

Quality improvement report

Implementing NICE guidelines: a group for parents of children with attention deficit hyperactivity disorder (ADHD)

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Introduction

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder in which there are severe problems with maintaining attention, poor impulse control, and hyperactivity. The symptoms must have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level and the impairment must be present in two or more settings.¹

The main form of treatment involves taking stimulant medication, in particular methylphenidate (Ritalin). Due to recent concerns with use of this medication, the National Institute for Clinical Excellence (NICE) produced a document giving guidelines for usage of stimulant medication.² The main message from the document was the recommendation of methylphenidate as part of a comprehensive treatment programme for children with ADHD. This included behavioural management and support to exhausted parents. As part of our clinical governance policy we were keen to adopt the NICE guidelines and also involve parents in partnership in determining the structure of the service offered. We therefore set up a pilot semi-structured support group in one of our clinics.

Method

Twelve parents of children with ADHD attending the Dunstable Child and Adolescent Mental Health Service (CAMHS) were invited to attend a pilot group. Five mothers agreed to participate. Two clinicians and a clinical psychologist in training facilitated the group. It ran for six weekly sessions each lasting two hours. In the first session, we asked group members what problem areas they would like help with. We then taught psychological techniques related to dealing with the problems originally raised. This took place in the first half of each session. The second half consisted of unstructured general discussion amongst group members.

Prior to, and on finishing the group, parents were asked to complete the Parent Stress Index (PSI) questionnaire and the Conners Parent Rating Scale – short form which gives a measure of the child's ADHD symptoms.^{3,4}

In one of the sessions, we invited two members of the Milton Keynes ADHD Family Support Group to give a brief talk on their organisation and general support.

Results

Quantitative evaluation

As expected there were no real significant changes in the pre- and post-ADHD scores on the Conners Parent Rating Scale.

Although PSI scores came down in four of the five parents, these scores still remained above clinically significant cut-off levels for abnormal stress.

Qualitative evaluation

All participating parents said that they had found the group beneficial.

The therapeutic factors that parents felt were important included learning from observation of other parents, ability to express how one was feeling, realising that one is not alone and obtaining practical advice on dealing with ADHD.

Parents also said it was helpful having therapists co-running the group and one particular parent suggested that therapists could learn from parents' 'real-life' experiences.

Discussion

Our group was an attempt to implement recommendations made in the document, *Guidance on the Use of Methylphenidate in Children*.² We had also felt that it was important to offer parents behavioural management, which had been shown to be effective in conjunction with medication.⁵ Some children with ADHD do not respond to medication and others may not be able to take it due to side-effects. We thus feel that in these circumstances parents should have access to non-drug treatment.

In our group we asked parents what they specifically would like help with and their answers formed the basis of the material and content covered in the group. This was in line with recent government NHS documents emphasising the need for patients to have a say in how and what services are offered.⁶ Parents commented that they felt they had part ownership of the group since they were the ones who set the agenda.

We were struck by the huge amount of stress and the emotional impact of being a parent of a child with ADHD. This was reflected in the high PSI scores before and after the group although the majority of parents felt less stressed than when they started the group. It is unlikely that health-related services alone can address the problems that these parents and

families face. We involved the local ADHD volunteers' group as we had felt that it was important for parents to hear about other sources of support and help. Local support networks can often provide much needed support and practical advice independent of health professionals.⁷

We were aware that none of the fathers had attended the sessions. Problems with taking time off work were cited as the main reason why fathers could not attend the group. Since behavioural management works best when there is a consistent approach by both parents, we feel it is important that fathers are encouraged to attend the group. One possible solution would be to hold evening groups for fathers.

Criticisms of new services and clinical projects have been the fact that when patients are directly asked about the new services, their opinions are often not wanted or are inconvenient for the target population.⁸ Our anonymous questionnaire specifically asked group members if they felt the group had been useful and also for their thoughts for a future group. All said they had found the group beneficial and all said that they would like to attend another similar group with very few changes needed.

Conclusions

A semi-structured group is a useful way of providing behavioural therapy and much needed support to parents of children with ADHD. These groups should run in parallel with medical clinics providing medication for ADHD.

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