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Predictors of and Barriers to service use for children at risk of ADHD: Longitudinal study

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ABSTRACT

Objective

Many children with, or at risk of, ADHD do not receive healthcare services for their difficulties. This longitudinal study investigates barriers to and predictors of specialist health service use.

Methods

This is a five year follow-up study of children who participated in a cluster randomised controlled trial, which investigated school-level interventions (provision of books with evidence-based information and/or feedback of names of children) for children at risk of ADHD. 162 children who had high levels of ADHD symptoms at age 5 (baseline) were followed up at age 10 years. Using baseline data and follow-up information collected from parents and teachers, children who had and had not used specialist health services over the follow-up period were compared and predictors (symptom severity, comorbid problems, parental perception of burden, parental mental health, and socio-demographic factors) of specialist service use investigated.

Results

The most common parent-reported barrier reflected lack of information about who could help. Amongst children using specialist health services who met criteria for ADHD at followup, 36% had been prescribed stimulant medication. Specialist health service use was associated with each one-point increase in teacher-rated symptoms at baseline (inattention symptoms (adjusted OR = 1.40; 95% CI 1.12-1.76) and hyperactivity/impulsivity symptoms (adjusted OR = 1.23; 95% CI 1.05-1.44)). Parental mental health problems were also independently associated with service use (for each one-point increase in symptoms, adjusted OR = 1.41; 95% CI 1.04-1.91).

Conclusions

Severity of teacher-rated ADHD symptoms in early school years is a determinant of subsequent service use. Clinicians and teachers should be aware that parental mental health problems are independently associated with service use for children at risk of ADHD.

Key words: ADHD, hyperactivity/inattention, school-based intervention, longitudinal, barriers, service use

INTRODUCTION

Attention Deficit-Hyperactivity Disorder (ADHD) is a common disorder, affecting around 5% of children [1], with at least a further 5% of children at risk of ADHD through having significant but sub-threshold levels of hyperactivity, impulsivity and/or inattention symptoms or associated impairment. The potential adverse consequences of ADHD include the development of additional disorders, educational problems including academic under-achievement, difficulties with social relationships, employment problems, and criminal activity [2-6]. It is therefore important that children with, or at risk of, ADHD are appropriately identified and they and their caregivers are able to access appropriate interventions and support. The clarification of factors that affect these children's outcomes and access to services has public health implications in terms of service organisation and provision, the interface between healthcare and other services, and health education approaches aimed at parents and teachers.

In the UK, around half of children with ADHD have not accessed specialist healthcare services despite clinical practice guidelines recommending that only specialist healthcare services should carry out diagnostic assessments and commence medication for ADHD [7]. Identifying and quantifying the barriers to accessing care is important, as addressing these barriers should improve the care pathways and quality of care received by those with or at risk of ADHD. An investigation of the possible factors (such as symptom severity, comorbid problems, parental perception of burden, parental mental health, and socio-demographic factors) that might influence the take-up of services is crucial in understanding the barriers to care and utilisation of services. This follow-up study builds on a longitudinal school-based intervention study [8] in order to assess the relative contribution of child, parent and socio-demographic factors in influencing service use. It aims to investigate predictors of and

barriers to specialist health service use for mental health or behavioural problems amongst atrisk children whose schools participated in a randomised controlled trial (RCT) of interventions for children with attention and hyperactivity problems.

METHODS

Baseline study and interventions

Full details of the baseline study and the five year follow-up of the RCT are described elsewhere [8,9]. A brief summary is presented here. Informed consent was obtained from participating parents and ethical approval for the study was received from Research Ethics Committees (IRBs) at Durham and Bristol Universities. At baseline, the teachers in the Reception year (the first year of school in England when children were aged 4-5 years) of participating schools completed a validated rating scale consisting of the 18 DSM-IV ADHD items on all children in their class at the end of the school year [8]. 'High scorers' were defined as children who had sufficient (≥ 6) symptoms relating to one of the DSM-IV ADHD sub-types (inattentive, hyperactive/impulsive, or combined). In total, this cut-off identified 11% of children as being high scorers. Following this, schools were randomised to receiving one of four interventions when the children were in the next academic year (parents were blinded to the intervention arm):

- 1) Identification of the names of high scoring children to the school (Identification).
- Receipt of a book containing information about ADHD and evidence-based ways of managing children with these difficulties in the classroom (Book).
- 3) Receipt of both identification information and the book.
- 4) No intervention control group.

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Five year follow-up study

Stage 1

Children from 308 primary schools (60% response rate) in England participated in the first stage of the five year follow-up study and these findings have been reported elsewhere [9]. These schools were located across 20 Local Education Authority (LEA; school district) areas to provide a good spread of socio-economic characteristics and also allow for validity checks of parent-reported information about the use of and location of local health services. In order to assess the longer-term impact of the intervention [9], baseline high scorers were oversampled but the current class teachers were kept blind as to the baseline scoring status. Parents were sent a letter through the school to invite their participation in the follow-up study - as described elsewhere [9], parental participation (41% response rate) was not associated with child gender or the type of intervention received. In terms of other attrition analyses, response was not associated with baseline high scoring status but was associated with attending schools in less deprived areas. Parents completed an extended version of the Strengths and Difficulties Questionnaire (SDQ) [10,11] about their child which provided information on symptom scores relating to hyperactivity/inattention, conduct problems and emotional problems; burden for the parent; and sources of help used since the Reception year in relation to the child's emotions, concentration or behaviour difficulties. The use of specialist health services was defined as a positive response to questions about seeing someone specialising in child mental health (e.g. a child psychologist or psychiatrist) or a physician specialising in children's general health (e.g. a paediatrician or school physician).

Stage 2

The present investigation of predictors of service use focuses specifically on baseline high scorers participating in Stage 1 of the five year follow-up study. After a telephone interview was arranged with the parent of each child who had used specialist health services ('service

user') they were individually matched (1:1 ratio) with a same-gender baseline high scorer from the same LEA (to minimise confounding associated with geographical service availability) who had not used specialist health services. Parents of 378 baseline high scorers (73% male) participated in Stage 1 with 103 indicating on the SDQ that their child had used specialist health services (275/378 indicated that their child had not used specialist health services). Of these 103 parents, 83 (81%) were interviewed in Stage 2. In terms of sample representativeness, interview response status was not associated with SDQ scores, all 20 LEA areas were represented in the interviewed sample and there were no differences in the baseline characteristics of the children across the 4 intervention arms.

Measures

These were collected from baseline data (children aged 4-5 years) and postal questionnaires and telephone interviews (at the five year follow-up).

1) Baseline data, collected at the end of the Reception year, included: a) child gender; b) teacher ratings of the DSM-IV ADHD items, scored 0-9 for inattention and hyperactive/impulsive symptoms; c) a measure of deprivation, the Jarman Underprivileged Area scores for the school postcode based on national census socio-demographic data [12]; and d) trial intervention arm.

The following measures were collected at the five year follow-up through postal questionnaires:

2) Parent-completed SDQ (based on the last 6 months) - the following scores were used: a) conduct problems (0-10), b) emotional problems (0-10) and c) burden score (0-3) which measures the extent to which the child's difficulties place a burden on the parent.

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3) Teacher-completed SDQ – The child's current teacher completed the SDQ (93% response rate) based on the last 6 months or current school year. The hyperactivity/inattention score (0-10) was used to inform about the pervasiveness of symptoms across settings.

The following information was collected during the telephone interviews (conducted at the five year follow-up):

4) Family status - who the child currently lives with (both parents or parent and partner vs. single parent).

5) Child ADHD - The hyperactivity/inattention section of the Parental Account of Children's Symptoms (PACS) [13,14] was used to establish the presence of ADHD. The PACS is a standardised, investigator-based, semi-structured interview that is a reliable and valid measure of child behaviour at home currently. It systematically enquires about possible symptoms of hyperactivity, impulsiveness, and inattention using items that reflect the DSM-IV criteria for ADHD. To monitor the quality of the PACS interview and measure inter-rater reliability, the first twenty and every tenth subsequent interview were recorded (total of 34) and rated by a second researcher (KS). As information on pervasiveness of symptoms and impairment related to symptoms is required for DSM-IV ADHD diagnoses, the presence of ADHD was based on meeting the following three criteria:

a) Parent-reported symptoms - a standardised algorithm [14], providing operational definitions for each symptom, was applied to the PACS information to assess each of the 18 DSM-IV ADHD symptoms (9 each relating to the inattention and hyperactivity/impulsivity subtypes). The symptom criteria were set as having 6 or more symptoms for the inattention and hyperactivity/impulsivity sub-types - the kappa inter-rater reliability (assessed by KS and JM) for this was 1.00.

b) Symptom-related impairment – at the end of the PACS interview, the parent was asked about any functional impairment related to ADHD symptoms. This reflected impairment across settings and takes school difficulties into account. The inter-rater reliability for the presence of any impairment was high; kappa = 0.90 (p<0.001).

c) Teacher-reported symptoms – A teacher-completed SDQ hyperactivity/inattention score of 6 or above was used to establish pervasiveness of symptoms [15]. Where teacher SDQs were not returned (7% of the sample), parent reports of ADHD symptoms at school were used as a proxy measure as high scores are predictive of diagnosis [16,17]. Using items from the Development and Well-Being Assessment (DAWBA) [18], parents were asked to report whether the teacher had complained of any of the following behaviours in their child in the last 6 months: i) "fidgetiness, restlessness, or overactivity"; ii) "poor concentration or being easily distracted"; iii) "acting without thinking, frequently butting in, or not waiting for their turn". The responses were scored as: 0 = no complaint, 1 = a little, 2 = a lot, giving a total score of 0-6. Where data were available on both measures, this score correlated modestly (correlation coefficient of 0.50) with the teacher-rated SDQ hyperactivity/inattention score.

6) Parental mental health - This was assessed using the Malaise Inventory, a commonly used 24-item questionnaire [19]. The items cover emotional disturbance and associated somatic symptoms (based on the last 3 months). Its reliability and validity have been demonstrated in two general population samples (n>11,000) - the population mean score is 2-3 and a cut-off point score of 5/6 has good sensitivity and specificity for depression [20].

7) Use of Services – The Children's Services Interview [21], a validated semi-structured interview, was used to elicit information on the child's use of specialist services since the age of 5 years. Parents were asked about sources of support and information and the specific services (including informal support, health services and educational services) that they had accessed for their child's behaviour and emotional difficulties. Information was obtained about the child's use of medication. Questions also elicited which aspects of service provision were perceived as presenting a barrier to service use. Items included the

availability of information about where to seek help, the attitudes and communication of professionals (both in the context of educational and health services), practical issues such as cost and convenience of getting to appointments, possible anxieties about confidentiality and concerns about what other people would think if they sought professional help.

Main outcome measure

Specialist health service use (since the age of 5 years) - This outcome was based on information gathered from the Children's Services Interview [21]. For the purpose of analyses, we classified children as service users or non-users based on the interview data. After completing the interviews with the parents of the 83 specialist service users (according to the information provided by the parent on the SDQ), we checked parents' descriptions against the type and locations of services and ascertained that five children had not used specialist services. Hence, these five children were re-classified as non-users. Conversely, whilst conducting the matched interviews, we established that three children who were initially reported to be non-users had accessed specialist health services for emotional or behavioural difficulties. Hence, these three children were re-classified as service users. This process of re-classification meant that were 81 service users in total (i.e. 83-5+3). These data indicate that 95% (154/162) of respondents accurately reported specialist service use on the questionnaire when compared against the interview information. In total, the final sample for analysis consisted of 162 children based on the interview information; 81 children were service users and they were matched with 81 non-users on gender and LEA for the relevant analyses. These 81 non-users selected for interview were representative of the wider sample of non-users in terms of parent-rated SDQ scores.

Analyses

The following sets of analyses were carried out:

1) Service users (n=81) were initially compared with matched non-users (n=81) in relation to different types of help-seeking, using McNemars test.

2) To investigate baseline predictors of service use, conditional logistic regression analyses (reflecting the matching on gender and LEA) were used. Variables collected when children were aged 5 years (teacher inattention and hyperactive/impulsive scores and Jarman Underprivileged Area score) were investigated as predictors of service use. These predictor measures were entered into a multivariable logistic regression model, that also adjusted for trial intervention arm, to provide adjusted odds ratio estimates.

3) To investigate correlates of service use, conditional logistic regression analyses (reflecting the matching on gender and LEA) were carried out to investigate the relative importance of other variables (measures collected at follow-up). Based on the literature [22-29], these included single-parent family status, ADHD status, parent-rated conduct and emotional problems (SDQ) as measures of comorbid symptoms, parent-reported burden (SDQ), and score on the Malaise Inventory as a measure of parental mental health. The multivariable logistic regression model adjusted for all these variables and adjusted odds ratios are presented. To avoid colinearity with ADHD status at follow-up (partially based on teacher ratings at follow-up), teacher-rated baseline inattention and hyperactive/impulsive scores were not included in this model. We also carried out a sensitivity analysis involving a hierarchical model with key variables introduced in turn: 1) single-parent family status; 2) teacher ADHD ratings (baseline) and parent report of ADHD symptoms at school (follow-up – this measure was used as teacher SDQs were missing on 11 children i.e. 11 data pairs); 3) parent-rated ADHD symptoms, conduct problems and emotional problems; and 4) parent-reported burden and the Malaise score.

RESULTS

Service and Medication Use

Most (68/81; 84%) service users were boys. Parents of service users reported that primary healthcare services (such as GPs or Health Visitors) were the most common source (40/81; 49%) of the referral to specialist services followed by education professionals (30/81; 37%) and other healthcare professionals such as the school nurse (10/81; 12%). 68% (54/81) of these parents said that they had requested the referral to specialist services. Parents of specialist service users were more likely than non-users to have sought help from teachers, family, friends, self-help groups and the internet (Table 1). They also described greater use of other healthcare services such as primary care and accident and emergency services. It is notable that over half of parents of non-users had also discussed their child's behaviour with the class teacher or family members. Almost half (46%) of service users had tried non-prescription dietary supplements such as fish oils compared to 5% of non-users. Since the age of 5 years, 21 (26%) service users had been prescribed medication for behavioural difficulties; 17 had been prescribed stimulant medication (5 in combination with melatonin, one in combination with risperidone), three melatonin only, and one alimemazine (a sedating anti-histamine).

Table 1 about here

Meeting criteria for ADHD at follow-up

Of 55 children who met parent-reported symptom and impairment criteria for ADHD, 37 had a teacher-rated SDQ hyperactivity/inattention score of at least 6. A further three children with no teacher SDQ had a high score (at least 5 out of 6) on the parent report of ADHD symptoms at school. Hence, a total of 40 children met symptom, impairment and pervasiveness criteria for ADHD. According to symptoms elicited with the PACS, their predominating sub-types were combined (20; 50%), inattentive-only (16; 40%) and hyperactive/impulsive-only (4; 10%). Of these 40 children, 36 (90%) were in the service use group. Amongst children using specialist health services who met criteria for ADHD at follow-up, 36% (13/36) had been prescribed stimulant medication since the age of 5 years. Conversely, amongst those prescribed stimulant medication since the age of 5 years, 76% (13/17) met criteria for ADHD.

Barriers to service use

The majority of parents of service users reported barriers to accessing services (Table 2). To a lesser extent, similar barriers were also endorsed by parents of service non-users. The most common barrier (described by 75% of those who had used services and 32% of non-users) was that insufficient information was available about who could help. Amongst parents of service users, around half reported that professionals did not listen when they asked for help, experience of unacceptable delays waiting for help or poor communication between involved professionals, and perceptions that nobody could help with this type of problem or that services were not available.

Table 2 about here

Predictors of Service Use

In terms of baseline predictors of service use (Table 3), after adjustment for number of symptoms, Underprivileged Area score, and intervention arm, both baseline inattention symptoms (adjusted odd ratio of 1.40 for each 1-point increase in symptoms) and hyperactivity/impulsivity (adjusted odd ratio of 1.23 for each 1-point increase in symptoms) were associated with specialist health service use. The unadjusted effect sizes were 0.38 for inattention and 0.44 for hyperactivity/impulsivity.

Table 3 about here

In terms of the predictor measures collected at follow-up, unadjusted analyses highlighted the importance of the presence of ADHD, comorbid problems, parent-reported burden and parental mental health problems as being associated with service use (Table 4). However, in a multivariable analysis that adjusted for all these predictors, only parental mental health problems remained associated with the service use (adjusted odd ratio of 1.41 reflecting each 1-point increase in the Malaise Inventory score; unadjusted effect size = 1.60). The findings were replicated in the model in the sensitivity analysis (see Online supplementary Table) Table 4 about here

DISCUSSION

In this follow-up study, severity of teacher-rated symptoms at baseline (even within an at-risk sample) was important in predicting health service use over the subsequent 5 years. Despite only focusing on high scorers at baseline (those who had \geq 6 symptoms), service users were more inattentive and more hyperactive/impulsive than non-users at the age of 5. Service non-users appeared to be a less severely affected group at baseline and were less likely to meet criteria for ADHD or have comorbid symptoms at follow-up. For some children, apparent ADHD-type behaviours at the age of 5 might have been due to immaturity or poor initial adjustment to school. As they grew older, it is possible that their behavioural symptoms reduced and so their parents did not seek help from specialist health services. The possibility that the presence of symptoms was not perceived as problematic is supported by the finding that, compared to parents of service users, a smaller proportion of parents of service non-users sought help from other sources. However, it is notable that most parents in the sample (regardless of whether the child was a service user or not) had sought help from the class teacher.

The most frequently reported barrier was that insufficient information was available about who could help. Other common barriers included delays in receiving help, professionals not listening or poor communication amongst professionals, and perceptions that nobody could help or that services were not available. Although it may seem surprising that parents of service users reported more barriers than non-users, this is likely to reflect the greater severity of their child's difficulties (e.g. 44% met criteria for ADHD) and their attempts to seek help for these. In negotiating these barriers to receive specialist healthcare, the majority of parents indicated that they had requested the referral – primary healthcare and education professionals were the most common referrers.

It was encouraging to note that most (90%) of the sample who met criteria for ADHD at follow-up had used specialist services. This suggests that the more severely affected children (whose symptoms and impairment persisted between the ages of 5 to 10 years) were better able to access services. Severity of problems is an important determinant of service use [7,25,27,28]. However, in adjusted analyses, neither ADHD nor the presence of associated comorbid symptoms predicted service use. The lack of association with comorbid symptoms and parental perception of burden is in contrast to other literature [7,22-26,28]. The main concurrent predictor of service use was a higher level of parental mental health problems. This finding contributes to the literature as other studies have not found this association in analyses that adjust for child-level clinical factors [7,24,28,29]. It is possible that some differences in findings across studies might relate to differences in study design, this study reflecting a case-control comparison of service users and non-users nested within a long-term follow-up study. For example, the design precluded investigation of the roles of child age and gender in determining service use.

In terms of medication use, amongst children who met criteria for ADHD and had seen specialist health services, 36% had been prescribed stimulant medication. Although this proportion is lower than a 54% rate reported in another UK study [7], it is broadly in keeping with other international literature involving community samples suggesting that less than half of children with ADHD receive medication [23,30-32].

Methodological Issues

Study strengths include the longitudinal study design and large sample size. A two-stage approach was used to enquire about service use, including the use of a reliable and valid interview to assess service use. Similarly rigorous criteria using information elicited from both teacher and parent were used to assess for the presence of ADHD. However, differential diagnoses may have not been considered sufficiently as the children were not assessed directly. The study has a number of limitations. First, although most parents of service users and non-users were successfully interviewed, there was considerable attrition in terms of the initial response rate to the SDQ [9]. Second, we relied on parental recall for prescribed medication and did not have information from case records about any clinical diagnoses received. Third, the gender matched case-control design meant that the role of gender in influencing service use could not be examined. To address this, future research should aim to over-sample girls [33]. Fourth, we did not obtain information about family history of ADHD and associated knowledge and help-seeking. Fifth, although we found that most parents had consulted a teacher, we are unable to illuminate how this influenced further help-seeking as we did not obtain information about teacher attitudes and beliefs towards ADHD [34].

Implications

Although the service users and non-users may reflect different groups in terms of baseline severity and persistence of symptoms, it is also possible that for some of the service nonusers there is a delay in accessing services. The service users would have been non-users at one stage and it is possible that factors other than symptom severity may have led to the specialist referral or parental decision to seek help (e.g. parental mental health difficulties). It is important for teachers and clinicians to be aware of the role that parental mental health symptoms may play in help-seeking for child behaviour. The development of care pathways needs to take into account the need for parents to receive appropriate help in their own right whilst also ensuring that children with behavioural problems whose parents do not have mental health problems are able to access services.

REFERENCES

- 1. Polanczyk G, de Lima MS, Horta BL et al (2007) The worldwide prevalence of ADHD: a systematic review and metaregression analysis. Am J Psychiatry 164:942-948.
- 2. Barbaresi WJ, Katusic SK, Colligan RC et al (2007) Long-term school outcomes for children with attention-deficit/hyperactivity disorder: a population-based perspective. J Dev Behav Pediatr 28:265–273.
- 3. Merrell C, Tymms PB (2001) Inattention, hyperactivity and impulsiveness: Their impact on academic achievement and progress. Brit J Educ Psychol 71:43-56.
- 4. Shaw M, Hodgkins P, Herve C et al (2012) A systematic review and analysis of longterm outcomes in attention deficit hyperactivity disorder: effects of treatment and non treatment. BMC Med 10:99.
- 5. Washbrook E, Propper C, Sayal K (2013) Pre-school hyperactivity and attention problems and educational outcomes in adolescence: prospective longitudinal study. Br J Psychiatry 203:265-271.
- 6. Willoughby MT (2003) Developmental course of ADHD symptomatology during the transition from childhood to adolescence: a review with recommendations. J Child Psychol Psychiatry 44:88–106.
- Sayal K, Ford T, Goodman R (2010) Trends in recognition and service use for Attention Deficit / Hyperactivity Disorder in Britain, 1999-2004. Psychiatr Serv 61:803-810.
- 8. Tymms PB, Merrell C (2006) The impact of screening and advice on inattentive, hyperactive and impulsive children. Eur J Spec Needs Educ 21:321-337.

- 9. Sayal K, Owen V, White K et al (2010) The impact of early school-based screening and intervention programs for ADHD on children's outcomes and access to services Follow-up of a School-Based Trial at Age 10 Years. Arch Pediatr Adolesc Med 164:462-469.
- 10. Goodman R (1999) The extended version of the Strengths and Difficulties Questionnaire: as a guide to child psychiatric caseness and consequent burden. J Child Psychol Psychiatry 40: 791-799.
- 11. Goodman R, Ford T, Meltzer H (2002) Mental health problems of children in the community. BMJ 324:1496-1497.
- 12. Jarman B (1984) Underprivileged areas: validation and distribution of scores. BMJ 289:1587-1592.
- 13. Taylor E, Sandberg S, Thorley G et al (1991) The epidemiology of childhood hyperactivity. Oxford University Press, Oxford.
- 14. Asherson P, Brookes K, Franke B et al (2007) Confirmation that a specific haplotype of the dopamine transporter gene is associated with combined-type ADHD. Am J Psychiatry 164:674-677.
- 15. Sayal K, Hornsey H, Warren S et al (2006) Identification of children at risk of ADHD: a school-based intervention. Soc Psychiatry Psychiatr Epidemiol 41:806-813.
- 16. Sayal K, Taylor E (2005) Parent ratings of school behaviour in children at risk of Attention Deficit/Hyperactivity Disorder. Acta Psychiatr Scand 111:460-465.
- 17. Sayal K, Goodman R (2009) Do parental reports of child hyperkinetic disorder symptoms at school predict teacher ratings? Eur Child Adolesc Psychiatry 18:336-344.
- 18. Goodman R, Ford T, Richards H, et al (2000) The Development and Well-Being Assessment: description and initial validation of an integrated assessment of child and adolescent psychopathology. J Child Psychol Psychiatry 41:645-655.
- 19. Rutter M, Tizard J, Whitmore K (1970) Education, Health, and Behaviour. Longman, London.
- 20. Rodgers B, Pickles A, Power C et al (1999) Validity of the malaise inventory in general population samples. Soc Psychiatry Psychiatr Epidemiol 34:333-341.
- 21. Ford T, Hamilton H, Dosani S et al (2007) The children's services interview: validity and reliability. Soc Psychiatry Psychiatr Epidemiol 42:36-49.
- 22. Bussing R, Zima BT, Belin TR (1998) Differential access to care for children with ADHD in special education programs. Psychiatr Serv 49:1226-1229.
- 23. Cuffe SP, Moore CG, McKeown R (2009) ADHD and health services utilization in the national health interview survey. J Atten Disord 12:330-340.

- 24. Ford T, Hamilton H, Meltzer H et al (2008) Predictors of service use for mental health problems among British school children. Child Adolesc Ment Health 13:32–40.
- 25. Sawyer MG, Rey JM, Arney FM et al (2004) Use of health and school-based services in Australia by young people with Attention-Deficit/Hyperactivity Disorder. J Am Acad Child Adolesc Psychiatry 43:1355-1363.
- 26. Sayal K (2004) The role of parental burden in child mental health service use: longitudinal study. J Am Acad Child Adolesc Psychiatry 43:1328-1333.
- 27. Sourander A, Santalahti P, Haavisto A et al (2004) Have there been changes in children's psychiatric symptoms and mental health service use? A 10-year comparison from Finland. J Am Acad Child Adolesc Psychiatry 43:1134-1145.
- 28. Tick NT, van der Ende J, Verhulst FC (2008) Ten-year increase in service use in the Dutch population. Eur Child Adolesc Psychiatry 17:373-380.
- 29. Verhulst FC, van der Ende J (1997) Factors associated with child mental health service use in the community. J Am Acad Child Adolesc Psychiatry 36:901-909.
- 30. Froehlich TE, Lanphear BP, Epstein JN et al (2007) Prevalence, recognition, and treatment of attention-deficit/hyperactivity disorder in a national sample of US children. Arch Pediatr Adolesc Med 161:857-864.
- 31. Sawyer MG, Rey JM, Graetz BW et al (2002) Use of medication by young people with attention-deficit/hyperactivity disorder. Med J Aust 177:21-25.
- 32. Tremmery S, Buitelaar JK, Steyaert J et al (2007) The use of health care services and psychotropic medication in a community sample of 9-year-old school children with ADHD. Eur Child Adolesc Psychiatry 16:327-336.
- 33. Bussing R, Zima BT, Gary FA, et al (2003) Barriers to detection, help-seeking, and service use for children with ADHD symptoms. J Behav Health Serv Res 30:176-189.
- 34. Moldavsky M, Groenewald C, Owen V, et al (2013) Teachers' recognition of children with ADHD: role of subtype and gender. Child and Adolescent Mental Health 18:18-23.

	Service	Non-users	p value (McNemar test)	
	users			
	(n=81)	(n=81)		
Class teacher	78 (96%)	51 (63%)	< 0.001	
Family	75 (93%)	42 (52%)	< 0.001	
Friends	75 (93%)	25 (31%)	< 0.001	
GP/Primary care	56 (69%)	7 (9%)	< 0.001	
Internet	48 (59%)	15 (19%)	< 0.001	
Accident and emergency	22 (27%)	1 (1%)	< 0.001	
Self-help group	13 (16%)	1 (1%)	0.002	
Telephone helpline	11 (14%)	2 (2%)	0.012	
Voluntary agency	8 (10%)	0 (0%)	-	
Private/alternative therapist	7 (9%)	0 (0%)	-	

Table 1: Where do caregivers seek help?

n (%) of those who had sought help from each source

Service users - had accessed specialist health services for emotional or behavioural difficulties Non-users - had not accessed specialist health services for emotional or behavioural difficulties

Table 2: Parent-reported barriers to service use

Barriers	Service User (n=81)	Service non-user (n=81)
A lack of information about who can help	61 (75%)	26 (32%)
Professionals did not listen when they asked for help	44 (54%)	5 (6%)
Experienced an unacceptable delay in waiting for help	40 (49%)	6 (7%)
Perception that no-one could help with their child's problems	40 (49%)	13 (16%)
Experience of poor communication between professionals involved with child	39 (48%)	6 (7%)
Perception that specialist services aren't available for this type of problem	35 (43%)	10 (12%)
Professionals refused to provide services or refer	24 (30%)	5 (6%)
Worried about what other people would think if help was sought	18 (22%)	2 (2%)
Worried about child being left with a record that might affect them in future	16 (20%)	4 (5%)
An earlier bad experience with professionals had put them off asking for help again	13 (16%)	4 (5%)
Worried about privacy and confidentiality	12 (15%)	3 (4%)
Perception of service offered as unacceptable	10 (12%)	0 (0%)
Worried about the cost of getting help in terms of travel or time off work	8 (10%)	2 (2%)
Services were not available at a time when parents could access them	6 (7%)	0 (0%)
Worried that their child might be taken away if help was sought	4 (5%)	1 (1%)

Service users - had accessed specialist health services for emotional or behavioural difficulties Non-users - had not accessed specialist health services for emotional or behavioural difficulties

Variable	Service	Service	Unadjusted	р	Adjusted	р
	User	Non-User	Odds Ratios	value	Odds Ratios*	value
	(n=81)	(n=81)	(95% CI)		(95% CI)	
	mean	mean				
	(s.d.)	(s.d.)				
Baseline	6.53	5.73	1.19	0.026	1.40	0.004
inattention (0-9)	(1.89)	(2.31)	(1.02-1.40)		(1.12-1.76)	
Baseline	5.00	3.69	1.20	0.006	1.23	0.009
hyperactivity/	(3.01)	(2.89)	(1.05-1.36)		(1.05-1.44)	
impulsivity						
(0-9)						
Underprivileged	2.11	0.93	1.08	0.075	1.12	0.065
Area score	(4.54)	(3.83)	(0.99-1.18)		(0.99-1.26)	

Table 3: Relationship between baseline predictor measures and service use

* Adjusted odds ratio estimates from a multivariable logistic regression model that mutually adjusts for baseline inattention and hyperactivity/impulsivity, Underprivileged area score and trial arm.

Variable	Service	Service	Unadjusted	p value	Adjusted	p value
(range)	User	Non-User	Odds Ratios		Odds Ratios	
	(n=81)	(n=81)	(95% CI)		(95% CI)*	
	n (%) or	n (%) or				
	mean	mean				
	(s.d.)	(s.d.)				
Single parent	23/80	13/80	2.00	0.074	0.64	0.599
family	(29%)	(16%)	(0.94-4.27)		(0.12-3.45)	
ADHD (y/n)	36 (44%)	4 (5%)	17.00	< 0.001	1.86	0.635
			(4.08-70.76)		(0.14-24.09)	
Emotional	4.54	2.17	1.46	< 0.001	1.17	0.346
problems	(2.52)	(2.13)	(1.23-1.73)		(0.85-1.62)	
(0-10)			``````````````````````````````````````			
Conduct	4.09	1.66	2.04	< 0.001	0.98	0.945
problems**	(2.56)	(1.47)	(1.49-2.80)		(0.59-1.64)	
(0-10)						
Parent-reported	1.79	0.34	4.79	< 0.001	2.03	0.178
Burden**	(1.00)	(0.59)	(2.52-9.09)		(0.72-5.69)	
(0-3)						
Malaise	6.58	1.03	1.91	< 0.001	1.41	0.027
score**	(4.58)	(1.76)	(1.38-2.64)		(1.04-1.91)	
(0-24)						

Table 4: Relationship between follow-up measures and service use

* Adjusted odds ratio estimates from a multivariable logistic regression model that mutually adjusts for single-parent family status, ADHD status, emotional problems, conduct problems, parent-reported burden (SDQ), and Malaise score.

**n=80