Access to diagnosis, treatment, and supportive services among pharmacotherapy-treated children/adolescents with ADHD in Europe: data from the Caregiver Perspective on Pediatric ADHD survey.

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Abstract

BACKGROUND:
Attention-deficit/hyperactivity disorder (ADHD) is one of the most common childhood psychiatric disorders and negatively impacts caregivers' lives. Factors including barriers to accessing care, dissatisfaction with support services, and lack of caregiver resources may contribute to this.

OBJECTIVES:
To report caregivers' experiences of ADHD diagnosis, behavioral therapy (BT), and supportive care for children/adolescents with ADHD.

METHODS:
The Caregiver Perspective on Pediatric ADHD (CAPPA) survey included caregivers of children/adolescents (6-17 years) from ten European countries who were currently receiving/had received ADHD pharmacotherapy in the previous 6 months. Caregivers reported experiences of obtaining an ADHD diagnosis, access to BT, availability of caregiver resources, and level of health care/school support. Pan-EU and country-specific descriptive statistics are reported; responses were compared across countries.

RESULTS:
Of 3,616 caregivers, 66% were female. The mean age of children/adolescents was 11.5 years; 80% were male. Mean time from the first doctor visit to diagnosis was 10.8 (95% confidence interval 10.2, 11.3) months; 31% of caregivers reported the greatest degrees of difficulty in obtaining an ADHD diagnosis; 44% of children/adolescents did not receive BT. Forty-seven percent of caregivers reported that sufficient resources were available, 44% were "very satisfied"/"satisfied" with medical care, and 50% found health care providers "very supportive"/"somewhat supportive". Mainstream schools were attended by 82% of children/adolescents. Of those, 67% of caregivers thought schools could help more with the child/adolescent's ADHD and 48% received extra help/special arrangement. Results varied significantly between countries (P<0.001, all parameters).

CONCLUSION:
Almost a third of caregivers reported a high degree of difficulty in obtaining an ADHD diagnosis for their child/adolescent, less than half felt that sufficient resources were available, and gaps in support from health care providers/schools were identified. Findings underscore the need to improve access to diagnosis and provision of supportive services to enable better standards of care, and potentially reduce the impact of child/adolescent ADHD on caregivers' lives.