

ORIGINAL ARTICLES

A Survey of Attention Deficit Hyperactivity Disorder Follow-up Services Provided by Child and Adolescent Psychiatry Departments in Scotland

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Abstract

Background/Aim

Current clinical guidelines offer few recommendations for follow-up of patients diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). We aimed to establish what follow-up services were in place for children and young people with ADHD across Scotland, to highlight variations within these services and to examine their level of adherence to those national guidelines on follow-up which do exist.

Method

A postal survey of child and adolescent psychiatry departments across Scotland was carried out. Seventeen departments were contacted and the response rate was 100%. We compared results from areas with and without designated ADHD follow-up teams. We looked specifically at numbers and type of professional involved and the structure of the follow-up services provided.

Results and Conclusion

Forty one percent of services had a designated ADHD follow-up team. These services held a significantly higher proportion of regular ADHD clinics and involved more staff from different professional groups. There were wide variations in services provided by child and adolescent psychiatrists for ADHD follow-up across Scotland. Further research on the effects on prognosis and outcome of designated ADHD services would allow for the enhancement of current clinical guidelines and more effective service planning and provision.

defines a subgroup of ADHD. HKD requires the presence of both inattention and hyperactivity before age six years, and that these symptoms are of long duration, are present in two or more settings and cause functional impairment.²

Prevalence estimates vary according to the population sampled, the method of ascertainment and the diagnostic criteria applied. The reported prevalence of ADHD in school aged children varies from 1.7% to 17.8% depending on the criteria used.³ Estimates in the United States of America have historically been higher than UK estimates due to the application of narrower diagnostic criteria by UK authors.⁴ Studies of UK populations have shown prevalence rates of between 2% and 5%, depending on whether DSM-IV or ICD-10 criteria were applied.^{4,5} Male to female ratio is thought to be at least four to one.⁶ Aetiology is unknown, hence the reluctance in Europe to use the term ADHD which implies causality in some form of defect of attention. Maternal alcohol and drug misuse, malnutrition, lead poisoning and low birth weight appear to be aetiological factors of some importance.⁷

In recent years national guidelines concerning the diagnosis and management of ADHD and HKD have been published. In October 2000, the National Institute for Health and Clinical Excellence (NICE) published a Technical Appraisal Guidance on the use of methylphenidate for ADHD in childhood.⁸ This was updated in March 2006 to include both atomoxetine and dexamphetamine. In June 2001 the Scottish Intercollegiate Guidelines Network (SIGN) published a guideline on Attention Deficit and Hyperkinetic Disorders in Children and Young People.⁹ A NICE guideline on pharmacological and psychological interventions in ADHD is currently in development with a publication date yet to be confirmed. The SIGN guideline is due for review, though the original recommendations are not likely to be changed by new available evidence. NHS Quality Improvement Scotland is currently undertaking a national review to assess the implementation of the SIGN guideline.

In Scotland, the publication of a national guideline on the diagnosis and management of ADHD reflected the wide variation in clinical practice around this disorder. There were concerns that affected children were going undiagnosed and untreated and, in other cases, unaffected children were being treated needlessly. There was a lack of consensus about how best to manage ADHD, particularly with regard to the use of stimulant medication in children.

The SIGN guideline aimed to provide a framework for evidence based assessment and management of ADHD, from which locally appropriate multidisciplinary approaches could be developed.⁹

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is among the most commonly diagnosed behavioural disorders in children and young people. Core symptoms comprise developmentally inappropriate levels of inattention, hyperactivity and impulsivity. Diagnostic criteria require that some of the symptoms were present before age seven years, have persisted for more than six months, are present in more than one setting, have caused significant functional impairment and are not accounted for by other mental disorders.¹ The diagnosis of Hyperkinetic Disorder (HKD), sometimes used by United Kingdom (UK) clinicians,

It makes various recommendations based on available evidence. The majority of these recommendations concern initial assessment and diagnosis and commencement of pharmacological and non-pharmacological therapy. There are very few specific recommendations guiding follow-up of patients who have been diagnosed and commenced on treatment. Those that there are, are based on evidence obtained from expert committee reports or opinions and/or clinical experiences of respected authorities (grade IV evidence). Alternatively they are Good Practice Points based upon the clinical experience of the guideline development group. These recommendations include: regular contact between the family and clinician when titrating psychostimulants, blood testing for haematological abnormalities at the discretion of the supervising clinician and only when clinically indicated, and regular (annual) short (up to 2 weeks) trial periods off treatment with subsequent alterations to medication if indicated.

Given the lack of national guidance and dearth of information on appropriate follow-up for children and young people being treated for ADHD, the likelihood of continued wide variation in clinical practice is high. We present a recent survey of ADHD follow-up services provided by child and adolescent psychiatrists in Scotland.

Method

The study was a postal questionnaire carried out between July and August 2004. NHS Trusts in Scotland were contacted and requested to provide contact details of child and adolescent psychiatry departments. Seventeen departments were contacted and asked to fill in a confidential, anonymous questionnaire. The response rate was 100%.

There were two independent groups: those areas with a designated ADHD follow-up team and those without a designated ADHD follow-up team.

The proportion of departments that involved particular professional groups in follow-up and the organisation of that follow-up was compared. Since the sample size was small ($n=17$), the counts in some cells were less than five, thus a Fishers exact test was used instead of the usual chi-squared test.

Results

Of the 17 departments surveyed, seven (41%) had designated ADHD follow up teams while the remaining 10 (59%) did not.

Table I compares the numbers of different professionals involved in ADHD follow-up between those departments with designated follow-up teams and those without.

In the departments with designated follow up teams there were 13 different professional groups involved in ADHD follow up compared with only three in the departments without a designated team. In the departments without designated teams only consultant psychiatrists, senior house officers and community paediatricians appeared to routinely perform ADHD follow up.

There were significantly higher proportions of nurses ($p = 0.015$), occupational therapists ($p = 0.051$) and specialist teachers ($p = 0.015$) involved in ADHD follow up in departments with designated follow up teams than in areas without. (Table I)

Table II compares the organisation of ADHD follow-up services provided by the designated ADHD teams with those areas where there is no designated ADHD team.

Total Departments Surveyed $n=17$		
	Those With Designated ADHD Follow-up Team $n=7$ (41%)	Those Without Designated ADHD Follow-up team $n=10$ (59%)
Consultant Psychiatrist	6 (86)	6 (60)
Staff Grade Psychiatrist	1 (14)	0
Senior House Officer	0	1 (10)
Community Paediatrician	3 (43)	2 (20)
Nurse	4 (57)	0
Occupational Therapist	3 (43)	0
Social Worker	1 (14)	0
Clinical Medical Officer	1 (14)	0
Community Mental Health Worker	2 (29)	0
Educational Psychologist	2 (29)	0
Specialist Teacher	4 (57)	0
School Nurse	1 (14)	0
Admin. Staff	2 (29)	0

Total Departments Surveyed $n=17$		
	Those With Designated ADHD Follow-up Team $n=7$ (41%)	Those Without Designated ADHD Follow-up team $n=10$ (59%)
Hold regular ADHD clinics	7 (100)	1 (10)
Clinics exclusively for review patients	3 (43)	0
Clinics held out with hospital setting	5 (71)	n/a
Standard review protocol used for ADHD follow-up patients	4 (57)	2 (20)
Services reviewing stable patients at least 3 monthly	3 (43)	1 (10)
Services reviewing stable patients 3 to 6 monthly	4 (57)	9 (90)
Annual drug holiday offered as standard	4 (57)	4 (40)
Follow-up provided by someone who can prescribe medication	5 (71)	9 (90)
Those with an exclusive ADHD secretary	1 (14)	0
ADHD service available for adults	0	0

In terms of the actual follow up services, those with designated follow up teams held a significantly higher proportion of regular ADHD clinics ($p < 0.001$) and had a higher proportion of clinics exclusively for the review of patients rather than assessment of new referrals ($p = 0.051$). (Table II)

Discussion

The results show a clear variation in the structure of services for ADHD follow-up provided by child and adolescent psychiatry departments across Scotland.

Areas with designated ADHD follow-up teams had significantly more and varied professions involved in the service. Follow-up in areas without designated teams was provided solely by medical staff, usually consultant psychiatrists. Where a multidisciplinary team is available, the detailed medical, educational and social assessment required for diagnosis and ongoing monitoring, as well as the implementation of psychosocial interventions, is likely to be more easily facilitated. In addition, a service staffed solely by medical professionals, particularly consultants, will be more expensive to provide than a service where work, which can be as effectively performed by others, is done by allied healthcare staff.

The multidisciplinary approach may also take the management of these young people out of the hospital setting. Seventy one percent of the designated follow-up teams were based in schools or community clinics. This may have positive implications for attendance rates. Young patients and their families are likely to face less practical travel difficulties and less perceived stigma if they can be seen locally rather than having to travel to a hospital centre which can be anxiety provoking for all.

In areas where a designated ADHD follow-up team exists, patients are more likely to be reviewed more frequently and using a standard review protocol. These protocols included physical monitoring such as height, weight and heart rate as well as repeat symptom measurement using standardised questionnaires.

With regard to the recommended guidelines for follow-up, 57% of designated ADHD follow-up teams offer an annual drug holiday versus 40% of the services in areas where there is no ADHD follow-up team.

The survey draws no conclusions on outcome, prognosis or patient satisfaction. It should be noted that in the areas where there is no dedicated ADHD follow-up team all services follow-up stable patients at least six monthly. Also 40% of these areas stated that they were in the process of developing ADHD follow-up services.

All services surveyed had access to a prescriber if follow-up was performed by a non-prescriber. Only one of the 17 departments surveyed had access to exclusive ADHD secretarial time. Efficient administration is a prerequisite for any service and the lack of specific secretarial time identified for ADHD follow-up is likely to be a reflection of a more pervasive shortage of such resources in the NHS.

There were no specific ADHD services for adults other than referral on to an adult community mental health team when patients reach the designated age limit for child and adolescent services. SIGN guidelines highlight that in some cases, treatment with psychostimulants may require to be long term and that they need not be automatically discontinued at the onset of puberty as efficacy in adolescents and adults with ADHD is well established. This raises the issue of service provision for these patients who require such treatment in to adulthood.

Conclusion

ADHD is among the most commonly diagnosed behavioural disorders in children and young people. Guidelines exist for diagnosis and instigation of treatment. There are no evidence based guidelines for the follow-up of ADHD patients. There are a few recommendations made based upon the clinical experience of guideline development groups. There are wide variations in services provided by child and adolescent psychiatrists for ADHD follow-up across Scotland with less than half of these departments having designated multidisciplinary ADHD follow-up teams. Further research to establish the effects on prognosis and outcome of designated ADHD services would allow for the enhancement of current clinical guidelines and more effective service planning and provision.

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