



## ABSTRACT

**Introduction:** Whereas the stress precipitated by the diagnosis of an infant's congenital abnormality is well recognized, this study examined parenting stress reported by parents of children older than 2 years with heart disease.

**Method:** Abidin's Parenting Stress Index was administered to parents of children ages 2 to 12 years with known heart disease during a cardiology outpatient clinic visit.

**Results:** Parents of children with heart disease were more likely than the normative population to report excessive parenting stress, especially related to characteristics of the child that make them difficult to parent. Approximately 1 in 5 parents expressed clinically significant levels of stress. These parents expressed difficulty with setting limits or discipline of the child with heart disease. Parenting stress was not related to the severity of the child's heart disease, family socioeconomic status, or time since most recent surgery. Older age of the child was associated with higher parenting stress scores.

**Discussion:** Clinicians must assess parenting stress at each health care visit to provide appropriate support and anticipatory guidance to families of children with heart disease. *J Pediatr Health Care.* (2003). 17, 163-168.

# Parenting Stress and Children With Heart Disease



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Congenital heart disease (CHD) occurs in approximately 1% of live-born infants. As a result of dramatic advances in the medical and surgical management of CHD, approximately 85% of babies born with cardiac anomalies today can expect to reach adulthood, with continued improvements anticipated in the future (Moller, Taubert, Allen, Clark, & Lauer, 1994). CHD is most often diagnosed soon after birth or within the first year of life. In recent decades, many cardiac anomalies have been surgically repaired during infancy. The renowned pediatric cardiologist Alexander Nadas has speculated that advances such as earlier correction of CHD during infancy would promote a "healthier" attitude of the parent toward the child with CHD, resulting in better psychosocial outcomes in these children (Nadas, 1983).

The stress experienced by parents at the time of their infant's diagnosis or hospitalization is well recognized by health professionals (Garson, Benson, Ivler, & Patton, 1978; Gudermuth, 1975; Menahem, 1998) and may alter the parents' response to their infant. Pelchat and colleagues (1999) studied the adaptation of parents in response to their 6-month-old infant's type of disability and reported that parents of a child with CHD or Down syndrome report significantly more stress and distress than control parents or parents of a child with cleft lip and/or palate. Specifically, they reported more stress related to acceptance of their child, suggesting that the child with CHD had characteristics that do not match the expectations the parents had for their child. Parents of an infant with CHD also perceived their parental situation as more uncontrollable and reported more doubts and stress regarding their parental competency. Goldberg, Morris, Simmons, Fowler, and Levison (1990) compared the responses of parents of infants with cystic fibrosis, infants with CHD, and parents with healthy babies. Parents of infants with CHD reported the highest amount of stress, again related specifically to their sense of parental competence and the acceptability of the child. In ad-

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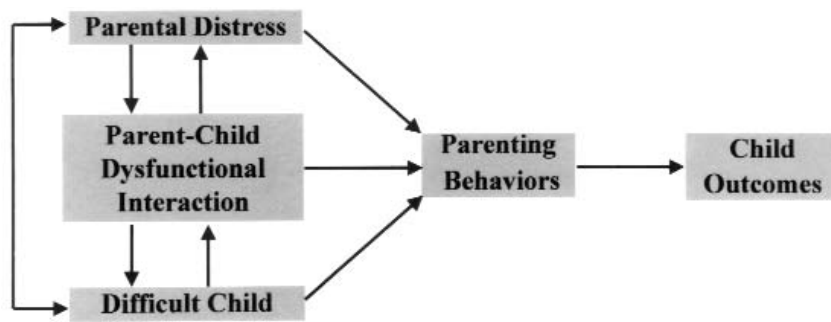
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**FIGURE 1** Abidin's theoretical model for the Parenting Stress Index. (Modified with permission from Abidin, R. R. (1995). *Parenting stress index*. Odessa, FL: Psychological Assessment Resources, Inc.)

**TABLE** Family/patient characteristics

Characteristic	No./%
Patient age (y)	
Mean	6.3 ± 3.1
Range	2.1 - 12.6
Patient sex	
Male	53
Female	27
Congenital heart disease	
Simple	41
Complex	39
Home	
1-Parent	25
2-Parent	55
Maternal education	
<High school	15%
High school	37%
Some college	26%
College graduate	22%
Paternal education	
<High school	15%
High school	29%
Some college	25%
College graduate	31%

dition, the parent of an infant with CHD was less likely to perceive his or her child as a source of positive reinforcement. Subsequently, Goldberg, Simmons, Newman, Campbell, and Fowler (1991) reported on the effect of CHD on early infant-mother relationships. Significantly fewer infants with CHD, in comparison with healthy peers, were considered to have secure relationships with their mothers. When Lobo (1992) assessed parent-infant interaction during feeding, infants with

CHD scored significantly lower than the control group on responsiveness to parent and clarity of cues. Mothers of infants with CHD scored significantly lower on the social-emotional growth fostering scale. These mothers were less apt to smile, make eye contact, touch, hum, or sing during the feeding (Lobo, 1992).

**E**xamination of subscale scores revealed that parents of children with CHD had significantly higher stress only on the Difficult Child subscale.

Factors such as family stress and the perceptions or appraisals of family members have been incorporated into many conceptual models of adaptation, including McCubbin and Patterson's (1982, 1983) Double ABCX Model of Adjustment and Adaptation. According to this model, in the face of a chronic medical condition, additional or concurrent family demands and stresses (aA) that are not mediated by resources (bB), coping, or appraisals (cC) will complicate medical treatment and the long-term adaptation of the family member (McCubbin, Needle, & Wilson,

1985). Our previous research, based on the Double ABCX model, demonstrated that the pile-up of family stressors and decreased family resources were important negative correlates of the pediatric heart transplant recipient's psychosocial adaptation, as manifest by behavior problems and social competence (Uzark et al., 1992). Consistent with this framework, Abidin's (1983, 1990) Parenting Stress Model (Figure 1) postulates that the stressors a parent experiences related to the role of being a parent, including characteristics of the child that were seen as stressors, will influence parenting behavior, which can have an impact on the psychosocial adaptation of the child. Parenting stress is the result of a series of appraisals made by the parent in the context of his or her level of commitment to the parent role (Abidin, 1992).

Past research has primarily focused on parental responses and stress during infancy. Parents could face important stresses during other periods of their child's development. In this study, we assessed parenting stress in parents of children with a prior diagnosis of heart disease who were older than 2 years.

## METHODS

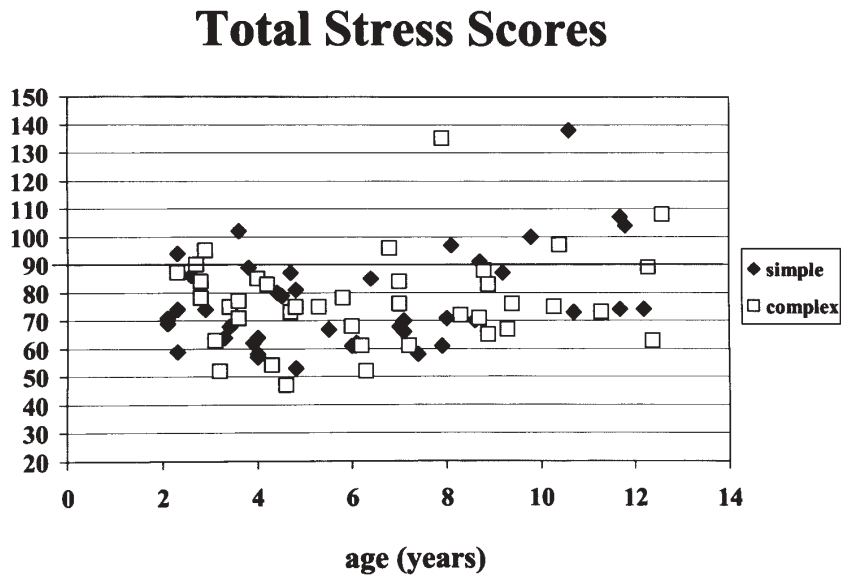
### Subjects

The study sample consisted of 80 parents, including 70 mothers and 10 fathers who accompanied their child to the pediatric cardiology outpatient clinic. The sample was predominantly (86%) White. Most of the parents had graduated from high school; 15% had less than a high school diploma, as shown in Table 1. The parent was currently married in 69% of the families. The mean socioeconomic status based on the Hollingshead (1975) four-factor index was 37.9, indicating on average a middle class socioeconomic status. The mean age of the child with CHD was 6.3 years, ranging from 2.1 to 12.6 years. There were 53 boys and 27 girls. Forty-one children had "simple" heart disease, defined as mild disease requiring no therapy, defects effectively treated nonoperatively (catheter therapy), or surgically corrected heart disease without significant residua. Heart disease was categorized as "complex" in 39 children who had surgical corrections (one or more procedures) with significant residua, palliative surgery (includ-

ing single ventricle), or uncorrectable heart diseases. Severity of heart disease was rated by a clinician blinded to parenting stress data. Parents were excluded from participation in the study if the child with CHD had a major developmental disability or associated noncardiac anomalies. Defensive responders, that is, subjects found to exhibit social desirability bias as described below, were also eliminated from the sample.

**Procedure/Measures**

A convenience sample of parents of children with known heart disease completed the Parenting Stress Index (PSI) short form (Abidin, 1990, 1995) as part of a larger study evaluating quality of life in this patient population. Informed consent was obtained by a research nurse in the cardiology clinic prior to the child’s evaluation by the cardiologist. The construction of the PSI was guided by the theoretical model shown in Figure 1. The total stress score is designed to provide an indication of the overall level of parenting stress an individual is experiencing. The PSI is further comprised of three subscales—Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child—and includes a defensive responding scale. The Parental Distress subscale determines the distress a parent is experiencing in his or her role as a parent as a function of personal factors that are directly related to parenting (eg, “I find myself giving up more of my life to meet my child’s needs than I ever expected”). The Parent-Child Dysfunctional Interaction subscale focuses on the parent’s perception that his or her child does not meet the parent’s expectations and that the interactions with his or her child are not reinforcing to him or her as a parent (eg, “My child doesn’t seem to learn as quickly as most children”). The Difficult Child subscale focuses on some of the basic behavioral characteristics of children that make them either easy or difficult to manage (eg, “My child makes more demands on me than most children”). The defensive responding scale, derived from the Marlowe-Crowne Scale of Social Desirability (Castaldi, 1988; Lafiosca & Loyd, 1986), assesses the extent to which the respondent approaches the questionnaire with a strong bias to present the most favorable picture of himself or



**FIGURE 2** Total stress scores on the Parenting Stress Index. A raw score of 90 = 90th percentile for normative population. (A score at or above the 90th percentile line shown indicates that the respondent’s score is equal to or greater than the scores of 90% of the subjects in the normative sample.)

herself and to minimize indications of problems or stress in the parent-child relationship (Abidin, 1995).

**O**verall, parents of children with heart disease reported stress related to parenting in excess of that expected on the basis of normative data.

The 36-item PSI short form is a direct derivative of the full-length PSI through a series of replicated factor analyses. The final descriptive statistics and normal ranges for the 36-item PSI short form were produced by combining the initial and replicative samples (n = 800 well children from a pediatric practice). Total stress on the PSI short form correlated 0.94 with the full-length PSI. The Parental Distress and Difficult Child subscales of the PSI

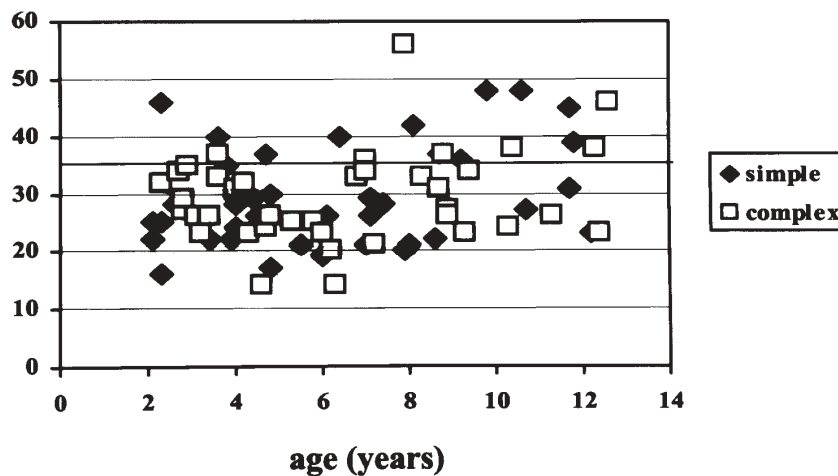
short form consisted of items derived from the Parent Domain and Child Domain of the full-length PSI. The Parental Distress subscale was highly correlated with the Parent Domain of the full-length PSI (r = 0.92), and likewise, the Difficult Child subscale score was highly correlated with the Child Domain score of the full-length PSI (r = 0.87). Test-retest and alpha reliabilities for the PSI/short form total score are .84 and .91, respectively (Abidin, 1995). Normative data were derived for each PSI scale from the raw score frequency distribution of scores (n = 800) from the mothers in the normative sample (Abidin, 1990).

**RESULTS**

Total stress scores on the PSI for parents of children with CHD ranged from 47 to 138 (mean ± SD = 77.0 ± 16.7). In comparison to the PSI short form normative sample (mean ± SD = 71.0 ± 15.4), parents of children with CHD report significantly greater stress (t = 2.64, P < .01). Fourteen parents (17.5%) obtained a total stress score at or above the 90th percentile (a raw score of 90), suggesting a clinically significant level of stress (Figure 2).

Examination of subscale scores revealed that parents of children with CHD had significantly higher stress

## Difficult Child Scores



**FIGURE 3** Difficult Child subscale scores. A raw score of 36 = 90th percentile for normative population. (A score at or above the 90th percentile indicates that the respondent's score is equal to or greater than the scores of 90% of the subjects in the normative sample.)

only on the Difficult Child subscale with a mean score of  $29.4 \pm 8.4$  in comparison with the normative sample mean of  $26.0 \pm 6.7$  ( $t = 2.76, P < .01$ ). Seventeen parents of children with CHD (21.3%), more than twice that expected, had scores at or above the 90th percentile (a raw score of 36) on the Difficult Child subscale (Figure 3). Within the Difficult Child scale, items with the highest mean scores included "My child reacts very strongly when something happens that my child doesn't like," "I have found that getting my child to do something or stop doing something is somewhat harder than I expected," "My child gets upset easily over the smallest things," and "There are some things my child does that really bother me a lot."

Overall, parenting stress was not related to the severity of the child's heart disease. As shown in Figures 2 and 3, parents of children with complex or more severe heart disease were not more likely to have greater stress. The mean total stress score for parents of children with complex CHD was  $76.9 \pm 16.4$ , not significantly different from parents of children with simple or repaired CHD (mean  $77.4 \pm 17.2, P = \text{not significant}$ ). Parenting stress was also not related to time since most recent

surgery ( $r = .190, P = \text{not significant}$ ). Parents of older children tended to report greater stress ( $r = .285, P < .05$ ). Parenting stress was not related to family socioeconomic status ( $r = -.061, P = \text{not significant}$ ) in this study.

**P**arenting stress and protectiveness or overindulgence of the child may reflect unrealistic fears concerning the child's cardiac condition and parental frustration regarding setting limits and discipline.

## DISCUSSION

Overall, parents of children with heart disease reported stress related to parenting in excess of that expected on the basis of normative data. Whereas the majority of parents (82%) had a total stress score within the normal range, one in five parents had significantly elevated levels of stress arising from child factors. According to Abidin (1995), high stress in the child domain may be associated with children who display qualities that make it difficult for parents to fulfill their parenting roles. In relation to children 2 years and older, these parents are typically experiencing difficulty in managing the child's behavior in terms of setting limits and gaining the child's cooperation. The study findings of increased parenting stress are in accord with previous research in families of infants with heart disease or other children with disabilities (Goldberg et al., 1990; Innocenti, Huh, & Boyce, 1992; Pelchat et al, 1999). Although it is possible that exclusion of "defensive responders" in our data analysis may have eliminated a parent who is, in fact, a very competent individual who handles the stress of parenting well, the exclusion process would also eliminate the parent who is giving socially desirable responses as well as the parent who is not sufficiently invested in the role of parent to experience the usual stresses associated with caring for a child. The defensive responding scale does not indicate by itself which of these hypotheses is most likely to be true in a given case (Abidin, 1995) and may represent a limitation of the study.

The findings of this study also suggest that parenting stress is unrelated to the severity of the child's heart disease. This is consistent with an earlier study by Davis, Brown, Bakeman, and Campbell (1998) that found that adjustment of mothers of children with CHD was not significantly associated with severity of the cardiac defect. A more recent study from Sweden also reported that parents of children with less severe cardiac malformations experience as much stress as do the parents of children with more complex CHD (Morelius, Lundh, & Nelson, 2002). Furthermore, DeMaso and associates (1991) found that maternal perceptions, not severity of heart disease, were potent predictors of the child's emotional ad-

justment. Low scores on the PSI were the best predictors of a lower incidence of behavior problems in children with CHD. In contrast to the DeMaso study, the present study found that parenting stress tends to be higher in parents with older children. It is easy to understand that with the child's advancing age, it may become more difficult for parents to set limits for their child and maintain control. Past parental anxieties and overprotection with unnecessary restrictions can lead to future parenting problems, particularly during adolescence when children strive for independence. In their examination of parenting practices related to child behavior problems, Fox, Platz, and Bentley (1995) found that the strongest correlation was between mothers' discipline practices and child behavior problem scores. Steinberg, Lamborn, Darling, Mounts, and Dornbusch (1994) also demonstrated that adolescents' adjustment varies as a function of their parents' style (eg, authoritative, authoritarian, indulgent, neglectful).

#### IMPLICATIONS

Although it is generally acknowledged that the birth of an infant with heart disease creates increased stress for families, this study suggests that these parents could face important stresses beyond infancy. As noted by Pelchat et al. (1999), such results point to the need to better understand parental reactions and adaptation during all stages of the child's development. Whereas feeding may be a major focus of parental concern during infancy (Svavarsdottir & McCubbin, 1996), parenting stress changes over time and may be unrelated to the child's physical condition. Clinicians must assess parenting stress at each health care visit beginning in infancy to provide appropriate support and guidance to these families. The PSI short form was developed at the request of clinicians who indicated the need for a valid measure that could be administered in less than 10 minutes to identify families most in need of follow-up services (Abidin, 1995). Furthermore, assessment cannot be limited to the families of children with severe disease. Certain critical biologic and physiologic variables can be profoundly abnormal without the patient having any symptoms (Wilson & Cleary, 1995). The parent of a young child with single ven-

tricle and Fontan palliation may see their child be as active as peers in spite of a decreased oxygen saturation and very abnormal cardiac anatomy. Alternatively, as suggested by Marino and Lipshitz (1991), perhaps the sicker the child the greater the parents need to reassure themselves of the child's normalcy. In contrast, the behavior of a child with mild disease or a repaired defect may be influenced by parental reaction to the "label" of CHD, the visibility of the sternotomy scar, or the need for even infrequent evaluation by the pediatric cardiologist.

**It is important to emphasize ways in which infants and children with heart disease are behaviorally normal.**

The perception of more difficult child characteristics may be related to parental misconceptions regarding their child's behavior and needs. Parents' extreme overestimate or underestimate of the severity of the child's heart condition may be an important clue to parental difficulties (Goldberg et al., 1991). Health care providers must take time to discuss parental perceptions of the child and the child's health. Parenting stress and protectiveness or overindulgence of the child may reflect unrealistic fears concerning the child's cardiac condition and parental frustration regarding setting limits and discipline. Discipline is necessary for the well-being of a child with or without heart disease.

It is important to emphasize ways in which infants and children with heart disease are behaviorally normal. Anticipatory guidance is needed to clarify expectations and misconceptions to promote optimal development and psychosocial functioning of the child. In a recently reported study by Carey, Nicholson, and Fox (2002), qualitative data revealed that mothers of young

children between 2 and 5 years of age with CHD reported higher levels of vigilance than did mothers of healthy children. Children with most heart defects can lead normal, active lives. It is unnecessary to restrict the activity of toddlers and young children, who should be allowed to explore their environment. No matter how active these children may appear, they will rest or seek less active play if needed. Most children can be encouraged to participate in activities such as baseball, swimming, bicycling, skating, golf, and many other recreational activities. Whereas some children may be restricted from dynamic isotonic exercise or competitive contact sports, participation in team sports is allowed after complete repair of most cardiac defects. Parental anxiety should be recognized and support systems identified among family members, other parents of children with heart disease, or health professionals. Ongoing communication between the pediatric cardiology and primary care teams is important.

Through skilled counseling, health care providers may significantly influence parenting behavior and psychosocial outcomes for children with heart disease. Further longitudinal studies that include measures of parenting stress, family resources, and child psychosocial outcomes are needed to better understand parental adaptation and factors that enhance quality of life in this pediatric population.

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The Journal is interested in publishing children's drawings of their responses to illness, treatment, or encounters with the health care system or personnel. Please enclose the child's assent/consent and parental consent to have the drawing published and commented on when you submit the drawing. Please send the drawing, along with the child's age, gender, any pertinent information regarding the child's condition, and the written consents, to:

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