Use of drug therapy in children with attention deficit hyperactivity disorder (ADHD): maternal views and experiences

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Aims and objectives. The aim of this paper is to explore maternal views and experiences of stimulant pharmacotherapy in children with attention deficit hyperactivity disorder (ADHD).

Background. The very nature of ADHD means that it exists in a climate of scepticism and doubt. However, parents must make decisions about how to treat their children affected by ADHD. Of the treatments available, the use of stimulant therapy is the most controversial.

Design. Qualitative.

Method. Snowball sampling was used to recruit mothers (n = 11) of children with ADHD and a narrative-based qualitative methodology was used.

Results. Decisions around the use of stimulant medication for children with ADHD were difficult for these mothers. Detailed findings are presented under the themes of: Ambivalence and confusion: everybody would be down on me like a ton of bricks; Influence of the media: so much bad publicity; Deciding against medication: you’re changing their whole personality; and, Deciding for medication: he’s just been wonderful.

Conclusions. While these mothers revealed that they were discriminating in selecting information to guide their decision-making, many of their friends and family were influenced solely by media reports. Mothers experienced misgivings from family and friends who were sceptical about the need for medication and the implications and ethics of administering stimulant medication to children.

Relevance to clinical practice. Nurses and healthcare professionals have an important role in providing accurate and current information for parents and families and should be aware of the pressures parents are under when making decisions about treatments for their children with ADHD.

Key words: adolescents, attitudes, child behaviour, medication, mental illness, parenting

Accepted for publication: 5 April 2008

Introduction

Attention deficit hyperactivity disorder (ADHD) is the term used to describe a neuro-developmental condition characterised by ‘inattention, hyperactivity, impulsivity and distractibility which typically manifest as a loss of self-control, poor self-regulation and a deficit in inhibitory control’ (Taylor et al. 2006, p. 113). The condition is also associated with several secondary problems including mental health difficulties such as anxiety and depression, and conduct and learning disorders (Monastra et al. 2002). Though estimates of prevalence vary, it is thought to affect approximately 3–7% of children (Barkley 1997, Mattox & Harder 2007), with prevalence higher in boys than in girls (Singh 2004).
ADHD is considered a chronic condition in that it cannot be cured, but various interventions such as stimulant medication, behaviour modification, counselling, diet and dietary supplements can be used to manage symptoms. Of the available approaches, the use of stimulant therapy is the most contentious (Bussing & Gary 2001, Daley 2006). There are several concerns, including the ethical issues associated with long-term stimulant medication use in young children (Daley 2006), the nature of any short or long-term effects of such use (Bussing & Gary 2001) and a quite widely held belief that drugs are used as a means of control to benefit carers rather than children themselves (Taylor et al. 2006, McLeod et al. 2007). Furthermore, the willingness of parents to administer drugs such as Ritalin© to their children is also affected by a fear that they could cause serious health problems or criminal behaviour in later life (Bussing & Gary 2001). Because of these debates and concerns, there is a degree of stigma associated with the use of stimulant drugs for the treatment of ADHD (Bussing & Gary 2001) and parents are subject to criticism and censure over the use (or conversely, the non-use) of stimulant medication (Taylor et al. 2006, McLeod et al. 2007).

Views about what constitutes the appropriate treatment for ADHD are polarised. At one end of the spectrum are those who believe that stimulant medication is the most efficacious and appropriate treatment for ADHD while, at the other, are those who advocate various alternative approaches and who may also hold the belief that stimulant medication is over-prescribed (Taylor et al. 2006). The use of medication can reduce the severity of some behavioural problems, thus allowing children to engage more appropriately with those around them. However, it has been noted that behavioural problems are rarely completely resolved through pharmacotherapy (Whalen et al. 2006).

In the midst of the polarised debate are parents who must make decisions about how to treat their children affected by ADHD. Bussing and Gary (2001) assert that despite professional practice guidelines which promote the use of stimulant therapy for children with ADHD, parents have reservations about their use. They go on to say that this could be because parents get much of their information from the news media and while scientific discourses are replete with evidence as to the efficacy and benefits of stimulant therapy, parents may not have access to this material (Bussing & Gary 2001).

Decisions around whether to use medication as a treatment for ADHD are difficult for parents (Bussing & Gary 2001) and there is literature to suggest that parents move through several stages before making the decision to medicate children (Taylor et al. 2006). However, there are relatively few studies exploring parental views and experiences of the use of stimulant medication. Given the implications for children, of not being able to benefit from the most efficacious treatments, it is important that health professionals have a greater awareness of the experiences and concerns of mothers in relation to the use of stimulant medication for ADHD (Bussing & Gary 2001, Whalen et al. 2006, Leslie et al. 2007).

The study
This paper is drawn from a larger study which sought to illuminate the experiences and concerns of mothers of children with ADHD. The aim of this paper is to explore maternal concerns and experiences in relation to stimulant medication in children with ADHD.

Methodology
A narrative-based qualitative methodology was used. Initial participants were recruited by means of a media release and, thenceforth snowball sampling was used (Borbasi et al. 2004). Mothers of children with ADHD who expressed an interest in participating were e-mailed information regarding requirements for participation and a consent form. Information given to these mothers conveyed the voluntary nature of participation and explained that they could withdraw their consent at any time without penalty.

Conversational-style interviews lasting between one and two hours were conducted with 11 participants, aged between 30–60 years. Interviews with the women were held in a private area on one of several allocated university campuses. They were audio-taped and transcribed verbatim. Data were analysed thematically. Both researchers carefully read and re-read the interviews to identify themes and patterns in the data (Borbasi et al. 2004). Common themes were highlighted and statements and phrases that were most illustrative of participants’ collective experiences are presented in the findings (Van Manen 1990).

Participants
Eleven women agreed to participate in the study (Table 1).

Ethical considerations
Prior to recruitment, ethics approval was obtained from the relevant Institutional Ethics Committee (IEC). Principles of informed consent were used and pseudonyms were allocated to each participant to ensure confidentiality.
Rigour

Rigour was initially achieved by listening to recorded narratives while reading the transcripts and ensuring that data had been accurately transcribed. Additionally, team analysis was employed to ensure agreement in data interpretation among researchers, thus enhancing credibility (Koch 1994). Also contributing to the rigour of the study is the way the data has been presented, using direct quotes from participants. Presentation of the data in this way contributes to confirmability by leading the reader through the research process and demonstrating how interpretations were obtained (Koch 1994, Polit & Beck 2006).

Findings

The decision to medicate their child (or not) was one that these women made very carefully. All the mothers had a deep commitment to doing the best by their child and many expressed reservations about the use of daily medication. Though there was acceptance that the medications could bring some benefits, some of the mothers wondered at what cost these benefits came. Some worried that their children’s personality would be altered, while others feared that their child’s emotional development could be stunted by using medication. They experienced a degree of ambivalence that was further complicated by the confusing array of conflicting information from various sources. Though decisions around medication were not taken lightly, the mothers described a climate of scepticism and disbelief, resulting in their having to repeatedly defend their eventual decisions to family and friends. Detailed findings are presented under the themes of: Ambivalence and confusion: ‘everybody would be down on me like a ton of bricks’; Influence of the media: ‘so much bad publicity’; Deciding against medication: ‘you’re changing their whole personality’; and, Deciding for medication: ‘he’s just been wonderful’.

Ambivalence and confusion: ‘everybody would be down on me like a ton of bricks’

The decision to medicate their children was a difficult one for the women in this study. They were aware of strong community feelings about the use of stimulant medication for the treatment of ADHD, which was sometimes at odds with the information provided by health professionals and teachers, from whom some mothers felt pressure to use medication. The mothers themselves also had strong feelings about the use of medication:

I’m nowhere near ready to consider it as an option. But I think I’ve certainly moved in the two years to accept that there may be a point where we need to and I’m just doing everything in my power to avoid that… My mother and I get into very heated discussions about it because she thinks that he should be medicated. She’ll present me with all this evidence on how it is the only effective way of treating it. But it doesn’t treat it. It only works for the hours that they’re in school. So we have very different views on how it should be addressed. (Kristy)

Generally, the mothers did not view medication as being necessarily complementary to non-pharmaceutical interventions and viewed them quite separately. While mothers accepted that the medications could bring some benefits, several wanted to try other options such as dietary interventions before trying medication:

I think medication is a last resort or even just to control the behaviour while other strategies are put into place. That’s just my feelings on it. (Kristy)

I want to use medication as a last resort. I want to exhaust everything before I get to medication… (Simone)

Friends, family members, teachers and health professionals all had (often conflicting) opinions on medication for children with ADHD. On the one hand, some of the mothers described feeling almost constantly pressured to medicate their children and this pressure came from many directions:

The school wants him medicated. My mother wants him medicated. Doctors want him medicated. I think, at the end of the day, I am his mother. I need to make that decision for him. In my heart, I just – I don’t think it’s the right thing for him. (Kristy)

The decision not to medicate, in the face of so much pressure left Kristy out on a limb. Because of her stance against

<table>
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<th>Pseudonym</th>
<th>Family structure</th>
<th>Gender of child</th>
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<td>Diana</td>
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Table 1 Participants

medicating her child, she felt that her health professionals turned their back on her son:

The doctors would not have anything to do with him either, because they said that, if I am not going to medicate him, they cannot do anything more for him. (Kristy)

On the other hand, other mothers in the study experienced considerable pressure, particularly from family and friends not to medicate:

My father is a doctor and he doesn’t believe in anything that’s not a disease. He doesn’t believe in any syndrome or anything like that. He just doesn’t believe that they exist. So that’s sort of hard because he says ‘you don’t want to give those terrible strong medications’. So you know, if I was to give the medication and then there was some obscure side effect, then everybody would be down on me like a ton of bricks. (Susan)

This scepticism and disbelief in the existence of ADHD as a ‘real’ condition and/or that it could or should be treated with drugs was widespread among the family and friends of participants. This scepticism contributed to some mother’s reluctance to administer prescribed medication to their children:

I delayed for years and years and I’m sorry that I did, because if they told me that my child had epilepsy, I would have put him on whatever the epilepsy drug was, if they told me it was diabetes, I would have put him on insulin. But for some reason, because they said it was ADHD, I didn’t want to put him on Ritalin®. for some reason I couldn’t really explain. (Rhiannon)

The mix of scepticism and the confusing array of information caused some participants to wonder whether medication would actually benefit the child and family by resolving the problem. Parents were discriminating about the sources of their information and actively sought what they believed was reliable information to help them in their decision-making:

Most of the anti-Ritalin® articles were written by either journalists or people who had some connection with that thing called Church of XX on the one hand and the pro-Ritalin® articles were written by real doctors with real qualifications who worked in hospitals and universities. (Rhiannon)

Influence of the media: ‘so much bad publicity’

Overwhelmingly, participants referred to the very negative media reports and images of inadequate parents willfully drugging children to quieten them down and make them more compliant and manageable. These images were very persuasive and influenced some of the women’s choices and decisions about the use of medication:

It’s always in the media, like the Ritalin®, the drug use and the over prescription... I don’t even know if there is a case out there of people just drugging their kids to have them sit there. But it is, it’s very negative, very negative and it’s very hard for parents to actually see that sort of thing on the media, especially people that are medicating children and it’s probably one of the reasons why I haven’t – (Simone)

The women believed that many media reports of Ritalin® use were presented in relation to undesirable and even criminal behaviour. In the minds of these women, both children using Ritalin® and their parents were stigmatised through the media’s representation:

Well, it gets so much bad publicity. The ADHD kids are the ones that do all the bad things and any kid that does something bad, you know steals something, well he’s probably got ADHD and he’s probably on Ritalin®. That’s from the press it gets. You’d think Ritalin® was almost causing the ADHD and causing the bad behaviours...(Gail)

The women had also sought information from sources other than the popular media, such as parent and family support websites, scientific journals and from health and education professionals. They were aware of the difference between the representations of medication use within these separate discourses. However, participants acknowledged how the popular media still influenced their thoughts and feelings in relation to the use of medication:

Even though I’m an intelligent person … you kind of absorb what people say and what’s in the media. All that’s been in the media and what people say is all the negative stuff… that they are those out of control kids. They’re going to get hooked on this stuff; it makes them into zombies and all of these kinds of things. It’s all so not true. (Diana)

Reactions of family and friends were important in that they influenced whether participants felt validated (or not). However, these were also largely shaped by media reports. Participants felt that most people in their lives gleaned almost all of their knowledge and beliefs about medication in ADHD from the popular media and sensationalist current affairs shows:

Everyone’s first reaction is ‘oh, you be really careful with that, because it gets such bad press’. I guess, they’d never say anything good about Ritalin® in the press – it’s always bad – and yet, everyone I know who takes Ritalin®, only says good things about it. Anyway, my sister said this and ‘oh you know, be really careful with it’. (Gail)
Nevertheless, the media was useful in providing forums for informed debate and discussion about the use of medication in ADHD. Through investigative journalism of this nature, parents had the opportunity to hear the thoughts and views of current thinking from some specialists in the field. However, for some parents, this reinforced their ambivalence and confusion, because it revealed that even experts do not agree on what constitutes the best treatment approaches:

They had the debate on – about to medicate or not to medicate. That was very interesting. Even the leading doctors, they can’t agree on anything about whether they (children with ADHD) need medication, whether they don’t and what works and what doesn’t. (Kristy)

Deciding against medication: ‘you’re changing their whole personality’

Some of the parents had made the decision not to use medication. This was because of the concern that the medication could change the innate personhood of their child – that the child would somehow be altered:

It’s not just a medication say if you have a headache and you take a tablet to get rid of the headache. It’s not like diabetes where you take insulin and it fixes you – well not fixes you, but it treats your symptoms. But this was different. It actually changed their whole personality. You think, ‘what’s that doing to them’? To just not be themselves. (Kristy)

Some participants disclosed their personal view that medication was being used as a means of controlling children to make parenting them easier, rather than to benefit the child directly. Where this view was held, it was a deterrent to the use of medication:

I’d always felt that there’s a lot of kids being whacked on Ritalin® or anti depressant drugs or whatever mainly because people are struggling with managing behaviour as opposed to the children really needing it. (Peta)

Still other parents had tried medication, but decided not to continue with it because of side-effects or for other reasons. Fiona reported the drug having a paradoxical effect and exacerbating the problems for her child:

Just prior to starting preschool, the year before, we actually tried him on amphetamine. That didn’t work for him. It had the opposite effect. (Fiona)

Theresa had tried medication, but noted negative changes in her child:

He was medicated for about five weeks but it just shut him down. He was just like a zombie walking around, he looked like he was on LSD or something so we took him off that. The paediatrician wanted to try other – some other medication but he didn’t want to do that until he was eight. (Theresa)

Kristy had also tried the medication, albeit reluctantly, and only at the request of school staff. She felt pressured into it and was unable to articulate any benefits to her child. Her experience was very negative and she remained quite firmly opposed to the use of stimulant medication in children with ADHD:

The school wanted me to medicate him and I tried him on the medication… we tried him on the Dexamphetamine for six months… Then after he had all the scans done, the doctor said no, he needs Ritalin®. They wouldn’t do anything else with him, except for that. So then he tried Ritalin® for six months. The side-effects were just awful. So I took him off that again. That was my experience with the medication. (Kristy)

Deciding for medication: ‘he’s just been wonderful’

Those mothers whose children were on medication at the time of the study felt that they had made the right decision for their children. However, it had taken quite some time to arrive at the decision:

Over the course of last year, I guess I have become more open minded about it and I’ve got a lot more accurate information. I was not scared of having my son try the drugs. In fact, I would have felt like I wasn’t doing my job as a parent if I wouldn’t have tested it out… I think you have to try everything. (Diana)

Gail felt that her decision was made easier because of the positive attitude of her husband to medication:

Like I noticed a lot of the other mothers of children with ADHD say ‘oh no, we couldn’t do the Ritalin® trial, my husband wouldn’t let us.’ Whereas my husband, after he’d read the books and seen the video, he was happy to do a trial, because he’d seen the evidence and he thought well, it’s worth giving it a go, because it might be really good and you don’t want to deprive your children if this is going to really help them. (Gail)

In making her decision, Rhiannon felt it useful to discuss her concerns with other mothers of children with ADHD. She recalled one specific conversation she had with another mother, which she had found particularly useful in clarifying her thoughts in relation to the use of medication:

She said, ‘examine your motives. Are you doing it for him or are you doing it for yourself? I said, …’I’m not doing it… just to make the child stop jumping on the sofa. I’m doing it, if I do it, to help him be able to concentrate as well as a normal 14 year old boy concentrates.’ (Rhiannon).
These mothers were confident that they had made the right decision, were happy with its effects and were able to articulate clearly the benefits they thought medication had brought to their children:

He used to have these aggressive outbursts every now and then. He couldn’t really control them. He found it very difficult. But since he’s found the Ritalin®, he’s just been like an angel. He hasn’t had any of those outbursts that he used to have and it’s been wonderful … family life has just been a dream. (Gail)

Mothers described benefits in home, school and socially. Diana felt that her child was better able to reflect and begin to understand the consequences of his behaviour. She attributed this to use of medication:

He was starting to get so much negative feedback and when he’s taking his Ritalin® now, that’s stopped. He doesn’t get it all the time anymore. I think when he does get it, he can see maybe I did – you know he’s still a typical kid right – so maybe I did do that and I shouldn’t do that. As opposed to what, what happened? (Diana)

Generally, the decision to use medication was arrived at slowly and after considerable deliberation and research. Once the decision was made and despite taking a very thoughtful and considered approach to administering medication to their children, women reported continuing to attract negative comments and having to justify their positions:

We’ve had some really negative responses from people. I said to a friend of mine ‘oh you know we think he [son] might have ADHD’. The first words out of her mouth were ‘oh gee, what are you going to do about it? It was ‘I hope you’re not going to put him on drugs’. I just didn’t know what to say…(Diana)

**Discussion**

The difficulties these mothers experienced in making decisions about the best way to manage their child’s condition were fuelled by media portrayal and public perception that considers ADHD a ‘social’ disorder rather than a ‘legitimate’ medical condition. This conflict is also evident in previous studies by Taylor et al. (2006) and Harborne et al. (2004), where parents’ differing opinions to some health-care professionals, family members and general members of the community, regarding the basis of the disorder, was the source of significant distress. Also noteworthy is that, if ADHD is perceived to be a legitimate disorder, stimulant medication becomes acceptable as a treatment (McLeod et al. 2007).

In this current study, this conflict also contributed to a climate in which mothers experienced constant misgivings from those around them about the implications and ethics of administering stimulant medication to their children and scepticism about the need for medication in the first place. The mothers were placed into the position of having either to repeatedly defend and justify their decisions, or ignore the well-meaning but often misinformed comments of family and friends. The strong influence of parental social networks in decisions about the use of stimulant medication is noted in findings by Leslie et al. (2007), who found that they played a part in both persuading and deterring medication use.

The experiences of the mothers in this study resonate with findings by Hansen and Hansen (2006, p. 1272) who described parental experiences as a ‘flux of dilemmas’, in which parents consider the positive benefits in relation to the negative effects of the medication. These parents also experienced uncertainty in relation to the use of stimulant medication and were concerned with how children would manage if they decided to stop the treatment (Hansen & Hansen 2006). Similar to other studies (for example, Bussing & Gary 2001), this current study has revealed parental apprehension to administer stimulant medication. Hansen and Hansen (2006) also acknowledge the general reluctance and aversion to the use of medication and dos Reis et al. (2003) suggest that the reluctance to treat children with medication may stem from the media’s adverse portrayal of the drug. In this study, the media, along with the general stigma associated with these medications, were identified as contributing to the reluctance to medicate.

Furthermore, the uncertainty regarding appropriate treatments experienced by the mothers in this study, including the reluctance to medicate their children, was fed by media reports regarding over-use of medication by parents to control children’s behaviour. This resonates with findings in the study by Taylor et al. (2006) where parents felt accused of medicating their children purely for their own time out. Singh (2004) conducted a study of mothers of male children with ADHD and has commented on the dilemma mothers are faced with in relation to the use of stimulant medication and the idea that they could be medicating children as a way of enhancing their own lives:

When mothers are accused of using Ritalin as a quick-fix to make their own lives easier, they stand accused of violating a cherished ideal of the sacrificing mother: Good mothers sacrifice themselves for their sons, not the other way around. (Singh 2004, p. 1203)

She further explained that ‘the dialectic of maternal sacrifice and maternal preservation is an essential factor in the controversy over ADHD and Ritalin’ and that while maternal sacrifice is worthy and in keeping with views of ‘good’ mothering, maternal ‘self-preservation is not’ (Singh 2004, p. 1203).
However, those mothers in this study who had made and adhered to the decision to use medication were generally happy with its effects. This paralleled findings by both Singh (2004) and Hansen and Hansen (2006) who note that, in accepting biomedical causation and treatment, there is a ‘shift of blame, whereby the focus of blame is moved from the mother to the child’s brain’ (Hansen & Hansen 2006, p. 1281). Current literature suggests that acceptance of biomedical causation is an important factor in uptake and adherence to medication (Leslie et al. 2007, p. 183).

However, many of the mothers in this study were affected by the climate of scepticism that surrounds the very existence of the syndrome as a valid and legitimate medical condition. Because of this doubt, they struggled with accepting the need for medication. After all, if there is no legitimate disorder, how can the administration of such controversial medication to children be justified? This ambiguity in diagnosis is compounded because there is no diagnostic test that can definitively establish ADHD and this raises concerns about incorrect diagnosis (Concannon & Tang 2005). Bussing and Gary (2001) have previously noted that the absence of a definitive diagnostic test can cause parental reluctance to administer medication.

Notwithstanding its contested status, even where there is acceptance of ADHD as a legitimate medical condition, medication is perceived by the public to be the least favourable treatment for ADHD (McLeod et al. 2007). Some of the women in the current study shared these public perceptions and also viewed medication as the least favourable option. These women preferred (at least initially) to explore non-pharmaceutical treatment options such as dietary modification, dietary supplements, behavioural programmes and counselling. Leslie et al. (2007) also found that some parents initially preferred to adopt a non-pharmaceutical treatment regime and noted that for these parents, the decision to use medication ultimately arose as a result of reframing ADHD into a biomedical problem, outside influences, increased functional impairment or inadequate responses to non-pharmaceutical interventions.

Limitations

The method and self-selected nature of the sample means that findings are not able to be generalised. Furthermore, all mothers participating in this study were middle-class, culturally homogeneous women and none were affected by extreme poverty. Poverty and lack of resources limit the options people have to problem-solve their family difficulties. The perspectives of mothers affected by poverty or those from multi-cultural perspectives were not captured in this study.

Relevance to clinical practice

Decisions around the use of stimulant medication for children with ADHD are difficult for parents. Parents are faced with a barrage of (often conflicting) information about the nature, causes and possible treatments for ADHD. While these mothers revealed that they were discriminating in selecting information to guide their decision-making, many of their friends and family were influenced solely by media reports and so their decisions generated continuing negative comments from friends and family, meaning that they had repeatedly to justify their positions. Furthermore, the very nature of the disorder means that it exists in a climate of scepticism and doubt that can raise serious questions in parents, making them reluctant to medicate their children.

It is important that parents are able to access accurate information and have the opportunities to raise concerns and express their feelings of ambivalence and indecision. Nurses have an important role to play in the provision of accurate and current information to parents. It is also important for nurses to reflect on their own thoughts and feelings about ADHD, so that we do not (even inadvertently) contribute to the scepticism and doubt facing parents.

Contributions

Study design: DJ, KP; data collection and analysis: DJ, KP and manuscript preparation: DJ, KP.

References


