Relating Parent and Family Functioning to the Psychological Adjustment of Children with Chronic Health Conditions: What Have We Learned? What Do We Need To Know?¹

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Reviewed research concerning the relationship of parent and family functioning to the psychological adjustment of children with chronic health conditions. More adaptive family relationships and parental psychological adjustment were associated with positive psychological adjustment while less adaptive family relationships (e.g., greater conflict and maternal psychological distress) consistently predicted problematic adjustment. Conclusions were limited by small, site-specific samples, reliance on self-report measures generally obtained from one parent, and general measures. Research progress would be enhanced by (a) more representative data sets; (b) process-oriented, illness-specific, and clinically relevant measures; (c) prospective analyses that clarify specific causal pathways between family functioning and children's adjustment; and (d) tests of interventions that modify risk and/or resistance factors.

KEY WORDS: chronic illness in children; chronic health conditions; psychological adjustment; family functioning; parental psychological adjustment.

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Several reviews have underscored the need to identify the sources of individual variation in the psychological adjustment of children with chronic health conditions, including differences between resilient children versus those who develop emotional disturbance (Lavigne & Faier-Routman, 1992, 1993; Pless & Nolan, 1991; Wallander & Thompson, 1995). Parent and family functioning have been identified as primary influences on children's psychological outcomes in the above reviews. However, to my knowledge the contributions and methods of recent research that focused explicitly on the role of parent and family functioning in children's adjustment have not been summarized nor critically evaluated. Lavigne and Faier-Routman's (1993) meta-analysis summarized the correlates of children's adjustment to physical disorders but did not focus on parent and family functioning. Drotar (1994) underscored the potential impact of site-specific variations in family relationship resources on the psychological outcomes of children with pediatric health conditions but did not review family research. Wallander and Thompson's (1995) comprehensive review of psychosocial adjustment of children with chronic health conditions also did not focus explicitly on the role of parent and family functioning. However, the large number of recent studies that concern the relationship of family factors to the psychological outcomes of children with chronic health conditions underscores a continuing need to critically evaluate the specific contributions and limitations of this research and to recommend critical next steps. This review was conducted to address these needs.

PROCEDURE

The following procedure was used to select studies to be reviewed. Research published after Pless and Pinkerton's (1975) comprehensive review was identified using Psych Lit and Medlines (1976-1995). Citations of reviewed papers were also examined. To be included in this review, research reports had to (a) be published in a peer-reviewed journal; (b) include a sample of children and/or adolescents who were age 18 or less and who had a chronic ongoing health condition lasting at least 12 months that required medical care (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993); (c) include at least one validated measure of parent or family functioning as an independent variable (not a proxy measure such as socioeconomic status); (d) include at least one validated measure of children's psychological adjustment as an outcome (studies that utilized adherence or physiologic disease status, e.g., diabetes control, as primary outcomes were not included). Information from the 57 published studies that met these criteria was obtained concerning theoretical framework and hypotheses, design, sampling procedures and characteristics, independent and dependent measures, findings, and conclusions.

STUDY CHARACTERISTICS: RESEARCH, DESIGN, SAMPLING AND MEASUREMENT

Sample sizes, groups, and methods of assessment in studies reviewed are summarized in Table I. Seven pairs of studies that utilized overlapping data sets are indicated. These studies were grouped together in summarizing study characteristics (n = 50). Most studies (n = 41) utilized correlational and/or multiple regression analyses to describe the relationship between parental and/or family variables and children's psychological functioning. However, 9 studies compared parent or family functioning among subgroups of adjusted versus maladjusted children as defined by parent or child reports of symptoms or psychiatric diagnosis. Three used both analytic methods. With the exception of only 5 prospective studies, which are indicated on the table, cross-sectional designs predominated. All but 3 studies, which utilized regional samples, involved children from one site.

The majority of studies (n = 41) sampled a very broad age range, most commonly early school age (e.g., 7 years) through early adolescence (age 13), while much fewer focused on specific age groups such as preschoolers (n = 2) or adolescents/young adults (n = 6). Conditions such as insulin-dependent diabetes mellitus (n = 13) were assessed most frequently, whereas others such as congenital heart disease (n = 2) or hemophilia (n = 2) were rarely studied. With the exception of 2 studies that utilized acutely ill children, comparison groups were physically healthy children.

SUMMARY OF FINDINGS

At least one measure of family/parental functioning related significantly to children's psychological adjustment in all but 4 studies. Measures of family/parental functioning that reflected supportive family relationships, for example, family cohesion, predicted fewer behavioral symptoms and more competent psychological functioning (e.g., self-esteem). In contrast, measures of problematic family qualities (e.g., conflict) generally predicted less competent psychological adjustment and/or higher levels of behavioral symptoms. More frequent maternal psychological adjustment problems (e.g., distress) were typically identified among maladjusted children with chronic health conditions compared with those who had age-appropriate psychological functioning.

However, such positive findings were by no means universal. Comparisons between multiple family/parental functioning variables and child psychological outcomes, which were made in almost every study, identified at least one nonsignificant relationship in all but three. Moreover, the amount of variance in children's psychological outcomes accounted for specifically by parental and/or

		Table I. Descripti	Table I. Description of Studies That Were Reviewed	Were Reviewed			
					Method of	Method of assessment ^b	
	Chronic	c		1V		DV	^
Study ^a	condition ^c	Comp. group ^d	Age range	Informant	Method	Informant	Method
Austin (1988)	111.5		8-12	М	0	M. C	0
Barakat & Linney (1992)	29°	28	6-11	W	~~	W	0
Breslau (1990)	157 _{c.d.e}	33	10-16	M	Q, I	с С	I
*Capelli et al. (1988)	33 ₆		8-16	Σ	0	M, C	0
*Capelli et al. (1989)	29 ^r	29	8-16	М, F	0	M, C	0
Carlson-Greene et al. (1995)	63 [°]		2-16	M	ð	M, C	0
Cowen et al. (1985)	41 [°]	31	2-5	X	0	М, F	0
Daniels et al. (1987)	72,	165	6-15	М, F	ø	U	0
DeMaso & Campis (1991)	66		4-10	X	ø	¥	ø
Fletcher et al. (1995)	70 _{6.1.k}	24	5-7	M	ð	M, C	Q
Gil et al. (1991)	72h		7-17	M, C	Ø	M, C	ø
Grey et al. (1980)	20 _m		6-13		ð	Σ	-
Hamlett et al. (1992)	30 <u>"</u> "	15	6-14	M	ø	X	ø
*Handford et al (1986)	50,		5-19	М, F	ð	U U	ø
**Mayes et al. (1988)	22 _n		5-9	М, F	Ø	υ	ø
Hanson et al. (1992)	95		11-22	M	0	M, C	ď
Hauser et al. (1985)	30	30"	10-16	X	0	ပ	0
**Heller et al. (1985)	165 _{1.0.0}	i	414	M	ð	M, C	ō, I
Hoare & Kerley (1991)	108		5-15	M	0	M, T	0
Johnson et al. (1988)	15 ₁		6-13	M	Ø	M	Ø
Kager & Holden (1992)	£,		7–15	M, C	Ø	ပ	ð
Kazak & Clark (1986)	56	53	1-15	M	Ø	U	Ø

Table I. Description of Studies That Were Reviewed

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M M, F, C M M M	N CC F N CC F	ΧX	C W W	M, C	M, C	Ψ
10–15 7–17 3–8 not	reported 7–13 7–13 7–13 7–13 7–13 7–13 7–19 4–14 4–14 4–14	4-17 4-14	7-12 7-14	7-12	7-14	5-15
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35 30 34, 57,	59 995, m 88 72 ⁸ 91 ^{6, 6} 72 ⁸ 88 72 ⁸	40 ₆ 35 ₉	50, 30,	83 ₁	41 _f	23 _h
Kazak & Meadows (1989) Kucia et al. (1979) Lavigne et al. (1988) Lewis & Khaw (1982)	Lothman & Pianta (1993) Mullins et al. (1992) Mulhern et al. (1992) Munch & Cohen (1989) Perrin et al. (1993) Pianta & Lothman (1994) Prior et al. (1983) Rait et al. (1992) Sanger et al. (1991) Steinhausen et al. (1983) Thenhund & Samuelsson	(1989) Thompson et al. (1989) Thompson, Zeman, et al. (1992)	*Thompson et al. (1993) **Thompson, Gil, et al. (1994)	*Thompson, Gustafson, et al. (1992)	**Thompson, Gustafson, et al. (1994)	Varni et al. (1988)

					Method of a	Method of assessment ^b	
	Chronic	Ċ		Ν		DV	,
Study ^a	(n)	Comp. group ^d	Age range	Informant	Method	Informant	Method
Varni et al. (1989a)	75 _m		6-16	Ψ	Ø	Σ	0
*Varni et al. (1989b)	42,		8-13	Μ	0	U	0
*Varmi et al. (1989c)	42,		8-13	Μ	'O	Σ	0
Varni et al. (1994)	41		8-13	с	0	M, C	0
*Varni & Setoguchi (1991)	51,		8-13	M, C	0	M, C	0
*Varni & Setoguchi (1993)	54,		8-13	M, F, C	0	с С	0
Walker et al. (1989)	70,	23	8-19	Μ	0	X	0
*Wallander & Vami (1989)	153, d.k.m.u		4-16	M	0	M	0
*Wallander et al. (1989a)	153 _{c.d.k.m.u}		4-16	M	0	M	0
Wallander et al (1989b)	50 _{6.4}		4-16	Ψ	0	W	0
**Wells & Schwebel (1987)	41 _{c.d.1}		6 mos-	Μ	ð	M, N	Ó, Q
			13 yrs.				
Wertlieb et al. (1986)	46 _m	29 _{al}	9-16	X	Ø	M	ð
Wysocki (1993)	115 _m		11-18	М, F, Q	δ	С	δ
^{a*} = overlaping data sets, ** =	** = prospective study.						

Table I. (Continued)

⁻¹ or traping and such the propriety of the mother; F = father; C = child; I = interview; O = observation; Q = questionnaire; T = teacher; N = vertices of the second structure of the second stnurse.

"Conditions (subscript letters): a = asthma; b = epilepsy; c = spina bifida/myclodysplasia; d = cerebral palsy; e = multiple handicaps; f = cystic fibrosis; g = cancer; h = juvenile rheumatoid arthritis; i = congenital heart disease; j = hydrocephalus; k = aqueductal stenosis; l = sickle cell anemia; m = insulin-dependent diabetes mellitus; n = hemophilia; o = cleft palate; p = hearing loss; q = Duchenne's muscular dystrophy; r = limb deficiency; s = mental retardation; t = congenital malformations; u = obesity.^dSubscript ai = acute illness.

family functioning variables was quite variable but was most commonly between 10-15%.

Summary of Findings From Prospective Studies

Because prospective studies are a more powerful way to identify relationships between family/parent functioning and children's adjustment, they are summarized separately. Paternal overprotection emerged as the most consistent predictor of decreases in children's self-control in Mayes, Handford, Kowalski, and Schaefer's (1988) 6-year longitudinal study of hemophilia. However, most parental attitudes and child-rearing practices in the above study did not relate to children's adjustment. Wells and Schwebel (1987) also identified parental overprotection among several family variables (e.g., parenting stress, conflict resolution) measured 2–3 weeks prior to orthopedic surgery, as a predictor of psychological distress, which was measured 1 week after hospitalization, among children with physical handicaps.

Three studies that employed 10- to 12-month prospective follow-ups had mixed findings. Heller, Rafman, Zuagulis, and Pless (1985) found that family functioning did not predict psychological maladjustment in children with birth defects. Thompson, Gil, et al.'s (1994) hypothesis that maternal distress would predict behavior problems among children with sickle cell disease was not supported. On the other hand, Thompson, Gustafson, George, and Spock (1994) found that maternal distress predicted psychological symptoms (based on child and maternal reports) among children with cystic fibrosis on 1-year follow-up.

PROGRESS AND LIMITS ON CONCLUSIONS

This review indicates significant progress in developing comprehensive conceptual models to guide research (Wallander, Varni, Babani, Banis, & Wilcox, 1989a; Thompson, Gil, Burbach, Keith, & Kinney, 1993) and identifying features of family and parental adjustment that consistently related to the psychological adjustment of children with chronic health conditions. However, this review also revealed several conceptual and methodological issues that temper the conclusions that can be drawn and have salient implications for future research.

Limited Generalizability of Findings. The marked prevalence of single-site studies clearly limits the generalizability of research findings to the broader population of children with chronic health conditions. Moreover, the inconsistencies in the strength of the relationships between parent/family variables and children's outcomes obtained across studies may reflect the influence of site-specific subject characteristics, and/or risk factors (Drotar, 1994).

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Problems in Hypothesis Testing. Wallander et al.'s (1989a) and/or Thompson et al.'s (1993) risk and resistance factor models have been quite influential and have guided choice of variables and hypotheses in 13 studies. Unfortunately, the majority of the studies reviewed (n = 32) did not test explicit conceptual models of expected relationships between family adaptation and children's psychological adjustment. Moreover, 21 did not state any hypotheses for expected relationships. A related concern is the potential for spurious findings in those studies (n = 16) that employed the troubling combination of no hypotheses, multiple independent and dependent measures, and several regression or correlational analyses without statistical correction for multiple comparisons.

Absence of Family-Level Data. Self-reports of family functioning (n = 26), especially the Family Environment Scale (n = 15) (Moos & Moos, 1981), from single family members (almost always the child's mother) and measures of parents' psychological adjustment (n = 22) were the most commonly used independent variables. However, only 8 studies included data from both fathers and mothers as independent variables, despite recognition that self-reports from a single family member do not provide data about family level influences (Kazak, 1991; Patterson, 1990). Measures of marital satisfaction or discord (n = 3), family members' interactions concerning illness-related issues or tasks (n = 3), or observation of parent-child interaction (n = 3) were rarely employed.

Limited Use of Illness-Specific Measures of Family Functioning. With some notable but infrequent exceptions (e.g., Hanson, DeGuire, Schinkel, Henggeler, & Burghen, 1992; Wysocki, 1993), family measures focused on general features of family functioning (e.g., perceived conflict or support) rather than specific behaviors (e.g., problem solving) that relate to illness management. However, illness-specific measures may reveal more powerful influences on child and parent adaptation. For example, Quittner, DiGirolamo, Michel, and Eigen (1992) found that measures of situation-specific stress accounted for substantially greater proportions of variance in maternal depression than global measures.

Alternative Interpretations of Findings. Significant correlations or regression coefficients between parent and/or family measures and child were almost always interpreted as supporting the influence of parental adjustment or family functioning on children's adjustment. However, alternative interpretations, for example, that children's psychological adjustment affected the quality of parental and family functioning, are certainly plausible, given the reciprocal nature of child and family influences (Lerner & Spanier, 1978) and the limitations of cross-sectional designs and regression analyses for testing causal relationships (Peyrot, 1996). The results of studies (n = 16) in which mothers were the sole informants for measures of their children's psychological adjustment *and* family/parent functioning may be affected by shared method variance (Breslau, Davis, & Prabucki, 1988). Psychological distress may cause mothers (or fathers) to portray their families as less supportive or cohesive and perceive their children as having more psychological symptoms.

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Failure to Develop and Test Specific Causal Models of Family Processes. Influential conceptual models (Thompson et al., 1993; Wallander et al., 1989a) have defined global variables (such as the quality of parental and family functioning) as resistance factors that moderate the negative effects of disease or disability-related risk factors (e.g., severity of illness; illness-related stressors) on children's psychological adjustment. However, the combined use of global theoretical constructs and measures has limited identification of specific family interactions and processes that affect children's psychological adjustment. Partly for this reason, even successful tests of general risk and protective factor models cannot tell us how risk (or protection) is transmitted (Rutter, 1990a, 1990b). For example, problematic family functioning may affect children's adjustment in several very different ways (e.g., by faulty modeling) limiting support for the child, altering child-rearing practices, and so forth (Rutter, 1990a). Available conceptual models also include a large number of variables that cannot be adequately represented by available samples and postulate reciprocal relationships, which are difficult, if not impossible, to test. Moreover, these models need to be modified in response to findings, for example, lack of consistent relationships between risk factors such as severity of illness and children's psychological adjustment (Lavigne & Faier-Routman, 1993). Finally, regression analysis has been the major method of testing the relationship of parent or family functioning to children's psychological adaptation, despite the limitations of such analyses in revealing causal influences (Peyrot, 1996) or describing changes in family adaptation over time (Willett, Ayoub, & Robinson, 1991).

Limited Consideration of How Illness Course and Child Development Affects Families. Research designs have not addressed the fact that critical events in the course of a child's illness (e.g., diagnosis), exacerbations in symptoms, may pose very different physical and relational demands on parents and families, which in turn may influence the quality of children's psychological adjustment (see Rolland, 1994). Little is known about how parent/family functioning affects children's adaptation to clinically significant illness-related changes such as worsening or improvement in physical status. The combination of a broad age range and relatively small samples has also precluded analyses of interactions among developmental status, parent/family factors, and children's adjustment, with some exceptions (Rait et al., 1992).

RECOMMENDATIONS FOR FUTURE RESEARCH

Enhance Generalizability of Predictive Models of Family Influences

Predictive models of family influences should be systematically replicated in samples that differ on relevant demographic characteristics (e.g., social class, race). In addition, studies of underrepresented age groups, especially preschoolers and late adolescents, and greater use of multisite and national data sets would enhance the generalizability of findings.

Develop and Test More Specific Models of Family Socialization Processes

More detailed and explicit models of how family members perceive and manage the specific physical and relationship demands that are associated with childhood chronic illnesses should be developed and tested. In this regard, the distinction between illness-specific family relationship tasks (e.g., social and task-oriented support of the child's adherence to regimens or management of illness-related distress) versus general features of family relationships (e.g., communication, demonstration of affection, flexibility) is potentially important but not well understood (Moos & Schaefer, 1989). Thus, one intriguing, but as yet unanswered question, is how the quality of a family's general functioning affects their ability to manage various illness-specific task and relationship demands and vice versa. Hanson et al.'s (1992) findings that general and illnessspecific family relationships were highly interrelated and that each predicted the psychological adjustment of children and adolescents with diabetes should be extended to other conditions.

A related priority is to develop and test explicit models of *how* family processes influence the psychological development of children with chronic health conditions. For example, Kliewer, Sandler, and Wolchik (1994) identified three alternative pathways by which families influence children's adaptation to stressful events: (a) coaching or direct instructions, including reinforcement of appraisals and coping patterns that suggest specific courses of action in responding to stress; (b) modeling of coping styles and strategies of stress (or illness) management; (c) general contextual influences that shape the family environments in which stable patterns of coping are learned (e.g., quality of family routines, communication, and/or relationships).

Tests of hypothesized pathways of family influence using detailed assessments of individual family members' responses to specific illness-related stressors, for example, symptoms or adherence tasks are very much needed (Quittner et al., 1996). One example of a promising method of assessment that could be employed more widely is a daily telephone diary that was designed to track type, duration, and quality of family activities and interactions (Quittner & Opipari, 1994). This method provided instructive information concerning differential maternal allocation of time and attention to siblings of chronically ill versus healthy children (Quittner & Opipari, 1994).

The clinical relevance of family research would be enhanced by assessments of the impact of variables such as problem solving or decision making (Bleckman & Delameter, 1993; Wysocki, 1993), which are potentially amenable to interven-

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tion (Robin & Foster, 1989). Examples of such interactional patterns that warrant greater empirical study include effective family communication (i.e., sending and receiving messages concerning problem solving), which has been identified as a resilience factor (Bleckman & Delameter, 1993), and behaviors that are hypothesized to be psychologically disruptive such as "miscarried helping," defined as well-intentioned but dysfunctional attempts by parents to enhance their children's adherence to treatment (Anderson & Coyne, 1991) or family conflict concerning the adolescent's emerging autonomy (Leffert, Sussman, & Collins, 1993).

Explicit tests of mediators, moderators, and causal processes that link family variables to children's psychological adjustment would best maximize the scientific yield by using more specific measures (Baron & Kenny, 1986; Peyrot, 1996). For example, given that the relationship between family conflict and psychological adjustment in childhood chronic illness has been reasonably well established, investigators now need to ask: How does conflict disrupt adjustment? Is this mainly a direct effect of stimulating the child's distress? (Cummings & Davies, 1994). Alternatively, is the effect of family conflict mediated by the effects on the parent/child relationship? Mann and Mackenzie (1996) and Peyrot (1996) have provided instructive examples of how causal modeling techniques can be used to articulate such specific pathways of family influence on children's adjustment.

Document Trajectories of Family Adaptation in Response to Illness Course and Developmental Transitions

Although the family demands of childhood chronic illness vary with the stage of the illness and the child's development, researchers have not assessed family response to the course of the child's illness and/or developmental transitions (Rolland, 1994). In this regard, Rait et al.'s (1992) interesting hypothesis that a high level of family closeness and support is essential to positive coping during the acute phases of illnesses such as cancer but may interfere with adolescent development as time goes on warrants an empirical test.

It would also be very instructive to conduct prospective studies of family response to clinically significant illness-related changes (e.g., exacerbation of symptoms or onset of handicap). New methods of statistical analysis, especially growth curve analysis, can be utilized effectively to describe individual differences in trajectories of family or parental adaptation in response to illness-related events or life stressors (Willett et al., 1991) and to test the impact of clustering or "pile-up" of stressful events on family adaptation (Patterson, 1988). Growth curve analyses can also be used to describe developmental trajectories of children's psychological functioning in response to family influences (see Duncan, Duncan, & Hops, 1996).

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Address Unanswered Questions Concerning the Impact of Family Influences

This review reveals at least two important but unanswered questions concerning the impact of family influences that should be addressed in future research. The first is: Are relationships between family risk and resistance factors and children's psychological outcomes comparables across different chronic health conditions? Several studies have suggested that children with some chronic conditions are differentially sensitive to family risk and resistance factors. Such findings include a positive relationship between internal maternal health locus of control and children's psychological adjustment in epilepsy but not in other conditions (Perrin, Ayoub, & Willett, 1993), positive relationships between problematic parent/family functioning and psychological adjustment in asthma but not in diabetes (Hamlett, Pelligrini, & Katz, 1992) or cystic fibrosis (CF) (Steinhausen, Shindler, & Stephan, 1983); and different patterns of psychological symptoms associated with maternal depression among children with diabetes versus CF (Mullins et al., 1995). Unfortunately, explanations for such interesting findings are not entirely clear because these studies generally lacked an explicit, a priori framework for data analysis. Moreover, parent and family functioning were measured at a global level, which limited effective tests of the impact of illness-specific parent/family influences (Quittner et al., 1992).

A second interesting, unanswered question is: Are relationships among risk and resistance factors and psychological outcomes comparable in chronically ill versus physically healthy children? Studies that have identified comparable relationships between parent and family functioning and psychological adjustment in chronically ill versus physically healthy children (Breslau, 1990; Daniels, Moos, Billings, & Miller, 1987) have supported the hypothesis that parental emotional adjustment and family functioning affect children's psychological adjustment in comparable ways, irrespective of their health status. However, only a handful of studies have made direct comparisons between families of children with chronic illnesses and those of physically healthy children.

Evaluate the Impact of Family-Centered Interventions

A critical need is to utilize findings concerning the relationship of parent and family functioning to children's adjustment to develop and test psychological interventions designed to modify the specific risk and/or protective factors that have been identified. For example, behavioral family systems intervention has been shown to lessen family conflict (Robin & Foster, 1989), which has been consistently identified as a risk factor for psychological maladjustment for children with chronic illness. If such family-centered interventions also can be shown to enhance the psychological adjustment of children with chronic health conditions, this would give us important information about the operation of family influences in this group of children.

SUMMARY OF RECOMMENDATIONS FOR FUTURE RESEARCH

The recommended next steps for research are summarized as follows: (a) systematic replication of findings in multisite studies and national data sets; (b) development of process-oriented theoretical models that describe the influence of key family socialization processes on psychological adjustment and illness-management; (c) more specific analytic tests involving moderating versus mediating influences and causal modeling, ideally using prospective designs; (d) greater use of illness-specific measures involving family variables such as problem solving, and so forth; (e) studies that clarify the relationships between risk and resistance factors and the psychological outcomes of children with different chronic conditions; and (f) studies of the impact of interventions designed to lessen the effects of family risk factors (or enhance resistance factors) that have been identified in descriptive research.

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