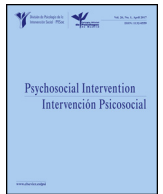




# Psychosocial Intervention

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## A cognitive-behavioural intervention improves cognition in caregivers of people with autism spectrum disorder: A pilot study

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### ABSTRACT

As postulated by the stress process model, chronically stressed individuals, such as caregivers of people with chronic psychological disorders, have poorer cognitive performance and higher age-related cognitive decline than individuals not exposed to chronic stress. When analysing this topic in caregivers, the majority of research has been conducted in populations in which the care recipient has dementia and/or Alzheimer's disease, while relatively few studies have analysed cognition in caregivers of offspring with autism spectrum disorder (ASD). The main objective of this pilot study was to analyse the effect of a cognitive-behavioural intervention on cognition in caregivers of people with ASD. Specifically, we sought to gather evidence on whether there were clinically significant improvements in speed/attention, memory, and visuospatial, language and executive functions after the intervention. The participants were 17 parents (mean age of 52 years, 59% females) of ASD-diagnosed people who had cared for their offspring for approximately 14 years. The study had a pre-post design. After the cognitive-behavioural intervention, ASD caregivers had better selective attention, short- and long-term memory for words, stories and images, naming, cognitive flexibility and planning skills ( $p = .01$  for all). Nevertheless, no changes were observed in general cognitive status, working memory for digits, verbal fluency, processing speed or inhibitory control ( $p > .05$  for all). These findings underline the relevance of proper support and respite services to help caregivers cope with and reduce stress. A comprehensive neuropsychological assessment together with adjuvant domain-specific procedures and programmes to improve cognitive abilities are required to improve caregivers' well-being and health.

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## La intervención cognitivo-conductual mejora la cognición de los cuidadores de personas con trastorno del espectro autista: estudio piloto

### RESUMEN

Según los postulados del modelo del proceso del estrés, los individuos con situación de estrés crónico, tales como los cuidadores de personas con trastornos psicológicos crónicos, tienen un desempeño cognitivo más pobre y un deterioro cognitivo relacionado con la edad más acentuado que los individuos no expuestos al estrés crónico. Al analizar esta cuestión en los cuidadores, la mayoría de los estudios se han realizado en poblaciones en las que los receptores de los cuidados padecen demencia y/o Alzheimer, y pocos estudios han analizado la cognición en los cuidadores de los hijos con trastorno del espectro autista (ASD). El objetivo principal de este estudio piloto fue analizar el efecto de una intervención cognitivo-conductual en los cuidadores de personas con ASD. De manera específica, tratamos de reunir evidencia sobre las posibles mejoras con significación clínica en cuestiones tales como velocidad/atención, memoria y funciones visuoespaciales, del lenguaje y ejecutivas tras la intervención. Los participantes fueron 17 padres (edad media de 52 años, 59% de mujeres) de personas diagnosticadas de ASD que habían cuidado

#### Palabras clave:

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de sus hijos durante aproximadamente 14 años. El estudio tenía un diseño pre-post. Tras la intervención cognitivo-conductual, los cuidadores de las personas con ASD tenían mejor atención selectiva, memoria a corto y largo plazo en relación con las palabras, cuentos e imágenes, es decir, flexibilidad cognitiva y técnicas de planificación ( $p=0.01$  en total). Sin embargo, no se observaron cambios con relación al estado cognitivo general, memoria operativa para cifras, fluidez verbal, velocidad de procesamiento o control inhibitorio ( $p>0.05$  en total). Estos hallazgos subrayan la relevancia de un respaldo adecuado y de unos servicios de relevo que ayuden a los cuidadores a enfrentarse al estrés, y reducir el mismo. Se precisan amplias valoraciones neuropsicológicas y procedimientos y programas adyuvantes, específicos en la materia, para mejorar las capacidades cognitivas, así como el bienestar y la salud, de los cuidadores.

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## Introduction

Over the years, the associations between chronic psychological stress and cognitive decline have been investigated in various different populations, including in caregivers of people diagnosed with a long-term psychological disorder (de Vugt et al., 2006; Mackenzie, Smith, Hasher, Leach, & Behl, 2007). The stress process model postulates that chronically stressed individuals have poorer cognitive performance and greater age-related cognitive decline than individuals not exposed to chronic stress (Scott et al., 2015).

The majority of research in caregivers has been conducted in populations in which the care recipient has dementia and/or Alzheimers' disease, few studies having analysed cognition in caregivers of offspring with autism spectrum disorder (ASD). A number of studies have identified poor performance in processing speed, selective attention, working memory for digits, words and visuospatial information, learning words and long-term memory for words in caregivers of people with dementia, Alzheimers' disease, stroke survivors, terminally ill family members, individuals with osteoporotic fractures and/or eating disorders compared to control participants (Caswell et al., 2003; Chen & Botticello, 2013; Corrêa et al., 2015; de Vugt et al., 2006; Mackenzie et al., 2007; Mcbean & Schlosnagle, 2016; Romero-Martínez, Ruiz-Robledillo, Moya-Albiol, 2016; Vitaliano, Ustundag, & Borson, 2016). Moreover, longitudinal studies have indicated that chronic stress in caregivers of people with dementia and/or Alzheimers' disease tends to accelerate age-related cognitive decline in several cognitive domains, including general cognitive status and processing speed (Dassel, Carr, & Vitaliano, 2015; Vitaliano et al., 2009). Nevertheless, some research has produced contradictory or non-significant results in relation to general cognitive status, as well as IQ verbal, abstract reasoning, logical memory, verbal fluency and inhibitory control (Bertrand et al., 2012; Corrêa et al., 2015; de Vugt et al., 2006; Mackenzie et al., 2007; Vitaliano et al., 2009). Hence, it seems that not all the cognitive domains are equally sensitive to the effects of chronic psychological stress in this type of population.

Helping caregivers to cope with stress and burden, as well as develop good communication skills could help to protect against cognitive decline and even improve their cognitive performance. For instance, a previous study with caregivers of people with dementia demonstrated that cognitive behavioural therapy (through a 13-week intervention) resulted in clinically meaningful cognitive improvements. In fact, caregivers who finished the intervention programme experienced an improvement in attention, and in working and long-term memory for verbal and visual information after the intervention. Nevertheless, no improvements were observed in verbal or visual recognition, visual-spatial processing, verbal fluency, abstract reasoning or set-shifting (Mackenzie, Wiprzycka, Khatri, & Cheng, 2013).

Around 50–70 years of age, parents who are caregivers of offspring with disabilities also often experience more physiological dysregulation and chronic health problems than parents of normative children, and this may be linked to functional outcomes

and may have an impact on their ability to provide adequate care (Romero-Martínez, González-Bono, Salvador, & Moya-Albiol, 2016). Our previous studies concluded that ASD caregivers (both men and women) had poorer declarative verbal memory, but they outperformed non-caregivers in inhibitory control and visuospatial skills (Romero-Martínez, Ruiz-Robledillo, et al., 2016; Romero-Martínez & Moya-Albiol, 2015). Moreover, this type of caregiver was found to have more retrospective and prospective memory failures (assessed by a questionnaire) in a diary over the course of a week than non-caregivers (Lovell, Elliot, Liu, & Wetherell, 2014; Mcbean & Schlosnagle, 2016). However, there is a gap in the scientific literature analysing whether cognitive-behavioural interventions, to reduce health complaints and stress levels, could be effective in offsetting normal age-related cognitive decline or even improving certain aspects of cognition in this population.

Our previous study with ASD caregivers demonstrated that a cognitive-behavioural intervention, which was adapted to the ASD care context, showed effectiveness to reduce somatic symptoms and level of depression and to improve mood states (Ruiz-Robledillo & Moya-Albiol, 2015). Hence, we considered that it would be interesting to assess whether this cognitive-behavioural intervention improved ASD caregivers' cognition. In this sense, the main objective of our study was to examine cognitive domains that could be affected in caregivers and to compare the caregivers' performance before and after the psychological intervention. Based on the results of Mackenzie et al. (2013) study, we hypothesized that ASD caregivers would obtain better scores in attention, working and long-term memory for verbal and visual information, but they would not show no changes in recognition (verbal or visual), visuospatial processing, verbal fluency, abstract reasoning or set-shifting after the intervention.

## Method

### Participants

The sample was composed of 17 parents (10 women and 7 men) of individuals diagnosed with ASD who had cared for their offspring for approximately 14 years. Participants' mean age was  $52.23 \pm 7.03$  years, and body mass index was  $27.88 \pm 5.46$ ; most of them were married (76.5%), the others being divorced (11.75%) or widowed (11.75%), and most had a high level of education (61.9%). With regard to the care recipients, 13 were males and 4 females with a mean disability rating of 76% (as measured by the local government). Caregivers were recruited from members of an association for relatives of people with ASD (*Asociación Valenciana de Padres de Personas con Autismo, APNAV*) in the region of Valencia (Spain).

### Procedure

Each participant in the study attended three sessions in the psychology laboratories of the University of Valencia. Firstly, a meeting was conducted with caregivers to explain the aim of the research

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