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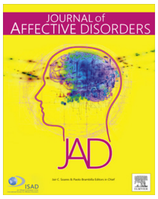

Research paper

The Caregiver Perspective on Paediatric ADHD (CAPPA) 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 (CAPPA) 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 CAPPA 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 CAPPA 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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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

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Abbreviations: AAP, atypical antipsychotic; ADD, attention-deficit disorder; ADHD, attention-deficit/hyperactivity disorder; APA, American Psychiatric Association; BT, behavioural therapy; CAPPA, 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, Societa' Italiana di Neuropsichiatria dell'Infanzia e dell'Adolescenza; WHO, World Health Organization

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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 agreed to be contacted to participate in research studies. These market research companies recruited patients from proprietary market research panels and those owned or maintained by various professional providers. Members were recruited to the market research panels using multiple approaches, including social media, online communities and website advertising.

An electronic screening questionnaire accessed via a URL was used to identify eligible participants. Caregivers were eligible to participate in the CAPPA survey if they reported that they were aged 18 years or older and a parent or legal guardian of at least one child aged 6–17 years with a diagnosis of attention-deficit disorder (ADD)/ADHD made by a physician at least 6 months prior to screening. The child/adolescent must have lived with the caregiver for at least 50% of the time in the 6 months prior to the survey. In addition, the child/adolescent had to be receiving, or have received within 6 months prior to the survey, pharmacotherapy for ADD/ADHD.

Caregivers were excluded if they reported having one or more of the following conditions: dementia, schizophrenia, schizoaffective disorder, schizophreniform disorder, brief psychotic disorder, delusional disorder, shared psychotic disorder, substance-induced psychotic disorder, psychotic disorder due to medical condition, or paraphrenia. Caregivers were also excluded if they reported consuming more than five alcoholic drinks per day, or if they reported that their child had significant cognitive impairment ($IQ < 70$).

After completing the screening questionnaire, eligible caregivers were directed to the survey itself. For caregivers with more than one child who met the study criteria, the screener was programmed to randomly select one of the eligible children as the subject for the survey. Use of specific software technology restricted completion of surveys to one per computer.

2.7. Analyses

To protect participant confidentiality, no identifying information was collected or received by the study team. A data cleaning procedure was utilized such that caregivers with ≥ 3 inconsistent (illogical) responses were excluded from analyses; caregivers with invalid responses to free-text questions (e.g. 'Other, please specify') were also evaluated for exclusion prior to any data analysis.

Sociodemographic characteristics of caregivers, sociodemographic and clinical characteristics of children/adolescents with ADHD, and treatment use data are presented here for the overall sample and by individual country; data on the impact of ADHD on work are presented for the overall sample, and data on school, the family and social activities are presented only for those patients with both on- and off-medication data. Data from Denmark, Finland and Norway were combined for analysis because of the small sample sizes available for individual countries and are hereafter termed 'Nordic countries'; data from Sweden are presented separately.

Disease burden and unmet needs may vary with medication use. Therefore, we assessed the influence of ADHD medication on disease burden and unmet needs using two mutually exclusive subgroups: children/adolescents who were receiving ADHD medication when the survey was conducted (designated 'current medication use') and those who had discontinued ADHD medication within the previous 6 months and were not receiving pharmacotherapy when the survey was conducted (designated 'recent medication use').

Descriptive analyses (number, percentage; median, range; mean, standard deviation [SD]) are reported for most outcomes. The Wilcoxon Signed Rank test was used to compare the distribution of responses on versus off medication; no formal statistical comparisons were made between countries.

3. Results

3.1. Participants

A total of 205,187 potential participants clicked on the URL to take the eligibility screening test; all participants were recruited through market research panels. Of these, 1.4% ($n=2870$) did not complete the screening process and 94.9% ($n=194,706$) failed to meet the required criteria. A total of 7611 (3.7%) participants passed the screening test and of these 50.8% ($n=3868$) completed the survey. Surveys from 180 (4.7%) participants with a high frequency of illogical or inconsistent responses were excluded. Subject disposition is presented in Supplementary Fig. S1. Thus, data on 3688 completed CAPPA surveys were evaluated. Percentages (numbers) of evaluable surveys by country are presented in Table 1a. The average length of time for survey completion was 31 min.

3.2. Sociodemographic characteristics of caregivers

The sociodemographic characteristics of the caregivers who participated in the survey are presented for the overall sample and by country (Table 1a). The majority of caregivers were female (66% overall) and most were married (81%). Approximately half (51%) were employed full-time and 21% were employed part-time. Employment status varied widely among countries; Italy had the highest proportion (71%) of caregivers employed full-time and the Netherlands the lowest (26%). Sweden and Spain had the highest unemployment rates (12% and 11%, respectively), and the UK the lowest (3%).

A small proportion (8%) of parents reported having ADHD themselves; this was highest in the 'Nordic countries' (16%) and lowest in the UK (3%). In total, 27% of caregivers reported that at least one other household member had ADHD. This varied among countries, with the Netherlands and Sweden having the highest proportion (46% and 44%, respectively), and the UK, Italy and Spain having the lowest proportion (19%, 21% and 21%, respectively).

Overall, 27% of caregivers reported receiving no training or education on ADHD for themselves or their children. For those who had received training/education, the most common form was written/verbal education (47%), followed by family therapy with the child (24%). Social and occupational therapies were the least common (12% for each).

Sociodemographic characteristics of children/adolescents with ADHD

Sociodemographic characteristics of the children/adolescents represented in the survey are given for the overall sample and by country (Table 1b). The majority (80%) of children/adolescents were male, ranging from 70% (Sweden) to 84% (France). Ages ranged from 6 to 17 years. Median age overall was 12 years, and ranged from 10 (France, Italy) to 13 (the Netherlands, Sweden) years.

Overall, 82% of the children/adolescents in the sample were currently attending a mainstream school. The Netherlands, 'Nordic countries' and France had the highest rates of children attending special needs schools (27%, 27% and 21%, respectively); Spain and Italy had the lowest rates (5% and 8%, respectively). According to the caregiver, poor or failing school marks had been received by 21% of children/adolescents in the overall sample; variation among countries was seen, ranging from 7% (Italy) to 41% (Sweden). Nearly a quarter of the overall sample (23%) had repeated a school year because of their ADHD; this was seen most frequently (30–40%) in the Netherlands, Spain and France. Overall, 4% of the sample had been expelled from school in the past 6 months, most frequently in France, the UK and Spain.

Table 1
Sociodemographic characteristics of (a) caregivers and (b) children/adolescents with ADHD as reported by caregivers.

a)	Pan-EU (N=3688, 100%)	France (n=486, 13.2%)	Germany (n=589, 16.0%)	Italy (n=468, 12.7%)	Netherlands (n=316, 8.6%)	Nordics (n=249, 6.8%[a])	Sweden (n=219, 5.9%)	Spain (n=574, 15.6%)	UK (n=787, 21.3%)
Females	2422 (65.7)	319 (65.6)	392 (66.6)	309 (66.0)	233 (73.7)	142 (57.0)	136 (62.1)	344 (59.9)	547 (69.5)
Caregiver's relationship to child									
Mother	2351 (63.7)	310 (63.8)	377 (64.0)	305 (65.2)	227 (71.8)	136 (54.6)	135 (61.6)	339 (59.1)	522 (66.3)
Father	1097 (29.7)	154 (31.7)	160 (27.2)	144 (30.8)	72 (22.8)	92 (36.9)	70 (32.0)	210 (36.6)	195 (24.8)
Other *(relative/ guardian)*	240 (6.5)	22 (4.5)	52 (8.8)	19 (4.1)	17 (5.4)	21 (8.4)	14 (6.4)	25 (4.3)	70 (8.9)
Prevalence of ADHD in family									
Mother	308 (8.4)	53 (10.9)	49 (8.3)	47 (10.0)	33 (10.4)	37 (14.9)	24 (11.0)	33 (5.7)	32 (4.1)
Father	235 (6.4)	25 (5.1)	38 (6.5)	24 (5.1)	33 (10.4)	27 (10.8)	27 (12.3)	27 (4.7)	34 (4.3)
Brother(s)	302 (8.2)	23 (4.7)	70 (11.9)	18 (3.8)	51 (16.1)	24 (9.6)	23 (10.5)	34 (5.9)	59 (7.5)
Sister(s)	171 (4.6)	8 (1.6)	39 (6.6)	10 (2.1)	22 (7.0)	19 (7.6)	27 (12.3)	17 (3.0)	29 (3.7)
None	2708 (73.4)	377 (77.6)	410 (69.6)	373 (79.7)	174 (55.1)	157 (63.1)	124 (56.6)	457 (79.6)	636 (80.8)
Self-reported ADHD diagnosis									
Mothers	221 (9.4)	39 (12.6)	39 (10.3)	35 (11.5)	28 (12.3)	26 (19.1)	16 (11.9)	19 (5.6)	19 (3.6)
Fathers	59 (5.4)	11 (7.1)	9 (5.6)	7 (4.9)	5 (6.9)	10 (10.9)	7 (10.0)	4 (1.9)	6 (3.1)
Marital status									
Married	2988 (81.0)	410 (84.4)	470 (79.8)	439 (93.8)	243 (76.9)	179 (71.9)	160 (73.1)	494 (86.1)	593 (75.3)
Single	342 (9.3)	38 (7.8)	44 (7.5)	18 (3.8)	32 (10.1)	33 (13.3)	39 (17.8)	24 (4.2)	114 (14.5)
Divorced	334 (9.1)	32 (6.6)	68 (11.5)	9 (1.9)	41 (13.0)	36 (14.5)	19 (8.7)	52 (9.1)	77 (9.8)
Widowed	24 (0.7)	6 (1.2)	7 (1.2)	2 (0.4)	0 (0.0)	1 (0.4)	1 (0.5)	4 (0.7)	3 (0.4)
Employment status									
Employed, full-time	1886 (51.1)	292 (60.1)	271 (46.0)	334 (71.4)	82 (25.9)	144 (57.8)	113 (51.6)	326 (56.8)	324 (41.2)
Employed, part-time	788 (21.4)	80 (16.5)	161 (27.3)	55 (11.8)	130 (41.1)	38 (15.3)	52 (23.7)	90 (15.7)	182 (23.1)
Homemaker	521 (14.1)	64 (13.2)	86 (14.6)	54 (11.5)	49 (15.5)	12 (4.8)	4 (1.8)	61 (10.6)	191 (24.3)
Retired/disabled	135 (3.7)	8 (1.6)	24 (4.1)	2 (0.4)	16 (5.1)	18 (7.2)	12 (5.5)	18 (3.1)	37 (4.7)
Other/student/self-employed	124 (3.4)	14 (2.9)	26 (4.4)	5 (1.1)	9 (2.8)	17 (6.8)	11 (5.0)	13 (2.3)	29 (3.7)
Unemployed	234 (6.3)	28 (5.8)	21 (3.6)	18 (3.8)	30 (9.5)	20 (8.0)	27 (12.3)	66 (11.5)	24 (3.0)
Highest level of education									
No formal qualifications	119 (3.2)	11 (2.3)	27 (4.6)	7 (1.5)	11 (3.5)	10 (4.0)	0 (0.0)	12 (2.1)	41 (5.2)
GCSE/O-level or equivalent	911 (24.7)	58 (11.9)	320 (54.3)	21 (4.5)	42 (13.3)	59 (23.7)	20 (9.1)	132 (23.0)	259 (32.9)
A-level or equivalent	1204 (32.6)	140 (28.8)	133 (22.6)	149 (31.8)	158 (50.0)	89 (35.7)	137 (62.6)	172 (30.0)	226 (28.7)
University or higher	1454 (39.4)	277 (57.0)	109 (18.5)	291 (62.1)	105 (33.2)	91 (36.5)	62 (28.3)	258 (44.9)	261 (33.2)
Children per household									
Mean (SD)	2.05 (1.01)	2.07 (0.91)	1.95 (0.97)	1.74 (1.00)	2.37 (0.99)	2.12 (1.05)	2.19 (1.14)	1.88 (0.83)	2.22 (1.11)
Range	1–10	1–6	1–8	1–10	1–10	1–9	1–7	1–9	1–8
ADHD education/training[b]									
None received	1012 (27.4)	174 (35.8)	151 (25.6)	118 (25.2)	86 (27.2)	47 (18.9)	45 (20.5)	152 (26.5)	239 (30.4)
Written and verbal information	1729 (46.9)	159 (32.7)	274 (46.5)	227 (48.5)	138 (43.7)	150 (60.2)	140 (63.9)	307 (53.5)	334 (42.4)
Group sessions (for caregivers)	759 (20.6)	66 (13.6)	126 (21.4)	92 (19.7)	72 (22.8)	69 (27.7)	70 (32.0)	113 (19.7)	151 (19.2)
Individual sessions (for caregivers)	533 (14.5)	65 (13.4)	107 (18.2)	88 (18.8)	58 (18.4)	42 (16.9)	34 (15.5)	51 (8.9)	88 (11.2)
Family therapy with child	874 (23.7)	123 (25.3)	141 (23.9)	129 (27.6)	77 (24.4)	64 (25.7)	35 (16.0)	128 (22.3)	177 (22.5)
Family therapy without child	493 (13.4)	59 (12.1)	81 (13.8)	75 (16.0)	48 (15.2)	49 (19.7)	26 (11.9)	83 (14.5)	72 (9.1)
Social therapy for child	426 (11.6)	30 (6.2)	113 (19.2)	59 (12.6)	65 (20.6)	21 (8.4)	7 (3.2)	64 (11.1)	67 (8.5)
Occupational therapy for child	428 (11.6)	35 (7.2)	118 (20.0)	26 (5.6)	53 (16.8)	35 (14.1)	25 (11.4)	49 (8.5)	87 (11.1)
Other *(including self-taught)*	120 (3.3)	24 (4.9)	40 (6.8)	1 (0.2)	15 (4.7)	6 (2.4)	12 (5.5)	23 (4.0)	12 (1.5)

Table 1 (*continued*)

b)	Pan-EU (N=3688)	France (n=486)	Germany (n=589)	Italy (n=468)	Netherlands (n=316)	Nordics (n=249)	Sweden (n=219)	Spain (n=574)	UK(n=787)
Males	2932 (79.5)	408 (84.0)	459 (77.9)	367 (78.4)	235 (74.4)	201 (80.7)	154 (70.3)	451 (78.6)	657 (83.5)
Median age (range), years	12 (6–17)	10 (6–17)	12 (6–17)	10 (6–17)	13 (6–17)	12 (6–17)	13 (6–17)	12 (6–17)	12 (6–17)
School type									
Mainstream	3041 (82.5)	374 (77.0)	500 (84.9)	423 (90.4)	219 (69.3)	177 (71.1)	178 (81.3)	542 (94.4)	628 (79.8)
Special needs specific	559 (15.2)	100 (20.6)	84 (14.3)	37 (7.9)	85 (26.9)	66 (26.5)	34 (15.5)	26 (4.5)	127 (16.1)
Home-schooled	44 (1.2)	11 (2.3)	2 (0.3)	6 (1.3)	1 (0.3)	4 (1.6)	5 (2.3)	5 (0.9)	10 (1.2)
Other[c]	44 (1.2)	1 (0.2)	3 (0.5)	2 (0.4)	11 (3.5)	2 (0.8)	2 (0.9)	1 (0.2)	22 (2.8)
Most recent school marks									
Excellent/good	1219 (33.1)	183 (37.7)	180 (30.6)	157 (33.5)	120 (38.0)	71 (28.5)	40 (18.3)	165 (28.7)	303 (38.5)
Fair	1698 (46.0)	191 (39.3)	319 (54.2)	278 (59.4)	158 (50.0)	120 (48.2)	89 (40.6)	260 (45.3)	283 (36.0)
Poor/failing	771 (20.9)	112 (23.0)	90 (15.3)	33 (7.1)	38 (12.0)	58 (23.3)	90 (41.1)	149 (26.0)	201 (25.5)
Repeated a year in school (ever)	853 (23.1)	148 (30.5)	160 (27.2)	45 (9.6)	127 (40.2)	44 (17.7)	46 (21.0)	206 (35.9)	77 (9.8)
School expulsion (in last 6 months)	146 (4.0)	29 (6.0)	19 (3.2)	11 (2.4)	7 (2.2)	5 (2.0)	5 (2.3)	28 (4.9)	42 (5.3)

All numbers are reported as n (%) unless stated otherwise.
ADHD, attention-deficit/hyperactivity disorder; SD, standard deviation.

[a] Denmark, 3.0%; Finland, 2.8%; Norway, 1.0%.

[b] Refers to education/training for both caregiver and child.

[c] Includes ‘not in school’ and ‘attending vocational school’.

3.3. *Clinical characteristics of children and adolescents with ADHD*

Age at diagnosis*:* Caregivers reported that their child/adolescent had been formally diagnosed with ADHD at a mean (SD) age of 6.9 (3.0) years (Table 2); this ranged from 6.3 (2.8) years in France to 8.3 (3.6) years in Sweden.

Duration since ADHD diagnosis*:* Overall, caregivers reported that their child/adolescent had been formally diagnosed with ADHD a mean (SD) of 4.6 (3.2) years prior to the survey; this ranged from 3.4 (2.4) years in Italy to 5.4 (3.1) years in Germany (Table 2). Children/adolescents who were currently receiving ADHD medication had a shorter duration since ADHD diagnosis than did those who had previously received medication (4.3 vs 4.9 years).

ADHD severity*:* About half (52%) of caregivers described their child/adolescent's ADHD as moderate in severity, with 24% describing it as very mild/mild and 25% as severe/very severe at the time of the survey (Table 2). Italy had the lowest proportion (12%) of caregivers describing their child/adolescent's ADHD as severe/very severe, and the highest proportion (37%) describing their child/adolescent as having very mild/mild ADHD. Germany (33%), the Netherlands (33%) and the UK (31%) had the highest proportions of caregivers describing their child/adolescent as having severe/very severe ADHD.

Comorbidities*:* Almost half of children/adolescents (49%) were reported by caregivers to have at least one comorbid condition or behaviour (Table 2); this varied from 36% (Spain) to 57% (Italy).

Anxiety, learning difficulties, conduct disorder and aggression were the most commonly reported comorbid conditions/behaviours; each was present in > 10% of the overall sample. Almost a quarter of Italian (23%) and French (22%) caregivers reported that their child/adolescent experienced anxiety. Germany had the highest percentage of children/adolescents reported to have learning difficulties (19%). French caregivers reported the highest number of children/adolescents with conduct disorder (24%). UK caregivers reported the lowest prevalence of conduct disorder (3%). Aggression was most frequently reported in Italy (17%), followed by the UK (15%).

Of other commonly reported comorbid conditions, 19% of caregivers in the Netherlands reported that their child/adolescent had autism compared with only 7% in the total pan-European sample. Caregivers in Sweden reported the highest percentage of children/adolescents with Asperger's syndrome (13%), followed by the UK (12%). The highest percentage of children/adolescents with comorbid depression (11%) was also reported for Sweden.

3.4. *ADHD treatment use*

Behavioural therapy: Caregivers reported that the majority (56%) of children/adolescents had received BT (or cognitive BT) for ADHD (Table 3). BT was least commonly reported in Sweden (23%) and most commonly reported in Germany (63%), Spain (65%) and Italy (77%). More than half (53%) of children/adolescents in Italy were still receiving BT at the time of survey completion.

Overall, 36% of children/adolescents received BT prior to pharmacotherapy. The rate was highest in Italy, where 61% of all children/adolescents received BT before starting medication. More than half (57%) of those who received BT prior to pharmacotherapy were reported to have done so for < 6 months before starting medication. One third (33%) of Swedish children/adolescents did not continue > 1 month, and none of the Swedish children/adolescents persisted with BT for > 12 months, prior to starting medication.

The most common reason for stopping BT selected by caregivers in the overall sample was that it did not help to improve (at least one of) hyperactivity, impulsivity, concentration or behaviour (44%). The second most common reason was that it was no longer needed with the aid of medication (30%); more than a third of caregivers in Spain (39%), Italy (36%), the Netherlands (35%) and ‘Nordic countries’ (34%) selected this reason.

Pharmacotherapy: Current or most recent medications received by children/adolescents are summarized in Table 4. Stimulants

Table 2
Clinical characteristics of children/adolescents with ADHD as reported by caregivers.

	Pan-EU (N=3688)	France (n=486)	Germany (n=589)	Italy (n=468)	Netherlands (n=316)	Nordics[a] (n=249)	Sweden (n=219)	Spain (n=574)	UK (n=787)
Age at formal diagnosis, years									
Mean (SD)	6.90 (3.02)	6.32 (2.79)	6.51 (2.61)	6.63 (3.18)	7.31 (3.18)	7.41 (3.17)	8.28 (3.58)	6.74 (3.02)	7.09 (2.91)
Range	0–17	0–16	0–16	0–15	0–16	0–16	0–16	0–15	0–17
Time since formal diagnosis, years									
Mean (SD)	4.58 (3.17)	4.33 (3.01)	5.40 (3.12)	3.40 (2.36)	5.09 (3.28)	4.64 (3.03)	4.14 (3.08)	4.82 (3.15)	4.55 (3.49)
Range	0–17	1–17	1–15	1–14	1–15	1–13	1–16	1–16	0–15
Reported current severity of ADD/ADHD[b]									
Very mild/mild	879 (23.8)	124 (25.5)	102 (17.3)	175 (37.4)	46 (14.6)	54 (21.7)	47 (21.5)	168 (29.3)	163 (20.7)
Moderate	1901 (51.5)	250 (51.4)	291 (49.4)	236 (50.4)	167 (52.8)	137 (55.0)	112 (51.1)	324 (56.4)	384 (48.8)
Severe/very severe	908 (24.6)	112 (23.0)	196 (33.3)	57 (12.2)	103 (32.6)	58 (23.3)	60 (27.4)	82 (14.3)	240 (30.5)
Reported comorbid conditions or behaviours									
None	1864 (50.5)	233 (47.9)	306 (52.0)	203 (43.4)	162 (51.3)	124 (49.8)	101 (46.1)	369 (64.3)	366 (46.5)
Aggression	395 (10.7)	66 (13.6)	62 (10.5)	80 (17.1)	16 (5.1)	15 (6.0)	19 (8.7)	18 (3.1)	119 (15.1)
Alcohol abuse	29 (0.8)	6 (1.2)	7 (1.2)	2 (0.4)	2 (0.6)	2 (0.8)	2 (0.9)	3 (0.5)	5 (0.6)
Anxiety	489 (13.3)	105 (21.6)	45 (7.6)	108 (23.1)	38 (12.0)	19 (7.6)	21 (9.6)	52 (9.1)	101 (12.8)
Asperger's syndrome	203 (5.5)	9 (1.9)	16 (2.7)	7 (1.5)	13 (4.1)	15 (6.0)	29 (13.2)	19 (3.3)	95 (12.1)
Autism	263 (7.1)	4 (0.8)	9 (1.5)	10 (2.1)	60 (19.0)	24 (9.6)	28 (12.8)	12 (2.1)	116 (14.7)
Bipolar disorder	61 (1.7)	17 (3.5)	7 (1.2)	20 (4.3)	1 (0.3)	2 (0.8)	5 (2.3)	5 (0.9)	4 (0.5)
Cerebral palsy	8 (0.2)	1 (0.2)	4 (0.7)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.5)	1 (0.2)	1 (0.1)
Conduct disorder	434 (11.8)	116 (23.9)	97 (16.5)	61 (13.0)	38 (12.0)	34 (13.7)	9 (4.1)	58 (10.1)	21 (2.7)
Depression	197 (5.3)	18 (3.7)	34 (5.8)	24 (5.1)	12 (3.8)	16 (6.4)	25 (11.4)	19 (3.3)	49 (6.2)
Drug abuse	31 (0.8)	1 (0.2)	8 (1.4)	3 (0.6)	3 (0.9)	1 (0.4)	3 (1.4)	8 (1.4)	4 (0.5)
Eating disorder	137 (3.7)	28 (5.8)	32 (5.4)	17 (3.6)	6 (1.9)	6 (2.4)	7 (3.2)	19 (3.3)	22 (2.8)
Epilepsy	46 (1.2)	11 (2.3)	2 (0.3)	6 (1.3)	1 (0.3)	6 (2.4)	2 (0.9)	10 (1.7)	8 (1.0)
Learning difficulties	462 (12.5)	74 (15.2)	111 (18.8)	53 (11.3)	31 (9.8)	30 (12.0)	28 (12.8)	46 (8.0)	89 (11.3)
Motor-coordination disorder	140 (3.8)	28 (5.8)	34 (5.8)	12 (2.6)	11 (3.5)	12 (4.8)	3 (1.4)	12 (2.1)	28 (3.6)
Obsessive compulsive disorder	116 (3.1)	14 (2.9)	10 (1.7)	11 (2.4)	5 (1.6)	8 (3.2)	10 (4.6)	18 (3.1)	40 (5.1)
Oppositional defiant disorder	163 (4.4)	26 (5.3)	25 (4.2)	14 (3.0)	14 (4.4)	10 (4.0)	8 (3.7)	23 (4.0)	43 (5.5)
Schizoaffective disorder	9 (0.2)	1 (0.2)	2 (0.3)	4 (0.9)	0 (0.0)	1 (0.4)	0 (0.0)	1 (0.2)	0 (0.0)
Schizophrenia	11 (0.3)	1 (0.2)	2 (0.3)	6 (1.3)	0 (0.0)	0 (0.0)	1 (0.5)	0 (0.0)	1 (0.1)
Sleep disorder	305 (8.3)	55 (11.3)	43 (7.3)	30 (6.4)	29 (9.2)	17 (6.8)	24 (11.0)	24 (4.2)	83 (10.5)
Speech/language disorder	183 (5.0)	23 (4.7)	30 (5.1)	28 (6.0)	4 (1.3)	15 (6.0)	12 (5.5)	26 (4.5)	45 (5.7)
Tourette's syndrome	56 (1.5)	4 (0.8)	9 (1.5)	2 (0.4)	2 (0.6)	10 (4.0)	3 (1.4)	3 (0.5)	23 (2.9)

All numbers are reported as n (%) unless stated otherwise.
ADD, attention-deficit disorder; ADHD, attention-deficit/hyperactivity disorder.

[a] Denmark, Finland and Norway.
[b] As described by the caregiver.

included methylphenidate (short- and long-acting) or amphetamine/dexamphetamine; non-stimulants included atomoxetine or guanfacine; atypical antipsychotics (AAPs; not licensed for the treatment of ADHD) included aripiprazole, risperidone, quetiapine and olanzapine.

The majority (78%) of children/adolescents included in the survey were currently prescribed pharmacotherapy for ADHD. Of these, most (83%) were currently receiving stimulant therapy. Across countries, the use of stimulant therapy was most prevalent in Germany and the Netherlands (93% each) and least prevalent in Italy (60%). Non-stimulant therapy was most common among current medication users in Sweden (18%) and France (15%). The most common combination of therapies currently being received was stimulant medication and an AAP (5%); this combination was most prevalent in Italy (10%) and France (8%).

Overall, 6.4% of children/adolescents were reported to be currently receiving AAPs as a component of combination therapy. A further 10% were currently receiving AAP monotherapy. AAP monotherapy use varied among countries; the highest rates of current AAP monotherapy use were reported in Italy (34%), France (11%) and Spain (11%; Table 4). Use of AAPs for the treatment of ADHD would represent off-label prescribing; however, AAPs are sometimes used to treat comorbidities. Therefore, we further evaluated comorbid conditions/behaviours that were reported among children/adolescents currently receiving AAP monotherapy. The most common were aggression (24%), anxiety (18%) and conduct disorder (16%). Almost half (45%) of children/adolescents receiving AAP monotherapy were reported to have no comorbid conditions/behaviours. The highest rates of AAP monotherapy for children/adolescents with no comorbidities were reported in 'Nordic countries' (88%), Sweden (80%) and Spain (61%).

For each country, broadly similar rates of use of ADHD medication classes were reported among children/adolescents who were currently on or off medication; Table 4).

Table 3
Behavioural therapy[a] for children/adolescents with ADHD as reported by caregivers.

Children/adolescents with ADHD	Pan-EU (N=3688)	France (n=486)	Germany (n=589)	Italy (n=468)	Netherlands (n=316)	Nordics[b] (n=249)	Sweden (n=219)	Spain (n=574)	UK (n=787)
Behavioural therapy experience									
Ever received since diagnosis	2047 (55.5)	287 (59.1)	370 (62.8)	360 (76.9)	151 (47.8)	98 (39.4)	50 (22.8)	375 (65.3)	356 (45.2)
Received prior to medication	1327 (36.0)	149 (30.7)	246 (41.8)	284 (60.7)	80 (25.3)	62 (24.9)	24 (11.0)	258 (44.9)	224 (28.5)
Presently receiving	1073 (29.1)	194 (39.9)	164 (27.8)	247 (52.8)	40 (12.7)	48 (19.3)	23 (10.5)	201 (35.0)	156 (19.8)
Duration of behavioural therapy before starting medication	(n=1327)	(n=149)	(n=246)	(n=284)	(n=80)	(n=62)	(n=24)	(n=258)	(n=224)
< 1 month	142 (10.7)	13 (8.7)	19 (7.7)	33 (11.6)	5 (6.3)	5 (8.1)	8 (33.3)	35 (13.6)	24 (10.7)
1 month to < 6 months	609 (45.9)	53 (35.6)	103 (41.9)	134 (47.2)	39 (48.8)	30 (48.4)	13 (54.2)	111 (43.0)	126 (56.3)
6 months to < 12 months	345 (26.0)	45 (30.2)	72 (29.3)	92 (32.4)	22 (27.5)	15 (24.2)	3 (12.5)	51 (19.8)	45 (20.1)
1 year to < 2 years	132 (9.9)	19 (12.8)	32 (13.0)	15 (5.3)	5 (6.3)	5 (8.1)	0 (0.0)	36 (14.0)	20 (8.9)
≥ 2 years	99 (7.5)	19 (12.8)	20 (8.1)	10 (3.5)	9 (11.3)	7 (11.3)	0 (0.0)	25 (9.7)	9 (4.0)
Reasons for ending behavioural therapy[c]	(n=974)	(n=93)	(n=206)	(n=113)	(n=111)	(n=50)	(n=27)	(n=174)	(n=200)
Did not improve hyperactivity	185 (19.0)	16 (17.2)	42 (20.4)	14 (12.4)	16 (14.4)	9 (18.0)	6 (22.2)	39 (22.4)	43 (21.5)
Did not improve impulsivity	164 (16.8)	21 (22.6)	34 (16.5)	17 (15.0)	14 (12.6)	5 (10.0)	4 (14.8)	29 (16.7)	40 (20.0)
Did not improve concentration	247 (25.4)	32 (34.4)	58 (28.2)	17 (15.0)	22 (19.8)	10 (20.0)	7 (25.9)	51 (29.3)	50 (25.0)
Did not improve behaviour	207 (21.3)	23 (24.7)	48 (23.3)	15 (13.3)	20 (18.0)	8 (16.0)	4 (14.8)	35 (20.1)	54 (27.0)
(At least one of the above)	432 (44.4)	57 (61.3)	87 (42.2)	46 (40.7)	34 (30.6)	16 (32.0)	11 (40.7)	82 (47.1)	99 (49.5)
No longer needed with medication	295 (30.3)	20 (21.5)	53 (25.7)	41 (36.3)	39 (35.1)	17 (34.0)	4 (14.8)	68 (39.1)	53 (26.5)
Child did not want therapy	168 (17.2)	24 (25.8)	33 (16.0)	22 (19.5)	19 (17.1)	11 (22.0)	10 (37.0)	14 (8.0)	35 (17.5)
No additional sessions available	155 (15.9)	13 (14.0)	51 (24.8)	13 (11.5)	15 (13.5)	10 (20.0)	3 (11.1)	16 (9.2)	34 (17.0)
Other[d]	113 (11.6)	7 (7.5)	21 (10.2)	4 (3.5)	33 (29.7)	11 (22.0)	8 (29.6)	26 (14.9)	10 (5.0)

All numbers are reported as n (%) unless stated otherwise.
ADHD, attention-deficit/hyperactivity disorder.

[a] Refers specifically to therapy for the child/adolescent, and also includes cognitive behavioural therapy. It is considered unlikely that caregivers included psycho-education within the category of behavioural therapy.

[b] Denmark, Finland and Norway.

[c] More than one reason could be selected by each participant.

[d] Includes 'problems solved/not helpful', 'dissatisfied', 'doctor recommendation', 'unavailable'.

3.5. Work, school, family and social impact

A greater proportion of caregivers reported that their child had no difficulty with social interactions (20% vs 9%; $p < 0.0001$ distribution of responses on vs off ADHD medication; Table 5). A greater proportion of caregivers also reported that their child had no difficulty with schoolwork (12% vs 2%) and there was no strain on the child's relationships with their caregiver (19% vs 7%) or siblings (17% vs 7%), when on medication compared with off medication (Table 5). However, a large proportion (80–88%) still reported some level of difficulty or strain in these domains when their child/adolescent was on medication (Table 5).

More caregivers reported no difficulty in their own social activities (32% vs 21%) and no strain in their relationship with their partner (24% vs 12%) and other children (31% vs 18%) when their child was on medication compared with off medication (Table 5). However, 68–76% still reported some level of difficulty/strain in these domains even when on medication (Table 5).

Significantly greater proportions of caregivers did not avoid taking their child to outside activities (39% vs 29%), did not avoid social activities (39% vs 28%) or got less enjoyment from them (34% vs 23%), and did not worry about other's perceptions of them as a parent (34% vs 28%) when their child/adolescent was on versus off ADHD medication (Table 5; $p < 0.0001$ distribution of responses for each of the domains). As before, however, 61–66% still reported some levels of difficulty or strain in these domains even when their child/adolescent was on medication.

More than a third (38%) of caregivers reported being late for work due to their child's ADHD in the past 4 weeks, with a mean (SD) 3.8 (8.1) hours of work being missed during this time (Table 6). Almost a third (31%) of caregivers reported having to alter their employment status due to their child/adolescent's ADHD; more than half (53%) of these changes occurred when the child/adolescent was on medication.

4. Discussion

Here we have described the sociodemographic and clinical characteristics of caregivers and children/adolescents with ADHD, and treatment use, reported in the CAPPA survey for 10 individual countries and the overall sample. We have also reported findings on the influence of medication on the burden on work, school and relationships that is associated with ADHD.

Caregiver-reported data from this survey provide useful information about diagnosis and severity of ADHD among children/adolescents across Europe and the prevalence of comorbid conditions/behaviours. In our survey, children/adolescents were reported to be diagnosed with ADHD at the youngest age in France (6.3 years) and oldest in Sweden (8.3 years). The overall reported

Table 4
Categories of medications[a] either currently or most recently[b] received by children/adolescents reported by caregivers.

	Pan-EU (N=3688)		France (n=486)		Germany (n=589)		Italy (n=468)		Netherlands (n=316)		Nordics (n=249) [c]		Sweden (n=219)		Spain (n=574)		UK (n=787)	
	Current	Most recent	Current	Most recent	Current	Most recent	Current	Most recent	Current	Most recent	Current	Most recent	Current	Most recent	Current	Most recent	Current	Most recent
Children/adolescents with ADHD	2890 (78.4)	798 (21.6)	374 (77.0)	112 (23.0)	465 (79.0)	124 (21.1)	316 (67.5)	152 (32.5)	272 (86.1)	44 (13.9)	202 (81.1)	47 (18.9)	176 (80.4)	43 (19.6)	453 (78.9)	121 (21.1)	632 (80.3)	155 (19.7)
Any use																		
Stimulant	2394 (82.8)	612 (76.7)	276 (73.8)	89 (79.5)	434 (93.3)	112 (90.3)	189 (59.8)	81 (53.3)	254 (93.4)	38 (86.4)	177 (87.6)	40 (85.1)	152 (86.4)	36 (83.7)	378 (83.4)	91 (75.2)	534 (84.5)	125 (80.6)
Non-stimulant	239 (8.3)	53 (6.6)	57 (15.2)	5 (4.5)	23 (4.9)	4 (3.2)	20 (6.3)	8 (5.3)	3 (1.1)	1 (2.3)	27 (13.4)	7 (14.9)	32 (18.2)	10 (23.3)	30 (6.6)	11 (9.1)	47 (7.4)	7 (4.5)
Antipsychotic	468 (16.2)	169 (21.2)	81 (21.7)	26 (23.2)	29 (6.2)	9 (7.3)	146 (46.2)	63 (41.4)	19 (7.0)	4 (9.1)	25 (12.4)	6 (12.8)	13 (7.4)	4 (9.3)	85 (18.8)	33 (27.3)	70 (11.1)	24 (15.5)
Other	163 (5.6)	48 (6.0)	17 (4.5)	10 (8.9)	7 (1.5)	3 (2.4)	5 (1.6)	8 (5.3)	17 (6.3)	3 (6.8)	21 (10.4)	3 (6.4)	18 (10.2)	2 (4.7)	12 (2.6)	2 (1.7)	66 (10.4)	17 (11.0)
Monotherapy																		
Stimulant	2175 (75.3)	546 (68.4)	239 (63.9)	77 (68.8)	410 (88.2)	107 (86.3)	152 (48.1)	68 (44.7)	245 (90.1)	37 (84.1)	155 (76.7)	32 (68.1)	131 (74.4)	28 (65.1)	341 (75.3)	78 (64.5)	502 (79.4)	119 (76.8)
Non-stimulant	162 (5.6)	26 (3.3)	48 (12.8)	2 (1.8)	12 (2.6)	2 (1.6)	10 (3.2)	5 (3.3)	3 (1.1)	1 (2.3)	14 (6.9)	2 (4.3)	17 (9.7)	4 (9.3)	21 (4.6)	4 (3.3)	37 (5.9)	6 (3.9)
Antipsychotic	284 (9.8)	121 (15.2)	43 (11.5)	15 (13.4)	15 (3.2)	6 (4.8)	108 (34.2)	53 (34.9)	10 (3.7)	3 (6.8)	8 (4.0)	3 (6.4)	5 (2.8)	1 (2.3)	51 (11.3)	23 (19.0)	44 (7.0)	17 (11.0)
Other	37 (1.3)	35 (4.4)	4 (1.1)	5 (4.5)	4 (0.9)	4 (3.2)	5 (1.6)	13 (8.6)	5 (1.8)	2 (4.5)	0 (0.0)	2 (4.3)	2 (1.1)	2 (4.7)	2 (0.4)	1 (0.8)	15 (2.4)	6 (3.9)
Combination therapy																		
Antipsychotic and stimulant	155 (5.4)	43 (5.4)	31 (8.3)	10 (8.9)	13 (2.8)	3 (2.4)	31 (9.8)	10 (6.6)	9 (3.3)	1 (2.3)	12 (5.9)	3 (6.4)	6 (3.4)	2 (4.7)	29 (6.4)	8 (6.6)	24 (3.8)	6 (3.9)
Antipsychotic and non-stimulant	13 (0.4)	4 (0.5)	3 (0.8)	1 (0.9)	0 (0.0)	0 (0.0)	4 (1.3)	0 (0.0)	0 (0.0)	0 (0.0)	3 (1.5)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.2)	2 (1.7)	2 (0.3)	1 (0.6)
Stimulant and non-stimulant	48 (1.7)	22 (2.8)	2 (0.5)	2 (1.8)	10 (2.2)	2 (1.6)	3 (0.9)	3 (2.0)	0 (0.0)	0 (0.0)	8 (4.0)	5 (10.6)	13 (7.4)	5 (11.6)	4 (0.9)	5 (4.1)	8 (1.3)	0 (0.0)
Antipsychotic, stimulant and non-stimulant	16 (0.6)	1 (0.1)	4 (1.1)	0 (0.0)	1 (0.2)	0 (0.0)	3 (0.9)	0 (0.0)	0 (0.0)	0 (0.0)	2 (1.0)	0 (0.0)	2 (1.1)	1 (2.3)	4 (0.9)	0 (0.0)	0 (0.0)	0 (0.0)

All numbers are reported as n (%) unless stated otherwise.
ADHD, attention-deficit/hyperactivity disorder.

[a] A predefined list of medications including those indicated for ADHD as well as atypical antipsychotics that are not indicated for ADHD but are used widely (Sikirica et al., 2013b) was provided for the caregiver to select from; an 'Other' field was also included to allow free text responses.

[b] Applies only to children/adolescents who were not currently receiving pharmacotherapy; reflects pharmacotherapy use within the last 6 months.

[c] Denmark, Finland and Norway.

Table 5
Difficulties, strains and time-related impacts described by caregivers of children with ADHD on versus off medication.

Characteristic: difficulties	**A tremendous amount**	**A lot**	**A moderate amount**	**A little**	**No difficulty**
How much difficulty does your child have with schoolwork due to ADHD? (n=3153)					
On medication	122 (3.9)	505 (16.0)	985 (31.2)	1178 (37.4)	363 (11.5)
Off medication	1101 (34.9)	1054 (33.4)	722 (22.9)	214 (6.8)	62 (2.0)
How much difficulty has your child had with social interactions with peers due to ADHD?* (n=3153)					
On medication	149 (4.7)	405 (12.8)	852 (27.0)	1110 (35.2)	637 (20.2)
Off medication	750 (23.8)	858 (27.2)	790 (25.1)	465 (14.7)	290 (9.2)
How much difficulty did you have participating in social activities? (n=3153)					
On medication	161 (5.1)	325 (10.3)	656 (20.8)	997 (31.6)	1014 (32.2)
Off medication	598 (19.0)	632 (20.0)	689 (21.9)	581 (18.4)	653 (20.7)
Characteristic: strain	**A tremendous amount**	**A lot**	**A moderate amount**	**A little**	**No strain**
How much strain did your child's ADHD put on relationship with you? (n=3153)					
On medication	123 (3.9)	351 (11.1)	889 (28.2)	1202 (38.1)	588 (18.6)
Off medication	784 (24.9)	920 (29.2)	783 (24.8)	447 (14.2)	219 (6.9)
How much strain did your child's ADHD put on their relationship with siblings? (n=2725)					
On medication	133 (4.9)	355 (13.0)	757 (27.8)	1024 (37.6)	456 (16.7)
Off medication	748 (27.4)	782 (28.7)	626 (23.0)	366 (13.4)	203 (7.4)
How much strain did your child's ADHD put on your relationship with your partner? (n=2843)					
On medication	127 (4.5)	343 (12.1)	697 (24.5)	997 (35.1)	679 (23.9)
Off medication	583 (20.5)	676 (23.8)	723 (25.4)	515 (18.1)	346 (12.2)
How much strain did your child's ADHD put on your relationship with your other children? (n=2725)					
On medication	79 (2.9)	227 (8.3)	592 (21.7)	986 (36.2)	841 (30.9)
Off medication	364 (13.4)	623 (22.9)	697 (25.6)	553 (20.3)	488 (17.9)
Characteristic: time	**A tremendous amount**	**A lot**	**A moderate amount**	**A little**	**No time**
How much time did you spend worrying or stressing about your child? (n=3153)					
On medication	352 (11.2)	602 (19.1)	861 (27.3)	1006 (31.9)	332 (10.5)
Off medication	925 (29.3)	915 (29.0)	720 (22.8)	456 (14.5)	137 (4.3)
Characteristic: how often over the past 6 months did you do each of the following:	**Almost all the time (>90%)**	**Most of the time (75%)**	**Some of the time (50%)**	**A little of the time (25%)**	**Never (0%)**
Keep in close contact with school/teachers* (n=3153)					
On medication	576 (18.3)	493 (15.6)	745 (23.6)	1033 (32.8)	306 (9.7)
Off medication	990 (31.4)	700 (22.2)	747 (23.7)	534 (16.9)	182 (5.8)
Avoid taking child to activities outside of home* (n=3153)					
On medication	176 (5.6)	274 (8.7)	591 (18.7)	879 (27.9)	1233 (39.1)
Off medication	538 (17.1)	494 (15.7)	659 (20.9)	541 (17.2)	921 (29.2)
Avoid social activities when with the child* (n=3153)					
On medication	174 (5.5)	279 (8.8)	547 (17.3)	936 (29.7)	1217 (38.6)
Off medication	577 (18.3)	478 (15.2)	662 (21.0)	544 (17.3)	892 (28.3)
Get less enjoyment from social activities when with the child* (n=3153)					
On medication	210 (6.7)	288 (9.1)	603 (19.1)	975 (30.9)	1077 (34.2)
Off medication	597 (18.9)	563 (17.9)	657 (20.8)	619 (19.6)	717 (22.7)
Worry of other's perceptions of me as a parent* (n=3153)					
On medication	344 (10.9)	313 (9.9)	547 (17.3)	865 (27.4)	1084 (34.4)
Off medication	722 (22.9)	466 (14.8)	540 (17.1)	538 (17.1)	887 (28.1)

All data are given as n (%). Responses relate to the 6-month period prior to the survey.

* $p < 0.0001$; Wilcoxon Signed Rank test comparing the distribution of responses on versus off medication.

Table 6
Impact of child/adolescent's ADHD on the caregiver's work.

Characteristic	Overall (N=3688)
In the past 4 weeks, how many hours of work did you miss dealing with your child's ADHD?[a]	
n	2872
Mean (SD)	3.8 (8.1)
Median	1
Q1–Q3	0–5
Range	0–148
In the past 4 weeks, were you ever late for work due to your child's ADHD?	
n	2875
Yes	1097 (38.2)
No	1778 (61.8)
In the past 4 weeks, how many times were you late for work due to your child's ADHD?	
n	1097
Mean (SD)	3.47 (3.16)
Median	2
Q1–Q3	2–4
Range	1–25
Have you had to alter your employment due to your child's ADHD?	
n	3688
Yes, had to change job	145 (3.9)
Yes, had to change work shift	300 (8.1)
Yes, had to cut back hours	505 (13.7)
Yes, had to quit working	210 (5.7)
No	2528 (68.5)
Did the work change happen while your child was on ADHD medications?	
n	1160
Yes	617 (53.2)
No	543 (46.8)

All data given as n (%) unless specified otherwise

[a] Three outliers who reported >160 work hours missed in 4 weeks were excluded from this analysis.

mean age at diagnosis of 6.9 years corresponds to ADHD clinical practice guideline recommendations (American Academy of Pediatrics, 2011; NICE, 2013; Taylor et al., 2004). It is widely recognized that ADHD should be diagnosed as early as possible (European Commission ADHD Project, 2002); a valid diagnosis can be made in children aged 5–6 years but the diagnosis of younger children is challenging (Taylor et al., 2004). The mean age at diagnosis in our survey is also in line with estimates of 6.6–10.0 years in previous observational studies of ADHD in Europe (Hodgkins et al., 2013; Preuss et al., 2006; Raman et al., 2015).

Reported severity of ADHD (while receiving treatment) varied among countries. For example, 12% of caregivers in Italy reported that their child/adolescent's ADHD was severe/very severe compared with 33% in Germany and the Netherlands. This variation may be attributable to country- and/or centre-specific differences in ADHD treatment practice. Cultural attitudes affect perceptions of child behaviour and social factors influence the degree of child behaviour that is considered problematic (Singh, 2008). For example, families, schools and wider cultures vary in their tolerance of hyperactivity (Ho et al., 1996). Such cultural differences in how caregivers perceive and interpret ADHD-related symptoms/behaviours could contribute to the variation observed across Europe in our survey.

According to caregivers' reports, almost half (49%) of children/adolescents with ADHD had at least one current physician-diagnosed comorbid condition/behaviour, most frequently anxiety, learning difficulties, conduct disorder or aggression. This general prevalence of comorbidities is consistent with rates reported by physicians in a previous observational study in Germany (Wehmeier et al., 2015) and a retrospective pan-European chart review (Hodgkins et al., 2013) but lower than in a Danish naturalistic study (Powell et al., 2011). Notably, the rates of most common comorbid psychiatric conditions reported by caregivers in the CAPPA population are lower than in the physician-reported Attention Deficit/Hyperactivity Disorder Observational Research in Europe (ADORE) study (Steinhausen et al., 2006).

The lower than expected rate of comorbidities in the CAPPA survey might be related to under-reporting by caregivers. In this survey, data on comorbidities are based on caregiver rather than physician reporting. Caregivers may be poorly informed of comorbidities and so may not recognize particular conditions/behaviours. In addition, the likelihood of caregiver reporting may be influenced by the relative impact of comorbidities on daily life. Moreover, caregivers may not perceive that the comorbid condition/behaviour still exists if their child/adolescent has received appropriate treatment.

Treatment use data should be evaluated in the context of European ADHD management guidelines (Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie und Psychotherapie, 2007; Health Ministry of Spain, 2010; Landelijke Stuurgroep, 2007; NICE, 2013; Seixas et al., 2012; SINPIA, 2002; Taylor et al., 2004). Current guidelines recommend that non-pharmacological treatment should be initiated before prescription medications in all but severe cases of ADHD. However, recent meta-analyses have shown limited efficacy of non-pharmacological interventions in ADHD, suggesting that treatment guidelines should perhaps be revisited (Cortese et al., 2015; Daley et al., 2014; Rapport et al., 2013; Sonuga-Barke et al., 2013). In our survey, the highest rates of BT use were reported in Italy, Germany and Spain, and possibly reflect good adherence to current ADHD treatment recommendations in these countries. Overall, 23–77% of children/adolescents were reported to have not received BT. This finding is consistent with a recent retrospective medical record review in which children/adolescents with ADHD were followed for at least 2 years after diagnosis in six European countries (Setyawan et al., 2015). Only 15% of children/adolescents in the Italian sample received no BT, whereas BT was not used in at least half of cases (50–53%) in the Netherlands, France and the UK (Setyawan et al., 2015).

All children/adolescents included in this survey were currently receiving medication for ADHD or had done so in the previous 6 months. During the survey, caregivers were asked to select relevant ADHD medications from a predefined list that included AAPs. Although AAPs are not licensed for the treatment of ADHD, they are prescribed for a substantial proportion of children/adolescents with ADHD worldwide (Ben Amor et al., 2014; Betts et al., 2014; Sikirica et al., 2012, 2013b; Wong et al., 2014). Indeed, the most common treatment combination currently being received by children/adolescents in this study was a stimulant plus an AAP (5.4%). It is possible that the AAP use reported in this survey was prescribed to treat comorbid conditions rather than ADHD per se. However, given the low rates of reported comorbidities in this study, the widespread use of AAPs among children/adolescents with ADHD warrants further investigation.

In most countries, the pattern of use of medications was similar among children/adolescents who recently received pharmacotherapy and those currently receiving pharmacotherapy. However, in France, the use of non-stimulant medications was more common among current than recent medication users. This finding was unexpected as the non-stimulant atomoxetine is not available in France (unlike in other European countries). Further investigation is needed to ascertain if this could be explained by cross-border or 'exceptional' prescribing of atomoxetine by French physicians.

ADHD had a considerable impact on the lives of children/adolescents in this study. Almost a quarter of children/adolescents with ADHD in this survey had repeated a school year; the lowest rates of grade repetition were reported in the UK and Italy. Educational culture, regulations and legislation governing grade repetition vary greatly among European countries (Eurydice, 2011). In the UK, children/adolescents repeat a school year only in exceptional circumstances (Eurydice, 2011). Population-wide estimates from 2009 suggest that 2% of pupils aged 15 years have repeated a school year in the UK versus 16% in Italy, 35% in Spain and 37% in France (OECD, 2010). Cultural differences towards grade repetition across European countries undoubtedly contribute to the widely different rates among patients with ADHD reported in this survey. For example, in some countries including Spain, France and the Netherlands, a common belief held by both teaching staff and parents is that repeating a year is beneficial for pupils' learning (Eurydice, 2011).

Overall, 15% of children/adolescents with ADHD in this survey attended a special needs school; the lowest rate (5%) was reported in Spain. Notably, at the time of this survey, ADHD was not recognized as a condition that requires special educational needs under Spanish law. However, a recently approved educational law does include ADHD and, therefore, we expect that the proportion of children/adolescents with ADHD who attend special needs schools in Spain will increase in the future (No authors listed, 2015). It should be noted that the survey did not assess the reasons for attending special needs schools, and the relationship between specific comorbidities and special needs school attendance was not investigated.

In the current survey, 4% of children/adolescents were reported by their caregivers to have been permanently expelled from school within the last 6 months. There are minimal published standardized data on school expulsion rates among children with or without ADHD across Europe. However, published data suggest that 0.06% of pupils (or 0.15–0.23% of those with special educational needs) were expelled from state-funded schools in England during the 2012–13 academic year (UK Department for Education, 2014). In the CAPPA study, 5.3% of children/adolescents (with ADHD) in the UK were reported by caregivers to have been expelled in the last 6 months; this is substantially higher than the published expulsion rate in England. The survey did not provide an explicit definition to distinguish between the terms 'exclusion' and 'expulsion'. Thus, it is possible that caregivers in our survey may have not consistently differentiated between temporary exclusion and permanent expulsion in their responses, which may have resulted in the incidence of expulsion being over-reported.

In the ADORE study, 73% of parents reported that their child/adolescent with ADHD caused conflict or tension within the family at least sometimes, and 73% also reported limited time to relax or participate in social activities (Riley et al., 2006b). Our findings are generally in line with these data. In the CAPPA survey, more caregivers reported that their child/adolescent had no difficulty with schoolwork or social interactions and caused no strain on family relationships when on versus off medication, but the vast majority (80–88%) reported some degree of difficulty or strain in these domains even when the child was receiving medication. Similarly, the majority of caregivers (68–76%) reported some level of difficulty or strain in their own social activities and family relationships even when their child was on medication.

Almost a third of caregivers altered their employment status (e.g. reduced their working hours or resigned) because of their child/adolescent's ADHD. These changes were required despite the child/adolescent being on medication in more than half of cases (53%), suggesting that there may still be unmet needs in the management of ADHD. Our findings are broadly in line with previous research showing the negative effect of ADHD on children/adolescents and their families, although differing study designs prevent direct comparison of data (Caci et al., 2014; Coghill et al., 2008; Kvist et al., 2013; Le et al., 2013; Noe and Hankin, 2001).

A number of potential limitations of this study should be noted. The CAPPA study was conducted from the caregiver's perspective and so may be subject to reporting and/or recall biases. The reported information may be influenced by caregivers' understanding of ADHD, their cultural beliefs and other underlying characteristics. As such, the survey findings should not be expected to be fully consistent with formal clinical assessments. Furthermore, there are likely to be differences in the way clinical information is conveyed to caregivers across Europe. This would make direct comparisons of caregiver reported data on the impact of ADHD between different countries challenging. In addition, the survey was based on an assumption that the caregivers had reasonable recall of their child/adolescent's ADHD when on versus off medication. Some children/adolescents were still receiving ADHD medication whereas others had discontinued up to 6 months previously. This variable recall period could lead to bias in caregiver responses.

Participants were recruited as a convenience sample through patient panels, which could introduce selection bias. For example, unemployment rates reported by caregivers in this survey in most countries were substantially lower than population-wide data from the same time period reported elsewhere (Eurostat, 2015). In addition, a large proportion of caregivers in the CAPPA survey were married (81%), which does not seem consistent with the high risk of divorce reported for parents of children/adolescents with ADHD and could indicate a selection bias (Kvist et al., 2013; Schermerhorn et al., 2012; Wymbs et al., 2008). One could speculate that divorced or single parents may have little time to participate in such surveys and, thus, the sample may have been biased towards married caregivers. Furthermore, the reported rate of ADHD among parental caregivers in this study was low (8%). High heritability (around 76%) of ADHD has been reported in twin studies of children and adolescents (Faraone et al., 2005) and, in a US study, childhood ADHD was shown to be more prevalent among mothers of children with ADHD than mothers of children without ADHD (Chronis et al., 2003). The low reported rate of ADHD among parents in our study may reflect a bias towards participation by caregivers without ADHD, or more general underdiagnosis and treatment of ADHD among adults in Europe (Ginsberg et al., 2014; Ramos-Quiroga et al., 2013).

Within-country heterogeneity may also be a study limitation as the geographic representativeness of samples within each country was not evaluated. In particular, families from villages or rural areas with lower socio-economic status may be under-represented because of the need for internet access to take part in this web-based survey.

In conclusion, this large cross-sectional survey provides valuable real-world observations from caregivers in 10 European countries on children/adolescents with ADHD who were currently receiving or had recently received pharmacotherapy. Descriptive data indicate that there is wide variation across Europe in the sociodemographic and clinical characteristics of caregivers and children/adolescents with ADHD, and in treatment use. There is also variation between countries in rates of reported ADHD comorbid conditions/behaviours. BT was a widely used treatment modality in some countries but rates varied across Europe; 29% of children/adolescents were reported to be currently receiving BT. Most children/adolescents (78%) were currently receiving pharmacological treatment; the majority received stimulants but high rates of AAP use were reported in some countries. Although ADHD medication helped to improve symptoms, the disorder was still associated with a considerable burden on the lives of caregivers and their child/adolescent. A negative effect of ADHD was seen on the caregiver's work and child's schoolwork, and on their relationships with family and friends. Indeed, most caregivers reported that their child/adolescent had difficulty with schoolwork due to ADHD and 4% had been expelled from school in the last 6 months; these data underscore the impact of ADHD on academic functioning. Our findings also highlight the need to further improve functional outcomes even among children/adolescents who are receiving medication for ADHD.

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Contribution of authors

E. Flood participated in the study design, data collection and analysis, and reviewed the manuscript drafts.

K. Gajria participated in the study design, data collection, analysis and interpretation, and reviewed the manuscript drafts.

V. Sikirica contributed to the study design, participated in data collection and analysis, and reviewed the manuscript drafts.

C. N. Dietrich contributed to the study design, participated in data collection and analysis, and reviewed the manuscript drafts.

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V. Harpin participated in the questionnaire trial, data interpretation, and reviewed the manuscript drafts.

T. Banaschewski contributed to the study design, participated in data collection and analysis, and reviewed the manuscript drafts.

J. Quintero participated in data analysis and reviewed the manuscript drafts.

M. H. Erder participated in the development of the study design and data collection instrument, data analysis, and review of manuscript drafts.

M. Fridman participated in data analysis and interpretation, and review of manuscript drafts.

K. Chen participated in data interpretation, manuscript draft content development and reviewed manuscript drafts.

All authors have seen and approved the final manuscript for publication.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at http://dx.doi.org/10.1016/j.jad.2016.04.011.

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