

Parents and GPs at cross-purposes over hyperactivity: a qualitative study of possible barriers to treatment

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SUMMARY

Background. Although childhood hyperactivity is a common, serious, and treatable disorder, most affected children in Britain do not receive effective treatment.

Aim. To investigate the views that parents and GPs hold about hyperactivity, and to explore how far these views, and clashes between these views, influence access to services.

Method. Qualitative study making use of semi-structured interviews with 10 general practitioners (GPs) and 29 parents of hyperactive children drawn from parents' groups, community services, and specialist clinics.

Results. The views of parents and GPs differed markedly. Parents generally saw severe hyperactivity as a long-lasting, biologically-based problem that needed treatment in its own right and that benefited from diagnosis. Most of the GPs were unsure whether hyperactivity was a medical disorder warranting a label and specific treatment, and often saw it as a passing phase related to family stresses. Parents worried that professionals would blame them for their child's problem, whereas many GPs saw the parent's tendency to medicalise as a way to avoid thinking about their own shortcomings in parenting.

Conclusion. Access to treatment was influenced by the views of parents and GPs, by the clashes between these views, and by each group's perceptions of the other group's beliefs. Clashes between the views of parents and GPs were particularly likely to lead to misunderstandings, dissatisfaction, and lack of access to effective help.

Keywords: hyperactivity; parents' views; general practitioners' views; barriers to treatment.

Introduction

THE empirical evidence suggests that, although hyperactivity disorders are common, serious, and treatable, they usually go untreated, at least in Britain.¹ Though the definition, and even the existence, of hyperactivity continues to be controversial, strictly defined hyperactivity disorders according to current psychiatric classifications affect approximately 1% to 2% of schoolchildren. These disorders are characterised by severe and persistent problems with restlessness, impulsiveness, and inattentiveness across a range of different settings; for example, both at home and at school. Common consequences include educational failure, behavioural problems, social isolation, and adjustment difficulties in adult life.¹ There is extensive scientific evidence that

hyperactive schoolchildren can derive considerable benefit from a range of interventions, including medication, diet, behavioural therapy, and educational support.^{1,2} Despite this, British studies suggest that hyperactive schoolchildren rarely receive any specialist help³ and that the minority who do are not necessarily the most severely affected.⁴

Parents and general practitioners (GPs) are key adults involved in recognising a child's hyperactivity and then initiating treatment or referral for specialist help. Their views are likely to play a key role in whether evidence-based treatments for this severe and common disorder are implemented or not. The present study is an anthropologically informed investigation of these adults' perceptions of hyperactivity as well as of their views of each other. Since clashes of perspective can have a negative impact on compliance, satisfaction, and use of health care resources,^{5,6} we anticipated that differences between parents' and professionals' views on hyperactivity would stand in the way of hyperactive children receiving evidence-based services.

Method

Qualitative investigations are particularly useful in investigating complex areas such as views or attitudes.⁷⁻⁹ Semi-structured interviews of about one to two hours duration were conducted with 10 GPs and the parents of 29 hyperactive children (19 where the mother only was interviewed, nine where both parents were interviewed together, and one where the parents were interviewed separately). All GPs and parents had volunteered to take part after hearing about the project; it was not possible to calculate participation rates since we do not know how many parents or GPs had heard about our study but chose not to volunteer.

Sampling was purposeful: recruitment of parents was designed to include a wide range of views about what hyperactivity meant rather than aiming for a representative sample.⁹ Thus, 10 patients came from a tertiary psychiatric referral centre; 10 were members of a hyperactivity support group that emphasised diet and complementary medicine; and the remaining nine patients had either been seen by community services, by the private sector, or by another parent support group that emphasised a more biomedical model. Although most (24/29) children had been diagnosed as suffering from hyperactivity, some were still waiting to see a specialist, and the formal inclusion criterion was the parental *belief* that their child was hyperactive.

The GPs who were interviewed all worked in central London surgeries. Many of them had academic appointments or a particular interest in children's services. It is likely that the participating GPs were better informed about, and more interested in, hyperactivity than the national average.

The semi-structured interviews asked informants for their views about hyperactivity, including the components of Kleinman's 'explanatory models';⁵ namely, aetiology, time and mode of onset of symptoms; pathophysiology; course of sickness; and treatment. Informants were encouraged to voice their views on their own areas of concern, even if they fell outside Kleinman's schema. Parents were also asked about their percep-

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tions of GPs' views, and vice versa.

Interviews were audiotaped and content transcribed; i.e. they were transcribed omitting repetitions and fillers such as 'erm'. All views were subsequently included in the coding process, and much of the data presented in this paper derives from information that could not easily be accommodated by Kleinman's categories.

Data transcription and content analysis followed the procedures of grounded hermeneutic research.¹⁰ Although Kleinman's five headings formed the starting point for data analysis, the coding process remained flexible and data were reanalysed and regrouped by both authors until categories emerged that best fitted the informants' statements. Thus, rather than imposing an *a priori* structure on the data, coding categories were developed during the course of the analysis. Informants discussed a number of issues including the definition of hyperactivity, treatment options, and sources of information. These data, including a full description of the methodology, are described elsewhere.¹¹ We identified six frequently mentioned themes that seemed related to the pattern of service use, and these form the basis for this paper. Three of them showed significant clashes of parents' and doctors' attitudes. Not surprisingly, the different themes overlap and the distinctions are sometimes arbitrary.

Results

Common themes

Theme 1: Hyperactivity — a medical disorder? Whether they preferred standard or complementary approaches, parents tended to see hyperactivity as a medical rather than as a psychological problem. Although some of them, especially fathers, avoided terms like 'illness', they still felt strongly that there was something wrong in the child's make-up. Especially when children were receiving medication, parents tended to employ medical language to describe their child's problem:

'It's a chemical imbalance; it's this dopamine that is missing; his body doesn't make enough of it. It's like with diabetes, it's genetic.'

Whereas parents from the specialist psychiatric clinic emphasised a dysfunction of brain chemicals, parents from the support group that emphasised diet tended to see hyperactivity as part of a wider medical problem, associated with allergies, bowel problems, or proneness to infection. Regardless of which group they were drawn from, parents rarely believed in a fully environmental or dietary cause of the difficulties, but emphasised that the child's constitution was important:

'If we all drink alcohol, we are all going to get drunk and fall over, but, if children have cola, only some are affected and others aren't.'

Parents often felt that professionals did not believe in hyperactivity as a medical problem, and many of them had experienced either blame or dismissal:

'You see, no one understands, no one believes you. It's like smashing your head against a brick wall.'

The GPs' own comments seemed to confirm this view. Most were unsure about the boundary between normality and abnormality and were struck by the social and cultural variation of acceptable behaviours:

'Some parents complain and their child concentrates well, other children cause havoc and their parents don't seem to mind.'

Referral for specialist help was more often determined by the parents' persistence or inability to cope than by a systematic assessment of the child's symptoms. Only two of the 10 GPs believed strongly in hyperactivity as a medical disorder: both had relatives or friends whose children had been diagnosed and treated for hyperactivity. This personal experience persuaded one GP that family factors were not the whole story because he '...knew there was nothing wrong with the parenting in that case', and convinced the other that hyperactivity is 'a real disorder that could benefit from treatment rather than from being swept under the carpet'.

Theme 2: Labelling — disabling or enabling? Although parents and GPs saw that labelling had advantages (e.g. extra help at school) as well as disadvantages (e.g. stigmatisation or creating a self-fulfilling prophecy), their overall views on labelling differed considerably. For most parents, getting a diagnosis was a very positive experience:

'I felt very, very happy that there was a name, that I hadn't been imagining things, that I didn't have a monster, that there was a reason for his behaviour. It answered so many things, it put so many things I had always worried about into one little box. It was like a big weight lifted off my shoulder ... it just takes the pressure away.'

A label often relieved parents of a disabling sense of guilt and provided them with access to relevant reading material, self-help groups, and expert help. Some parents mentioned that, prior to receiving a medical label, their children had already been labelled non-medically.

'At school he was labelled as 'lazy' because of his handwriting.'

'If you are labelling the child as 'naughty' or as a 'problem child', you are just dumping guilt on the parents.'

According to the parents, realising that the child was not just being 'naughty' commonly led to improved parent-child relationships, and parents felt they could have avoided many mistakes, especially blaming or punishing the child, if they had known about hyperactivity earlier. One parent, who had previously resisted going to parenting classes, was happy to accept advice on parenting once the child had a hyperactivity label, since she then wanted to learn strategies for dealing with 'this ultra-specialised job of bringing up this special child'.

Despite the fact that some parents found it difficult to accept that their child was suffering from a chronic problem that was not likely to disappear, half of them felt that the diagnosis was the biggest help they had experienced; the other half felt more critical towards labels but still thought the advantages clearly outweighed any disadvantages. Parents' attitudes towards labels did not differ substantially depending on which parents' group they were recruited from or according to their preference for complementary therapies; all were keen on a clear diagnosis. Commonly, parents felt that professionals were against labels, trying either to normalise the child's behaviour or to demedicalise the problem.

This perception of professionals' views may well have been correct, since seven of the 10 GPs interviewed felt that labelling hyperactive children did more harm than good. Most of them were not against labelling in general, seeing labels as helpful when they identified a clear group of patients for whom a specific and beneficial treatment was available. As they tended to see hyperactivity as 'an artificial, ill-defined, and overused category' without useful treatments, they generally avoided labelling

hyperactive children. Many GPs felt that parents' views of hyperactivity as a medical problem were an attempt to avoid dealing with possible shortcomings in their parenting:

'They [parents] need to learn to help their child to concentrate, give the right input, the right kind of stimulation ... The label just distracts from the issue, externalises the problem. It does not particularly empower the child but tends to disempower it.'

Only three GPs felt a label of hyperactivity was generally helpful to parents and children, as it relieved families from stress, gave access to help, and encouraged families to get on with solving their problems.

Theme 3: Family dysfunction — cause or effect of the child's hyperactivity? Parents and GPs emphasised that hyperactivity was often associated with family or social stresses. GPs were aware that living with a hyperactive child could be very stressful, especially for families living in overcrowded areas with little space to play and let off steam. However, they tended to emphasise the view that family dysfunction could either lead to problem behaviour in the child or to the presentation of the child on behalf of a dysfunctional family. Therefore they frequently felt that, if parents were unable to set boundaries, the child might behave in a hyperactive way, or that, if a mother were depressed, she might not be able to cope with normal boisterous behaviour, interpreting it as hyperactive. Consequently, most GPs saw hyperactivity predominantly as an effect of a dysfunctional family. A frequent approach was to treat the adults before considering the diagnosis of hyperactivity (particularly since they knew more about adult disorders than about childhood hyperactivity).

Parents often emphasised that family stresses were effects not causes of their child's hyperactivity. Looking after a hyperactive child was described as extremely tiring, as parents always had to be prepared for dangerous or destructive behaviour.

'He was such a handful that I had a breakdown because I didn't know where to go, what to do with this child. My house was like a war zone.'

Parents were sometimes worn out by lack of sleep and often felt socially isolated because their child's behaviour was unacceptable to friends and family. Marital problems were common, with partners blaming each other and being unable to agree on how best to deal with the child. Sometimes husbands spent as much time as possible away from the chaos at home. Feelings of depression, anxiety, and anger were common. Parents often perceived their anger as potentially dangerous:

'This is when you get battered babies, if you have a hyperactive child and nobody believes you.'

Almost all mothers had gone through periods where they felt extremely guilty about their child:

'A lot of the time you think it's something you have done or not done ... I felt very guilty. I never felt very warm to him, maternal work was so hard.'

Despite these frequent family stresses and guilt feelings, parents commonly took it amiss if they perceived professionals to be focusing, not on the child's hyperactivity, but on parental mental health, marital friction, or general family functioning. This not only influenced their willingness to share information with professionals, but also sometimes had serious implications for treatment decisions. Thus, one mother who had waited for a long time to see a specialist was thinking of turning down the appoint-

ment because she had received a questionnaire that focused on the family. This had reactivated her fear that her concerns for the child would be prematurely dismissed and that she and her family would be blamed.

Other themes related to service use. Parents and GPs commonly talked about the time course of hyperactivity, and when help and services were most needed. They agreed that hyperactivity generally started in the pre-school years, and felt that not enough specialist help was available for this age group. GPs were often not aware of specialist help available for hyperactive school-age children. Parents reported that they first approached their GPs in the pre-school years. In some instances, their GPs' attempts to reassure them at this stage, or to give parenting advice, made them feel rebuked and not taken seriously. This often stood in the way of presenting again when the problem persisted into the school years.

Parents and GPs felt that information on hyperactivity was often conflicting and ambiguous. Both groups used a variety of information sources, including the media, the Internet, and scientific articles. The differences between the broader American concept of attention deficit hyperactivity disorder and the narrower European concept of hyperkinesis caused particular confusion. Parents felt that GPs were often badly informed and that it was largely a matter of chance whether they received useful help and information. Many GPs also felt that they had not had sufficient undergraduate or postgraduate training in the assessment and treatment of hyperactivity:

'You have to learn all about these diseases that have a prevalence of about one in a million, and this relatively common problem is hardly mentioned.'

Parents and GPs felt they lacked the specialist backup services they needed. GPs were commonly not certain who to refer to and complained about vague, long, and unhelpful letters from specialists. Parents felt that there were too few specialists and that their waiting lists were too long. The diagnostic process from the time parents first approached their GP until the time a diagnosis was made ranged from nine months to five years. Rapid referral and diagnosis was often linked to parental persistence or inability to cope, rather than to the severity of the hyperactivity.

Discussion

Parents and GPs saw hyperactivity from different perspectives. While both groups had a coherent picture of the disorder, which made sense in the context of their own experience, our findings suggest that clashes between their views formed barriers to effective treatment.

Parents, especially mothers, felt under an enormous pressure because of their hyperactive children. Not only did they suffer the stress of looking after their difficult child, but the misbehaviour of the child often reflected badly on them, and all mothers had felt guilty and said they had been blamed by friends or relatives. Asking for professional help in this situation was not always easy, and parents were often oversensitive, especially as they perceived professionals as likely to disbelieve or blame them. Although many parents believed in complementary treatment methods for hyperactivity, their main concern was that the disorder should be recognised, and their belief in complementary medicine did not deter them from seeking help from their GP. Nevertheless, their explanatory models did affect treatment decisions: perceived incongruities with professionals' views seemed to influence whether they gave full histories, kept appointments, or complied with treatment.

General practitioners had relatively little experience of hyperactivity and saw the problem in the context of a larger group of troublesome children. For many of these children, parenting advice, family work, or treatment of parental depression can be reasonable and effective strategies. However, for children with severe hyperactivity, more specific treatments are available, and epidemiological data show that most British children are currently deprived of these treatments.³ GPs worried that parents' views of hyperactivity as a medical problem could lead to the child being made a scapegoat and could prevent family changes. However, by emphasising parenting and family factors, they fed into parents' beliefs that they were going to be blamed, thus alienating parents and causing further polarisation between parents and professionals.

Our conclusions are necessarily tentative, as the sample of parents and GPs was relatively small and their views and experiences may have been unrepresentative. In particular, our sampling strategy would have excluded children with similar problems who had not been conceptualised as hyperactive or who had been helped to grow out of such problems by GPs' accurate reassurances. The study was also limited by the fact we arrived at the coding categories conjointly rather than independently. Although we feel that the categories fit informants' accounts very closely, themes overlap, and other researchers might have arrived at slightly different categories. Nevertheless, our findings suggest that incongruencies between parents' and practitioners' views, especially with regard to medicalisation, labelling, and causation of hyperactivity, contribute to problems in service use.

How could services be improved without incurring the opposite risk of over-diagnosis, scapegoating, and needless medication? Drawing from our findings, we suggest some changes that could be evaluated in quantitative studies. An important point is that the exploration of the families' explanatory models, including their views about professionals, should become a routine part of the assessment of children with behavioural problems, as it not only helps to establish rapport, but also clarifies expectations, fears, and possible misunderstandings. To help GPs to differentiate between hyperactive and conduct disordered children, we suggest the use of simple screening methods at home and school.¹² Furthermore, it seems important to help the parents of young children by providing simple management strategies while also encouraging them to return if problems have not resolved by the time the children reach school age. Finally, during the assessment, professionals need to bear in mind that family stresses can be effects as well as causes of the child's symptoms.

The fact that evidence-based treatments of hyperactivity currently only reach a very small proportion of affected children, cannot be explained solely in terms of GPs' and parents' attitudes; parental initiative and local resources also play key roles. The study suggests enormous inconsistencies with regard to pathways to care. This needs further epidemiological and quantitative exploration. Part of the problem seems to be confusion about the roles of secondary services, and further qualitative studies might show that a mismatch of models *between* professionals could add to the problems. Only empirical testing can establish whether our own culture-bound views as child psychiatrists have any validity. As one GP commented to us:

'You psychiatrists are absolutely mad about labels, exact definitions and things like that. I see it as an attempt to add structure to something that is actually very difficult to add structure to.'

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