The caregivers' perspectives of burden before and after an internet-based intervention for young persons with ADHD or autism spectrum disorder.

Söderqvist H, Kajsa E, Ahlström BH, Wentz E.

doi: 10.1080/11038128.2016.1267258. [Epub ahead of print]

Abstract

BACKGROUND:
Everyday life in a family with a young person with attention-deficit/hyperactivity disorder (ADHD) and/or autism spectrum disorder (ASD), is multifaceted and may be a burden to the caregivers. The aim was to explore experiences of the caregiver situation, and how they were affected when the young persons received Internet-Based Support and Coaching (IBSC).

METHOD:
A multiple descriptive case design was used. Ten caregivers of 10 young persons with ADHD and/or ASD participated, and completed a questionnaire, measuring caregiver burden. Three analysis methods were used; statistical analysis of the caregivers' scores, case reports and qualitative content analysis of an open question.

RESULTS:
Most of the caregivers never had to provide hands-on help with primary ADL and were able to cope with the young person's problems. The caregivers' role required patience. They had major worries about the future when they would no longer be around to provide support. After the intervention, there was no common trajectory for all caregivers; their situation either remained unchanged, improved or deteriorated.

CONCLUSIONS:
The caregiver's burden is more or less complex when the young person undergoes the transition into adulthood. The caregiver burden decreased in some families following the young person's participation in IBSC.