau, 1997). Additionally, depressed parents may be more likely to see continued psychopathology in their children and less likely to recognise improvements resulting from medication thereby increasing the risk that they will discontinue treatment. People with depression may have a negative cognitive style, resulting in less positive beliefs and expectations regarding treatment efficacy (DiMatteo et al., 2000b) and more concerns regarding potential side effects, toxicity and the risk of dependence (Bane, Hughes & McElnay, 2006), again increasing the risk of discontinuation. Alternatively, parents with depression may find their children's behaviour particularly challenging, have higher levels of anxiety regarding their children's difficulty and consequently be more likely to pursue treatment. Lower-levels of parenting self-efficacy may result in a lower threshold for seeking treatment as parents feel unable to cope with the demands of caring for their child.

2.8.3.3 Parental ADHD

Grizenko et al., (2006) studied children with ADHD aged 6-12 taking part in a randomised, placebo-controlled trial of methylphenidate to compare children classed as good responders to medication with children who were poor responders. It was found that children who responded well to methylphenidate were more likely to have a first-degree relative with parental ADHD. They were also more likely to have a second-degree relative with anti-social personality disorder. However, there were no significant differences between the families of good and poor responders on affective

disorders, substance abuse disorders, and antisocial personality disorders in first-degree relatives, CD, ODD or schizophrenia.

High levels of parental psychopathology have been found in children with ADHD compared to control children. It has been suggested that this is representative of a severe form of ADHD characterised by genetic risk factors for familial psychopathology (Biederman et al., 1996). This highly heritable and severe form of ADHD may have a strong neurochemical basis and may therefore be more responsive to pharmacological treatment as Grizenko et al. (2006) suggest.

2.9 Family context: A vehicle for successful treatment response?

The MTA study highlights the importance of familial factors in determining successful outcomes for ADHD. It appears that some families may be more able to provide a supportive home environment that fosters a positive response to medication. In particular, low SES families, parents with less education and parents with mental health difficulties such as depression may not derive optimal benefit from pharmacological treatment. By contrast, Grizenko et al., (2006) found that parental ADHD predicts good response to methylphenidate and suggest that this is indicative of a more severe form of ADHD, which is highly responsive to medication.

The next chapter will return to this theme and consider research into the impact of family factors on pediatric treatment response both in the general literature and specifically in ADHD, in order to identify potential avenues of investigation.

2.10 Family factors and adherence

The above research also suggests that family factors may affect whether or not a child takes medication regularly as prescribed, or whether a child continues or discontinues taking medication.

It is therefore important to consider what factors may facilitate adherence to medication in ADHD.

2.11 Adherence to medication in ADHD

Any effective pharmacological treatment depends on the medication actually being taken. Adherence rates to medication regimens are typically fair to low for children and adolescents (Sleator, 1985; Tinkleman, Smith, Cole, & Silk, 1995).

Studies have found varying rates of adherence to medication for ADHD. The definition of adherence is particularly important. Studies looking at the percentage of pills taken have found high levels of adherence to drug treatment in ADHD. Ibrahim (2002) found that the majority of families (approximately 80%) took between 70-100% prescribed pills, whereas a small minority of participants had very low adherence (less than 20% pills). Similarly, Kauffman et al. (1981) studied adherence to methylphenidate and amphetamine in boys aged 6-12 years over six weeks. Pill counts revealed that 87% methylphenidate pills were taken and 82% amphetamine pills were taken. However, Kauffman, only studied 12 participants. Brown et al (1987) studied adherence to methylphenidate in 58 children with ADHD and estimated that approximately 75% of pills were taken. However, pill counts may over-estimate actual adherence and drug assays to assess whether or not children have actually taken the drug may be more accurate (Kauffman et al., 1981). Johnston and Fine (1993) estimated adherence to be between 67 and 100% using a mixture of urine analysis, pill counts, parent-report, teacher-report and physician-report.

This is high in comparison to pediatric adherence in other conditions. Pediatric adherence to asthma medications is usually estimated to be between 40 and 60% of dosages taken (Bender et al., 2000; Burkhart, Dunbar-Jacon & Rohay, 2001; McQuiad, Kopel, Klein & Fritz, 2003). This is also higher than the average adherence to medications by patients with mental health disorders, typically estimated to be around 50% (Bradley, 1990; Gerard, Mamon & Scott, 1987).

Discontinuation of medication is more of an issue in ADHD treatment than children not taking the medication that is prescribed. In a relatively early study looking at continuation versus discontinuation of medication, it was found that 26% parents of children with ADHD refused medication altogether, 20% of those who did use medication discontinued by the end of the 4th month and 40% by the end of the 10th month. Less than 10% of those who discontinued sought medical advice about their decision (Firestone, 1982).

Recent long-term studies have examined continuation in children aged 6-12 years, followed-up over five years. It has been found that 81% adhere for one year, 67% for two years, 52% for three years and 20% for five years (Charach et al., 2004; Thiruchelvam, Charach, & Schachar, 2001). However, this is not to say that those families who discontinued medication discontinued permanently, 40% of those who discontinued at least once in the first two years had restarted medication by year-3. Therefore, it may be important to view adherence as a more dynamic and flexible process as continuation versus discontinuation. Weiss, Jain and Garland (2000b) argue that discontinuation is necessary, particularly for adolescents to find non-pharmacological ways of managing their condition, or for the adolescent to experience what it is like to be off-medication and make their decision whether or not to take medication.

It has been found that children who continue to take stimulants over extended periods of time show greater reduction in ADHD symptoms (Charach et al., 2004), and better job performance and social skills than those who do not take stimulants consistently (Hechtman et al., 1984). It is therefore important to assess what factors are associated with long-term adherence to stimulant medication.

2.12 Factors that influence adherence

2.12.1 Medication type

The most popular stimulant prescribed for ADHD is methylphenidate. However, it has several limitations. Methylphenidate has a short behavioural half-life and is rapidly absorbed after oral administration. Its effects appear within one hour and last up to four. This necessitates regular multiple doses (Barkley, 1976). In more severe cases, a third dose may be prescribed in order to manage the child in the evening (Pelam et al., 1999).

More recently longer acting preparations of methylphenidate, which require only one dose daily, have been developed. Initial research suggests that these medications are equally well tolerated and effective in reducing ADHD symptoms in children and adolescents (Wilens et al., 2003a).

Meta-analyses of the literature on medication adherence across many different medications and diseases shows that adherence tends to be higher when fewer daily

doses are required (Claxton, Cramer, & Pierce, 2001). In a recent clinical trial comparing an extended release preparation of methylphenidate (Concerta) with a standard preparation, children who took the extended preparation were less likely to discontinue treatment and less likely to take a break from treatment (Lage & Hwang, 2004).

2.12.2 Family factors

2.12.2.1 Parental attitudes and beliefs

Children with ADHD are dependent on their parents to administer and regulate their treatment, whether psychosocial or pharmacological. Parental beliefs are therefore likely to influence if and how well treatment is implemented, and therefore its effectiveness. Parental willingness to pursue medical treatment for ADHD is predictive of adherence to both pharmacological and psychosocial treatments for children with ADHD (Ibrahim, 2002; Rostain , Power, & Atkins, 1993).

A number of studies examining adherence to medication in ADHD have suggested that attitudes to medication may be important. Firestone (1982) reported that parents who discontinued medication during a trial reported pressure from teachers to do so. However, this data was collected in the early 1980s. In the 1990s, there was a 2.5-fold increase in the prevalence of methylphenidate use in the US (Safer, Zito & Fine, 1996). The more widespread use of medication may mean that teachers are familiar with the benefits of medication so this may no longer be such an issue.

Fine and Johnston (1993) proposed that high adherence rates might be facilitated by systematic evaluation of the child's progress over several functional domains (classroom behaviour, academic performance, peer relationships etc). Half the families were assigned to a medication trial involving systematic monitoring, and half to standard clinical procedures. No difference was found on adherence at either 6-weeks or 3-months. However, parents in the medication trial group reported higher satisfaction with treatment than parents in the standard procedures group. Longitudinal research may reveal differences in long-term continuation of treatment contingent on systematic monitoring.

Parents may have ethical concerns about medication e.g. concerns about labelling children, discomfort about the use of psychotropic drugs, particularly in children

(Perring, 1997). They may be prejudiced by reports in the popular media that ADHD is not a real disorder but just "boys being boys" and medication being a panacea (Kaminester, 1997), or scare stories about stimulants leading to later drug use, although research suggests a reduced risk of substance abuse in children with ADHD who are treated with stimulants compared with those who are not (Barkley, 2003). However, research suggests that the increased availability of stimulant medication is leading to increasing levels of stimulant abuse (Poulin, 1998). This may increase parents' levels of concern about giving their child a medication which has a significant abuse potential.

2.12.2.2 Parental IQ

Children whose parents have higher IQs are more likely to adhere to medication over longer time-periods (Brown et al., 1988; Firestone, 1982). The evidence concerning how the level of parental education affects parental willingness to pursue pharmacological treatment is contradictory. Ibrahim (2002) points to his participants' high levels of education as a reason for the high levels of treatment adherence and perceived acceptability of medical treatment for ADHD in his study. Lui et al. (1991) found that more educated parents were more likely to perceive stimulants as socially acceptable when presented with a vignette. However, Rostain et al. (1993) found that when asked about their own children prior to attending a treatment clinic for ADHD, more educated parents were less likely to rate medication as acceptable.

2.12.2.3 Family coping

Ibrahim (2002) found decreased adherence to pharmacological treatment in families with inadequate family coping, and in particular single parent families. Previous studies have found that families with lower SES are more likely to miss appointments and more likely to skip doses of medication than families from more advantaged backgrounds (Brown, Borden, Wynne, Spunt, & Clingerman, 1987). Additionally, high levels of family adversity have been associated with treatment drop-out (Thiruchelvam et al., 2001).

As previously mentioned, family context may play an important role in fostering a favourable medication response. Rostain et al. (1993) suggest that successful outcomes to psychosocial intervention related to long-term adherence is also associated with having supportive and skilled parents who are willing and able to

participate in long term therapy, rather than having long-term therapy per se. Similarly, ADHD treatment with stimulants seems more effective in families with higher SES (Handen et al., 1984; Jensen et al., 1999a). Families that are able to invest in long-term treatment may be more able to cope with and support a child with ADHD by providing warm relationships, suitable discipline and family activities, which, create an environment that fosters a favourable response to medication.

2.12.2.4 Parental ADHD

The author knows of no empirical studies assessing the impact of parental ADHD on adherence to pharmacological treatment. Parents with ADHD may be at risk for non-adherence, not only because of associated psychosocial risks of parental ADHD, but also because inattentiveness and impulsivity are likely to lead to difficulties in managing daily routines, such as administering medication consistently (Stine, 1994; Weiss et al., 2000a).

Research has shown that parents with ADHD are at risk for experiencing other psychosocial adversities such as marital breakdown (Klein and Mannuzza, 1991a) and mental health problems (Minde et al., 2003). As commented above, this in itself may be detrimental for treatment response. Sonuga-Barke et al. (2002) compared the outcomes of a psychosocial intervention (parent training) for preschool ADHD and found the intervention was largely ineffective when maternal ADHD was present. For families where maternal ADHD was not present, the intervention proved effective in reducing child ADHD symptoms. Additionally, parents with ADHD showed lower levels of parental satisfaction and self-efficacy and higher levels of depression, which seem to decrease the effectiveness of psychosocial intervention. These factors may likewise affect the effectiveness of pharmacological intervention.

2.12.2.5 SES

Rostain et al. (1993) found that family factors such as SES, parenting stress and family coping style did not predict parental willingness to adhere to a medication regime. Although families with low SES may be willing to adhere to treatment, they are more likely to miss appointments and to skip doses of medication than those from more advantaged backgrounds (Brown et al., 1987). This may be due to psychosocial risks associated with lower SES, or due to practical barriers such as access problems due to transport difficulties and/or financial cost of treatment. This

may be particularly important in countries such as the USA where families with lower SES may have more difficulties in accessing healthcare. Additionally, parents may have competing time schedule demands (e.g. working more than one job, needing additional child care) that make getting to appointments difficult (MacNaughton & Rodrigue, 2001).

2.12.3 Child factors

2.12.3.1 Child age

Sleater (1984) found that 65% of children who were taking stimulant medication for ADHD admitted to avoiding ingesting the medication openly or by covert methods. Children who are older are more likely to refuse medication than younger children (Brown, 1988; Thiruchelvam et al., 2001).

The child's attitudes to medication may be particularly important in determining adherence in adolescence. This may be due to the adolescent's need to assert independence. Older children may be more vulnerable to the experience stigma associated with ADHD, making them more likely to resist taking medication. If an adolescent sees medication as a means of limiting their autonomy rather than widening it, they may be more likely to resist taking it (Weiss et al., 2000b).

2.12.3.2 Comorbid ODD

Thiruchelvam et al. (2001) found that ODD was the most salient factor predicting discontinuation of medication. This is unsurprising as children with ODD are more likely to resist following adult requests to take medication and less likely to accept feedback from teachers or parents that the medication is helpful (Weiss et al., 2000b).

2.12.3.3 Severity and subtype of ADHD

Families are more likely to pursue treatment if they perceive the child's behaviour to be a significant problem (Brown, Borden, & Clingerman, 1985). Similarly, Charach et al. (2004) and Thiruchelvam et al. (2001) found that higher levels of baseline ADHD symptoms predicted adherence. However, other research has found that higher levels of inattentive symptoms predict non-adherence (Brown et al., 1985; Brown,

1988). This could be because inattentive symptoms are less challenging for parents and teachers and consequently reduce the motivation to ensure consistent administration of medication.

As previously commented, children who have more severe ADHD symptoms are more likely to continue taking medication. This is likely due to the more dramatic response seen in such children, particularly in improved classroom behaviour, which motivates continued adherence (Thiruchelvam et al., 2001).

2.12.3 Cultural environment

Undergraduate teachers living in rural settings have been found to be more accepting of both pharmacological and behavioural interventions for ADHD than teachers in urban settings. It is suggested that teachers in rural areas have less experience with disruptive behaviours and are therefore more likely to perceive them as problematic and in need of treatment (Stinnett, Crawford, Gillespie, Cruce, & Langford, 2001). It is unclear whether Stinnet's results generalise to parents of children with ADHD living in rural and urban settings. However, it highlights the potential impact of socio-demographic factors on attitudes to ADHD and its treatment.

Research suggests that parents from different cultures may have different understandings of ADHD. For example, African American parents are less sure about the potential causes and treatments for ADHD than Caucasian parents (Bussing et al., 2003b; Bussing, Schoenberg & Perwein, 1998).

Data from the MTA study suggests that children from ethnic minorities benefit equally from medication as Caucasian children when socio-economic factors are controlled (Arnold, 2003). However, as attitudes concerning medication may vary between cultures, this may be an important factor in determining adherence.

2.13 The Risk-Resistance Model: a model for understanding the relationship between condition management, adherence and positive outcomes in ADHD?

In line with the above research highlighting the importance of family factors in determining outcomes in ADHD treatment, literature in pediatric health psychology suggests that the family environment is critical in supporting children with the

management of long-term conditions. One important model is the risk-resistance model proposed by Wallander and Varni (1992). Designed to be a generic model, applicable to any chronic pediatric disorder the risk-resistance model conceptualises the chronic disorder as an ongoing strain for children and other family members. The whole family system is seen as crucial within the risk-resilience model as chronic health conditions impact the family system as much as the individual child.

Wallander and Varni (1998) argue that the way in which a family functions generally in terms of interaction patterns, rules, organisation, general beliefs influences the way in which the whole family adapts to the child's health-related difficulties. Adaption is a key concept within the risk-resilience model and can be defined as *"the ability to produce an outcome, such as adherence, that relates to successful identification of strategies that assist with managing and coping with the illness and mastery of the social and physical environment."* (Amer, 1999, p. 19). Children and families are said to be well adapted when they are able to adhere to the medical demands of the illness (e.g. drug regimens, diet, exercise program.) This adherence should enable the child and their family to achieve optimal health physically, psychologically and socially. Poorly adjusted children are those who do not demonstrate optimal mastery of their condition and may struggle with their physical, social and psychological wellbeing (e.g. missing school, hospital admissions, poor self-esteem, behavioural difficulties.) In ADHD, adherence could involve the successful use behavioural management strategies and the use of medication to support their child to manage their symptoms and achieve maximum mastery in academic, social and psychological domains (e.g. achieving academic potential, successful friendships and psychological wellbeing.) Poor adaptation in ADHD could be indicated by behavioural difficulties, academic under-performance or secondary comorbid conditions such as depression or anxiety associated with repeated academic and social difficulties.

How a family adjusts to the chronic strains associated with long-term pediatric health conditions is proposed to be moderated by a variety of risk and resistance factors.

2.13.1 Risk factors

Risk factors include disease/disability parameters, functional independence and psychosocial stress.

2.13.2 Disease/disability parameters

Disease/disability parameters include diagnosis, severity, visibility and cognitive functioning. These can have a direct impact on adjustment and also indirect effects by increasing the care strain and psychosocial stress experienced by the child and their parents. Research in this are has been inconsistent. Some has found that pediatric cancer diagnosis (leukaemia versus other cancers) does not correlate with measures of psychological adjustment in newly diagnosed cancer patients (Varni, Katz Colegrove & Dolgin, 1995, 1996). However, it does seem to correlate with negative affectivity at 9 months diagnosis (Varni & Katz, 1998) and in long-term leukaemia survivors. Research involving children with limb deficiencies has indicated that the degree of limb loss was not associated with depression, anxiety or behaviour problems in children and adolescents (Varni & Setoguchi, 1992, 1996). However, Varni and Setoguchi (1996) found a correlation between degree of limb loss and general self esteem in adolescents (Varni & Setoguchi, 1996). This relationship was not found in younger children (Varni, Setoguchi, Rappaport & Talbot, 1991).

Research examining parental adjustment has not found differences in maternal adjustment associated with disability severity, type of disability (e.g. motor, speech, hearing) or child cognitive ability (Noojin & Wallander, 1996; 1997). Research has also failed to find differences in maternal adjustment between the mothers of children with different illnesses (Wallander, Pill & Mellins, 1998, Wallander et al., 1989)

In a recent review of the literature, Wallander and Varni (1998) concluded that disability and disease parameters are not the most important influence on adjustment.

2.13.3 Functional independence

Functional dependence is the impact of the child's condition on his/her ability to care for him/herself (e.g. hygiene, mobility, communication). This can have a direct effect

on adjustment, but also an indirect effect by increasing the psychosocial distress experienced by the family due to increased demands on family members to provide direct care and assistance to the child. Problems with functional dependence have been found to relate to emotional distress and somatic symptoms in children and adolescents with cancer (Varni, Katz, Seid, Quiggins, Friedman-Bender & Castro, 1998). However Wallander et al. (1989) failed to find a relationship between the level of care strain placed on mothers and maternal adjustment. In a systematic review of the literature, Wallander and Varni (1998) suggest that functional independence is unlikely to be the most critical factor in determining maternal adjustment.

2.13.4 Psychosocial stress

Psychosocial stress includes the impact of the child's difficulties on the demands and stresses placed upon the child and their family as well as the levels of daily hassles and significant life events experienced by the family that add to their experience of stress (Wallander and Varni, 1998).

Varni and Katz (1998) found that perceived stress (from both disease and non-disease related stressors) was a predictor of negative affect in newly diagnosed pediatric cancer patients across time (within one month of diagnosis and at 6 and 9 months post-diagnosis. Varni and Wallander (1998) argue that this approach emphasises the role of cognitive appraisal in the experience of stress as conceptualised by Lazarus and Folkman (1984).

Daily stressors have been found to predict maternal adjustment in the mothers of children with different chronic disorders (Thompson, Gustafson, George & Spock, 1992; Thompson, Zeman, Fanurik & Sirotkin-Roses, 1992).

2.13.5 Resistance factors

Resistance factors include intrapersonal factors, social-ecological factors and stress processing factors.

2.13.6 Intrapersonal factors

Intrapersonal factors such as personality, temperament, locus of control, psychiatric functioning and psychosocial development status may predispose a child to certain

patterns of behavioural adjustment or maladjustment. Research has suggested that child emotionality predicts poor adjustment both directly and in interaction with family environmental factors such as family cohesion (Varni et al., 1989). Mothers of children who had cognitive style characterised by hopefulness experienced less disability-related stress and maladjustment (Horton & Wallander, 1997).

2.13.7 Socio-ecological factors

Wallander and Varni (1998) propose that intrapersonal factors manifest themselves in better or worse functioning via the interplay between the child's temperament and environmental demands. Socio-ecological factors such as family cohesion, family relationships and social support (e.g. from wider family networks, from the child's school) also support or hinder a children and families' adjustment to chronic conditions. Varni et al. (1996) found that family cohesion and expressiveness predict better adjustment in children with cancer. Non-family perceived social support (e.g. from peers and teachers) also predicts the adjustment of children with newly diagnosed cancer (Varni, Katz, Colegrove & Dolgin, 1994). Similarly, social support from classmates has been found to predict adjustment, lower levels of stress and higher levels of self-esteem in children with limb deficiencies (Varni, Setoguchi, Rappaport & Talbot, 1989; 1991; 1992).

2.13.8 Stress processing

Stress processing refers to appraisals of circumstances or events and the cognitive and behavioural efforts adopted to manage this. Children and families' perception and appraisal of the child's illness may determine the child's self-esteem and levels of anxiety and depression. This concept of stress-processing draws from Lazarus and Folkman's (1984) model of stress and coping, which emphasizes the importance of the meaning attributed to the event/circumstance in determining whether it is perceived as stressful by the individuals. It has been found that children's perception of their physical appearance both in children with physical deformities and in studies of physically healthy children (e.g. Lerner et al., 1991; Varni, 1991). Similarly, in parents perception of illness-related stress are associated with adjustment problems (Noojin & Wallander, 1997).

Family processes, child development and condition management

Within the risk-resistance model, the family is important in determining how the child is supported both generally in their development and specifically in the management of their health difficulties (Kazajm, Segal-Andrews & Johnson, 1995). For example, research has highlighted the importance of general family organisation and routine in determining adherence to medication. For example, studies have shown that families who generally follow structure and routine (e.g. eating breakfast, watching favourite television programs, having set dinner and bedtimes) are more likely to adhere to pharmacotherapy in HIV (Wagner & Ryan, 2004) and asthma (Irvine et al., 2002). Those families that are generally able to support optimal child development are also likely to be families that are best able to manage the demands of an illness-related regimen.

2.13.10 Family factors in ADHD

Consistent with the risk-resistance model, family factors seem important in determining outcomes to ADHD treatment as highlighted above. For example, Stimulant treatment usually leads to improved parenting practices (Barkley et al., 1984; Barkley et al., 1988). However, parents with low SES have shown an unexpected decrease in positive parenting practices when the child is on medication (Jensen et al., 1999a). They may also be less adherent to treatment programs (Ibrahim et al., 2002; Reippi et al., 2002; Rostain et al., 1993). Subsequent analyses of the MTA data have also suggested that parental mental health and parenting style may also play a role in successful treatment outcomes both via their impact on family functioning and via adherence to treatment (Hoza et al., 2000; Owens et al., 2003).

Child factors including age, the presence of a disruptive behaviour disorder and ADHD symptom severity may also be important in determining adherence.

This highlights two possible pathways whereby familial factors may influence pharmacological treatment outcome (see Figure 2.1):

i) Facilitative Context: Some families may be more able to provide an environment conducive to successful pharmacological treatment response.
ii) Adherence: Some families may be more able to administer medication consistently.

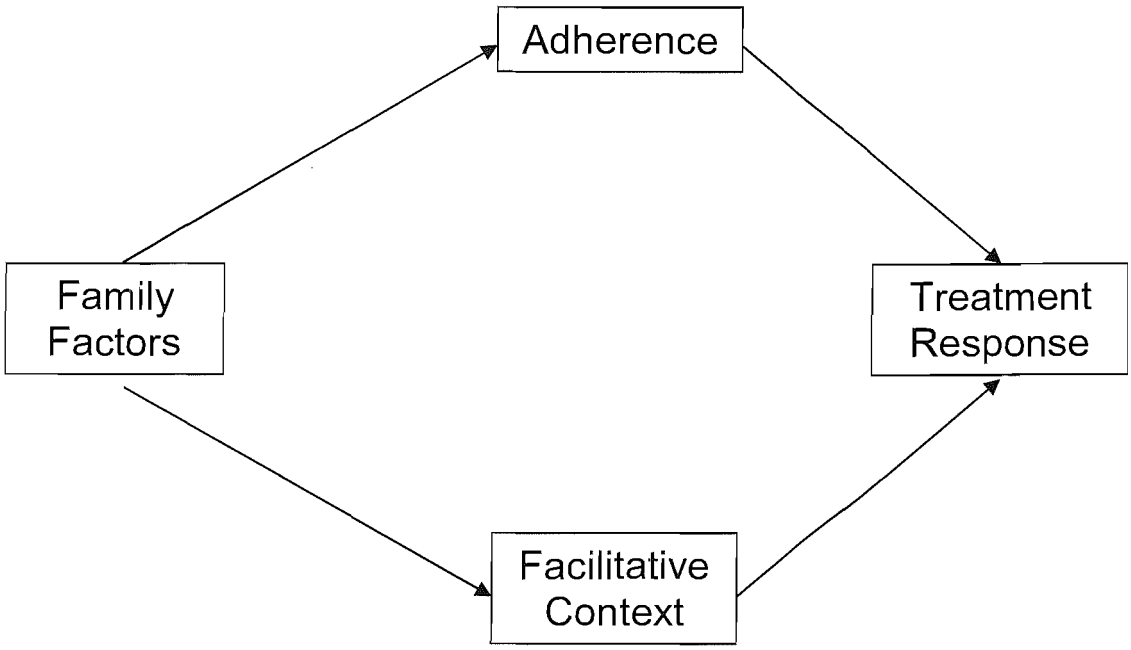


Figure 2.1. Two pathways whereby family factors may influence treatment response in ADHD.

2.14 Conclusions

Psychosocial interventions for ADHD have had only limited success in treating the condition and in improving functional outcomes in behavioural, social and educational domains. Pharmacotherapy, most notably with stimulant medication, is the most common treatment and the current literature would suggest it is the most effective. Most children with ADHD respond positively to stimulant medication. However, there is some uncertainty as to the rate of non-response to stimulants but the most comprehensive review suggests approximately 30% of children do not respond positively to stimulant medication. Post-hoc analysis of the MTA data suggests that children from lower SES families and children with comorbid behaviour or anxiety disorders do best on combined treatment. For other children, combined treatment does not seem to confer any advantage over pharmacotherapy alone.

A number of factors that may influence response to stimulant medications have been identified. Family factors seem to be particularly important. Stimulant treatment usually leads to improved parenting practices (Barkley et al., 1984; Barkley et al.,

1988). However, parents with low SES have shown an unexpected decrease in positive parenting practices when the child is on medication (Jensen et al., 1999a). They may also be less adherent to treatment programs (Ibrahim et al., 2002; Reippi et al., 2002; Rostain et al., 1993). Subsequent analyses of the MTA data have also suggested that parental mental health and parenting style may also play a role in successful treatment outcomes both via their impact on family functioning and via adherence to treatment (Hoza et al., 2000; Owens et al., 2003).

Child factors including age, the presence of a disruptive behaviour disorder and ADHD symptom severity may also be important in determining adherence. The risk-resilence model of family adaptation to chronic health condition highlighted two pathways whereby family factors may influence outcome to ADHD treatment by providing a facilitative context to support optimal child and family adjustment and by promoting adherence to medication regimens.

The next chapter will consider these two pathways, drawing from the literature regarding treatment adherence in the impact of family factors on treatment outcome.

The aim of this review will be to identify factors that may be salient in predicting successful, or unsuccessful, treatment with medication for ADHD, rather than to develop or adapt a specific model to look at adherence in ADHD.

Chapter 3

Models of health behaviour and medication related attitudes and behaviours in ADHD

The previous chapter proposed a model whereby family factors influence treatment outcomes via two pathways: the adherence pathway, and the facilitative context pathway. This chapter critically reviews theoretical models of treatment adherence. In particular, it concentrates on four social cognitive models of adherence: the Health Belief Model (HBM), the Theory of Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Self Regulation Model (SRM). Each of these models highlights the importance of beliefs and attitudes in determining adherence behaviours. The chapter turns to qualitative research to identify specific ways in which beliefs and attitudes influence medication related behaviours. The role of cultural context in the development of attitudes and behaviours is considered. Importantly, stigma is identified as a crucial factor in determining health behaviours.

As the focus of the current thesis is medication related behaviours and attitudes in childhood ADHD, issues in pediatric adherence are given particular attention: In particular, the importance of parental beliefs, developmental issues and family factors in determining adherence behaviour. The role of family environment as a facilitative context is considered. Although there is much less research that conceptualises family environment as a facilitative context for pharmacological treatment response, it is argued that the family context is likely to be particularly crucial in ADHD treatment response. Finally, the current literature on children with ADHD and their parents' attitudes to medication is reviewed. Potential differences between parent and child attitudes are highlighted. This chapter sets the context for a qualitative study to gain greater understanding of parents' and children's ADHD medication related behaviours and attitudes.

3.1 Social cognition models

Social cognition models are based on the assumption that attitudes and beliefs are major determinants of health related behaviours (Horne and Weinman, 1998). The HBM, TRA, TPB and SRM are considered.

3.2 HBM

The HBM (Figure 3.1.) was developed to explain why people do not take preventative measures (e.g. health screening) prior to symptom onset (Becker & Maiman, 1975; Rosenstock, 1974). The original model (Rosenstock, 1974) proposes that a person's likelihood of engaging in preventative health behaviour is determined by their beliefs concerning the **threat** of the disease, and their assessment of the relative risks (e.g. embarrassment, cost, pain of screening) and benefits (e.g. early detection of disease) of the health behaviour. Becker and Maiman (1975) added another component to the model, suggesting that a **cue to action** must occur to trigger the behaviour. The HBM predicts that a person will carry out a particular health behaviour if they perceive the threat of disease to be high, if their perceived benefits of behaviour outweigh the perceived barriers and they are cued to carry out the action.

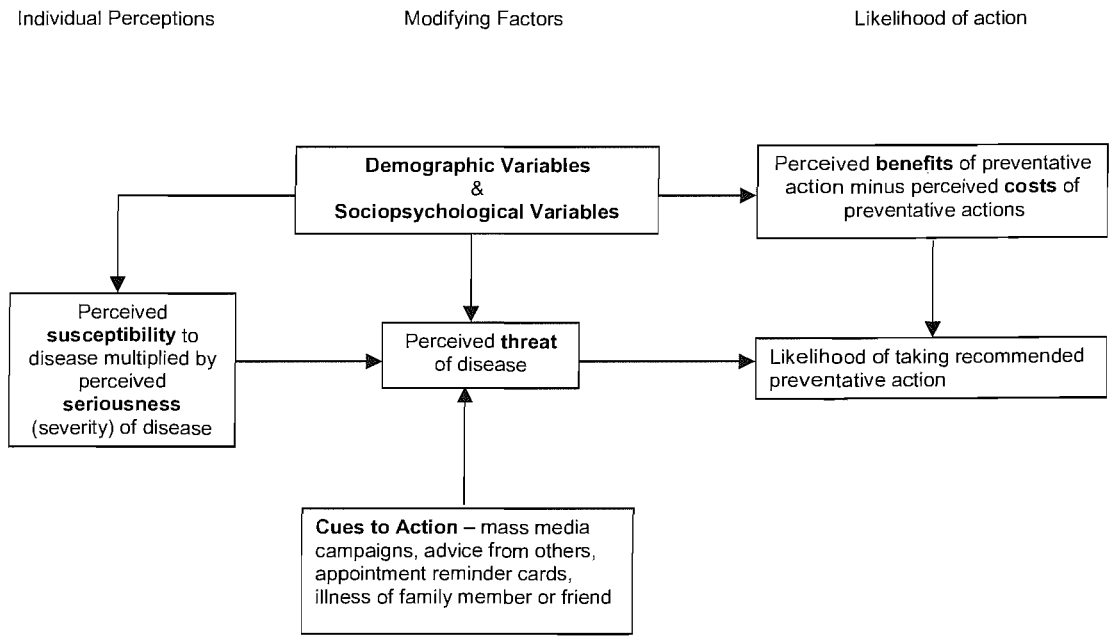


Figure 3.1. HBM (Becker & Maiman, 1975).

3.2.1 Research utilising the HBM

Thomas, Fox, Leake and Foetzheim (1996) used the HBM to predict uptake of mammography screening among women aged 65-years or older. Belief in the benefits of screening (e.g. that it would ease anxiety) was the most significant predictor of screening. Ho et al. (2005) found that perceived lack of barriers/costs and strong perception regarding the seriousness of breast and cervical cancer was associated with attendance for screening.

The HBM has been utilised in a large number of research studies examining health related behaviours, including adherence to dietary recommendations, dental behaviour and adherence to treatment in medical conditions (see Sheeran & Abraham, 1996 for a review). Perceived costs have been associated with non-adherence to antiretroviral therapy in people with HIV (Johnson et al., 2005). In mental health, the HBM has been used to demonstrate an association between symptom severity and perceived benefits with adherence to anti-depressants (Adams & Scott, 2000; Budd et al., 1996).

3.2.2 Evaluation of the HBM

The HBM highlights the importance of beliefs in determining health behaviours and identifies a range of salient themes (benefits of treatment, costs of treatment, beliefs concerning susceptibility to and seriousness of the illness). A meta-analysis of studies examining the HBM as a predictor of preventative health behaviours found that the model accounted for an average of 24% of health behaviour (Zimmerman & Vernberg, 1994).

However, the HBM conceptualises adherence as a "one-off" rational decision, not an on-going phenomenon. Therefore, it is most applicable to one-off preventative behaviours such as cancer-screening rather than long-term maintenance treatment such as is necessary for chronic conditions (Janz & Becker, 1984; Sheeran & Abraham, 1996). This suggests that the HBM would be limited in predicting long-term adherence and continuation of treatment for ADHD.

3.2 TRA

Like the HBM, the TRA (Ajzen & Fishbein, 1980) proposes that attitudes and beliefs predict behaviour. The central tenant of the TRA is that intention precedes behaviour and that intentions are determined by attitudes towards the behaviour. Unlike the

HBM, the TRA also accounts for social influences on behaviour. The TRA proposes that normative beliefs regarding the wishes of significant others influence health behaviour. The TPB (Azjen, 1991; Azjen, 1985) builds on the TRA to include beliefs concerning one's ability to carry out the behaviour.

3.3 TPB

According to the TPB (see Figure 3.2.), behaviour is guided by three considerations:

(i) Beliefs about the likely outcomes of the behaviour
(ii) Beliefs about the normative expectations of others
(iii) Beliefs about ability to carry out that behaviour

Beliefs about the likely outcomes of the behaviour give rise to attitudes towards the behaviour. Normative beliefs give rise to a perceived social pressure to carry out that behaviour or a 'subjective norm'. Control beliefs give rise to perceived behavioural control. This in turn leads to an intention to carry out (or not carry out) the behaviour and the intention leads to the behaviour itself.

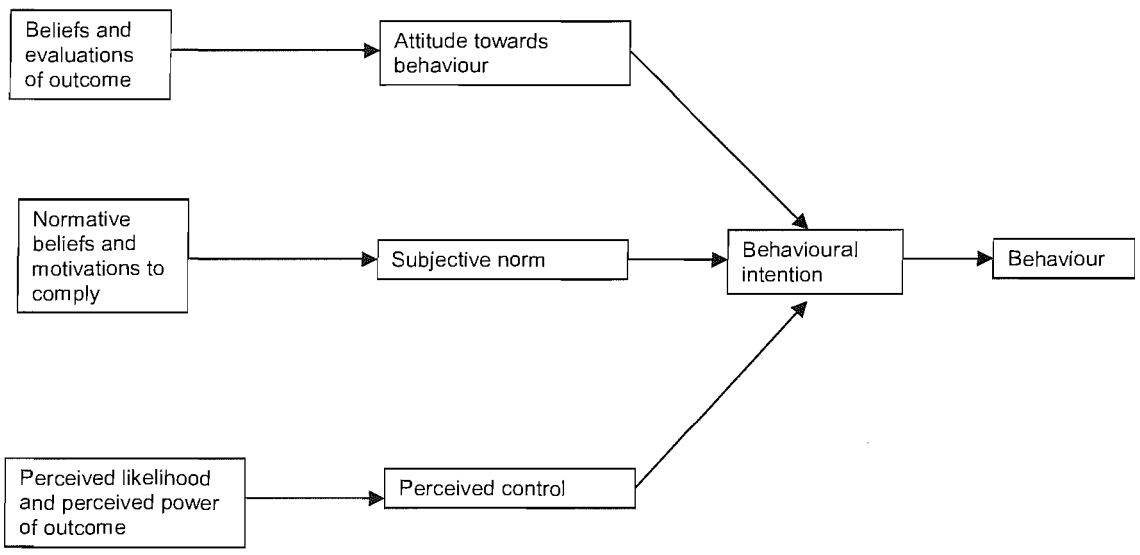


Figure 3.2. The TPB (Azjen, 1985)

3.3.1 Research utilising the TPB

The TPB has been widely used to predict health behaviours including adherence to diet and exercise programs (Baker, Bakhshi, Surujlal-Harry & Rees, 2005; Palmer, Burwitz, Dyer & Spray, 2005) and to preventative screening programs (Michie, Dormandy, French & Marteau, 2004). Importantly, the TPB has been used widely to predict adherence to long-term medical conditions such as hypertension (Miller, Wikoff & Hiatt, 1992; Taylor, Bagozzi & Gaither, 2005). All three components of the TPB are moderately predictive of adherence to medication in adolescents with asthma (van Es et al., 2002).

3.3.2 Evaluation of the TPB

In the main, there is support for the hypothesis that attitudes and subjective norms influence behavioural intentions (Connor and Sparks, 1996). The TPB typically predicts around 30-40% of the variance in intentions and health behaviours across studies (Godin & Kok, 1996).

There is increasing evidence that attitudes and beliefs about medication are at least as important as side effects in predicting adherence to treatment in people with depression and bipolar disorders. Specific beliefs about psychotropic medications such as 'as long as you are taking anti-depressants, you don't know if you actually need them', that the medication is addictive, or that the medication can alter one's personality, decrease the likelihood that an individual will adhere to a medication regimen (Frank, Kupfer & Siegel, 1995; Katon et al., 1992; Kessing et al, 2005; Schaub, Berghoefer & Muller-Oerlinghausen, B, 2001; Schumann et al., 1999).

Unlike the HBM, the TPB takes social beliefs and attitudes into account in predicting adherence. This issue is of particular importance when examining adherence to psychotropic medication. Normative beliefs, particularly whether a person believed significant others to be supportive of their regimen, are predictive to lithium adherence in adults with bipolar disorder (Cochran & Gitlin, 1988).
Kessing et al., (2005) found that non-adherence to anti-depressant medication was predicted by a negative view of medication when partners also agreed with the patient's negative beliefs. Sher, McGinn, Sirey and Meyers (2005) studied the relationship between caregivers' attributions for the causes of depression and adherence to antidepressant medication. Attributions were classed as either cognitive/attitudinal or medical/biological. Patients whose caregivers attributed

depression to cognitive/attitudinal causes had significantly reduced adherence. However, medical/biological attributions were not associated with adherence.

However, like the HBM, the TPB is a static model of adherence. In ADHD, long term, continued adherence throughout the lifespan from childhood to adolescence is a particular concern (Charach, Ickowicz & Schachar, 2004). Therefore, it is necessary to conceptualise adherence to ADHD medication as a dynamic and continual process.

3.4 SRM

The basis of the SRM (Leventhal, Meyer & Nerenz, 1980; Leventhal, 1993) (Figure 3.3.) is a conceptualisation of the patient as an active problem-solver, aiming to close the perceived gap between their current health and a future goal state. Patients respond to illness in a dynamic way based on their interpretation and evaluation of the illness. The patient chooses to carry out, or not carry out, a particular health behaviour (e.g. taking medication) based on whether or not it makes sense in the light of their own ideas and personal experience concerning their illness.

Leventhal (1993) proposes three stages of processing which occur in parallel on both cognitive and emotional levels.

(i) The cognitive representation of the health threat and the emotional meaning that the individual attributes to it: This can come from external cues (e.g. a diagnosis) or internal cues (e.g. symptoms).

(ii) The development and implementation of an action plan/coping procedure to deal with the health threat.

(iii) The appraisal of the action plan's outcome.

This model is characterised by the dynamic interaction between these three processes. As can be seen in Figure 3.3, these processes influence each other in both directions. The patient's action plan may arise from their representation of the health threat, but likewise, their appraisal of the coping procedure can feedback into their representation of the illness.

Like the HBM and the TPB, the SRM highlights the importance of individual's cognitive representations (i.e. their beliefs) of illness and treatment in determining health behaviour. However, unlike the HBM and the TPB, the SRM emphasises the interaction between cognition and behaviour. Rather than seeing adherence as a single decision, the SRM sees adherence as a continuous process of illness representation, action, appraisal and feedback.

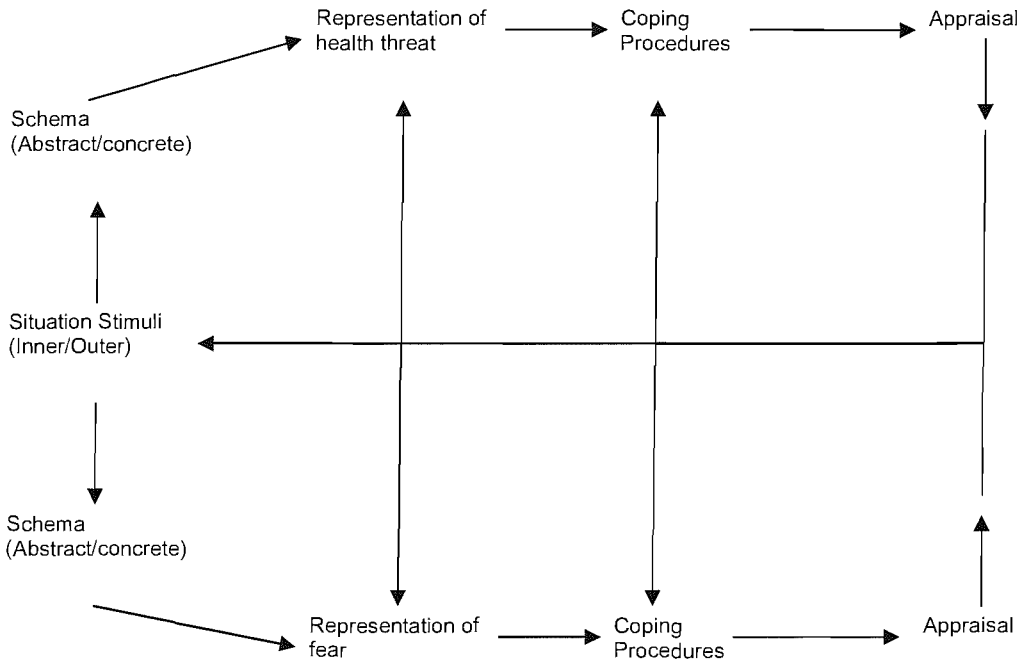


Figure 3.3. The SRM (Leventhal, 1993)

Leventhal proposed that illness cognitions are organised around five components:

(i) Identity of the Illness: the symptoms experienced and abstract label attached to them.

(ii) Consequences: the expected outcomes in physical, psychological and social terms.

(iii) Cause: ideas about how one gets the disease.

(iv) Timeline: beliefs as to the likely course of the condition and the duration of symptoms.

(v) Control/Cure: beliefs as to the controllability of their illness.

Additionally, Leventhal (1994) proposed that illnesses were represented both cognitively and emotionally. This emotional representation exists in parallel with the cognitive representation, influencing the actions taken. Decruyenaere et al. (2000) describes the complex interplay between emotions and cognitions in cancer-screening behaviour. For example, a woman may delay seeking help for breast cancer symptoms because she fears a diagnosis. The delay in seeking help can be understood as a coping mechanism to avoid fearful emotions (Phelan, Dobbs & David, 1992). The same phenomenon of fear leading to a delay in seeking help has also been observed in men with symptoms of testicular cancer (Mason & Strauss, 2004).

3.4.1 Research utilising the SRM

The SRM has been used to predict adherence to treatments in a variety of conditions, including medication and diet in people with hypercholesteroaemia (Brewer, Chapman, Brownlee & Leventhal, 2002; Coutu, Dupuis, D'Antono & Rochon-Goyer, 2003), and genetic testing for breast cancer risk (Decruyenaere et al., 2000).

In a meta-analysis of the literature using the SRM, Hagger and Orbell (2003) found that illness representations were highly predictive of coping strategies. Maladaptive coping strategies such as avoidance and emotionality were related to a number of factors, namely: a strong illness identity; perception of the illness as incurable/uncontrollable; perception of the illness as chronic; and perception of the illness having serious consequences. In contrast, perception of the illness as controllable was positively associated with adaptive coping strategies, psychological wellbeing and social functioning and negatively associated with emotional distress.

However, the complexity of the SRM has made it difficult to operationalise as a model for research purposes (Horne & Weinman, 1998). More often, the SRM has informed qualitative studies which have contributed to an in-depth understanding of patients' beliefs and attitudes and the specific behaviours they adopt in order to manage their condition and treatment regimens.

3.4.2 How do beliefs and attitudes influence medication related behaviour?

Qualitative research studies of adherence from patients' perspectives have demonstrated that adherence to medication is a dynamic phenomenon shaped by patients' personal and cultural attitudes, beliefs and emotions (Wrubel et al., 2005). Adherence itself is a dynamic concept, and may mean different things to different people. Adherence or non-adherence may mean self-care, taking or not taking medication, adapting medication regimes to personal circumstances etc. Certainly, it is important to understand how and why patients deviate from medical regimens and to understand this from a patient, rather than from a medical perspective (Playle & Keeley, 1998; Trostle, 1988; Stimson, 1974). Some researchers have suggested that "treatment-related behaviours" may be a more helpful concept to explore how people manage and adapt treatment recommendations (La Greca & Bearman, 2001).

In an interview study examining epilepsy patients' attitudes and medication related behaviours, Conrad (1985) identified four primary reasons why patients deviated from prescribed medication regimens.

(i) Testing: Individuals may take themselves off a medication or change the dosage to see what the effect might be. For individuals with chronic conditions, this testing may be an attempt to evaluate the progress of the condition.

(ii) Control of dependency: Although epilepsy medications aim to increase self-reliance by reducing the risk of seizures, the medication can be experienced as a threat to self-reliance as they become symbolic of the dependence created by having certain chronic illnesses.

(iii) Destigmatisation: Some individuals in Conrad's study experienced taking medication as a constant reminder of a stigmatising illness. For these individuals, not taking medication was a way of avoiding the stigma attached to having epilepsy.

(iv) Practical considerations: Individuals in Conrad's study reported altering the medication regimen depending on their particular needs at particular times. For example, some reduced medication when they wanted to consume alcohol to avoid

problems associated with mixing alcohol and anti-convulsants. Others increased the dosage during times of high stress when they believed they were more vulnerable to seizures.

Conrad's study highlights the importance of understanding what medication and adherence means from patients' perspectives: both in terms of patients' beliefs and attitudes towards the medication, and in terms of how they adapt the medication regimen according to their particular circumstances. It is likely that similar issues are involved in taking medication for ADHD. In particular, stigma is recognised as a central issue in pediatric mental health (Hinshaw, 2005) and may play a crucial role in what children and their families believe and feel about medication, and in their behaviours around medication (timing, dosage, drug holidays etc.).

In the mental health literature, considerable divergence between health professionals' and patients' beliefs and goals has been demonstrated. For example, Jorm et al., (1997) demonstrated that the public believe psychiatric medications are harmful and potentially addictive. Such negative beliefs about psychiatric medications are likely to have an adverse effect on adherence. Similarly, Perkins (2001) suggested that patients might see taking medication as a threat to their personal autonomy. Symptom relief may be less important to some patients than maintaining a sense of personal autonomy and control by not taking medication.

3.4.3 Evaluation of the SRM

As with the HMB, TRA and TPB the SRM emphasises the importance of beliefs and attitudes in determining health behaviours. Additionally, the SRM incorporates emotional processing into the adherence model and accounts for changes in attitudes, beliefs and behaviours over time.

The SRM may be particularly useful in research into adherence in mental health conditions because people might not view their symptoms as an illness. Therefore, there is a high likelihood of considerable divergence between patient and medical perspectives (Lobban, Barrowclough & Jones, 2003). "Insight", that is, the recognition that one has a mental health problem, is strongly associated with adherence to medication in depression and psychosis (Jackson et al., 1998; White et al., 2000).

The SRM does not explicitly take the beliefs and attitudes of significant others into account. However, cognitive representations held by carers are likely to be extremely important in mental health treatment (Kessing et al., 2005; Sher et al., 2005). The emotional response of a relative to an individual's mental health may influence the individual's progress and their beliefs concerning the illness and treatment (Lobban, Barrowclough & Jones, 2003). Additionally, cultural and social norms may be influential in the development of an individual's and their relatives' beliefs about mental illness (Leventhal et al., 1997). Social and family factors are likewise crucial for children's adherence to treatment as children are reliant on parents to administer any treatment they are prescribed.

The SRM may be particularly useful in investigating adherence to treatment in mental health. However, it is also essential to recognise the importance of the attitudes of significant family members and friends, and the impact of social and cultural norms on the development of illness cognitions. However, the complexity of the model and the fact that illness cognitions may be highly individualised means the SRM has been largely under-utilised in research (Horne & Weinman, 1998).

3.5 The role of culture in health beliefs

Social and demographic factors such as race, education and socio-economic status have an important influence on health beliefs. Ho et al. (2005) examined predictors of screening for breast and cervical cancer and found that socio-demographic variables including high educational level, family history of cancer and older age were predictive alongside health beliefs. Vadaparampil et al. (2003) compared the HBM as a predictor of mammography adherence in African-American and Caucasian women. The model was more predictive in Caucasian women than in African-American women. Additionally, African-American women reported more negative beliefs about mammography. In a study examining beliefs about modern pharmaceutical medication amongst 500 UK students, Horne et al. (2004) found that students from European backgrounds had more experience of prescribed medication and were more positively orientated towards medication in general. Asian students were more likely to see medication as intrinsically harmful and something to be avoided. This highlights the importance of social and cultural variables in the development of health beliefs.

3.6 Stigma and adherence

3.6.1 Definition of stigma

The term "stigma" originates with the ancient Greeks to denote the physical branding of members belonging to tainted groups such as traitors or slaves. Today the term has a more psychological meaning, denoting an invisible, internal mark of shame related to membership of a deviant or castigated subgroup (Goffman, 1963, cited in Hinshaw, 2005). Having a "mental illness" generally activates negative attitudes, stereotypes and creates a position of social distance and rejection for people with mental illness (Hayward & Bright, 1997; Mueller et al., 2006). Studies have consistently linked the diagnosis of a mental health condition with the elicitation of negative attitudes. For example, the belief that people with schizophrenia are likely to be violent (Angermeyer & Matschinger, 2003; Watson et al., 2005).

3.6.2 Stigma as a predictor of adherence

Stigma is consistently identified as a strong predictor of non-adherence across a wide range of conditions and treatment regimens, including: antiepileptic medications (Buck, Jacoby, Baker & Chadwick, 1997); anti-depressants (Ayalon, Arean & Alvidrez, 2005; Sirey, Bruce, Alexopoulous, Perlick, Friedman & Meyers, 2001); and medication for schizophrenia (Freudenreich, Cather, Evins, Hnderson & Goff, 2004).

Stigma may be particularly crucial in adherence to treatment for mental health conditions. People with mental health conditions frequently report being shunned and avoided (Wahl, 1999). In one study of medication adherence in schizophrenia, stigma was the strongest predictor of non-adherence, with adverse reactions, forgetfulness and a lack of social support also playing an important role (Hudson et al., 2004).

Additionally parental stigma may be important in pediatric adherence. Wrubel et al., (2005) found that some mothers of children with HIV who felt stigmatised skipped doses in order to avoid giving anti-retroviral medication in public. Other mothers who felt stigmatised did not explain to their children why they needed to take medication,

which may lead to nonadherence on the part of the child. Roberts (2005) reported that some children with HIV see medication as a reminder of a stigmatising condition and thus avoid taking it.

3.7 Pediatric adherence

3.7.1 The role of parental beliefs in pediatric adherence

Children's beliefs and attitudes towards medication are heavily influenced by those of their parents. Mothers who have positive attitudes about health care professionals, procedures and settings have children who mirror those beliefs (Bachanas & Roberts, 1995; Hackworth &McMahon 1991). Children's perceptions of AIDS are strongly associated with parental attitudes (McElreath & Roberts, 1991). For children with chronic illnesses, parental attitudes are also important in determining their attitude. Children's beliefs about the benefits and drawbacks of medication for asthma were highly correlated with those of their parents (DePaola, Roberts, Blaiss, Frick & McNeal, 1997).

Pediatric adherence is complicated by interactions between parents and children regarding medication. Families must adapt to the changing needs of the child, and to the child's developing understanding of their illness and responsibility for taking medication (De Civita & Dobkin, 2004). Wrubel et al. (2005) examined pediatric adherence to antiviral medication for HIV. They found that mother-child interactions had a strong impact on adherence behaviours. Mothers and children were found to argue about taking medication, and adherence to medication often involved an emotional cost on the part of the mother.

"It hurts me for her to go through life like that. It kills me inside. And I've got this feeling because I have to make her take it whether she want to take it or not, see?" (Wrubel et al., 2005, p2428).

Children, some as young as three, were also reported to engage in non-adherent behaviours, such as spitting the medication out and hiding it or throwing it away. Sometimes, the emotional demand of dealing with a non-adherent child could lead to non-adherent behaviour in the mother.

Parental mental health is also an important influence on child health behaviours. Parents who have significant mental health problems may have more difficulty in caring for a child. Mothers with depression are less likely to administer vitamins, place young children in a car seat and provide a non-smoking environment for their children (Leiferman, 2002). Depression has been strongly associated with non-adherence to treatment in both children and adults (DiMatteo, Lepper & Croghan, 2000b). In ADHD, specifically, depressed parents may not derive maximum benefit from medication as they are less likely to change their parenting behaviour (Hoza et al., 2000). They may also be less likely to administer medication regularly, particularly if the child is uncooperative (Hoza et al., 2000; Owens et al., 2003).

3.7.2 Developmental issues in pediatric adherence

3.7.2.1 Parent-child conflict

Developmental issues also played an important role in Wrubel et al's., (2005) study of adherence to anti-retroviral medication in children with HIV. Mothers of older children and teenagers often reported conflict around the young person taking responsibility for the medication for themselves. Research examining pediatric adherence to diabetes, pediatric arthritis and asthma regimens has also emphasised the importance of developmental issues and negotiations between parents and teenagers as the young person assumes greater responsibility for treatment (Anderson et al., 1990; Hayford & Ross, 1988; McQuaid et al., 2001). This is a complex issue, as adolescents may not be ready to take responsibility for their treatment. Parents must strike a delicate balance between encouraging adolescent autonomy and monitoring treatment adherence in order to prevent potentially serious consequences of non-adherence.

3.7.2.2 Adolescence

Studies have consistently found poor adherence amongst adolescents. Difficulties with adherence increase markedly at age 11 and peak during mid-adolescence (see Shaw, 2001 for a review). Adolescents with chronic diseases such as cystic fibrosis have consistently been found to deny non-adherent behaviour (Lask, 1994). Adolescents frequently underestimate risk and view themselves as invincible. This may lead adolescents to believe they do not need to adhere to treatment (Harris & Linn, 1985).

One of the principal developmental tasks an adolescent faces, is to separation-individuation (Allen et al., 1994; Blos, 1967). The need for autonomy places considerable strain on the parent-child relationship. It is suggested, that adolescents may see long-term medication as a threat to their autonomy and react by refusal to adhere to medication (La Greca, 1990; Shaw, 2001).

3.7.2.3 Peer influences

Peer influences are crucial during adolescence. An adolescent's perceived social norm, may take more account of perceived peer opinion than parental or medical opinions (Holmbeck, 2002; Shaw, 2001). Adolescents often have negative attitudes towards mental illness. For example, they may see people with mental illness as violent and out of control (Angermeyer & Maschinger, 2003; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Phelan & Link, 1998; Watson, Miller & Lyons, 2005). Adults in the UK also report believing that people with depression and anxiety are "difficult to talk to", increasing the likelihood of social isolation for people with mental illness (Crisp et al., 2000).

Brook and Geva (2001) examined high school students' understanding of and attitudes towards ADHD and learning disabilities. Children knew less about ADHD, and were less tolerant of their peers with ADHD and more sympathetic towards their peers with learning disabilities. However, Brook and Geva conducted their study in Israel. Attitudes to ADHD may vary between countries. An exhaustive literature search failed to find any research pertaining to children's attitudes in the UK or the USA. Negative peer attitudes towards ADHD may result in stigma, which has been associated with reduced adherence to medication in many studies, as outlined above.

3.7.2.4 Behaviour problems

Behaviour problems, such as are common in children with ADHD (Taylor et al., 1996), are predictive of non adherence in asthma (Christiaanese, Lavinge & Lerner, 1989). Thiruchelvam et al. (2001) found that ODD was the most salient factor predicting discontinuation of medication in children with ADHD.

3.7.3 Family factors

Family factors play an important role in children's adherence. Geiss et al. (1992) studied adherence in children with cystic fibrosis. Low marital satisfaction in mothers was associated with poor adherence. In a review of studies examining family functioning and adherence in children with diabetes, Hauser et al. (1990) found that family support, cohesion and organisation were predictive of higher adherence. In a study of compliance to imipramine for adolescent depression, side effects did not predict adherence, however, highly rigid and highly disengaged families as assessed by the FACES-II (Family Adaptability and Cohesion Scales) were significantly associated with greater non-adherence (Bernstein et al., 2000).

Family conflict, particularly parent-child conflict may compromise adherence. Schobinger et al. (1993) suggest that day-to-day management of pediatric asthma may be difficult if there is a high degree of parent-child conflict. A lack of communication, supervision and parent-child cooperation may lead to the child being non-cooperative with treatment regimens. High levels of family conflict have been associated with poor adherence in children with diabetes (Hauser et al., 1990; Miller-Johnston et al., 1994), asthma (Christiaanse, Lavigne & Lerner, 1989; Wamboldt et al., 1995) and cancer (Kennard et al., 2004).

Warm and supportive parent-child relationships seem to support childhood adherence. Children with asthma whose parents are more affectionate towards them are more adherent than children whose parents report no affectionate behaviours (Bender, Milogrom, Rand & Ackerson, 1998). Likewise, open communication within families is associated with better adherence to asthma medication (Weinstein & Faust, 1997).

3.8 Impact of family factors on treatment outcomes: the facilitative context hypothesis

The quality of the parent child relationship may be related both to adherence and to improved treatment response. Family functioning, and in particular, parental warmth, has been linked to both better adherence and better glycemic control in diabetes treatment (Davis et al., 2001; Hauser et al., 1990; Miller-Johnson et al., 1994). A high quality mother-child relationship has been found to be more predictive of childhood adjustment to congenital heart disease than the severity of the disease symptoms (DeMaso et al., 1991).

The impact of family factors on child physical health has been studied extensively with respect to children's asthma symptoms. In particular, caregiver psychological functioning is consistently associated with severity of asthma symptoms in children (Kaugars, Klinnert & Bender, 2004). Caregiver mental health problems are also associated with children's asthma symptoms and the need for acute medical treatment (Wood et al., 2002). In one study, children whose mothers reported being depressed were 40% more likely to require emergency asthma treatment in the next six months (Bartlett et al., 2001). Similarly, children whose caregivers had clinically significant mental health problems were more likely to be hospitalised than children whose caregivers did not have high psychopathology scores (Weil et al., 1999). Negative life events have also been associated with high asthma symptoms and the need for medical intervention (Shalowitz, Berry, Quinn & Wolf, 2001).

However, these studies utilised parental reports of both parental health and children's asthma. Other studies incorporating objective measures of asthma severity do not find relationships between asthma severity and caregiver mental health, but do find relationships between caregiver depression and caregiver report quality of life (Price, Bratton & Klinnert, 2002). Depressed parents are also more likely to report their child's asthma as having a negative effect on their family (Frankel & Wamboldt, 2001). This suggests that parental mental health may have a strong effect on how parents interpret their child's symptoms and the extent to which their child's symptoms cause them distress.

Family relationships may also have an effect on treatment response. Wamboldt et al. (1995) studied adolescents who had been hospitalised with severe asthma. Adolescents whose parents were highly critical as rated by a five-minute speech sample, showed greater improvement in their asthma, greater reduction in steroid medication use and had shorter lengths of stay in hospital. Walmboldt et al. suggest that some children's asthma symptoms may be triggered by emotional over-arousal caused by parental criticism. There is some evidence that psychological stressors arising within the family can trigger an adverse physiological reaction, exacerbating asthmatic symptoms (Miller & Wood, 1997; Kaugars, Klinnert & Bender, 2004).

Family context is a crucial factor in ADHD treatment. Research has consistently shown that stimulant treatment produces favourable changes in parenting behaviour (Barkley, 1988; Barkley et al., 1984; Wells et al., 2000). Where parenting behaviour

does not change for the better, e.g. parents with lower socio-economic status (Jensen et al., 1999a) or parents with depression (Hoza et al., 2000), children derive less therapeutic benefit from pharmacological treatment alone. Family context is likely to be particularly important in facilitating a positive treatment response in ADHD.

3.9 Medication related attitudes and behaviours in ADHD

The remainder of this chapter will review the current literature on what children with ADHD and their parents think and feel about ADHD and medication.

3.10 Parent attitudes towards ADHD medication

Research has demonstrated that parents of children who are taking stimulant medication for ADHD generally rate it as having significant benefits for their child (Cohen & Thompson, 1982; Dosreis et al., 2003; Efron, Jarman & Barker, 1998; McNeal, Roberts & Barone, 2000).

Dosreis et al. (2003) collected data from 302 parents of children who were taking medication for ADHD. Most parents were highly satisfied with medication, believing that it had improved their child's social relationships and self-esteem. Socio-demographic variables were predictive of parental attitudes to medication. Non-white parents were less likely to prefer medication to counselling and were less satisfied with medication. Non-white parents were also more likely to believe that sugar causes hyperactivity, that medication leads to drug abuse and that medication has serious side effects. Cultural differences in beliefs may be an important factor in determining whether a parent chooses medication. Over half of parents reported initial reluctance to use medication for ADHD because of reports in the lay-press.

Parent knowledge about ADHD and medication may also be important in determining their attitudes towards treatment. McNeal, Roberts and Barone (2000) found that parents with lower levels of knowledge concerning the effects of stimulants were associated with higher levels of illness concern in both parents and children. Additionally, parents with lower levels of knowledge also had higher perceptions of costs and barriers associated with medication. McNeal et al. (2000) suggest that not understanding medication may lead mothers to feel that their children's behaviour is influenced by something they do not understand and cannot control. This may

heighten their stress and anxiety around their child's ADHD symptoms. Additionally, parental anxiety may in turn influence children's concerns about their ADHD symptoms and medication.

Clinicians have recognised that the meanings parents attribute to ADHD medication may be important in determining their attitudes and behaviours. For example, a parent may believe that stimulant medication is a way of managing a neuro-behavioural problem and thereby improve academic performance. Another parent may see it as an excuse for laziness and a sign that their child is not coping (Jensen, 2004). A thorough understanding of parents' beliefs and attitudes towards medication is necessary and the lack of research in this area is striking.

3.11 Parental disagreement about ADHD medication

Stein, Deller, Resnikoff and Shapiro (2001) report on a common and challenging problem in prescribing medication for children's ADHD: namely, disagreement between parents as regards the best treatment. Divorced/separated parents may face particular challenges if one parent disagrees with the diagnosis or with the use of medication. This may have particularly deleterious consequences for the child as taking or not taking the medication is construed as an act of disloyalty to one of their parents. However, an extensive literature search failed to find any systematic research in this area.

3.12 Child attitudes towards ADHD medication

There is relatively little research as to what children think and feel about medication. One study asked 45 children with ADHD to complete questionnaires about how they felt about stimulant medication. The majority of the children (89%) said that they felt the medication was helpful. However, most of the children (85%) also reported experiencing side effects (Bowen, Fenton & Rappaport, 1991). Other studies have reported similar results of children reporting high levels of perceived benefits from stimulant medication (Cohen & Thompson, 1982; Efron, Jarman & Barker, 1998).

These studies contrast with Sleator's (1984) finding that 65% of children who were taking medication admitted to avoiding taking the medication openly or by covert methods; a wealth of clinical experience documenting abrupt adolescent refusal to take ADHD medication (e.g. Stein, Wells & Stephenson, 2001; Weiss, Jain &

Garland, 2000); and with research reporting high drop out rates from stimulant treatment (Charach et al., 2004; Firestone, 1982; Thiruchelvam, Charach, & Schachar, 2001). It seems that although children may find the medication helpful, some children may have other reasons for not wanting to take it. Research utilising the SRM may offer an explanation. People may avoid taking medication as the medication acts as a reminder of a stigmatising condition (e.g. Conrad, 1985). Clinical experience has highlighted that children may be teased by their peers or feel stigmatised for taking medication. Some children may see medication as an indication that they are flawed individuals who need medication in order to be acceptable to other people (Jensen, 2004). Children who recognise the benefits of medication may resist taking medication because of the negative meaning attached to it.

Children's beliefs about ADHD may also be important in determining their attitudes towards medication. Using the HBM model, McNeal et al. (2000) demonstrated that the level of illness concern (i.e. how concerned a child was about their ADHD) was positively associated with children's perception of medication benefit. It may be that children who are worried about their ADHD symptoms are more aware of the improvement when they take medication. However, approximately half the children in McNeal's study did not see their ADHD as an illness. It is suggested that because children generally associate taking medication with being ill, they may not understand why they are given medication for ADHD.

3.13 Differences between parent and child attitudes to ADHD medication

Consistent with other health literature (Bachanas & Roberts, 1995; DePaola et al., 1997; Hackworth &McMahon 1991; McElreath & Roberts, 1991) parents' and children's attitudes to ADHD medication are highly correlated (Cohen & Thompson, 1982; Efron, Jarman & Barker, 1998). However, some studies have found that mothers report more benefits to medication than children (McNeal et al., 2000), and that children report more costs (Efron, Jarman & Barker, 1998).

3.14 Parental knowledge of ADHD and treatment acceptability

Research into how parental knowledge of ADHD impacts willingness to pursue treatment options has been contradictory.

Rostain et al. (1993) examined parental willingness to pursue treatment for ADHD. They identified two dimensions – a willingness to pursue parent counselling and a willingness to pursue pharmacological treatment. Family factors (socio-economic status, parenting stress, family adaptability, family cohesion and parent sense of competence) were unrelated to willingness to pursue treatment. However, parental knowledge of ADHD was negatively associated with their willingness to pursue pharmacological treatment. It may be that well-informed parents are likely to be cautious regarding medication for their own child. A history of medication use was mildly associated with increased willingness to pursue medication again, suggesting that past experience of treatment may have an impact on attitudes to future treatment options.

Similarly, Corkum, Rimer and Schachar (1999) found that parental knowledge of ADHD was associated with higher acceptability of parent training groups, but not pharmacological treatment. However, parents with more knowledge about ADHD were more likely to enrol in both pharmacological treatment and in non-pharmacological treatment for ADHD, suggesting that knowledge of ADHD may increase the likelihood of enrolling in any treatment program. However, parental knowledge of ADHD did not predict adherence to either pharmacological or non-pharmacological treatment.

In contrast to this, Bennett, Power, Rostain and Carr (1996) found that parental knowledge of ADHD was related to willingness to pursue pharmacological treatment, but not to whether or not they actually pursued treatment.

3.15 The impact of past experience on treatment acceptability

The SRM suggests that previous experiences may have an important impact on patients' understanding of their condition and what treatment they pursue in the future. There is some evidence that past experience of ADHD medication may facilitate future medication use. Johnston and Fine (1993) assigned parents randomly to two groups: normal treatment protocol and a second condition where the child's progress was systematically monitored. Consistent with Rostain et al. (1993), parents in both groups became more accepting of medication after experience of using medication.

3.16 Measuring beliefs about medication

There are established measures of illness and medication related beliefs within the health psychology literature based on Horne's theoretical framework of medication beliefs.

Horne (2003; 1999) proposes a two-fold structure in which patients' illness beliefs (their perception of the problem) and treatment beliefs (their perception of possible solutions) are considered in parallel. This approach draws from the self-regulatory model in proposing that people's views of their illness/condition will guide their choice of coping strategy (e.g. taking or not taking medication.) Horne differentiates between beliefs about medicines in general and treatment specific beliefs (i.e. peoples' beliefs about the specific treatment or medication suggested for their particular problem). Research suggests that some people have generally negative views about medication, e.g. that medication is unnatural, harmful and over-prescribed. People with these sorts of negative beliefs are more likely to perceive complementary treatments as natural and safer and may reject orthodox medical treatment such as vaccinations and elect homeopathic or herbal treatments (Horne, Weinman & Hankins, 1999; New & Senior, 1991). Other people may have generally positive views of medication, and may be more likely accept medication. Alternatively, over-positive views of medication may lead to inappropriate demands for prescriptions (e.g. anti-biotics for viral illnesses) or medication for self-limiting conditions that typically heal without medical intervention such as diarrhea (Boath & Blenkinsop, 1997; Haak, 1998). General beliefs about medication may be related to socio-demographic factors such as social class or over-riding cultural meta-narratives and folk stories regarding medicine (Lim, Schwarz & LO, 1994; Pachter, 1994).

Horne and Weinman (1999) suggest that while general beliefs about medications influence a person's overriding orientation towards medicine in general, adherence behaviours are more likely to be determined by the person's personal views about the specific prescribed medication. In particular their cost-benefit analyses of the relative necessarily the medication for maintaining or improving health versus concerns about the potential adverse effects of taking it.

Horne, Weinman and Hankins (1999) developed the Beliefs about Medicines Questionnaire (BMQ) to assess peoples general attitudes towards medication and their assessment of the benefits, harmfulness and overuse of medication. This questionnaire has been used to predict adherence across a number of conditions including asthma, renal disease, heart disease and cancer (Horne & Weinman, 1999).

The use of the BMQ to assess parents' and children's beliefs about ADHD was considered. However, ADHD is a psychiatric disorder and medication is primarily used to treat attentional and behavioural difficulties rather than a clearly identifiable medical problem such Horne & Weinman have investigated. Additionally, the use of medication to treat ADHD in children has generated emotive controversy amongst the general public and amongst some professionals who work with children with ADHD (Barry, Lyman & Klinger, 2000; Biederman et al., 1995; Breggin, 2001; Faraone, 2005; Golding, 2004; Hodgens, Cole & Boldizar, 2000; Klein & Mannuzza, 1991; Murphy & Barkley, 1996; Stormont, 2000; Timimmi & Taylor, 2004; Vetere, 2004; Weiss & Hechtman, 1993). Given this context, it is likely that there are salient beliefs and emotions surrounding the use of medication to treat ADHD that are specific to this condition. It was therefore decided to seek to identify and develop a condition-specific instrument to assess beliefs about medication to treat ADHD.

3.17 A qualitative approach to understanding medication related attitudes and behaviours in ADHD

Qualitative research utilising the SRM has demonstrated that patients' attitudes to treatment and their treatment related behaviours may form a very dynamic process, and that patient and medical attitudes to medication can be highly divergent. The above research examines patients' behaviours with a medical paradigm and does not conduct in depth examination and analysis of what parents and children think and feel about medication for ADHD. Importantly, the above studies have not examined parents' and children's motivations for taking medication for ADHD, and do not examine what they actually do with the medication they are prescribed. La Greca and Bearman (2001) suggest that "treatment-related behaviours" may be a more helpful concept to explore how people manage treatment regimens.

Although the qualitative research concerning attitudes to ADHD medication and treatment-related behaviours is limited, one recent paper, involving in-depth parental interviews, demonstrated that parents have numerous motivations and, at times, ambivalent or contradictory beliefs about medication. Singh (2005) interviewed 17 mothers and 10 fathers of children who took stimulant medication for ADHD. Parents described a belief that medication restores their child's authenticity, allowing them to "be themselves" and to achieve in academic and sporting pursuits. In contrast to this, when these same parents chose not to medicate their children over the weekend or during holidays, medication was viewed as suppressor of the child's natural state, and parents spoke about letting their children "be themselves" at the weekend without medication. Parents, particularly fathers, also worried about the social stigma associated with taking medication, and expressed fears about medication preventing their son's from "being boys" and enjoying their boyhood as their fathers had done.

Singh's study demonstrates that parents have complex and contradictory motivations for giving, and not giving, medication. The meaning of medication also seems to differ depending on context (e.g. letting the child "be themselves" at school so they can achieve, or preventing the child from "being themselves" when at home).

In order to understand the process of continuing or discontinuing medication for ADHD over time, an understanding of these complex attitudes and behaviours is vital.

3.18 Conclusions

Social cognitive models of treatment adherence stress the importance of beliefs and attitudes in health related behaviour. The HBM is most useful for predicting one-off preventative health behaviours such as screening for cancer. Therefore, it is unlikely to be the most suitable model for predicting adherence to ADHD treatments. The TPB stresses the importance of normative beliefs and social pressure to carry out health behaviours. Social influences are likely to be of critical importance in ADHD treatment, particularly as adolescents are highly influenced by peer attitudes. Additionally, stigma is likely to play an important role in parents' and children's attitudes to medication for ADHD. However, like the HBM, the TPB is a static model of behaviour and does not take into account developmental processes which may impact children's and parents' behaviour over time.

The SRM is a more dynamic model of health behaviour that accounts for the effects of previous experience and emotional factors in predicting health behaviour. Research utilising the SRM has highlighted the complexity of attitudes and their relationships to medication related behaviours. Therefore, it is important to investigate attitudes, beliefs and behaviours from a patient rather than a medical perspective. Another important aspect to consider is the role of stigma in determining peoples' attitudes, beliefs and behaviours. This is likely to be crucial in ADHD treatment because children with ADHD and their parents may encounter considerable stigma.

Pediatric adherence is complicated by the interactions between parents' and children's attitudes and behaviours. Developmental issues such as adolescence, parent-child conflict, peer influences and family factors are crucial influences on young people's medication related attitudes and behaviours. Additionally, the family environment and parent-child relationship may, in themselves, influence the effectiveness of treatment.

Although the literature on parents' and children's attitudes to ADHD medication is sparse, the general thrust seems to suggest that both parents and children report significant benefits associated with taking medication. Parent and child attitudes and beliefs regarding ADHD medication tend to correlate highly. However, children tend to report fewer benefits and more drawbacks to taking medication than parents. There is some evidence that knowledge of ADHD and prior experience of ADHD medication are positively associated with pharmacological treatment acceptability. Most research examining parents' and children's attitudes to medication has adopted a top-down approach. Qualitative research has suggested that parents have mixed, and often contradictory attitudes regarding medication.

3.19 Research direction

For the purposes of this thesis, it was decided not to test the HBM or the TPB as a predictor of treatment behaviour in ADHD. The reasons for this are two-fold. Firstly, little is known about what parents and children think and feel about medication for ADHD. Before the HBM or TPB could be utilised in ADHD research, instruments to assess parents' and children's attitudes to medication are necessary. Secondly, as ADHD treatment typically starts in childhood and continues through adolescence, the

importance of developmental factors and the family context in which a child is treated are likely to be crucial. Nevertheless, the HBM and the TPB highlight the importance of identifying and understanding parents' and children's beliefs and attitudes to ADHD medication, which will be one of the primary aims of this thesis. The TPB also draws attention to the importance of subjective norms and the likelihood that perceived stigma will play an important role in determining treatment related behaviours in ADHD.

In line with the SRM, this thesis argues that a grounded approach is necessary to explore what beliefs, perceptions, attitudes and behaviours may be important in pharmacological treatment of ADHD in childhood. In particular, the SRM suggests that parents' and children's understanding of ADHD medication may be different from that of the medical community. Parents and children may develop ways of managing ADHD using, or not using, prescribed medication that may deviate from prescribed medication regimens. The next study will therefore be a qualitative study to identify attitudes, beliefs, emotions and medication related behaviour from a parental perspective.

However, the SRM is a highly complex model and it is beyond the scope of this thesis to operationalise the SRM as a model of looking at medication related behaviour in ADHD given the current lack of understanding of parent and child medication related beliefs, attitudes and behaviours. The next study continues in the SRM tradition of grounded research in seeking to identify and understand medication related attitudes and behaviours and to understand the context in which they occur.

The aims of this thesis are:

(i) To identify salient medication related attitudes and behaviours from a patient perspective

(ii) To design a questionnaire whereby parents' and children's medication related attitudes and behaviours can be assessed

(iii) To explore how medication related attitudes and behaviours are related to family factors such family dysfunction, parent psychopathology, child psychopathology and child age.

The next study will be a thematic analysis of semi-structured interviews with parents of children with ADHD in order to identify and define what medication related attitudes and behaviours are important to families of children with ADHD.

Chapter 4

Study 1: Identification of ADHD medication related attitudes and behaviours in parents of children with ADHD

This chapter describes an interview study designed to identify key ADHD medication related attitudes and behaviours. Content and thematic analyses are used to explore the data and identify key issues. These issues are placed within the context of the current literature on ADHD medication related behaviours and attitudes. In particular, the small literature drawing from clinician's experiences of treating children with ADHD with medication is considered. The limitations of the study and future research directions are also discussed.

4.1 Rationale for the study

The literature regarding parent and child attitudes to medication for ADHD is sparse and contradictory. The general thrust of the literature seems to be that both parents and children see medication as beneficial (Cohen & Thompson 1982; Dosreis et al., 2003; Efron, Jarman & Barker, 1998; McNeal, Roberts & Barone, 2000). However, discontinuation of medication is a clinically significant problem, particularly in adolescence (Charach et al., 2004; Firestone, 1982; Sleater, 1984; Stein Wells & Stephenson, 2001; Thiruchelvam, Charach & Schachar, 2001; Weiss, Jain & Garland, 2000b). Qualitative research has indicated that parents often have highly mixed and contradictory feelings about medication for ADHD. For example, the same parent who regards medication as a way of enabling their child to be themselves and to achieve at school, may see medication as a threat to their child's personality and uniqueness over the weekend (Singh, 2005). e

Research in other conditions suggests that patients may attempt to self-regulate medication regimens in a systematic way, dependent on their beliefs about medication and the meaning medication holds for them (Conrad, 1985). However, there is a lack of such understanding as to what motivates parents or children to take, or not take, medication. Little is known as to how parents or children may adapt

ADHD medication regimens to suit their personal situations or in response to their attitudes or feelings regarding medication.

4.2 Study aims

The aims of this study are:

(i) To gain an understanding of parent attitudes and beliefs regarding medication for ADHD
(ii) To identify salient attitudes and beliefs from a parental perspective
(iii) To explore how parents manage and regulate medication regimens for children with ADHD
(iv) To identify salient medication related behaviours

4.3 Methods

4.3.1 Participants

The participants were volunteers recruited from support groups for parents of children with ADHD in the Hampshire area. Twelve families were contacted and all agreed to take part in the study. The sample included nine mothers and three couples who preferred to be interviewed together. Altogether, seven families were married couples (including both the father and mother of the child with ADHD), three were step-families, and two were single parents. Ten of the families had one child who had been diagnosed with ADHD and two had more than one. Thirteen of the children were male, six were female. The age of the children/young adults ranged from 10 to 22, with a mean of 15.4 years and standard deviation of 3.2 years. All but three of the children/young adults were currently taking stimulant medication for ADHD. Two young adults had chosen to discontinue medication, and one parent had decided to take her child off medication due to cardiovascular side effects.

4.3.2 Interviews

The researcher visited the participants in their homes and interviewed the participants with the aim of eliciting information about parental beliefs, attitudes and

experiences concerning ADHD treatment and medication. Each interview lasted approximately one hour and was recorded on audio tape.

The interview (Appendix A) consisted of four sections:

(i) Questions about the family structure, number of children diagnosed with ADHD, what medication they were taking and how the child with ADHD had affected the family.

(ii) Questions about the behaviour of the child(ren) with ADHD

(iii) Questions about participants' experiences and beliefs regarding medication

(iv) Questions about other treatments for ADHD and how they compared with their experience of medication

Questions in each section were open ended and participants were prompted to talk as openly and honestly about their experiences as they could.

4.4 Results

4.4.1 Content analysis

The analysis was concerned with identifying the attitudes, beliefs, concerns and behaviours of families as regards pharmacological intervention for ADHD with stimulant medication. Thematic analysis was employed to identify and explore recurring attitudes and behaviours.

Boyatzis (1998) was used as a guide for coding and analysing the data. Interviews were transcribed verbatim and read several times by the researcher to get a thorough sense of what participants were saying. In order to protect participant anonymity, all names were changed in the transciption process. As with any semi-structured interview, a wealth of information was obtained. Therefore, it was necessary to reduce the raw information into units of analysis. Following close reading, extracts where participants spoke directly about medication and issues surrounding ADHD treatment were selected for further analysis.

Six major themes and 18 sub-themes were identified and compiled into a coding manual (see Appendix B). Each extract was assigned exclusively to one category. Additionally, four sub-themes (positive effects of medication, negative effects of medication, parent medication related behaviour and school medication related behaviour) were further divided in order to distinguish between different beliefs and behaviours that were incorporated into those categories. A list of codes, number of coded units and the number of interviews which contained units within each code is displayed in Table 4.1.

Inter rater-reliability was assessed using random selection of 100 extracts (between two and five from each sub category). A psychology research student who was not part of the current study coded the themes according to the manual. A kappa value of .82 was obtained indicating more than satisfactory reliability.

Table 4.1 Number of coded units within each category, and number of participants giving at least one statement within that code

THEME	NUMBER OF UNITS	NUMBER OF PARTICIPANTS
EFFECTS OF MEDICATION		
Positive effects	34	11 (91.7%)
-Medication used to manage behaviour	6	4(33.3%)
-Medication used to give the child	9	5(41.7%)
freedom/independence	21	8 (66.6%)
Negative effects	14	6(50%)
-Minor side effects	4	3(25%)
-Tics/Tourettes Sydrome	2	2(16.7%)
-Changes child's personality	1	1(8.4%)
-Cardiovascular symptoms	15	4 (33.3%)
Limitations	11	9 (75%)
Effect on other people		
MEDICATION RELATED BEHAVIOUR (MRB)		
Parent MRB	69	12 (100%)
-Monitoring the medication regimen	13	7(58.3%)
-Adjusting the regimen to manage symptoms	10	7(58.3%)
-Adjusting the regimen to manage side effects	6	3(25%)
-Drug holidays	8	4(33.3%)
-Communicating with the child about medication	2	2(16.7%)
-Not communicating with the child about medication	1	1(8.4%)
-Managing child resistance	15	8(66.6%)
-Forgetting to give child medication	5	4(33.3%)
Child MRB	26	12 (100%)
-Serious Resistance	14	6(50%)
-Resistance, but not a problem	7	5(41.7%)
-Child forgets to take medication	5	4(33.3%)
School MRB	27	7 (58.3%)
-Schools forget to give the child medication or do not give the child medication at the right time	4	3(25%)
-Schools unwilling to take responsibility for the child's medication regimen	4	3(25%)
-Parents avoid having the school involved in medication	4	3(25%)
-Schools make sure the child gets medication on time	7	4(33.3%)
-Schools use medication to keep the child quiet and fail to help the child academically	4	2(16.7%)
-Teachers are indiscreet about medication	2	2(16.7%)
-Schools take inadequate care with the medication	2	1(8.4%)
ATTITUDES TO MEDICATION		
Parent Attitudes (Positive)	8	6 (50%)
Parent Attitudes (Negative)	24	9 (75%)
Parent Attitudes (Neutral)	8	3 (25%)
Child Attitudes (Positive)	5	3 (25%)
Child Attitudes (Negative)	22	7 (58.3%)
Other people's attitudes (Positive)	7	5 (41.7%)
Other people's attitudes (Negative)	10	7 (58.3%)

RELATIONSHIP WITH MEDICAL PROFESSION		
Relationship with Medical Professionals (Positive)	3	2 (16.7%)
Relationship with Medical Professionals (Negative)	14	7 (58.3%)
ADOLESCENCE	34	8 (66.6%)
OTHER TREATMENTS	33	8 (66.6%)

4.5 Thematic analysis

Thematic analysis is a process for encoding qualitative information in order to make sense of seemingly unrelated material. Boyatzis (1998, p.5) defines a theme as *"a pattern found in the information that at a minimum describes and organises the possible observations and at a maximum interprets aspects of the phenomenon."*

The aim of the thematic analysis was to systematically describe parents' emotions, beliefs and experiences of using medication as a treatment for ADHD in order to gain greater insight into medication related attitudes and behaviours as experienced by parents of children with ADHD.

4.5.1 Theme 1: the effects of medication

Participants reported a range of positive, negative and neutral effects of ADHD medication on the child. Additionally participants reported that the medication had an effect on other people in the child's lives including parents, siblings and extended family members.

4.5.1.1 Positive effects of medication

In general, participants reported the medication as having at least some positive effect on the child. All but one participant mentioned some benefit that they experienced when the child was taking medication. For some parents the effect seemed to have been dramatic, whereas for others the benefits of medication were more subtle.

'But once Kevin took his Ritalin, he was great. He was a different child and he'd do anything you asked him to, he was like you'd waved a magic wand and made him somebody different, he wasn't rude, he was nice, it used to make such a difference.' (P.10)

'This isn't a new child, where they've got some cases on TV that have been like that where the child was really bad, they've popped a Ritalin in and half an hour later he's calm. We've never experienced that. There may be a slight difference, but not a lot.' (P11)

Some of the participants experienced the benefits of taking medication both at home and at school. For others, the benefits were only experienced at school.

'He carried on with dex[1] for quite a while...we didn't see that much difference, but the school seemed to think he, it, made an improvement.' (P.11)

This may have been because some children are prescribed medication during school hours and still exhibit symptoms of inattentiveness and hyperactivity at home. However, one parent commented that once the medication had helped the child cope in school, the situation at home also improved.

'Since he started taking Ritalin it took the frustration away from school, which then took the frustration away from him taking hell on us at home, because he had problems at school, does that make sense?' (P.3)

Participants reported a wide range of positive effects of the medication, including direct effects on ADHD symptoms such as improved concentration levels and decreased hyperactivity. Close reading of the interviews however suggested a subtle dichotomy in the way in which parents perceived medication as being effective. Some parents emphasised that the medication made their child more manageable or controllable, for example:

'It's (the medication) made, to start with, it made things a lot more peaceful, it made him a lot more manageable.' (P.7)

'He's much easier to control when he's on the medication.' (P.4)

In contrast, other parents stressed that the medication enabled their child to have control over themselves and their own lives and to achieve things that they wanted to

[1] Dextroamphetamine

do such as playing on sports teams, holding down a job or going out with friends independently.

'He's now got Ritalin all day, and he's been asked to play for the top football team, they've never seen him so focused... He wouldn't go without it, he knows he would never keep his job without it because he wouldn't be able to control himself.' (P12)

Given that one of the most critical tasks for adolescent development is to attain autonomy from parents (Allen et al., 1994; Blos, 1967), it is likely that parents', and perhaps more importantly adolescents', perceptions of the benefits of medication will have important implications for adolescents' behaviour in relation to treatment. Whether the adolescent perceives medication as a means of gaining independence or as a means of authority figures (e.g. parents, teachers, medical professionals) keeping them under control may be critical in determining their willingness to continue treatment.

4.5.1.2 Negative effects of medication

Most parents (eight out of twelve) reported experiencing some negative effects from the medication. These ranged from commonly reported side effects (e.g. reduced appetite, headaches during the first few weeks of titration, difficulty going to sleep when taking the medication) to serious cardiovascular side effects. Although most parents reported at least some of these negative effects, most did not perceive them as being a serious problem. Participants frequently reported that side effects could be managed, for example, by giving medication after meals in order to manage the appetite suppressing effects of stimulant medication or not giving medication in the evening in order to avoid sleep problems.

A minority of parents reported more severe side effects such as heart palpitations, which meant that the child was taken off the medication. Two parents reported that higher doses of stimulant medication had led to an exacerbation of their children's Tourette's syndrome. This is very much in line with the pharmacological literature, which recommends that stimulants should be used with caution for children with comorbid ADHD and Tourette's disorder (Jimenez-Jimenez & Garcia-Ruiz, 2001).

Two parents also perceived the medication as altering their child's personality, making the child, *'like a robot'* (P.9), and reporting that, *'He was controlled, but not*

like, it just didn't seem like the same person.' (P.9). This participant had made the decision to take her child off stimulants after several months of treatment. Another participant who reported very positive effects of medication, also stated that while her child needed the medication for school, she did not see his hyperactivity as being a problem in other environments, and wanted him to be *"free to be himself"* when not in school.

'Well because, he's got, I like him to be Laurence as well...I like that bubbly character, but there's a time and a place, you've got to be sensible at school, do you know what I mean. But you know, at home...he's just bubbly and what's wrong with that' (P.3)

4.5.1.3 Limitations of medication

While parents generally found the medication to have positive effects, most parents did not seem to perceive medication as a panacea and emphasised that although medication helped to treat the core symptoms of ADHD such as inattentiveness and hyperactivity, the child still had emotional and behavioural problems which the medication did not deal with.

Interviewer:	*In what way was behaviour still a problem?*
Respondent:	*Massive explosions in mainstream (school), um going absolutely out of his mind because he found it difficult to cope in such a large environment...but the medication, yes it helped concentration, but no, it didn't help social skills or controlling his behaviour.* (P1.)

Other parents emphasised that, although medication was vital, parenting and educational interventions were also essential. Medication was seen as providing *'a window of opportunity'* (P.12) which made other interventions and successful parenting possible.

'Ritalin is not a cure, it doesn't cure all symptoms plus it gives the parents a chance, the parents have to work really really hard, in conjunction with the school, in conjunction with the teachers.' (P.6)

4.5.1.4 Effect on other people.

As well as having an effect on the child with ADHD, nine out of twelve participants referred to ways in which the medication had an impact on them as parents, their family, the child's siblings and other significant people. In particular, parents emphasised that the medication had benefited the overall family unit.

'I'm probably a lot less stressed than when he was little...you know when its working and when it works well and that helps everybody because it's a bit more calmer and you know he's not just going to jump up and do something wacky.' (P.2)

One participant even commented that the medication had enabled her child to stay within the family, and not go into care..

'It helped us to keep him here...I don't think there was any way I could have coped otherwise.' (P.4)

Other beneficial effects mentioned were that younger siblings were not scared of the child with ADHD when he/she had taken medication and was much calmer and less aggressive. Additionally, extended family members such as grandparents, aunts and uncles were able and willing to spend time with the child when he/she had taken medication.

4.5.1.5 Effects of medication: summary

To summarise, parents had diverse experiences of the effects of medication. The majority of parents perceived the medication as having some positive effect, with some reporting dramatic improvements in the child's condition, and others reporting more subtle effects. Similarly, some parents reported that the medication had benefited the child only in school, and others reported benefits in wider domains. Participants reported a variety of positive effects including direct effects on the core ADHD symptoms of inattentiveness and hyperactivity and improvements in child behaviour. Subtle differences in the meaning of "benefits" to parents were noted. Some parents emphasised that the medication enabled them to better control and manage the child. Others reported that it better enabled the child to manage himself/herself and have more freedom, such as being able to socialise independently with friends, play on sports teams and hold down a job. While the overwhelming consensus seemed to be that medication had positive effects, most

participants reported experiencing some side effects. For the most part these were not considered serious, with the exception of one parent whose child had experienced heart palpitations. Comorbidity seemed to present a serious problem for pharmacological treatment, with two participants whose children had comorbid ADHD+Tourette's reporting that higher doses of some stimulant medications exacerbated Tourette's symptoms. Although medication perceived to have positive effects for children with ADHD and their families, some parents emphasised that it did not deal with all symptoms. While the medication led to clear improvements for core ADHD symptoms of inattentiveness and hyperactivity, it did not have an effect on the child's emotional, behavioural and educational difficulties. Parents stressed the need for parents and schools to exert effort to help the child in these areas. As well as having positive effects on the child, participants also reported positive effects on other family members and medication seemed to lead to improvements in the immediate and extended family life of children with ADHD.

4.5.2 Theme 2: medication related behaviour (MRB)

4.5.2.1 Parent MRB

Parents reported a wide variety of behaviours in relation to the management and implementation of medication regimens for ADHD. Close analysis of parent MRB units revealed several categories. These included monitoring the medication regimen, timing and dosage of the medication, drug holidays, communicating with the child about medication, and dealing with child resistance to taking medication.

4.5.2.1.1 Monitoring the medication regimen

Parents reported a number of ways in which they ensured that the child was taking the medication as prescribed. These included using weekly pill-boxes, where the medication for each day was put in a small box. This allowed the parent to keep track of what medication the child had taken each day. Some parents reported that they kept a supply of medication close to hand at all times to ensure that they were always available and the child never missed a dose when he/she needed one.

'No, it ends up when you have a supply of tablets in your handbag, in the car, everywhere isn't it, you've got packets.' (P.5)

Most of the parents reported that they watched the child take the medication or gave it to them themselves to ensure it was taken.

Interviewer: *Um, how do you know that Nick has taken it?*
Respondent: *Because I stand there and watch him! I make sure and I get him to open his mouth* (P.5)

No parent reported forgetting to give a dose of medication. This is unsurprising given the immediate affects of stimulant medication on ADHD symptoms. However, parents did report that they may have been late in giving the medication, but would realise fairly soon because of their child's behaviour.

Respondent A: *he has gone from up to half past 2, 3 o'clock and then he's starting to give you the signs, you know he's driving you up the wall.*
Respondent B: *And that's when he gets it*
Respondent A: *Yeah, oh hang on a minute, he hasn't had his last Ritalin*
Respondent B: *Give it to him now, yeah* (P.8)

Two mothers reported that the child's father might forget to give the child medication, but commented that this was not because the father was unsupportive of the medication regimen, but because he was forgetful, or had ADHD himself. This is in line with the suggestion that parents with ADHD may find it difficult to administer medication consistently (Weiss et al., 2000a).

Interviewer: *What sort of situation was it when his father forgot?*
Respondent: *Well he just, I mean if Craig and his father are at home and I go shopping, his father, he's got ADHD, yes, and you come home and Craig comes down and he's really bouncy. Ah! Its not deliberate you see.* (P.6)

4.5.2.1.2 Managing the timing of the medication regimen

Parents reported a variety of ways in which they managed the timing of the medication regimen. Some parents reported the need for flexibility in timing the medication regimens in order to get the maximum benefit for each child.

'..you could move the medication around to get the best value for yourself, well for yourself and your child, and you could fiddle with it, the dosage and the timing to see how quickly the child metabolised it, and he takes one tablet every two and a half hours depending on how much pressure he's under.' (P.6)

Other parents reported reducing the dosage in order to decrease side effects, and it was common to give medication after meals to manage the appetite suppressing side effects.

Interestingly, there seemed to be differences in the way in which parents managed giving medication outside of school hours. Some parents tended to report giving medication when the child's behaviour was particularly challenging.

Respondent A: *If he's on seven a day, some days he has five, some days he'll have seven, some times, there have been occasions, when he's had to have an eighth because if he didn't*

Respondent B: *We'd kill him*

Respondent B: *No, he would end up doing damage to himself...*

Respondent A: *He's gone absolutely ballistic, hasn't he, I mean, he's kicking the door down, he's throwing everything out of his room.* (P.8)

By contrast, other parents reported that they gave children medication outside of school to enable them to do things that they wanted to do, such as school trips, sports teams and socialising with friends.

'Its not just that we've only been given it for school, we've been given it at all times, he's ok to take it. Its just us, we chose not to give it at most of those other times, but I would, he loves going fishing, but there's no way he can fish if he doesn't take Ritalin, because he'll scare the fish, they'll jump out of the water (laugh). It depends what he wants to do, or if he wants to go into town on a bus with his friends, you know, I need to know that he's taken his Ritalin.' (P.3)

This would seem to represent a similar dichotomy between parents perceiving and using the medication as a means of managing their child's behaviour and parents

perceiving and using the medication as a means of facilitating their child's independence.

4.5.2.1.2 Drug holidays

Some parents reported giving their children 'drug holidays', meaning that they did not give medication during certain periods, such as the weekends or school holidays. A number of reasons for doing this were offered. Some parents felt that it give the child an opportunity to learn to manage without medication. Others reported not wanting to *'pump him full of drugs, especially not drugs that took away his sparkle'* (P.1). Some felt medication was not necessary outside of school and the child was not under any pressure. Others gave the child a drug holiday as a compromise: the child was allowed to not take medication at the weekend on the condition they took medication without fuss during the week. Some parents also reported using drug holidays as a way of allowing their child to have a growth spurt.

'He would actually grow two inches in those two weeks, it was like he was growing over night...' (P.4, referring to Christmas and Easter holidays when the child was not taking medication.)

Weiss, Jane and Garland (2000a) suggest that systematic drug holidays may be a helpful way of enabling adolescents to monitor the effects of medication and make informed decisions concerning continuation or discontinuation of treatment. If adolescents are not encouraged to have drug holidays, it may be that they will engineer a drug holiday of their own.

4.5.2.1.3 Communicating with the child about medication

Differences emerged in the way in which parents tended to communicate with their children about medication. Some parents did not seem to communicate with their child concerning the purpose of the medication.

'Didn't explain it to him, he wouldn't have understood. We just said, this is a new medication and you are going to try it. Take this for mummy, there's a good boy.' (P.8)

By contrast, other parents did discuss it with their children, emphasising that they always explain to the child why they should take medication.

'Yeah, we've always told him, you know if he's had to change tablets or have another added or whatever, we've always told him exactly, this tablet is for this and you should feel better.' (P.5)

4.5.2.1.4 Dealing with child resistance to taking medication

Children often seemed reluctant or resistant to taking medication and parents mentioned a variety of ways in which they dealt with such situations. Some parents reported that they would physically force their child to take medication if necessary.

'If I have to sit on his head at the time, he will take it...I get him by his arm, say, 'you ain't going nowhere til you have it' (P.8)

Other parents used behavioural techniques such as offering the child two choices, and providing consequences if the child did not take the medication.

'...he does dig his heels in, he will have a paddy but it does get taken in the end, because basically, it's a case of you either take it or you don't get to do what you want to do, because its two choices.' (P.2)

Two parents reported dissolving the medication in a hot drink so that the child took it without realising that they were taking it, although it came across that they did not think this was ideal.

'Well, to be honest, I mean, this is going on tape, but I used to, when I used to wake him up I'd take him up a cup of hot coffee or tea and I'd already put the thing in there because he would not take it. I'd already mixed the Ritalin up because he would not take it.' (P.10)

4.5.2.1.5 Parental disagreement about medication.

Two participants mentioned disagreement between divorced parents concerning medication. One participant reported that her ex-husband would give her child additional medication on top of what was prescribed, a source of considerable worry for her.

'His dad used to, he was terrible for it. Mark was on 1½ two times a day, and his dad would give him 1½ when he got home from school as well, but part of that was because not enough was done to keep Mark occupied so he would act up in the evenings out of boredom. Um, but yeah, his dad was terrible for doing that. That used to worry me ...especially when he was on a, quite a high dose when he went to his dad's anyway.' (P.4)

Another parent commented that her ex-husband was not in agreement concerning giving the child medication, and would not give him medication when the child was at his house.

'The only way I can describe his dad and the way he sees it, is if Pete's having a good day and he's with him, he won't give him his medication, and then he'll send him back to me going off his head. That's his dad.' (P.2)

Biederman (1995) documented a particularly high rate of conflict and divorce amongst families with children with ADHD compared to control families. Familial conflict and adversity predicts persistence of ADHD from childhood into adolescence (Biederman et al., 1996). Stein, Diller, Resnikoff and Shapiro (2001) reported that parental disagreement concerning treatment for ADHD, particularly the use of stimulant medication was a particularly challenging issue for clinicians. It seems plausible then that parental disagreement concerning treatment may have an influence on how the child perceives treatment and may play a role in mediating adherence, or child medication related behaviour or treatment outcome.

4.5.2.2 Child MRB

Parents reported considerable problems with their child(ren)'s MRB, most notably that children resisted taking it. All but one participant mentioned experiencing some form of resistance from their child. These behaviours included hiding the medication, lying about taking it, pretending to take it and spitting it out and screaming, hitting or

kicking when asked to take medication. Six parents reported child resistance to be a serious problem.

'He closes up his mouth, puts his hand over and shouts and screams and has a little kick. Depends what kind of mood he's in really, if he's in a mad mood you get all the abuse and he sort of just runs round and he'll hide round the chairs and he'll stand there, closes his mouth or puts his hand over his mouth.' (P.2)

Five parents reported resistance behaviours in the past, or very occasional resistance that was not a current problem. Only two parents reported that their children where happy to take medication.

'She's happy to take it. She's quite good on the whole.' (P.12)

Four parents also reported that their child forgot to take the medication For example, forgetting to go and get it at school.

"He forgets at college, he is supposed to go take it at lunch time but he doesn't remember." (P.6)

4.5.2.3 School MRB

4.5.2.3.1 Difficulties in following medication regimens at school

Parents reported specific difficulties in following medication regimens at school and difficulties in ensuring their child takes medication at school. Two participants commented that colleges for adolescents over the age of 16 would not take responsibility for adolescents' medications. This meant that the adolescent had to take responsibility for the medication during school, which they would often forget to do.

Other adherence difficulties at school were noted. Parents reported that their child forgot to go to the school office in order to get medication. Others reported that children were more resistant at school, as teachers, unlike parents, were unable to force the child to take it. Some participants also reported that the teachers would forget to give the children medication.

Parents also reported that schools were not always good at giving their child medication at the right time, for example, giving it before meals.

'I didn't know why he was bringing home his lunch every day, til I worked out that they were getting their Ritalin and then going to get their lunch half an hour later. The schools have no idea at all!' (P.12)

Parents also reported problems with teachers being indiscreet as regards their child taking medication in school and reported that this resulted in their child being very embarrassed.

"The teachers aren't very good at hiding it. They do the opposite, they will point it out to everybody and if one of them does do something, it will be, 'Have you taken your tablets today?'" (P.11)

Some parents used sustained-release in order to eliminate the need for the school to be involved in the medication regimens.

'He's taking Concerta[2] now so that solves that problem because he doesn't have to take it in school. I think Concerta is brilliant for that. We don't have to involve the school on the medication side of things at all.' (P.11)

4.5.2.3.2 Teachers' motivations for giving medication

Some parents reported that the school had good procedures for ensuring the child got their medication regularly and that their child always got their medication in school.

'He has a learning support assistant, she's lovely, and she reminds him to take the medication and makes sure he gets it, makes sure he's alright.' (P.5)

Other parents reported that the school were very keen to make sure the children got medication as it enabled them to control their behaviour and made them less disruptive in class.

[2] Concerta is a sustained release formulation of methlyphenidate

'Interviewer:	*When he was at school did he always get the medication he was meant to get?*
Respondent:	*Yes, because he was such a problem in mainstream school, yes, he did...it's the first thing they make sure that happens.'* (P.1)

For some parents, this was problematic as they felt that the school used the medication as a means of keeping the child quiet and not giving them the extra educational help they needed. Parents reported that serious disagreement with the school over the issue of medication and educational support for their child, and difficulties in obtaining special educational needs support for their children.

'... the LEA[3] was saying there was nothing wrong with my child because Ritalin was keeping her quiet in the corner. If she's not giving the teachers any grief, they don't have to deal with her do they? They don't have to address anything' (P.12)

4.5.2.3.3 Concerns about medication abuse in schools

Some parents had concerns about the manner in which the schools stored the medication, fearing that it was not secure and that there was a possibility of other children stealing the medication.

'Kids have taken it out of the teacher's drawers...I don't understand why the schools are not aware what the circumstances for storing Ritalin are. They're not supposed to allow any access to anybody. It's a class A drug!' (P.12)

Given that research has found that many children taking stimulant medication may have their medication stolen by their peers at school (Poulin, 1998), this is a matter of concern.

4.5.3 Theme 3: attitudes to medication

[3] LEA stands for Local Education Authority

Participants commented on their own attitudes to medication as parents of children with ADHD; their children's attitudes; and other peoples' attitudes.

4.5.3.1. Parent attitudes to medication

Despite most participants reporting some positive benefits associated with medication, only half of the participants expressed positive attitudes towards medication. On the whole, most parents seemed to have mixed feelings and attitudes towards the medication.

Positive attitudes towards medication included feeling relieved about being offered medication, as it seemed like confirmation that there was something wrong with the child and meant moving forward would be possible.

'I was just thankful that somebody had stopped looking at me as the cause of Mark's problems, and saying Mark actually had something wrong with him...I was also quite positive, that now we know what's wrong with him we can move forward, and change the way that he behaves.' (P.4)

Parents often reported initial negative feelings, such as being scared about giving psychotropic medication to children and being worried about side effects, and the long-term implications of treatment. Often parents commented that they did not feel as though they had a choice, and used the medication as a last resort, after trying everything else (behavioural modification, dietary treatment, herbal medication). For example, one participant commented *'we didn't really have much choice about medication because things were horrendous'* (P.7). Similarly, parents reported using the medication as a last resort, but still having considerable anxiety concerning its long-term effects.

'we had to make the decision that if Ritalin was actually going to kill him by the time he was 30, but in the meantime he could have a quality of life, then we were prepared to do it, because he had no quality of life' (P.6)

However, despite serious reservations and concerns, all but one participant were happy for the children to be taking medication and reported changes in attitudes after they had tried the medication. One participant described herself as being *'anti-drug'*

but had decided to try medication as a last resort out of desperation, appeared to have a dramatic change of attitude.

'and I can honestly say now, that, I felt guilty because I hadn't allowed him to have more of his childhood...that he could have enjoyed, we could have enjoyed if he'd been on the Ritalin, instead of having the slanging matches that we used to have and the fighting, not being able to go out, socialise, have days out when he was younger.' (P.8)

Another participant, who had withdrawn her child from stimulant treatment, expressed the belief that medication was an *'easy option'* and that she would *'rather she coped with her problems'* (P.9). This however was the exception rather than the norm and parents tended to assert that medication was not an easy option and that further intervention and effort to manage behaviour and provide extra educational help were necessary.

'Medication is very important, it makes it easier to get behaviour therapy up and running because child is more focused.' (P.4)

Despite initial negative attitudes towards medication and for some, continuing concern about side effects and fears concerning the long-term implications of stimulant treatment, parents on the whole, seemed to express more positive attitudes towards medication after they had tried it.

4.5.3.2 Child attitudes to medication

The overwhelming impression from the interviews was that children had negative attitudes to medication, with only three participants giving any sense that the child had a positive or accepting attitude towards taking medication. One of these participants commented that her child had *'accepted the medication helps...but he still doesn't like taking the tablets.'* (P.2.). The parents of the other two children who were positive about taking medication reported that the child perceived the medication as having a positive impact on their lives.

'...he's quite happy because he knows that it helps him get on, helps him get where he wants to go.' (P.12)

'He was happy to try (the medication), because he kept getting into lots of trouble at school, and so, when he found that it stopped him from getting into trouble, and he was getting praised, because he was doing work.' (P.3)

The parent-reported attitudes of these children stood in contrast to the largely negative picture painted by the other participants. Five participants reported their children as feeling different from everybody else, and in particular being embarrassed about taking medication.

'He hates having to take tablets, and he's weird and why does he have to be different from everybody else, you know. Well, you're not the only one, lots of people have to take pills. But he thinks that other people think that he's different as well.' (P.2)

Again, there seemed to be a difference between children who perceived the medication in a positive light and who perceived the medication as having a positive impact on their lives, enabling them to do well at school, or *'get on'* in life. Other children, perceived the medication to have a negative effect, preventing them from being able to *"be themselves"* and do as they want to.

'This is me he will say, this is how I am...He's voiced the opinion he doesn't like the medication, because it brings him down, it makes him feel a bit calmer and he likes that feeling of being on the edge, living life to the max as he puts it (laughs), whatever that is.' (P.11)

Again, there seems to be a difference in the way in which parents report their children's attitudes towards medication. Some parents reported children as perceiving the medication as having an enabling effect, helping them to control their behaviour to achieve their own goals. By contrast, others reported that children felt as though the medication made them different from other people, and disliking the effect, feeling that the medication controlled them and prevented them from "being themselves".

4.5.3.3 Attitudes of other people

Participants reported a variety of attitudes that they experienced from other people. Some reported positive attitudes, such as other people being able to see the positive impact of medication.

'Everyone's seen the difference, my neighbour is a good example actually, because she keeps saying to me all the time, she goes, 'he's lovely, isn't he, he wasn't such a good boy when he first moved here,' you know everyone used to steer clear.' (P.3)

Other participants reported experiencing negative reactions and attitudes concerning the medication from other people, such as feeling judged by other people, people thinking that they were being cruel, or sedating their children. Other people talked about anti-Ritalin protest groups. However, the consensus seemed to be that such attitudes were not worth listening to. For example, one parent commented that her brother was against her giving medication to her child, but that, *'his children are now shop lifting and glue sniffing and God knows what so he's not the person to be giving advice as far as I'm concerned so no we don't listen'* (P.7). Another parent commented on her opinion of an anti-Ritalin campaigner:

'She was the best example that I've ever seen of an undiagnosed, untreated adult ADHD sufferer and she was anti-Ritalin because her daughter had been given it. She interrupted the doctor, she was rude to him... she was ignorant of the research...' (P.12)

To summarise, parents reported a range of attitudes towards medication. For the most part, attitudes to medication were initially negative, with parents having considerable worries and anxiety concerning side effects and potential long-term negative effects of using medication. However, most parents reported more positive attitudes after their child had taken medication. Parents did not tend to view medication as a cure for ADHD, and emphasised that they still had to put hard work into parenting, and other forms of intervention, such as behaviour therapy or educational support. Many parents saw medication as providing *'a window of opportunity'* that makes this work possible.

Children seemed to have largely negative attitudes towards medication. In particular, they saw it as a means of preventing them from "being themselves" and inhibiting their freedom. A minority of children adopted a more positive outlook concerning medication and recognised that it enabled them to have more control over their lives and achieve their goals. Again, there seems to be a dichotomy in the way in which medication is perceived by children – some as a means of obtaining control and enabling them to live a more positive life, and others as a means of preventing them

from having the freedom to "be themselves". It is likely that child medication related behaviour may be heavily mediated by these kinds of attitudes, which in turn may influence treatment outcomes.

Participants reported that they had experienced both positive and negative attitudes from other people, however, it was generally considered that those with negative attitudes towards medication were not worth listening to.

4.5.4 Theme 4: relationships with medical professionals

The overwhelming impression from the interviews was that participants had largely negative relationships with medical professionals. Only two participants reported anything positive concerning their relationship with medical professionals. One reported a trusting relationship with her GP who had initially suggested he would try Ritalin if his child exhibited similar symptoms, and another who said that the psychiatrist had a good manner with her child and helped him to understand the medication.

'Well it was Dr. Smith, she was brilliant. She explained everything to him. She told him that we're going to try these tablets, you know, and we're going to try, because they might make you better, and the way she put it over was lovely.' (P.3)

In contrast, other participants focussed on negative aspects of their relationships with medical professionals and frequently reported disagreements over medication, such as not wanting to give their child drug holidays or decrease the dosage as recommended by doctors. Participants reported that doctors did not want to talk to the child and did not take time to build up any relationship with him/her.

'...some days, you'd turn up for an hour appointment and spend the whole hour finding out how it had gone with school and what had happened there but not once actually directing, directly addressing Mark.' (P.4)

A lack of information concerning the medication and ADHD was reported, and participants felt that their doctors did not have enough awareness concerning ADHD or medication. In particular, participants commented that doctors in America, Australia and South Africa were better at treating ADHD than doctors in the UK.

'They're (British medics) still behind...getting a professional who actually, to understand or help, or even do talks to the groups was absolutely impossible, which is why we ended up doing a massive conference where we brought in American speakers.' (P.8)

Parents tended to concentrate on their relationship with medical professionals, and made minimal mention of the doctor-child relationship. This was also true when talking about adolescent children and young adults. As previously mentioned, one of the critical developmental tasks of adolescence is to achieve autonomy. As such, it would seem sensible to suggest that children and adolescents with ADHD should be encouraged to form relationships with medical professionals and to help make decisions about their own treatment plans.

Current thinking in adolescent medicine suggests that mental health services treating adolescents should shift their focus from relating to the parents of children with health or mental health problems and place emphasis on interacting with the adolescent (Clarke, 1998). Buxton (2002) suggests mental health clinics should take the views of children and adolescents into consideration and encourage staff to develop empathetic communication skills with the children and adolescents themselves. Buxton argues that positive professional-adolescents relationships would boost adolescent help-seeking, clinic attendance and adherence rates.

It seems sensible to propose that doctor-patient relationships have a crucial influence on the medication is perceived by children and their families. In particular, children who have positive relationships with the prescribing doctor may be less likely to see medication as a means of being controlled by an authority figure. In turn, this may influence medication related behaviour, adherence and treatment outcomes. This would seem to be a critical issue in adolescence, when the crucial task of development is to gain autonomy and independence.

4.5.5 Theme 5: adolescence

Adolescence emerged as a critical time for the treatment of ADHD. A variety of experiences with adolescent children were reported. Parents whose children were not yet adolescents expressed concern about what would happen when their child grew up and how they would manage resistant behaviours.

'...he's coming up ten and obviously now...what am I going to do when he's 13 or 14 and he just refuses to take it? If he still feels the way he does now about it, if this carries on. I mean I'm not going to be able to make him take it.' (P.2)

Parents generally reported increased resistance to taking medication in adolescence. Some reported that adolescents came to resent taking medication, and often spat it out or lied about taking it. Several adolescents decided, against the wishes of their parents, to discontinue stimulant treatment, leading to serious problems for the adolescent and their family.

'Everything came crashing down about his ears and our ears didn't it. He got into trouble with the police...He lost his job. He landed a wonderful job, a great opportunity, got in trouble with the police, he didn't know whether he was coming or going, he was just all over the place. He was just a wreck you know, he wasn't functioning properly.' (P.11)

However, withdrawing stimulant treatment did not seem to have negative consequences for all adolescents and young adults. One participant reported that while one of her children with ADHD had stayed on medication because he needed it to cope, that another child was successful without it.

'My son stopped taking medication the day he left school, the day he wrote his last exam and he's not looked back, and he tells me..."Ritalin helped me achieve at school, I don't need it now, but I wouldn't have been able to cope with school without it"' (P.12)

Parents also reported that after the negative consequences experienced when they discontinued medication, some young adults reconsidered their decision.

'I think he'd like to try it (going back on medication) for his own peace of mind to know whether it actually does make a difference, because that was his actual suggestion...I'm sure he probably would take them, because he desperately wants to get his life in order, he was talking about working abroad and things like that' (P.10)

In addition, one young adult, after getting into trouble at work for impulsive and dangerous behaviour when he stopped taking stimulant medication, was asked by

his employer to sign an agreement to take medication during working hours, as his doctor recommended that he would only be safe to work if he had taken medication.

However, not all participants with adolescent children reported such difficulties. Some reported that their children were more aware of the effect of the medication and how it benefited them and that they no longer resisted taking medication and that they wanted help for their difficulties. For example, one participant talking about a teenager commented *'he resisted more when he was younger...now he wants help and tries to do what he is told to do with medication.'* (P.5)

Parents felt it was necessary to give older children a degree of responsibility for taking their medication. One parent suggested that children should start taking medication themselves at the age of 11, so that they would be less likely to refuse to take it as teenagers. Other parents reported that it was necessary to allow their adolescent to stop taking medication, and not interfere with negative consequences, so the child would realise they needed medication for themselves.

'We don't fight any more, we just say, fine its your decision. We didn't argue with him, we had to wait until everything crashed around his ears before we pointed out gently that perhaps this is because...' (P.11)

Other parents reported that ADHD symptoms would mean adolescents would forget to take their medication and felt it was unwise to give them any responsibility over their medication.

The relatively small research literature concerning treatment of ADHD in adolescence highlights discontinuation of medication as a problem in this population (Cromer and Tarnowski, 1989; Garland, 1998; Thiruchelvam, Charach and Schachar, 2001). Literature drawing on clinicians' experiences in treating adolescents with ADHD likewise highlights this as a particular concern in this age group (Garland, 1998b; Stein, Wells & Stephenson, 2001; Weiss et al., 2000b). Stein Wells and Stephenson (2001) describe a typical case of an adolescent, who having been treated with stimulant medication for 5 years, abruptly chooses to stop treatment, resulting in concentration difficulties and academic underperformance.

Weiss et al. (2000b) and Garland (1998b) suggest that discontinuation may be related to a need for autonomy and to adolescent sensitivity towards peer opinions,

not wanting to be different and resenting treatment. Weiss, Jain and Garland (2000b) suggest that adolescents should be given some degree of responsibility to enable them to feel *'psychologically in charge'* (p.721) of their own treatment. Again, the need for adolescents to attain a sense that they are in control seems to be important.

Thiruchelvam et al. (2001) carried out a study looking at moderators of adherence to stimulant treatment in adolescence and found that absence of teacher-rated oppositional defiant disorder, more teacher-rated ADHD symptoms, and younger age when stimulant treatment commenced predicted adherence. However, Thiruchelvam et al. (2001) defined adherence as continuation versus discontinuation of stimulant treatment.

However, the current study highlights a variety of motivations for discontinuation, and suggested that discontinuation of medication was not a negative experience for all participants. Weiss et al. (2000b) suggest that for some adolescents and young adults, cessation of stimulant treatment might represent a new opportunity for them to successfully manage their ADHD symptoms without medication. There seems to be a need to explore the ways in which families with children, particularly adolescents with ADHD, behave and think concerning medication. In particular, whether or not the medication is seen as a means of giving control to the child/adolescent or as a means of controlling the child/adolescent may be critical.

4.5.6 Theme 6: other treatments

Participants reported trying a number of alternative treatments for ADHD including dietary intervention, family therapy, herbal medication (evening primrose oil). Some parents had found that certain foods (e.g. fizzy cola drinks, chocolate, coloured sweets) could lead to hyperactivity, but felt that a very restrictive diet did not help. Only one parent, who had withdrawn stimulant treatment for ADHD from her child, found that her child's ADHD could be successfully controlled by following an organic diet. On the whole, participants viewed medication as the most effective treatment available.

'I know the Ritalin works and the other stuff didn't, and that's it really. It didn't and that one does so you stick with what you know works at the end of the day don't you!' (P.2)

4.6 Conclusions

A wealth of information was obtained from the interview data, revealing parents of children with ADHD to be a heterogenous group with wide-ranging experiences and perceptions concerning stimulant treatment of ADHD. Six main themes emerged from the data, including: the effect of medication, medication related behaviour, attitudes concerning medication, relationships with medical professionals, adolescence and other treatments.

In general, participants perceived the medication as having positive effects. However, side effects were reported. Participants emphasised that medication only targeted the core symptoms of ADHD, and did not treat wider emotional, behavioural and educational difficulties. There seemed to be a subtle difference in the ways in which parents perceived positive effects with some parents viewing medication as a means of increasing the manageability of their child, while others emphasised that it enabled the child to gain more independence. Children with comorbid disorders such as Tourette's syndrome tended to find high doses of some stimulants exacerbated their tics.

Participants reported a wide range of behaviours surrounding the monitoring and implementation of medication regimens. These included checking that the child had taken the medication, timing of the medication, giving drug holidays, communicating with the child concerning medication, dealing with child resistance and parental disagreement over treatment. Again, differences emerged in how parents gave their children medication when the child was not at school. Some parents gave medication when the child was being highly disruptive, while others gave medication to enable them to go out with friends or join sports teams. Again, an over-riding theme concerning controlling the child's behaviour and giving the child greater freedom seemed to emerge. Children were reported to resist taking medication and particular difficulties concerning giving medication at school emerged, such as the school forgetting or not giving the medication at the right time (e.g. after meals rather than before) were apparent. Parents were also concerned that the schools used the medication in order to keep their child quiet rather than addressing their child's educational needs.

Parents reported a range of attitudes concerning medication. In particular, they reported feeling particularly reluctant or fearful concerning medication prior to giving

the child the drugs. However, in general participants were positive about giving the medication to their child and perceived the medication as improving their child's quality of life. Parents emphasised that they did not view medication as being a cure for ADHD, but rather that it enabled them to parent the child and to make use of other treatments, such as behaviour therapy. A minority of participants reported that their child had positive attitudes towards medication as they saw it as enabling them to achieve things that are important to them. Many parents reported that the child viewed the medication as *'making them different'* from other people, or of taking away their enjoyment of life. Again, there seemed to be a difference in the way in which children perceive medication, some appearing to view it as a means of attaining independence, others as a means of other people controlling them. Various attitudes from other people were reported. These were largely positive in nature, and negative attitudes were not considered worth listening to.

Parents reported largely negative relationships with medical professionals, and disagreements concerning medication were commonly reported. Little or no mention was made of the child's relationship to medical staff, which stands in contrast to current recommendations in clinical literature. Improved adolescent-doctor relationships might help to improve help-seeking behaviours and adherence to treatment. This seemed to be a particular problem within this sample.

Adolescence frequently emerged as a critical time period in the treatment of ADHD and one which parents of younger children were particularly concerned about. A diverse range of experiences were reported. Some adolescents chose to discontinue medication. For some, this was a positive experience as they found they were able to cope without it. For others, discontinuation proved to have serious consequences. Some adolescents continued taking medication as they wanted help and believed the medication might help them to achieve goals that were important to them. The current literature in this field is minimal and does not seem to recognise the diversity of experiences of adolescents with ADHD.

Participants also reported trying other treatments for ADHD, such as dietary treatment, family therapy and herbal medication. However, with the exception of only one parent, these were not found to be effective when compared to medication.

4.7 Limitations of the study

4.7.1 Generalisability

Qualitative research is often criticised for its lack of generalisability and its subjectivity (e.g. Malterud, 2001). The results of the current study are specific to the population studied, that is parents of children with ADHD who are taking (or who haven taken) medication in the past and who are actively involved in parent-led support groups. This raises important issues regarding the generalisability of the results. Parents who are part of support groups may be particularly well-informed about ADHD and medication. They may also be representative of parents who are particularly motivated to help their children with ADHD and/or are particularly concerned about their child's ADHD (and thus are keen to seek the support of other parents). Of particular note is the fact that no parents objected to the use of medication on the grounds of principle, and it is unlikely that people with this view would be actively involved in the support groups this study drew its participants from. It is likely that participants who are actively involved in the parent-led support groups have strongly held views about medication, and have influenced the views of other parents within the group. This may not be representative of parents who elect to use medication for their children but who are not activiely involved in local support groups.

Approaches to ADHD treatment vary cross-nationally. For example, British practicioners tend to be more conservative in their prescribing practices than their American counterparts (Bramble, 2003; Wolraich, 2003). The experiences of the participants may be unique to UK parents.

This study only included parents of children with experience of medication for ADHD, not parents who had never used medication. Further research into why some parents of children with ADHD never use medication may identify very different, but important attitudes to ADHD medication. Children and young people were not interviewed as part of this study. It is likely that children, particularly adolescents, have perspectives on ADHD and medication that contrast with those of their parents. Further research, interviewing adolescents with ADHD would therefore be a worthwhile endeavour. However, this is beyond the scope of this thesis, due to practical and ethical considerations.

4.7.2. The role of the interviewer in qualitative research

The role of the interviewer is particularly important in qualitative studies in selecting questions and drawing information out of participants. Consequently, interview data is potentially highly influenced by the researcher's views and biases. In order to address this, the interviewer asked parents to speak as openly and honesty as they could. Experientially, the interviewer found that most participants talked openly and freely and the semi-structured interview schedule (Appendix A) was adhered to very flexibly, suggesting that the interviewing methods enabled participants to share their perspective freely. Inter-rater reliability helps to confirm that the themes emerging from the data were recognisable by people other than the researcher. However, it is a weakness of the current study that participants were not invited to further triangulate the data by offering their perspective on the themes extracted.

A strength of qualitative research is that it allows for the emergence of unexpected ideas and insights from the research participants (e.g. Amber, Adler, Adler & Detzner, 1995; Ambert, 1994). A number of unanticipated themes emerged in the current dataset. Of particular note was the tension between using medication as a means of managing children's behaviour and using medication as a means of enabling children to have independence and maximise their potential. To the author's knowledge, this dichotomy is not discussed in the current literature and had not occurred to the researcher prior to the study.

However, despite these limitations, a wealth of information as to ADHD medication related attitudes and behaviour was obtained through the interviews. The attitudes and behaviours reported in this study extend the current literature on attitudes to medication in ADHD, particularly the literature produced by clinicians in the field (e.g Garland, 1998b; Stein, Wells & Stephenson 2001; Stein, Diller, Resnikoff and Shapiro; Weiss et al., 2000b).

The study identified a number of issues which may be pertinent to ADHD, in particular stigma and the tension between medication as a means of behavioural control versus enabling the child to gain independence would seem to be salient. This lends further justification to the decision to design a measure of parent and child attitudes specific to ADHD rather than using a generic questionnaire such as already established in the literature (e.g Horne, Weinman & Hankins, 1999).

4.8 Research direction

This study identified key ADHD medication related attitudes and behaviours. The next stage of the research is to develop a questionnaire based on these key issues. The next chapter will review the design of a questionnaire based on this study and on the current literature concerning the importance of beliefs, attitudes and behaviours in relation to medication regimens, and specific issues relating to pediatric behaviour and ADHD.

CHAPTER 5

Study 2: The development of the ADHD Medication Related Attitudes and Behaviours questionnaires

This chapter reports on the development of the ADHD Medication Related Attitudes and Behaviours (AMRABs) questionnaires. Two provisional questionnaires (one for parents and one for children) were designed based on the literature and the results of study 1. These provisional questionnaires were piloted with parents of children with ADHD and their children via ADHD support groups in the UK and Republic of Ireland. Additionally, questionnaires were put on the internet and ADHD support group websites were invited to link to the site. The data collected was then analysed using principal components analysis with the aim of developing two concise questionnaires with clear and reliable component structures. The analysis clearly identified four key variables (benefits, costs, stigma and resistance). However, participant feedback suggested that some adjustments were necessary. Finally, the reliability of the scales was examined separately in the internet and support group samples in order to assess the appropriateness of the internet as a means of data collection in this type of research.

5.1 Aims of Study 2

(i) To obtain psychometric data regarding the component structure and reliability of the provisional questionnaires

(ii) To develop a concise questionnaire with reliable psychometric properties which can be used to assess AMRABs, from both parents' and children's perspectives

(iii) To compare data collected via the internet with that collected via traditional methods in order to assess the suitability of the internet as a research tool in the current study

5.2 Method

5.2.1 Provisional questionnaire design

Study 1 (chapter 4) identified some key themes as to parents' ADHD medication related attitudes and behaviours. The provisional questionnaire design (Appendix C) was based on the following broad themes:

- Child resistance to taking medication (questions 1-6)
- Medication as a means of controlling the child (questions 7-12)
- Benefits of taking medication (questions 13-27)
- Costs of taking m
- edication (questions 28-34)
- Child attitudes to medication (questions 35-49)
- Children's relationships with doctors (questions 50-53)
- Parent medication related behaviour, including medication regimen management (questions 54-65)
- Parent medication related behaviour, the use of drug holidays (questions 66-70)
- Stigma associated with taking medication (questions 71-82)
- Issues associated with taking medication in school (questions 83-96)
- Family issues associated with taking medication for ADHD, e.g. differing parental attitudes to ADHD/medication (questions 97-113)
- Parents' relationships with doctors (questions 114-122)

Participants were also asked for their child's gender, child's date of birth, their relationship to the child (i.e. father, mother, foster carer etc.), marital status, family make-up, what medication the child was taking, how long the child had been taking it and if the child had been diagnosed with any comorbid conditions. For ethical reasons, children were not asked what conditions they had been diagnosed with, their parents' relationship with medical professionals and whether or not their condition had put strain on their parents' relationship or played a part in a relationship breakdown.

5.2.2 Participants

Parents of children who were receiving pharmacological treatment for ADHD were invited to participate in a questionnaire study. Parents were provided with a letter outlining the study and explaining that participation was voluntary. Additionally, parents were invited to ask their child to fill out the child questionnaire. Again, it was stressed that this was voluntary and the child questionnaire could be returned blank. Participants were advised that the questionnaire might raise issues around medication that they have not previously thought of, and, if they had any questions they should approach the prescribing doctor. A letter outlining the study to the doctor was provided. Copies of all materials sent to participants are provided in Appendix C. Participants were recruited from three sources: ADHD support groups, a national ADHD conference, and the internet.

A total of 980 questionnaires were sent out via support groups for parents of children with ADHD throughout the UK and the Republic of Ireland. Support group leaders were also asked to be aware that the questionnaire asked about sensitive issues and that some parents may require additional information and support after taking part in the study. 62 parent and 37 child questionnaires were returned in this way. This gives a postal questionnaire response rate of 8.2%. Although very low, this response rate was not surprising. Goyder (1985) reports that the typical response rate for postal surveys is less than 30%. Additionally, the questionnaires were distributed via support group leaders to their groups, rather than individual participants so it is unknown how many questionnaires actually reached individuals. Nevertheless, this response rate is low and it is likely that the sample was biased towards participants who were particularly interested in research about ADHD medication.

The researcher attended the annual ADDISS conference at Liverpool in 2004. ADDISS is a nationwide information and support service in the UK for families and professionals seeking information about ADHD. Parents attending the conference were invited to participate. 18 parents were recruited at the conference. These parents were asked to take a child version of the questionnaire home and return it later. Six child version questionnaires were returned from the conference sample.

5.2.3 Use of the internet to collect data

The use of the internet to collect data holds a number of advantages and disadvantages. Internet mediated research allows large volumes of data to be collected quickly and inexpensively (Gosling, Vazire, Srivastava & John, 2004; Hewson, 2003; Senior & Smith, 1999). Research suggests participants on the internet are more likely to be candid and social desirability effects may be reduced (Joinson, 2001; Joinson, 1999). This may confer a particular advantage in the current study regarding sensitive issues in relation to ADHD medication. Current research suggests that data collected via the internet is comparable to that collected via traditional methods. For example, Buchanan and Smith (1999) found the psychometric properties of a personality profile were comparable between an internet and non-internet sample. Srivastava, John, Gosling and Potter (2003) also found that the effects of age and gender on a big-five personality inventory within an internet dataset were similar to those found in traditionally collected dataset.

However, the socio-demographic characteristics of internet users may result in an inherent bias within internet samples. Internet users are more likely to be technologically proficient, educated, middle-upper class, white and male than the general population (Buchanan & Smith, 1999; Gosling et al., 2004; Hewson, 2003; Smith & Leigh, 1997). This is of concern as children with ADHD are likely to come from lower socio-economic status groups (Biederman et al., 2000a; Counts et al., 2005; Rutter 1985). Additionally, lower socio-economic status has been associated with poorer outcomes to pharmacological treatment (Jensen et al., 1999a).

Although, the internet may fail to reach many families of children with ADHD, it was decided to utilise the internet to ensure a sufficiently large sample size, which allowed for a reliable principal components analysis. Hewson (2003) and Senior & Smith (1999) suggest comparing data collected via the internet with data collected using traditional methods such as postal surveys in order to determine whether the samples are similar on demographic variables and whether the results are consistent across samples. In accordance with this, the two samples will be compared on demographic variables prior to the principal components analysis. The reliability of the scales derived from the principal components analysis will also be examined separately in each sample.

Online ADHD support groups were invited to host a link to an online version of the questionnaire. A total of 64 participants replied via the internet. In order to ensure that children did not access the questionnaire without parental permission, children could only access the questionnaire after the parent version was completed. Parents provided a password which allowed access to the child questionnaire and enabled the researcher to match each child's data to that of their parents. If children did not complete the questionnaire within 24 hours, parents were emailed a reminder providing the web address for the study and reminding them of their password should they wish their child to participate. Only 10 children were recruited via the internet.

5.2.4 Sample characteristics

The overall sample consisted of 135 parents and 58 children.

5.2.4.1 Age and gender of the children

The mean age of the children was 11.52 years (sd = 2.65), ranging from 5.18 to 17.47 years. 81% of the sample were male and 19% female, which is reflective of the 4:1 male: female ratio in ADHD diagnosis (Barkley, 1990).

5.2.4.2 Respondents' relationships to the children

92% of the parent questionnaires were completed by mothers of children with ADHD, 5% by fathers, 1% by grandparents and 1% by foster parents.

5.2.4.3 Marital status of respondents

77% of parent respondents were married, 10% single and 13% were divorced or separated. However, only 54% reported that their child with ADHD lived with both their biological parents, 19% lived with their mother only, 2% with their father only, 22% with mother and step father, 2% with foster parents and 1% with an adoptive family.

5.2.4.4 Medications used by children in the study

Children in the study were taking a variety of medications for ADHD. Most (80.4%) were taking methylphenidate preparations (Ritalin, Concerta, or Equasym); 8% were taking dexamphetamine sulphate (Dexamphetamine); 5% were taking Atomoxetine (Strattera). Some children were taking various combinations of these medications, as displayed in Table 5.1. 63 % parents reported that their children had been taking medication for more than a year; 15% for 6-12 months; 9% for 2-6 months; 9% for 1-3 months and 4% for less than one month. However, numerous participants commented that their child had been on medication for much longer than twelve months, so it is likely that a substantial proportion of children in the sample had been on medication for several years or more.

Table 5.1 Medications that children were taking

Child's Medication	%Participants
Short-acting methlphenidate (e.g. Ritalin)	35.6
Sustained-release methylphenidate	36.4
Dexamphetamine	7.0
Strattera	4.9
Adderall	4.9
Combination of short-acting and sustained-release methylphenidate	10.5
Combination of methylphenidate and dextroamphetamine	2.8

5.2.4.5 Comparison of internet and postal samples

In order to determine the appropriateness of combining the internet and non-internet samples, they were compared on demographic characteristics. An independent t-test did not reveal any significant difference in age between the internet (μ = 11.30 years, sd = 2.53) and postal (μ = 11.70, sd = 2.74) samples (t = .881, df = 133, p = ns). Chi-square analyses showed no difference on child gender, informant, marital status of informant and family make up. The only significant demographic difference between the internet and postal samples was nationality (χ^2= 48.27, df = 8, p<.001). The postal sample was made up almost entirely of participants from the UK and Republic of Ireland. The internet sample contained participants from a variety of countries (Table 5.2). This difference is unsurprising as the internet questionnaire was

available internationally whereas the questionnaires collected by post and at the ADDISS conference were only available in the UK and Republic of Ireland.

As both samples were similar, except on nationality, and a large data set is necessary for an effective and reliable principal components analysis, the data from both samples was pooled for the analysis.

Table 5.2 Percentage of nationalities represented in the postal and internet samples

	% Postal Participants n=75	% Internet Participants n=60
UK	82.5	55.0
Republic of Ireland	16.3	-
South Africa	1.3	-
United States	-	30.0
Australia	-	6.7
Canada	-	3.3
Afghanistan	-	1.7
Germany	-	1.7
New Zealand	-	1.7
Total	**100**	**100**

5.3 Item selection

As the number of items in the questionnaires was large and the sample size relatively small, many items had to be excluded from the analysis. Item selection was based on the following three criteria. First, it was decided only to include questions specifically relating to medication related attitudes and behaviours within a family environment. Second, participant feedback enabled items to be removed if they lacked clarity or sensitivity. Third, the statistical properties of the items and component structure was examined in order to produce a questionnaire with a robust structure and high internal reliability.

5.3.1 Target questions

It was decided to focus solely on questions directly asking about medication within the family environment as this is the focus of the research. Although medication in school, family-doctor relationships and parental agreement/disagreement concerning the use of medication are important issues, they will be beyond the scope of this questionnaire. For this reason items that were not specifically about medication were excluded from the analysis (items 16, 40-41, 48-53, 82-100, 107-122). However, because friendships and stigma are key issues in adolescence, backed up by both the initial interview study and the literature, questions concerning friendships and stigma were retained.

5.3.2 Participant feedback

Feedback from participants was particularly useful in identifying items that lacked clarity or sensitivity. A number of participants, particularly at the ADDISS conference where face to face feedback from individual participants was possible, commented that some items (in particular, 7-12, 57, 59-60, 101-107) caused offence by suggesting that some parents may employ unsuitable practices in administering medication to their children, or that parents would use medication because of the benefits to them rather than to their child. These items were excluded.

5.3.3 Statistical properties

Descriptive statistics were used to identify items that lacked discriminative validity. Prinicipal components analysis was used to identify which items provided a robust component structure with high internal reliability.

5.3.3.1 Discriminative validity

Descriptive statistics for each item on the parent questionnaire were examined and those with variances (items 61 and 64) of less than .5 were excluded on the basis that they lacked discriminative validity (Table 5.3).

Table 5.3 Descriptive Statistics used to examine discriminative validity

Item	Minimum Score	Maximum Score	Variance
1. My child tries to get out of taking their ADHD pills	1	5	1.47
2. I have to make my child take their ADHD pills	1	5	2.16
3. My child pretends to take, hides or spits out their ADHD pills	1	5	.81
4. I always check that my child has swallowed their ADHD pills	1	5	2.69
5. My child doesn't mind taking their ADHD pills	1	5	1.86
6. My child would take their ADHD pills even if I didn't insist on it	1	5	2.35
13. The ADHD pills help my child to do well at things	1	5	1.65
14. The ADHD pills help my child to do things they want to do	1	5	1.62
15. The ADHD pills help my child to behave	1	5	1.48
17. My child is able to be involved in decisions about their ADHD pills	1	5	1.95
18. The ADHD pills help my child to be more like other children	1	5	2.14
19. My child takes ADHD pills so they can spend more time with their friends	1	5	1.91
20. The ADHD pills help my child to pay attention	1	5	1.08
21. The ADHD pills calm my child down	1	5	1.03
22. The ADHD pills help my child to do better at school	1	5	1.19
23. The ADHD pills help my child to be good	1	5	1.70
24. The ADHD pills help my child to get on better with their family	1	5	1.38
25. The ADHD pills help my child to get on better with their friends	1	5	1.51
26. The ADHD pills help my child to think before they act	1	5	1.49
27. The ADHD pills are good for my child	1	5	1.86
42. My child tries to remember to take their ADHD pills	1	5	1.95
43. The ADHD pills help my child to do their best	1	5	1.24
44. My child thinks it is unfair that they have to take ADHD pills	1	5	1.89
45. Taking ADHD pills is no big deal for my child	1	5	1.91
46. If my child didn't take ADHD pills things would be a lot worse	1	5	1.29
47. Taking the ADHD pills doesn't help my child	1	4	.74

54. I forget to give my child their ADHD pills	1	4	.57
55. I forget to give my child their ADHD pills on time	1	4	.67
56. We are very careful about taking the ADHD pills as the doctor has instructed	1	5	2.51
61. My child is able to take their ADHD pills in a way that fits in with what they want to do	1	5	3.23
62. I get confused about what medication my child is to take and when	*1*	2	*.16**
63. My child has a pill box to help us remember what pills they need to take	1	5	1.31
64. I get confused when the doctors change my child's pills	*1*	*3*	*.23**
65. It is easy to remember what ADHD pills my child needs to take	1	5	2.61
66. My child has a break from taking ADHD pills during the school holidays	1	5	2.31
67. My child doesn't take ADHD pills during the weekends	1	5	1.94
68. My child doesn't take ADHD pills in the evenings	1	5	3.56
69. When my child has a break from taking ADHD pills it helps us to see how the ADHD pills help when they do take them	1	5	2.22
70. Not taking ADHD pills over the holidays or weekends helps my child to learn how to cope without them.	1	5	1.73
71. My child's friends do not know that they are taking ADHD pills	1	5	2.03
72. My child finds it easier to get on with their friends when they are taking the ADHD pills	1	5	1.57
73. My child is able to spend more time with their friends because they take their ADHD pills	1	5	2.05
74. My child would be embarrassed if their friends knew that they took ADHD pills	1	5	2.07
75. Other children make fun of my child because they take ADHD pills	1	5	1.47
76. My child's friends like to be with them when they have not taken their ADHD pills	1	5	1.49
77. Other children don't want to be friends with my child because they take ADHD pills	1	5	1.23
78. Other children think my child is mad because they take ADHD pills	1	5	1.53
79. My child feels they taking ADHD pills makes them different from other children	1	5	2.09
80. My child wouldn't want their friends to know about their ADHD pills	1	5	2.29
81. My child's friends help them to remember to take their ADHD pills	1	4	1.26

** Low variance, item excluded*

5.3.3.2 Principal components analysis

The data was analysed using a principal components analysis. Principal components analysis examines a large set of variables and identifies groups of variables which form coherent subsets that are relatively independent of each other. Items were excluded if they did not load on any, or cross-loaded on several, components. In line with Tabachnick and Fidell (2001), items were deemed not to load if the factor loading was less than .32 as this equates to approximately 10% overlapping variance with other items on that component.

Both varimax and direct oblimin rotations were used. Varimax rotation maximises the variance of component loadings by extending the extremes, i.e. high loadings become higher and low loadings become lower for each component (Tabachnick & Fidell, 2001, p595). Direct oblimin rotation is an oblique method of rotation which allows factors to correlate (Costello & Osborne, 2005). This may be particularly useful for the AMRABs questionnaires as the attitudes and behaviours measured are likely to be inter-related. However, both rotation methods produced the same component structure. For ease of presentation only the varimax rotation is presented.

An outline of the various steps involved in excluding items from the analysis is depicted in Figure 5.1.

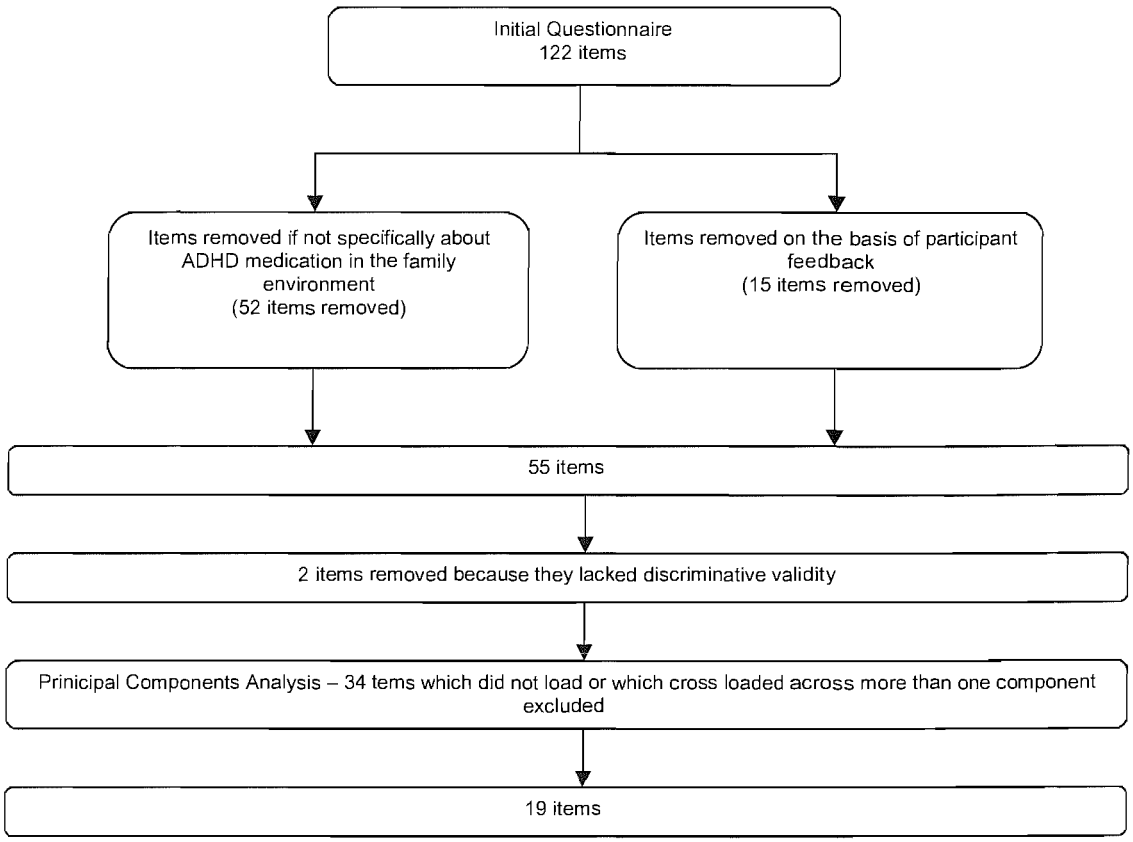


Figure 5.1 Stages involved in excluding items from the original questionnaire

5.4 Component structure of the parent questionnaire

Unfortunately, it was not possible to recruit a larger number of participants for the current study due to practical constraints. Therefore, the initial principal components analysis was carried out on 53 items with ratio of 2.55 participants per item. However, this analysis made it possible to exclude variables which did not appear to be loading or which cross loaded in order to obtain an acceptable principal components analysis. For the parent questionnaire, a six-component structure was obtained on the basis of 19 items (Table 5.4). The scree plot showed discontinuity after five factors. Tabachnick and Fidell (2001) suggest that a minimum of 5 participants per item is necessary for a robust factor analysis. In the current analysis there were 7.1 participants per item, which was deemed acceptable. Additionally, Tabachnick and Fidell (2001) recommend that the Kaiser measure of sampling adequacy should be above .6 and the Bartlett's test

of sphericity be significant. In this analysis the Kaiser measure of sampling adequacy was .652 and the Bartlett's test of sphericity was significant (χ^2= 823.23 df = 171, p<.001), indicating that the principal components analysis was appropriate.

In order to be considered clearly identifiable as a component, components had to have an Eigenvalue of 1.0 or greater. Five components were clearly identifiable:

(i) benefits of medication
(ii) costs of taking medication
(iii) resistance to taking medication
(iv) stigma
(v) drug holidays

However, the drug holiday items were less clear than the other four factors, and two items are not sufficient to form a reliable and robust factor. It was decided to reword these questions in future versions of the questionnaire.

A sixth factor was hinted at in the analysis, namely parents forgetting to give medication. This had an eigenvalue of 1.0, but was based on only one question. This may be reflective of parents' competence in administering medication. It was decided to devise a more suitable scale to assess parental competence in administering medication.

Alpha values for each of the five components were above .7 and therefore considered reliable.

5.5 Component structure of the child questionnaire

In order to develop a comparable questionnaire for children, the equivalent items from the parent questionnaire were used in the analysis of the child questionnaire, with the exception of the items loading on the flexibility and forgetting factors which were excluded.

Principal components analysis with varimax rotation on sixteen items from the child questionnaire yielded a similar structure to the analysis of the parent questionnaire. Four clear factors were identifiable with eigenvalues of greater than 1.0. The scree plot also indicated a 4-factor solution. Despite the small number of child participants (3.4 participants per item) the Kaisser normalisation (.590) was just under Tabachnick and Fidell's (2001) suggested acceptable level. The Bartlett's test of sphericity was significant (χ^2= 372.99, df=120, p<.001). As the factor structure was similar to the parent questionnaire, and the alpha values were above .7, it was felt that the components were accepted as reliable (Table 5.5).

Table 5.4 Component structure for the Parent ADHD Medication Questionnaire

	Stigma	Costs	Benefits	Resistance	Drug Holidays	Competence
75. Other children make fun of my child because they take ADHD pills	**.802**	.081	-.159	-.059	.055	.091
77. Other children don't want to be friends with my child because they take ADHD pills	**.806**	-.028	-.006	.135	-.078	.103
78. Other children think my child is mad because they take ADHD pills	**.858**	.039	-.238	.040	.064	-.077
79. My child feels taking ADHD pills makes them different from other children	**.748**	.247	-.010	.156	-.032	-.221
29. The ADHD pills take away my child's personality	.198	**.791**	-.082	.019	.144	-.071
30. The ADHD pills stop my child from doing things they want to do	.055	**.659**	-.068	.206	.136	-.172
31. The ADHD pills make my child "dazed" or "spaced-out"	.007	**.805**	-.080	.095	-.130	.237
32. The ADHD pills have a bad effect on my child	.027	**.824**	-.133	.006	.107	-.008
22. The ADHD pills help my child to do better at school	-.131	-.044	**.763**	-.052	.114	.163
23. The ADHD pills help my child to be good	-.105	-.095	**.728**	-.130	-.031	-.142
24. The ADHD pills help my child to get on better with their family	-.098	-.127	**.794**	-.113	-.075	-.038
25. The ADHD pills help my child to get on better with their friends	-.041	-.078	**.810**	-.062	-.134	-.091
1. My child tries to get out of taking their ADHD pills	.118	-.059	-.172	**.873**	.007	.064
2. I have to make my child take their ADHD pills	.132	-.008	-.198	**.840**	.060	.043
3. My child pretends to take, hides or spits out their ADHD pills	.122	.270	.046	**.673**	-.099	.079
6. My child would take their ADHD pills even if I didn't insist on it	.097	-.128	.057	**-.684**	.072	.132
66. My child has a break from taking ADHD pills during the school holidays	-.039	.176	-.008	-.028	**.890**	.167
67. My child doesn't take ADHD pills during the weekends	.038	.049	-.096	-.064	**.917**	.013
55. I forget to give my child their ADHD pills on time	-.026	-.020	-.096	.030	.163	**.914**
Eigenvalue	**4.36**	**2.33**	**2.22**	**2.03**	**1.54**	**1.00**
% variance explained	**22.96**	**12.28**	**11.37**	**10.68**	**8.10**	**5.12**
Correlation with stigma		.20*	-.22*	.18	.04	
Correlation with costs			-.15	.20*	.11	
Correlation with benefits				.18*	-.20	
Correlation with resistance					-.05	
ALPHA	**.84**	**.80**	**.79**	**.75**	**.80**	**--**

* Correlation is significant at the .5 level

KMO Measure of Sampling Adequacy: .652

Bartlett's Test of Sphericity Approx Chi Square: 823.232, df=171, p< .001

Table 5.5 Component structure for the Child ADHD Medication Questionnaire

	Benefits	Costs	Stigma	Resistance
22. The ADHD pills help me to do better at school	**.704**	-.016	-.190	-.431
23. The ADHD pills help me to be good	**.827**	.017	-.177	-.180
24. The ADHD pills help me to get on better with my family	**.892**	-.037	.156	.053
25. The ADHD pills help me to get on better with my friends	**.833**	-.242	.121	-.105
29. The ADHD pills stop me from being myself	-.208	**.797**	-.074	-.046
30. The ADHD pills stop me from doing things I want to do	-.040	**.739**	.334	-.003
31. The ADHD pills make me feel "dazed" or "spaced out"	-.009	**.786**	-.226	.022
32. The ADHD pills have a bad effect on me	-.036	**.755**	.035	.203
75. Other children make fun of me because I have to take ADHD pills	.134	-.011	**.868**	-.059
77. Other children don't want to be my friends because I take ADHD pills	-.036	-.098	**.651**	.173
78. Other children think I am mad because I take ADHD pills	-.180	.012	**.862**	.098
79. Taking ADHD pills makes me different from other children	.113	.454	**.562**	.014
1. I try to get out of taking my ADHD pills	-.117	.234	.138	**.774**
2. My parents have to make me take my ADHD pills	-.063	.010	.113	**.711**
3. I pretend to take, hide or spit out my ADHD pills	-.069	-.138	-.003	**.724**
6. I would take my ADHD pills even if my parents didn't make me.	.124	-.111	.025	**-.690**
Eigenvalue	**3.85**	**2.56**	**2.43**	**1.68**
% Variance Explained	**24.04**	**16.00**	**15.19**	**10.51**
Correlation with Benefits		-.177	-.027	-.253
Correlation with Costs			.114	.165
Correlation with Stigma				.152
ALPHA	**.867**	**.761**	**.750**	**.734**
KMO Measure of Sampling Adequacy:	.590			
Bartlett's Test of SphericityApprox Chi Square:	372.986, df=120, p< .001			

5.6 Provisional AMRABs subscales

Parent and child-report benefits, costs, resistance and stigma were calculated by adding together the respective items from the questionnaires. Item 6 from the resistance score was reversed coded for both parent and child-report resistance. A total score of between 4 and 20 was obtained for each subscale (Table 5.6). It is important to note that the means for parent and child-report benefits are well above the mid-point on the 4-20 scale, while the means for parent and child-report costs, resistance and stigma were well below it. This suggests that participants in this sample are generally positive about medication, perceiving high levels of benefits and low levels of costs, resistance and stigma.

Table 5.6 Medication Related Behaviour and Attitudes Questionnaires Descriptive Statistics

	Mean	SD
Parent-report benefits	14.51	2.95
Child-report benefits	15.16	3.58
Parent-report costs	6.81	3.87
Child-report costs	7.04	3.35
Parent-report resistance	10.17	3.87
Child-report resistance	10.05	3.95
Parent-reported stigma	8.61	3.85
Child-report stigma	8.54	4.08

5.7 Comparison between internet and non-internet data

Participants who took part via support groups (parent n = 75; child n = 50) and participants recruited online (parent n = 60; child n = 8) were compared on both parent and child-report AMRABs. Descriptive statistics are reported in Table 5.7. A MANOVA did not find any significant difference on parent-report AMRABs (Table 5.8). However a similar MANOVA found a trend (p = .10) for children who took part via the internet to report lower levels of stigma than children who took part through support groups (Table 5.9).

Separate principal components analyses were not carried out because the smaller sample sizes would render it unreliable. However, analyses using Cronbach's alpha found comparable values for all scales within the parent questionnaires in both

samples. Cronbach's alpha was slightly lower for the child-report sub-scales in the internet sample, but this is likely to be due to the smaller number of participants (n = 8) (Table 5.10).

Table 5.7 Descriptive statistics for parent and child-report AMRABs between the support group and internet participants

	Mean (Postal Sample)	Mean (Internet Sample)
Parent-report benefits	14.89 (2.84)	14.04 (3.04)
Parent-report costs	7.00 (3.15)	6.59 (2.85)
Parent-report stigma	8.87 (3.72)	8.28 (4.02)
Parent-report resistance	10.43 (3.77)	9.85 (4.01)
Child-report benefits	15.31 (3.58)	14.25 (3.69)
Child-report costs	7.14 (3.45)	6.38 (2.88)
Child-report stigma	8.88 (4.17)	6.29 (2.69)
Child-report resistance	10.26 (4.08)	8.75 (2.92)

Numbers in parentheses represent standard deviations

Table 5.8 MANOVA examining differences between parent-report AMRABs scores between support group and internet participants

Source	Type III Sum of Squares	Df	F
Between Subjects			
Factor			
Source (Support group or internet)			
Multivariate λ = .95			
Parent-report benefits	11.46	1	1.32
Parent-report costs	7.03	1	.76
Parent-report stigma	12.53	1	.82
Parent-report resistance	13.26	1	.87
Error			
Parent-report benefits	920.85	107	(8.61)
Parent-report costs	993.53	107	(9.29)
Parent-report stigma	1631.66	107	(15.25)
Parent-report resistance	1628.06	107	(15.22)

Values enclosed in parentheses represent mean square errors

*p<.05 **p<.01 ***p<.001

Table 5.9 MANOVA examining differences between child-report AMRABs scores between support group and internet participants

Source	Type III Sum of Squares	Df	F
Between Subjects			
Factor			
Source (Support group or internet)			
Multivariate λ = .92			
Child-report benefits	.03	1	.00
Child-report costs	3.27	1	.28
Child-report stigma	44.98	1	2.70(*)
Child-report resistance	19.13	1	1.28
Error			
Child-report benefits	585.93	47	(12.47)
Child-report costs	559.55	47	(11.91)
Child-report stigma	784.41	47	(16.69)
Child-report resistance	704.79	47	(15.00)

Values enclosed in parentheses represent mean square errors

(*) p <.10 *p<.05 **p<.01 ***p<.001

Table 5.10 Reliability analysis within the internet and support group samples

	Alpha (Internet sample)	Alpha (Support group sample)
Parent-report benefits	.82	.76
Parent-report costs	.81	.78
Parent-report resistance	.89	.80
Parent-report stigma	.79	.72
Parent-report drug holidays	.90	.74
Child-report benefits	.83	.74
Child-report costs	.65	.88
Child-report resistance	.68	.78
Child-report stigma	.64	.74

5.8 Discussion

5.8.1 Further consideration of the preliminary questionnaires

After piloting, four key components (benefits, costs, resistance and stigma) emerged in both the parent and child preliminary questionnaires. These components were clearly distinguishable using a principal components analysis with varimax rotation. The components showed high internal reliability. The analysis of the parent questionnaires suggested two additional factors: flexibility in administering the medication and competence in administering the medication regimen. However, further development and piloting is necessary to assess the psychometric properties of these scales.

Participant feedback suggested that the Likert scale (never, seldom, sometimes, often, always) was confusing, as most items were more attitudinal than behavioural. Therefore, it was decided that this scale would be revised in future versions of the questionnaires to measure the extent of participants' agreement/disagreement with the various items.

The questionnaires have a number of notable gaps. Disappointingly, they do not distinguish between participants (parent or child) who perceive the medication as a means of gaining independence and those who perceive it as a means of managing behaviour. Participant feedback suggested that the items originally designed to assess these issues caused offence to participants. It is possible that questionnaire measures are not able to tap into subtle differences in parental motivations as the qualitative methodology utilised in study 1 allowed.

The sample used was a convenience sample of volunteers who took part in parent support groups, attended conferences on ADHD or who were motivated to complete a relatively long questionnaire about ADHD on the internet. It would seem likely that this particular group of participants were uniquely motivated to take part in the study. Most of the support groups who distributed the questionnaire amongst their members and the websites who hosted the questionnaire were active supporters of medication. Some of the groups, (e.g. ADDISS) are actively involved in raising awareness of ADHD and the effectiveness of medication to the general public. This political aim is likely to attract parents who have positive experiences of medication and who are willing to use medication to treat their child's ADHD in the long-term. Indeed, 62% of the sample had been taking medication for more than a year and numerous participants commented

that they had been on medication considerably longer than this. Therefore, caution is necessary when interpreting the results of this study as participants may not be representative of all families of children who have ADHD. Future studies should attempt to address this by recruiting participants from ADHD clinics.

5.9 Further development of the AMRABs questionnaires

Once the components of the questionnaires had been identified, several items were added to the provisional parent questionnaire. The final items for the questionnaire were made up of the components for benefits, costs, resistance and stigma, and the additional items as follows:

5.9.1 Benefits

Three of the items on the benefits scale were left as they were. However, the item, *"The ADHD pills help my child to be good"* was reworded to "*The ADHD pills help me to manage my child's behaviour."* This was decided because several participants commented that they did not see their child as being more good on medication, the implication being that the child was naughty when they were not taking medication, but that it did help to make their child more manageable.

5.9.2 Costs

The items for the cost scale were left as they were.

5.9.3 Resistance

The resistance scale was left exactly as it was.

5.9.4 Stigma

Three of the items for the 'stigma' scale were left as they were. However item 78 was changed from *"Other children think my child is mad because they take ADHD pills*" to *"Other children think my child is crazy because they take ADHD pills".* The respective question was also changed on the child-report questionnaire. Participant feedback highlighted that the word "mad" denotes anger in America, whereas in the UK it denotes mental health difficulties.

5.9.5 Flexibility

Two questions about drug holidays were combined into one overall question (*"I give my child a break from taking the ADHD pills during the weekends and/or school holidays"*). Two additional questions (*"I sometimes will give my child a pill in the evenings or weekends if I think they need it"* and *"I think it is beneficial to be flexible as regards giving pills to my child"*) to assess flexibility were also added.

5.9.6 Competence in administering medication regimen

The items in the original questionnaire (items 54, 55, 62, 64, 65) that were designed to assess competence in administering the medication regimen were not included in the analysis because their variance was very low (<.5), or because they did not load on the component structure. Additionally, participant feedback suggested that the items had caused some offence in suggesting that parents were ineffective in administering the regimen.

The items were reworded to assess how difficult parents found following the medication regimen, rather than asking directly whether or not they forget to give medication. Three items (*"Sometimes it is difficult to remember to give my child their ADHD pills on time"; "Sometimes it is difficult to remember whether or not my child has taken their ADHD pills"* and *"Sometimes it is difficult to remember what dose my child is on"*) were added with the aim of assessing competence in administering the medication regimen.

5.9.7 Parental stigma

It was noted that all the items in the stigma scale related to stigma experienced by the child rather than the parent. Participant feedback suggested that parents might experience stigma associated with having a child who takes medication for ADHD. Parents of children with mental health difficulties often face stigmatising attitudes from professionals, wider family and friendship networks and the media (Corrigan & Miller, 2004; Hinshaw, 2005; Hinshaw & Cicchetti, 2000; Wahl, 1995; Wahl, 1999; Wahl & Harman, 1989; Wahl, Warn & Richards, 2002). Media portrayals of mental illness typically include violent characters, both the US (Diefenbach, 1997) and the UK (Rose, 1998). Children's media is no exception, with characters with mental illness portrayed

as frightening and violent (Coverdale & Nairn, 2000; Wahl., Wood, Zaveri, Drapalski & Mann, 2003; Wilson, Nairn, Coverdale & Panapa, 2000).

Goffman (1963) described the phenomenon of 'courtesy stigma' as a form of social disapproval for family members associated with a stigmatised individual, (e.g. the wife of a prison inmate). In families where a child has a mental disorder, parents may be stigmatised, particularly in the light of a cultural tendency to blame parents as causing their child's difficulties (Hinshaw, 2005). Parents of children with ADHD often perceive that parents of children without ADHD hold harsh views of the disorder and feelings of stigmatisation associated with having a child with ADHD (Norvitilis, Scime & Lee, 2002). Parental stigma may represent a significant obstacle to families' willingness to seek help for their children's difficulties (Hinshaw, 2005).

It was decided to broaden the questionnaire and assess parents' sense of stigma around giving ADHD medication to their child. To this end, five items were developed to assess parental stigma. These items were:

- *I feel embarrassed if people know my child takes ADHD pills*
- *I sometimes worry that giving ADHD pills to children is not right*
- *I am confident that ADHD pills are right for my child*
- *The fact that my child is taking ADHD pills sometimes makes me question whether I am a good parent*
- *I am concerned that other people think I am a bad parent because my child takes ADHD pills*

5.9.8 Development of the child questionnaire

The items for each scale of the child questionnaire were kept as identical to the original list. No additional items were added.

5.10 Discussion: comparison of data collected via the internet with data collected via support groups

Data collected via the internet was comparable with that collected via ADHD support groups on both demographic variables (with the unsurprising exception of nationality). Participants in each sample scored similarly on the preliminary AMRABs scales, with the exception of child-report stigma.

It is notable that significantly fewer children took part online than took part via support groups. It may be that many children do not have the technical ability required to complete an online questionnaire. Additionally, child-report stigma was lower in the internet sample. Children who experienced higher levels of stigma may have been less willing to take part in an internet survey. This potential response bias in the internet sample is important to consider.

Nevertheless, it seems that parent-report AMRABs data gathered via the internet is comparable with data collected via postal questionnaires. The internet may represent an opportunity to collect a large amount of data to confirm the component structure of the revised AMRABs questionnaires. However, care should be taken to consider a potential selection bias in child-report data obtained via the internet.

5.11 Conclusions

The primary aim of this study was to develop concise questionnaires with reliable psychometric properties which can be used to assess parents' and children's AMRABs in future studies. This aim was achieved and the revised AMRABs questionnaires (Appendix C.4) were developed. The revised questionnaires need to be piloted and their psychometric properties assessed in order to confirm the integrity of their component structures and the internal reliability of their components.

One of the unique features of this study was the use of the internet to recruit parents of children with ADHD. Data from the internet sample was comparable with data collected via support groups. This suggests that the internet is a reliable and convenient way to recruit a large sample that allows for appropriate analyses of the data's component structure and reliability.

However, it is important to note that one of the limitations of this study is that the participants were from a convenience sample of parents who are active members of ADHD support groups and/or motivated to seek out information and engage in discussion about ADHD on the internet. It would seem likely that this particular group of participants were uniquely motivated and interested in ADHD medication. 62% of the participants reported being on medication for over one year. It is therefore likely that a large proportion of this sample were long-term adherers to medication. This sample may not be representative of all families of children with ADHD. While this is less of a

problem for assessing the component structure of the questionnaires, future studies should aim to include participants from other sources, .e.g. ADHD clinics in order to obtain a more representative sample. The small number of participants to items ratio in the preliminary principal components analysis is a significant limitation of the current study. Had a larger number of participants been recruited it may have been possible to obtain a different factor structure and perhaps examine more subtle differences in the way parents perceive the benefits and costs of medication (e.g. the tension between management and giving independence identified in study 1). Nevertheless, it was possible to identify key components in the current questionnaires and obtain participant feedback regarding the clarity of the questions in order to produce a revised version of the questionnaire for re-piloting.

The next study will test the revised AMRABs questionnaires. The internet will be used as the current study suggests that it is a reliable way of collecting a large amount of data. However, participants will also be recruited via ADHD clinics with the aim of reducing the selection bias inherent in recruiting via the internet and support groups.

Chapter 6

Study 3a - Psychometric properties of the AMRABs questionnaires

This chapter reports psychometric data regarding the component structure and internal reliability of the AMRABs questionnaires as developed in chapter 5 (Appendix C.4). Analyses to assess the suitability of combining participants from the internet, support groups and ADHD clinics in the future research studies are carried out.

6.1 Study aims

The aims of this study are:

(i) To obtain psychometric data regarding the component structure and reliability of the AMRABs questionnaires in order to confirm their suitability to use in further research

(ii) To explore differences between data collected though ADHD clinics, support groups and the internet, in order to examine whether data is comparable from each of these groups

6.2 Questionnaire design

The demographic questions were the same as the initial questionnaires, except that a more comprehensive list of medications was included and parents were asked if their child was given medication in school. In addition, the questionnaires as developed in chapter 5 were used to assess parents' and children's attitudes and behaviours in relation to ADHD medication. As with the previous study, participants were provided with a covering letter and a letter to give to their doctor should they have any questions following the study. A complete set of the materials used for this study are included in Appendix C.

6.3 Participant recruitment

Participants were recruited from four sources. First, participants who took part in study 2 and who had given permission for further contact were invited to complete

the revised questionnaires. Second, local ADHD clinics in the Hampshire area of the UK distributed questionnaires amongst patients. Third, questionnaires were distributed at an ADHD clinic in New York (USA). Fourth, a concerted effort was made to recruit participants via the internet.

ADHD support groups on the internet were invited to post a link to an online version of the questionnaire. Owners of electronic mailing lists relating to ADHD on 'Yahoo', 'AOL' and 'MSN' were contacted and asked if they would forward an invitation to their list to take part in the study. As with study 2, parents provided a password, which allowed their data to be matched with that of their child. If children did not complete the questionnaire within 24 hours, parents were emailed a reminder providing the web address for the study and reminding them of their password should they wish their child to participate. As so few children participated online in study 2, parents were also emailed one week later in an attempt to increase participation from children.

Altogether, 360 parent questionnaires were completed. A total of 29 participants came from UK clinics; 13 from the USA clinic, 278 from the internet and 34 from support groups. In addition, some participants from support groups offered to forward copies of the questionnaire to other members. This was welcomed, and 11 questionnaires were collected in this way.

A total of 123 questionnaires were collected from children. Of these, 27 were from the UK clinic, 13 from the USA ADHD clinic, 47 from the internet, 26 from previous participants who had taken part via support groups and 10 were collected via word-of-mouth amongst support group participants.

6.4 Sample characteristics

The overall sample consisted of 365 parents and 123 children who completed questionnaires.

6.4.1 Age and gender of the children

The mean age of the children was 10.95 years (SD=2.98 years), ranging from 5.46 to 17.94 years. 79% of the sample was male and 21% female, which is reflective of the 4:1 male:female ratio in ADHD diagnosis (Barkley, 1990).

6.4.2 Respondents' relationships to the children

93% of the parent questionnaires were completed by mothers of children with ADHD, 5% by fathers, 2% by grandparents or foster parents.

6.4.3 Marital status of the respondents

73% of parent respondents were married, 11% single and 16% were divorced or separated.

6.4.4 Medication used by children in the study

Children's medication regimens were classified as: short acting methylphenidate (Ritalin or Focalin); sustained release methylphenidate (Concerta, Ritalin XR, Ritalin LA or Metadate CD); Dextroamphetamine; Adderall; Atomoxetine (Strattera) or a combination of these as displayed in Table 6.1. 4% parents reported that their children had been taking medication for less than one month; 12% for 1-6 months; 12% for 6-12 months, 20% for 1-2 years, 24% for 2-4 years and 28% for more than four years. It is notable that the majority of the current sample consists of children who have been taking medication for several years.

6.4.5 Sample characteristics: comparisons between participants from the internet, support groups and ADHD clinics

In order to confirm that it was appropriate to combine data from the four sources (UK ADHD clinics, US ADHD clinics, internet and support group), the groups were compared on demographic variables. An ANOVA revealed differences in age between the three groups ($F_{3,369} = 6.56$, $p<.001$) (Table 6.2). Post-hoc analysis using Bonferroni correction showed that children from the internet were younger than children from the UK clinics and support group. Although the difference was not statistically significant, children from ADHD clinics in the UK were also older than children from the USA clinic. Given the small number of participants from the clinic samples, it is important to consider the impact of age on the analyses.

Table 6.1 Medications that children were taking

MEDICATION	% Cases
Short acting methylphenidate (Ritalin, Focalin)	14.9
Sustained release methylphenidate (Concerta, Ritalin XR, Ritalin LA, Metadate CD)	36.9
Adderall	14.6
Atomoxetine (Strattera)	8.0
Dexamphetamine	2.1
Combination of short acting methylphenidate and sustained release methylphenidate	9.2
Combination of methylphenidate and adderall	4.2
Combination of methylphenidate and atomoxetine	7.9
Combination of methylphenidate and dextroamphetamine	.3
Combination of adderall and atomoxetine	.9
Combination of dextroamphetamine and adderall	.3
Combination of dextroamphetamine and atomoxetine	.3
Combination of methylphenidate, adderall and atomoxetine	.6

Table 6.2 Mean age of children from ADHD clinics, internet and support group samples

	Mean age (Years)	Standard Deviation
UK Clinics	12.43	2.32
USA Clinics	10.58	2.15
Internet	10.57	2.81
Support Group	12.21	2.81

Chi square analyses showed no difference on child gender (χ^2= 8.19, df = 3, p = ns), informant (χ^2= 2.27, df = 6, p = ns), or marital status of informant (χ^2= 7.18, df = 6, p = ns). Unsurprisingly, there were differences in the nationalities of the samples (χ^2= 144.98, df = 30 p <.001). The UK and the USA ADHD clinics only contained participants from their respective countries. The internet sample contained many diverse nationalities and the support group sample contained participants from the UK and Republic of Ireland. Table 6.3 displays the number of participants from each country from each of the four groups of participants.

The data from all four samples was pooled in order to produce a large principal components analysis.

Table 6.3 Percentage of nationalities represented in the internet, ADHD clinic and support group samples

	% UK ADHD Clinic Participants n=29	% USA ADHD Clinic Participants n=13	% Internet Participants n=278	% Support Group Participants n=36
UK	100	--	31.5	--
United States	--	100	59.8	76.6
Canada	--	--	3.6	--
Germany	--	--	1.1	--
Australia	--	--	1.1	--
Israel	--	--	.7	--
Singapore	--	--	.7	--
Republic of Ireland	--	--	.4	23.4
South Africa	--	--	.4	--
Brazil	--	--	.4	--
Malaysia	--	--	.4	--
Total	**100**	**100**	**100**	**100**

6.5 Results

6.5.1 Principal components analysis of the revised AMRABs questionnaires

Principal components analyses with varimax and direct oblimin rotations were carried out in order to identify recognisable components within the parent and child questionnaires. Both methods of rotation yielded the same factor structure, but for ease of presentation only the varimax rotation is presented.

Seven components in the parent questionnaire had Eigenvalues of above 1.0 and the scree plot also showed discontinuation after seven components. The relevant item loadings on each component were .4 or greater (Table 6.4). The components were identified as benefits of taking medication; costs associated with taking medication;

child stigma associated with taking medication; parental stigma associated with taking medication; child resistance to taking medication; flexibility in using medication; and competence in using medication. Alpha analyses showed satisfactory internal reliability (α >.7) for all components except competence in using medication, which had an alpha of .67. However, as competence was assessed using only three items, this slightly low alpha is not surprising. It was decided to keep competence as a component in future analyses.

Four components were identifiable in the child questionnaire. Each had Eigenvalues of 1.0 or above. The scree plot also showed continuation after four components. The relevant item loadings on each component were .4 or greater (Table 6.5). The components were identified as benefits associated with taking medication; costs associated with taking medication, stigma associated with taking medication and resistance to taking medication. Alpha analyses of internal reliability were all above .7.

Additionally, informal feedback from clinicians and established researchers in the field of ADHD confirmed the credibility and face validity of the component structure and the assigned labels.

Table 6.4 Principal components analysis of the revised parent AMRABs questionnaire

	Costs	Flexibility	Resistance	Benefits	Child Stigma	Parental Stigma	Competence
3. The ADHD pills stop my child from doing what they want to do	**.702**	-.014	.129	-.105	.200	-.013	.051
11. The ADHD pills take away my child's personality	**.792**	.179	.117	-.144	.111	.224	.032
15. The ADHD pills make my child "dazed" or "spaced out"	**.810**	.108	.109	-.200	.100	.175	.088
26. The ADHD pills have a bad effect on my child	**.638**	.048	.238	-.303	.140	.290	.044
4. I vary the dose/timing of the medication if I think my child needs it (e.g. giving medication at the weekends if the child wants to do an activity, where it is better for them to be on medication)	.028	**.791**	.126	.191	.094	.035	-.005
12. I think it is good to be flexible regarding giving pills to my child	-.027	**.710**	-.052	.043	.055	.081	.066
27. I sometimes will give less medication if I think my child doesn't need it (e.g. giving less medication during the school holidays)	.156	**.845**	-.041	.061	.034	.085	.025
29. I give my child a break from taking ADHD pills during the weekends and/or school holidays	.102	**.831**	-.035	-.131	-.008	.123	-.024
7. I have to make my child take their ADHD pills	.009	.003	**.846**	-.036	.086	-.036	.133
13. My child would take their ADHD pills even if I didn't insist on it	-.062	.065	**-.776**	.073	.036	-.115	.191
19. My child pretends to take, hides or spits out their ADHD pills	.238	-.018	**.653**	.018	.122	.053	.194
23. My child tries to get out of taking their ADHD pills	.218	.064	**.834**	.022	.182	.114	.140
1. The ADHD pills help my child to do better at school	-.259	.166	-.108	**.640**	-.255	-.167	-.178
5. The ADHD pills help my child to get on better with their family	-.256	-.029	-.009	**.801**	.021	-.124	-.046
16. The ADHD pills help me to manage my child's behaviour	.008	.001	.032	**.812**	.000	.046	.050
32. The ADHD pills help my child to get on better with their friends	-.188	.102	-.030	**.811**	-.057	-.067	-.089
2. Other children make fun of my child because they take ADHD pills	.062	.012	.039	-.049	**.834**	.050	.100
18. Other children don't want to be friends with my child because they take ADHD pills	.127	.051	.001	-.151	**.818**	.158	.136
22. My child feels that taking ADHD pills makes them different from other children	.220	.112	.252	.029	**.540**	.220	.023
25. Other children think my child is crazy because they take ADHD pills	.161	.061	.141	-.007	**.787**	.187	.169
10. The fact that my child is taking ADHD pills makes me sometimes question whether I am a good parent	.137	.012	.063	-.042	.216	**.754**	.045

14. I sometimes worry that giving ADHD pills to children is not right	.317	.123	.097	-.219	.121	**.625**	-.168
20. I am concerned that people think I am a bad parent because my child takes ADHD pills	.013	.054	.028	.032	.187	**.813**	.053
30. I feel embarrassed if people know my child takes ADHD pills.	.145	.211	.062	-.095	.015	**.651**	.136
8. Sometimes it is difficult to remember whether or not my child has taken their ADHD pills	.037	.004	.052	-.060	.215	-.061	**.764**
28. Sometimes it is difficult to remember to give my child their ADHD pills on time	-.085	.133	.129	-.041	.055	.116	**.787**
31. Sometimes it is difficult to remember what dose my child is on	.209	-.058	.031	-.055	.093	.064	**.701**
Eigenvalue	**6.34**	**2.95**	**2.49**	**2.05**	**1.70**	**1.30**	**1.15**
% Variance Explained	**23.47**	**10.93**	**9.21**	**7.50**	**6.31**	**4.82**	**4.28**
Correlation with costs		.212**	.351**	-.439**	.404**	.453**	.177**
Correlation with flexibility			.025	.069	.155**	.223**	.086
Correlation with resistance				-.110*	.300**	.184*	.188*
Correlation with benefits					-.192**	-.234**	-.151**
Correlation with child stigma						.392**	.309*
Correlation with parent stigma							.134*
ALPHA	**.830**	**.824**	**.817**	**.814**	**.793**	**.752**	**.670**

**Correlation is significant at the .01 level; *Correlation is significant at the .5 level

KMO = .818, Bartlett's Test of Sphericity: Chi-Square = 3113.42, df=351, p<.001

Table 6.5 Principal components analysis of the revised child AMRABs questionnaire

	Stigma	Benefits	Costs	Resistance
2. Other children make fun of me because I take ADHD pills	**.853**	.021	.087	.082
5. Taking ADHD pills makes me different from other children	**.585**	-.020	.343	.177
12. Other children think I am crazy because I take ADHD pills	**.860**	-.036	.165	.069
14. Other children don't want to be friends with me because I take ADHD pills	**.770**	.097	.096	.069
1. The ADHD pills help me to do better at school	-.091	**.744**	-.052	-.168
7. The ADHD pills help me to get on better with my family	.134	**.775**	-.106	-.130
9. The ADHD pills help me to be good	.071	**.810**	.006	.054
13. The ADHD pills help me to get on better with my friends	-.051	**.831**	-.172	.009
3. The ADHD pills have a bad effect on me	-.037	-.119	**.799**	.177
6. The ADHD pills make me feel "dazed" or "spaced out"	.191	.031	**.739**	.004
10. The ADHD pills stop me from doing what I want to do	.225	-.130	**.613**	.264
15. The ADHD pills take away my personality	.287	-.175	**.692**	.148
4. I try to get out of taking my ADHD pills	.182	.052	.279	**.791**
8. My parents have to make me take my ADHD pills	.132	.036	.016	**.847**
11. I pretend to take, hide or spit out my ADHD pills	.150	-.172	.110	**.661**
16. I would take my ADHD pills even if my parents didn't insist on it	.260	.300	-.289	**-.552**
Eigenvalue	**4.37**	**2.81**	**1.70**	**1.28**
% Variance Explained	**27.34**	**17.56**	**10.65**	**7.99**
Correlation with stigma		.002	.452*	.357**
Correlation with benefits			-.255*	-.104
Correlation with costs				.158
ALPHA	**.821**	**.817**	**.759**	**.789**

**Correlation is significant at the .01 level; *Correlation is significant at the .5 level
KMO = .785, Bartlett's Test of Sphericity: Chi-Square = 712.03 df=120, p<.001

6.6 AMRABs scores

Scores on the AMRABs scales were calculated by reverse coding question 13 on the parent questionnaire and question 7 on the child questionnaire. Then, scores were calculated by adding together the respective items from the questionnaires to obtain a total score between 4 and 20 for parent-report benefits, costs, child stigma, parental stigma, resistance and flexibility and child-report benefits, costs, stigma and resistance. A score of between 3 and 15 was obtained for parent-report competence. It is important to note that higher competence scores actually represent lower levels of competence in administering medication (e.g. finding it difficult to remember to give the child their pills on time).

The means and standard deviations for these scores are tabulated in Table 6.6. It is important to note that the means for parent and child-report benefits are well above the mid-point on the scales while the means for parent and child-report costs, stigma and resistance and parent-report parental stigma and competence are well below it. This suggests that participants in this sample are generally positive about medication, perceiving high levels of benefits, low levels of costs, child stigma, parental stigma and resistance, and consider themselves to be competent in administering medication.

Table 6.6 Descriptive statistics for AMRABs variables

Variable	Mean	Standard Deviation
Parent-report benefits	15.88	3.59
Parent-report costs	7.86	3.70
Parent-report resistance	9.33	4.09
Parent-report child stigma	8.74	3.55
Parent-report parental stigma	9.88	3.94
Parent-report flexibility	11.28	4.62
Parent-report competence	5.26	2.31
Child-report benefits	14.29	3.88
Child-report costs	8.83	3.86
Child-report resistance	8.69	4.16
Child-report stigma	10.29	3.30

6.7 Comparison between data collected via ADHD clinics, support groups and the internet

6.7.1 AMRABS scores in each sample

The mean AMRABS scores of participants in each of the four samples are reported in Table 6.7.

Table 6.7 Mean AMRABs scores in each of the samples

	UK ADHD Clinic	USA ADHD Clinic	Internet	Support Group
Parent-report benefits	15.88	16.08	15.72	16.95
	(3.80)	(2.43)	(3.70)	(2.87)
Parent-report costs	7.19	7.85	7.98	7.40
	(3.58)	(4.52)	(3.72)	(3.61)
Parent-report resistance	9.61	7.69	9.18	10.53
	(4.37)	(3.95)	(4.00)	(4.39)
Parent-report child stigma	10.28	7.31	8.63	8.80
	(2.98)	(2.98)	(3.48)	(3.88)
Parent-report parental stigma	10.61	10.31	9.90	8.75
	(3.17)	(5.18)	(4.04)	(3.44)
Parent-report flexibility	12.42	12.46	11.29	10.45
	(5.73)	(5.75)	(4.54)	(4.86)
Parent-report competence	4.84	4.23	5.39	4.48
	(2.03)	(1.64)	(2.31)	(2.21)
Child-report benefits	13.88	11.92	14.06	15.82
	(3.69)	(4.34)	(4.10)	(3.04)
Child-report costs	8.77	8.25	9.74	7.64
	(3.35)	(4.71)	(4.14)	(3.32)
Child-report resistance	10.07	8.58	11.06	10.34
	(3.13)	(2.23)	(3.65)	(3.45)
Child-report stigma	9.15	6.41	9.50	8.42
	(4.02)	(3.45)	(4.55)	(4.03)

Numbers in parentheses represent standard deviations

MANCOVAs were carried out to investigate potential differences in parent (Table 6.8) and child-report AMRABs (Table 6.9) between participants from UK clinics, participants from the USA clinic, participants from the internet and participants from support groups. Previous analyses found that children from support groups were older than children from other sources and that there were more nationalities represented within the internet sample. Therefore, age and country were controlled for in the analysis. No significant effects of sample source on AMRABs were found.

Table 6.8 MANCOVA examining differences in parent-report AMRABs between sample sources (UK clinic, USA clinic, internet and support group) controlling for age and country

Source	Type III Sum of Squares	Df	F
Between Subjects			
Covariates			
Child Age			
Multivariate λ = .95		7.000	2.23*
Parent-report benefits	1.453	1	.11
Parent-report costs	.094	1	.01
Parent-report child stigma	17.668	1	.22
Parent-report parental stigma	80.561	1	5.19*
Parent-report resistance	11.374	1	.70
Parent-report flexibility	14.376	1	.71
Parent-report competence	18.114	1	3.38**
Country			
Multivariate λ = .90		7	4.68***
Parent-report benefits	30.443	1	2.27
Parent-report costs	.449	1	.03
Parent-report child stigma	2.823	1	21.30***
Parent-report parental stigma	53.960	1	3.47
Parent-report resistance	89.699	1	.174
Parent-report flexibility	96.810	1	3.95
Parent-report competence	52.912	1	1.29
Factor			
Sample Source			
Multivariate λ = .91		21.000	1.31
Parent-report benefits	31.423	3	.78
Parent-report costs	11.051	3	.27
Parent-report child stigma	39.639	3	1.85
Parent-report parental stigma	43.389	3	.82
Parent-report resistance	89.699	3	.93
Parent-report flexibility	98.810	3	1.49
Parent-report competence	82.912	3	2.39
Error			
Parent-report benefits	3964.435	300	(13.43)
Parent-report costs	4095.397	300	(13.88)
Parent-report child stigma	3441.843	300	(11.67)
Parent-report parental stigma	4577.633	300	(15.51)
Parent-report resistance	4777.319	300	(16.19)
Parent-report flexibility	6414.426	300	(21.74)
Parent-report competence	1581.780	300	(5.36)

Values enclosed in parentheses represent mean square errors

*p <.05 **p <.01 *** p <.001

Table 6.9 MANCOVA examining differences in child-report AMRABs between sample sources (UK clinic, USA clinic, internet and support group) controlling for age and country

Source	Type III Sum of Squares	Df	F
Between Subjects			
Covariates			
Child Age			
Multivariate λ = .78		4.000	3.92*
Child-report benefits	4.376	1	.32
Child-report costs	63.566	1	6.75*
Child-report stigma	31.384	1	.142
Child-report resistance	.002	1	.00
Country			
Multivariate λ = .93		4.000	1.77
Child-report benefits	.902	1	1.78
Child-report costs	6.597	1	.49
Child-report stigma	43.801	1	3.07
Child-report resistance	6.390	1	.63
Factor			
Sample Source			
Multivariate λ = .84		16.000	1.25
Child-report benefits	73.646	3	1.78
Child-report costs	25.858	3	.60
Child-report stigma	16.550	3	.49
Child-report resistance	62.287	3	2.05
Error			
Child-report benefits	1253.115	91	(13.77)
Child-report costs	1023.241	91	(11.24)
Child-report stigma	1300.167	91	(14.29)
Child-report resistance	923.782	91	(10.15)

Values enclosed in parentheses represent mean square errors

*p<.05 **p<.01 ***p<.001

6.7.2 Reliability of the AMRABs variables in each sample

Separate principal components analyses were not carried out as the smaller sample sizes would render them unreliable. However, reliability analyses demonstrated that high alpha scores (.60 or higher) were reasonably consistent across samples (Table 6.10).

Table 6.10 Reliability analysis within each sample

	Alpha (UK Clinic)	Alpha (USA Clinic)	Alpha (Internet)	Alpha (Support Group)
Parent-report benefits	.74	.60	.83	.79
Parent-report costs	.80	.94	.83	.81
Parent-report resistance	.87	.81	.78	.82
Parent-report stigma	.77	.74	.83	.78
Parent-report parental stigma	.63	.89	.76	.66
Parent-report flexibility	.72	.90	.83	.82
Parent-report competence	.74	.75	.66	.64
Child-report benefits	.75	.90	.83	.71
Child-report costs	.68	.89	.75	.74
Child-report resistance	.61	.61	.84	.75
Child-report stigma	.72	.80	.86	.80

6.8 Discussion

This study had two main aims. First, to obtain psychometric data to confirm the structure and reliability of the AMRABs questionnaires. Second, to assess the suitability of drawing participants from multiple samples in the current research.

6.8.1 Psychometric properties of the AMRABs questionnaires

After piloting, seven key components (benefits, costs, child stigma, parental stigma, resistance, flexibility in using medication and competence in using medication) emerged in the parent questionnaire. Four components emerged in the child questionnaire (benefits, costs, stigma and resistance). These components were clearly distinguishable using principal components analyses with varimax rotation. All

components had satisfactory internal reliability. It was decided that the AMRABs questionnaire was suitable to use in further research.

6.8.2 Comparison of participants from different samples

Participants from the UK clinics, USA clinic, internet and support groups were comparable on all demographic variables except age and country. Participants from the support groups and UK clinics were older than participants from the internet and USA clinic. Unsurprisingly the internet contained more diverse nationalities, the UK and USA ADHD clinics only contained participants from their respective countries, while the support group contained participants from the UK and the Republic of Ireland.

Mean AMRABs scores were comparable on all measures except parent-report competence when age and country were controlled for in the analysis. The AMRABs scales also showed acceptable internal reliability across samples. These similarities suggest that data collected from ADHD clinics, the internet and support groups is comparable and that recruiting participants from various sample sources is a suitable way of maximising the amount of data collected.

However, as with study 2 (chapter 5), the number of child participants collected via the internet was small in comparison to the number of parents who participated online. This may be indicative of a selection bias on the internet, or it may be more difficult to recruit children via the web for example, through a lack of technical ability or unwillingness to complete questionnaires online. Similarly, parents may feel less confident in returning to a website and entering their chosen password despite reminders and instructions from the researcher.

6.8.3. Limitations of the current study

As with study 2, the majority of the current sample had been taking ADHD medication for several years. More than half had been taking medication for two years or more, and more than a third for four or more years. The current sample is most likely representative of long-term adherers to ADHD medication. The largely positive attitudes towards medication reported by participants in the current samples would seem to reflect this. The current study does not assess the perspectives of families who refuse or drop out of pharmacological treatment and may not be representative of all families of children with ADHD. Additionally, the current study is likely to be

representative of families who take a keen interest in ADHD and who were particularly interested in contributing to research concerning medication, which is similarly likely to have biased the sample.

6.9 Summary and conclusions

The AMRABs questionnaires were concluded to have a robust component structure and high internal reliability. Mean AMRABs scores and the internal reliability of the AMRABs scales were comparable across all four samples when age and country were controlled. However, the current sample seems biased towards families who are long-term adherers to ADHD medication.

The next stage in the research is to develop and test hypotheses about the relationships between the AMRABs variables and demographic variables such as age based on the current literature.

Chapter 7

Study 3b: Relationships between the AMRABS subscales, age, medication type and cultural differences

This chapter aims to develop and test hypotheses regarding:

(i) Relationships between parent and child AMRABs scores
(ii) Relationships between AMRABs scores and age
(iii) Relationships between the AMRABs subscales
(iv) Relationships between AMRABs scores and medication type
(v) Cross-cultural differences in AMRABs scores between the UK and USA.

Additionally the consistency of the results across samples (ADHD clinics, internet and support groups) and between the UK and the USA is examined for each hypothesis.

7.1 Development of working hypotheses

Clear factors were identified within the parent and child AMRABs questionnaires as described in chapter 6. Hypotheses regarding these factors were made on the basis of the current literature.

7.1.1 Relationship between parent and child AMRABs scores

Previous research has found that parents' and children's attitudes to health related issues are typically highly correlated (Bachanas & Roberts, 1995; DePaola et al., 1997; Hackworth & McMahon 1991; McElreath & Roberts, 1991). Research into ADHD medication has found inconsistent results in this area. Some research has found a high correlation between parents' and children's attitudes to ADHD medication (Cohen & Thompson, 1982; Efron, Jarman & Barker, 1998). Other research has suggested that parents tend to rate more benefits and children more drawbacks to taking ADHD medication (Efron, Jarman & Barker, 1998; McNeal, Roberts & Barone, 2000).

On the basis of this literature, two hypotheses are made. First, that parents' and children's scores on each of the AMRABS subscales (benefits, costs, stigma and resistance) will be significantly correlated. Second, that children will report fewer benefits and more costs than their parents.

7.1.2 The effect of age on stigma & resistance

Previous research indicates that adolescents are more likely to experience stigma than younger children, and are more likely to resist or engage in conflict with parents over taking medication (Anderson et al., 1990; Harris & Linn, 1985; Hayford & Ross, 1988; LaGreca, 1990 Lask, 1994; McQuaid et al., 2001; Shaw, 2001). Similarly, older children with ADHD are more likely to refuse medication than younger children (Brown, 1988; Sleator, 1984; Thiruchelvam et al., 2001; Weiss et al., 2000b).

Therefore, it is hypothesised that older children have higher stigma and resistance scores than younger children.

7.1.3 Relationship between stigma and resistance

Refusal or reluctance to adhere to medication regimens in adolescence may be related to adolescents' developing awareness of issues such as stigma associated with their condition. Previous research has highlighted a significant relationship between stigma and non-adherence in a variety of conditions (Ayalon, Arean & Alvidrez, 2005; Buck et al., 1997; Freudenreick et al., 2004; Hudson et al., 2004; Roberts, 2005; Sirey et al., 2001).

Therefore, it is hypothesised that stigma will be associated with resistance to taking medication.

7.1.4 Sustained-release medications and stigma

It has been suggested that sustained-release formulations of stimulant medications may reduce stigma for children with ADHD by eliminating the need for medication to be given in school (Greenhill, Halperin & Abikoff, 1999; Santosh & Taylor, 2000).

Therefore, it is hypothesised that children who are taking a sustained-release medication will experience less stigma than children taking short-acting medications.

7.1.5 Cross-cultural differences

It is generally acknowledged that practice guidelines in the UK are not necessarily appropriate in other cultural settlings (Overmeyer and Taylor., 1999). The current

literature suggests that there may be differences between American and British attitudes towards ADHD, particularly amongst medical professionals. British medics are more conservative in their prescribing attitudes compared to their American counterparts. For example, stimulant drugs can only be prescribed by psychiatrists in the UK, whereas they are widely prescribed in primary care in America (Bramble, 2003; Wolraich, 2003). Qualitative research in the UK suggests that General Practitioners (GPs) are reluctant to "medicalise children's behaviour", fearing that a diagnosis can be a self-fulfilling prophecy. Additionally, GPs are concerned to avoid stigmatising a child by giving them a medical label. This contrasts with the experience of many parents, who find the diagnosis of ADHD legitimates their concerns (Klasen, 2000; Klasen & Goodman, 2000). Klasen (2000) and Klasen & Goodman (2000) interviewed parents of children who had been diagnosed as "hyperactive". When parents first approach a GP with concerns about their child's behaviour, many GPs attempt to reassure parents that there is nothing wrong with their child or offer parenting advice. Klasen (2000) suggests that this confounds parents' sense of blame, de-legitimising and consequently, increasing their distress.

Given the widespread prescription of stimulant medications for ADHD in primary care in America, it is possible that medication is more culturally acceptable in America than in the UK. Therefore, it is hypothesised that participants in the UK will report higher levels of parental and child stigma than participants in America

To summarise the following hypotheses are made:

(i) Parents' and children's scores on each of the AMRABS subscales will be significantly correlated
(ii) Children will report fewer benefits and more costs to taking medication than their parents
(iii) Older children will show higher levels of resistance than younger children
(iv) Older children will show higher levels of stigma than younger children
(v) Stigma will be associated with resistance to taking medication
(vi) Children who do not need to take medication during school will experience less stigma associated with taking medication than those who do
(vii) Parents and children in the UK will report more child and parental stigma than parents and children in America.

7.2 Methods

The participants and materials used in this study were described in chapter 6 (6.2-6.4). The scores on the AMRABs sub-scales were calculated as described in 6.7.1. The descriptive statistics were as reported in Table 6.6.

7.3 Results

7.3.1 Relationship between parent and child AMRABS

7.3.1.1 Hypothesis: Parents' and children's scores on each of the AMRABS subscales will be significantly correlated

In order to control for multiple comparisions, the Bonferroni correction procedure was used and the cut-off p-value necessary for a significant result was set at .0125. All of the parent and child-report AMRABs were significantly correlated at the .01 level (Table 7.1). These results were consistent across all samples and between the UK and USA, with the exception of the USA clinic sample on parent and child-report resistance (Appendix E, Table E.1). This may be an anomaly associated with the small number of participants in this sample.

Table 7.1 Correlations between parent and child-report AMRABs subscales

Comparison Pair	Pearson's R
Parent-report benefits & child-report benefits	.409**
Parent-report costs & child-report costs	.703**
Parent-report resistance & child-report resistance	.568**
Parent-report stigma & child-report stigma	.701**

**Correlation is significant at the .01 level

7.3.1.2 Hypothesis: Children will report fewer benefits and more costs to taking medication than their parents

Parent and child AMRABs scores were compared using paired-samples t-tests (Table 7.2) to identify differences between parent and child AMRABs. The subscales used contained equivalent questions and scores on both the parent and child-report questionnaires. As this test uses multiple comparisons, the Bonferroni correction procedure was used to adjust the p-value necessary for any differences to be

confirmed as significant. This gave a cut off point at p=.025. As predicted, children did report fewer benefits and more costs than their parents. Both differences were highly significant at the .001 level.

Child-report benefits was consistently lower than parent-report benefits across all samples and between the UK and the USA. However, child-report costs was only significantly higher than parent-report costs in the UK clinic and internet samples. The result for costs was significant when all UK participants were examined together, but not significant for participants from the USA (Appendix E, Table E.2).

Table 7.2 T-test to compare parent and child AMRABs

	Mean	S.D.	T	DF	P
Parent-report benefits	16.04	3.13	5.60	108	<.001
Child-report benefits	14.34	3.72			
Parent-report costs	7.38	3.45	-3.31	105	<.001
Child-report costs	8.37	3.51			

7.3.2. Age-related differences in AMRABS

7.3.2.1 Hypothesis: Older children will show higher levels of resistance than younger children

Linear regression analysis demonstrated a significant positive relationship between age and parent-report resistance ($F_{1,352}$ = 4.20, p = <.05). However, it should be noted that age only accounted for 1% of the variance in parent-report resistance scores. No relationship was found between age and child-report resistance ($F_{1,108}$ = .435, p = ns) (Appendix D, Table D.1).

The relationship between age and parent-report resistance was not consistent across samples. There were negative trends between age and parent-report resistance in the UK and USA clinics and no relationship in the internet or support group samples. Overall, there was no relationship between age and parent-report resistance in either the UK ($F_{1,143}$ = .72, p = ns) or the USA ($F_{1,177}$ = .97, p = ns), (Appendix E, Table E.3).

This pattern of results was also found for child-report resistance. There was a negative relationship between age and child-report resistance in both the UK and USA clinics, but no relationship in the internet or support group samples. Overall, there were no

relationships between age and child-report resistance in either the UK ($F_{1,70}$ = .48, p = ns) or the USA ($F_{1,101}$ = .17, p = ns) (Appendix E, Table E.3).

Although the original analysis examining the relationship between age and parent-report resistance was significant, when age was entered into the analysis with country, the effect of age was no longer significant, while the effect of country was marginally significant ($F_{2,331}$ = 3.51, p <.10), (Appendix D, Table D.2). The children in the UK sample were older than children from the US sample (t_{338} = 4.67, p<.001), suggesting that this effect was mediated by the slightly higher levels of resistance in the UK sample. No relationship was found between age or country with child-report resistance when examined together ($F_{2,97}$ = 1.51, p = ns) (Appendix D, Table D.3). Therefore, it is concluded that age is not related to resistance in the current sample.

7.3.2.2 Hypothesis: Older children will show higher levels of stigma than younger children

7.3.2.2.1 Age and parent-report child stigma

A significant positive relationship was found between age and parent-report stigma ($F_{1,355}$ = 13.62, p = <.001). Again, it should be noted that age only accounted for 3% of the variance in parent-report child stigma scores (Appendix D, Table D.1).

This result was not consistent across samples. Age was negatively associated with parent-report stigma in the UK clinic sample, and positively associated in the internet and support group samples. No relationship was found in the USA clinic sample (Appendix E, Table E.3). There was no relationship between age and parent-report child stigma in the overall UK sample ($F_{1,145}$ = .17, p = ns). However, there was a small positive relationship between age and parent-report stigma in the US sample ($F_{1,173}$ = 3.78, p <.05) (Appendix E, Table E.3).

The effect of age on parent-report stigma was small, explaining only 2% of the variance in stigma scores within the US sample. When country and age are entered together into a multiple regression to predict parent-report child stigma, the effect of age was not significant, but the effect of country was, suggesting that cultural context is more important in predicting parent-report child stigma ($F_{2,331}$ = 18.81, p <.001) (Appendix D, Table D.4).

7.3.2.2.2 Age and child-report stigma

There was no relationship between age and child-report stigma ($F_{1,107}$ = .619, p = ns) (Appendix D, Table D.1.) However, this result was not consistent across samples. Child-report stigma was negatively associated with age in the UK clinic sample, but no association was found in the USA clinic, internet or support group samples (Appendix E, Table E.3).

There was a negative relationship between age and child-report stigma in the overall UK sample ($F_{1,70}$ = 5.31, p = <.05). A smaller negative relationship between age and child-report stigma was found in the overall USA sample ($F_{1,29}$ = .45, p = ns) (Appendix E, Table E.3). When both age and country were entered together into the analysis, both were significant predictors of child-report stigma ($F_{2,97}$ = 3.90, p = <.05), suggesting that both age and country have a role to play in predicting child-report stigma (Appendix D, Table D.5).

7.3.3 Relationships between AMRABs

7.3.3.1 Hypothesis: Stigma will be associated with resistance to taking medication

Linear regression analyses demonstrated a positive relationship between parent-report child stigma and parent-report resistance, ($F_{1,350}$ = 36.37, p <.001). Parent-report child stigma accounted for 9% of the variance in parent-report resistance. Likewise, child-report stigma was associated with child-report resistance, accounting for 4% of the variance ($F_{1,106}$ = 4.27, p <.05) (Appendix D, Table D.6). The relationship between stigma and resistance was consistent across samples and in the overall UK ($F_{1,150}$ = 12.19, p <.001 for parent-report data; $F_{1,71}$ = 4.08, p <.05 for child-report data) and USA ($F_{1,188}$ = 20.77, p< .001 for parent-report data; $F_{1,27}$ = 5.34, p<.05 for child-report data) samples (Appendix E, Table E.4).

Parent-report child stigma was also associated with child report resistance, accounting for 3% of the variance ($F_{1,108}$ = 4.32, p <.05). Vice-versa, child-report stigma was associated with parent-report resistance explaining 5% of the variance ($F_{1,105}$ = 6.36. p <.05) (Appendix D, Table D.6).

The relationship between parent-report child stigma and child-report resistance was not significant in either the UK or USA samples, but was in the predicted direction ($F_{1,70}$ = 1.60, p = ns in the UK; $F_{1,30}$ = 1.35, p = ns in the USA) (Appendix E, Table E.4). A positive relationship between parent-report child stigma and child-report resistance was found in all samples, except the USA clinic sample, where no relationship was found.

Child-report stigma was marginally associated with parent report resistance in the UK in both the UK ($F_{1,68}$ = 3.60, p = .06 in the UK) The relationship failed to reach significance in the USA ($F_{1,29}$ = .59, p = ns) (Appendix E, Table E.4). Again, a positive relationship was found in all samples, except the USA clinic sample, where no relationship was found. The USA clinic results may be anomallies associated with the small number of participants in this sample.

7.3.4 Hypothesis: Children who do not need to take medication during school will experience less stigma associated with taking medication

An independent samples t-test found that children given medication in school (N = 277) had significantly higher parent-report scores stigma than children who were not (N = 76; Table 7.3). No differences were found for child-report stigma.

This result was not consistent across samples. The analysis could not be carried out in the USA clinic sample as only one child in that sample took medication at school. Parent-report child stigma was higher for children who took medication at school in the UK clinic and internet samples. Parents in the support group whose children took medication in school reported lower child stigma than those whose children did not. For child-report stigma, children who were given medication at school in the UK clinic reported higher stigma than those who were not. No differences in child-report stigma were found in the other samples.

Comparisons between the UK and the USA revealed that children in the UK were more likely to take medication at school (32.1%) than children in the USA (13.8%) (χ^2=16.65, df = 1, p<.001). T-tests did not find a difference in parent or child-report stigma between children taking medication in school and children who did not in the overall UK sample. By contrast, parent-report child stigma was higher in children who took medication at school than in children who did not in the USA sample (Appendix E,

Table E.5). Child-report stigma could not be examined in the USA, as child-report data was only available for one child in the USA sample who took medication at school.

Examined together, both country and taking medication at school were associated with parent-report child stigma, with children from the UK and children who take medication at school reporting higher stigma ($F_{2,340}$ = 19.67, p <.001). Only country was predictive of child-report stigma, again, with children from the UK reporting higher stigma ($F_{2,99}$ = 2.64, p <.05) (Appendix D, Tables D.7 and D.8).

Table 7.3 T-tests to examine differences in parent and child-report stigma between children who are given medication in school and children who are not

	Mean	S.D.	T	DF	P
Parent-report stigma for children who are not given medication in school	8.44	4.04	2.89	104.5	<.01
Parent-report stigma for children who are given medication in school	9.84	3.32			
Child-report stigma for children who are not given medication in school	8.36	4.08	.64	105	ns
Child-report stigma for children who are given medication in school	8.96	3.98			

7.3.5 Hypothesis: Parents and children in the UK will report more child and parental stigma than parents and children in the USA

7.3.5.1 Differences in child stigma between the UK and USA.

A t-test was used to identify that the children in the UK sample were significantly older than those in the USA sample (t_{338} = 4.67, p<.001). Multiple regression analysis found a significant effect for country, but not age on parent-report child stigma ($F_{2,331}$ = 18.81, p <.001) (Table D.4). Parents from the UK reported higher levels of child stigma (μ= 9.86, sd = 3.74, N = 151) than parents from the USA (μ = 7.78, sd. = 2.96, N = 183).

This pattern of results was also found for child-report stigma ($F_{2,97}$ = 3.90, p <.05) (Table D.5). Children from the UK reported higher levels of stigma (μ= 8.80, sd = 3.86, N = 71) than children from the USA (μ= 7.17, sd = 3.43, N = 29).

Both country and age were associated with parental stigma ($F_{2,331} = 9.33$, $p < .001$) (Table D.9). Parents from the UK reported higher levels of parental stigma, and child age was negatively associated with parental stigma. The association between age and parental stigma was consistent across all samples (Appendix E, Table E.3).

7.3.5.2 Categorical differences in child stigma between the UK and USA: do more participants in the UK report stigma?

The relationships between country and parent-report child stigma, parental stigma and child-report stigma were further investigated in order to identify what proportion of participants in each country experienced stigma. Participants who scored less than 11 on the stigma scales (i.e. had consistently answered disagree or strongly disagree to questions concerning stigma) were classed as not experiencing stigma (no stigma). Participants who scored 13 or more (i.e. had consistently answered strongly agree or agree to questions concerning stigma) were classified as experiencing stigma (stigma). Participants who scored 12 were considered neutral and excluded from the analysis.

Chi-square analysis revealed that 29.7% of parents from the UK were classed as reporting high levels of child stigma, compared with only 8.0% of parents from the USA ($\chi^2 = 26.74$, df=1, $p<.001$) (Figure 7.1). The difference between the UK and the USA on parental stigma was small and not significant when examined using categorical variables ($\chi^2 = .217$, df=1, p = ns). Chi-square analysis revealed that 23.3% of children were categorised as experiencing stigma, compared with 10.3% of the American sample (Figure 7.1). However, this difference was statistically only marginally significant ($\chi^2 = .21$, df = 1, p = .11).

Descriptive statistics for AMRABs variables in the overall UK and USA samples are reported in Appendix E, Table E.6. MANCOVAs examining differences in AMRABS between the UK and US controlling for child age, did not find any other differences on parent or child-report AMRABs by country (Appendix E, Tables E.7 and E.8).

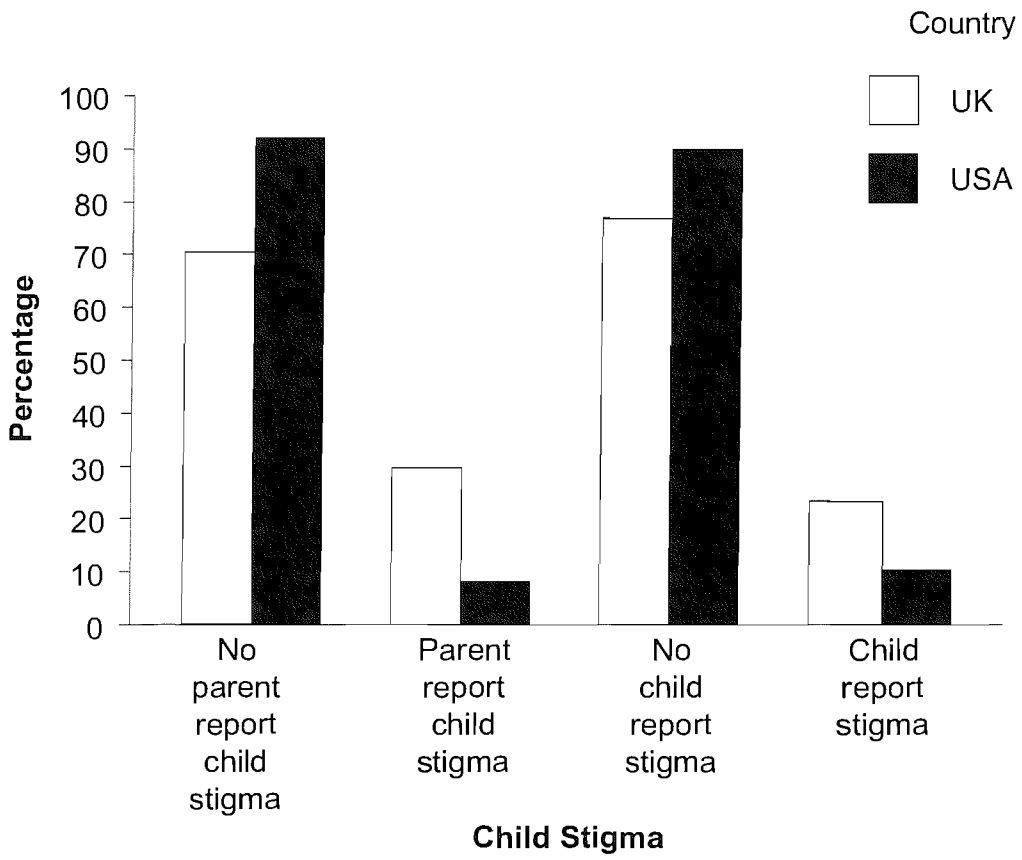


Figure 7.1 Percentage of parents and children experiencing child stigma within the UK and the USA

7.4 Summary of Results

This study found:

- Parent and child-report AMRABs were significantly correlated. This result was consistent across samples.
- Children consistently reported lower benefits than their parents. Children in the USA reported higher costs than their parents, but no difference was found in the UK.
- No consistent relationships between age and parent or child-report resistance
- No consistent relationships between age and parent-report child stigma

- A small negative relationship between age and child-report stigma in the UK sample, but not within the USA sample.

- Stigma was positively associated with resistance. This result was consistent across all samples.

- Parent-report child stigma was higher for children who took medication at school in the USA sample, but not in the UK sample. There was no difference in child-report stigma between children who took medication at school and children who did not.

- Parents and children in the UK reported more child stigma than parents and children in the USA.

- Child age was negatively associated with parental stigma, and parents in the UK reported higher levels of parental stigma.

7.5 Discussion

This study had two main aims. First, to test hypotheses about the relationships between AMRABs. Second, to explore cultural differences in AMRABs between the UK and USA. This study drew participants from multiple sample sources. Therefore, the consistency of results across samples was examined.

7.5.1 Relationships between parent and child AMRABs

7.5.1.1 Agreement between parent and child-report AMRABs

Two hypotheses were made concerning the relationship between parent and child AMRABs. First, that parent and child AMRABs would be correlated. Second, that children would report fewer benefits and more costs than their parents. Both hypotheses were supported by the data. This is in line both with previous research which suggests parents' and children's attitudes to health related issues are highly correlated (Bachanas & Roberts, 1995; DePaola et al., 1997; Hackworth & McMahon 1991; McElreath & Roberts, 1991; Cohen & Thompson 1982); and with literature which suggests children are more likely to report negative attitudes towards medication than

parents. All parent and child-report AMRABs were highly correlated in this sample. This is in line with previous research that has found a high correlation between parents' and children's attitudes to health-related issues and to ADHD medication specifically (Cohen & Thompson, 1982; Efron, Jarman & Barker, 1998).

This result was consistent across samples, with the exception of resistance in the USA clinic sample. This anomaly may be explained by the small sample size in the US clinic.

However, the recruitment methods used in this study cannot guarantee the independence of the child data. Future studies that ensure that children complete the questionnaire independently of their parents may provide a more accurate picture of the extent of the agreement or disagreement between parent and child AMRABs.

7.5.1.2 Differences between parent and child-report AMRABs

This study also found that children reported fewer benefits and more costs associated with medication than their parents (Efron, Jarman & Barker, 1998; McNeal, Roberts & Barone, 2000). Child-report benefits were consistently lower than parent-report benefits across all samples. However, there was no difference between parent and child-report costs in the USA sample.

This finding may be of clinical importance in highlighting the need to investigate children's attitudes towards medication, and, in particular, to understand why children may experience less benefits associated with taking medication than their parents. Additionally, it seems that cultural factors may play a role in determining whether children experience more drawbacks to taking medication than their parents in the UK, but not in the USA.

7.5.2 Relationship between age and AMRABs

It was hypothesised that older children would show more resistance and experience more stigma associated with taking medication than younger children.

7.5.2.1 Relationship between age and resistance

There was no relationship between age and parent or child-report resistance when country was included in the analysis. Analysis of the data collected in different samples, did not find any consistent relationship between age and parent or child-report resistance. This study does not support the hypothesis that age is associated with resistance.

7.5.2.2 Relationship between age and stigma

When country was considered in the analysis, there was no relationship between age and parent-report child stigma. There was a very small positive association between age and parent-report child stigma in the USA sample. The inconsistent results between the clinic, internet and support group samples suggest that contextual factors may moderate the relationship between age and stigma. Future research should consider how stigma develops and what factors within the family and social environment contribute to its development, maintenance and reduction.
When both age and country were considered together as predictors of parent-report child stigma, only country was a significant predictor, suggesting that context plays the most crucial role in predicting parent-report child stigma.

The original analysis did not find any association between age and child-report stigma. However, subsequent analysis considering the role of country in predicting stigma found a small negative relationship in the UK sample, but not the USA sample. The relationship between age and child-report stigma was in the opposite direction than was predicted in the UK sample. It may be that children who feel stigmatised are more likely to drop out of treatment (and therefore less likely to be eligible to take part in this study) as adolescents. It may also be that older children who felt stigmatised may have been unwilling to complete the questionnaire. Therefore, this result needs to be interpreted with caution. Again, country was found to be the most crucial predictor of child-report stigma, emphasising the importance of context in the experience of stigma.

Subsequent analyses of data collected via different samples found that there was a negative relationship between age and parent-report child stigma in the UK clinic, no relationship in the US clinic and small positive associations in the internet and support group samples. Similarly, a negative relationship between age and child-report stigma was found in the UK clinic sample, but there was no relationship between age and

child-report stigma in any of the other samples. These results suggest that there is no consistent relationship between age and stigma across samples and once again highlight the likelihood that contextual factors are important in the experience of stigma.

However, as this study adopted a cross-sectional approach, it is not possible to examine whether parents and children experience a decrease or an increase in stigma over time. It may be that parents and children who feel highly stigmatised are more likely to drop out of treatment, and hence, most of the participants eligible for this study (i.e. currently taking medication) were families for whom stigma was not a major issue. The overall low stigma scores within the dataset may be reflective of this potential response bias. Future research adopting a longitudinal paradigm is therefore necessary to explore whether or not the experience of stigma changes over time and whether or not it is predictive of treatment drop-out.

7.5.3 Relationship between stigma and resistance

Both parent and child-report stigma were correlated positively with parent and child-report resistance, suggesting that stigma may be an important factor in children's resistance to taking medication. This relationship was robust across all samples and between the UK and the USA.

That stigma predicts resistance highlights the likelihood that stigma plays an important role in adherence behaviours and potential drop out from medication treatment. Future studies taking a longitudinal approach are necessary to examine if resistant behaviours and stigma predict continuation/discontinuation of pharmacological treatment for ADHD.

7.5.4 Taking medication at school and stigma

Parent-report child stigma was higher for participants who took medication in school within the USA sample but not within the overall UK sample. However, children in the UK were less likely to be taking a long acting medication. The results from the overall USA sample lend some support to recent suggestions that sustained-release versions of stimulant medications may help to reduce the stigma that children experience associated with taking medication for ADHD (Santosh & Taylor, 2000; Greenhill, Halperin & Abikoff, 1999).

The lack of consistency across findings suggests contextual factors may play an important role. The results may also be coloured by prescription practices, particularly in the UK, where children seem less likely to be prescribed a sustained-release medication as a matter of course. It may be that children who feel particularly stigmatised are prescribed sustained-release medication in order to eliminate the need for a dose during the school day.

The current study is limited by its cross-sectional design. Longitudinal research is necessary in order to determine whether stigma levels decrease when children switch from a short acting medication to a sustained-release formulation, which eliminates the need to take medication during school.

7.5.5 Child stigma in the UK and USA

Cross-cultural comparisons revealed that UK parents reported more child stigma on average than USA parents. Categorical analysis revealed more than three times the number of parents in the UK reported that their child experienced stigma than parents in the USA. This pattern of results was mirrored when stigma was measured by child-report, although the chi-square assessing child stigma categorically did not reach significance.

This difference is striking, particularly when considered alongside research highlighting stigma as a critical barrier to long-term treatment adherence (Ayalon et al., 2005; Buck et al., 1997; Conrad, 1985; Freudenreich et al., 2004; Hudson et al., 2004; Roberts, 2005; Sirey et al., 2001). The relatively high proportion of UK parents reporting that their child experiences stigma associated with taking ADHD medication may have important implications for parents' and children's long-term attitudes to medication and their decision to continue or discontinue treatment.

The current study highlights the likelihood that Americans understand ADHD differently from people from the UK. In a study of how ADHD is represented in the popular media within the USA, Schmitz, Filippone and Edelman (2003) found a dominance of biological and genetic explanations for ADHD, with a particular interest in research involving brain-imaging technology. Despite a comprehensive literature search, the author could not find any similar surveys of UK media. However, Klasen (2000) and Klasen and Goodman (2000) suggest that GPs in the UK may be reluctant to adopt a medical approach to ADHD. Perhaps more strikingly, clinical psychologists in the UK

have expressed very sceptical attitudes towards the diagnosis and pharmacological treatment of ADHD, arguing that ADHD is the expression of normal childhood energy, the result of boring classrooms, highly competitive educational environments and over-stressed parents or teachers (Baughman, 2001; Breggin, 2001; Breggin, 2002; Diller 1998; McCubbin & Cohen, 1997; Radcliffe, Sinclair & Newnes, 2004). Others have argued that the behaviours associated with ADHD are associated with an adverse family environment, attachment difficulties and domestic violence (Golding, 2004; Vetere, 2004). Rejecting the neurobiological model of ADHD, critics argue emotively that pharmacotherapy is inappropriate (Breggin, 2000; Breggin 2001; Breggin, 2002; Brown, 2004; McCubbin & Cohen, 1997; Myatt, Rostill & Wheeldon, 2004; Radcliffe & Timimi, 2004; Timimi, 2004; Woodhouse, 2004). Critics have described stimulant medication as *"virtually indistinguishable from the street drugs speed and cocaine"* (Radcliffe & Timimi, 2004, p8), *"highly addictive"* and *"brain-disabling"* (Radcliffe & Timimi, 2004, p.11). Radcliffe and Timimi (2004) believe that *"Behind the rise in diagnoses and the liberal prescription of such dangerous medicines lurks a deep malaise that is infecting our Western culture: hostility to children. For in our modernist, hyperactive, individualistic lifestyles. children 'get in the way'."* (p.11). Instead of pharmacological treatment, these writers argue that lifestyle issues such as slowing down the pace of family life, having regular family time, opportunities for exercise, a good diet, promoting parent-child attachment and improving parents' behavioural management should be employed and are sufficient to treat children who are diagnosed with ADHD (Armstong, 1995; Breggin, 2000; DeGrandpre, 1999; Stein, 2001; Woodhouse, 2004).

Farr (1995) suggests that societal level understandings and representations of health and illness impacts on the likelihood that persons within that society will seek diagnosis and treatment. In particular, negative representations of an illness may result in a reduction of self-esteem in persons diagnosed with that condition, and may impact on the likelihood of adherence to recommended treatments (Krueger and Kendall, 2001; Leventhal, 1997; Schmidt, Filippone & Edelman, 2003). It seems plausible to suggest that the medical model of ADHD and the use of pharmacological treatment is less culturally acceptable in the UK than in the USA, resulting in elevated stigma for families of children diagnosed with ADHD in the UK.

In addition, research has highlighted the importance of ethnicity in predicting whether parents are likely to access mental health services for their children. African and Latin-American parents are less likely to seek mental health care for their children (McMiller

& Weisz, 1996). Additionally, African-American parents are more likely to have negative expectations of mental health professionals than Caucasian parents (Richardson, 2001). American research has found that Latin-American, Hispanic and African-American children are less likely to receive pharmacological treatment for ADHD than their Caucasian counterparts (Bauermeister et al., 2003; Olfson, Gameroff, Marcus & Jensen, 2003). Olfson et al. (2003) found that African-American young people were 2.6 times less likely to receive pharmacological treatment for ADHD than Caucasian young people, and that this difference was not attributable to lower socio-economic status. Wasserman et al. (1999) reported equal rates of ADHD diagnosis in African-American and Caucasian young people. The MTA study reported that African-American young people benefited comparably from pharmacological treatment as Caucasian children (Arnold et al., 2003). It therefore seems reasonable to suggest that families from different ethnic backgrounds may have differing beliefs and attitudes regarding ADHD medication. Further research examining AMRABs in different social and ethnic groups may provide important insights into how parents and children experience taking medication for ADHD. This in turn may have important implications for clinical practice and practitioners' awareness of and ability to respond to issues that may be particularly important for the families they treat.

7.5.6 Parental stigma, age and country

Country and age interacted in predicting parental stigma. Age was negatively associated with parental stigma, but this effect was stronger in the USA sample. Although not directly hypothesised, it may be more culturally acceptable to give medication to older children than to younger children. Additionally, when the difference in age was controlled for, parents from the UK reported more parental stigma than parents from the USA. Again, it seems that parents in the UK are more likely to experience stigma than parents in the USA. Although parental stigma seems to decrease with age, it may be that parents in the UK are more reluctant to start a medication regimen because of the stigma associated with it. Future research to examine whether parental stigma is associated with acceptance of pharmacological treatment may prove helpful in understanding why some parents decline pharmacological treatment.

7.6 Summary

No consistent relationships were found between age and parent-report AMRABs, suggesting that context may be more important than age in predicting AMRABs. However, stigma was consistently associated with resistance to taking medication, suggesting that stigma may play an important role in predicting adherence behaviours. This study is limited by its cross sectional design and future research tracking AMRABs scores, medication adherence and treatment continuation/discontinuation over time are necessary to understand more fully the relationship between stigma and medication related behaviours in families of children with ADHD.

Taking medication at school was associated with lower stigma scores in the overall USA sample, but not in the UK sample. Again, this study is limited by its cross sectional design. Future studies examining change in stigma and other AMRABs in children who change from a standard short-acting medication to a sustained-release medication are necessary.

The cross-cultural comparison of AMRABs between participants from the UK and participants from the US was particularly striking. This study documents higher levels of stigma in the UK population when compared to the US population, suggesting that cultural factors may play a critical role in the experience of stigma. Future research to examine why parents and children in the UK are more vulnerable to stigma is necessary. Additionally, it would seem prudent to examine stigma in different social and ethnic groups as this has important implications for clinical practice,

7.7 Research direction

It is beyond the scope of this thesis to conduct a longitudinal study of AMRABs. However, the current study, and previous research has highlighted the importance of context in AMRABs. The next study will consider the impact of family context on AMRABs, drawing from the current literature, which suggests that children from families characterised by low levels of adversity, good parental mental health and positive parenting styles do better on medication. The aim of this study will be to examine the relationship between family factors and AMRABS variables.

CHAPTER 8

Relationships between family factors and AMRABs

8.1 Chapter outline

The initial literature review highlighted a possible association between family factors and outcomes to pharmacological treatment in ADHD. Two pathways whereby family factors may influence treatment response were suggested. First, family factors may influence adherence to a pharmacological regimen. Second, family factors may provide a facilitative context, which fosters optimal treatment response.

The social cognitive models of health behaviour outlined in chapter 3 highlighted the importance of attitudes in predicting health related behaviours. It is beyond the scope of this thesis to examine the relationships between AMRABs with adherence and treatment outcome. However, the current study aims to explore how family factors (children's behavioural problems, parent mental health, family relationships and parenting style) are associated with AMRABs.

The literature regarding the importance of family factors in predicting attitudes to medication and treatment is reviewed and hypotheses made concerning the relationship between family factors and AMRABs. These hypotheses are then tested in a questionnaire-based study involving children with ADHD and their parents.

8.2 Children's behavioural problems and AMRABS

Previous studies have found that comorbid disruptive behavioural disorders such as ODD and CD are salient factors in predicting discontinuation of medication (Thiruchelvam et al., 2001). Weiss et al. (2000b) suggests that children with ODD or CD are more likely to resist following adult requests to take medication and less likely to accept feedback from parents and teachers that medication is beneficial.

It is therefore hypothesised higher levels of externalising behavioural problems will be associated with higher levels of parent and child-report resistance.

8.3 Parental mental health and AMRABS

8.3.1 Parental depression

Poor parental mental health, in particular depression, decreases the likelihood of a positive response to pharmacological treatment (Owens et al., 2003; Hoza et al., 2000). Two pathways that may help to explain poorer response to medication for children whose parents are depressed are suggested. First, parents who are depressed may differ in their beliefs from parents who are not depressed. Second, parents who are depressed may differ in their parenting abilities than parents who are not depressed.

8.3.2 Parental beliefs and depression

A consistent relationship between depression and poor adherence to medical treatment has been found consistently across studies, including those examining adherence to diabetes regimens (Ciechanowski, Katon & Russo, 2000); antiretroviral medication for HIV (Molassiotis et al., 2002; Stone, 2001); and immuno-suppressants following cardiac transplantation (DeGeest et al., 2001). In a meta-review, DiMatteo, Lepper and Croghan (2000b) report that people who are depressed are three times more likely to be non-adherent to medical treatment than people who are not depressed. Bartlett et al. (2004) report that maternal depression is associated with children's difficulties in using asthma inhalers and increased likelihood of skipping doses. Parental depression is likely, then, to impact children's adherence to treatment, as parents are responsible for administering children's medication regimens.

The distored cognitions associated with depression may impact on parents' beliefs about medication. DiMatteo et al. (2000b) suggest patients who are depressed may have less positive expectations and beliefs as regards treatment efficacy. Similarly, depressive symptoms have been associated with more concerns regarding the long-term toxicity and the risk of dependence to medication for cardiovascular disease (Bane, Hughes & McElnay, 2006). It may be that people with depression will be less likely to perceive benefits of medication, and more anxious regarding potential negative effects. Additionally, mothers who are depressed are more likely to over-rate psychopathology in their children (Boyle & Pickles, 1997; Chi & Hinshaw, 2002; Chilcoat & Breslau, 1997). This may mean that mothers who are depressed are more

likely to perceive psychopathology and less likely to recognise improvements resulting from medication. Alternatively, depressed parents may see themselves as less effective as parents and consequently more likely to perceive the need for medication to manage their child's behaviour. This may lead to depressed parents rating the benefits of medication more highly than non-depressed parents.

Therefore, it is hypothesised that parental depression will be associated with parents' beliefs about the benefits and costs of taking medication.

8.3.3 Depression and parenting self-efficacy

The concept of parenting self-efficacy fits within the wider conceptual framework of self-efficacy. Self-efficacy is a person's belief in their ability to influence their environment, which leads them to take deliberate actions to produce intended results (Bandura, 1997). Self-efficacy has been defined as "the motivation, cognitive responses, and courses of action needed to exercise control over given events" (Ozer & Bandura, 1990, p. 472). Parenting self-efficacy refers specifically to parents' beliefs and expectations regarding their parenting abilities (Teti & Gelfand, 1991). It has been defined, as "one's perceived ability to exercise positive influence on the behaviour and development of one's children." (Coleman & Karraker, 1997, p. 58).

Research within the self-efficacy tradition has highlighted a relationship between depression and self-efficacy. People who are depressed have low beliefs in their ability to change their environment (Maddux and Meier, 1995). Likewise, depression has been associated with low parenting self-efficacy (Cutrona & Troument, 1986; Donovan et al., 1990; Teti & Gelfrand, 1991). Hoza et al. (2000) suggest that the poorer outcomes to pharmacological treatment in ADHD associated with maternal depression may be related to parental self-efficacy and its implications for parenting behaviours.

Self-perceptions of efficacy have been associated with motivation to engage in challenging activities (Sexton & Tuckman, 1991). People with high self-efficacy tend to exert more effort and persist in the face of difficulty (Bandura, 1982; Bandura, 1989; Berry & West, 1993; Pintrich & DeGroot, 1990). By contrast, people with low self-efficacy expect failure, give up easily and lose faith in themselves quickly (Bandura, 1982; Bandura, 1989).

Parental self-efficacy is associated with greater competence as a parent. High maternal self-efficacy is associated with adaptive parenting skills, including, responsiveness and non-punitive discipline (Donovan, 1981; Donovan & Leavitt, 1985; Donovan et al., 1990; Unger & Waudersman, 1985); direct and active parenting interactions (Mash & Johnson, 1983a); and an interest in the child's concerns (Dumka et al., 1996). Conversely, low maternal self-efficacy has been associated with defensive and controlling behaviours (Donovan et al., 1990); perception of child behaviour problems and coercive discipline (Bugental & Shennum, 1984); and actual behaviour problems in children (Mash & Johnston, 1983a). Mash and Johnston (1983b) found that the relationship between maternal self-efficacy and maternal behaviours was moderated by the child's behaviour. Mothers with low self-efficacy were more likely to withdraw when their child displayed challenging behaviour. Donovan et al. (1990) suggest that while parents with high self-efficacy may view challenging behaviour as necessitating greater effort in applying their parenting skills, parents with low self-efficacy perceive the behaviour as a threat that is beyond their ability to manage.

It may also be that parents with depression, and consequently low self-efficacy are less likely to administer medication consistently, especially if faced with child resistance (Hoza et al., 2000).

On the basis of this literature the following four hypotheses are made.

- First, that there will be an association between parental depression and child resistance
- Second, that the relationship between parental depression and resistance will be mediated via parenting self-efficacy
- Third, that parental depression will be associated with lower competence in administering medication
- Fourth, that the relationship between parental depression and competence in administering medication will be mediated via parenting self-efficacy

8.4 Parental ADHD and parenting

In order to consider the impact parenting and parental ADHD may have on AMRABs, Baumrind's (1971) parenting model is considered.

8.4.1 Parenting style

Baumrind's (1971) model of parenting styles construes parents' attempts to control and socialise their children along two dimensions: "demandingness" and "responsiveness". Demandingness, or behavioural control, is "the claims parents make on children to become integrated into the family whole, by their maturity demands, supervision, disciplinary efforts and willingness to confront the child who disobeys." (Baumrind, 1991, pp.61-62). Responsiveness, or parental warmth, is "the extent to which parents intentionally foster individuality, self-regulation, and self-assertion by being attuned, supportive, and acquiescent to children's special needs and demands (Baumrind, 1991, p.62).

These two dimensions give rise to four parenting styles: authoritative, authoritarian, permissive and uninvolved (Maccoby & Martin, 1983).

8.4.1.1 Authoritative parenting

Authoritative parents are both demanding and responsive. They provide a secure environment with clear boundaries, whilst also providing warmth and nurturance for their children. "They monitor and impart clear standards for their children's conduct. They are assertive, but not intrusive and restrictive. Their disciplinary methods are supportive, rather than punitive. They want their children to be assertive as well as socially responsible, and self-regulated as well as cooperative." (Baumrind, 1991, p.62). Children of authoritative parents tend to have high self-esteem, have high expectations of themselves and tend to conform to parents' and teachers' expectations of them (Lamborn, Mounts, Steinberg & Dornbusch, 1991)

8.4.1.2 Authoritarian parenting

Authoritarian parents are highly demanding, but lack in parental responsiveness and warmth. "They are obedience and status-orientated, and expect their orders to be obeyed without explanations." (Baumrind, 1991, p.62) Children of authoritarian parents tend to be obedient and conform to the expectations of their parents and other authority figures. However, unlike children of authoritative parents, they tend to have low self-esteem (Lamborn et al., 1991).

8.4.1.3 Permissive parenting

Permissive parents are responsive but do not make demands of their children. "They are more responsive than they are demanding. They are non-traditional and lenient, do not require mature behaviour, allow considerable self-regulation, and avoid confrontation." (Baumrind, 1991, p.62). Children of permissive parents tend to have high self-confidence, but are also more likely to have behavioural problems at school and are more likely to engage in non-conformist behaviour such as substance abuse in adolescence (Lamborn et al., 1991).

8.4.1.4 Uninvolved parenting

Uninvolved parents are neither responsive nor demanding towards their children. Parents who fall on the extremes of being both non-responsive and non-demanding could be characterised as neglectful.

8.4.2 Parents with ADHD

Clinicians have written about difficulties that adults with ADHD have with parenting, suggesting that chronic inattention, impulsivity and hyperactivity interfere with parents' ability to consistently implement daily routines, monitor children's behaviours and problem solve when their children display difficult behaviours (Weiss et al., 2000a). Empirical research also highlights an association between parental ADHD and parenting difficulties. Arnold et al. (1997) found that paternal ADHD symptoms were associated with over-reactive and authoritarian parenting. More recently, Murray and Johnston (2006) found that maternal ADHD symptoms were associated with difficulties in monitoring children's behaviour and less consistency in disciplining children.

The inattentiveness and impulsivity associated with ADHD may lead to difficulties in managing daily routines, such as administering medication (Weiss et al., 2000a). Murray and Johnston (2006) also suggest that difficulties in supervising children's daily activities and providing a structured routine may make it challenging for parents with ADHD to consistently administer medication and verify that their child has taken it.

Therefore, it is hypothesised that parental ADHD will be associated with lower competence in administering medication and that this association will be mediated via parenting style. Specifically, it is expected that parental ADHD will be associated with lower levels of authoritative parenting and higher levels of authoritarian parenting.

8.5 Family relationships and stigma

In order to explore the potential impact of family relationships on stigma, the circumplex model is outlined, and the importance of stigma for families of children with ADHD is considered.

8.5.1 The circumplex model of family systems

Olson's circumplex model of family systems (Olson, 1989) offers a conceptual framework within which to explore the relationship between family functioning and AMRABs. The model consists of two dimensions: cohesion and flexibility. Family cohesion is defined as "the emotional bonding that family members have toward one another" (Olson, McCubbin, Barnes, Larsen, Muxen & Wilson,1992, p1). It represents the degree to which family members are bonded or separated from each other, the strength of their emotional bond, the extent to which they spend time together, know one another's friends, make decisions together, and share interests and recreational activities. Family adaptability is defined as "the ability of a marital or family system to change its power structure, role relationships, and relationship roles in response to situational and developmental stress."

Within the original circumplex model (Figure 8.1), cohesion and flexibility were conceptualised as operating on a curvilinear continuum from low to high, with the middle area being the most conducive to healthy family functioning (Olson, Sprenkle & Russel 1979). However, large-scale studies have found linear relationships between measures of family well-being including family and marital satisfaction (Green, Harris, Forte & Robinson, 1991a; Green, Harris, Forte & Robinson, 1991b). Low levels of cohesion and adaptability have been linearly associated with depression, anxiety, low self-esteem, school misconduct, low academic achievement and marital disagreement (Farrell & Barnes, 1993). High levels of cohesion and adaptability have been associated with quicker recovery and less perceived crisis following a miscarriage (Day & Hooks, 1987), and better parent-adolescent

communication (Barnes & Olson, 1985). Similarly, families where there is significant psychopathology can be distinguished from healthy control families by their low levels of cohesion and adaptability. Prange, Greenbaum, Silver, Friedman and Kutash (1992) found that adolescents who were classed as having severe emotional disturbances were more likely to come from families who were extremely low in cohesion and in adaptability, but that the relationship between emotional disturbance and the dimensions of adaptability and cohesion did not deviate from linearity. Low levels of cohesion and adaptability have also been reported by survivors of childhood sexual abuse (Alexander & Lupfer, 1987).

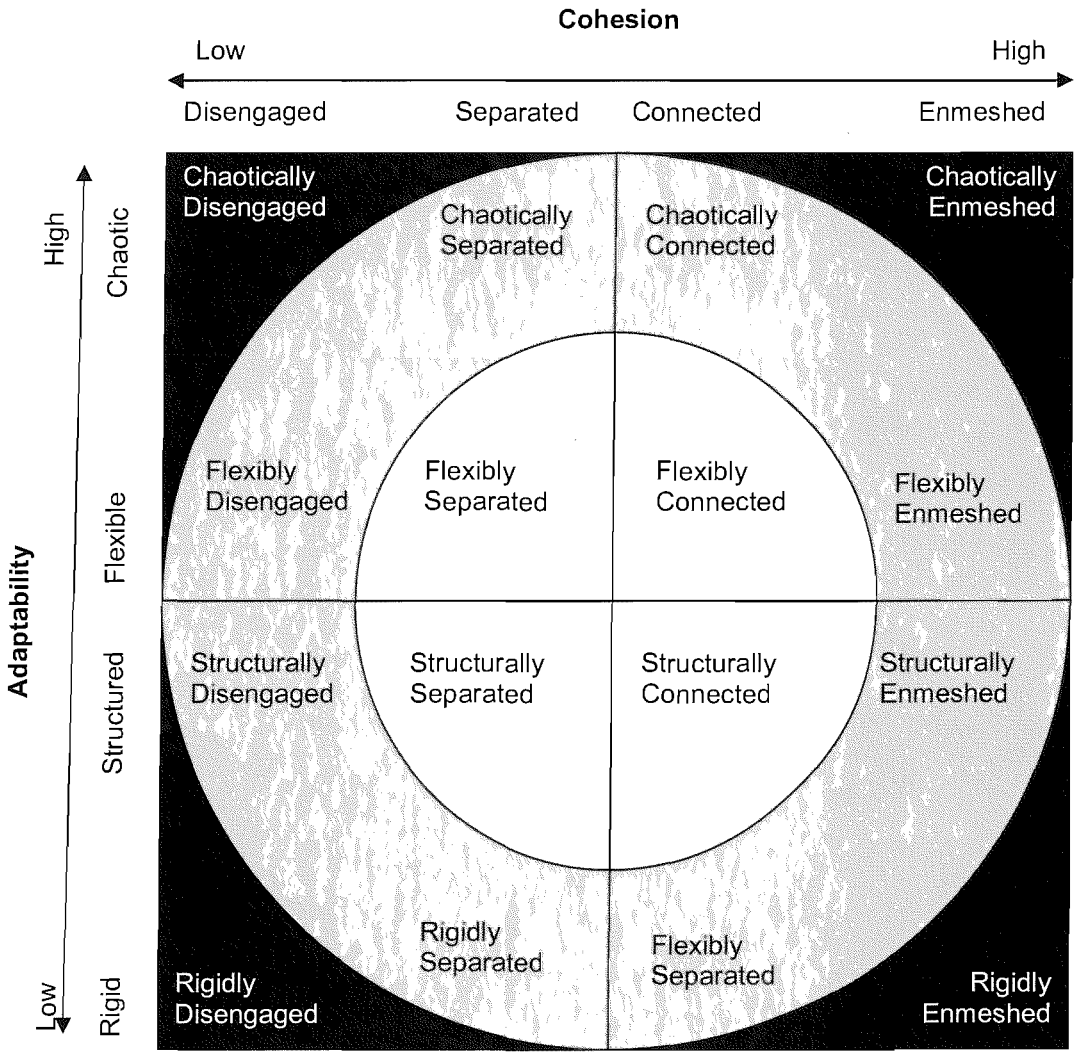


Figure 8.1 Circumplex Model, adapted from Olson et al. (1992)

The general consensus is that adaptability and cohesion as measured by Olson's questionnaires based on the circumplex model should be examined linearly rather than curvilinearly with high levels of cohesion and high levels of adaptability being associated with optimal family health and functioning. (Cluff, Hicks & Madsen, 1994; Green et al., 1991a; Green et al., 1991b; Olson, 1991; Olson et al., 1992). Adaptability and cohesion have been found to be predictive of adherence in asthma (Bernstein et al., 2000).

8.5.2 Stigma

Stigma is recognised as a crucial issue within the field of pediatric mental health, both for children and for parents who are affected by the stigma of having a child with mental heath difficulties (Hinshaw, 2005). The general public may have many misconceptions concerning mental illness, leading to the stigmatisation of people who have a mental health disorder (Angermeyer & Matschinger, 2003; Hayward & Bright, 1997; Mueller et al., 2006; Watson et al., 2005).

The author could only find one study pertaining to children's attitudes to ADHD, which was carried out in Israel and reported that school-age children were less tolerant of their peers with ADHD than their peers with learning disabilities (Brook & Geva, 2002). However, stigma is likely to be a particularly critical issue in ADHD because of the media controversy surrounding the disorder (Faraone, 2005).

Despite the widespread recognition of the disorder amongst the medical and scientific community, the disorder has generated significant controversy (Faraone, 2005; Timimi & Taylor, 2004). Critics of the ADHD diagnosis have argued that ADHD is not a disorder but an the expression of normal childhood energy, the result of boring classrooms, highly competitive educational environments and over-stressed parents or teachers (Baughman, 2001; Breggin, 2001; Breggin, 2002; Diller 1998; Diller, 1999; McCubbin & Cohen, 1997; Radcliffe, Sinclair & Newnes, 2004). Others have argued that the behaviours associated with ADHD are associated with an adverse family environment, attachment difficulties and domestic violence (Golding, 2004; Vetere, 2004).

The dominant perspective within the international medical and scientific communities is that ADHD is a psychiatric condition with a neuro-biological etiology and that pharmacological treatment with stimulants is an appropriate and effective intervention

(American Academy of Child and Adolescent Psychiatry; American Academy of Pediatrics, 2000; American Academy of Pediatrics 2001; Barkley, Cook, Diamond et al., 2002). Hinshaw (2005) proposes that such attitudes perpetuate a culture of parent blaming and exacerbate courtesy stigma. Additionally, the popular media often present both sides of the argument as if they were on an equal footing, leading to misconceptions about the diagnosis and treatment of ADHD (Kwasman, Tinsley, & Lepper, 1995), further stigmatising families who are affected by the condition (Faraone, 2005).

Given the public and emotive nature of this debate, stigma is likely to be a crucial issue for children with ADHD and their families, particularly in the context of considerable controversy concerning its diagnosis and the appropriateness of pharmacological interventions.

8.5.3 Family relationships and stigma

In the field of adult mental health perceived stigma has been associated with lower quality of life (Graf et al., 2004), lower self-esteem (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001) and the avoidance of social interactions outside of the family leading to less social integration and limited use of community leisure facilities (Link, Cullen, Struening, Shrout & Dohrenwend, 1989; Link, Mirotznik & Cullen, 1991; Perlick, Rosenhack, Clarkin, Sirey, Salahi, Struening & Link, 2001). The effect of stigma on social integration is independent from baseline measures of symptom severity (Perlick et al., 2001). The impact of stigma on well-being is also found to continue after a person has recovered from a mental illness (Link, Struening, Rahav, Phelan & Nuttbrock, 1997).

Increased levels of stigma have been associated with perceived social support and positive social relationships for people with depression (Roeloffs, Sherbourne, Unutzer, Fink, Tank & Wells, 2003), for users of an assertive community treatment services (Prince & Prince, 2002); for people with severe mental illness (Mueller, Nordt, Lauber, Rueesch, Meyer & Roessler, 2006) and for people with stigmatising physical conditions such as hepatitis C (Zickmund, Ho, Masuda, Ippolito & LaBrecque, 2003). Parents of children with special needs have been found to report less stigma if they have social support and positive relationships from their children's grandparents (Mickleson, 2001). This suggests that social support and positive

relationships within the family may protect children and parents from the impact of the stigma associated with ADHD.

Four hypotheses are made.

- First, that family cohesion will be negatively associated with parental stigma
- Second, that family cohesion will be negatively associated with child stigma
- Third that parental warmth will be negatively associated with child stigma
- Fourth, that negative parent-child relationships characterised by high levels of parental criticism will be associated with increased child stigma

8.6 Socio-economic status (SES)

Low SES has been associated with poorer outcomes to pharmacological treatment in ADHD (Jensen et al.,1999b), and with reduced treatment adherence (Brown et al., 1997; Reippi et al., 2002). Therefore, it is important to consider the impact of SES in the analysis.

8.7 Aims of the current study

The overarching aim of the current study is to examine how family factors are associated with AMRABs.

Specifically the following hypotheses are made:

(i) Higher levels of behavioural problems will be associated with higher levels of parent and child-report resistance

(ii) Parental mental health symptoms will be associated with parents' perceptions of benefits and costs.

(iii) Parental mental health symptoms will be associated with higher parent and child-report resistance

(iv) The relationship between parental mental health symptoms and resistance will be mediated via parenting self-efficacy

(v) Parental mental health symptoms will be associated with higher competence scores (i.e. parents with poorer mental health will have more difficulties in administering medication)

(vi) The relationship between parental mental health symptoms and competence will be medicated via parenting self-efficacy

(vii) Parental ADHD will be associated with lower competence in administering medication

(viii) The relationship between parental ADHD and competence will be mediated via parenting style – specifically, lower levels of authoritative parenting and higher levels of authoritarian, permissive and uninvolved parenting

(ix) Family cohesion will be negatively associated with child stigma

(x) Family cohesion will be negatively associated with parental stigma

(xi) Parental warmth will be negatively associated with child stigma

(xii) Negative parent-child relationships characterised by high levels of criticism will be associated with increased child stigma.

Due to the preliminary nature of this study and the novelty of the hypotheses, all analyses were carried out using two-tailed hypotheses testing.

8.8 Methods

8.8.1 Procedure and participants.

The research protocol was approved by the Hampshire and Isle of Wight NHS ethics committee in the UK, the Institutional Review Board at the Child Study Center in New York University Medical School and by the School of Psychology ethics committee at the University of Southampton.

Participants were asked to complete a series of questionnaires and return these via email or post. Once the questionnaires were returned, participants were called and a measure of expressed emotion was taken using the five minute speech sample (FMSS) by telephone.

Participants were recruited from four sources including, ADHD clinics in Hampshire; an ADHD clinic in New York; via invitations posted on internet based support groups for parents of children with ADHD; and participants from support groups who took part in study 3 were asked if they would like to participate in an extended study.

The participants were 93 mothers and 82 of children with ADHD who were being treated with medication at the time of the study. 28 parents and 25 children were recruited from the UK clinics; 13 parents and 12 children from the New York clinic; 34 parents and 27 children from the internet and 18 parents and 18 children from support groups. A total of 66 parents and 58 children were from the UK and a total of 27 parents and 24 children were from the USA

84% of the parents were reporting on male children, 16% on female, which is reflective of the 4:1 male: female ratio in ADHD diagnosis (Barkley, 1990). The children aged from 7.24 to 17.45 years with a mean age of 12.18 (sd = 2.49). 69% of the parents were married, 19% divorced/separated and 9% single (3% did not report their marital status).

All of the children were currently taking medication for ADHD. Children's medication regimens were classified using the same system as outlined in chapter 7 and as displayed in Table 8.1. 44% of the sample had been taking medication for more than 4 years, 28% for 2-4 years, 17% for 1-2 years, 10% for 1-6 months and 1% for less than one month. As with the previous study, there seems to be a sample bias towards participants who are long-term adherers to medication.

Table 8.1 Medications that children were taking

MEDICATION	% Cases (N=93)
Short acting methylphenidate (Ritalin, Focalin)	15.1
Sustained release methylphenidate (Concerta, Ritalin XR, Ritalin LA, Metadate CD)	49.5
Adderall	8.6
Atomoxetine (Strattera)	5.4
Dextroamphetamine	5.4
Combination of short acting methylphenidate and sustained release methylphenidate	11.8
Combination of methylphenidate and atomoxetine	4.3

8.8.2 Measures

Participants were asked to complete the following measures:

8.8.2.1 AMRABs questionnaires

The AMRABs questionnaires, as refined in chapter 7 (Appendix C.4) were given to all participants. These include parent and child ratings of perceived benefits, costs, child stigma associated with taking medication and child resistance to taking medication, and parent-report parental stigma, competence and flexibility in administering medication.

8.8.2.2 Strengths and Difficulties Questionnaire (SDQ)

The SDQ (Goodman, 1999) is a behavioural screening questionnaire that asks participants to rate a child on 25 attributes, some positive and some negative on a three point Likert scale (not true, sometimes true and certainly true). The 25 items are divided into five subscales of five items each, and yield scores for conduct problems, hyperactivity, emotional problems, peer relationship problems and pro-social behaviour.

The SDQ has been found to have high internal reliability (Cronbach α = .82) and high test-retest reliability (Cronbach α = .82) (Goodman, Fort, Richards, Gatward & Meltzer, 2000). The five-factor structure of the SDQ has been confirmed in large-scale UK studies, which have demonstrated high internal reliability and independence between factors (Goodman, 2001). However, studies in the USA have yielded contradictory results. Dickey & Blumberg (2004) found that the best-fitting solution in a large USA study included three factors (internalising, externalising and pro-social), suggesting that parents in the USA may construe behavioural problems differently from parents in the UK. However, Bourdon, Goodman, Rae, Simpson & Cortez (2005) found high internal reliability for four subscales of the SDQ (Cronbach α between .63 and .77) and fair for peer relationships (Cronbach α = .46). Only the conduct problems scale, which has high reliability in the UK and USA, is used in this study.

8.8.2.3 Adult ADHD rating scales

An 18-item self-report questionnaire based on the DSM-IV criteria for ADHD was used to assess mothers' current level of ADHD symptoms (Murphy & Barkley, 1995). The questionnaire asks participants to rate their behaviour over the past six months on a four point Likert scale (never, occasionally, often and very often). Nine items are used to give an overall score for hyperactivity and nine are used to give an overall score for inattentiveness. These can then be added together to give an overall ADHD symptoms score. The scales have been found to have a high reliability (Cronbach α = .88) and are recognised as a suitable screening tool for adult ADHD (Faraone & Biederman, 2005; Murphy & Adler, 2004; Weiss & Murray, 2003).

8.8.2.4 Child ADHD rating scales

An 18-item parent-report questionnaire based on the DSM-IV criteria for ADHD was used to assess children's current level of ADHD symptoms (DuPaul, Anastopoulos, Power, Reid, McGoey & Ikeda, 1998). The questionnaire asks participants to rate their children's behaviour over the past six months on a four point Likert scale (never, occasionally, often and very often). Nine items are used to give an overall score for hyperactivity and nine are used to give an overall score for inattentiveness. Two distinct factors are found (hyperactivity and impulsivity). These factors are highly correlated, indicating that the symptoms tend to co-occur (DuPaul et al., 1998).

8.8.2.5 General Health Questionnaire (GHQ)

The GHQ a self-report questionnaire to detect psychiatric disorders in the general population (Goldberg, 1978). It asks participants about their general levels of happiness, depression, anxiety, self-confidence and stress over the past few weeks. Originally, the GHQ was scored in a bi-modal fashion (0-0-1-1). However, this was criticised for under-identifying participants with psychological problems (Newman, Bland & Orn, 1988). It is generally accepted that a Likert type scale (0-1-2-3) is the most appropriate for statistical analyses (Andrich & Van Schoubroeck, 1989; Campbell, Walker & Farrell, 2003; Jacobsen Hasvold, Hoyer & Hansen, 1995). The GHQ-12 has a high reliability rating (Cronbach α between .82 and .86) (Goldberg et al., 1997). The GHQ was chosen because of its ability to detect threats to psychological health that may not necessarily constitute a formal psychiatric

condition. Such threats to psychological health are likely to be prevalent amongst parents of children with ADHD.

There has been some debate in the literature as regards the factor structure of the GHQ, with some studies suggesting a three-component factor structure (Campbell et al., 2003). However, Goldberg et al., (1997) suggest that the GHQ-12 should be treated as a unitary measure of psychological distress. The shorter version of the GHQ (GHQ-12) was chosen for this study because of its brevity. Previous studies have suggested that it is comparable in reliability to longer versions (Goldberg et al., 1997).

8.8.2.6 Parenting Sense of Competence (PSOC)

The PSOC (Johnston & Mash, 1989) is a 17-item self-report questionnaire, which assesses two dimensions of parenting self-esteem, namely, parenting satisfaction and parenting self-efficacy. Parenting self-efficacy is defined as *"the degree to which a parent feels competent and confidence in handling child problems"* (Mash & Johnston, 1989, p.451). Parenting satisfaction is defined as *"the quality of affect associated with parenting."* (Johnston & Mash, 1989, p.451). The questionnaire shows a robust factor structure and high internal consistency (Cronbach α = .79 for the whole scale and .75 and .76 for the satisfaction and self-efficacy scales respectively).

8.8.2.7 Parenting Styles and Dimensions (PSD)

The PSD instrument (Robinson, Mandleco, Olsen & Hart, 2001) was used to assess authoritative and authoritarian parenting styles. Mothers were asked to report both on their behaviours and on their spouse's behaviours, if relevant. The PSD measures three dimensions from Baumrind's model of parenting: authoritative parenting measured by three subscales (warmth and support, reasoning induction, and autonomy granting); authoritarian parenting measured by three subscales (physical coercion, verbal hostility and punitive punishment); and permissive parenting measured by one subscale. Participants rate a series of questions regarding themselves and their spouses where relevant on a Likert scale from 1 (never) to 5 (always). An overall score for each subscale and overall parenting style is obtained by taking the mean of the relevant items. Each of the scales of the PSD is reported to have high reliability (Cronbach α between .69 and .91) (Russell, Hart, Robinson & Olsen, 2005).

8.8.2.8 Family Adaptability and Cohesion Scales (FACES-II)

The FACES II (Olson et al., 1992) scale was used to assess cohesion and adaptability as defined by Olson's circumplex model. Items are rated on a 5-point Likert scale from "almost never" to "almost always" with respect to how well each item describes the family. The scales can be looked at on a continuum. Alternatively, the cohesion score can be used to categorise families as very flexible, flexible, structured or rigid, and the adaptability score to categorise families as very connected, connected, separated or disengaged. Internal consistency (Cronbach α = .87 and .78 for cohesion and adaptability respectively) and test retest reliability (r = .77 and .62 for cohesion and adaptability respectively) are reported to be good (Olson et al., 1992). The current study will examine the cohesion scale on a continuum.

8.8.2.9 Expressed emotion (EE)

The concept of EE was originally developed within the field of adult mental health to investigate how family factors influence relapse in schizophrenia (Brown, Carstairs & Topping, 1958). Brown, Monck, Carstairs and Wing (1962) demonstrated that high levels of expressed emotion, and in particular the level of hostility directed towards the person with schizophrenia predicted deterioration and relapse in the following year. EE is most commonly assessed using the 'five minute speech sample (FMSS) (Magana-Amato, Goldstein, Karno, Miklowitz, Jenkins & Falloon, 1986). The FMSS asks participants to talk about their relative for five minutes. This monologue is then coded, taking both tone and content into consideration to index the two main components of EE: criticism and emotional over involvement (EOI).

Speech samples are rated as highly critical if any of following scores are rated:

(i) A negative initial statement
(ii) A negative rating on the quality of the relationship
(iii) One or more critical remarks

EOI is coded if the speech sample contains

(i) Emotional display (e.g. crying)
(ii) The participant reports over-protective and self-sacrificing behaviour
(iii) Expression of feelings about the person

(iv) Exaggerated praise

The FMSS has been found to have high inter-rater reliability (Magana-Amato et al., 1986) and good test-retest reliability (Barnes-McGuire & Earls, 1994). EE scores based on the FMSS have also been compared to EE scores derived from the Camberwell Family Interview, a more intensive semi-structured interview used to assess relatives' attitudes towards a person by asking them to describe the behaviour of the person and the quality of their relationship. A high concordance between the two indicated the reliability of the FMSS to assess EE (Magana-Amato et al., 1986). Inter-rater reliability for the current study was obtained by asking a second rater, experienced in coding FMSS, for 20 participants. Agreement was attained on 18 of the samples, with the disagreement on two samples, being between participants rated as borderline and high critical, giving a high kappa value of .90.

EE is considered to offer a reflection of the style of interaction between the interviewee and the person they are describing. High levels of EE have shown strong associations with measures of negative emotions, conflict and rigidity within the relationship (Hubschmid & Zemp, 1989). However, it should be noted that EE most likely reflects a reciprocal pattern, influenced as much by the personality of the interviewee as by the behaviour of the person they are describing. For example, maternal psychopathology is predictive of high EE ratings when mothers are asked to describe their children. In particular, maternal anxiety is reported to be predictive of higher levels of criticism towards the child, whereas, maternal affective disorder is predictive of EOI (Hirshfield, Biederman, Faraone & Rosenbaum, 1997). However, it is clear that child behaviour and psychopathology also plays an important role. Hibbs, Hamburger, Rapoport, Kruesi, Keysor & Goldstein (1991) found that parents of children with disruptive behaviour disorder (DBD) and children with obsessive compulsive disorder (OCD) were more likely to exhibit high EE compared to parents of normal controls. However, Hibbs et al. (1991) also found higher levels of parental psychopathology in the parents of children with DBD and OCD. Hibbs, Hamburger, Kruesi and Lenane (1993) found that maternal and child psychopathology contributed independently to higher maternal EE, whereas paternal psychopathology, but not child psychopathology contributed to higher paternal EE.

EE may play an important role in the progression of ADHD. Taylor et al., (1996) found that maternal critical EE at age 7 was predictive of conduct disorder at age 17 years for boys with pervasive hyperactivity. This effect occurred independantly of

children's behavioural disburbance. Therefore it is likely that EE plays an important role in successful treatment outcome.

High levels of criticism as assessed by the FMSS are predictive of asthma symptoms in adolescents (Wamboldt et al., 1995), and persistence of depressive symptoms for children treated in hospital for depression (Asarnow, Goldstein, Tompson & Guthrie, 1993).

The usefulness of the EOI rating is questioned when examining parent-child relationships due to developmental issues. The categories pertaining to EOI relate to features of adult-to-adult relationships such as the ability to communicate or interest in the relatives hobbies. The dependency of a younger child on their parent is developmentally healthy and necessary. Therefore, many researchers do not consider the EOI construct useful in examining parent-child relationships (Vostanis, Nicholls and Harrington, 1994; Wamboldt, O'Connor, Wamboldt, Gavin and Klinnert, 2000). The current study will only consider the criticism component of the FMSS speech sample.

It is also important to note possible cultural differences in EE between the UK and the USA. Leff and Vaughn (1985) studied EE in the families of people with schizophrenia and people with 'depressive neurosis' in the UK and the USA and found higher levels of critical EE in the American sample.

8.8.2.10 SES

Participants were asked for their and their spouse's occupation. The International Standard Classification of Occupations (ISCO-88) (International Labor Office, 1990) was used to classify the occupational status of the participants within nine categories:

1 Legislators, Senior Officials, Managers
2 Professionals
3 Technicians & Associated Professionals
4 Clerks
5 Skilled Workers, Shop and Market Sales Workers
6 Skilled Agricultural and Fishery Workers
7 Craft and Related Trades Workers
8 Plant and Machine Operators and Assemblers

9 Elementary Occupations

The ISCO-88 has been used across a variety of western cultures including the USA and the UK and is considered an acceptable tool for analysis across countries (Ganzeboom & Treiman, 1996). Where the occupational status of the spouse was different from that of the informant, the higher occupational status was coded. As the current sample size is relatively small, the ISCO-88 was recoded into two categories: High SES incorporating groups 1-4 and Low SES incorporating groups 5-9.

A complete list of questionnaires administered to participants is included in Appendix F.

8.9 Results

8.9.1 Sample characteristics: participants from the internet, support groups and ADHD clinics

Participants from the four sources (UK clinics, USA clinic, internet and support groups) were compared on the demographic variables of age, gender, nationality, marital status, occupational status.

A univariate ANOVA showed that participants from the support group sample were significantly older than participants from the USA clinic and the internet ($F_{3,89}$ = 6.20, p <.001) (Appendix H, Table H.1).

Chi-square analyses revealed no difference on gender (χ^2= 5.31, df = 3, p = ns) or marital status (χ^2= 4.18, df = 3, p = ns). Unsurprisingly, there were differences in the nationalities between the groups (χ^2= 56.84, df = 3, p <.001) with all participants from the UK clinics and support groups coming from the UK, all participants from the USA clinic coming from the USA and 60% of participants from the internet coming from the UK and 40% from the USA.

Socio-economic data was available on 72 participants. There was also a marginal difference in SES scores between the groups (χ^2= 6.15, df = 3, p = .10) (Appendix H, Table H.2). In particular, it is notable that all participants from the USA clinic and, 74% in the internet category were classed as being within the "high SES" category,

compared with 61% and 67% in the UK clinic and support group samples respectively. This is likely due to the nature of the clinic in the US, in that it was a private facility, which did not accept patients on Medicaid. Similarly, the higher proportion of professionals in the internet sample compared to the UK clinics and support groups may be a reflection of the socio-economic status of internet users.

Descriptive statistics examining AMRABs within the high and low SES groups are displayed in Appendix G, Table G.1. MANOVAs examining differences in parent and child AMRABs between the SES groups revealed a significant difference on parental stigma but not on other AMRABs variables with parents from higher SES groups reporting significantly higher parental stigma (Appendix G. Tables G.2 & G.3). Participants from high SES groups consistently reported higher levels of parental stigma across all samples and between the UK and the USA (Appendix H, Table H.3).

The difference in SES is important to consider as SES has been found to have important implications for treatment outcome (Jensen et al., 1999b). SES will therefore be controlled in analyses examining parental stigma.

8.9.2 Sample characteristics: participants from the UK and USA

Participants from the UK and USA were also compared on demographic variables. As with study 3, children from the UK were significantly older than children from the USA (T_{93} = 3.78, p<.001). Chi-square analyses found differences between the UK and USA on SES, with 66% of UK participants being classed as "high SES" compared with 88% of participants from the USA (χ^2= 4.08, df = 1, p <.05). There were no differences between the UK and USA on gender (χ^2= .629, df = 1, p = ns), or marital status (χ^2= 2.68, df = 2, p = ns).

8.9.3 Hypothesis: Higher levels of behavioural problems will be associated with higher levels of parent and child-report resistance

The relationship between childhood behaviour problem scores on the SDQ and resistance was examined using linear regression analyses. Conduct problem scores on the SDQ were positively associated with both parent ($F_{1,88}$ = 14.17, p < .001) and child-report resistance ($F_{1,77}$ = 11.89, p < .001) (Appendix G, Table G.4) (Figures 8.2 and 8.3). Conduct problems explained 13% of the variance in parent report

resistance and 12% in child report resistance. This result was consistent across samples and between the UK and the USA (Appendix H, Table H.4).

8.9.4 Hypothesis: Parental mental health symptoms will be associated with parents' percevied benefits and higher costs

There was a negative relationship between maternal mental health difficulties as measured by the GHQ and parent-report benefits, explaining 5% of the variance ($F_{1,88} = 4.60$, $p<.05$). Conversely, there was a positive relationship between maternal mental health difficulties and parent-report costs explaining 4% of the variance ($F_{1,88} = 4.47$, $p < .05$). (Appendix G, Table G.5). These relationships were consistent across samples and between the UK and the USA (Appendix H, Table H.5) (Figures 8.4 and 8.5).

8.9.5 Hypothesis: Parental mental health symptoms will be associated with higher parent and child-report resistance

The was a significant assoication between maternal GHQ and parent-report resistance, explaining 10% of the variance ($F_{1,64} = 3.65$, $p <.05$). The relationship between GHQ and child report resistance was marginally significant, explaining 3% of the variance ($F_{1,60} = 2.53$, $p = .10$) (Appendix G, Table G.5). These relationships were consistent across samples and between the UK and the USA (Appendix H, Table H.5).

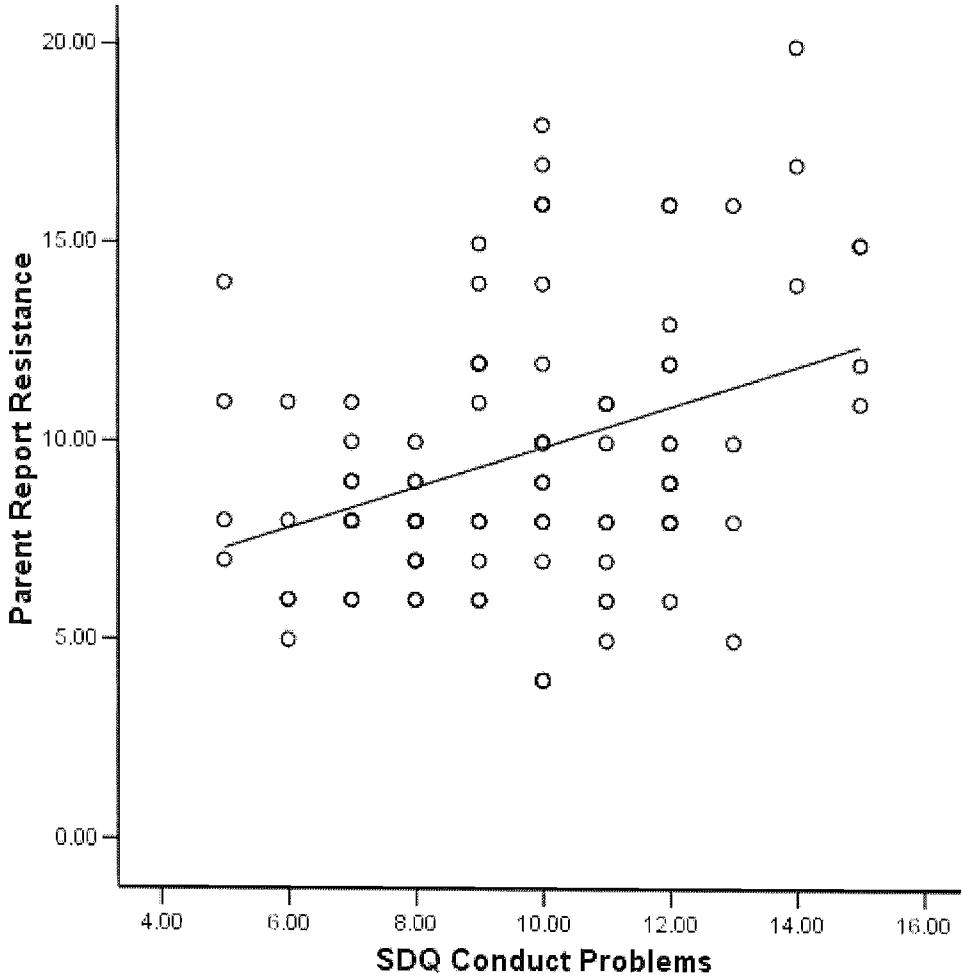


Figure 8.2 Relationship between conduct problems and parent-report resistance

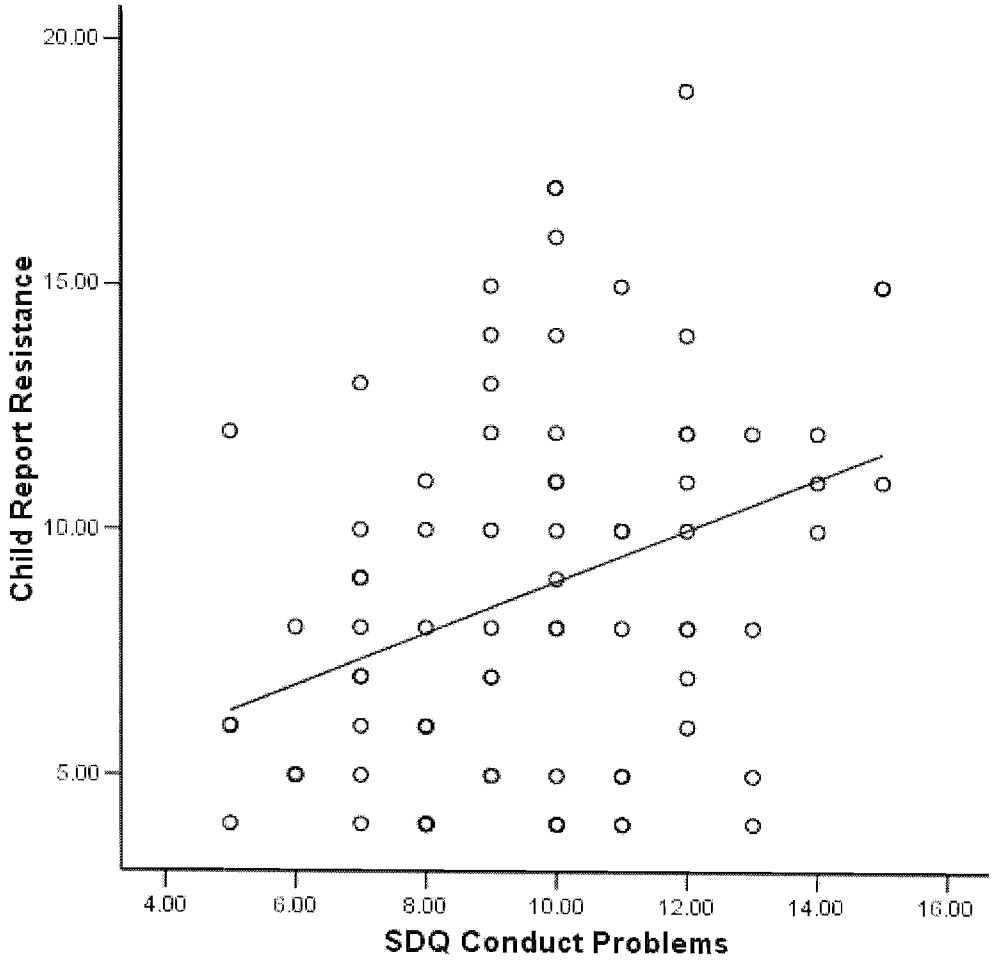


Figure 8.3 Relationship between conduct problems and child-report resistance

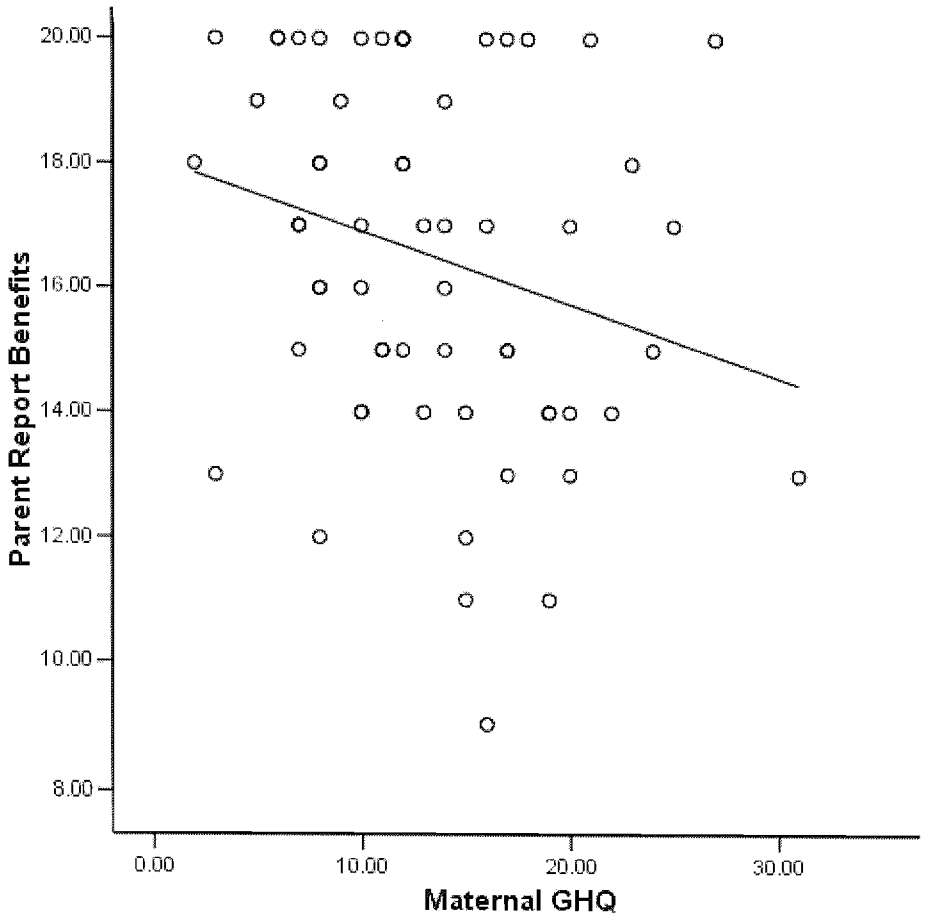


Figure 8.4 Relationship between maternal GHQ and parent-report benefits

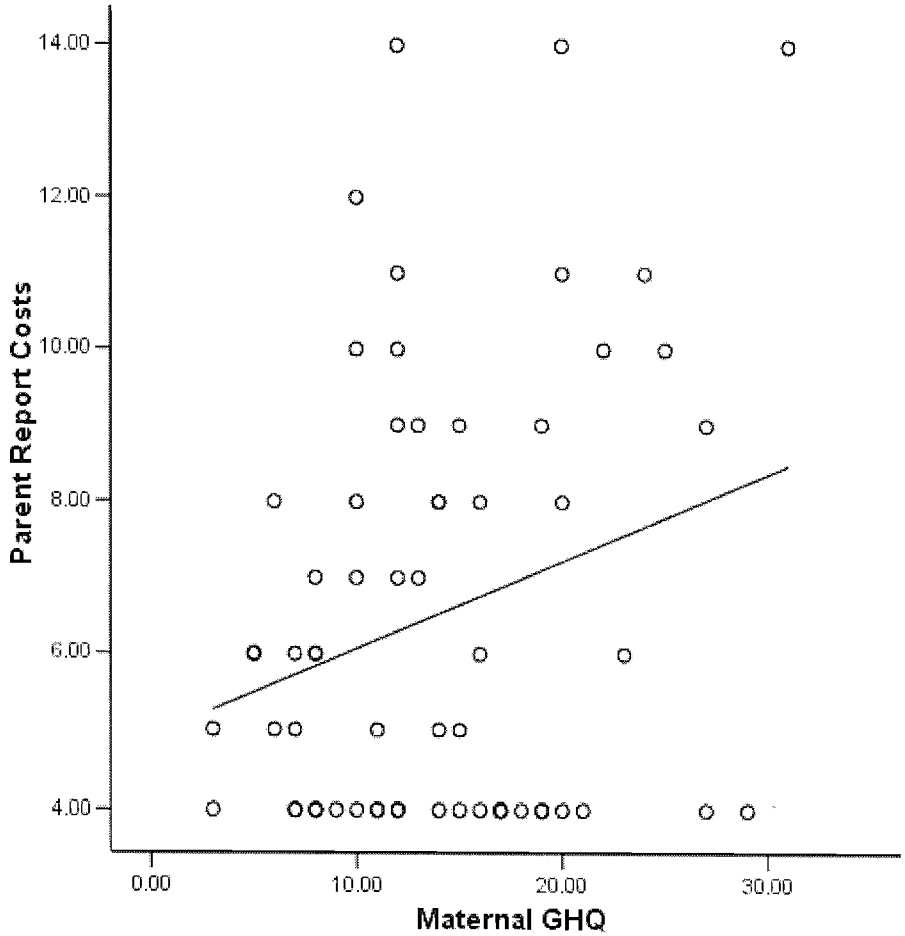


Figure 8.5. Relationship between maternal GHQ and parent-report costs

8.9.5.1 Hypothesis: The relationship between parental mental health symptoms and resistance will be mediated via parenting self-efficacy

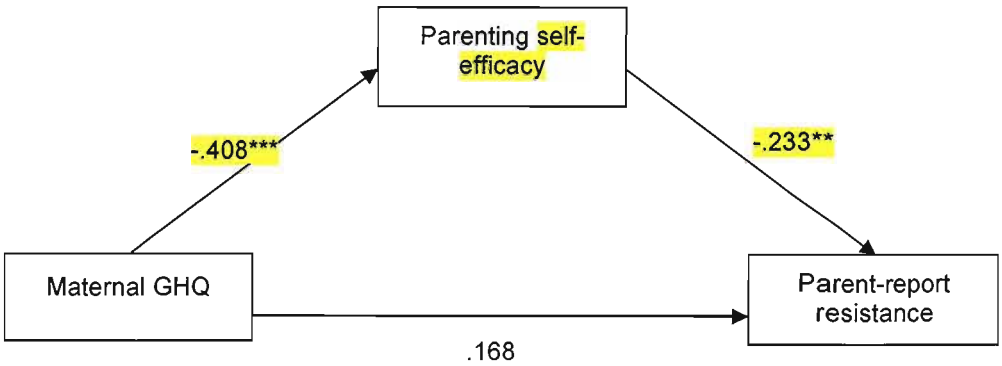
Baron and Kenny (1986) identify four criteria with which to identify a mediating relationship. First, there must be a relationship between the predictor (GHQ) and the dependant variable (resistance). Second, there must be a relationship between the predictor (GHQ) and the DV (resistance). Third there must be a relationship between the predictor (GHQ) and the mediator (parenting self-efficacy). Fourth, the relationship between the predictor and the dependant variable must not be significant when the mediator and predictor are entered together in a regression analysis.

The relationship between GHQ and resistance is documented above meeting the first criterion. GHQ scores were negatively related to both parenting self-efficacy ($F_{1,64}$ = 5.04, p < .05) and parenting satisfaction ($F_{1,64}$ = 12.58, p = <.001) meeting the second criterion. GHQ scores were also negatively associated with overall parenting self-esteem as calculated by combining the efficacy and satisfaction subscales from the PSOC, meeting the third criterion ($F_{1,64}$ = 11.39, p = <.001) (Appendix G, Table G.6). These associations were consistent across samples and across country (Appendix H, Table H.6).

Multivariate regression analyses revealed that the relationship between maternal GHQ and parent-report resistance was no longer significant when parenting self-efficacy was included in the analysis, thereby meeting Baron and Kenny's fourth criterion ($F_{2,62}$ = 3.47, p <.05) (Appendix G, Table G.7). The Sobel test was then used to confirm whether parenting self-efficacy carried the influence of maternal GHQ on parent report resistance. However, this was not significant (z=.03, se=.25, p = ns)

It was therefore concluded that parenting self-efficacy did not significantly mediate the relationship between maternal GHQ scores and parent-report resistance in the current sample (Figure 8.6).

Maternal GHQ only marginally predicted child report resistance. However, when maternal GHQ and parenting self-efficacy were included to together in the analysis (Appendix G, Table G.5), neither significantly predicted child-report resistance ($F_{2,58}$ = 1.68, p = ns) (Appendix G, Table G.8). Therefore, it was concluded that parenting self-efficacy did not mediate the relationship between GHQ and child-report resistance.



*** significant at the .001 level
**significant at the .05 level
*marginally significant (p<.10)

Figure 8.6 Parenting self-efficacy as a mediator of the relationship between maternal mental health and parent-report resistance

8.9.6 Parental mental health symptoms will be associated with higher competence scores

There was no relationship between maternal GHQ and competence scores (F1,65 = .06, p = ns) (Appendix G, Table G.5). This result was consistent across samples (Appendix H, Table H.5),

8.9.6.1 Relationship between parenting self-efficacy and competence in administering medication

There was no relationship between GHQ and competence in administering medication. However, there was a direct relationship between parenting self-efficacy and competence in administering medication, with parents who have lower parenting self-efficacy also seeing themselves as less competent in administering medication ($F_{1, 92}$ = 6.16, p = < .05) (Figure 8.7) (Appendix G, Table G.9). This result was consistent across samples and between the UK and the USA (Appendix H, Table H.9).

8.9.7 Hypothesis: Maternal ADHD symptoms will be associated with lower competence in administering medication

Maternal ADHD symptoms were positively associated with competence scores explaining 5% of the variance. This indicates that mothers with higher levels of ADHD symptoms had more difficulties in administering the medication regimens ($F_{1,80}$ = 4.79, $p < .05$) (Appendix G, Table G.10) (Figure 8.8). This result was consistent across samples and in the UK and USA (Appendix H. Table H.10).

8.9.7.1 Is the relationship between maternal ADHD and competence mediated by parenting style?

Maternal ADHD was not associated with authoritative ($F_{1,74}$ = .03, p = ns) or permissive parenting ($F_{1,73}$ = .00, p = ns). However there was a marginally significant relationship between ADHD symptoms and authoritarian parenting, explaining 3% of the variance ($F_{1,61}$ = 3.16, p = .08) (Appendix G, Table G.11). Subsequent analyses examining the relationship between maternal ADHD found contradictory results across samples – notably, maternal ADHD was associated with higher authoritarian and lower authoritative parenting in the USA sample, but not in the UK sample. Additionally a negative association between maternal ADHD and authoritarian parenting was found in the support group sample. The results for permissive parenting were particularly contradictory with negative associations found in the UK clinic and internet samples and positive associations found in the US clinic and support group samples (Appendix H, Table H.11). No consistent associations between maternal ADHD and parenting style were found.

Additionally, authoritarian parenting was not associated with competence in administering medication ($F_{1,69}$ = 2.68, p = ns) (Appendix G, Table G.12). Therefore, it is concluded that differences in parenting style do not mediate the relationship between maternal ADHD and competence in administering medication in the current sample.

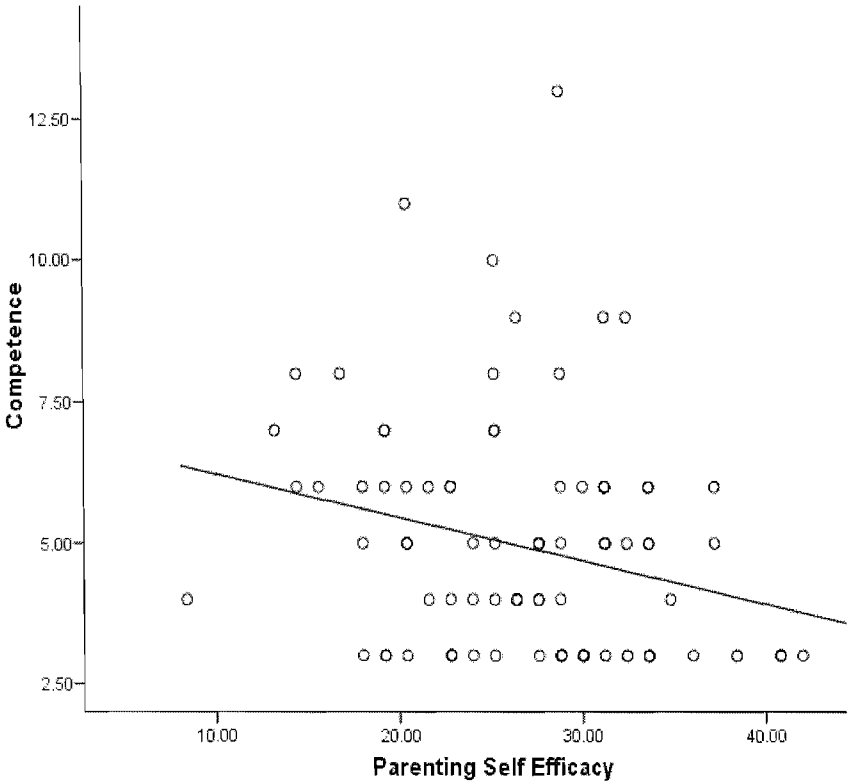


Figure 8.7 Relationship between parenting self-efficacy and difficulties in administering medication

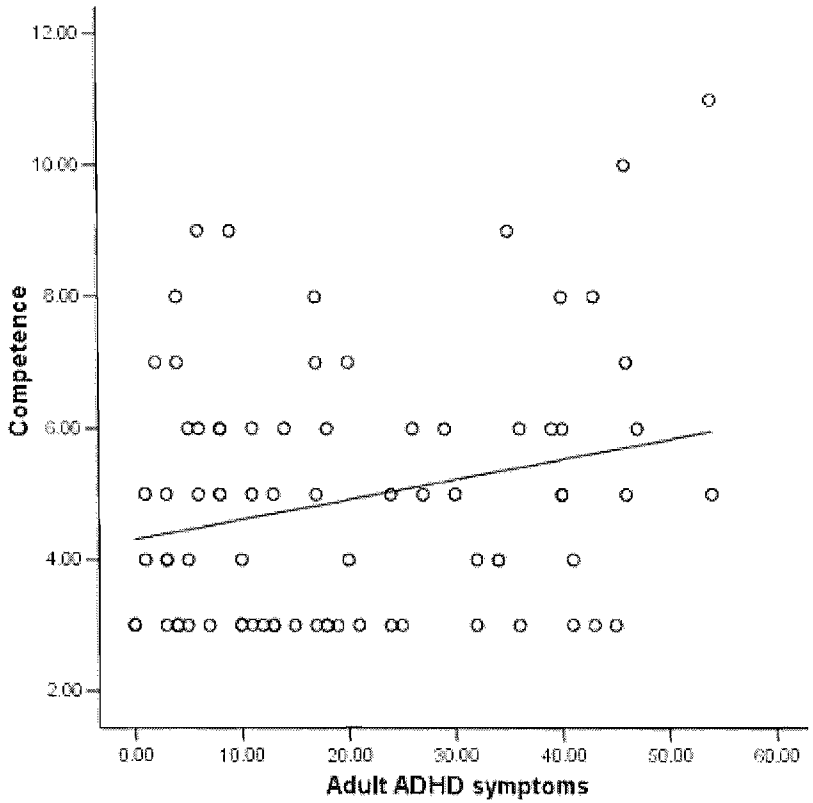


Figure 8.8 Relationship between maternal ADHD and difficulties in administering medication

8.9.8 Hypothesis: Family cohesion will be negatively associated with child stigma

Regression analyses showed that family cohesion was associated with parent-report child stigma ($F_{1,92} = 3.99$, $p < .05$) but not child-report stigma ($F_{1,79} = .64$, p = ns) (Appendix G, Table G.13). However, subsequent analyses found relationships between family cohesion and parent-report child stigma ($F_{1,25} = 6.87$, $p < .05$); and child-report stigma ($F_{1,22} - 5.37$, $p < .05$) in the USA, but none in the UK. In the USA, family cohesion explained 19%, and 17% of the variance in parent-report child stigma and child-report stigma respectively (Appendix H, Table H.12).

When entered together into a regression analysis country significantly predicts parent-report child stigma ($F_{2,92} = 6.26$, $p < .01$) and child stigma ($F_{2,79} = 4.55$, $p < .01$), the effect of cohesion is no longer significant while the effect of country explains 11% of the variance in both parent and child-report child stigma (Appendix G, Tables G.14 and G.15). However, the significant effect of family cohesion on parent and child-report child stigma suggests family cohesion may have a protective effect against child stigma in the USA, but not in the UK.

8.9.9 Hypothesis: Family cohesion will be negatively associated with parental stigma

Regression analyses found a relationship between family cohesion and parental stigma ($F_{1,90} = 4.19$, $p < .05$) (Appendix G, Table G.16). However, analyses examining this effect found a significant relationship explaining 16% of the variance in the USA sample (F1, 24 = 5.46, $p < .05$), but no relationship in the UK sample (Appendix H, Table H.12).

The relationship between family cohesion and parental stigma was no longer significant when SES was controlled for in the analysis ($F_{2,87} = 2.70$, $p = .06$). (Appendix G, Table G.17). However, only 3 participants within the USA sample were classed as having low SES, therefore, the effect of SES on the USA sample cannot be assessed in the current study. When cohesion, SES and country are included together in the analysis, only SES is marginally predictive of parental stigma ($F_{3,67} = 1.90$, p= .13) (Appendix G, Table G.18).

8.9.10 Hypothesis: Parental warmth will be negatively associated with child stigma

Linear regression analyses revealed no relationship between self-report ($F_{1,92}$ = .06, p = ns) or spouse parental warmth on the PSD questionnaire ($F_{1,74}$ = 1.57, p = ns) with parent-report child stigma. However, both self-report parental warmth ($F_{1,79}$ = 4.42, p <.05) and spouse parental warmth ($F_{1,64}$ = 5.01, p <.05) were negatively associated with child-report stigma explaining 4% and 6% of the variance respectively (Appendix G, Table G.19).

Subsequent analyses examining participants in the UK and USA separately found no relationship between self-report parental warmth and either parent or child-report stigma in the UK sample. However, both were negatively associated in the USA sample with self-report parental warmth explaing 7% of the variance in parent-report and 26% of child-report stigma in the USA sample (Appendix H, Table H.13).

Country was a more significant predictor of parent-report child stigma than either self-report parental warmth ($F_{2,92}$ = 6.29, p <.01) (Appendix G, Table G.20) or spouse parental warmth ($F_{2,74}$ = 5.11, p <.01) (Appendix G, Table G.21). However, country and self report parental warmth ($F_{2,79}$ = 5.34, p <.05) were both predictive of child-report stigma together explaining 9% of the variance (Appendix G, Table G.22). Likewise, country and spouse parental warmth ($F_{2,64}$ = 6.30, p <.01) were also predictive of child-report stigma, together explaing 14% of the variance (Appendix G, Table G.23).

8.9.11 Hypothesis: Negative parent-child relationships characterised by high levels of criticism will be associated with increased child stigma

Not all participants were willing to give a FMSS. Measures of expressed emotion were obtained from 59 mothers. Of these, 32 were rated as "not critical", 16 as "borderline critical" and 11 as "highly critical". An ANOVA revealed an association between maternal criticism and parent-report child stigma ($F_{2,56}$ = 4.04, p<.05).

Post-hoc analysis using Tukey HSD revealed significant differences between parents rated as 'Not critical' and parents rated as 'borderline critical' or 'highly critical' (Appendix G, Table .24) (Figure 8.9).

The relationship between criticism on EE and child-report stigma mirrored this pattern of results (Figure 8.10). An ANOVA revealed that maternal criticism was associated with child-report stigma ($F_{2,53}$ = 4.76, p<.05) and post hoc analysis revealed one significant difference between parents rated as not critical and parents rated as highly critical (Appendix G, Table G.25). It was not possible to conduct separate analyses between samples owing to the small numbers of participants in each group who scored high or borderline on critical EE. However, participants in the not critical group in each sample were consistently lower in parent and child-report child stigma than participants in the borderline and high critical groups (Appendix H, Table H.14).

The small number of participants who scored as borderline or highly critical within the UK and USA when examined separately, made it difficult to assess. However, participants who scored as "not critical" on EE showed lower levels of both parent and child-report stigma across samples and between the UK and the USA. When examined together, both country and critical expressed emotion were predictive of parent ($F_{2,58}$ = 5.75, p < .01) (Appendix G, Table G.26) and child-report stigma ($F_{2,52}$ = 6.93, p < .01) (Appendix G, Table G.27)

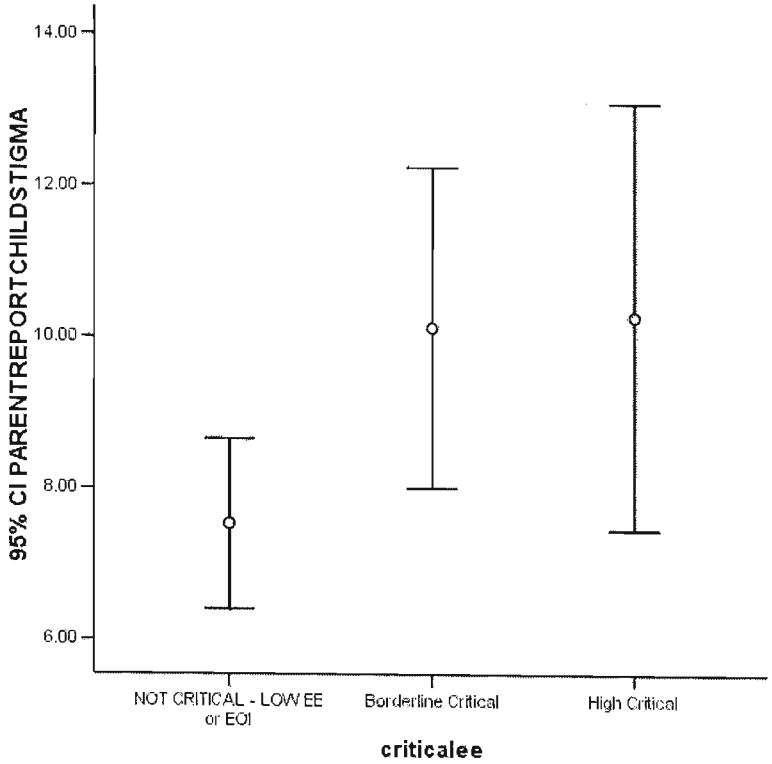


Figure 8.9 Differences in parent-report stigma between parents classed as not critical, borderline critical and highly critical on EE

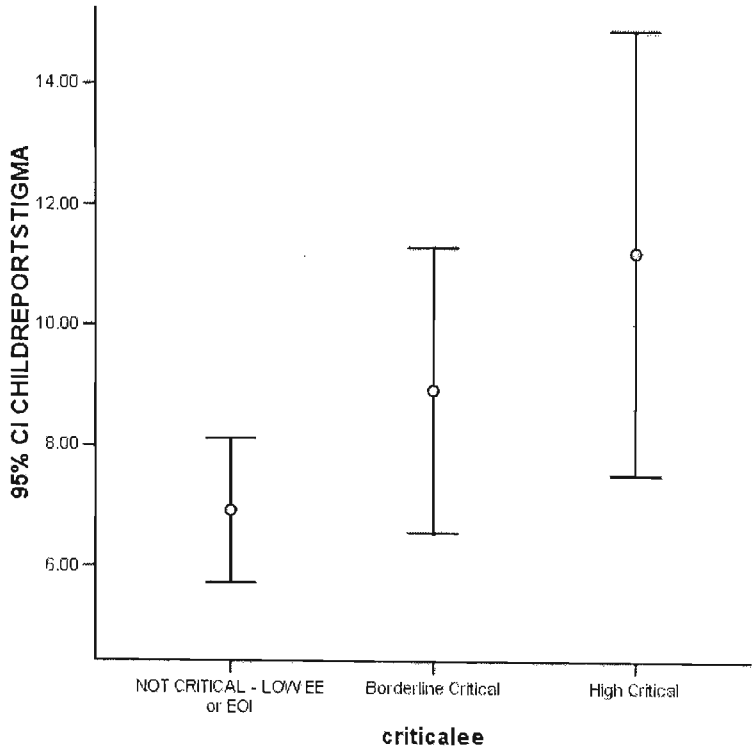


Figure 8.10 Differences in child-report stigma between parents classed as not critical, borderline critical and highly critical on EE

8.10 Summary of results

This study found[4]:

- Child conduct problems were associated with parent and child-report resistance to taking medication
- Maternal mental health was associated with reporting fewer benefits and more costs of taking medication
- Maternal mental health was associated with parent and child-report resistance to taking medication. However, this was not significantly mediated via parenting self-efficacy.
- No relationship between maternal mental health and competence
- Low levels of parenting self-efficacy were associated with more difficulties in administering medication
- Maternal ADHD was associated with more difficulties in administering medication
- Family cohesion was associated with parent-report child stigma and child-report stigma in the USA, but not in the UK
- Country was more salient than cohesion in predicting child stigma with UK participants reporting higher levels of stigma
- High SES was associated with parental stigma
- Self-report parental warmth was associated with parent-report and child-report child stigma in the USA but not in the UK
- Country was more salient than self-report parental warmth in predicting child stigma with UK participants reporting higher levels of stigma

[4] Unless otherwise stated the results were consistent across samples

- Spouse parental warmth was not significantly associated with parent-report child stigma, but was significantly associated with child-report stigma in both the UK and the USA

- Both country and spouse parental warmth contribute to overall child-report stigma scores

- Critical EE ratings were associated with parent and child-report child stigma

8.11 Discussion

The aim of this study was to examine how family factors are associated with AMRABs. Additionally, differences between the UK and the USA were identified and SES was found to have a role in the prediction of parental stigma.

8.11.1 Children's behavioural problems and AMRABs

Children's behavioural problems were predictive of both parent and child-report resistance across samples. This is in line with Weiss et al.'s (2000b) suggestion that children with ODD or CD are more likely to resist taking medication. Although, it is beyond the scope of this study to investigate the long term implications of ODD and CD on adherence to medication, it seems likely that comorbid behavioural problems may put children at risk for non-adherence (e.g. by the child's refusal to take medication). This is consistent with Thirucelvam et al. (2001), who found that ODD was a strong predictor of pharmacological treatment drop-out in ADHD.

8.11.2 Parental mental health and AMRABs

8.11.2.1 Maternal mental health and benefits & costs

Poor maternal mental health as assessed by the GHQ was associated with less positive beliefs (benefits) and more negative beliefs (costs) about ADHD medication. However, the effect sizes were relatively small and maternal GHQ scores explained only 4% and 5% of the variance in parent-report benefits and costs respectively.

The GHQ is a screening tool for general mental health symptoms (Goldberg, 1997). It does not indicate specific mental health problems such as depression, which may be particularly important in determining parents' cognitions regarding ADHD medication. Future research should consider using a more specific assessment of depression to assess the relationship between parental depression and AMRABs.

These results have important clinical implication as parents of children with ADHD are at risk for experiencing mental health difficulties such as depression (Biederman et al., 1995a; Brown & Pacini, 1989; Mash & Johnson, 1983a). However, the cross-sectional nature of this research prevents drawing firm conclusions in this area. Future research should seek to replicate this result, and explore whether parental depression and beliefs regarding the benefits and costs of taking medication are associated with long-term motivation and adherence to pharmacological treatment.

Additionally, maternal mental health may be associated with poorer outcomes to pharmacological treatment as mothers who are depressed may not be able to provide the optimal environment to foster positive outcome. It is unclear then, whether maternal mental health is associated with parents' perceptions of medication or the actual benefits and costs their child derives from taking medication. Future research should also consider the relationships between perceived benefits and costs and functional treatment outcomes as rated by parents and other raters (e.g. teachers, researchers) to control for the effect of parental depression on parental perception of child psychopathology.

8.11.2.2 Maternal mental health and resistance

Maternal GHQ scores were associated with parent and child-report resistance. However, parents who are depressed may be more likely to perceive behavioural problems in their children, and may therefore over-estimate their children's resistance (Boyle & Pickles, 1997; Chi & Hinshaw, 2002; Chilcoat & Breslau, 1997). Therefore care should be taking in interpreting this relationship. Additionally, the data relies on one self-report measure of child resistance and parenting self-efficacy. Future research employing multiple informants and observational measures of child resistance may more accurately examine this relationship.

Again, this result has important clinical implications as parents who face more resistance from their children, and who also have less positive beliefs regarding

medication may be less motivated to continue with pharmacological treatment. Longitudinal research is necessary to examine this relationship.

8.11.2.3 Maternal parenting self-efficacy and competence

Mothers who had lower parenting self-efficacy reported more difficulties in administering medication to their children. This finding has important clinical implications as parents who have poor parenting self-efficacy may benefit from interventions to improve their self-efficacy, which in turn may have an impact on their abilities and confidence in administering medication. Future research should examine whether parenting self-efficacy and competence in administering medication are predictive of long term adherence and treatment outcome and whether interventions to improve parenting self-efficacy increase parents' ability to cope with resistance to medication.

8.11.2.4 Maternal ADHD and competence

As predicted, maternal ADHD symptoms were associated with more difficulties in administering the medication regimen. Again, this finding has important clinical implications as children whose parents have ADHD may be at risk of non-adherence as their parents may be less able to administer medication consistently. Such families may benefit from simplified medication regimens (e.g. one-a-day preparations).

Adherence research has generally found an association between fewer daily doses and improved adherence (Bloom, 2001; Claxton, Cramer & Pierce, 2001; Maggiolo et al., 2005). This may be particularly important for parents with ADHD who may find administering multiple daily doses challenging. An additional consideration may be that parents with ADHD may be more likely to have more than one child with ADHD because of the genetic link between parental ADHD and child ADHD (Gjone, Stevenson, & Sundet, 1996a; Gjone, Stevenson, & Sundet, 1996b; Levy, Hay, McStephen, Wood, & Waldman, 2003; Sherman, Iacono, & McGue, 1997; Siliberg et al., 1996). Consequently, parents may have to administer multiple medication regimens to their children, making consistent administration to each child more challenging.

The relationship between maternal ADHD and competence was not mediated by differences in parenting style. However, it is important to note that parenting style is a measure of a parent's overall attitude to parenting, rather than specific parenting behaviours. It may be that specific behaviours such as monitoring children's behaviour and implementing routine and structure within the family, which Murray and Johnson (2006) found to be negatively associated with parental ADHD, are more important in administering medication regimens consistently. Future research should consider incorporating more specific measures of parenting behaviour that are relevant to the consistent administration of medication.

However, it should be noted that the measure of maternal ADHD symptoms used was a screening tool and not considered to be diagnostic (Murphy & Adler, 2004; O'Donnell, McCann, & Pluth, 2001). Future research examining the impact of parental ADHD on competence in administering medication should consider a more formal psychiatric assessment of parental ADHD. Additionally, this study only examined mothers' ADHD symptoms. This was justifiable as the participants in this study were the primary parents responsible for the administration of medication. However, as ADHD is more common amongst males than females, paternal ADHD may also be important to consider.

8.11.3 Family cohesion and child stigma

Family cohesion was predictive of parent-report child stigma and child-report stigma in the USA, but not in the UK. Country was more salient in predicting both parent and child-report child stigma than family cohesion, with participants in the UK reporting higher levels of stigma. It appears that family cohesion and high levels of family may have a protective effect against stigma within the USA, but that wider cultural issues within the UK are more salient causes of stigma within the UK context.

8.11.4 Family cohesion and parental stigma

Family cohesion was only associated with lower levels of parental stigma in the USA sample, not in the UK. However, SES seems to be a more pertinent factor with families with higher SES reporting higher levels of parental stigma.

8.11.5 SES and parental stigma

Families with high SES reported higher levels of parental stigma. However, the measure of SES used in the current study was crude, and only 3 participants within the USA were classed as having low SES. Consequently, it was not possible to examine the relationship between SES and parental stigma within the USA sample.

This finding needs to be replicated in future research involving participants from a wider range of socio-economic groups. It may be that it is less acceptable to give children ADHD medication in higher socio-economic groups. As ADHD is more common in people from lower socio-economic groups (Biederman et al., 2000a), medication may be more acceptable, and families may have easier access to the social support of other families whose children have ADHD, thereby reducing parental stigma.

8.11.6 Parental warmth and child stigma

The relationship between self-report parental warmth and child stigma mirrored that of the relationship between family cohesion and child stigma. Namely, that self-report parental warmth was associated with lower levels of child stigma in the USA, but not in the UK. Again, when both country and self-report parental warmth are included in the analysis, only country significantly predicts parent and child-report stigma. It appears that family cohesion and high levels of parental warmth may have a protective effect against stigma within the USA, but that wider cultural more salient causes of stigma in the UK.

Spouse parental warmth was not associated with parent-report child stigma in either the UK or the USA. However, it was associated with child-report stigma in both samples. Included together in the analysis, both country and spouse parental warmth were associated with child-report stigma.

It therefore seems that a warm paternal relationship may be important in protecting children against the stigma associated with taking medication for ADHD. It is a limitation of the current study, that multiple informants were not used, as relationships with other significant persons, particularly fathers, within the family may be important in protecting children from stigma. Additionally, social desirability may have played a role in determining mothers' ratings of their own parenting behaviour.

8.11.7 Critical EE and child stigma

As predicted, both parents and children reported higher levels of child stigma when mothers were assessed as being critical on EE. Both criticism on EE and country were significant predictors of parent and child-report stigma.

It is notable that unlike other self-report measures of parent-child relationship, the relationship between EE and stigma was significant in both the UK and the USA. EE may be a more accurate measure of parent-child relationships as it may reduce social-desirability effects by putting the participant on the spot.

Once again, future research should examine how family relationships and stigma impact on treatment outcome and adherence over longer time periods.

8.12 Why do children in the UK experience higher levels of stigma?

It is beyond the scope of this study to fully investigate cultural factors, which may lead to higher levels of child stigma in the UK than in the USA. This may be due to the attitudes of professionals and the general public to ADHD within the UK. Studies have indicated that GPs within the UK may be reluctant to "medicalise" children's behaviour (Klasen, 2000; Klasen & Goodman, 2000). The author knows of no research regarding the attitudes of other professionals (e.g. teachers, social workers, clinical psychologists etc.). However, psychologists writing in a special issue of "Clinical Psychology" published in August 2004 adopt a sceptical stance regarding the validity of the ADHD diagnosis and the utility of pharmacological treatment (e.g. Golding, 2004; Myatt, Rostill & Wheeldon, 2004; Radcliffe, Sinclair & Newnes, 2004; Radcliffe & Timimi, 2004; Timimi, 2004; Vetere, 2004; Woodhouse, 2004). These views may be representative of a wider cultural context within the UK that rejects the validity of ADHD as a diagnosis, judges parents as responsible for their children's difficulties and has ethical objections to the use of medication to treat psychological difficulties. However, the author does not know of any systematic studies examining differences between the UK and USA on attitudes to ADHD in either professionals working with children, or in the general population.

8.13 Limitations of the current study

The current study presents with a number of limitations. As discussed in relation to study 3a., there are a number of sampling biases inherent in the current study. Participants tended to be long-term adherers to medication and many were actively involved in parent-led support groups or seeking information regarding ADHD on the internet. Additionally, the current study suggests that the sampling methods were biased towards participants from higher socioeconomic groups. The current study did not recruit participants who had discontinued medication or who had chosen not to start. It is likely that the recruitment methods attracted participants who have had positive experiences of medication. Future research addressing these issues in samples including participants from across the socio-economic spectrum, participants who are not involved in parent-led support groups and participants who have discontinued or decided not to use medication to treat ADHD is necessary to explore the relationship between family factors and AMRABs, and in particular to identify family factors which may be associated with negative AMRABs and poorer treatment outcomes.

The current research is cross-sectional in nature. In order to explore the impact of family factors and AMRABs in predicting treatment adherence and outcome, longitudinal research is necessary.

A number of key factors were not addressed in the current study. The study did not obtain any measures of actual treatment outcome. The use of more objective measures (e.g. changes children's performance on cognitive tests of attention when on and off medication, or teacher ratings of ADHD symptoms) would help to explore the complex interplay between family factors, treatment outcome, and AMRABs, such as would be predicted by the risk-resistance model. For example, families who are generally organised, warm and supportive will tend to facilitate better treatment outcomes. Consequently, they may be more likely to rate their experiences of ADHD medication as positive and report positive attitudes on the AMRABs scales. Parents attitudes and beliefs about medication may be related to their level of education and their knowledge about ADHD and ADHD treatment. This may be influenced by medical professionals, personal research (e.g. seeking out research papers and books about ADHD), the popular media or extended family and friend networks. Assessing participants' knowledge about ADHD may help to understand parents' and children's attitudes.

8.14 Summary and conclusions

The results of the current study indicate that family factors play an important role in AMRABs. In particular, children's behavioural problems are associated with higher levels of resistance. Poor maternal mental health is associated with parents perceiving fewer benefits and more costs associated with taking medication. However, the current study cannot assess whether this is indicative of maternal perceptions of the benefits and costs of taking medication or functional treatment outcome. Maternal ADHD and low parenting self-esteem are associated with more difficulties in administering medication consistently. Family cohesion was predictive of parent and child-report child stigma in the USA, but not in the UK. Similarly, maternal warmth was associated with child-report stigma in the USA but not the UK. Paternal warmth was associated with lower levels of child-report stigma in both countries. Criticism on EE was associated with higher levels of parent and child-report child stigma in both countries.

Again, the results indicate that parents and children in the UK report more child stigma than parents and children in the USA. Although the reasons for this are unclear, it seems wider cultural factors are important in determining whether children experience stigma associated with taking medication for ADHD.

Although no hypothesis was made regarding the relationship between SES and parental stigma, the results suggest that participants with high SES may be more likely to experience parental stigma.

The results indicate that both family and wider cultural factors are important in determining AMRABs. Future research with a longitudinal design, more representative participants and multi-informant measures of treatment outcome is necessary to explore how these may be related to long-term treatment adherence and treatment outcomes.

Chapter 9

Overview of the thesis: conclusions, clinical implications and suggestions for further research

This chapter will review the aims of this thesis and the studies conducted. Theoretical implications and suggestions for future research are considered and the relevance of the current studies for clinical practice are discussed.

9.1 Overview of the Thesis

9.1.1 Aims

This thesis had three main aims:

(iv) To identify salient medication related attitudes and behaviours from a patient perspective

(v) To design a questionnaire whereby parents' and children's medication related attitudes and behaviours can be assessed

(vi) To explore how medication related attitudes and behaviours are related to family factors such family dysfunction, parent psychopathology, child psychopathology and child age.

9.1.2 Summaries of the four studies

Four studies were carried out addressing these aims.

9.1.2.1 Aims and summary of study 1

Study one involved in depth qualitative interviews with parents of children with ADHD who are taking medication for ADHD in order to identify salient medication related attitudes and behaviours from a patient perspective.

Parents reported a range of medication related attitudes and behaviours. In particular, parents highlighted positive effects of taking medication including improved behaviour at school and home and improved academic performance. Some

parents seemed to believe medication gave their children control over themselves, enabling them to achieve things that they wanted to do. Others seemed to see medication as a means of making their child more manageable and controllable.

Parents also reported a number of negative effects of taking medication including side effects and personality changes. Parents also emphasised that medication was not a panacea for ADHD and that parents of children with ADHD worked hard to help their children. Parents also reported that medication had a positive effect on other people, including their immediate and extended family.

Parents also reported a number of behaviours associated with using medication for ADHD, including: ways of monitoring medication regimens so as to ensure their children took medication regularly; adjusting the regimen to their child's needs; giving their children a break from taking medication; and ways of managing children's resistance to taking medication. Parents also reported disagreements between parents as to the use of medication.

Parents reported that some children resisted taking medication while others were very happy to take it. Parents reported difficulties in giving medication at school, particularly with teachers giving medication consistently at the correct time. Parents had mixed experiences of schools, with some schools being very supportive of their children in school, other parents believing that the school used medication to keep their child quiet, and some parents reporting that teachers lacked discretion and sensitivity in managing their child.

Parents generally reported positive attitudes to medication and believed medication had numerous benefits. Parents also reported negative attitudes towards medication, including that it was an "easy option" and anxieties regarding the possible long-term effects of taking medication. Parents reported that children had negative attitudes towards medication, including a belief that medication changed their personality and feeling stigmatised for taking medication. Parents also reported that some other people had positive attitudes towards their child taking medication, while other people could be judgemental of their decision to treat their child's ADHD with medication.

Parents reported difficulties with medical professionals. In particular, professionals were not always willing to help their children and that medical professionals did not

take time to develop a relationship with their child. A minority of parents reported a trusting relationship with their doctor.

Parents reported adolescence as a critical time for children with ADHD, and particularly, that their children had refused to take medication as adolescents (or that they were worried this may happen). Others reported adolescence as a time in which their child took more responsibility for taking medication and that medication enabled them to gain the independence associated with being an adolescent.

Parents also mentioned trying other treatments for ADHD, but most believed medication was the most effective.

The results of this study need to be interpreted cautiously given the selection bias inherent in recruiting participants from parent-led support groups, who are likely to influence each other's attitudes regarding ADHD, likely to be well informed and may hold their attitudes more strongly than parents who are not actively involved in support groups. They may also be parents who experience a higher degree of difficulty with their child with ADHD, and thus feel the need to seek out the support of other parents. The themes derived from the analysis reflect only the attitudes of a specific group of parents. Recruiting participants who are not involved in support groups, and participants who elect not to use medication or who have discontinued medication, or from support groups with an anti-medication bias may have elicited a more diverse range of attitudes.

9.1.2.2 Aims and summary of study 2

Study 2 involved the compilation of provisional questionnaires to measure parents' and children's ADHD medication related attitudes and behaviours based on the data collected in study 1. These provisional questionnaires were piloted with participants through ADHD support groups and the internet. The provisional questionnaire was adjusted on the basis of participant feedback and psychometric properties in order to derive AMRABs scales which could be utilised in further research.

This study also confirmed that data collected via the internet was comparable to that collected through support groups.

However, the results of this study are also limited by a sampling bias as participants were recruited from the internet and support groups. Such parents are likely to be very interested in ADHD and motivated to take part in research. Informally, many participants commented to the researcher that they were keen to know the outcome of the studies and that they tried to keep up to date with the current research. Most participants had been using medication for ADHD for a long period of time, suggesting the sample was biased towards long-term adherers to ADHD medication. Further research recruiting participants from ADHD clinics may avoid the bias inherent in recruiting parents who are actively involved in parent-led support groups or seeking out information or support regarding their child's ADHD on the internet. It is necessary to confirm the robustness of the component structure in a more representative sample, and in participants with less positive attitudes to medication (e.g. participants who have discontinued or elected not to start medication treatment).

9.1.2.3 Aims and summary of Study 3a

Study 3a piloted the AMRABs scales as designed in study 2 with a large sample of participants from ADHD clinics in the UK and the USA, support groups and the internet. Seven components (benefits, costs, resistance, child stigma, parental stigma, flexibility and competence) were identified in the parent questionnaire. Four components were identified in the child questionnaire (benefits, costs, resistance and stigma). Both the parent and child versions had a robust component structure and high internal reliability for each subscale.

This study took steps to include participants from ADHD clinics, helping to obtain a more representative sample. However, the number of participants recruited via clinics was small. The results suggested that data collected via the internet is comparable with that collected via clinics and support groups. Further research using a larger sample recruited from ADHD clinics would help to confirm this. The sample seemed to be biased towards long-term adherers to ADHD medication and did not include participants who had never started medication or who had elected to discontinue medication. Indeed, this bias appears to be evident in the generally positive attitudes reported by participants in this study. Further research which includes participants who have not chosen medication, participants who have only taken medication for a short period of time and participants who have discontinued medication is necessary to confirm the psychometric properties in the AMRABs scales in these populations.

9.1.2.4 Aims and summary of Study 3b

Study 3b tested working hypotheses regarding the relationships between the AMRABs subscales with age, each-other, medication type and cultural differences in AMRABs scores between the UK and the USA.

AMRABs variables were not related to age, but stigma was associated with resistance and participants in the UK reported higher levels of child stigma than participants in the USA.

This study was limited by its cross sectional design and biased towards participants who were long-term adherers to ADHD medication. Again, further research to examine the hypotheses made in this study with wider range of participants (e.g. those who have chosen not to take medication, participants who have only taken medication for a short period of time, participants who have discontinued medication) is necessary. Recruiting a more repesentative sample from a multiple ADHD clinics across the UK and America is necessary to confirm the cultural differences in the stigma associated with ADHD medication use.

9.1.2.5 Aims and summary of Study 4

Study 4 tested hypotheses regarding the relationships between the AMRABs subscales and family factors. The results indicated that family factors were associated with AMRABs.

Child conduct problems were associated with resistance to taking medication. Maternal mental health difficulties were associated with lower perceived benefits and higher perceived costs of taking medication. Maternal mental health difficulties were also associated with resistance to taking medication, mediated via lower levels of parenting self esteem. Poor parenting self-esteem and maternal ADHD symptoms were also associated with difficulties in administering medication consistently.

Once again, cultural differences in stigma were evident. The strongest predictor of stigma was country, with UK participants reporting higher levels of stigma. However, low levels of family cohesion were also predictive of child stigma in the USA. Low spouse parental warmth and critical EE were also associated with child stigma in both the UK and the USA. High SES was associated with parental stigma.

This study also confirmed that data collected via the internet was comparable with data collected via support groups and ADHD clinics.

However, as with the previous studies, this study was biased towards participants who were long-term adherers to ADHD medication and was limited by its cross sectional design. Again, further research to examine the hypotheses made in this study with wider range of participants is necessary. This study did not obtain any measures of treatment outcome, which may have enabled an exploration of the complex interplay between family factors, treatment outcome and AMRABs. Future research needs to avoid the sampling biases inherent in the current study and incorporate multi-informant ratings of family factors and treatment outcomes.

9.2 Limitations of the research

The current studies have a number of limitations that need to be considered when interpreting the results. In particular, the selection bias towards long-term adherers to medication, the cross sectional nature of the research and the limitations of the AMRABs domains are considered.

9.2.1 Selection bias

Of key importance is the selection bias of the current studies. As participants had to be taking ADHD medication in order to participate in the questionnaire studies, the sample was biased towards participants who were long-term adherers to medication for ADHD. This bias may be reflected in the largely positive attitudes to medication reported in the current studies. Families who choose not to initiate pharmacological treatment or who discontinue medication may offer different perspectives. The current research is limited to those families who have elected to use medication, and the use of parent-led support groups and recruiting via the internet may have attracted parents with particularly positive views of medication.

The use of the internet to collect a substantial proportion of the data in the current studies may present a limitation as the sample is likely to be biased towards the demographic characteristics of internet-users. In particular, this may be reflected in the high SES of most participants in the final study.

However, data collected via the internet was comparable to data collected via ADHD clinics and support groups. The use of the internet proved to be particularly helpful in obtaining a suitably large sample to enable meaningful statistical analysis of the component structure of the AMRABs scales. Additionally, relatively few participants were assessed as having low SES, and future studies may need to consider how to include participants from across the socio-economic spectrum.

The recruitment of a larger sample from ADHD clinics, and from families of children who are diagnosed with ADHD but who do not use medication may provide different results. The component structure of the questionnaire needs to be replicated in more respresentative samples in order to assess its robustness. The hypotheses tested in chapters 7 and 8 likewise need to be examined in more representative samples.

9.2.2 Cross sectional design

The cross-sectional design of the current studies did not allow any assessment of changes in AMRABs over time. Study 1 indicated that parents often expressed a high level of anxiety regarding the decision to start pharmacological treatment, but that these anxieties were relieved quickly after the implementation of a successful regimen. It seems prudent, then, to consider what attitudes towards medication, beliefs about the potential benefits, costs and associated stigma predict the acceptability of pharmacological treatment to parents, and whether these may be associated with broader family and cultural factors.

Additionally the current studies were unable to examine whether or not AMRABs predict long-term adherence and clinical outcomes to medication.

9.2.3 AMRABs domains

Study 1 indicated that parents used a variety of methods to adapt medication regimens to their child's needs. Some parents in study 1 used medication proactively, giving their child medication in order to help them cope with situations they may find difficult. For example, giving medication to a teenager on a weekend to allow them to participate in social activities with their friends. By contrast, other parents used medication as a means of managing their child's behaviour when it became particularly challenging. Additionally, some parents employed coercive methods of ensuring their children took medication, for example, physical force or covertly giving

medication in food. It was not possible to assess these domains within the AMRABs questionnaires for several reasons. First, there were ethical implications of asking parents whether they used medication in ways that would be considered coercive. Second, when items designed to assess these behaviours were included in the preliminary questionnaires, they had extremely low variability, suggesting that they were either unusual behaviours, or that social desirability effects prevented parents from reporting them. Additionally, it may be that such differences in the use of medication are too subtle to be measured by questionnaire, and that in-depth interviews are a more useful method of eliciting such information from parents. However, the AMRABs questionnaire is unable to assess whether parents use coercive methods in administering medication to their children or parents' motivations for giving medication.

9.3 Theoretical implications of the current studies and suggestions for further research

9.3.1 Study 1 and the SRM

The SRM sees the individual as an active problem-solver, choosing to carry out, or not carry out, particular health behaviours on the basis of whether it makes sense in the light of their cognitive representation and personal experiences of their health condition and previous health behaviours (Leventhal, Meyer & Nerenz, 1980; Leventhal, 1993). In particular, the SRM suggests that patient and medical perspectives regarding health behaviours may be divergent (Playle & Keeley, 1998; Trostle, 1988; Stimson, 1974)

Many of the participants in this study had negative relationships with medical professionals. Qualitative research suggests that GPs in the UK may be reluctant to prescribe medication or to view ADHD as a neuro-biological disorder (Klasen, 2000; Klasen & Goodman, 2000). This highlights the likelihood that medical professionals and parents, in the UK at least, may have rather different perspectives and understanding of ADHD and of pharmacological treatment. Therefore, the understanding of parents' perspectives is critical in understanding medication related behaviour in ADHD.

The interview study identified a number of ways in which parents and children, particularly in adolescence, may adapt their medication regimen to suit the individual needs of the child.

Parents may give a child medication before mealtimes in order to ensure their child eats sufficiently and the appetite suppressing effects of stimulant medication are not a problem. Parents also reported giving their child drug holidays because of their belief that the child should be "allowed to be himself" during the holidays.

Some parents reported proactively giving their child medication to enable them to go on school trips, go out for social activities with their peers and play on sports teams. Other parents reported giving their children medication in reaction to child misbehaviour in order to make their behaviour more manageable. Parents also reported changing the medication regimen from a short-acting stimulant to a sustained-release formulation in order to eliminate the need for schools to be involved in medication. Interestingly, parents reported older adolescents and young adults discontinuing medication when they finished school, only to re-start later when not taking medication had resulted in difficulties at work or in the young person getting into trouble with the police. The behaviours of young adults with regard to ADHD medication may be particularly interesting to study within the SRM perspective. It seems likely that qualitative methodologies may be the most suitable for examining the behaviours individual young people may use to manage their ADHD and/or adapt their medication regimen to suit their individual needs and goals.

This study highlighted a number of ways in which parents, and also young adults, may adapt their medication regimen, take a break from medication, discontinue or restart medication in line with their beliefs, personal experiences and emotions associated with ADHD and ADHD medication.

9.3.2 Stigma and the SRM

Later studies, in particular study 3b and study 4, highlighted the importance of stigma for parents and children with ADHD. In particular, both child and parental stigma were more pervasive in UK participants than in participants from the USA. Taking medication at school and levels of family cohesion was associated with increased child stigma in the USA, but not in the UK. Maternal criticism (as assessed using EE)

and spouse parental warmth were both associated with higher levels of child stigma. Participants from higher SES groups reported higher levels of parental stigma.

Of particular interest, was the finding that stigma predicts resistance. This is in line with previous studies which have highlighted a consistent link between stigma and non-adherence across a range of conditions (Ayalon et al., 2005; Buck et al.,1997; Freudenreick et al., 2004; Hudson et al., 2004;Sirey et al., 2001). The SRM has demonstrated how non-adherence may be a means of avoiding stigma associated with taking medication (Conrad et al., 1985); that mothers who feel stigmatised because of their child's HIV status may avoid giving medication in public (Wrubel et al., 2005) and that children who feel stigmatised may avoid taking medication (Roberts, 2005).

It seems likely that families who experience high levels of stigma may wish to avoid using medication in public (e.g. at school). Future research to examine whether parents or children who feel stigmatised would prefer a medication regimen which avoided taking medication at school and whether stigma decreases when children do not take medication at school may be fruitful in understanding how stigma impacts on parents' and children's medication related behaviours.

That people who feel stigmatised may avoid taking medication in public may also be important in determining whether or not children with ADHD avoid social activities which may necessitate taking medication outside of the family home (e.g. trips involving overnight stays or after-school activities which may necessitate a late-afternoon/early evening dose of medication). As this may have important implications for children's social development and peer relationships, it may be a clinically pertinent issue to consider in further studies.

9.3.3 Studies 2 and 3a: the AMRABs questionnaires

The AMRABs questionnaires were developed in studies 2 and 3a. These questionnaires examine parents' and children's attitudes and beliefs concerning ADHD medication, based on qualitative information obtained from British parents of children with ADHD. The scales have a robust component structure and high internal reliability. Future research to examine test-retest reliability may provide another measure of the scales reliability.

9.4 Possible uses of the AMRABs questionnaires in further research within a social-cognitive framework

9.4.1 To predict continuation/discontinuation of medication

The AMRABs questionnaires may provide an important tool for future research examining parents' and children's attitudes to ADHD. In particular, the questionnaires present the opportunity to examine whether attitudes to medication predict long-term continuation/discontinuation of medication as socio-cognitive models of health behaviour suggest.

9.4.2 To predict acceptance of pharmacological treatment

The current research was biased towards families of children who were long-term adherers to medication for ADHD, and who, therefore, are very likely to have a positive attitudes and beliefs regarding ADHD medication.

The questionnaires could be adapted to examine parents' and children's beliefs about medication prior to treatment, and whether these predict their decision to accept pharmacological intervention. The utilisation of the Health Belief Model (HBM) may be useful here, to examine parents' and children's perceived severity/threat of ADHD symptoms and how their perceived costs and benefits of medication, together predict the likelihood of accepting pharmacological treatment.

9.4.3 To predict change in AMRABS following interventions

Study 1 suggests that parents were initially reluctant and anxious regarding the use of pharmacological treatment, but that parents' concerns were alleviated quickly when children started on medication regimens. The examination of parents' attitudes before and after starting pharmacological treatment may therefore be helpful in understanding how attitudes to medication may change, particularly in the early states of pharmacological treatment.

Secondly, numerous researchers have suggested that sustained release formulations of medication may be helpful in reducing stigma by eliminating the need to take medication in school (Santosh & Taylor, 2000; Greenhill, Halperin & Abikoff, 1999). The current study found contradictory findings in this area, with sustained

release medications being associated with less child stigma in the USA but not in the UK. It is difficult to interpret this result, as children who report stigma to the prescribing physician may be prescribed a sustained-release medication because of their stigma. This may be particularly relevant in the UK, where children seem less likely to be prescribed a sustained-release medication as a matter of course. In order to examine this assumption, research examining changes in stigma following a change from a short-acting to a sustained-release formulation is necessary.

9.4.4 To examine the beliefs of people without ADHD

The current studies highlighted the role of country in predicting both child and parental stigma associated with ADHD. In particular, participants from the UK reported markedly higher levels of stigma than participants from the USA. It would therefore seem pertinent to study the beliefs and attitudes of the general population in each country towards pharmacological treatment of ADHD. Additionally, the attitudes of professionals in the UK and the USA towards pharmacological treatment of ADHD may be important. This may enable a better understanding of why families of children with ADHD in the UK seem more likely to experience stigma associated with taking ADHD medication than families in the USA.

9.4.5 To study medication related attitudes in other conditions

Although the AMRABs questionnaires were designed to assess attitudes to medication in ADHD, there may be mileage in adapting the questionnaires to study other pediatric health/mental health conditions and other kinds of medication. In particular, it may be of interest to study whether all children who take regular medication (e.g. for asthma or diabetes) experience similar levels of stigma as children who take medication for ADHD.

Additionally, as the use of psychotrophic medication for children in both primary care and specialised psychiatry clinics increases (Harpaz-Rotem & Rosenheck, 2006), there is increasing recognition of the need to understand the perspectives of children, young people and their parents in order to promote therapeutic alliance and encourage adherence to medication (Joshi, 2006). Adaptations of the AMRABs questionnaire for use with families of children with other mental health conditions may present a way of assessing the perspectives of parents and children.

9.4.6 To study patient-report outcomes in head-to-head and placebo-controlled medication trials

There is a range of medications now available for the treatment of ADHD including methylphenidate (in both short-acting and sustained-release formulations), Adderall, dexamphetamine and Atomoxetine.

The AMRABs questionnaires may offer an opportunity to study the relative costs and benefits of different drugs. Of particular interest may be whether parents and children are more concerned by some drugs than others using the costs subscales of the questionnaires. For example, are parents more concerned about Adderall following recent scares which resulted in the drug being withdrawn in Canada for a period of time (Biron, Mintzes and Lexchin, 2006; Kondro, 2005)? Additionally, it may be of interest to study whether parents are more concerned by newer medications such as Atomoxetine in comparison to more widely prescribed medications such as methylphenidate.

The AMRABs questionnaires may offer a way of studying patient-report outcomes as a way of examining the relative cost-benefits from patient perspectives. For example, do the more expensive, longer-acting preparations of methylphenidate reduce the stigma associated with medication so much as to offset the additional financial cost of the medication? Given the increasing range of medications available to treat ADHD, studying patient-report experiences on stimulants compared with selective norepinephrine reuptake inhibitors (Atomoxetine), which have a different pharmacokinetic profile may provide valuable information regarding the relative costs and benefits of each medication from patient perspectives.

The AMRABs questionnaires may also provide a patient-report outcome measure for placebo-controlled trials.

9.4.7 To study AMRABs across cultures

The current study found that parents and children in the UK experienced markedly higher levels of stigma than parents and children in the USA. This raises questions regarding the experiences of children with ADHD and their families in other cultures. Of particular interest may be to compare western and non-western cultures on AMRABs variables.

Research has indicated that ADHD may be perceived differently in non-western cultures. ADHD rating scales such as the Conners rating scales have been found to be suitable for use in non-western cultures (Luk & Leung, 1989; Luk, Leung & Lee, 1988, Yang & Schaller, 1997). However, there is also evidence that ADHD may be perceived differently in non-western cultures in comparison to the USA. Chinese children diagnosed with ADHD have been found to have lower levels of impairment as assessed by parent and teacher-report child behaviour checklist compared to children from the USA (Liu et al., 2000; Li et al., 1989). Luk et al. (1988) report that Chinese teachers report twice the levels of hyperactivity than teachers in the USA. Mann et al. (1992) found that Chinese mental health professionals had lower thresholds for rating hyperactive behaviour than Americans. Additionally, when Chinese and American college students were asked to rate which symptoms were important in a diagnosis of ADHD, Chinese students rated hyperactive symptoms as the most important whereas American students rated inattentive symptoms as the most important (Norvilitis and Fang, 2005). Norvilitis and Fang (2000) also studied college students' beliefs about ADHD. Chinese students were more likely to agree that ADHD was biologically based, that parents of children with ADHD "just don't know how to control their children" and that "children with ADHD are bored and need more to do". By contrast, Americans were less likely to endorse statements implying that ADHD is caused by lack of effort on the part of either parents or children. However, American students were also more sceptical about ADHD than Chinese students, believing it to be over-diagnosed and that medication should only be used as a last resort, implying a certain amount of ambivalence about the diagnosis and pharmacological treatment of ADHD.

The above studies demonstrate differences in the perception of ADHD and pharmacological treatment between America and non-western cultures. In particular, non-western cultures seem more attuned to hyperactivity as deviant behaviour, whereas western cultures seem more concerned about inattentive symptoms. Therefore, a study of AMRABs in families of children treated with medication in non-western and western cultures may offer an interesting perspective on the patient perceptions of the benefits, costs and stigma associated with treatment between cultures.

9.5 Studies 3b and 4: family factors and AMRABs

This thesis utilised the AMRABs scales to examine the relationship between family factors and parents' and children's attitudes to medication for ADHD. This sits within the Health Belief Model (HBM) which suggests demographic and socio-psychological factors may be important in determining peoples' beliefs about medication, and consequently the likelihood of taking action against a health threat (Becker & Maiman, 1975; Rosenstock, 1974).

This seems particularly important in treatment for ADHD, where family factors such as parental depression, parenting self-efficacy, family relationships and SES have been found to be predictive of treatment outcome (Hoza et al., 2000; Jensen et al., 1999b; Owens et al., 2003). It seems that these factors are associated with differences in AMRABs that may influence treatment outcome.

The current study is limited by its cross sectional design and future research to examine how family factors and AMRABs impact on long-term adherence and outcome to pharmacological treatment is necessary.

9.6 Clinical Implications of the Current Research

9.6.1 Self-regulatory behaviours

In identifying ways in which parents, children, particularly older adolescents and young adults, with ADHD may adapt their medication regimens to suit their lifestyles and their beliefs about ADHD and medication, study 1 highlights the need for clinicians to be aware of the beliefs and attitudes of families of children with ADHD and how this may impact their use of medication, in either beneficial or potentially harmful ways. This may also enable clinicians to advise parents on sensible ways of adapting medication regimens to suit their child's needs.

9.6.2 Cultural and social differences

The striking difference between the UK and the USA on stigma raises questions for clinical practice and, in particular, how practice guidelines developed in one culture may not be suitable in another. In particular, clinicians in the UK may need to be

especially aware of the potentially stigmatising effects of being diagnosed with ADHD and treated with medications.

Further research to examine the social understandings of ADHD within the UK may highlight directions for public education.

Parents from higher socio-economic groups may experience more parental stigma associated with ADHD medication. This may effect their willingness to seek help for ADHD or accept pharmacological treatment (Farr, 1995; Klasen, 2000; Leventhal et al., 1997).

9.6.3 Role of family factors in predicting attitudes

Clinicians working with children with ADHD may need to consider how family factors may impact on parents' and children's beliefs regarding medication.

In particular, parents of children with comorbid conduct problems and parents who have low parenting self-efficacy may benefit from advice regarding managing child resistance to taking medication. Parents who are depressed or who have low self-efficacy may have different beliefs about the benefits and costs of medication. Future research could address whether parents who are depressed benefit from systematic monitoring of their children's response to medication (e.g. through systematic teacher-ratings of ADHD symptoms, behaviour and academic performance at frequent, regular intervals) in order to help them accurately assess the benefits of medication and support treatment decision-making, both for the parent and for the prescribing clinician.

Parents who have ADHD may have more difficulties in administering medication, and may benefit from simple medication regimens (e.g. one-a-day dosing), particularly if several children in the family are taking medication.

Close family relationships may protect children from the stigma associated with ADHD. In families where children's relationships with their parents are characterised by high levels of criticism, interventions to improve parent-child relationships may impact on children's stigma, and, indirectly on their willingness to take medication as stigma is associated with resistance.

9.7 Summary and conclusions

The current studies identified parental beliefs, attitudes and behaviours in relation to pharmacological treatment of ADHD. Two questionnaires with robust psychometric properties in the current samples were designed to assess parent and child attitudes to medication. However the biased sampling methods limit the generalisability of the results and it is necessary to assess the robustness of the psychometric properties in more representative samples.

These questionnaires were found to be associated with a number of social and family factors. Most striking of all, participants in the UK reported markedly higher levels of stigma than participants in the USA. It is likely that family factors, and their association with parents' and children's attitudes to medication will impact on treatment adherence and treatment outcome. However, longitudinal research with more representative participants is necessary to explore the complex interplay between family factors, treatment outcome, treatment adherence and AMRABs.

Appendices

Appendix A

Semi-Structured Interview used in Study 1, Chapter 4

Semi-Structured Interview to Explore ADHD Medication Related Attitudes and Behaviours amongst Parents of Children with ADHD.

Part 1 - Questions about family

- How many people live in your home & who are they?
- How old are each of your children?
- How many children in your family have been diagnosed with ADHD and by who? How old are the children with ADHD diagnoses?
- Do they see the same doctor?
- If they don't see the same doctor – what advice has each doctor given you about ADHD & medication?
- Are they on medication? Which?
- Do you think that the medication been effective?
- Are there any children who have not been diagnosed who you think might have ADHD? Why do you think this? Who have you spoken to about it? What does their school/pre-school think?
- Children vary in the way in which they think and feel about themselves. How would you describe your child?
- How do you think your partner (step-parent/natural parent) would describe your child?
- What do other members of your family think about your child with ADHD? How have they responded to your child with ADHD?
    - father (if interviewing mother)
    - grandparents
    - aunts/uncles
    - step-parents
    - siblings
    - any other significant family members or friends
    - neighbours
    - children's friends
    - school teachers / preschool teachers
- How has having a child with ADHD affected your family?
- How has your child affected your working ability and career? How as your child effected your partner's working ability & career?

Part 2 - Questions about the behaviour of child with ADHD

- What activities are there in your area for children to do? Does your child take part in any of these? What are his/her experiences (e.g. of youth clubs etc.)
- Does your child go out to play in the garden/other people's gardens/street? Is this supervised or unsupervised?
- Does your child have many friends?
- What time does your child usually go to bed at?
- Do you have a fixed bedtime for the child?
- How do you find putting him/her to bed?
- Does he stay in bed or does he get up during the night? Is this a problem in the family?
- Does your child usually eat his meals with you?
- Does he refuse to eat his food? Why do you think this is (e.g. to get attention, general defiance, faddy eater etc.)
- Does your child tidy his own room? Do you ask him to?
- How do you find getting your child dressed in the morning?
- Is it difficult to get your child to do the things that you ask him to do?

Part 3 - Questions about Medication & treatment

- What do you know about ADHD? Where did you obtain this information (internet, books, professionals, friends, other family members, support groups...etc.)
- Do you believe what you have been told/read about ADHD?
- What do you think causes ADHD?
- What medication is your child taking & what for? How much and how often is your child supposed to take this medication?
- What do you know about this medication? Where did you obtain this information? (internet, books, professionals, friends, other family members....etc.)
- Did you get information from the clinic?
- Do you believe what you have been told/read about the medication your child is taking?
- Who first suggested that your child should take medication for ADHD?
- What did you think/feel when it was suggested that your child should take medication for ADHD?
- What did your child think?
- Who told the child?
- Did you discuss the medication with the child?
- Who did you talk to/seek advice from as to giving the child medication?
- What effect has your child taking medication had on...
    - your child?
    - you as a parent?
    - your family?
- What do you think/feel about your child taking medication for ADHD now?
- What do other people in the family/family friends/extended family think about your child taking medication for ADHD?
- Where do keep your child's medication?
- How do you know if your child has taken his medication?
- Do you give your child his medication yourself, or is he responsible for taking it?
- Do you think at any age, that the child should be made responsible for taking his/her own medication?
- Does your child ever resist taking his medication

- Does your child ever refuse to take his medication?
- Does your child ever pretend to take his medication?
- Does your child ever spit it out?

- ***If problems with medication...*** Is this just a problem with the medication for ADHD, or all medications in general (e.g. if prescribed antibiotics or other short-term medication, or if on other medication regimes such as for asthma.)

- Do you ever give your child an extra dose of medication? Can you tell me about situations when you have done that (planned/reactive)?
- Have you ever forgotten to give your child his medication? How often? Tell me about a situation when that happened?
- Have you ever made a decision not to give your child his medication? Tell me about a situation when that has happened?
- How often do these things happen?

Part 4 - Questions about other kinds of treatment

- Have you tried any other kinds of treatment for ADHD? (Psychosocial intervention, diet, alternative medicine etc.)
- When did you try this? Where did you find out about this treatment (through friends, professionals etc.)?
- Can you tell me about your experience using these treatments? How did it effect you as a parent, the child, other family members?
- Has your experience with other kinds of treatment effected how you think about medication for ADHD?

Appendix B

Coding Manual – Study 1, Chapter 4

THEME	SUBTHEME	DESCRIPTION	EXAMPLE
Theme 1 - Effects of Medication	Positive Effects	Units where parents report medication as having a positive effect, e.g. enabling the child to concentrate at school, making the child easier to control. This category also includes statements concerning the child's behaviour when not on medication by means of comparison, e.g. the child has behaviour problems when not taking medication.	"But once Kevin[1] took his Ritalin, he was great. He was a different child and he'd do anything you asked him to, he was like you'd waved a magic wand and made him somebody different, he wasn't rude, he was nice, it used to make such a difference."
	Medication used to manage behaviour	In addition, some units from the positive effects category can be coded into the categories "Medication used to manage behaviour" or "Medication used to give the child more freedom/independence". Units were placed in this category when they demonstrated medication being used to manage children's behaviour.	"he's argumentative, aggressive, obnoxious, really shocking but give him his Ritalin and after half an hour he's calmed down. He's much easier to control when he is on it."
	Medication used to give the child more freedom/independence	Units where parents talked about medication giving the child more freedom or independence, and improving their quality if life.	"He's able to go out by himself, into town with his friends on the bus when he's had his Ritalin. It means I know he's safe and he can do things that he couldn't do before."
	Negative Effects	Units where parents report medication as having a negative effect, e.g. side effects such as appetite loss, headaches, sleep problems, or medication taking the child's personality away. This also includes problems with the medication such as it being contra-indicated because of comorbid Tourette's syndrome.	"She was controlled [on medication], but not like, it just didn't seem like the same person"
	Minor Side Effects	Side effects which parents mentioned and which were deemed minor. Side effects that were transitory (e.g. headaches for a week after giving medication), controllable (e.g. by reducing the dose, or giving the child medication after meals to avoid problems with reduced appetite) were included in this category.	"It was only in the first week or so, he did have headaches, but not any more."
	Tics/Tourettes Sydrome	Units where parents talked about serious Tics or Tourettes syndrome starting or worsening when the child was taking medication.	"He started getting more aggressive on dex, swearing a hell of a lot, spitting, making noises like groaning and things like that. He had to come of it, he's been off it now for about 3

[1] All names have been changed to protect participants' anonymity

			years."
	Changes child's personality	Units where parents talked about medication changing their child's personality	"He just didn't seem like the same person, he was you know, controlled or something. He just wasn't himself, not the same person."
	Cardiovascular symptoms	Units where parents talked about the medication causing cardiovascular symptoms e.g. heart palpitations.	"She had to go to the GP just before I took her off Ritalin, because she started getting palpitations, so that's partly why I took her off it."
	Limitations	Units where parents expressed that the medication was helpful but that it did not deal with all of the child's symptoms or difficulties.	"...the medication, yes it helped concentration but no, it didn't help social skills or controlling his behaviour."
	Effect on other people	Units where parents comment on the impact that the child taking medication had on the family, such as less family stress, younger siblings being less scared of the child with ADHD when taking medication, grandparents being willing to have the child over to visit, or to babysit etc.	"I'm probably a lot less stressed than when he was little...you know when its [the medication] working and when it works well and that helps everybody because it's a bit more calmer and you know he's not just going to jump up and do something wacky."
Theme 2 - Medication Related Behaviour (MRB)	Parent MRB	Behaviours which the parents utilised in implementing the medication regimes, such as managing the appetite reducing side effects of stimulant by giving the medication after meals rather than before, giving the child drug holidays, changing the timing or dosage of the medication in order to get the optimal effect for the child and their family, forcing the child to take the medication, giving extra doses when the child was badly behaved, forgetting the medication etc. Where the mother was interviewed alone, this also included statements about fathers' MRB.	"...you could move the medication around to get the best value for yourself, well for yourself and your child, and you could fiddle with it, the dosage and the timing to see how quickly the child metabolised it, and he takes one tablet every two and a half hours depending on how much pressure he's under."
	Monitoring the medication regimen	Units where parents talked about ways in which they ensured their child took medication regularly and monitored what medication they had taken	"We have this thing (weekly pill box) that I set up on a Sunday evenings, so I know exactly what he's had each day"
	Adjusting the regimen	Units where parents reported changing medications, dosages or	"The Ritalin does make a difference. Although it

to manage symptoms	the timing of medication in order to best suit their child or to manage their child's symptoms.	does only have a short period of action with him. Most kids it will last sort of four hours, his is really only about two, two and a half, and then he'll go on the slippery slope down, so, he's on Ritalin little and often so he gets a level throughout the day."
Adjusting the regimen to manage side effects	Units where parents reported altering the dosage or the timing of the medication in order to manage the side effects, e.g. reducing the medication dosage in order to reduce side effects, or ensuring that the child had eaten a meal before giving the medication.	"We found that if we give him his Ritalin before his lunch or breakfast he wouldn't eat...so we don't any more, he gets his Ritalin after he's eaten and he eats like a horse."
Use of medication to manage challenging behaviour	Units where parents talked about using the medication to control the child's behaviour and/or in response to child misbehaviour.	"Interviewer: Can you tell me about a situation in which you have given when you have given him an extra dose of medication? Respondent: Its usually in the evening when he's gone absolutely ballistic. I mean, he's kicking the door down, he's throwing everything out of his room. Its not a case of giving him extra, he might have missed one, but he needs it, to calm him down."
Use of medication to give child freedom	Units where parents talked about using medication to enable their child to enjoy themselves or have more independence/freedom.	"The only time we really give him any extra was when he was on his long days out, you know when we've had trips out or we've had trips with the school and I've allowed them to give him an extra one. I mean a couple of times they've been up to Thorpe Park[2] and they've been up to Alton Towers[3] and he wants to enjoy himself. He needs the Ritalin or he wouldn't be able to go."
Drug holidays	Units where parents talked about giving their child a break from medication, e.g. for the weekend or over the school holidays	"We save up and go to France, camping on a campsite where there's lots of activities...he thought this was wonderful, so he didn't need his

[2] Thorpe Park is a large theme park
[3] Alton Towers is a large theme park

		Ritalin. He don't have to sit still in a classroom, he doesn't have to concentrate on with their teacher is saying and process, language processing problems, but he doesn't have to process language in the park, so he always has a bit of a break."
Communicating with the child about medication	Units where parents talked about communicating with the child about medication	"We've always told him, you know if he's had to change tablets or have another added or whatever, we've always told him exactly, this tablet is for this and you should feel like this. I mean there was a time when we went through depression and he was on dex-amphetamine and an antidepressant, and when that new tablet came in, he'd automatically say, 'What's that?". You know, and we'd say, this one makes you feel better and be a bit more happy."
Not communicating with the child about medication	Units where parents talked about not communicating or explaining what the medication was for to their child.	"I told him he was going to take medication. Didn't explain it to him, he wouldn't have understood it. Take this, this is a new medication and you're going to try it for mummy, there's a good boy."
Parental Disagreement about Medication	Units where parents talked about having disagreement with the child's other parent about medication, or concerns that another parent was abusing the medication.	"The oinly way I can describe his dad and the way he sees it, is if Steve's having a good day and he's with him, he won't give him his medication, and he'll send him back to me going off his head. That's his dad!"
Managing child resistance	Units where participants talked about managing their child's resistance or reluctance to take medication.	"I watch him take it (the medication). If I turn my back then I won't know if he's taken it, so I do have to watch him, or I'll physically hand him the tablets and then scout around after him to check to see if he's dropped it anywhere."
Forgetting to give child	Units where participants talked about forgetting to give their	"Occasionally I have forgotten, but it doesn't last

medication	children medication	long because I've usually got some on me, so if we've gone out and we're really acting up it usually clicks, oh God he hasn't had his medication so he always gets it."
Child MRB	Units where parents talked about behaviours the child displayed in relation to taking medication	"He closes up his mouth, puts his hand over and shouts and screams and has a little kick. Depends what kind of mood he's in really, if he's in a mad mood you get all the abuse and he sort of just runs round and he'll hide round the chairs and he'll stand there, closes his mouth or puts his hand over his mouth."
Serious Resistance	Units where parents describe child resisting taking medication e.g. hiding it, lying about taking it, spitting it out, screaming or kicking when asked to take medication. Units where parents say that their child used to resist taking medication or that their child only rarely resists taking medication are coded as "Resistance, but not a problem".	"He spits it out, he'll go, and you'll find it, usually stick, he has a great habit of sticking it to the door on the side unit and because its been sat in his mouth, its half melted and he'll fun down and stick it on the mirror of his bedroom or on the back door of his bedroom. But at the end of the day, he hasn't taken it, he's won and I don't know about it until I clean his room and find his tablets stuck everywhere."
Resistance, but not a problem.	Units where parents say their children used to resist taking medication but no longer take medication or say that their child only resists taking medication very rarely or that their child's resistant behaviour is not a problem.	"Sometimes he will try not to take it, but not in a horrible way, in a hypey way. He's very hypey. He stuffs them down the settee and then says, 'Ha, ha, you don't know where my tablet is!" But its just to get me going, but that's him being at the hypey end of the scale. He thinks its really funny but he doesn't follow it through. I just get him another tablet and he takes it. I'll find it later when it goes up the hoover, the little monkey. He's the same with other things, like his school tie. He just thinks its funny to wind mum up. But its not a problem, he's just playing."

Child forgets to take medication	Units where parents say their child forgets to take medication, e.g. at school.	"She's very bright, but she forgets to take it sometimes. If I don't remind her in the morning she will forget."
School MRB	Units where parents talked about taking medication in school, or avoiding taking medication in school.	"He has a learning support assistant, she's lovely, and she reminds him to take the medication and makes sure he gets it, makes sure he's alright."
Schools forget to give the child medication or do not give the child medication at the right time	Units where parents say that the school forgets to give the child medication or does not give the child medication at the right time.	"they phone me at half past two in the afternoon when the finish at 3 o'clock to tell me he's not had his medication. Defeats the whole object of it.'
Schools unwilling to take responsibility for the child's medication regimen	Units where parents say that their child's school/college is unwilling to take responsibility for administering their child's medication	"We're having problems with college....they're not able to control him all day, or take responsibility for his medication. They're not allowed to take responsibility for it."
Parents avoid having the school involved in medication	Units where parents say that they have chosen a sustained release medication (e.g. concerta) to avoid having the school involved in giving the child medication.	"He's taking concerta now so that solves that problem because he doesn't have to take it in school. I think concerta is brilliant for that. We don't have to involve the school on the medication side of things at all."
Schools make sure the child gets medication on time	Units where parents say that the school ensures their child gets their medication on time, but **not** where parents say the school makes sure the child gets the medication on time so that they don't have to help the child.	"He has a learning support assistant, she's lovely, and she reminds him to take the medication and makes sure he gets it, makes sure he's alright."
Schools use medication to keep the child quiet and fail to help the child academically	Units where parents say the school uses medication in order to keep their child quiet or to avoid helping the child with their academic work.	"the LEA[4] was saying there was nothing wrong with my child because Ritalin was keeping her quiet in the corner. If she's not giving the teachers any grief, they don't have to deal with her do they? They don't have to address

[4] LEA stands for Local Education Authority

			anything"
	Teachers are indiscreet about medication	Units where parents say the teachers or other school personnel are not discreet about the child needing to take medication.	"The teachers aren't very good at hiding it. They do the opposite, they will point it out to everybody and if one of them does do something, it will be, 'Have you taken your tablets today?'"
	Schools take inadequate care with the medication	Units where parents say the schools do not take adequate care ensure the medication is stored appropriately and securely.	'Kids have taken it out of the teacher's drawers...I don't understand why the schools are not aware what the circumstances for storing Ritalin are. They're not supposed to allow any access to anybody. It's a class A drug!'
Theme 3 – Attitudes to Medication	Attitudes of Other People (Positive)	This includes comments about the attitudes or beliefs of other people such as teachers, doctors, friends, family members towards medication. Some of these statements were positive such as recognising that the medication was effective or commenting on the difference the medication made to the child's life, doctors assuring the parents that giving the child medication was the kindest thing the parents could do for him.	'Everyone's seen the difference, my neighbour is a good example actually, because she keeps saying to me all the time, she goes, 'Ben, he's lovely, isn't he, he wasn't such a good boy when he first moved here,' you know everyone used to steer clear.' (P.3)
	Attitudes of Other People (Negative)	This includes negative comments about the attitudes or beliefs of other people, for example people who were anti-Ritalin, or who had moral objections to the use of medication in children.	"His teacher said we were being cruel to give our child medication, she thought we were drugging our child."
Theme 4 – Relationships with Medical Professionals	Relationships with Medical Professionals (Positive)	Units where participants made positive comments about medical professionals such as the doctor being good with the child, or having trust in the doctor's opinion.	"Well it was Dr. C, she was brilliant, she explained everything to him. She told him that we're going to try these tablets, you know, and we're going to try, we're going to try, because they might make you better, and the way she put it over was lovely."
	Relationships with Medical Professionals (Negative)	Units where participants report negative experiences with medical professionals, such as doctors having prejudices, not being willing to recognise the child's problems, arguments about medication, doctors being ill-informed about ADHD or not getting on well with the child.	"...some days, you'd turn up for an hour appointment (with the psychiatrist) and spend the whole hour finding out how it had gone with school and what had happened there but not once actually directing, directly addressing Paul."
Theme 5 -	Adolescence	Statements about the child's feelings towards the medication	"...he's coming up ten and obviously now...what

Adolescence	specifically in adolescence, behaviour towards medication during this time period and experiences of adolescents who stopped taking medication or continued taking medication.	am I going to do when he's 13 or 14 and he just refuses to take it? If he still feels the way he does now about it, if this carries on . I mean I'm not going to be able to make him take it."
Theme 6 – Other Treatments	Units where the participants talk about other treatments for ADHD which they have tried and whether or not they have found them helpful, particularly in relationship to medication as a treatment for ADHD, such as being less or more effective, or complementary.	"We've tried all sorts, diets and everything. But nothing worked like the Ritalin and you stick to what works don't you."

Appendix C

The development of the AMRABs questionnaires

C1 Information letter to parents

C2 Information letter for parents to give to their doctor

C3 Provisional Parent and Child ADHD Medication Related Attitudes and Behaviours Questionnaires

C4 Revised Parent and Child ADHD Medication Related Attitudes and Behaviours Questionnaires

Appendix C.1
Letter to Parents

Dear Parent,

I am Ruth Ann Harpur, a PhD student at the University of Southampton. I am requesting your participation in a study about the experiences of families with children and young people who are taking medication for ADHD. You should have received two questionnaires, one to be filled out by you and another to be filled out by your child.

The child version of the questionnaire is suitable for children aged 10 and over. Before giving this questionnaire to your child, we would suggest that you read it first and decide if you are happy for your child to fill it in. If you do not wish your child to fill in the questionnaire, or your child does not want to, please return this questionnaire to us blank.

The questionnaire may raise sensitive matters surrounding medication and the experiences of children with ADHD and their families. Should it raise any such issues for you or your child, we would suggest that you approach someone working with your family, for example the prescribing physician to discuss the matters further. A letter is provided for you to give to this person should you wish to do so.

Personal information will not be released to, or viewed by anyone, other than researchers involved in this project. Results of this study will not include your name or any other identifying characteristics.

Pre-paid envelopes are provided for the questionnaires return. If you return the questionnaires filled in, we will take this as permission for your data to be entered in the study and that you understand that published results of this research project will maintain your confidentially. Your participation is voluntary and you may withdraw your participation at any time.

If you have any questions concerning this study, please do not hesitate to contact me by phone or email.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 3995.

Best Wishes,

Ruth Ann Harpur

Appendix C.2
Letter to Doctor

Dear Doctor,

My name is Ruth Ann Harpur and I am studying towards a PhD at the University of Southampton. I am interested in the experiences of children who are taking medication for ADHD and their families.

As such, I am carrying out a study to design a questionnaire concerning the experiences of children and their families with ADHD medication. Participants were given two questionnaires, one to be filled out by a parent and another to be filled out by the child.

The questionnaire explored areas such as how the child and parents feel about the medication, the benefits and drawbacks of medication they experience, attitudes around medication, relationships with medical professionals, issues surrounding the ways in which medication is used (e.g. taking it at specific times, drug holidays etc), how the child's friends and school respond to the child's ADHD and stress ADHD might place on the family.

It is possible that the questionnaire may have raised concerns for the parent or child filling it in. If so, participants were advised to approach their doctor if they had any additional concerns regarding treatment.

Should you wish any further information or copies of the questionnaires, please do not hesitate to get in touch.

Yours faithfully,

Ruth Ann Harpur

Appendix C.3

Provisional AMRABs questionnaires

ADHD MEDICATION QUESTIONNAIRE – Parent Version

My name is Ruth Ann Harpur and I am studying for a PhD at the University of Southampton. I am interested in the experiences of families with children and young people who are taking medication for ADHD. I would be grateful if you could fill out the following questionnaire. All of your answers will be kept confidential.

You do not have to answer any questions that you do not want to. If you have any questions please feel free to get in touch.

If you have any questions after filling out the questionnaire or would like more information about the study please contact me.

Thank you.

Ruth Ann Harpur

Psychology Department,
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University of Southampton,
Highfield,
Southampton.
SO17 1BJ.
United Kingdom

Email: R.A.Harpur@soton.ac.uk

Phone: 02380 594593

What is your relationship to the child/children with ADHD?

Mother ☐

Father ☐

Step-mother ☐

Step-father ☐

Other (please specify) .....

Are you...

Married ☐

Single ☐

Divorced or Separated ☐

What Country are you from: .....

Who does your child live with?

Biological mother and father ☐

Mother only ☐

Father only ☐

Mother and step-father ☐

Father and step-mother ☐

Foster parents ☐

Adoptive family ☐

What is your child's date of birth? ___/___/___

Is your child Male ☐

Female ☐

What medication has your child been prescribed? (Please give the name of the medication and the dosage.)

Ritalin ☐

Concerta ☐

Dextroamphetamine ☐

Other(s) Please specify

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On an average day, at what time does your child take their medication?

Morning ☐

Afternoon ☐

Evening ☐

Other (Please specify)

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How long has your child been taking medication for ADHD?

Less than 1 month ☐

1 to 3 months ☐

3 to 6 months ☐

6 to 12 months ☐

More than 12 months ☐

What medication has your child been on in the past. (Please tick all that apply).

Ritalin ☐

Slow Release Ritalin ☐

Concerta ☐

Dex-Amphetamine ☐

Other(s) Please specify

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Has your child been diagnosed with any of the following conditions (please tick all that apply)

ADHD ☐

Autism/Asperger's ☐

Anxiety Disorder ☐

Conduct Disorder ☐

Depression ☐

Learning Disability ☐

Oppositional Defiance Disorder ☐

Tourettes Syndrome ☐

Developmental co-ordination disorder or dyspraxia ☐

Other (Please specify)

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The following questions are about your experiences as a parent with a child receiving treatment for ADHD. Please consider the following statements and consider how much they are true of your experiences over the last 3 months of treatment and rate each statement on a scale of 1 to 5 as follows.

1 - Never
2 - Seldom
3 - Sometimes
4 - Often
5 – Always

Resistance

	1 (Never)				**5 (Always)**
1. My child tries to get out of taking their ADHD pills	1	2	3	4	5
2. I have to make my child take their ADHD pills	1	2	3	4	5
3. My child pretends to take, hides or spits out their ADHD pills	1	2	3	4	5

	1 (Never)				5 (Always)
4. I always check that my child has swallowed their ADHD pills	1	2	3	4	5
5. My child doesn't mind taking their ADHD pills	1	2	3	4	5
6. My child would take their ADHD pills even if I didn't insist on it	1	2	3	4	5
How medication helps parents					
7. I give my child more ADHD pills if they are naughty	1	2	3	4	5
8. The ADHD pills help my child to be less naughty	1	2	3	4	5
9. I give my child ADHD pills so that they calm down and I can get on with things	1	2	3	4	5
10. The ADHD pills make my life easier	1	2	3	4	5
11. I give my child ADHD pills when I am angry	1	2	3	4	5
12. I give my child ADHD pills when I feel sad or depressed	1	2	3	4	5
How medication helps children					
13. The ADHD pills help my child to do well at things	1	2	3	4	5
14. The ADHD pills help my child to do things they want to do	1	2	3	4	5
15. The ADHD pills help my child to be good	1	2	3	4	5
16. I want my child to be independent and do things for him/her self	1	2	3	4	5
17. My child is able to be involved in decisions about their ADHD pills	1	2	3	4	5
18. The ADHD pills help my child to be more like other children	1	2	3	4	5
19. My child takes ADHD pills so they can spend more time with their friends	1	2	3	4	5

	1 (Never)				5 (Always)
Benefits of Medication					
20. The ADHD pills help my child to pay attention	1	2	3	4	5
21. The ADHD pills calm my child down	1	2	3	4	5
22. The ADHD pills help my child to do better at school	1	2	3	4	5
23. The ADHD pills help my child to be good	1	2	3	4	5
24. The ADHD pills help my child to get on better with their family	1	2	3	4	5
25. The ADHD pills help my child to get on better with their friends	1	2	3	4	5
26. The ADHD pills help my child to think before they act	1	2	3	4	5
27. The ADHD pills are good for my child	1	2	3	4	5
Negative Effects of Medication					
28.I worry about the side effects my child experiences when they take their ADHD pills	1	2	3	4	5
29. The ADHD pills take away my child's personality	1	2	3	4	5
30. The ADHD pills stop my child from doing things they want to do	1	2	3	4	5
31. The ADHD pills make my child 'dazed' or spaced out	1	2	3	4	5
32. The ADHD pills have a bad effect on my child	1	2	3	4	5
33. The ADHD pills make my child behave badly	1	2	3	4	5
34. My child's behaviour is worse when the ADHD pills have worn off than when they are not taking any ADHD pills at all.	1	2	3	4	5
Child Attitudes					
35. My child feels different from other children because of taking ADHD pills	1	2	3	4	5

	1 (Never)				5 (Always)
36. If it was my child's choice, they wouldn't take the ADHD pills	1	2	3	4	5
37. The ADHD pills make my child feel that they are not him/her self	1	2	3	4	5
38. My child does not like taking ADHD pills	1	2	3	4	5
39. My child thinks the ADHD pills really helps them	1	2	3	4	5
40. My child wants help with their ADHD	1	2	3	4	5
41. My child doesn't think there is anything wrong with them	1	2	3	4	5
42. My child tries to remember to take their ADHD pills	1	2	3	4	5
43. The ADHD pills help my child to do their best	1	2	3	4	5
44. My child thinks it is unfair that they have to take ADHD pills	1	2	3	4	5
45. Taking ADHD pills is no big deal for my child	1	2	3	4	5
46. If my child didn't take ADHD pills things would be a lot worse	1	2	3	4	5
47. Taking the ADHD pills doesn't help my child	1	2	3	4	5
48. My child thinks that our family don't understand what it is like to have ADHD	1	2	3	4	5
49. My child thinks that our family don't understand what it is like to have to take ADHD pills every day.	1	2	3	4	5

Your Child's relationship with the doctors

50. The doctors listen to what my child has to say	1	2	3	4	5
51. The doctors help my child to understand their ADHD	1	2	3	4	5
52. My child hates going to see the doctor	1	2	3	4	5
53. The doctors don't help my child	1	2	3	4	5

	1 (Never)				5 (Always)
Taking Medication					
54. I forget to give my child their ADHD pills	1	2	3	4	5
55. I forget to give my child their ADHD pills on time	1	2	3	4	5
56. We are very careful about taking the ADHD pills as the doctor has instructed	1	2	3	4	5
57. I put my child's pills in a drink to make them easier to swallow	1	2	3	4	5
58. I make my own decisions about when to take the ADHD pills and how much to take	1	2	3	4	5
59. I give my child less ADHD pills when they are well behaved	1	2	3	4	5
60. If my child is badly behaved, I give him more ADHD pills	1	2	3	4	5
61. My child is able to take their ADHD pills in a way that fits in with what they want to do	1	2	3	4	5
62. I get confused about what medication my child is to take and when	1	2	3	4	5
63. My child has a pill box to help us remember what pills they need to take	1	2	3	4	5
64. I get confused when the doctors change my child's pills	1	2	3	4	5
65. It is easy to remember what ADHD pills my child needs to take	1	2	3	4	5
Drug Holidays					
66. My child has a break from taking ADHD pills during the school holidays	1	2	3	4	5
67. My child doesn't take ADHD pills during the weekends	1	2	3	4	5
68. My child doesn't take ADHD pills in the evenings	1	2	3	4	5

	1 (Never)				5 (Always)
69. When my child has a break from taking ADHD pills it helps us to see how the ADHD pills help when they do take them	1	2	3	4	5
70. Not taking ADHD pills over the holidays or weekends helps my child to learn how to cope without them.	1	2	3	4	5

Friends

71. My child's friends do not know that they are taking ADHD pills	1	2	3	4	5
72. My child finds it easier to get on with their friends when they are taking the ADHD pills	1	2	3	4	5
73. My child is able to spend more time with their friends because they take their ADHD pills	1	2	3	4	5
74. My child would be embarrassed if their friends knew that they took ADHD pills	1	2	3	4	5
75. Other children make fun of my child because they take ADHD pills	1	2	3	4	5
76. My child's friends like to be with them when they have not taken their ADHD pills	1	2	3	4	5
77. Other children don't want to be friends with my child because they take ADHD pills	1	2	3	4	5
78. Other children think my child is mad because they take ADHD pills	1	2	3	4	5
79. My child feels that taking ADHD pills makes them different from other children	1	2	3	4	5
80. My child wouldn't want their friends to know about their ADHD pills	1	2	3	4	5
81. My child's friends help them to remember to take their ADHD pills	1	2	3	4	5
82. My child's ADHD does not matter to their friends	1	2	3	4	5

	1 (Never)				5 (Always)
School					
83. My child is happy to take their ADHD pills at school	1	2	3	4	5
84. At school the teachers keep their ADHD pills a secret	1	2	3	4	5
85. The teachers make sure my child gets their ADHD pills	1	2	3	4	5
86. The school supports my child	1	2	3	4	5
87. The ADHD pills have helped my child to do better at school	1	2	3	4	5
88.The ADHD pills have helped my child to do more fun things at school, such as playing sports or after school clubs	1	2	3	4	5
89. The teachers really help my child out	1	2	3	4	5
90. My child forgets to go to get their ADHD pills at school	1	2	3	4	5
91. The teachers forget to give my child their ADHD pills	1	2	3	4	5
92 My child is embarrassed about taking their ADHD pills at school	1	2	3	4	5
93. The school give my child their ADHD pills before lunch so my child is not hungry at lunch time	1	2	3	4	5
94. The school give my child the ADHD pills to keep them quiet	1	2	3	4	5
95. The school don't give my child the help they need	1	2	3	4	5
96. The teachers embarrass my child by letting other children know about their ADHD	1	2	3	4	5

Family

We recognise that children live in a variety of kinds of families, e.g. step families, foster homes, single parent families etc and that not all questions in this section will be relevant to everyone.

Where the questions ask about the child's other parent, please regard this to mean the other parent that is closest to the child, e.g. step-father/mother, foster father/mother or natural father/mother regardless of whether or not this parent lives in the same home as the child.

Please feel free to disregard any questions that you do not feel are relevant for your family or to clarify in the 'Any additional comments' section.

	1 (Never)				**5 (Always)**
97. I argue with my child's other parent about their condition	1	2	3	4	5
98. My child's other parent does not think my child has ADHD	1	2	3	4	5
99. I do not think my child has ADHD	1	2	3	4	5
100. I get stressed about my child's ADHD	1	2	3	4	5
101. My child's other parent doesn't give my child their ADHD pills	1	2	3	4	5
102. I don't give my child their ADHD pills	1	2	3	4	5
103. My child's other parent gives my child more ADHD pills than they are supposed to have.	1	2	3	4	5
104. I give my child more ADHD pills than they are supposed to have	1	2	3	4	5
105. My child's other parent doesn't think my child should be taking ADHD pills	1	2	3	4	5
106 I don't think my child should be taking ADHD pills	1	2	3	4	5
107.I work together with my child's other parent to support my child	1	2	3	4	5
108. My child's ADHD has brought out their strengths	1	2	3	4	5
109. My child's ADHD has brought out my strengths	1	2	3	4	5

	1 (Never)				5 (Always)
110. My child's ADHD has brought out my child's other parent's strengths	1	2	3	4	5
111. My child's ADHD has brought out the strengths in our family	1	2	3	4	5
112. My child's condition has put considerable strain on our marriage or relationship	1	2	3	4	5
113. My child's condition contributed to the break-down of my relationship with a partner	1	2	3	4	5
Parent Relationship with Doctors					
114. I have disagreements with the doctor(s) concerning medication	1	2	3	4	5
115. The doctor(s) are very reluctant or unwilling to prescribe medication for my child	1	2	3	4	5
116. The doctor(s) are too keen to prescribe medication for my child	1	2	3	4	5
117. I have a good relationship with the doctor(s) responsible for treating my child	1	2	3	4	5
118. The doctor(s) listen(s) to what I have to say	1	2	3	4	5
119. I trust what the doctor(s) have to say about my child's condition and medication	1	2	3	4	5
120. I don't understand what the doctor(s) say(s)	1	2	3	4	5
121. The doctor(s) take(s) time to explain my child's condition	1	2	3	4	5
122. The doctor(s) give(s) me clear and helpful advice about the medication	1	2	3	4	5

Do you have any additional comments about the issues raised in this questionnaire?

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Thank you for taking the time to complete this questionnaire. Please feel free to contact me if you have any further questions

ADHD MEDICATION QUESTIONNAIRE – Child Version

My name is Ruth Ann Harpur and I am studying for a PhD at the University of Southampton. I am studying what children think about taking medicine for ADHD. If you would like to help, please answer the following questions.

All of your answers will be kept confidential and no-one will know what you have said.

You do not have to answer any questions that you do not want to.

If you have any questions or you don't understand anything you could ask someone to help or call me on 02380 594593

If you have any questions after answering the questions or would like more information about the study please contact me.

Thank you.

Ruth Ann Harpur

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SO17 1BJ.
United Kingdom

Email: R.A.Harpur@soton.ac.uk

Phone: 02380 594593

When is your birthday?

Date ____ Month ____ Year ____

How old are you? _____years

Are you

Male ☐

Female ☐

What ADHD pills do you take? (please tick)

Ritalin ☐

Slow Release Ritalin ☐

Concerta ☐

Dex-Amphetamine ☐

Other(s) What are they?

.....

.....

.....

On an average day, at what times do you take your ADHD pills?

Morning ☐

Afternoon ☐

Evening ☐

Other (What time?)

.....

.....

How long have you been on these pills?

Less than 1 month ☐

1 to 3 months ☐

3 to 6 months ☐

6 to 12 months ☐

More than 12 months ☐

What ADHD pills have you taken in the past. (Please tick all that apply).

Ritalin ☐

Slow Release Ritalin ☐

Concerta ☐

Dextroamphetamine ☐

Other(s) What are they?

.....

.....

.....

The following questions are about what you think about taking ADHD pills for ADHD. Please think about the questions and if they are true in your opinion. There are no right and wrong answers, this is just about what you think.

Then rate each question on a scale of 1 to 5

1. Never
2. Seldom
3. Sometimes
4. Often
5. Always

	1 (Never)				**5 (Always)**
How I feel about taking my ADHD pills					
1. I try to get out off taking my ADHD pills	1	2	3	4	5
2. My parents have to make me take my ADHD pills	1	2	3	4	5
3. I pretend to take, hide or spit out the ADHD pills	1	2	3	4	5
4. My parents always check that I have swallowed my ADHD pills	1	2	3	4	5
5. I don't mind taking ADHD pills	1	2	3	4	5
6. I would take my ADHD pills even if my parents didn't make me	1	2	3	4	5
How the ADHD pills help my parents					
7. My parents give me more ADHD pills when I am naughty	1	2	3	4	5

	1 (Never)				5 (Always)
8. The ADHD pills help me to be less naughty	1	2	3	4	5
9. My parents give me my ADHD pills so that I calm down and they can get on with things.	1	2	3	4	5
10. The ADHD pills make my parents' lives easier	1	2	3	4	5
11. My parents give me ADHD pills when they are angry	1	2	3	4	5
12. My parents give me my ADHD pills when they feel sad	1	2	3	4	5
How the ADHD pills help me.					
13. The ADHD pills help me to do well at things	1	2	3	4	5
14. The ADHD pills help me to do things I want to do	1	2	3	4	5
15. The ADHD pills help me to be good	1	2	3	4	5
16. My parents want me to do things for myself	1	2	3	4	5
17. My parents listen to what I have to say about my ADHD pills	1	2	3	4	5
18. The ADHD pills help me to be more like other children	1	2	3	4	5
19. I take my ADHD pills so I can spend more time with my friends	1	2	3	4	5
Good things about taking ADHD pills					
20. The ADHD pills help me to pay attention	1	2	3	4	5
21. The ADHD pills calm me down	1	2	3	4	5
22. The ADHD pills help me to do better at school	1	2	3	4	5
23. The ADHD pills help me to be good	1	2	3	4	5
24. The ADHD pills help me to get on better with my family	1	2	3	4	5
25. The ADHD pills help me to get on better with my friends	1	2	3	4	5

	1 (Never)				5 (Always)
26.The ADHD pills help me to think before I act	1	2	3	4	5
27. The ADHD pills are good for me	1	2	3	4	5
Bad things about taking ADHD pills					
28. I am worried about the way the ADHD pills make me feel	1	2	3	4	5
29 The ADHD pills stop me from being myself	1	2	3	4	5
30. The ADHD pills stop me from doing things I want to do	1	2	3	4	5
31. The ADHD pills make me 'dazed' or 'spaced out'	1	2	3	4	5
32. The ADHD pills have a bad effect on me	1	2	3	4	5
33. The ADHD pills make me behave badly	1	2	3	4	5
34. My behaviour is worse when the ADHD pills have worn off than when I am not taking any ADHD pills at all	1	2	3	4	5
How you feel about taking ADHD pills and having ADHD					
35. I feel different from other children because I take ADHD pills	1	2	3	4	5
36. If it was my choice, I wouldn't take the ADHD pills	1	2	3	4	5
37. The ADHD pills make me feel like I am not myself	1	2	3	4	5
38. I do not like taking ADHD pills	1	2	3	4	5
39. The ADHD pills really help me	1	2	3	4	5
40. I want help with my ADHD	1	2	3	4	5
41. I don't think there is anything wrong with me	1	2	3	4	5
42. I try to remember to take my ADHD pills	1	2	3	4	5
43. The ADHD pills help me to do well at things	1	2	3	4	5
44. It's not fair that I have to take ADHD pills	1	2	3	4	5

	1 (Never)				5 (Always)
45. Taking ADHD pills is no big deal	1	2	3	4	5
46. If I didn't take the ADHD pills things would be a lot worse	1	2	3	4	5
47. Taking the ADHD pills doesn't help me	1	2	3	4	5
48. My family don't understand what it is like to have ADHD	1	2	3	4	5
49. My family don't understand what it is like to have to take ADHD pills every day	1	2	3	4	5
Your Relationship with the Doctors					
50. The doctors listen to what I have to say	1	2	3	4	5
51. The doctors help me understand my ADHD	1	2	3	4	5
52. I hate going to see the doctor	1	2	3	4	5
53. The doctors don't help me	1	2	3	4	5
Taking the ADHD pills					
54. I forget to take my ADHD pills or my parents forget to give them to me	1	2	3	4	5
55. My parents forget to give me my ADHD pills on time	1	2	3	4	5
56. My parents give me the pills exactly the way the doctor tells them to	1	2	3	4	5
57. My parents and I make our own decisions about when to take the ADHD pills and how many to take	1	2	3	4	5
58. If I am well behaved my parents give me less ADHD pills	1	2	3	4	5
59. I put the ADHD pills in a drink to make them easier to swallow	1	2	3	4	5
60. If I am badly behaved my parents give me extra ADHD pills	1	2	3	4	5
61. I am able to take my ADHD pills in a way that fits with what I want to do.	1	2	3	4	5

	1 (Never)				5 (Always)
62. I get confused about what pills I am to take and when	1	2	3	4	5
63. I have a pill box to help me to remember what pills I need to take	1	2	3	4	5
64. I get confused when the doctors change my ADHD pills	1	2	3	4	5
65. Its easy to remember what ADHD pills I need to take	1	2	3	4	5
Drug Holidays					
66. I have a break from taking ADHD pills during the school holidays.	1	2	3	4	5
67. I don't take ADHD pills during the weekends	1	2	3	4	5
68. I don't take ADHD pills in the evenings	1	2	3	4	5
69. When I have a break from taking ADHD pills, it helps me to see how the ADHD pills help me when I do take them	1	2	3	4	5
70. Not taking ADHD pills over the holidays or weekends helps me to learn how to cope without them	1	2	3	4	5
Friends					
71. My friends do not know that I am taking ADHD pills	1	2	3	4	5
72. I find it easier to get on with my friends when I have taken my ADHD pills	1	2	3	4	5
73. I am able to spend more time with my friends because I take my ADHD pills	1	2	3	4	5
74. I would be embarrassed if my friends knew I took ADHD pills	1	2	3	4	5
75. Other children make fun of me because I have to take ADHD pills	1	2	3	4	5
76. My friends like to be with me when I haven't taken my ADHD pills	1	2	3	4	5
77. Other children don't want to be my friends because I take ADHD pills	1	2	3	4	5

	1 (Never)				5 (Always)
78. Other children think I am mad because I take ADHD pills	1	2	3	4	5
79. Taking ADHD pills makes me different from other children	1	2	3	4	5
80. I don't want my friends to know about my ADHD	1	2	3	4	5
81. My friends help me to remember to take my ADHD pills	1	2	3	4	5
82. My ADHD does not matter to my friends	1	2	3	4	5
School					
83. I am happy to take my ADHD pills at school	1	2	3	4	5
84. At school, the teachers keep my ADHD pills a secret	1	2	3	4	5
85. My teachers make sure I get my ADHD pills	1	2	3	4	5
86. My school support me	1	2	3	4	5
87. The ADHD pills have helped me to do better at school	1	2	3	4	5
88. My ADHD pills help me to do more fun things at school such as playing sports or after school clubs	1	2	3	4	5
89. My teachers really help me out	1	2	3	4	5
90. I forget to go and get my ADHD pills at school	1	2	3	4	5
91. My teachers forget to give me my ADHD pills	1	2	3	4	5
92. I am embarrassed about taking my ADHD pills at school	1	2	3	4	5
93. My school give me my ADHD pills before lunch so I am not hungry at lunch time	1	2	3	4	5
94. The school gives me my ADHD pills to keep me quiet	1	2	3	4	5
95. The school don't give me the help I need	1	2	3	4	5
96. My teachers embarrass me by letting other children know about my ADHD	1	2	3	4	5

Family

Children live in a different kinds of families, e.g. step families, foster homes, single parent families etc., so the questions in this section may not all be relevant to you.

Where the questions ask about your mum or dad, this could mean your foster parents or step parents. Please answer the questions as though they were asking about your family.

You don't have to answer any questions if they don't describe your family. If you want to say anything more about your family, you can write something at the end where it says, 'Do you have anything else you would like to say?'

	1 (Never)				5 (Always)
97. My parents argue about my condition	1	2	3	4	5
98. My dad doesn't think I have ADHD	1	2	3	4	5
99. My mum doesn't think I have ADHD	1	2	3	4	5
100. My parents get stressed about my ADHD	1	2	3	4	5
101. My dad doesn't give me my ADHD pills	1	2	3	4	5
102. My mum doesn't give me my ADHD pills	1	2	3	4	5
103. My dad gives me more ADHD pills than I am meant to have	1	2	3	4	5
104. My mum gives me more ADHD pills than I am meant to have	1	2	3	4	5
105. My mum doesn't think I should be taking ADHD pills	1	2	3	4	5
106. My dad doesn't think I should be taking ADHD pills	1	2	3	4	5
107. My parents work together to help me	1	2	3	4	5
108. Having ADHD has brought out my strengths	1	2	3	4	5
109. My ADHD has brought out my mum's strengths	1	2	3	4	5
110. My ADHD has brought out my dad's strengths	1	2	3	4	5
111. My condition has brought out strengths in our family	1	2	3	4	5

Do you have anything else you would like to say?

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Thank you for taking the time to complete this questionnaire!

Please feel free to contact me if you have any further questions.

Appendix C.4
Revised AMRABs Questionnaires

ADHD MEDICATION RELATED ATTITUDES AND BEHAVIOURS QUESTIONNAIRE – PARENT VERSION

My name is Ruth Ann Harpur and I am studying for a PhD at the University of Southampton. I am interested in the experiences of families with children and adolescents who are taking medication for ADHD. I would be grateful if you could complete the following questionnaire. All of your answers will be kept confidential.

You do not have to answer any questions you do not want to. If you have any questions about the research or would like any more information please do not hesitate to contact me.

Thank you.

Ruth Ann Harpur
School of Psychology
Shackleton Building
University of Southampton
Highfield
Southampton
SO17 1BJ

Email: R.A.Harpur@soton.ac.uk
Phone: (44) 23 8059 4593

What is your relationship to the child/children with ADHD?

Mother ☐

Father ☐

Other (please specify)

What is your marital status?

Married ☐

Single ☐

Divorced or Separated ☐

What Country are you from:

UK ☐

Republic of Ireland ☐

United States ☐

Other (please specify)

What is your child's date of birth? / / (DD/MM/YY)

What is your child's sex?

Male ☐
Female ☐

What medication has your child been prescribed? (Please give the name of the medication and the dosage.)

Ritalin	☐	Slow Release Ritalin (Ritalin XR)	☐
Concerta	☐	Dex-Amphetamine	☐
Adderall	☐	Adderall XR	☐
Metadate	☐	Metadate CD	☐
Focalin	☐	Ritalin LA	☐
Strattera	☐	Other(s). Please specify:	

How many times a day does your child need to take medication?

Once in the morning ☐

Twice a day (morning and afternoon, or morning and evening) ☐

Three times a day (morning, afternoon and evening) ☐

More than 3 times a day ☐

Does your child need to be given a medication by their school?

Yes ☐ No ☐

How long has your child been on taking medication?

Less than 1 month	☐	1 year – 2 years	☐
1 to 6 months	☐	2 years - 4 years	☐
6 to 12 months	☐	More than 4 years	☐

The following questions are about your experiences as a parent with a child receiving medication for ADHD. Please consider the following statements and consider how much they are true of your experiences over the last 3 months of treatment and rate each statement on a scale of 1 – 5 as follows.

Scale:
1. Strongly Disagree
2. Disagree
3. Neither Agree nor Disagree
4. Agree
5. Strongly Agree

	1 Strongly Disagree				**5 Strongly Agree**
1.The ADHD pills help my child to do better at school	☐1	☐2	☐3	☐4	☐5
2. Other children make fun of my child because they take ADHD pills	☐1	☐2	☐3	☐4	☐5
3. The ADHD pills stop my child from doing what they want to do	☐1	☐2	☐3	☐4	☐5
4. I vary the dose/timing of the medication if I think my child needs it (e.g. giving medication at the weekends if the child wants to do an activity, where it is better for them to be on medication)	☐1	☐2	☐3	☐4	☐5

	1 Strongly Disagree				5 Strongly Agree
5. The ADHD pills help my child to get on better with their family	☐1	☐2	☐3	☐4	☐5
6. I confident that ADHD pills are right for my child.	☐1	☐2	☐3	☐4	☐5
7. I have to make my child take their ADHD pills	☐1	☐2	☐3	☐4	☐5
8. Sometimes it is difficult to remember whether or not my child has taken their ADHD pills	☐1	☐2	☐3	☐4	☐5
9. I am worried that other children pick on my child because they take ADHD pills	☐1	☐2	☐3	☐4	☐5
10. The fact that my child is taking ADHD pills makes me sometimes question whether I am a good parent	☐1	☐2	☐3	☐4	☐5
11. The ADHD pills take away my child's personality	☐1	☐2	☐3	☐4	☐5
12. I think it is good to be flexible regarding giving pills to my child	☐1	☐2	☐3	☐4	☐5
13. My child would take their ADHD pills even if I didn't insist on it	☐1	☐2	☐3	☐4	☐5
14. I sometimes worry that giving ADHD pills to children is not right	☐1	☐2	☐3	☐4	☐5
15. The ADHD pills make my child "dazed" or "spaced out"	☐1	☐2	☐3	☐4	☐5
16. The ADHD pills help me to manage my child's behaviour	☐1	☐2	☐3	☐4	☐5
17. It is important to me that the ADHD pills help me to manage my child	☐1	☐2	☐3	☐4	☐5
18. Other children don't want to be friends with my child because they take ADHD pills	☐1	☐2	☐3	☐4	☐5

	1 Strongly Disagree				5 Strongly Agree
19. My child pretends to take, hides or spits out their ADHD pills	☐1	☐2	☐3	☐4	☐5
20. I am concerned that people think I am a bad parent because my child takes ADHD pills	☐1	☐2	☐3	☐4	☐5
21. I am worried about the negative effects the ADHD pills have on my child	☐1	☐2	☐3	☐4	☐5
22. My child feels that taking ADHD pills makes them different from other children	☐1	☐2	☐3	☐4	☐5
23. My child tries to get out of taking their ADHD pills	☐1	☐2	☐3	☐4	☐5
24. It is important to me that the ADHD pills help my child to get on in life	☐1	☐2	☐3	☐4	☐5
25. Other children think my child is crazy because they take ADHD pills	☐1	☐2	☐3	☐4	☐5
26. The ADHD pills have a bad effect on my child	☐1	☐2	☐3	☐4	☐5
27. I sometimes will give less medication if I think my child doesn't need it (e.g. giving less medication during the school holidays)	☐1	☐2	☐3	☐4	☐5
28. Sometimes it is difficult to remember to give my child their ADHD pills on time	☐1	☐2	☐3	☐4	☐5
29. I give my child a break from taking ADHD pills during the weekends and/or school holidays	☐1	☐2	☐3	☐4	☐5
30. I feel embarrassed if people know my child takes ADHD pills.	☐1	☐2	☐3	☐4	☐5
31. Sometimes it is difficult to remember what dose my child is on	☐1	☐2	☐3	☐4	☐5
32. The ADHD pills help my child to get on better with their friends	☐1	☐2	☐3	☐4	☐5

ADHD MEDICATION RELATED BEHAVIOURS AND ATTITUDES QUESTIONNAIRE – CHILD VERSION

My name is Ruth Ann Harpur and I am studying for a PhD at the University of Southampton. I am studying what children think about taking medicine for ADHD. If you would like to help, please answer the following questions.

All of your answers will be kept confidential – no-one will know what you have said.

You do not have to answer any questions that you do not want to.

If you have any questions or don't understand something, you could ask someone to help you, or call me on 023 8059 4593.

If you have any questions or want to know more about my work, please contact me.

Thank you for your help!

Ruth Ann Harpur

Ruth Ann Harpur
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Email: R.A.Harpur@soton.ac.uk
Phone: (44) 23 8059 4593

When is your birthday?

(day) (month) (year)

How old are you? years

Are you

Male☐ Female☐

What pills do you take? (please tick)

Ritalin	☐	Slow Release Ritalin (Ritalin XR)	☐
Concerta	☐	Dex-Amphetamine	☐
Adderall	☐	Adderall XR	☐
Metadate	☐	Metadate CD	☐
Focalin	☐	Ritalin LA	☐
Strattera	☐	Other(s). What are they?	

On an average day, at what times do you take your pills?

Once in the morning ☐

Twice a day (morning and afternoon, or morning and evening) ☐

Three times a day (morning, afternoon and evening) ☐

More than three times a day

How long have you been taking pills for your ADHD?

Less than 1 month	☐	1 to 6 months	☐
6 to 12 months	☐	1 year - 2 years	☐
2 years – 4 years	☐	More than 4 years	☐

The following questions are about what you think about taking pills for ADHD. Please think about the questions and if they are true in your opinion. There are no right and wrong answers, this is just about what you think.

Then rate each question on a scale of 1 to 5

Scale:

1. **Strongly Disagree**
2. **Disagree**
3. **Neither Agree nor Disagree**
4. **Agree**
5. **Strongly Agree**

	1 Strongly Disagree				**5 Strongly Agree**
1.The ADHD pills help me to do better at school	☐1	☐2	☐3	☐4	☐5
2. Other children make fun of me because I take ADHD pills	☐1	☐2	☐3	☐4	☐5
3. The ADHD pills have a bad effect on me	☐1	☐2	☐3	☐4	☐5
4. I try to get out of taking my ADHD pills	☐1	☐2	☐3	☐4	☐5
5. Taking ADHD pills makes me different from other children	☐1	☐2	☐3	☐4	☐5
6. The ADHD pills make me feel "dazed" or "spaced out"	☐1	☐2	☐3	☐4	☐5
7. The ADHD pills help me to get on better with my family	☐1	☐2	☐3	☐4	☐5
8. My parents have to make me take my ADHD pills	☐1	☐2	☐3	☐4	☐5
9. The ADHD pills help me to be good	☐1	☐2	☐3	☐4	☐5
10. The ADHD pills stop me from doing what I want to do	☐1	☐2	☐3	☐4	☐5
11. I pretend to take, hide or spit out my ADHD pills	☐1	☐2	☐3	☐4	☐5
12. Other children think I am crazy because I take ADHD pills	☐1	☐2	☐3	☐4	☐5

	1 Strongly Disagree				5 Strongly Agree
13. The ADHD pills help me to get on better with my friends	☐1	☐2	☐3	☐4	☐5
14. Other children don't want to be friends with me because I take ADHD pills	☐1	☐2	☐3	☐4	☐5
15. The ADHD pills take away my personality	☐1	☐2	☐3	☐4	☐5
16. I would take my ADHD pills even if my parents didn't insist on it	☐1	☐2	☐3	☐4	☐5

Appendix D

Analyses for Study 3b.

Table D.1 Linear regression analyses of the relationship between age and AMRABs subscales

Predictor	Variable	B	SE B	β	P	ΔR^2
Child age	Parent-report resistance	7.73	.073	.109	<.05	.01
Child age	Child-report resistance	.079	.119	.064	ns	.00
Child age	Parent-report child stigma	.228	.06	.190	<.001	.03
Child age	Child-report stigma	-.116	.148	-.076	ns	.00

Table D.2 Multivariate regression examining the relationship between age and country in predicting parent-report resistance

Variable	B	SE B	β	P
Child age	.103	.080	.075	ns
Country (UK or US)	-.411	.239	-.100	.09
				$\Delta R^2 = .01$

Table D.3 Multivariate regression examining the relationship between age and country in predicting child-report resistance

Variable	B	SE B	β	P
Child age	.051	.065	.051	ns
Country (UK or US)	.074	.418	.020	ns
				$\Delta R^2 = .00$

Table D.4 Multivariate regression examining the relationship between age and country in predicting parent-report child stigma

Variable	B	SE B	β	P
Child age	.079	.066	.067	ns
Country (UK or US)	-1.021	.196	-.289	<.001
				$\Delta R^2 = .09$

Table D.5 Multivariate regression examining the relationship between age and country in predicting child-report stigma

Variable	B	SE B	β	P
Child age	-.383	.167	-.248	<.05
Country (UK or US)	-1.456	.483	-.326	<.01

$\Delta R^2 = .08$

Table D.6 Linear Regression Analyses of the relationship between stigma and resistance

Predictor	Variable	B	SE B	β	P	ΔR^2
Parent-report child stigma	Parent-report resistance	.357	.069	.307	<.001	.09
Child-report stigma	Child-report resistance	.198	.095	.198	<.05	.04
Parent-report child stigma	Child-report resistance	.211	.101	.197	<.05	.03
Child-report stigma	Parent-report resistance	.256	.101	.240	<.05	.05

Table D.7 Multivariate regression examining the relationship between taking medication at school and country in predicting parent-report child stigma

Variable	B	SE B	β	P
Take medication at school	-1.193	.447	-.141	<.01
Country (UK or US)	-.921	.186	-.261	<.001

$\Delta R^2 = .09$

Table D.8 Multivariate regression examining the relationship between taking medication at school and country in predicting child-report stigma

Variable	B	SE B	β	P
Take medication at school	-.068	.952	-.007	ns
Country (UK or US)	-.961	.439	-.225	<.05

$\Delta R^2 = .03$

Table D.9 Multiple regression analysis of child age and country in predicting parental stigma

Variable	B	SE B	β	P
Child age	-.247	.063	-.217	<.001
Country (UK or US)	-.479	.222	-.120	<.05

$\Delta R^2 = .04$

Appendix E

Analyses for study 3b across samples and within the UK and the USA

Table E.1 Correlations between parent and child-report AMRABs variables in each of the samples

Comparison Pair	UK Clinic	USA Clinic	Internet	Support Group	UK	USA
Parent-report benefits & child-report benefits	.524**	.484(*)	.458**	.322	.503**	.373*
Parent-report costs & child-report costs	.500*	.531(*)	.714**	.612**	.635**	.602**
Parent-report resistance & child-report resistance	.601**	-.097	.585**	.687**	.603**	.554**
Parent-report stigma & child-report stigma	.653**	.530(*)	.727**	.825**	.731**	.464**

**Correlation is significant at the .01 level

*Correlation is significant at the .05 level

(*)Correlation is marginally significant at the .10 level

Table E.2 Paired-samples t-tests comparing differences on parent and child-report costs in each sample

Sample	Variable	Mean	S.D.	T	DF	P
UK Clinic	Parent-report benefits	15.80	3.76	2.67	24	<.05
	Child-report benefits	13.88	3.59			
UK Clinic	Parent-report costs	6.60	3.09	-3.20	24	<.01
	Child-report costs	8.68	3.38			
USA Clinic	Parent-report benefits	16.17	2.52	2.07	11	.06
	Child-report benefits	12.75	4.86			
USA Clinic	Parent-report costs	7.58	4.62	-.511	11	ns
	Child-report costs	8.25	4.71			
Internet	Parent-report benefits	16.00	3.23	3.07	39	<.01
	Child-report benefits	14.20	3.84			
Internet	Parent-report costs	8.00	3.38	-1.67	37	.10
	Child-report costs	8.71	3.50			
Support Group	Parent-report benefits	17.50	2.34	3.22	35	<.01
	Child-report benefits	15.80	3.00			
Support Group	Parent-report costs	7.14	3.33	-1.21	34	ns
	Child-report costs	7.74	3.33			
UK	Parent-report benefits	16.51	3.31	4.93	72	<.001
	Child-report benefits	14.51	3.63			
UK	Parent-report costs	7.08	3.31	-4.14	72	<.001
	Child-report costs	8.45	3.29			
USA	Parent-report benefits	15.97	2.76	2.75	31	<.01
	Child-report benefits	13.72	4.01			
USA	Parent-report costs	8.09	3.95	-.299	30	ns
	Child-report costs	8.29	4.13			

Table E.3 Relationship between age and resistance & stigma

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	Child age	Parent-report resistance	-.47	.36	-.253	ns	.03
USA Clinic	Child age	Parent-report resistance	-.244	5.55	-.134	ns	.00
Internet	Child age	Parent-report resistance	.12	.08	.09	ns	.00
Support Group	Child age	Parent-report resistance	.45	.24	.29	ns	.06
UK	Child age	Parent-report resistance	.11	.131	.071	ns	.00
USA	Child age	Parent-report resistance	.098	.099	.074	ns	.00
UK Clinic	Child age	Child-report resistance	-.49	.28	-.33	ns	.07
USA Clinic	Child age	Child-report resistance	-.39	.31	-.39	ns	.08
Internet	Child age	Child-report resistance	.15	.22	.11	ns	.00
Support Group	Child age	Child-report resistance	.41	.20	.34	ns	.09
UK	Child age	Child-report resistance	.124	.179	.083	ns	.00
USA	Child age	Child-report resistance	.053	.126	.042	ns	.00
UK Clinic	Child age	Parent-report child stigma	-.702	.289	-.423	<.05	.17
USA Clinic	Child age	Parent-report child stigma	.119	.415	.086	ns	.00
Internet	Child age	Parent-report child stigma	.268	.068	.232	<.001	.05
Support Group	Child age	Parent-report child stigma	.243	.200	.193	ns	.01
UK	Child age	Parent-report child stigma	-.015	.112	-.011	ns	.00
USA	Child age	Parent-report child stigma	.150	.077	.146	<.05	.01
UK Clinic	Child age	Child-report stigma	-.917	.339	-.483	<.05	.20
USA Clinic	Child age	Child-report stigma	.091	.487	.059	ns	.00
Internet	Child age	Child-report stigma	.067	.262	.042	ns	.00
Support Group	Child age	Child-report stigma	-.058	.263	-.041	ns	.00
UK	Child age	Child-report stigma	-.499	.217	-.267	<.05	.06
USA	Child age	Child-report stigma	-.167	.250	-.125	ns	.00
UK Clinic	Child age	Parental stigma	-.424	.251	-.309	<.10	.06
USA Clinic	Child age	Parental stigma	-.670	.719	-.283	ns	.01
Internet	Child age	Parental stigma	-.178	.067	-.157	<.01	.02
Support Group	Child age	Parental stigma	-.325	.148	-.328	<.05	.08
UK	Child age	Parental stigma	-.178	.097	-.190	<.05	.03
USA	Child age	Parental stigma	-.297	.084	-.255	<.001	.06

Table E.4 Relationship between resistance & stigma

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	Parent-report child stigma	Parent-report resistance	.295	.170	.328	ns	.07
USA Clinic	Parent-report child stigma	Parent-report resistance	.303	.243	.367	ns	.05
Internet	Parent-report child stigma	Parent-report resistance	.291	.047	.343	<.001	.11
Support Group	Parent-report child stigma	Parent-report resistance	.197	.124	.236	ns	.03
UK	Parent-report child stigma	Parent-report resistance	.323	.092	.275	<.001	.07
USA	Parent-report child stigma	Parent-report resistance	.397	.087	.316	<.001	.10
UK Clinic	Child-report stigma	Child-report resistance	.289	.174	.321	<.10	.06
USA Clinic	Child-report stigma	Child-report resistance	.119	.139	.289	ns	.02
Internet	Child-report stigma	Child-report resistance	.381	.150	.310	<.05	.08
Support Group	Child-report stigma	Child-report resistance	.302	.215	.238	ns	.03
UK	Child-report stigma	Child-report resistance	.293	.145	.235	<.05	.04
USA	Child-report stigma	Child-report resistance	.418	.181	.415	<.05	.14
UK Clinic	Parent-report child stigma	Child-report resistance	.215	.211	.204	ns	.02
USA Clinic	Parent-report child stigma	Child-report resistance	.010	.263	.013	ns	.00
Internet	Parent-report child stigma	Child-report resistance	.244	.180	.214	ns	.02
Support Group	Parent-report child stigma	Child-report resistance	.146	.193	.137	ns	.01
UK	Parent-report child stigma	Child-report resistance	.161	.127	.151	ns	.01
USA	Parent-report child stigma	Child-report resistance	.274	.235	.212	ns	.01
UK Clinic	Child-report stigma	Parent-report resistance	.307	.203	.307	<.05	.05
USA Clinic	Child-report stigma	Parent-report resistance	-.009	.169	-.021	<.05	.00
Internet	Child-report stigma	Parent-report resistance	.355	.143	.377	<.05	.11
Support Group	Child-report stigma	Parent-report resistance	.204	.230	.162	ns	.01
UK	Child-report stigma	Parent-report resistance	.230	.121	.226	.06	.04
USA	Child-report stigma	Parent-report resistance	.181	.235	.144	ns	.01

Table E.5 T-tests to examine differences in parent and child-report stigma between children who are given medication in school and children who are not*

Sample	Variable	Mean	S.D.	T	DF	P
UK Clinic	Parent-report stigma for children who are not given medication in school	10.09	3.83	.51	27	ns
	Parent-report stigma for children who are given medication in school	11.00	4.15			
UK Clinic	Child-report stigma for children who are not given medication in school	8.30	3.77	1.43	24	ns
	Child-report stigma for children who are given medication in school	11.00	5.01			
Internet	Parent-report stigma for children who are not given medication in school	8.24	4.32	4.13	81.34	<.001
	Parent-report stigma for children who are given medication in school	10.50	3.95			
Internet	Child-report stigma for children who are not given medication in school	8.97	4.32	.47	37	ns
	Child-report stigma for children who are given medication in school	9.70	3.97			
Support Group	Parent-report stigma for children who are not given medication in school	9.10	3.99	-.06	33	ns
	Parent-report stigma for children who are given medication in school	8.06	3.29			
Support Group	Child-report stigma for children who are not given medication in school	8.45	4.09	-.89	43	ns
	Child-report stigma for children who are given medication in school	8.36	4.11			
UK	Parent-report stigma for children who are not given medication in school	9.79	3.66	.449	152	ns
	Parent-report stigma for children who are given medication in school	10.29	4.00			
UK	Child-report stigma for children who are not given medication in school	9.03	4.29	.615	71	ns
	Child-report stigma for children who are given medication in school	9.59	4.34			
USA	Parent-report stigma for children who are not given medication in school	7.56	2.69	2.63	28.6	<.01
	Parent-report stigma for children who are given medication in school	9.73	4.06			

*This analysis could not be carried out for parent-report or child-report child stigma in the USA clinic sample as only one child within the sample was taking medication at school.

*This analysis could not be carried out for child-report stigma in the USA sample as child-report data was only available for one child.

Table E.6 Descriptive statistics for age & AMRABs subscales in the UK and USA

	UK Sample Mean N = 154 parents 75 children	USA Sample Mean N = 193 parents 33 children
Age	12.22	10.53
Parent-report benefits	16.17	15.46
Parent-report costs	7.72	8.01
Parent-report resistance	10.03	8.97
Parent-report child stigma	9.95	7.84
Parental stigma	10.12	9.63
Parent-report flexibility	11.74	10.78
Parent-report competence	5.49	5.30
Child-report benefits	14.47	13.61
Child-report costs	8.46	8.09
Child-report resistance	8.50	10.25
Child-report stigma	9.21	7.29

Table E.7 MANCOVA comparing parent-report AMRABs between participants from the UK and USA, controlling for child age

Source	Type III Sum of Squares	Df	F
Between Subjects			
Covariates			
Child Age			
Multivariate λ = .92		7.000	3.87***
Parent-report benefits	.584	1	.04
Parent-report costs	.406	1	.03
Parent-report child stigma	9.76	1	1.20
Parent-report parental stigma	200.73	1	12.97***
Parent-report resistance	47.144	1	.58
Parent-report flexibility	67.94	1	.404
Parent-report competence	.845	1	3.70
Factor			
Country			
Multivariate λ = .88		7.000	6.00***
Parent-report benefits	50.72	1	3.85
Parent-report costs	8.38	1	.616
Parent-report child stigma	259.13	1	22.54***
Parent-report parental stigma	76.386	1	4.94*
Parent-report resistance	47.14	1	2.81
Parent-report flexibility	67.94	1	3.16
Parent-report competence	.845	1	.149
Error			
Parent-report benefits	4072.66	309	(13.18)
Parent-report costs	4204.67	309	(13.61)
Parent-report child stigma	2552.69	309	(11.50)
Parent-report parental stigma	4781.95	309	(15.48)
Parent-report resistance	5186.43	309	(16.79)
Parent-report flexibility	6653.85	309	(21.53)
Parent-report competence	1755.34	309	(5.681)

Values enclosed in parentheses represent mean square errors
*p<.05 **p<.01 ***p<.001

Table E.8 MANCOVA comparing child-report AMRABs between participants from the UK and USA, controlling for child age

Source	Type III Sum of Squares	DF	F
Between Subjects			
Covariates			
Child Age			
Multivariate λ = .88		4.000	3.29**
Child-report benefits	1.08	1	.08
Child-report costs	17.06	1	1.37
Child-report child stigma	94.03	1	6.11*
Child-report resistance	.01	1	.001
Factor			
Country			
Multivariate λ = .87			
Child-report benefits	18.37	1	1.32
Child-report costs	6.72	1	.54
Child-report child stigma	134.99	1	8.78**
Child-report resistance	.002	1	.00
Error			
Child-report benefits	1359.55	98	(13.87)
Child-report costs	1225.141	98	(12.50)
Child-report child stigma	1507.45	98	(15.38)
Child-report resistance	1140.87	98	(11.64)

Values enclosed in parentheses represent mean square errors

*p<.05 **p<.01 ***p<.001

Appendix F

Materials used in Study 4*
(*AMRABs questionnaires are in Appendix C.4)

F.1 Information letter to parents
F.2 Information letter to children
F.3 Questionnaires

F.1 Information letter to parents

Dear Parent,

My name is Ruth Ann Harpur and I am a PhD Student in the School of Psychology at the University of Southampton. I am interested in how parents and children think and feel about medication. 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.

Purpose of the Research

Treatment with medication is currently recommended as frontline treatment for children with ADHD. Children often need support from parents in order to take medication. In the first two years of my PhD, I interviewed parents of children with ADHD and designed a questionnaire to find out about what parents and children think and feel about the medication they are giving their children.

Why have I been chosen?

You have been invited to take part in this research because you have a child with ADHD who is taking medication. We hope to study around 100 participants.

Do I have to take part?

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 to me if I take part?

You will be asked to fill in a series of questionnaires about your child and your family that will take approximately 1 hour to complete. You will then be asked to give a short 5 minute interview about your relationship with your child that will be audiotaped. Your child will also be asked, with your permission, if they would like to complete a short questionnaire about what they think about medication for ADHD.

What are the advantages and disadvantages of taking part?

Some of the questions may be sensitive but you do not have to answer any questions you do not want to. You can withdraw at any time without giving a reason and this will not affect the standard of care you receive.

However, we hope that the information we get from this study will help doctors be more supportive to families of children with ADHD in the future.

What if I have a complaint?

If you have any complaints about this study or how it has been conducted, the normal National Health Service complaints mechanisms are available to you. The researcher is also open to hearing your comments, positive or negative about this study, as it will help us develop studies in the future.

Will my taking part in this study be kept confidential?

We will ask for your permission to access your child's medical records and all the information collected about you and your child during the study will be available to the researchers. Everything will be kept strictly confidential and your personal information such as your name and address will not leave the clinic.

What will happen to the results of the research study?

The raw data will be stored in a secure, password protected server at the University of Southampton. Your name and personal details will be stored separately from the information you give in this study. If you consent to being audiotaped, the tapes will be stored in a locked filing cabinet in the School of Psychology and no-one except the researchers will have access to them. Tapes will be identified using an anonymous ID number. The results will be published in a PhD thesis in 2006, and we hope also in scientific journals over the next two years. We will send you a summary of the results of this study if you are willing for us to take your name and address. You are not under any obligation to give any personal information if you do not wish to. Any publication will not include your name or any information that might identify you.

Who is organising and funding the research?

This research is organised by the School of Psychology at the University of Southampton and is sponsored by the Economic and Social Research Council and Janssen-Cilag Pharmaceuticals. Your doctor receives no financial benefit from this research.

Who has reviewed the study?

This study has been reviewed by the Southampton Local Research Ethics Committee, the School of Psychology Ethics Committee at the University of Southampton and the Institutional Review Board at the School of Medicine at New York University.

Contact for Further Information

If you would like further information please contact
Ruth Ann Harpur
School of Psychology
University of Southampton
Southampton
SO17 1BJ
R.A.Harpur@soton.ac.uk
023 8059 4593

Thank you for taking the time to read this information sheet and for your interest in this study.

F.2 Information letter to children

My name is Ruth Ann Harpur and I am a student in the School of Psychology at the University of Southampton. I would like to ask you to take part in some research. This sheet will tell you about it, but you can also ask questions from your parents, the researcher or your doctor if you want to.

Why are you doing this research?

We are trying to find out how children and their parents feel about taking medicine for ADHD, and how best we can help children with ADHD.

Why am I being asked to answer questions

We are asking children and teenagers who take medicine for ADHD to tell us what they think. We hope to ask about 100 children and teenagers.

Do I have to answer the questions?

No, it is your choice if you want to take part or not. If you do want to take part you can keep this information sheet and you will be asked to sign a form to say that you are happy to take part. Just tell your parents or the researcher and you don't have to take part.

What will happen to me if I take part?

You will be asked some questions about what you think about taking medication for ADHD.

What is good and bad about taking part?

☺ If you take part, we hope that your answers will help doctors to understand what children with ADHD think about medicine for ADHD so they can help children and teenagers in the future.

☹ Sometimes, children and teenagers don't like being asked questions about their ADHD. If you don't like answering the questions, you can change your mind. Just tell your parents or the researcher. You won't be in trouble if you change your mind.

Will my taking part in this study be kept confidential?

What you tell us is confidential. That means no-one will know what you have said, except the researcher.

What will happen to my answers?

We will put your answers into a computer at Southampton University. Your name will not be entered – so there is no way anyone can find out what you have said, except the researcher. We will study all the answers given by all the children who take part and publish this so other doctors can find out what children and teenagers think. But we will never publish your name or any information about you.

What should I do if I want more information?

You can ask your doctor or the researcher, Ruth Ann Harpur (023 8059 4593)

F.3 Questionnaires

Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True about your child. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months.

	Not True	Somewhat True	Certainly True
1. Considerate of other people's feelings	☐	☐	☐
2. Restless, overactive, cannot sit still for long	☐	☐	☐
3. Often complains of headaches, stomach-aches or sickness.	☐	☐	☐
4. Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
5. Often has temper tantrums or hot tempers	☐	☐	☐
6. Rather solitary, tends to play alone	☐	☐	☐
7. Generally obedient, does what adults request	☐	☐	☐
8. Many worries, often seems worried	☐	☐	☐
9. Helpful if someone is hurt, upset or feeling ill.	☐	☐	☐
10. Constantly fidgeting or squirming	☐	☐	☐
11. Has at least one good friend	☐	☐	☐
12. Often fights with other children or bullies them	☐	☐	☐
13. Often unhappy, down-hearted or tearful.	☐	☐	☐
14. Generally liked by other children	☐	☐	☐
15. Easily distracted, concentration wanders	☐	☐	☐
16. Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
17. Kind to younger children	☐	☐	☐
18. Often lies or cheats	☐	☐	☐
19. Picked on or bullied by other children	☐	☐	☐
20. Often volunteers to help others (parents, teachers, other children).	☐	☐	☐
21. Thinks things out before acting	☐	☐	☐
22. Steals from home, school or elsewhere	☐	☐	☐
23. Gets on better with adults than with other children	☐	☐	☐
24. Many fears, easily scared	☐	☐	☐
25. Sees tasks through to the end, good attention span	☐	☐	☐

Adult ADHD Rating Scales

Please tick the box which best describes your behaviour over the past six months.

Frequency Code: **0=never**
1=occasionally
2=often
3=very often

1. Fail to give close attention to details or make careless mistakes at work	0☐	1☐	2☐	3☐
2. Fidget with hands or feet or squirm in seat	0☐	1☐	2☐	3☐
3. Have difficulty sustaining attention in tasks or fun activities	0☐	1☐	2☐	3☐
4. Leave seat in situations where seating is expected	0☐	1☐	2☐	3☐
5. Don't listen when spoken to directly	0☐	1☐	2☐	3☐
6. Feel restless	0☐	1☐	2☐	3☐
7. Don't follow through on instructions and fail to finish Work	0☐	1☐	2☐	3☐
8. Have difficulty engaging in leisure activities quietly	0☐	1☐	2☐	3☐
9. Have difficulty organizing tasks and activities	0☐	1☐	2☐	3☐
10. Feel "on the go" or "driven by a motor"	0☐	1☐	2☐	3☐
11. Avoid, dislike, or are reluctant to engage in work that requires sustained mental effort	0☐	1☐	2☐	3☐
12. Talk excessively	0☐	1☐	2☐	3☐
13. Lose things necessary for tasks and activities	0☐	1☐	2☐	3☐
14. Blurt out answers before questions have been completed	0☐	1☐	2☐	3☐
15. Easily distracted	0☐	1☐	2☐	3☐
16. Have difficulty awaiting turn	0☐	1☐	2☐	3☐
17. Forgetful in daily duties	0☐	1☐	2☐	3☐
18. Interrupt or intrude on others	0☐	1☐	2☐	3☐

Child ADHD Rating Scales

We are interested in what ADHD symptoms your child experiences. Please complete the following questions. Each rating should be considered in the context of what is appropriate for the age of your child.

Frequency Code: **0=never**
1=occasionally
2=often
3=very often

1. Fails to give attention to details or makes careless mistakes in schoolwork	0☐	1☐	2☐	3☐
2. Has difficulty sustaining attention to tasks or activities	0☐	1☐	2☐	3☐
3. Does not seem to listen when spoken to directly	0☐	1☐	2☐	3☐
4. Does not follow through when given directions and fails to finish activities (not due to refusal or failure to understand)	0☐	1☐	2☐	3☐
5. Has difficulty organizing tasks and activities	0☐	1☐	2☐	3☐
6. Avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort	0☐	1☐	2☐	3☐
7. Loses things necessary for tasks or activities (school assignments, pencils, or books)	0☐	1☐	2☐	3☐
8. Is easily distracted by extraneous stimuli	0☐	1☐	2☐	3☐
9. Is forgetful in daily activities	0☐	1☐	2☐	3☐
10. Fidgets with hands or feet or squirms in seat	0☐	1☐	2☐	3☐
11. Leaves seat in classroom or in other situations in which remaining seated is expected	0☐	1☐	2☐	3☐
12. Runs about or climbs excessively in situations in which remaining seated is expected	0☐	1☐	2☐	3☐
13. Has difficulty playing or engaging in leisure activities quietly	0☐	1☐	2☐	3☐
14. Is “on the go” or often acts as if “driven by a motor”	0☐	1☐	2☐	3☐
15. Talks excessively	0☐	1☐	2☐	3☐
16. Blurts out answers before questions have been completed	0☐	1☐	2☐	3☐
17. Has difficulty waiting in line	0☐	1☐	2☐	3☐
18. Interrupts or intrudes on others (e.g., butts into conversations/games)	0☐	1☐	2☐	3☐

General Health Questionnaire

We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Circle the response that best applies to you. Thank you for answering all the questions.

Have you recently:

1. been able to concentrate on what you're doing?

better than usual (0) | same as usual (1) | less than usual (2) | much less than usual (3)

2. lost much sleep over worry?

not at all | no more than usual | rather more than usual | much more than usual

3. felt that you are playing a useful part in things?

more so than usual | same as usual | less useful than usual | much less useful

4. felt capable of making decisions about things?

more so than usual | same as usual | less so than usual | much less capable

5. felt constantly under strain?

not at all | no more than usual | rather more than usual | much more than usual

6. felt you couldn't overcome your difficulties?

not at all | no more than usual | rather more than usual | much more than usual

7. been able to enjoy your normal day to day activities?

more so than usual | same as usual | less so than usual | much less than usual

8. been able to face up to your problems?

more so than usual | same as usual | less so than usual | much less able

9. been feeling unhappy or depressed?

not at all | no more than usual | rather more than usual | much more than usual

10. been losing confidence in yourself?

not at all | no more than usual | rather more than usual | much more than usual

11. been thinking of yourself as a worthless person?

not at all | no more than usual | rather more than usual | much more than usual

12. been feeling reasonably happy, all things considered?

more so than usual | about the same as usual | less so than usual | much less than usual

Parenting Sense of Competence

This Questionnaire is about your attitudes and feelings that relate to parenting. Please circle the answer that most closely resembles how you feel. **There are no right and wrong answers.**

Code: 1 = Strongly Disagree
2 = Disagree
3 = Slightly Disagree
4 = Slightly Agree
5 = Agree
6 = Strongly Agree

	Strongly Disagree					**Strongly Agree**
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired	1	2	3	4	5	6
2. Even though being a parent could be rewarding, I am frustrated now while my child is at this age	1	2	3	4	5	6
3. I go to bed the same way I woke up in the morning – feeling I have not accomplished a whole lot	1	2	3	4	5	6
4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated	1	2	3	4	5	6
5. My parents were better prepared to be a good parent than I am	1	2	3	4	5	6
6. I would make a fine model for a new parent to follow in order to learn what she would need to know to be a good parent	1	2	3	4	5	6
7. Being a parent is manageable, and any problems are easily solved	1	2	3	4	5	6
8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one	1	2	3	4	5	6
9. Sometimes I feel like I'm not getting anything done	1	2	3	4	5	6
10. I meet my own personal expectations for expertise in caring for my child	1	2	3	4	5	6
11. If anyone can find the answer to what is troubling my child, I am the one	1	2	3	4	5	6

Please turn over, there are more questions on the other side...

Parenting Sense of Competence (condt.)

Code: 1 = Strongly Disagree
2 = Disagree
3 = Slightly Disagree
4 = Slightly Agree
5 = Agree
6 = Strongly Agree

	Strongly Disagree					**Strongly Agree**
12. My talents and interests are in other areas, not in being a parent	1	2	3	4	5	6
13. Considering how long I've been a parent, I feel thoroughly familiar with this role	1	2	3	4	5	6
14. If being the parent of a child were only more interesting, I would be more motivated to do a better job as a parent	1	2	3	4	5	6
15. I honestly believe I have all the skills necessary to be a good parent to my child	1	2	3	4	5	6
16. Being a parent makes me tense and anxious	1	2	3	4	5	6
17. Being a good parent is a reward in itself	1	2	3	4	5	6

Parenting Styles and Dimensions Instruction Form

This questionnaire is designed to measure

1. how often your spouse/partner exhibits certain behaviours towards your child
2. how often you exhibit certain behaviours towards this child

Please read each item on the questionnaire and think about how often your spouse/partner exhibits this behaviour and place your answer on the **first** line to the life of the item (headed Spouse):

[Spouse] [I]

____ ____ **[Spouse allows]** [I allow] our child to choose what to wear to school

SPOUSE EXHIBITS THIS BEHAVIOUR
1 = never
2 = once in a while
3 = about half of the time
4 = very often
5 = always

2. Then rate how often you exhibit this behaviour and place your answer on the second line to the left of the item (headed I)

[Spouse] **[I]**

____ ____ [She allows] **[I allow]** our child to choose what to wear to school

I EXHIBIT THIS BEHAVIOUR
1 = never
2 = once in a while
3 = about half of the time
4 = very often
5 = always

Please turn over

REMEMBER: Make two ratings for each item; (1) rate how often your spouse exhibits this behaviour with your child and (2) how often you exhibit this behaviour with your child.

SPOUSE EXHIBITS BEHAVIOUR
1 = never
2 = once in a while
3 = about half of the time
4 = very often
5 = always

I EXHIBIT THIS BEHAVIOUR
1= never
2 = once in a while
3 = about half of the time
4 = very often
5 = always

1. __ __ [Spouse is] [I am] responsive to our child's feelings or needs

2. __ __ [Spouse uses] [I use] physical punishment as a way of disciplining our child.

3. __ __ [Spouse takes] [I take] our child's desires into account before asking the child to do something

4. __ __ When our child asks why he/she has to conform, [spouse states] [I state]: because I said so, or I am your parent and I want you to.

5. __ __ [Spouse explains] [I explain] to our child how we feel about the child's good and bad behaviour.

6. __ __ [Spouse spanks] [I spank] when our child is disobedient

7. __ __ [Spouse encourages] [I encourage] our child to talk about our child's troubles

8. __ __ [Spouse finds] [I find] it difficult to discipline our child.

9. __ __ [Spouse encourages] [I encourage] our child to freely express him/her self even when disagreeing with parents.

10. __ __ [Spouse punishes] [I punish] by taking privileges away from our child with little if any explanations.

11. __ __ [Spouse emphasises] [I emphasise] the reasons for rules.

12. __ __ [Spouse gives] [I give] comfort and understanding when child is upset

13. __ __ [Spouse yells and shouts] [I yell and shout] when our child misbehaves.

14. __ __ [Spouse gives] [I give] praise when our child is good.

15. __ __ [Spouse gives] [I give] into our child when the child causes a commotion about something.

16. __ __ [Spouse explodes] [I explode] in anger towards our child.

17. __ __ [Spouse threatens] [I threaten] our child with punishment more often than actually giving it.

18. __ __ [Spouse takes] [I take] into account our child's preferences when making plans for the family.

19. __ __ [Spouse grabs] [I grab] our child when being disobedient.

20. __ __ [Spouse states] [I state] punishment to our child and does/do not actually do them.

21. __ __ [Spouse shows] [I show] respect for our child's opinions by encouraging our child to express them.

22. __ __ [Spouse allows] [I allow] our child to give input into family rules.

23. __ __ [Spouse scolds and criticises] [I scold and criticise] to make our child improve.

24. __ __ [Spouse spoils] [I spoil] our child.

25. __ __ [Spouse gives] [I give] our child reasons why rules should be obeyed.

26. __ __ [Spouse uses] [I use] threats as punishment with little or no justification.

27. __ __ [Spouse has] [I have] warm and intimate times together with child

28. __ __ [Spouse punishes] [I punish] by putting our child off somewhere alone with little if any explanations.

29. __ __ [Spouse helps] [I help] our child to understand the impact of behaviour by encouraging our child to talk about the consequences of own actions

30. __ __ [Spouse scolds or criticises] [I scold or criticise] when our child's behaviour doesn't meet our expectations

31. __ __ [Spouse explains] [I explain] the consequences of our child's behaviour.

32. __ __ [Spouse slaps] [I slap] our child when the child misbehaves.

Family Questionnaire ~ Describe your family - Please be careful to tick only one box

	Almost never	Once in a while	Some-times	Frequently	Almost always
1. Family members are supportive of each other during difficult times					
2. In our family, it is easy for everyone to express his/her opinion					
3. It is easier to discuss problems with people outside the family than with other family members					
4. Each family member has input in major family decisions					
5. Our family gather together in the same room					
6. Children have a say in their discipline					
7. Our family does things together					
8. Family members discuss problems and feel good about the solutions					
9. In our family, everyone goes his/her own way					
10. We shift household responsibilities from person to person					
11. Family members know each other's close friends					
12. It is hard to know what the rules are in our family					
13. Family members consult other family members on their decisions					
14. Family members say what they want					
15. We have difficulty thinking of things to do as a family					
16. In solving problems, the children's suggestions are followed					
17. Family members feel very close to each other					
18. Discipline is fair in our family					
19. Family members feel closer to people outside the family than to other family members					
20. Our family tries new ways of dealing with problems					
21. Family members go along with what the family decides to do					
22. In our family, everyone shares responsibilities					
23. Family members like to spend their free time with each other					
24. It is difficult to get a rule changed in our family					
25. Family members avoid each other at home					
26. When problems arise, we compromise					
27. We approve of each other's friends					
28. Family members are afraid to say what is on their minds					
29. Family members pair up rather than do things as a total family					
30. Family members share interests and hobbies with each other					

Personal Information

What is your ethnicity?

White/Caucasian ☐

Black ☐

Asian ☐

Hispanic ☐

Other (Please specify) ☐

.....

What is your occupation

.....

What is your partner's occupation (if relevant)

.....

Has your child and/or family had any other treatment other than medication?

What?

Family Therapy ☐

Parenting Skills training ☐

Behavioural Intervention ☐

Educational Intervention ☐

Other, Please specify

.....

.....

.....

.....

Expressed Emotion

Five Minute Speech Sample: Instructions to parents

"I would like to hear your thoughts and feelings about [child's name], in your own words, without me interrupting with any questions or comments. When I ask you to begin, I would like you to speak for five minutes. Tell me what sort of child [child's name] is and how the two of you get along together. During the five minutes I would prefer if there were no other interruptions or questions, but do you have any questions before we begin?"

Once any questions have been answered.

"I would now like you to relax, collect your thoughts and start whenever you feel that you are ready."

Appendix G

Study 4 Analyses

Table G.1 Descriptive Statistics: Mean AMRABs within high and low SES groups

	High SES	Low SES
Parent-report benefits	16.24 (2.67)	16.42 (3.14)
Parent-report costs	7.23 (3.39)	6.42 (2.96)
Parent-report resistance	8.92 (3.03)	10.32 (3.67)
Parent-report child stigma	8.32 (3.35)	8.73 (3.75)
Parental stigma	9.90 (3.92)	7.57 (3.07)
Parent-report flexibility	11.96 (5.11)	9.89 (4.72)
Parent-report competence	4.96 (1.83)	2.10 (2.10)
Child-report benefits	14.16 (3.57)	15.70 (3.08)
Child-report costs	8.24 (3.37)	7.70 (3.42)
Child-report resistance	7.55 (3.60)	9.41 (2.96)
Child-report stigma	8.24 (3.84)	7.70 (4.34)

Table G.2 MANOVA comparing parent-report AMRABs between participants from low and high SES groups

Source	Type III Sum of Squares	Df	F
Between Subjects			
Factor			
SES			
Multivariate λ = .87		7	1.30***
Parent-report benefits	1.75	1	.19
Parent-report costs	9.83	1	.90
Parent-report child stigma	35.17	1	3.57
Parent-report parental stigma	4.11	1	.36
Parent-report resistance	69.18	1	4.48*
Parent-report flexibility	68.98	1	2.88
Parent-report competence	.00	1	.00
Error			
Parent-report benefits	609.44	65	(9.38)
Parent-report costs	712.11	65	(10.96)
Parent-report child stigma	640.02	65	(9.85)
Parent-report parental stigma	739.00	65	(11.37)
Parent-report resistance	1003.30	65	(15.44)
Parent-report flexibility	1557.77	65	(23.97)
Parent-report competence	227.08	65	(3.50)

Values enclosed in parentheses represent mean square errors

*p<.05 **p<.01 ***p<.001

Table G.3 MANOVA comparing child-report AMRABs between participants from low and high SES groups

Source	Type III Sum of Squares	Df	F
Between Subjects			
Factor			
SES			
Multivariate λ = .85		59	2.54
Child-report benefits	31.94	1	2.80
Child-report costs	4.07	1	.36
Child-report child stigma	42.14	1	3.64
Child-report resistance	2.94	1	.19
Error			
Child-report benefits	708.00	62	(11.42)
Child-report costs	694.93	62	(11.21)
Child-report child stigma	717.61	62	(11.57)
Child-report resistance	942.81	62	(15.21)

Values enclosed in parentheses represent mean square errors

*p<.05 **p<.01 ***p<.001

Table G.4 Relationship between SDQ conduct scores and parent-report resistance

Predictor	Variable	B	SE B	β	P	ΔR^2
SDQ Conduct	Parent-report resistance	.522	.139	.374	<.001	.13
SDQ Conduct	Child-report resistance	.558	.162	.368	<.001	.12

Table G.5 Linear regression analyses of the relationship between maternal GHQ and AMRABS

Predictor	Variable	B	SE B	β	P	ΔR^2
Maternal GHQ	Parent-report benefits	-.108	.050	-.223	<.05	.04
Maternal GHQ	Parent-report costs	.115	.054	.258	<.05	.05
Maternal GHQ	Parent-report resistance	.161	.057	.342	<.05	.10
Maternal GHQ	Child-report resistance	.117	.074	.204	.10	.03
Maternal GHQ	Competence	.011	.043	.032	ns	.00

Table G.6 Relationships between maternal GHQ and PSOC subscales

Predictor	Variable	B	SE B	β	P	ΔR^2
Maternal GHQ	Parenting self-efficacy	-.251	.112	-.274	<.05	.06
Maternal GHQ	Parenting satisfaction	-.342	.097	-.408	<.001	.17
Maternal GHQ	Parenting self-esteem	-.614	.181	-.395	<.001	.14

Table G.7 Multiple linear regression analysis examining the relationship between maternal GHQ, parenting self-efficacy and parent-report resistance

Predictors	Variable	B	SE B	β	P	ΔR^2
GHQ	Parent-report resistance	.088	.066	.168	ns	.07
Parenting self-efficacy		-.132	.074	-.233	<.05	

Table G.8 Multiple Linear regression analysis examining the relationship between maternal GHQ, parenting self-efficacy and child-report resistance

Predictors	Variable	B	SE B	β	P	ΔR^2
GHQ	Child-report resistance	3.49	.078	1.01	ns	.03
Parenting self-efficacy		-.102	.090	-.155	ns	

Table G.9 Relationship between parenting self-efficacy and competence

Predictors	Variable	B	SE B	β	P	ΔR^2
Parenting self-efficacy	Competence	-.077	.031	-.252	<.05	.05

Table G.10 Relationship between maternal ADHD and competence in administering medication

Predictors	Variable	B	SE B	β	P	ΔR^2
Maternal ADHD	Competence	.030	.013	.239	<.05	.05

Table G.11 Relationship between maternal ADHD and self-report parenting style

Predictor	Variable	B	SE B	β	P	ΔR^2
Maternal ADHD	Authoritative parenting	.001	.005	-.021	ns	.00
Maternal ADHD	Authoritarian parenting	.020	.011	.224	.08	.03
Maternal ADHD	Permissive parenting	.000	.005	-.006	ns	.00

Table G.12 Relationship between self-report authoritarian parenting and competence in administering medication

Predictor	Variable	B	SE B	β	P	ΔR^2
Authoritarian parenting	Competence	.253	.155	.195	ns	.02

Table G.13 Relationships between cohesion and stigma

Predictor	Variable	B	SE B	β	P	ΔR^2
Family cohesion	Parent-report child stigma	-.081	.040	-.205	<.05	.03
Family cohesion	Child-report stigma	-.041	.051	-.090	ns	.00

Table G.14 Multiple linear regression analysis examining the relationship between family cohesion and country in predicting parent-report child stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Family cohesion	Parent-report child stigma	-.049	.041	-.124	ns	.11
Country		-1.119	.390	-.294	<.01	

Table G.15 Multiple linear regression analysis examining the relationship between family cohesion and country in predicting child-report stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Family cohesion	Child-report stigma	.006	.052	.014	Ns	.11
Country		-1.346	.465	-.329	<.01	

Table G.16 Relationships between cohesion and parental stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Family cohesion	Parental stigma	-.096	.047	-.212	<.05	.03

Table G.17 Relationships between cohesion and parental stigma controlling for SES

Predictors	Variable	B	SE B	β	P	ΔR^2
Family Cohesion	Parental Stigma	-.081	.061	-.159	ns	.05
SES		-2.187	1.093	-.239	<.05	

Table G.18 Relationships between cohesion, country, SES, and parental stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Family Cohesion	Parental Stigma	-.093	.064	-.182	ns	.04
Country		.323	.546	.077	ns	
SES		-2.012	1.137	-.220	.08	

Table G.19 Linear regression analyses of the relationship between self-report parental warmth and child stigma

Predictor	Variable	B	SE B	β	P	ΔR^2
Self-report parental warmth	Parent-report child stigma	-.179	.756	-.025	ns	.00
Self-report parental warmth	Child-report stigma	-1.839	.874	-.232	<.05	.04
Spouse parental warmth	Parent-report child stigma	-.495	.395	-.145	ns	.01
Spouse parental warmth	Child-report stigma	-1.034	.462	-.271	<.05	.06

Table G.20 Linear regression analysis examining the relationship between self report parental warmth and country in predicting parent-report child stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Self Report Parental Warmth	Parent-report child stigma	-.169	.670	-.025	ns	.10
Country		-1.301	.368	-.353	<.001	

Table G.21 Linear regression analysis examining the relationship between spouse parental warmth and country in predicting parent-report chid stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Spouse parental warmth	Parent-report child stigma	-.366	.338	-.119	ns	.10
Country		-1.156	.384	-.332	<.01	

Table G.22 Linear regression analysis examining the relationship between self report parental warmth and country in predicting chid-report stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Self-report parental warmth	Child-report stigma	-1.586	.807	-.212	<.05	.09
Country		-.991	.432	-.248	<.05	

Table G.23 Linear regression analysis examining the relationship between spouse parental warmth and country in predicting chid-report stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Spouse Parental Warmth	Child-report Stigma	-1.009	.407	-.287	<.01	.14
Country		-1.051	.426	-.286	<.01	

Table G.24 Post-hoc analysis of ANOVA differences in parent-report child stigma related to criticism on EE

Group	Comparison Group	Mean Difference	Standard Error	P (Tukey HSD)
Not critical	Borderline critical	-2.59	1.09	<.05
	Highly critical	-2.74	1.24	<.05
Borderline critical	Highly critical	-.15	1.40	ns

Table G.25 Post-hoc analysis of ANOVA differences in child-report stigma related to criticism on EE

Group	Comparison Group	Mean Difference	Standard Error	P (Tukey HSD)
Not critical	Borderline critical	-2.00	1.21	ns
	Highly critical	-4.29	1.45	<.01
Borderline critical	Highly critical	-2.29	1.60	ns

Table G.26 Relationship between country and critical EE with parent-report child stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Critical EE	Parent-report child stigma	1.311	.597	.273	<.05	.14
Country		-1.132	.545	-.258	<.05	

Table G.27 Relationship between country and critical EE with child-report stigma

Predictors	Variable	B	SE B	β	P	ΔR^2
Critical EE	Child-report stigma	1.810	.683	.342	<.05	.19
Country		-1.148	.601	-.246	<.05	

Appendix H

Analyses for study 4 across samples and within the UK and the USA

Table H.1 Mean age of participants in the UK clinic, USA clinic, support group and internet samples

Sample	Mean Age	Standard Deviation
UK Clinic	12.67	2.27
USA Clinic	11.07	2.09
Internet	11.32	2.25
Support Group	13.85	2.49

Table H.2 Socio-economic status within the internet, ADHD clinic and support group samples

	% UK ADHD Clinic Participants	% US ADHD Clinic Participants	% Internet Participants	% Support Group Participants
High SES	61.1	100	74.1	66.7
Low SES	38.9	--	25.9	33.3

Table H.3 SES and parental stigma

Sample	SES	N	Mean Parental Stigma	S.D.	T	DoF	P
UK Clinic	Low	7	8.71	3.45	1.38	18	ns
	High	11	11.09	3.68			
Internet	Low	7	6.14	1.07	2.43	23	<.05
	High	18	9.83	3.95			
Support Group	Low	5	8.00	5.34	.634	13	ns
	High	10	9.50	3.77			
UK	Low	16	7.88	3.76	1.63	44	<.10
	High	30	9.73	3.62			
US	Low	3	6.00	1.73	2.95	7.14	<.05
	High	21	10.14	4.52			

This analysis could not be carried out in the USA clinic sample as no participants were in the low SES group

Table H.4 Relationship between SDQ conduct and parent-report resistance across samples

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	SDQ conduct	Parent-report resistance	.484	.302	.305	ns	.06
USA Clinic	SDQ conduct	Parent-report resistance	.545	.450	.358	ns	.05
Internet	SDQ conduct	Parent-report resistance	.532	.223	.384	<.05	.12
Support Group	SDQ conduct	Parent-report resistance	.215	.397	.130	ns	.04
UK	SDQ conduct	Parent-report resistance	.557	.176	.365	<.01	.12
USA	SDQ conduct	Parent-report resistance	.290	.252	.247	ns	.03
UK Clinic	SDQ conduct	Child-report resistance	.248	.346	.148	ns	.02
USA Clinic	SDQ conduct	Child-report resistance	.990	.365	.692	<.05	.41
Internet	SDQ conduct	Child-report resistance	.625	.326	.352	.06	.09
Support Group	SDQ conduct	Child-report resistance	.538	.437	.294	ns	.03
UK	SDQ conduct	Child-report resistance	.489	.217	.287	<.05	.08
USA	SDQ conduct	Child-report resistance	.461	.283	.342	.11	.07

Table H.5 Relationship between maternal GHQ and AMRABs across samples and within the UK and USA

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	GHQ	Parent-report benefits	-.217	.137	-.340	ns	.07
USA Clinic	GHQ	Parent-report benefits	-.166	.104	-.419	ns	.18
Internet	GHQ	Parent-report benefits	-.109	.086	-.247	ns	.03
Support Group	GHQ	Parent-report benefits	-.039	.102	-.109	ns	.07
UK	GHQ	Parent-report benefits	-.120	.073	-.228	ns	.03
USA	GHQ	Parent-report benefits	-.089	.070	-.247	ns	.02
UK Clinic	GHQ	Parent-report costs	.148	.106	.273	ns	.03
USA Clinic	GHQ	Parent-report costs	.209	.131	.433	ns	.11
Internet	GHQ	Parent-report costs	.250	.084	.518	<.01	.23
Support Group	GHQ	Parent-report costs	.064	.093	.193	ns	.04
UK	GHQ	Parent-report costs	.050	.064	.110	ns	.00
USA	GHQ	Parent-report costs	.216	.101	.392	<.05	.12
UK Clinic	GHQ	Parent-report resistance	.107	.099	.255	ns	.01
USA Clinic	GHQ	Parent-report resistance	.280	.097	.472	ns	.19
Internet	GHQ	Parent-report resistance	.154	.094	.311	ns	.06
Support Group	GHQ	Parent-report resistance	.148	.127	.319	ns	.04
UK	GHQ	Parent-report resistance	.050	.064	.110	ns	.00
USA	GHQ	Parent-report resistance	.216	.101	.392	<.05	.12
UK Clinic	GHQ	Child-report resistance	.070	.135	.118	ns	.02
USA Clinic	GHQ	Child-report resistance	.166	.069	.625	ns	.32
Internet	GHQ	Child-report resistance	.156	.127	.260	ns	.04
Support Group	GHQ	Child-report resistance	.122	.122	.251	ns	.01
UK	GHQ	Child-report resistance	.101	.089	.163	ns	.01
USA	GHQ	Child-report resistance	.168	.093	.386	<.05	.01
UK Clinic	GHQ	Competence	-.008	.128	-.064	ns	.00
USA Clinic	GHQ	Competence	.011	.043	.032	ns	.00
Internet	GHQ	Competence	-.011	.103	-.024	ns	.00
Support Group	GHQ	Competence	-.036	.058	-.191	ns	.00
UK	GHQ	Competence	-.004	.050	-.012	ns	.00
USA	GHQ	Competence	.046	.095	.145	ns	.00

Table H.6 Relationship between maternal GHQ and PSOC self-efficacy

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	GHQ	PSOC self-efficacy	-.244	.277	-.203	ns	.01
USA Clinic	GHQ	PSOC self-efficacy	-.458	.231	-.498	<.10	.18
Internet	GHQ	PSOC self-efficacy	-.396	.176	-.410	<.01	.13
Support Group	GHQ	PSOC self-efficacy	-.080	.333	-.069	ns	.01
UK	GHQ	PSOC self-efficacy	-.249	.157	-.221	ns	.03
USA	GHQ	PSOC self-efficacy	-.384	.280	-.381	ns	.17

Table H.7 Relationship between maternal GHQ and parent-report resistance – change in β when parenting self-efficacy is included in the analysis

	Relationship between maternal GHQ & Parent-report resistance - β	Relationship between maternal GHQ & Parent-report resistance when parenting self-efficacy was included in the analysis- β
UK Clinic	.255	-.084
USA Clinic	.472	-.364
Internet	.311	.221
Support Group	.319	.306
UK	.264	.216
USA	.187	-.105

Table H.8 Relationship between maternal GHQ and child-report resistance – change in β when parenting self-efficacy is included in the analysis

	Relationship between maternal GHQ & child-report resistance - β	Relationship between maternal GHQ & child-report resistance when parenting self-efficacy was included in the analysis- β
UK Clinic	.118	.067
USA Clinic	.625	.488
Internet	.260	.228
Support Group	.251	.057
UK	.163	.109
USA	.425	.398

Table H.9 Relationship between parenting self-efficacy and competence in administering medication

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	PSOC self-efficacy	Competence	-.174	.085	-.386	<.05	.11
USA Clinic	PSOC self-efficacy	Competence	-.161	.046	-.715	<.01	.47
Internet	PSOC self-efficacy	Competence	-.054	.044	-.211	ns	.02
Support Group	PSOC self-efficacy	Competence	-.013	.064	-.049	ns	.01
UK	PSOC self-efficacy	Competence	-.048	.041	-.146	ns	.01
USA	PSOC self-efficacy	Competence	-.125	.047	-.466	<.05	.18

Table H.10 Relationship between maternal ADHD and competence in administering medication

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	Maternal ADHD	Competence	.059	.027	.428	<.05	.15
USA Clinic	Maternal ADHD	Competence	.112	.035	.708	<.05	.45
Internet	Maternal ADHD	Competence	.022	.022	.204	ns	.01
Support Group	Maternal ADHD	Competence	.032	.036	.257	ns	.02
UK	Maternal ADHD	Competence	.033	.016	.272	<.05	.06
USA	Maternal ADHD	Competence	.033	.031	.219	ns	.03

Table H.11 Relationship between maternal ADHD and parenting styles

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	Maternal ADHD	Authoritative parenting	-.001	.012	-.028	ns	.00
USA Clinic	Maternal ADHD	Authoritative parenting	-.027	.030	-.286	ns	.00
Internet	Maternal ADHD	Authoritative parenting	-.015	.009	-.341	ns	.07
Support Group	Maternal ADHD	Authoritative parenting	.003	.018	.047	ns	.00
UK	Maternal ADHD	Authoritative parenting	.007	.006	.163	ns	.02
USA	Maternal ADHD	Authoritative parenting	-.013	.006	-.453	<.05	.17
UK Clinic	Maternal ADHD	Authoritarian parenting	.018	.023	.201	ns	.03
USA Clinic	Maternal ADHD	Authoritarian parenting	.107	.028	.806	<.05	.60
Internet	Maternal ADHD	Authoritarian parenting	.033	.019	.365	ns	.09
Support Group	Maternal ADHD	Authoritarian parenting	-.031	.030	-.314	ns	.01
UK	Maternal ADHD	Authoritarian parenting	.007	.015	.071	ns	.00
USA	Maternal ADHD	Authoritarian parenting	.052	.019	.534	<.01	.24
UK Clinic	Maternal ADHD	Permissive parenting	-.012	.008	-.312	ns	.05
USA Clinic	Maternal ADHD	Permissive parenting	.034	.023	.468	ns	.12
Internet	Maternal ADHD	Permissive parenting	-.005	.007	-.123	ns	.00
Support Group	Maternal ADHD	Permissive parenting	.013	.009	.352	ns	.02
UK	Maternal ADHD	Permissive parenting	-.001	.005	-.042	ns	.00
USA	Maternal ADHD	Permissive parenting	.002	.012	.047	ns	.00

Table H.12 Relationship between family cohesion and stigma

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	Family cohesion	Parent-report child stigma	-.104	.078	-.254	ns	.03
USA Clinic	Family cohesion	Parent-report child stigma	-.243	.065	-.734	ns	.50
Internet	Family cohesion	Parent-report child stigma	-.045	.069	-.120	ns	.01
Support Group	Family cohesion	Parent-report child stigma	.117	.102	.090	ns	.00
UK	Family cohesion	Parent-report child stigma	-.017	.050	-.041	ns	.00
USA	Family cohesion	Parent-report child stigma	-.158	.060	-.472	<.05	.19
UK Clinic	Family cohesion	Parental stigma	-.128	.069	-.341	ns	.08
USA Clinic	Family cohesion	Parental stigma	-.326	.139	-.560	ns	.25
Internet	Family cohesion	Parental stigma	-.072	.091	-.148	ns	.01
Support Group	Family cohesion	Parental stigma	.040	.113	.085	ns	.00
UK	Family cohesion	Parental stigma	-.073	.052	-.171	ns	.01
USA	Family cohesion	Parental stigma	-.256	.110	-.438	<.05	.16
UK Clinic	Family cohesion	Child-report stigma	.017	.085	.040	ns	.00
USA Clinic	Family cohesion	Child-report stigma	-.139	.125	-.226	ns	.01
Internet	Family cohesion	Child-report stigma	-.157	.098	-.437	ns	.12
Support Group	Family cohesion	Child-report stigma	.152	.119	.313	ns	.04
UK	Family cohesion	Child-report stigma	.065	.065	.134	ns	.00
USA	Family cohesion	Child-report stigma	-.157	.068	-.451	<.05	.17

Table H.13 Relationship between parental warmth and child stigma

Sample	Predictor	Variable	B	SE B	β	P	ΔR^2
UK Clinic	Self Report parental warmth	Parent-report child stigma	1.015	1.355	.151	ns	.00
USA Clinic	Self Report parental warmth	Parent-report child stigma	-2.790	1.611	-.447	<.10	.13
Internet	Self Report parental warmth	Parent-report child stigma	-1.285	1.383	-.160	ns	.00
Support Group	Self Report parental warmth	Parent-report child stigma	1.059	1.646	.159	ns	.00
UK	Self Report parental warmth	Parent-report child stigma	.322	.819	.049	ns	.00
USA	Self Report parental warmth	Parent-report child stigma	-1.875	1.077	-.323	.09	.07
UK Clinic	Self Report parental warmth	Child-report stigma	.254	1.356	.041	ns	.00
USA Clinic	Self Report parental warmth	Child-report stigma	-4.497	1.538	-.661	<.01	.38
Internet	Self Report parental warmth	Child-report stigma	-3.202	2.043	-.294	ns	.05
Support Group	Self Report parental warmth	Child-report stigma	-2.101	2.028	-.267	ns	.01
UK	Self Report parental warmth	Child-report stigma	-.934	1.018	-.125	ns	.00
USA	Self Report parental warmth	Child-report stigma	-3.589	1.149	-.546	<.01	.26
UK Clinic	Spouse parental warmth	Parent-report child stigma	.384	.939	.096	ns	.00
USA Clinic	Spouse parental warmth	Parent-report child stigma	-1.185	.643	-.470	<.10	.16
Internet	Spouse parental warmth	Parent-report child stigma	.119	.596	.040	ns	.00
Support Group	Spouse parental warmth	Parent-report child stigma	-2.145	.992	-.529	<.05	.22
UK	Spouse parental warmth	Parent-report child stigma	-.432	.478	-.131	ns	.00
USA	Spouse parental warmth	Parent-report child stigma	-.272	.441	-.125	ns	.00
UK Clinic	Spouse parental warmth	Child-report stigma	-.500	.938	-.132	ns	.00
USA Clinic	Spouse parental warmth	Child-report stigma	-1.853	.855	-.547	<.05	.23
Internet	Spouse parental warmth	Child-report stigma	-.061	.636	-.022	ns	-.05
Support Group	Spouse parental warmth	Child-report stigma	-2.111	1.342	-.429	ns	.11
UK	Spouse parental warmth	Child-report stigma	-1.233	.578	-.320	<.05	.08
USA	Spouse parental warmth	Child-report stigma	-.678	.513	-.277	ns	.04

Table H.14 Descriptive statistics exploring differences on child stigma associated with Critical EE ratings

	High Critical	Borderline Critical	Low Critical
UK Clinic	14.00	13.00	9.55
Parent-report child stigma	(3.64)	(2.16)	(3.87)
USA Clinic	Not calculated	Not calculated	5.67
Parent-report child stigma	n = 1	n = 1	(1.86)
Internet	7.31	7.66	5.67
Parent-report child stigma	(2.71)	(3.51)	(1.86)
Support Group	7.66	10.71	6.50
Parent-report child stigma	(4.72)	(4.30)	(2.00)
UK	9.90	11.23	8.09
	(4.23)	(3.54)	(3.26)
USA	Not calculated	6.30	5.33
	n = 1	(2.50)	(1.15)
UK Clinic	10.50	9.75	8.56
Child-report stigma	(4.94)	(4.11)	(3.90)
USA Clinic	Not calculated	Not calculated	4.67
Child-report stigma	n = 1	n = 1	(.816)
Internet	12.33	7.27	6.67
Child-report stigma	(5.85)	(3.79)	(5.25)
Support Group	9.33	9.11	5.33
Child-report stigma	(5.50)	(4.99)	(.577)
UK	10.75	9.46	7.89
	(4.09)	(4.31)	(3.45)
USA	Not calculated	6.40	5.10
	n = 1	(2.50)	(1.28)

Numbers in parenthesis represent standard deviations

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