




Family Burden of Raising a Child with ADHD

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Published online: 23 February 2019

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Abstract

The purpose of the study was to estimate the burden to families of raising a child with attention-deficit/hyperactivity disorder (ADHD). Data were drawn from a longitudinal sample recruited in western Pennsylvania. When participants were between 14 and 17 years old, parents completed a questionnaire assessing economic burden over the course of raising their children. Domains of economic burden to families included direct costs related to child's behaviors (excluding treatment expenses) and indirect costs related to caregiver strain. On average, participants with ADHD incurred a total economic burden over the course of child development that was more than five times greater compared to youths without ADHD (ADHD = \$15,036 per child, Control = \$2,848 per child), and this difference remained significant after controlling for intellectual functioning, oppositional defiant symptoms, or conduct problems. Parents of participants with ADHD were more likely to have changed their job responsibilities or been fired and reported lower work efficiency. The current evaluation of economic burden to individual families extends previous estimates of annual societal cost of illness (COI) of ADHD. Our rough annual estimate of COI for ADHD in children and adolescents is \$124.5 billion (2017 US Dollars). Findings underscore the need for interventions to reduce the costly dysfunctional outcomes in families of children with ADHD.

Keywords ADHD · Cost analysis · Family burden · Economic impact

Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder affecting approximately 10% to 12% of youths in the United States (Visser et al. 2014) that substantially impacts functioning across domains (e.g., academic, social) and settings (e.g., home and school) (Barkley

2014). Despite extensive research on characteristics and pathways of functional impairments related to ADHD, the associated economic impacts are far less well investigated. However, a comprehensive understanding of the financial burden of ADHD is a vital aspect of advocating for, justifying, and planning intervention efforts.

The *family burden* associated with ADHD comprises all challenges experienced by family members due to an individual's illness (Sales 2003). These challenges include direct costs (e.g., purchasing stimulant medication), indirect costs (e.g., missed time at work), and intangible costs (e.g., marital tension) (Jo 2014). Previous investigations of the costs associated with raising a child with ADHD to families have focused predominately on direct expenses within the healthcare system and indirect costs related to parental productivity loss (e.g., Bernfort et al. 2008; Birnbaum et al. 2005; De Ridder and De Graeve 2006; Doshi et al. 2012; Gupte-Singh et al. 2017; Hakkaart-van Roijen et al. 2007; Matza et al. 2015; Meyers et al. 2010). Emerging studies on family burden related to raising children with autism spectrum disorders (ASD) have included other important domains (see Beecham 2014, for a review). These studies have included costs outside the healthcare system, such as costs of childcare, academic

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s10802-019-00518-5>) contains supplementary material, which is available to authorized users.

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support, legal services, and productivity losses of parents, and found that including these additional domains provides a more accurate estimate of the substantial family burden of ASD (Buescher et al. 2014; Ganz 2007; Lavelle et al. 2014). Similar to ASD, ADHD can result in direct costs associated with children's special needs and indirect costs related to other areas of caregiver strain.

Nonmedical expenditure is an important component of direct costs (Jo 2014) and can be substantial to families raising children with ADHD. The symptoms of ADHD and related impairments reflect a complex set of behavioral and cognitive difficulties (Wehmeier et al. 2010) that arguably incur substantial expenses to families. For instance, academic underachievement and classroom behavior problems often lead to direct costs to families, including private tutoring, summer classes, computer software, or other learning services beyond those provided by the education system (Marks et al. 2009; Robb et al. 2011). Children with ADHD often lose belongings and school supplies that require replacement, experience dismissal from extracurricular activities, and miss lessons or extracurricular activities after parents have already paid fees or purchased equipment. Additionally, adolescents diagnosed with ADHD in childhood have a higher rate of automobile accidents (Thompson et al. 2007), which is likely to result in out-of-pocket expenses due to damaged vehicles, fines, tickets, and increased costs of automobile insurance. Furthermore, a small subset of the families may experience high economic burden associated with delinquency (Fletcher and Wolfe 2009; Sibley et al. 2011), such as costs of legal defense. Therefore, the need for additional commodities and services can pose significant expenses to families over the course of raising a child diagnosed with ADHD.

In addition to paying for services, such as those mentioned above, parents of youths diagnosed with ADHD also experience indirect costs associated with caregiver strain. Caregiver strain refers to the negative impact (e.g., productivity losses, socio-emotional burden) and additional costs and responsibilities (e.g., additional childcare) associated with taking care of a child with emotional and behavioral difficulties (Brannan and Heflinger 2001). Working caregivers of youths diagnosed with ADHD can miss work for a variety of reasons, such as the need to attend in-school conferences, pursue or revise special education services (e.g., Individualized Education Plan [IEP] meetings) and manage accidents or other legal involvements. Missing work may impact a parent's job performance and/or lead to altered employment (e.g., switching from full-time to part-time, or quitting jobs both of which can negatively impact long-term career trajectories (Flood et al. 2016; Fridman et al. 2017). Besides financial and occupational impact, caregivers also experience socio-emotional burden, such as strained relationships between parenting partners, difficulty engaging in pleasurable social activities, high parenting

stress, and substance/alcohol problems (Bussing et al. 2015; Fridman et al. 2017; Pelham and Lang 1993; Pelham et al. 1997; Theule et al. 2010; Wymbs et al. 2008). The socio-emotional burden experienced by caregivers may result in spending more on services for their own difficulties.

Current cost estimates of the societal impact of ADHD have not comprehensively captured the significant economic burden of aforementioned direct and indirect costs at the individual family level (Pelham et al. 2007). Incremental costs to families in the existing studies were largely focused on parental productivity loss, which was monetized based on official absenteeism in insurance claims (e.g., Birnbaum et al. 2005) or national surveys (e.g., Gupte-Singh et al. 2017). Secondary data analysis of insurance claims databases and national surveys is limited in its assessment of family burden. For example, Gupte-Singh et al. (2017) multiplied the number of missed school days for youths by the daily average wage across all occupations. Identifying individual wage or salary specific to the caregivers and considering many other occasions of work absenteeism associated with children's behaviors are essential to providing a more accurate overall estimate of parental productivity loss. Beyond monetized productivity loss, raising a child with ADHD leads to many other subdomains of indirect costs and direct costs (excluding treatment costs).

Given the need of understanding the substantial costs in addition to treatment directly related to the disorder, the current study developed an in-depth questionnaire to comprehensively assess family-level costs directly and indirectly related to children's behavioral difficulties across development. The purpose of this study was to provide an estimate of the incremental family burden of raising a child with ADHD compared to typically developing children. The specific aims of the current study were to: (1) estimate the incremental household financial impact (i.e., direct cost related to children's behaviors and indirect cost related to caregiver strain) of ADHD, and (2) probe social-occupational burden and reduced work efficiency of caregivers.

Method

Participants

The current study was conducted using the sample at the Pittsburgh site of *the Preschool Study* (Lahey et al. 1998), which was a longitudinal project that examined the validity of diagnostic criteria for ADHD in young children. The study was approved by the Institutional Review Board of the University of Pittsburgh. Written consent from parents and oral assent from children were obtained. Two cohorts of participants were recruited at age four to six from university clinics or through flyers or newspaper advertisements. Participants were excluded if they had received clinical

diagnoses of pervasive developmental disorder, psychosis, mental retardation, or seizure disorder. At baseline assessment, probands met diagnostic criteria for ADHD according to the *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed., rev.; *DSM-III-R*; American Psychiatric Association 1987). Comparison participants, matched on age, sex, and ethnicity, were recruited from the same schools as probands or comparable neighborhood schools. Comparison children had never been referred for mental health services yet were not excluded if they met *DSM* diagnostic criteria for a mental health condition other than ADHD based on the baseline ratings. Follow-up assessments were conducted annually until participants reached 18 years old or the end of the study (2010). Design and funding-related changes during the final years of the project resulted in the reduction of the comparison sample by approximately 50%. Parents at the Pittsburgh site were offered the opportunity to participate in the current study at the 12th or 13th assessment year of the Preschool Study. A total of 56 parents in the ADHD group and 30 parents in the control group completed the current study. Retention in adolescence in the current study in Pittsburgh was 94%. Descriptive statistics for ADHD and control groups in the current study are provided in Table 1.

Measures

ADHD Diagnoses in Childhood

Baseline ADHD diagnoses were established if the child (1) met *DSM-III-R* ADHD symptom criteria and (2) experienced impairments in at least one setting (i.e., peer, school, family). A symptom was deemed present if the parent reported it on the *Diagnostic Interview Schedule for Children* (DISC; Shaffer et al. 2000) or the teacher rated “pretty much” or “very much” on *DSM-IV* version of the *Disruptive Behavior Disorder Rating Scale* (DBD; Pelham et al. 1992). Impairment was deemed present if parents reported child’s ADHD symptoms caused problems at home, with friends, or at school during the DISC interview, or if the parent or teacher rated 3 or above on the overall impairment item of the Impairment Rating Scale (IRS; Fabiano et al. 2006). This diagnostic procedure complies with standard guidelines for diagnosing ADHD (Pelham et al. 2005).

ODD and CD Symptoms in Adolescence

Considering that some probands and comparison participants may have a change of Oppositional Defiant Disorder (ODD) or Conduct Disorder (CD) symptoms after the baseline assessment, we used parental ratings of symptoms in adolescence (ages 14–17) as covariates, rather than baseline ratings. A symptom was deemed present if either parent or teacher endorsed “pretty much” or “very much” on the *DSM* symptoms of ODD and CD on the DBD rating scale (Pelham et al. 1992). Parent ratings on the DBD were used instead of the DISC to

standardize measures across parents and teachers during the annual assessments when participants were ages 14 to 17. Parent-rated DBD is internally consistent with alphas ranging from 0.82 to 0.85 (Pelham et al. 2005).

Household Burden Variables

Household burden variables were collected using retrospective parent report about the child’s entire life on the *Impact Questionnaire*, developed by the research team (Supplementary 1). Caregivers were asked to report on monetized and unmonetized burden associated with their children’s special needs or behavioral difficulties, using a variety of *yes/no*, open-ended, and multiple-choice questions. For instance, one initial *yes* or *no* item asked, “Has your child ever been evaluated or re-evaluated for special education services?” If caregivers responded *yes*, they answered several follow-up questions including if they had missed work to attend school meetings and the amount of work they had missed in hours, as well as if they needed additional childcare and the amount of money spent on extra childcare. We prompted the parents to report details of the events related to costs and expenses (e.g., reasons for evaluation, school staff at conferences, length of conferences), because asking for details is helpful in improving recall accuracy (Friedenreich 1994).

Burden is further categorized into direct costs associated with participants’ behavioral and emotional difficulties and indirect costs related to caregiver strain. Subdomains included special education services (e.g., IEP meetings), in-person conferences, phone call/written communication with teachers and other school staff, discipline problems at school (i.e., suspension, detention, expulsion), juvenile delinquency, accidents, injury, doctor appointments, and others. Item responses were compiled to create a profile of each family’s monetary expenses and work absenteeism associated with target youths’ behavioral problems and services. All monetary cost estimates were adjusted to 2017 dollars using the Consumer Price Index (<https://www.bls.gov/cpi/>).

Monetized Burden Numeric responses of direct and indirect costs were summed to arrive at a total monetary cost (excluding treatment costs).

Direct Costs Direct costs included costs related to youths’ behavioral problems (excluding treatment costs) and additional services the child required (e.g., academic achievement). Expenses related to academic support included purchases of educational software, tutoring, and extra books. Spending related to accident and injury included out-of-pocket payments and increase in insurance premiums. Expenditures related to discipline and legal involvement included lawyer and court fees.

Indirect Costs Indirect costs associated with children’s emotional and behavioral difficulties included reported income loss

Table 1 Demographic and clinical characteristics

	ADHD (<i>n</i> = 56) <i>M</i> (<i>SD</i>) or %	Control (<i>n</i> = 30) <i>M</i> (<i>SD</i>) or %	<i>t</i> or X^2	<i>d</i> or <i>V</i>	<i>df</i>	<i>p</i>
Caregiver characteristics at baseline						
Education (years)						
Mother	13.53 (2.1)	14.33 (2.4)	−1.57	−0.36	79.00	0.12
Father	13.67 (2.5)	14.75 (2.8)	−1.66	−0.42	70.00	0.10
Marital status			4.76	0.24	2.00	0.09
Married	56.40%	70%				
Divorced	34.50%	13.30%				
Others	9.10%	16.70%				
Family income	\$31,991 (\$26,772)	\$40,550 (\$32,207)	−1.29	−0.30	81.00	0.20
Child characteristics						
Male	76.80%	70%	0.47	0.07	1.00	0.49
Age at baseline	5.18 (0.7)	5.0 (0.8)	1.06	0.24	84.00	0.29
Race/ethnicity			3.69	0.21	3.00	0.30
White/Caucasian	69.60%	73.30%				
Black/African American	19.60%	26.70%				
Asian	1.80%	0%				
Others	8.90%	0%				
ADHD subtypes at baseline			–	–	--	--
ADHD-H/I	19.60%	0%				
ADHD-I	5.46%	0%				
ADHD-C	67.90%	0%				
Comorbid CD or ODD at baseline	57.10%	3.30%	23.92	−0.53	1.00	< 0.01
IQ at baseline	90.64 (15.8)	99.73 (13.8)	−2.65	−0.60	84.00	0.01
Comorbid symptoms in adolescence						
ODD	1.68 (2.4)	0.33 (1.3)	3.25	0.64	80.89	< 0.01
CD	0.56 (1.5)	0.13 (0.7)	1.74	0.33	79.32	0.09

M Mean, *SD* Standard Deviation, *CD* Conduct Disorder, *ODD* Oppositional Defiant Disorder, *d* Cohen's *d*, *V* Cramér's *V*, *df* degree of freedom. Based on reported data. Welch two-sample *t*-tests were used in the case of unequal variance

due to being fired and changed job responsibilities, imputed income loss from missed work, additional childcare expenses, and treatment for the parent's mental health concerns (e.g., psychoactive medication, therapy). Imputed income loss for parents was calculated by multiplying aggregated hours of work missed and the Bureau of Labor Statistics' national estimate of hourly wage (U.S. Department of Labor 2016).

Unmonetized Burden Parents of children with ADHD also experienced burden that is not easily monetized, such as socio-emotional burden and reduced work efficiency.

Occupational and Socio-Emotional Burden Parents were explicitly asked if they had lost a job, changed job responsibilities, received mental health treatment, missed activities in which they would have participated otherwise, and needed additional childcare services *because of* their child's problems or special needs. Binary variables were created to examine group differences in occupational and socio-emotional burden.

Reduced Work Efficiency We asked the caregivers to identify a specific age of their child when their child had the most severe social and behavioral difficulties. Questions related to reduced work efficiency during the identified timeframe included how often working parents lost concentration, repeated a task, worked more slowly than usual, had nonwork-related conversations about their child, felt tired, and did not get any work done. Each item was rated on a Likert scale. Responses were converted to interval data using midpoint for analyses (0 = *None of the time or 0 h in an 8-h day* to 7.5 = *All of the time or 7–8 h in an 8-h day*).

Data Analytic Plan

We conducted inferential and descriptive analyses using STATA 14 (STATA Corp 2015) and R open source statistical software (R core team 2016). Item-level missing data of burden variables were substituted by conditional means when national estimates were unavailable. Blind to clinical and

demographic information of all families, multiple evaluators from the research team generated and applied consistent decision rules (e.g., the two-way commute time at Pittsburgh was estimated to be 40 min). Outliers and influential points were identified via visualization of the Violin plot (Fig. 1) (Hintze and Nelson 1998) and calculation of Cook's distances (Cook 1977). We retained the outliers and influential cases to ensure the generalizability and representativeness of the sample because they represented a small subset of families of adolescents at risks for severe delinquency problems and high costs. A 5% alpha was used for all analyses.

Monetized Burden Mean comparisons of total monetary costs were conducted using *t*-tests. Due to the non-normal distribution of the sample, we conducted regression models using negative binomial distribution (Model 1 & Model 2) in which total monetary cost was the dependent variable and baseline ADHD diagnosis was the independent variable ($\theta = 0.2$, AIC = 1526.7) (Gardner et al. 1995; Hilbe 2011; Jackman 2008).¹ Because of the significant difference in IQ between ADHD group ($M = 90.64$, $SD = 15.8$) and comparison group ($M = 99.73$, $SD = 13.8$), baseline IQ was entered as a covariate (Model 3). Considering that comorbid ODD and CD symptoms are commonly observed (Anderson et al. 1987) and may increase family burden (Meyers et al. 2010), we entered the following two variables as covariates: symptom count of ODD in adolescence (Model 4) and symptom count of CD in adolescence (Model 5). Three participants had missing data on CD and ODD symptoms in adolescence. Listwise deletion for models including ODD or CD was used, because a missing rate of 3% is considered inconsequential (Dong and Peng 2013).

Unmonetized Burden Categorical analyses with more than two categories were performed using chi-square tests. All 2×2 categorical analyses were performed using unconditional Fisher–Boschloo's test (Calhoun 2013), which is more powerful and appropriate for small sample sizes and unbalanced designs than traditional Fisher's test and chi-square test (Lydersen et al. 2009; Mehrotra et al. 2003). Mean comparisons of reduced work efficiency were conducted using *t*-tests.

Results

Monetized Burden

Over the course of child development, participants diagnosed with ADHD in childhood ($M = \$15,036$, $SD = \$38,269$)

¹ Although the negative binomial model (NB) (Model 1) has better fit statistics than the zero-inflated negative binomial model (ZINB) (Model 2) (BIC-corrected Vuong $z = 1.67$, $p = 0.05$) (Desmarais and Harden 2013), results from ZINB were presented to account for zero-inflation and measurement errors.

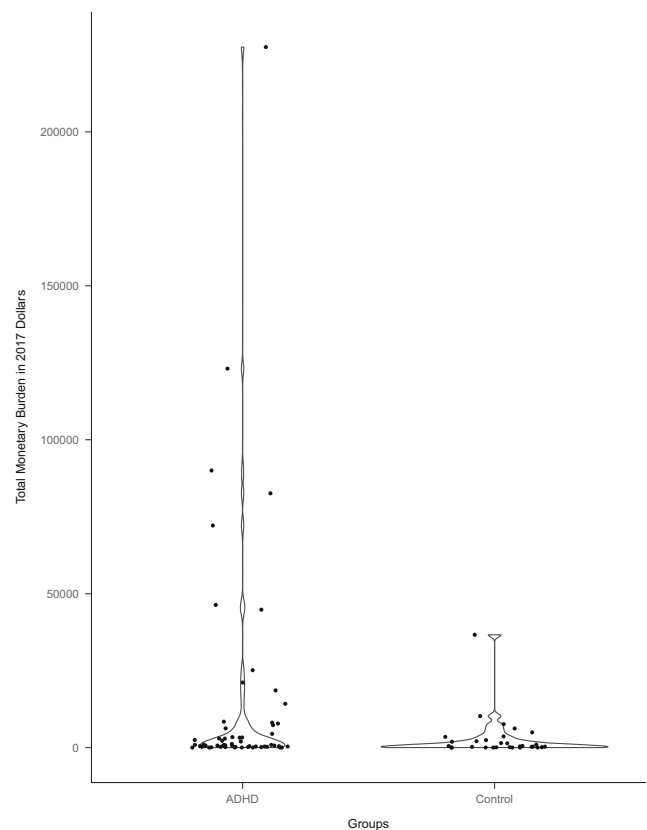


Fig. 1 Total Monetized costs by group

incurred over five times higher total financial burden, compared to comparison children ($M = \$2,848$, $SD = \$6,868$), $t(61.39) = 2.31$, $p = 0.02$, Cohen's $d = 0.39$ (Table 2 and Fig. 1). Group differences in estimated monetary costs for specific domains are displayed in Table 2. Participants in the ADHD group incurred significantly more costs due to missing activities relative to comparison participants (ADHD: $M = \$49$, $SD = \$126$; Comparison: $M = \$9$, $SD = \$40$), $t(72.75) = 2.20$, $p = 0.03$, Cohen's $d = 0.39$. Regarding indirect costs, families of participants in the ADHD group experienced substantial income loss due to getting fired ($M = \$3,609$, $SD = \$15,695$) and changing job responsibilities ($M = \$3,478$, $SD = \$10,668$), while comparison parents reported no losses in these categories. Additional childcare expenses made up 19.7% of total cost in the ADHD group compared to 1% in the control group.

In order to assess whether violations of assumptions impacted the primary results, we investigated the association between ADHD diagnosis and total costs under alternative parameterizations and after controlling for confounding effects of IQ, ODD, or CD (Table 3). Results from negative binomial models were consistent with those of the two-tailed *t*-test, which indicated that families of individuals diagnosed with ADHD in childhood experienced more than five times as much total monetary burden

Table 2 Monetized costs to families over the course of child development

Cost categories	ADHD (<i>n</i> = 56)		Control (<i>n</i> = 30)		<i>d</i>	<i>t</i>	<i>df</i>	<i>p</i>
	<i>M</i> (<i>SD</i>)	[<i>Min</i> , <i>Max</i>]	<i>M</i> (<i>SD</i>)	[<i>Min</i> , <i>Max</i>]				
Direct costs related to child's behaviors								
Legal Involvement	141 (478)	[0, 2,380]	107 (465)	[0, 2,499]	0.07	0.32	84.00	0.75
Accident/injury	290 (995)	[0, 5,950]	62 (231)	[0, 1,071]	0.28	1.63	65.37	0.11
Lost belongings	118 (361)	[0, 2,083]	50 (84)	[0, 238]	0.23	1.35	65.37	0.18
Missed activities *	49 (126)	[0, 595]	9 (40)	[0, 216]	0.39	2.2	72.76	0.03
Damaged property	94 (344)	[0, 1,785]	24 (130)	[0, 714]	0.24	1.36	77.83	0.18
Academic achievement	686 (2,931)	[0, 18,445]	514 (1,439)	[0, 7,140]	0.07	0.36	83.55	0.72
Indirect costs related to caregiver strain								
Income loss due to getting fired	3,609 (15,695)	[0, 108,290]	0	[0, 0]	–	–	–	–
Income loss due to changed responsibilities	3,478 (10,668)	[0, 59,500]	0	[0, 0]	–	–	–	–
Imputed income loss due to missing work ^a	3,611 (12,433)	[0, 81,995]	2,048 (6,340)	[0, 33,886]	0.15	0.77	83.87	0.44
Parental mental health services	25 (117)	[0, 883]	0	[0, 0]	–	–	–	–
Additional childcare	2,936 (15,162)	[0, 81,674]	34 (176)	[0, 968]	0.24	1.43	55.03	0.16
Total Cost *	15,036 (38,269)	[0, 227,544]	2848(6,868)	[0, 36,634]	0.39	2.31	61.39	0.02

Variables were computed using retrospective parent report about child's entire life. All values are in 2017 USD

M Mean, *SD* Standard Deviation, *Min* Minimum, *Max* Maximum, *df* degree of freedom

*0.01 < *p* < 0.05

^a The imputed income loss for parents was calculated by multiplying aggregated hours of missing work due to their child's behavioral problems and the Bureau of Labor Statistics' national estimate of hourly wage

as their demographically similar peers. Baseline ADHD diagnosis significantly predicted high total monetary burden (Model 1), $b = 1.66$, $SE = 0.57$, $t(84) = 2.94$, $RR = 5.28$, $p < 0.01$. The association between ADHD and total monetary burden remained significant after controlling for zero inflations (Model 2), $b = 1.52$, $SE = 0.46$, $t(81) = 3.30$, $RR = 4.59$, $p < 0.01$. The logistic model predicting excessive zeroes in total monetary burden was not statistically significant, $p > 0.05$, which suggested that ADHD and control families did not differ in their likelihood of having zero additional financial burden.² The association between ADHD and total monetary burden remained significant after controlling for baseline IQ (Model 3), ODD symptom count in adolescence (Model 4), and CD symptom count in adolescence (Model 5), $ps < 0.05$. Neither ODD nor CD symptom count in adolescence accounted

for a significant amount of variance in the total monetary burden ($ps > 0.05$).

Unmonetized Burden

Occupational and Socio-Emotional Burden Group differences in occupational and socio-emotional burden over the course of raising a child are reported in Table 4. Regarding socio-emotional burden, 15% of parents of participants diagnosed with ADHD reported having received psychosocial services (e.g., treatment for depression), while no parents of comparison participants reported pursuing mental health services.

Reduced Work Efficiency When asked to identify a time when their child had most severe social and behavioral difficulties, forty caregivers in the ADHD group were able to identify a specific age of their child ($M_{age} = 11.45$, $SD = 4.24$), whereas twelve of the control families were able to identify a specific age when their child experienced the most difficulties ($M_{age} = 12.13$, $SD = 3.80$). The parents in the ADHD group experienced reduced work efficiency with medium effect sizes in comparison to those in the control group (Table 5). Compared to parents of control participants, parents of children with ADHD reported that they spent more time unable to concentrate, repeating a task, working more slowly than usual, having nonwork-related conversations, and feeling tired, $ps < 0.05$, Cohen's $ds > 0.49$.

² The ZINB has two parts: (a) a logistic regression to predict the presence of any excessive zero economic burden (i.e., whether burden > 0) and (b) a negative binomial model to predict total monetary burden, conditional on burden being present. In contrast, in hurdle models, all zeroes come from one "structural" source (i.e., all zeroes suggested that families experienced zero monetary burden in the given categories). The ZINB was chosen because zeroes in our dataset included families who reported zeroes due to recall errors (e.g., some caregivers had difficulty remembering the costs across the entire 14 to 17 years assessed in the survey), as well as the families who actually experienced zero monetary burden in the given categories.

Table 3 The association between childhood ADHD and total monetized family burden

	<i>RR</i>	β	<i>SE</i>	<i>t</i>	<i>df</i>	<i>p</i>	<i>AIC</i>	θ
Model 1: ADHD (no covariate)	5.28	1.66	0.57	2.94	84	< 0.01	1526.3	0.20
Model 2: ADHD (zero-inflation)	4.59	1.52	0.46	3.30	81	< 0.01	1527.6	0.27
Model 3: ADHD (covariate: IQ)	4.63	1.53	0.01	3.16	83	< 0.01	1528.4	0.24
Model 4: ADHD (covariate: ODD) ^a	3.85	1.35	0.49	2.74	80	0.01	1467.5	0.24
Model 5: ADHD (covariate: CD) ^a	4.59	1.52	0.48	3.18	80	< 0.01	1469.2	0.23

RR rate ratio, *SE* standard error, *AIC* Akaike information criteria, *df* degree of freedom for the fitted model. All models used negative binomial distribution

^a *N* = 83

Discussion

Our results were consistent with initial hypotheses. First, we aimed to estimate the incremental household financial impact associated with childhood ADHD (i.e., direct costs associated with child’s behaviors and indirect costs related to caregiver strain). Relative to controls, not including treatment costs, the families of children diagnosed with ADHD experienced five times higher monetized financial burden over the course of raising their child. Substantial differences in household burden between families of children diagnosed with ADHD and comparison families remained significant after controlling for covariates (i.e., IQ scores, ODD symptoms, and CD symptoms) and under alternative parameterizations (i.e., negative binomial regression models) (see Table 3). Additionally, we assessed occupational burden, socio-emotional burden, and reduced work efficiency of parents. Families in the ADHD group experienced higher socio-occupational burden and lower work efficiency when their child was most impaired, compared to control families.

Our findings indicate that direct and indirect costs are substantial for families raising a child with ADHD (see Table 2). Aggregating costs from multiple domains (e.g., academic

achievement, income loss due to getting fired, income loss due to changed job responsibilities, additional childcare costs) yielded a lifetime estimate of \$12,188 in incremental costs. This estimate does not include the costs associated with the treatment of ADHD. Our direct cost estimates are consistent with previous investigations of functional outcomes of adolescents diagnosed with ADHD (Barkley 2014), such as high risk for automobile accidents (Thompson et al. 2007) and delinquent behaviors (Fletcher and Wolfe 2009; Sibley et al. 2011). This estimate is also consistent with previous research suggesting increased utilization of special education services among youths diagnosed with ADHD (Robb et al. 2011). Our results regarding indirect costs are consistent with previous research on dysfunctional family outcomes (Harpin 2005; Johnston and Mash 2001), caregiver strain (Bussing et al. 2003), and productivity loss (Doshi et al. 2012) in families of individuals diagnosed with ADHD.

The substantial difference in total monetized burden can be largely attributed to the high unmonetized burden (i.e., occupational and socio-emotional burden, reduced work efficiency) experienced by the families in the ADHD group (see Tables 4 and 5). A total of 20% reported a reduction in work hours and 11% reported losing their jobs due to their child’s

Table 4 Group differences of parental occupational and socio-emotional burden

Burden categories	ADHD (<i>n</i> = 56) %	Control (<i>n</i> = 30) %	Difference	<i>OR</i>	Test statistic ^a	Nuisance parameter	<i>p</i>
Occupational burden							
Changed job responsibilities	20%	3%	17%	8.08	0.05	0.5	0.04
Quit a job or got fired	11%	0%	11%	–	0.09	0.72	0.07
Socio-emotional burden							
Received mental health treatment	15%	0%	15%	–	0.05	0.5	0.04
Missed other leisure activities	11%	10%	1%	1.11	>0.9	0.63	>0.9
Needed additional childcare	27%	10%	17%	3.33	0.1	0.7	0.07

Unconditional Fisher–Boschloo’s test was used to calculate *p*-values

OR odds ratio

^a The *p*-values from traditional Fisher’s exact test are used as test statistics when tail probabilities are maximized across nuisance parameters. Degree of freedom = 1 for all models

Table 5 Group differences of parental reduced work efficiency

Burden categories	ADHD ($n = 45$) ^a $M (SD)$	Control ($n = 25$) ^b $M (SD)$	t	df	p	Cohen's d
Lost concentration	1.07 (1.5)	0.26 (0.5)	3.26	58.88	< 0.01	0.64
Repeated a task	0.28 (0.7)	0.02 (0.1)	2.67	47.55	0.01	0.50
Worked more slowly than usual	0.64 (1.3)	0.10 (0.3)	2.72	53.46	0.01	0.52
Nonwork-related communication	1.09 (1.8)	0.36 (0.7)	2.39	64.28	0.02	0.49
Felt fatigued at work	1.43 (2.4)	0.30 (1.0)	2.81	63.79	0.01	0.57
Did not get any work done	0.04 (0.1)	0	–	–	–	–

Caregivers were asked to identify a specific age of their child when their child had the most severe social and behavioral difficulties. Identified age is comparable in ADHD and comparison groups (ADHD: $M_{age} = 11.45$, $SD = 4.24$; Control: $M_{age} = 12.13$, $SD = 3.80$)

M Mean, SD Standard Deviation. All Mean and SD values are in hours per day. Welch two-sample t -tests were used due to unequal variance

^a Parents of 9 participants in the ADHD group were not working, one could not identify a time in which their child's problems were most severe, and one parent missed the page

^b Five participants in the control group were excluded because their parents were not working

difficulties in the ADHD group. These percentages are comparable to those reported in an online survey sample in Europe, in which 30% of caregivers reported that their child's ADHD caused them to change job positions or schedules, reduce work hours, or quit their jobs (Flood et al. 2016; Fridman et al. 2017). The aforementioned occupational burden may be exacerbated when their child experienced the most difficulties, as parents often felt inattentive, redundant, inefficient, and tired. Our findings related to socio-emotional burden (e.g., receiving psychosocial services or medication, requiring additional childcare services) are consistent with previous work on caregiver strain and parenting struggles associated with raising a child diagnosed with ADHD. Fifteen percent of ADHD group parents received psychosocial services to help manage their own social and emotional difficulties. These findings are consistent with past research demonstrating that many caregivers of children with ADHD experienced marital discord (Wymbs et al. 2008), parenting stress (Theule et al. 2010), and substance/alcohol problems (Pelham and Lang 1993; Pelham et al. 1997).

Our study has multiple strengths. First, we included a variety of cost domains that cannot be extracted from medical insurance claims and national surveys. The current study is the first attempt to include direct costs related to youths' social, behavioral and academic difficulties, by encompassing parental expenditures related to domains such as legal matters, accidents, and academic achievement. Second, we conducted analyses on a sample of parents of individuals who were well diagnosed with ADHD in childhood using standard *DSM* criteria, as compared to their demographically similar peers. The sample was followed from childhood through adolescence, thus providing the opportunity to assess family burden over the course of child development. Third, our approaches of incorporating parent-reported data and national estimates allowed us to conduct a

more comprehensive estimate than previous investigations (e.g., Birbaum et al. 2005; Gupte-Singh et al. 2017). Indirect costs of the current study included parents' treatment costs, income loss, and childcare expenses. Specifically, our income loss estimates were derived from parent-reported number of hours missed at work, parent-reported income difference between altered positions and during unemployment, and national average data. In contrast, existing studies have either used official absenteeism reported in insurance claims (Birbaum et al. 2005) or youths' missed school days (Gupte-Singh et al. 2017) to estimate parental productivity loss.

The study had limitations. This small sample was drawn entirely from the Pittsburgh metropolitan area. Thus, it is similar to other well-published longitudinal samples in Pittsburgh (e.g., Pittsburgh ADHD Longitudinal Study [PALS]). However, childhood ADHD and its burden to families can be associated with a variety of socioeconomic factors (Larsson et al. 2014). For example, in terms of family income, spending \$15,000, the average incremental cost of raising a child with ADHD, has a very different impact on a family making \$35,000 per year versus one that is making \$100,000 per year. Considering racial/ethnic backgrounds, compared to Caucasian families, families of more collective cultures, such as families from Latino/Hispanic ethnic backgrounds, may experience higher or lower indirect and intangible burden due to the value of familialism (Bauermeister 2016; Shin and Brown 2009). Additionally, parental ADHD may have slightly inflated the estimates of family burden, given its elevated prevalence in parents of children diagnosed with ADHD and associated functional impairments. In addition to the potential impact of SES factors and parental psychopathology, it is worth emphasizing that data were collected from a naturalistic longitudinal sample including families of adolescents with ADHD and controls recruited during childhood. Given the case-control design of

this study and many other longitudinal follow-up studies in the field of mental health, our ability to draw causal inferences about ADHD and family burden is limited. Further investigations with longitudinal assessments and larger sample sizes in other communities and states are needed to examine potential mediators, moderators, and causal pathways of family burden.

Our lifetime estimates were based on parental retrospective report, thus raising concerns about recall errors and cognitive biases. However, we are not aware of any reason that recall errors or biases would be worse of parents in the ADHD group compared to parents in the control group. Furthermore, long-term retrospective recall has been demonstrated as a reliable and valid information source for parenting, child development, and adults' own experiences (Bornstein et al. 2018; Brewin et al. 1993; Kuriyan et al. 2014; Moon et al. 2016; Richters 1992). For instance, in families of individuals diagnosed with ADHD, Kuriyan et al. (2014) reported 80% concordance for psychoactive medication history from prekindergarten to grade 12 between parent's retrospective report and physician's record. To further address the potential measurement errors, we also tested the robustness of results in our presented zero-inflated model.

Beyond measurement issues, the incremental total burden to families may also be more significant if we adopt a timeframe including young adulthood. Altszuler et al. (2016) reported that young adults diagnosed with ADHD in childhood earned lower incomes and were more likely to depend on their parents for financial support relative to comparison participants, suggesting that substantial burden to families continue into young adulthood. Further, Pelham and colleagues (under review) projected significantly lower lifetime earnings and retirement savings in adults with childhood ADHD diagnoses relative to those without the disorder, indicating that enormous burden to families and the society in general continues into at least middle adulthood. Future studies computing lifetime estimates would be strengthened by collecting prospective data across a broader timeframe.

Despite its limitations, this study has significant implications for public policy and clinical practice, as it offers clear evidence that caregivers of children and adolescents diagnosed with ADHD experience substantial financial and socio-emotional burden. To reduce the financial burden to families, practitioners and policymakers should ensure families are aware of and have access to existing support programs for which they may be eligible (e.g., Supplemental Security Income, Social Security Disability Insurance, Family Medical Leave, and options for respite care). Currently, these programs are significantly underutilized in families of youths with disabilities (Pilapil et al. 2017). Implementing evidence-based interventions that reduce parents' burden may help reduce the dysfunctional outcomes for which we have provided costs estimates (i.e., direct costs, indirect costs). Behavioral parent training is a well-established intervention that is among the most recommended for families of children diagnosed with ADHD (Evans et al. 2018). Therefore, increasing competency

and engagement of parents while minimizing treatment-related burden is vital. For instance, providing childcare services to target children and their siblings during parent training may reduce dropout rates and offset the burden associated with treatment at the family and system levels. Future studies should examine whether the commonly recommended treatment for childhood ADHD (i.e., stimulant medication, behavioral modification, and the combination of the two) can reduce the economic burden of ADHD to families across child development.

Raising a child diagnosed with ADHD incurs substantial direct, indirect, and intangible costs to families that are above and beyond medication and services directly related to treatment for the disorder. These costs have not been systematically assessed in prior studies. Although these cost estimates may not seem large to some academic readers, according to a recent report from the Federal Reserve Board (2017), nearly half of the sampled American households reported that they could not easily afford an emergency expense of \$400—substantially less than the costs that we reported herein.

In a previous report on the societal costs of ADHD (Pelham et al. 2007), data on family costs were unavailable. Based on the current study of family costs, the current U.S. prevalence of ADHD in youths (11%; Visser et al. 2014), and the recent US childhood population estimates (73 million; U.S. Census Bureau 2017), our societal estimate of the annual economic burden of ADHD to American families is \$5.8 billion (2017 US Dollars). Applying the estimates for other cost categories from our previous report, adjusting for inflation, and using this estimate of family costs and the current prevalence rates, our rough annual estimate of cost of illness (COI) for ADHD in children and adolescents in the U.S. is \$124.5 billion (2017 US Dollars). Notably, this number is greater than recent estimates of annual COI for adult depression (\$90 billion) (Greenberg et al. 2015) and ASD (\$65 to \$70 billion) (Buescher et al. 2014) in the US. Clearly, ADHD is a costly mental health condition in the US with substantial incremental costs to families. Joint efforts from practitioners, employers, and policymakers may help to offset the incremental costs to families raising children diagnosed with ADHD.

Acknowledgments This research was supported by a grant from the National Institute of Mental Health Grant (R01-MH-53554). Additional support was provided by grants from the National Institute of Mental Health (MH069614, MH069434, MH092466, MH065899, MH62988), the Institute of Education Sciences (R324J060024, LO30000665A, R324B060045), the National Institute of Alcohol Abuse and Alcoholism (AA11873), and the National Institute on Drug Abuse (DA12414, DA12986, T32DA039772).

Funding This research was supported by a grant from the National Institute of Mental Health Grant (R01-MH-53554). Additional support was provided by grants from the National Institute of Mental Health (MH069614, MH069434, MH092466, MH065899, MH62988), the Institute of Education Sciences (R324J060024, LO30000665A, R324B060045), the National Institute of Alcohol Abuse and Alcoholism (AA11873), and the National Institute on Drug Abuse (DA12414, DA12986, T32DA039772).

Compliance with Ethical Standards

Conflicts of Interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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