Delay of Attention-deficit–Hyperactivity Disorder Diagnosis in France – Reasons and Resolutions

a report by
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Attention-deficit–hyperactivity disorder (ADHD) is a frequent, chronic and impairing condition that persists into adulthood in a significant number of patients. ADHD is characterised by age-inappropriate levels of impulsivity, inattention and motor hyperactivity, and is frequently associated with other disruptive behaviours, learning disorders, anxiety or substance use. ADHD is a multifactorial and heterogeneous disorder determined by complex interactions between genes and environment. In addition to the impairments associated with the behavioural and cognitive symptoms of ADHD, patients and their families also may suffer from social stigma and general misconceptions about the disorder. Adequate diagnosis and treatment of ADHD are needed to improve not only ADHD core symptoms, but also social, academic and familial functioning. Current guidelines recommend the use of evidence-based criteria to improve the reliability and validity of diagnosis. Multimodal treatments combining behavioural interventions and well-monitored medications tailored to individual needs have shown significant benefits in short- and medium-term outcomes (Multimodal Treatment Study of ADHD [MTA] trial). Factors associated with under- (and over-) diagnosis and diagnostic delay should be assessed and addressed in order to optimise the patient’s access to appropriate care. Despite similar rates of ADHD in North America and Europe, with an aggregated prevalence of 5.9% in epidemiological studies with standardised assessments, local medical culture, public health policies and beliefs carried by media and general opinion may influence the diagnosis of ADHD and available treatment options.

Attention-deficit–Hyperactivity Disorder – Delays in Time to Appointment and Diagnosis and Related Factors

A recent study investigating predictors of diagnostic delay in a French sample of referred ADHD patients showed that the mean delay between the first appointment for impairing symptoms and ADHD diagnosis was 2.8 years. Another investigation in nine other countries showed that mean time to diagnosis was generally below two years, except in Italy, where there was a diagnostic delay of 3.1 years. This makes the diagnostic delay in France among the longest reported worldwide.

Several factors were related to time to ADHD diagnosis in the French sample, including co-morbidity profiles and patterns of healthcare access. In the majority of cases, the professionals suspecting ADHD were general practitioners. Paradoxically, previous contact with mental care professionals was associated with a longer time to diagnosis. Clinical presentation of symptoms, specifically ADHD with co-morbid anxiety/depressive disorders, was also linked to a significantly larger diagnostic delay related to overlapping symptoms (e.g. impaired sustained attention) between the conditions. These results also indicate that there may be differences between mental health professionals and primary care practitioners with regard to ADHD diagnosis or suspicion, the latter being more familiar with evidence-based medicine. Psychodynamic and sociological approaches to behavioural disorders, popular among many child psychiatrists in France, sometimes promote critical attitudes towards diagnostic criteria, biological underpinnings of behaviour and medications. In this context, ADHD symptoms may be preferentially attributed to other diagnostic categories (e.g. behavioural expression of internalised disorders, protection from depressive breakdown) or considered a reaction to environmental factors (e.g. stressful parent–child interactions, early trauma).

In some cases, ADHD may have been suspected but not discussed with parents. Fear of overdiagnosis of ADHD and overprescription of stimulants may also affect diagnostic delay. The widespread public perception of ADHD as ‘overdiagnosed’ is possibly shared by a number of healthcare professionals. In a recent analysis, Sciutto et al. showed no evidence that the rate of false-positives was greater than the rate of false-negatives in ADHD. Similarly, the public perception of ADHD not being a ‘real’ disorder contrasts with general scientific agreement on its validity, even in the absence of relevant biological markers. In addition to a long time to diagnosis in ADHD, there was also a significant delay between the first impairing symptoms appearing and the first healthcare appointment (mean three years) in the French ADHD sample. This may be due to the reluctance of parents to seek help, or limited access to mental healthcare.

Regulatory and Healthcare Specificities of Attention-deficit–Hyperactivity Disorder in France

Factors related to a delay in ADHD diagnosis in France should be examined in the context of the organisation of healthcare facilities and regulatory aspects. Methylphenidate is currently the only compound marketed in France for ADHD in children above six years of age. It has been on the
market since 1995. There are different presentations available: 10mg immediate-release tablets (Ritaline®) and two slow-release compounds, Ritaline LP® (20, 30 or 40mg, acting for eight to 10 hours) and OROS® methylphenidate (MPH) (Concerta®, 18, 36 or 54mg, acting for up to 12 hours). In France, MPH is classified by regulatory services as a schedule II drug with restricted conditions placed upon prescription and delivery.

The initial prescription of MPH is limited to hospital settings and can only be issued by child psychiatrists, child neurologists and paediatricians. Special prescription forms are used, with treatment name and dose written in letters. The maximum duration of treatment before renewing the prescription is 28 days. General practitioners and specialists in private practice can then renew prescriptions for up to one year. A yearly prescription must be issued by a specialist in a hospital setting. These regulatory restrictions are intended to limit overprescription and misuse of stimulants, but may also hinder access to medication in children with debilitating ADHD symptoms.

There is still a lack of hospital settings offering specific assessments, medication titration and follow-up for patients with suspected ADHD. Referral procedures to these second-line centres often involve written information from parents, schools and health professionals, and most of them have long waiting lists. A recent study carried out in the US showed that children from low socioeconomic status families are the most likely to meet criteria for ADHD, but receive less appropriate medication compared with children from wealthier backgrounds. In France, disparities in mental healthcare access have not been specifically studied in ADHD but, if present, may be more related to disparities in healthcare on offer, complexity of referral procedures and level of awareness of parents about ADHD than to reimbursement issues. Appropriateness and access to healthcare, along with pharmacoeconomic issues, should be assessed in representative samples across different countries.

**Prescription Trends**

A recent survey of MPH prescription prevalence in children and adolescents obtained from one of the three main national insurance funds (representing 4.5% of health insurance beneficiaries) showed low general levels of MPH prescription but a rapidly increasing trend between 2003 and 2005. The annual prevalence of MPH prescription per 1,000 persons increased from 1.1 to 1.8 during the observation period. The use of immediate-release methylphenidate has decreased since 2004 with the marketing of sustained-release compounds: 41% immediate-release and 59% sustained-release forms were prescribed in 2005. Increasing prescription trends have been documented in the US and several European countries, but the prevalence of MPH use in France remains comparatively low. Even in this context, rising prescription rates for ADHD and concerns about the safety of medications fuel the debate about overprescription of stimulants. Studies in other countries show that these prescription trends can be attributed to different factors, including overprescription, but may also be an indication of improved recognition, because rates rise more rapidly in groups that are often under-recognised, such as young girls and adults. The low prescription rates of stimulants in France also raise questions about the adherence of health professionals to best practice assessments and off-label use of medications (e.g. antidepressants, antipsychotics) in ADHD.

Knellwolf and al. also assessed reimbursement patterns in new medication starters. Unexpectedly in the treatment of a chronic condition, more than 50% of these patients seemed to be short-term or occasional MPH users. This finding may be related to the reluctance of parents or physicians to enter children into long-term treatment. Poor compliance, short-term side effects and problems with treatment indication or monitoring may also play a part. Parents may be exposed to negative opinions about ADHD medication without having the chance to discuss these issues in follow-up appointments. Reasons for this irregular and short-term usage pattern should be further explored to improve monitoring and conditions of shared care follow-up for children and adolescents receiving medication for ADHD.

**Improving the Diagnosis and Treatment of Attention-deficit–Hyperactivity Disorder**

Perceptions of the validity of ADHD and levels of awareness about ADHD symptoms, functional impairment and treatment options may influence the willingness of parents to seek help. The general perception of ADHD may also affect the development of healthcare and school services, as well as attitudes of professionals involved with ADHD patients. This parameter and the treatment histories of patients need to be investigated in non-referred samples. Evaluation of knowledge about ADHD, adherence to best practice guidelines and diagnostic criteria should be assessed in general practitioners and mental health professionals to further improve early recognition and appropriate treatment. Communicating accurate information about ADHD and providing education in primary and secondary care settings has to be developed, as well as specific guidance for teachers. An assessment of prescription trends needs to be implemented in France as well as in other countries, along with an investigation of variables possibly involved in differences in treatment strategies. High rates of short-term use of medications should encourage improvement of follow-up. For example, specialised centres should provide advice to families and physicians by means of a telephone hotline, or allow contact with specialised nurses or other members of the team.