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

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Key words:
Reaction to diagnosis;
Family functioning;
Children's narratives;
Chronic illness;
Narratives

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 months	24–36 months	.17
Illness severity (0 to 3 scale)	1.62 (.95)	1.37 (.82)	.28
Mean hospitalizations in past year	.48 (.90)	.51 (.94)	.89