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Family Functioning and Pediatric Chronic Illness:

A Critical Review

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Chronic illness is defined as a condition that either interferes, or will likely interfere, with an individual's daily functioning for at least three months of a year, or a condition that will require hospitalization for more than one month of a year.[1] Estimated prevalence rates indicate that 10 to15% of American children and adolescents suffer from chronic illness in childhood.[2,3] The impact of chronic illnesses upon children and their families can range from minimal disruptions to severe distress and functional limitations.

Advances in medical care and technology have increased the lifespan of children with chronic illness as well as decreased the frequency of readily observable disease impacts on this population. To enhance our understanding of the more subtle, but equally important, impacts of pediatric chronic illnesses, researchers have expanded the domains assessed to include measurement of child adjustment. Of the psychosocial measures of child adjustment, family functioning has been investigated more often than any other variable (Wallander & Thompson, 1995). Family functioning has been demonstrated to play an essential role in adjustment to chronic illness (Thompson et al., 1999).

Family functioning is a broad construct and is often used as an umbrella term that encompasses several constructs including parents' satisfaction with their parenting role, positive parent-child interactions, family communication, family adaptability, and family cohesion (Rolland, 1993). Without these components of good family functioning, it can be difficult for parents and their children to adhere to the strict treatment regimens required for optimal health.[7,8] In addition, good family functioning has been demonstrated to be more important than disease severity in predicting the psychosocial outcomes of children with chronic illness.[9-11] Researchers

examining the relation between family functioning and rearing a child with a chronic illness have found deficits in family cohesion, family adaptability, parent-child interactions, family conflict, and family problem-solving skills.[12-14] Understanding the nature and development of these deficits in family functioning is key to the formulation of interventions designed minimize the impact of childhood chronic illness on family functioning. Additionally, exploring the role of chronic illness on family functioning will clarify the role of the mechanisms that lead to shifts in family functioning.

We currently know that family functioning is related to the physical and mental well-being of children with chronic illness; however, we lack a clear understanding of whether families with chronically ill children are significantly more likely to have difficulties in functioning compared to families of healthy children. The purpose of the present paper was to review the studies examining the functioning of families of children with a range of chronic illnesses, critique the body of studies; and highlight parallels across the literature and provide directions for future study in the area of family functioning of chronically ill children.

There are several reasons for only including studies that have employed healthy control families. By using demographically matched healthy control group researchers reduce several methodological limitations and draw stronger conclusions regarding the impacts of childhood chronic illness on family functioning than when standardized instrument norms are used for comparison. In a meta-analytic review examining children's adjustment to chronic illness, authors concluded that although many researchers found elevated rates of adjustment difficulties for these children; these elevations were not significant in research comparing the functioning of chronically ill children to that of healthy controls.[15] Additionally, measures of family functioning have traditionally been developed with families of children without chronic illnesses. This raises the question of whether factors associated with adaptive family functioning in families of

children with chronic illnesses are the same as those found in families of physically healthy children.

Cystic fibrosis (CF), juvenile rheumatoid arthritis (JRA), type 1 diabetes/juvenile onset diabetes, asthma, hemophilia and sickle cell disease (SCD) were selected for this review because they represent some of the most common chronic childhood illnesses, and comprise a broad spectrum of childhood chronic illness. Although there are some substantial differences between across these six illness groups, they are similar in that they are all chronic, can result in disability, and require adherence to a demanding treatment regimen.

REVIEW INCLSION CRITERIA

The current review used the following inclusion criteria: (a) articles were listed in MEDLINE or PsycINFO databases under the following combined search terms: (i) cystic fibrosis OR juvenile rheumatoid arthritis OR diabetes OR asthma OR hemophilia OR sickle cell disease; (ii) family functioning OR family coping OR family adjustment; (b) the study population focused on pediatric, as opposed to adult, chronic illness; and (c) a healthy control group was included for comparison. Following a literature search, 15 articles were identified that met these criteria. Given the limited number of studies and the range of outcome measures, employing meta-analytic techniques to evaluate this body of work was not feasible. Therefore the following represents a critical review of the available literature.

REVIEW OF THE LITERATURE

All 15 of the studies included in the current review are detailed in Table 1. Many of the studies reviewed included self-report of family functioning from both mothers and fathers when available (n = 8) and half of those also included child or adolescent report (n = 4). Two of the studies employed observational measures of family functioning, and one of those also included a child and parent report measure. The remaining 5 studies only included mother-only or

individual parent report of family functioning. All studies employed group designs, and one study employed a longitudinal design. On average, there were 28 families in the chronically ill groups (range = 12 to 47) and 32 families in the physically healthy control group (range = 12 to 62). Child age ranged from 1 month to 18 years.

Cystic fibrosis. The literature examining family functioning of families with a child with CF indicates varying results with regard to the impact of chronic illness on family functioning. Researchers have employed parent-report measures to assess parenting stress levels and aspects of marital relationships.[14,16] Results demonstrate that, when compared to parents of children without chronic illnesses, parents of children with CF reported significantly higher levels of parenting stress. Additionally, mothers of children with CF reported decreases in time available to spend with their spouses.

Although self-report measures, such as those employed by Sawyer et al.[14] and Goldberg et al.[16], are practical and require minimal family involvement and disruption, they are also subject to reporting biases and are not always predictive of actual behavior. Observational measures, such as the one employed by Spieth et al., are considered by many to be the gold standard of measurement in that they allow researchers to obtain highly objective and quantifiable information on aspects of family functioning, such as how families interact during mealtime. [17] In their study of family functioning, Spieth et al. employed an observational coding system to systematically evaluate videotapes of family meals. Researchers concluded that the functioning of families with a child with CF was significantly lower than that of healthy control families on domains of communication, interpersonal involvement, affect management, behavior control, and role allocation.

Although much of the available research comparing the functioning of families with children with CF to families of physically healthy children demonstrated decrements in

functioning, some research has demonstrated that having a child with CF can result in few differences and even improved family functioning on some domains. Specifically, researchers found no significant differences between the family functioning of families with children with CF compared to families of physically healthy children on parent-report measures of families functioning.[18,19]

Other researchers have demonstrated improved family functioning in families of children with CF as compared to healthy control families. On an in-vivo problem solving task, families of adolescents with CF were more likely to be categorized as good problem solvers than were families of physically healthy adolescents.[18] A possible explanation of the improved functioning in families of children with CF is that families of children with CF may encounter challenges, such as logistical problems associated with managing medical care, on a more frequent basis. As such, families with an adolescent with CF may have developed greater proficiency in resolving these challenges over the years. Cowen et al. found that fathers of young children with CF were more likely to report positive family functioning than were fathers of physically healthy children.[20] This pattern of elevated ratings of family functioning in fathers could indicate improvements in family functioning in these families, or a pattern of coping adopted by the fathers of these children. Specifically, researchers noted that parents of children with CF demonstrated elevations on scales assessing social desirability as well as those assessing denial. Therefore, the researchers concluded that fathers' response pattern might reflect the adoption of a coping style centered upon minimizing or denying the impact of illness related stressors on family life in an effort to cope with the long-term challenges of parenting.

Type 1 diabetes. Similar to examinations of family functioning in CF, research investigating the family functioning of children with type 1 diabetes centered on the use of parent-report measures. For the most part, researchers comparing family functioning in families

of children with type 1 diabetes to that of families with physically healthy children found few to no significant differences on domains of family functioning.[21-23] Similar to researchers investigating family functioning in families with a child with CF, research investigating families of children with type 1 diabetes found that mothers of children with diabetes reported having less time to engage in activities with their children as compared to mothers of physically healthy children.[22] Also consistent with the CF literature, parents of children with type 1 diabetes reported adopting a somewhat differing set of family values as compared to families of physically healthy children. Specifically, they were significantly more likely to describe their families as less achievement oriented when compared to families of physically healthy children.[22]

Juvenile rheumatoid arthritis. Research investigating functioning in families of children and adolescents with JRA as compared to families of physically healthy control children is consistent with the CF and type 1 diabetes literature in both the predominate reliance on parent report measures and in the lack of significant differences between the family functioning of these groups.[24-26] For the most part, researchers found no differences between families of children with JRA and physically healthy families.[24-26] A strength of this literature is the research conducted by Huygen et al., which included a comparison families of children (ages 6 to 11 years) to families of adolescents (ages 12 to 16 year).[25] Because the challenges faced by these families can vary dramatically as a function of the child age, separating these two groups proved to be useful in identifying differences in family functioning. Researchers demonstrated that children (ages 6 to 11 years) with JRA reported greater family cohesion and less family adaptability than did children without JRA. This finding was not demonstrated by the adolescent group. Possible explanations for the reports of increased family cohesion in families of children with JRA include that the emphasis that these families place on caring for the physical needs of

their child. Adaptability is also likely to be influenced by child disease status; in that parents of physically healthy children likely have fewer restrictions on their activities when compared to parents of children with JRA, who are likely to have many of their activities dictated by their child's treatment regimens.

Sickle Cell Disease. The prospects of investigating family functioning in children with Sickle Cell Disease (SCD) highlights the importance of including a healthy control groups. Because children with SCD are predominately from an ethnic minority groups and many of these families experience higher than average rates of economic hardship, the possibility of drawing inaccurate conclusions regarding the impact of SCD on family functioning is elevated.[27,28]

Unfortunately, research comparing the functioning in families of children with SCD to families of physically healthy children is sparse, with only two published articles meeting our criteria. Interestingly, despite assessing family functioning via the same method (parent report) and measure (Family Environment Scale) the results of these two studies provide divergent conclusions regarding the functioning of families with a child with SCD. Specifically, while Noll and colleagues found no significant differences in the functioning of families with children with SCD as compared to physically healthy children, Midence and colleagues found greater parent-reported cohesiveness and reductions in family conflict.[29,30] A possible explanation of these divergent findings is the geographical differences between the samples, with one study drawing their population from a group of British families with SCD and the other study from families residing in the United States. Also of note is the extensive cultural sensitivity training and careful monitoring of the data collectors in the former, but not the later study. Midence and colleagues posit that although the improved functioning reported by families of children with SCD could simply reflect improved family functioning, another explanation could be a pattern whereby parents demonstrated increases in family protectiveness and a resultant decrease in reporting of

family conflict.[30] The emphasis Noll and colleagues placed on cultural sensitivity training might have resulted in families of children with SCD feeling less threatened and being less likely to respond in a protective manner.[29]

Hemophilia. Only one article was found comparing the family functioning of families with a child with hemophilia to families of physically healthy children.[31] This area of research is unique in that hemophilia occurs predominately in males, highlighting the importance of considering the role of child gender in family functioning issues. The researchers of this article found no significant difference between the parent reports of the functioning in families with a boy with hemophilia as compared to families with physically healthy boys. This authors did note that, in general, the parents of boys with hemophilia were reported a greater total number of family functioning difficulties, but that their small sample size prevented these differences from being in the significant range.

Asthma. Given the prevalence of asthma in the general population, it is surprising that only one study was identified in which researchers compared the functioning of families of children with asthma to those of families with physically healthy children.[21] This study included a group of children with diabetes and was reviewed above. Briefly, this article revealed that although mother's of children with asthma reported elevated rates of problems with social support, child behavior, and stressful events, no significant differences emerged on measures of family functioning.

CRITICAL EVALUATION

In summarizing the results that can be drawn from this body of literature, it is first essential to consider the findings in light of the methodological limitations present in the research reviewed. The majority of the investigations included in this review employed a single measure of family functioning, and two of the studies obtained mother report alone. [11,16,17,19-22,30,31] Family

functioning is a multifaceted construct, and it is unlikely that any single measure or single report could capture the many important dimensions that comprise family functioning.

Research has demonstrated that factors outside of family functioning, including children's medication adherence and parental depression, can influence parental report of family functioning and parental ratings of their children's behavior.[15,32] Other researchers found that parent report of activities may not accurately reflect true behaviors. For example, Quittner et al. found that although mothers of CF children do not perceive their parenting role differently than mothers of healthy children, behavioral assessment revealed significant differences in the activities of mothers of CF children compared to mothers of healthy children.[32] These findings support the need for multi-informants and multiple methods of assessment when investigating family functioning.

An additional limitation of this research is the extreme variation in the age of the child participants. Had the sample sizes been larger, problems associated with the large age range might not have been as severe. Illness related issues that impact family functioning might differ at different ages and developmental periods. For example, whereas families of children with CF and those with physically healthy children may face many of the same stressors, the declines in health associated with increased age in CF individuals may make age an important variable when investigating family functioning. Similarly, parents of adolescents with type 1 diabetes and JRA may experience greater conflict associated with treatment adherence issues than they experienced when their children were younger. By including all participants in the same group, regardless of age, the researchers may have diluted effects that could have been present if larger groups of same age range participants were examined.

The majority of research reviewed attempted to match the healthy and control families by including a healthy child who was similar in age, gender and ethnicity to the chronically ill child.

Unfortunately, few studies considered additional variables when matching. For example, only two studies considered the number of other children in the home.[17,22] By matching not only basic demographics, but also for other important variables, such as the number of other children in the families, researchers would have been better able to attribute any differences between the two families to disease status rather than to extraneous differences such as stress resulting from parenting a large number of children. In addition, only two groups of researcher appeared to have queried the families as to whether any of their other children had chronic illnesses.[19,22] Since all illness groups included in this review have some genetic or hereditary components, it is possible that some families had more than one child with a chronic illness. The impact of two or more chronically ill children on family functioning could be quite different than the impact of a single chronically ill child.

Throughout the literature reviewed, the majority of the researchers neglected to consider how illness-related factors, such as disease severity and amount of time that the child has been ill, relate to family functioning. Some researchers only included children with illness severe enough to be considered active or to require daily treatment.[21,25] By including only participants with active illnesses, the researchers increase the likelihood that they will be able to find differences between the two groups, should such differences exist. Other researchers investigated the relation between disease severity and family functioning.[11,29] Only a few researchers required a specific post-diagnosis time period.[19,21,23] This selection criterion represents a strength in the research, since it allows for some control of functioning difficulties related to adjustment to a recent diagnosis. Researchers have demonstrated that families are typically shocked when their child is first diagnosed with type 1 diabetes.[33] Families that have not had much time to adjust to the diagnosis may be functioning far worse than they would be once they have had time to adjust to the illness and to incorporate the treatment regimen into their lives. By grouping together

participants who have been ill for a number of years with those who have been recently diagnosed, the relation between childhood chronic illness and family functioning may have been less apparent.

RECOMMENDATIONS FOR FUTURE RESEARCH

Future examinations of family functioning and childhood chronic illness should include multi-method assessments of family functioning. Ideally, research examining family functioning would include reports of the family functioning from all members of the family, in addition to observational measures to directly assess family interactions. By obtaining information concerning family functioning from multiple sources, researchers will have a richer and more accurate picture of the families' true functioning. Observational measures of family functioning will allow researchers and clinicians to identify objective indices of family functioning that can be evaluated during research and treatment. Such indices might include frequency of arguments between family members and expression of positive affect displayed during family interactions. For example, researchers could observe how compliant a child is with their parent's requests to take their medications. Although this would be time-consuming and expensive for researchers to obtain and code this data, it would provide researchers with objective and quantifiable data that cannot reliably be obtained through parent-report.

Multi-site research, rather than sampling from a single clinic group, will allow researchers to increase the size of their samples and the generalizability of their findings. In addition to considering the site from which participants are drawn, other participant characteristics deserve consideration in future research. These include the impact of previous parenting experience on family functioning, child gender and ethnicity, whether additional children with chronic physical or mental illnesses reside in the home, and whether the family in question is a traditional, two-biological parent family or whether they are a non-traditional

family. By neglecting to consider these participant variables, previous researchers may have been unable to fully discern the influence of chronic illness upon family functioning.

Although difficult to conduct, longitudinal investigations of family functioning are needed to explore the processes by which chronic childhood illnesses influence and impact family functioning. By examining families as they progress from initial diagnosis to key developmental phases, such as school entry and adolescence, we can determine the periods that are most challenging and develop protocols to mediate these threats to optimal family functioning. Additionally, longitudinal research allows for the identification of the role of other variables, such as disease severity, in predicting family functioning.

By conducting methodologically sound, high quality research in this area it will be possible to conclude whether families with chronically ill children are indeed at increased risk for problematic functioning. Such research would also bolster the current understanding of the process by which families confront stressful events and how these events relate to their functioning. In addition, assessment work in this vein should highlight directions for intervention and delineate recommendations to other families about how to navigate stressful life events.

SUMMARY

Family functioning, broadly defined, has been shown to relate to a number of variables key to successful management and treatment of children with chronic illness. To understand how families of chronically ill children function, research comparing the functioning of families with children who had CF, type 1 diabetes, JRA, SCD, hemophilia and asthma to healthy control families was reviewed. Despite the methodological limitations described above, several important conclusions can be drawn from the reviewed literature. Most importantly, it appears that childhood chronic illness does not have a systematic negative impact family functioning. Furthermore, families appear to be able to adapt effectively to the challenges they face in the job

of raising a child with a chronic illnesses. One of the more consistent findings was that parents of children with chronic illness, and mothers in particular, report having less time available to spend with their spouse or other children, or on activities outside the home.[14,22] In light of this finding, one is not surprised to learn than parents of children with chronic illnesses are reporting some increases in parenting stress.[16] These shifts in available time for other activities do not necessarily result in negative changes in family functioning. Many families appear to adapt and thrive in light of their child's illness by developing improved problems solving skills, shifts in how they value external achievement and higher levels of family cohesion.[18,22,25]

Taking the limitations into account, there does seem to be initial support for the notion that families with a child with chronic illness encounter barriers to optimal family functioning, however, most families function similarly to families of healthy children. Whether families with a child with chronic illness learn and use effective coping skills, have high resiliency, focus on the positive, have the ability to adapt to stressors, or possess other adaptive characteristics are intriguing ideas that deservers further investigation. Other suggestions for future research include longitudinal research designs, multiple informants, and the use of more sensitive measures to evaluate family functioning.

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