

**The Social and Cultural Context of Coping  
With Sickle Cell Disease: III. Stress,  
Coping Tasks, Family Functioning,  
and Children's Adjustment**

**Oscar A. Barbarin**

*University of Michigan*

**Charles F. Whitten**

*Wayne State University Medical School*

**Sandy Bond**

**Rhonda Conner-Warren**

*Comprehensive Sickle Cell Clinic,  
Children's Hospital of Michigan*

*Conceptions of individual and family coping with sickle cell disease (SCD) must incorporate several disease and sociocultural factors. This article proposes an integrative model and tests the relative contribution of model parameters to the prediction of social, academic, and psychological adjustment of children with SCD. The individual coping and family functioning variables most highly predictive of the child's psychological outcomes (anxiety, depression, and positive mood) include parental psychological functioning, maturity demands made of the ill child, and the quality of relations with parents and siblings. Academic adjustment was significantly predicted by parental academic expectations and by the child's rejection of a restrictive sick role. Competent social functioning also was predicted by the extent to which the ill child rejected the role of being sick.*

As a result of the distress associated with chronic disease, ill children and their siblings experience a twofold increase in risk of psychosocial impairment as compared to non-ill children (Cadman, Boyle, & Offord, 1988;

---

AUTHORS' NOTE: *Support for the data analysis and preparation of this article were provided through a W. T. Grant Faculty Scholar grant to Oscar Barbarin and through Grant R01-HD23968 from the National Institute of Child Health and Development.*

JOURNAL OF BLACK PSYCHOLOGY, Vol. 25 No. 3, August 1999 356-377  
© 1999 The Association of Black Psychologists

Cadman, Boyle, Szatmari, & Offord, 1987). When the family is poor, the added demands or coping tasks of illness pose an even greater challenge to the ability of the child to cope and to the family's already threatened sense of well-being (Kazak, 1989).

#### **COPING TASKS IN SICKLE CELL DISEASE**

The identification of key coping tasks or challenges is a useful way in which to index the primary stresses associated with childhood disease and to identify aspects of the illness experience implicated in the increased risk of dysfunction. Coping with a disease such as sickle cell disease (SCD) involves responses by the whole family and often requires changes in the ways in which families operate (Chesler & Barbarin, 1987). To cope well with the tasks of a chronic illness such as SCD, the family must develop and sustain a routine around medical care. At the same time, the family must avoid becoming so rigid that its members see the child as fragile and unnecessarily restrict the range of the child's activities. The family also must solve problems related to the child's limited stamina or other restrictions imposed by the illness. Managing tasks related to maintaining health involves attention to factors such as nutrition, rest, and hygiene (which influence the general health of the child) and compliance with medical regimens when the child experiences complications. A significant and often unexpected demand on the family is dealing with the insensitivity or ignorance of others whose stigmatizing reactions create unnecessary stress for the child. Teasing or excessive pity from peers is a source of significant anxiety for children and adolescents with SCD because it increases self-consciousness about delayed growth and the late onset of puberty and because it reinforces the desire to conceal the illness from others, even when it is in the best interest of these children to disclose the status of their illness (Noll et al., 1996).

The most common coping task of SCD centers around dealing with episodes of excruciating pain (Gil et al., 1996). Although these may be linked to major life stress, overexertion, or exposure to chilling, it is difficult to predict when they will occur or for how long. Pain attacks are distressing not only because of physical discomfort for the child but also because of the emotional arousal they engender in family members (McCrae & Lumley, 1998). Pain episodes disrupt the child's life at school, undermine academic achievement, interfere with parents' employment, and may threaten the family's financial stability. For family members, managing their own emotional responses and anxiety when the child is in pain is a most difficult coping task. This is especially true when the family lacks accurate information about the implication

of serious pain for the child's survival. Those who consider pain episodes life threatening suffer unduly. This extreme arousal may contribute to behavioral and emotional overreaction on the part of the ill child and siblings. The overreaction may be expressed in terms of treating the child as though he or she were fragile and as though the child's life were under immediate threat. Consequently, parents might overprotect and unnecessarily restrict the child's activities and, ultimately, undermine the child's ability to make responsible decisions regarding his or her health (Barbarin, 1999 [this issue]). Parental anxieties about the child's well-being not only might lead to increased protectiveness but also might influence how the parents come to view the child and, thereby, shape messages sent to the ill child about his or her incapacity and diminished life prospects.

Alternatively, too little anxiety also can lead to disastrous consequences for the psychological and physical health of the child. A family might have so little anxiety and be so acquiescent that vigilance and precautionary action occur only in the presence of very serious pain episodes or palpable evidence of danger. For example, parents might not recognize the importance of follow-up clinic visits and prophylactic penicillin if the child appears to be doing well. When the child does not have a fever or is not in pain, parents might become complacent about follow-through with preventive care. This approach has had particularly unfortunate consequences for some children who have succumbed to overwhelming infection or experienced significant loss of cognitive function after a second or third stroke that went undetected because the child did not appear sick.

#### **FAMILY COPING**

These problems reveal the complexity of the demands that SCD places on families and how much of a challenge it is for families to cope effectively. Models of family stress and coping try to delineate the components of family functioning that differentiate effective and ineffective functioning and that mediate physical and psychological sequelae of illness (Sterling, Peterson, & Weekes, 1997). Model parameters often focus on cognitive, behavioral, and social processes in families. They include constructs such as personal coping styles and family factors such as family paradigms, family relations, and social support (see, e.g., Kazak, 1989; McCubbin, 1979; Reiss, 1981). Investigations of coping by families of children with other chronic illness identify open communication, support, marital quality, and absence of concurrent stress as highly associated with long-term coping (Kupst & Schulman, 1988).

This same work suggests that effectiveness of coping in an early stage of the illness is associated with the quality of coping at later stages. Similarly strong evidence is available about the contagion effect in that the quality of coping of one family member is related to how other family members cope. Barbarin (1983) proposed a model of family coping intended to integrate features ascribed to functioning in African American families. Religiosity, egalitarian decision making, the use of externalizing explanatory styles, and the dominance of single-parent and extended family structures shape how African American families respond to stressful situations. What individuals perceive, believe, and understand about the stress and the explanations families offer influences how family members will respond behaviorally and emotionally to the stressful situation and, in turn, might affect the outcomes for the individual and the family (Lazarus & Folkman, 1984).

*Appraisal processes* generally refer to a broad set of cognitions that encompass the worldviews or paradigms that guide interpretations of events or situations. These include expectancies, fears, beliefs about control over life, shame, causal attributions, perceived control, religiosity, the role of God in daily affairs, the meaning of life and death, and so on. The importance of family cognitions and appraisal is amplified by ambiguity or lack of information. They may result in a set of myths or beliefs about the danger and threat of the illness. For example, uncertainty about life expectancy of a child with SCD leaves room for optimism or pessimism to influence how actively the child should prepare for a productive life as an adult (Lewis & Kliever, 1996). Optimism in the family may be reflected in the belief that the child will survive to become an adult. This positive expectation of survival justifies self-control and rejection of the passivity and resignation associated with adoption of the sick role. If the family promotes a sense of self-efficacy, then hard work and academic achievement might be valued. Uncertainty about a child's survival might shape parental expectations and the way in which siblings treat the ill child.

Two other aspects of family functioning are relevant to coping outcomes: the effectiveness of the executive subsystem and the emotional support within the family (Midence, McManus, Fuggle, & Davies, 1996). The effectiveness of the executive function pertains to the decision making, leadership, control, standard setting, and resource acquisition functions of the family. The greater the extent to which people occupying the executive subsystem set high expectations and make maturity demands, the better the outcomes for the ill child. In addition, the psychological functioning of parents or parent figures also can have a tremendous impact on the child's functioning. Parents who themselves are not functioning well—who are impaired by emotional

distress, anxiety, or depression—might lack the psychic energy to be involved with the child and to provide the guidance that the child needs. Presumably, affective disorders impair the ability of parents to act consistently in the role of parents, to be involved emotionally, and to provide the support needed by the child, avoiding the danger of over- or underinvolvement. This is especially critical with respect to monitoring and being involved in the child's life at school, to the performance of academic work, and to conduct at school.

The coping style of the ill child also can be crucial in determining psychosocial outcomes because of its potential for moderating stress. In coping with illness, some children adopt the sick role, use their illness for secondary gain, and magnify slight discomfort to avoid undesirable activities or tasks. Other children reject the sick role and discount pain because they want to go on with their lives. Some even conceal the severity of a painful episode from parents either to spare family members or to avoid hospitalization. Colloquially, this coping strategy might be described as "taking it in stride."

In its most simple form, the family stress and coping model proposes relationships among life stress related to factors such as pain episodes, medical care and finances, individual and family coping styles, appraisal, individual coping, family functioning, and child adjustment (see Figure 1). A primary assertion of this model is that the impact of stress on social, academic, and psychological adjustment of ill children is mediated by parameters of coping, in other words, family paradigms (cognitive appraisal of the illness such as optimism and fear), individual coping styles, and family functioning (e.g., family relations, protectiveness, maturity demands). This research tests the hypothesized mediation effects of illness-relevant paradigms of personal and family coping on illness adjustment outcomes. The predictable relation between medical stress and adjustment is moderated by family appraisals of the illness and how the ill child and family function with respect to the illness. Specifically, in the case of SCD, stressors such as illness severity, stigma, and poverty ordinarily should be correlated with poor psychosocial outcomes, particularly psychological symptoms of anxiety and depression, poor school adjustment, and poor social functioning. However, the strength of these relations is attenuated or mediated by how the family appraises the illness (e.g., concern about imminent death of the child, hopelessness) and by how the child and family cope with the illness (e.g., adoption of sick role, parental depression and anxiety, sibling coping, maturity demands, overprotection). To the extent that the family copes well (i.e., manages emotional arousal, adopts an accepting hopeful outlook, avoids overprotection, sets high standards and performance expectations, and is supportive of the ill child and siblings), the better the ill child's adjustment will be in the social, academic,

<i>Stress</i>	<i>Coping</i>	<i>Child Adjustment</i>
Pain Episodes	Appraisal	Psychological
Stigma	Optimism	Social
Financial Need	Acceptance	Academic
Obstacles to care	Fear	
	Ill Child Coping Style	
	Sick Role Adoption	
	Taking It in Stride	
	Sibling Coping Style	
	Fear	
	Avoidance	
	Acting Out	
	Parental Functioning	
	Depressive Symptoms	
	Anxiety	
	Family Coping Styles	
	Family Relations	
	Protectiveness	
	Maturity Demands	

**Figure 1: Family Stress and Coping Model**

and psychological spheres. Similarly, the child who copes by adopting a stance of grim determination not to let the illness stand in the way of leading a normal life will be better adjusted than will the child who adopts the role of being sick or uses the illness as an excuse to sidestep demands and opportunities in his or her life.

## METHOD

### PARTICIPANTS

Participants were 116 children (8-12 years of age) and 66 adolescents (13-17 years of age) with SCD in treatment at a children's hospital affiliated with a comprehensive sickle cell program in the Midwest between 1981 and 1988. For 96% of the patients, mothers were the primary guardians and, therefore, the primary sources of information about the children and families.

Of this group, about 55% were male and 45% were female. The distribution of annual family income was skewed toward the low end. More than one

third of the sample had total annual family incomes of less than \$6,000, and more than 50% had incomes of less than \$13,000. Although 50% of families had at least one family member employed, 59% relied on public assistance or an entitlement program (e.g., welfare assistance, social security, disability) as a primary or supplementary source of income. More than 20% of the families reported that they did not have adequate incomes to provide for basic life needs. About one third of the children lived in single-parent, female-headed households. With respect to the mothers' marital status, roughly an equal number (40%) were married as were formerly married, and 20% never were married. The mothers' mean education was 12 years, whereas that of the fathers was 11.8 years. The family sizes were somewhat large by today's standards, with 47% having three or more children. In a number of cases, families had more than one child with SCD.

#### **PROCEDURE**

As part of comprehensive and preventive health care for sickle cell patients, complete medical examinations are conducted annually. Included in the exam are psychosocial assessments of the patients and their families. The assessments are conducted through interviews with individual parents/guardians and patients. They are conducted by clinical nurse practitioners or adult social workers who have had extensive experience with SCD patients and their families. Guardians (mostly mothers) are the primary source of information. In addition to obtaining information from the parents, children respond to the same questions posed to guardians regarding health status, self-perceptions, school performance, and personal functioning.

#### **PSYCHOSOCIAL ASSESSMENT**

The assessment information is obtained through a structured interview developed by the second author. It uses open- and closed-ended questions administered orally in a private office in the outpatient clinic. The interview covers demographics (e.g., marital status, employment of parent and patient, household composition, parent education, family income, source of income); problems experienced by the family; information on financial need and resources; access to medical care; medical, social, academic, and work adjustment; mood and personality ratings of patient and parents; parental concerns and expectations; impact of the illness on the family; family functioning; and objective knowledge of SCD.

Information provided in the assessment interview is coded and used to form the following quantitative indexes used in the analysis.

### **Stress**

*Pain* is the number of pain episodes severe enough to require a visit to a hospital emergency room for treatment.

*Stigma* is a measure of the self-consciousness and teasing experienced by children related to their disease and its physical sequelae such as growth delay, yellowing of eyes, and loss of bladder control. Responses are on a 4-point rating scale.

*Financial Need* is a 2-point (yes/no) code indicating whether the respondent feels that the family has enough money to buy necessities such as food, housing, medical care, clothing, and transportation.

*Obstacles to Medical Care* is a sum of eight problems that the respondent indicates make it difficult to obtain medical care such as finding or paying for transportation, getting off from work, finding competent medical or dental care, and not being able to pay for such care. The range is 0 to 8.

### **Appraisal/Family Paradigms**

*Optimism* is an index that gauges the degree of hope or optimism with which the family views the child's future, especially with regard to achievement. It is a measure of how bright and promising the child's future is when viewed in light of the illness and beliefs about how much the child can overcome the effects of the illness to achieve as an adult.

*Fear* is an index that assesses the imminence of the threat the family perceives that the illness poses to the physical well-being and survival of the child. It reflects the degree of fear or the persistence of concern on the part of the family regarding the possibility of complications or death due to SCD.

### **Family Member Coping**

*Sick Role Adoption* is an index that assesses a particular strategy for coping with SCD characterized by adoption of the sick role. The index reveals the extent to which the ill child is perceived as using the illness as an excuse to avoid age-appropriate responsibilities, acts as though the illness were a problem on a day-to-day basis, and acts as though giving in to the illness rather than taking it in stride.

*Sibling Coping Response to Illness* is an index composed of five indicators of sibling reactions to SCD: jealousy, avoidance of ill child, acting out, fear, and overprotectiveness.

*Parental Acceptance* is an index that depicts the emotional stance toward or feeling about having a child with SCD. The response ranges from *negative* to *accepting*.

*Parental Anxiety* is an index that is a linear combination of the ratings of four items (afraid, worried, relaxed, and overworked). The parent rates his or her own mental state using a 4-point frequency scale (1 = *never*, 2 = *once in a while*, 3 = *frequently*, 4 = *almost all the time*). The range is 4 to 16.

*Parental Depressive Symptoms* is an index that is a linear combination of the ratings of three items (angry, hopeless, and shame) that the parent makes of his or her own mood using a 4-point frequency scale (1 = *never*, 2 = *once in a while*, 3 = *frequently*, 4 = *almost all the time*). The range is 4 to 16.

### **Family Functioning**

*Protectiveness* is an index composed of three items related to beliefs that the ill child's activities and aspirations should be restricted because of SCD and babying by siblings. It reflects the stance of parents and siblings toward the ill child in which they view the child as fragile, incapable, and endangered as a consequence of the illness. As a result, they might try to shield the child from demands or responsibilities they consider taxing. For example, the parent indicates whether there have been any things that the ill child wanted to do during the past year that the parent did not think the child should do because of the SCD.

*Maturity Demands* reflects the extent to which responsibilities are required of the ill child in the form of having and performing chores around the house (2-point scale).

*Family Relations* is an index that assesses the absence of problems or conflicts between the ill child and parents and the ill child and siblings.

### **ILL CHILD ADJUSTMENT**

Measures of adjustment outcomes were obtained from two different respondents: from parents/guardians for ill children under 18 years of age and from ill children over 8 years of age. Thus, reports from the two different sources were available for all patients between the 8 and 18 years of age. Correlations of adjustment outcomes from the two sources were significant and averaged about .35 across the six outcome indexes used in this study.

### Psychological Functioning

*Depressive Symptoms* is an index that is a linear combination of the ratings of four items (angry, lonely, hopeless, and depressed) made by the parent using a 4-point frequency scale (1 = *never*, 2 = *once in a while*, 3 = *frequently*, 4 = *almost all the time*). The range is 4 to 16.

*Anxiety* is an index that is a linear combination of the ratings of three items (afraid, worried, and ashamed) made by the parent using a 4-point frequency scale (1 = *never*, 2 = *once in a while*, 3 = *frequently*, 4 = *almost all the time*). The range is 4 to 16.

*Positive Mood* is an index that is a linear combination of 0/1 coding of responses made by the parent indicating whether the following adjectives were generally descriptive of the ill child: happy, ambitious, confident, outgoing, talkative, and friendly.

*Negative Mood* is an index that is a sum of the following items indicated by the parent as characteristic of the child's personality: shy, hot-tempered, moody, sad, insensitive, and lazy.

*Social Functioning* is an index that is composed of four items in which the parent indicates whether the statement is true of the child. This index shows the extent to which the parent believes that the ill child needs more friends, has the wrong types of friends, has a hard time getting along with friends, or does not have special friends to whom the child is close. In addition, it includes the parent's rating of satisfaction with the child's friends.

*Academic Functioning* is an index of school adjustment that is a linear combination of ratings (yes/no) of the following problems that the child has in school: failing grades; retention in grade; motivation problems; trouble with teacher; transportation problems; and needs to be in another school, class, or program.

*Total Adjustment Index* is an index that is a summary score for adjustment across the domain of anxiety, depressive symptoms, negative mood, positive mood, academic functioning, and social functioning. This index is based on parental reports. It is scored in the negative direction, with higher scores indicating greater problems of adjustment. The Cronbach's alpha estimate of internal consistency for this index is .66.

## RESULTS

Multiple regression analysis constitutes the primary analytic tool for assessing the utility of the family stress and coping model in predicting

outcomes and mediating the effects of stress on the functioning of the ill child. First, the zero-order correlation within and across the different groups of variables is examined to detect potential problems of multicollinearity. For these initial analyses, variables are grouped by stressors (pain episodes, stigma, financial need, and obstacles to care) and coping (outlook, fear, worry, ill child coping style, parental anxiety, parental depression, family relations, sibling coping, protectiveness, and maturity demands).

Zero-order correlations computed for the stressor variables revealed that pain episodes, stigma, financial need, and obstacles to care were not significantly correlated to one another except for stigma and financial need ( $r = .21$ ,  $p \leq .01$ ). This correlation suggests that the more financially needy, the more likely the child was subject to stigma related to the illness. Low income and financial need might mean that the child was more likely to be exposed to delayed growth and teasing. Conversely, growing up in a financially secure household might buttress the child against ridicule by others.

Numerous correlations among the coping variables were significant. Hopefulness of outlook was negatively correlated with parental anxiety ( $r = .25$ ,  $p \leq .001$ ) and ill child adoption of the sick role as a means of coping with the illness ( $r = .26$ ,  $p \leq .001$ ). Optimistic parents were less likely to be anxious. Perhaps hope served to neutralize the experience of anxiety. Hope might provide enhanced serenity in the face of the challenge of caring for an ill child. Parental fear was positively correlated with strain, anxiety, depressive symptoms, and ill child coping (Table 1).

Strain was significantly correlated with all coping variables except family relations. With the exception of mood, all measures were significantly correlated with one another, suggesting reasonably good coherence and consistency among these measures. Even more interesting is that the depression and anxiety scales correlated at .68, which is similar to correlations between anxiety and depression reported elsewhere (see review by Barbarin, 1990). The experience of academic problems was strongly correlated with adjustment to the illness, anxiety, depression, and academic functioning. Similarly, ill child adoption of the sick role as a coping style was correlated significantly with all coping variables except parental depressive symptoms.

Family protectiveness of the ill child was significantly correlated with parental worry, anxiety, and depressive symptoms. It also was related to sibling coping. These correlations reveal that the more family members responded to SCD with worry and fear, the more they overprotected the ill child. For siblings, this fear and worry might be expressed in avoidance or jealousy. This suggests that efforts to deal with family concerns and anxiety about the illness will pay dividends with respect to minimizing overprotection and promoting autonomy for the ill child. Conflict and problems in

**TABLE 1**  
**Zero-Order Correlations Among Independent Variables in the Coping Model**

	<i>Optimism</i>	<i>Fear</i>	<i>Acceptance</i>	<i>Sick Role</i>	<i>Sibling Coping</i>	<i>Parental Anxiety</i>	<i>Parental Depression</i>	<i>Family Relations</i>	<i>Protection</i>
Optimism									
Fear	.12								
Acceptance	-.09	-.09							
Sick role	-.16**	-.22***	.02						
Sibling coping	-.04	-.09	.01	.21***					
Parental anxiety	-.10	-.42***	-.09	.27***	.22***				
Parental depression	.02	-.29***	.02	.30***	.12*	.48**			
Family relations	.00	.10	.03	.09	-.36***	.23**	.06		
Protection	.00	-.09	-.05	.08	.05	.13	-.11	.03	
Maturity demands	-.06	-.17*	.11	.29***	-.06	.32***	-.10	-.06	.06

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

**TABLE 2**  
**Zero-Order Correlations Between Stressors**  
**and Coping Model Variables**

	<i>Illness Severity</i>	<i>Need</i>	<i>Stigma</i>	<i>Obstacles</i>
Optimism	-.11	-.19**	-.14	-.09
Fear	-.30***	-.21**	-.04	.20***
Acceptance	-.01	.14**	.02	.09
Sick role	.20**	.14*	.13*	.24***
Parental anxiety	.25***	.20***	.12	.17**
Parental depression	.27***	.16**	.08	.16**
Family relations	.18***	.30***	-.01	.26***
Protection	.14	.03	.01	.01
Maturity demands	-.01	.18*	.06	.26***

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

family relations displayed an interesting relationship to parent and sibling functioning. For parents, troubled family relationships were negatively correlated with parental anxiety ( $r = -.21, p \leq .01$ ). The more conflict in family relations, the less anxious were the parents. However, avoidance, jealousy, and acting-out behavior in the sibling coping index was positively correlated with problems in family relations ( $r = .19, p \leq .01$ ).

Table 2 presents the correlations between two important measures of stress (illness severity and financial need) and indexes of coping. Both illness severity and financial need were positively correlated with parental anxiety, fear, strain, and ill child adoption of the sick role as a way of coping. In addition, financial need was correlated with maturity demands, and illness severity was significantly correlated with problems in family relations. Stigma was correlated with avoidance coping styles of siblings.

Table 3 presents correlations among measures of adjustment. The table reveals a pattern of highly significant correlations among the outcome measures. This pattern contributes to the evidence of convergent validity and adds considerably to our confidence in the construct validity of the indexes employed in this study.

Tables 4 to 10 present the results of the multiple regression analysis in which child anxiety, child depression, academic adjustment, positive mood, negative mood, social adjustment, and the total adjustment index, respectively, are used as the dependent variable and the stress and coping variables are the independent or predictor variables. The tables contain zero-order and partial correlations relevant to testing the hypothesized mediation effects of

**TABLE 3**  
**Zero-Order Correlations Among Child Outcome Variables**

	<i>Anxiety</i>	<i>Depression</i>	<i>Positive Mood</i>	<i>Negative Mood</i>	<i>Academic Adjustment</i>
Anxiety					
Depression	.55***				
Positive mood	-.20**	-.45***			
Negative mood	.11	.20**	.14**		
Academic adjustment	.21**	.31**	-.20**	.20**	
Social adjustment	.30***	.31***	.04	.24***	.24***

\*\* $p < .01$ . \*\*\* $p < .001$ .

**TABLE 4**  
**Regression Analysis Using Child Anxiety Index as the Dependent Variable and Stress and Coping Variables as Predictors**

<i>Variable</i>	<i>Zero Order</i>	<i>Partial R</i>	<i>Beta</i>	<i>t Value</i>
Optimism	-.15	.029	.013	0.340
Fear	-.35	-.126	-.310	-1.450
Acceptance	.16	.168	.237	1.940*
Sick role	.32	.188	.133	2.180*
Sibling coping	.15	.046	.112	0.528
Anxiety	.50	.336	.251	4.060***
Depression	.33	.054	.136	0.623
Family relations	.15	.132	.251	1.520
Protection	.16	.108	.167	1.240
Maturity	-.05	-.337	-4.330	-4.090***
Pain	.18	-.068	-.015	-0.778
Need	.24	.005	.018	0.066
Stigma	.16	.055	.012	0.628

NOTE:  $F(13, 143) = 7.49, p \leq .001$ ; multiple  $R = .65, R^2 = .43$ .

\* $p < .05$ . \*\*\* $p < .001$ .

the coping variables. Because of the high correlation between obstacles to care and financial need, obstacles to care was dropped from the regression analysis to minimize the problem of multicollinearity.

Child anxiety was significantly predicted by the stress and coping variables,  $R^2 = .43, F(13, 143) = 7.49, p \leq .001$ . Child anxiety was most strongly related to aspects of family functioning (maturity demands), parental functioning (parental anxiety), appraisal process (acceptance), and child coping

**TABLE 5**  
**Regression Analysis Using Child Depression Index as the Dependent Variable and Stress and Coping Variables as Predictors**

<i>Variable</i>	<i>Zero Order</i>	<i>Partial R</i>	<i>Beta</i>	<i>t Value</i>
Optimism	-.14*	-.00	-.004	-.
Fear	-.29**	-.05	-.279	-.
Acceptance	.13	.13	.389	0.078
Sick role	.49**	.37	.580	4.590***
Sibling coping	.24	.14	.712	1.620
Anxiety	.40	.09	.136	1.070
Depression	.33	.01	.065	0.145
Family relations	.13	-.17	-.692	-2.020*
Protection	.18	.16	.522	1.870
Maturity	.07	-.14	-3.730	-1.700
Pain	.19	.01	.007	0.187
Need	.21	.12	.812	1.440
Stigma	.15	.01	.007	0.192

NOTE:  $F(13, 143) = 5.43, p \leq .001$ ; multiple  $R = .59, R^2 = .35$ .

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

(sick role adoption)(Table 4). Depression in the child was significantly predicted by coping style (sick role adoption) and family functioning (conflictual family relationships and family overprotectiveness),  $R^2 = .35, F(13, 143) = 5.43, p \leq .001$  (Table 5). Problems of academic adjustment were significantly predicted by appraisal process (optimistic outlook) and child coping (adoption of sick role). Problems of academic adjustment were less likely to occur when the family adopted an optimistic outlook and when the child rejected the sick role,  $R^2 = .23, F(13, 143) = 3.47, p \leq .001$  (Table 6). Positive mood was significantly predicted by appraisal process (optimism) and financial need. The more optimistic the family outlook and the less financially needy the family, the more positive the mood of the child,  $R^2 = .20, F(13, 143) = 2.45, p \leq .01$  (Table 7). Negative mood was best predicted by the ill child's coping style (sick role adoption) and family functioning (frequent conflict in family relations),  $R^2 = .25, F(13, 143) = 3.46, p \leq .001$  (Table 8). Social adjustment was significantly predicted by the stress and coping variables,  $R^2 = .18, F(13, 143) = 2.17, p \leq .01$  (Table 9). It was most strongly related to how the ill child copes. Problems of social adjustment were less likely to occur when the ill child rejected the sick role and took the illness in stride.

The regression analysis for the total adjustment index shows that the stress and coping variables together account for a significant proportion of the

**TABLE 6**  
**Regression Analysis Using Academic Adjustment as the Dependent**  
**Variable and Stress and Coping Variables as Predictors**

<i>Variable</i>	<i>Zero Order</i>	<i>Partial R</i>	<i>Beta</i>	<i>t Value</i>
Optimism	-.16	-.177	-.056	-2.030*
Fear	-.13	.046	.075	0.523
Acceptance	.11	.004	.004	0.054
Sick role	.33	.252	.121	2.950**
Sibling coping	.14	.071	.112	0.811
Anxiety	.26	.084	.040	0.960
Depression	-.16	-.081	-.136	-0.922
Family relations	.10	.088	.111	1.000
Protection	.04	-.018	-.019	-0.208
Maturity	.08	-.041	-.332	-0.464
Pain	.15	.059	.009	0.673
Need	.20	.074	.158	0.849
Stigma	.06	-.090	-.013	-1.030

NOTE:  $F(13, 143) = 3.47, p \leq .001$ ; multiple  $R = .48, R^2 = .23$ .

\* $p < .05$ . \*\* $p < .01$ .

**TABLE 7**  
**Regression Analysis Using Positive Mood Index as the Dependent**  
**Variable and Stress and Coping Variables as Predictors**

<i>Variable</i>	<i>Zero Order</i>	<i>Partial R</i>	<i>Beta</i>	<i>t Value</i>
Optimism	.17	.17	.090	2.000*
Fear	.06	-.00	-.025	-0.105
Acceptance	-.02	.05	.088	0.654
Sick role	-.16	-.16	-.125	-1.860
Sibling coping	-.05	.02	.055	0.243
Anxiety	-.09	-.15	-.118	-1.740
Depression	.04	-.09	-.270	-1.110
Family relations	.09	.09	.191	1.050
Protection	-.16	-.12	-.215	-1.430
Maturity	-.04	.12	1.680	1.430
Pain	-.04	.14	.036	1.670
Need	-.12	-.18	-.676	-2.200*
Stigma	-.04	.08	.019	0.935

NOTE:  $F(13, 143) = 2.45, p \leq .01$ ; multiple  $R = .44, R^2 = .20$ .

\* $p < .05$ .

**TABLE 8**  
**Regression Analysis Using Negative Mood Index as the Dependent Variable and Stress and Coping Variables as Predictors**

<i>Variable</i>	<i>Zero Order</i>	<i>Partial R</i>	<i>Beta</i>	<i>t Value</i>
Optimism	-.02	-.04	-.017	-0.502
Fear	-.02	-.05	-.121	-0.678
Acceptance	.01	-.10	-.122	-1.190
Sick role	.23	.18	.111	2.160*
Sibling coping	.11	.09	.182	1.050
Anxiety	.06	-.01	-.007	-0.146
Depression	.03	-.01	-.035	-0.194
Family relations	-.39	-.33	-.559	-4.070***
Protection	-.05	-.11	-.144	-1.260
Maturity	.14	.14	1.490	1.660
Pain	.03	.03	.006	0.410
Need	.07	.02	.077	0.337
Stigma	.03	-.06	-.012	-0.792

NOTE:  $F(13, 143) = 3.47, p \leq .001$ ; multiple  $R = .51, R^2 = .26$ .

\* $p < .05$ . \*\*\* $p < .001$ .

**TABLE 9**  
**Regression Analysis Using Social Adjustment as the Dependent Variable and Stress and Coping Variables as Predictors**

<i>Variable</i>	<i>Zero Order</i>	<i>Partial R</i>	<i>Beta</i>	<i>t Value</i>
Optimism	-.06	-.02	.022	-0.237
Fear	-.17	-.15	-.882	-1.790
Acceptance	.09	.01	.053	0.189
Sick role	.30	.21	.352	2.500**
Sibling coping	.24	-.01	-.101	-0.215
Anxiety	.14	.10	.171	1.200
Depression	.08	.15	.931	1.840
Family relations	-.36	.00	-.003	-0.010
Protection	.14	.05	.213	0.684
Maturity	.06	-.06	-1.920	-0.783
Pain	-.06	.08	.046	1.010
Need	-.03	.00	.021	0.033
Stigma	.12	.11	.060	1.380

NOTE:  $F(13, 143) = 2.17, p \leq .01$ ; multiple  $R = .42, R^2 = .18$ .

\*\* $p < .01$ .

**TABLE 10**  
**Regression Analysis Using Total Adjustment Index as the Dependent Variable and Stress and Coping Variables as Predictors**

<i>Variable</i>	<i>Partial R</i>	<i>Beta</i>	<i>t Value</i>
Optimism	-.050	-0.361	-0.566
Fear	-.167	-6.340	-1.900
Acceptance	.024	0.526	0.000
Sick role	.297	3.320	3.500***
Sibling coping	-.014	-0.526	-0.159
Anxiety	.127	1.390	1.440
Depression	.155	6.020	1.770
Family relations	-.032	-0.950	-0.367
Protection	.085	2.050	0.959
Maturity	-.110	-20.300	-1.240
Pain	.090	0.317	1.010
Need	.047	2.310	0.537
Stigma	.101	0.343	1.140

NOTE:  $F(13, 143) = 3.54, p \leq .001$ ; multiple  $R = .52, R^2 = .27$ .

\*\*\* $p < .001$ .

variance. The regression produces a multiple  $R$  of .51 and accounts for 26% of the variance in adjustment,  $F(13, 139) = 3.54, p \leq .001$ . The regression analysis reveals that although the stressor variables of financial need and severity have high zero-order correlations, with adjustment their partial correlations are reduced to .04 and .09, respectively (not shown). This suggests that the coping model variables do mediate the relationship of these stressors to the outcome. For pain and financial need, the relationship to adjustment outcome no longer is significant. The coping variables that most strongly account for this mediation effect on adjustment are ill child coping style (adoption of sick role) and parental functioning (parental anxiety, strain, and fear). In addition, aspects of family functioning (maturity demands, overprotection, and problems in family relations) also predict adjustment.

## DISCUSSION

Coping with SCD involves confronting many medical, social, interpersonal, instrumental, and psychological stressors. If not handled well, these stressors have the potential for disrupting family functioning, impeding

normal development, and placing individuals and their families at risk for affective psychological disorders (depression and anxiety). This research has examined patterns of individual and family functioning in response to illness. The family coping model proposed in this article attributes a central role to family factors as important mediators of adjustment outcomes for seriously ill children. The results of these analyses support the family stress and coping model and its relevance for adjustment outcomes for children. The data provide particularly strong support for assertions about the importance of family functioning in the adjustment of children and adolescents. The manner in which family members (especially parents) cope with the illness strongly influenced the adjustment of the ill children. If parents were anxious and did not cope well, then children did not do well psychologically, socially, or academically. Family relationships characterized by conflict were reflected in the poor adjustment of ill children. This has important service implications for the development of comprehensive health programs. Programs that seek to address the needs of chronically ill children must focus on family if they are to be successful. In addition, the data provide a basis for refining the model insofar as it links particular aspects of appraisal processes, parental coping, and family functioning to adjustment. The expected relations between family functioning and adjustment were borne out in several domains such as mental health, social adjustment, and academic adjustment.

An unmistakable message emerges from these data for service providers regarding the family nature of the illness. The model of family coping tested here strongly shows the connection between how well the parent (almost always the mother) is doing and how well the child fares. Specifically, mental health outcomes for children appear to be strongly related to mental health functioning of parents. Parental (and, in our case, maternal) anxiety and strain are associated with several outcome domains. When the parent is doing well on these dimensions, the child tends to turn out well. The quality of family relations, the role of family paradigms about the illness, and the mental health of family members reinforce the crucial role of family functioning in adjustment and suggest important directions for intervention in chronic illness. We cannot effectively serve the needs of the ill child without addressing the psychosocial needs of the family, particularly the mother. The relationship among maternal worry, anxiety and depressive symptoms, and child functioning reinforces the importance of providing informational, emotional, and (when needed) material support to mothers. Efforts to help the child will be enhanced by adopting a family approach, especially one focused on attenuating the problems and distress of the mother.

Barbarin, Whitten, Bond, and Conner-Warren (1999 [this issue]) have shown that psychosocial functioning is influenced by the severity of the

illness, as indexed by frequency of pain. However, an important implication of the data presented here is that the degree of psychosocial impairment and the degree of life disruption in children with SCD are not determined solely by the severity of the physical course; they also are influenced by how the child and family view the illness situation. Paradigms about the illness and the cognitive appraisal of the illness situation clearly mediated the outcomes for children. Children who fared better were those who cognitively and behaviorally rejected the sick role, took the stance that they were normal, and tried to live their lives as fully as possible and not treat the illness as a master status that would dominate all other aspects of personal identity. Those children who adopted the stance that they were, in most ways, normal kids whose lives were circumscribed only in part by SCD functioned better than those who succumbed to the illness. This approach on the part of the children to coping with the illness is one of the most powerful determinants of adjustment.

An important unanswered question is how the child adopts such a stance. An important influence is the family. This pattern might have its roots in the early socialization around the illness. It is tied to development of family paradigms about how incapacitating the illness is expected to be. Whether the child is reinforced for sick role behavior by being permitted to avoid unpleasant tasks, whether the child is discouraged from taking chances and exploring new social activities, and whether the family conveys expectations to the child of meeting high performance standards all influence how the child will cope. If the child is overprotected early in the illness and is led to believe that persons in the social environment will accept the illness as an excuse for inaction or nonfulfillment of duty, then the child might learn to use it to avoid or escape tasks judged to be onerous or undesirable. This finding lends credence to often repeated admonitions against overprotection and advice to treat the ill child as normally as possible.

This research lends empirical support to the model of family coping outlined by Barbarin (1983), but it does not constitute the most rigorous test possible. Certain sociocultural parameters central to the functioning of African American families are missing from this model. For example, social identity, racial attributions, perception of discrimination, religiosity, and support from extended family must be assessed if the model is to be fully tested. At this point, what has been demonstrated is that certain appraisal processes relevant to the stressor under study effectively predict adjustment. Also admirably demonstrated is the important role of individual coping and family functioning. These are theoretically meaningful for persons espousing theories of family stress and coping, but more remains to be done. Thus, the findings here are useful from theoretical and service perspectives. Family stress and

coping theories provided a very meaningful way in which to think about responses to stressful situations and to point to avenues for intervention for professionals serving those experiencing these stressors. The results of this study suggest that the child will have better overall adjustment if he or she takes the illness in stride and if the parents are able to temper the degree of worry, anxiety, and fear associated with the illness; avoid overprotection; make maturity demands on the part of the ill child; and have a degree of closeness and accord in family relations.

Clinical experience amply proves how difficult it is for families to maintain the right balance between being too anxious and too complacent, too intrusive and too detached, and too overreactive and too neglectful. Yet, according to our data, such a balance is strongly predictive of how well children cope and of the probability of problems in psychosocial adjustment. Clearly, managing ill children without overprotection and unduly curtailing the life experiences and potential of children with the disease requires nerves of steel and the wisdom of Solomon. Like earlier research, our data suggest that families can maintain a judiciously vigilant posture only when they successfully have confronted and moderated their guilt and anxiety about the illness (Evans, Burlew, & Oler, 1988). But not all families can achieve this alone. They may benefit from supportive family interventions. Too often, programs intended to serve children with SCD and other illnesses have underestimated the significant role of family members in the adjustment of ill children and have not recognized that to help the children, we must help the families. There are model programs to help families improve their functioning by reinforcing their executive system, eliciting mutually supportive communication and behavior, sharing tasks, resolving conflicts, and encouraging personal autonomy; to develop appropriate expectations and behavioral standards for the ill children; to handle medical care routinely and treat pain episodes in a noncrisis manner; and to increase family involvement in the children's educations.

## REFERENCES

- Barbarin, O. (1983). Coping with ecological transitions by Black families: A psychosocial model. *Journal of Community Psychology*, 2, 308-322.
- Barbarin, O. (1990). Family functioning and adjustment of school-aged children. In F. J. Medway & T. P. Cafferty (Eds.), *School psychology: A social psychological perspective*. Hillsdale, NJ: Lawrence Erlbaum.

- Barbarin, O. (1999). Do parental coping, involvement, religiosity, and racial identity mediate children's psychological adjustment to sickle cell disease? *Journal of Black Psychology, 25*, 391-426.
- Barbarin, O., Whitten, C., Bond, S., & Conner-Warren, R. (1999). The social and cultural context of coping with sickle cell disease: II. The role of financial hardship in adjustment to sickle cell disease. *Journal of Black Psychology, 25*, 294-315.
- Cadman, D., Boyle, M., & Offord, D. R. (1988). The Ontario Child Health Study: Social adjustment and mental health of siblings of children with chronic health problems. *Journal of Developmental and Behavioral Pediatrics, 9*, 117-121.
- Cadman, D., Boyle, M. H., Szatmari, P., & Offord, D. R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. *Pediatrics, 79*, 805-813.
- Chesler, M., & Barbarin, O. (1987). *Childhood cancer and the family*. New York: Brunner/Mazel.
- Evans, R. C., Burlew, A. K., & Oler, C. H. (1988). Children with sickle cell anemia: Parental relations, parent-child relations, and child behavior. *Social Work, 33*, 127-130.
- Gil, K. M., Wilson, J. J., Edens, J. L., Webster, D. A., Abrams, M. A., Orringer, E., Grant, M., Clark, W. C., & Janal, M. N. (1996). Effects of cognitive coping skills training on coping strategies and experimental pain sensitivity in African American adults with sickle cell disease. *Health Psychology, 15*(1), 3-10.
- Kazak, A. E. (1989). Families of chronically ill children: A systems and social-ecological model of adaptation and change. *Journal of Consulting and Clinical Psychology, 57*, 25-30.
- Kupst, M., & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up. *Journal of Pediatric Psychology, 13*, 7-22.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lewis, H. A., & Kliever, W. (1996). Hope, coping, and adjustment among children with sickle cell disease: Tests of mediator and moderator models. *Journal of Pediatric Psychology, 21*, 25-41.
- McCrae, J. D., & Lumley, M. A. (1998). Health status in sickle cell disease: Examining the roles of pain coping strategies, somatic awareness, and negative affectivity. *Journal of Behavioral Medicine, 21*(1), 35-55.
- McCubbin, H. (1979). Integrating coping behavior in a family stress theory. *Journal of Marriage and the Family, 41*, 237-241.
- Midence, K., McManus, C., Fuggle, P., & Davies, S. (1996). Psychological adjustment and family functioning in a group of British children with sickle cell disease: Preliminary empirical findings and a meta-analysis. *British Journal of Clinical Psychology, 35*, 439-450.
- Noll, R. B., Vannatta, K., Koontz, K., Kalinyak, K., Bukowski, W. M., & Davies, W. H. (1996). Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development, 67*, 423-436.
- Reiss, D. (1981). *The family's construction of reality*. Cambridge, MA: Harvard University Press.
- Sterling, Y. M., Peterson, J., & Weekes, D. P. (1997). African-American families with chronically ill children: Oversights and insights. *Journal of Pediatric Nursing, 12*, 292-300.