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Original Research

Parents' Perceptions of Functioning in Families Having a Child with a Genetic Condition

Kathleen A. Knafl,[1,4] George J. Knafl,[1] Agatha M. Gallo,[2] and Denise Angst[3]

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In a study of families having a child with a genetic condition, patterns of family functioning were identified through cluster analysis of families with two spouses. Patterns were based on both parents' assessments of family satisfaction and hardiness, as measured respectively by the Family APGAR and Family Hardiness Index. The validity and clinical significance of the clusters were supported by demonstrating that cluster membership distinguished between parental reports of their own quality of life and their child's functional status, as measured by the Quality of Life Index and the Functional Status II, respectively. The clusters were non-categorical in the sense that they did not depend on the type of genetic condition. These findings point to the importance of addressing family functioning as part of genetic counseling.

KEY WORDS: family research; genetic condition in childhood; cluster analysis.

INTRODUCTION

Research on psychosocial issues facing families in which one or more children have a genetic condition complements human genome research directed toward risk expression and mechanisms of disease. Advances in genetic science, especially when not accompanied by curative treatments, raise complex practical, emotional, and psychological issues for families (Street and Soldan, 1998). Psychosocial research on family response to a child's single-gene genetic condition has begun to highlight the unique challenges these families face and the ways in which their experiences differ from those of families in which a child has another type of health-related condition. Prior studies have identified a number of distinctive sources of stress for families having a child with a genetic condition, including lack of understanding of risk, lag time between genetic discoveries and available treatments, fear of loss of privacy, stigma and possible discrimination in employment, insurance, or school admission (Blanck and Marti, 1996; Collins and Jenkins, 1997; Feetham, 1999; Gallo *et al.*, 2005; Greely, 2005; Hudson *et al.*, 1995; Kass *et al.*, 2004; Plantinga *et al.*, 2003; Sorenson *et al.*, 2003).

Recognizing the unique challenges of genetic conditions for parents and families, researchers have begun to study family response and functioning in families having a child with a genetic condition. For the most part, studies comparing such families to families with all healthy children have found comparable levels of functioning (Sawyer, 1992; Thanarattanakorn *et al.*, 2003). These and other studies report healthy levels of family functioning and overall satisfaction with family life (Chernoff *et al.*, 2001; Hilbert *et al.*, 2000).

[1] Oregon Health & Science University, School of Nursing, Portland, OR.
[2] University of Illinois at Chicago, College of Nursing, Chicago, IL.
[3] Advocate Health Care, Oak Brook, IL.
[4] Correspondence should be directed to Kathleen A. Knafl, Oregon Health & Science University, School of Nursing, Portland, 3455 Veterans Hospital Road, MAILCODE SN-ADM, Portland, OR 97239; e-mail: knaflk@ohsu.edu.

Researchers also have addressed the relationship between family functioning and the health and psychosocial adaptation of children with genetic conditions. Although studies have documented that having a genetic condition puts children at risk for psychosocial problems, research also points to the moderating effect of family functioning on child outcomes (Balfour-Lynn *et al.*, 1995; Eddy *et al.*, 1998; Fanos, 1997; Fanos and Johnson, 1995a, 1995b; Geller, 1995; Loader *et al.*, 1996; Thompson *et al.*, 1999, 2003; Wertz *et al.*, 1994). Findings from these studies indicate the potentially negative effects of a genetic condition on multiple aspects of child functioning, including decreased self-esteem and self-worth, disruption of parent-child or sibling-sibling relationships, and increased anxiety and guilt. Despite these risks, however, there is evidence that family variables can be a significant protective factor for children. For example, in a study of 289 children with sickle cell disease, Thompson *et al.* (1999) found that only a small group of mothers (9%) consistently reported behavioral problems in their children. In contrast to the majority of children participating in the study, those with behavioral problems lived in families characterized by high levels of conflict. Similarly, in a study of 73 families of children with cystic fibrosis, Patterson *et al.* (1990) found that the family variables of family stress and resources explained 22% of the variance in children's height, weight, and pulmonary functioning over a 15-month time span. Though based on different measures of family functioning, studies such as these highlight the importance of understanding family functioning in the context of a child's genetic condition and the contribution of family processes to child outcomes.

Although current research provides initial insights into the nature and importance of family functioning in the context of a child's genetic condition, it has relied heavily on maternal reports and single measures of family functioning. As such, research to date provides a limited view of how family systems adapt to the challenges of a child's genetic condition. Moreover, most studies have focused on a single condition, usually cystic fibrosis or sickle cell disease, making it difficult to know if there are patterns of family response that characterize a variety of genetic conditions. In order to develop a more sophisticated understanding of family functioning in the context of a child's genetic condition, it is necessary to study varied genetic conditions and to gather data from multiple family members on multiple aspects of family life. In this paper, using the statistical technique of cluster analysis, we describe patterns of family functioning based on mothers' and fathers' assessments of two aspects of family functioning—satisfaction and hardiness. In addition, evidence for the clinical significance of the identified patterns is provided based on an analysis of their relationship to parental quality of life and child functioning.

METHODS

Study Design

This paper reports on a subgroup of a larger, mixed-methods study of 86 families (142 parents) in which a child has a genetic condition (Gallo *et al.*, 2001). The overall aims of this non-categorical study focused on the identification of patterns of family information management with regard to a child's genetic condition. A non-categorical design focuses attention on living with a genetic condition rather than on the biological aspects of disease management (Perrin *et al.*, 1993) and directs attention to common psychosocial challenges.

Following institutional review board approval at all sites, families were recruited from three outpatient specialty clinics in the Chicagoland area that served urban and suburban children with genetic conditions. Families were contacted about participation by a letter from the clinic director or in person by a member of the research team. Parents were eligible if the child with the genetic condition (a) had a single-gene genetic condition, (b) was 3–15 years of age, (c) was the biological offspring of at least one parent, and (d) attended a regular school classroom. In families in which there was more than one child with the condition, the interview focused on parents' experiences with the oldest child; in two-parent families both parents were invited to participate. Of those parents who initially indicated interest in the study ($N = 155$), 13 declined to participate.

Parents individually participated in semi-structured interviews that addressed how they accessed, interpreted, and used genetic information. They also completed standardized measures of individual and family functioning. This report, which is based on data from the standardized measures, describes parents' perceptions of family functioning. Findings based on the interview data are reported elsewhere (Gallo *et al.*, 2005).

Sample

This report is based upon those families having a child with a genetic condition in which both parents participated ($n = 52$ pairs). We focused on families in which both parents participated in the study in order to consider both parents' perceptions of family functioning as well as the degree to which those perceptions were shared or discrepant.

Measures

Parents completed structured measures of individual and family functioning. The current analysis draws on parents' reports of family functioning as measured by the Family APGAR (Austin and Huberty, 1989; Smilkstein, 1978) and the Family Hardiness Index (H. McCubbin and Thompson, 1991; H. McCubbin *et al.*, 1996). These two measures were selected because they tapped important, conceptually distinct aspects of family life and focused on family functioning and strengths rather than dysfunction.

The Family APGAR is a 5-item instrument designed to measure family members' satisfaction with five basic components of family life: adaptation (family problem solving), partnership (sharing responsibility and decision making), growth (physical and emotional maturation as well as self-fulfillment), affection (caring or loving relationships within the family), and resolve (commitment to share time, space, and material resources with other family members). Item scores range from 0–4 with overall scores from 0–20. Higher scores indicate better family satisfaction. Prior studies have reported high internal consistency reliability, indicating that the Family APGAR is a unidimensional measure of satisfaction with family life (Sawin and Harrigan, 1995). Internal consistency reliability was high in the current study, with Cronbach's alpha of .86.

The Family Hardiness Index (FHI) measures the internal strengths and durability of the family. Hardiness is among the critical aspects of family resiliency (M. McCubbin and McCubbin, 1996) and is conceptualized as mitigating the negative effects of stress on family functioning. The FHI was selected because of its active orientation; it is a measure of how families work together to manage challenges. Family hardiness is characterized by a sense of control over outcomes of life events and hardships, a view of change as beneficial and growth-producing, and an active rather than a passive orientation in adjusting to and managing stressful situations. The FHI has been used in other studies of families in which a child has a chronic condition (Donnelly, 1994; Failla and Jones, 1991) and is comprised of 20 items rated from 0–3, producing an overall score between 0–60. Higher scores indicate a greater degree of family hardiness. The developers of the scale reported an internal consistency reliability of .82 (Sawin and Harrigan, 1995). The internal consistency reliability in the current study was .81.

Parents also completed structured measures of their quality of life and the functional status of the child with the genetic condition. These individual functioning measures were used to assess the validity and clinical significance of the clusters generated from family functioning measures. It was hypothesized that different patterns of family functioning would be associated with different levels of parental and child functioning. These measures were selected because prior research has demonstrated that the functioning of individual family members is moderated by the overall functioning of the family system (Knafl and Gilliss, 2002; Wallender and Varni, 1998).

Quality of life was measured using the overall scale of the Quality of Life Index (QLI) (Ferrans and Powers, 1985, 1992). Items are separated into two main types: satisfaction items assessing how satisfied respondents are with aspects of their life and importance items assessing how important respondents think those aspects of life are. Scores, which range from 0–30, incorporate both satisfaction and importance ratings. As such, they reflect respondents' satisfaction with aspects of life they value. Higher scores indicate better levels of quality of life. Internal consistency reliability for the overall scale is supported by alphas ranging from .90–.95, while the value for the current study was .95.

Functional status was measured by the Functional Status II (Stein and Jessop, 1990). This measure assesses parents' perceptions of the affected child's ability to perform age-appropriate roles and tasks, and considers communication, mood, mobility, energy, sleeping, eating, and toileting. Behavior in the home, neighborhood, and school is assessed. It is appropriate for children from 0 to 16 years, and its strength is in measuring the health status of children with chronic physical conditions who are not disabled. Internal consistency is supported by an alpha of .80. The alpha value for the current study was .83.

Procedures

Data collection took place in the family home or other quiet setting, with parents participating in individual interviews and completing the standardized measures. The principal investigator, project director, and research assistants (either advanced practice nurses or graduate students in nursing) participated in data collection.

Cluster analysis was used to identify patterns of family functioning based on both parents' scores on the Family APGAR and FHI. Cluster analysis is a statistical technique used for identifying patterns of response across multiple variables and/or subjects (Johnson and Wichern, 1992; Press, 1972). Through cluster analysis, it is possible to identify cases with similar ranges of scores on dimensions of interest; in this analysis we used mothers' and fathers' assessment of family satisfaction and hardiness. Cluster analysis has been advocated as a useful analytic approach by family researchers interested in identifying different patterns of family functioning and interaction (Filsinger, 1990; Miller and Olson, 1990).

Ward's minimum variance method was used to generate clusters. While a wide variety of other clustering procedures are available, Ward's method has been used successfully before with family data (Fisher *et al.*, 1998, 2000) and has performed well in a variety of simulation studies of clustering procedures (Milligan, 1981; SAS Institute Inc., 2004). Clusters were generated using the hierarchical clustering procedure PROC CLUSTER of SAS (SAS Institute Inc., 2004). The validity and clinical significance of generated clusters was assessed by analyzing their relationship to parental quality of life and child functional status as reported by both fathers and mothers. Using hierarchical linear modeling (Raudenbush and Bryk, 2002), the impact of cluster membership on quality of life and functional status was assessed after controlling for possible effects of type of parent (mother versus father) and the interaction between type of parent and cluster membership. A post hoc analysis also was conducted for each measure using a Bonferroni multiple comparisons approach based on generalized least-squares means (SAS Institute Inc., 2004). Finally, whether or not generated clusters were non-categorical was assessed by testing the hypothesis of an association between cluster membership and type of genetic condition using Fisher's exact test.

RESULTS

Sample Characteristics

With the exception of one stepmother and three stepfathers from four different families, all participants (52 pairs of spouses) were biological parents of the child with a genetic condition. Parents' ages ranged from 22–54 years with a mean of 41 years. Most parents (72%) had at least some college education, and most (63%) were employed fulltime. Although predominantly White (73%), the sample included African American (13%), Asian (4%), and Hispanic (3%) parents as well. Most parents reported being either Catholic (49%) or Protestant (28%), and most (85%) reported annual household incomes of $50,000 or more. The children had a variety of genetic conditions, including PKU (27%), cystic fibrosis, (25%), neurofibromatosis (17%), sickle cell disease (12%), thalassemia (8%), hemophilia (6%), and Marfan's syndrome (6%). Despite the genetic condition, most parents rated their child's health as excellent (59%) or good (38%). Children ranged in age from 3 to 15 years with a mean of 10 years, and most (60%) were female.

Patterns of Family Functioning

Based on the cluster analysis, five distinct patterns of family functioning were identified (Table I). Names were assigned to the clusters to describe the patterns of family functioning suggested by scores on the two measures for parents within the clusters. Cluster 1 is the largest cluster with 21 families. Clusters 2–4 are similar in size to each other and approximately half the size of cluster 1. Cluster 5 is very small, consisting of only 2 families. Table I summarizes the distinguishing characteristics of the five patterns. Summary statistics for the five clusters are reported in Table II. Ranges of values and medians are provided for family satisfaction and hardiness reported by mothers and fathers within each cluster. Scores for family satisfaction and family hardiness for parents in each pattern are displayed in Figs. 1–5. Each figure contains two plots, one for family satisfaction and the other for family hardiness. Mothers' scores are plotted on the horizontal axis and fathers' scores are on the vertical axis. Thus, scores below the diagonal reflect higher scores for the mother; scores above the diagonal reflect higher

Table I Patterns of Family Functioning for Families Having a Child with a Genetic Condition

Pattern	Cluster	*n* (couples)	Description
Well-Adapted	1	21	Both parents tend to rate satisfaction and hardiness as high
Discrepant	2	10	Mothers tend to rate satisfaction and hardiness as high while fathers tend to rate them both as moderate
Diminished			Both parents tend to rate satisfaction and/or hardiness as moderate
More in Satisfaction	3	8	Mothers tend to consider satisfaction to be diminished more than hardiness
Same or More in Hardiness	4	11	Mothers tend to consider hardiness to be diminished as much or more than satisfaction
Compromised	5	2	Both parents tend to rate both satisfaction and hardiness as low

scores for the father. Higher scores are indicative of greater satisfaction and hardiness. Each axis covers the maximal range for the associated scale, partitioned into four equal-sized quadrants, representing four intervals of family functioning scores increasing from very low to low, moderate, and high levels of the associated measure.

In cluster 1, the Well-Adapted Pattern, parents give high-level ratings to both family satisfaction and hardiness as evidenced by scores clustering in the highest quadrant for both parents on both measures (Fig. 1). Parents in the Well-Adapted Pattern have a shared, positive view of family functioning.

In cluster 2, the Discrepant Pattern, the distinguishing characteristic is mothers' and fathers' differing views of family functioning. Mothers in this pattern tend to rate satisfaction and hardiness high, with their scores clustering in the highest quadrant for both measures. On the other hand, fathers in this pattern tend to have distinctly lower scores than mothers, with moderate-level values clustering in the second highest quadrant for both satisfaction and hardiness (Fig. 2).

In clusters 3 and 4, the Diminished Patterns, parents tend to rate satisfaction and/or hardiness lower than parents in clusters 1 and 2. In cluster 3, mothers tend to have lower family satisfaction than mothers of the Well-Adapted and Discrepant Patterns. Moreover, their satisfaction scores tend to be lower than those of fathers. On the other hand, mothers in cluster 3 typically have higher hardiness scores than those of fathers (Fig. 3).

In cluster 4, parents cluster in the top two quadrants for satisfaction with family life. However, they rarely are in the same quadrant. When the mother's score is in the top quadrant, then father's most often is in the second quadrant. Conversely, when the father's score is in the top quadrant, the mother's score most often is in the second quadrant. For the Family APGAR, the preponderance of scores below the diagonal indicates that mothers typically have higher family satisfaction scores than

Table II Summary Statistics for Family Functioning Clusters

		Family satisfaction				Family hardiness			
		Mother		Father		Mother		Father	
Cluster	Size	Range	Median	Range	Median	Range	Median	Range	Median
1 Well-adapted	21	13–20	17.0	14–20	18.0	43–59	50.0	43–57	51.0
2 Discrepant	10	11–20	18.0	10–15	14.0	46–57	55.0	33–46	37.0
3 Diminished Satisfaction	8	7–13	11.5	12–15	13.0	43–50	48.0	38–48	43.0
4 Diminished Hardiness	11	11–20	16.0	12–18	15.0	36–47	38.0	33–49	45.0
5 Compromised	2	8–10	9.0	2–10	6.0	30–37	33.5	32–37	34.5

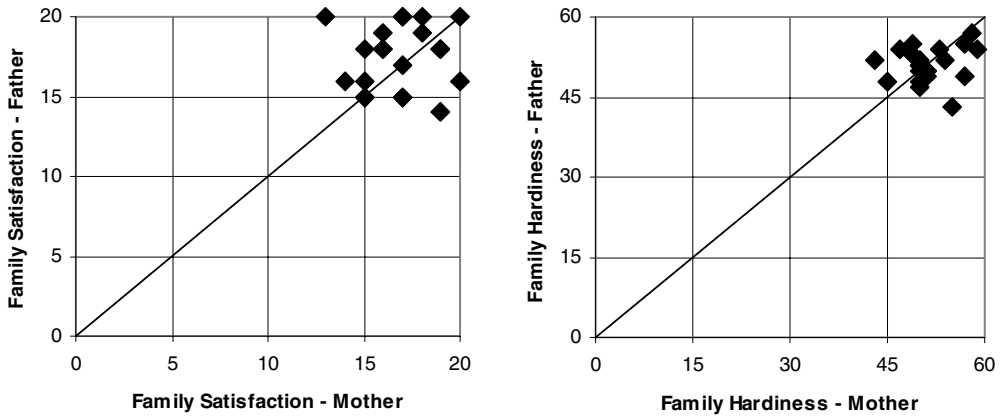

Fig. 1. Family Satisfaction and Family Hardiness by Parent for cluster 1: Well-adapted (both parents tend to rate satisfaction and hardiness as high).

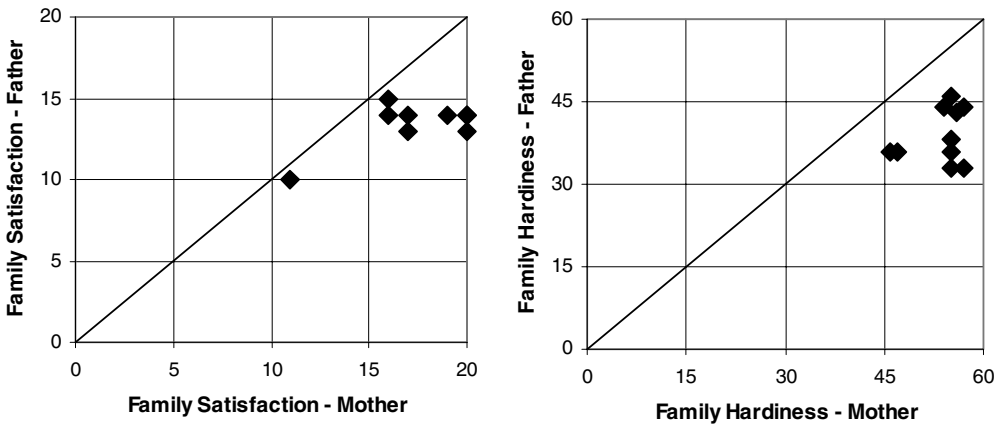

Fig. 2. Family Satisfaction and Family Hardiness by Parent for cluster 2: Discrepant (mothers tend to rate satisfaction and hardiness as high while fathers tend to rate them both as moderate).

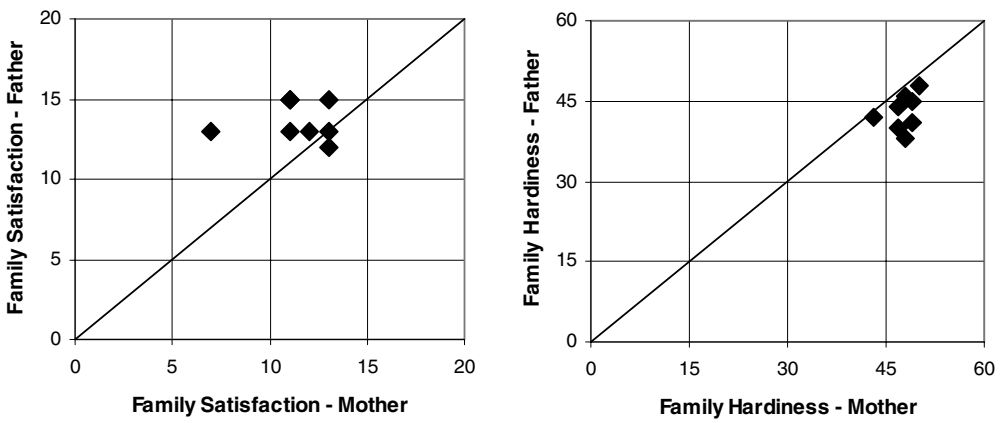

Fig. 3. Family Satisfaction and Family Hardiness by Parent for cluster 3: Diminished More in Satisfaction (mothers tend to consider satisfaction to be diminished more than hardiness).

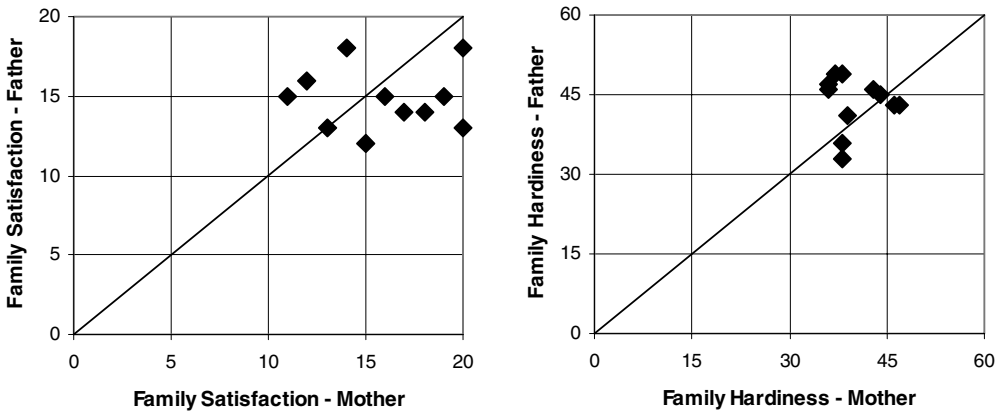

Fig. 4. Family Satisfaction and Family Hardiness by Parent for cluster 4: Diminished Same or More in Hardiness (mothers tend to consider hardiness to be diminished as much as or more than satisfaction).

fathers. Parents' ratings on hardiness also cluster in the top two quadrants, with fathers tending to have similar or somewhat higher ratings than mothers on hardiness (Fig. 4).

Compared to families of the Well-Adapted Pattern, one or both parents from the two Diminished Patterns have lower scores on satisfaction or hardiness. Similar to parents in the Discrepant Pattern, these parents also can have different views of family functioning. However, in contrast to parents of the Discrepant Pattern, where mothers consistently have more positive views than fathers on both measures of family functioning, parents in the Diminished Patterns evidence different types of discrepancies. Mothers and fathers from the Diminished Patterns have different views regarding the relative strengths and weaknesses of family functioning.

The notable distinguishing characteristic between clusters 3 and 4 is the mother's assessment of what aspect of family functioning is more diminished. A comparison of the Fig. 3 plots reveals that mothers' family satisfaction scores tend to be in lower quadrants than their family hardiness scores, indicating that in cluster 3 mothers' satisfaction is more diminished than hardiness. On the other hand, a comparison of the Fig. 4 plots indicates that mothers' hardiness scores cluster in the second quadrant, while their satisfaction scores cluster in the top quadrant, suggesting that mothers' perceptions of hardiness are more diminished than satisfaction in cluster 4 families.

Cluster 5, the Compromised Pattern, includes only 2 families. This pattern is distinct in that both parents rate satisfaction and hardiness as low. These parents have a shared negative view of family functioning (Fig. 5). This pattern occurs only in exceptional cases for families in this sample.

Relationship Between Family Patterns and Parent and Child Characteristics

In order to provide beginning support for the validity and clinical significance of the identified patterns, we assessed their relationship to parental and child functioning and to selected demographic characteristics. Because cluster 5 had the potential to be overly influential in these analyses due to its small size, the analyses reported in this section were conducted in terms of a reduced 3-cluster solution that combined clusters 3–5 into a composite Diminished/Compromised Pattern.

The analysis of the relationship between family pattern and parental functioning indicated that expected quality of life changed significantly with cluster membership ($p < .01$) and with the interaction between cluster membership and type of parent (mother versus father; $p = .01$), but not with type of parent alone ($p = .06$). A post hoc analysis indicated that expected quality of life was lower for Diminished/Compromised parents than for Well-adapted parents, with the difference being greater for Diminished/Compromised mothers than for fathers (joint Bonferroni $p < .05$). Expected quality of life also was lower for fathers in Discrepant families than for mothers in those families (joint Bonferroni $p < .05$).

Expected child functional status also changed significantly with cluster membership ($p = .01$), but

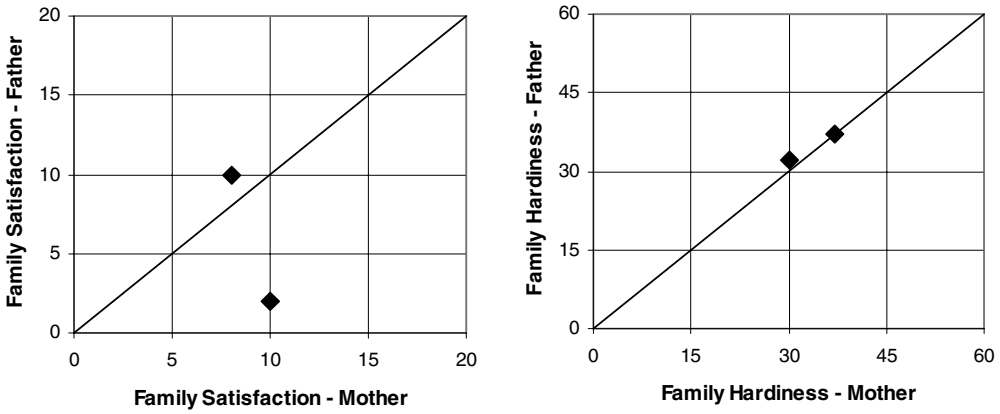

Fig. 5. Family Satisfaction and Family Hardiness by Parent for cluster 5: Compromised (both parents tend to rate both satisfaction and hardiness as low).

not with type of parent alone ($p = .37$) nor with the interaction between cluster membership and type of parent ($p = .47$). A post hoc analysis indicated that functional status was lower for children of Diminished/Compromised parents than for children whose parents were in the Well-adapted and Discrepant clusters (joint Bonferroni $p < .05$). Combining the Well-adapted and Discrepant Patterns revealed that these two patterns contained significantly more families in which the child with a genetic condition was a girl ($p = .04$) than did Diminished/Compromised families. Pattern of functioning was not significantly associated ($p = .92$) with type of genetic condition (PKU, cystic fibrosis, neurofibromatosis, sickle cell disease, thalassemia, hemophilia, Marfan's syndrome).

DISCUSSION

Research on families and children with genetic conditions has focused on the nature of family functioning and the relationship between family functioning and child outcomes (Balfour-Lynn *et al.*, 1995; Chernoff *et al.*, 2001; Eddy *et al.*, 1998; Fanos, 1997; Geller, 1995; Hilbert *et al.*, 2000; Loader *et al.*, 1996; Sawyer, 1992; Thanarattanakorn *et al.*, 2003; Thompson *et al.*, 1999, 2003; Wertz *et al.*, 1994). However, as Street and Soldan (1998) point out, researchers rarely have taken a family perspective or studied multiple genetic conditions. Thus, there is limited understanding of how genetic conditions impact family life and how families adapt to these impacts, making it difficult for clinicians to address effectively the psychosocial challenges confronting these families. Based on measures of two distinct aspects of family functioning completed by both mothers and fathers, our analysis contributes to the literature by identifying patterns of family functioning that characterize multiple genetic conditions and the relationship between these patterns and selected parent and child outcomes.

There is a growing body of evidence that similar to families in which a child has a non-genetically-based chronic condition, families in which a child has a genetic condition also maintain healthy levels of functioning (Barbarin, 1999; Gilliss and Knafl, 1999; Knafl and Gilliss, 2002; Wallender and Varni, 1998). Our results support this body of evidence. Consistent with past research, the analysis found healthy levels of family functioning in many of the families studied. In 21 families (40%) both parents gave high ratings to satisfaction with family life and family hardiness, and in only two families (4%) did both parents give low ratings to both measures of family functioning. In the remaining families, one or both parents gave moderate to high ratings to at least one of the measures of family functioning.

At the same time, these results also point to the importance of obtaining data from multiple family members and taking into account both individual evaluations of family functioning as well as the extent to which such evaluations are shared across family members. In the current sample, over half the couples ($n = 29$, 56%) had differing views of one or both of the two aspects of family functioning studied. Moreover, there were multiple patterns of difference in how parents perceived satisfaction with family

life and family hardiness. In the Discrepant pattern, mothers had consistently more positive views than fathers on both aspects of functioning. The distinguishing characteristic of this pattern was the magnitude of difference between parents' scores. Whereas mothers in the Discrepant Pattern were as positive as parents in the Well-Adapted Pattern, fathers in this pattern were among the most negative in the sample.

On the other hand, parents in the two Diminished Patterns had differing perceptions of what were the more and less positive aspects of family life. The two Diminished Patterns were distinguished from the others by the magnitude of parents' scores and the nature of differences between their scores. In comparison to the Well-Adapted Pattern, where parents had shared highly positive assessments of satisfaction and family hardiness, parents in the Diminished Patterns had relatively more negative *and* more discrepant views of family life. In contrast to the Discrepant Pattern, fathers in the Diminished Patterns gave relatively high ratings to one of the aspects of family life assessed.

The relationships between the patterns identified in the analysis and parental perceptions of child functioning and parental quality of life provide beginning support for the validity and clinical significance of the patterns and point to the importance of eliciting both parents' assessment of family life in two-parent families. The results suggest that in two-parent families it is important to consider both parents' evaluation of the quality of family life as well as the extent to which they have shared views. Not surprisingly, parents in the Well-Adapted Pattern, those with shared, positive views, also reported significantly better quality of life and child functional status than parents in the combined Diminished/Compromised Patterns where parents had relatively lower and more discrepant ratings of family functioning. In the two Patterns where mothers rated family life most positively (Well-adapted and Discrepant), the child with the genetic condition was more likely to be a girl. This result suggests that mothers perceive a daughter's genetic condition as having less of an impact on the quality of family functioning, and is consistent with the research reporting better family functioning in families where the child with a chronic condition is a girl (Holden *et al.*, 1997).

Parents in the Discrepant Pattern were an especially interesting group. In some respects they appeared more similar to the Well-Adapted Pattern and in some ways more similar to the Diminished/Compromised Patterns. They did not differ from parents in the Well-Adapted Pattern on either perceptions of child functioning or quality of life, and they had significantly more positive perceptions of their child's functioning than parents in the Diminished/Compromised Patterns. On the other hand, fathers in the Discrepant Pattern rated their own quality of life significantly lower than their wives, making this the only pattern where parents' reports differed significantly from one another. These results suggest that in the Discrepant cluster, fathers' negative views of family life were linked to negative personal outcomes in terms of lower quality of life, but not to negative perceptions of their child's functioning.

The patterns we have identified provide a family perspective on childhood genetic conditions that is linked to clinically relevant outcomes. The results also demonstrate the importance for both clinicians and researchers of assessing perceptions of family life from the perspective of multiple family members. Not only can these views differ, but the differences can be related to differences in individual functioning outcomes. Although other authors have found differences in how mother and fathers experience a child's genetic condition (Hovey, 2005; Lord *et al.*, 2005), they have not explored the relationship between these differences and parental and child outcomes.

Implications

Genetic counseling often reflects a teaching rather than a therapy model (Biesecker and Peters, 2001), although both have been identified as important (Kessler, 1997). The findings reported here support the view that a therapy approach to genetic counseling, which seeks to facilitate communication and problem-solving rather than impart information, may be key to family and child functioning. Parents' reports of negative and/or discrepant views of family functioning should be cause for concern as they may indicate that both the child with the condition and the parents are at risk for poor functional outcomes. In two-parent families, assessment of both parents' views can contribute to insights on how to support family strengths and address the distinct challenges facing families with differing patterns of response to a child's genetic condition. For example, when both parents have a positive, shared view of current family functioning, the focus of counseling can be on acknowledging the quality of family adaptation as

well as anticipatory guidance regarding possible future challenges. On the other hand, identification of perceptions of dissatisfaction or vulnerability should lead to further discussion of how to address problematic aspects of family life. Detection of differing parental views also merits further assessment of the extent to which differences are viewed as complementary or a source of conflict. Counseling sessions can provide an opportunity to facilitate communication between parents about the significance of their diverse views of family life and the implications of differing perceptions for individual and family functioning.

A recent analysis of the goals of genetic counseling stated that counseling "should bring the psychosocial component into every aspect of the work" (Weil, 2003, p. 207); our findings support this conclusion and point to the importance of addressing family functioning in particular. In their discussion of psychosocial interventions for families coping with genetic conditions, McDaniel and colleagues (McDaniel *et al.*, 2006) recommend a family consultation at the time of diagnosis and periodically thereafter as a way to assess family adaptation. The literature contains multiple, well-established measures of family functioning that are concise, easy to administer, and suitable for clinical practice (Sawin and Harrigan, 1995). Counselors are encouraged to include measures of family functioning as part of their overall assessment of children with a genetic condition. Since parents often have different perceptions of family life, they should provide individual assessments of functioning. Results of these assessments can be shared with parents and used as a vehicle for enhancing parental communication and problem solving.

The absence of a relationship between type of genetic condition and pattern of family functioning is noteworthy as well, and provides support for taking a non-categorical approach to the study of family response to having a child with a genetic condition (Rolland and Williams, 2005; Street and Soldan, 1998). Although much of the research on family response to chronic conditions, including those with a genetic condition, addresses the challenges that specific conditions present to children and families (Wallender and Varni, 1998), researchers and clinicians have noted the limitations of focusing exclusively on disease categories when one's primary interest is the psychosocial as opposed to the physiological consequences of chronic conditions (Rolland, 1994; Rolland and Williams, 2005; Stein and Jessop, 1982; Wallender and Varni, 1998). In their review of the effects of chronic physical illness on children and their families, Wallender and Varni (1998) concluded that an approach that "focuses on commonalities in the class of chronic physical disorders could enhance the understanding of their impact on the psychosocial adjustment of children and their families and could improve care" (p. 29). The fact that the clusters identified in this analysis were not linked to specific genetic conditions suggests that they may reflect broad patterns of family response to the psychosocial challenges of having a child with a genetic condition.

On the other hand, this analysis was limited by a relatively small sample size, the inclusion of only two-parent families, and the absence of data from the child with the genetic condition. A larger sample will make it possible to address how non-categorical aspects of illness such as severity of the condition and timing of disease in the family life cycle interact with other family variables in predicting child outcomes (Rolland and Williams, 2006). Larger samples will also make it possible to address the interplay of non-categorical and disease specific variables in predicting child and family outcomes. Our intent in future studies is to expand our sample to include a broader array of family types and to gather data directly from the child with the genetic condition as well as well siblings, in addition to parents.

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