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RUNNING HEAD: Caregiving in Children of a Parent with MS

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The Nature of Caregiving in Children of a Parent with Multiple Sclerosis from Multiple Sources and the Associations between Caregiving Activities and Youth Adjustment Overtime

MS is the most common neurological disorder among young people, with onset often occurring during childrearing years. Hence, many people with MS confront the demands of parenting along with MS-related disability that can interfere with parenting roles and functions. Indeed, many parents with MS report concerns about the impact of their illness on their children and difficulties associated with parenting (Braham et al., 1975; De Judicibus & McCabe, 2004). One of the effects of parental MS on children is the redistribution of roles and tasks in the family. Much of the informal care of people with MS is provided by family members and children make an important contribution in this regard. Although research has neglected the caregiving provided by children in the context of parental MS, preliminary data suggests that compared to children of 'healthy' parents, children of a parent with MS reported greater family responsibilities and poorer adjustment in some domains (Pakenham & Bursnall, 2006). However, little is known about the specific types of caregiving tasks these children adopt and whether caregiving activities in various domains have differential impacts on adjustment outcomes. It is also unclear whether the perspectives of children on their caregiving converge with those of their parents'. The purpose of this study is to explore the nature of caregiving in children of a parent with MS from the child's and parents' perspectives, and to examine the associations between caregiving domains and child negative and positive adjustment outcomes overtime.

MS affects approximately 2.5 million persons worldwide (World Health Organisation, 2004). The prevalence is about twice as high in women as in men (Matthews & Rice Oxley, 2001). In recent decades there has been an increase in the prevalence of MS, largely due to longer survival, and an overall increase in the incidence of MS in women (Koch-Henriksen & Sørensen, 2010). The aetiology of MS remains largely unknown and appears to include a complex relationship between individual genetic susceptibility and environmental factors. Clinical symptoms vary widely (e.g., cognitive impairment, pain, sexual dysfunction, fatigue, loss of bowel or bladder control, mobility and visual impairments, and emotional changes). There is currently no cure and often only minimal symptomatic relief (Rao, Huber & Bornstein, 1992). MS is a complex illness that has profound physical and psychosocial impacts on most, if not all, areas of a person's life. Not surprisingly, people with MS have a higher prevalence of emotional disorders relative to other patient groups with comparable degrees of physical disability (Ra et al., 1992), and report lower quality of life than community comparison groups (McCabe & McKern, 2002).

The wide range of clinical symptoms produces disability in most areas of functioning making it difficult to undertake many fundamental self-care and instrumental activities of daily living. Consequently, children of parents with MS often take on a range of caregiving responsibilities, and preliminary data suggests that they undertake higher levels of family responsibilities than children of 'healthy' parents (Pakenham & Bursnall, 2006; Yahav, Vosburgh & Miller, 2005). Although there are anecdotal descriptive reports of the many caregiving tasks undertaken by children, these have not been empirically delineated (e.g., Turpin, Leech & Hackenberg, 2008). However, the domains of adult MS caregiving have been identified with the Caregiving Tasks in MS Scale (CTiMSS) (Pakenham, 2007a). Factor analyses revealed four domains: instrumental (e.g., grocery shopping, housework), activities of daily living (ADL; e.g., toileting, feeding), psycho-emotional (e.g., managing the care recipient's [CR's] emotional difficulties and personality changes), and social-practical care (e.g., providing companionship, assisting with physical exercises).

A review of research investigating youth caregiving in the context of family illness identified numerous limitations in measures used to assess caregiving tasks including: the use of study-specific or purpose-built measures, a lack of rigorous measure development data, and an absence of adequate consultation with young carers in scale development (Ireland & Pakenham, 2010). Furthermore, a recent broader review of youth caregiving across a wide range of contexts highlighted the need for a clearer operationalisation of caregiving that clearly distinguishes the types of youth caregiving activities (East, 2010). To address these limitations Ireland and Pakenham (2010) developed an empirically derived psychometrically sound multi-item scale of caregiving tasks performed by young people in the context of family illness/disability, called the Youth Activities of Caregiving Scale (YACS). The derivation sample consisted of 135 youngsters aged 10 to 24 with an ill/disabled family member. Factor analyses performed on the YACS yielded four factors: instrumental, social-emotional, personal-intimate, and domestic-household care. These factors reflect the major domains of young caregiving (East, 2010) and those identified in adult MS caregiving. Both the YACS and CTiMSS yielded an instrumental domain, the YACS social-emotional care domain was similar to the CTiMSS psycho-emotional and social-practical care domains, and the YACS personal-intimate care domain was similar to the CTiMSS ADL care dimension. In the present study we use the YACS to explore the dimensions of caregiving activities in children of a parent with MS.

Given the wide range of potentially demanding caregiving tasks that children may undertake, it is not surprising that a recent review of adjustment in children of a parent with MS concluded that parental MS has a negative impact on children (Bogosian, Moss-Morris & Hadwin, 2010). For example, compared to children who have 'healthy' parents, children of a parent with MS have reported higher levels of distress and interpersonal difficulties, and lower life satisfaction and positive affect (Arnaud, 1959; Pakenham & Bursnall, 2006; Yahav, Vosburgh, & Miller, 2005). Although qualitative studies suggest that the caregiving children undertake for a parent with MS are associated with a range of negative impacts including isolation, restrictions on school, social and recreational activities, and psychological problems (e.g., Turpin et al., 2008), only one quantitative study has examined the association between youth caregiving and adjustment in the parental MS field. This study found that greater engagement in family responsibilities was associated with higher depressive and anxiety symptoms, and lower positive affect (Pakenham & Bursnall, 2006). Similarly, young carers of family members with a range of illnesses/disabilities have been shown to report numerous negative impacts associated with caregiving (see review Pakenham, 2009). However, the Pakenham and Bursnall (2006) study was limited by a small sample, a cross-sectional design, the assessment of caregiving at only a broad level, and a reliance on self-report from children only.

Recent research has shown that caring for a parent with MS can also be associated with benefits, and the wider young carer literature suggests that youth caregiving in a range of family illness contexts can be associated with positive outcomes including self-perceived maturity, increased confidence in caring, and strengthened relationships (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006; Pakenham, Chiu, Bursnall, & Cannon, 2007). This pattern of positive and negative outcomes associated with young caregiving reflects the costs and benefits associated with caregiving that is evident in adult carer research (Pakenham, 2005).

Evidence indicates that specific caregiving dimensions differentially relate to adjustment outcomes. For example, in adult MS caregiving all of the CTiMSS factors except instrumental care evidenced an association with one or more adjustment outcomes overtime (Pakenham, 2007a). Specifically, higher levels of psycho-emotional and social-practical care were related to higher benefit finding, whereas higher ADL care was related to lower life satisfaction and positive states of mind, and higher psycho-emotional care was also related to more distress. With respect to youth caregiving assessed by the YACS, higher social-emotional care and domestic-household care were related to greater prosocial behaviour, however, social-emotional care was

also related to poorer health. Evidence of beneficial and adverse effects of youth caregiving on adjustment suggests that caregiving activities may act as both risk and protective factors.

From a parentification framework youth caregiving tasks are likely to be a risk factor for adjustment difficulties in young carers (Earley & Cushway, 2002), whereas according to attachment theory these tasks may be a protective factor (Ireland & Pakenham, 2010). Consistent with parentification theory, children are at increased risk of adverse psychosocial outcomes if they adopt inappropriate, adult-like caring responsibilities which may interfere with developmental processes (Chase, 1999; Earley & Cushway, 2002). The documented negative outcomes associated with youth caregiving support the parentification view. However, as mentioned above youth caregiving is not always associated with negative outcomes, and the parentification framework does not account for the complex reciprocal and interdependent nature of caregiving (Walmsley, 1993). While under some circumstances youth caregiving may be accurately conceptualised as pathological role reversal with adverse outcomes, it may also be viewed as a form of functional ‘adaptive parentification’ (Chase, 1999).

Consistent with attachment theory (Bowlby, 1969), youth caregiving may strengthen parent-child bonds resulting in positive outcomes that have been observed in young carers (e.g., Ireland & Pakenham, 2010; Pakenham et al., 2006). In support of this view is the association between more secure child-ill parent attachment and greater engagement in youth caregiving and more positive caregiving experiences (Ireland & Pakenham, In press). Both parentification and attachment mechanisms are likely to be in play and fluctuate over the often long haul of youth caregiving. Hence, consistent with prior empirical data and the view that caregiving tasks may be both risk and protective factors, we expect that caregiving tasks involved in caring for a parent with MS will be associated with both positive and negative outcomes in children.

Youth caregiving research has been criticised for relying on only one source of data; either parent or child. Given evidence that children and their parents often have differing perspectives on the impact of parental disability on the child (e.g., Deatrick et al., 1998; Kirshbaum & Olkin, 2002), and the child’s level of caregiving (e.g., Bauman, Foster, Silver, Gamble & Muchaneta, 2006), it is important to collect data from both the parent and child. Children have been found to report performing more care tasks than their ill parents (e.g., Bauman et al., 2006) and ‘healthy’ parents (Bauman, Silver, Berman & Gamble, 2009) report.

There are a range of factors that define the caregiving situation that are likely to be associated with youth caregiving activities (e.g., level of parental illness severity and disability, child’s perceived choice in

caregiving, co-residence, and family size). While many of these factors have not been systematically examined as potential correlates or predictors of youth caregiving activities, greater CR disability is one factor shown to be consistently related to higher levels of caregiving in quantitative research in young carers (e.g., Ireland & Pakenham, 2010; Pakenham et al., 2006) and adult carers (e.g., Pakenham, 2007a). Another factor associated with caregiving activity is appraisal of the caregiving situation. According to stress and coping theory (Lazarus & Folkman, 1984), appraisal is an evaluative process that reflects the person's interpretation of a situation, such as caregiving. Events are appraised with respect to how stressful they are. Higher stress appraisals related to caregiving have been shown to be related to greater caregiving activity in a mixed sample of young carers (Pakenham et al., 2006), and adult MS carers (Pakenham, 2007a).

In summary, the present study has four aims. The first aim is to explore the dimensions of caregiving in children of a parent with MS using the YACS. We expect to replicate the four YACS caregiving dimensions. As part of this aim we investigate the psychometric properties of the caregiving dimensions. The second aim is to examine relations between the caregiving dimensions and child demographic, parental illness and caregiving context variables. We expect that higher levels of caregiving activity will be associated with greater CR disability and higher caregiving stress appraisals. The third aim is to examine associations between the caregiving dimensions and child positive (life satisfaction, positive affect and prosocial behaviour) and negative (emotional and behavioural difficulties, and somatisation) adjustment outcomes, concurrently and over a 12-month interval. We expect caregiving dimensions to be associated with positive and negative adjustment outcomes, reflecting both the protective/reward and risk/cost elements of youth caregiving, respectively. The fourth aim is to examine levels of correspondence between parent and child ratings of the child's caregiving activities. Consistent with prior evidence, we expect children to report higher levels of caregiving activity than both the parent with MS and the healthy parent.

Method

This study reports on data collected from a larger longitudinal study of coping with parental MS. This study used child and parent data collected during an initial assessment (Time 1) and child data collected 12 months later (Time 2). The study received ethical clearance from the University of Queensland.

Participants and Recruitment Procedures

Participants were parents with MS, their partners, and their children aged 10–20 years recruited from four Australian states. Participants from Queensland (QLD) and Western Australia (WA) were recruited via their local MS Societies. MS Society members from these states who had been identified as parents were sent an information sheet, consent form, questionnaire and return envelope. Inclusion criteria included being a parent with MS of children aged 10 to 20 years. A total of 462 parents from the QLD and WA MS Societies were sent invitations to participate. In Victoria (VIC) and New South Wales (NSW) parents with MS were not identified in the data-base, so 500 MS Society members were randomly selected and sent invitations to participate. Parents with MS were invited to provide written consent for their children (identified by name and age), and to indicate whether they and their partner wanted to participate in the study. On receipt of signed consent forms, each family member who consented to participate was then forwarded a personalised information sheet, questionnaire and return envelope.

Accurate response rates for QLD and WA could not be calculated because only parents with children between 10 to 20 years were invited to participate and individuals fitting this criterion could not be identified from the data-bases, hence, some parents would have been sent invitations who did not meet inclusion criteria. A response rate for VIC and NSW could not be calculated because parents with MS were not identified on the data-bases. A total of 88 families where two or more family members completed questionnaires participated; 85 parents with MS, 55 partners, and 130 children completed questionnaires at Time 1. For two families only children completed questionnaires and for one family only the healthy parent and children completed questionnaires. Time 2 questionnaires were completed by 71 parents with MS, 48 partners, and 91 children, yielding 16%, 13% and 30% attrition rates, respectively.

The mean age of children was 14.22 years ($SD=3.12$), 46% were male, and 31% had casual employment. Regarding education, 30% were in primary school, 55% secondary school, and 15% were in tertiary studies. The mean age of parents with MS was 44.27 ($SD=5.24$; range 33–55) and most were mothers (84%). The mean age of healthy parents was 55 ($SD=5.52$; range 34–57) and most were fathers (73%).

Measures

Two age-appropriate youth questionnaires were developed: 10-13 years and 14-20 years. The questionnaires were identical except for several words that were changed to make them more age-appropriate. Identical versions of these questionnaires have been used in prior young carer research (e.g., Pakenham et al., 2006). Questionnaires for parents included questions on demographics and a parent version of the YACS. The

questionnaire for parents with MS also included measures of illness duration, disease severity, disability, cognitive impairment, other illnesses, depression and anxiety.

Demographics. In addition to the demographics mentioned above, information was obtained from youth on number of additional people living at home ($M=3.05$, $SD=1.02$; range 1-6), number of siblings ($M=2.22$, $SD=0.52$; range 1-4), and dual (76% children in 74% of participating families) vs. single (24% in 26% of participating families) parent households.

MS Parent Illness Variables. Parents with MS completed the following illness variables at Time 1: illness duration, disease severity, disability, cognitive impairment, additional illnesses, depression, and anxiety. Regarding *illness duration*, participants provided the number of months since diagnosis ($M=8.24$ years, $SD=5.79$; range 4 months – 25 years). *Disease Severity* was assessed via a self-report version of the physician's Disease Steps Scale (Hohol, Orav & Weiner, 1995) that has been used in prior MS research (Simmons, Tribe & McDonald, 2010) and which measures the degree of mobility limitations associated with MS. Respondents nominate their level of mobility, using eight mobility scenarios, ranging from 0 (*normal*) to 8 (*bedridden*). A ninth scenario assesses the presence of symptoms that limit activity but are not related to mobility (e.g., eyesight or memory problems). Respondents are classified into three broad categories: mild (44%), moderate (44%), and severe (12%) MS. *Disability* was measured using 13 items from the 15-item ADL Self-Care Scale for persons with MS (Gulick, 1987). Two items were excluded as they were considered to be confounded with social support (i.e., "Exchange loving glances with someone special" and "Confide in someone"). The modified scale assesses how frequently ADLs are performed on a typical day and has been used in prior research (e.g., Pakenham, 2007b). Items are rated on a 6-point scale (0 *never* to 5 *always*), with higher scores indicating lower disability. *Cognitive impairment* was assessed using the 6-item cognitive subscale of the Mayo-Portland Adaptability Inventory which assesses impairment in communication, memory, attention, problem solving, visuospatial abilities, and common knowledge (MPAI; Malec, Machulda & Moessner, 1997; Malec & Thompson, 1994). Each item is rated on a standardized 4-point scale (0=*no impairment* to 3=*complete or nearly complete loss of function*) with higher scores indicating poorer cognitive functioning. Prior MS research has demonstrated high positive correlations between patient and carer ratings of patient's cognitive impairment using the MPAI (Pakenham, 2001). The criteria used for severe cognitive impairment which may jeopardise the reliability of self-report was a score of two or more standard deviations

above the mean and a score of three (indicating severe impairment) on two or more of the six items. None of the participants reached criteria indicative of severe cognitive impairment. *Additional parental illness* was assessed by asking whether an additional illness was present (42% indicated *yes*), and to describe it/them. These were then coded and the total mean number of additional illnesses calculated ($M = .69$, $SD=1.15$; range 0-7). *Depression and anxiety* subscales of the widely used 21-item Depression Anxiety and Stress Scale (Lovibond & Lovibond, 1995) were used to assess these domains of distress. Participants are asked to rate on a 4-point scale how much each statement applied to them (0 *Did not apply to me at all* to 3 *Applied to me very much or most of the time*).

Caregiving Context Variables. The following information was collected from youth at Time 1: 96% lived with the parent with MS and had daily contact with the parent, and the mean number of months youth had cared for their parent was 4.47 ($SD=3.86$, range <1–24). In addition, youth rated the extent to which they thought they had a choice in helping their parent on a 4-point scale (1 *no choice*, 2 *a little choice*, 3 *quite a lot of choice*, 4 *I am free to make any choice*). Unpredictability of the parent's MS was measured by a 5-item scale used in prior research (Pakenham & Bursnall, 2006). Respondents rated the extent to which they agreed with each item on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*). In order to obtain a global stress appraisal of caregiving, youth were asked to rate on a scale from 1 to 100 (0 *not stressful at all* to 100 *most stressful ever*) the extent to which helping their parent was stressful.

Family responsibilities. The 11-item family responsibilities subscale of the Young Carer of Parents Inventory (YCOPI; Pakenham et al., 2006) was used to examine convergent validity of the YACS in this sample and was completed at Times 1 and 2. The YCOPI is a self-report measure of young carers' diverse positive and negative caregiving experiences. The family responsibilities subscale assesses the extent to which respondents contribute to a range of very broad family tasks and responsibilities. Items are rated on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*).

YACS. The YACS (Ireland & Pakenham, 2010) was developed from a review of relevant literature and consultation with young carers and health professionals. Respondents rate how much help they provide the ill/disabled family member on 30 care tasks with a 5-point scale (0 *No help at all* to 4 *Lots of help*). A modified parental version of the YACS asked the parent to rate "how much your child (or children) between 10-20 years old helps you with" each of the 30 care tasks. The YACS was completed by youth at Times 1

and 2 and by parents at Time 1. In the derivation study on young carers, the four factors (described above) were shown to be internally reliable (alphas ranged .74 - .92), and evidenced good convergent and predictive validity (Ireland & Pakenham, 2010).

Adjustment. Four youth adjustment domains were assessed at Times 1 and 2: (1) behavioural, emotional, and social functioning, (2) somatisation, (3) positive affect, (4) life satisfaction. *Behavioural, emotional, and social functioning.* The self-report version of the 25-item Strengths and Difficulties Questionnaire (SDQ; Goodman, Meltzer, & Bailey, 1998) was used to assess behavioural, emotional, and social functioning. The SDQ consists of five subscales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour. The first four subscales are summed to give a total difficulties score, whereas the prosocial behaviour subscale is used as a measure of positive adjustment. SDQ items are worded as thoughts, feelings, and behaviours to which respondents rate the extent it represents them across 0 (*not at all*), 1 (*a little, sometimes*), or 2 (*very much, all of the time*). The SDQ has demonstrated external validity in both clinical and non-clinical samples, as well as across a broad age-range (Muris, Meesters, Eijkelenboom, & Vincken, 2004; Van Roy, Grøholt, Heyerdahl, & Clench-Aas, 2006). *Somatisation.* Given reports of elevated somatic complaints in children of a parent with MS, the 6-item somatisation subscale of the Brief Symptom Inventory-18 (Derogatis, 2000) was used. Respondents indicated how much each problem had upset them in the past seven days using a 5-point scale (0 *not at all* to 4 *extremely*). *Positive Affect.* Positive affect was measured by a modified version of the Bradburn Affect Balance Scale (Bradburn, 1969). An additional three items were added to Bradburn's (1969) five positive affect items ('Cheerful', 'Inspired', 'Satisfied'). Participants rated the extent to which they felt each of the eight positive states during the past few weeks (1 *not at all* to 5 *very often*). *Satisfaction with Life.* The 5-item Satisfaction with Life Scale (Pavot & Diener, 1993) was used to assess participant's global judgement of life satisfaction. Items are rated on a 7-point scale (1 *strongly disagree* to 7 *strongly agree*).

Results

Data Screening

All data were inspected for distributional properties and for missing data and cleaned for out of range values. Missing values accounted for <5% of the data at either Time 1 or Time 2, not counting respondent

attrition. Given the large number of variables, missing values were imputed at the composite level for all variables. The EM method within SPSS V18 was employed to impute missing values. Beyond the three parents with MS who did not complete the questionnaire, a further three parents did not complete any of the YACS items, nor large portions of the other variables. For these six parents data were not able to be imputed leaving 82 parents with MS with useable data.

Factor Analysis of YACS Items

The 30 Time 1 Child YACS items were subjected to Principle-Components Analysis (PCA). The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was high (.89) and Bartlett's test of sphericity was significant ($p < .001$) indicating that the data was suitable for factorability. Although six factors with eigenvalues greater than 1.0 emerged, after examining solutions ranging from 3 to 7 solutions, a four factor solution broadly replicating Ireland and Pakenham (2010) was most interpretable, exhibiting the most coherent sets of items on the four factors. The same four factors were clearly identifiable in the obliquely rotated four factor solution: instrumental care, social-emotional care, personal-intimate care, and domestic-household care. Together, the four factors accounted for 70.39% of the total variance. The eigenvalues, percentage variance accounted for by each factor, and the loadings are presented in Table 1.

A strict set of criteria were used when retaining items: loadings $> .50$; no cross-loadings $> .32$ and the difference between an item's primary loading and that on a second factor $< .20$. These criteria lead to 10 of the original items being dropped. Several of these items (e.g., Item 2 "Using public transport", and Item 3 "Getting around when we are out of the house") appeared to form the basis of a mobility caregiving factor, but the solutions were not sufficiently stable when including this factor for it to be retained. This does suggest further work might successfully capture such a factor. Several other items cross-loaded too highly suggesting that the domain of helping was not clearly specified in the item, or that the item was implicated in multiple helping domains. For example, item 28, "picking things up", loaded on both the social-emotional and the personal-intimate care factors.

A four factor solution was then requested for the child Time 2 scores, and also for the Time 1 scores for the parent with MS and the healthy parent. Regarding the child Time 2 scores, the same four factors emerged. Only two items changed the factor onto which they loaded: item 25 "Medicines and/or injections",

which loaded onto the domestic-household care factor, and item 18 “Remembering things”, which weakly loaded onto the domestic-household care factor, but only marginally more strongly than it did on the expected social-emotional factor. Item 22 also cross-loaded onto instrumental care.

Using the same items, a four factor solution was also requested for both the healthy parent and the parent with MS. While the same general factors emerged, they were not as clean. For the healthy parent, two items loaded on different factors, specifically item 2 “Shopping” loaded onto the social-emotional care factor, and item 30 “Keeping partner safe” loaded onto the personal-intimate care factor. Two further items also cross-loaded substantially: item 25 “Medicines and/or injections” cross-loaded onto the instrumental care factor, and item 6 “Making telephone calls” cross-loaded onto the social-emotional care factor. Despite these differences, the overall structure of the solution strongly resembled that for the child data.

The solution for the MS parent was more degraded. Two factors, social-emotional and domestic-household care, emerged reasonably cleanly. The other two factors, instrumental and personal-intimate care were not as clean, and exhibited substantial cross-loadings. The eigenvalues, percentage of variance accounted for by each factor, and the loadings for all four sets of caregiving scores, are presented in Table 1.

Psychometrics. Cronbach’s reliabilities for the YACS factors are shown in Table 1; all exceed .80. Means and standard deviations for each of the factors are presented in Table 2. Personal-intimate and instrumental care had the lowest means at each time point, whereas domestic-household care had the highest means. Correlations among the YACS factors and between the YACS factors and the YACS total are summarised in Table 2. All correlations among the YACS factors at each time point were positive and significant (range .34-.66). Correlations between the YACS factors and total at each time point ranged from .67 to .84. Retest correlations showed that each Time 1 YACS factor and the Time 1 total YACS score was significantly positively correlated with its respective Time 2 score (range .49 - .78, $p < .001$). Regarding convergent validity, all correlations between the YACS factors and total scale and the YCOPI family responsibilities subscale at both Time 1 and 2, were positive and significant (range: Time 1 = .41 - .53, Time 2 = .41 - .65; all $p < .01$).

Relationships between YACS and Child Demographics, Caregiving Context and Parental Illness Variables

Analyses were conducted to establish whether the YACS factors and total score varied as a function of child demographics (age, gender, education, employment status, co-residence with parents, family size, dual or single parent household, and number of siblings), parental illness variables (months since diagnosis, disease severity, cognitive impairment, ADL, number of other medical conditions, depression and anxiety), and caregiving context variables (choice in helping, illness unpredictability, stress, caregiving duration).

Of the child demographic variables, only gender exhibited significant associations with the YACS scores. Girls reported significantly higher levels of caregiving than did the boys for personal-intimate care $F(1, 128)=4.98, p=.03, R^2=.04$ (girls: $M=.44, SD=.78$, boys: $M=.18, SD=.47$), domestic-household care $F(1, 128)=5.63, p=.02, R^2=.04$ (girls: $M=1.90, SD=.91$, boys: $M=1.55, SD=.78$) and total caregiving $F(1, 128)=6.13, p=.02, R^2=.05$ (girls: $M=1.15, SD=.75$, boys: $M=.88, SD=.47$).

With respect to child caregiving context variables, higher levels of caregiving across all YACS factors and total scale were correlated with less choice in helping ($-.20, p<.05$ to $-.37, p<.001$), and higher parental illness unpredictability ($.25, p<.01$ to $.40, p<.001$) and stress ($.37, p<.001$ to $.47, p<.001$). Caregiving duration was correlated with higher instrumental ($.22, p<.05$) and domestic-household care ($.21, p<.05$) and total caregiving ($.19, p<.05$).

Regarding parental illness, higher levels of caregiving across all YACS factors and total scale were significantly correlated with greater disease severity ($.31, p<.001$ to $.47, p<.001$) and disability ($-.25, p<.01$ to $-.52, p<.001$). Time since diagnosis was associated with higher personal-intimate care ($.24, p<.01$), anxiety was related to higher personal-intimate care ($.19, p=.03$) and total caregiving ($.18, p=.04$), while cognitive impairment, other medical conditions and depression were unrelated to all YACS factors and total scale.

Associations among Caregiving Dimensions and Child Adjustment

The third aim was to examine the effects of the caregiving factors on child positive (life satisfaction, positive affect and prosocial behaviour) and negative (emotional and behavioural difficulties, and somatisation) adjustment outcomes, concurrently and over 12 months. Correlations among caregiving and child adjustment at Times 1 and 2 are provided in Table 2. The correlations revealed that caregiving was most strongly associated with life satisfaction, somatisation and total difficulties.

While many researchers include standard demographic variables such as age and gender as control variables, we decided not to use any control variables in the regression analyses. Control variables are most appropriately used to either purify measures or to account for confounding effects. As argued in Spector and Brannick (2010) demographic control variables are rarely the substantive variables of interest and operate as proxies for the psychological processes under examination. The same confounding effect occurs in the current research context for parental health measures; as outlined above, diminished parental health is associated with higher amounts of caregiving and the degree to which illness is associated with adjustment, the relationships of interest here, caregiving and child adjustment, will be removed from the analysis.

Given 80 children were not sampled from unique families, the children's data violates the independence of observation assumptions of regression. To take this into account, we used the Huber-White sandwich estimator for standard errors. All regression analyses were performed using Stata 10.2.

To assess concurrent effects, a set of regressions were conducted for Time 1 and 2 variables separately in which each adjustment outcome was regressed onto the caregiving factors assessed at that same time. Results (see Table 3) showed that there were relatively few contemporaneous effects. At Time 1, higher total caregiving was associated with lower life satisfaction and higher somatization and total difficulties. Higher total difficulties was also associated with greater social-emotional care. At Time 2, there were only two contemporaneous effects. Higher instrumental care was associated with lower life satisfaction and higher total caregiving was associated with increased prosocial behaviour.

The second set of regression analyses examined the lagged effect of caregiving on child adjustment over 12 months (Table 4). These relationships were examined by estimating a series of conditional change models (Finkel, 1995) via OLS regression, one for each of the five adjustment outcomes. For each regression, the first step included Time 1 caregiving, and the second step added Time 1 adjustment. In the first step, the coefficients for the caregiving variables can be interpreted as the lagged association of Time 1 caregiving on Time 2 adjustment. In the second step, the coefficients for caregiving can be interpreted as the association of Time 1 caregiving with a *change* in the level of adjustment from Time 1 to Time 2.

Results indicate there were few lagged associations from Time 1 caregiving to Time 2 adjustment levels (step 1 of the models shown in Table 4), but more evidence of Time 1 caregiving being associated with

change in adjustment from Time 1 to Time 2 (step 2 in Table 4). Regarding the lagged associations of Time 1 caregiving on adjustment at Time 2, higher amounts of social-emotional care at Time 1 was associated with increased total difficulties at Time 2. Further, increased instrumental care at Time 1 was associated with lower life satisfaction at Time 2. Total caregiving at Time 1 was also associated with decreased life satisfaction and increased somatization and total difficulties.

Regarding the effects of Time 1 caregiving on *change in adjustment* from Time 1 to Time 2 (see step 2 of Table 4), there were no significant relationships exhibited for the prediction of change in somatisation. For the remaining adjustment outcomes, there were several significant effects. The three positive adjustment outcomes exhibited an increase across time associated with higher personal-intimate care at Time 1, while higher personal-intimate care at Time 1 was associated with a decrease in total difficulties from Time 1 to Time 2. Higher instrumental care at Time 1 was associated with a decrease in life satisfaction between Time 1 and Time 2, and a trend toward increased total difficulties between the two time periods ($p=.09$). Last, increased Time social-emotional care was linked with a decrease in prosocial behaviour from Time 1 to 2.

A final set of regressions examined the effect of changes in caregiving from Time 1 to Time 2 on changes in adjustment across time. No effects reached statistical significance.

Correspondence between Parent and Child Ratings of Child Caregiving

The final aim of the study was to examine the level of agreement between children and their parents regarding the level of caregiving provided by the child. To explore this, we calculated a range of statistics including James r_{wg} agreement ratings (James, Demaree & Wolf, 1984) and the absolute magnitude of the differences between caregiving scores, for children and each parent for each of the four caregiving factors and total caregiving. We also assessed agreement between the two parents. Results are presented in Table 5. It should be noted that the factor structure was not as stable as would be desirable for these analyses, but nevertheless they are informative about the levels of agreement. The r_{wg} was used because it assesses the level of agreement between raters in terms of the proportional reduction in error variance, rather than consistency between raters, as do correlations (LeBreton & Senter, 2008). It is conventional to accept levels of agreement $>.70$ as indicating agreement. When multiple ratings are undertaken, it is also suggested that the mean of the r_{wg} ratings be used as an indicator of agreement. We also provide the percentage of pairs that fell below the .70

cut-off. It is also acknowledged that r_{wg} performs better with more raters (LeBreton & Senter, 2008); in this case there are only two in each calculation with the effect that agreement scores are more likely to be attenuated, a conservative outcome.

As shown in Table 5, there were reasonable levels of agreement among all comparisons, evidenced by both mean absolute differences all being less than 1 on a 5 point scale and only one mean r_{wg} falling below .70. Caregiving factors with low levels of use, personal-intimate and instrumental care, exhibited the strongest agreement. Very few parents with MS and their children agreed absolutely on levels of social-emotional and domestic-household care. Children and their parents exhibited highest agreement on personal-intimate, instrumental and total caregiving, and least on domestic-household and social-emotional care. Paired samples *t*-tests on child vs. parent with MS, child vs. healthy parent, and parent with MS vs. healthy parent scores revealed no significant differences on average between caregiving ratings. The distribution of scores for one rater being higher or lower were reasonably evenly distributed around a difference of zero.

Discussion

Results showed that youth caregiving tasks in the context of parental MS fall into four psychometrically sound dimensions: instrumental, domestic-household, social-emotional and personal-intimate care. All four domains reflect those identified in qualitative studies of children of a parent with MS (e.g., Turpin et al., 2008), and encapsulate the core domains of young caregiving (Pakenham, 2009). Instrumental and personal-intimate care tasks were less frequently endorsed than the other two caregiving domains, perhaps because these tasks are not typically undertaken by children. In contrast domestic-household care tasks are similar to the usual caregiving tasks that children perform, and the social-emotional care tasks are more likely to naturally flow from child-parent interactions. A range of youth demographics, parental illness characteristics and caregiving context variables emerged as potential risk or protective factors associated with these domains of caregiving tasks. Importantly the caregiving task factors evidenced differential relations with concurrent negative and positive adjustment outcomes and changes in these outcomes over 12 months.

As expected, the caregiving dimensions were associated with positive and negative adjustment outcomes, reflecting both the protective/reward and risk/cost elements of youth caregiving, respectively. The strongest evidence supporting the influence of caregiving activities on youth adjustment emerged in analyses

that investigated the effects of Time 1 caregiving on changes in adjustment over 12 months. A notable consistent pattern of associations that emerged in analyses that examined the lagged effects of Time 1 caregiving on Time 2 adjustment and the effects of Time 1 caregiving on changes in Time 2 adjustment involved links between higher levels of instrumental care and social-emotional care and poorer adjustment, and between higher personal-intimate care and better adjustment. The beneficial effects of higher personal-emotional care were most evident on the positive adjustment outcomes, whereas the adverse effects of higher instrumental care were mostly evident in the life satisfaction adjustment domain. Social-emotional care had lagged effects on higher Time 2 difficulties and was associated with decreases in Time 2 prosocial behaviour. The domestic-household care dimension was unrelated to adjustment. Increased total caregiving was associated with lower life satisfaction at Time 2, and increased somatisation and total difficulties. This overall pattern of associations differs from those that emerged in the YACS derivation study with a mixed sample of young carers (Ireland & Pakenham, 2010), and the study of adult MS caregiving domains (Pakenham, 2007a). The link between personal-intimate care and positive adjustment outcomes may be due to the selection of children with better adjustment into undertaking such caregiving (East, 2010). It is also possible that providing personal care strengthens attachment between parent and child and involves personally rewarding care tasks (Ireland & Pakenham, In press). In contrast, consistent with parentification theory instrumental and social-emotional care tasks are likely to be more burdensome perhaps because some of the related tasks involve more adult-like interactions such as “speaking to doctors, pharmacists, or other professionals” and “keeping parent safe”. The absence of any association between domestic-household care and adjustment may be due to these tasks being somewhat more similar to the usual activities that children perform in families where there is no parental illness. It should be noted that the total variance explained in the adjustment variables by the YACS factors is only modest, ranging 0 to 22%. Clearly while caregiving is differentially associated with children’s adjustment, other factors also play a larger role.

The YACS factors were related to many caregiving parameters and most of these associations reflected circumstances that increased caregiving demands such as, caring for a parent who is more disabled, has more severe MS, unpredictable symptoms, and anxiety, and when the child perceives less choice in caregiving. Together this pattern of results provides convergent validity for the YACS scales. Consistent with prior research girls reported higher levels of caregiving than boys (e.g., East, 2010).

The psychometric properties of each of the YACS factors were very good; all internal reliabilities were above .80, all retest reliability coefficients were above .49 and significant, demonstrating consistency over time in the relative amounts of caregiving provided by children, and the factors were moderately inter-correlated. The convergent validation data suggest that each of the factors was related to a global measure of young caregiving. Further validation data is evident in the numerous significant associations between each of the YACS factors and the caregiving context variables. The differential relations between the YACS factors and dimensions of adjustment provide supportive criterion validation data. Overall, the results demonstrate that increased caregiving is associated with decreased life satisfaction and increased somatisation and total difficulties.

The strongest agreement between parent and child reports of the child's caregiving occurred on the personal-intimate and instrumental care tasks, whereas lower levels of agreement emerged in the social-emotional and domestic-household care domains. This may be due to the fact that personal-intimate and instrumental care tasks were less frequently performed, are less typically carried out by children and, therefore, more noticeable to both child and parent. In contrast, domestic-household care tasks are more typically carried out by children, and social-emotional care tasks are not discrete behaviours and are likely to be embedded in interactions and, therefore, they are not easily detected. The *t*-tests revealed no significant differences on average between child and parental ratings of caregiving, but at the individual child/parent pair, there were sizeable numbers of parents and children who provided different ratings in the amount of caregiving provided, especially on social-emotional and domestic-household caregiving. These differences were not consistently skewed toward higher ratings by either parents or children, but differed across different pairs. Hence, unexpectedly and in contrast to other studies, children did not consistently report higher levels of caregiving activity than their parents' reported. The few quantitative studies that have examined the correspondence between child and parent reports of child caregiving in the context of parental illness have not used multi-dimensional psychometrically sound caregiving scales and statistical analyses that provide a more detailed examination of levels of agreement (e.g., Bauman et al., 2006).

The present study has several limitations including the use of a non-random sample which restricts the generalisability of findings, the absence of measures of the frequency and amount of time spent on caregiving, and where multiple children in the specified age range were present in a family, parental ratings of child

caregiving were not child specific. In addition, many of the YACS items excluded in factor analyses appeared to reflect a fifth caregiving dimension related to helping the parent with MS with mobility. The factor analyses were conducted with sample sizes that are smaller than is ideal, although the solutions were surprisingly robust. Nevertheless, larger samples are required to confirm the solutions found. **Another potential limitation is the wide age range. However, the correlations between child age and adjustment and between child age and caregiving factors were all less than .16 in absolute magnitude and none reached statistical significance. Partial correlations between child adjustment and caregiving dimensions while controlling for age changed only minimally for most dimensions (mean change in partial correlations = .02). The inclusion of child's age in the regression analyses did not alter the results. A final limitation is the lack of a comparison group of children with “healthy” parents, which would shed light on whether the patterns of findings in this study are specific to children who have a parent with an illness.**

Nevertheless, these limitations are off-set by the strengths of the study including: longitudinal design, the application of comprehensive scale development strategies, multiple sources of data, and the use of both positive and negative adjustment outcomes. Further, non-independence of the data due to sampling multiple children from the same families was taken into account by correcting the regression results for these clustering effects. Findings delineate the key dimensions of youth caregiving tasks in the context of parental MS and show the differential links between caregiving dimensions and various caregiving parameters. Findings also suggest that parents and children have similar perceptions of levels of child caregiving in relation to tasks that are not usually performed by children, whereas perceptions are more likely to differ with respect to tasks typically performed by children or caring that is embedded in interactions. Finally, this study provides preliminary supportive reliability and validity data on the application of the YACS as a measure of youth caregiving in the context of parental MS. Such an instrument is important for theory building, across study comparisons and the development of services for enhancing the caregiving and quality of life of young carers. Future research should explore how children get selected into caregiving, investigate the caregiving of younger children and include a longer follow-up assessment to examine the utility of the YACS in predicting longer-term outcomes, such as difficulties in the transition to adulthood.

References

- Arnaud, S. H. (1959). Some psychological characteristics of children of multiple sclerosis. *Psychosomatic Medicine, 21*, 8-22.
- Bauman, L. J., Foster, G., Silver, E.J., Berman, R., Gamble, I., & Muchaneta, L. (2006). Children caring for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies, 1*, 56-70.
- Bauman, L. J., Silver, E.J., Berman, R., & Gamble, I. (2009). Children as caregivers to their ill parents with AIDS. In K. Shifren (Ed.), *How caregiving affects development: Psychological implications for child, adolescent, and adult caregivers*. Washington DC: American Psychological Association.
- Bogosian, A., Moss-Morris, R., & Hadwin, J. (2010). Psychosocial adjustment in children and adolescents with a parent with multiple sclerosis: A systematic review. *Clinical Rehabilitation, 24*, 789-801.
- Bowlby, J. (1969). *Attachment and loss, Vol I: Attachment* Middlesex: Penguin Books.
- Bradburn, N. M. (1969). *The structure of psychological well-being*. Oxford, England: Aldine.
- Braham, S., Houser, H. B., Cline, A., & Posner, M. (1975). Evaluation of the social needs of non-hospitalized chronically ill persons: 1. Study of 47 patients with multiple sclerosis. *Journal of Chronic Diseases, 28*, 401-419.
- Chase, N. D. (1999). *Burdened children: Theory, research, and treatment of parentification*. Thousand Oaks, CA: Sage Publications.
- De Judicibus, M. A., & McCabe, M. P. (2004). The impact of parental multiple sclerosis on the adjustment of children and adolescents. *Adolescence, 39*(155), 551-569.
- Deatrick, J. A., Brennan, D., & Cameron, M. E. (1998). Mothers with multiple sclerosis and their children: effects of fatigue and exacerbations on maternal support. *Nursing Research, 47*(4), 205-210.
- Derogatis, L. R. (2000). *Administration and procedures manual: BSI-18*. Minneapolis: National Computer Systems Inc.
- Earley, L., & Cushway, D. (2002). The parentified child. *Clinical Child Psychology and Psychiatry, 7*(2), 163-178.
- East, P. L. (2010). Children's provision of family caregiving: Benefit or burden? *Child Development Perspectives, 4*, 55-61.
- Finkel, S. E. (1995). *Causal analysis with panel data*. Thousand Oaks: Sage Publications, Inc.

- Goodman, R., Meltzer, H., & Bailey, V. (1998). The strengths and difficulties questionnaire: A pilot study on the validity of the self-report version. *European Child and Adolescent Psychiatry, 7*, 125-130.
- Gulick, E. E. (1987). Parsimony and model confirmation of the ADL Self-care Scale of Multiple Sclerosis Persons. *Nursing Research, 36*(5), 278-283.
- Hohol, M.J., Orav, E.J. & Weiner H.L. (1995). Disease steps in multiple sclerosis: A simple approach to evaluate disease progression. *Neurology, 45*, 251-255
- Ireland, M., & Pakenham, K.I. (2010). The nature of young caregiving in families experiencing chronic illness/disability: Development of the Youth Activities of Caregiving Scale (YACS). *Psychology and Health, 25*, 713-731.
- Ireland, M., & Pakenham, K.I. (In press). Youth adjustment to parental illness or disability: The role of illness characteristics, caregiving, and attachment. *Psychology, Health and Medicine*.
- James, L. R., Demaree, R. G., & Wolf, G. (1984). Estimating within-group interrater reliability with and without response bias. *Journal of Applied Psychology, 69*, 85-98.
- Kirshbaum, M., & Olkin, R. (2002). Parents with physical, systemic, or visual disabilities. *Sexuality and Disability, 20*(1), 65-80.
- Koch-Henriksen, N., & Sörensen, P. S. (2010). The changing demographic pattern of multiple sclerosis epidemiology. *Lancet Neurology, 9*, 520-532.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. NY: Springer.
- LeBreton, J. M., & Senter, J. L. (2008). Answers to 20 questions about interrater reliability and interrater agreement. *Organizational Research Methods, 11*, 815-852.
- Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales* (2nd ed.). Sydney: Psychology Foundation of Australia.
- Malec, J. F., Machulda, M. M., & Moessner, A. M. (1997). Differing problem perceptions of staff, survivors, and significant others after brain injury. *Journal of Head Trauma Rehabilitation, 12*(3), 1-13.
- Malec, J. F., & Thompson, J. M. (1994). Relationship of the Mayo-Portland Adaptability Inventory to functional outcome and cognitive performance measures. *Journal of Head Trauma Rehabilitation, 9*(4), 1-15.

- McCabe, M. P., & McKern, S. (2002). Quality of life and multiple sclerosis: comparison between people with multiple sclerosis and people from the general community. *Journal of Clinical Psychology in Medical Settings, 9*(4), 287-295.
- Muris, P., Meesters, C., Eijkelenboom, A., & Vincken, M. (2004). The self-report version of the Strengths and Difficulties Questionnaire: Its psychometric properties in 8-to 13-year-old non-clinical children. *British Journal of Clinical Psychology, 43*, 437-448.
- Pakenham, K. I. (2001). Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health and Medicine, 6*(1), 13-27.
- Pakenham, K. I. (2005). The positive impact of multiple sclerosis on carers: Associations between carer benefit finding and positive and negative adjustment domains. *Disability and Rehabilitation, 27*(17), 985-997.
- Pakenham, K. I. (2007a). Making sense of Multiple Sclerosis *Rehabilitation Psychology, 52*, 380-389.
- Pakenham, K. I. (2007b). The nature of caregiving in multiple sclerosis: Development of the Caregiving Tasks in Multiple Sclerosis Scale. *Multiple Sclerosis, 13*, 929-938.
- Pakenham, K. I. (2009). Children who care for their parents: the impact of disability on young lives. In C. A. Marshall, Kendall, E., Banks, M., & Gover, R.M.S. (Ed.), *Disability: Insights From Across Fields and Around the World* (Vol. II, pp. 39-60). Westport, CT: Praeger Press.
- Pakenham, K. I., & Bursnall, S. (2006). Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with MS and comparisons with children of healthy parents. *Clinical Rehabilitation, 20*, 709-723.
- Pakenham, K. I., Bursnall, S., Chiu, J., Cannon, T., & Okochi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: comparisons between young caregivers and non-caregivers. *Rehabilitation Psychology, 51*(2), 113-126.
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology, 12*(1), 89-102.
- Pavot, W., & Diener, E. (1993). Review of the Satisfaction With Life Scale. *Psychological Assessment, 5*(2), 164-172.

- Rao, S. M., Huber, S. J., & Bornstein, R. A. (1992). Emotional changes with multiple sclerosis and Parkinson's disease. *Journal of Consulting and Clinical Psychology, 60*(3), 369-378.
- Simmons, R.D., Tribe, K. & McDonald, E. (2010). Living with multiple sclerosis: Longitudinal changes in employment and the importance of symptom management. *Journal of Neurology, 257*, 926-936.
- Turpin, M., Leech, C., & Hackenberg, L. (2008). Living with parental multiple sclerosis: Children's experience and clinical implications. *Canadian Journal of Occupational Therapy, 75*, 149-156.
- van Roy, B., Groholt, B., Heyerdahl, S., & Clench-Aas, J. (2006). Self-reported strengths and difficulties in a large Norwegian population 10-19 years: Age and gender specific results of the extended SDQ-questionnaire. *European Child and Adolescent Psychiatry, 15*, 189-198.
- Walmsley, J. (1993). Contradictions in caring: Reciprocity and interdependence. *Disability, Handicap and Society, 8*, 129-141.
- World Health Organisation. (2004). *Atlas: Country Resources for Neurological Disorders. Results of a collaborative study of World Health Organisation and World Federation of Neurology. Programme for Neurological Diseases and Neurosciences Department of Mental Health and Substance Abuse.* Geneva: World Health Organisation.
- Yahav, R., Vosburgh, J., & Miller, A. (2005). Emotional responses of children and adolescents to parents with multiple sclerosis. *Multiple Sclerosis, 11*, 464-468.

Table 1

Results of Principal Components Analysis of the YACS Items

Factor and item labels	Child Time 1 (n = 124)					Child Time 2 (n = 91)					Healthy Parent Time 1 (n = 51)					MS Parent Time 1 (n = 82)				
	4-Factor solution				1-F ^a	4-Factor solution				1-F ^a	4-Factor solution				1-F ^a	4-Factor solution				1-F ^a
	1	2	3	4		1	2	3	4		1	2	3	4		1	2	3	4	
<i>Personal - Intimate Care</i>																				
24 Bladder or bowel Control	.94				.71	.83				.63	.94				.66	.75				.66
26 Getting in and out of bed	.86				.79	.86				.69	.89				.64	.72				.75
23 Dressing	.83				.83	.76				.72	.91				.75	.24			.45	.75
20 Going to the toilet	.81				.71	.94				.55	.99				.67	.22			.56	.68
25 Medicines and/or injections	.75				.67	.28		.71		.54	.45			.46	.71	.64				.65
22 Showering and bathing	.69				.72	.70		-.42		.53	.97				.71	.33			.63	.67
<i>Social - Emotional Care</i>																				
16 Keeping parent happy		.83			.64	.88				.63	.87				.55	.87				.58
30 Keeping parent safe		.81			.61	.83				.40	.51	.36			.72	.27	.62			.62
17 Helping parent when they are feeling bad		.77			.57	.68				.57		.82			.61	.83				.69
18 Remembering things		.73			.55	.28	.34			.48	.61				.70	.53		.51		.51
13 Keeping parent company		.73			.70	.76				.61	.82				.64	.76				.62
15 Keeping parent occupied		.71			.72	.71				.65	.72				.69	.82				.62

Table 1 Results of Principal Components Analysis of the YACS Items (continued)

Factor and item labels	Child Time 1 (n = 124)					Child Time 2 (n = 91)					Healthy Parent Time 1 (n = 51)					MS Parent Time 1 (n = 82)					
	4-Factor solution				1-F ^a	4-Factor solution				1-F ^a	4-Factor solution				1-F ^a	4-Factor solution				1-F ^a	
	1	2	3	4		1	2	3	4		1	2	3	4		1	2	3	4		
<i>Domestic - Household Care</i>																					
05 Household chores			.83		.58			.84		.55			.85		.52			.83		.67	
11 Chores outside like mowing, cleaning, or gardening			.83		.42			.58		.58			.80					.42		.82	.56
01 Preparing meals			.77		.51			.70		.56			.72		.60			.67		.69	
08 Shopping			.59		.54			.66		.66		.41	.34	.42	.74			.61		.65	
<i>Instrumental Care</i>																					
09 Arranging and attending appointments and meetings				.78	.76			.90		.76			.94	.74	.55			.36		.80	
10 Speaking to doctors, pharmacists, or other professionals				.77	.68			.88		.77			.81	.61	.87					.67	
07 Paying bills and managing money				.59	.78			.91		.76			.67	.76	.89					.74	
06 Making telephone calls, filling out forms or writing letters				.48	.68			.46		.85			.57	.69	.73			-.36		.26	.67
Eigenvalue	8.86	2.14	1.90	1.19	8.86	2.91	8.03	1.59	1.81	8.03	3.58	8.77	1.62	1.48	8.77	8.85	2.33	1.11	1.16	8.85	
% of variance	44.28	10.69	9.48	5.94	44.28	14.56	4.13	7.95	9.07	4.13	16.79	44.82	8.10	7.42	44.82	44.23	11.63	5.55	5.81	44.23	
Cronbach alpha	.92	.89	.81	.86	.92	.87	.84	.81	.94	.91	.93	.89	.80	.85	.92	.85	.87	.80	.86	.92	

Note. ^a 1-Factor solution

Table 2

Means, Standard Deviations, and Correlations among Time 1 and Time 2 YACS Factors and Total YACS Score and Child Adjustment

	YACS Time 1					YACS Time 2				
	Pers-Int. ^a	Instrum. ^b	Soc-Emot. ^c	Dom-Hhld ^d	Total	Pers.Int. ^a	Instrum. ^b	Soc-Emot. ^c	Dom-Hhld ^d	Total
<i>YACS Factors</i>										
Time 1 Pers-Int. ^a										
Time 1 Instrum. ^b	.66***									
Time 1 Soc-Emot. ^c	.50***	.54***								
Time 1 Dom-Hhld ^d	.40***	.55***	.39***							
Time 1 Total	.79***	.82***	.84***	.69***						
Time 2 Pers-Int. ^a	.78***	.46***	.37***	.27**	.58***					
Time 2 Instrum. ^b	.65***	.68***	.36***	.35**	.61***	.55***				
Time 2 Soc-Emot. ^c	.34**	.28**	.49***	.17	.45***	.34**	.49***			
Time 2 Dom-Hhold ^d	.31**	.33**	.14	.54***	.38***	.38***	.55***	.55***		
Time 2 Total	.62***	.53***	.45***	.40***	.63***	.67***	.80***	.83***	.79***	
<i>Adjustment Outcomes</i>										
Time 1 Life satisfaction	-.27**	-.29**	-.26**	-.14	-.30**	-.29**	-.32**	-.12	-.19	-.27**
Time 1 Positive affect	-.12	-.11	.04	.02	-.04	-.16	-.02	.04	.05	-.02
Time 1 Prosocial behaviour	.09	-.02	.15	.01	.10	.05	.14	.00	.08	.07
Time 1 Somatisation	.42***	.38***	.43***	.23**	.47***	.33**	.24*	.17	.20	.29**
Time 1 Total difficulties	.15	.09	.33***	.04	.23**	.09	.09	.22*	.14	.19
Time 2 Life satisfaction	-.07	-.29**	-.25*	-.11	-.24*	-.05	-.23*	-.01	-.05	-.10
Time 2 Positive affect	.15	-.03	.02	-.07	.03	.11	.06	.12	.06	.12
Time 2 Prosocial behaviour	.15	.01	-.05	.09	.04	.12	.20	.19	.21*	.23*
Time 2 Somatisation	.34**	.32**	.34**	.17	.39**	.34**	.32**	.24*	.19	.34**
Time 2 Total Difficulties	.09	.24*	.36**	.10	.29**	.05	.09	.07	-.04	.06
Mean (SD)	.32 (.67)	.44 (.72)	1.64 (1.01)	1.74 (.87)	1.03 (.65)	.22 (.52)	.37 (.82)	1.42 (.89)	1.65 (.92)	.90 (.61)

Note: Child Time 1 $n = 130$, Child Time 2 $n = 91$. ^a Personal-Intimate Care; ^b Instrumental Care; ^c Social-Emotional Care; ^d Domestic-Household Care. * $p < .05$; $p < .01$; $p < .001$.

Table 3

Concurrent Prediction of Child Adjustment from YACS Factors at Time 1 and Time 2

Predictors	Time 1 Child Adjustment Outcome				
	Life Satisfaction β	Positive Affect β	Prosocial Behaviour β	Somatisation β	Total Difficulty β
Time 1 Personal-Intimate care	-.11	-.13	.14	.24 ^t	.06
Time 1 Instrumental care	-.17	-.16	-.21	.08	-.13
Time 1 Social-Emotional care	-.12	.16	.19	.27 ^t	.39**
Time 1 Domestic-Household care	.04	.10	-.01	-.02	-.06
Adjusted R^2	.08	.01	.01	.22	.10
$F(4,87)$	4.50**	1.14	0.99	6.44***	4.10**
YACS Total Time 1	-.30**	-.04	.10	.47**	.23**
Adjusted R^2	.08	.01	.00	.22	.05
$F(1,87)$	15.94***	0.16	0.93	24.47**	1.71**
Predictors	Time 2 Child Adjustment Outcome				
	Life Satisfaction β	Positive Affect β	Prosocial Behaviour β	Somatisation β	Total Difficulty β
Time 2 Personal-Intimate care	.09	.10	-.01	.23 ^t	.02
Time 2 Instrumental care	-.36**	-.05	.10	.16	.12
Time 2 Social-Emotional care	.10	.12	.08	.11	.10
Time 2 Domestic-Household care	.07	-.01	.12	-.04	-.18
Adjusted R^2	.03	.02	.02	.11	.02
$F(4,66)$	5.18***	0.52	2.66*	3.02*	0.77
Time 2 YACS Total	-.10	.12	.23**	.34**	.06
Adjusted R^2	.00	.00	.05	.10	.00
$F(1,66)$	0.78	1.04	7.79**	7.42**	0.32

Note: Huber-White robust cluster corrected standard errors used for all significance tests. ^t $p < .10$, * $p < .05$, ** $p < .01$.

Table 4

Hierarchical Regression Analyses of the Effects of the YACS Factors at Time 1 and Time 1 Adjustment on Time 2 Adjustment

Predictors	Time 2 Life Satisfaction		Time 2 Positive Affect		Time 2 Prosocial Behaviour		Time 2 Somatisation		Time 2 Total Difficulties	
	Reg. 1 ^a β	Reg. 2 ^b β	Reg. 1 ^a β	Reg. 2 ^b β	Reg. 1 ^a β	Reg. 2 ^b β	Reg. 1 ^a β	Reg. 2 ^b β	Reg. 1 ^a β	Reg. 2 ^b β
Step 1										
Time 1 Personal–Intimate care	.20		.28*		.24 ^t		.20			-.15
Time 1 Instrumental care	-.33*		-.14		-.10		.11			.16
Time 1 Social-Emotional care	-.17		0.00		-.13		.19			.35**
Time 1 Domestic-Household care	.03		-.10		.09		-.02			-.03
Time 1 YACS Total		-.24*		.03		.04		.39**		.29**
$F(4, 66)^a / (1, 66)^b$	3.51**	6.31*	1.17	.06	1.23	.13	2.69*	8.81**	2.77*	9.47**
Adjusted R^2	.08	.05	.01	-.01	0.00	-.01	.13	.14	.11	.07
Step 2										
Time 1 Personal-Intimate care	.37*		.42**		.24*		.04			-.23*
Time 1 Instrumental care	-.28*		-.14		-.02		.11			.25 ^t
Time 1 Social-Emotional care	-.08		-.07		-.23*		.04			.10
Time 1 Domestic-Household care	.09		-.16		.05		-.02			-.06
Time 1 Adjustment	.68**	.64**	.53**	.46**	.55**	.53**	.57**	.57**	.58**	.57**
Time 1 YACS Total		.03		.04		.01		.13		.08
$F(5, 66)^a / (2, 66)^b$	16.85**	16.16**	1.84**	13.60**	1.18**	1.18**	7.88**	13.29**	8.53**	14.47**
Adjusted R^2	.46	.38	.28	.19	.31	.26	.38	.40	.38	.35

Note: ^a Regression 1 predictors include 4 YACS factors; ^b Regression 2 predictors include total YACS score.

^t $p < .10$, * $p < .05$, ** $p < .01$.

Table 5

Agreement between Child and Parental Ratings on YACS at Time 1

Agreement Pair	YACS Factor	<i>n</i>	Mean Absolute Difference	% Exact Agreement	r_{wg} Mean	% with $r_{wg} < .70$
Child – MS Parent	Personal-Intimate care	124	.28	46.15	.92	7.26
	Instrumental care	124	.47	4.77	.84	14.52
	Social-Emotional care	124	.92	6.92	.65	33.06
	Domestic-Household care	124	.79	8.46	.76	22.58
	Total	124	.51	3.08	.88	8.87
Child – Healthy Parent	Personal-Intimate care	86	.27	36.92	.92	10.47
	Instrumental care	86	.57	16.92	.82	19.77
	Social-emotional care	86	.86	2.31	.70	26.74
	Domestic-Household care	86	.81	4.62	.73	26.74
	Total	86	.50	2.31	.88	11.63
MS Parent – Healthy Parent	Personal-Intimate care	48	.29	32.95	.89	10.42
	Instrumental care	48	.47	2.45	.83	20.83
	Social-emotional care	48	.87	2.27	.71	33.33
	Domestic-Household care	48	.68	4.55	.80	16.67
	Total	48	.50	0.00	.87	8.33