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Caregivers of Children with Autism Are Better, Despite Their Poorer Memory, Completing Tasks of Daily Living

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ABSTRACT

Familial caregivers typically have more trouble completing fundamental tasks of daily living compared with non-caregivers. The ability to complete tasks of daily living relies on prospective memory (PM). PM, however, is typically poorer in familial caregivers. It would make sense, therefore, that poorer PM would mediate caregivers' greater difficulties completing tasks of daily living. This was explored here. A sample of $n = 500$ participants (196 caregivers of autistic children and 304 parents of non-autistic children) completed a questionnaire assessing PM failures. An abbreviated version of the Everyday Problems Test (EPT) was used to measure participants' ability to complete tasks of daily living, such as managing medications and paying bills. Caregivers reported more PM failures. EPT scores were lower in caregivers, reflecting fewer problems completing tasks of daily living. PM failures were unrelated to EPT scores, ruling out mediation. Caregivers of autistic children were better at completing basic tasks of daily living despite their poorer PM. Whether quality of life for the autistic child might be related to caregivers' ability to complete tasks of daily living should be the focus of future research.

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Autism; caregiving; daily tasks; prospective memory

Introduction

The cognitive consequences of familial caregiving (i.e. providing unpaid care for a loved one with a longstanding illness) have been widely reported. Indeed, research has reported that memory, especially episodic, working and declarative memory, is poorer for familial caregivers compared with non-caregivers (Correra et al., 2015; de Vugt et al., 2006). Caregivers were also found to perform poorly on lab tasks assessing immediate and delayed recall (Mackenzie et al., 2007, 2009; Vitaliano et al., 2005). The negative cognitive impact of familial caregiving has also been observed in other domains. For example, research has shown that caregivers experience more problems than their non-caregiving counterparts completing lab tasks assessing attentional control and speed of information processing (Caswell et al., 2003; Vitaliano et al., 2007, 2009). Some researchers have concluded that global cognitive functioning, spanning all cognitive domains, is impaired in the context of familial caregiving (Lee et al., 2004; Oken et al., 2011). Several review

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papers have reported the same, finding caregivers to be more compromised than non-caregivers across a wide spectrum of cognitive domains (Fonareva & Oken, 2014; Romero-Martínez et al., 2020). Much of this research, however, has involved elderly caregivers (i.e. caring for a spouse with dementia). This makes it hard to know whether the observed cognitive deficits are due to natural, age-related cognitive decline or caregiving-induced stress. To answer this question, researchers have started to ask whether younger caregivers (e.g. parents of autistic children) who are not contending with age-related cognitive decline might also be cognitively compromised. Studies have shown that younger caregivers, like their older caregiving peers, experience more memory failures, especially in the domains of declarative and episodic memory, relative to controls (Chan et al., 2017; Romero-Martínez et al., 2016; Song et al., 2016). Prospective memory (PM), the ability to remember to do things in the future (e.g. 'I must remember to attend my doctor's appointment tomorrow at 5pm'), has also been shown to be impaired in caregivers of autistic children. This has been demonstrated using both self-report assessments (i.e. questionnaires) and objective performance-based tasks of PM (Lovell et al., 2014, 2019; MCBean & Schlosnagle, 2016).

Compromised cognition, especially PM, could negatively impact caregivers' ability to complete essential caregiving tasks. For example, autistic children are more likely to be taking medication compared with non-autistic children (Cummings et al., 2016). It was in fact recently estimated that 40% of autistic children are taking at least two types of medication concurrently (Zerbo et al., 2019). Qualitative research indicates that it is caregivers, more so than anyone else, who are responsible for interpreting medical instructions, planning medication schedules and administering medication to the autistic child (Byrne et al., 2018; Fowler & O'Connor, 2021). The ability to complete fundamental tasks of daily living such as managing medications depends on intact PM. Indeed, research has shown that PM failures, assessed subjectively and objectively, positively predict errors in medication management tasks in the lab (Pirogovsky et al., 2012). Poorer PM has also been linked with greater difficulties completing other basic daily tasks, such as housekeeping and financial planning (Woods et al., 2008, 2014). This is important because planning finances, especially as they relate to medical insurance and the cost of accessing autism services, is fundamental to caring for an autistic child (Altieri & von Kluge, 2009). Communication with doctors, schools and insurance providers is another essential part of caring for an autistic child (DePape & Lindsay, 2015). Communication (e.g. speaking on the phone, writing letters) and financial planning (e.g. paying bills) are two role-plays the UCSD performance-based skills assessment (UPSA) incorporates to objectively assess everyday functional ability. Research has shown that individuals with poorer PM perform poorer on UPSA, finding it more challenging to complete everyday tasks involving communication, financial planning and managing medications (Twamley et al., 2008).

The negative impact of caring for an autistic child on PM has been documented (Lovell et al., 2014, 2019; MCBean & Schlosnagle, 2016), as has the importance of intact PM for completing the kinds of daily tasks (e.g. medication management, communication, financial planning) critical for caretaking. Whether caregivers of autistic children might have more difficulties with these kinds of daily tasks, and whether this might be because of their poorer PM, has not been explored. Several lines of evidence converge to suggest this might be the case. For example, older caregivers experience levels of

stress comparable to parents of autistic children, and these caregivers find completing tasks of daily living more challenging than age matched, non-caregiving controls. Moreover, it was caregivers' poorer cognition, taking the form of slower attentional processing, that was implicated as a likely mediator of this effect (Vitaliano et al., 2007). It has been widely documented that caregivers of autistic children often report levels of depression in the clinical range (Shepherd et al., 2021). Depressed individuals have been found to perform poorer on cognitive tasks, especially tasks involving PM, and make more errors on tasks assessing daily functioning (Cohrs & Leslie, 2017; Gallo et al., 2003).

To date, caring for an autistic child has been linked with greater PM failures. Completing tasks of daily living such as managing medications and financial planning rely on intact cognition, especially PM. Whether caring for an autistic child might be associated with finding the completion of daily tasks more challenging has not been explored. However, research with other familial (older) caregivers found this to be the case. Whether caring for an autistic child might be associated with greater difficulties completing tasks of daily living, and whether this might be mediated by poorer PM, was explored here.

Research Methods

Participants and Procedure

A priori power analysis with GPower revealed that 352 participants would be needed to provide adequate power (80%; $\alpha = 0.05$) to detect a moderate effect size ($f^2 = 0.15$). A sample of $n = 542$ participants, of which 204 were caregivers of autistic children and 338 were controls (i.e. parents of non-autistic children), were recruited via adverts posted on parenting support groups on social media sites. Participants were recruited according to strict criteria. For caregivers, these included (a) parenting at least one child (aged 3–19 years old and living at home full time) with a clinical diagnosis (as confirmed by general practitioner or paediatrician) with autism, (b) not caring for another person (e.g. partner, parent, other relative, or friend) with a chronic illness, (c) not managing any chronic illness and (d) not currently experiencing, or in the last 12 months experienced, any long-term stressors (e.g. bereavement, divorce). Parents of non-autistic children were recruited to the same criteria with one exception; they should not be, or have in the past been, providing informal care for a child (or another person) with chronic illness.

A total of 36 participants failed to provide any responses to one or more of the study measures. These participants were removed. Six other participants with z scores > 3.29 for one or more outcome variables were also removed as per Tabachnick and Fidell (2012). Statistical analysis, therefore, was conducted on a final sample of $n = 500$ participants (194 caregivers and 306 parents of non-autistic children).

Participants were asked to complete questionnaires assessing demographic (e.g. gender, age), lifestyle (e.g. exercise, alcohol) and family (e.g. relationship status, number of children) information. Caregivers were also asked questions about their autistic child(ren) (e.g. current age, age at diagnosis). PM failures were also measured via questionnaire. An abbreviated, six-item version of the Everyday Problems Test (EPT) was used as an objective measure of participants' ability to complete tasks of daily living.

The Faculty of Health and Life Sciences Ethics Committee approved the study. All participants provided fully informed consent to take part and received no recompense.

Measures

Control Variables

Socio-demographic (gender, age, ethnicity, annual income), lifestyle (smoking, alcohol, exercise, relationship status, sleep duration) and family (number of children) information, and information about the autistic child(ren) (current age, age at diagnosis), was collected to safeguard against spurious relationships emerging between study variables. Each of these variables has been shown to be influential for cognition, particularly memory, and daily functioning.

Prospective Memory

The 16-item Prospective and Retrospective Memory Questionnaire (PRMQ) is made up of two subscales. One measures failures in prospective (e.g. *do you forget to tell someone something you had meant to mention a few minutes ago?*), and the other failures in retrospective (e.g. *do you forget what you watched on television the previous day?*), memory (Crawford et al., 2003). Each item was scored using a 5-point Likert type scale (1 = *not at all*, 5 = *all the time*). Total scores were calculated by summing across relevant subscale items, with total scores ranging between 8 and 40. Higher scores reflected poorer memory (i.e. greater failures). Only the PM subscale was used here. The PRMQ showed good internal consistency ($\alpha = .95$) in studies involving similar samples (Lovell et al., 2014). This was also the case in the current sample ($\alpha = .90$).

Tasks of Daily Living

An abbreviated version of the Everyday Problems Test (EPT) was used to objectively assess participants' ability to complete daily tasks (Willis & Marsiske, 1993). The original version of the EPT uses 24 items. Here, however, we selected only six items. We did this to minimise study attrition, recognising that caregivers of autistic children have little available free time (Davy et al., 2022). The six items selected included medical instructions, insurance forms and food processing guidelines. These items were selected due to being particularly relevant to caregiving (Meadan et al., 2015). Participants were shown an item (e.g. medical instructions) and, after studying it for as long as needed, asked to complete two tasks (e.g. 'what is the maximum acceptable dose for a period of 24-hours?'). Participants were asked to complete 12 problems in total, two for each item. One point was awarded for every correct answer. Total scores were calculated by summing correct responses and ranged from 0 to 12. Higher scores reflected fewer problems completing tasks of daily living. Internal consistency ($\alpha = .94$) for the EPT was good in previous research (Wills, 1996), as was the case here for the abbreviated version ($\alpha = .87$).

Table 1. Sample characteristics by group.

	Caregivers <i>n</i> = 194	Controls <i>n</i> = 306	<i>p</i> =
Gender (Female)	185 (94%)	300 (99%)	<.01
Ethnicity (Caucasian)	186 (96%)	296 (99%)	.09
Smoker (No)	155 (79%)	232 (76%)	.47
Relationship status (Partnered)	152 (78%)	253 (83%)	.10
Mean age (Years)	39.7 ± 7.5	35.5 ± 7.8	<.01
Mean alcohol (Drinks per week)	3.1 ± 5.6	5.4 ± 7.6	<.01
Mean exercise (Occasions per week)	2.2 ± 2.2	2.1 ± 2.1	.61
Mean sleep duration (Hours)	6.3 ± 1.3	6.7 ± 1.3	<.01
Mean number of children at home	2.4 ± 1.1	2.1 ± 1.1	.02
Mean PM failures	3.3 ± .83	3.0 ± .80	<.01
Mean EPT scores	9.5 ± 2.2	8.8 ± 3.0	.02

PM = prospective memory, EPT = Everyday Problems Test.

Statistical Analysis

A series of independent *t* tests and chi-square (χ^2) tests were used to compare groups with respect to socio-demographic, lifestyle and family variables. A series of bivariate correlations were used to explore whether PM failures and EPT scores might be related to age of the autistic child and age at diagnosis. The SPSS PROCESS macro (model 4) with bootstrapping (5000 iterations), as per Hayes (2012), was used to explore the direct and indirect effects between study variables.

Results

Control Variables

Groups were statistically comparable with respect to ethnicity, relationship status, smoking and exercise (all *ps* > .09). Caregivers of autistic children, however, were older ($t(5.9) = 498$, $p < .001$) and had more children living at home ($t(2.4) = 498$, $p = .02$). They also consumed less alcohol ($t(-3.1) = 461.5$, $p < .01$) and slept fewer hours ($t(-3.6) = 494$, $p < .001$). These variables were controlled in all subsequent analyses. EPT scores (all *ps* > .89) and PM failures (all *ps* > .18) were unrelated to the age of the autistic child or age at diagnosis. Table 1 displays means (standard deviations) by group.

Mediation Analysis

The total effect of the predictor variable (group: caregiver/control) on the outcome (EPT scores) was significant ($\beta = -0.58$, $SE = 0.25$, $p = 0.02$), as was the relationship between the predictor and the mediator (PM failures) ($\beta = -0.35$, $SE = 0.07$, $p < 0.001$). PM failures, however, did not predict EPT scores after adjusting for group ($\beta = -0.17$, $SE = 0.15$, $p = 0.25$), and the relationship between group and EPT scores remained significant when PM was included in the model ($\beta = -0.64$, $SE = 0.26$, $p = 0.01$). Data, therefore, did not support an indirect effect of caregiving for an autistic child on daily task completion via PM failures ($CI_{95} = -0.05, 0.18$). Findings were unchanged following statistical adjustments for age, alcohol, number of children and sleep.

Discussion

Few studies have explored the cognitive impact of caring for an autistic child, and even fewer how caregivers' cognitive failures might predict their ability to complete basic tasks of daily living critical for providing quality caregiving. Here, caring for an autistic child was associated with greater self-reported PM failures. This finding is in keeping with results from several other studies (Lovell et al., 2014, 2019; MCBean & Schlosnagle, 2016). However, despite their poorer PM, caregivers performed better on the EPT, making fewer errors. This finding was interesting for two reasons. First, research has shown greater PM failures to be associated with more problems completing tasks of daily living (Pirogovsky et al., 2012; Twamley et al., 2008). Second, other caregiving groups, comparable with caregivers of autistic children in terms of emotional distress, experienced more difficulties completing tasks of daily living compared with age matched controls (Gallo et al., 2003; Vitaliano et al., 2007). Findings reported here, therefore, speak to an apparent disassociation between caregivers' cognition, assessed via PM, and ability to complete tasks of daily living. Methodological decisions might explain this. Participants' ability to complete everyday tasks was assessed here using an abbreviated version of the EPT, an objective, performance-based measure of daily functioning. However, previous studies have tended to rely almost exclusively on self-report assessments that ask participants to rate, using Likert-type scales, how confident they would feel completing daily tasks. These methodological variations might be important. Indeed, our findings suggest that the relationship between PM and daily functioning, and between caregiving and daily functioning, might be moderated by type of measurement tool. That is, when daily functioning was assessed via self-report, as it was in previous studies, PM failures predicted it. Moreover, when assessed via self-report, daily functioning was poorer in caregivers (Woods et al., 2008). In the current study, however, the completion of daily tasks was assessed objectively with an abbreviated version of the EPT, and EPT scores were unrelated to PM failures. Moreover, caregivers performed significantly better than controls on this objective assessment of daily functioning, making fewer errors. Caregivers appear to perceive themselves, when using Likert-type scales, to be poorer than their non-caregiving counterparts when completing daily tasks. Objectively, however, the opposite appears to be true, with caregivers outperforming controls on the EPT.

It might not be altogether surprising that caregivers of autistic children are better than controls when completing tasks of daily living, especially if those tasks, like the ones in the current study, involve solving problems in printed materials. Indeed, caregivers have commented in qualitative studies about the volume of paperwork associated with the caregiving experience, calling for key workers to help them navigate it (DePape & Lindsay, 2015). Extracting relevant information from printed documents such as school admission applications, medical insurance forms and applications for respite and other autism services is fundamental to caring for the autistic child (Lopez et al., 2018; Meadan, 2015; Van Bourgondien et al., 2014). Researchers have found that the ability to sift through printed items and extract relevant information relies to a large degree on verbal working memory, and caregivers have outperformed controls in this cognitive domain (Bertrand et al., 2012; Oken et al., 2011; Revheim & Medalia, 2004). Findings reported here, showing caregivers to be better at solving problems in everyday printed materials, are also in keeping with the healthy caregiving hypothesis. The hypothesis, formulated by Bertrand

et al. (2012), posits that caregivers' cognition is constantly being exercised and challenged by the cognitive demands of caretaking and will therefore be less likely to deteriorate. This might explain our findings. It might be the case that caregivers' better performance on the EPT is mediated by better verbal working memory. This is one avenue for future researchers to explore.

The findings reported here have clear implications for clinicians. Indeed, findings indicate that caregivers are better, when assessed objectively, at completing tasks of daily living. Finding positives amidst the stress of the caregiving experience is common in the context of caregiving for an autistic child, and caregivers who find more of these positives tend to report lower stress (Lovell & Wetherell, 2020). Clinicians, therefore, might do well to help caregivers recognise their strengths and areas in which they excel. This might have stress-mitigating effects for caregivers, and lower stressed caregivers tend to feel more confident about providing good-quality caretaking (Batool & Khurshid, 2015). In addition, PM has been found to be amenable to change via intervention. Researchers recently found that interventions using external memory aids supported by printed materials were especially effective at improving PM (Jones et al., 2021). Caregivers in the current study were markedly better than controls at solving problems in printed materials borrowed from daily life, and this might make them a particularly appropriate group for these kinds of PM enhancing interventions.

The findings reported here, however, should be tempered by several limitations. The cross-sectional nature of the work precludes drawing causal inferences; longitudinal studies are needed to explore changes in caregivers' PM failures and ability to complete tasks of daily living over time. Some characteristics of the autistic child, particularly verbal ability, behavioural problems and symptom severity, were not measured here. Research has shown these variables to be influential for caregivers' reported levels of stress (Eisenhower et al., 2005), and more stressful caregivers are typically poorer cognitively (Lovell et al., 2014). These variables should be assessed and, where appropriate, controlled in the future research.

In conclusion, caregivers of autistic children were better, despite their poorer cognition (prospective memory), at completing basic tasks of daily living. Future research might explore whether caregivers' ability to complete these kinds of daily tasks predicts quality of life outcomes, behavioural, social and communicative, for the autistic child.

Disclosure Statement

No potential conflict of interest was reported by the author(s).

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