Factors associated with caregiver burden among pharmacotherapy-treated children/adolescents with ADHD in the Caregiver Perspective on Pediatric ADHD survey in Europe.

Fridman M, Banaschewski T, Sikirica V, Quintero J, Erder MH, Chen KS.


Abstract

BACKGROUND:
The burden on caregivers of children/adolescents with attention-deficit/hyperactivity disorder (ADHD) is multidimensional but incompletely understood.

OBJECTIVE:
To analyse caregiver burden across the concepts of work, social/family life, and parental worry/stress, in relation to selected contributing factors.

METHODS:
The online Caregiver Perspective on Pediatric ADHD survey was fielded in ten European countries. The analysis included children/adolescents (6-17 years) who were receiving/had received ADHD pharmacotherapy in the previous 6 months. Caregivers recorded their child's/adolescent's symptoms "on"/"off" medication (ie, when the caregiver reported that the child/adolescent forgot/chose not to take medication, before the onset of medication effect, or medication worn off). Effects of ADHD severity, comorbidities, and medication adherence on each burden outcome were assessed (multiple regression models).

RESULTS:
In total, 2,326 caregivers were included (children/adolescents' mean age: 11.5 years, 80% male). Caregivers reported missed/altered work, avoiding social activity, increased parental worry/stress, and strain on family life, despite using ADHD pharmacotherapy. Child/adolescent comorbidities and ADHD severity were significantly related to all burden concepts measured; the strongest comorbidity associations were with altered work (odds ratios [ORs] =1.68 [95% confidence interval {CI} 1.33, 2.12], 1.87 [1.37, 2.54], 3.47 [2.51, 4.78] for 1, 2, 3+ comorbidities, respectively) and planning the day around the child/adolescent (OR =1.42 [95% CI 1.17, 1.72], 1.73 [1.33, 2.15], 2.65 [1.99, 3.53]); the strongest severity associations were: quitting a job (OR =1.41 [95% CI 1.26, 1.59]) and planning a day around the child/adolescent (OR =1.26 [95% CI 1.20, 1.32]). Increased medication adherence was most associated with reducing the caregiver burden for altered work (OR =0.57 [95% CI 0.45, 0.72]), worrying about how they are being perceived as a parent (OR =0.68 [0.56, 0.83]), and avoiding social activity (OR =0.56 [0.45, 0.68]), but not family or stress burden.

CONCLUSION:
Burdens related to work, social activity, family life, and parental worry/stress were experienced by the caregivers of children/adolescents with ADHD, despite using ADHD pharmacotherapy. Better understanding of clinical/treatment characteristics most associated with the components of caregiver burden may help improve ADHD management and may ease caregiver burden.