Daily Coping Practice Predicts Treatment Effects in Children With Sickle Cell Disease

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Objective: To examine the 1-month effects of a pain coping skills intervention in children with sickle cell disease (SCD).

Methods: Forty-six African American children (8–17 years old) were randomly assigned to either a coping skills condition or a standard care control condition. Children were asked to practice daily with audiotaped instructions of skills (e.g., relaxation, imagery).

Results: Multivariate analyses of summary measures indicated that children in the coping intervention (versus control group) reported a significantly more active approach to managing pain. Multilevel random effects models applied to daily diary data indicated that on pain days when children practiced their strategies, they had fewer health care contacts, fewer school absences, and less interference with household activities than on days when they did not practice.

Conclusions: Brief training in coping skills followed by minimal therapist contact may lead to a range of benefits when children practice with their skills on a consistent basis.

Key words: sickle cell disease; daily pain diaries; coping skills training; pediatric pain.

Growing empirical support indicates that cognitive-behavioral interventions are efficacious in the treatment of disease-related pain in adults (Compas, Haaga, Keefe, Leitenberg, & Williams, 1998; Wilson & Gil, 1996). However, psychological intervention research focused on disease-related pain in children is quite limited (Walco, Sterling, Conte, & Engel, 1999). This is especially true for sickle cell disease (SCD) pain.

Recurrent pain from SCD can result in frequent and costly health care contacts, repeated school absences, and reduced physical and social activity in children (Brown, Doepke, & Kaslow, 1993; Gil, 1989; Gil, Porter, et al., 2000). Many children with SCD experience depression, anxiety, or peer and interpersonal problems due in part to their pain (Gil, 1989; Thompson, Gil, Burbach, Keith, & Kinney, 1993). Results from our prior studies indicate that coping strategies explained significant portions of the variance in pain report and psychosocial and functional adjustment in patients with SCD, even after controlling for demographics and disease severity (Gil, Abrams, Phillips, & Keefe, 1989; Gil, Ab-
rants, Phillips, & Williams, 1992; Gil, Williams, Thompson, & Kinney, 1991; Gil et al., 1993; Gil et al., 1995; Gil, Edens, et al., 1997). Specifically, we have found that children who reported using multiple cognitive and behavioral attempts to deal with pain had fewer emergency room visits and were more active during painful episodes. Children who were more passive in their approach had more health care contacts and were less active. Children who reported frequent negative thoughts during pain episodes had more symptoms of depression and anxiety. Furthermore, longitudinal assessment studies have revealed that, without intervention, coping strategies were relatively stable over time for adults. Similar longitudinal assessment studies in children, however, have indicated that coping strategies are less stable over time and, thus, possibly amenable to change (Gil, Wilson, & Edens, 1997), suggesting potentially beneficial results from early interventions.

We developed a coping skills intervention for patients with SCD based on these findings (Gil et al., 1996; Gil, Wilson, Edens, Workman, et al., 1997). In the first study evaluating the efficacy of the coping intervention, adults in the intervention group learned coping strategies, through modeling and practice, including breathing relaxation, imagery, calming self-statements, and distraction techniques. Individuals were provided with audiotaped instructions of the techniques and an assignment to practice daily with the strategies. At posttreatment (Gil et al., 1996), we found that, in comparison to the randomly assigned control condition, brief training in coping skills resulted in increased coping attempts, decreased negative thinking, and lower tendency to report pain during laboratory-induced noxious stimulation. Moreover, follow-up data indicated that daily practice with coping skills was directly related to clinical improvements. Specifically, on pain days when participants practiced their strategies, they had fewer major health care contacts than on days when they did not utilize the coping strategies (Gil, Carson, et al., 2000).

In the first intervention study with children, adolescents, and their parents (Gil, Wilson, Edens, Workman, et al., 1997), children and adolescents were randomly assigned to either brief coping skills training or a standard care control condition without coping training. In the published article of the postintervention results (Gil, Wilson, Edens, Workman, et al., 1997), we reported on changes that occurred immediately after completion of the intervention. We found that, in comparison to the control condition, brief training in coping skills resulted in decreased negative thinking and lower pain during low intensity laboratory pain stimulation. However, we did not report on the postintervention clinical status measures (e.g., depression, school activities, health care use) in that first study, primarily because changes in clinical measures could not be meaningfully evaluated within the study time frame (2 to 3 weeks).

The purpose of this study was to evaluate the 1-month follow-up effects of the intervention. During the month after initial training sessions, children were given an assignment to continue to practice their coping skills daily using audiotaped instructions of the skills. Minimal therapist contact was maintained through weekly telephone contact. We hypothesized that children trained in coping skills would be significantly improved on clinical measures as compared to children from a standard care control condition. Moreover, we hypothesized that, when children practiced with their skills more consistently, they would realize greater clinical benefits (e.g., lower daily pain, more activity, fewer health care contacts).

Data from two sources were analyzed to evaluate treatment outcome. Global summary measurements of pain sensitivity, coping strategies, activities, health care use, and psychological distress were repeated at the 1-month follow-up evaluation. In addition, children completed daily prospective diaries of pain, health care contacts, medication use, and activity reduction over the course of the intervention and 1-month follow-up period. We used multilevel random effects models to analyze the diary data (Schwartz & Stone, 1998). Multilevel analyses offer several advantages over ordinary regression models in which daily assessments are aggregated (Gil, Porter, et al., 2000; Jaccard & Wan, 1993; Porter, Gil, Carson, Anthony, & Ready, 2000; Schwartz & Stone, 1998; West & Hepworth, 1991). First, these models preserve and make full use of the rich detail contained in data sets that record individuals’ day-to-day clinical events as they occur in naturalistic situations. Another advantage is that multilevel models explicitly accommodate the two levels of sampling that occur in daily diary measurement, that is, variation within individuals and variation across individuals. Multilevel modeling is also preferable because of its ability to readily handle data sets with numerous missing data points, which is often the case in studies that require intensive daily monitor-
Throughout training and follow-up periods, children in both conditions kept a daily diary of their pain intensity, activity reduction, and health care use. Children in the coping skills conditions also monitored practice with coping skills. More complete information on the manualized training sessions, therapist training, and treatment integrity and credibility can be found in Gil, Wilson, Edens, Workman, et al. (1997). The following is a brief description of the conditions, as well as details on the clinical status measures not previously reported.

**Conditions**

**Coping Skills Training Sessions.** In the first in-clinic session, children were trained to use three coping strategies: deep breathing relaxation, pleasant imagery, and calming self-talk. Strategies were presented using a self-management approach (Avia & Kanfer, 1980; Turk, Meichenbaum, & Genest, 1983) that involved modeling and practice with the strategies. At the end of the session, children were provided with audiotaped instructions of the techniques, a tape player, and a daily assignment to practice with the new strategies. They also were asked to start keeping a daily diary of coping practice. In a second in-clinic session scheduled from 1 to 2 weeks later, strategies were reviewed prior to posttesting. At no point during the intervention was advice given about how and when to take medication or to seek health care services. The therapists for this condition were behavioral psychologists with experience in pain coping skills training. (See Gil, Wilson, Edens, Workman, et al., 1997, for additional details).

After posttesting, children were instructed to continue to practice with their skills on a daily basis. Minimal therapist contact was maintained over the month through weekly telephone contacts. The telephone protocol included review of coping practice diaries, reinforcement for and encouragement to practice on a daily basis, and problem solving of obstacles to practice.

**Standard Care Control Condition.** Children in this condition received no intervention beyond routine medical care. They completed measures at each of the evaluations (baseline, posttreatment, and 1-month follow-up), as well as daily diaries throughout the 1-month follow-up period. The diaries were identical to the diaries kept by children in the coping skills condition in that children monitored daily pain intensity, activity reduction, and health care use. The only difference in the daily monitor-
ing was that children in the standard care control condition were not asked to record coping practice (see the section on Daily Pain Diary). All children in this condition were given the option to receive coping skills training after completion of their participation in the study. Several children elected this option; however, no data were collected for these children.

**Pain Sensitivity**

Pain sensitivity was measured using the Forgione-Barber focal pressure stimulator (Forgione & Barber, 1971) and procedures previously described (see Gil, Wilson, Edens, Workman, et al, 1997; Gil, Edens, et al., 1997, for more details). Briefly, four stimulus intensities were used: light (force = 2.83 × 10^5 dynes), medium (force = 3.89 × 10^5 dynes), heavy (force = 6.02 × 10^5 dynes), very heavy (force = 8.76 × 10^5 dynes). Thirty-two experimental trials (eight trials at each of four intensities) and two practice trials were used. For each trial, children assigned the sensory experience to one of the response categories on a 10-point scale of verbal descriptors (not noticeable, 1; slight discomfort, 2; distinctly uncomfortable, 3; very faint pain, 4; faint pain, 5; painful, 6; definitely painful, 7; extremely painful, 8; excruciatingly painful, 9; worst possible pain, 10). The child was prompted for a response at 15 sec or until the child did not want to tolerate the pressure and was able to withdraw the finger. If the child withdrew, a value of 10 was assigned.

The stimulus-response data were analyzed using Sensory Decision Theory (SDT) procedures (Clark, 1987; McNicol, 1972). The two indices derived from SDT analyses are sensory discrimination, that is, P(A), and report criterion or response bias, that is, B. P(A) measures the accuracy with which an individual distinguishes among stimuli of various intensities, with higher values indicating better discriminability. Report criterion, B, represents the attitudinal component of pain report; it is relatively independent of discrimination and reflects the subject's bias toward reporting pain.

**Coping Strategies Questionnaire for SCD**

The Coping Strategies Questionnaire (CSQ) used in this study contains several basic subscales (Rosenstiel & Keefe, 1983) and several new subscales that were added (Gil et al., 1991; Gil et al., 1993) to assess cognitive, behavioral, and physiological strategies specifically relevant to SCD pain. Three factor scores (Gil et al., 1991) were computed for the CSQ: factor 1: coping attempts; factor 2: negative thinking; and factor 3: illness-focused strategies. The internal consistency of the CSQ has been established in previous studies (Gil et al., 1989; Gil et al., 1991).

**Summary Measures of Depression and Anxiety**

Children's Depression Inventory (CDI; Kovacs, 1992). The CDI is a 27-item self-report scale based on the Beck Depression Inventory (Beck, Rush, Shaw, & Emery, 1979). It assesses a variety of depressive symptoms, including sleep disturbance, appetite loss, and dysphoria. The measure possesses acceptable psychometric characteristics and is the most widely used and researched measure of childhood depression in children 8 to 17 years of age (Kovacs & Beck, 1977).

Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985). The RCMAS is a 37-item self-report scale designed to assess the level and nature of anxiety in children and adolescents in four areas: physiological anxiety, worry, social concerns, total anxiety. There is adequate reliability and validity data for use of this instrument with school-age children (Reynolds, 1985). The total score was used in the analyses.

**Daily Pain Diary**

Children completed the daily pain diary (Gil, 1994; Gil, Porter, et al., 2000). On each day, pain intensity was rated on a scale from 0 (no pain) to 10 (pain as bad as it can be). Medication use was reported by indicating whether analgesics or narcotics were taken that day. Health care contacts were reported each day as (yes/no) emergency room visits (ER), hospitalizations, clinic visits, or phone calls to physicians (or other health care providers). Activity reduction because of pain was indicated (yes/no) in three categories: work/school, social, and household chores. A second page was added to the diary for children in the coping skills condition. On this page, children indicated (yes/no) whether they practiced with the audiotapes that day, and the total number of times that they had practiced with the tapes that day. In a recent study (Gil, Porter, et al., 2000), we determined that parents and adoles-
cents generally agreed on daily pain response, especially for salient events such as health care visits, suggesting that the diary method is reliable.

**Structured Pain Interview**

At posttesting and follow-up, parents were asked to recall pain and health care contacts since pretesting using the Structured Pain Interview (Gil, 1994). The categories of the interview (mostly) parallel the daily diary. Thus, participants were asked the frequency, average duration, and intensity (0 to 10) of pain. Health care contacts were reported as the total number of ER visits, hospitalizations, and phone calls/visits to physicians. Reliability and validity of the Structured Pain Interview has been reported in several prior studies (e.g., Gil et al., 1991; Gil et al., 1993).

**Results**

**Effects of Training From the Analysis of the Follow-up Summary Measures**

Four MANCOVAs were used to determine whether the coping skills condition differed significantly from the control condition on the measures of pain sensitivity, coping strategy use, and the clinical measures from the structured pain interview (i.e., SCD pain: frequency, duration, severity; health care contacts: ER visits, hospitalization, phone calls/visits to health care providers) at 1-month follow-up. Covariates for these analyses included the respective pretraining scores for each index. The first MANCOVA evaluating whether the groups differed on the two pain sensitivity measures (sensory discrimination, report criterion) was not significant, Wilks’ lambda, \( F(2, 34) = .54, p = .59 \). The second and third MANCOVAs evaluating group differences on the clinical measures from the structured pain interview, SCD pain variables, and health care contacts, were also not significant, Wilks’ lambda, \( F(3, 25) = .52, p = .67 \), and Wilks’ lambda, \( F(3, 24) = .30, p = .83 \), respectively. The fourth MANCOVA for coping strategy use (coping attempts, negative thinking, illness-focused strategies) revealed a significant main effect, Wilks’ lambda, \( F(3, 31) = 3.73, p < .03 \). Follow-up univariate ANCOVAs revealed significant follow-up differences for coping attempts, \( F(1, 36) = 5.00, p < .04 \), but not for negative thinking or illness-focused strategies. At the follow-up evaluation, children in the coping skills condition reported that they took a significantly more active approach to managing their pain (\( M = 90.00, SD = 33.5 \)) than those in the control condition (\( M = 57.44, SD = 30.9 \)).

A fifth MANCOVA was conducted to determine whether the coping skills condition differed significantly from the control condition on the summary measures of depression and anxiety at 1-month follow-up. The results were not significant, Wilks’ lambda, \( F(2, 33) = .52, p = .60 \).

**Multilevel Model Analyses of Daily Diaries**

The effects of the intervention on the daily diary measures were analyzed via multilevel models. We applied several statistical controls in the process of integrating data from multiple children’s diaries. To control for individual differences, we utilized random effects components of multilevel models, in which the mean and variance across individual intercepts were estimated and incorporated into a persons-related error term. To correct for possible relationships between outcome variables and other within-person factors, we used person-centered transformations of all within-person predictors (Schwartz & Stone, 1998). This ensured that effects reflected nothing other than pure within-person influences. Autocorrelation between participants’ successive measurements of variables was handled by applying a continuous first-order autoregressive error structure to all diary variables. PROC MIXED in SAS (SAS Institute, 1996) was used to generate all multilevel model analyses, with alpha levels set at .05.

**Analysis of Group Effects on Daily Pain and Health Care Contacts.** Children completed diaries on 1,071 days out of 1,937 potentially reportable days, yielding an overall completion rate of 55% (range: 7% to 100%). The number of potentially reportable days for each participant included the period between pre- and posttesting (typically 7 to 10 days) and the period between post- and 1-month follow-up tests (typically 30 to 40 days). General linear models indicated individual completion rates were not related to children’s age, gender, or disease severity. They were also not related to parental demographic variables, such as marital status, employment status, or level of education, nor did they differ by group assignment.
Effects of group assignment (coping versus control; between-person effects) on the daily diary variables of pain, medication use, health care contacts, and activity reduction (within-person variables) were evaluated by multilevel models. There were no significant group effects on any of these indices of clinical outcome. Hence, in conformance with the global summary results, multilevel model analyses of pain diaries did not reveal significant group effects on clinical measures during the 1-month follow-up.

Analysis of Daily Coping Practice. Children in the coping skills training condition reported on a total of 519 days regarding whether or not they used the coping skills audiotapes. On 339, or 65.32% of these days, children had practiced their skills. Individual daily practice rates ranged from 0 to 100%. Children practiced with audiotapes at an average rate of 1.3 times per day. General linear regression analyses were performed to investigate the relations between demographic and disease variables and daily coping practice. Several significant results were significant. First, age predicted the frequency with which children practiced their coping skills, $F(1, 948) = 35.06, p < .01$, with younger children practicing more frequently. Second, gender predicted the frequency of coping practice, $F(1, 948) = 15.97, p < .01$, with girls practicing their coping skills more frequently each day than boys. In regard to disease severity, children who experienced more chronic disease complications were less likely to practice their coping skills, $F(1, 948) = 53.61, p < .01$. Also, children’s disease type predicted the frequency of coping practice, $F(2, 947) = 123.35, p < .05$. Children with sickle beta thalassemia syndromes practiced their strategies the most, followed by children with hemoglobin SC disease, and then children with sickle cell anemia.

General linear models were also used to investigate the relationships between parental demographic variables and daily coping practice. The results indicated that parental level of education, $F(1, 905) = 15.42, p < .01$; marital status, $F(2, 904) = 103.78, p < .01$; and employment status, $F(1, 905) = 153.66, p < .01$, all significantly predicted the frequency of coping practice. Higher levels of education in parents predicted more frequent daily coping practice in children. Children whose reporting parent was divorced practiced most frequently, followed by children of married parents, and then by children of never-married parents. Daily practice was higher in children whose parents were working, either full- or part-time, than in children whose parents were either unemployed or disabled.

We used multilevel random effects models to examine the relationship between daily pain and daily coping practice. These models indicated that on a day-to-day basis, higher pain levels were significantly related to increases in the number of times children practiced with audiotapes on that day ($B = .0266, t [1, 1008] = 2.36, p < .0183$). Thus, it appears that children were more inclined to practice their coping skills when in pain.

This evidence of greater practice during times of higher pain indicated that it was important to control for pain levels in analyzing the relationships between coping practice and daily health care contacts, daily medication use, and daily activity reduction. To examine how the combination of higher pain and greater coping practice was associated with these clinical outcome indices, we constructed multilevel models with three predictors: daily pain, daily coping practice, and the interaction term of pain and coping practice. For health care contacts, we combined ER visits, hospitalizations, and clinic visits into one variable called major health care contacts. We did this primarily because the overall frequency of these relatively costly contacts was low over the 1-month follow-up period (1.4% of days, with each type of service on .2% to .8% of days).

Table I presents these predictors’ associations with daily health care contacts and medication use. As expected, higher levels of pain were strongly associated with higher levels of all dependent variables. Independent of pain levels, coping practice was not significantly related to either daily health care contacts (i.e., major health care contacts or phone calls) or medication use. However, over and above the association between pain and the dependent variables, the interaction term indicated that higher pain combined with greater coping practice was significantly related to decreases in major health care contacts ($B = -.0179, t [1, 1006] = -4.54, p < .01$). There was also a trend for an association between the combination of higher pain and greater coping practice, and decreases in phone calls to physicians ($B = -.0048, t [1, 1006] = -1.80, p = .07$). With regard to medications, coefficients suggested that the interaction of higher pain and greater coping practice was not related to either analgesic or narcotic use.

The multilevel model tests applied to daily ac-
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Table I. Multilevel Random Effects Estimates for Daily Health Care Contacts and Medication Use as Predicted by Daily Pain and Daily Coping Practice

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major health care contacts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily pain</td>
<td>.0184</td>
<td>6.45</td>
<td>.0001**</td>
</tr>
<tr>
<td>Daily coping practice</td>
<td>-.0056</td>
<td>-.70</td>
<td>.4825</td>
</tr>
<tr>
<td>Pain* coping practice</td>
<td>-.0179</td>
<td>-.54</td>
<td>.0001**</td>
</tr>
<tr>
<td>Phone calls to physicians</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily pain</td>
<td>.0142</td>
<td>7.37</td>
<td>.0001**</td>
</tr>
<tr>
<td>Daily coping practice</td>
<td>-.0071</td>
<td>-.30</td>
<td>.1947</td>
</tr>
<tr>
<td>Pain* coping practice</td>
<td>-.0048</td>
<td>1.80</td>
<td>.0719</td>
</tr>
<tr>
<td>Analgesic use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily pain</td>
<td>.0703</td>
<td>16.62</td>
<td>.0001**</td>
</tr>
<tr>
<td>Daily coping practice</td>
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<td>-.18</td>
<td>.8559</td>
</tr>
<tr>
<td>Pain* coping practice</td>
<td>-.0014</td>
<td>-.24</td>
<td>.8072</td>
</tr>
<tr>
<td>Narcotic use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily pain</td>
<td>.0474</td>
<td>14.57</td>
<td>.0001**</td>
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</tr>
<tr>
<td>Pain* coping practice</td>
<td>-.0037</td>
<td>-.87</td>
<td>.3848</td>
</tr>
</tbody>
</table>

Major health care contacts include ER and clinic visits and hospital admissions.

*p < .01.

**p < .001.

Coping practice with SCD. However, the pattern of results from the summary measures was different at 1-month than at posttesting. At posttesting, significant group (coping skills versus control) differences were found in negative thinking and in pain sensitivity, with those in the coping condition having less negative thinking and less tendency to report pain during low levels of painful stimulation. These findings were not present at 1-month follow-up. Thus, brief training in coping skills may lead to only transient changes in negative thinking and laboratory pain perception that do not maintain with minimal therapist contact. At 1-month follow-up, children in the coping condition had significantly more coping attempts. Thus, children receiving coping skills training may need time to practice and apply their skills to achieve improvements in coping attempts. Minimal therapist contact after initial training may be sufficient for these skills to emerge. More important, however, there were no significant findings between groups on the clinical measures using either traditional analyses of variance strategies or multilevel analyses of the group effects on daily diary measures. Overall, the group level analyses do not provide compelling evidence for the efficacy of the intervention.

The within-group multilevel analyses of the daily diary data may help explain why participation in the coping group, by itself, was not sufficient for children to realize benefits. In this study, we used daily diary methods and multilevel models to analyze the ways in which individual daily patterns of practice with coping skills related to clinical improve-

Discussion

The findings indicate that brief training in coping skills followed by minimal therapist contact over a 1-month period led to some benefits for children
ments. We found that when children practiced their skills on a day with pain, they were significantly less likely to have a major health care contact such as an ER or clinic visit or hospital admission. Moreover, on pain days when children practiced with skills, they were significantly more likely to remain involved in school activities. The overall pattern of increased coping practice in the presence of increased pain implies a greater personal and perhaps family capacity to manage pain effectively at home, as evidenced by less need of major, urgent medical treatment and continued participation in school and home activities.

These results are important because they provide the first evidence that daily use of coping skills may lead to more successful home management of pain in children with SCD. The importance of daily practice with skills for children is consistent with our recent finding in adults who participated in a similar intervention (Gil, Carson, et al., 2000) and consistent with findings from similar interventions studies of children with other pediatric problems such as migraine headaches (e.g., Allen & McKeen, 1991). Moreover, the results support the inclusion of multiple outcome measures in intervention research and suggest that daily measures of pain, coping, and functional outcomes may provide a more comprehensive way to determine impact of interventions on day-to-day quality of life.

The findings about school activities are especially interesting. Chronically ill children in general and children with SCD in particular have high rates of school absenteeism, due in part to illness complications, medication side effects, and hospitalizations (Cook, Schaller, & Krischer, 1985; Fowler, Johnson, & Atkinson, 1985; Thompson & Gustafson, 1996). As school attendance and participation in school activities enhance academic achievement as well as social and emotional adjustment (Stein & Jessop, 1986; Weitzman, Walker, & Gortmaker, 1986), coping skills training may lead to a broad array of benefits over time, especially if the interventions keep children involved in school.

The multilevel analyses of the daily diary data were able to document the benefits of the intervention because of their ability to closely examine within-person effects. That is, these methods permitted us to follow what was happening for each child on a day-to-day basis as he or she experienced oscillations in daily pain levels and variation in coping practice. Analyses at the group level (i.e., whether or not someone was in the coping skills training condition or in the control condition) may have missed the significant relationship between coping skills and clinical improvements. There are several reasons. First, the group level analyses did not account for the fact that on some days, children in the coping condition did not use their skills, even though they had been instructed to practice their skills each day. Second, the group level analyses were unable to explore relationships between pain, coping practice, and health care contacts within a given individual on a day-to-day basis. Last, daily diary measures provide unique advantages over summary measures. Diaries appear to offer improved accuracy, reduced recall biases, and increased recall of more minor pain and related events, especially regarding the temporal sequencing of events (Porter et al., 1998; Stone, Kessler, & Haythornthwaite, 1991; Verbrugge, 1980).

Regarding home practice, younger children were more likely to practice than older children, and girls were more likely to practice than boys. In addition, children whose parents were more educated and working outside the home practiced more consistently. Future research is needed to determine the mechanisms by which these factors relate to home practice (e.g., by providing more structure or more direct encouragement to practice). Finally, disease complications and phenotype were related to home practice such that children with more severe disease were less likely to practice. Future studies need to examine ways to promote daily practice in children with severe disease since these are the very children who might have the greatest need to practice their skills.

There are several limitations of this study. First, the study utilized a standard care control condition and therefore did not control for potential nonspecific effects such as time spent with a therapist or time spent at home on a structured activity. Future studies might include a disease-education control condition such as the one we used in our prior adult study in which participants met for weekly sessions with an educator/therapist and were given pamphlets and other materials to read at home (Gil, Carson, et al., 2000). Second, children in both the coping condition and the standard care control condition were asked to keep daily diaries. Thus, the lack of group differences could, in part, be due to the fact that both groups of children recorded pain and other variables on a daily basis. A self-monitoring effect may have mitigated differences between the coping and control conditions. Future
researchers might consider the potential utility of including a control group not asked to keep daily diaries, although this design would limit the type of data available for analyses. Third, as is often the case in studies that require intensive daily monitoring of events, there were many missing days in the diary information. Although the multilevel models have statistical strategies to handle large numbers of missing data, there may be systematic influences that bias the data. For example, on stressful days, children may have neglected to record information (Porter et al., 2000). Future studies should attempt to determine the specific reasons for missing diary information in order to analyze for any systematic influences. Fourth, the questions about coping practice on the diary specifically asked whether children used their audiotapes. In the future, we should include diary questions about practice that children do on their own without the tapes.

Another important issue for discussion relates to the duration and intensity of the intervention. This study examined a relatively brief, two-session coping skills intervention with minimal therapist contact over a 1-month period. The components of this intervention study were rather specific and included only cognitive-based skills. We did not include direct instructions about how to manage activity patterns on pain days or how and when to take medication or to seek health care services. More intensive and comprehensive skills training might yield greater and longer-term clinically significant outcomes. For example, given that children with SCD pain often reduce their physical, social, and school activity, a clear rationale exists to include additional intervention sessions devoted to training in behavioral strategies such as activity pacing or scheduling pleasant activities during pain episodes. Future studies need to empirically determine which treatment components and what levels of treatment intensity and duration are optimal. Studies might also examine the benefits of an integrated psychological and disease management approach (i.e., instructions on effective medication and health care use strategies), since a more comprehensive pain control protocol might have larger and broader effects. Furthermore, longer follow-up studies of 1 year or more postintervention might be needed to fully appreciate the effects of the coping interventions on clinical outcome. These longer-term studies might require periodic daily monitoring interspersed with intervals of no monitoring to keep children fully involved in the study.

In conclusion, the findings of this study suggest that brief training in coping skills followed by minimal therapist contact may lead to a range of clinical benefits in children when they practice with their skills on a consistent basis. Future studies need to evaluate strategies that will enhance daily practice, perhaps through direct training or more intensive involvement of parents who could serve as active coaches of their children to use their skills.

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References


Compas, B. E., Haaga, D. A. F., Keefe, F. J., Leitenberg, H.,


Thompson, R. J., Gil, K. M., Burbach, D. A., Keith, B. R., &


