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## **Memory failures for everyday tasks in caregivers of children with autism**

### **Abstract**

The stress of caring for a loved one with chronic illness has been linked with impairments in cognitive processes such as attention and problem solving, though few studies have examined the impact on memory. Compromised cognition, in particular, aspects of everyday functioning such as remembering medical instructions and appointments, might affect caregivers' ability to maintain the consistency and quality of care needed by the child. A sample of 31 caregivers of children with autism and 51 parents of neuro-typical children completed an electronic survey assessing levels of psychological distress and everyday memory. Data confirmed that perceived levels of stress and memory failures for everyday tasks were higher in caregivers compared with the control group. Data also revealed a significant positive relationship between caregivers' perceived levels of stress and everyday memory failures. These findings might have implications for interventions that aim to improve caregivers' cognitive well being through targeting the psychological sequelae associated with the caregiving experience.

**Keywords:** caregiving; cognition; everyday memory; perceived stress

## 1. Introduction

Comparing parents of children with developmental disabilities (DD) such as autism with parents of neuro-typical children has become one well established paradigm for assessing the psychophysiological corollaries of chronic stress (Lovell & Wetherell, 2011). Indeed, the demands associated with caring for a child with autism, which typically include, but are not restricted to concern over the child's future, financial hardship, social isolation, and witnessing the mental/physical decline of a loved one, far exceed those of parenting a neuro-typical child (Baker, Blacher, Crnic, & Edelbrock., 2002; Fletcher, Markoulakis, & Bryden, 2012). Perhaps unsurprisingly, relative to parents of neuro-typical children, parents of children with autism experience considerable psychological distress (Lovell & Wetherell, 2011), as well as alterations in disease relevant physiological processes such as such neuroendocrine (Seltzer et al., 2010), cardiovascular (Gallagher & Whiteley, 2012) and immune functioning (Lovell, Moss, & Wetherell, 2012). Deficits in cognitive processes such as complex attention (Caswell et al., 2003) and speed of information processing (de Vugt et al., 2005) have also been observed in caregivers, and relative to normative controls, caregivers have also been shown to be impaired on tests of global cognitive functioning (Lee, Kawachi, & Grodstein, 2004). In addition, using a longitudinal design, Vitaliano et al (2005) demonstrated that cognitive decline across a two year period was markedly accelerated in spousal caregivers of dementia patients. However, not all caregivers are equally affected, and research has indicated that caregivers' cognitive well being might vary according to psychological factors such as distress and burden. Indeed, in a study involving older dementia caregivers, Caswell et al (2003) observed that caregivers' perceived levels of burden were inversely related to their performance on tasks demanding problem solving skills and psychomotor speed. More recently, dementia

caregivers who reported the greatest levels of depression also performed more poorly on tasks requiring complex attention (Vitaliano et al., 2009).

Despite showing impairments in other important aspects of cognitive functioning such as attention and processing speed, the impact of caregiver stress on memory has been scarcely examined. To date, research has demonstrated that caregivers are impaired on tasks of immediate and delayed recall (Lee et al., 2003; Mackenzie, Smith, Hasher, Leach, & Behl, 2007), and verbal memory (de Vugt et al., 2005). The dearth of research in this area is surprising; indeed, caregivers, who are required to act as responsible decision makers for the child, are routinely tasked with remembering complex medication schedules and medical instructions, coordinating medical appointments, as well as feeding back on the condition of the child to healthcare practitioners (Bertrand et al., 2012; Macmillan, 2005). As such, compromised cognition, and in particular, memory for everyday tasks, might affect caregivers' ability to maintain the consistency and quality of care needed by the child. Indeed, the positive relationship between caregivers' well being and quality of life for the care recipient has been widely evidenced (Addington, Coldham, Jones, Ko, & Addington, 2003; Burgess & Gutstein, 2007).

Several lines of evidence converge to suggest that everyday memory might be impaired in the context of caring for child with autism. Indeed, cognitive dysfunction, as evidenced by poorer performance on tasks of episodic (Peavy et al., 2009) and working memory (Lupien, Maheu, Tu, Fiocco, & Schramek, 2007) has been widely observed in other chronically stressed populations. Moreover, dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis, which has been observed in caregivers of children with autism (Seltzer et al. 2010), has been linked with atrophy of the hippocampus, one brain region that underlies cognitive processes including memory

(Sapolsky, Romero, & Munck, 2000). In addition, to cope with the stress of the caregiving experience, caregivers often turn to health comprising behaviours such as smoking and use of alcohol (Hoffman, Lee, & Mendez-Luck, 2012), both of which have been linked with memory failures for everyday tasks (Heffernan, O'Neill, & Moss, 2010, 2012).

Cognition, in particular, aspects of daily functioning such as remembering medical instructions and routines, is particularly pertinent to the carer-recipient dyad. To extend the relatively small research base in this area, this study examined whether everyday memory might be impaired in the context of caring for a child with autism. It was hypothesised that (a) memory failures for everyday tasks would be greater in caregivers compared with controls, and (b) perceived levels stress would be positively related with caregivers' everyday memory failures.

## **2. Methods**

### *Potential confounds*

Demographic (e.g., age, gender, education) and lifestyle (e.g., use of nicotine and alcohol) data was collected to assess whether caregiver related differences in everyday memory failures might reflect the contribution of other variables.

### *Participants*

A sample of 102 participants was recruited via online caregiver support groups, special schools and charities, and via a staff/student population. Caregivers of children with autism were recruited according to strict criteria: (a) caring for at least one child aged 3-19 years old with a clinically verified diagnosis (by paediatrician) of autism, and (b) who was living at home full time, and (c) not caring for another individual with

chronic illness. Parents of neuro-typical children, a normative control group, were recruited according to the same criteria, but to be eligible, must not have been caring for a child, spouse, family member or friend with chronic illness. Typical of data collection using electronic platforms (Reips, 2002), 10 participants failed to answer any items on the survey, and an additional 10 participants failed to complete the measure of memory. Therefore, statistical analysis was conducted on a final sample of 82 participants (n=31 caregivers / n=51 controls). Sample characteristics by group are presented in Table 1.

### *Psychological and cognitive outcomes*

Psychological distress was quantified using the Perceived Stress Scale (PSS), a 14 item questionnaire that measures how often over the last month participants felt that life was overwhelming, uncontrollable, and unpredictable (Cohen, Kamarck, & Mermelstein, 1983). Scale responses range from 0 (*never*) to 4 (*very often*), and higher scores indicate greater levels of psychological distress. The PSS has achieved excellent internal consistency in previous studies involving caregivers of children with autism (Gallagher, Phillips, Oliver, & Carroll, 2008), and this was also the case here ( $\alpha = 0.83$ ).

Everyday memory was assessed using the Prospective and Retrospective Memory Questionnaire (PRMQ) (Crawford, Smith, Maylor, Della-Salla, & Logie, 2003). The PRMQ is a 16 item scale that quantifies memory failures for everyday tasks over two subscales: prospective memory (e.g., do you forget appointments if you are not prompted by someone else or by a reminder such as a calendar or diary?) and retrospective memory (e.g., do you fail to do something you were supposed to do a few minutes later even though it's there in front of you, like take a pill or turn off the kettle?). Scale responses range from 1 (*never*) to 5 (*very often*), and higher scores

indicate poorer everyday memory. The PRMQ achieved excellent internal consistency in the current sample ( $\alpha = 0.95$ ).

### *Procedures*

Consenting participants were asked to complete self report measures of psychological distress and everyday memory using the electronic data collection platform, Survey Monkey. This study and all its procedures were approved by the Faculty of Health and Life Sciences Ethics Committee.

### *Statistical analysis*

A series of chi square ( $\chi^2$ ) and one way ANOVAs were used to assess group differences on potential confounds. One way ANCOVAs were used to determine caregiving related disparities with respect to perceived levels of stress and memory failures for everyday tasks, with partial eta squared ( $\eta_p^2$ ) as the measure of effect size. Subsequent analysis within the caregiver group was by Pearson product moment correlation. Bivariate correlations were used to determine whether perceived levels of stress might differentially affect everyday memory failures in the caregiver group.

## **3. Results**

### *Potential confounds*

Data indicated that caregivers and controls were comparable on age, level of education, marital status, number of children, and on use of nicotine and alcohol (all  $ps > 0.07$ ). However, gender, which significantly differentiated the groups ( $\chi^2 = 5.96$ ,  $df = 1$ ,  $p = 0.02$ ), was controlled in all subsequent analysis.

Table 1

*Means and standard deviations for demographic and lifestyle characteristics, perceived levels of stress and everyday memory failures by group*

	Caregivers (N = 31)	Controls (N = 51)	<i>p</i> =
<b>Gender</b>			<b>0.02</b>
Male	1	12	
Female	30	39	
<b>Age</b>	42.8 (7.3)	41.6 (9.7)	0.54
<b>Level of Education (%)</b>			0.72
School	6	7	
College	10	19	
Undergraduate	12	14	
Postgraduate	3	7	
<b>Marital Status</b>			0.08
Partnered	21	43	
Not partnered	10	8	
<b>Number of children</b>	2.3 (0.8)	1.9 (0.7)	0.07
<b>Nicotine (cigarettes per week)</b>	8.7 (23.1)	5.8 (23.4)	0.60
<b>Alcohol (units per week)</b>	7.3 (7.4)	7.0 (7.7)	0.90
<b>Perceived levels of stress</b>	30.9 (7.3)	22.9 (6.6)	<b>&lt; 0.01</b>
<b>Everyday memory failures</b>			
Prospective memory	3.4 (0.9)	2.5 (0.8)	<b>&lt; 0.01</b>
Retrospective memory	2.7 (0.9)	2.1 (0.7)	<b>&lt; 0.01</b>
Total PRMQ score	3.1 (0.8)	2.3 (0.7)	<b>&lt; 0.01</b>

#### *Psychological and cognitive outcomes*

Data indicated that perceived levels of stress were elevated in the caregiver group ( $F(1, 79) = 19.7, p < 0.01, \eta_p^2 = 0.20$ ). Caregiving related disparities with respect to everyday memory were also observed, such that failures in prospective ( $F(1, 79) =$

13.05,  $p = 0.04$ ,  $\eta_p^2 = 0.14$ ) and retrospective memory ( $F(1, 79) = 8.64$ ,  $p < 0.01$ ,  $\eta_p^2 = 0.10$ ), and total PRMQ scores ( $F(1, 79) = 12.1$ ,  $p < 0.01$ ,  $\eta_p^2 = 0.13$ ) were significantly greater in the caregiver group.

#### *Within group analysis*

Data yielded a significant positive relationship between caregivers' perceived levels of stress and their scores on the prospective ( $r = 0.69$ ,  $p < 0.01$ ) and retrospective memory ( $r = 0.45$ ,  $p = 0.01$ ) components of the PRMQ. Total PRMQ scores, which provide a measure of everyday memory, were also positively correlated with caregivers' perceived levels of stress ( $r = 0.61$ ,  $p < 0.01$ ).

#### **4. Discussion**

This study examined the impact of caring for a child with autism on everyday memory, one important aspect of day to day cognitive functioning. Indeed, compromised cognition, in particular, aspects of daily functioning such as remembering, understanding and carrying out medical instructions, might affect caregivers' ability to maintain the quality and consistency of care needed by the child.

Data confirmed the *a priori* assumption that caregivers of children with autism experience greater levels of stress compared with a normative control group. That is, relative to parents of neuro-typical children, perceived stress scores were higher in the caregivers. This finding resonates with the wider caregiver literature. Indeed, caregivers of children with DD have been shown to experience increased psychological morbidity, as indexed by clinically elevated levels of anxiety and depression (Gallagher et al., 2008), and higher perceived levels of stress (Lovell et al., 2012). Cognitive dysfunction, manifested here by greater memory failures for everyday tasks, was also evident in

caregivers. These findings converge with studies that have linked chronic caregiver stress with deficits in other important cognitive domains such as complex attention (Mackenzie et al., 2007), speed of information processing (Caswell et al., 2003), and on tests of general cognitive functioning (Lee et al., 2004). These findings might have implications for the care recipient, whose quality of life is interlinked with the health and well being of the care provider (Addington et al., 2007). Indeed, adhering to medication routines and medical instructions has been shown to be more difficult for care recipients of cognitively impaired caregivers (Boucher, Renvall, & Jackson, 1996), and in a study involving older dementia caregivers, poorer performance on a task of verbal memory predicted reduced feelings of caregiver competence (de Vugt et al., 2005).

Data further revealed a positive relationship between caregivers' perceived levels of stress and everyday memory failures. Research has previously demonstrated how psychological factors such as distress and burden might differentially affect the cognitive functioning of chronically stressed caregivers (Caswell et al., 2003; Vitaliano et al., 2009), and data reported here corroborates this work. Moreover, these findings might inform the development and delivery of interventions that aim to improve the cognitive well being of caregivers through targeting the psychological sequelae associated with the caregiving experience. Indeed, stress reduction interventions, which have been shown to be effective for alleviating caregivers' psychological distress, have also been linked with adaptive changes in executive function and other cognitive indices (Lavretsky et al., 2013).

Findings from this study should be evaluated in the context of its limitations. First, physiological determinants for poorer everyday memory in the caregivers were not assessed. Indeed, dysregulated HPA activity, which has been observed in caregivers

of children with autism (Seltzer et al., 2010), has been linked with alterations in brain regions such as the hippocampus (Sapolsky et al., 2000), which are central for cognitive processes such as memory. Most recently, research demonstrated an inverse association between the cortisol awakening response (CAR), one marker for HPA axis functioning, and memory failures for everyday tasks (Bäumler et al., in press). Accordingly, future studies might assess whether alterations in HPA indices such as the CAR might account for caregivers' compromised cognition. Second, everyday memory failures were assessed by self report only, and several studies have reported on the poor concordance between subjective (i.e., questionnaire) and more objective measures of cognitive functioning (Heffernan et al., 2012). Therefore, future studies might incorporate the use of lab based paradigms such as CAMPROMPT as more objective checks on caregivers' everyday memory (Heffernan et al., 2010). Finally, cognitive dysfunction has been evidenced in poorer sleepers (Ferrie et al., 2011), and as such, findings reported here might not be independent of sleep related factors.

In conclusion, relative to normative controls, caregivers of children with autism reported higher levels of psychological distress and greater memory failures for everyday tasks. The negative impact of caring for a child with autism on everyday memory was particularly salient in caregivers experiencing higher perceived levels of stress. Compromised cognition, in particular, aspects of daily functioning such as remembering, understanding and carrying out medical instructions, could have serious practical and functional implications for caregivers, and for the quality of life of the child.

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## **Conflict of Interest**

None declared

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