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Test of a Model of the Effects of Parental Illness on Youth and Family Functioning

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Abstract

Objective. Parental illness (PI) may have adverse impacts on youth and family functioning. Research in this area has suffered from the absence of a guiding comprehensive framework. This study tested a conceptual model of the effects of PI on youth and family functioning derived from the Family Ecology Framework (FEF; Pedersen & Revenson, 2005). **Methods.** A total of 85 parents with multiple sclerosis and 127 youth completed questionnaires at Time 1 and 12 months later at Time 2. **Results.** Structural equation modeling results supported the FEF with regards to physical illness disability. Specifically, the proposed mediators (role-redistribution, stress and stigma) were implicated in the processes that link parental disability to several domains of youth adjustment. The results suggest that the effects of parental depression (PD) are not mediated through these processes; rather, PD directly affects family functioning, which in turn mediates the effects onto youth adjustment. Family functioning further mediated between PD and youth wellbeing and behavioral-social difficulties. **Conclusions.** The results support the effects of PI disability on youth and family functioning via the mediational mechanisms proposed by FEF but not those of PD. Rather, PD affects youth adjustment principally via family functioning, and the effects are additive with illness disability.

Key words: parental illness, youth adjustment, family functioning, stigma, stress, caregiving

Parental illness (PI) may have adverse effects on development in youth. Although studies examining the effects of PI on youth have increased recently, research in this area remains largely undeveloped. A major impediment to research progress in this field has been the absence of a framework to guide research. This study tests a model of the effects of PI on youth and family functioning derived from the Family Ecology Framework (FEF; Pedersen & Revenson, 2005).

The FEF draws on general systems, human ecology and stress/coping theories, and describes pathways through which PI affects youth and family functioning. The FEF proposes that, PI affects family and youth functioning indirectly through individual (e.g., youth stress and stigma) and family-level (e.g., role-distribution) mediators. Although the FEF has not been fully tested, Pedersen and Revenson (2005) reviewed evidence supporting the proposed pathways. We examine all key FEF components except youth daily hassles. The model derived from the FEF tested in this study is summarized in Figure 1. The components are: PI disability, three individual-level mediators, youth stress and stigma and role-redistribution, and the outcomes, family functioning and youth adjustment. Although not included in the FEF, we also consider the additive effects of parental depression (PD) on family and youth outcomes given the co-occurrence of depression and serious illness (Turvey et al., 2009). For example, multiple sclerosis (MS) has a lifetime prevalence rate of 50% for depression (Siegert & Abernathy, 2005) and up to 59% MS parents report depression (Steck et al., 2007). PD has been viewed as exacerbating illness-related disability and interfering with parental functioning (Armistead et al., 1995). Hence, we conceptualize PI as severity of disability and depression.

We test the model on youth of a parent with MS. MS has an unpredictable course, a wide variation in symptoms and is the most common neurological disorder among young people, with onset often occurring during child rearing years. Hence, many people with MS confront disability that can interfere with parenting roles (De Judicibus & McCabe, 2004).

Each of the model components in Figure 1 is discussed below. Given that Pedersen and Revenson (2005) have reviewed research support for the pathways in Figure 1, we limit discussion of

each model component to the parental MS context given the focus of this study, and that MS was excluded from their review. First we consider the effects of PI and PD on family and youth outcomes, and then the proposed mediators of the effects of PI and PD on outcomes.

Associations between Parental Illness and Family Functioning

Increasing parental disability is likely to impair parental functioning which will place greater demands on family members. Frequently examined aspects of family functioning in the context of PI are cohesion and conflict. Youth of a parent with MS have reported higher conflict and lower cohesion than children with healthy parents (Peters & Esses, 1985), which is similar to findings in other PI contexts (e.g., Dura & Beck, 1988; Lewis et al., 1989). Although the association between PD in MS and family functioning is unexamined, families with a depressed parent have reported less cohesion and more conflict than families of non-depressed parents (e.g., Timko et al., 2002).

Associations between Parental Illness and Youth Wellbeing

Children of ill parents have been found to exhibit elevated mental health difficulties (e.g., Diareme et al., 2007; Sieh, Meijer, Oort, Visser-Meily, & Van der Leij, 2010). A 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). Specific impacts include elevated distress, interpersonal difficulties and somatization, and deficits in life satisfaction and positive affect (Pakenham & Bursnall, 2006; Yahav et al., 2005).

There is also a link between PD in MS and poorer youth adjustment. Higher PD is related to more youth problems (De Judicibus & McCabe, 2004; Diareme et al., 2007; Steck et al., 2007), which is consistent with findings in the broader literature showing that PD is a risk factor for youth behavioral and emotional problems (Beardslee, Versage, & Gladstone, 1998). Preliminary evidence suggests that PD in the context of physical illness may have both direct and indirect impacts on youth adjustment, whereas indicators of physical PI have exhibited an indirect effect on youth adjustment via family process variables (Steele, Forehand, & Armistead, 1997). We therefore test for the

presence of direct and mediated effects of PD on family and youth functioning. Possible mediators are discussed next.

Mediators of the Effects of Parental Illness on Family Functioning and Youth Adjustment

The FEF posits that three related mechanisms link PI to youth and family functioning (see Figure 1). First, greater PI disability causes an increase in youth caregiving, which in turn affects family and youth functioning. The second process is a perception of stigma associated with PI. Both of these processes also result in youth stress appraisals, again in turn leading to changes in youth and family functioning. These three processes are examined in more detail in the context of MS.

Role-redistribution. Families often meet PI demands by the redistribution of roles among family members (Stetz, Lewis, & Primomo, 1986). In this study, role-redistribution is operationalized as youth caregiving and is assessed at the individual level. Although some caregiving during childhood is normative, caregiving undertaken by children of ill parents is often exaggerated and not congruent with their age (Aldridge & Becker, 1999). For example, children of parents with MS undertake more family responsibilities than children of healthy parents (Pakenham & Bursnall, 2006; Yahav et al., 2005). Greater PI disability is related to higher caregiving in youth of a parent with MS, which in turn is associated with higher youth distress, and lower positive affect (Pakenham & Bursnall, 2006).

The ways families approach role-redistribution in the context of PI may also impact family functioning (Power & Dell Orto, 2004). Power (1985) found that families with a parent with MS that exhibited a willingness to share household responsibilities were more cohesive than families in which all members did not contribute equally. Conflict may arise when role-redistribution leads to family members feeling over-burdened by their increased responsibilities (Power & Dell Orto, 2004).

Youth Stigma. Children may experience stigma by association with a family member's disability (Bolas et al., 2007). Goffman (1963) described this as 'courtesy stigma', which occurs when stigma experienced by the person with disability is shared with family members by virtue of

their proximity. Children of a parent with illness may engage in stigma concealment (Bolas et al., 2007), which can lead to secrecy and withdrawal, which in turn may result in isolation which may interfere with developmental processes (e.g., autonomy and individuation) that are sustained by peer relations (Pakenham, 2009).

Youth Stress. Caregiving and stigma perceptions are sources of stress for youth. Greater PI disability is related to higher caregiving demands and associated appraised stress. According to stress/coping theory (Lazarus & Folkman, 1984), appraisal is an evaluative process that reflects the person's interpretation of a situation. Events are appraised with respect to how stressful they are. Higher caregiving stress appraisals were related to greater caregiving activity and poorer adjustment in a mixed sample of youth of a parent with illness (Pakenham, Chiu, Bursnall, & Cannon, 2007), and in youth of a parent with MS (Pakenham & Bursnall, 2006).

In summary, drawing on the FEF we test a model of the effects of PI on youth and family functioning. Our first aim is to test the prediction that role-redistribution, and youth stress and stigma mediate the adverse effects of PI disability on family and youth functioning. The FEF does not specify pathways for the effects of parental mental health problems that often co-occur with serious illnesses. Hence, the second aim was to examine the direct and mediated effects of PD on family and youth functioning. Given evidence indicating that PD is likely to be related to youth caregiving, stress and stigma (e.g., Champion et al, 2009), the effects of PD on family and youth functioning may also be mediated by the proposed mediators. However, preliminary evidence suggests that in the context of PI, direct effects of PD on youth adjustment are also likely (Steele et al., 1997). We therefore test for both indirect and direct effects of PD on youth and family functioning. Given that the FEF specifies bi-directional relationships between family and youth functioning, we test one possible path. Hence, the third aim was to test the prediction that family functioning will impact on youth adjustment, providing another pathway from PI to youth adjustment.

Method

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

Participants and Recruitment Procedures

Participants were parents with MS 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 permission for their children, and to indicate whether they and their partner wanted to participate in the study. On receipt of signed parental permission forms, family members were forwarded personalized information sheets, questionnaires and return envelopes.

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 databases, hence, some parents would have received 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 a parent and one or more children completed questionnaires participated; for two families only children completed questionnaires and for one family only the healthy parent and children completed questionnaires. Data from these three families were removed; 85 families including 85 parents with MS and 127

children completed questionnaires at Time 1. Time 2 questionnaires were completed by 70 parents with MS and 90 children, yielding 18% and 29% attrition rates, respectively. Missing data was managed by a full information maximum likelihood (FIML) estimation method which allows all available data to be in the analysis providing data for 127 children clustered within 85 families.

Youth mean age was 14.22 years ($SD=3.12$), 54% were female, and 31% had casual employment (variable working hours). Regarding education, 30% were in primary school, 55% secondary school, and 15% were in tertiary studies. Youth also reported a mean of 3.05 additional people living at home ($SD=1.02$; range 1-6), a mean of 2.22 siblings ($SD=0.52$; range 1-4), and most (76%) indicated that they lived in a dual parent household.

The mean age of parents with MS was 44.27 ($SD=5.24$; range 33–55) and most were mothers (84%). The mean illness duration was 8.24 years ($SD=5.79$; range 4 months – 25 years). Parents with MS were screened for severe cognitive impairment by 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 (Malec & Thompson, 1994). None of the participants reached criteria indicative of severe cognitive impairment.

Measures

Identical versions of the youth questionnaires have been piloted on 10 – 20 year olds and used in prior research on youth caregiving in Australia with all measures shown to have satisfactory reliability and validity (e.g., Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006). Questionnaires for parents with MS included questions on demographics and illness duration, and widely used measures of disease severity, cognitive impairment, disability and depression.

MS Parent Illness Variables. In the absence of objective medical markers of disability, 13 items of the 15-item Activities of Daily Living Self-Care Scale for persons with MS was used (Gulick, 1987). Two items were excluded as they were confounded with social support (i.e., “Exchange loving glances with someone special” and “Confide in someone”). The scale assesses

how frequently activities of daily living are performed. Items were rated by parents on a 6-point scale (0 *never* to 5 *always*), with higher scores indicating lower disability. The term ‘parental illness disability’ will be used here-on to refer to MS physical disability and illness severity.

PD was assessed by the depression subscale of the widely used 21-item Depression Anxiety and Stress Scale (Lovibond & Lovibond, 1995). Items were rated by parents on a 4-point scale (0 *Did not apply to me at all* to 3 *Applied to me very much or most of the time*).

Youth Stress. A single global caregiving stress appraisal item, asked youth to rate on a scale from 1 to 100 (1 *not stressful at all* to 100 *most stressful ever*) the extent to which helping their parent with MS was stressful. In the analyses stress scores were rescaled by dividing them by 10 (possible range therefore 1 to 10) due to estimation problems resulting from the much larger variance of this variable in its original scaling compared to all other variables.

Role-redistribution. The 11-item family responsibilities subscale of the Young Carer of Parents Inventory (Pakenham et al., 2006) was used to assess role-redistribution. The inventory is a self-report measure of youth’s caregiving experiences in the contest of parental illness. The family responsibilities subscale assesses the extent to which respondents contribute to family tasks (e.g., *My parent(s) relies on me to help them with household chores*). Items were rated by youth on a 5-point scale (0 *strongly disagree* to 4 *strongly agree*).

Youth Stigma. Youth perceptions of stigma related to their parent with MS were measured by a 6-item stigma scale developed by Perkins, Holburn, Deaux, Flory and Vietze (2002). This scale is based on research which suggests that stigma is most evident in social settings (Goffman, 1963), and is designed to measure associative rather than direct stigma. The scale assesses the extent to which the child is comfortable being seen in public with their parent (with MS) and how comfortable the child is to have friends around their parent (e.g., *How familiar are your friends with your parent?*). Youth rated each item on a 3-point scale (1 *a lot*, 2 *somewhat*, 3 *not at all*). Answers were averaged to create a total score, with higher scores indicating greater perception of stigma.

Youth Adjustment. Five youth adjustment domains were assessed: (1) behavioral-social difficulties, (2) pro-social behavior, (3) somatization, (4) positive affect, (5) life satisfaction.

Behavioral-social difficulties and pro-social behavior. The self-report version of the 25-item Strengths and Difficulties Questionnaire (Goodman, Meltzer, & Bailey, 1998) consists of five subscales: conduct problems, hyperactivity/inattention, peer relationship problems, emotional symptoms, and pro-social behavior. The first four subscales are summed to give a Behavioral-Social Difficulties score, whereas the pro-social behavior subscale is a measure of positive adjustment. Youth rated items on a 3-point scale (0 *not at all*, 1 *a little, sometimes*, 2 *very much, all of the time*).

Somatization. Given reports of elevated somatic complaints in children of a parent with MS, the 6-item somatization subscale of the Brief Symptom Inventory-18 (Derogatis, 2000) was used. Youth 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*). Youth 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) assessed participants' life satisfaction. Youth rated items on a 7-point scale (1 *strongly disagree* to 7 *strongly agree*).

Family Functioning. The cohesion and conflict subscales from the Family Environment Scale (Moos & Moos, 1986) were used to gauge parent perceptions of family functioning. Each scale consists of nine items, which parents indicated as either *true* or *false* for their family.

To prevent undue overlap of measures assessed at one time, parental illness disability and depression were assessed at Time 1 and were used to predict family functioning and youth adjustment assessed at Time 2. Stigma was only assessed at Time 1 and was considered to be

relatively stable (Perkins et al., 2002), whereas role redistribution and youth stress were considered more contextually sensitive (Ireland & Pakenham, 2010) and were assessed at Time 2.

Data Analysis

Given that the youth data were clustered within families, the assumption of independence of observations was broken which biases standard errors and significance tests. To correct these, a multilevel modeling approach could be employed, or correct standard errors computed directly. Multilevel modeling is appropriate when all outcomes of interest are assessed at the lowest level of clustering, which in this study was the child. As family functioning was assessed by parents to avoid over-reliance on one data source, we did not use multilevel modeling; rather, correct standard errors were computed directly employing clustered robust standard errors (Fitzmaurice, Laird & Ware, 2004), also known as Huber-White standard errors, which are robust to non-independence of observations.

Path analysis using Mplus V6.1 was employed to conduct the analyses. So as to capture positive youth adjustment, the three youth positive outcomes (positive affect, life satisfaction and pro-social behavior) were used to form a single latent factor called ‘youth wellbeing’. Parental illness disability and PD were allowed to predict the three youth mediators, which in turn were allowed to predict family functioning and youth adjustment. Family functioning was also permitted to predict youth adjustment. Following Taylor, MacKinnon and Tein (2008) direct effects were included between parental illness disability and PD on the one hand, and family and youth outcomes on the other. Parental illness disability and PD were allowed to covary, as were the errors between family conflict and cohesion, and among the youth adjustment variables.

Taylor, et al. (2008) recommend establishing mediation by bootstrapping standard errors of indirect effects or to use the joint significance test. Due to the presence of clustered data, bootstrapping standard errors was not possible. Therefore, we used the joint significance test as the primary method for establishing mediation supplemented by estimates of the indirect effects along

with statistical tests of significance using standard errors employing the delta method (Taylor, et al. 2008). As outlined in Shrout and Bolger (2002), a significant correlation between the start and end variables of a mediation chain is not necessary before indirect effects can be claimed, especially if the two measures are temporally distal as in the current study.

Given the small sample size, statistical power was a concern. A post-hoc power analysis using the results of the study as population values indicated that most paths that reached statistical significance were suitably powered (.80 to 1.00). A number of hypothesized paths that were non-significant had very low power. For example, the paths from PD to the mediators exhibited low power (< .10) as a result of the small estimates. Other estimates exhibited midrange power: specifically those from stigma to youth stress (power = .70) and from youth stress to behavioral-social difficulties (power = .58).

Results

Means, standard deviations and Pearson correlations among all variables, including child age and gender, are presented in Table 1. When interpreting results related to parental illness disability it is important to note that higher scores reflect increased mobility, that is, less disability. Child age exhibited no significant correlations and compared to boys, girls exhibited less stigma and more pro-social behavior¹.

Model fit results and modifications. The model exhibited a reasonable fit to the data (Model 1: robust $\chi^2 = 42.29$, $df = 19$, $p < .01$, CFI = .92, RMSEA = .10, SRMR = .05). While the CFI and SRMR were acceptable the RMSEA was higher than is commonly accepted, and the chi square value for the model was significant, suggesting that the model was incorrect in some part. The residuals and correlations suggested that parental illness disability did not predict the youth wellbeing factor, but was more specific in its effects, demonstrating a relationship with only life satisfaction.

¹ Attempts to include these as control variables in modeling resulted in unstable estimation and thus were dropped.

Thus, the path from parental illness disability to the youth wellbeing latent factor was dropped, and a path added from parental illness disability to life satisfaction. The model fit indices (Model 2) indicated that these changes accounted for the model misfit in its entirety (robust $\chi^2 = 23.23$, $df = 19$, $p = .23$, CFI = .99, RMSEA = .04, SRMR = .04).

Despite good model fit, two path estimates appeared to be problematic when compared to the zero order correlations. For both paths, the correlations were very small and non-significant but the standardized regression coefficients were larger than the associated correlation and both just reached statistical significance (parental illness disability to family cohesion, standardized coefficient = .25, $p = .05$, $r = .06$, $p = \text{NS}$; youth stress to family cohesion, standardized coefficient = -.22, $p = .05$, $r = -.15$, $p = \text{NS}$). These two paths were removed, and the model re-estimated (Model 3). The model was still a good fit to the data (robust $\chi^2 = 31.82$, $df = 21$, $p = .06$, CFI = .96, RMSEA = .06, SRMR = .05), although fit was slightly worse than that of model 3 (Satorra-Bentler scaled χ^2 difference = 9.47, $df = 2$, $p < .01$)². Given these final estimates overall appear more consistent with the data, these are the results reported. The coefficients and significance levels of all paths from this final model are reported in Table 2, and all significant paths are shown in Figure 2.

² To evaluate model robustness, three sensitivity tests were conducted. First, all path estimates in models 2 and 3 were compared and only small differences in estimates were observed ($< .04$ in standardized terms). The one exception was the path from youth stress to family conflict, which reduced from .52 to .39, a value more consistent with the zero order correlation ($r = .45$). Second, the results of a multiple regression predicting Time 2 family cohesion from the 5 predictors was consistent with the results of the final model. Third, we constrained the two problematic paths to two other reasonable values: to the values of the unstandardized regression coefficient estimated from the regression just discussed; and to the values of the unstandardized regression coefficient estimated from a regression with only that single predictor. In both cases, the model fit improved slightly, as would be expected, but changes to estimates of all other paths were very small and none changed the conclusions drawn in this paper.

Direct and indirect effects of parental illness disability on mediators. The final results showed that parental illness disability directly and significantly predicted increased levels of stigma and greater role-redistribution, but exhibited no direct relationship with youth stress. Rather, parental illness disability exhibited a significant indirect effect on youth stress via role-redistribution. The total indirect effect was significant (standardized indirect effect = $-.20$, $p < .01$), with the majority of the effect via role-redistribution (specific standardized indirect effect = $-.14$, $p = .02$).

Direct and indirect effects of parental illness disability on youth and family functioning. Parental illness disability exhibited no significant direct effect on family functioning, a result consistent with the correlations. An indirect effect from parental illness disability to family conflict was supported. Specifically, the joint significance test of the path from parental illness disability to role-redistribution to youth stress to family conflict was supported, and the indirect effect almost reached statistical significance (standardized indirect effect = $.05$, $p < .06$). The only direct relationship parental illness disability exhibited with youth outcomes was with life satisfaction. In support of the model, however, significant indirect effects from parental illness disability to three of the five youth outcomes were found. There was a significant total indirect effect from parental illness disability to youth wellbeing (standardized indirect effect = $.19$, $p < .01$); significant indirect effects were exhibited to two positive adjustment outcomes via the latent factor (positive affect: standardized effect = $.14$, $p = .01$; life satisfaction: Standardized effect = $.15$, $p = .01$); the indirect effect to pro-social behavior almost reached conventional significance levels (standardized effect = $.09$, $p = .06$). Two main indirect pathways were implicated in these effects: from parental illness disability via stigma to youth wellbeing, and the other via role-redistribution and youth stress to youth wellbeing. The paths from parental illness disability through role-redistribution to youth somatization were also significant, and the indirect effect itself almost reached conventional significance levels (standardized indirect effect = $.13$, $p = .06$).

Direct and indirect effects of PD on mediators and on youth and family functioning. PD was not significantly directly related to any of the mediators, but did exhibit significant direct relationships with the two family functioning domains (conflict and cohesion) and youth somatization. Further, family functioning was a significant mediator between PD and four youth adjustment outcomes. First, there was a significant indirect effect to the latent factor youth wellbeing through family cohesion (standardized indirect effect = $-.18$, $p = .03$); significant indirect effects were exhibited to all three positive adjustment outcomes via the latent factor (pro-social behavior: standardized effect = $-.08$, $p = .03$; positive affect: standardized effect = $-.14$, $p = .05$; life satisfaction: Standardized effect = $-.14$, $p = .02$). Second, family functioning (primarily family cohesion) mediated the impact of PD on youth behavioral-social difficulties (standardized indirect effect = $.15$, $p = .03$). These results suggest that the effects of PD on youth wellbeing and behavioral-social difficulties are fully mediated through family functioning, and primarily via family cohesion.

Together, these results provide support for the FEF with regards to parental physical illness disability. Specifically, the results suggest that the three mediators proposed in the FEF are implicated in the processes that link parental illness disability to youth adjustment. The results suggest that the effects of PD are not mediated through these processes; rather, PD directly affects family functioning which, in turn, affects youth adjustment outcomes.

Interactions between parental illness disability and depression. We also tested for the presence of interactions between parental illness disability and PD on the mediators and outcome variables. Only one interaction reached statistical significance, that predicting youth behavioral-social difficulties ($b = -.63$, $p = .02$). This interaction indicates that as both parental illness disability and PD increased, youth behavioral-social difficulties also increased. It should be noted that overall model fit did not improve with the addition of this one interaction; the result should be treated with some caution.

Discussion

This study tested a model derived from the FEF linking parental illness to family functioning and youth adjustment. The first aim was to test the prediction that role-redistribution, youth stress and stigma mediate the adverse effects of parental illness disability on family functioning and youth adjustment. The results of the path analysis provided support for the proposed mediating mechanisms with regards to the effects of parental illness disability on youth outcomes but not family functioning. The second aim was to examine the direct and mediated effects of PD on family and youth outcomes. Results showed that, unlike parental illness disability, the effects of PD on the outcomes were not mediated through the three mediators. Rather, PD exhibited only direct relationships with family functioning and also with youth somatization. The third aim was to test if family functioning operates as a further mediator between parental illness and youth adjustment. Results indicated that family functioning further mediated between PD and youth wellbeing and behavioral-social difficulties. The results pertaining to each of these aims are discussed in turn.

As predicted the adverse effects of parental illness disability on youth adjustment were mediated by role-redistribution, youth stress and stigma, although regarding the latter, parental illness disability exhibited an indirect effect on youth stress mainly via role-redistribution. As might be expected, the extra caregiving that youth assume when a parent has an illness is associated with stress because caregiving may compete with other activities and tax resources and coping mechanisms (East, 2010; Pakenham & Bursnall, 2006); the additional demands are appraised as stressful and this in turn affects youth adjustment. The second mediated pathway from parental illness disability was via youth stigma. Given the dearth of published research on youth stigma in the context of parental illness, the finding in this study of stigma mediating the adverse effects of parental illness disability on youth positive outcomes is noteworthy. A commonly used strategy for managing stigma is concealment (Goffman, 1963). The strain associated with managing concealment can be burdensome and lead to guardedness, shame, and impaired relationships (Goffman, 1963; Pachankis, 2007).

Regarding PD, in contrast to parental illness disability, results indicate that the adverse effects of PD on youth adjustment and family functioning are not mediated through role-redistribution, and youth stress and stigma. Instead, PD evidenced direct effects on youth somatization and on family functioning and the latter, in turn, mediated the effects on youth wellbeing and behavioral-social difficulties. These findings are similar to those of Steele et al. (1997) which showed that depression in both the ill parent and the healthy parent directly predicted youth internalizing problems in addition to a weaker indirect effect on youth adjustment via family processes. Other potential mediators of the adverse effects of PD on youth adjustment include individual-level coping factors not included in the present study. For example, Langrock, Compas, Keller, Merchant and Copeland (2002) found that youth coping strategies mediated the association between PD related stressors and youth mental health. Studies have also shown that perceptions of stress associated with PD mediate the impact of PD on child adjustment (e.g., Hammen, 2000). In the present study, caregiving stress was measured, which was more likely to have gauged the strain associated with stressors specific to parental physical disability rather than depression.

The third aim of the study was to examine the relationship between family functioning and youth adjustment, and specifically whether family functioning operated as a mediator between parental illness disability and youth adjustment. The findings indicate that family functioning mediates the adverse effects of both parental illness disability and PD on youth adjustment, which supports the key role of family processes in shaping youth adjustment (Rolland, 1999). Regarding youth adjustment outcomes, the direct link between greater role-redistribution and youth somatization is consistent with reports of the adverse effects on youth health of the physical demands of caregiving (Aldridge & Becker, 1999), and the link between PD and youth somatization is consistent with the association between PD and internalizing problems found by Steele et al. (1997). Noteworthy are the differential effects of the mediators on the various domains of youth adjustment, highlighting the need to measure multiple adjustment domains.

Findings suggest intervention at the youth, parent and or family levels. Given the mediating roles of youth stigma and stress appraisals of the adverse effects of parental illness, interventions should target these cognitive processes with strategies such as psycho-education about the illness, cognitive restructuring, and peer support. A pilot study of a residential camp for youth of a parent with MS, which incorporated these and other cognitive and behavior therapy intervention techniques, showed significant improvements across many domains including youth distress, stress appraisals, and social support (Coles, Pakenham, & Leech, 2007). Regarding parent-level intervention, flexible alternative supports for parents with illness are necessary to lessen the load placed on children. While the detrimental effects of depression in physically healthy parents on family and youth functioning have been widely reported (see review Beardslee et al., 1998), findings from the present study confirm preliminary data from other similar studies suggesting such effects are potentially complicated by the adverse effects of parental physical illness. Hence, in view of the reported inadequate assessment and treatment of depression in MS (Ghaffar & Feinstein, 2007), findings highlight the importance of clinicians routinely screening for and treating depression in parents with MS. Regarding family-level intervention, the role of family functioning as both an outcome of parental illness and a mediator of the effects of parental illness on youth adjustment underscores the need for working with the whole family in the context of parental illness.

In terms of theoretical implications of findings, this study provides important preliminary data that supports the FEF for understanding how youth adjust to parental illness. Results in the main support the effects of parental illness disability on youth and family functioning via the proposed mediational mechanisms. The adverse effects of parental illness disability occur mainly through youth appraisal processes (perceived stress and stigma). However, given the co-occurrence of depression and serious medical conditions, the FEF needs to be expanded to account for the effects of PD, which appears to affect youth and family functioning via different individual-level mediators. Findings suggest that in the context of MS, PD directly affects youth somatization, but has an

indirect effect on other areas of youth adjustment via family processes, whereas the adverse effects of parental illness disability on youth adjustment are primarily via the proposed mediators. Hence, based on the present findings future research should test a revised model of the FEF that includes the additive direct effects of PD on youth physical health, and the indirect effects on youth mental health via family processes. Future research should also investigate whether the additive effects of PD on family and youth functioning occur via different pathways when levels of PD are clinically significant. Findings also help to clarify the role of caregiving in youth adjustment to parental illness. The medical-sociological literature ascribes caregiving as the key contributing factor to youth adjustment difficulties in the context of parental illness (e.g., Aldridge & Becker, 1999). Results of this study suggest that caregiving has a direct effect on youth somatic problems, but the effects of caregiving (role-redistribution) on other youth adjustment domains are mostly indirect via stress appraisals and or family functioning.

This study has several limitations including the use of a non-random sample which restricts the generalizability of findings, the measurement of only individual-level mediators and the modest sample size. In addition, according to the FEF the mediating pathways may be affected by a range of individual (e.g., youth coping style and gender), dyadic and family (e.g., family's attachment style) and societal (e.g., cultural norms) level contextual or moderator variables not explored in this study. The significant correlations between youth gender and stigma and pro-social behavior in the present study highlight the importance of including these in further tests of the FEF. It is also possible that parental illness differentially impacts on a range of positive and negative youth outcomes, as this study shows. The stability of this pattern needs to be replicated in other samples. We therefore need to be cautious about the model modification to include the effect of parental physical disability on youth life satisfaction specifically, and not to positive youth wellbeing, and the additional constraints included in the model due to two unconvincing estimation results. Another limitation is the measurement of role-redistribution at a broad level which may have obscured the potential beneficial

effects of youth caregiving evident in other research (e.g., Ireland & Pakenham, 2010). Evidence suggests that youth caregiving in the context of parental illness is multidimensional with differential relations between caregiving domains and youth outcomes (e.g., Ireland & Pakenham, 2010; Pakenham & Cox, In press). A final limitation is that stigma was only assessed at Time 1 whereas the other mediators were assessed at Time 2. This decision was based on the view that stigma was more likely to be stable and exhibit lagged effects (Perkins et al., 2002) than the other two mediators. If this is not the case and the effect of stigma occurs over a shorter period of time, then the results may not accurately reflect the role stigma plays.

In view of these limitations, future work should capture variables more completely at both the individual and family levels, particularly with respect to role-redistribution and stigma. Studies with large samples are required to test more complex inter-relations among more FEF components not able to be explored in this study. A multilevel modeling approach which explicitly partitions family from individual level effects on youth adjustment could then be conducted. Future research should explore the FEF using other parental illnesses and samples with mixed diagnoses given that different medical conditions carry different threats or challenges.

The strengths of this study include the use of data from both parents and youth and multiple measurement points, the assessment of both positive and negative youth adjustment outcomes, the use of clustered standard errors to control for the potential lack of independence of observations due to using multiple children from some families, and the use of an analytical approach to test the multiple pathways linking parental illness, anticipated mediators, and youth and family outcomes. Regarding the latter, in a field bereft of theory driven research this study represents an important foundational advancement in the application of a conceptual framework to understanding the impact of parental illness on children. Although results support the effects of parental illness disability on youth and family functioning via the mediational mechanisms proposed by the FEF, the additive

effects of PD on youth physical and mental health occur through direct and indirect (via family functioning) pathways, respectively.

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Table 1. Means, standard deviations, correlations and internal consistency among all variables.

Variable	Mean (SD)	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Parent T1 Parental Illness Disability	4.04 (.94)	.92													
2. Parent T1 Depression	.50 (.51)	-.21*	.87												
3. Child T2 Role-Redistribution	1.24 (.82)	-.41***	.13	.88											
4. Child T1 Stigma	1.57 (.38)	-.31***	.07	.12	.68										
5. Child T2 Youth Stress	2.84 (2.76)	-.37***	.02	.44***	.28*	-									
6. Parent T2 Family Conflict	1.89 (.23)	-.10	.25*	.17	.03	.44***	.74								
7. Parent T2 Family Cohesion	1.20 (.22)	.06	-.47***	-.02	-.12	-.15	-.59***	.73							
8. Child T2 Positive Affect	3.54 (.67)	-.06	-.12	-.08	-.27*	-.34***	-.33**	.42***	.87						
9. Child T2 Life Satisfaction	5.31 (1.21)	.35***	-.27*	-.19	-.45***	-.48***	-.36***	.37***	.60***	.87					
10. Child T2 Pro-Social Behavior	1.58 (.35)	.09	-.21	.00	-.28**	-.03	-.18	.28*	.35**	.42***	.63				
11. Child T2 Behavioral - Social Difficulties	2.66 (1.36)	-.17	.19	.22*	.28*	.32***	.34**	-.37**	-.46***	-.54***	-.21*	.79			
12. Child T2 Somatization	.48 (.59)	-.30***	.37***	.36***	.15	.21*	.15	-.21*	-.07	-.29**	.02	.51***	.79		
13. Child Gender (m=1, f=2)	1.54 (.50)	.00	-.05	-.05	-.34***	.09	.12	-.08	.19	.15	.31***	-.01	.14		
14. Child Age	14.22 (3.12)	-.10	-.08	.03	.04	.10	.07	-.02	-.05	-.04	-.05	-.14	-.04	.02	

Note: * $p < .05$; ** $p < .01$; *** $p < .001$. T1 = Time 1; T2 = Time 2. Scale Cronbach alpha coefficients reported on diagonal.

Table 2. Unstandardized and standardized path estimates, *t* values, significance levels and R squared values from Model 3.

Outcome	Predictor	Unstand. Est.	<i>t</i>	Sig.	Stand. Est.	R Sq.
Child T1 Stigma	Parent T1 Illness Disability	-0.13	2.16	0.03	-0.31	.10
	Parent T1 Depression	0.01	0.10	0.91	0.01	
Child T2 Youth Stress	Child T1 Stigma	1.36	1.38	0.17	0.19	.28**
	Child T2 Role-redistribution	1.16	3.15	0.00	0.35	
	Parent T1 Illness Disability	-0.56	1.40	0.16	-0.19	
	Parent T1 Depression	-0.50	0.97	0.33	-0.09	
Child T2 Role-redistribution	Parent T1 Illness Disability	-0.36	3.89	0.00	-0.40	.17*
	Parent T1 Depression	0.07	0.54	0.59	0.04	
Parent T2 Family Conflict	Parent T1 Illness Disability	-0.01	0.43	0.67	-0.06	.21
	Parent T1 Depression	0.12	2.56	0.01	0.26	
	Child T2 Youth Stress	0.03	3.65	0.00	0.39	
	Child T1 Stigma	0.06	0.94	0.35	0.11	
	Child T2 Role-redistribution	0.01	0.46	0.65	0.05	
Parent T2 Family Cohesion	Parent T1 Illness Disability	0.00			0.00	.25*
	Parent T1 Depression	-0.21	3.48	0.00	-0.48	
	Child T2 Youth Stress	0.00			0.00	
	Child T1 Stigma	-0.06	1.19	0.24	-0.11	
	Child T2 Role-redistribution	-0.02	0.80	0.43	-0.07	
Child T2 Youth Wellbeing	Parent T1 Depression	-0.10	0.37	0.71	-0.05	.44***
	Child T1 Stigma	-0.73	2.65	0.01	-0.28	
	Child T2 Youth Stress	-0.12	2.44	0.02	-0.34	
	Child T2 Role-redistribution	0.13	1.01	0.31	0.11	
	Parent T2 Family Conflict	-0.19	0.25	0.80	-0.04	

	Parent T2 Family Cohesion	1.66	2.38	0.02	0.37	
	Parent T1 Illness Disability	0.00			0.00	
Child T2 Life Satisfaction						
	Parent T1 Illness Disability	0.38	2.91	0.01	0.28	.80**
Child T2 Somatization						.26**
	Parent T1 Depression	0.32	2.46	0.01	0.27	
	Parent T1 Illness Disability	-0.08	1.22	0.22	-0.12	
	Child T1 Stigma	0.05	0.31	0.76	0.03	
	Child T2 Stress	0.01	0.47	0.64	0.06	
	Child T2 Role-redistribution	0.18	2.13	0.03	0.26	
	Parent T2 Family Conflict	0.17	0.53	0.60	0.07	
	Parent T2 Family Cohesion	-0.26	0.73	0.47	-0.10	
Child T2 Behavioral-Social Difficulties						.26**
	Parent T1 Depression	-0.03	0.07	0.94	-0.01	
	Parent T1 Illness Disability	-0.11	0.66	0.51	-0.07	
	Child T1 Stigma	0.59	1.35	0.18	0.16	
	Child T2 Stress	0.07	0.92	0.36	0.13	
	Child T2 Role-redistribution	0.16	0.91	0.36	0.10	
	Parent T2 Family Conflict	0.60	0.76	0.45	0.10	
	Parent T2 Family Cohesion	-1.76	1.78	0.08	-0.28	
Correlations						
	Parent T1 Depression with Parent T1 Illness Disability	-0.21*				
	Child T2 Behavioral-Social Difficulties with Child T2 Youth Wellbeing	-0.45***				
	Parent T2 Family Conflict with Parent T2 Family Cohesion	-0.59***				
	Child T2 Behavioral-Social Difficulties with Child T2 Somatization	0.46***				

Note: * $p < .05$; ** $p < .01$; *** $p < .001$. T1 = Time 1; T2 = Time 2. Higher ADL scores reflect increased mobility, that is less parental illness disability.

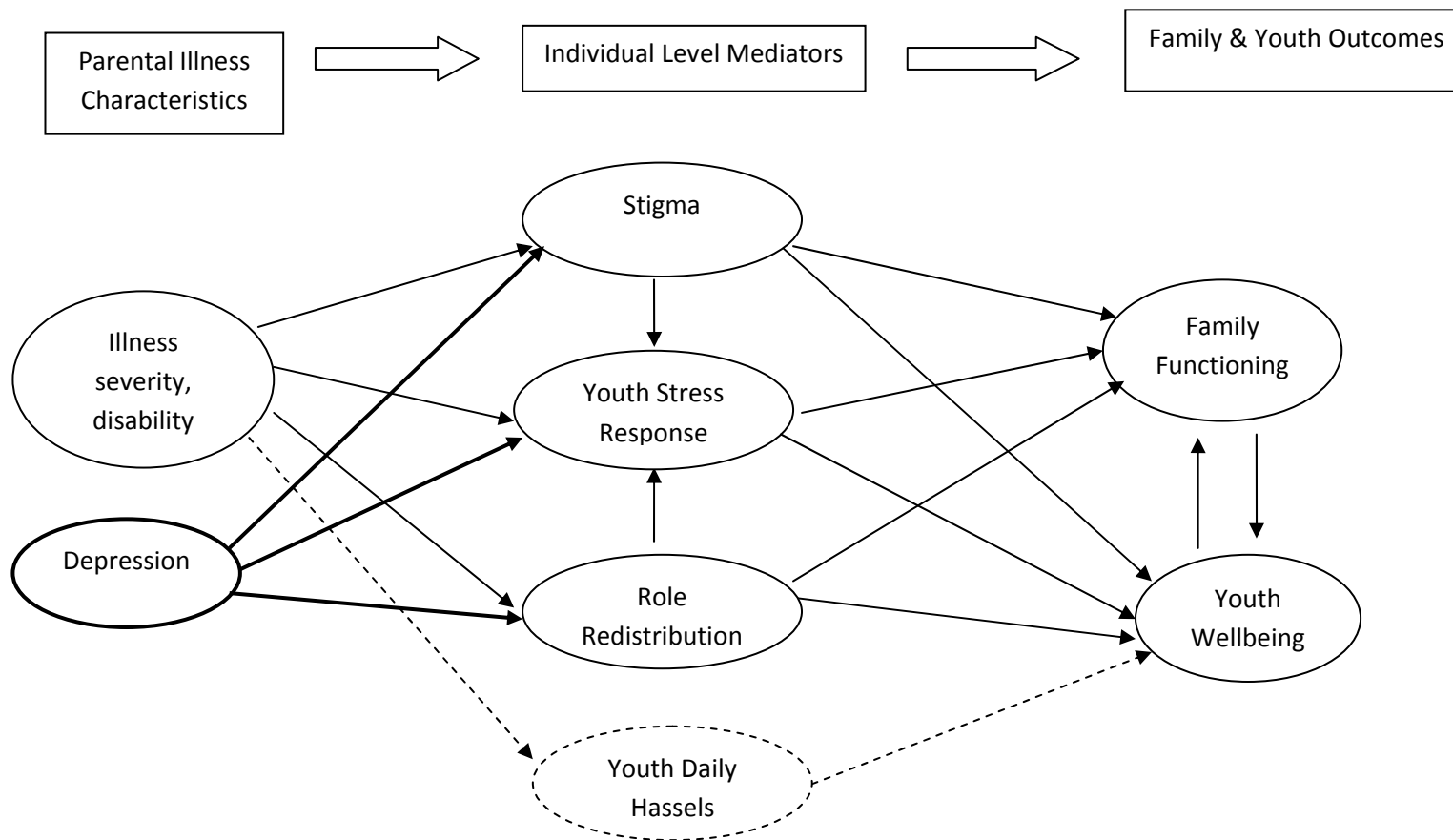


Figure 1. Family Ecology Framework (based on Pedersen & Revenson, 2005).

Note: Dotted lines and ellipse represent variable and paths in original model not tested; Bolded lines and ellipse represent variable and paths added to model.

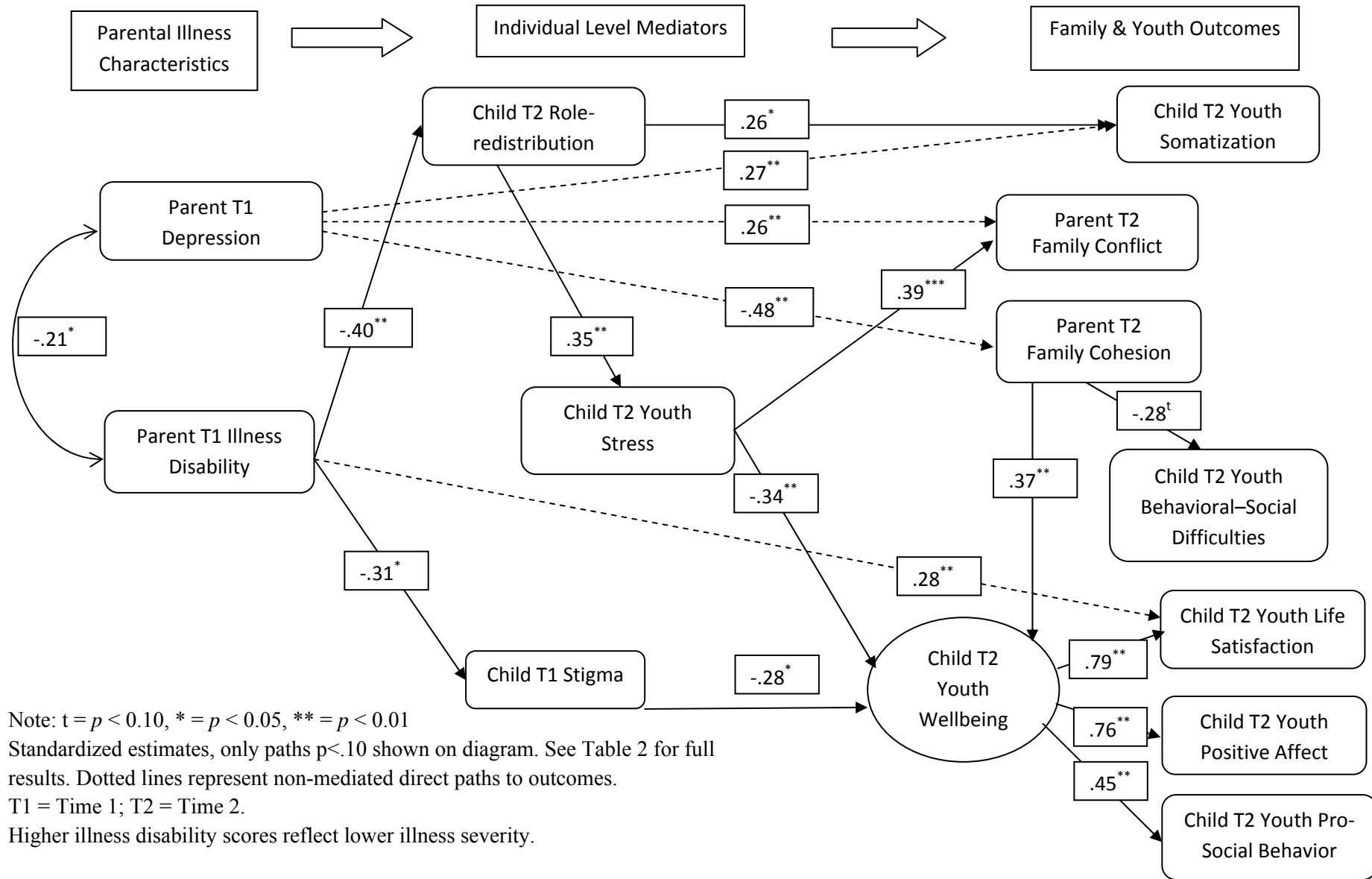


Figure 2. Significant Standardized Direct Effects From Final Model (Model 3).