

Young People's Experience of ADHD and Stimulant Medication: A Qualitative Study for the NICE Guideline

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Background: The NICE ADHD Guideline Group found a lack of research evidence on young people's experiences with stimulant medications. The present study was commissioned to help fill this gap in the evidence base and to inform the Guideline. **Method:** Focus groups and 1:1 interviews with 16 UK young people with ADHD. **Results:** Young people were positive about taking medication, feeling that it reduced their disruptive behaviour and improved their peer relationships. Young people experienced stigma but this was related more to their symptomatic behaviours than to stimulant drug medication. **Conclusions:** The study's findings helped to inform the NICE guideline on ADHD by providing evidence that young people's experiences of medication were in general more positive than negative. All NICE Guidelines involving recommendations for the treatment of young people should draw on research evidence of young people's experiences of treatments.

Key Practitioner Message:

- Young people who are already taking stimulant medication are more positive about medication than about other interventions
- Young people are more likely to be aware of a positive impact of medication in their social relationships than in other areas such as academic performance
- Young people's experiences of bullying are more often connected to their ADHD behaviours than to taking tablets.
- Close friendships are important to young people with ADHD and are sometimes used to protect them from bullying and in other difficult situations
- Young people with ADHD believe that physical activity is helpful to them and of those activities sports (especially boxing) are most helpful

Keywords: Attention Deficit/Hyperactivity Disorder; ADHD; Stimulants; Methylphenidate

Introduction

In the UK and the US there has been an exponential rise in the number of young people diagnosed with ADHD, as indicated by the increase in numbers of young people being prescribed medication for the condition: an increase from 0.5/1000 to 3/1000 over the last 30 years in the UK and 12/1000 to 35/1000 over the same period in the US (Olfson et al., 2003). While the benefits of medication are well-recognised in the treatment of ADHD, concerns have also been raised about excessive use of stimulants and unknown side effects of long-term use of stimulants

by young people (Kutcher et al., 2004; DuPaul & Barkley, 1990).

The NICE guideline on the diagnosis and management of attention deficit hyperactivity disorder (ADHD) in young people and adults (NICE, 2008) made recommendations covering a wide range of topics including medication, parent-training programmes, psychological treatments for young people, interventions in the classroom, diet and the validity of the diagnosis. However, unsurprisingly, the use of methylphenidate elicited the most attention from the British media (for example, Boseley, 2008; Clout, 2008; Laurance, 2008; MacRae, 2008).

Young people are primary consumers of stimulant drugs but the necessity of these drugs is determined by adults. In developing the NICE guideline the full range of existing research regarding methylphenidate was identified and analysed, including studies of efficacy, effectiveness and side effects, as well as the experiences of parents of children with ADHD. However, there is very little research documenting young people's own experiences with stimulant drugs (McNeal et al., 2000; Kendall et al., 2003; Meaux et al., 2006).

Because the NICE guideline development group (GDG) was concerned with the absence of evidence about the experience of young people taking stimulant medication, NICE took the unusual step of commissioning a brief primary qualitative study to supplement the evidence searches and analyses.

Methods

Study design

The researchers convened focus groups to explore the perceptions of, knowledge about and attitudes towards stimulant medication of young people with ADHD. The diagnostic process, the experience of having ADHD and the use of other interventions were also considered. Some of the young people were unable to attend the focus groups or preferred to be interviewed individually and were interviewed on a one-to-one basis. Within the format of the focus groups and interviews, a topic guide that included semi-structured questions, games and a vignette were used.

Ethical approval was obtained from the UCLH-A research ethics committee and from local R&D committees. Human subjects consent and assent was obtained from all participants and legal guardians.

Sampling

Purposeful sampling was undertaken to achieve a heterogeneous group of young people who met the inclusion criteria. Young people were approached by clinicians at three hospitals (two in London and one in Nottingham). Of 20 young people approached, 16 of those (14 boys and 2 girls) aged between 9 and 14 agreed to participate in the study. All were identified as suitable candidates by consultant psychiatrists collaborating in the study, based on age at the time of recruitment (9 to 14 years), primary diagnosis (of ADHD), treatment (with stimulant medication¹) and IQ (above 80). All young people were white-British, except for one child who was British of middle-eastern descent. Eleven young people had a parent in class III occupations (skilled manual and non-manual positions); two had a parent in class II occupations (managerial/technical); and two had a parent in class I occupations (professional positions). One parent was unemployed at the time of the study.

The age range, 9–14, for participants in this study was decided on the basis that it was important to obtain the views of young people through the period of middle childhood to the onset of adolescence during which time the initial diagnosis of ADHD is usually made, and

stimulant treatment is initiated. We did not include young people older than 14 because adolescence is normally a time of significant experimentation and identity conflict which can lead to a shift in views about medication and problems with compliance. It was felt therefore that proper assessment of the adolescent experience of stimulant medications would require a separate set of research methods and analyses. Indeed, the unique aspects of adolescent experiences of stimulant medication were represented by the oldest participants in this study. Further research focusing on adolescent experiences of stimulant medication is much needed.

Young people in this study had a primary diagnosis of ADHD, and young people with documented severe co-morbidities were excluded due to the desire to de-limit heterogeneity within this small sample of young people. Several parents reported that their children had learning difficulties, two young people reported significant problems with aggression, and two mothers reported that their children exhibited high anxiety levels.

14 out of 16 young people had prescriptions for Concerta 18 mg or 36 mg on a daily basis. The remaining two young people had prescriptions for a short acting stimulant, which they took 2–3 times a day in 10 mg or 5 mg doses. Two of the young people prescribed Concerta also had prescriptions for short acting stimulants, which were used occasionally to 'top up' when Concerta appeared to be wearing off. Length of time on medication among young people in this study ranged from several months to 5 years.

Topic guide development and data collection

Because of the specific requirements of the ADHD GDG and the relatively brief timescale for the research, topic guide development was informed by the 'framework approach' (Ritchie & Spencer, 1993). IS discussed the specific research questions with the ADHD GDG and then drew on her extensive research with this group of young people to develop a list of questions and tasks that would both address the research questions and engage the participants. The construction of the topic guide and the length of the focus groups and interviews were determined by this population's capacity to focus and attend, particularly in a social context. The use of questions, games and a vignette is similar to the approach used by IS in previous qualitative research with young people (Singh, 2007a).

IS conducted focus groups and interviews in a conversational style. The first half of the topic guide included a standard set of broad open-ended questions followed by more specific probe questions about the young people's understanding of how stimulant medication did or did not help their behaviours, experiences of stigma and the impact of the medication on their perceptions of personal agency. Issues around their diagnosis and non-pharmacological interventions for ADHD were also peripherally explored.

The second part of the topic guide consisted of games and a vignette designed to place young people's perceptions of drugs within their perceptions or experiences of other means to improve behaviour and to elicit their ideas about resources that could help them have more positive experiences of ADHD diagnosis and medication.

¹Those taking atomoxetine were excluded.

The focus groups took place at hospital clinics and lasted approximately 1 hour. Thirteen of the young people took part in the focus groups (in three groups of three, five and five). The researchers attended to the balance of young people's ages and gender in the groups so that all of the young people felt empowered to speak. The three remaining young people were interviewed in the clinical setting one-to-one. Written assent and consent were obtained from the participant and from one parent. Parents were also asked to complete a basic demographic questionnaire.

Data processing and analysis

All interviews were digitally recorded, transcribed and analysed using qualitative coding practices that meet established criteria of validity and relevance to qualitative health research (Pope et al., 2000; Miles & Huberman, 1984). In keeping with the framework approach (Ritchie & Spencer, 1993), the analytic process was more deductive than inductive. However, the process of interpretation was informed by both the research objectives and the themes that emerged spontaneously in the data. A coding frame was drawn up by IS, which responded explicitly to the pre-set aims and objectives of the project, and was validated in a coding team of three researchers. The coding team applied the same codes to two transcripts in order to discuss the code definition and categories and to refine the individual codes. Transcript excerpts elucidated the codes. The team agreed on the validity of a majority of codes. This process captured the data on two analytic levels: single concepts were coded first, then these concepts were grouped together under higher order themes. Systematic coding meant that it was possible to code at both the individual and the group level. Group-level data were excerpted and analysed separately to follow the meanings and dynamics of the interchange among participants. The frequency with which concepts and themes were spontaneously expressed by group members was noted, alongside the emotional intensity and valence expressed by group members and the time spent on themes. This allowed for an assessment of the relative salience of concepts and themes for the group.²

Results

Perception of the impact of medication

Young people identified a number of ways in which their medication helped them (see Figure 1) and medication was discussed primarily in terms of its impact on social behaviour, rather than on school work and school-

Concentration	Writing
Impulsiveness	Reading
Physical aggression	Maths
Peer relationships	Homework
Relationship with teacher	Behaviour towards teacher
Performance on tests and school marks	Self-confidence
Relationship with parents and siblings	Self-esteem

Figure 1: Areas in which medication helps

related functioning. The positive effects of medication (helping them to calm down, think first before acting out and not to feel angry) were reported most clearly and consistently by young people with aggression problems. Young people felt that these positive effects had an associated positive impact on their ability to make and retain friendships.

The most frequently mentioned impact of medication in the classroom was its perceived effect on disruptive behaviour, both verbal and physical. Most groups had to be encouraged to identify other ways in which medication had an impact on school work and school-related functioning. A majority of young people thought that medication had a positive effect on their ability to focus and concentrate, which overlapped with an improvement in containing their physical and verbal energies. About half the young people attributed improvements in aspects of their school work, such as writing and maths, to medication, and several young people said that better marks in school and on standardised tests were in part due to medication.

However, when discussing the positive impacts of medication on school work there were frequent disagreements regarding its validity. For example, the perception that medication had a positive impact on reading, writing and maths was debated in all focus groups. The degree of effects on school work and school-related functioning was also debated, with some young people feeling that while medication did improve their focus and concentration, they still had significant trouble with school work.

Knowledge about and attitudes towards medication

Young people felt generally positive about their medication, with almost all young people feeling that it was necessary for them and a normal part of their lives. They resisted alternatives largely because they were unwilling to experiment with something different; young people felt their tablets were familiar, relatively easy to take and safe. When asked to consider how a list of non-medical means of improving behaviour might compare with medication in terms of efficacy, all young people felt medication was the most efficacious treatment for ADHD. Significantly, they also felt that medication was an essential part of treatments that incorporated non-medical means of improving behaviour.

However, negative feelings about medication were also frequently expressed, the most frequent being a feeling that medication was 'annoying'. The young people appeared to have a shared understanding of this experience, even though they found it difficult to explain. The 'annoying' nature of medication was most often related to the need to take tablets, but it was unclear whether it was the practicalities of taking

²Follow-up respondent validation was not possible given the time-frame of the study. However, some of the children are also participating in another ongoing study conducted by IS on the moral self-evaluations of children with ADHD (see www.adhvoices.com). In interviews conducted by IS and another researcher for the latter study, children's individual responses to questions about their experiences of ADHD and stimulant drug treatment did not deviate either from their individual responses nor from the collective findings of the present study. Therefore both the reliability of individual participants in this study, and the validity of the findings of the study, have been positively assessed.

tablets, the requirement to take them, or the more existential meaning of the need for medication (for example, having a mental disorder and being 'different') that was most distressing. All these dimensions were inherent to varying degrees in the expressed experiences of medication being annoying.

Some young people were told by friends that they had become 'less fun' after they started taking medication. The young people agreed they had become less impulsive and 'crazy.' Both the girls in this sample, but none of the boys, missed the 'fun' part of themselves sometimes. Both girls wanted to behave more in line with their friends' desires; but they also recognized that such behaviour would have negative consequences within a school setting and they accepted the need for medication.

Young people did not have strong anxieties about taking medication. When asked to rank a list of stressors (including global warming, having ADHD, taking tablets, exams, homework and friendships) from least to most anxiety-provoking, medication was consistently at or near the bottom.

Almost all young people believed that they needed their medication (a perception that ranged from medium to high). If a child questioned his/her need, other young people would frequently challenge this view. Understanding of how long it was necessary to stay on medication was not as frequently shared. Some young people felt that they would grow out of ADHD; others felt it was a life-long illness. Some referenced the fact that adult ADHD was now a recognised disorder. Most young people believed it would become possible to cope with ADHD without the help of medication. Older young people were more likely than younger children to

question the need for life-long medication and express a desire to stop medication in the near future.

Self-understanding

Conceptions of self and identity

Young people tended to have a continuous, rather than a dichotomous, sense of themselves on and off medication. Only a few expressed feeling that they were a different person but on further probing, such initially dichotomous perceptions were amended into continuous self-descriptions. However, most young people expressed ambivalent self-conceptions on and off medication. For example, some young people felt they were more fun off medication, but these same young people knew that when they were not taking medication they could also be more annoying to others and out of control. Some young people described themselves as more normal off medication, which was a positive self-description, but they described their normal selves as 'berserk' and 'mental', which was fun in certain situations, but distressing in others. Young people had a good understanding of the context-bound nature of how their behaviours would be interpreted and associated their evaluations of their own behaviours and need for medication with a certain context.

Conceptions of personal agency

All young people in this study reported feeling that their behaviours were problematic to some degree. None attributed these solely to their ADHD or to a lack of medication; indeed, when individual young people made such attributions they would be challenged by the

(The following statements are based on a sample of young people who have agreed to take medication.)

Young people are more positive about medication than about other interventions.

When compared with common childhood stressors, methylphenidate treatment is one of the least anxiety-producing stressors.

Young people tend to believe that they will have a choice about whether or not to continue taking medication.

Young people express anxiety about being able to cope without medication in the future but believe that eventually it would become possible to cope.

Young people are aware of the effects of medication on their behaviour.

Although young people don't like taking their tablets, they perceive medication to have a predominantly positive impact on personal functioning, especially in terms of social behaviour and relationships.

Young people do not feel that medication entirely resolves their problematic behaviours or social problems.

Although adults describe young people as 'being a different person' on medication, this dichotomous representation is generally not reflected in young people's experiences of self when on and off medication.

Young people with ADHD are aware of others' negative attitudes toward them, which appears to lead to lower self-esteem.

Young people with ADHD commonly experience bullying.

Young people's experiences of bullying are more often connected to their ADHD behaviours, than to taking tablets.

Close friendships are important to young people with ADHD and are sometimes used to protect them from bullying and in other difficult social situations.

In the classroom, young people feel that teachers frequently focus on their behaviour and their diagnosis, rather than on the needs of young people with ADHD.

Young people sometimes use their diagnosis as an excuse for their behaviours.

Young people believe that physical activities are helpful to them, and of those activities sports (especially boxing) are the most helpful.

Young people with ADHD desire better public understanding of their condition.

Figure 2: Summary of results

group. Nevertheless all young people admitted sometimes using their diagnosis as an excuse for their behaviours. The young people generally felt responsible for managing their behaviour and found medication helped with self-management to some degree, although none of them felt that medication entirely resolved their problematic behaviours.

While they agreed that some of their behaviours were problematic, young people generally did not feel that they had a say in how their behaviours were classified and defined. Young people expressed the greatest degree of agency in discussing situations where peer-generated social codes had more moral authority than adult-generated behavioural prohibitions. One frequently mentioned situation was bullying that involved denigration or disrespect to the child's mother. Young people generally agreed that aggressive retaliation was socially and morally justified in such circumstances and defined their behaviour in moral terms, even if the impulsive, aggressive behaviours were also indicative of clinical symptoms. The young people rarely regretted their behaviour following such incidents. Following a fight, they sometimes used their ADHD diagnosis and/or lack of medication strategically, as an excuse for their behaviour and to try to minimise the punishment.

Lack of agency was most frequently experienced in the classroom. Some young people felt that because of their ADHD diagnosis teachers were unfairly focused on their behaviour and assumed that it would be more challenging than that of other young people. Some young people felt that teachers were watching them to see whether their behaviours were a sign that they had forgotten to take their medication. A majority of young people felt that teachers frequently defined young people's behaviours according to the needs of teachers, rather than young people's needs. For example, teachers would use ADHD as justification not to address problematic behaviour in a constructive way, rather than attempting to help young people with ADHD by initiating structural changes in the classroom and/or the school day.

The young people generally felt that they would be able to exercise choice regarding their future, although they also acknowledged their limitations. Many of them were concerned about whether they would need to keep taking medication as they grew up, although they all felt that this would be their own decision to make.

Social experiences and relationships

Experiences of stigma and bullying

Stigma was more generally related to a diagnosis of ADHD and behavioural symptoms rather than to medication. However, young people felt exposed by the need to take their medication, especially if they needed to take it at school, which made them feel different in a negative way. A majority of young people reported being called names (for example, 'druggie', 'tablet boy') and were bullied about their ADHD behaviours and/or ADHD diagnosis and need for tablets. This had an impact on the young people's sense of self, resulting in feelings of low self-confidence and self-esteem. The young people frequently got into fights as a result of being verbally bullied.

Some of the young people reported having close friendships that helped to protect them from bullying and several had friends who knew about their diagnosis and would come to their rescue in a fight that was the direct result of bullying. The rescue was often an effort to get the child with ADHD to stop and think about what they were doing, but sometimes friends would drag the child with ADHD away from the situation. Conversely, an ADHD diagnosis could also serve as protection in situations that arose as a result of stigma. For example, friends would use it to frighten off a name-calling bully, as in: 'he told them I had ADHD and I was crazy'. ADHD was also frequently used as an excuse following a fight, or to get out of similar situations, by almost all the young people.

Public understanding of ADHD

In general young people felt there was a lack of empathy and understanding of young people with ADHD. They felt that others' negative assumptions were very burdensome and they said that they received negative differential treatment because of their diagnosis. All young people reported feeling that their ADHD gave them a bad reputation with peers, teachers and parents of peers. There was general agreement that young people with ADHD were thought to be stupid. Two young people kept their diagnosis secret from friends and members of their extended family. Both girls (in separate groups) felt that teachers completely ignored them because of their ADHD diagnosis and had given up on them.

Alternatives to medication

Few young people reported experiences of non-pharmacological interventions that were memorable or helpful; some received additional support at school and of three young people who received counselling, two said that this was helpful. Several young people played sports that helped release energy and made them feel good. Most parents had experimented with non-pharmacological and diet-related interventions and although young people tended to be aware of these they expressed no strong opinions.

The young people were asked to brainstorm means of helping a child with ADHD manage their behaviour and they easily thought of helpful strategies; there was agreement within and across groups as to the efficacy of the proposed methods. Playing sports, drawing and stress balls were most frequently mentioned, while reading, watching television and playing computer games were less frequently mentioned. When asked to compare the likely effectiveness of non-pharmacological methods with the effectiveness of medication, none of the young people felt non-pharmacological methods would be more effective and all felt that non-pharmacological methods would be most effective if used together with medication.

All groups and individual young people were asked to think of something they would want to invent to help young people with ADHD. Alternative drug delivery systems were discussed, including drugs that tasted better and did not need to be taken frequently, and drug dosing on demand, such as one child's suggestion of a 'scratch dot' that could be scratched when the drug was

needed to deliver an immediate dose lasting an hour or two. This desire for medication with short-term, targeted effects was associated with wanting a drug that did not have pervasive effects (expressed in terms such as: 'I wish it only affected the parts of me that need it'). However, other young people were glad that they only needed to take medication once a day and were happier knowing that 'it's always working in me'. Young people also wished to find ways to communicate to others what it was like to have ADHD, such as via a book or video about the condition.

Discussion

Major findings of the study

This study used focus groups and individual interviews to explore the experiences of 16 young people taking stimulant medication to control their ADHD symptoms. Systematic and rigorous methodology was applied during both the data gathering and the analysis and the findings have within-group validity. However, several limitations qualify the generalisability of the findings. The relatively small number of participants in the study meant that the sample was illustrative rather than representative of the large number of children and young people taking medication for ADHD in the UK. The importance of certain themes may have been amplified in groups consisting predominantly of young boys, who responded honestly but also wished to impress one another and the interviewer. In addition, selection bias may have influenced the largely positive responses to medication. Only two girls participated in the study and both were teenagers. While the number of girls in the sample accurately reflects the proportion of girls with ADHD in UK ADHD clinic samples, this study cannot claim to adequately capture experiences that might be unique to girls with ADHD.

The study found that the young people had a reasonable understanding and expectations of medication. Medication was not viewed as a panacea, but almost all of the young people felt that they needed their medication and their experiences of medication were generally positive. 'Annoying' dimensions of taking medication were tolerated in return for the perceived benefits. The young people primarily associated medication with helping to improve their social behaviours, and, consequently, their relationships with peers. Social outcomes (young people's friendships and quality of social interaction) are not typically viewed as the target for stimulant medication and hence, may not be adequately explored or evaluated by clinicians when monitoring treatment effectiveness. A greater focus on social outcomes (regarded as most important by young people) could help to improve treatment adherence and the therapeutic relationships.

Side effects of medication were commonly experienced by young people, particularly appetite suppression and insomnia, but these were not a major theme of the discussions. The young people had varied experiences of both formal and informal non-pharmacological interventions. They all believed medication to be the most effective treatment for ADHD, with few other interventions were thought to be very effective apart from sport.

Findings from this study are similar to other recent qualitative findings (Singh, 2007a, 2007b) that do not

support ethical concerns that treating young people with ADHD with stimulant medication threatens young people's agency (for example, President's Council on Bioethics, 2003). The young people in this study expressed a significant degree of agency and understood that neither their diagnosis nor medication absolved them of responsibility for their behaviours. When discussing a process of making moral assessments of situations and choosing and judging their behaviour according to these assessments, the young people expressed a significant trust in their personal agency.

Similarly, concerns that taking medication could confer significant stigma on young people (for example, Conrad, 2006) were not supported by this study. While the young people did report experiences of stigma arising directly from taking medication, experiences of stigma because of their ADHD diagnosis and behaviours were far more frequently expressed. These experiences, which included bullying, name-calling, negative assumptions and differential treatment, were distressing to the young people and negatively affected their self-evaluations, self-esteem and self-confidence. However, this group of young people reported that ADHD diagnosis and stimulant treatment caused them relatively lower levels of anxiety, when compared with other common stressors for UK school-age children. Almost all of the young people ranked ADHD diagnosis as more worrying than taking tablets for ADHD, which adds to a consistent picture that the young people had relatively more negative experiences of their diagnosis and behaviours when compared with taking medication.

Close friendships were an important protective factor against fights that arose when young people with ADHD were bullied, with friends being mentioned at least as often as medication as a factor that helped them restrain their impulse to fight. Feelings of being different and alienation were also stronger around ADHD diagnosis and behaviours, than around the need for medication. Indeed, as the young people felt that medication helped to foster peer relationships by alleviating some symptoms, it appears that the social benefits of medication outweigh the social burdens. It is also notable that one of the most strongly stated desires communicated by this group of young people was for better public understanding of ADHD, which they felt would create empathy and relieve them of some of the stigma associated with ADHD.

Conclusions

This study made an important contribution to the NICE ADHD guideline and fills a gap in our knowledge about young people's experiences of stimulant drug medication that has wide clinical implications. The NICE guideline recommends close working among the key adults involved in the life of a child with ADHD; this may include parents, teachers and mental health workers, for example when participating in parent-training programmes (NICE, 2008). Adults understanding and sharing information with children about the experience, personal benefits and disadvantages of methylphenidate may well prove to be a promising approach to enhance clinical progress for the child with

ADHD. A detailed understanding of the role that methylphenidate can play in an individual child's family, educational and social life, with greater emphasis on the latter than had previously been the case, may lead to new treatment strategies aimed at stabilising a child's social interactions and social integration. All too often, the care and treatment of young people does not take into account the young people's experiences with specific treatments. While this research made an important contribution specifically to the ADHD guideline (NICE, 2008), it strongly suggests that future guidelines relating to the treatment of children and young people should also be informed by research on young people's experiences with specific treatments.

Acknowledgments

Funding from the National Collaborating Centre for Mental Health.

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