The Relationship of Maternal and Child Illness Uncertainty to Child Depressive Symptomatology: A Mediation Model

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Objective To examine the relationship of parent and child ratings of illness uncertainty to depressive symptomatology in children with a chronic illness using a mediational model framework.

Method Mother–child dyads (N = 103 pairs) each completed measures of perceived illness uncertainty, while youth also completed a measure of depressive symptomatology. Results Maternal uncertainty was directly related to child depressive symptoms; however, this relationship was mediated by child uncertainty. Conclusion It would appear that a key mechanism by which parent-related uncertainty influences child depressive symptoms is through child uncertainty, underscoring the importance of examining cognitive appraisal variables and means of transmission in parent–child interactions.

Key words adjustment; chronic illness; psychosocial functioning.

Introduction

It is well established that child adjustment to pediatric chronic illness does not occur in a vacuum; rather, contemporary models of child adjustment posit that adjustment is an interrelated and bidirectional process among the child and his/her family (e.g., Kazak, Rourke, & Navsaria, 2009; Thompson, Gustafson, Gil, Kinney, & Spock, 1999). Theoretically, the relative degree of adjustment is hypothesized to come from a combination of factors, including demographic variables (e.g., ethnicity, socioeconomic status), disease characteristics (e.g., duration of illness, severity), and parent and child variables (e.g., maladaptive cognitions, distress), each of which can exert an effect on the entire family system. Although studies have documented the important influence of demographic and disease-related variables (e.g., Gee, Abbott, Conway, Etherington, & Webb, 2003; Kupst & Schulman, 1988), research has also begun to delineate the contribution that parent and child cognitive variables make in predicting adjustment outcomes (e.g., Anthony, Gil, & Schanberg, 2003; Colletti et al., 2008; Power, Dahlquist, Thompson, & Warren, 2003).

One such cognitive variable is illness uncertainty (e.g., Mullins et al., 2001; Steele, Aylward, Jensen, & Wu, 2009). Illness uncertainty has been defined as a cognitive appraisal context that occurs when the meaning of illness-related events is unclear, outcomes are unpredictable, and there is a lack of information or cues (e.g., Jessop & Stein, 1985; Mishel, 1984, 1990; also see Mast, 1995 for an extensive review of this construct). Many chronic illnesses are by their very nature unpredictable and highly variable in their course and involve complex, intrusive, and often painful treatment regimens. As such, heightened levels of perceived uncertainty are likely to develop for many children and their parents.

Indeed, the extant chronic illness literature indicates that perceived illness uncertainty is a highly consistent, robust predictor of adjustment for both children and parents.
across a range of populations, including asthma, type 1 diabetes, cystic fibrosis, and cancer (for a comprehensive review see Stewart & Mishel, 2000). Specifically, researchers found that increased levels of illness uncertainty were associated with increased psychological distress in older adolescents and young adults with asthma (Mullins, Chaney, Pace, & Hartman, 1997), in adolescents newly diagnosed with cancer (Neville, 1998), children and adolescents with solid organ transplants (Maikranz, Steele, Dreyer, Stratman, & Bovaird, 2007; Steele et al., 2009), in adolescents with type 1 diabetes (Hoff, Mullins, Chaney, Hartman, & Domek, 2002), and in a mixed sample of children with chronic conditions including type 1 diabetes, asthma, cystic fibrosis, cancer, sickle cell disease, and juvenile rheumatic disease (Pai et al., 2007). Likewise, parents of children with various chronic illnesses often report high levels of illness uncertainty during the prediagnostic, treatment, and posttreatment phases of the child’s illness (Horner, 1997; Turner, Tomlinson, & Harbaugh, 1990) and are particularly affected by the cumulative exposure to multiple and prolonged uncertain illness situations (Tomlinson, Kirschbaum, Harbaugh, & Anderson, 1996).

In addition to the robust association between illness uncertainty and psychological adjustment in youth with a chronic illness, this cognitive appraisal variable has been found to be related to health behaviors. For example, in a sample of pediatric liver and renal transplant patients, Maikranz et al. (2007) found that higher levels of illness uncertainty were related to higher depression and anxiety scores and that depression mediated the relation between illness uncertainty and medical regimen adherence (e.g., self-report and electronic monitoring). Likewise, youth- and parent-reported illness uncertainty have been found to be related to parent-reported youth adaptive functioning (e.g., daily living, functional communication, adaptability, leadership, and social skills) in a sample of liver and renal transplant patients (Steele et al., 2009). Accordingly, determining the level of illness uncertainty experienced by youth has also been recommended as a potentially useful clinical tool in determining the risk of nonadherence and poor health outcomes (e.g., acute rejection or loss of the transplanted organ). These findings suggest that illness uncertainty is a clinically meaningful and an important cognitive appraisal for both parents and children in the context of a chronic illness.

Although the salience of illness uncertainty for both parents and children with a chronic illness is clear and evidence for the role of illness uncertainty as a cognitive appraisal mechanism that directly influences discrete markers of distress is accumulating, little is understood about specific transactional relationships of illness uncertainty. Previous research has demonstrated that parental and child uncertainty can indeed be interrelated (Steele et al., 1997); however, the mechanism of how parental uncertainty may influence child distress is unclear. For example, in the few papers that examined the relationship between parental uncertainty and child depression, both Steele et al. (2009) and Maikranz et al. (2007) found that parental uncertainty did not significantly predict child depression in youth who had undergone organ transplants. Notably, however, these studies included child uncertainty when modeling the relationship of parental uncertainty to child depression. Therefore, questions remain with regard to the precise transactional relationship of parental and child uncertainty to child distress. Specifically, given that other parental cognitive appraisal variables have been found to be related to child distress (Mullins et al., 2007) and that Steele et al. (2009) and Maikranz et al. (2007) did not report on the direct relationship between parental uncertainty and child uncertainty, it follows that parental uncertainty may indeed have a direct effect on child distress. Moreover, the lack of a relationship between parental uncertainty and child distress when child uncertainty is included in a model (Maikranz et al., 2007; Steele et al., 2009) suggests that child uncertainty potentially functions as a key mediating variable in this transactional relationship.

Therefore, the purpose of the current study was to further examine the transactional relationship between maternal and child uncertainty and child depressive symptomatology in a sample of children (8- to 12-years old) using several pediatric illness groups. Given that van Dongen-Melman et al. (1995) have documented that parental uncertainty is a hallmark characteristic of serious childhood illness regardless of the characteristics of the specific illness, and that this is the first study to address these specific relationships, a noncategorical approach (Perrin et al., 1993; Stein & Jessop, 1982) was adopted in order to generate findings that may be generalizable to a broad range of chronic illnesses. In doing so, we hoped to ascertain whether illness uncertainty, a construct strongly linked to the chronic illness experience, could be identified as a potential predictor of child distress. Building on previous studies (Maikranz et al., 2007; Steele et al., 2009), it was hypothesized that the relationship between maternal illness uncertainty and child depression would be mediated by child illness uncertainty. In this regard, we propose that the mechanism through which maternal uncertainty serves to influence child depressive symptoms is child uncertainty.
Method

Participants

The current study included 103 mother–child dyads. Participants were children who had been diagnosed with a chronic illness, were between 8 and 12 years of age, and had a parent/caregiver willing to participate and provide consent. Children who evidenced a level of cognitive functioning that precluded them from understanding the questionnaires were excluded from the study. Due to the small number of fathers recruited for the study, they were excluded from the analyses. The child participants were diagnosed with either type 1 diabetes (n = 43), asthma (n = 45), or cystic fibrosis (n = 15). Please see Table I for a description of the demographic characteristics for the sample. Notably, there were no differences between illness groups on mother’s age, child’s age, family income, maternal rating of how well the child was coping with his/her illness, maternal uncertainty, child uncertainty, or child depression. The only significant differences were that children with diabetes were diagnosed later than children with the other illness groups and therefore had been living with the disease for less time. However, neither disease duration nor age at diagnosis was related to any of the model variables. The ethnic breakdown of the current sample is consistent with the ethnic distribution of the geographic region in which this study was conducted.

Procedure

Participants were recruited through several different clinics in the Southwestern USA. Eligible families who met the study inclusion criteria were first identified by a clinic physician. Next, only eligible families were sent a solicitation letter describing the purpose of the study as well as a return postcard on which they could indicate their interest in participating. Families who expressed interest were mailed consent and assent forms, questionnaire packets, and self-addressed, stamped envelopes. After the packets were mailed, a trained graduate research assistant called the families to ensure receipt of the packet, to determine if the family had any questions, and to encourage the family members to complete their questionnaires independently. Those families who returned completed consent/assent forms and questionnaires were sent back a thank you letter and $10.00 gift certificate. All procedures were approved by the university Institutional Review Board and were in compliance with the ethical standards of the American Psychological Association. Approximately 92% of the parents who received solicitation letters agreed to participate in the study, and of those parents, 78% completed their packets of questionnaires.

Instruments

Demographic Information

A questionnaire was completed by mothers in order to obtain the following information: gender, race, marital status, annual household income, child’s diagnosis, and date of diagnosis. This form also included items that screened for mental retardation or other developmental/learning disabilities that would interfere with the child’s ability to read and understand any questionnaires. The child’s diagnosis and date of diagnosis were confirmed with the information that was provided by the physician during the initial recruitment procedure in which patients who met eligibility criteria for the current study were identified. The child’s duration of illness was calculated by subtracting the date of diagnosis from the date of participation.

Children’s Depression Inventory

The Children’s Depression Inventory (CDI; Kovacs, 1992) is a 27-item, self-report measure. The CDI consists of five factors, including negative mood, interpersonal problems, ineffectiveness, anhedonia, and negative self-esteem, as well as a summary score. For the purposes of the current study, the summary score was used as the outcome variable. The CDI has a good internal consistency reliability in the normative sample (α = .86) and a 2–4 week test–retest reliability ranging from .38 to .87. The wide use of the CDI has also been well established through a variety of techniques (Kovacs, 2003). Cronbach’s α in the current sample was .85.
Mishel Uncertainty in Illness Scales—Parents

The Mishel Uncertainty in Illness Scales—Parents (PUIS; Mishel, 1983) is a 31-item, parent-report measure of their uncertainty about their child’s illness. Items include questions such as: “I don’t know what is wrong with my child,” “My child’s treatment is too complex to figure out,” and “The results of my child’s tests are inconsistent.” Respondents are asked to respond on a 5-point scale ranging from (1) “strongly disagree” to (5) “strongly agree.” The measure consists of four factors, including ambiguity, lack of clarity, lack of information, and unpredictability, as well as a summary score (which was used in the current study). The PUIS has high internal consistency (α = .91; Mishel, 1983). Cronbach’s α in the current sample was .88.

Child Illness Uncertainty Scale

The Child Illness Uncertainty Scale (CUIS; Mullins & Hartman, 1995) is a 23-item, self-report measure of the child’s perceived uncertainty about the course, prognosis, and treatment of their illness. The CUIS is an adapted version of the Mishel Uncertainty in Illness Scale—Community Form (Mishel, 1983), which was altered to be developmentally appropriate for children and adolescents and is designed to be used across multiple illness groups. The CUIS addresses four components of illness uncertainty: ambiguity, lack of clarity, lack of information, and unpredictability. Items include questions such as: “I don’t know if my illness is getting better or worse,” “My treatment is hard to figure out,” and “I never know how I will feel, I have good days and bad days.” Respondents are asked to respond on a 5-point scale ranging from (1) “very true” to (5) “very false.” A CUIS total score of illness uncertainty is obtained by summing across all items, with higher scores indicating higher levels of uncertainty. The CUIS showed good internal consistency across illness groups and in children as young as 7 years of age (α = .87; Hartman, Mullins, Hoff, & Chaney, 2001; Pai et al., 2007; Steele et al., 2009). Reliability analyses for the measure for the current study revealed good internal consistency (α = .87).

Overview of Analyses

Please see Table II for descriptive statistics for all variables. Meditational analyses were conducted using regression to determine if child uncertainty mediated the relation between maternal uncertainty and child depressive symptoms following previously published guidelines (i.e., Baron & Kenny, 1986; Holmbeck, 1997). First, the direct relation between maternal uncertainty and child depressive symptoms was examined. Next, the association of maternal uncertainty and child uncertainty was analyzed. Then, the relation between child uncertainty and child depressive symptoms was investigated. Finally, the association of maternal uncertainty and child depressive symptoms was analyzed while simultaneously controlling for child uncertainty. Because the hypothesized meditational relation was found, planned post hoc probes of the indirect effect of child uncertainty on the maternal uncertainty to child depressive symptoms relation were conducted using bootstrapping (MacKinnon, Lockwood, Hoffmann, West, & Sheets, 2002). Bootstrapping has been identified as a preferred alternative to the traditional Sobel test because it offers increased power which is especially important when using modest sample sizes (MacKinnon et al., 2002; Preacher & Hayes, 2004). The indirect effect was created by using resampling with replacement to estimate 5,000 samples of the indirect effect that were derived from the original sample (Preacher & Hayes, 2004). The indirect effect was classified as being significantly different from zero if the 95% confidence interval (95% CI) of the indirect effect does not include zero.

Results

Regression analyses revealed a significant direct relation between maternal uncertainty and child depressive symptoms [β = .23, t(101) = 2.39, p = .019] such that higher levels of maternal uncertainty were related to higher levels of child depressive symptoms. Next, a significant relation between maternal uncertainty and child uncertainty [β = .38, t(101) = 4.17, p < .001] was found, such that higher maternal uncertainty was related to higher child uncertainty. Analyses also demonstrated a significant relation between child uncertainty and child depressive symptoms [β = .53, t(101) = 6.33, p < .001] such that greater child uncertainty was associated with greater child depressive symptoms. Finally, after controlling for child uncertainty, maternal uncertainty was found to no longer be significantly related to child depressive symptoms [β = .03, t(101) = 0.34, p > .05] thereby indicating that child uncertainty mediated the relation of maternal uncertainty to child depressive symptoms. Planned post hoc bootstrapping analyses revealed a significant indirect effect indicating that child uncertainty mediated the relation of maternal uncertainty to child depressive symptoms.

### Table II. Descriptive Statistics of Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>M (SD)</th>
<th>Possible range</th>
<th>Observed range</th>
</tr>
</thead>
<tbody>
<tr>
<td>PUIS</td>
<td>67.30 (15.53)</td>
<td>31–155</td>
<td>33–110</td>
</tr>
<tr>
<td>CUIS</td>
<td>59.63 (13.32)</td>
<td>23–115</td>
<td>23–97</td>
</tr>
<tr>
<td>CDI</td>
<td>6.12 (5.89)</td>
<td>0–54</td>
<td>0–32</td>
</tr>
</tbody>
</table>

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Discussion

The current study contributes to the existing literature in pediatric chronic illness by demonstrating transactional relationships between maternal uncertainty, child uncertainty, and child depressive symptoms. This study demonstrated for the first time that maternal uncertainty was directly linked to child depressive symptoms, which in turn was mediated by child uncertainty. Consistent with previous studies, these findings provide further evidence that uncertainty is an important illness-related cognitive mechanism that acts transactionally and influences depressive symptoms (Maikranz et al., 2007; Steele et al., 2009). Extending previous findings, this study also highlights the salience of transactional uncertainty–distress relationships across multiple pediatric chronic illness groups.

While the exact mechanism by which parental uncertainty is transmitted to children in the context of pediatric illness is not explicitly known, a number of possibilities exist. Although speculative, it is suggested that the transmission of uncertainty may be a result of parenting behavior that inadvertently occurs secondary to a parent’s heightened level of uncertainty. For example, in cases when parents are experiencing uncertainty, they may expose the child to conversations that reflect a lack of knowledge of illness outcomes, perceived noncontingency between treatment efforts and illness course, and dissatisfaction with care from medical personnel. Such communications may contribute to an increased sense of uncertainty on the part of the child, eventually culminating in an increased experience of distress, specifically depressive symptoms (Steele et al., 2009). Other literature suggests that when parents are experiencing heightened levels of uncertainty, they are at risk for feeling insecure about their ability to parent (Stewart & Mishel, 2000). This insecurity may negatively affect a parent’s ability to make decisions that are in their child’s best interest (Shewchuk, 1995) or can exacerbate the distress related to making urgent decisions regarding their child’s treatment (Stewart & Mishel, 2000). Furthermore, parents who are feeling insecure about their ability to make a decision regarding the child’s treatment may be modeling a sense of uncertainty, which can result in the child’s uncertainty increasing and subsequent psychological distress (Bandura, 1976).

Alternatively, it may be that uncertainty on the part of the parent may influence the manner in which a parent interacts with their child in other ways. Previous research has suggested that parenting capacity variables, specifically parenting stress, overprotection, and perceptions of vulnerability are linked to uncertainty on the part of children with a chronic health condition (Holmbeck et al., 2002; Mullins et al., 2007). Indeed, to the extent that a child is restricted in their activities by a parent due to the perception that they are fragile, a diminished sense of autonomy and internalizing symptoms may result. Specifically, when parents either directly or indirectly communicate to their children that they cannot perform certain activities, that they are different from other children, and that the parent worries excessively for them, increased distress and anxiety on the part of the child may result (Eiser, Eiser, & Greco, 2004; Ungar, 2009). This type of “miscarried helping” on the part of the parent could be yet another mechanism that ultimately contributes to increased uncertainty.

Particular strengths of this study are that it clearly differentiates parent and child uncertainty, includes a measure of child-reported depression, uses a relatively restricted age range, and includes several chronic illness groups. It is noted that although adopting a noncategorical approach may increase the generalizability of the current findings, disease-specific implications are not known.
Certainly, the current study is limited by its correlational nature and what may be considered a relatively small sample size. In addition, similar to many studies of parent–child interaction, this study only includes mothers and while some research suggests that mother–child, and father–child dyads respond similarly, others suggest they respond to their child’s illness quite differently (Chaney et al., 1997; Holmbeck et al., 1997; Robinson, Gerhardt, Vannatta, & Noll, 2007; Santrock, 2008). Although not confirmed through direct observation, every effort was made to ensure family members completed their measures independently. Other variables which could have influenced the child distress outcomes (e.g., maternal depression, illness severity) were not assessed in the current study. Finally, health behavior outcomes were not measured in the current study.

Although the correlational nature of this study cautions against causal explanations, the results have important clinical implications. The current study suggests that concentrating clinical efforts on reducing maternal uncertainty may prevent downstream child depressive symptoms. Notably, Hoff et al. (2005) developed an effective intervention to help ameliorate uncertainty in sample of parents with children newly diagnosed with type 1 diabetes. Therefore, clinicians may be well served to use components of this intervention to reduce maternal uncertainty by normalizing the ambiguity surrounding chronic illness symptoms and disease course, working on problem solving skills, and discussing methods to appropriately communicate with medical personnel. The indirect relationship between maternal uncertainty and child depression suggests that child uncertainty should also be a target for clinical intervention. Child uncertainty may be reduced by ensuring that children receive education about their illness, symptoms, and course. Additionally, although not studied in the current project, it is possible that heightened levels of uncertainty are related to other types of distress, including anxiety and somatization (Stewart & Mishel, 2000). Reducing a child’s level of uncertainty may therefore have the potential to positively affect aspects of child distress beyond depression. Finally, although the specific mechanisms by which maternal uncertainty is communicated to children are unknown, it may be beneficial for clinicians to target this transactional process by openly discussing the causes and symptoms of illness uncertainty with both the parent and child.

In addition to clinical implications, the current data are indeed suggestive of directions for future research, including tracking the uncertainty–distress interrelationship in longitudinal fashion in a larger sample. This study also brings to the forefront the potential generalizability of the uncertainty construct across chronic illness groups. Future studies are needed in different populations of children and their parents to identify potential illness-specific factors that may influence perceptions of uncertainty. Research determining the relation between paternal uncertainty, child uncertainty, and child adjustment should also be an aim for future research. In addition, research is certainly needed that more carefully examines the specific nature of the transactions taking place between parents and their children that contribute to child perceptions of uncertainty and subsequently depressive symptoms. Studies examining whether similar indirect effects are found in relation to other symptomatology (e.g., anxiety) also appear warranted. Although this study examined a relatively restricted age range (e.g., 8- to 12-year-olds), it will be important to determine the degree to which, and the process by which, parental uncertainty influences adolescent uncertainty. Given the importance of health behaviors as a downstream outcome, future research should incorporate such measures (Maikranz et al., 2007). Finally, intervention studies are needed to demonstrate the extent to which changes in illness uncertainty serve as an active mechanism of intervention outcomes. Specifically, uncertainty has been found to be directly (Maikranz et al., 2007), as well as indirectly, related to medical adherence through its relation with depression or psychopathology (e.g., McGrady, Laffel, Drotar, Repaske, & Hood, 2009; Shaw, Palmer, Blasey, & Sarwal, 2003). Thus, interventions teaching families to manage illness uncertainty could ultimately improve medical regimen adherence.

Acknowledgments

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Conflicts of interest: None declared.

References


