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Assessing the standard of care for child and adolescent attention-deficit hyperactivity disorder in Elgin County, Ontario: a pilot study

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Objective: To examine the current practice of rural family physicians in managing children with attention-deficit hyperactivity disorder (ADHD).

Design: Chart review of children and adolescents with a recorded diagnosis of ADHD. The data collected include the patient's age at diagnosis, the diagnosing physician, the number and type of presenting symptoms, whether the *Diagnostic Statistical Manual, 4th ed* (DSM-IV) criteria were met, pertinent treatment regimens, family history and comorbid conditions. Participating physicians were asked to complete a questionnaire.

Setting: Elgin County, Ontario

Results: Thirty-six family physicians were contacted and 11 agreed to participate. Thirty-nine charts were reviewed. The average number of presenting symptoms was 2.9 for ADHD-inattentive subtype and 2.1 for ADHD-hyperactivity subtype. A diagnostic protocol was included in 20.5% of the charts. Of the 39 charts reviewed, 25.6% had sufficient information for the patients to meet the ADHD criteria. Family physicians diagnosed 5.1% of the cases, and the duration of time between referral to specialist and appointment was 47.2 weeks.

Conclusions: Together the lack of symptom recording, the long duration between referrals, and the low percentage of family physicians diagnosing ADHD all suggest the need for developing diagnostic protocols for family physicians and increasing their knowledge of diagnosing and managing ADHD.

Objectif : Étudier la pratique actuelle des médecins de famille ruraux en ce qui concerne la prise en charge des enfants atteints du trouble d'hyperactivité avec déficit de l'attention (THADA).

Concept : Étude du dossier d'enfants et d'adolescents chez lesquels on a diagnostiqué officiellement un THADA. Les données recueillies comprennent l'âge du patient au moment du diagnostic, le nom du médecin diagnosticien, le nombre et le type de symptômes, l'atteinte ou non des critères du *Manuel diagnostique et statistique, 4^e éd.* (DSM-IV), les protocoles de traitement pertinents, les antécédents familiaux et des problèmes comorbides. On a demandé aux médecins participants de répondre à un questionnaire.

Contexte : Comté d'Elgin, Ontario

Résultats : On a communiqué avec 36 médecins dont 11 ont consenti à participer. On a étudié 39 dossiers. Le nombre moyen de symptômes s'est établi à 2,9 dans le cas du sous-type THADA-inattention et à 2,1 dans celui du sous-type THADA-hyperactivité. On a inclus un protocole de diagnostic dans 20,5 % des dossiers. Sur les 39 dossiers analysés, 25,6 % contenaient suffisamment d'information pour que les patients satisfassent aux critères relatifs au THADA. Des médecins de famille ont diagnostiqué 5,1 % des cas et il s'est écoulé en moyenne 47,2 semaines entre la référence à un spécialiste et le rendez-vous.

Conclusions : Pris ensemble, la non-consignation des symptômes, la longueur de la période écoulée entre les références et le faible pourcentage de médecins de famille qui diagnostiquent le THADA indiquent qu'il faut élaborer des protocoles de diagnostic à l'intention des médecins de famille et améliorer leur connaissance du diagnostic et de la prise en charge du THADA.

Emotional and behavioural problems in children and adolescents are becoming increasingly prevalent.¹ The most common psychiatric disorder in children and adolescents is attention-deficit hyperactivity disorder (ADHD). The prevalence rate of ADHD is 3%–5%,² with up to 10% of boys and 5% of girls of elementary school age meeting its diagnostic criteria.³ The importance of this disorder is often underestimated. A common misconception is that ADHD is limited to childhood. In fact, 75% of adolescents with ADHD continue to experience difficulties in the home and school environment.⁴ Ten percent of children with an ADHD diagnosis have clinically significant disorders in adulthood,⁵ and 60% have difficulties with concentration.⁶ Clearly, ADHD is a condition that persists into adulthood and is associated with significant morbidity.

Currently there is a shortage of child psychiatrists in Ontario; there is approximately 1 child psychiatrist for every 6148 pediatric patients with mental health problems.⁷ In addition, Ontario child psychiatrists are disproportionately concentrated in large metropolitan centres such as Toronto, leaving them vastly under-represented in rural Ontario communities. Since only 30% of urban child psychiatrists provide outreach services to smaller communities,⁷ rural family physicians (FPs) bear the weight of dealing with the majority of childhood behavioural and emotional problems. Approximately 60% of children identified with a *Diagnostic Statistical Manual*, 4th ed (DSM-IV) disorder continue to be treated by their FPs.⁸ This emphasizes the significant position of the primary care physician in detecting and intervening in child and adolescent mental health problems. Therefore, it is critical that FPs be able to identify, assess and treat them.

A recent survey of FPs in rural and underserved Southwestern Ontario found that 80% of FPs do not feel comfortable in their knowledge and skills in managing children's mental health problems.⁹ Approximately 84% of the practitioners felt that they needed more training, principally in the areas of behavioural disorders, ADHD and problem adolescents. These FPs would like increased access to child and adolescent mental health services and additional training in child psychiatry. The survey results are not surprising given that a 1998 study, which examined the amount and type of child psychiatry in Canadian Family Medicine training programs, found that merely 4 of the 16 Family Medicine Residency teaching programs across Canada have recognized training in child psychia-

try.¹⁰ Interestingly, the Family Medicine program directors also remarked on the significance of teaching about behavioural issues, depression, suicide and ADHD.¹⁰

There is a dearth of literature on how FPs are assessing and treating children with ADHD. We decided to conduct a pilot study to determine how FPs are currently diagnosing and managing children with ADHD in rural family practices in Elgin County, Ontario. In 2002, we carried out a quality-control by objective criteria audit of the office charts of 11 of 36 FPs in Elgin County. Physicians also completed a supplementary questionnaire. The FPs' approach was compared with the current protocols recommended by the American Academy of Child and Adolescent Psychiatry (AACAP).³ Since ADHD frequently continues into adulthood⁵ and is commonly accompanied by poor psychosocial outcome and comorbid conditions,^{5,11} it is important to determine the current state of FPs' assessment and management of ADHD.

METHOD

The study comprised a chart review of children and adolescents diagnosed with ADHD by FPs in Elgin County, Ontario. Initially, 1 clinic with 5 FPs in St. Thomas was randomly selected and agreed to participate in the study. Subsequent to reviewing charts in this office, it was decided that the study would be extended to include all FPs in Elgin County, as the number of charts obtained was low. The Public Relations office at the St. Thomas–Elgin General Hospital provided a list of FPs in Elgin County. This list was compiled in February 2002, and all 36 of the physicians on the list were contacted for participation in the study. Those who agreed in the first 3 phone call attempts ($n = 11$) were included in the study and their charts were reviewed by one of the study investigators. The participating family practice offices were asked to pull the charts of all patients with a recorded diagnosis of ADHD for which treatment was sought.

In order to be included in the study, the patients whose charts were reviewed had to be under the age of 18 years at the time of diagnosis. In addition, it was necessary that the chart listed a diagnosis of ADHD and that some form of treatment was administered. Charts of patients with hyperactive, impulsive or inattentive symptoms were excluded from the study if the diagnostic term of ADHD was not used. A data collection sheet was created to facilitate the chart review process. The information

collected included the age at time of diagnosis, the diagnosing physician, the number and type of presenting symptoms, whether DSM-IV criteria were met,² the number and type of specialist referrals, as well as information on treatment regimens. Data on comorbid conditions, family history and other factors for differential diagnoses were also gathered.

To supplement the chart review, physicians were asked to complete a questionnaire that was developed by the authors, and mail it back to the project coordinators. The purpose of the questionnaire was to collect background information on the different practices as well as to examine the physicians' perspectives on how they assess and treat children and youth with ADHD.

The pilot study was conducted and all data were collected during July and August of 2002. Prior to the commencement of this project, approval was received from the University of Western Ontario's Ethics Review Board. Chart and questionnaire data were analyzed using SPSS, version 11.5.

RESULTS

Eleven physicians agreed to participate in this study, and 9 of the 11 physicians completed the supplementary questionnaire. Eight of the 9 questionnaires provided values that estimated the number of pediatric patients in the practice. The number of pediatric charts per office ranged from 347 to approximately 1000, with the average number being 583. The number of ADHD charts pulled in each of the offices ranged from 1 to 9, with the mean chart number being 3.5.

The total number of ADHD charts reviewed in this pilot study was 39, of which 76.9% were for male patients. The most common current age range was 8–12 years old (58.9%) with the mean age being 12.1 years and the median age 11 years. The age at diagnosis was recorded for 27 of the 39 charts, and the majority of the diagnoses (55.6%) were made between the ages of 0–7 years. The mean and median ages at the time of diagnosis were 7.7 and 8 years, respectively.

The average number of inattention symptoms recorded was 2.9, and the average number of hyperactivity symptoms recorded was 2.1. Charts were examined for diagnostic protocols that could have aided in the diagnosis of ADHD. In particular, the investigators looked for standardized rating scales such as the Conners' Teacher Rating Scale (CTRS-R),¹² Conners' Parent Rating Scale (CPRS-R),¹³ the SNAP-IV (revised version of the Swanson, Nolan

and Pelham [SNAP] 1983 Rating Scale),¹⁴ a checklist of DSM-IV ADHD criteria² or completed forms by school psychologists. Diagnostic protocols were included in 20.5% of the charts, and the FP made the diagnosis in 5.1% of cases. Ten patients (25.6%) had sufficient criteria in their charts to be diagnosed with ADHD (Table 1).

All patients were referred to specialists, with pediatricians (59.0%) being the most common specialists for referral (Table 1). The average duration between time of referral and appointment with a specialist was approximately 47.2 weeks.

In 64.1% of the charts, there was no mention of a family history of ADHD (Table 1). Forty-nine percent of all patients had a record of some form of psychometric testing, and, of these patients, 23.1% received the Wechsler Intelligence Scale for Children, 3rd ed (WISC-III),¹⁵ 23.1% underwent behavioural testing and 20.5% received educational tests.

Thirty-four percent of the patients had a significant past or comorbid medical and/or psychiatric condition. The most common conditions were oppositional defiant disorder (10.3%), depression and/or anxiety (10.3%), hearing loss (5.1%), learning disabilities (5.1%) and recurrent otitis media (5.1%).

Eighty-seven percent of the patients received treatment in the form of medication at some point after the diagnosis of ADHD was made. The average number of prescription changes was 1.7. The most common medication prescribed at any time

Table 1. Chart information for children and adolescents diagnosed with attention-deficit hyperactivity disorder (ADHD) by family practitioners in Elgin County, Ontario

Chart information	% of charts
Sufficient criteria for diagnosis of ADHD	25.6
ADHD-hyperactivity subtype	2.6
ADHD-inattentive subtype	12.8
ADHD-combined subtype	10.3
Diagnostic protocol included	20.5
Mention of family history	35.9
Family history positive for ADHD and/or Learning Disorder	28.2
Patient referred to	
Pediatrician	59.0
Child psychiatrist	41.0
Psychologist	12.0
Social worker	12.8
Treatment prescribed	
Ritalin	71.8
Ritalin SR	48.7

was Ritalin (Table 1). Other medications prescribed include dextroamphetamine, clonidine, and pemo-line; the latter is currently not on the market.

None of the physicians who answered the questionnaire reported having received training in diagnosing and/or treating ADHD. However 55.6% felt comfortable diagnosing ADHD and 44.4% were comfortable treating ADHD patients. Thirty-eight percent of the physicians agreed that they follow a diagnostic protocol when dealing with a suspected ADHD patient, and these protocols ranged from referring to a pediatrician, to observing the child's behaviour in the office and to reading school reports. All 9 physicians agreed that they would refer a suspected ADHD patient to a pediatrician, and 33.3% would also consider sending the patient to a child psychiatrist. In terms of ADHD management, 33.3% of the physicians assumed primary responsibility for treating their ADHD patients, 22.2% only managed ADHD patients following pediatric referrals and 44.4% did not manage ADHD cases.

Sixty-three percent of the FPs indicated that they make prescription changes based on parent and teacher reports. Twenty-five percent base their decision on side effects, and 38% make changes on the basis of symptom severity. Thirteen percent agreed that they adjust medication doses subsequent to specialist recommendations. The duration between follow-up visits with the FP ranged from 1 to 5 months, with the average being 3 months.

DISCUSSION

According to the DSM-IV, the prevalence of ADHD among school aged children is 3%–5%.² The male:female ratio ranges from 3:1 to 4:1 depending on the subtype of ADHD.² The male:female ratio in this study (3.3:1) is consistent with reported prevalence rates. Nevertheless, when one looks at the prevalence of ADHD and the number of pediatric patients in each practice, between 140 and 233 ADHD charts should have been pulled for data collection; only 39 charts were pulled in all 11 offices. This is approximately 20% of what would have been expected assuming that the above demographic information is correct.

There are various reasons why the total number of charts reviewed may be lower than expected. ADHD may be underdiagnosed by rural FPs. As previously mentioned, 80% of rural FPs do not feel confident in their knowledge and skills in managing children with mental health needs. Many feel that

they would benefit from additional training in pediatric and adolescent problem areas, such as ADHD.⁹ This is further supported by this study's questionnaire, which found that only 55.6% of the physicians were comfortable diagnosing ADHD and 44.4% felt comfortable managing ADHD. Therefore, physicians may be lacking the confidence and skills required to detect, diagnose and manage ADHD, and this could have contributed to a low chart number.

In support of this theory, the charts of many children who were considered to have a diagnosis of ADHD lacked a list of symptoms or a copy of a diagnostic protocol that would have confirmed the diagnosis. According to the information collected in the chart reviews, only 25.6% of the patients had sufficient criteria in their charts to be diagnosed with ADHD and 20.5% of the total charts had a copy of a diagnostic protocol. The lack of information in the charts may indicate that the diagnosis was made by a physician to whom the patient was referred. It may also indicate that FPs may not know the full DSM-IV criteria for ADHD or that they do not have enough time to chart all symptoms. It could also imply that some FPs make the diagnosis based on a symptom or cluster of symptoms that resemble ADHD. Clear diagnostic protocols for ADHD, including existing questionnaires such as the SNAP,¹⁴ together with a thorough history and physical examination, may assist FPs in identifying children and adolescents with ADHD.

Many disorders tend to co-occur with ADHD. Previous studies have found that comorbidity is present in as many as two-thirds of clinically referred patients with ADHD, including up to 50% for oppositional defiant disorder, 15%–20% for mood disorders and 20%–25% for anxiety disorders.^{11,16} In this pilot study, approximately one-third of the patients were diagnosed with a comorbid condition. Oppositional defiant disorder was the most common comorbid condition, followed by anxiety and/or depression; nevertheless, they were both present in only 10% of the patients. It is possible that this divergence between the predicted rate of comorbidity and what was actually seen is due to the small sample size of the pilot study. It may be a reflection of a lack of FP confidence and/or knowledge in diagnosing mental health problems in children and adolescents. Similarly, learning disabilities, hearing loss and recurrent otitis media may certainly co-occur with ADHD, but they may also independently interfere with attention, therefore leading to a misdiagnosis of ADHD. The high prevalence of co-

existing medical/psychiatric conditions suggests that there may be a need to further educate FPs about comorbidity and how to distinguish the symptoms of other conditions from ADHD.

In this study, all patients were referred to a specialist, with pediatricians and child psychiatrists making the diagnosis in the majority of cases, and FPs diagnosing only 5.1% of the cases. However, when one looks at the long duration between referrals, the average being 47.2 weeks in Elgin County, it becomes apparent that FPs could be instrumental in diagnosing and treating ADHD quickly, thereby reducing morbidity for the child/adolescent and their families. The development of an ADHD diagnostic protocol specific for FPs could increase the probability that children with ADHD are being detected and managed much earlier in the course of the disorder.

The treatment of ADHD generally encompasses both psychosocial interventions and pharmacotherapy. In the present study, the pharmacological treatments, but not psychotherapeutic interventions, were examined. It was found that 87% of patients received some form of medication following their diagnosis with ADHD; this is in accordance with recent guidelines.¹⁷ Similarly, the first line of treatment in the majority of patients was a stimulant, and this agrees with the 1999 guidelines published in the Texas Children's Medication Algorithm Project.¹⁷ Clearly, rural FPs are treating patients with medication according to currently accepted practice guidelines. In retrospect, it would have been beneficial to examine how many patients were prescribed treatment for ADHD before being seen at the referral appointment with the psychiatrist or pediatrician.

Limitations

It is important to note that there may have been a bias in the physician population that participated in this pilot study. In retrospect, it would have been helpful to gather information on physician age, gender, education and years in practice. Although it has been found that female physicians have as broad a scope of practice as their male counterparts,¹⁸ some differences have been noted. For example, the proportion of female physicians who attend births tends to be higher than the proportion of males, regardless of years in practice in rural communities.^{18,19} One may speculate that perhaps younger and female physicians may have been more likely to have young families in their practice. Similarly, it is possible that FPs who have been educated in the

treatment of ADHD may see more children and adolescents with ADHD. For these reasons, the physicians who agreed to participate may not be representative of the 36 FPs practising in Elgin County. This supplementary information may help to determine whether the age and gender of the physician and their educational background affects the management of children and adolescents with ADHD.

A methodological limitation of the pilot study itself may have partly attributed to the low chart number. Although the FP offices were asked to pull files of all children that had a firm diagnosis of ADHD for which treatment was sought, it is likely that there were some variations in the way that this was conducted. For example, some offices may have pulled charts using recall of patient profiles while in other circumstances it is possible that if a patient was being seen at the time of the chart review, that perhaps the file was unavailable. Clearly, the lack of electronic medical records made accurate identification of charts of all ADHD patients difficult. This may have led to both under-representation and/or misrepresentation of the patient sample. Furthermore, this study must also be interpreted within the limitations of all studies conducted by retrospective chart review. A recommendation for future study of this topic would be to follow patients assessed by FPs prospectively.

CONCLUSIONS

The results of this pilot study demonstrate that FPs in Elgin County varied in their degree of success in following the AACAP's criteria of good care for patients with ADHD. It also suggests — at the very least, based on the physicians' perspectives — the need of assisting FPs with the acquisition of the requisite skills, knowledge and diagnostic tools required to manage children's mental health needs. In order to enhance the diagnosis and treatment of children and youth with ADHD a number of recommendations are proposed. Education in the area of children's mental health needs to occur at a variety of levels. More child psychiatry teaching should be incorporated into the medical school curriculum both didactically and clinically. Most importantly, family medicine residency programs need to be targeted. Of particular concern is the lack of teaching of child psychiatry in 12 of the 16 Family Medicine programs across Canada.¹⁰ Ideally the training of child psychiatry needs to occur during the Family Medicine residency programs so that future FPs

become alert to children's mental health problems early in their careers. In addition, continuing medical education of FPs would be important so that they can continue to learn about new ways to diagnose and manage children and youth with ADHD.

It would be invaluable to develop a protocol specific for FPs that is directed at diagnosing ADHD. This protocol would have to be easy to use and needs to take into consideration the time constraints of a busy family practice.

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Competing interests: Dr. Margaret Steele has been involved with the following companies for industry-funded research: Janssen Pharmaceuticals, Eli Lilly (current), Wyeth-Ayerst, Smith Kline Beecham, and Pfizer. She has been on National Advisory Board meetings for Janssen Pharmaceuticals and for Eli Lilly. She has also spoken for the following companies: Janssen Pharmaceuticals, Shire Biochem Inc., and Organon, and has obtained unrestricted educational grants for conferences or CME (for the UWO Division of Child Psychiatry) from Janssen Pharmaceuticals, Eli Lilly, Shire Biochem Inc., Organon, Glaxo Smith Kline, Wyeth Ayerst, Astra Zeneca, and Lundbeck. No competing interests were declared for Natalie Kotowycz or Susan Crampton.

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