

**The Social and Cultural Context of Coping
With Sickle Cell Disease: II. The Role of
Financial Hardship in Adjustment
to Sickle Cell Disease**

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Recent evidence on the negative psychological effects of poverty suggests that economic status alone might account for the adjustment problems attributed to sickle cell disease (SCD). The relationship of SCD and financial hardship to adjustment was examined in 327 ill children and their parents. SCD and hardship contributed independently to impaired child and parental functioning. For parents, illness severity had more negative effects than did financial hardship, but for

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children, the reverse was true. Moreover, the distinction between poverty defined as low income and poverty defined as material deprivation proved to be important. When basic needs were met, low income did not contribute to adverse psychosocial outcomes. In the absence of material deprivation, low-income parents were less anxious and angry and had higher academic expectations for their ill children compared to high-income parents. This supports claims that safeguarding against material want and providing social services strengthens adjustment to chronic illness.

Chronic illnesses such as SCD are unquestionably distressing and adversely affect psychological adjustment (Barbarin, 1990). As a consequence of sickle cell disease (SCD), children and their families are confronted by diverse physical and emotional challenges. These include fatigue; serious pain episodes; strokes; leg ulcers; disruption of school, work, and recreational activities; social isolation and loneliness; loss of control over life; delayed physical maturation; stigma, teasing, and rejection by peers; and uncertainty about the future (Gil et al., 1993; Iloeje, 1991; Whitten & Nishiura, 1985). These challenges threaten the psychological well-being of ill children and perhaps even the well-being of their families. In the process, children with SCD might come to be less autonomous, less socially adept, and less confident than peers (Noll et al., 1996). They experience psychological impairment in the form of emotional immaturity, dependence, weak ego development, anxiety, depression, social withdrawal, and low self-esteem (Yang, Cepeda, Price, Shah, & Mankad, 1994).

A wealth of empirical research on the effects of SCD has confirmed the existence of psychosocial problems that were first identified in clinical settings (Williams, Earles, & Park, 1983). Specific evidence has been obtained regarding high rates of psychological dysfunction, social immaturity, excessive school absences, academic underachievement and failure, school dropouts, and unemployment (Conyard, Krishnamurthy & Dusik, 1980; Nishiura & Whitten, 1980). Problems related to cognitive and linguistic development as well as academic achievement also have been noted as serious problems for children and adolescents with SCD (Barbarin, 1990; Gentry, Hayes, Dancer, & Davis, 1997).

A conceptual and empirical difficulty with this analysis is that many of the behavioral, emotional, and academic problems attributed in this research to SCD also have been consistently linked to poverty and economic deprivation. Material deprivation and poverty are common experiences for many persons with SCD. Poverty is highly prevalent among African Americans and is estimated to affect 46% of African American children (Garfinkel, 1996). The evidence linking economic hardship to deficits in cognitive development, academic achievement, and mental health is quite convincing (McLoyd,

1998), so much so that poverty or financial hardship alone might account for psychosocial outcomes frequently attributed to illness. By focusing exclusively on medical factors, the impact of important contextual factors such as financial hardship are seriously underestimated or ignored entirely. At the same time, exclusive reliance on medical factors seriously limits our ability to account for variations in adjustment observed among persons who do not differ greatly by any index of disease severity.

Following similar reasoning, some researchers have questioned whether problems reported for children with SCD occur at rates that are higher than those in matched control groups and whether the observed effects can be attributed entirely to the illness (Richard & Burlew, 1997). The evidence is inconclusive. Several studies that employed siblings as a comparison (Lee, Phoenix, Brown, & Jackson, 1997) or non-ill control groups matched for age, gender, and socioeconomic status (SES) found scant evidence of psychosocial deficits attributable to SCD (Lemanek, Horwitz, & Ohene-Frempong, 1994a, 1994b; Lemanek, Moore, Gresham, Williamson, & Kelley, 1986). Others employing matched controls do report some differences (Fowler et al., 1988). Consequently, there has been considerable uncertainty about the extent to which the adverse outcomes enumerated heretofore are attributable to the illness itself. Arguments for the illness affecting psychosocial functioning must account for the failure to observe such effects in a number of studies that used non-ill comparison groups. Suitable control groups of non-ill children are not always available, nor is the use of such groups the only approach to testing illness effects. An alternative way of testing for an illness effect in the absence of a well-matched non-ill control group is to compare groups that differ in illness severity. For example, comparisons could be made between children diagnosed with an illness but who are asymptomatic and children with moderate and high levels of medical symptomatology related to the disease. To the extent that psychosocial impairment of children with chronic illness is a direct sequela of the illness, the degree of impairment ought to be a function of illness severity. Such an approach is feasible in the study of the effects of sickle cell anemia given wide variations in symptoms among children with the disease. It is possible that adjustment problems occur primarily in children with the most severe manifestations of the disease.

In lieu of a very precise measure of illness severity, frequency of pain episodes is the widely adopted method for indexing severity in SCD. Serious pain episodes are especially disruptive because they can neither be predicted perfectly nor be prevented entirely. For this reason, pain might have the greatest impact of any aspect of the illness on psychosocial adjustment. Reliable assessment of pain, however, is problematic because pain is inherently subjective. What is barely noticeable or tolerable discomfort for one individual

might constitute excruciating and unbearable misery for another. Although any measure of severity based on self-reported pain will be imperfect, we believe that illness severity can be represented reliably when defined as the number of pain episodes so intense that the child has to take the extraordinary measure of seeking medical attention at a hospital emergency room.

Medical factors such as disease severity might not be the most important determinants of illness adjustment. Lemanek et al. (1986) suggest that problems of adjustment in SCD may arise as much from social factors (e.g., poverty) as from medical factors (e.g., frequency of pain episodes). Consequently, even when we are able to gauge illness severity with precision and confidence, we might discover that social and psychological adjustment has scant relationship to disease severity per se (Hurtig, Koepke, & Park, 1989). In addition, medical severity and stressors emanating from other aspects of the child's life are not necessarily independent factors and might, in fact, be linked reciprocally. The exacerbation of the child's physical condition may arise because financial resources are inadequate to provide proper medical care or to provide adequate nutrition and shelter. In this way, poverty and financial hardship also may amplify the psychosocial impairment through its adverse impact on the child's health. As a consequence, children whose families experience poverty and financial hardship are highly susceptible to experiencing a more severe course of illness and with more physical complications than are those who come from more advantaged backgrounds. Thus, poverty and financial distress play a potentially important role in influencing the well-being of children with SCD. They complicate families' attempts to cope with SCD, compromise health care, and may affect the course of the disease and its psychosocial sequelae.

In this article, the terms *poverty*, *financial need*, and *economic hardship* are used interchangeably. Like pain, they are subjective constructs that are difficult to measure reliably. Not even the U.S. government poverty index is free of controversy. The U.S. poverty standard is defined as three times the annual family income needed to provide a minimally adequate diet for a year, which in 1987 was \$10,000 for a family of three (Bane & Ellwood, 1989). This standard is challenged as invalid and inexact because of regional variations in the cost of living, inadequate accounting for noncash in-kind benefits and bartering, and failure to factor in taxes and work-related or other special expenses such as the cost of medical care for a seriously ill child. The accuracy of self-reported income, the basis of most measures, is in doubt. Too frequently, respondents are unable to recall precisely or might be motivated to inflate or deflate income reports depending on what they perceive as the stakes involved in responding to inquiries regarding their incomes. Even when respondents attempt to be scrupulously exact, it might be unclear what

should be included. If there are multiple wage earners, should the study use figures based on the incomes of all family members including minors? Should the figure for total income reflect unearned income, gifts, funds earned by children and contributed directly or indirectly to the household, vendored payments for utilities and rent deducted from entitlements or welfare payments, food stamps, Title VIII (e.g., rent supplements or other forms of assistance such as WIC [Women, Infants, and Children] food supplements)? The solution we have chosen to gauge financial distress is to ask respondents about that directly. An approach to dealing with this dilemma is the use of two different sources of information to designate financial status: total income and financial need (or subjective poverty). Subjective poverty relies on a family's perception that it did not have sufficient resources to meet its need for basic life necessities.

Although high concordance exists among disease severity, life stress, and problems of psychosocial adjustment, questions remain unanswered about the nature and causal direction of the relationship underlying this concordance. Is SCD alone sufficient to give rise to adjustment problems? Alternatively, to what extent are the adjustment problems observed among children and adolescents with SCD a result of life stress emanating from poverty or financial hardship and have little to do with illness? The relative ability of illness severity and poverty-related life stress to account for the adjustment has theoretical, policy, and service implications. It is highly likely that financial hardship, which by itself exposes children to many other stresses, may exacerbate illness. It may magnify the adverse psychosocial sequelae of illness. For example, if illness results in high absenteeism from school, then poor families might have few resources with which to supplement instruction missed at school. This might lead to school failure, contribute to poor academic self-concept, and diminish achievement motivation. The reciprocal effects of life stress and physical pathology are particularly germane to SCD because of the difficulty of ascertaining whether the pain and discomfort experienced by individual patients is an expression of hematological pathologies or socioeconomic circumstances or a combination of the two. Does life stress associated with poverty exacerbate illness, which in turn impairs psychosocial functioning? Answers to these questions inform decisions about the relative emphasis of medical or psychosocial strategies in prevention of adjustment problems.

The primary goal of this research is to investigate whether financial hardship and illness severity are related to psychological, social, academic, and family adjustment of children and adolescents with SCD. This article examines the extent to which adjustment problems differ significantly as a function of frequency of serious pain episodes, financial need, or the interaction

of the two. Three empirically testable relations emerge from this line of reasoning: a main effect of illness on adjustment, a main effect of financial hardship on adjustment, and an effect for the statistical interaction of the two on adjustment. Is illness severity alone a necessary and sufficient explanation of adjustment problems? Do life stresses, such as those resulting from financial hardship that are independent of the illness, account better for observed adjustment problems in children and their families than does illness itself? Do independent sources of distress combine with and exacerbate the effects of illness for children and their families? The disease itself might be so distressing that it results in significant adjustment problems for individuals and their families. The more severe the illness, the greater the number of problems and the greater the degree of impairment. Second, life stress such as that emanating from financial need can interfere with psychosocial adjustment. Third, complex reciprocal interactions among poverty and illness also might account for the observed relationships. Families experiencing financial need might suffer more frequently and more severely from disease and thereby experience more negative outcomes due to poor disease adjustment.

METHOD

PARTICIPANTS

Data for this article are drawn from interviews of 327 children 4 to 17 years of age and their parents who were provided treatment for SCD in a comprehensive clinic at an urban children's hospital. The interviews were conducted between 1981 and 1988. The breakdown of age groups represented in the sample was as follows: 144 children (44% of the total sample) were under 8 years old, 117 (36%) were 8 to 13 years old, and 66 (20%) were 13 to 17 years old. Of these, 182 were male (56%), and 145 were female (44%). In the case of children under the age of 16, mostly mothers were the primary source of information. However, children over 8 years of age were asked to respond to many of the same questions posed to guardians regarding health status, self-perception, school performance, and personal functioning.

PROCEDURE

As part of comprehensive and preventive health care for children with sickle cell, a complete medical examination is conducted annually. Included

in the annual examination is a psychosocial assessment of the children and their families developed by the second author. The psychosocial assessment takes the form of a personal interview of parents/guardians and patients conducted in the outpatient sickle cell clinic of the hospital by clinical nurse practitioners who have had extensive experience with SCD. In the case of this sample, the nurse practitioner, social worker, and psychologist conducting the interviews have been known for several years by the families and often are used as counselors, confidants, and gatekeepers for supplemental social and material resources. The relationships between the interviewers and the families were typically long-standing, close, and supportive. This lends credibility to the candor and accuracy of the assessment information.

The *psychosocial interview* uses both open-ended questions and numerical ratings to gather information about basic needs, family resources, use of medical care, disease adjustment, family relations, and psychosocial adjustment of the child and family. More specifically, the interview covers demographics (e.g., marital status and employment of parent and patient, household composition, parent education, family income, source of income); problems currently experienced by the family; information on financial need and resources; access to medical care; medical, social, academic, and work adjustment; mood ratings of patient and parent; parental concerns and expectations; family impact of the illness; family functioning; and objective knowledge of SCD. Information provided in the assessment interview is coded and used to form the following quantitative indexes used as independent and dependent variables in the analyses of variance (ANOVAs).

INDEPENDENT MEASURES

Illness Severity (pain) is based on the number of pain episodes so severe that they required the patients to seek medical attention, primarily through the hospital emergency room. Children who were asymptomatic and experienced no pain episodes during the past year were assigned to the mild group. Children who had one or two pain episodes requiring medical attention during the past year were classified as moderate. Those with more than two pain episodes requiring medical attention were classified as severe.

Poverty/Financial Hardship is defined using a combination of objective and subjective indicators. The objective indicator is the total annual family income from all sources; families indicated where they fell within several income ranges. The subjective indicator of poverty or financial hardship is a subjective evaluation by the families of whether they were able to meet basic needs, that is, whether they had enough money for food, clothing, shelter, and

necessary transportation. The sample was divided into three groups based on an objective (annual family income) and subjective (self-report of financial need) index. The hardship group consisted of all respondents without regard to total family income who indicated that, at some point during the past year, they did not have adequate resources for family necessities. The other two groups consisted of children whose parents indicated that they did not have any basic unmet needs. These latter groups did differ in total annual family income. Those in the low income group had a total annual income of less than \$6,000, and those in the moderate income group had a family income of \$6,000 or more (in 1987 dollars).

DEPENDENT MEASURES

Day-to-Day Problems Living With Illness is a 3-point index of the extent to which the illness is perceived of and treated as a problem that disrupts day-to-day life (1 = *no*, 3 = *very much*).

Sick Role Adoption is an index of the extent to which the children take illness on as a master status or primary feature of personal identity. It represents a tendency to allow their lives and aspirations to be governed by a belief that they are not normal and that the illness imposes severe restrictions on what is possible. This index is a combination of five 3-point frequency ratings (*never*, *occasionally*, and *often*) of the extent to which children acquiesce to the illness, view it as interfering with making friends or having a social life, and use it as a means of avoiding social obligations such as chores and school attendance (range = 5-15). High scores indicate high sick role adoption.

Obstacles to Medical Care is a sum of the number of items rated as interfering with access to medical care. The obstacles include lack of transportation or funds for transportation, difficulty in identifying medical practitioners capable of caring for children with SCD, obtaining time off from work, and lack of medical insurance or money to pay for medical care (range = 0-8).

Psychological Functioning is a measure in which parents rated themselves and their children over 7 years of age on frequency of symptoms of depression and anxiety using a 4-point scale (1 = *never*, 4 = *almost all the time*). Ratings of anxiety symptoms indicate the frequency with which the parents or children exhibit fear, worry, or shame. Ratings of depressive symptoms reflect the extent to which the parents or children experience anger, loneliness, hopelessness, or depression. Range of the depressive symptoms index is 4 to 16, whereas the anxiety index range is 3 to 12. Depression and anxiety were inappropriate for and difficult to assess in younger children. Consequently, these items were not administered when the children were less

than 8 years of age. This reduced the sample to 183 for analysis involving anxiety and depression. In addition, adolescents rated themselves on these items. The concordance between the parents' and adolescents' ratings of the adolescents was high, with Pearson product-moment correlations averaging above .60.

Positive Mood is a sum of six items endorsed by parents as generally descriptive of the children: happy, ambitious, confident, outgoing, talkative, and friendly (range = 0-6). Higher scores correspond to more positive mood states and psychological functioning.

Problems in Social Functioning is an index composed of four items in which the parents indicate how well their children are functioning in the social arena specifically with respect to having enough friends, having close friends, parents approving of their children's friends, and getting along with friends and acquaintances (range = 0-5). Higher scores indicate more problems.

Problems in Academic Functioning is a linear combination of children's school adjustment problems including failing grades, grade retention, lack of motivation, and trouble with teachers (range = 0-4). These were administered only if the children were of school age at the times of the interviews.

Academic Expectations is an indicator of the educational attainment that parents expect of their children, expressed in years of formal education. It ranges from less than high school through graduate or professional training.

Parental Reactions to Illness consists of two indexes of parents' self-reported emotional responses to SCD: anger (one item) and anxiety (two items). Each response is rated on a 4-point frequency scale.

Parental Acceptance is an index of the extent to which parents are able to maintain a posture of resignation and acceptance of the things they cannot control in dealing with day-to-day demands of the illness. It assesses parents' ability to adapt to the difficulties of SCD and to go on with their lives.

Parental Strain is an index of the level of stress experienced by parents as a consequence of the disease and its complications and impact on the lives of their children, as reflected in career or work limitations, physical complications of the disease itself, or concern about premature death or meeting their children's special needs (range = 0-5).

Note that with the exception of academic expectations and positive moods, high index scores indicate problems or difficulties for those domains.

RESULTS

SAMPLE CHARACTERISTICS

The median annual household income of SCD families was \$7,500 (in 1987 dollars). The distribution of annual family income was skewed negatively, with 122 (37%) reporting less than \$6,000, 81 (25%) reporting \$6,000 to \$13,000, 43 (13%) reporting \$13,000 to \$21,000, and 75 (23%) reporting more than \$21,000 per year. Although 50% ($n = 163$) had at least one family member employed at some level, 59% ($n = 192$) had incomes low enough to qualify for some form of public assistance such as Aid to Dependent Children, Social Security Disability, and Medicare to pay for food, shelter, and medical care. Even then, about 1 in every 4 families reported some unmet material needs. Interestingly, the proportions of people experiencing financial hardship were roughly equivalent across each of the income bands. Accordingly, some families with low incomes reported no unmet needs with respect to having access to the basic necessities of life such as adequate food, shelter, and clothing. On the other hand, families with annual incomes above \$17,000 per year indicated that they did not have enough money to meet all of their basic needs.

Most of the informants were mothers (96%). Only 3% of informants were fathers. The remaining informants were other guardians or patients who were not accompanied to their clinic appointments by parents or guardians. A total of 115 (35.3%) of the children lived in single-adult, female-headed households. With respect to marital status of the mothers, 40% were married, 40% were formerly married, and 20% were never married at the times of the interviews. The mean education levels were 12.0 years for mothers and 11.8 years for fathers. The family sizes were somewhat large by today's standards, with 47% having three or more children. With respect to family composition, 60 children (19%) had no siblings at all, 94 (29%) had one sibling, 85 (26%) had two siblings, and 38 (12%) had three or more siblings. Many families had more than 1 child with SCD. About 27% of patients reported having siblings with SCD. This means that more than 1 in 4 of our sample participants had not just one child but at least two with SCD.

When measured in terms of emergency room visits, the range of serious episodes was 0 to 20 episodes per year, with a mean of 4.3. About 28% ($n = 91$) children experienced no serious pain episodes at all, 21% experienced 1

episode, 21% experienced 2 episodes, 10% experienced 3 episodes, 9% experienced 4 episodes, 3% experienced 5 episodes, 3% experienced 6 episodes, and 5% experienced 7 to 20 episodes during the year. The mild group (28%) consisted of those who experienced no pain episodes serious enough for them to seek medical attention. The moderate group constituted about 42% of the sample, and approximately 30% fell into the severe group.

Chi-square analyses were computed to determine whether sociodemographic variables were related to the independent variables in ways that might compromise the interpretability of our test for the effects of financial need and severity. The financial status and illness severity groups had statistically similar numbers of males, females, children, and adolescents. This was true in spite of the fact that adolescents had a slightly higher mean number of pain episodes than did the younger children, $F(1, 179) = 5.0, p \leq .03$. The illness severity groups did not differ in family composition or source of income.

Two-way ANOVAs were computed to test the effects of illness severity and financial status. Table 1 presents the means and F values for the main effects of illness severity and financial status on the three indexes related to illness adjustment. Table 2 presents the means and F values for the main effects of these independent variables on the parental functioning variables. Table 3 presents the corresponding data and results for indexes of child adjustment. With the exception of social functioning and parental acceptance, the main effects for financial status all are significant. In general, the trend is that ill children and parents from families experiencing financial hardship reported more problems, more psychological symptoms, and more difficulty dealing with the illness than did the low- and high-income families who were not experiencing financial hardship. Illness severity was significant, but on fewer of the dependent measures than was the case with financial hardship.

INTERACTIONS OF FINANCIAL NEED AND ILLNESS SEVERITY

Interactions were not significant for any of the disease adjustment or child functioning variables. However, two-way interaction terms between financial status and illness severity were statistically significant on three measures of parental functioning: anger, $F(4, 174) = 3.7, p \leq .01$; anxiety, $F(4, 174) = 2.6, p \leq .05$; and academic expectations, $F(4, 174) = 2.5, p \leq .05$. In general, higher levels of financial hardship and illness severity resulted in higher levels of anger, higher levels of anxiety, and lower academic expectations. However, the orderly pattern of increasing problems with increasing economic

TABLE 1
Means and *F* Values for Illness Adjustment Measure by Financial Hardship and Illness Severity Groups

	<i>Total</i> (<i>N</i> = 227)	<i>Financial Status</i>			<i>F Value</i>	<i>Illness Severity</i>			<i>F Value</i>
		<i>Financial Hardship</i> (<i>n</i> = 81)	<i>Low Income, No Hardship</i> (<i>n</i> = 75)	<i>High Income, No Hardship</i> (<i>n</i> = 91)		<i>Mild</i> (<i>n</i> = 91)	<i>Moderate</i> (<i>n</i> = 135)	<i>Severe</i> (<i>n</i> = 90)	
Obstacles to medical care	1.67	1.74	2.55	1.24	61.5***	1.56	1.59	1.88	n.s.
Problem living with sickle cell disease	1.21	1.12	1.31	1.19	3.9*	1.09	1.21	1.32	5.4**
Sick role adoption	4.62	4.01	5.36	4.59	4.3**	4.96	4.61	4.32	n.s.

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

TABLE 2
Means and *F* Values for Parental Adjustment Measures by Financial Hardship and Illness Severity Groups

	<i>Total</i> (<i>N</i> = 227)	<i>Financial Status</i>			<i>F Value</i>	<i>Illness Severity</i>			<i>F Value</i>
		<i>Financial Hardship</i> (<i>n</i> = 81)	<i>Low Income, No Hardship</i> (<i>n</i> = 75)	<i>High Income, No Hardship</i> (<i>n</i> = 91)		<i>Mild</i> (<i>n</i> = 91)	<i>Moderate</i> (<i>n</i> = 135)	<i>Severe</i> (<i>n</i> = 90)	
Academic expectations	14.79	15.10	14.02	15.04	3.9*	14.92	14.80	14.60	n.s.
Depressive symptoms	9.45	9.56	9.93	9.17	3.7*	9.59	9.33	9.46	n.s.
Anger	1.37	1.42	1.58	1.25	5.8**	1.21	1.28	1.65	11.6***
Anxiety	4.88	4.75	5.34	4.74	8.0***	4.41	4.85	5.37	7.1***
Acceptance	3.63	3.65	3.72	3.57	n.s.	3.84	3.66	3.39	5.8**
Strain	2.08	2.03	2.25	2.02	1.4**	1.89	2.03	2.32	5.3***

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

TABLE 3
Means and *F* Values for Child Adjustment Measures by Financial Hardship and Illness Severity

	<i>Financial Status</i>				<i>F Value</i>	<i>Illness Severity</i>			<i>F Value</i>
	<i>Total</i> (<i>N</i> = 183)	<i>Financial Hardship</i> (<i>n</i> = 39)	<i>Low Income, No Hardship</i> (<i>n</i> = 51)	<i>High Income, No Hardship</i> (<i>n</i> = 98)		<i>Mild</i> (<i>n</i> = 63)	<i>Moderate</i> (<i>n</i> = 72)	<i>Severe</i> (<i>n</i> = 48)	
Anxiety	4.18	3.79	4.80	3.99	4.9**	3.98	4.03	4.67	n.s.
Depressive symptoms	5.16	4.74	5.80	4.98	3.6*	4.79	4.93	6.00	6.1**
Positive mood states	4.01	4.50	3.42	4.09	6.2**	3.62	4.30	4.08	3.8*
Social functioning	1.62	1.40	1.79	1.63	n.s.	1.60	1.50	1.82	n.s.
Academic functioning	1.27	1.24	1.57	1.16	7.0***	1.27	1.18	1.48	2.9*

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

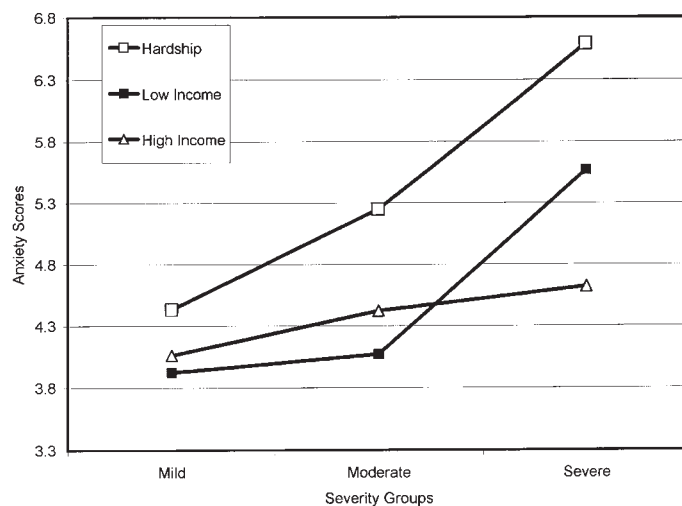


Figure 1: Mean Parent Anxiety Scores by Financial Status and Illness Severity

hardship and illness severity did not hold for the higher income parents. The high-income non-needy parents of children whose illness was only moderately severe had more difficulty with anxiety, anger, and strain than did parents whose children were asymptomatic or had frequent pain.

FINANCIAL STATUS AND ILLNESS MANAGEMENT

Planned comparisons show that financially needy families reported significantly more obstacles to care, $t = 16.8, p \leq .001$, more day-to-day problems in living with the illness, $t = 3.9, p \leq .05$, and more problems of sick role adoption by the ill children, $t = 4.1, p \leq .05$, than did families with adequate financial resources. A similar pattern is observed in comparing the two groups of families that did not experience economic hardship. The non-needy low-income families experienced significantly more obstacles to care, $t = 77.9, p \leq .001$, day-to-day problems living with the illness, $t = 5.9, p \leq .05$, and sick role adoption, $t = 6.0, p \leq .05$, than did the high-income families. Financial need is implicated in medical adjustment to a greater extent than is absolute income or SES. Although low-income non-needy families understandably reported more obstacles to medical care than did the moderate-income group, $t = 9.9, p \leq .01$, they did not differ significantly on sick role adoption and day-to-day problems with the illness.

**FINANCIAL STATUS AND PSYCHOSOCIAL
FUNCTIONING OF THE CHILDREN WITH SCD**

Children from needy families were described by their parents as having less positive moods, higher levels of anxiety and depressive symptoms, and poorer academic functioning compared to children from families that experienced no economic hardship. Moreover, the means show an orderly trend across the financial status groups such that the needy group showed the highest level of problems, followed by the low-income non-needy group, and then the high-income group. Comparison of group means reveals that children from economically disadvantaged families had more symptoms of depression, $t = 10.3, p \leq .01$, anxiety, $t = 8.6, p \leq .01$, less positive moods, $t = 12.4, p \leq .001$, and more problems in school, $t = 4.9, p \leq .05$, than did children in poor but non-needy families. Again, the pattern is the same when children from needy families are compared to children from moderate-income non-needy families. The children from needy families are higher in symptoms of depression, $t = 7.2, p \leq .01$, anxiety, $t = 9.9, p \leq .01$, positive moods, $t = 4.4, p \leq .05$, and academic problems, $t = 8.6, p \leq .05$, than are children in moderate-income families. Differences in psychological symptoms occurred with differences in financial need but not in income level per se. The two non-needy groups did not differ from one another on symptoms of anxiety or depression. However, the low-income group was significantly higher in positive mood than the moderate-income group, $t = 4.4, p \leq .05$.

**FINANCIAL STATUS AND
PARENTAL FUNCTIONING**

Parents from financially needy families evidenced higher levels of depressive symptoms, $t = 4.4, p \leq .05$, more frequent experience with anger, $t = 4.8, p \leq .05$, more strain, $t = 7.8, p \leq .01$, and more anxiety, $t = 18.5, p \leq .001$, than did the low-income non-needy group. Similarly, the financially needy group had higher levels of depressive symptoms, $t = 16.0, p \leq .001$, more strain, $t = 4.7, p \leq .05$, and more anxiety, $t = 18.5, p \leq .001$, than did the moderate-income group. Differences between the low- and high-income groups on parental strain and anxiety were not significant. There were no significant differences among the groups with respect to parental acceptance of the illness. However, there were significant differences in parental academic expectations of the ill children. Parents from needy families had lower academic expectations for their children than did parents from the two non-needy comparison groups.

ILLNESS SEVERITY AND ILLNESS MANAGEMENT

There were no significant differences among the mild, moderate, and severe groups in the number of obstacles encountered in seeking medical care or in sick role adoption. Predictably, those in the high-severity group behaved as though SCD were more of a problem in their daily lives to a significantly greater extent than did those in the mild-severity group, $t = 14.9, p \leq .001$, and moderate-severity group, $t = 6.3, p \leq .01$. The mild- and moderate-severity groups did not differ significantly. Interestingly, children with mild forms of the illness tended to be judged by their parents as adopting the sick role and using the illness as an excuse to avoid responsibilities to a significantly greater extent than did children in the moderate group, $t = 14.9, p \leq .001$, and severe group, $t = 6.3, p \leq .01$.

ILLNESS SEVERITY AND CHILD FUNCTIONING

No significant differences were found among the illness severity groups on measures of child functioning related to anxiety and social functioning. However, differences were found with respect to academic functioning, depression, and positive moods. With respect to depressive symptoms, children in the high-severity group evidenced depressive symptoms more frequently than did those in the moderate-severity group, $t = 4.0, p \leq .05$, and the low-severity group, $t = 4.1, p \leq .05$. The moderate- and low-severity groups did not differ significantly from one another. We obtained a very interesting and unexpected pattern on the ratings of positive moods among the three groups. The moderate-severity group was highest on positive moods but differed significantly only from the mild-severity group, $t = 3.8, p \leq .05$. Although there were no differences among the severity groups in parental academic expectations for their children, problems of academic functioning were greatest for children with more severe forms of illness. Children in the high-severity group had significantly greater problems in school than did children in the moderate-severity group, $t = 7.7, p \leq .01$, and the mild-severity group, $t = 4.7, p \leq .05$. The low- and moderate-severity groups did not differ significantly on academic problems.

ILLNESS SEVERITY AND PARENTAL FUNCTIONING

Disease severity also had a strong relationship to parental adjustment. Parents of children in the high-severity group reported significantly more strain, anxiety, and anger and less acceptance than did parents of children with mild

and moderate severity. In each of these cases, the high-severity group differed significantly from the mild- and moderate-severity groups, but the two non-hardship groups did not differ significantly from one another. With respect to depressive symptoms, no significant differences were found among parents whose children differed in illness severity.

EFFECTS OF OTHER DEMOGRAPHIC VARIABLES

Finally, one-way ANOVAs were computed to test competing explanations of differences in functioning. In spite of the preponderance of low-income families in the financially needy group, tests of the effects of income alone on the measures of adjustment revealed no significant differences among families of different income levels on parental and child functioning or on sick role adoption. We also examined the extent to which gender differences occurred in the measure of adjustment. Gender was unrelated to pain episodes, academic functioning, social adjustment, anxiety, depression, and age. However, gender was related to the extent to which the disease presented a day-to-day problem in the lives of children, $F(1, 309) = 4.6, p \leq .03$, and to the positive mood of the children, $F(1, 176) = 5.8, p \leq .02$. SCD presented a greater problem in daily living for girls than it did for boys, but at the same time, girls were significantly higher in parental ratings of positive mood than were boys. With respect to positive mood, boys received a mean rating of 3.71 compared to 4.29 for girls. The average age of children in a sample of boys was 8.9 years and of girls was 8.9 years. The average number of pain episodes for boys was 9.9 and for girls was 10.59. The mean rating of the extent to which sickle cell posed a problem for daily living for boys was 1.16 and for girls was 1.28. When comparisons were made among children of families drawn from the working poor and families supported principally by public assistance, no significant differences were found.

DISCUSSION

In general, this study confirms suspicions that adjustment problems reported by the families of children with sickle cell do not arise entirely from the illness and its sequelae. In fact, the effect of financial hardship on academic, psychological, and familial outcomes is striking. Financial hardship plays an unmistakable role in accounting for important psychological, academic, and social outcomes often attributed to SCD. At the same time, the results reconfirm the detrimental effects of illness on adjustment. Illness

severity is related both to parents' psychological functioning and to emotional and academic problems in the children. Even among poor families, biomedical factors cannot be discounted as significant contributors to the difficulties observed in their lives. The more severe the illness, the more serious the adjustment problems.

CUMULATIVE EFFECTS OF ILLNESS AND HARDSHIP

The effects of psychosocial risks associated with illness severity and poverty are cumulative. Financial hardship and frequent pain episodes combine to produce the highest levels of impairment across all domains. Thus, the poorest levels of disease adjustment and psychosocial functioning occurred for children and parents who experienced financial hardship and frequent pain episodes. These results suggest that the risks associated with poverty and illness are cumulative. The greater the financial hardship and the more frequent the pain, the greater the risk of psychosocial dysfunction.

Academic achievement is an area in which it is easy to understand how the effects of poverty reinforce or exacerbate the adverse effects of illness. School participation of children with SCD frequently is disrupted by pain episodes. Poor children also can be saddled from the beginning with low expectations of academic achievement. Children who are both poor and sick can suffer from even lower expectations of their success. Children from poor families generally reside in financially strapped school districts that might be less well staffed, equipped, and organized to respond to the attendance patterns and associated instructional needs of chronically ill children. School systems in poor neighborhood might take little note of, or not be concerned about, the regular absences of ill children. Teachers might be unlikely to question the need for extended absences and unable to make adaptations necessary to encourage and make possible active participation of the ill children in school.

DISTINCT EFFECTS OF ILLNESS AND POVERTY

Although financial hardship and illness severity both contribute to adverse outcomes, their effects are not identical. Comparisons of the relative effect sizes of illness severity and financial need reveal an interesting pattern. Surprisingly, illness severity exerts greater influence than financial hardship on parental functioning, but the opposite situation obtains for ill children in that financial hardship produces larger effects on children's behavioral, emotional, and social outcomes than does illness severity.

Interestingly, the impact of illness severity is most pronounced for high-income parents. Whereas the difference made by more severe illness is slight among low-income parents who do not report economic hardship, severe forms of SCD make a very big and negative difference with respect to the emotional well-being of high-income parents. Specifically, low-income non-needy parents did not show large increases in anger or anxiety and did not reduce their expectations for the academic achievement of their children as a consequence of illness severity. However, increasing severity led to much higher levels of anxiety and anger among high-income parents and contributed to lower expectations regarding the academic achievement of their ill children.

PSYCHOSOCIAL ADJUSTMENT AS A MULTIPLY DETERMINED PHENOMENON

It is clear that multiple factors in the lives of children and parents affect adjustment to SCD. If SCD were the only source of difficulty that these children and their families faced, then they would have more than enough to deal with already. Unfortunately, families of the children in our sample are confronted with a panoply of life stresses that are impossible to ignore because they so adversely affect well-being and the quality of family life. For example, poverty brings with it another layer of demands and exposes the children and families to a host of other community dangers and personal stresses such as crime victimization, ecological toxins, neighborhood violence, joblessness, poor schools, residential transience, and a lack of basic necessities. Many patients and their families continue to encounter obstacles to the acquisition of medical care. When parents lack the ability to provide for basic life necessities, children clearly have more difficulty emotionally and academically. These results also move us a step closer to explaining the considerable variation observed in the adjustment of individuals and families who share a condition such as SCD. This finding demonstrates the value of comprehensive psychosocial risk assessments in the design of programs intended to promote adjustment to SCD.

SUBJECTIVE VERSUS OBJECTIVE MEASUREMENT OF POVERTY

Whereas reported income is not consistently related to adjustment problems, financial need is. What is most interesting about this finding is that it is at odds with the conventional wisdom in the social sciences. This suggests

that efforts to gauge financial distress by using annual income alone or some index of SES might miss the mark with respect to evaluating adjustment difficulties related to financial need and poverty. These results have important implications for ways to measure poverty for the purposes of behavioral research. When poverty is defined in terms of persistent inability to acquire basic life necessities such as food, shelter, medical care, and transportation, we find a strong relationship between poverty and psychosocial functioning of the children and families. This relationship is not as clearly discernible when annual family income alone is used as the criterion. Moreover, we assessed financial need this way in a situation where there was no direct incentive for distorting the information and where the interview staff had long-term ongoing relationships with respondents, which likely minimized over- and underexaggeration of need. When these circumstances exist, measuring financial status in terms of ability to acquire specific basic life necessities provides superior information compared to annual income alone. Importantly, this suggests that poverty and its psychosocial effects occur not only among those whose incomes happen to fall within the government's poverty guidelines.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

Clearly, the dual burden of financial need and illness makes children from poor families a high-risk group for whom special attention is warranted to minimize the adverse outcomes. Ill children in financially distressed families have more problems in academic and psychological domains than do children whose families are able to provide for necessities. Therefore, concern about persons with SCD cannot be restricted to their physical health; it also must extend to a host of problems observed in the psychological, social, academic, and family arenas. Moreover, their parents are highly susceptible to the strain of caring for ill children with inadequate resources. Given the importance of education for long-term psychological and financial well-being, this is an ominous sign for what the future holds for chronically ill children. The data presented here suggest that many of the most seriously ill children might survive to live nonproductive adult lives of dependence. Poverty and illness in children make a lethal combination. Our data suggest that each of these ingredients has the potential for posing considerable impediments to the healthy development of children. Each has its independent effects, but together they make a powerful brew requiring considerable personal and social resources to overcome the impediments. The wide array of problems

associated with financial need and inadequate resources makes a convincing case for action. The price of neglect is the unnecessary loss of a generation of ill children who might live to be a burden because of their dependence.

Academic and social problems are among the most consistently observed and intractable problems. In light of the low academic expectations of children with SCD, under the guise of sympathetic adaptation, some school administrators relegate ill children to the limited instruction available through a weekly homebound teaching program rather than insist on the full instructional program that the children would receive by attending regular school. But what can be done? Extending the school year to compensate for school absences, setting high performance expectations, expanding the use of tutors, and implementing after-school enrichment activities all are better approaches to the academic problems faced by children with SCD. Clearly, the resolve to act must be informed by intervention research to find ways in which to prevent and ameliorate these problems.

Collaboration among physicians, nurses, social workers, and psychologists is essential to the development of coping strategies that promote a positive adaptation to illness. In light of the present study, it is especially important to minimize pain episodes and avoid the adoption of a stance toward life in which children with SCD and families surrender the possibility of a somewhat normal life. This study also demonstrates the protective benefits of ensuring that the basic needs of children and their families are met, benefits that accrue not only to children and their families but also to society in general. When adequate nutrition, shelter, clothing, and safety are available, the psychological, social, and academic consequences of SCD are not nearly as devastating for children, who can then become independent and productive as adults. There can be no stronger rationale for medical care providers and community groups to advocate for an adequate social safety net for children and their families.

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