



Research paper

The Caregiver Perspective on Paediatric ADHD (CAPP) survey: Understanding sociodemographic and clinical characteristics, treatment use and impact of ADHD in Europe



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ABSTRACT

Background: Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder that affects the lives of patients and their families. The Caregiver Perspective on Paediatric ADHD (CAPP) survey was conducted to evaluate the burden associated with ADHD in Europe and to identify unmet needs. Here, we describe sociodemographic and clinical characteristics, treatment use and impact of ADHD.

Methods: The cross-sectional web-based CAPP survey was fielded in 10 European countries among caregivers of children/adolescents (aged 6–17 years) with ADHD who were currently receiving or had received pharmacotherapy in the previous 6 months.

Results: Data on 3688 completed CAPP surveys were evaluated. Children/adolescents were diagnosed with ADHD at a mean age of 6.9 years; 80% were male. Most children/adolescents (56%) had undergone behavioural therapy. Overall, 78% of children/adolescents currently received ADHD pharmacotherapy; high rates of atypical antipsychotic use were reported in some countries. Overall, 23% of children/adolescents had repeated a school year and 4% had been expelled recently. Most caregivers (68–88%) reported difficulty with schoolwork, social interactions/activities and family relationships, even when the child/adolescent was receiving ADHD medication. Almost one third (31%) of caregivers felt the need to change employment status despite their child/adolescent receiving ADHD medication in 53% of these cases.

Limitations: Information was reported by caregivers recruited through market research panels; reporting, recall and selection biases may be present.

Conclusion: Variation across Europe was observed in characteristics of caregivers and children/adolescents with ADHD, and treatment use. Even with medication, ADHD compromised or negatively impacted caregivers' work and children/adolescents' schoolwork, their social interactions and family relationships.

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Abbreviations: AAP, atypical antipsychotic; ADD, attention-deficit disorder; ADHD, attention-deficit/hyperactivity disorder; APA, American Psychiatric Association; BT, behavioural therapy; CAPP, Caregiver Perspective on Paediatric ADHD; DGKJP, Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie und Psychotherapie; DSM, Diagnostic and Statistical Manual of Mental Disorders; IRB, institutional review board; SD, standard deviation; SINPIA, Società Italiana di Neuropsichiatria dell'Infanzia e dell'Adolescenza; WHO, World Health Organization

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1. Introduction

Attention-deficit/hyperactivity disorder (ADHD) affects 3–5% of children and adolescents worldwide (Polanczyk et al., 2007, 2014, 2015). This neurodevelopmental disorder is characterized by core features of hyperactivity, impulsivity and inattention (American Psychiatric Association, 2013; NICE, 2013). Functional impairment must also be present to meet ADHD diagnostic criteria (American

Psychiatric Association, 2013; NICE, 2013; World Health Organization, 2010). Psychological, social, educational and/or occupational impairment can have long-term consequences for an individual's health-related quality of life (Danckaerts et al., 2010; Klassen et al., 2004; Riley et al., 2006a). ADHD can also adversely affect the daily lives of parents or caregivers and other family members by causing difficulties at home and strain on relationships (Escobar et al., 2005; Harpin, 2005). The influence of hyperactivity and impulsivity on academic and social functioning also adds to the burden of families of children/adolescents with ADHD (Chen et al., 2014).

ADHD diagnostic and management practices vary by geographic location (Hinshaw et al., 2011; Seixas et al., 2012; Setyawan et al., 2015). Medical and behavioural therapy (BT) help reduce ADHD symptoms (MTA Cooperative Group, 1999) but the availability of, and access to, different treatment modalities varies across countries (Hinshaw et al., 2011; Hodgkins et al., 2013; Seixas et al., 2012; Setyawan et al., 2015). In general, European guidelines recommend multidisciplinary management that involves pharmacological treatment plus educational, psychological and behavioural interventions (Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie und Psychotherapie, 2007; Health Ministry of Spain, 2010; Landelijke Stuurgroep, 2007; NICE, 2013; SINPIA, 2002; Taylor et al., 2004). Pharmacotherapies currently approved for use in Europe include short- and long-acting formulations of stimulants such as methylphenidate and amphetamines, and the non-stimulants atomoxetine and guanfacine extended-release. European guidelines suggest the use of methylphenidate for initial pharmacological treatment of ADHD (Banaschewski et al., 2006; Taylor et al., 2004), and national guidelines in the UK, Spain, Germany, the Netherlands and Italy are generally consistent with this approach (Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie und Psychotherapie, 2007; Health Ministry of Spain, 2010; Landelijke Stuurgroep, 2007; NICE, 2013; SINPIA, 2002). Although pharmacological and non-pharmacological interventions may help reduce ADHD symptoms, some individuals continue to experience symptoms or functional impairment that negatively affect their own/their family's lives (Preuss et al., 2006; Ralston and Lorenzo, 2004). For example, approximately 30% of children/adolescents with ADHD fail to respond to treatment with a single stimulant and 10% do not respond to any stimulants (Arnold, 2000; Spencer et al., 1996).

'Real-world' studies can be used to identify and evaluate a broad range of issues that concern patients with ADHD and their families. Furthermore, real-world information on treatment use from patients or caregivers includes a broader and more heterogeneous population than those who are enrolled in clinical trials and may better reflect actual practice. The web-based cross-sectional Caregiver Perspective on Paediatric ADHD (CAPPA) survey was designed to evaluate the burden associated with ADHD and its treatment, and identify unmet needs in the management of this condition. To our knowledge, this is the first and largest community-based study to report on the burden and unmet needs of ADHD across many European countries. Sociodemographic and clinical characteristics, and treatment use, are described for the survey sample. We also present data on the impact of ADHD on the caregiver's social and family interactions and work, and on their child/adolescent's social interactions and schoolwork.

2. Methods

2.1. Study design

This cross-sectional survey of caregivers of children/adolescents aged 6–17 years with ADHD was conducted online between

November 2012 and April 2013 in Denmark, Finland, France, Germany, Italy, the Netherlands, Norway, Spain, Sweden and the UK.

2.2. Survey development

The survey was developed using concept elicitation methods that involved collection and analysis of qualitative data from 38 caregivers and 28 adolescents on areas of unmet need affecting children/adolescents with ADHD and their caregivers (Sikirica et al., 2015). Key domains identified were: difficulty obtaining a diagnosis; treatment effectiveness, satisfaction and compliance; impact of ADHD on the child (academic, family, social); impact of the child's ADHD on the caregiver (time, emotions, family, social, work); perceived support from school and healthcare systems; and perceived quality of care (Sikirica et al., 2015).

2.3. Survey questionnaire

The survey included questions on sociodemographic characteristics of caregivers and their child/adolescent with ADHD. From a predefined list based on those previously identified as common in an ADHD claims database study (Sikirica et al., 2013a), caregivers were asked to select any comorbid conditions/behaviours for which their child/adolescent has a current physician diagnosis. Caregivers were also required to record which medication(s) their child/adolescent received for ADHD using a pre-specified list identified using various treatment guidelines and clinical input, or a free-text field (i.e. 'Other, please specify').

Caregivers were asked to report on the child/adolescent's ADHD when 'on medication' and 'off medication'. Time off medication was defined as the following: the child/adolescent forgot to take medication; the child/adolescent intentionally chose not to take medication (e.g. holidays or weekends); in the afternoon or evening when the medication had worn off; or in the morning prior to the medication taking effect. These questions were included to evaluate the influence of ADHD treatment on the child/adolescent (in terms of symptoms [using the ADHD-Rating Scale-IV] and academic, family and social functioning), and the impact of the child/adolescent's ADHD on their caregiver (in terms of time, emotions, family, social and work). Only caregivers who reported that their child/adolescent had been off medication for any time in the past 6 months answered the off medication questions.

2.4. Survey translation

A cognitive debriefing study was conducted among UK caregivers (n=52) to confirm their ability to understand and complete the survey, and the appropriateness/comprehensiveness of survey items and response options. The survey was translated into local languages using single forward and backward translation methodology, and linguistically and culturally validated through cognitive interviews with five caregivers from each non-English-speaking country.

2.5. Ethical review

The study was reviewed and approved by a central institutional review board (IRB), MaGil IRB, and was performed in accordance with ethical standards of the Declaration of Helsinki. Caregivers were asked to provide informed consent before completing the survey.

2.6. Participants

Potential participants were identified by two market research companies using patient panels comprising individuals who had

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