Published in final edited form as:
J Pediatr Nurs. 2013 ; 28(6): 523–535. doi:10.1016/j.pedn.2013.03.006.

Patterns of Family Management of Childhood Chronic Conditions and Their Relationship to Child and Family Functioning

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Abstract

Understanding patterns of family response to childhood chronic conditions based on a configuration of multiple variables or qualitative themes provides a comprehensive understanding of health-related challenges and their influence on family and child functioning. In this paper, we used the six scales comprising the Family Management Measure (FaMM) in a cluster analysis to describe a typology of family management and data from other measures of child and family functioning to validate and explain those clusters. The sample of 575 parents from 414 families of children who had diverse chronic conditions endorsed four patterns of response (Family Focused, Somewhat Family Focused, Somewhat Condition Focused, Condition Focused). We also considered the extent to which couples had shared or discrepant views of family management. Most (57%) families were in either the Family Focused or Somewhat Family Focused pattern. Single mothers were significantly less likely to be in the two patterns reflecting greater ease in family management and significantly more likely to be in the two patterns reflecting more difficulty. Patterns of family management were related significantly to family and child functioning, with families in the Family Focused and Somewhat Family Focused patterns demonstrating significantly better family and child functioning than families in the other two patterns.

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Families respond in varying ways to the challenges presented by a child's chronic condition. Responses vary with regard to the quality of family functioning in the context of a child's chronic condition and the ways in which families incorporate condition management into everyday family life. Prior reviews of studies addressing family functioning present a mixed picture, with some researchers reporting good and others reporting poor family functioning and lending support to the conclusion that many, but not all, families manage the chronic condition with minimal negative impact on family life (Cohen, 1999; Gilliss & Knafl, 1999; Herzer et al., 2010; Holmbeck, Greenley, Coakley, Greco, & Hagstrom, 2006; McClellan & Cohen, 2007; Wallander & Varni, 1998). Determining which families and children are at risk for management difficulties and poor functioning is a continuing issue for researchers and clinicians. Studies and reviews of the relationship between demographic variables and family and child outcomes also present a mixed picture, although there is considerable evidence that income and family structure (single versus two-parent family) influence outcomes, with low-income and single parent families evidencing poorer adaptation (Brown et al., 2008; Cadman, Rosenbaum, Boyle, & Offord, 1991; Drotar & Bonner, 2009; Kazak et al., 2012). One review addressing the relationship between demographic variables and treatment adherence in families of children with asthma reported that minority status, in addition to socioeconomic and marital status, was related consistently to poorer adherence (Drotar & Bonner, 2009). On the other hand, child age, gender, parental education, and duration of the condition have not been linked consistently to child or family outcomes.

Authors of review articles also have reported that, among children with chronic conditions, variation in the nature and quality of family response is an important predictor of child response, with the family variables of conflict, cohesion, and expressiveness often related to the quality of children's adaptation to a chronic condition (Berge & Patterson, 2004; Graf, Landolt, Mori, & Boltshauser, 2006; Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2006; Thompson et al., 2003).

Prior studies of the contribution of family variables to the quality of family and family member functioning have been focused on demographic characteristics of the family (e.g., composition, socioeconomic status [SES]) and on family processes such as problem solving and decision making, with relatively few studies aimed at identifying overarching patterns of family response and their relationship to child and family functioning (Conlon, Strassle, Vinh, & Trout, 2008; Kendall & Shelton, 2003; Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl, Knafl, Gallo, & Angst, 2007; Rohan et al., 2011; Scharff et al., 2005). Some family researchers, especially those interested in health-related outcomes, however, have noted the usefulness of identifying patterns of family response that are based on a configuration of multiple variables or qualitative themes and can provide a more comprehensive understanding of how the family as a system adapts to a health-related challenge (Deatrick, Alderfer, Knafl, & Knafl, 2006; Fisher et al., 1998; Henry, Tolan, & Gorman-Smith, 2005; Mandara, 2003). The identification of multiple patterns or a typology of response, when linked to differences in family and family member outcomes, advances the understanding of the intersection of family and health and contributes to the evidence base for intervention development. In this paper, we address the following questions:

1. What are patterns of family management of childhood chronic conditions?
2. What is the relationship between family management pattern and demographic characteristics of the family and family members?
3. What is the relationship between family management pattern and child and family functioning?

By family management, we mean the efforts that family members make to incorporate the demands of the treatment regimen and their child's special needs into everyday family life (Knafl, Deatrick, & Gallo, 2008; Knafl, Deatrick, & Havill, 2012).

Background

The study of family response to a child's chronic condition is a diverse field of inquiry that includes studies of the quality and predictors of family and family member functioning (Aitken et al., 2009; Driscoll et al., 2010; Gavin & Wysocki, 2006; Litzelman, Catrine, Gangnon, & Witt, 2011; Lutz, Barakat, Smith-Whitley, & Ohene-Frempong, 2004) as well as studies of the relationship between family and parenting variables and child outcomes (Cuneo & Schiaffino, 2002; Fedele, Mullins, Wolfe-Christensen, & Carpentier, 2011; Fiese, Winter, Anbar, Howell, & Poltrock, 2008; Helgeson, Janicki, Lerner, & Barbarin, 2003; Markson & Fiese, 2000). The current analysis is grounded in a body of research that has been focused on family management and the efforts families make to incorporate condition management into everyday family life. We have been especially interested in identifying different patterns of management and examining their relationship to child and family functioning.

Family Management of Childhood Chronic Conditions

A child's chronic condition presents families with a unique set of challenges. Parents are expected to master the demands of the treatment regimen, which may necessitate changes to usual family routines and patterns of interaction. The child with the condition is expected to cooperate with required treatments and accept possible changes to usual activities. Siblings also are expected to adjust to changes to the family's usual routine and may be asked to assume new responsibilities. Researchers studying how the family system responds to a child's chronic condition have described the nature of family life in the context of childhood chronic conditions and strategies parents use to incorporate condition management into everyday family life (Barton, Sulaiman, Clarke, & Abramson, 2005; Bjork, Nordstrom, Wiebe, & Hallstrom, 2011; Martin, Wolters, Klaas, Perez, & Wood, 2004; McCubbin, Balling, Possin, Frierdich, & Byrne, 2002). There is considerable evidence that, following an initial period of adjustment, parents' efforts are directed toward minimizing the disruptiveness of the condition and creating a relatively normal life for the affected child (Alexander, Rennick, Carnevale, & Davis, 2002; Bedell, Cohn, & Dumas, 2005). Investigators studying varied conditions have reported that parents often are successful in their efforts to create a normal life for their child and family, a process that often is referred to as *normalization* (Gantt, 2002; Glasscoe & Smith, 2011; Hayes & Savage, 2008). Normalization entails strategies parents develop to adhere to the treatment regimen, while sustaining usual child and family activities (Deatrick, Knafl, & Murphy-Moore, 1999).

Researchers also have studied how the seriousness or pervasiveness of certain conditions or the intensity of treatments can pose barriers to normalization and contribute to condition management becoming the focus of family life (Earle, Clarke, Eiser, & Sheppard, 2007; Knafl, Darney, Gallo, & Angst, 2010; Rehm & Bradley, 2005; Rehm & Franck, 2000). Although normalization usually is equated with successful family management, the absence of normalization is not always an indicator of poor adaptation. Rehm and Bradley, for example, reported that parents of children who were severely disabled believed their family was living a good life, while acknowledging that it would not be considered a normal life by other people's standards. Like other investigators, they described how normalization might entail the creation of a new normal rather than a return to a prior family life (Carpenter & Narsavage, 2004; Clarke-Steffen, 1997).

Typological Approach to Family Research

Family researchers also have developed typologies of family response comprised of groupings of individuals, families, or some other unit of interest, with group membership based on similarity on one or more quantitative variables and/or qualitative themes (Henry et al., 2005; Teddlie & Tashakkori, 2009). Mandara (2003) proposed that a typological approach provides a useful middle ground between variable and case-centered research that can capture the multidimensional nature of family life. Typology development has been used to advance our understanding of a wide variety of family situations. For example, using the statistical technique of cluster analysis, researchers have identified typologies of parenting an adolescent (Simons and Conger, 2007), dual earner couples' efforts to balance the demands of work and childcare (Cullen, Hammer, Neal, & Sinclair, 2009), and types of homeless families (Danseco & Holden, 1998).

Qualitative researchers have developed typologies based on shared qualitative themes that describe some aspect of family response to a health-related challenge. Larsen, Heilmann, Johansen, and Adamsen (2011) developed a typology of parenting roles during a child's stem cell transplantation that reflected the nature of interactions between parents, child, and staff during treatment. DosReis et al. (2009) identified four patterns of parental perspectives on the appropriateness, anticipated effects, and meaning of medication for their child's attention-deficit/hyperactivity disorder. Beyond their ability to convey an integrated view of some aspect of family life, typologies have the potential to advance understanding of the relationship between the variables or themes comprising the subgroups of the typology and other variables of interest.

Beginning with Davis's (1963) classic study of children with polio and their families, early investigators using qualitative methods described patterns of family management of a child's chronic condition. Davis described two patterns that anchored the endpoints of a continuum of family response - normalization and disassociation. The two were differentiated by family members' perceptions of the ill child and their family and the nature of their interactions with those outside the family. Normalizing families minimized the importance of differences between their child and family and others, and expected to interact with people as they had prior to the child's illness. In contrast, families in the disassociation pattern believed they were different from other families, avoided social contact, and did not expect to relate to

others as they had in the past. In an early study of 25 families with a child with a birth defect, Darling (1979), identified 4 different patterns of response (normalization, altruism, crusadership, and resignation), based on the way in which parents attempted to access the services they needed to address their child's complex needs and their success in doing so. Using an earlier version of the framework on which the current analysis is based, Knafl et al. (1996) studied a sample of 60 families in which children had varying chronic conditions and identified five distinct family management styles (thriving, accommodative, enduring, struggling, and floundering) that reflected variations in how families incorporated condition management into everyday life. The intent of these studies was to provide detailed descriptions of family life in the context of childhood chronic conditions and begin to identify key differentiating aspects of different patterns of management. Relatively little attention was directed to the relationship between pattern of family management and other aspects of child or family functioning.

More recently, investigators have examined the relationship between patterns of family management and family and family member outcomes. For example, Fiese and Wamboldt (2003) used narrative analysis techniques to identify three patterns (Reactive, Coordinated care, Family partnership), reflected in the *story* parents were asked to tell about how asthma had affected family life. The patterns were differentiated by the extent to which families had an established routine and how they worked with one another and healthcare providers to carry out prescribed treatments. There was a significant relationship between group membership and adherence to the treatment regimen, with the Reactive group being significantly less adherent than the other two groups.

Other investigators have used the quantitative technique of cluster analysis to develop typologies of family response to a child's genetically based condition (Knafl, Knafl, et al., 2007) and the contribution of family processes to individual family member response (Scharff et al., 2005), and have examined the relationship between typology membership and other child and family variables. Scharff et al. used a combination of measures addressing both family and child functioning to identify subgroups of children with chronic pain. Cluster analysis revealed three distinct patterns. Children in the Distressed/Low Functioning cluster scored relatively high on depression, functional disability, behavior problems, and distress. In contrast, Children in the High Functioning cluster scored within established population means on these same variables, and parents of children in both groups reported similar normative levels of family cohesion. The final cluster, Family Dysfunction, was characterized by the very low levels family cohesion as reported by parents, despite scores on children's functioning and distress within the normative range. The three patterns were related to significant differences in the children's coping strategies, with children in the Family Dysfunction Group significantly more likely to cope through accepting responsibility. Discussing the contribution of family processes to the adolescent's chronic pain, the authors (Scharff et al., 2005) speculated that "overwhelming family stress" (p. 437) might contribute to the adolescent's physical symptoms.

In a study of families in which a child had a genetic condition, Knafl, Knafl, et al. (2007) used reports of family functioning from mother-father dyads to identify four patterns of response: Well-adapted, Discrepant, Diminished, and Compromised. The patterns were

differentiated by the parents' level of satisfaction with family life and perceptions of family hardiness as well as by the extent of agreement between members of the dyad. Patterns were significantly related to parental reports of their own quality of life and their child's functional status, with parents' quality of life being significantly lower for parents in the Diminished and Compromised versus Well-adapted families, and child functional status being significantly lower in the Diminished and Comprised cluster than either the Well-adapted or Discrepant clusters. This analysis pointed to the usefulness of developing a typology that took into account family members' scores on variables of interest and the degree to which members of the same family had similar scores.

The current analysis was focused on family functioning in the context of a child's chronic condition. We incorporate data on multiple aspects of family management of a child's chronic condition from mothers and fathers in single and two-parent families to extend the understanding of the nature of family management and the implications of different management patterns for child and family functioning.

Method

Data for the current analysis come from a study of 575 parents from 414 families. The primary purpose of the survey was to gather data to assess the underlying dimensions and psychometric functioning of a new instrument, the Family Management Measure (FaMM), which assesses how families incorporate condition management into everyday family life (Knafl et al., 2011). Since the instrument development study provided strong support for the reliability and validity of the FaMM and its six underlying scales, we proceeded with the subsequent analysis presented in this paper to identify patterns of family management based on the FaMM scales. More detailed reporting of the development and testing of the FaMM has been published previously (Knafl, Deatrick, et al., 2007; Knafl et al., 2011).

Sample

Inclusion criteria for the instrument development study specified the child be between 2 and 18 years of age; have been diagnosed for 6 months or longer; and be within one school grade of expected level for age. Parents of children with cancer or whose child was hospitalized or in the midst of an exacerbation were excluded. *Family* was defined as a group of intimates living together or in close geographic proximity with strong emotional bonds and with a history and a future (Fisher et al., 1998). Consistent with this definition of family, *parent* was defined in terms of function rather than biology or structure as those persons who viewed themselves as assuming major responsibility for the child's care. Because of our interest in how families incorporated condition management into their daily lives, we limited the sample to parents who resided in the same household as the child. In two-parent families, both parents were invited to participate.

Families most often were two-parent; in 161 of the 349 two-parent families, both parents participated; in the remaining two-parent families, only the mother participated. There were 65 single-parent families in the final sample. Children, who were on average 11.2 years old, had a broad array of chronic conditions; with the most frequent being type 1 diabetes, Crohn's disease, cystic fibrosis, and arthritis (Knafl, Deatrick, et al., 2011). The families'

SES varied, with annual family incomes ranging from less than $40,000 (30%) to over $100,000 (23%); 87% of the sample reporting their race as Caucasian.

Procedure

Subjects were recruited from 20 different sites, predominately in Illinois, Connecticut, and Pennsylvania. Between September 2004 and August 2006, data were collected via telephone interviews with parents. In addition to responding to the FaMM and providing demographic information, parents completed other measures of child and family functioning that were used in the instrument development study to assess the construct validity of the FaMM.

The FaMM is a 53-item measure based on the Family Management Style Framework (FMSF; Knafl & Deatrick, 2003; Knafl et al., 2008; Knafl et al., 2012). The FMSF is a conceptualization of important aspects of how families with a child having a chronic condition incorporate condition management into everyday family life. The FMSF framework, which addresses how family members define their situation, their approach to condition management, and their beliefs about the consequences of the condition for family life, guided the initial development of items for the FaMM. The instrument development study (Knafl, Deatrick, et al., 2007; Knafl et al., 2011) yielded a measure comprised of six scales: Child's Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, View of Condition Impact, and Parental Mutuality. Only partnered parents completed the 8 items for the Parental Mutuality scale. In the instrument development survey, internal consistency reliability was .70 or greater for all scales.

The FaMM scales address important dimensions of family life in the context of a child's chronic condition. For three scales (Child's Daily Life, Condition Management Ability, Parental Mutuality), higher scores are indicative of a more normal family life and greater ease in condition management. For the three remaining scales (Condition Management Effort, Family Life Difficulty, View of Condition Impact), higher scores are indicative of a family life that is perceived as focused on the work of managing the condition and the difficulties associated with condition management.

The General Functioning Scale of the Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983), the Eyberg Child Behavior Inventory (ECBI; Eyberg & Pincus, 1999), and the Functional Status Measure II (FSM-II; Stein & Jessop, 1990), were used originally to assess the construct validity of the FaMM, and were used in this analysis to provide evidence of the validity of the identified patterns of family response. The General Functioning Scale of the FAD is used to assess the overall quality of family functioning, with lower scores indicating less dysfunctional aspects and therein better family functioning. It is a well-established measure, and the internal consistency reliability for the sample reported on here was .89 for mothers and .87 for fathers. The ECBI is a measure of problem behaviors in children that asks parents to respond to both the frequency of the behavior (Intensity Scale) and the degree to which parents think the behavior is problematic (Problem Scale). In the sample used in this analysis, internal consistency reliability for the Intensity Scale was .92 for both mothers and fathers and .82 and .81 for mothers and fathers, respectively, on the Problem Scale. The FSM-II is used to measure a child's ability to

accomplish age-appropriate roles; internal consistency reliability was .79 and .81 for mothers and fathers, respectively, in the sample for the FaMM development study.

Analysis

Patterns of family management were identified based on a cluster analysis of the six FaMM scales. The K-means approach to clustering was used, since it allows for missing data, making it possible to treat the family as the unit of analysis by entering together 12 scale scores for families with both parents participating; 6 scale scores for families with only a partnered mother participating; and 5 scale scores for families with a nonpartnered mother, who would not have completed the items from the Parental Mutuality Scale. Because scores for both participating parents were entered together, partners were in the same cluster. This approach allowed us to inspect the pattern of scale scores for families within and across clusters as well as the extent to which the partnered parents in the clusters had similar or divergent scores on the FaMM scales. Partnered mothers whose partner did not participate were assigned to the cluster for which their scores on the 6 FaMM scales were similar to scores for mothers in the cluster whose partners did participate. Single mothers were assigned to the cluster for which their scores on the 5 FaMM scales other Parental Mutuality were similar to the scores for other mothers the cluster. Thus, all mothers within a given cluster had a similar pattern of FaMM scores, as did all fathers. The number of clusters was determined using a likelihood-based cross-validation approach (Knafl, Delucchi, et al., 2010).

Six clusters were generated, described below in terms of four meaningful patterns, with two of the patterns comprised of two clusters each. To validate the generated clusters, we assessed if they were significantly related to family and child functioning. Means for family functioning, child behavioral problems, and child functional status were compared across clusters using one-way analysis of variance (ANOVA) fixed effects models. In these analyses we controlled for within-family correlation using linear mixed models and *post hoc* analyses based on the Tukey least squares means multiple comparisons approach. We also compared cluster membership across family types (i.e., partnered vs. single mother and one vs. two responding parents) using χ^2 tests. All computations were conducted in SAS Version 9.2.

Results

The analysis generated six family management clusters with interpretations based on the mothers' and fathers' mean scores on each FaMM scale in comparison to the mean scale scores of mothers and fathers in other clusters (Table 1). To simplify comparison across clusters, we ranked the mean scale scores for the fathers and mothers in each cluster. A rank of six indicated the most positive perception of the aspect of family management the scale measured; a rank of one indicated the least favorable perception. Thus, the *highest* mean scores for the FaMM scales tapping positive aspects of family management (Child Daily Life, Management Ability, Parental Mutuality) were ranked as 6, as were the *lowest* mean scores for the FaMM scales addressing problematic aspects of family management (Condition Management Effort, Family Life Difficulty, View of Condition Impact). A rank

of 6 indicated that parents viewed their child's life as similar to that of other children, were confident of their ability to manage the condition, incorporated condition management into family life with minimum difficulty, viewed the effort needed to manage the condition and the impact of the condition on family life as relatively minor, and (for partnered parents) were satisfied with how they worked together as a couple to manage the condition. A rank of 1 was indicative of the opposite, and the intermediate ranks of 2–5 reflected gradations in the ease or difficulty parents experienced in managing the various aspects of family life addressed by the FaMM. The rankings allowed us to interpret the pattern of scores across clusters (e.g., parents in a cluster ranked highest on all FaMM scales). In addition, when both parents in the family participated, we were able to consider the extent to which they had shared or discrepant scores (e.g., mothers in a cluster ranked higher than fathers in that cluster on all scales).

Description of Patterns

The six clusters identified in the analysis fell into four meaningful patterns (Table 1). The four patterns reflected a continuum with regard to the extent family life was focused on usual family routines and activities (Family Focused Pattern) versus the demands of condition management (Condition Focused Pattern). Between these two patterns that anchored the ends of the continuum were the Somewhat Family Focused and the Somewhat Condition Focused patterns, each of which was comprised of two subgroups that were differentiated by whether mothers or fathers were more positive in their perceptions of family management. Mothers in each subgroup who were unpartnered or whose partners did not participate had the same pattern of scores as the other mothers in the subgroup.

In the next section, the four patterns are described, beginning with the two anchoring each end of the continuum. Following this description, the composition of the patterns with regard to sample characteristics and child and family functioning are compared.

Family focused pattern—With one exception of fathers who ranked fifth on Parental Mutuality, the 139 parents (40 dyads) in the Family Focused pattern, ranked sixth on all FaMM scales with the highest mean scores on the three scales indicative of ease in family management (Child Daily Life, Condition Management Ability, Parental Mutuality) and the lowest mean scores on the three FaMM scales indicative of problematic management (Condition Management Effort, Family Life Difficulty, View of Condition Impact; Table 1). In this pattern, parents' perceptions of family strengths were apparent in their Management Ability and Parental Mutuality scores. These parents minimized the difficulties associated with condition management and the effect of the condition on their child's and family's life. Parents' perception of Condition Management Effort (on average 9.7 and 9.0 for mothers and fathers, respectively, over a possible range of 4–20), although low in comparison to the other patterns, indicated that parents acknowledged the work of managing the condition. However, based on their scores on the other scales, there was considerable evidence that they had succeeded in incorporating the work of condition management into their everyday routine, thereby diminishing its effect on the family and the child with the condition. Partnered parents in this cluster not only evidenced a high level of Parental Mutuality, they scored remarkably similarly across scales, averaging within two points of each other on all

six scales. Overall, parents in the Family Focused pattern conveyed a picture of families who were managing child's chronic condition effectively, while not having to focus family life on condition management.

Condition focused pattern—The scores on the FaMM scales for the 44 parents (9 dyads) in the Condition Focused pattern revealed a strikingly different family management experience in comparison to the Family Focused pattern. Mothers and fathers in this pattern ranked one on all scales, with the lowest mean scores on the FaMM scales reflecting ease in family management and the highest mean scores on the scales addressing management difficulties. Parents' scores indicated that they viewed their child's life as different from that of peers, and that they put considerable effort into condition management, but doubted their ability to manage effectively. Parents in this pattern emphasized the difficulties associated with condition management and the impact it had on their family life. For mothers in this pattern, scores on the Condition Management Ability scale were especially low, and scores on the Family Life Difficulty scale were especially high in comparison to those of parents in the other three patterns. Partnered parents in this pattern had on average the lowest Parental Mutuality scores, though the sample as a whole scored relatively high on this scale (average score of 29.2/32.2 over a possible range of 8–40 for mothers and fathers in the Conditioned Focus pattern and higher for mothers and fathers in the other patterns).

Mothers' and fathers' average scores were within 1 point of each on three scales (Child's Daily Life, Condition Management Effort, View of Condition Impact), but more dissimilar on the remaining three scales. As such, the average scores of mothers and fathers in this pattern were more discrepant than those of parents in the Family Focused pattern. This difference between parents was especially apparent with regard to Management Ability, with mothers scoring on average almost 5 points lower than fathers. In stark contrast to parents in the Family Focused pattern, those in the Condition Focused pattern conveyed a picture of family life that centered on the difficult work of condition management and responsibilities parents did not feel entirely competent to manage.

Somewhat family focused pattern—Similar to parents in the Family Focused pattern, those in the Somewhat Family Focused pattern also demonstrated successful incorporation of condition management into everyday family life, though to a lesser degree. In the first of the two subgroups in this pattern (31 parents; 10 dyads), fathers reported more positive perceptions than mothers when both participated in the study. Fathers ranked fifth on all FaMM scales in this subgroup, reflecting a consistent pattern of positive views of family management and family life. The differences between mothers and fathers were most pronounced in the Condition Management Ability and the Condition Management Difficulty scales, where fathers' scores were on average 9 points higher on Management Ability and 9 points lower on Management Difficulty than those of mothers.

The pattern for mothers in this subgroup was more complex. Although they were fourth ranked on five of the FaMM scales, indicating a relatively positive view of family management, mothers in this subgroup ranked second on the Condition Management Ability scale, scoring on average only 3 points higher than mothers in the Condition Focused pattern and almost 15 points lower than mothers in the Family Focused pattern. Thus, despite

having moderately positive views of the overall normalcy of their child's life, the amount of effort required to manage the condition, the difficulties associated with condition management, and the impact of condition management on family life, mothers in this subgroup questioned their ability to manage effectively. Despite the differences between the mothers' and fathers' scores on some of the FaMM scales, Parental Mutuality was relatively high, with the average score for fathers exceeding that of mothers by 3 points.

The second subgroup (163 parents; 49 dyads) in this pattern also reflected a moderate emphasis on the families' successful incorporation of condition management into everyday family life. Mothers ranked 4 or 5 on all scales; fathers ranked 3 or 4 on all scales. Thus, both parents reported a consistent, moderately positive view of family management. Despite mothers having a more positive view of family management across all scales, the differences in mothers' and fathers' average scale scores were relatively small (between 1 and 3 points). For partnered parents, Parental Mutuality scores were moderately high and differed by only one point on average.

Somewhat condition focused pattern—Although less extreme than parents in the Condition Focused pattern, parents in the Somewhat Condition Focused pattern also emphasized the effort and difficulties associated with condition management and the impact of the condition on their child and family. As in the prior pattern, the two subgroups in the Somewhat Condition Focused pattern were differentiated by differences in mothers' and fathers' scores. In subgroup one (74 parents; 22 dyads), mothers reported a more negative view of family management and ranked 2 or 3 on all FaMM scales. Fathers in this subgroup ranked 3 or 4 on all scales. Mothers' negative perceptions were most evident in the scores for the Child's Daily Life, Management Effort, Family Life Difficulty, and View of Impact scales. Although mothers had somewhat more positive views of Condition Management Ability and Parental Mutuality (rank of 3), their overall portrayal of family life focused on the problematic, negative aspects of family management. Differences between mothers and fathers in this subgroup were especially apparent in their average scores on the Family Life Difficulty Scale, with mothers' scores on average 7 points higher than fathers. In two-parent families, both parents reported a moderately high level of Parental Mutuality.

There was a similar emphasis on the demands of managing the condition and associated problems in the second subgroup of the Somewhat Condition Focused pattern (124 parents; 31 dyads). In this subgroup, fathers ranked 2 on all scales, reflecting a consistent pattern of predominantly negative views of family management. The pattern for mothers, though generally more positive than fathers, was also more varied. Although mothers ranked third on four of the FaMM scales (Child's Daily Life, Family Life Difficulty, Condition Management Effort, View Condition Impact), they had a moderately positive view of their Child's Daily Life (rank of 4), but an especially negative view of Parental Mutuality (rank of 2). Similar to the prior subgroup, the largest difference between mothers and fathers was on the Condition Management Difficulty scale, with fathers' scores exceeding mothers on average by 7 points. The low Parental Mutuality ranking of 2 was shared by both mothers and fathers in this pattern.

Comparisons and Relationships Across Patterns

The distribution of family respondents across the four family management patterns, including the clusters that comprise the subgroups of the Somewhat Family Focused and Somewhat Condition Focused patterns is summarized in Table 2. Approximately a fourth (24%) of the families was in the Family Focused pattern. An additional 33% of families were in one of the two Somewhat Family Focused subgroups, indicating that parents in a majority of families (57%) reported they had, for the most part, incorporated condition management successfully into everyday family life, and did not believe the condition or the management of it had significant negative consequences for their child or family. Only 8% of families were in the Condition Focused pattern, but an additional 35% of families were in the Somewhat Condition Focused pattern. Thus, although relatively few families perceived family management as highly problematic, over a third described their family management as moderately problematic.

There were few demographic differences across patterns, with only family income and structure significantly related to cluster membership. Families with incomes of less than $50,000 comprised 34% of the Family Focused and Somewhat Family Focused patterns, 40% of the Somewhat Condition Focused pattern, and 66% of the Condition Focused pattern ($\chi^2 = 11.92$, $df = 3$, $p < .01$). In addition, chi square analysis ($\chi^2 = 13.8$, $df = 3$, $p < .01$) revealed that single mothers were more likely to be in the Condition Focused (17% vs. 7%) and Somewhat Condition Focused (44% vs. 33%) patterns, and significantly less likely to be in the Somewhat Family Focused (18% vs. 35%) and Family Focused (20% vs. 24%) patterns. There was a nonsignificant relationship between family management pattern and child's age and sex, and parental age, education, and race (White versus non-White).

Considering the relationship between pattern membership and who in the family participated in the study, the relationship was not significant ($\chi^2 = 4.7$, $df = 3$, $p = .19$). Thus, whether or not the spouse of a partnered mother participated in the study was not related to the mother's pattern membership.

To assess the usefulness of the patterns for revealing important information about how family management influences child and family functioning, analyses were conducted of the relationship between pattern membership and child and family functioning, using the data for both fathers and mothers and adjusting for possible intrafamilial correlation. One-way analysis of variance identified a significant relationship between pattern membership and both family and child functioning ($p < .01$ for all cases; Table 3). *Post hoc* analysis indicated that both family functioning and child adaptation were significantly better for families in the Family Focused and Somewhat Family Focused patterns than for families in the Condition Focused or Somewhat Condition Focused patterns. Mean family dysfunction increased across family management patterns, with family functioning means significantly lower (less dysfunction) for the Family Focused and Somewhat Family Focused patterns than for the other two patterns and significantly lower for the Somewhat Condition Focused pattern than for the Condition Focused pattern (joint $p < .05$). There was not a significant difference in family functioning between the Family Focused and Somewhat Family Focused patterns.

Regarding child adaptation, the mean frequency of child behavior problems increased across the four management patterns. The mean frequency of child behavior problems was significantly lower for the Family Focused and Somewhat Family Focused patterns than for the other two patterns (joint $p < .05$). There was not a significant difference in frequency of child behavior problems between the Family Focused and Somewhat Family Focused patterns or between the Condition Focused and Somewhat Condition Focused patterns. The degree to which parents viewed children's behaviors as problematic also increased across the four management patterns, with means significantly lower for the Family Focused and Somewhat Family Focused patterns than for the other two patterns (joint $p < .05$), but not significantly different for the Family Focused and Somewhat Family Focused patterns nor for the Condition Focused and Somewhat Condition Focused patterns.

Mean child functional status also varied significantly across patterns, with differences in the expected direction. There were significant (joint $p < .01$) declines in mean child functional status between each pair of family management patterns (Family Focused vs. Somewhat Family Focused; Somewhat Family Focused vs. Somewhat Condition Focused; Somewhat Condition Focused vs. Condition Focused). These differences across the four patterns provide further evidence that the four patterns distinguish meaningful differences in management across families.

Discussion

The six scales of the Family Management Measure tap different aspects of family response to childhood chronic conditions. Considered individually, the scales provide information about important dimensions of family management of the child's condition and areas of family strength and difficulty. Some of the FaMM scales address parents' views of the impact of the condition on their child and family; others address the work of incorporating condition management into everyday family life and parents' assessment of their management abilities, the effort they expend, and the difficulties they attribute to condition management. The Parental Mutuality scale provides data on the extent to which, in two parent families, parents see themselves as working together as a team to manage the condition.

Through cluster analysis, we were able to take a more integrated look at family management and uncover configurations formed by considering parents' scores on all six FaMM scales simultaneously. The analysis also allowed us to consider similarities and differences in partners' perceptions of family management. Across the four family management patterns identified, there was a steady decline in scores on all six FaMM scales. In this sample of parents, no patterns were comprised of relatively positive views on some scales and relatively negative views on others, indicating that parents had consistently positive, moderate, or negative views of their situation across all aspects of family management. The coherence and integrated nature of these configurations are consistent with the FMSF framework, in that each aspect of family management is relevant and they are reciprocally related (Knafl & Deatrick, 2003; Knafl et al., 2008; Knafl et al., 2012). What did vary across patterns was the degree to which a positive or negative perspective prevailed and that such differences were consistently evident across all of the FaMM scales.

There are similarities between the four patterns identified in the current analysis and the five styles identified in our prior qualitative study of 66 families in which there was a child with a chronic physical condition (Knafl et al., 1996). In that study, a predominantly positive and a predominantly negatively management style were identified also, with three intermediate styles reflecting differing degrees and sources of management difficulties. The FaMM measure was based, in part, on the results of that earlier study and generated a more detailed look at the different aspects of family management and the different patterns of agreement and disagreement in parents within families reflected in the current results.

Parents were more likely to report a highly positive than highly negative view of family life, with 24% of the sample in the Family Focused pattern and only 8% in the Condition Focused pattern. This is consistent with prior studies of family patterns of response that also found that most families believed they had successfully incorporated condition management into their usual routine and adapted well to the challenges of having a child with a chronic condition (Davis, 1963; Deatrick et al., 1999; Knafl et al., 1996; Robinson, 1993). Similar to past studies, for some families, condition management became the focus of family life.

Relatively little attention has been paid to describing those patterns of family response that reflect more moderate levels of ease or difficulty in family management. In the current analysis, most families (68%) were in one of the two intermediate patterns in which both positive (Somewhat Family Focused) and negative (Somewhat Condition Focused) views were more moderate. The large percentage (35%) of families falling into the Somewhat Condition Focused pattern provides evidence that, for many families, having a child with a chronic condition shapes everyday family routines and parents' views of their child and family life without becoming the exclusive focus of family life.

In families with two parents participating, parents' scores on the FaMM scales were more similar in the Family Focused and Condition Focused patterns than in either the Somewhat Family Focused or Somewhat Condition Focused patterns. The extent to which differences between parents were complementary or a source of conflict that inhibited family management is unknown. However, the relatively high levels of Parental Mutuality across patterns, suggests that parental differences in the areas tapped by the FaMM were not a source of family conflict for most families.

Similar to other studies (e.g., Fiese et al., 2008; Knafl, Knafl, et al., 2007; Scharff et al., 2005) using a typological approach to study family response to a child's chronic condition, a relationship was found between pattern membership and other family and child variables, providing evidence that the patterns identified reflect meaningful differences in family management of childhood chronic conditions. Our analysis also provides evidence of the interplay of family management and demographic variables in shaping family response to a child's chronic condition. Like others (e.g., Brown et al., 2008; Cadman et al., 1991; Drotar & Bonner, 2009; Kazak et al., 2012), single parent families and those with lower incomes had significantly more difficulty adapting to a child's illness. On the other hand, the four patterns of family management did not differ significantly on child age or sex and parental age, education, or race, indicating that the four patterns of family management were diverse with regard to these demographic variables.

The finding that patterns reflected consistently high, moderate, and low scores on all FaMM scales makes it difficult to know which of the dimensions of family management would be the most likely intervention target and whether a focus on single or multiple dimensions of family management would be more effective. To individualize and tailor interventions, families could identify a problem or area of family life they would like to change. The FaMM could be used to help them assess their families' strengths and areas of potential difficulty and identify target areas for either supporting effective management or enhancing self-identified aspects of management.

Limitations

The analysis was based on a sample that included parents of children with many different conditions, and this was both strength and a limitation of the study. The diversity of conditions on which the patterns are based provides evidence that they are broadly applicable. On the other hand, the limited number of children with most conditions limited our ability to look at the relationship between condition and patterns of response. Studies that include a smaller number of conditions would be better positioned to further our understanding of the common versus condition specific aspects of family management and to identify those conditions that are most challenging for families to manage. Ideally, the conditions sampled would be selected to further our understanding of characteristics of the condition that the literature suggests are most likely to shape family response (e.g., visible versus nonvisible, life-threatening versus non-life-threatening; Rolland, 1984).

Other limitations of the current analysis were the cross-sectional nature of the data, the absence of measures of parent functioning or quality of life, and the absence of child reported data or an objective measure of child health status. Longitudinal studies of families are needed to determine the stability of management patterns over time and to identify condition and family-related variables that contribute to changes in family management and how such changes are related to family and family member outcomes. Longitudinal studies also would further the identification of usual versus unusual trajectories of family management and child, family, and condition factors that trigger changes.

Although the FaMM scales address aspects of family management that are likely to affect the functioning and quality of life of all family members, the current analysis only had data on the individual functioning of the child and no data on the relationship between quality of life and family management. Although past studies have identified considerable variability in the functioning of parents and siblings of children with a chronic condition as well as the quality of life of all family members (Barlow & Ellard, 2006; Grootenhuis & Last, 1997; Pai et al., 2007; Sharpe & Rossiter, 2002; Wilkins & Woodgate, 2005), understanding of the relationship between family management and these variables is limited, and future studies should include a fuller assessment of family member functioning. Finally, understanding of the relationship between family management and objective indicators of child health and control of the condition are important areas for future inquiry.

Acknowledgments

We acknowledge the financial support of the National Institute of Nursing Research, National Institutes of Health (1R01, NR08048) and the Donaghue Medical Research Foundation.

The authors wish to thank Valerie Parham-Thompson for her editorial assistance with this paper.

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Table 1

Mean Scale Scores and Description of Four Family Management Patterns

Patterns	Family Management Style Scales (Range)						
	Child's Daily Life (5–25) Mother/Father	**Condition Management Ability (12–60) Mother/Father**	**Condition Management Effort (4–20) Mother/ Father**	**Family Life Difficulty (14–70) Mother/Father**	**View Condition Impact (10–50) Mother/Father**	**Parental Mutuality (8–40) Mother/Father**	**Ranking on FaMM Scales**
Family Focused	21.6/23.2	53.4/53.9	9.7/9.0	19.9/19.0	21.8/20.2	36.0/36.8	Mother ranked 6 on all scales; father ranked 6 on 5 scales
Somewhat Family Focused							Ranked 3–5 on most scales
Father More Positive	16.6/20.9	41.1/52.0	12.3/9.8	28.6/20.4	29.8/26.0	34.6/37.6	
Mother More Positive	20.1/19.3	51.3/50.0	13.0/13.4	26.2/29.2	25.1/27.4	34.3/35.5	
Somewhat Condition Focused							Ranked 2–4 on all scales
Father More Positive	13.2/17.3	46.3/50.4	17.2/12.7	45.4/31.7	31.1/27.7	32.6/34.8	
Mother More Positive	16.8/14.1	48.7/43.4	15.9/15.7	35.2/42.8	29.6/32.7	30.3/32.9	
Condition Focused	11.3/12.3	38.5/43.1	17.3/16.4	52.7/49.3	34.3/34.4	29.2/32/2	Ranked 1 on all scales

Notes.

FAMM = Family Management Measure

Table 2

Comparison of Composition of Family Management Clusters

Family Management Pattern	% Families[a] (*n* = 414)	% Partnered Mothers (*n* = 349)	% Single Mothers (*n* = 65)	% Fathers (*n* = 161)
Family Focused	24	25	20	25
Somewhat Family Focused – Fathers More Positive	5	6	2	6
Somewhat Family Focused – Mothers More Positive	28	30	17	30
Somewhat Condition Focused – Fathers More Positive	13	12	14	14
Somewhat Condition Focused - Mothers More Positive	22	21	31	19
Condition Focused	8	7	17	6

Notes.

[a]Identical % frequencies were derived for the 575 parents.

Table 3

Comparison of Mean Family and Child Functioning Across Four Patterns of Family Management*

Pattern of Family Management	Family Functioning (range = 1–4)	Child Behavior Frequency/Problem (ranges = 36–252/0–36)	Child Functional Status (range = 0–100)
Family Focused	1.4[ab]	78.4/5.0[ab]	96.3[abc]
Somewhat Family Focused	1.5[cd]	83.3/5.8[cd]	92.6[ade]
Somewhat Condition Focused	1.7[ace]	96.0/9.2[ac]	87.1[bdf]
Condition Focused	1.9[bde]	106.3/11.5[bd]	79.0[cef]

Notes.

*Analysis combined the two clusters in the Somewhat Family Focused and the Somewhat Condition Focused patterns. One-way analysis of variance between the patterns was significant for each variable ($p < .01$).

Differences between patterns in *post hoc* analysis are indicated by alphabetic (a–f) superscripts such that pairs of values with the same letter are significantly different (joint $p < .05$). *Post hoc* differences between patterns are identical for the two child behavior variables (Frequency and Problem), so these are indicated with a single set of superscripts.