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Maternal Factors Related to Parenting Young Children with Congenital Heart Disease

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Abstract: *The purpose of this study was to compare the early child-rearing practices between mothers of young children with congenital heart disease (CHD) and mothers of healthy children. In addition, maternal stress, parental developmental expectations, and the early behavioral and emotional development of their children were explored. Maccoby's (1992) socialization theory emphasizing the reciprocal nature of mother-child interactions provided the framework for this study. Findings from quantitative self-report measures and videotaped parent-child interactions showed a remarkable similarity between mothers of children with CHD and mothers of healthy children. In contrast, qualitative data revealed important differences with mothers of CHD children reporting high levels of vigilance with their children. The important role of promoting the principle of normalization among mothers of children with CHD and ensuring a sufficient support system is discussed.*

Parents and other significant caregivers play an important role in children's development (Collins, Maccoby, Steinberg, Hetherington, & Bornstein, 2000). There are numerous factors that influence the quality of parenting that children receive (Belsky, 1990). The health status of a child, including the onset of a chronic illness, is one of many factors that can contribute to the quality of child rearing (Kazak, 1989). When considering that up to 30% of children have a chronic health condition (Newacheck & Halfon, 1998), 11% of whom are living with conditions considered moderate to severe (Newacheck, Stoddard, & McManus, 1993), a significant number of families are faced with an even more challenging future than they had anticipated. How parents respond to this situation can affect both the short- and long-term developmental outcomes for their children.

Conceptual Model

The family context is an important contributing factor in the socialization of children (Maccoby & Martin, 1983). More specifically, the role of parents in influencing their children's outcomes has increasingly been the focus of research. What has emerged is the general finding that parents and children influence each other in a reciprocal manner (Maccoby, 1992). For example, children who have difficult temperaments are likely to bring out different responses in

their parents than children who are more easy-going. Similarly, children born with significant health impairments may also elicit unique parental responses (e.g., overprotective). How parents respond over time can influence the children's short- and long-term developmental outcomes. In general, an authoritative parenting style (i.e., parents who are responsive to their children's needs and set reasonable limits on their behavior) produces the most favorable childhood outcomes (Steinberg, Lamborn, Darling, Mounts, & Dornbusch, 1994).

There are multiple determinants that impact parenting practices (Belsky, 1990), including socioeconomic and maternal factors. For example, Fox, Platz, and Bentley (1995) reported less favorable parenting practices among mothers who were younger, single, from lower income and educational levels, and who had more than one child living at home. Numerous other factors including marital satisfaction, level of spousal support, and the mental health of the parent can influence childrearing practices (Simons, Beamon, Conger, & Chao, 1993). In addition, the child's unique characteristics, including temperament (O'Conner, Deater-Deckard, Fulker, Rutter, & Plomin, 1998) and health status (Dolgin, Phipps, & Harrow, 1990) also influence parenting practices. Regarding the rearing of chronically ill children, Maccoby's (1992) model would predict that parents may significantly alter their child-rearing patterns to accommodate these children's special needs. In fact, Van Dongen-Melmen and Sanders-Woudstra (1986) suggested that it would be difficult to imagine parents who would not be at least somewhat overly protective of their children. This overprotective parenting style, fueled at least in part by parental anxiety, could hamper the overall development of these children (Utens et al., 1994).

Purpose

The purpose of this study was to compare the early child-rearing practices between mothers of children with congenital heart disease (CHD) and mothers of healthy children. In addition, parenting stress, parental expectations of their young children, and the early behavioral and emotional development of toddlers and preschoolers were explored.

Review of the Literature

Parents often respond with shock and disbelief when a diagnosis of a chronic illness in their child is first made (Sabbeth, 1984). Parenting a child with a chronic illness has been considered to be a highly stressful, demanding experience for the parents and family (Austin, 1991). However, positive adaptation and growth has also been reported among these families (Clawson, 1996).

Most available studies regarding the parenting of children with CHD have emphasized parental adjustment to the diagnosis (Emery, 1989), the demands and related stress that these children place on the family (Svavarstottir & McCubbin, 1996), and early care-giving issues, particularly infant feeding difficulties (Lobo, 1992). Relatively less attention has been devoted to the emotional adjustment of these children (DeMaso, Beardslee, Silbert, & Fyler, 1991). Goldberg, Simmons, Newman, Campbell, and Fowler (1991) studied mother-infant interactions in mothers of children with CHD and mothers of healthy children. Maternal-child attachments in the CHD group were less secure than attachments in the healthy group. In the CHD group, securely attached infants showed greater improvement in their physical health than those infants who were less securely attached. DeMaso, et al. (1990) found that the behavioral adjustment of children with CHD was significantly related to the level of parenting stress.

With recent medical advances significantly improving the prognosis for children with CHD (Marino & Lipshitz, 1991), the concept of normalization (Krulik, 1980) has been extended to these families. Normalization is described as “the constant process of actively accommodating the changing physical and emotional needs of the child” (Deatrick, Knafl, & Walsh, 1988, p. 17). To accomplish normalization in families of children with chronic illnesses, health care professionals commonly advise these parents to raise their children as close to normal as possible (Deatrick, Knafl, & Murphy-Moore, 1999). This normalization philosophy is intended to minimize the impact of a chronic health condition and optimize the child’s normative development while fostering a greater acceptance of the child with a chronic illness within society (Holaday, 1984).

Methodology

Two groups of mothers with children between 2 and 5 years of age from a large urban area in the Midwest made up the study sample. The first group included mothers of children with moderate to severe CHD, recruited through a large pediatric cardiology clinic at a children’s hospital. Cardiac severity was rated by each child’s pediatric cardiologist using the Cardiologist’s Perception of Medical Severity (DeMaso, et al., 1991), which has a rating scale ranging from 1 = insignificant (disorder has no impact on child’s health) to 5 = severe (uncorrectable lesion or only complex, palliative repair possible), and an inter-rater reliability of .97. Five pediatric cardiologists participated in this study. Subjects in the CHD group required a severity rating of at least moderate (3 or higher) to be included in this study. The second group included mothers of healthy children (absence of chronic illnesses, significant health conditions, or birth anomalies) who were recruited from pediatric medical practices and school

settings and matched with the first group on the child's age and gender and maternal marital and socioeconomic status.

Subjects who met the inclusion criteria were visited in their homes by the first author who reviewed the study procedures and obtained written informed consent. The home visits averaged about 1.5 hours in length. Mothers received $50 for participating and their children were given a toy or book.

An adapted family form, piloted in previous research (Nicholson, Anderson, Fox, & Brenner, in press), was used to obtain family demographic information and to seek maternal responses to questions regarding how parenting was different than expected, whether or not they had attended parenting classes or sought professional help for their child's behavior, and the amount of social support they received for parenting. Next, the child and mother were videotaped playing together with a standard set of safe and age appropriate toys. A behavioral observational system adapted from the Dyadic Parent-Child Interaction Coding System (DPCICS; Eyberg, Robinson, Kniskern, & O'Brien, 1978) was followed to structure the videotaping and code the mothers' and children's behaviors. For the first 5 minutes of the videotaped session, the mother was directed to let the child choose an activity and play with the child according to his or her rules. The mother was then directed to choose an activity and play with the child for the next 5 minutes according to the mother's rules. Finally, the mother was instructed to have the child help in cleaning up the play area.

After the videotaping, the instruments described below were administered. The Parent Behavior Checklist (PBC; Fox, 1994) is a 100-item rating scale developed to measure parenting behaviors and parental expectations of young children between the ages of 1 year and 4 years, 11 months. Normed on an urban population of 1,056 mothers, the PBC measures parenting behaviors on three subscales: (1) *discipline* measures parental responses to children's challenging behaviors (e.g., "When my child has a temper tantrum, I spank him or her"), (2) *nurturing* measures specific positive parent behaviors that promote a child's psychological growth (e.g., "I praise my child for learning new things"), and (3) *expectations* measures parents' developmental expectations (e.g., "My child should be old enough to share toys"). More effective parenting strategies are associated with lower scores on discipline, higher scores on nurturing, and mid-range scores on expectations. Internal consistencies and test-retest reliabilities for each subscale, respectively, are as follows: discipline = .92, .87; nurturing = .91, .81; and expectations = .97, .98. The PBC was selected for this study to assess the parental expectations and reported parenting practices of the families of children with CHD.

The Parenting Stress Index-Short Form (PSI) is a 36-item, self-report measure of the amount of stress experienced by parents of young children (Abidin, 1995). The PSI measures parenting stress on three subscales: (1) *parent distress* measures the amount of distress a parent is experiencing in his or her role as a parent or as a function of personal factors that are related to parenting; (2) *parent-child dysfunctional interaction* measures the parent's perception that his or her child does not meet the parent's expectations and the interactions with his or her child are not reinforcing; and (3) *difficult child* measures the basic behavioral characteristics of children that make them either easy or difficult to manage. High scores on any of these subscales are indicative of an increased level of parental stress. Test-retest and alpha reliabilities for the PSI total score are .84 and .91, respectively. This measure was selected to detect potential parental stress related to rearing a child with CHD. The Eyberg Child Behavior Inventory (ECBI; Eyberg & Ross, 1978) is a 36-item inventory that measures behavior problems common to children 2 to 16 years old. An intensity score is determined through the rating of the frequency of each behavior on a scale from 1 (never occurs) to 7 (always occurs). A problem score is determined by having respondents identify each behavior as a current problem with a "yes" or "no" response. The ECBI discriminates between problem and nonproblem children (Robinson, Eyberg, & Ross, 1980). Reliabilities of this scale range from .86 (test-retest) to .98 (internal consistency). The Behavior Screening Questionnaire (BSQ; Richman & Graham, 1971) is a screening tool used to identify behavioral and emotional problems in preschool children. Inter-rater reliabilities are reported between .77 and .94. A correlation of .88 between the BSQ and clinical rating of 3-year-old children has been reported. For the purposes of this study, the BSQ was adapted to include 12 behavior problem categories common among young children such as sleeping, toileting, and tantrums. New items also were added that assessed prosocial behaviors such as child helps clean up messes, is affectionate, and imitates others. The ECBI and BSQ were selected for this study to assess the present level of behavioral development of children with CHD.

Results

A total of 39 prospective mothers of children with CHD met the study's criteria and could be contacted by phone or mail. Mothers were contacted consecutively until a sample size of 30 was reached. Six subjects could not participate due to personal reasons (e.g., moving, caring for a seriously ill parent). The sample of 30 mothers of healthy children was matched with the CHD sample based on the children's age and gender and maternal marital and socioeconomic status.

For the CHD group, children's mean age was 3.44 years (SD = 0.93), mothers' mean age was 33.5 years (SD = 4.45), and the family included an average of 2.03 children (range = 1-5). For the healthy group, children's mean age was 3.43 years (SD = 0.94), mothers' mean age was 32.13 years (SD = 4.16), and the family included an average of 2.20 children (range = 1-4). Additional demographic data for both study groups are shown in Table 1. Chi-square analyses found a significant difference between the groups on maternal employment (p = .045) with more mothers of children with CHD as full-time homemakers (36.7%) than mothers of healthy children (16.7%).

Analyses of additional demographic variables including maternal age, child age, child gender, number of children in the family, and mother's and father's number of hours working outside of the home, family socioeconomic status (based on main wage earner's occupation), and maternal marital status showed no differences between groups (all $p > .05$). There was a trend ($p < .058$) for mothers of children with CHD to report higher levels of social support for their parenting (76.7%) compared to mothers of healthy children (53.3%). None of the families had sought professional help for their children's behavior. Additional characteristics of the CHD sample are shown in Table 2.

For the CHD group, all of the children had been diagnosed by nine months of age, with most diagnosed within the first month of life (86.7%). Tetralogy of Fallot was the most common diagnosis (n = 6), followed by hypoplastic left heart syndrome (n = 4) and aortic stenosis (n = 2); the remaining diagnoses were unique to particular children in the sample (e.g., bicuspid aortic valve and mild aortic stenosis; tricuspid atresia; ventricular septal defect). Of the sample, 46.7% were taking cardiac medications, although none of the children's activities were restricted at the time of this study.

Self-Report Parenting and Child Behavior Measures

A series of analyses were computed with group assignment as the independent variable (CHD, healthy) and the scores on the self-report measures as the dependent variables. Scores that were conceptually related were analyzed together using multivariate analyses of variance (MANOVA); other scores were analyzed using one-way, analyses of variance (ANOVA). Significant MANOVAs were followed up with univariate F tests. Mothers' scores on the four self-report measures are shown by group in Table 3.

A MANOVA was computed with the discipline and nurturing subscales of the PBC. No significant differences were found between mothers of children with CHD and mothers of healthy children (p = .69). Based on an ANOVA, a significant difference between groups was found for the expectations scores on the PBC [F (1,58) = 4.51, p = .038). As shown in Table 3,

mothers of children with CHD had significantly lower expectations than mothers of healthy children. A MANOVA was computed for the three subscale scores of the Parenting Stress Index; no significant effect was found (p = .75). A MANOVA including the two subscales of the ECBI and the problem behavior subscale of the BSQ was not significant (p = .42). A final ANOVA with the prosocial behavior subscale of the BSQ also was not significant (p = .30).

Videotaped Parent-Child Interactions

Coding of the videotaped parent-child interaction was completed using an adapted version of the DPCICS (Eyberg, et al., 1994). This system allows observers to rate the frequency of selected behaviors for both the child and the mother in 5-minute time blocks. For the present study, nine behaviors were measured for the mothers (e.g., commands, questions, praise) and eight for the children (e.g., compliance, physical positive, whines). To remove the effects of observer bias, an individual trained and experienced in using the coding system coded the videotapes. This individual had already achieved high interobserver reliability for this observation measure, being trained to an 80% agreement criterion using other videotapes of parent-child interactions. A second trained observer rated one third (20) of the tapes to obtain an estimate of interobserver reliability. A Pearson correlation was computed between observers for each of the mother and child behaviors combined across the three phases of the directed interaction (child directed play, parent directed play, and clean up); the average inter-rater reliability coefficient was .85.

For purposes of data analyses, the 17 separate mother and child behaviors were combined across the three observations (child directed play, parent directed play, and clean up) into the following seven variables: *parent positives* (total number of questions, praise, and physical positives expressed by the mother); *parent negatives* (total criticisms, yells, whines, physical negatives, and destructive behaviors by the mother); *child positives* (physical positive behaviors by the child); *child negatives* (total number of criticism, yells, whines, physical negative behaviors, and destructive behaviors by the child); *total commands* by the mother; *total compliant behaviors* by the child; and *total noncompliant behaviors* by the child. This combination of separate variables was necessary because of some variables yielding zero frequencies during the videotaped observation (e.g., parent yells, parent physical negative behaviors, destructive child behaviors). The combined behavioral frequencies are shown in Table 4. A series of analyses were computed on these variables. A MANOVA with group assignment (mothers of children with CHD, mothers of healthy children) as the independent variable, and parent positives and child positives as the dependent variables, was not significant (p = .37). A second MANOVA with two dependent variables, parent negatives and child

negatives, also was not significant (p = .41). Separate ANOVAs were computed and no significant differences were found between mothers of children with CHD and mothers of healthy children for parent commands (p = .60), child compliance (p = .49), and child noncompliance (p = .65). An additional analysis was done by computing a child's compliance percentage (compliance percentage = child compliance behaviors/parent commands x 100). The compliance percentage for children with CHD (M = 67%, SD = 21%) did not differ significantly (p = .82) from healthy children (M = 68%, SD = 19%).

Qualitative Parenting Responses

Each mother was asked the following question during the interview: "How is parenting (child's name) different from what you expected?" The responses were transcribed by the interviewer at the time of the home visit. An exploratory content analysis was conducted on the interview data, and themes for each of the separate interviews were identified. All themes were reviewed separately for mothers of children with CHD and mothers of healthy children; common themes for each of the groups were delineated. Supportive data, in the form of maternal quotes, were anchored to the common themes. Two independent reviewers provided content validation by reviewing the emerging themes and supportive interview data. Final content themes revisions were made. The most frequently endorsed themes and the supporting interview statements for each group of mothers are shown in Table 5. In addition to these themes, seven or more mothers of children with CHD reported using differential discipline, being concerned about comments from other parents with healthy children, feeding issues, and the children's unique temperaments. One additional theme generated by mothers of healthy children was the difficulties of balancing home and work.

Discussion

The purpose of this study was to compare the parenting practices of mothers of children with CHD and mothers of healthy children. With the exception of more mothers of children with CHD being full-time homemakers (n = 11) compared to mothers of healthy children (n = 5), these two groups were highly similar on several maternal, child, and family factors known to influence child rearing, including mother's age and marital status, child's age and gender, and family's socioeconomic status. Consequently, the only important variable that distinguished the two groups was the presence or absence of child with CHD.

What emerged from the analyses of quantitative data obtained from the maternal self-report inventories and the coded, videotaped mother-child interactions were the remarkable similarities between mothers of children with CHD and mothers of healthy children. Both

maternal groups reported similar nurturing and discipline practices with their young children. In addition, the parent stress levels related to child rearing did not differ between groups. These self-report findings were further validated by the videotaped parent-child interactions. Despite coding 17 different maternal and child behaviors, no significant differences for any of these behaviors were found between the two groups of mothers and their children. In fact, the only significant difference that was found between groups was that mothers of children with CHD had lower expectations for their children than mothers of healthy children. This difference in expectations also has been reported between mothers of mildly handicapped and nonhandicapped preschoolers (Tucker & Fox, 1995). However, when interpreting this difference for the present study, it is important to note that the mean expectations scores for both groups were well within one standard deviation of the mean and thus could be considered as “normal” developmental expectations. The outcomes for the children also were similar. Children with CHD did not differ from healthy children in terms of the frequencies of their challenging or prosocial behaviors.

These findings are surprising and would have been difficult to predict based on the study’s conceptual model, namely that parents and children influence each other in a reciprocal manner (Maccoby, 1992). The literature (Davis, Brown, & Campbell, 1998) clearly shows that mothers of children with CHD experience high levels of daily stress. In response to this difficult situation, this study’s conceptual model would predict that these mothers should be more likely to engage in an overly protective and more permissive parenting style than mothers of healthy children. Yet with the exception of parental expectations, which were lower for mothers of children with CHD, these two groups of mothers appeared very similar in their parenting practices and in their experiences of parental stress related to childrearing issues. Moreover, the outcomes for their children’s social-emotional development, based on the frequency of reported and observed challenging and prosocial behaviors, were unexpected. Based on our conceptual model, had we been correct in predicting a permissive parenting style among mothers with children with CHD, it would have followed that there would be less positive outcomes for their children (Brenner & Fox, 1999). However, based on the present data, children with CHD could not be distinguished from healthy children by their behavior.

Perhaps for this group of mothers with children with CHD, the normalization advice they received from the health care professionals had a beneficial impact on their child rearing. Based on interviews with members of the health care team, the pediatric cardiology clinic fully embraces the concept of normalization for its families. The concept of “treat your child normally” is routinely communicated to families by physicians and the nursing staff (see Moller, Neal, &

Hoffman, 1988). However, we did not collect specific data on the level of normalization advice provided to each mother or on their ability to understand and apply this principle with their children. Also, there was a range of responses on the self-report measures suggesting that some mothers of CHD children may have applied normalization strategies better than others. This conclusion is supported by recent research that suggests a continuum of family management strategies in response to a child's chronic illness ranging from thriving to floundering (Knafl, Breitmayer, Gallo, & Zoeller, 1996).

The quantitative data collected in the present study does not tell the whole story. Mothers in both groups were asked how their parenting was different from what they had expected it to be. Qualitative analyses of their responses to this question resulted in a very different picture emerging for mothers of children with CHD compared to mothers of healthy children. These mothers did not expect to have a child with a serious health condition and were experiencing significant uncertainty regarding their child's future. These mothers responded to this situation by maintaining heightened levels of vigilance regarding their child's ongoing health status. One result was an increased reported level of stress by the mothers and other members of the family, including siblings, in the day-to-day management of the child with CHD. It is surprising and reassuring in the face of this ongoing concern that mothers were able to respond to their child in a way that produced positive parental and child outcomes. None of the children in the present study were in acute distress or hospitalized. The literature does suggest that parenting practices may be influenced by the stability of a child's chronic illness (Walker, Ford, & Donald, 1987). Also, the normalization advice these mothers consistently received from the clinic physicians and nurses, combined with the high level of social support they reported for their parenting, may have helped them cope more effectively with some of the negative aspects associated with their children's health conditions. Clearly, more research is needed regarding the impact of this heightened state of vigilance on the mother and other aspects of family functioning (e.g., marital satisfaction, maternal depression).

Limitations

There were a number of inherent limitations with this study that does limit its generalizability. The sample only included mothers and was largely from middle to upper middle socioeconomic class. The majority of the sample was Caucasian and included mothers who were well-educated. Other known determinants of parenting practices such as marital satisfaction, maternal mental health, and level of spousal support were not studied. The children were receiving excellent health care at a pediatric cardiology clinic in a large, urban children's

hospital. Consequently, the present findings are most relevant to families with similar characteristics and who are receiving similar quality health care. The study measures, including the self-report instruments and the direct observations of the mother-child interactions, were carefully selected to be technically sound and meet the purposes of the study. However, all measures, particularly self-report measures, are limited by the number of areas they can assess; also, these measures may be susceptible to a socially desirable response set. For example, the child measures used sampled primarily behavioral and emotional development. Clearly other areas of child development such as adaptive, cognitive, language, and social development also are important but were not addressed in this study. Also, parents are unlikely to report or demonstrate on videotape child-rearing techniques that may violate social mores (e.g., yelling, spanking children). Finally, the issue of normalization surfaced as a potentially important variable in this study. However, despite this principle being well embraced by the pediatric cardiology clinic staff and routinely discussed with parents, we did not collect specific data on how much information parents received and the degree to which it influenced their child rearing philosophy or practices.

Implications for Practice

There is no question that families meet a diagnosis of CHD with considerable anxiety and concern. However, with proper attention and support by an interdisciplinary health care team, the present study's results suggest that families can cope very well with this chronic childhood illness. Specific strategies that strengthen and maintain the parenting role should be included in nursing practice (Deatrick, Knafl, & Murphy-Moore, 1999). These include support, education and anticipatory guidance, and active listening.

Support

Social support is an important element in facilitating adaptation and adjustment to parenting a young child with CHD. The need for a comprehensive psychosocial and family assessment is indicated. This assessment should address social supports, strengths, and resources available to the family. Assisting parents to identify and develop formal and informal social support networks is a strategy that clinicians can use to help families. Family supports, church networks, and involvement with other community resources should be assessed. However, practitioners need to look beyond the "obvious" supports such as family and friends, and also consider support groups, relationships with health care providers, and on-line resources as other possible sources of support. Chat rooms, on-line support groups, and

Internet access with other parents who have a child with a similar diagnosis may be helpful to some parents.

Education and Anticipatory Guidance

Parents need to understand the specific nature of their child's CHD, including the diagnosis, prognosis, treatment plan of care, and the health care strategies needed to use within the home. The complexity of the diagnosis and treatment compounds the need for education focused on the individual needs of the child and provided in the most meaningful way to the parents. This is built on an assessment of the parents' learning style and knowledge base. At the same time, parents need consistent encouragement to raise their children as "normal" as possible including age-appropriate expectations, nurturing, and discipline strategies. Discussing normalizing strategies and helping families identify and implement these behavioral strategies are clinical applications that can be implemented by the nurse. Normalization is a complex process and clinicians need a sound understanding of the attributes of normalization.

Active Listening

The collection of the qualitative data in the present study was valuable and provided rich information regarding the parenting experience. Providing time for families to tell their stories is critical to understanding the lived experience of parenting a child with congenital heart disease. This need of mothers to tell stories and share their personal experience of parenting was also evident in the population of mothers of healthy children. An important role for the nurse is to help to slow the system down and to provide the time and opportunity for mothers to tell their stories. Through the listening of the stories, the nurse also is provided valuable information related to the stresses and strengths of the parenting experience. This can be helpful in designing strategies to support families during this life experience.

Further Research

A final implication for nurses is the need to conduct further clinical research. The normalization process needs to be further studied as it affects individual families of children with chronic illnesses. The recent work of Knafl, Breitmayer, Gallo, and Zoeller (1996) is an example of such needed work. Further work also is needed on the heightened levels of maternal vigilance reported in this study and their short- and long-term impact on maternal health. An important related need is to identify interventions that may help mothers and fathers as they parent their young child with a chronic illness. In this time of diminished resources and cost containment, it is prudent to consider the value of nursing interventions as related to positive family outcomes. The role of the interdisciplinary team, but particularly the contributions of nurses in providing support, education, and care, cannot be discounted.

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Notes

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Appendix

Table 1

Demographic Characteristics of Families by Study Group

Variable	Congenital Heart Disease		Healthy	
	n	%	n	%
Marital status				
Married	25	83.4	25	83.4
Not married	5	16.6	5	16.6
Mother's education				
High school or less	7	23.3	5	16.7
Beyond high school	23	76.7	25	83.3
Father's education				
High school or less	12	40.0	9	30.0
Beyond high school	18	60.0	21	70.0
Mother's employment				
Homemaker	11	36.7	5	16.7
Working outside the home	19	63.3	25	83.3
Father's employment				
Professional	10	33.3	14	48.3
Nonprofessional	20	66.6	15	51.7
Family income				
$50,000 or less	17	56.7	11	36.7
More than $50,000	13	43.3	19	63.3
Children's gender				
Male	17	56.6	17	56.6
Female	13	43.3	13	43.3
Children's ethnicity				
African American	4	13.3	4	13.3
Caucasian	25	83.3	25	83.3
Biracial	1	3.3	1	3.3
Birth order				
First	7	23.3	10	33.3
Middle	1	3.3	5	16.7
Last	12	40.0	13	43.3
Only	10	33.3	2	6.7
Parenting classes				
Yes	7	23.3	6	20.0
No	23	76.7	24	80.0
Amount of social support				
Low	1	3.3	4	13.3
Medium	6	20.0	40	33.4
High	23	76.7	16	53.3

Table 2
Health-Related Characteristics of Children with Congenital Heart Disease

Variable	n	%	M	SD*	Range
Time of diagnosis					
Fetal diagnosis	2	6.7			
At birth	14	46.7			
First month of life	10	33.3			
After first month of life	4	13.3			
Cardiologists' perception of medical severity					
3-Moderate	2	6.7			
4-Marked	20	66.6			
5-Severe	8	26.7			
Total hospitalizations			2.37	1.15	0-5
Total days in hospital			30.57	22.10	0-106
Cardiac operations			2.10	1.15	0-5
Cardiac catherizations			1.57	1.16	0-5
Outpatient visits since diagnosis			12.50	4.82	4-28

*SD = Standard deviation

Table 3
Summary Scores for Self-Report Measures by Study Group

Variable	Congenital Heart Disease		Healthy	
	M	SD*	M	SD*
Parent behavior checklist				
Expectations	45.16	9.99	50.53	9.56
Discipline	40.43	10.02	42.43	7.91
Nurturing	55.53	11.78	56.03	11.48
Parenting stress index				
Parental distress	26.00	6.65	24.77	8.50
Parent-child dysfunction	18.10	5.98	16.77	4.21
Difficult child	26.50	6.38	26.03	8.07
Eyberg child behavior inventory				
Intensity	100.17	28.69	99.13	25.59
Frequency	10.30	16.70	9.20	12.61
Behavior screening questionnaire				
Problem behaviors	23.13	4.40	21.77	3.65
Prosocial behaviors	44.17	5.12	44.20	4.48

*SD = Standard deviation

Table 4
Combined Maternal and Child Behaviors from Videotaped Interactions

Variable	Congenital Heart Disease		Healthy	
	M	SD*	M	SD*
Parent positive	60.13	4.98	59.53	4.98
Parent negative	1.83	0.49	0.93	0.49
Child positive	0.00	0.03	0.06	0.03
Child negative	2.77	1.03	2.07	1.03
Parent commands	27.97	3.12	25.67	3.12
Child compliance	17.30	1.64	15.70	1.64
Child noncompliance	7.00	1.41	6.10	1.41

*SD = Standard deviation

Table 5
Most Frequently Endorsed Interview Themes and Supporting Statements for Mothers of Children with Congenital Heart Disease (CHD) and Mothers of Healthy Children

Interview Theme	Number of Respondents	Supporting Maternal Statements
Mothers of Children with CHD		
(1) The unexpected	19	We didn't learn about his condition until he was 1 ½ weeks. Then we found out about his heart and it was a complete shock.
(2) Vigilance	19	We are not comfortable leaving her overnight. I have not slept away from my kids for 4 years.
(3) Uncertainty	19	He sleeps with us each night. I am afraid he will stop breathing. There is always that fear.
(4) Positive outlook	14	We try to live each day fuller now; we don't take a day for granted.
(5) Normalization	11	I would say I do not treat him differently. Just make sure he gets his medicine. I watch his activity level, if he is out of breath or turning blue. Otherwise, I treat him like a normal kid, he is a normal kid.
(6) Stress	10	It's a lot more stressful on the whole family. I feel bad for our older daughter. I think she had to grow up fast.
Mothers of Healthy Children		
(1) Temperament	22	He has a strong personality and he will keep asking until we give in.
(2) Strains	13	I always thought it (parenting) would be a lot of work and it is. But I am surprised at the amount of energy it takes.
(3) Rewards	11	I knew we would enjoy parenthood, but I didn't realize all the rewards and special times that go along with it.
(4) Expectations	9	Hardest job on earth. It really is; nothing could have prepared me for it.
(5) Discipline	9	I didn't expect to feel inadequate, not knowing if I am doing the right thing. Like when I discipline her.
(6) Comparisons	7	I can compare him with my other child. He is much more active and independent.