



Parent Adaptation and Family Functioning in Relation to Narratives of Children With Chronic Illness

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Background: This study assessed the experience of parents who have a child diagnosed with chronic illness and whether children's narratives mirror these experiences. **Method:** A total of 66 parents completed assessments about adaptation and family functioning. Children with type 1 diabetes or asthma participated in a story-stem narrative task. **Results:** Forty-one percent of parents were unresolved about their child's diagnosis, regardless of time since diagnosis. Unresolved parents reported lower family functioning, and children in these families had more family conflict themes. **Conclusions:** Parental/Child narratives may provide unique insights into family adjustment. Future work may consider interventions related to family communication and expression of emotion.

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TYPE 1 DIABETES AND asthma represent two of the most common childhood illnesses. Burdens associated with managing these two illnesses may be difficult for families when a young child is diagnosed. In fact, there is some evidence that early age of diagnosis is associated with poor adherence and later psychological problems (Goldston, Kovacs, Obrosky, & Iyengar, 1995). Young children require more assistance from parents to manage medications and may not recognize symptoms of an asthma attack or hypoglycemia (e.g., Hatton, Canam, Thorne, & Hughes, 1995). Given these increased demands, it is understandable that parents are at risk for psychological distress and poor family functioning. Little is known in the pediatric literature about young children's perceptions of family functioning, due in part to a lack of appropriate measures for this age group. Children's narratives have provided information about how they perceive family relationships (Shamir, Schudlich, & Cummings, 2001); however, narratives are not commonly used with chronically

ill children. The current study uses a story-stem technique as a way to understand young children's representations of family functioning.

Previous work interviewing parents about their child's illness has provided insight into the process of coming to terms with and accepting the diagnosis. "Resolving" their child's diagnosis can be difficult for some parents, yet it has considerable consequences for the well being of the family system. According to Pianta and Marvin (1993), having an ill child may be perceived as a threat that disrupts existing parental representations of attachment/caregiving. Resolution is the process of integrating information and emotion in a way that allows parents to adapt to the diagnosis and reorganize caregiving behaviors (Pianta, Marvin, Britner, & Borowitz, 1996) that can promote parent-child relationships (Marvin & Pianta, 1996). Resolved parents have moved on from the grieving process and acknowledge a change in intensity of the emotional response over time. Unresolved parents may appear stuck in a pattern of grieving over the diagnosis and adopt a coping style that could fuel ongoing feelings of distress and preoccupation with possible causes

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for the illness (Pianta & Marvin, 1993). More recent studies have described a process similar to Marvin and Pianta's initial ideas of resolution and reaction to diagnosis (e.g., Bowes, Lowes, Warner, & Gregory, 2009; Trollvik & Severinsson, 2004; Yeh, 2003).

Various studies have been conducted on maternal reaction to diagnosis to several disorders (e.g., cerebral palsy, epilepsy, and phenylketonuria (PKU) and found that unresolved mothers reported more stress and lower marital satisfaction (Lord, Ungerer, & Wastell, 2008; Sheeran, Marvin, & Pianta, 1997). Additionally, evidence suggests that quality of the parent-child relationship may distinguish resolution status (Feniger-Schaal & Oppenheim, 2013; Kearney, Britner, Farrell, & Robinson, 2011) and that unresolved mothers are more likely to have children with insecure attachments to them (Barnett et al., 2006). One factor not contributing to resolution in the studies above has been time since diagnosis, suggesting that resolution may be a coping style that parents have in relation to stress. The current study builds upon previous work by looking at parental psychological distress and family functioning in resolved/unresolved parents.

In addition to parents' reaction to diagnosis, tapping into a child's internal working model (or schema) of close relationships may expand our understanding of how children with illness perceive their families. Early on, children have the capacity to construct a narrative that is an appraisal of their world. Narratives contain the meaning or representation that the child ascribes to certain experiences (Oppenheim, 2006), as well as feelings about relationships with others (Emde, 2003). Story stem methods have demonstrated considerable validity in this regard through investigations with normative samples (Oppenheim, 2006) and children having known behavioral illnesses (Holmberg, Robinson, Wiener, & Corbitt-Price, 2007; Robinson, 2007). Children's family representations have also been investigated and demonstrated associations between marital conflict, elevated parental distress, and children's negative representations of family relationships (Davies & Cummings, 1998; Shamir et al., 2001).

In the current study, we theorize that chronically ill children's experiences with their parents may give rise to representations about how their parents approach illness management (i.e., through closeness, warmth, and care or through distress, anger, and conflict). We identified asthma and type 1 diabetes because of their high incidence among young children and because they require significant adaptations to family life. Young children with these illnesses present symptoms that may be alarming, suggesting a threat to life, and require prompt coping and symptom management on the part of parents. We anticipated the illnesses to be more similar than different on our study variables and examined this issue in preliminary analyses. We hypothesize that, independent of illness severity and time since diagnosis, parents who lack resolution about the diagnosis will report greater psychological distress and lower family functioning than parents who are resolved. Addition-

ally, we hypothesize that children of unresolved parents will experience more distressed parents and will tell narratives that include less frequent representations of cohesiveness and care and more family conflict than children of parents who are resolved.

Method

Participants

Participants included 66 children (37 with diabetes, 29 with asthma) and their parents (66 mothers, 43 fathers). Child mean age was 6.8 years ($SD = 1.01$; range = 5–8 years). The sample included children who were White (76%), Hispanic (11%), Black (7%), and biracial (6%), according to parent report. Means and standard deviations of family and illness characteristics can be found in Table 1. The diabetes and asthma groups were similar on most demographic variables except for marital status ($p = .04$) and child gender ($p = .05$).

Table 1 Demographic Characteristics between Illness Groups.

	Diabetes ($n = 37$)	Asthma ($n = 29$)	p
Family race/ethnicity			.68
White	29 (78%)	21 (72%)	
Hispanic	3 (8%)	4 (14%)	
Black	2 (5%)	3 (10%)	
Biracial	3 (8%)	1 (3%)	
Mean age mother (SD)	38 (6)	38 (8)	.91
Mean age father (SD)	43 (6)	41 (8)	.52
Education			.73
12th grade or less	20 (54%)	13 (44%)	
Associate's degree	2 (5%)	3 (10%)	
College degree	6 (16%)	7 (24%)	
Graduate school	9 (24%)	4 (21%)	
Income			.37
<\$40,000	9 (24%)	9 (29%)	
\$40,000–\$60,000	8 (20%)	6 (21%)	
\$60,000–\$80,000	4 (11%)	0	
>\$80,000	16 (43%)	14 (48%)	
Marital status			.04
Married	31 (83%)	19 (66%)	
Not married	1 (3%)	7 (24%)	
Divorced	5 (13%)	3 (10%)	
Child mean age (SD)	6.8 (1.13)	6.6 (1.04)	.47
Child gender (% male)	15 (40%)	19 (65%)	.05
Median time since diagnosis	18–24	24–36	.17
	months	months	
Illness severity (0 to 3 scale)	1.62 (.95)	1.37 (.82)	.28
Mean hospitalizations in past year	.48 (.90)	.51 (.94)	.89

Children were recruited from a children's hospital in the northeast, USA, and pediatric offices in the same area. Inclusion criteria included: (a) primary caregiver(s) and children, ages 5 to 8 years, with type 1 diabetes or moderate–severe asthma, (b) child illness duration of 3 months to 5 years, (c) no other chronic medical condition, (d) no siblings with a chronic medical condition, and (e) English speaking. In total, 133 caregivers were recruited to be in the study (seven were not interested, 34 could not be contacted, and 26 were ineligible).

Procedures

The principal investigator contacted interested families to screen and schedule for data collection. During the home visit, the principal investigator administered the story-stem battery while a trained research assistant collected information from parents. Mothers completed the reaction to diagnosis interview in all but one instance in which one father was the primary caregiver. Child and parent interviews were videotaped for coding, and parents were given a \$25 gift card for participating. All procedures were in compliance with institutional review board procedures.

Measures

Demographic and Illness History

A demographic measure was created for this study. Parents reported on basic demographics and their child's illness severity.

Parental Narratives

The Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1993) was administered to assess parent's feelings/thoughts about their child's diagnosis. The interview can be found in Pianta et al. (1996). The RDI classifies a parent's resolution to their child's diagnosis as either resolved/unresolved. To be classified as resolved, an individual must indicate a change in feelings since their child's diagnosis that suggests that they have moved on from the trauma or disorganization that often occurs at diagnosis. They may express a period of mourning/distress, but have moved on and able to focus on their child's needs. They are oriented toward the present and future. Unresolved mothers talk about little change in thoughts/feelings since diagnosis and are preoccupied with their emotional response to the news; others may be emotionally cut off from the experience. Lack of resolution may also be characterized by unrealistic beliefs about their child, and parents may continue to be preoccupied with why this happened.

Two coders independently rated each interview to determine resolution status. In the current study, the principal investigator and a research assistant who was not involved with administration were trained on the RDI coding using training tapes provided by the interviews' developers. Both

raters independently coded all 66 RDIs (82% agreement; $\kappa = .64$; $p < .001$). Consensus was reached for the discrepancies by the two coders.

Parental Psychological Adjustment

Parental adjustment was assessed using the Brief Symptom Inventory (BSI; Derogatis, 1993). The BSI is a 53-item self-report measure of psychological distress with respect to nine symptom dimensions. The BSI has demonstrated validity and reliability (Derogatis & Melisaratos, 1983). The Global Severity Index was used in this study ($\alpha = .95$).

Family Adjustment

Parents completed The Family Environment Scale (FES; Moos & Moos, 2009) to assess family functioning. In the current study, family cohesion, expressiveness, and conflict subscales were used. Internal consistency ($\alpha = .61-.78$) and test–retest reliability ($r = .68-.86$) have been reported (Moos & Moos, 2009).

Children's Narratives

Children in this study were asked to complete eight stories; six were drawn from the MacArthur Story Stem Battery (MSSB) (Bretherton & Oppenheim, 2003), one from Shamir et al. (2001), and one created for this study. The stories focus on everyday emotional challenges within a family, including mishaps, injury, disobedience, and arguments. After enacting the dramatic high point of the stem, the examiner asks the child, "show me and tell me what happens next." Dolls, toys and props relevant to the stem were used to introduce the story.

Content codes used in this study were drawn from the MacArthur Narrative Coding Manual (Robinson et al., 2004) and Warren's (2003) narrative emotion codes. Two aggregate constructs were created to increase reliability among several theoretically similar content codes that assess children's representations of family dynamics. Family cohesion was comprised of: unified parent role, empathy/helping, disciplining/maturity demands, conflict resolution, and positive/neutral narrative ending. Internal consistency reliability for family cohesion was .63.

A family conflict construct was comprised of blaming, shaming, child power (e.g., child tells parents how to behave), and continuing/escalating danger. Internal consistency reliability for the family conflict subscale was .45. The low reliability is likely due to the infrequent occurrence of any single code across stories.

Story responses were scored by an independent coder who was an advanced graduate student who was blind to illness group. The first author of the MSSB coding manual trained the coder on a previous dataset and scored 10 tapes from the current project, which served as reliability. Intraclass correlation reliability coefficient for family cohesion was .75 and for family conflict .80.

Data Analysis Plan

Descriptive analyses were calculated for study variables. Prior to main analyses, differences between the illness groups were conducted to determine if the groups could be combined. Because the illness groups did not differ significantly on disease characteristics (Table 1) and resolution status, they were combined. MANOVAs were run to test differences in resolution status and outcome variables. Significance levels of $p < .05$ were used but because of relatively low power in this study, we calculated effect sizes using Cohen's d with 95% confidence intervals. All analyses were run using SPSS v.17.

Results

Descriptive Data

Parent-reported measures were consistent with questionnaire norms (Derogatis, 1993, Moos & Moos, 2009). Mean T-score for mothers on the BSI-Global Index was 54 ($SD = 11$) and 55 ($SD = 12$) for fathers. This indicates that most parents fell within normal levels of distress; approximately 26% of mothers and fathers reported clinical distress (T score > 63). In general, parents reported average levels of family functioning on the FES.

For all parents, 59% ($n = 39$) were classified as resolved, and 41% ($n = 27$) were unresolved on the RDI. One unresolved mother in this study expressed how difficult the diagnosis was on her [the mother] and the dreams that she had for her child. She says, "I was outside myself, listening to the doctors tell me that my child had diabetes. I felt sick to my stomach." When asked about her change in feelings about the diagnosis and what she wonders about with regard to the diagnosis, she says, "Sometimes I can't believe it still. I used to punish myself. What did I do to deserve this? I have accepted it a little but it comes back...feeling sorry for myself and why did this happen to us? I am always questioning myself, why do I have a child with diabetes?" In contrast, one resolved mother states, "I initially felt shock, sadness, and then acceptance for the diagnosis. We just deal with it and act like she is every other child with a few minor inconveniences. We just do what we have to do, accept it. It could be worse." She continues to say that she does not feel she has done anything to contribute to her child's diagnosis and does not really wonder why this has happened to them. There was no difference in time since diagnosis between resolved and unresolved ($p = .69$). Unresolved parents reported more child hospitalizations in the past year ($p = .03$) and greater illness severity ($p = .04$). Consequently, these variables were used as covariates.

Means, standard deviations, and distributions were also computed for children's representations (Table 2). Family cohesion themes were common in children's stories; the

Table 2 Means and Standard Deviations for Parent Self Reports and Children's Family Representations.

	Diabetes		Asthma		<i>p</i>
	Mean	<i>SD</i>	Mean	<i>SD</i>	
Maternal self report ($n = 66$)					
Psychological distress	56	10.77	52	12.05	.18
Family cohesion	7.69	1.09	7.62	1.29	.80
Family conflict	2.44	1.71	2.55	1.95	.81
Family expressiveness	5.97	1.69	6.17	2.08	.67
Paternal self report ($n = 43$)					
Psychological distress	57	11.74	48	11.65	.02
Family cohesion	7.87	1.22	7.36	1.73	.26
Family conflict	2.75	1.89	3.26	2.07	.40
Family expressiveness	5.95	1.60	5.94	1.84	.98
Children's representations ($n = 66$)					
Family cohesion	.53	.13	.43	.12	.00
Family conflict	.13	.07	.11	.07	.39

sample average of .49 reflects that children typically included two or three of the five cohesion themes in their stories. Family conflict themes were less common; however, data were normally distributed and few children ($n = 4$) had no conflict at all.

Resolution Status and Individual/Family Functioning

A significant multivariate effect was found between resolution status and maternal self-report measures (Wilks's $\lambda = .78$, $F(4, 55) = 3.69$, $p = .01$). Between-subjects effects revealed statistically significant differences for family cohesion, $F(1, 64) = 4.50$, $p < .05$; $d = .49$, 95% CI = $-.02, .98$, family expressiveness, $F(1, 64) = 8.96$, $p < .01$; $d = .82$, 95% CI = $.30, 1.33$, and family conflict $F(1, 64) = 4.94$, $p < .01$; $d = .46$, 95% CI = $.05, .95$, on the FES. Unresolved mothers had significantly lower report of family cohesion and expressiveness and greater family conflict than resolved parents (Table 3).

There was no significant overall multivariate effect between parental resolution status and paternal self-report measures (Wilks's $\lambda = .88$, $F(4, 36) = 1.17$, $p = .34$). However, a between-subjects effect revealed statistically significant differences for paternal report of family expressiveness, $F(1, 43) = 4.29$, $p < .05$; $d = .68$, 95% CI = $.01, 1.32$. Fathers of children with unresolved mothers reported significantly lower family expressiveness than fathers of children with resolved mothers. There were no significant differences between resolution status and parent distress.

Resolution Status and Children's Family Representations

A significant multivariate effect was found between parental resolution status and children's family representations (Wilks's

Table 3 Means and Standard Deviations of Parent and Child Measures by Resolution Status.

	Resolved (<i>n</i> = 39)	Unresolved (<i>n</i> = 27)	<i>p</i>
Maternal self report			
BSI-global distress	53.00 (12.11)	56.85 (10.17)	.55
FES-cohesion	7.89 (1.03)	7.33 (1.30)	.03
FES-expressiveness	6.65 (1.84)	5.22 (1.57)	.00
FES-conflict	2.15 (1.71)	2.96 (1.87)	.03
Paternal self report			
BSI-global distress	52 (12.58)	54 (12.51)	.67
FES-cohesion	7.82 (1.36)	7.28 (1.68)	.26
FES-expressiveness	6.31 (1.58)	5.21 (1.71)	.04
FES-conflict	2.82 (1.87)	3.28 (2.19)	.48
Child represented family cohesion	0.48 (0.13)	0.51 (0.14)	.49
Child represented family conflict	0.10 (0.06)	0.15 (0.08)	.00

$\lambda = .865$, $F(2, 54) = 4.20$, $p = .02$). Univariate analyses of variance performed for dependent variables revealed statistically significant differences for children's representations of family conflict, $F(1, 62) = 8.01$, $p < .01$; $d = .73$, 95% CI = .21, 1.22. Children of unresolved parents had significantly more representations of family conflict (Table 3). For example, a child in this study had escalating danger in a majority of her stories (e.g., doll getting injured again, stealing another piece of candy, and running away from home), assertions of child power (e.g., child doll looking for the lost keys instead of the parents), and instances of shaming/blaming the child (e.g., parents saying, "Why did you do that? We told you not to do that.") in several stories during the assessment.

Discussion

The main goal of this study was to understand the experience of parents who have a child diagnosed with chronic illness and whether children's narratives mirror the experiences expressed by parents. By and large, a majority of families in this study were functioning well in terms of levels of distress and family functioning. Overall, 41% of parents were unresolved with their child's diagnosis, similar to previous studies (Kearney et al., 2011; Sheeran et al., 1997). In addition, resolution was not a function of time since diagnosis, which suggests that parental meaning making about their child's diagnosis tends to remain constant over time (Barnett et al., 2006; Rentinck et al., 2010). To illustrate this point, an unresolved mother from the current study describes hearing the diagnosis: "I couldn't even retain what they were saying. I was so upset for several days after hearing the news." When asked if her feelings have changed: "No, unfortunately it is still very difficult and hard. There isn't a single second that I don't think about why she got this and what is going to

happen down the road and who is going to take care. It's a 24 hour thing."

It was hypothesized that parents who were unresolved in terms of their child's diagnosis would report greater psychological distress and lower family functioning. Findings partially support this hypothesis; parents who were unresolved had mothers report higher family conflict and lower family cohesion; both mothers and fathers in unresolved households also reported significantly lower family expressiveness. For some mothers in this study, the process of adaptation is difficult and may be related to more stress in the family system (Kazak, 1989). Specifically, family members may communicate in less healthy ways, increasing conflict and separation among members. This maladaptive pattern can put children at an increased risk for psychological difficulties (Jobe-Shields et al., 2009; Kaugars, Klinnert, & Bender, 2004) and developing poor strategies for coping (Kliewer, Fearnow, & Miller, 1996).

Children's narratives also shared commonalities with the experience of parents who were unresolved. Specifically, children of unresolved parents included more frequent preoccupations with family conflict in their stories. Given the reports from mothers and fathers about levels of conflict, cohesion, and withholding of emotions among unresolved parents, it makes sense that children would be preoccupied by family conflict. For example, in a story in which the doll gets burned, one child in the study says: "(Mom asks) Why did you touch it (the stove)? You got soup all over my pants. Then, dad says, you are grounded. Then the sister steps in it, cries, and says that hurt." The examiner prompts about the hurt hand and the child says: "Mom told her, but she didn't listen." In this response, there is blaming and shaming towards the child doll, along with escalating danger when the sister gets injured. The child does not address the burn even after the prompt. Research demonstrates that increased family conflict may be a risk factor for emotional/behavior problems in children with illness (Holmes, Yu, & Frenz, 1999; Thompson, Gustafson, Gil, Kinney, & Spock, 1999).

Overall, this study suggests that story stem narratives enabled children to share difficult aspects of their experience. Winter, Fiese, Spagnola and Anbar (2011) looked at narratives as a way to understand meaning making in young children with asthma and found a relationship between asthma severity and representations of family as less involved, cohesive, and secure. Similarly, children's narratives of poor family functioning were related to increased emotional/behavioral problems in children (Spagnola & Fiese, 2010). This work, along with the current study, adds to recent commentaries on family-centered research and care (e.g., Rosenbaum, 2011). Specifically, the story-stem procedure in this mixed methods study provides a new perspective (from the child) on family functioning by looking at children's internalized representations of family functioning (Fiese & Spagnola, 2005; Robinson, 2007). Moreover, this study included assessments from the perspective of fathers, providing a more comprehensive and perhaps accurate view of family climate.

Health professionals strive to help parents and families who may be suffering from their child's illness. Our findings related to differences in family expression of emotion between resolved/unresolved parents may also emphasize the need for targeted services about expression of feelings and conflict resolution within the family. In addition, health professionals may need to be aware that regardless of time since diagnosis, some parents may have continued suffering regarding their child's diagnosis. This may involve mental health professionals talking with parents about their diagnosis experience and encouraging them to seek additional support in coming to terms with their child's illness.

Limitations of this work include reliance on parental report of psychological adjustment and family environment through questionnaires that contribute to shared method variance in the association between parents' narratives about diagnosis and family relationships. Further, resolution of the child's diagnosis was assessed only for the primary caregiver (i.e., in most instances, the mother). In addition, this study had a limited sample size, with participants completing data at one time point. Despite our sample including a low occurrence of representations of family conflict, the codes that encompass this construct (e.g., escalation of danger in the story) may have greater clinical relevance regardless of occurrence (Oppenheim, 2006).

Future work should include more mixed methods approaches to understand how a child's diagnosis affects the well-being of the family, especially when developmentally appropriate measures are unavailable. Additionally, further analysis of young children's narratives regarding illness management or coping may be beneficial. These future directions would be enhanced by larger sample sizes that are demographically representative which may require multiple sites for data collection.

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