The Perceptions of Mothers of Sons with ADHD

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This article describes mothers' own reports of bringing up a son diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). The effects of this widely misunderstood condition on the child, the family, and the wider social network (including medical and education systems) are many and complex. Although there is evidence for a biological basis for this condition, ADHD symptoms are also seen in children of abusive, or other disordered parenting. Children showing ADHD symptoms are often seen to be undisciplined, and their parents assumed to be either abusive or overindulgent. Many problems suffered by these families, particularly the mothers, may be due to the confusion of these two aetiologies. Rather than being seen as suffering from brain dysfunction, children are responded to with generalised social disapproval and ultimately ostracism. The article will describe the effects of the behavioural symptomatology as it influences the thinking, in accordance with the beliefs of casual observers, about its underlying causes.

The condition known as Attention Deficit Hyperactivity Disorder (ADHD) has a long history, having first been described by Still (1902) whose observations were supported by the research of Tredgold (1908). Since then, there has been much research to investigate possible causes of the condition and some of its complicating (comorbid) disorders.

Research on the Aetiology of the Disruptive Behaviours

The aetiology has remained elusive until recent work using neuroimaging identified certain structural cerebral anomalies in some of these children. The researchers (Perez-Arjona, 2003; Ford & Racusin, 1999; Balbernie, 2001) identified these as being correlational with the observed symptomatology. The research has shown that these anomalies may be due, prenatally, to either developmental or genetic mishap, or to the direct result of certain dysfunctional environmental conditions, which may include brain injury *in utero*, or smoking, alcohol consumption and the use of recreational drugs by mothers during pregnancy. According to these researchers and many others, postnatal injury to the brain in the first two years of life, a critical stage of development, also affects its further normal development.

A Brief Comment on a Neuropsychological Theory

Barkley (1999) proposed a neuropsychologically based theory to explain the particular problems associated with hindsight, forethought and planning. The theory points to deficiencies primarily in the self-regulation of affect, self-motivation and arousal, and secondarily in the capacity for rule-governed behaviour, moral reasoning and reflection. These stem from essential impulsivity. Complicating this, short-term memory deficits observed in these children (Barkley, 1999) render them significantly less competent in taking advantage of past experience. These diagnostic aspects of the work on ADHD are beyond the scope of this article, and the findings are tentative at this stage. However, they are mentioned here because of their future promise to provide objective diagnostic criteria without which the symptomatology of ADHD may be seen as that of a poorly disciplined or inadequately nurtured child (Barkley, 1998). This confusion frequently draws responses in the form of inappropriate and sometimes punitive management, as well as public scorn.

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Neglect of Psychosocial Research

Unfortunately the interest in and the research focus on this new interpretation of ADHD has turned out to be a double-edged sword, as Rubia and Smith (2001) have pointed out. They have identified a neglect of research on the causes and management of psychosocial problems due to the current focus on biologic–genetic model of ADHD, which has explored the effects of medication while at the same time neglecting possible environmental problems and management of the condition. This current study is the first of a wider series aiming to redress this shortfall.

Previous Studies of the Experiences of Parents

There have been only a few studies of the experiences of mothers of sons suffering from ADHD. A qualitative study by Harborne and Wolpert (2004) focused on the current professional understanding of research findings in relation to the aetiology of the disorder, and the mothers' understandings of the variety of different causes ascribed to it, as gained from their own readings. The mothers described their efforts to understand from books and other literature as confusing them even more, due to the contradictory ideas put forward. In addition, the study demonstrated the adverse effects on mothers, and of the one father who participated, of the judgmental attitudes of both lay and professional people with whom they had contact, and of scepticism regarding any question of biological or psychiatric causes. The mothers described experiencing negative attitudes from those who believe ADHD to have a purely psychosocial basis, to the extent that they felt socially ostracised. This is consistent with the findings of the current study.

Kendall (1998) described the experiences of parents and of siblings in two qualitative studies of families with an affected son. This study showed that there is a need for increased social and mental-health services to be directed towards the disorder and its effects. It reported on the manner in which the parents of these children coped with their behaviours, noting the overinvolved and, to some extent, overprotective management they offered the children. She also described a developmental trajectory in which parents adjust their management of the disorder as their sons achieve maturity, eventually 'relinquishing [hope] for a good ending' (854).

In a further study Kendall (1999) examined the effects of the condition on the siblings of the diagnosed sufferers, and showed that the effects on these children can, potentially, be quite deleterious to their health and wellbeing. Strategies used by siblings in their attempts to cope ranged from retaliatory aggression, to avoidance, to accommodation — a sad story reflecting a family structure organised around the affected child's disability. Although not mentioned in Kendall's paper, aggressive responses of siblings to ADHD behaviours may put them at risk of habitual socially inappropriate responses to antagonism. Strategies of avoidance could lead to more general learned helplessness entailing a degree of self-effacement. These ways of behaving, which deny or mask any distress experienced by the siblings, are not adaptive in the long run. While appearing on the face of it to be an adaptive coping mechanism, avoidance is in fact a hidden danger. It puts siblings at risk of learning and entrenching behaviours likely to inhibit psychosocial development.

Participants in the Project

I elected to focus my research question on the mothers for two reasons. First, at the time of writing, this is the only study in Australia to investigate the effects of ADHD on mothers, as described by themselves. Second, mothers are the main custodians of children even in the present social climate where many mothers work outside the home (Barkley, 1998). A further reason for their usually major commitment to the affected child, to some extent at the expense of other family members, might be due to the long-held social convention that it is the mother's job to care for the children (Barkley, 1998). The mothers in the present study have reported feeling alone in their battles to achieve some sort of normality in the lives of their sons. These mothers report coping virtually single handed in their struggle, largely without family, social or educational support.

A Hitherto Neglected Research Dimension

While taking these theories into account as far as they refer to ADHD-related behaviours, it is nevertheless important to recognise the effects of a third dimension on the child's behavioural development; that is, the effects of the child's adaptation to the specific environment in which he is living, and the learning experience by which the child responds to events in his life in the most effective way he knows. He responds in ways which 'work' for him in the short term, employing goal-directed behaviours. These do not necessarily promote his long-term welfare. These strategies may in some cases draw a beneficial response but, in many cases, they have the opposite effect. In the latter case, a commonly described example in a

child diagnosed with ADHD is the excuse offered, when confronted with some task he is reluctant to perform, that he cannot do it 'because of my ADHD' (Voeller, 2004; MTA Cooperative Group, 1999).

This article reports findings from a qualitative study examining the perceptions and experiences of a group of mothers of boys who carry a diagnosis of ADHD. Ten mothers were recruited from regional ADHD Support Groups in New South Wales. The number was limited to 10 because of constraints on time and money.

Methods

Following established qualitative in-depth interviewing procedure, a topic guide formed the basis of the semistructured interview. This consisted of five areas presumed to be most relevant and significant. These were nuclear family, extended family, social network, education system and medical system. The purpose of the topic guide was to allow respondents to raise, within these guidelines, issues most important to them (Fontana & Frey, 1999; Grbich, 1999). Thus the interviews were aimed at obtaining rich in-depth information to enable the investigator to gain understanding of the mothers' experiences (Patton, 2002). A grounded theory method informed the structure and form of the interviews, the conceptual analysis following the traditions set by Glaser (2001). These describe a strategy using a set of inductive strategies for analysing the data. The process requires close examination and interpretation of transcripts of the interviews in order to develop abstract conceptual categories, each identified by a code. This helps to amalgamate the data into a pattern and facilitates its explanation and the understanding of relationships within it. Inductive reasoning then leads to the development of hypothesis formulation on the basis of information received from the interviewees. This is distinct from the preemptive hypothesising used in quantitative research which is formulated on the basis of established ideas.

The interviews lasted from one to one-and-a-half hours. Each of them was audiotaped and transcribed to assist with coding and retrieval of significant data, in preparation for subsequent analysis. Assurances of confidentiality were given at this point. In addition the women were given a statement to read, and were then offered a consent form to sign if they agreed to the conditions of the study. They were assured that the consent was not binding, and that they could leave the study at any time without explanation or obligation. They were also told that in the event of this happening they could ask that all records of the interview be erased. None of the mothers took these options.

Results

The results are grouped into the five thematic areas mentioned above.

Nuclear Families

Material gathered indicates that some of the mothers are making sense of their almost sole responsibility for the special needs of the ADHD child in terms of their daylong proximity to the child. A number of them said, 'Well, I'm with him all the time' to explain this. One other mother said, 'Well, he's my kid'. So in a sense they justify the fact that they are not getting support, and although some do describe fathers helping in some peripheral way, by washing up, or making the beds, the fathers are not involved in the direct care of the child apart from administering some well-intentioned but sometimes mistaken and heavy-handed discipline. This apparent detachment on the part of the fathers is consistent with that reported by Singh (2003).

Information from the mothers during interviews reflects the unrelenting vigilance demanded of them as they try to help and protect their sons. Some illustrative quotes follow. The names of the interviewees have been changed.

> **Mary:** 'My husband is a teacher. He's with kids all day and when he comes home he doesn't even want to hear his own kids' voices. I try to give him a break by keeping them quiet for an hour or so.'
>
> **Margaret:** 'Their father goes kayaking for a week or a weekend from time to time with his mates. I cry when he goes because then it's all on me. He knows I'm upset when he goes, but he needs a break from the kids.'
>
> **Anne:** 'He cries when I tell him what our son has done, so I don't tell him much. And he's doing a course, so he's busy with that. I don't like to bother him.'

The sentiments expressed by these mothers are reflective of an unquestioning acceptance that their role as *mater familias* is set in tablets of stone, requiring them to take full and unaided responsibility for the nurturant care of the children under all circumstances. They accept that this is not expected of fathers.

Siblings

The usual sibling tensions apply, but the mothers describe what they experience as a greater tension

between their own children as compared with the unaffected children of their friends and relatives. The mothers described their protective instincts coming to the fore in these situations, and it may be that the tension between the siblings is exacerbated by the mother's 'taking sides' against the unaffected child. The following quote illustrates this:

> **Nanette:** 'I tell my [older] son, "If you ever say *anything* to put him down, I will *annihilate* you"'.

There was also ambivalence about the ADHD child expressed by some of the mothers, thus:

> **Celia:** 'Sometimes I try to think of the things I love about him.'
>
> **Christine:** 'I feel so ashamed of him when we're out.'

The mixed feelings of the mothers toward their children, both affected and unaffected by ADHD, can be seen as natural manifestations of instinctive maternal protectiveness. However, in the case of ADHD children, there is also empathic grief and guilt, these emotions being shown during interviews with almost all of the mothers. This is consistent with the findings of Clarke et al. (2002).

Extended Families

There were various experiences reported by the mothers in relation to their extended families. On the one hand were reports of both practical and emotional support, and on the other, sad stories of the abandonment of any contact, usually due to contradictory beliefs about the diagnosis and management of ADHD. The statements made by mothers, such as those illustrated below, also indicate the guilt most of the mothers felt in allowing themselves to criticise the relatives who offered support at the same time that it was gratefully accepted.

> **Jan:** 'My son and I live with my Mum now. I left my husband when he refused to get a job himself but told me to get one, and to get someone else to look after our son. I feel terrible sometimes because of the dreadful tantrums the boy has and Mum having to hear them.'
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> **Nanette:** 'I'm by myself in this because they don't seem to understand what I'm trying to do.'
>
> **Bronwyn:** 'My in-laws don't believe there is such a thing as ADHD. They think he's just a naughty boy. They certainly don't think he should be on medication. My sister and my mother have joined together on this and I don't see or hear from them any more.'

The number of mothers who got support was outweighed by those who did not. Those who did get support were very appreciative, but with some of them the appreciation was mixed with guilt for the difficulties they knew they were imposing on their relatives. For those who had been abandoned, the sorrow of that renunciation seemed to be just one more burden to carry.

Social Network

> **Toni:** ' I think the hardest part of having a child with ADHD is the lack of understanding of other people. The remarks you get. The looks you get. From that you start to scrutinise yourself, and your parenting … not doing a good job … Is it my parenting skills? Am I not disciplining him enough? Am I disciplining him too much?'
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> **Lisa:** 'A friend of mine, we've known each other since we were little kids at school. She's been my best friend all my life. I've talked to her a lot, but she said to me last time I saw her that she didn't want to hear any more. She said, "We all have our problems"'.

The mother wept as she said this. Her grief at the loss of her long-time friend who was her trusted confidante left her feeling isolated and miserable, with nobody to turn to.

> **Pam:** 'I was waiting at the checkout one afternoon. My son was with me. He was behaving as usual. A woman near me said to me, "Give him to me for an afternoon. I'll soon sort him"'.

Pam must have been feeling quite desperate because she said, 'Take him'. So the other woman did. She was back with him in half an hour saying, 'He's yours!'.

Experience is evidently a great educator.

Education System

Themes Related To Teachers

The mothers' statements shown below represent two of the many experiences that these mothers have in trying to find understanding and help from the schools their children attend. They indicate that they feel unheard and that they respond with anger, sorrow, and a shameful sense of having failed both as parents and as people who should be able to negotiate with the teachers. They feel worried about putting themselves at a constant and continuing disadvantage with the teaching staff. On the positive side, one mother said that during her first interview with the school principal she experienced such a level of compassion and practical advice about her school's resources that she wept. She said she will send both her children to that school now, and would not think of moving

them. However, even in the most understanding of schools, it seems that the children's learning, behaviour and social problems were unchanged. An important source of the mother's experience of relative peace of mind comes from feeling she is understood at the school, even if the child's academic skills do not improve. Conversely the mothers reported feeling increasingly anxious when they were misunderstood.

> **Janet:** 'The schools, it's so hard to get through to them. They don't listen to mums. He's been suspended four times, and the next time I'm told he'll be expelled.'

> **Barbara:** 'I decided to change my son's school because he came home every day crying. The teacher tore up his work and told him to do it again, time after time because he was colouring outside the lines. He was only six years old.'

> **Lisa:** 'He gets into trouble for calling out. I told his teacher – he calls out because he knows the answer, and he's so pleased he knows the answer. I told her that's his ADHD. She just rolled her eyes.'

It is easy to understand the frustration of these mothers. They often feel that their most urgent concerns are being passed off as trivial, or arising out of an inappropriate level of overprotectiveness toward an undisciplined child with no academic interests or social skills. At the same time the dilemma of teachers is very real. Their difficulties in trying to teach a child with marked learning and behaviour disorders, while at the same time being responsible for teaching 25 or more other children, would seem to be problems which urgently require addressing.

Themes Related to Class Bullies

All the mothers reported that their sons fell victim to bullies. The mothers report that their very differences from other children mark them out for this special attention. In the main, the mothers see these differences arising out of their poor social skills and low self-esteem which is seen to be part of the symptomatology (Barkley, 1998). I believe these children are thus poorly equipped to protect themselves against being specifically targeted in this way. They are reported by their mothers to make impulsive ill-considered responses, such as crying or hitting back, or trying to take over a game in progress, without knowing how to be part of a team. Sometimes it is a response to aggression. The bullying then takes on secondary characteristics, such as scapegoating, followed by labelling, thus setting up a repetitive pattern which all too frequently leads to the boy with ADHD being identified as a troublemaker. The labelling is entrenched and consolidated by other children reporting to the teacher that this boy was the initiator of the trouble whether he was or not. This may well be identified as a 'bullying cycle'. Having a teacher on playground duty does not always solve the problem because of the difficulty of trying to supervise all of the children all of the time.

> **Debra:** 'The principal called me and said he wanted to see me. He said that my son had hit and jumped on another kid at lunch time. I said to him, "Well, I don't see how it could have been him. He's home sick today".'

This describes the not infrequent misunderstanding arising out of the 'bullying cycle'. The secondary characteristics of bullying, that is, scapegoating, followed by labelling, are clearly illustrated in this quote. The principal's undoubted difficulties in attempting to deal with the incident must surely not be an isolated incident, given that the mothers report that their sons are frequently bullied. One mother did say that her son often started it.

Medical System

From the comments the mothers made it would seem that they have searched until they found a doctor who was helpful; either that or they took matters into their own hands and tried alternative medications.

> **Barbara:** 'We took our son to a big clinic. We were there all day. They tested him on some schoolwork type of stuff with and without medication, before and after – you know. They even tested him using two different kinds of medication and neither of them made any difference, but they still wanted me to put him on it. I tried it for a while but it didn't make any difference that I could see. I've got him on fish oil now because they say it's good for concentration.'

> **Catherine:** 'You take him for appointments with the doctor every three months, and you have this huge list of problems, and you see him for 10 minutes and all he says is, "Well, we'll see how he is in another three months". I am so angry.'

> **Lisa:** 'It used to be so good at the clinic I went to first. You went to see the doctor every three months, for him to see me and my son, and get prescriptions. You went to the psychologist every month. If you didn't keep your appointments with the psychologist, you didn't get your prescriptions updated. Then we moved to another city and after we arrived my son was really agitated. I rang the local clinic and told them, "My son is having a two-week tantrum and I need to see someone urgently". They said, "We can give you an appointment in eight months". I couldn't believe it. I insisted it was urgent and they finally sent me to a parenting group.'

> **Toni:** 'It's so good now. I took him away from the first clinic I tried and now he's doing so well with a doctor who sees him alone as well as seeing me. He really listens to him and to me.'
>
> **Elizabeth:** 'The clinic I go to has a wonderful psychologist. She is my rock. She's there for me.'
>
> **Mary:** 'I've got a really good doctor now. He sees me and my son, both alone and together, and we really work things out between us.'

Supportive professionals were reported to be a great source of comfort to these mothers. Most of them said they had ultimately connected with a medical system that offered them support.

Discussion

The findings reported in this study are limited by the small number of participants, and whatever bias may have arisen out of the participants' memberships in the support groups. This may have influenced them not only to join the study but to cooperate with the interviews. These biases may be a function of their trust in the groups and their interest in learning whatever may become available to them through the interview process, by insights that may have occurred to them as a result of the process, or from discussing it among themselves later. Information obtained during interviews suggests that these mothers are enmeshed in a rigid system consisting of interactive subsystems connecting them to what may be imagined as a powerful unseen force. Conceptual interpretation indicates that the origins of the symptoms, biological or psychosocial, are impossible to separate simply by observing behaviours. It is important to recognise that biological symptoms are necessarily associated with psychosocial symptoms. Psychosocial symptoms are not necessarily associated with biological symptoms. Together, however, they are an amalgamation of powerful but invisible entities (the imaginary powerful unseen force) formed by the confusion of manifest symptoms of ADHD with those of a similar behavioural aberrations which arise from external environmental causes. The latter are those which are associated with what Barkley refers to as 'psychological causes such as "spoiled" child rearing practices or delinquent family rearing practices' (1998: 6).

It is of concern that there is no government scheme to support the needs of these children. After hearing the stories of the mothers, I believe that their sons should not be mainstreamed in school classes, for their own sakes as well as those of the teacher and the other children in the class. It remains to be seen whether any broad-ranging plan can be developed to help them with their education and social adaptation to life. The schools involved with the families in this study had had no instruction about the management of the disturbing behaviours they may encounter in the classroom. The measures they seem forced to resort to, such as banishing the child, do not change his behaviours, but do deprive him of education. Under the current circumstances, I believe that teachers are placed in an impossible situation with regard to the educational and behavioural management of these children. All they can do is abide by school policy.

"It is of concern that there is no government scheme to support the needs of these children."

Thus far, attempts put in place for any wide-ranging strategies to help these children have produced two main treatment regimes which show promise. These were both aimed at research with ultimate intent to treat. One of these was the large-scale US Multimodal Treatment Study of Children with Attention Deficit Hyperactivity Disorder (MTA) by the MTA Cooperative Group (1999). In that study, the results showed that a combination of medication with behavioural modification achieved the best results. This was found not only to reduce the severity of the symptoms but also to permit, in due course, reduction of medication dosage.

The other intervention program, proposed by Barkley, consists of parent training in 10 stages. The results of the study were in broad agreement with the MTA study. Both studies emphasised the need for treatment programs to extend over months, or even years. Both recognise that there are many and various problems suffered by these children and no particular program is able to deal with all of the difficulties. Barkley stated that 'classroom implementation of behaviour modification techniques' produced significant short-term improvements in ADHD children (2002: 42).

In the meantime, the burden borne by the women in this study — lonely and vulnerable due to the chronicity of the condition their children suffer and the ensuing social disapproval and educational misunderstanding — should not be dismissed lightly.

The descriptions they give of their untiring efforts to help their children to be accepted in their social and educational community reveal a strength of purpose and commitment that can only be admired.

In view of the extreme difficulties facing mothers who are involved with these children, it is clear that much more research is required. It is to be hoped that, along with increasing sophistication in neuroimaging techniques, attention will be paid to the psychosocial factors entailed. The urgency of this is obvious, but may be made clearer when it is more widely realised that some of the children later find themselves in gaol as adults due to the development and continuance of antisocial behaviours, a result of comorbid conditions such as psychopathy which complicate ADHD (Rasmussen, 2001; e.g. Richardson, 2000).

Let us spend money on these children now instead of waiting until they are ultimately at risk of running foul of the law.

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