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Effect of an Intervention to Reduce Procedural Pain and Distress for Children With HIV Infection

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Objective: **To evaluate a multicomponent pain management intervention, including cognitive behavioral strategies, for children with human immunodeficiency virus (HIV) infection undergoing routine venipuncture.**

Methods: **Following a baseline venipuncture, children were exposed to an intervention including preparation, relaxation, distraction, reinforcement, parent involvement, and EMLA (eutectic mixture of local anesthetics) cream, and followed for three additional venipuncture procedures. After each procedure, child distress was rated on the Procedure Behavior Checklist (PBCL), child self-report of pain was obtained using the FACES scale, and parent anxiety was reported on the State Trait Anxiety Inventory—State Scale (STAI).**

Results: **Significant reductions in child distress and pain were found by the second postintervention procedure and maintained at the third. Parent anxiety was significantly reduced by the second postintervention procedure, but many parents chose not to participate in the third postintervention procedure.**

Conclusions: **With repeated exposure, a multicomponent pain management intervention, including cognitive behavioral strategies and EMLA, appears effective at reducing pain, distress, and parent anxiety for children with HIV.**

Key words: *HIV infection; children; procedural pain management; intervention; distress; parent anxiety.*

Most children with human immunodeficiency virus (HIV) infection will experience many painful experiences during the course of their medical care. These experiences may include pain caused by infectious complications, pain as a result of side effects of drugs and therapy, pain associated with the HIV itself, and, perhaps most commonly, pain and distress related to medical procedures (Hirschfeld & Morris, 1995). Children with HIV infection followed on an outpatient basis experience frequent needle sticks, including venipuncture for blood draw and intravenous (IV) insertion, injection of medication and immunizations, and PPD (purified protein derivative) placement to screen for tuberculosis. When inpatient treatment is required for acute illness, children with HIV experience frequent painful procedures such as venipuncture, nasogastric tube insertion, and central line insertion, and painless but anxiety- and distress-provoking procedures such as magnetic resonance imaging (MRI) or computer tomography (CT) scans. One chart review

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study revealed that 22 children with HIV infection experienced a total of 193 painful procedures in 1 year (Strafford et al., 1991).

Although treatment of children with cancer has long included the integration of pain management interventions, health care professionals working with pediatric HIV have only recently begun to explore the pain management needs of this population. To date, limited investigation has focused on the chronic and symptomatic pain associated with pediatric HIV infection (Hirschfeld, Moss, Dragisic, Smith, & Pizzo, 1996; Torrance, Lewis, La Brie, & Czarniecki, 1995; Yaster & Schechter, 1996). No studies have examined the procedural pain experienced by children with HIV infection or evaluated the use of available pain management strategies with this population.

In the treatment of other pediatric conditions, attention has focused on providing children with a multicomponent intervention "package," based on cognitive behavioral therapy, that teaches effective coping skills to reduce children's distress during painful procedures (e.g., Ellis & Spanos, 1994; Jay, Elliott, Fitzgibbons, Woody, & Siegel, 1995; Jay, Elliott, Woody, & Siegel, 1991). This package commonly includes preparation, rehearsal, breathing exercises for relaxation and distraction, and positive reinforcement and may also incorporate pharmacologic approaches to pain management. Each intervention component is described briefly below.

Preparation includes the provision of detailed information on the events to follow and modeling and behavioral rehearsal of the upcoming procedure. The level of information provided during preparation must be tailored to the developmental level of the child. *Relaxation* and *distraction* can be promoted through the use of breathing exercises with or without the aid of bubbles or other devices (French, Painter, & Coury, 1994; Manne, Bakeman, Jacobsen, Gorfinkle, & Redd, 1994). Children who are taught a specific technique, such as breathing exercises, believe that they have more control over a painful situation; this generally results in a higher pain threshold and tolerance (Jay & Elliott, 1983). *Reinforcement,* in the form of verbal praise, stickers, fancy bandages, or small toys, is intended to reward the child for attempting to comply with assigned tasks, such as keeping still or doing breathing exercises. The purpose of reinforcement is to provide an incentive for engaging in coping behaviors, thus increasing the likelihood that the child will perform the behaviors again in the future.

Two additional interventions, the application of EMLA (eutectic mixture of local anesthetics) cream and increasing the role of parents during the procedure, have also received support in recent years. EMLA is a topical skin anesthetic (2.5% lidocaine, 2.5% prilocaine) intended to reduce the pain associated with needle sticks. This cream is applied to the site of the procedure 1 hour before and covered with an airtight bandage. Results of a major pediatric clinical trial indicate that EMLA significantly reduces a child's perceived pain from procedures (Joyce, Skjonsky, Taylor, Morrow, & Hess, 1992). Subsequent investigations have supported this finding (e.g., Arts et al., 1994). However, evidence suggests that the effectiveness of EMLA may be due in part to children's expectations that it will be helpful (Goodenough et al., 1997).

Parents can play an important role in efforts to promote children's coping during painful procedures (Varni, Blount, Waldron, & Smith, 1996). Though children tend to display more behavioral distress when a parent is present during medical procedures, they generally prefer to have their parent present and thus may experience less subjective distress (Gonzalez, Routh, & Saab, 1989; Gross, Stern, Levin, Dale, & Wojnilower, 1983; Shaw & Routh, 1982). In addition, parents generally prefer to be present when their children undergo medical procedures (Boie, Moore, Brummett, & Nelson, 1999). Beyond merely being present, the parent can play an important role, including providing support, encouragement, reinforcement, and coaching the child in the use of coping strategies (Blount, Powers, Cotter, Swan, & Free, 1994; Manne et al., 1994; Powers, Blount, Bachanas, Cotter, & Swan, 1993). For example, Jacobsen and colleagues (1990) found that parents affect their child's level of distress by providing explanations of the procedure. Parent anxiety during the procedure may also affect the level of distress the child presents (Jacobsen et al., 1990; Jay, Ozolins, Elliot, & Caldwell, 1983).

Intervention packages using combinations of the strategies described are now "well established" treatment for pediatric procedural pain (Powers, 1999). Numerous studies have demonstrated reduced distress in children undergoing procedures ranging from routine immunizations to more invasive procedures (e.g., Blount et al., 1994; Cohen, Blount, Cohen, Schaen, & Zaff, 1999; Dahlquist, Gil, Armstrong, Ginsberg, & Jones, 1985; Elliott & Olson, 1983; Jay et al., 1991, 1995; Kazak, Penati, Brophy, & Himelstein, 1998). For example, Kazak and colleagues found that integration of cognitive behavioral techniques with pharmacologic inter-

ventions reduced subjective distress in children with leukemia receiving lumbar puncture and bone marrow aspiration. Similarly, other investigators have found that distraction and coaching, either alone or with EMLA, were more effective in reducing behavioral distress during procedures than was EMLA alone (Cohen et al., 1999; Fanurik, Koh, & Schmitz, 2000). In one study examining the venipuncture procedure, behavioral distress was reduced in children with cancer through a behavioral intervention including parent coaching, distraction, and positive reinforcement, and reductions were maintained over the course of three intervention trials (Manne et al., 1990).

Unfortunately, we cannot assume that pain management interventions used with children with cancer, other medical conditions, and healthy children will be effective for children with HIV infection. Children with HIV infection differ from other pediatric groups in a number of ways. For example, in contrast to the pediatric oncology population in which incidence rates are highest for Caucasian children (Gurney, Severson, Davis, & Robison, 1995), more than 90% of pediatric HIV occurs in minority families (African American and Hispanic) and families of lower socioeconomic status (SES). These families are often forced to cope with multiple, pervasive stressors in addition to HIV-related concerns (Black, Nair, & Harrington, 1994). Minorities have also traditionally been an underserved population with significant distrust of the health care system (Lipson, 1993). In addition, parents of children with HIV may have difficulty coping with their child's medical procedures due to their own illness, or to feelings related to the vertical transmission of the virus (from mother to child). Multiply infected families may also result in the child's loss of a parent, as well as changes in caregivers. For these reasons, children with HIV infection and their families may differ from other pediatric groups in their response to established interventions for procedural pain. For example, families may be less open or responsive to practitioners' suggestions and may be too overwhelmed with other stressors to focus on their child's procedural coping. Changes in caregivers and difficulties with adherence to treatment may compromise teaching and maintaining strategies.

This study was initiated in response to a significant clinical need identified by the staff of the multidisciplinary special immunology clinic in which the study was subsequently conducted. Concerns were raised regarding frequent episodes of anticipatory anxiety and, in particular, behavioral distress and resistance displayed by the children with HIV infection seen in the clinic. Although children who were frequently admitted to the inpatient unit, and those with the most extreme distress, received pain management consultation from a pediatric psychologist or child life specialist, such intervention was not widely provided on an outpatient basis. We proposed introducing a procedural pain management intervention to the more medically stable children seen in the outpatient setting, so as to provide these children with skills to cope with current and future medical procedures and prevent the development of conditioned procedural distress. This also provided an opportunity for the first investigation of procedural pain management for pediatric HIV infection.

Thus, this study was designed to evaluate the effectiveness of a multicomponent procedural pain management intervention with children with HIV infection. By investigating well-established interventions, we hoped to learn if they were effective for children with HIV and to determine if any modifications would be appropriate to best serve this population in the future. We hypothesized that exposure to the intervention would decrease children's behavioral distress and subjective pain as compared to preintervention levels and that these decreases would be maintained over repeated procedures. We also hypothesized that parent anxiety during the venipuncture procedure would decrease following intervention.

Method

Participants

Children between the ages of 4 and 12 years were recruited from the population of children with HIV seen for continuing care at the special immunology clinic at an urban children's hospital. Children were eligible for participation if they were followed by the clinic at 3-month intervals based on the following criteria: stable T-cell counts, generally good physical growth and cognitive development, and few illnesses and opportunistic infections. Children followed more frequently due to less stable health status were not eligible to participate because they received less predictable and more variable medical procedures. Though 47 children were initially recruited, one child was subsequently excluded from the study due to developmental delay, and three

children did not complete data collection due to poor clinic attendance or declines in health status necessitating more frequent invasive procedures. Only one parent approached for the study refused to participate with the stated reason that her child had no difficulty with procedures and therefore would not benefit.

The final sample of 43 children who completed the study included 16 boys and 27 girls. The mean age was 7 years, 1 month, and the sample was primarily African American (93%). Each child was recruited with one caregiver, who was identified as a primary caregiver (to be referred to as "parent"). This included mothers (55.8%), fathers (4.7%), grandparents (16.3%), other custodial relatives (20.9%), and nonfamily foster parents (2.3%). Eighty-five percent of the sample had been diagnosed with HIV before 2 years of age; the mean age of diagnosis for this sample was 1 year, 4 months. At recruitment into the study, the mean time since diagnosis was 5 years, 9 months.

Design

A single-group, repeated measures design was implemented to examine within-subject changes in child distress, child pain, and parent anxiety across three postintervention venipuncture procedures as compared to a baseline preintervention procedure. This design was desirable given the potential for significant individual differences in baseline coping and response to treatment. It also appeared appropriate for the detection of changes over time and repeated exposure to the intervention. Although the lack of a control group is a significant limitation on conclusions regarding the effects of the intervention, such a design was not implemented for two reasons. First, given the limited potential sample size, we were concerned that we could not recruit a sufficient number of subjects to implement a two-group design. Second, the clinical team strongly objected to withholding the intervention from children over the course of the repeated procedures thought necessary to detect an effect. Parents surveyed informally also responded negatively to such a design.

Procedures

Recruitment of subjects was conducted through procedures approved by the hospital's institutional review board. A member of the research team approached parents of eligible children while at the clinic for regularly scheduled appointments. The purpose and procedures of the study were explained. If parents agreed to participate, informed written consent was obtained along with informed written assent from children 7 years or older.

Clinic visits for the children in this sample typically included a venipuncture (blood draw) procedure to obtain a complete blood count, T-cell count, and viral load. The procedures were routinely performed in the hospital lab by phlebotomists who had no particular training in pain management. During the course of this study, children were observed and data were collected for a total of four procedures at 3-month intervals. On the day of recruitment, baseline data were obtained for a routine venipuncture procedure under standard conditions in the hospital lab. EMLA cream had recently been introduced to the clinic staff and was not provided for the baseline venipuncture procedure. None of the children had previous experience with EMLA or other pain management interventions prior to study participation.

During the child's next clinic visit, the pain management intervention was introduced (described below) including the application of EMLA, and the venipuncture procedure was performed in one of the clinic examining rooms by a clinic nurse, rather than at the hospital lab. Performing the procedure in the clinic allowed for the extra time and space needed for coaching and distractions and encouraged parents and children to feel more comfortable trying the new strategies. This would not have been feasible in the crowded, fast-paced setting of the lab. Parents also reported that the opportunity to have the procedure in the clinic was an advantage as it saved them potentially long waits at the lab. This may have encouraged continued study participation. On the third visit (also in a clinic room), the parent and child received a booster session of the intervention; however, the psychologist did not coach the parent and child during the procedure. EMLA was provided for this procedure. On the fourth and final visit, the parent and child returned to the lab for a venipuncture under standard lab conditions with a trained observer present to determine if any changes would be maintained under those conditions. No specific reminders were given to use the pain management strategies. However, EMLA was provided and a reinforcement sticker was available following the procedure. During each procedure, a trained observer completed a measure of

child behavioral distress. Parent and child report measures were completed immediately following the procedure. Researchers had no contact with the families between clinic visits and thus provided no additional intervention reinforcement between procedures.

Intervention

The procedural pain management intervention included several components. First, EMLA cream was applied to the venipuncture site prior to all three postintervention procedures. It was explained to the child that the cream would make the area numb so he or she would "hardly feel the needle at all." Prior to the venipuncture procedure, a pediatric psychologist met with the child and parent to provide preparation for the procedure, including information, modeling, and rehearsal. The steps of the procedure were reviewed with the child in a developmentally appropriate way. The rationale underlying the pain management intervention and approach to coping was explained to the parent. The procedure was demonstrated with a doll. The child was then taught relaxation breathing through the use of bubbles or a pinwheel. The child was instructed that his or her "job" was to keep the target arm still and perform the breathing. The child was given choices, such as where he or she would sit during the procedure and what would be used for distraction during the procedure (in addition to the bubbles or pinwheel, toys, books, and music were available). The parent was asked to participate by "coaching" the breathing and providing verbal reinforcement. Then, the child and parent were asked to practice the procedure with the doll, with the child acting as provider, and then with the child practicing the assigned jobs while role-playing the procedure as the patient. In addition to verbal reinforcement for the child's cooperation, use of coping skills, and attempts to do the assigned "jobs," children received rewards following the procedure, including decorative bandages and stickers. The psychologist spent approximately 20 minutes with each child during the first intervention session. During the first postintervention venipuncture, the psychologist played a major role in coaching the child through the procedure, although the parent was also encouraged to do so.

Prior to the second postintervention procedure, a booster session of preparation, rehearsal, and coping strategy training was provided. This session was shorter than the first presentation of the intervention, requiring approximately 10 minutes. During the subsequent venipuncture procedure, the psychologist provided less direct coaching to the child and encouraged the parent to be the primary coach. For the third, final postintervention procedure, no intervention session was provided. However, EMLA and reinforcement stickers and decorated bandages were provided.

Measures

A trained observer rated the child's behavioral distress during the procedure. The observers used the Procedure Behavior Checklist (PBCL; LeBaron & Zeltzer, 1984), which lists eight distress behaviors, including muscular tension, screaming, crying, restraint used, pain verbalized, anxiety verbalized, verbal stalling, and physical resistance. The observer rates the intensity of each behavior and assigns a value from 0 to 5 (0 = no distress, 1 = very mild distress, 5 = extremely intense distress). For this study, the total score for the checklist was used as the measure of behavioral distress. The validity of the PBCL has been established, and ratings of behavioral distress using the PBCL have been strongly related to self-reported pain and anxiety.

Whereas the PBCL was initially developed to assess distress during lumbar punctures and bone marrow aspirations, similarly developed checklists have been used to assess distress during venipuncture, such as the Procedural Behavioral Rating Scale-Revised (PBRS-R; Katz, Kellerman, & Siegel, 1980, 1981) (e.g., Carlson, Broome, & Vessey, 2000; Jacobsen et al., 1990; Manne et al., 1990). The PBCL lists distress behaviors identicial or similar to those on the PBRS-R, but has the advantage of including ratings of the intensity of each behavior, rather than simply the number of behaviors presented. Based on this advantage, and the fact that the PBCL can be used during the procedure without requiring videotaping for later coding, we chose this measure. Although measures of distress that require videotaping the medical procedure for coding in small time intervals are generally preferable for reliability, an informal survey of parents before this study indicated that most would refuse to participate in a study including videotaping due to concerns regarding confidentiality and privacy. Instead, to establish observer reliability, 10% of the total number of procedures observed during the course of the study were observed by two trained observers and

their ratings compared. Correlation coefficients between observer ratings ranged from .84 to .98 for individual behavior categories. The correlation coefficient between observer ratings for the total PBCL score was .99.

The child's subjective experience of pain during the venipuncture procedure was measured by self-report using the FACES scale (Wong & Baker, 1988). The scale consists of six cartoon line drawings of faces ranging from smiling to crying scored on a scale from 0 (no pain) to 5 (worst pain ever). The scale was shown to the children using the descriptions suggested by Wong and Baker, including "Face 0 is happy because there is no hurt; face 1 hurts just a little bit; face 2 hurts just a little more,"and so on. Following the procedure, the children were asked to point to the face that showed how much they hurt during the blood draw. Test-retest, construct, and discriminant validity have been established for the scale for use with children ages 3 to 18 years (Keck, Gerkensmeyer, Joyce, & Schade, 1996; Stein, 1995; Wong & Baker, 1988). In addition, children and parents report a preference for the FACES scale over other faces pain measures (Chambers, Giesbrecht, Craig, Bennett, & Huntsman, 1999).

Children in this study were also asked to provide a self-report of pain on a Visual Analog Scale (VAS; Abu-Saad & Holzemer, 1981), a widely used measure in which the length of a line is adjusted to match the intensity of pain. Though the psychometric properties of the VAS are strong (Gift, 1989; McGrath, 1986; Weivers & Lowe, 1990), the measure has generally been considered valid for use only with children at least 5 to 7 years old. It was therefore unclear whether the younger children in this sample fully understood the nature of this task. Therefore, scores on the VAS were not used in this investigation as a measure of child pain. However, it is worth noting that scores on the VAS were significantly correlated with FACES scores in this sample ($r = .74$, $p < .001$). This is consistent with other investigations and provides support for the validity of the FACES scores presented.

Parent anxiety was measured using the State scale of the State-Trait Anxiety Inventory (STAI; Spielberger, 1983). The State scale measures a transitory emotional response to a stressful situation and consists of 20 phrases with responses on a 4-point Likert scale. The total score is the weighted sum of the 20 responses. The STAI is used extensively in the anxiety literature and has been shown to have strong internal consistency and reliability. The STAI has also been commonly used with parents to assess their anxiety during pediatric procedures, including venipuncture (e.g., Frank, Blount, Smith, Manimala, & Martin, 1995; Jay et al., 1983; Tyc, Fairclough, Fletcher, Leigh, & Mulhern, 1995). Parents completed the STAI immediately following the procedure.

Results

Preliminary analyses examined the relationships between demographic variables and the measures of coping with venipuncture during the baseline venipuncture procedure, including observed behavioral distress, child report of pain, and parent anxiety. Child distress was rated on the PBCL, child self-report of pain was obtained using the FACES, and parent anxiety was obtained using the STAI. Pearson product-moment correlation coefficients revealed significant relationships between age at baseline and observed behavioral distress as indicated by total PBCL score ($r = -.42$, $p < .01$) and between age and child reported pain ($r = -.50$, $p < .001$), with younger children displaying more distress and reporting more pain. Once the effect of child's age was controlled for, there were no significant gender differences observed in either behavioral distress or reported pain. Neither the child's age nor the child's gender was related to the level of reported parent anxiety. In addition, the amount of time since diagnosis was not significantly related to distress, pain, or parent anxiety.

Because distress and pain were related dependent variables ($r = .76$, $p < .001$), a multivariate repeated measures analysis of variance (MANOVA) was performed to address the hypothesis that exposure to the intervention would result in significant decreases in observed child distress and child reported pain. This procedure indicated significant overall within-subject changes over time, $F(6, 252) = 5.18$, $p < .001$. Subsequent univariate ANOVAs also indicated significant within-subject changes for both variables and are presented in Table I. Table I also presents comparisons of scores at each postintervention venipuncture with the baseline procedure. The results indicate significant decreases in both behavioral distress and reported pain as a result of the intervention. Although neither distress nor pain was reduced significantly dur-

Table I. Intervention Effects on Child Distress, Pain, and Parent Anxiety Ratings Over Time

		Comparisons (*F* values)			
Measure	*n*	Repeated Measures	Time 1 vs. Baseline	Time 2 vs. Baseline	Time 3 vs. Baseline
Observed distress[a]	43	11.59***	1.95	17.16***	25.86***
Child-reported pain[a]	43	2.68*	0.24	4.12*	9.75**
Parent anxiety[b]	24	3.64*	2.08	6.97*	

Time 1, Time 2, and Time 3 refer to the first, second, and third postintervention procedures.
[a]For repeated measures ANOVA, $df = 3, 126$; for individual ANOVA, $df = 1, 42$.
[b]For repeated measures ANOVA, $df = 2, 46$; for individual ANOVA, $df = 1, 23$.
*$p < .05$.
**$p < .01$.
***$p < .001$.

Table II. Means and Standard Deviations of Child Distress, Pain, and Parent Anxiety Ratings

Measure	*n*	Baseline *M* (*SD*)	Time 1 *M* (*SD*)	Time 2 *M* (*SD*)	Time 3 *M* (*SD*)
Observed distress	43	10.72 (11.20)	8.49 (10.10)	5.19 (7.36)	3.23 (4.74)
Child-reported pain	43	1.63 (2.07)	1.42 (2.04)	1.12 (1.79)	0.77 (1.56)
Parent anxiety	24	40.50 (12.34)	35.71 (13.33)	32.54 (10.72)	

ing the first postintervention venipuncture procedure, both decreased significantly by the second postintervention procedure and maintained the decrease during the third, final procedure.

Also presented in Table I are the results of analyses addressing the hypothesis that exposure to the intervention would result in a significant decrease in parent anxiety. Due to missing data for this variable, only a subsample of parents was included in the analyses. Missing data occurred primarily when children were brought to a clinic appointment by someone other than the primary caregiver with whom they were recruited at baseline. Only 24 parents who initially participated at baseline also participated in the first and second postintervention procedures. In addition, for the third, final postintervention procedure, only 13 parents accompanied their child for the venipuncture. As a result of this unexpected dropout, the final procedure was excluded from the analyses as including it would have resulted in too few subjects available for the overall ANOVA. Due to the small sample size and limited procedures examined, the analyses for parent anxiety should likely be considered exploratory.

As presented in Table I, the intervention did result in an overall reduction in parent anxiety. As with behavioral distress and child-reported pain, parent anxiety did not significantly decrease for the first postintervention procedure, but did so by the second. Due to parent dropout, it is unknown whether this decrease would have been maintained by the third postintervention procedure.

Although it is most appropriate to test for the effect of the intervention by examining within-subject changes, group mean scores for each venipuncture procedure are presented in Table II to help illustrate the decreases in scores on the measures. The large variability in individual scores, indicated by substantial standard deviations, highlights the importance of examining changes over time using a within-subject design.

Discussion

The results of this investigation provide support for the effectiveness of a multicomponent intervention, including cognitive behavioral strategies and EMLA cream, in reducing the behavioral distress, pain, and parent anxiety associated with venipuncture for children with HIV infection. Whereas the intervention package used is similar to those that have been effective with other pediatric groups who experience invasive procedures, the interventions had not previously been evaluated for use with children with HIV infection. These children typically

differ from other pediatric populations in terms of illness course, as well as such factors as lower SES, minority status, multiple family members infected, and changing caregivers.

Improvements in behavioral distress, child-reported pain, and parent anxiety emerged over time and repeated exposure to the intervention. Other researchers have similarly reported increased effects of interventions over repeated trials with children with cancer (Manne et al., 1990). Children with HIV infection have typically experienced considerable repeated exposure to painful procedures and may develop conditioned responses including anticipatory anxiety, distressed behavior, and expectations regarding pain. As our results suggest, one-time interventions may be inadequate to produce changes in the behavior or the subjective experience of these children. Thus, empirical investigations of the efficacy of behavior pain management for children with chronic illness should likely include more than one exposure to the intervention and examine coping over a series of procedures. In the clinical setting, it may be important to modify the expectations of practitioners and parents of children displaying procedural distress. These individuals may expect immediate results and require encouragement to stick with intervention efforts over time.

To allow for time and space to introduce, practice, and implement the intervention, the first and second postintervention venipuncture procedures were performed in our clinic, a change from the baseline procedure, which was performed under standard conditions in the busy hospital lab. This raises the question of whether the reductions in pain and distress found by the second postintervention procedure were due at least in part to this change in setting. Staff in the clinic did tend to have more experience in pain management than lab phlebotomists and may have contributed to the intervention through their interactions with the child and parent. However, the decreases in pain and distress were maintained for the third, final venipuncture procedure, which was performed back in the hospital lab by phlebotomists. This suggests that the effects of the intervention generalized to standard procedure conditions and were not limited to the effect the clinic setting. Ideally, similar future investigations should add additional long-term follow-up to determine if improvements in coping can be maintained through the course of treatment.

The final venipuncture procedure was also notable for the decision of many parents not to be present for their child's procedure. This dropout may have been due to increased anxiety or discomfort in the lab setting versus the clinic. Though parent anxiety decreased during the procedures performed in the clinic, this may have been due to the setting rather than our intervention. It is also unclear whether the decreased anxiety could have generalized outside the clinic setting. However, in at least some cases, the parent's decision not to accompany the child appeared to be due to greater comfort with the procedure and the belief that the child no longer required the parent's presence. As one mother said, "She's doing much better with it now, so she doesn't need me." This is not a response reported in similar studies with other pediatric populations. In fact, parents tend to report a desire to be present when their children undergo medical procedures (Boie et al., 1999) and are seen as a good source of coping promotion over time (Varni et al., 1996). Our results suggest that the typical approach of teaching parents to be coaches during painful procedures, and modeling this role for them, may not be adequate or the most appropriate for parents of children with HIV. It is unclear whether this is due to cultural differences, differences in parenting style, parents' medical experiences, or other factors. Future investigations with this population should explore the role of parents during typical procedures and consider new approaches to intervention.

Contributing to this issue was a lack of consistency regarding who brought children to the clinic. Family members other than the primary caregiver recruited to participate in the study, such as grandparents, aunts, and older siblings, sometimes accompanied children to clinic visits. Thus, our approach of focusing on teaching the primary caregiver, and reducing his or her anxiety, was not compatible with some families' arrangements. For an intervention to be most effective at teaching and maintaining pain management strategies, all caregivers who participate in the child's treatment should likely be included. The effectiveness of such an approach could be examined in future investigations. Despite the difficulties raised regarding parent participation in this study, exploratory results suggest that parents who consistently participated did experience decreased anxiety during their children's procedures.

In this study, younger children presented more behavioral distress and reported more pain than did older children. This was consistent with previous re-

search with other pediatric populations (Carlson et al., 2000; Fanurik et al., 2000; Goodenough et al., 1997; Jay et al., 1983; Kazak et al., 1998; Manne, Bakeman, Jacobsen, & Redd, 1993) and underscores the need for developmentally appropriate interventions for younger children. In addition, time since diagnosis, and presumably experience with the venipuncture procedure, was not related to distress and coping with the procedure in this investigation. The absence of such a relationship indicates that time and experience alone may not improve coping with painful procedures for children with HIV and reinforces the need for appropriate interventions.

Observations by the clinical team suggested that at least some of the changes found in this study were clinically meaningful. For example, some of the children who had been particularly resistant and disruptive were observed to be appropriately calm and cooperative at the study's conclusion. Specifically, the need for physical restraint was eliminated by the final procedure in 16 of the 19 children who required restraint at baseline. In addition to improved procedural behavior, the children's subjective experience also appeared to improve qualitatively in many cases. Following the completion of the study, most children routinely requested EMLA (which they called "magic cream"), bubbles, and stickers and reported that the needle did not hurt.

Many parents also expressed confidence in their child's ability to cope with venipuncture and other procedures following study participation. As noted, many parents appeared to believe their child was coping well enough to no longer require parental presence during the final venipuncture studied. Finally, the procedures and results of this investigation influenced the clinical practice of the treatment team. Many team members expressed satisfaction with the increase in cooperation and decrease in distress they observed in many patients. In addition, during the course of the study, the intervention strategies used were adopted into the standards of practice for the clinic. This included the use of EMLA for all needle sticks, the use of both verbal and tangible positive reinforcement, assigning children "jobs" during procedures, giving them choices whenever possible, and increased use of distraction.

This study presented several methodological limitations. First, due to a small potential sample size, as well as clinical team and parent objections, a control group was not included in the study design. This raises the important question of whether the changes observed were due to the effects of time, maturation, or experience with the procedure, rather than the intervention per se. Although our clinical observations prior to this investigation do not suggest this to be the case, it would be desirable to control for these factors in a future investigation by including a no treatment control group. However, given the difficulty of implementing such a design in a clinical practice setting, investigators could instead compare groups receiving different components of the treatment package. In this study, we were unable to determine the differential contribution of individual components of the intervention, as all subjects were exposed to multiple intervention strategies. Even though investigations with other pediatric groups found that EMLA alone is not as effective as cognitive behavioral strategies with or without EMLA (Cohen et al., 1999; Fanurik et al., 2000), this conclusion cannot be drawn for pediatric HIV infection based on our results. Further research is needed with this population to compare the relative effectiveness of the strategies included in our intervention, as well as to examine individual differences in response to these strategies. This will benefit clinical practice, allowing for treatment plan individualization following assessment of each patient's response.

Other limitations of this study include the focus on only one procedure experienced by children with HIV (venipuncture) and on patients who were relatively stable medically. Evaluating the intervention with other procedures and more acutely ill children will be valuable. In addition, limited sources of data were available for each outcome variable of interest. Future research with this population would be strengthened by multiple measures of pain and distress, including more sophisticated methods of observing and coding procedural behavior, and physiological measures of distress, such as heart rate.

Although further research is needed, our findings are an important first step in examining procedural pain management for pediatric HIV infection. As discussed, future investigations should compare the effects of the components of the intervention package, include longer term follow-up, and explore ways of tailoring the intervention to the specific needs of this population, such as finding creative ways to address parental participation. The intervention used in this study provides a good starting point for these efforts, as it is relatively

brief, easy to use with even very young children, and resulted in significantly improved procedural coping.

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