

Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY) – a pharmacoepidemiological and qualitative study

ICK Wong,^{1*} P Asherson,² A Bilbow,³
S Clifford,¹ D Coghill,⁴ R DeSoysa,⁵ C Hollis,⁶
S McCarthy,¹ M Murray,¹ C Planner,¹ L Potts,⁷
K Sayal⁶ and E Taylor⁸

¹Centre for Paediatric Pharmacy Research, School of Pharmacy,
University of London, London, UK

²MRC Social, Genetic and Developmental Psychiatry Centre,
Institute of Psychiatry, London, UK

³ADDISS, Edgware, Middlesex, UK

⁴Section of Psychiatry, University of Dundee, Dundee, UK

⁵Royal Liverpool Children's NHS Trust, Alder Hey, Liverpool, UK

⁶Division of Psychiatry, Queen's Medical Centre, Nottingham, UK

⁷Mental Health and Neuroscience Clinical Trial Unit, Institute of Psychiatry,
London, UK

⁸Department of Child and Adolescent Psychiatry, Institute of Psychiatry, London, UK

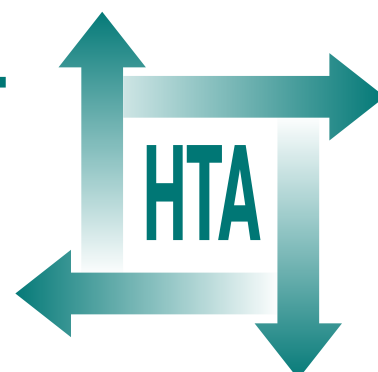
*Corresponding author



Executive summary

Health Technology Assessment 2009; Vol. 13: No. 50
DOI: 10.3310/hta13500

Health Technology Assessment
NIHR HTA programme
www.hta.ac.uk





Executive summary

Background

There is increasing evidence to suggest that attention deficit hyperactivity disorder (ADHD) is no longer a condition of childhood alone. Studies have shown that the condition can persist into adulthood in a significant proportion of patients. What is unknown at present is the extent to which adolescents and young people continue with medication as they get older, the reasons for treatment cessation and the experience of patients undergoing this process. This report aims to review current practice in treating patients with ADHD so that more information will be available to plan for future clinical trials and service provision.

Objectives

1. To estimate the prevalence of ADHD treatments in the target population using a large general practice automated database.
2. To describe the demographic and clinical details of patients in the target population who received ADHD pharmacological treatment including duration of treatment, age of medication cessation and dosage.
3. To estimate the percentage of patients in the target group who stopped the ADHD pharmacological treatments and investigate possible factors affecting the continuation or cessation of pharmacological treatments.
4. To search the literature for potentially appropriate quality of life (QoL) measures for this patient population and to test feasibility with interviewees.
5. To conduct in-depth interviews with patients attending or discharged from specialist clinics to identify the reasons for cessation of ADHD pharmacological treatments (and the effects on symptoms), to explore perceptions of the process and outcome of cessation and to explore issues of QoL.
6. To conduct in-depth interviews with clinicians to obtain their perceptions of the process and outcome of cessation of ADHD pharmacological treatments (and the effects on symptoms).

Design

This project combined quantitative and qualitative approaches to investigate current practice in the UK.

Setting

The General Practice Research Database (GPRD) was used to answer objectives 1–3 (Part 1). The Part 2 study was designed to answer objectives 4–6. A literature review on QoL was undertaken in March 2007 to identify appropriate QoL questionnaires for patients with ADHD. Patients and clinicians were recruited from London, Nottingham, Dundee and Liverpool to take part in interviews.

Participants

Part 1

The GPRD is one of the world's largest computerised databases of anonymised patient data from general practice. It currently contains information on over 3.5 million patients, equivalent to approximately 5% of the UK population. As of 2 June 2006, there were 668,387 patients registered on the database aged 19 years.

Part 2

A total of 15 eligible patients (active and discharged) were recruited. An active patient was defined as a patient who is under the care of the collaborating clinics for their ADHD management. A discharged patient was defined as a patient who was no longer under the care of the collaborating clinics (includes patients who have either stopped treatment, transferred to adult psychiatric care or primary care or who have moved away). Patients were stratified into the following three groups: patients who remain on treatment and have not attempted stopping; patients who have successfully stopped treatment; patients who were unsuccessful in stopping treatment. A total of 10 clinicians were interviewed. This included community paediatricians (associated with mental health

clinics), child and adolescent psychiatrists and adult psychiatrists. The clinicians were recruited from the collaborating centres.

Results

Part 1: Patient characteristics and prevalence

Prevalence of prescribing averaged across all ages (15–21 years) increased eightfold over the study period, from 0.26 per 1000 patients in 1999 to 2.07 per 1000 patients in 2006. The increase in prevalence over the study period occurring in the younger patients was less evident in the older patients. The prevalence of 15-year-old males receiving a prescription for a study drug increased from 1.32 per 1000 patients in 1999 to 8.31 per 1000 patients in 2006, whereas the prevalence of 21-year-olds rose from 0 per 1000 patients in 1999 to only 0.43 per 1000 patients in 2006. A survival analysis was conducted to investigate the cessation of treatment and showed that the rate of treatment cessation largely exceeded the estimated rate of persistence of ADHD. The reduction in prescribing was most noticeable between the ages of 16 and 17 years. Kaplan–Meier analysis was also conducted to examine the restarting of treatment. Approximately 18% of patients restarted treatment if they had stopped treatment after the age of 15. For those patients who restarted treatment, they were more likely to restart within the first year following treatment cessation.

Part 2: Quality of life literature review

Twelve QoL scales were identified; eight had been used in children and four in adults. The most frequently used scale in the UK studies was the Child Health and Illness Profile (CHIP) and, overall, it was the second most cited QoL scale used in ADHD. The CHIP-CE scale is a generic scale used to assess QoL; however, it has been validated for use in children with ADHD in the UK. On this basis, the CHIP was chosen as the QoL questionnaire to be tested (in the Part 2 study), in terms of feasibility for use in future studies. Due to the age range of the study participants, the adolescent version of the CHIP (CHIP-AE) was selected and administered to patients after the interview and in accordance with the instructions outlined in the user manual. Of the 15, a total of nine patients completed the questionnaire; the time it took to complete ranged from 12 to 25 minutes. Four participants had difficulties with

reading and comprehension and so took the questionnaire home so they could have more time and support from parents; only one was returned. Two participants did not have time to complete the questionnaire during the session because of the time taken to conduct the interviews, but were given the questionnaire to take home; neither were returned. Of those participants who completed the questionnaire, all described it as easy to work through, but considered it lengthy. The majority of participants asked for clarification of questions that would be more appropriate for young people in the USA.

Interview study

The results of the qualitative study showed that although some young people felt able to cope after stopping medication, others felt the need to restart to control symptoms. Some patients had difficulty re-engaging with services and clinicians recognised the lack of services for young adults. Patients continuing on treatment considered cessation as an option for the future, although were concerned about the process of stopping and impact on behaviour. The process of cessation varied depending on the individual and whether it was planned or unplanned. From a clinical perspective the process typically involved four key stages: preparation, choosing an appropriate time to stop, commencing cessation and follow-up.

Conclusions

The Part 1 study demonstrated that the prevalence of prescribing by general practitioners to patients with ADHD drops significantly from age 15 to 21. The fall in prescribing is greater than the reported age-related decrease in symptoms, raising the possibility that treatment is prematurely discontinued in some young adults where ADHD symptoms persist. The Part 2 study also identified that some young adults had difficulty in obtaining treatments after discharge from the paediatric services. This scoping exercise shows further research is needed to improve the care of young people with ADHD.

Implications for healthcare

CADDY was commissioned as a scoping project with a focused objective to identify current practice in ADHD treatment cessation in order to support the planning of an randomised

controlled trial. Hence, it can only make very limited recommendations. Nevertheless, both the pharmacoepidemiological and interview studies raise the possibility that treatment may be prematurely stopped by or for some adolescents and young adults with ADHD. Also overall the fall in treatment prevalence may be out of step with the numbers of people who still require treatment as young adults. In addition, deficiencies in ADHD services within adult mental health have been highlighted both in the literature and by respondents in the interview study. Factors in adult services such as poor transition arrangements from child services, lack of resources, poor training of adult psychiatrists in the diagnosis and management of ADHD, competing priorities, unwillingness to prescribe unlicensed medications, and beliefs that the condition does not exist in adulthood are all likely to contribute to patients failing to be identified for initiation or continuation of treatment for ADHD, even where this is clinically indicated. Guidelines and further research are needed to help patients, families and clinicians make informed and evidence-based decisions about whether cessation is appropriate.

Recommendations for research

In light of the results obtained from this study and the latest results from the Multimodal Treatment Study of Children with ADHD (MTA) and the NICE guideline, the research priorities should be:

1. investigations into whether stimulants, particularly methylphenidate, are still effective after long-term treatment, i.e. by conducting a randomised placebo-controlled trial
2. once the above study is conducted, then a further study optimising the cessation and/or continuation process is needed to guide clinicians on future practice.

Publication

Wong ICK, Asherson P, Billow A, Clifford S, Coghill D, R DeSoysa R, *et al.* Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY) – a pharmacoepidemiological and qualitative study. *Health Technol Assess* 2009;**13**(50).



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The research reported in this issue of the journal was commissioned by the HTA programme as project number 04/36/02. The contractual start date was in May 2008. The draft report began editorial review in July 2008 and was accepted for publication in March 2009. As the funder, by devising a commissioning brief, the HTA programme specified the research question and study design. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the referees for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

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ISSN 1366-5278

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Published by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk), on behalf of NETSCC, HTA.

Printed on acid-free paper in the UK by The Charlesworth Group.