

‘He’s just enthusiastic. Is that such a bad thing?’: Experiences of Parents of Children with ADHD

Ruth McIntyre and Eilis Hennessy

School of Psychology, University College Dublin

Abstract

Parenting a child with Attention Deficit Hyperactivity Disorder (ADHD) is a challenging experience. The hyperactivity, impulsivity and inattention of a child with ADHD often put parenting skills to the test. The present study thus aimed to explore the experiences of parents of children with ADHD in Ireland. Eighteen parents of 7-12 year old boys with a diagnosis of ADHD took part in open-ended interviews. Thematic analysis was carried out on the interview content. Six major themes were identified: i) getting your head around ADHD, ii) the child takes over, iii) emotional impact, iv) inconsistency of structural supports, v) ignorance and discrimination and vi) it’s not all bad. Results are discussed in terms of the need to implement family centred supports for ADHD. The importance of educating the population at large about ADHD is also discussed. Finally, the need to take a more positive, strengths-based approach to ADHD is highlighted.

Keywords: *attention deficit hyperactivity disorder, ADHD, parents’ experiences, qualitative, interviews*

Introduction

Research looking at the experiences of families of children with Attention Deficit Hyperactivity Disorder (ADHD) has stagnated since initial interest in the latter half of the 20th century (Johnston & Mash 2001). Instead the focus of research has been on genetic influences and behavioural outcomes. Johnston and Mash (2001) argue that regardless of the genetic propensity, the interaction between family circumstances and child characteristics must be considered. This view is in line with Bronfenbrenner's (1979; 1986) ecological model which promotes the bi-directional nature of the parent-child relationship and asserts that the family is an important context in which to consider development.

Parents of children with ADHD are faced with significantly more challenges than parents of children without any difficulties (Anastopoulos, Guevremont, Shelton & DuPaul 1992). Given that the worldwide prevalence rate of childhood ADHD is estimated at 5.29% (Polanczyk, Silva de Lima, Horta, Biederman & Rohde 2007) a considerable number of parents may be faced with a more challenging parenting role. However, as ADHD is not a homogenous disorder (Taylor 2009) parents' experiences may vary. There is some evidence that families of children with the combined subtype of ADHD may have more problems than families of children with either the inattentive or hyperactive-impulsive subtypes (Paternite, Loney & Roberts 1996). The presence of co-morbid disorders, namely oppositional defiant disorder and conduct disorder, may further exacerbate family functioning (Paternite et al. 1996).

There is inconsistent evidence regarding the links between family factors and child ADHD, with further research recommended to clarify the situation (Johnston & Mash

2001). Nonetheless, a host of difficulties have been found to be experienced by parents of children with ADHD. For instance, parents of children with ADHD experience elevated levels of parental stress (Johnston & Mash 2001; Blew & Kenny 2006), increased depressive symptoms (Brown & Pacini 1989; Faraone & Biederman 1997), elevated rates of anxiety disorders (Perrin & Last 1996), increased alcohol consumption (Cunningham, Bennes & Siegel 1988) and disruptions in family functioning (Johnston & Mash 2001). The shared genetic element of ADHD means that some parents of children with the disorder may also have to deal with their own symptoms (Faraone, Biederman & Milberger 1994). For these parents, compared to those without ADHD, heightened rates of depression and anxiety may be coupled with lower self-esteem and poorer coping (Rucklidge & Kaplan 1997). Parents of children with ADHD may also experience negative treatment from those around them. For instance, they may be exposed to criticism from those close to them, acquaintances and strangers (e.g. Norvilitis, Scime & Lee 2002) and they may be less likely to receive helpful social support from extended family members than parents of children without ADHD (Cunningham, Bennes & Siegel 1988). Perhaps unsurprisingly parents of children with ADHD tend to experience lower parenting satisfaction and a lower sense of parenting efficacy and competence (Mash & Johnston 1983; Shelton et al. 1998).

To best understand the impact of ADHD it is important to understand the bidirectional relationship between the children who are affected and their parents. The family, specifically parents, are the primary source of influence for the child's development (Bronfenbrenner 1979; 1986). However, Bronfenbrenner's theory also postulates that relationships within the family are reciprocal, therefore not only is the child influenced by his/her parents but the parents are also influenced by the child. As such it would be ineffectual to consider parents and children in isolation of one another (Kuczynski & Parkin 2009). For example, just as a child's challenging behaviours can increase parental distress, a disturbed family environment can exacerbate the symptoms of ADHD (Podolski & Nigg 2001). Bearing this in mind it is important to give due consideration to the perspectives of parents who are in a unique position to offer insights into family life. The perspectives of parents may be particularly pertinent when it comes to implementing

supports for the child. Indeed, Harrison and Sofronoff (2002) emphasise the “crucial role of parents and family functioning in the long-term outcomes of the child with ADHD” (p. 704). For example, when parents of children with ADHD have a heightened sense of self-efficacy and self-esteem their children are more likely to benefit from behavioural, pharmacological and combined treatments (Hoza, Owens & Pelham 2000).

In order to fully grasp the complexities of ADHD it is therefore useful to seek the views and experiences of parents who are among the most regularly affected by the condition (Firmin & Phillips 2009). Indeed a growing body of research has begun to consider the unique perspectives of parents of children with ADHD. However, there appears to be an emphasis on exploring the management, treatment and causes of the disorder. For instance, several in-depth qualitative studies have been carried out in relation to parents’ perceptions of stimulant medication (e.g. Wright 1997; Bussing & Gary 2001; Bull 2006; Charach, Skyba, Cook & Antle 2006; Jackson & Peters 2008). Parents’ views on the causes of ADHD (Harborne, Wolpert & Clare 2004; Perry & Kendall 2005), the provision of treatment information (Kendall, Leo, Perrin & Hatton 2005) and the general management of ADHD (Perry, Hatton & Kendall 2005) have also been investigated. In those exploratory studies where children’s views are also sought the conclusions drawn tend to highlight medication or treatment issues (Neophytu & Webber 2005; Travell & Visser 2006; Hughes 2007). Based on the literature review carried out for this article only two studies have been identified which broadly investigate the general and everyday experiences of parents of children with ADHD (Firmin & Phillips 2009; Peters & Jackson 2009). Of these only the research carried out by Peters and Jackson (2009) took an entirely open-ended methodological approach. Considering the array of difficulties facing parents of children with ADHD documented in the quantitative literature (e.g. Brown & Pacini 1989; Cunningham et al. 1988; Johnston & Mash 2001; Blew & Kenny 2006; Xiang, Luk & Lai 2009) this scarcity of broad exploratory research is surprising.

The present study thus hopes to address this gap in the literature and add to the very small body of research which prioritises the general and lived experiences of parents of children with ADHD. To do so the present study aims to carry out an in-depth and comprehensive exploration of all aspects of the parental experience of ADHD. In this

way parents are given the opportunity to talk about what they feel are the important issues in their experience.

Method

Background

This study was part of a larger project investigating the experiences of 7-12 year old boys with ADHD in Ireland. Given that the family is an important context in which to understand the child's development (Bronfenbrenner 1979; 1986) the child's experience at home was considered. Thus, the unique perspective of parents was explored in order to understand the impact of ADHD on parents and on the family as a whole. To maintain a homogenous group only parents of boys with ADHD took part in this study. The age range of their children was 7–12 years since, a) children are not usually diagnosed with ADHD until seven years; b) as children approach adolescence they are more susceptible to developing complications to their condition; and c) at around twelve years children in Ireland start secondary school where they are no longer in a class with just one teacher (Hughes 2007). Such variables may give rise to an altogether different experience.

Ethical Approval

Ethical approval was granted for this study from the UCD Human Research Ethics Committee and the Ethics Board of the relevant Child and Adolescent Mental Health service.

Recruitment

Families of children with ADHD were recruited through two national support groups, an eastern region child and adolescent mental health service and two special education schools. The snow-balling method of recruitment was also implemented whereby already

participating families were asked to pass on details of the research to others who may be interested in taking part. Due to the restrictions on the child’s age limit and gender recruitment of parents of children with ADHD was a slow process. Over a period of approximately one year fifteen families committed to taking part in this study.

Participants

In total eighteen parents/caregivers took part in this study. The majority of their children were 7 years of age (40%), with one or two children fitting into each of the other age categories. For full details of participant characteristics see table 1.

Table 1: Participant Characteristics

Variable		Mean	N	%
<i>Parents:</i>				
Gender	Female	-	16	89
	Male	-	2	11
Age in years	25 or under	-	1	6
	26-35	-	4	22
	36-45	-	11	61
	46-55	-	0	0
	56 or above	-	2	11
Parental status	Parenting alone	-	6	33
	Parenting with partner	-	12	67
Education	Secondary School	-	6	33
	Undergraduate Degree	-	2	11
	Postgraduate Degree	-	7	39
	Other	-	3	17
Number of children		2	-	-

Children:

Age in years		9.64	-	-
Years diagnosed		4.5	-	-
ADHD Subtype*	Inattentive	-	1	7
	Hyperactive-impulsive	-	4	26
	Combined	-	10	67
Co-morbidity	ODD**	-	7	47
	CD***	-	2	13
	Other	-	6	40
Treatment	Psycho-stimulant	-	8	53
	None	-	6	40
	Other	-	1	7
Schooling	Mainstream	-	12	80
	Special School	-	3	20

* As indicated by the Conner's ADHD Rating Scale

** Oppositional Defiant Disorder

*** Conduct Disorder

Procedure:

Open-ended interviews were carried out in the homes of eighteen parents/caregivers of children with ADHD. Interviews began with the researcher inviting parents to tell their story and talk about their experiences as a parent of a child with ADHD. As a guideline, the researcher suggested that parents begin telling their story in relation to their child's diagnosis and the events leading up to it. In some cases the researcher was required to prompt parents by introducing the following topics: diagnosis, strengths and difficulties of the child, treatment, the effect of ADHD on family life, stigma, social/emotional effect on parent and advice for other parents. The length of interviews ranged from forty minutes to one hour thirty minutes.

Measures:

Parents also completed a demographic questionnaire and the Conners' 3™ ADHD scale (CADS; Conners 1997). The CADS - Parent Version is a proxy-rated scale of ADHD symptoms. The full-length version, which was used here, includes 110 items. It was used to confirm diagnosis of ADHD and to assess the severity of symptoms from the parent's perspective. The Conners' 3 is a reliable tool for identifying ADHD but also for identifying co-morbid disorders such as conduct disorder and oppositional defiant disorder.

Data Analysis

Qualitative Measures:

All interviews were transcribed verbatim and analysed using the principles of thematic analysis (Braun & Clarke 2006). The researcher first became familiar with the data, through transcription and the reading and re-reading of the data. Initial ideas and themes were noted down at this stage. The researcher then went through the data in a more systematic fashion, generating initial codes, which represented specific features of the data. Approximately four thousand initial codes were generated. These were then collated into potential themes with key extracts from the data set identified. These themes were then reviewed to ensure that they made sense in relation to the coded extracts and the entire data set. Through constant reference to the data the themes were refined several times, until seven key themes were produced. Once the researcher was satisfied that each theme was mutually exclusive and exhaustive, final names and definitions of the themes were generated. The final stage of analysis involved the selection of interesting and relevant extracts from the data set, which represent the experiences of the parents of children with ADHD. An independent researcher coded approximately 10% of the data. The two coders were in agreement 82.8% of the time, with any discrepancies resolved through discussion. Themes and sub-themes were also reviewed by an independent researcher with minor clarifications recommended ensuring that each theme was meaningful and distinctive.

Quantitative Measures:

Descriptive analysis was carried out the parent version of the Conners' 3 ADHD scale. This confirmed the number of children who fit the criteria for the combined, hyperactive-impulsive and inattentive subtypes of ADHD.

Results

Theme:	Example:
1. Getting Your Head Around ADHD	<i>On the one hand you're trying to be lenient because of the ADHD then on the other hand...you have to be able to distinguish between ordinary naughty behaviour and ADHD, you cant just white-wash it and say [child] can do whatever he wants...that he can do things that no other child is allowed to do just because he has ADHD. (Mother of 7 year old boy)</i>
2. The Child Takes Over	<i>It's like he rules...you have to be very very careful in not letting him take over everything...you could really give [daughter] very little attention you have to remind yourself and I do feel awful guilty about her sometimes...he demands so much of your time...she's very much left out of the picture. (Mother of 8 year old boy)</i>
3. Emotional Impact	<i>It kind of broke my heart at times thinking that people were picking on him or worrying about will he be able to look after himself when he's older and will he be able to have a proper career and will he be able to have a relationship...all the normal things like would it be harder for him. (Mother of 11 year old boy)</i>
4. Ignorance and Discrimination	<i>People don't know an awful lot about this and it's only coming out now that there are different types of behaviour and there are different types of children being born into this world...but people you know once they see you're different in anyway umm have a tendency to block you out and that's the way it is. (Mother of 7 year old boy)</i>

5. Inconsistency of Structural Supports	<i>I demanded that [the health service] intervene because we weren't getting the help that he needed, he clearly needed OT and clearly needed a lot of help in regulation and we weren't getting any of it, so we got the [health service] to intervene...the psychiatrist couldn't understand to date why [child] had been really neglected. (Mother of 7 year old boy)</i>
6. It's Not All Bad	<i>I think he has a good success story at the moment he's been a good success story from where he has come two years ago. (Mother of 9 year old boy)</i>

1. Getting your head around ADHD

Parents continually spoke of trying to understand and make sense of their son's ADHD. This process often began in early infancy with some parents instinctually knowing something wasn't quite right with their child. Other parents reported not realising anything was amiss. First time parents were at a particular loss, often putting the high energy and activity levels of their child down to typical boyhood behaviour. One parent said:

"It was a case of boys will be boys" (Mother of 7 year old boy)

Following diagnosis many parents reported struggling to figure out the best way to deal with their son's behaviour. One parent described seeking the advice of a psychologist in her attempts to make sense of ADHD:

*"I remember saying...is it like giving out to a deaf person because they can't hear you and... she said well the deaf person has to learn to communicate as well".
(Mother of 8 year old boy)*

Several parents also reported making comparisons with other children in their attempts to understand the relationship between their role and their child's behaviour. One parent compared her ability to parent her two children:

“She'd be having a little tantrum and I'd say fine and then she'll just get up and stop and I'm like oh my god hold on that worked I actually can do these things I have good parenting skills it's just they never worked on him”. (Mother of 8 year old boy)

In making such comparisons parents reported being able to relinquish blame and recognise themselves as competent parents.

Parents described their difficulty in seeing beyond their child's diagnosis of ADHD. One parent commented:

“He was a child with ADHD and I saw that more than him”. (Mother of 11 year old boy)

This was linked to parents' confusion in distinguishing between ADHD, personality and “being bold”. For one parent this was the crux of the issue in getting her head around ADHD:

“Maybe that's his personality maybe that's ADHD maybe ADHD is personality and vice versa I genuinely don't know”. (Mother of 7 year old boy)

2. The Child Takes Over

All parents described the demanding nature of their child with ADHD. Children with ADHD required so much attention that other children in the family barely got a look in. For some parents this resulted in feelings of guilt. One parent admitted:

“I feel very very sorry for [other son] because...when he grows up he’ll think God I got no look-in in that house at all and it’s terrible”. (Mother of 7 year old boy)

Parents reported that parental relations were also disrupted as a result of the child with ADHD’s extreme need for attention. One parent described how her son’s attempts at getting attention literally come between herself and her husband:

“From a very young age if myself and [husband] were sitting down to relax he would climb in between us if you’re having a hug he’d climb in between us if [husband] put his arm around me he’d climb in between us...every time we were having a conversation we were interrupted” (Mother of 8 year old boy)

The majority of parents in this study communicated that parenting a child with ADHD is a physically exhausting role. One parent recounted:

“I was on extreme exhaustion from fighting, from the sheer exhaustion of just being with [child], even though coming back from school I’ve only got him for about three hours and then he goes to bed...but you are exhausted”. (Mother of 7 year old boy)

According to parents in this study the role of a parent of a child with ADHD is a complex one, which can literally sap a parent’s energy. This was highlighted by one parent:

“To be a teacher, mother, minder, carer, everything and twenty four [hours] round the clock it’s just an exhausting experience”. (Mother of 7 year old boy)

Another parent described how dealing with her son's ADHD had really taken its toll on her:

“It's really aged me I can tell you and taken it out on me”. (Mother of 7 year old boy)

The extent to which parents are willing to invest their time and energy into their child's well-being was illustrated by the personal sacrifices made by parents in this study. Several parents reported giving up work in order to focus their energies on looking after their child. In the words of one parent:

“I gave up work...so I could be at home because it was just madness I was just chasing my tail”. (Mother of 8 year old boy)

Changes in their social life were also mentioned by parents in this study. One parent commented on the extent of this change as a direct consequence of her son's ADHD:

“It was interesting because friends of mine would have known me as successful, very animated and I had a lot of energy and I had a great place in my social world and all of a sudden I had nothing. I had to shut a lot of what was my world out because I couldn't access it anymore...my self-esteem plummeted” (Mother of 7 year old boy)

Prioritising their child's well-being over new and existing romantic relationships was also commonly reported by parents in this study:

“It made me very wary of getting into a relationship with someone how they would deal with it and if they would be able to cope” (Mother of 11 year old boy)

3. Emotional Impact

The emotional impact on parents of children with ADHD was demonstrated in this study. All parents described a range of concerns and worries that they were regularly plagued with. One parent recounted her concerns about the future:

“It’s the behaviour wise that I am more concerned about because if there is nothing done about it now it could escalate to a lot more you know and that’s what I’d be afraid of” (Mother of 10 year old boy)

Despite investing considerable time and energy into their son’s well-being parents still worried about whether they were doing enough. In the words of one parent:

“That’s what I kind of worry about that we’re not doing the right things for him” (Mother of 10 year old boy)

Other concerns included concern about specific symptoms, concern about social and academic difficulties, concern about medication and concern about the transition to secondary school.

Such dedication to their child can leave parents feeling depressed and overwhelmed. One parent illustrated this when she said:

“You do get down, get really sad and when you think of it, [it] just seems like such a huge... it’s like a mountain in front of you sometimes”. (Mother of 11 year old boy)

Another parent spoke about how she found dealing with her son’s ADHD so challenging and all-encompassing that she neglected spending quality time with him:

“It wasn’t easy...it was very very difficult I used to spend more time crying at home on my own than enjoying spending time with him” (Mother of 11 year old boy)

Linked with these feelings of sadness parents reported feeling like they were dealing with their son's ADHD on their own. One parent commented:

“You really are on your own. You're on a desert island with no sand with no nothing”. (Mother of 7 year old boy)

Less commonly parents reported feeling anger and frustration as a result of their child's behaviour. One parent described losing control during confrontations with her son:

“He just would not say sorry and I was getting more annoyed...I lost control... there are times here he might be acting up pushing pushing pushing and I'd let a roar or sometimes I'd bang the sweeping brush or if I curse and say 'Shut the f*** up' and then he can be quiet and good...I don't know if he wants me to explode”. (Mother of 8 year old boy)

4. Ignorance and Discrimination

All parents spoke about the lack of understanding surrounding ADHD. For many parents in this study such ignorance was reportedly linked to misconceptions about the condition. One parent described the “unfairness” of being “pigeon-holed” as people make assumptions about children with ADHD and their parents. The lack of understanding, by family members, friends, schools, services, media, other parents and the general public, resulted in various experiences of prejudice and discrimination for parents in this study. One parent explained how people tend to shun those who are different:

“It's difficult for parents to accept their children in the present society. In present society if you have a child [with ADHD] ahh that's funny people stay away from them.” (Father of 7 year old boy)

This perceived prejudice resulted in many parents in this study becoming more and more isolated. Parents described losing friends because of their child's ADHD and being unable to turn to family members for the support they desperately needed. Schools and crèche's were also sources of discrimination for some parents. Complaints and allegations made by other parents were commonly experienced. Several parents reported being asked to remove their child from an early years setting or of their child being unfairly treated.

“The crèche had become increasingly frustrated with his behaviour and didn't want him a part of the group anymore...he also had an incident where his hands were tied on the chair so that was very distressing” (Mother of 7 year old boy)

Several parents also recounted how attempts were made to keep their child away from other children. One parent described how her child was not allowed to associate with another child because of his ADHD:

“She [teacher] had a word with a mother of one of the boys, [child's] best friend, and advised the mother not to let the son hang out with [child] anymore that he was having a negative effect on the child, that he was stressing him out” (Mother of 7 year old boy)

Another parent described how even when the school appeared to be doing its best to be supportive she still felt that her son's rights weren't being properly considered:

“He was behind a screen, they felt that he would be too stimulated by the classroom but again I felt that he was being isolated and... marginalised. We felt the teacher felt he was just in the way”. (Mother of 9 year old boy)

Linked with the general ignorance surrounding ADHD, the majority of parents in this study felt they were being blamed for their son's ADHD. Family members, school staff

and total strangers were all perceived as quick to “point the finger” at parents. In the words of one mother:

“I was told by somebody in the school...that I was a really bad parent...a lot of people just thought we were dreadful parents and it wasn't that at all but that's very hard to take...that's the hardest thing” (Mother of 9 year old boy)

This was linked to the notion that ADHD was not a real disorder and was in fact an excuse for poor parenting:

“Shortly after he got his assessment and I told [the principal] the outcome of it and ‘oh the usual, oh they have names for everything nowadays’, you know this kind of thing...like it's another name for being bold was what she meant” (Mother of 8 year old boy)

Prejudice and discrimination were also evident in one mother's description of what happened when she went to sign her other son up to playschool:

“Well the grilling I got and is [other son] affected by [ADHD] and I was thinking oh jai pers, you know I think [other son] will be guilty by association because of his brother, I'd say he will be up against difficult times” (Mother of 8 year old boy)

In order to deal with such stigmatising experiences several parents reported using the coping mechanisms of secrecy, withdrawal and education (Link et al. 1989). Some parents felt it was best to hide their child's diagnosis of ADHD from others in order to avoid their child being labelled. Another parent described how his wife's mother “would practically disown her” if she knew that their son was taking psycho-stimulant medication. Several parents reported avoiding situations where they were likely to meet other parents for fear of being judged. Others opted for the strategy of trying to explain

their child's behaviour to those around them. One parent described how she had enough of being blamed by her family and attempted to educate her family about ADHD:

“I got the appropriate documents from [ADHD support group] site and I just plonked them in the kitchen, I said read that because you obviously haven't, you're putting me through hell and I don't need that right now.” (Mother of 7 year old boy)

5. Inconsistency of structural supports for ADHD

Parents gave mixed reports of their experiences of structural supports for their children. Parents were keen to give praise to schools and services where praise was due, particularly in terms of individual teachers or doctors. However, for the most part parents expressed extreme dissatisfaction with the quality of services they and their child had received. One parent described feeling let down by what she perceived as the “farcical” nature of the services she had entrusted her son's psychological well-being to:

“You are relieved that you're in with people who you would think you can turn responsibility to... umm that has proven to date, I was totally wrong...there is no back-up there, there is absolutely no back-up whatsoever...they know so little about the brain.” (Mother of 7 year old boy)

The lengthy assessment and diagnostic process was also described as arduous for parents. One parent described herself as “lucky” having to wait six-months for her son's first appointment and eighteen months “from referral to diagnosis”. Other parents indicated that the services they received were dependent on where they were living. One parent even went so far as to move house in the hope that her son would be in a better position to access appropriate services. Another parent reported her frustration with the lack of any real conclusions or treatment plans coming from services, despite being in the system for four years:

“There’s a file about that thick and there is absolutely nothing that will make any sense because they’re all observations and they’re all, they haven’t concluded anything, they haven’t put anything in place, they haven’t looked for OT...”

(Mother of 7 year old boy)

Many parents recounted the sheer quantity of administrative duties that accompany the struggle to gain access to services for their son. One parent described it like a full-time job:

“And trying to get a diagnosis, there was a huge amount like it was full-time job dealing with you know all the stuff on the health side, this therapist that we were going through then trying to, going to the GP getting a referral desperately then trying to get the team in [service] to take him on, all the emails and faxes trying to do all of that and then dealing with the school....so I mean all of that was kind of a full-time job” (Mother of 7 year old boy)

The shortage of satisfactory supports was described by nearly all parents. As one parent commented, “there is not enough help in the right areas”. Parents wished for more behavioural therapy alongside practical advice on dealing with their son’s ADHD. Other parents reported little or no follow-up from services, including inadequate monitoring of medication; travelling long distances to access services; not being given enough one-to-one support; being dismissed as a priority; and not being offered any alternatives to medication as a treatment for ADHD. One parent commented on the transient nature of her contact with services in relation to son:

“They’ve kind of finished with us now I suppose you know in that we haven’t seen [service] in awhile. I hope they’re going to review [child] but I’m sure they’re very busy and you know I hope they’ll review him...[the psychologist] said they would probably do a review of [child] but I haven’t heard anything from them, I’m sure they’re very busy you know they have a lot of people to see”

(Mother of 7 year old boy)

On account of the limited supports available within the public system many parents explained that they were forced to seek private help. This however puts a significant financial strain on families. One parent referred to her son's need for additional therapies and expressed her dissatisfaction that these were not available for him in this country:

“In [service] they're not very good at all, I'm considering going back to getting speech and language...he's got domiciliary care allowance now but that's only 300 euro...I was reading this thing on the internet, an American family with a child with ADHD, they have four sessions of speech and language a week, they have two occupational therapy sessions...I brought [child] to an occupational therapist and the assessment cost 500 euro and I couldn't bring him to any session because I couldn't afford it so it was mental...I brought him to another speech and language specialist thing, it was a summer camp thing that was 1500 euro...it's very expensive and it's not something that is sustainable” (Mother of 7 year old boy)

Several parents reported that they had to fight for their child's right to basic services and in particular for special needs assistance in schools.

“You just have to learn about [your] child's rights and what [your] child is entitled to and keep fighting for them because you know school will make you feel like you're lucky to have a place for your child instead of you know your child has a right to be educated...sometimes you have to stand up for your child” (Mother of 8 year old boy)

Even where special needs assistance was in place parents expressed their dissatisfaction with what was on offer. One parent commented on how government cut-backs have affected her son's experience in school:

“[His special needs assistant] is there until two whereas he finishes at three, something to do with cutbacks or something, they were going to actually take his assistant off him...and have [another child’s] assistant dealing with both of them but what they did instead was they just cut his assistant’s hours back now in fairness it’s only one hour a day which is like five hours a week but within that hour, that’s the hour he writes down his homework, that’s the hour he has to put his books in his bags, that’s the hour you know where everything’s getting ready to go so a lot of things happen” (Mother of 7 year old boy)

Some of the parents in this study reported having no other choice but to consider special needs schools for their children. However, this was not necessarily an easy process either. One parent commented that “no one was queuing up to give us a place”. Another parent described how she “tormented” one principal with her persistent phone-calls, desperately hoping for a place in the school for her son. One parent described her feelings about sending her son to a particular special needs school:

“Initially we weren’t happy about it because [the special school] had a bad name...it has a name I suppose as a school for severe behavioural difficulties...and people from deprived homes...so initially I was not anxious to put him in but then I felt there was no other alternative and I was happy to have the school...we didn’t want [child] to go back to that school where it would only be two hours [of resource teaching] again and to be honest I think for [child] he needed to get out of it, his self-esteem was low and he wanted to get away from the memories of it” (Mother of 9 year old boy)

For those parents who did choose to send their son to a special needs school they reported experiencing great relief and support. One parent described how she immediately felt “at ease” having witnessed the knowledge and understanding of the principal. Another parent commented on how fortunate her son was to get a place in one of these schools:

“I was lucky because in the end at the very eleventh hour a place came up and I couldn’t believe somebody dropped out and that was just it otherwise God knows where he would be this year.... [child] is so happy there at the moment you know he loves it, says school is better than a theme park” (Mother of 7 year old boy)

Unfortunately such positive experiences may be short-lived as highlighted by one parent:

“That school is the best thing that’s ever happened to [child] but unfortunately they only take them for two, three years and then he has to go to another school...back to mainstream.” (Mother of 7 year old boy)

6. It’s Not All Bad

Despite the challenges associated with parenting a child with ADHD several parents in this study took an optimistic approach and aired their positive viewpoints too. One parent described how the relatively rare good times can compensate for the bad times:

“It’s actually living with insanity to be honest and yet there are moments... of very very precious moments... because he is literally so sensitive, so intuitive, so visual, you have this great sense of humour and there are great rewards when he actually achieves something”. (Mother of 7 year old boy)

Indeed all parents had something positive to say about their child with ADHD. The children of these parents were described as kind, caring, funny, individual and full of zest for life. Oftentimes this was in spite of the regular challenges they were forced to face. As one parent commented:

“He’s got a whole little eccentric and endearing side to him, he’s very beautiful and he’s very loving...he’s got a huge capacity for caring which is amazing considering all the stuff he’s had to go through” (Mother of 7 year old boy)

Other parents' thoughts reflected the need for a changing attitude towards ADHD. Indeed it was one parent's view that ADHD is a gift and it is only because of cultural ignorance that it is viewed as a disability in this country. In his words:

“It (ADHD) is a gift, it's a gift. There is unfortunately a problem with society not understanding it...the negative side of ADHD, which is the disability side, will only develop if the positive side is not developed or utilised” (Father of 7 year old boy)

Another parent commented that “nature has a balance and nature will work on areas” to highlight the fact that all children have strengths, even those with ADHD. In line with this optimistic outlook, many parents spoke about the benefits of focusing on their son's strengths in order to support their learning and development. One parent recognised her son's incredible capacity for knowledge about sport and put it to good use:

“I have incorporated football into geography you know countries in South America and countries in Europe and even now he had an exercise about learning the capitals of the EU so I tried to find a footballer from every capital...he's learning geography that way”. (Mother of 11 year old boy)

Other parents believed in their son's ability to do well in life so long as their unique skills were honed and developed:

“He would be very good with his hands; he is very kind of constructive he loves all that, so I would imagine if he gets the chance that he will do well.” (Mother of 10 year old boy)

Other parents referred to the many successful people, in the public eye, who have ADHD. For one parent this was a way to encourage her son's goals and build his confidence in his abilities:

“He [child] got this long list of people who have ADHD, he talks a lot about Michael Phelps who got eight gold medals in Beijing and he has ADHD...so he knows that some very big intelligent people have it...it seems to give him more confidence, if they did it I can do it”. (Mother of 9 year old boy)

Many parents in this study also took a no-nonsense, pro-active approach to dealing with their son’s ADHD. One parent commented that, “it’s not a problem unless it’s a problem” while another felt that it was “a loving attitude that you have to take to the ADHD”. Another parent described how she has learned to let go of any expectations for her son and to be happy that he is happy:

“I don’t think it’s the be all and end all if he’s going to do great in school, to me now the most important thing is that he actually maintains relationships with people in school and that he’s happy in school....sometimes when I look at his work I think oh my god how is he ever going to do [final secondary school exams], I have to kind of stop and think is he happy at the moment is he complaining about school, if he’s not complaining about school, if he’s not saying he has a headache or he feels sick going to school well then that’s kind of enough”. (Mother of 8 year old boy)

Finally, nearly all parents in this study reported that they had seen improvements in their son’s behaviour over the years. One parent recounted that:

“You can see the difference, this year he is after coming on leaps and bounds”.
(Mother of 10 year old boy)

Another parent expressed her optimism that things can only get better once you know that your child has ADHD:

“You’ll have your ups and downs but it will only get better”. (Mother of 10 year old boy)

Discussion

Findings from this study highlight the unique experiences of a group of parents of children with ADHD in Ireland. Being a parent of a son with ADHD is not an easy role according to parents in this study. These parents struggled to make sense of their son’s behaviour and to figure out their role in the appropriate handling of ADHD symptoms. All parents were challenged by the constant demands of their son’s need for attention and the intensity of the accompanying emotions. To make things more complicated parents were also faced with inadequate supports and services for themselves and their child. Parents also disclosed their experiences of prejudice and discrimination which they perceived as arising from a limited understanding of ADHD. Despite the pervasive challenges some parents adopted an optimistic and pro-active approach to the role they had been dealt with. For the most part these findings support conclusions drawn from previous research. The demanding nature of parenting a child with ADHD, the emotional distress associated with it, the experience of stigma and the limitations of services have all been acknowledged (Johnston & Mash 2001; Harborne, Wolpert & Clare 2004; Travell & Visser 2006; Firmin & Phillips 2009; Peters & Jackson 2009). However the more positive elements are much less likely to be documented in the literature. Only one study carried out by Perry, Hatton & Kendall (2005) briefly reported that most parents in their sample “maintained a sense of optimism and hope for the future” and were “careful to point out their child’s strengths”.

There were some limitations to the present study, which may have influenced the findings. First the small sample size means that findings cannot be generalised to a large

population of parents of children with ADHD. Nevertheless findings from this study may add to the growing body of literature on this topic, which is an essential aspect of qualitative research (Firmin & Phillips 2005). In addition, the analysis carried out in this study did not account for the variability of experiences associated with different subtypes of ADHD. Indeed parents' experiences may be quite different depending on the specific subtype their son was diagnosed with (Bauermeister et al. 2009). In fact, there was only one parent in this study who had a child with purely inattentive ADHD. This shortcoming may reflect the fact that parents of girls and parents of adolescents were not included in this study. This may be influential given that the inattentive subtype of ADHD is more commonly diagnosed in girls (Carr 2001) and in older children/adolescents (Selikowitz 2004). The presence of co-morbid disorders and other family stressors, which may have unduly influenced the findings of this study, were also not considered in this study. A final limitation of this study was that it included a self-selected sample and relied on retrospective accounts from parents. It is possible that parents who participated in this study may have had an agenda or may have been biased in the reporting of their experiences. Indeed, parents who often act as advocates for their children (Peters & Jackson 2009) may not see the point in talking about their positive experiences. On the other hand, it may be that the parents who have had particularly bad experiences were less inclined to participate in the research at all. The difficulties with recruitment may suggest a certain reluctance to share personal experiences. Indeed one parent who did participate commented that she did think it was a bit "strange" at first. The parents who did choose to take part then may be the ones who are managing pretty well and merely wish to help other families going through similar difficulties.

Aside from these limitations there were several strengths to this study. The qualitative methodology employed allowed the richness of parents' experiences to be revealed (Camic, Rhodes & Yardley 2003). Specifically the open-ended interview style allowed parents to raise issues that they felt were important aspects of their experience (Greig & Taylor 1999). This method also enabled interviewees to reject any interpretations made by the interviewer which did not make sense to them (Camic, Rhodes & Yardley 2003). This may be particularly empowering for parents of children with ADHD whose self-

efficacy is often diminished (Johnston & Mash 2001). Moreover this method allowed a broad exploration to be carried out with the researcher aiming to cover all aspects of these parents' experiences. As context and the meanings associated with context are important considerations in qualitative research (Hayes 1997) conducting interviews in the "real-life" setting of the family home, may also have enhanced the ecological validity of the study. The fact that the child's diagnosis was confirmed through the Conners' ADHD Rating Scale was also important. This offers greater assurance that the experiences reported in this study truly represent the experiences of parents of children with ADHD. It is possible that parents could claim to have a child with ADHD before an official diagnosis is made. Finally the chosen method of analysis was a particular strength of this study. Thematic analysis was deemed the most appropriate analytic method due to its flexible approach and its ability to glean a rich description of data while summarising the key features (Braun & Clarke 2006).

There are several practical applications and recommendations arising from the findings of this study. First, with parents of children with ADHD facing considerable stress and strain it is important that their needs are also taken care of. Given the bi-directional nature of the parent-child relationship (Bronfenbrenner 1979), if parents are not feeling supported the likelihood of their child feeling supported is also diminished. It would therefore be advisable to instigate a move towards a more family centred approach to the treatment of childhood ADHD. This would also include supports for siblings of children with ADHD who may also be at risk of emotional and behavioural problems (Listug, Zevenbergen & Petros 2008). Development for both parents and children occurs in context thus consideration needs to be given at all levels of the ecological system. Indeed the general lack of societal understanding about ADHD needs to be addressed in order to control the escalating stigmatising experiences of parents and children with ADHD (Gage & Wilson 2000). For example, new and existing teachers need to be given thorough training in the area of ADHD to ensure that all children receive the appropriate education that is their fundamental human right. Widespread efforts need to be initiated to take the blame off parents of children with ADHD and to create a more tolerant and non-judgemental atmosphere. The media which typically plays a negative role in the portrayal

of ADHD (Harpin 2005) also needs to make some radical changes, for example, by representing all sides of the ADHD debate. Indeed it may be time for a changing view of ADHD to extend across all communities and nations. Parents in this study highlighted the positive side of “difference” by looking to the individuality of their own child and focusing on his strengths. From an evolutionary perspective, typical ADHD characteristics such as high energy, lack of self-consciousness and heightened senses serve an adaptive purpose which ought not to be overlooked (Stolzer 2005). Thus it is our job to ensure that these children are enabled to make use of their unique strengths and are not forced to conform to society’s idea of appropriate childhood behaviour.

In conclusion, this study found that parents of children with ADHD have a unique parenting experience and have much to contribute to our understanding of this somewhat mysterious condition. Of course these findings reflect the experiences of just one small group of parents in Ireland and further research is required to investigate these issues more thoroughly. Nevertheless it would seem that parents’ thoughts and ideas need to be prioritised with changes at all levels of the ecological system being incorporated. For example, a campaign for greater public awareness and understanding of ADHD may radically alter the negative public perception of ADHD. The introduction of a more strengths-based approach to the education of children with ADHD may engage these children and do much to eliminate parent worries about their future. At a more basic level services need to step up the mark by developing a cohesive and consistent system which does not allow any child to fall by the wayside.

References

- Anastopoulos, A.D., D.C. Guevremont, T.L. Shelton, and G.J. DuPaul (1992). Parenting stress among families of children with attention deficit hyperactivity disorder. *Journal of Abnormal Child Psychology* 20: 503-520.
- Blew, H. and G. Kenny (2006). Attention deficit hyperactivity disorder: the current debate and neglected dimensions. *Journal of Child Health Care* 10, no.3: 251-263.
- Braun, V. and V. Clarke (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77-101.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press, Cambridge, Massachusetts and London, England.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology* 22 no. 6: 723-742.
- Brown, R.T. and J.N. Pacini (1989). Perceived family functioning, marital status, and depression in parents of boys with attention deficit hyperactivity disorder. *Journal of Learning Disabilities* 22 no.9: 581-587.
- Bull, C. and T. Whelan (2006). Parental schemata in the management of children with attention-deficit hyperactivity disorder. *Qualitative Health Research* 16 no.5: 664-678.
- Bussing, R. and F.A. Gary (2001). Practice guidelines and parental ADHD treatment evaluations: Friends or Foes. *Harvard Review of Psychiatry* 9: 223-233.
- Camic, P.M., J.E. Rhodes and L. Yardley (Eds.) (2003). *Qualitative research in*

- psychology: Expanding perspectives in methodology and design*. Washington DC: American Psychological Association.
- Carr, A. (2001). *Abnormal Psychology*. Psychology Press: Taylor Francis Group. Hove and New York.
- Charach, A., A. Skyba, L. Cook and B.J. Antle (2006). Using stimulant medication for children with ADHD: What do parents say? A brief report. *Journal of the Canadian Academy of Child and Adolescent Psychiatry* 15 no.2: 72-83.
- Conners, C.K. (2008). *Conners' 3rd Edition Manual*. Toronto, Ontario, Canada. Multi-Health Systems.
- Cunningham, E., B.B. Bennes and L.S. Siegel (1988). Family functioning, time allocation, and parental depression in the families of normal and ADDH children. *Journal of Clinical Child Psychology* 17 no.2: 169-177.
- Faraone, S.V., and J. Biederman (1997). Do attention deficit hyperactivity disorder and major depression share familial risk factors? *Journal of Nervous and Mental Disease* 185: 533-541.
- Faraone, S.V., J. Biederman and S. Milberger (1994). An exploratory study of ADHD among second degree relatives of ADHD children. *Biological Psychiatry* 35: 398-402.
- Firmin, M. and A. Phillips (2009). A qualitative analysis of families and children possessing diagnoses of ADHD. *Journal of Family Issues* 30 no.9: 1155-1174.
- Gage, J.D. and L.J. Wilson (2000). Acceptability of attention deficit hyperactivity disorder interventions: A comparison of parents. *Journal of Attention Disorders* 4 no.3: 174-182.
- Greig, A., and J. Taylor (1999). *Doing research with children*. London: Sage.
- Harborne, A., M. Wolpert and L. Clare (2004). Making sense of ADHD: A battle for understanding? Parents' views of their children being diagnosed with ADHD. *Clinical Child Psychology and Psychiatry* 9:327-338.
- Harrison, C. and K. Sofronoff (2002). ADHD and parental psychological distress: Role of demographics, child behavioural characteristics and parental cognitions. *Journal of the American Academy of Child and Adolescent Psychiatry* 41 no.6: 703-711.
- Hayes, N. (1997). *Doing qualitative analysis in psychology*. Hove: Psychology Press.

- Hoza, B., J.S. Owens, W.E. Pelham, J. Swanson, C.K. Conners, S.P. Hinshaw and L.E. Arnold (2000). Effect of parent cognitions on child treatment response in attention-deficit/hyperactivity disorder. *Journal of Abnormal Child Psychology* 28: 569-583.
- Hughes, L. (2007). The reality of living with AD/HD: children's concern about educational and medical support. *Emotional and Behavioural Difficulties* 12 no.1: 69-80.
- Jackson, D. and K. Peters (2008). Use of drug therapy in children with attention deficit hyperactivity disorder (ADHD): maternal views and experiences. *Journal of Clinical Nursing* 17: 2725-2732.
- Johnston, C. and E.J. Mash (2001). Families of children with attention-deficit/hyperactivity disorder: Review and recommendations of future research. *Clinical Child and Family Psychology Review* 4 no.3: 183-207.
- Kendall, J., M.C. Leo, N. Perrin and D. Hatton (2005). Service needs of families with children with ADHD. *Journal of Family Nursing* 11 no.3: 264-288.
- Kuczynski, L. and C.M. Parkin (2009). Pursuing a dialectical perspective on transaction: A social relational theory of micro family processes. In A. Sameroff (Ed.) *Transactional Processes in Development*, 247-268, APA.
- Link, B.G., F.T. Cullen, E. Struening, P.E. Shrout, B.P. Dohrenwend (1989). A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review* 54 no.3: 400-423.
- Listug, L., A.A. Zevenbergen and T.V. Petros (2008). Psychological symptomatology in siblings of children with ADHD. *Journal of Attention Disorders* 12 no.3: 239-247.
- Mash, E.J. and C. Johnston (1983). Parental perceptions of child behaviour problems, parenting self-esteem, and mothers' reported stress in younger and older hyperactive and normal children. *Journal of Consulting and Clinical Psychology* 51: 86-99.
- Norvilitis, J.M., M. Scime and J.S. Lee (2002). Courtesy stigma in mothers of children with Attention-Deficit/Hyperactivity Disorder: A preliminary investigation. *Journal of Attention Disorders* 6: 61-68.

- Paternite, C.E., J. Loney and M.A. Roberts (1996). A preliminary validation of subtypes of DSM IV attention deficit disorder with hyperactivity. *Journal of Abnormal Child Psychology* 23: 453-471.
- Perrin, S. and C.G. Last (1996). Relationship between ADHD and anxiety in boys: Results from a family study. *Journal of the American Academy of Child and Adolescent Psychiatry* 35: 988-996.
- Perry, C.E., D. Hatton and J. Kendall (2005). Latino parents' accounts of attention deficit hyperactivity disorder. *Journal of Transcultural Nursing* 16 no.4: 312-321.
- Peters, K. and D. Jackson (2009). Mothers' experiences of parenting a child with attention deficit hyperactivity disorder. *Journal of Advanced Nursing* 65 no.1: 62-71.
- Podolowski, C. and J.T. Nigg (2001). Parent stress and coping in relation to child ADHD severity and associated child disruptive behaviour problems. *Journal of Clinical Child Psychology* 30 no.4: 503-513.
- Polanczyk, G., M. Silva de Lima, B.L. Horta, J. Biederman and L.A. Rohde, (2007). The worldwide prevalence of ADHD: A systematic review and metaregression analysis. *American Journal of Psychiatry* 164 no.6: 942-948.
- Rucklidge, J.J. and B.J. Kaplan, (1997). Psychological functioning of women identified in adulthood with attention deficit/hyperactivity disorder. *Journal of Attention Disorders* 2: 167-176.
- Selikowitz, M. (2004). *ADHD: The Facts*. Oxford University Press, Oxford.
- Shelton, T.L., R.A. Barkely, C. Crosswait, M. Moorehouse, K. Fletcher, S. Barrett, L. Jenkins and L. Metevia (1998). Psychiatric and psychological morbidity as a function of adaptive disability in preschool children with aggressive and hyperactive impulsive inattentive behaviour. *Journal of Abnormal Child Psychology* 26: 475-494.
- Stolzer, J. (2005). ADHD in America: A bioecological analysis. *Ethical Human Psychology and Psychiatry* 7 no.1: 65-75)
- Taylor, E. (2009). Developing ADHD. *Journal of Child Psychology and Psychiatry* 50 no.1-2: 126-132.

- Travell, C. and J. Visser (2006). 'ADHD does bad stuff to you': young people's and parents' experiences and perceptions of attention deficit hyperactivity disorder (ADHD). *Emotional and Behavioural Difficulties* 11 no.3: 205-216.
- Wright, S.F. (1997). 'A little understood solution to a vaguely defined problem': parental perceptions of Ritalin. *Educational and Child Psychiatry* 14 no.1: 50-59.
- Xiang, Y., E.S.L. Luk, and K.Y.C. Lai (2009). Quality of life of parents of children with attention deficit hyperactivity disorder in Hong Kong. *Australian and New Zealand Journal of Psychiatry* 43: 731-738.