Child-Rearing Practices of Primary Caregivers of Children With Sickle Cell Disease: The Perspective of Professionals and Caregivers

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Objective: To obtain caregiver and medical professional opinions regarding the child-rearing practices of caregivers of children with sickle cell diseases (SCD).

Methods: We obtained self-reports of parenting practices from 48 caregivers of children with SCD and 48 caregivers of matched classroom comparison peers using the Child-Rearing Practices Report (CRPR). CRPR ratings were also obtained from 12 experts in pediatric SCD regarding their predictions of how a parent of a child with SCD would respond. The experts predicted differences in protectiveness, discipline, and excessive worry. Objective interim and lifetime illness severity scores were obtained for the children with SCD.

Results: Caregivers showed similarity between the two groups, disagreement with the experts, and minimal relationship to illness severity.

Conclusions: Experts who work with children with chronic illnesses such as SCD seem to have stereotyped ideas that do not correspond with parental reports of their child-rearing practices, suggesting the need for careful clinical evaluations.

Key words: child-rearing practices; sickle cell disease.
nances, work, transportation, and changes to daily routines (Whitten & Fischoff, 1974). Additional research has suggested that mothers of children with SCD are at risk for excessive anxiety, depressed mood, guilt, social isolation, and personal health problems (Brown, Kaslow, Doepke, Buchanan, Eckman, Baldwin, & Goonan, 1993; Burlew, Evans, & Oler, 1989; Evans, Burlew, & Oler, 1988; Williams, Earles, & Pack, 1983). Current theory in pediatric psychology utilizing disability-stress-coping models is congruent with these empirical data (Thompson, Gil, Burbach, Keith, & Kinney, 1993; Wallander, Varni, Babani, Banis, & Wilcox, 1989).

Primary caregivers of children with SCD are described as excessively worried, overprotective, and unable to discipline effectively (Eiser, 1985; Nevergold, 1987; Vavasseur, 1987; Williams et al., 1983). This is thought to be especially troublesome for single parents of children with SCD (Evans et al., 1988). Difficulties with child-rearing can also occur if parents feel guilty about having caused their child's illness or if parents feel sorry for their chronically ill child (Burlew et al., 1989; Nevergold, 1987; Williams et al., 1983). Learning more about these issues for African American families seems especially important, since the impact of a chronic illness on child-rearing practices will clearly be influenced by minority status (Jones, 1991) and the high value placed upon independence by the African American community (Willis, 1994).

It should be noted that while the literature consistently identifies difficulties with child-rearing for parents who have a child with SCD, there are severe methodological shortcomings including reliance on clinical impressions, lack of appropriate comparison groups, use of nonstandardized instruments, small sample sizes, and a failure to examine the role of disease severity. One recent investigation has suggested that parents of children with SCD may not have as many difficulties with parenting as previously indicated. Armstrong, Lemanek, Pegelow, Gonzalez, and Martinez (1993) reported that parents of preschool children with SCD did not differ from parents of comparison children in knowledge of discipline methods. Further, these parents were observed to treat their children more competently and utilize more reinforcement to control behavior (Schuman, Armstrong, Pegelow, & Routh, 1993).

The current project had three aims. The first was to examine the clinical perceptions of professionals who work with families who have children with SCD. It was hypothesized that professionals who provide care for children with SCD would report that caregivers of children with SCD worried excessively, were overprotective, and were unable to discipline effectively. The second was to examine self-reported child-rearing practices of parents who have school-age children with SCD. Using methodology adapted from research on child-rearing practices of parents who have children with cancer (Davies, Noll, DeStefano, Bukowski, & Kulkarni, 1991), we compared responses of primary caregivers of children with SCD to responses by primary caregivers of matched classroom comparison peers (MCCP) without a chronic illness. We hypothesized that the specific child-rearing concerns selected by the professionals would differentiate the child-rearing practices of the two groups of caregivers. The third was to examine the relationships between child-rearing practices and disease severity. We hypothesized that the specific child-rearing concerns selected by the professionals would be more descriptive of caregivers with children who had more severe disease.

**Method**

This work is part of a larger ongoing longitudinal study comparing the functioning of children with chronic illness (e.g., cancer, hemophilia, juvenile rheumatoid arthritis, SCD, migraine headache), their parents, and family life, to matched comparison children and their families (Noll, Gartstein, Hawkins, Vannatta, Davies, & Bukowski, 1994; Noll, Swiecki, Gartstein, Vannatta, Kalinyak, Davies, & Bukowski, 1995; Noll, Vannatta, Koontz, Kalinyak, Bukowski, & Davies, 1996).

**Participants**

*Children With SCD*. Children with SCD were recruited from clinic rosters that listed all patients receiving treatment at Children's Hospital Medical Center (CHMC) in Cincinnati, Ohio. Because CHMC is the only facility in the study area with board-certified pediatric hematologists, nearly every child with SCD in the catchment area receives treatment at this facility. Inclusion criteria were (a) 8 to 15 years of age, (b) no full-time special education, and (c) no history of a cerebrovascular incident. Two children were excluded by criteria (b) and none by (c). Fifty-two children with SCD met the eligibility criteria; however, two families could not be lo-
cated and two declined to participate. Twenty-five of the 48 children had either Hgb SS or Hgb Sβ thal, and the others had either Hgb SC or Hgb Sβ+ thal (n = 23). All children who met inclusion criteria were African American.

MCNP. Using a case-by-case matching procedure, each youth with SCD was paired with a classmate who was the same gender and race and closest in date of birth. Children were matched on these variables to ensure that target status (i.e., SCD) was not confounded with multiple economic, social, or cultural factors. To accomplish this matching, a class roster was constructed that included the name, gender, race, and date of birth of all children in the classroom of the child with SCD. The family of the same race and gender youth whose birthday was closest to the child with SCD was contacted first. Although our two groups of families were selected on the basis of child factors (same classroom/race/gender, closest date of birth), our experience with this technique has consistently been that families/parents are matched on numerous demographic variables (Noll, Gartstein, et al., 1995; Noll, Swiecki, et al., 1994). During this contact by phone, screening was done to ensure that the potential comparison family did not have a child with a chronic illness. For the purpose of this study, chronic illness was defined as a medical condition that required (a) repeated visits to the doctor, (b) care by a pediatric subspecialist, (c) repeated hospitalizations, or (d) restriction of the child’s daily activities. If the first family contacted chose not to participate or did not meet inclusion criteria, the family of the child with the next closest date of birth was contacted. For 41 of 48 (85%) potential comparison families, the first family contacted agreed to participate in the project. The final sample consisted of 17 males and 31 females in each group.

Medical Professionals. Twelve medical professionals in pediatric hematology (six African American, six Caucasian) were recruited for the present study. These professionals had a minimum of two years clinical experience working directly with children who have SCD (M = 10.4 years; SD = 10.3; range: 2–38 years). To ensure the generalizability of their input, we recruited professionals from both varied disciplines and multiple treatment centers. Recruitment took place at a national sickle cell meeting. All professionals who were initially contacted agreed to participate in the project. The group consisted of three physicians, two clinical psychologists, two nurses, four social workers, and one sociologist.

Measures

Demographic Background Questionnaire. This instrument assesses basic background characteristics of the adults (i.e., the child’s primary caregivers) who complete the measure. Adequate data are available to ascertain the SES of each family with the Revised Duncan (TSEI2; Nakao & Treas, 1992), an occupation-based measure of SES. This measure was selected as a result of work by sociologists suggesting that occupation-based measures represent a contemporary indicator of SES (Hauser, 1994).

Child-Rearing Practices Report (CRPR). The CRPR (Block, 1980) was selected from among several parenting instruments (e.g., Parenting Stress Index, Family Experiences Questionnaire) by members of the research team with extensive experience in pediatric chronic illness. Their decision reflected a judgment that this instrument contained more items directly relevant, especially overprotection, excessive worrying, and difficulties with discipline.

The CRPR is a 91-item measure for assessing values, attitudes, and goals of parents about child-rearing. Each CRPR item is written on a card. Participants are required to sort the cards into a fixed, seven-category, rectangular distribution of 13 items per category. The seven categories are labeled most descriptive or most like you (7), very descriptive (6), somewhat descriptive (5), neither descriptive nor undescrptive (4), somewhat undescrptive (3), very undescrptive (2), and most undescrptive or least like you (1). Higher or lower scores are not indicative of problematic discipline approaches, but the respondent’s placement of the card into one of seven categories. This forced-choice procedure minimizes the potential for obtaining socially desirable responses, which is a weakness of most self-report parenting measures.

The CRPR has been used longitudinally to examine the stability of parental child-rearing attitudes across time (McNally, Eisenberg, & Harris, 1991; Roberts, Block, & Block, 1984). It has been used to examine the relationship between parent-reported child-rearing practices during early childhood with adolescent self-esteem, intelligence, aspects of moral judgment, ego-control and resiliency (Vaughn, Block, & Block, 1988); and adolescent drug use (Block, Block, & Keyes, 1988). It has also been used cross-sectionally to examine child-rearing attitudes in physically abusive families (Susman, Trickett, Iannotti, Hollenbeck, & Zahn-
Waxler, 1985; Trickett & Susman, 1988); families with depressed parents (Stoneman, Brody, & Burke, 1989; Susman et al., 1985); and families with children who have cancer (Davies et al., 1991). In addition, considerable coherence has been found between self-report descriptions provided by mothers and observed parenting behaviors recorded independently (Block, 1980; Kochanska, Kuczynski, & Radke-Yarrow, 1989). Across a broad variety of populations and cultures, including Chinese American (Lin & Fu, 1990), African American (Durrett, O’Bryant, & Pennebaker, 1975; Susman et al., 1985), and Mexican American (Durrett et al., 1975), investigations using the CRPR support the sensitivity of this measure to evaluate current child-rearing practices and the ability of the CRPR to predict future adaptations of children.

The majority of research utilizing the CRPR has made use of the factor-analytically derived scales included in the manual for the instrument (Block, 1980). These factors have not been used in this study because (1) Block (1980) cautioned that these factors should not be used beyond the sample from which they were derived; (2) some work (Davies et al., 1991) has shown that the original factor structure does not replicate in other populations; and (3) the present study did not include sufficient subjects to investigate the factor structure for this sample. For these reasons, it was decided that expert predictions of individual items could be used, as in previous work with this methodology (Block & Gjerde, 1986; Davies et al., 1991). For this research, the procedure involved obtaining expert opinions regarding specific CRPR items that were distinctive of the child-rearing practices of parents of children with SCD and then determining whether the items selected by the experts actually differentiate between the groups of parents.

**Illness Severity.** Rather than utilize a large number of indicators of disease severity, meticulous chart reviews were completed by the medical director of the pediatric sickle cell clinic (KK, a board-certified pediatric hematologist) to develop interim and lifetime disease severity scores, thus permitting examination of proximal measures of illness severity (past six months) and chronic difficulties (lifetime) (Cameron, Christian, Lobel, & Gaston, 1983). Our analytic strategy was to utilize two indicators of illness severity initially so that the number of comparisons was minimized. If significant effects were detected between either of our global indicators of illness severity and the psychological measures, subsequent analyses would be conducted to determine the specific components of disease severity that were contributing to the significant effect.

These chart reviews provide a detailed and comprehensive assessment of the child’s medical condition since this medical center is the only inpatient pediatric facility in the region. These objective indices of disease severity have been shown to correspond to medical provider perceptions of disease severity in children with SCD (Cameron et al., 1983). Lifetime severity indices were based upon age of first SCD symptom; number of hospitalizations per year for SCD; average number of sequestration, aplastic, or vaso-occlusive episodes per month; major organ involvement (e.g., renal, priapism, stroke); the occurrence of major infections (e.g., sepsis, osteomyelitis); amount of growth delay; and so on. Six-month severity scores were based upon the occurrence of specific symptoms during a specific six-month interval such as number of hospitalizations for SCD; number of pain episodes; number of SCD complications (e.g., sequestration, aplasia); major organ involvement (e.g., renal, stroke, priapism); and so on.

The mean interim severity for the youth with Hgb SS or Hgb Sβthal was 4.43 (SD = 2.7); for youth with Hgb SC or Hgb Sβ+thal it was 2.78 (SD = 2.1), t(1, 39) = 7.65, p < .001. Lifetime severity scores were 10.25 (SD = 3.1) for the former group, and 4.14 (SD = 2.06) for the second group, t(1, 43) = 4.14, p < .001. While some earlier work has attempted to link estimates of illness severity to the psychological functioning (i.e., Brown et al., 1993), this work does not include a systematic review of the child’s entire medical history to develop reliable and valid indices of illness severity. Insofar as SCD is related to child-rearing practices, a disease severity effect might be anticipated.

**Procedures**

Due to the specific nature of the question asked of the professionals in this study, the CRPR was not given to them as a Q-sort. They were given the 91 CRPR items as a questionnaire with the following instructions: “Please indicate which items you feel strongly that parents of children with SCD would be more or less likely to endorse than parents of children without SCD. Items that you do believe will differentiate parents of children with SCD from controls are to be left blank.”

Each participating family completed numerous questionnaires and interviews during a 3-4-hour data collection session in the family home (Noll,
Table 1. Self-Reported Child-Rearing Practices of Primary Caregivers of Children With SCD (n = 48) and MCCP (n = 48) on 15 Items Selected by Expert Consensus

<table>
<thead>
<tr>
<th>CRPR Item</th>
<th>Sickle Cell Mean</th>
<th>SD</th>
<th>MCCP Mean</th>
<th>SD</th>
<th>t(1,94)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Protectiveness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tend to spoil child</td>
<td>4.25</td>
<td>1.82</td>
<td>3.92</td>
<td>1.90</td>
<td>0.88</td>
</tr>
<tr>
<td>Let child make decisions by self*</td>
<td>3.96</td>
<td>1.68</td>
<td>4.00</td>
<td>1.58</td>
<td>0.13</td>
</tr>
<tr>
<td>Give up own interests for child</td>
<td>4.33</td>
<td>1.72</td>
<td>4.33</td>
<td>1.77</td>
<td>0.00</td>
</tr>
<tr>
<td>Help child when being teased</td>
<td>4.10</td>
<td>1.76</td>
<td>4.48</td>
<td>1.53</td>
<td>-1.11</td>
</tr>
<tr>
<td>Expect child to handle trouble by self*</td>
<td>2.17</td>
<td>1.55</td>
<td>2.73</td>
<td>1.59</td>
<td>-1.75</td>
</tr>
<tr>
<td>Give child comfort when upset</td>
<td>6.06</td>
<td>1.31</td>
<td>6.15</td>
<td>1.30</td>
<td>-0.31</td>
</tr>
<tr>
<td>Let child take many chances*</td>
<td>5.27</td>
<td>1.53</td>
<td>5.21</td>
<td>1.56</td>
<td>0.20</td>
</tr>
<tr>
<td>Stop child from playing rough games</td>
<td>3.92</td>
<td>1.66</td>
<td>3.65</td>
<td>1.72</td>
<td>0.78</td>
</tr>
<tr>
<td><strong>Discipline</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficult to punish child</td>
<td>2.96</td>
<td>1.81</td>
<td>2.98</td>
<td>1.39</td>
<td>-0.06</td>
</tr>
<tr>
<td>Give child many duties/responsibilities*</td>
<td>4.06</td>
<td>1.76</td>
<td>4.42</td>
<td>1.77</td>
<td>-0.98</td>
</tr>
<tr>
<td><strong>Concern/worry</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worry about health of child</td>
<td>5.85</td>
<td>1.66</td>
<td>4.73</td>
<td>1.69</td>
<td>3.29***</td>
</tr>
<tr>
<td>Feel too Involved with child</td>
<td>2.46</td>
<td>1.46</td>
<td>3.00</td>
<td>1.82</td>
<td>-1.61</td>
</tr>
<tr>
<td>Watch closely what child eats</td>
<td>4.10</td>
<td>1.52</td>
<td>4.27</td>
<td>1.63</td>
<td>-0.52</td>
</tr>
<tr>
<td>Don't want child seen as different</td>
<td>5.13</td>
<td>1.65</td>
<td>3.81</td>
<td>1.79</td>
<td>3.74***</td>
</tr>
<tr>
<td>Worry about bad/sad things that can happen to my child</td>
<td>4.54</td>
<td>1.65</td>
<td>4.94</td>
<td>1.77</td>
<td>-1.13</td>
</tr>
</tbody>
</table>

*CRPR items are sorted into 7 stacks of 13 cards each. Values assigned to each pile of cards range from 1 to 7, where 1 = least descriptive of parent's beliefs; 7 = most descriptive of parent's beliefs.
*Items keyed in negative direction (i.e., professionals believe these items are unlike the parents of children with SCD).
*Item selected by unanimous consensus of professionals.
***p < .001, 1-tailed tests.

Results

Professional Ratings

Agreement by 8 of the 12 professionals was used as the criterion for determining that an item was seen as critical by this group. This criterion was chosen to ensure that these items were nearly unanimously endorsed. Examination of results using criteria of 7/12 and 9/12 revealed small changes in the number of items but no substantive change in the domains of consensus. Overall, there was marked agreement among the professionals. For 64 of 91 (70.3%) CRPR items, 8 of 12 professionals agreed on whether the item would discriminate the child-rearing practices of parents who have a child with SCD from those of parents of comparison children. These 64 CRPR items contained two groups: (1) 15 items expected to discriminate (Table I); and (2) 49 items expected not to discriminate (e.g., items such as "I express affection by hugging, kissing, and holding my child" or "I encourage my child always to do her best"). The 15 CRPR items that were anticipated to differentiate parents of children with SCD involved three parenting domains: (1) protectiveness (eight items), (2) parental concern or worry (five items), and (3) discipline (two items). These results provide strong support for our first hypothesis.

Parent Reports

Demographic Information. Information is reported for primary caregivers only, because only 26 of 96 families (13 SCD; 13 MCCP) had two adult caregivers living in the home. The term "primary care-
### Background Characteristics of Families of Children With SCD (n = 48) and Families of Matched Classroom Comparison Peers (n = 48)

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Sickle Cell</th>
<th></th>
<th>MCCP</th>
<th></th>
<th>t(1,94)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>25.20</td>
<td>15.32</td>
<td>25.31</td>
<td>16.50</td>
<td>-0.04</td>
</tr>
<tr>
<td>SD</td>
<td>17.16</td>
<td>15.01</td>
<td>19.84</td>
<td>19.51</td>
<td>-0.76</td>
</tr>
<tr>
<td>Income per person</td>
<td>4.50</td>
<td>3.58</td>
<td>4.85</td>
<td>4.58</td>
<td>-0.42</td>
</tr>
<tr>
<td>Age of target child</td>
<td>13.20</td>
<td>1.55</td>
<td>13.00</td>
<td>1.63</td>
<td>0.62</td>
</tr>
<tr>
<td>Age of primary caregiver</td>
<td>38.03</td>
<td>6.98</td>
<td>39.17</td>
<td>6.46</td>
<td>-1.05</td>
</tr>
<tr>
<td>Years of education of primary caregiver</td>
<td>12.69</td>
<td>2.17</td>
<td>12.98</td>
<td>2.20</td>
<td>-0.66</td>
</tr>
<tr>
<td>Number of children living at home</td>
<td>2.65</td>
<td>1.39</td>
<td>2.81</td>
<td>1.08</td>
<td>-0.65</td>
</tr>
<tr>
<td>Number of two-parent households</td>
<td>13 (27%)</td>
<td></td>
<td>13 (27%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Revised Duncan Socioeconomic Index (Nakao & Treas, 1992).

**In thousands of dollars.

Represents the average Income per person living in the household supported by the family's gross income, in thousands of dollars.

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giver” is used instead of “mother” because several children were being reared by adults other than their biological mother. No significant differences were found between the two groups of families (Table II), despite the fact that selection was based entirely on same classroom at school, same race/ gender, and closest date of birth for the children. The mean Duncan SES index for these groups of families suggests occupations such as laborers, food handlers, domestics, orderlies, etc.

**Child-Rearing Practices.** One-tailed univariate t tests were used to compare the families on the 15 CRPR items selected by the professionals and used as our hypotheses. To preclude the possibility of Type 1 error, we used Holm’s procedure (Holm, 1979). This is a variation of the Bonferroni procedure that yields increased power while simultaneously constraining Type 1 error probability, but at the expense of increased complexity of implementation (see Holland & Copenhaver, 1989, for a discussion of improved Bonferroni-type multiple testing procedures). Significant differences were obtained for two of the 15 hypotheses (Table I): (1) “I worry about the health of my child,” and (2) “I don’t want my child to be looked upon as different from others.” There were no significant differences between the two groups of caregivers for the remaining 13 hypotheses. It should be noted that our correction for multiple statistical tests did not change any significant results. These findings do not support our second hypotheses.

**Illness Severity and Child-Rearing Practices.** The two illness severity scores were correlated with the caregiver ratings of the 15 CRPR items (30 correlations). Higher interim severity correlated with the caregiver stating that allowing the child to make decisions for himself/herself is more descriptive of their child-rearing practices ($r = .33, p < .05$), however, this was in the opposite direction predicted by the professionals. Greater lifetime severity correlated with the caregiver stating that not wanting their child to be seen as different from others ($r = .37, p < .05$) was more descriptive of their child-rearing practices, and this was in the direction predicted by the professionals. The average correlation between interim severity and the 15 CRPR items was .11 (SD = .14); for lifetime severity it was .09 (SD = .14), suggesting that illness severity was generally not related to the CRPR parental ratings. These findings do not support our third hypothesis.

**Discussion**

The 15 CRPR items selected suggested that the group of professionals who care for children with SCD perceives these parents as (a) more protective, (b) more worried, and (c) less effective with discipline. These findings are consistent with clinical reports (Eiser, 1985; Nevergold, 1987; Vavasseur, 1987; Williams et al., 1983). In addition, these results are strikingly similar to results from an analogous study of professionals who care for children with cancer. Davies et al. (1991) used the CRPR and questioned a group of professionals who care for children with cancer regarding the child-rearing practices of parents who have a child with cancer. Results suggested that professionals who work with parents of children with cancer perceive them as having difficulties in the same three domains. In the Davies study, the professionals who work with families of children with cancer chose 11 CRPR
cancer did not endorse this item more often in the current study (or the Davies et al., 1991 study) asked whether we were interested in fathers or mothers, illness severity, or the child's gender or age.

Two of the 15 CRPR items selected by the experts showed significant differences between the primary caregivers of children with SCD and the MCCP. First, primary caregivers of children with SCD reported more worry about the health of their children. This is the only CRPR item that deals directly with the child's health. Children with SCD commonly endure numerous physical sequelae from their disease. It is not surprising that parents of children with SCD report greater worry about their children's health.

Second, caregivers of children with SCD also indicated that they do not want their child to be seen as different from others, and this was related to lifetime disease severity. Parents of children with cancer did not endorse this item more often in the Davies et al. report. This attitude by caregivers of children with SCD may reflect the reality for poor inner-city Black families with external systems constantly impinging upon them (Hines & Boyd-Franklin, 1982), which results in a strong desire to keep personal information private. The perceived extra burden of SCD for a Black child by parents who have experienced institutional biases of American society may result in strong positive attitudes ("healthy cultural paranoia") towards protective privacy (Baker, 1988). Because children with SCD must deal with a majority White culture with a history of negative interactions based upon skin color (Baker, 1988; Jones, 1991), parents may believe that SCD will be one more reason for prejudice. Similarly, given the high value placed upon independence and empowerment by the African American community (Willis, 1994), it is feasible that parents believe if their child is seen as different because of a chronic condition, life will be even more difficult.

In general, there was little support for the hypotheses developed from the opinions of the professionals and minimal evidence for a relationship between illness severity and child-rearing practices. The caregivers' self-reported child-rearing practices suggested few significant differences. Although these findings suggest that some changes in child-rearing concerns may be associated with SCD (e.g., parents worry more about their child's health), global changes in parenting practices were not found. To explore the possibility that other areas of differences occurred between these two groups, independent group t tests (two-tailed) were conducted on the remaining 76 CRPR items. Only 2 of 76 t tests showed statistically significant (p < .05) group differences; this is well below the number to be expected due to chance alone.

There are several potential explanations for these findings. First, we did not administer the CRPR as a Q-sort to the professionals. It is possible that this variation of procedures resulted in an unusual set of responses or that the CRPR is not valid for use with medical professionals. This seems unlikely when one considers the marked similarity among professional opinions in existing clinical literature on SCD, the Davies et al. (1991) study of families who have children with cancer, and the nature of the professionals' responses.

Second, the professionals may be correct in their perceptions of the caregivers' behaviors, but caregivers are unaware of their true behavior. If the professionals' perceptions are correct, then one must ask why caregivers are unaware of their behavior. Perhaps the caregivers' desire for their children not to be different also pertains to their own behaviors, including child-rearing practices. This would suggest that there may be differences in child-rearing practices between the groups of caregivers, but another methodology such as observational studies may be required to detect these differences.

Third, changes in child-rearing practices may occur during intense disease episodes that require...
clinic visits or hospitalizations (e.g., during a pain crisis). These temporary changes may not generalize to periods when the child is feeling well. Because most professionals who work with children with SCD interact with these families in an atypical setting for the family (clinic or hospital), it is conceivable that the professionals perceive caregivers' behaviors in these settings as representative of their day-to-day functioning. If this is the case, it may be helpful to implement some type of educational program for professionals emphasizing differences between parents' daily behaviors and those exhibited during more stressful periods such as clinic visits or hospitalizations.

Although the findings from the current study are inconsistent both with the existing clinical literature describing caregivers of children with SCD and the predictions of the professionals, the data are similar to those of empirical studies of families of children with other chronic illnesses and recent work reported regarding preschool children with SCD (Armstrong et al., 1993; Schuman et al., 1993). Studies that use matched comparison families and standardized measures have shown few differences between the child-rearing attitudes of parents of children with cancer (Davies et al., 1991), cystic fibrosis (Walker, Ford, & Donald, 1987), and hemophilia (Markova, MacDonald, & Forbes, 1980). These null findings re-emphasize the necessity of conducting controlled research in order to eliminate potential confounds that may significantly affect a study's outcome. Results from the present study, in conjunction with empirical findings from more rigorous studies of other chronic illnesses, suggest a need to re-evaluate the commonly held beliefs of professionals regarding the effects of chronic illness on child-rearing practices. Our findings do not confirm an association between chronic illness in the child and higher levels of difficulty as predicted by disability-stress-coping models (Thompson et al., 1993; Wallander et al., 1989).

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References


Parenting of Children With Sickle Cell Disease


