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Information Management in Families Who Have a Child with a Genetic Condition

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In families with genetic conditions, information management is critical for individuals to understand the condition itself and to appreciate its implications related to genetic risk for immediate and extended family members. The term information management encompasses a complex process that involves the interplay of beliefs and behaviors related to accessing and interpreting genetic information as well as making decisions and taking action based on information (Gallo, Knafl, & Angst, 2001). In the case of parents of children with genetic conditions, information management may influence how they view their child, their reproductive decision making and how, when, what and why they communicate about the condition to other family members.

Health care professionals convey information to parents through information sessions and individual counseling to assist them in accepting, understanding, and adapting to their child's condition (Coyne, 1997; Fisher, 2001; Holaday, 1984; Logan, Radcliffe & Smith-Whitley, 2002). Much of the work around this information exchange between parents and health care providers has focused on this experience during the diagnostic period (Nuutila & Salanterä, 2006). Far less is known about how information is shared and received beyond the diagnosis, when parents' understanding may have waned, but is still critical related to management of condition and information sharing with the growing child and other family members.

In the context of genetic conditions, much of the education related to the genetic aspects of the condition occurs around newborn testing, diagnosis, or when parents access genetic counseling in order to assist with future reproductive decisions. How much parents receive and understand about genetic aspects beyond diagnosis is not well known, though people often have inaccurate perceptions of risk and find it difficult to understand risks and probabilities to use them in decision making (Timmermans, 2005). For example, in a study on parents' misunderstanding of carrier status in children with cystic fibrosis, some parents did not have an accurate

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understanding of the implications of carrier status, and about half of parents reported feeling confused about their increased risk of having a child with cystic fibrosis (Gross et al., 2004). Prior work suggests that health care providers give limited or unclear information to people on genetic aspects of the condition (Timmermans, 2005). Moreover, many parents are dissatisfied with the information they receive (Starke & Moller, 2002), and turn to the Internet for information (Bernhardt & Felter, 2004). Appreciating parents' limited understanding of genetic aspects of their child's condition is important because health care providers are in an ideal position to develop comprehensive communication plans to assess and counsel parents over time.

The use of genetic information by families is complex and important, yet little research to date has been directed toward how parents of children with known genetic conditions access, interpret, convey and use genetic information. The purpose of this study was to identify unique patterns of information management and to explore the relationship between these patterns and individual and family characteristics and functioning.

Conceptual Model

The study was grounded in the Family Management Style Framework (FMSF), which addresses how individual family members define, manage, and perceive the consequences of having a child with a chronic condition (Knafl & Deatrick, 2003). The FMSF is meant to guide research aimed at identifying patterns of family response to health-related challenges. The framework focuses on how individual family members' perspectives and behaviors come together to form a pattern that is called family management style.

In this study we focused on one aspect of family management, information management, and collected data from parents regarding how they accessed, interpreted, and conveyed genetic information to others. We assumed parents would manage information in varying ways and that we would identify different patterns of family response. We believed the results would be fundamental to understanding the implications of genetic information for families.

Methods

Design

This study employed a mixed-method design using both in-depth interviews and standardized measures to explore information management in families of children with genetic conditions. The sampling plan was non-categorical in that families were sought whose children had varied genetic conditions. This approach centers on the common challenges that cut across conditions rather than on the unique aspects of one condition or treatment (Perrin et al., 1993).

Sample

The sample was comprised of 142 parents (83 mothers; 53 fathers; 6 other family members) in 86 families in which a child had a single gene condition, namely, sickle cell disease, cystic fibrosis, phenylketonuria (PKU), neurofibromatosis, Marfan syndrome, hemophilia, von Willebrand disease, or thalassemia. Families were recruited into the study if the parents spoke English and the child had one of the aforementioned conditions, was 3-15 years of age, was biological for at least one parent, and was within two years of the appropriate grade in school. Respondents were either parents or primary caregivers of the child with the genetic condition. For simplicity, the term "parents" is used throughout this article to refer to both parents and primary caregivers. In families with two parents, both parents were invited to participate. No limitations were placed on the sample with regard to socioeconomic status, ethnicity, or race.

Measures

Interview guide—Based on the FMSF and a review of literature on information management, a 37-item semi-structured interview guide was developed that focused on how parents accessed, interpreted, and conveyed information relating to their child's genetic condition. The guide included both open-ended questions and specific probes. To assess the content validity of the interview guide, two consultants who were familiar with the FMSF, had research background in genetics and families, and an understanding of information management, evaluated the individual questions and the entire guide for relevance and appropriateness. See Table 1 for example interview questions by information management aspects: accessing, interpreting and conveying information.

Standardized Measures

In addition to the interviews, parents also completed structured measures of individual and family functioning. Family functioning was measured by the Family APGAR (Austin & Huberty, 1989; Smilkstein, 1978) and the Family Hardiness Index (McCubbin & Thompson, 1991; McCubbin, Thompson, & McCubbin, 1996); quality of life was measured by the Quality of Life Index (QLI) (Ferrans & Powers, 1985, 1992).

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) (Smilkstein, 1978). The overall scores range from 0-20 with item scores ranging from 0-4. Higher scores indicate better family satisfaction. Previous studies have reported high internal consistency reliability, indicating that the Family APGAR is a unidimensional measure of satisfaction with family life (Sawin & Harrigan, 1995). Internal consistency reliability was high in the current study with a Cronbach's alpha of .86.

The Family Hardiness Index (FHI) measures the internal strengths and durability of the family and how families work together to manage challenges. Hardiness is conceptualized as mitigating the negative effects of stress on family functioning and is among the critical aspects of family resiliency (McCubbin & McCubbin, 1996). 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 is comprised of 20 items rated from 0-3 with 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 & Harrigan, 1995). The internal consistency reliability in the current study was .81.

Quality of life was measured using the overall scale of the Quality of Life Index (QLI) (Ferrans & 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 range from 0-30 and reflect the perceived importance and satisfaction with aspects of everyday life. Higher scores indicate better levels of quality of life. Internal consistency reliability for the overall scale ranged from .90-.95. In the current study this reliability was .95.

Data Collection Procedures

The institutional review boards at the universities of the investigators and the participating clinical sites approved the study prior to data collection. Parents were recruited either in person by a member of the research team during a clinic visit or through a letter mailed to them by

the clinic director. Data collection took place in a location chosen by the parents, typically in the family's home. After informed consent, each parent individually participated in the data collection session which included the interview and completion of standardized and demographic measures. The principal investigator, project director, research assistant, or an advanced practice nurse conducted all interviews. The data collection session lasted 60 to 120 minutes on average and each parent received \$50.00 for their time and travel.

Data Analysis

Interviews—Each interview was audio-recorded, transcribed, and processed using the Atlas.ti software (version 4.2), a program designed to store and retrieve qualitative coded data (Muh, 1997). Interview transcripts were compared to the audio-recorded interview to ensure transcription accuracy. Recorded interviews were then erased according to the approved institutional review board protocol. To develop codes and identify themes and subthemes related to information management, the research team read the verbatim transcripts with the goal of determining individual parents' views and experiences with accessing information, interpreting information, and conveying information to others. Our research aim, conceptual framework, interview guide questions, interview data, and a start list of codes from prior work contributed to the development of descriptive coding categories for this study (see Table 2 for example of descriptive codes by information management aspects).

Through a series of analytic matrices (Miles & Huberman, 1994) and narrative case summaries, the team displayed, sorted and compared parent responses within and across families to identify the full range of themes reflected in the sample based on one or two parents (Ayres, Kavanaugh, & Knafl, 2003; Knafl & Ayres, 1996). The basis for the overall patterns of information management was the configuration of themes about how parents accessed, interpreted, and conveyed information to others.

Standardized measures—All analyses were conducted using the Statistical Package for Social Science (SPSS), Version 11.0. Descriptive statistics were used to describe the characteristics of parents who were identified as the primary caregivers in each family. Statistical significance level of $p < .05$ was used for all comparisons. Contingency table analyses were conducted to examine the differences between information management patterns and categorical demographic characteristics. One-way analyses of variance (ANOVAs) were conducted to test the mean differences in individual and family functioning across demographic characteristics.

Results

Sample Characteristics

Although both mothers and fathers contributed data in most two-parent families, the parent characteristics reported represent those of the parent in each family who was identified as the primary caregiver (see Table 3). The majority of the primary caregivers were the biological mothers of the child with a genetic condition. Most of the parents were married and ranged in age from 23 to 57 years. The majority were either White or African American/Black and either Protestant or Catholic. Almost three-quarters of the parents were from a two-parent family. The majority of the parents completed high school and about one-third completed college or graduate school. Most parents were employed full-time or not employed. Of the 82 parents who provided annual household income, 20% reported incomes less than \$20,000 per year and about 30% reported incomes of \$75,000 or greater.

The children had various genetic conditions and ranged in age from 3 to 15 years of age; about half were female. The majority of parents rated the general health of their children as either

excellent or good. Fifteen (17%) of the families had multiple children with the genetic condition.

Information Management Patterns

Four distinct information management patterns were identified based on parents' understanding of the genetic aspects of the condition: Accurate Understanding-Open, Accurate Understanding-Selective, Discrepant Understanding and Confused Understanding (see Table 4). In two patterns, Accurate Understanding-Open and Accurate Understanding-Selective, over half (59%) of the parents had an accurate understanding of the genetic aspects of the condition, and the patterns were differentiated from one another by parents' views about sharing information with others. In the Discrepant Understanding pattern, that included only two-parent families, one parent had an accurate understanding and one parent a confused understanding of the genetic aspects of the condition. In the Confused Understanding pattern, parents had an inaccurate understanding of one or more the genetic aspects of the condition.

Accurate Understanding-Open pattern—Parents in this pattern had an accurate understanding of the child's genetic condition. Although these parents were varied in the level of detail they provided in describing the genetic aspects of the condition, they had a basic understanding of how it was transmitted from parent to child, the likelihood of others in the family having the condition, and the likelihood of the child passing on the condition. One mother of a child with cystic fibrosis explained,

For a child to have CF, both the mother and the father have to carry a CF gene. Any child we have has a one in four chance of having CF; they have a two in four chance of being a carrier, and one in four chance of not [being a carrier of] CF.

A mother, who herself had one of the four main types of sickle cell disease, sickle-hemoglobin C disease (HbSC), described her understanding of how sickle cell anemia (HbSS) was passed on to her daughter,

Well, my mom and dad had different traits ... I got the S trait from my mom and the C trait from my dad, which gave me sickle cell [disease]. Neither one of them had it, but they had the trait, which gave me the full blown disease. I have SC. Selma has the SS. So, she got the S from her father, and the S from me. And that gave her sickle cell [anemia].

Parents in this pattern took it upon themselves to actively seek out information about the condition beyond what they were told by health care professionals. For example, the mother of a child with PKU provided a detailed description of what it meant to have a recessive genetic condition and then added: "We read through all the information the clinic provided. I went to the library and got a lot of stuff. We have a very active parent group here and they provide lots of information." Parents also relied on other parents, available printed materials and companies who supplied therapies and treatments in order to learn more information about their child's condition. One mother of a child with hemophilia noted ways that she sought out information,

You get plenty from other parents. You get information from magazines you read. There are plenty of magazines in the hemophilia community for you to rely on ... the pharmacy companies - the middle man companies who supply patients who are treated at home.

In this pattern, parents were open in sharing information and did not hesitate to tell others including family, friends and neighbors, and personnel at their workplace and their child's school that their child had a genetic condition. A father of a child with PKU who shared information with others on an ongoing basis stated, "I think we told everyone-family, my boss, the babysitter. We didn't like put up a billboard, but we gradually ended up telling everyone."

These parents openly told others because they felt the need for both emotional and social support to manage their child's daily symptoms and treatments or because they wanted others to know in case their child became ill.

Accurate Understanding-Selective pattern—Although parents in the Accurate Understanding-Selective pattern had accurate understandings of the genetic aspects of the conditions, they were more varied in their approaches to seeking and/or sharing information. Parents sometimes relied on others, usually health care professionals, to teach them about the condition and/or they were more selective in whom they told about the condition. In the two-parent families in this pattern, parents often varied in their approaches.

Parents in this pattern struggled with sharing information with others because they wanted to balance their need for support with their belief of protecting their children and families from being treated differently. Many of these parents only shared information with others on a “need to know” basis including those in their child's school or their own workplace. Concerning her reluctance to tell others about her daughter's condition, a mother of a child with neurofibromatosis, stated,

We haven't told a lot of people. We've told family and dear friends because we need support and want support and they care about us and Maddi. You weigh wanting support with not wanting other people to begin to see her as sick and unfortunate. These are hard decisions.

Some parents talked about their reliance on health providers for information, whereas others used multiple sources to find information. Regarding her approach to information seeking, a mother whose child had cystic fibrosis expressed how she sought information from health care providers, “I don't actively go out looking. If there is something that I need to know, I can call and talk to a nurse or leave a message and they will get back to me.” A mother of a child with Marfan syndrome indicated the sources she used to learn about the condition,

I have gotten lots of pamphlets. I know that the last time we visited the bone doctor, he gave me a couple of inserts from a book pertaining to Marfan syndrome and the skeletal system. I received a big package, but don't know where I got it. Everywhere that I go, I always pick up pamphlets and information.

Discrepant Understanding pattern—In contrast to parents in the Accurate Understanding-Open and the Accurate Understanding-Selective patterns, in the Discrepant Understanding pattern parents within a family differed in the accuracy of their understanding of the genetic aspects of the condition. In these two-parent families, one person had an accurate and the other person had a confused understanding of the genetic aspects of the condition. While mothers in this pattern usually had an accurate understanding of the genetic aspects of the condition, fathers were more likely to have inaccurate understanding of the genetic aspects. For example, the father of a child with PKU whose wife had provided an accurate description of the genetic aspects of the condition noted, “as far as I am concerned if both parents are carriers, it is definite that you will have a child with PKU.”

Like the Accurate Understanding-Selective pattern, both within and across families, these parents were quite varied in their beliefs about and approaches to seeking and sharing information. For example, one couple of a child with sickle cell disease had different views on sharing information with others. The mother was more selective in her sharing than the father who openly shared information. As the mother described her ambivalence in sharing, “I didn't want to tell people because I didn't want them to treat him differently, but that at the same time, if they were going to be around him and care for him, they might be afraid.” While the father's response was,

We tell everybody-family, friends, everybody-even people we don't like. One thing I believe is that if you put information out there and you have a listening ear, it'll carry to another person. So, it's okay if I talk about it to them, because they'll tell someone else who may have it and needs the information. So, I just tell everybody.

Confused Understanding pattern—In these families, all parents were confused about one or more genetic aspects of the condition including how the condition was transmitted from parent to child, the likelihood of others in the family having the condition, and the likelihood of the child passing on the condition. Parents sometimes stated they did not understand the genetic aspects of the condition, noting that they were told at the time of diagnosis, but “don't recall anymore,” or they were not told and they did not ask. For example, one father of a child with sickle cell disease noted,

There are lots of questions I still have because I don't understand. It's just people ask me, what is sickle cell, what does that mean? And I try to explain it to them as best I could, but I don't know if I'm explaining it to them right.

Other times, parents would struggle to describe the genetic basis for the condition or the likelihood of transmission. For example, one mother of a child with cystic fibrosis said,

I guess my husband and I just had one of those genes that once we connected our daughter was going to have CF. But I don't know, I guess there is a high probability that my brother could have one of those genes. I don't know ...

Like the Accurate Understanding-Selective and the Discrepant patterns, both within and across families, these parents were quite varied in their beliefs about and approaches to seeking and sharing information. For example, a mother of a child with thalassemia noted that she did not share information with her family or others because “We felt guilty and blamed ourselves.” A mother of a child with sickle cell disease explained that she did not have an understanding of the condition and therefore felt unable to share information with others,

I hid it ... I hid it from [her father] and my mother because I didn't know how to tell them. I didn't really know what it was. I didn't know or understand nothing about sickle cell. All I knew is that I had sickle cell trait ... so I thought she had sickle cell trait, but she had sickle cell full blown.

Comparisons Across Patterns

Other themes were common across the four patterns of information management. For example, in most families (91%; $n = 78/86$) parents described how they used multiple sources to access information, including health care providers, the Internet, support groups and organizations associated with the condition. Families in the Confused pattern, however, were more likely to report using a single source ($n = 5/8$) as compared to families in other patterns ($n = 3/8$).

Parents across information management patterns were also generally satisfied with their understanding. Regardless of the accuracy of their understanding of the condition, 89% of parents ($n = 76/86$) expressed satisfaction with what they knew about the genetic aspects of the condition. In fact, 17% of families ($n = 24/131$) who were satisfied with their understanding of the condition, were also confused about the genetic aspects of the condition.

Standardized Measures

Information management patterns and demographic characteristics—With regard to the four information management patterns and demographic characteristics, there were statistically significant differences in parents' education, family annual income and health insurance coverage (see Table 5). Half (50%) of the Accurate-Understanding Open parents

received a college or graduate school degree in contrast to 92% of the Discrepant Understanding parents whose highest level of education was high school and 87% of Confused Understanding parents whose highest level of education was high school or elementary school ($\chi^2 (9, N = 86) = 22.1, p = .009$). The modal annual income for the Accurate Understanding-Open parents was \$75,000 or more (52%) as compared with 52% of Accurate Understanding-Selective parents earning \$50,000 – 74,999 and 43% of the Confused Understanding parents earning only \$10,000-29,999 ($\chi^2 (12, N = 82) = 37.1, p = .0001$). Finally, there was a significant difference in health insurance coverage with the 67% of the Confused Understanding parents relying on public insurance in contrast to the other three patterns ranging from 75% to 84% who could afford private health insurance ($\chi^2 (6, N = 79) = 23.2, p = .001$). There were no significant differences between the information management patterns and the child's genetic condition, gender, parent race/ethnicity or religion.

Individual and family functioning measures—No significant differences were found in the four standardized measures (Family APGAR, Family Hardiness Index, Feetham Family Functioning Survey, and Quality of Life Index) by either information management pattern, recruitment site, the genetic condition, the child's age or gender, or family structure (e.g., single versus two-parent families).

Discussion

We identified four distinct patterns of information management in families who have a child with a genetic condition. They were distinguished by parents' accuracy of understanding about the genetic aspects of the condition. However, even in those families where parents were accurate in their understanding, there was notable variation in the comprehensiveness and level of detail of this understanding. With the exception of the Accurate Understanding-Open pattern, where parents' accurate understanding was accompanied by active information seeking and open sharing of information with others, the patterns were quite mixed with regard to information seeking and sharing. Accuracy of understanding was the only distinguishing aspect of the three remaining patterns. What parents understood about the genetic aspects of the condition was not clearly linked to how they went about seeking or sharing information. Moreover, regardless of the accuracy or sophistication of their understanding related to the genetic aspects of the condition, parents appeared satisfied with what they knew.

Although many families had an accurate understanding of the genetic aspects of the condition, confusion was not uncommon in families with fewer resources. We were not able to locate specific studies that examined the association between individual and family characteristics and parents' understanding of genetic aspects when their school age child has a genetic condition. However, two related studies found difficulties in understanding complex genetic concepts among persons with lower levels of education (Clayton, et al., 1995; Marteau, et al., 2000), and because of this misunderstanding, some parents may have difficulty conveying genetic information to others. The literature also shows that health care providers are sometimes less likely to provide information to parents who are less well educated or have lower incomes because they perceive such parents as unable to understand and make appropriate use of the information (Porterfield & McBride, 2007; Stevens & Shi, 2003; van Ryan & Burke, 2000; Waitzkin, 1985). In our study, it was unclear if parental confusion was grounded in parents not perceiving a need for information and therefore not asking for more information, or if confusion resulted from information from health providers or other sources that were not understandable to parents. Moreover, it is important to keep in mind that most families had received the diagnosis in the past. Their initial understanding of the genetic aspects of the condition may have been accurate, but over time they may have forgotten the specifics.

There are some limitations related to sample and methods. Our study included predominantly parents of school age children. It may be that genetic information management is not the most salient aspect of having a child with a genetic condition for parents of children in this age group. It is plausible that genetic aspects may be a more prominent focus for parents of young children around diagnosis and at adolescence, when parents are thinking about future reproductive decisions for themselves or their adolescents. We were not able to conduct an analysis related to the child's age at the time of diagnosis because we did not collect data about time since diagnosis. Another limitation is that we did not objectively assess (e.g., through knowledge test) parents' understanding or knowledge about the genetic aspects of the condition.

Implications for Practice

From a clinical point of view, this analysis supports the need for health providers to actively partner with parents to ensure they have a basic understanding about the genetic aspects of the condition. Parents described the time around the child's diagnosis as when they had learned most about the condition. They readily admitted that they had forgotten much of what they were told initially and did not indicate that they viewed this as problematic. Further, since parents seemed to be satisfied with their understanding and often were unaware of their confusion, they may not ask questions or seek additional information about the genetic aspects of the condition. Health care providers should not simply ask parents if they have any questions about the condition, but need to delve deeper in order to assess the accuracy and depth of parents' understanding of the nature of the condition and its genetic aspects. Even though parents consider management of their child's condition as top priority, health providers can ask parents about their views and attitudes about their readiness and need to learn more about the genetic aspects in order to accurately and confidently share information with others including their children (Gallo et al., 2005). These findings also point to the importance of assessing the level and accuracy of understanding of both parents in two-parent families. Discrepant understanding between parents is not uncommon and may mean the child with the condition, siblings, and other family members receive inconsistent and/or inaccurate information about the genetic aspects of the condition.

In the current health care environment, health care providers may have limited opportunities to evaluate family members' understanding of genetic aspects of the condition. By being aware of families with fewer resources, we may be able to identify those who may be most at risk for confusion and target interventions and education to these harder to reach families who may not recognize the need for information about the genetic aspects of the condition.

Implications for Future Research

Future research needs to continue to document and draw attention to the importance of information management in families and between family members, and study how information management varies over time both in terms of the child's development and the family's life cycle. Studying how information management occurs in families with adolescents and young adults with a genetic condition and their unaffected adolescent and young adult siblings can further our understanding about how information is understood and shared with children as they get older and begin to look at issues during their childbearing years. Further research is needed on how information management is situated in overall family management of illness and the contribution of information management to child and family functioning. Finally, the role of the health care providers in helping families to access, interpret and use information over time is an important area of research.

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Table 1

Sample Interview Questions by Information Management Aspects

Information management aspect	Interview guide questions
Accessing	<p>When you first found out that your child had [condition], how were you told? What were you told? Who gave you the diagnosis? Who was with you?</p> <p>You told me earlier about the sources you use to get information on the condition in general. Do you use the same sources to get information on how the condition is passed on in the family? How do you know what is a “good” source and/or “bad” source of information?</p> <p>Who else or what other sources or ways have you used to learn about your child's condition? How have the sources changed over time?</p>
Conveying	<p>Since diagnosis, who have you told, or needed to tell about the child's condition? How did you decide to tell these people? How difficult or easy was it for you tell others?</p> <p>What have you decided about telling others about how the condition is passed on in the family?</p> <p>What have you told your children about the condition and how it is passed on in the family? How did you decide this?</p> <p>Is there anyone you prefer did not know about how the condition is passed on in the family? What would happen if you told them?</p>
Interpreting	<p>Can you tell me how the condition is passed on in the family? What are the chances of other children or family members having the condition? What are the chances of other children or family members being a carrier of the condition? What do you still find confusing or difficult to understand about how the condition is passed on?</p>

Table 2

Examples of Descriptive Codes by Information Management Aspects

Information management aspect	Descriptive code
Accessing	Family history of illness
	Family's knowledge of others with condition
	Seeking information
	Receiving information
	Information sources
Interpreting	Understanding the genetic condition
	Illness and treatment management
	Understanding genetic transmission to child
	Understanding genetic risk to others
	Own satisfaction with understand
Conveying	Sharing information with child/siblings
	Sharing information with others
	Prefer not knowing
	Information withholding

Table 3

Sample Characteristics (N = 86)

Characteristic	N (%) ^a
Relationship to Child	
Mother	81 (94)
Father	2 (2)
Grandmother	2 (2)
Stepmother	1 (1)
Marital Status	
Married	59 (69)
Divorced	11 (13)
Never Married	16 (19)
Parent Age (range: 23-57 years)	
Mean (SD)	39.84 (7.59)
Ethnicity (N = 85)	
Asian	3 (4)
African American/Black	32 (38)
Hispanic or Latino	3 (4)
White	45 (52)
Other	2 (2)
Religious Preference (N = 85)	
Protestant	32 (38)
Catholic	28 (33)
Jewish	3 (4)
Muslim	2 (2)
No preference	10 (12)
Other	10 (12)
Family Type	
Two-parent	64 (74)
Single-parent	22 (26)
Highest Education Level	
Elementary school	4 (5)
High school	53 (62)
College	20 (23)
Graduate/Professional	9 (11)
Employment Status	
Full-time	34 (40)
Part-time	19 (22)
Not employed	33 (38)
Annual Family Income (N = 82)	
Less than \$20,000	16 (20)
\$20,000-39,999	13 (16)
\$40,000-59,999	15 (18)
\$60,000-74,999	13 (16)

Characteristic	N (%) ^a
\$75,000- 99,000	15 (18)
\$100,000 or more	10 (12)
Health Insurance (<i>N</i> = 79)	
Private	54 (68)
Public	24 (30)
None	1 (1)
Child's genetic condition	
Sickle cell disease	29 (34)
Phenylketonuria	16 (19)
Cystic fibrosis	16 (19)
Neurofibromatosis	10 (12)
Bleeding Disorders	7 (8)
Thalassemia	4 (5)
Marfan syndrome	4 (5)
Child (range: 3.7-15.9 years)	
Mean (<i>SD</i>)	10.1 (3.18)
Child Gender	
Female	45 (52)
Male	41 (48)
Child's General Health	
Excellent	40 (47)
Good	41 (48)
Fair	5 (6)

Note:

^aTotals may not equal 100% because of rounding.

Table 4
Patterns and Aspects of Information Management in Families

Aspect of Management	Information management pattern (N = 86)			
	Accurate Understanding-Open (n = 30; 35%)	Accurate Understanding-Selective (n = 21; 24%)	Discrepant Understanding ^b (n = 13; 15%)	Confused Understanding (n = 22; 26%)
Interpreting ^a : Understanding of genetic aspects of the condition	Accurate	Accurate	One parent Accurate & one parent Confused	Confused
Conveying: Sharing information with others	Open	Varied	Varied	Varied
Accessing: Seeking information about the genetic condition	Active	Varied	Varied	Varied

Note:

^aDimension that differentiated patterns.

^bTwo-parent families only

Table 5
Demographic Characteristics by Information Management Patterns

Characteristic	Information management pattern				χ^2
	Accurate- Open <i>n</i> (%) ^a 30 (35)	Accurate- Selective <i>n</i> (%) ^a 21 (24)	Discrepant Understanding <i>n</i> (%) ^a 13 (15)	Confused Understanding <i>n</i> (%) ^a 22 (26)	
Parent Education					22.11 *
Elementary	1 (3)	0 (0)	0 (0)	3 (14)	
High School	14 (47)	11 (52)	12 (92)	16 (73)	
College	8 (27)	8 (38)	1 (8)	3 (14)	
Graduate School	7 (23)	2 (10)	0 (0)	0 (0)	
Family Income					37.09 **
< \$10,000	1 (4)	1 (5)	1 (7)	6 (29)	
\$10,000–29,999	6 (22)	0 (0)	2 (15)	9 (43)	
\$30,000–49,000	2 (7)	3 (14)	0 (0)	1 (5)	
\$50,000–74,999	4 (15)	11 (52)	7 (54)	3 (14)	
\$75,000 or >	14 (52)	6 (29)	3 (23)	2 (10)	
Health Insurance					23.24 **
Private	22 (82)	16 (84)	9 (75)	7 (33)	
Public	5 (19)	3 (16)	2 (17)	14 (67)	
None	0 (0)	0 (0)	1 (8)	0 (0)	

Note:

*
 $p < .01$

**
 $p = < .001$.

^aTotals may not equal 100% because of rounding.