Family Functioning in the Context of Pediatric Chronic Conditions

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Abstract

Objective—The aims were to describe and compare *generic* family functioning in children with five different chronic conditions and healthy comparisons, and to examine the relations between family functioning and sociodemographic variables.

Methods—A secondary data analysis from six independent studies including 301 children (Cystic Fibrosis: n=59; Obesity: n=28; Sickle Cell Disease: n=44; Inflammatory Bowel Disease: n=43; Epilepsy: n=70; Healthy Comparison Group: n=57) was conducted. In each study, parents completed the Family Assessment Device (FAD).

Results—Across all five chronic conditions, between 13% and 36% of families endorsed levels of functioning in the "unhealthy" range, with the greatest proportions in the following domains: Communication, Roles, and Affective Involvement. No significant group (i.e., between all 6 groups, namely 5 chronic conditions as well as healthy comparisons) differences were observed on FAD scales (model $F (35, 1335) = 0.81$, $p = .79$). Older child age, fewer children living in the home, and lower household income were significantly related to poorer family functioning in as the areas of Communication, Roles, Affective Involvement, and General Functioning.

Conclusions—Families of children with and without chronic conditions do not differ significantly from each other on *generic* family functioning. However, risk factors for poor family functioning include older child age, less children in the home, and lower household income. These risk factors combined with data suggesting that a subset of families exhibit "unhealthy functioning" warrants the need for close monitoring of how families function in the context of a pediatric condition.

Keywords

children; chronic illness; family functioning

There is widespread recognition that the presence of a chronic pediatric condition can be a source of increased stress and distress among family members, which can lead to disruptions in intrafamilial relationships, family structure, and family cohesion.[1–3] Pediatric researchers have consistently demonstrated that family functioning is a powerful determinant of overall quality of life and well-being in youth with chronic medical conditions. Specifically, adaptive

family relationships and parental adjustment have been linked to positive psychological functioning.[4, 5] In contrast, disruptions in family life have been linked to poorer emotional and behavioral functioning[6] and poor adherence to medical regimens.[5, 7] Family functioning in the context of a chronic pediatric condition is thus an important area of research and intervention.

Other family-specific factors known to be associated with family functioning include socioeconomic status (SES), caregiver marital status, and the number of children living in the home. For example, prior research has shown that lower SES has been associated with negative consequences in families, including poorer family functioning, marital conflict, and parenting stress.[8–10] Caregiver marital status[8], specifically being in a single-mother household, and having more children living in the home[9] have also been linked with greater difficulties in family functioning and parenting stress. Thus, the composition and structure of families are key components in understanding the manner in which families function. Child-specific factors such as child age have also been linked with a family's functioning. Specifically, older child age has been linked to family conflict and poor communication[10], resulting in more family-based interventions targeted at adolescents[11] in recent years.

Much research has been devoted to family functioning in pediatric conditions; however findings have been largely mixed. Furthermore, few studies of family functioning have been conducted in conditions such as cystic fibrosis (CF), obesity, sickle cell disease (SCD), inflammatory bowel disease (IBD), and epilepsy. In fact, existing data is equivocal for all of these chronic conditions regarding family functioning, with some researchers documenting significantly poorer family functioning (e.g., CF[13, 14], Obesity[12, 13], IBD[14], Epilepsy[15]) and others finding no differences (e.g., CF[16], SCD[17], IBD[18], Epilepsy[15]) or better functioning relative to a healthy comparison group (e.g., SCD[19]). Overall, prior literature highlights variability in family functioning across chronic pediatric conditions and there is a need for research to elucidate our understanding of the impact of chronic conditions on family functioning compared to a healthy comparison group.

Family functioning can be impacted differently based on specific characteristics of a child's chronic condition. Rolland's psychosocial typology of illness,[20] which continues to be applied to clinical research with families,[21] provides a framework for categorizing pediatric chronic conditions based on key disease characteristics, such as course (e.g., progressive, constant, or relapsing/episodic) and outcome (e.g., fatal, life-shortening, nonfatal), and subsequently making predictions about the impact on family functioning. In the case of CF and SCD, the chronic, progressive, and life-shortening nature of both conditions combined with the presence of recurrent exacerbations (e.g., pulmonary exacerbations in CF and pain exacerbations in SCD) and complexity of the treatment regimens, may allow a family few periods of relief from the ongoing demands of the illness and the need for continual adaptation and reorganization of family roles. In fact, prior research suggests that families with CF compared to asthma spend significantly more time in medical activities (e.g., following treatment regimens and attending clinic visits) and less time in recreational activities,[22] highlighting the additional demands related to chronic and progressive conditions. Childhood epilepsy and IBD, non-life shortening and episodic conditions, are characterized by periods when the child is asymptomatic and periods of unexpected flare-ups or events. This may require a high level of flexibility within families to move back and forth between acute stress periods and periods of remission. Treatments for these diseases are also less complex, primarily involving oral medications. Thus, compared to diseases that have high regimen burden and unpredictability (e.g., CF, SCD), family functioning in children with epilepsy and IBD is likely to be more stable. Little is known about how characteristics of pediatric obesity impact family functioning and in fact, obesity is completely neglected from Rolland's framework. Childhood obesity can be conceptualized as a constant condition with associated life-shortening comorbidities (e.g., heart disease, hypertension). For children with obesity seeking active medical treatment, the family

may eventually engage in lifestyle modifications, including increasing physical activity and restricting calories. Compared to acute and progressive conditions, reorganization of family roles and responsibilities may not occur until treatment has been initiated and family functioning may remain relatively stable prior to treatment initiation.

A number of methodological concerns in the extant literature make drawing conclusions about the impact of chronic childhood conditions on family functioning quite challenging, and limits our ability to interpret differences in family functioning across illness groups. First, prior research has measured family functioning using different assessment tools such as self-report and observational measures, many of which tap into different dimensions (e.g., global family functioning, dyadic family relationships).[23, 24] Second, use of a healthy comparison group has not been implemented consistently, thereby making it difficult to draw conclusions regarding the level of impairment or lack thereof compared to normative family processes.[25] Third, to our knowledge, no theory has been used to provide a framework for understanding family functioning across multiple disease groups and relative differences between these groups. Fourth, some studies assessing family functioning have used measurement tools with poor psychometric properties (for a review of measures see Alderfer et al., 2008). Finally, various characteristics of family composition shown to impact family functioning (e.g., caregiver marital status)[8] have frequently been neglected from prior research.[26] Overall, these limitations make interpreting family functioning in pediatrics a difficult task.

The McMaster Model of Family Functioning (MMFF[27]) is one model used to conceptualize family systems based on over 20 years of research and clinical work with families. This model focuses on six dimensions shown to have the greatest impact on the emotional and physical health of family members: Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, and Behavior Control. No single dimension is believed to create the foundation for family behavior; rather, each dimension contributes equally to the functioning of a family system. As a result, the level of impairment in functioning within a family unit is influenced by the effectiveness of the family in each of the six dimensions. The McMaster Model of Family Functioning has been applied successfully in both research and clinical contexts and several measures have been developed to assess family functioning based on this model, including observation (e.g., Mealtime Interaction Coding System[28]), interview (e.g., McMaster Structured Interview of Family Functioning[29]), and self-report methods (e.g., Family Assessment Device (FAD)[30]). The FAD is a parent and child (8 years and older) self-report measure, which encompasses the above dimensions and a General Functioning dimension. A recent review of empirically-validated assessment tools in pediatric psychology[23] suggests that among self-report questionnaires, the FAD is one of three "well-established"[31] family functioning measures, based on its excellent psychometric properties, broad applicability, and frequent use in the pediatric peer-reviewed literature. The internal consistency of the FAD factor structure has received some criticism;[32] however the FAD was originally developed to be psychometrically sound around a theory and FAD dimensions were derived from self-report and interviews with families in order to be of maximal clinical utility. [29, 33] To date, the FAD has been applied in a variety of settings, translated into at least 20 languages, and used in countries including China, Japan, the Netherlands, Mexico, Spain, South Africa, England, and India,[34, 35] suggesting broad cultural applicability.

The purpose of the current study was to examine parent-report of family functioning across several chronic pediatric conditions and a healthy comparison group using secondary data analyses. The specific aims were twofold: 1) to describe and compare family functioning in five chronic condition groups (e.g., CF, obesity, SCD, IBD, epilepsy) and a healthy comparison group, controlling for statistically significant *family-based* variables and 2) to examine the relations between domains of family functioning and sociodemographic variables. Based on mixed findings in the broader family functioning literature and application of Rolland's

typology of illness, it was hypothesized that families with children who are otherwise medically healthy (i.e., "comparison group") would endorse the highest level of family functioning on all FAD dimensions (i.e., Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, Behavior Control, and General Functioning), followed by families with obese children, families with epilepsy and IBD, and lastly families with CF and SCD. Caregiver marital status (e.g., single caregiver), more children in the home, less family income, and older child age were hypothesized to be significantly associated with poorer family functioning.

METHODS

Participants

Data were pooled from six independent studies which examined family functioning within the context of a chronic childhood condition. These studies were selected for two reasons: 1) they collectively represent a set of pediatric conditions that are under-represented in the family functioning literature, and 2) availability of the FAD across studies. Demographic and medical information for each group is presented in Table 1.

Procedure

Data was collected as part of a larger battery of measures specific to the aims of each study. Detailed information on each study can be found in Table 2. Approval was obtained from the appropriate Institutional Review Boards for each study. Parental consent was obtained and questionnaires were administered.

Measures

Demographic and Medical History Questionnaires—Although there was some variability in the measures used in each study, primary caregivers completed questionnaires assessing basic demographic (e.g., age, race, gender, household income) and medical information for the child.

Family Assessment Device (FAD[29])—The FAD is a 60-item measure based on the McMaster Model that assesses family functioning on six different dimensions: Problem Solving (ability to resolve problems), Communication (exchange of clear and direct verbal information), Roles (division of responsibility for completing family tasks), Affective Responsiveness (ability to respond with appropriate emotion), Affective Involvement (degree to which family members are involved and interested in one another), and Behavior Control (manner used to express and maintain standards of behavior). The FAD also includes an independent dimension of General Functioning (overall functioning of family). FAD items require individuals to rate their level of agreement/disagreement on specific family behaviors (e.g., "We try to think of different ways to solve problems" and "We don't talk to each when we are angry") using a 4-point Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). Higher scores are indicative of poorer family functioning. Miller[33] documented clinical cut-off scores differentiating "healthy" versus "unhealthy" family functioning for each dimension. For the current study, internal consistencies for FAD dimensions were as follows: Problem Solving, $\alpha = .74$; Communication, $\alpha = .77$; Roles, $\alpha = .74$; Affective Responsiveness, $\alpha = .72$; Affective Involvement, $\alpha = .71$; Behavior Control, $\alpha = .75$; General Functioning, $\alpha = .73$.

Statistical Analyses

Descriptive statistics were calculated including means and standard deviations. The percentage of families in each group meeting clinical cut-off scores ("unhealthy") for each FAD dimension was also calculated. Due to this study being a secondary data analysis, only significant family-

based variables that were available for most participants were used as covariates in multivariate analyses. Child variables (e.g., age) were not included as covariates because they either 1) did not capture the entire family system (i.e., only specific to one of the potentially many children in the family) or 2) were intrinsically tied to disease group (e.g. race for CF and SCD). A multivariate analysis of covariance (MANCOVA) was then conducted to examine group differences on family functioning dimensions. Chi-square analyses were utilized to examine group differences in the proportion of families exhibiting "unhealthy functioning" on all FAD dimensions. Finally, Pearson correlations and independent t-tests were used to examine the relations between family functioning and all sociodemographic variables such as child age, child gender, and household income. Analyses were conducted in SPSS 15.0 (SPSS Inc., Chicago, IL). Since this was a secondary data analysis combining six independent studies, an a priori power analysis was not feasible and is not supported in the statistical literature.[36]

RESULTS

Descriptive Statistics

Based on cut-off scores established by the authors of the FAD,[37] group means on all FAD dimensions fell below the established cut offs for "unhealthy" functioning. However, there was a high percentage of families meeting clinical cut-offs ("unhealthy" family functioning) as presented in Table 3. Across all five chronic conditions, between 13% to 36% of families endorsed "unhealthy" levels of functioning: 13% in Problem-Solving, 28% in Communication, 36% in Roles, 16% in Affective Responsiveness, 36% in Affective Involvement, 21% in Behavior, and 25% in General Functioning.

Group Differences on Demographic Variables and Family Functioning

Significant group differences (i.e., between all 6 groups) for family-based variables were found on household income ($\chi^2 = 58.70$, $p < .01$), marital status ($\chi^2 = 55.49$, $p < .01$), and number of children living in the home ($\chi^2 = 111.00$, $p < .01$) (see Table 1 for post-hoc results). After controlling for income and marital status[1], a MANCOVA indicated no significant group differences on all FAD dimensions; (model F (35, 1335) = 0.81, $p = .79$, $\beta = 0.83$) (see Table 4 for estimated marginal means). No significant group differences (i.e., between all 6 groups) were found on the proportion of participants who fell in the "unhealthy" range of family functioning for each FAD dimension; Problem Solving ($\chi^2 = 6.32$, $p = .28$), Communication ($\chi^2 = 6.75$, $p = .24$), Roles ($\chi^2 = 3.00$, $p = .70$), Affective Responsiveness ($\chi^2 = 9.76$, $p = .08$), Affective Involvement ($\chi^2 = 6.76$, $p = .24$), Behavior Control ($\chi^2 = 5.91$, $p = .32$), General Functioning ($\chi^2 = 2.12$, $p = .83$).

Relation between Family Functioning and Sociodemographic Variables

Due to lack of group differences on FAD scales, all groups were combined to evaluate the association between family functioning and sociodemographic variables. Significant correlations were found between child age and Communication ($r = .12$, $p < .05$), Affective Responsiveness ($r = .13$, $p < .05$), and General Functioning ($r = .12$, $p < .05$). Number of children living in the home was also significantly correlated with Communication ($r = -.15$, $p < .05$) and General Functioning ($r = -.12$, $p < .05$). Independent t-tests revealed significant differences in household income on Roles, t (288) = 2.17, $p < .05$, and Affective Involvement, t (288) = 1.96, $p = .05$. No significant family functioning differences were found for child gender, child minority status, or caregiver marital status.

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[1]Since data on the number of children living in the home was only available for 26 out of 57 children in the comparison group, this variable was excluded from analyses. However, an exploratory MANCOVA was performed with number of children as a covariate, yielding similar results.

DISCUSSION

Contrary to our hypothesis, data from the current study highlight that despite differences in treatment regimens, disease course, and prognosis, children across a variety of chronic conditions have similar family functioning to one another, as well as children who are otherwise medically healthy. Specifically, results revealed that group means for all family functioning dimensions were in the "healthy" range when using an empirically-supported family functioning assessment tool. This suggests that the presence of a specific chronic medical condition alone does not negatively influence *generic* family functioning. Despite the absence of significant group differences, our findings suggest that approximately one-quarter (e.g., general family functioning domain) of the families met clinical cut-offs for "unhealthy" family functioning, highlighting that a subsample of families would benefit from additional assistance or referrals for intervention.

Approximately 28% of families with chronic conditions perceived "unhealthy" family functioning in terms of the exchange of clear and direct verbal information among family members (Communication) and 36% perceived "unhealthy" functioning in the degree to which family members are involved and interested in one another (Affective Involvement). Families with a child with obesity or sickle cell disease appear to be at greatest risk based on clinical cut-off scores. These findings are consistent with prior research which documents less cohesion between family members and/or poorer communication among families with a child with a chronic pediatric condition.[38] Specifically, in childhood obesity, research has demonstrated that mothers of obese children characterized their family environment as having significantly less cohesion between family members compared to mothers of non-obese children[12]. Also, in sickle cell disease, medical crises and hospitalizations are believed to reduce the quality of time that families are able to spend with one another (e.g., Affective Involvement[39]) and tend to each other's needs.[40] Additionally, 36% of families endorsed "unhealthy" functioning in terms of the division of responsibility for completing family roles (Roles). Consistent with Rolland's typology of illness and prior research, many pediatric chronic conditions require complex daily treatments and/or ongoing monitoring[41] to attain positive health outcomes.[42] It is also not uncommon for roles within a family to shift during acute periods of pain, flare-ups, or exacerbations. For example, if a child is hospitalized, one caregiver may need to stay with the ill child in the hospital while the other caregiver negotiates care for siblings and household tasks. These findings likely have important implications for clinical practice. For example, families may benefit from strategies to improve communication, time management, and conflict resolution. Family functioning may also improve if roles are better negotiated prior to or during crises to promote optimal disease management.[43, 44] Within clinical settings, such cut-off scores may be useful in identifying specific areas within which families may experience difficulty, and consequently guide clinical intervention.

Results regarding the relations between family functioning and sociodemographic variables supported our a priori hypothesis and were generally consistent with prior literature; however, it is important to note that these associations were small. Older child age was associated with poorer Communication, Affective Responsiveness, and General Functioning. Developmentally, increasing child age, especially adolescence, is accompanied by attempts to achieve increasing levels of autonomy and challenge parental authority which,[45] as prior literature documents, often leads to greater family conflict, less parent-child cohesion, and poor communication.[46] This has led to increases in family-based interventions that target adolescents with pediatric conditions.[11] Significant differences on Roles and Affective Involvement were also found for household income, with poorer functioning for lower income households. It may be that lower household income is associated with a higher frequency of daily basic need demands which the primary caregiver (and FAD respondent) perceives falls inequitably to him/her. Lower SES has also been linked with greater marital conflict and

parenting stress,[8, 47] both of which can impede the degree to which family members are involved in one another's lives and daily activities (i.e., affective involvement). In addition, inconsistent with prior literature, better Communication and General Functioning was linked to a higher number of children living in the home. This may reflect that the presence of more children in the home necessitates more direct communication of needs, as well as providing a greater support network for solving problems and making daily decisions. The absence of differences in family functioning based on minority and marital status is somewhat inconsistent with earlier work.[8] One potential reason for these two findings is that the FAD is not sensitive to socio-cultural differences compared to measures used in prior studies. However, to date the FAD has been translated into at least 20 languages and has been applied cross-culturally, suggesting that the FAD is culturally competent and has broad cultural applicability.[34, 35] Taken together, these findings are a preliminary step in understanding family functioning in pediatric populations that are under-represented; however, future prospective studies should examine the role of these important socio-demographic variables.

Data from the current study builds upon the extant literature in several ways. First, prior research has documented inconsistent findings regarding family functioning in these chronic pediatric conditions, which may in part be due to the significant variability in how family functioning is defined and the measurement methods used.[24] Thus, the use of one empirically-supported generic family functioning assessment measure provides consistent data on this construct in chronic pediatric conditions, thereby increasing the generalizability of the findings. Second, this is one of the first studies to document family functioning across a wide age range for rarer conditions using larger samples (e.g., CF, IBD, SCD) and its association with sociodemographic factors. Finally, this study compared family functioning among several chronic pediatric conditions instead of only comparing to children who are otherwise medically healthy, by considering key disease characteristic (e.g., course, outcome) based on Rolland's established theory of disease typology and family processes.

However, our findings must be interpreted within the context of some limitations. First, the FAD assesses general components of family functioning, not disease-specific features of family functioning that may be more salient. For example, the pediatric diabetes literature illustrates the advantages of taking a disease-specific approach to understanding family functioning because communication around areas of disease management have been shown to be significantly related to outcomes.[48, 49] The FAD also relies on self-report of family functioning and does not provide an objective assessment of a family's actual functioning. This may be a limitation as families may overestimate their functioning to present themselves more favorably. Third, the impact of pediatric chronic conditions on family functioning was conceptualized according to only one theoretical framework, namely Rolland's psychosocial typology of illness.[20] Other theoretical models may take a different approach to understanding family functioning and yield different findings. Fourth, this study only assessed perceptions of family functioning from the primary caregiver and not children themselves. Children's perceptions of their own families influence their psychological adjustment and approach to disease management.[50, 51] Child functioning may consequently influence how parents perceive the family system, as well as the way they shape the family environment.[23] Future research examining perspectives of family functioning from multiple family members may provide a better representation of the family unit and subsequent focused goals related to clinical intervention (e.g., modeling, parent-child communication). Fifth, this study did not assess the impact of family functioning on child outcomes or whether the relationship between family functioning and child adjustment is different for children with and without a chronic pediatric condition. Lastly, because race is intrinsically tied to some of disease groups (e.g., SCD), the relation between race and family functioning was not examined, thereby decreasing our ability to speak to the cultural factors that relate to family functioning.

Secondary data analyses also impose some limitations. First, assessing family functioning at one time point using secondary data analyses (e.g., several independent studies) did not allow us to examine subtle variations in family patterns longitudinally or make causal inferences. Because families are constantly changing and they are required to adapt to ongoing illness-related demands and maintain homeostasis[50], future research should examine whether family functioning vacillates over time and identify critical periods that may pose particular challenges for families, placing them at risk for poor adjustment. It may be that family functioning is a stable construct that shows little variation pre- to post-illness. For example, when managing the stress of a child's chronic condition, high functioning families may continue to function at a high level. In contrast, families with a low pre-existing level of family functioning may continue to function poorly and ineffectively manage the child's condition. Second, secondary data analyses are constrained by the manner in which some variables are grouped or categorized across each independent study. Here, the manner in which household income was categorized (i.e., above/below 50K) may not have adequately captured the impact of income on family functioning, as documented by prior research. Though not possible in this study, examining income as a continuous variable or as distinct categories (e.g., $25K – $50K) may yield different findings.

Overall, findings from this study indicate that despite inherent differences in the nature of each chronic condition, families with children with and without pediatric conditions are not significantly different from each other. Our data suggest some family resiliency despite the presence of a chronic condition. However, it is important to recognize that some families exhibit deficits in communication and the division of responsibility for completing family tasks. This may require psychosocial interventions because it is likely that family functioning changes over time and may be "unhealthier" during acute periods of stress when the family system is disrupted.

Acknowledgments

REFERENCES

1. Cohen LL, La Greca AM, Blount RL, et al. Introduction to Special Issue: Evidence-Based Assessment in Pediatric Psychology. J Pediatr Psychol 2006;33:911–915. [PubMed: 16675715]

2. Holmbeck GN, Coakley RM, Hommeyer JS, et al. Observed and perceived dyadic and systemic functioning in families of preadolescents with spina bifida. J Pediatr Psychol 2002;27(2):177–189. [PubMed: 11821501]

3. Quittner, AL.; Drotar, D.; Iveres-Landis, C., et al. Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods, and interventions. Lawrence Erlbaum Associates Publishers; Mahwah, NJ US: 2000. Adherence to medical treatments in adolescents with cystic fibrosis: The development and evaluation of family-based interventions; p. 383-407.

4. Grey M, Boland EA, Yu C, et al. Personal and family factors associated with quality of life in adolescents with diabetes. Diabetes Care 1998;21(6):909–914. [PubMed: 9614606]

5. Hanson CL, De Guire MJ, Schinkel AM, et al. Comparing social learning and family systems correlates of adaptation in youths with IDDM. J Pediatr Psychol 1992;17(5):555–572. [PubMed: 1432481]

6. Whittemore R, Kanner S, Singleton S, et al. Correlates of depressive symptoms in adolescents with type 1 diabetes. Pediatr Diabetes Sep;2002 3(3):135–143. [PubMed: 15016153]

7. Duke DC, Geffken GR, Lewin AB, et al. Glycemic control in youth with type 1 diabetes: family predictors and mediators. J Pediatr Psychol 2008;33(7):719–727. [PubMed: 18296726]

8. Hayden LC, Schiller M, Dickstein S, et al. Levels of family assessment: I. Family, marital, and parent-child interaction. J Fam Psychol 1998;12(1):7–22.

9. Georgiades K, Boyle MH, Jenkins JM, et al. A multilevel analysis of whole family functioning using the McMaster Family Assessment Device. J Fam Psychol 2008;22(3):344–354. [PubMed: 18540763]

10. Laursen B, Coy KC, Collins WA. Reconsidering changes in parent-child conflict across adolescence: a meta-analysis. Child Dev 1998;69(3):817–832. [PubMed: 9680687]

11. Wysocki T, Harris MA, Buckloh LM, et al. Randomized, controlled trial of Behavioral Family Systems Therapy for Diabetes: maintenance and generalization of effects on parent-adolescent communication. Behav Ther 2008;39(1):33–46. [PubMed: 18328868]

12. Zeller MH, Reiter-Purtill J, Modi AC, et al. Controlled study of critical parent and family factors in the obesigenic environment. Obesity (Silver Spring) 2007;15(1):126–136. [PubMed: 17228040]

13. Stradmeijer M, Bosch J. Family Functioning and Psychosocial Adjustment in Overweight Youngsters. Int J Eat Disord 2000;27(1):110–114. [PubMed: 10590457]

14. Engstrom I. Inflammatory bowel disease in children and adolescents: Mental health and family functioning. J Pediatr Gastroenterol Nutr 1999;28:S28–S33. [PubMed: 10204521]

15. Rodenburg R, Meijer AM, Dekovic M, et al. Family factors and psychopathology in children with epilepsy: a literature review. Epilepsy Behav 2005;6(4):488–503. [PubMed: 15907744]

16. Ievers CE, Drotar D. Family and parental functioning in cystic fibrosis. J Dev Behav Pediatr 1996;17 (1):48–55. [PubMed: 8675714]

17. Noll RB, Swiecki E, Garstein M, et al. Parental distress, family conflict, and role of social support for caregivers with or without a child with sickle cell disease. Fam Syst Med 1994;12(3):281–294.

18. Mackner LM, Crandall WV. Brief Report: Psychosocial Adjustment in Adolescents with Inflammatory Bowel Disease. J Pediatr Psychol 2006;31(3):281–285. [PubMed: 15802606]

19. Midence K, McManus C, Fuggle P, et al. Psychological adjustment and family functioning in a group of British children with sickle cell disease: preliminary empirical findings and a meta-analysis. Br J Clin Psychol 1996;35(Pt 3):439–450. [PubMed: 8889085]

20. Rolland JS. Toward a psychosocial typology of chronic and life-threatening illness. Fam Syst Med 1984;2:245–262.

21. Rolland JS, Walsh F. Facilitating family resilience with childhood illness and disability. Curr Opin Pediatr 2006;18:527–538. [PubMed: 16969168]

22. Modi AC, Quittner AL. Utilizing computerized phone diary procedures to assess health behaviors in family and social contexts. Child Health Care 2006;35:29–45.

23. Alderfer MA, Fiese BH, Gold JI, et al. Evidence-based assessment in pediatric psychology: family measures. J Pediatr Psychol 2008;33(9):1046–1061. [PubMed: 17905801]

24. Drotar, D. Promoting adherence to medical treatment in childhood chronic illness: Concepts, methods, and interventions. Lawrence Erlbaum Associates; Mahwah, NJ: 2000.

25. McClellan CB, Cohen LL. Family functioning in children with chronic illness compared with healthy controls: a critical review. J Pediatr 2007;150(3):221–223. [PubMed: 17307532]

26. Brown RT, Wiener L, Kupst MJ, et al. Single parents of children with chronic illness: an understudied phenomenon. J Pediatr Psychol 2008;33(4):408–421. [PubMed: 17906331]

27. Epstein NB, Bishop DS, Levin S. The McMaster Model of Family Functioning. J Marital Fam Therapy 1978;4(4):19–31.

28. Dickstein, S.; Hayden, LC.; Schiller, M., et al. Providence Family Study mealtime family interaction coding system. Adapted from the McMaster Clinical Rating Scale. E.P. Bradley Hospital; East Providence: 1994.

29. Miller IW, Kabacoff RI, Epstein NB, et al. The development of a clinical rating scale for the McMaster model of family functioning. Fam Process 1994;33(1):53–69. [PubMed: 8039568]

30. Epstein NB, Baldwin LM, Bishop DS. The McMaster Family Assessment Device. J Marit Fam Ther 1983;9(2):171–180.

31. Cohen. Families coping with chronic childhood illness: A review. Fam Syst Health 1999;17:149–164.

32. Ridenour TA, Daley JG, Reich W. Factor analysis of the Family Assessment Device. Fam Process 1999;38:497–510. [PubMed: 10668625]

33. Miller IW, Epstein NB, Bishop DS, et al. The McMaster Family Assessment Device: Reliability and validity. J Marital Fam Ther 1985;11(4):345–356.

34. Ryan, CE.; Epstein, NB.; Keitner, GI. Evaluating and treating families: The McMaster approach. Taylor & Francis Group, L.L.C.; New York: 2005.

35. Wenniger W, Hageman W, Arrindell W. Cross-national validity of dimensions of family functioning: First experiences with the Dutch Version of the McMaster Family Assessment Device (FAD). Pers Indiv Diff 1993;14:769–781.

36. Goodman SN, Berlin JA. The use of predicted confidence intervals when planning experiments and the misuse of power when interpreting results. Ann Intern Med 1994;121:200–206. [PubMed: 8017747]

37. Kabacoff RI, Miller IW, Bishop DS, et al. A psychometric study of the McMaster Family Assessment Device in psychiatric, medical, and nonclinical samples. J Fam Psychol 1990;3(4):431–439.

38. Janicke DM, Mitchell MJ, Stark LJ. Family functioning in school-age children with cystic fibrosis: an observational assessment of family interactions in the mealtime environment. J Pediatr Psychol 2005;30(2):179–186. [PubMed: 15681312]

39. Mitchell MJ, Lemanek K, Palermo TM, et al. Parent perspectives on pain management, coping, and family functioning in pediatric sickle cell disease. Clin Pediatr 2007;46(4):311–319.

40. Spieth LE, Stark LJ, Mitchell MJ, et al. Observational assessment of family functioning at mealtime in preschool children with cystic fibrosis. J Pediatr Psychol 2001;26(4):215–224. [PubMed: 11329481]

41. Modi AC, Quittner AL. Barriers to Treatment Adherence for Children with Cystic Fibrosis and Asthma: What Gets in the Way? J Pediatr Psychol 2006;31(8):846–858. [PubMed: 16401680]

42. Wethers DL. Sickle cell disease in childhood: Part 1. Laboratory diagnosis, pathophysiology, and health maintenance. Am Fam Physician 2000;62:1013–1034. [PubMed: 10997528]

43. DiMatteo MR. The role of effective communication with children and their families in fostering adherence to pediatric regimens. Patient Educ Counsel 2004;55(3):339–344.

44. Kazak AE. Comprehensive care for children with cancer and their families: A social ecological framework guiding research, practice, and policy. Child Serv: Soc Policy, Res Pract 2001;4:217–233.

45. Santrock, JW. Adolescence. 8th ed.. McGraw-Hill; Boston: 2000.

46. Allison BN, Schultz JB. Parent-adolescent conflict in early adolescence. Adolescence 2004;39(153):101–119. [PubMed: 15230069]

47. Conger RD, Donnellan MB. An interactionist perspective on the socioeconomic context of human development. Annu Rev Psychol 2007;58:175–199. [PubMed: 16903807]

48. Anderson BJ, Brackett J, Ho J, et al. An office-based intervention to maintain parent-adolescent teamwork in diabetes management. Impact on parent involvement, family conflict, and subsequent glycemic control. Diabetes Care 1999;22(5):713–721. [PubMed: 10332671]

49. Hood KK, Butler DA, Anderson BJ, et al. Updated and revised Diabetes Family Conflict Scale. Diabetes Care 2007;30(7):1764–1769. [PubMed: 17372149]

50. Kazak AE. Families of chronically ill children: a systems and social-ecological model of adaptation and challenge. J Consult Clin Psychol 1989;57(1):25–30. [PubMed: 2647800]

Table 1

Sociodemographic and Health Variables by group

	Cystic Fibrosis (a) n = 59	Obesity (b) n = 28	Sickle Cell Disease (c) n = 44	Inflammatory Bowel Disease (d) n = 43	Epilepsy (e) n = 70	Comparison Group (f) n = 57
	M(SD) or %	M (SD) or %	M (SD) or %	M (SD) or %	M (SD) or %	M (SD) or %
Family-based Variables						
*Income:> 50K	54%b, c, d	25%a, d, f	16%a, d, e, f	93%a, b, c, e, f	42%c, d	51%b, c, d
*Marital Status: single	15%b, c, e, f	62%a, d, e	71%a, d, e, f	5%b, c, e, f	36%a, b, c, d	38%a, c, d
# children in the home	2.3 (0.9)d, e, f	2.0 (0.8)c, d, e, f	2.7 (1.6)b, d	1.3 (1.0)a, b, c, e, f	2.8 (1.1)a, b, d	3.2 (1.9)a, b, d**
Caregiver: mothers	81%	92%	84%	91%	81%	91%
Child-based Variables						
*Child Age in years	12.5 (4.2)b, c, d,e,f	9.9 (2.0)a, d, f	10.8 (1.5)a, d, e	15.4 (1.4)a, b, c, e, f	8.85 (2.0)a, c, d, f	11.4 (3.2)a, b, d, e
	Range: 6–18	Range: 5–12	Range: 7–13	Range: 13–18	Range: 5–13	Range: 6–17
*Child Sex: female	58%e	68%d, e	50%	40%b, f	37%a, b, f	67%d, e
Child Race	White: 98%	White: 32%	Black: 100%	White: 88%	White: 67%	White: 70%
	Black: 2%	Black: 54%		Black: 7%	Black: 20%	Black: 25%
		Other: 14%		Other: 5%	Other: 13%	Other: 5%
Health/Disease Status or Severity Indicator	FEV$_1$ % predicted: 78.2 (25.3)	BMI: 32.4 (5.7) zBMI: 2.5 (0.3)	SS: 83% SC: 11% SS+Thal: 6%	PCDAI: 13.3 (10.1) LCAI: 3.1 (4.7)	Partial: 56% Generalized: 31% Unclassified: 13%	N/A

Note.

FEV 1: Forced expiratory volume in one second, BMI: Body Mass Index, zBMI: Standardized BMI, SS: Sickle Cell Anemia, SC: Sickle-Hemoglobin C Disease, SS+Thal: Sickle Beta-Plus Thalassemia, PCDAI: Pediatric Crohn's Disease Activity Index, LCAI: Lichtiger Colitis Activity Index.

* Significant group differences were noted; superscript letters denote significant post-hoc differences.

** Data was only available for n=26 of 57 children only.

Table 2

Study Characteristics

Chronic condition	Study Type	Site	Recruitment Method	Recruitment Rate
Cystic fibrosis (N = 59)	Cross-sectional: Examining psychosocial functioning in patients with CF	CCHMC	1.) Initial mailing 2.) Approached in clinic/hospital	86%
Obesity (N = 28)	Cross-sectional: Assessing family functioning and mealtime behavior among obese children at treatment initiation and nonoverweight comparisons	CCHMC	1.) Initial mailing 2.) Approached at initial clinic visit	89%
Sickle Cell Disease (N = 44)	Cross-sectional: Focus group study to understand how parents and children manage SCD pain	CCHMC, NCH & RBCH	1.) Initial mailing 2.) Phone calls	Unknown due to recruitment methods
Inflammatory Bowel Disease (N = 43)	*Longitudinal: Examining nonadherence in IBD, and family/patient behavioral correlates of nonadherence	CHOP & CCHMC	1.) Patient lab report lists 2.) Approached in clinic visit	76%
Epilepsy (N = 70)	*Longitudinal: Examining adherence and psychosocial functioning in children with new-onset epilepsy	CCHMC	1. Approached at initial clinic visit	96%
Comparisons (N = 27)	Cross-sectional: Assessing family functioning and mealtime behavior among obese children at treatment initiation and nonoverweight comparisons	CCHMC	1. Initial mailing to volunteers in a healthy controls clinical database, the pediatric primary care (PPC) clinic, or a general hospital-wide email 2. PPC patients were approached at a regular clinic appointment	89%
(N = 30)	Cross-sectional: Comparing psychosocial functioning of children with and without immunodeficiency disorders	WV	1.) Approached during routine visit to pediatrician	94%

Note.

CCHMC – Cincinnati Children's Hospital Medical Center; NCH -Nationwide Children's Hospital; RBCH – Rainbow Babies and Children's Hospital; CHOP – Children's Hospital of Philadelphia; WV – West Virginia University School of Medicine.

*
All FAD data from longitudinal studies were collected at the baseline visit.

Table 3

Proportion (%) of each group meeting clinical cut-off ("unhealthy" family functioning) across FAD dimension.

FAD Dimension	CF	Obesity	SCD	IBD	Epilepsy	Healthy Comparisons	All Chronic Conditions	χ^2
	%	%	%	%	%	%	%	
Problem Solving	8	21	16	12	13	7	13	6.32
Communication	27	46	25	30	23	23	28	6.75
Roles	41	36	41	30	31	30	36	3.00
Affective Responsiveness	7	25	23	19	14	10	16	9.76
Affective Involvement	29	50	45	28	34	37	36	6.76
Behavior Control	19	21	30	12	21	15	21	5.91
General Functioning	22	29	32	26	23	24	25	2.12

Note. CF - Cystic fibrosis; SCD - Sickle cell disease; IBD - Inflammatory bowel disease. No significant group differences were found on the proportion of participants who fell in the "unhealthy" range of family functioning for each FAD dimension.

Table 4

Family Functioning Across Groups

FAD Dimension	Cystic Fibrosis M (SE)	Obesity M (SE)	Sickle Cell Disease M (SE)	Inflammatory Bowel Disease M (SE)	Epilepsy M (SE)	Healthy Comparisons M (SE)	F	Effect Sizes Cohen's d
Problem Solving	1.86 (.05)	1.82 (.08)	1.88 (.08)	1.88 (.06)	1.84 (.05)	1.78 (.05)	.50	−.08 – .25
Communication	1.86 (.05)	1.92 (.08)	1.98 (.08)	2.04 (.07)	1.88 (.05)	1.82 (.05)	1.94	−.39 – .41
Roles	2.22 (.05)	2.19 (.08)	2.15 (.08)	2.22 (.07)	2.13 (.05)	2.12 (.06)	.58	−.07 – .23
Affective Responsiveness	1.72 (.06)	1.74 (.09)	1.79 (.09)	1.82 (.08)	1.65 (.06)	1.67 (.06)	1.0	−.28 – .42
Affective Involveme	1.88 (.06)	1.97 (.09)	1.91 (.09)	1.89 (.07)	1.86 (.05)	1.88 (.06)	.24	−.30 – .32
Behavior Control	1.59 (.05)	1.54 (.08)	1.60 (.08)	1.60 (.07)	1.54 (.05)	1.52 (.06)	.31	−.18 – .33
General Functioning	1.64 (.05)	1.68 (.08)	1.77 (.08)	1.74 (.07)	1.60 (.05)	1.58 (.05)	1.52	−.22 – .32

Note. No significant group differences were found on FAD scales. Clinical cut-off scores for FAD scales are as follows: Problem Solving = 2.20; Communication=2.20; Roles=2.30; Affective Responsiveness=2.20; Affective Involvement=2.10; Behavior Control=1.90; General Functioning=2.00. Means presented are estimated marginal means; Covariates appearing in the model were evaluated at the following values: income = .51, marital status = .66.