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 (Gallaher & 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 (Mackenzie, Smith, Hasher, Leach, & Behl, 2007), and verbal memory (de Vugt et al., 2005). The dearth of research in this area is perhaps 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, & Munc, 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, and 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

2.1. 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.

2.2. 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.

2.3. 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 (α = 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 ($\alpha = 0.95$).

2.4. 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.

2.5. 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

3.1. 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 $p > 0.07$). However, gender, which significantly differentiated the groups ($\chi^2 = 5.96, df = 1, p = 0.02$), was controlled in all subsequent analysis.

3.2. 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.

3.3. 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, and in particular, aspects of daily functioning such as remembering, understanding and carrying out our 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 caregiver group. This finding resonates with the wider caregiver literature. Indeed, caregivers of children with DD have been shown to experience considerable psychological distress, as indexed by clinically elevated levels of anxiety and depression (Gallagher et al., 2008), and higher perceived stress scores (Lovell et al., 2012). Cognitive dysfunction, manifested here by greater memory failures for everyday tasks, was also evident in the caregivers. These findings are in accord 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 important implications for the care recipient, whose quality of life is interlinked with the well being of the care provider (Addington et al., 2003). 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 of older dementia caregivers, poorer performance on a task of verbal memory predicted diminished feelings of caregiver competence (de Vugt et al., 2005).

Data reported here also indicated the impact of caring for a child with autism on everyday memory was moderated by perceived levels of stress. That is, memory failures for everyday tasks were greater in caregivers who reported higher perceived stress scores. This finding resonates with studies that have also demonstrated how psychological factors such as distress and burden can differentially affect the cognitive functioning of chronically stressed caregivers (Caswell et al., 2003; Vitaliano et al., 2009). This finding 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 reducing caregivers’ psychological distress, have also been linked with positive changes in cognitive indices such as executive function (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 (Baümmer et al., 2014). 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, caregivers of children with autism reported higher levels of psychological distress, as well as greater self-reported memory failures for everyday tasks. The negative impact of caring for a child with autism on everyday memory was exacerbated in caregivers with higher perceived levels of stress. Compromised cognition, and in particular, aspects of daily functioning such as remembering, understanding and carrying out medical instructions, might 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.

References
