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The Effect of Preparation for Lumbar Puncture on Children Undergoing Chemotherapy

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At the University Hospital in Lund, Sweden, a preparation program was developed for children undergoing lumbar punctures (LPs) during chemotherapy for leukemia or lymphoma. Subsequently, a study was initiated to determine whether a preparation program for children prior to treatment would reduce their anxiety and improve their cooperation. This study also was undertaken to examine whether reinforcing the preparation information prior to each LP would be beneficial. The 30 children who participated in the study were divided into three groups: a control group whose members did not receive preparation and two other groups whose members were exposed to different numbers of preparation programs. The parents and the nurse in charge evaluated the children's reactions during treatment using two 6-point rating scales: an anxiety scale and a noncooperation behavior scale. Two unbiased, trained observers later viewed video recordings of the children's reactions and evaluated them using the same tools. In addition, each child rated his or her experience of pain on a 10 cm visual analogue scale. Based on these ratings, the groups were analyzed to determine if within-group differences existed from one treatment to the next and to determine if between-group differences existed at the various times of treatment. Few statistically significant differences were found, but the results indicate that the children in the most informed group exhibited sustained reductions in their perceptions of pain. This may signify that reinforcing the preparation information before each of the LPs enabled these children to cope with the pain more effectively. (*Oncology Nursing Forum*, Vol. 20, No. 1, pp. 39–45, 1993.)

Children admitted to a hospital face a new and unfamiliar situation. Pediatric patients with cancer may undergo many procedures and treatments over an extended period of time; therefore, helping children cope with this situation is important for the nursing staff. The international literature on hospitalized children suggests that all children need some kind of psychological preparation for the hospital experience (Chan, 1976; Eckhardt & Prugh, 1978; Mahan & Mahan, 1987; Ritchie, 1979; Schreier & Kaplan, 1983).

Numerous investigators have studied the effect of enrolling children in a preparation program prior to hospitalization and surgery. Most preparation methods emphasize the communication of information about forthcoming events. Vaughan (1957) studied a group of 40 children with a mean age of 5.9 years (range = 2.3–9.2 years). He found that psychological distress was more common in unprepared children than in prepared children. Tarnow and Gutstein (1983) presented data showing that the preparatory play behavior of children ages 4–9 may provide a means for predicting their adaptation to surgery and that coping behavior is related to what children are doing, thinking, and feeling during a stressful situation. Visintainer and Wolfer (1975) have shown that children ages 3–12 who receive a combination of systematic preparation, rehearsal, and supportive care prior to stressful procedures exhibit significantly less distress and are more likely to cooperate. Melamed and Siegel (1975) found reduced sweat gland activity, fewer self-reported medical concerns, and fewer anxiety-related behaviors in a prepared group of children ages 4–12.

Several investigators have studied the reactions of patients undergoing bone marrow aspirations and lumbar punctures (LPs). Brown (1984) found that children, infants, and toddlers become anxious and distressed, as indicated by crying, squirming, and perspiring, when they are subjected to LPs. The mother or an other family member seem to be the child's best source of security. Pediatric patients with cancer and their parents report that bone marrow aspirations and LPs are by far the most painful and traumatic events in the entire sequence of cancer treatment (Jay, Elliot, Ozolins, Olsson, & Pruitt, 1985). In their study of children undergoing repeated bone marrow aspirations, Kellerman, Zeltzer, Ellenberg, & Dash (1983) concluded that a significant relationship existed between anxiety behavior and the asking of questions. They also concluded that, over time, children do not habituate to (or become less distressed about) repeated procedures.

The purpose of the present study was to investigate the value of a psychological preparation program for children

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undergoing LPs during chemotherapy for leukemia or lymphoma. The hypothesis for the study was that a psychological preparation program would affect the children's and family's anxiety and the children's sense of pain. The study also was undertaken to examine whether reinforcing preparation information prior to each LP would be beneficial. The Committee on Ethics at the University Hospital in Lund, Sweden, gave its consent for the study.

Methods

Thirty children (11 girls, 19 boys) who were admitted for treatment of leukemia or lymphoma participated in the study. Their median age at diagnosis was 8.2 years (range = 4–17 years). The children were divided into three groups of 10. Children who already were receiving treatment were automatically assigned to Group 1, the control group. The remaining children were assigned randomly to Group 2 or Group 3.

The children in **Group 1** (seven boys, three girls; median age = 8.4 years; range = 4–17 years) already were receiving treatment, including LPs, when the study began. This group received no specific preparation.

The program nurse exposed the children in **Group 2** (five boys, five girls; median age = 8.0 years; range = 4–13 years) to the preparation program on one occasion prior to their first LP. These children were evaluated prior to each of their three LPs.

The program nurse exposed the children in **Group 3** (seven boys, three girls; median age = 7.5 years; range = 4–12 years) to the preparation program prior to each of their three LPs. The children in this group also were evaluated at each of these three occasions.

Clinical therapy during induction (in groups 2 and 3) consisted of

- Conventional induction therapy for lymphoblastic leukemia consisting of oral prednisone and weekly injections of vincristine and, over a six-week period, three injections of doxorubicin. Intrathecal methotrexate was administered four times during this six-week period. The evaluation was performed during three of these intrathecal treatments.
- A topical local anesthetic creme was applied to the intact skin one hour prior to the LP.
- Premedication consisting of 5–10 mg of benzodiazepine IV was administered in 20 of the 70 treatments (seven times in Group 1, six times in Group 2, and seven times in Group 3).

During the LP, the child rested on his or her side on the examination table with his or her back arched outward. The LP was performed by an experienced pediatric oncologist who always described to the child what was happening during the procedure. The LP usually lasted 10–15 minutes, beginning from the time when the child entered the examination room and ending when the child left the room.

The preparation program was adapted from a program proposed by Petrillo and Sanger (1980) and consisted of two major components:

- The program nurse used a doll named Martin to demonstrate the LP to the child and to familiarize the child with materials that would be used in the procedure (e.g., needle, syringe, sterile gloves, masks). The child or the program nurse performed an LP on Martin.
- The program nurse also reviewed with the child a book of photographs illustrating events from the time when the child is lying on the table during the procedure, with his or her back arched outward, until when the child is resting afterwards.

The program nurse assessed the child's understanding of the procedure and corrected any possible misconceptions.

The program nurse began the preparation program approximately one hour prior to treatment. The parents were present while the child received the information from the nurse. At least one parent and the nurse in charge were present during each LP. The child was videotaped during the procedure.

Instruments

Each child in Group 1 was evaluated during one LP. Four of these children had been receiving treatment for approximately 23–70 months prior to the observed LP, which was performed and evaluated during a relapse. The other six children in this group had been receiving treatment from one to eight months prior to the evaluation. The evaluations were obtained during the first two to three months after diagnosis for groups 2 and 3.

The children were evaluated using an anxiety scale and a noncooperation behavior scale. Both 6-point scales are based on objective, specific, and readily observable details of behavior that were tested and reported to be reliable and valid by Venham, Gaulin-Kremer, Munster, Bengston-Audia, and Cohan (1980) (see Figure 1). The scales have proven to be useful in assessing children's

Anxiety Rating Scale		Noncooperation Behavior Scale	
Score	Description	Score	Description
(0)	Is relaxed; is willing and able to converse	(0)	Cooperates fully; does not cry
(1)	Briefly protests; may have tears in eyes	(1)	Gives mild, soft verbal protest; exhibits appropriate behavior
(2)	Appears scared; verbally protests; cries quietly	(2)	Protests more forcefully; cries and gives hand signals
(3)	Shows great reluctance; protests (out of proportion to threat)	(3)	Complies with demands reluctantly; moves body
(4)	Appears distressed; generally cries (not related to treatment); moves body	(4)	Protests loudly; disrupts the procedure; moves body more forcefully
(5)	Cries loudly; is unable to listen to verbal communication; exhibits escape behavior	(5)	Generally protests; does not comply or cooperate; must be physically restrained

Figure 1. Anxiety and Noncooperation Scales Used for Rating Children's Reactions to Lumbar Punctures

responses to dental stress. A paired comparison technique had been used to establish interval level properties and accurate numerical scaling for the rating procedures. Inter-observer reliability coefficients, computed by correlating the three observers' ratings, ranged from 0.78 to 0.98.

The parents and the nurse in charge rated the responses immediately after the LP. Two medically or psychologically trained observers, who did not know the children, to which group they were assigned, or their diagnoses, later evaluated the video recordings. The observers also did not know about the circumstances (i.e., the preparation program study) involving the children, parents, or the doctor who performed the LPs. The observers watched the videos together, made notes separately, discussed each child, and then decided on the ratings together. Spearman-rank coefficients were calculated as a measure of agreement among the various observer categories (i.e., parent, nurse, or trained video observer). In all three comparisons, inter-rater reliability coefficients approached 0.8 ($p < 0.001$).

In addition, the children measured their perception of pain. Immediately after the procedure, each child was asked, "How much pain did you feel?" They responded by pushing the measuring stick of a visual analogue scale (VAS), which is a graphic rating scale ranging from 0 cm ("no pain") to 10 cm ("severe pain"). This technique is a modified version of a self-rating method described by Clarke and Spear (1964). An attempt was made to assess the method's sensitivity and reliability when used at frequent intervals. The method has been used in studies of children, primarily for measuring pain (Abu-Saad, 1984; Genti, Balint, & Borbas, 1980; Huskinson, 1974; Seldrup, 1977). Because pain essentially is a subjective experience, when assessing a child's pain, the child's perception of the experience must be emphasized.

Statistical Analysis

The VAS and behavioral scales, as ordinal scales, were analyzed using nonparametric procedures. The Mann-Whitney U test for significance of between-group differences was used for statistical evaluations. Correlations between the anxiety scale and noncooperation behavior scale were analyzed in all three groups using Spearman-rank correlation and contingency tables (chi-square). Nonetheless, some measures of central tendency and dispersion are presented as mean values and standard deviations (SDs). The paired t-test (two-tailed) was used to analyze the differences among the groups at different occasions.

Results

No statistically significant differences were found among the groups with respect to age or sex distribution.

None of the children in the study were under intensive care during the induction period. Four children in Group 1 had been treated with radiation therapy before their LPs were observed. All of the children were in good physical condition during the study, except for one child from Group 1 who had acute myelocytic leukemia (AML). The LPs were noneventful from a technical point of view. All of the children in Group 1 were outpatients, except for the child with AML. All of the children in groups 2 and 3 were inpatients.

All of the evaluations in this study were performed for Group 1 after one LP and for groups 2 and 3 after three LPs. At the time this study was conducted, 6 of the 10 children in Group 1 were to receive their 3rd through 10th LPs; the 4 remaining children had a history of more than 10 previous treatments. Presumably, the results from Group 1 would be comparable to the results from groups 2 and 3 at their third treatment, but this could neither be rejected nor confirmed based on the statistics from the observations. The children in Group 1 reported more pain, on average, than those in either Group 2 or Group 3 at the third treatment, but this is not statistically significant. The children in Group 1 who had received 10 or more previous LPs did not rate their pain higher than the children who had received a smaller number of previous LPs.

A comparison of the children's ratings on the anxiety and noncooperation scales revealed a strong degree of mutual association between these variables (see Figure 2). Paired anxiety and noncooperation ratings existed for 210 separate observations (all children and all occasions combined). Technically, a scale with only six discrete values is not amenable to rank correlation analysis (because of excessive numbers of ties). However, the degree of association between anxiety and noncooperation observations is evident. Seventy-three percent of the pairs showed exact agreement, while 95% were in agreement within a ± 1 margin of error. Therefore, these ratings were combined into a single rating (see Figure 2).

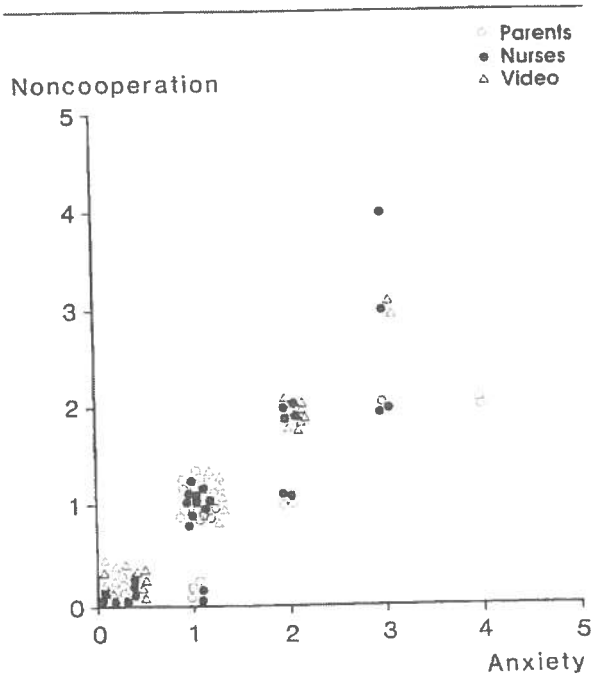

Figure 2. Association Between Parent, Nurse, and Video Observer Ratings of Anxiety and Noncooperation at T_3

Similarly, the ratings provided by parents, nurses, and the trained video observers were strongly associated at all occasions for the combined anxiety and noncooperation ratings (see Figure 3).

Spearman-rank correlation coefficients were calculated as a measure of agreement among the series of observations: parents versus nurses, $r = 0.79$ ($p < 0.001$); parents versus video observers, $r = 0.78$ ($p < 0.001$); and nurses versus video observers, $r = 0.83$ ($p < 0.001$). Based on these findings, the ratings of the three observer groups were combined and averaged and are referred to as "adult ratings" in this article.

In Table 1, mean adult ratings are presented by sex and age. No significant difference existed between boys and girls; however, a marginal difference was noted at time 3 (T_3), where girls were evaluated higher than boys ($p < 0.05$).

By age group, however, children under 8 years of age had higher adult ratings (i.e., the adults felt that the children cooperated less and exhibited more anxiety at all occasions) than the older children ($p < 0.001$ at time 1 [T_1], $p < 0.05$ at time 2 [T_2] and T_3). Children under 8 years of age evaluated their own pain on the VAS higher than did older children at all occasions ($p < 0.05$ at T_1). All three groups included approximately the same number of children under 8 years of age (Group 1, five; Group 2, six; and Group 3, five).

The VAS ratings decreased in groups 2 and 3 from the first to the second occasion; the control group's VAS rating was higher than that of the other two groups (see Figure 4). However, the changes were not statistically significant.

Table 2 demonstrates the percent reduction in mean scores over time. Adult rating reductions only slightly differed between groups 2 and 3. VAS ratings for Group 3 (these children were prepared three times), conversely, showed greater proportional reductions at T_2 and T_3 than the ratings for Group 2.

Adults tended to give low evaluations (i.e., less than 2.5) in association with high child VAS scores (i.e., greater than 4.5). Twenty-seven of the 70 observations of all groups at all occasions combined demonstrate this tendency. The incidence of low adult evaluations consistently was greater for Group 2 than for Group 3 (see Figure 5).

Table 1. Mean Adult and Child Ratings at Each Treatment Time by Sex and Age Group

Variable	Mean Adult Ratings			Mean Child Ratings (VAS Scores)		
	T_1	T_2	T_3	T_1	T_2	T_3
Gender						
Boys	1.93	0.92	1.24*	4.83	3.83	4.26
Girls	1.36	1.21	1.41*	4.63	3.88	4.36
Age						
< 8 years	2.76†	1.47*	1.80*	5.82*	4.09	4.38
≥ 8 years	0.41†	0.50*	0.73*	3.44*	3.56	4.21

VAS–visual analogue scale
* $p < 0.05$
† $p < 0.001$

Finally, the children's comments changed on successive occasions. Prior to the first LP, the children in groups 2 and 3 had many questions about the procedure, especially regarding the prospect of pain. After the preparation, they were surprised that the pain was not going to be worse. After the LP, they evaluated their pain as moderate. Four children in Group 3 asked specific questions about the procedure during preparation prior to the second treatment. One child declined more verbal information but looked at the photos ". . . to be sure what was going to happen."

At T_3, three children in Group 3 did not talk further about pain, instead they asked about the materials used in the treatment. In addition, two more children declined further information. After the LP, these five children rated their pain as 0 ("easy" or "no pain at all") on the VAS.

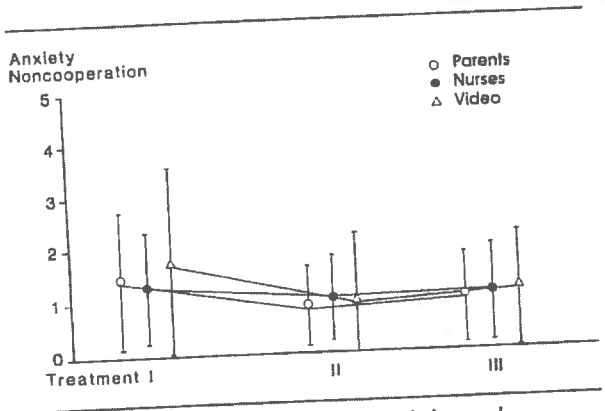

Figure 3. Combined Average Anxiety and Noncooperation Ratings by Parents, Nurses, and Video Observers at T_1, T_2, and T_3

Discussion

The children in this study were undergoing a long and difficult treatment for a potentially life-threatening disease. Chan (1976) states that a child's fear of the unknown is painful at any age. Preparing children helps them to cope in stressful situations (Blom, 1958; Broome & Hellier, 1987; Eckhardt & Prugh, 1978; Jay et al., 1985; Visintainer & Wolfer, 1975). The present study attempted to determine whether or not preparing children reduces their anxiety and their experience of pain.

Adult ratings for anxiety and noncooperation were very similar. Anxiety and noncooperation are closely related. Mahaffy (1965) reported that children ages 2–10 reflect their fear, apprehension, and anxiety in behavioral and physical reactions. Psychoanalytic theory based on clinical case studies suggests that the behavioral manifestations are symptoms resulting from anxiety in response to the hospital experience in children ages 2.5–14 (Jessner, Blom, & Waldfogel, 1952).

In this study, the ratings of the parents, nurses, and trained video observers revealed such a high degree of agreement that the reliability of these ratings must not be underestimated. They clearly describe something perceived jointly by the adult observers that is not necessarily shared in the children's reporting of their perceptions.

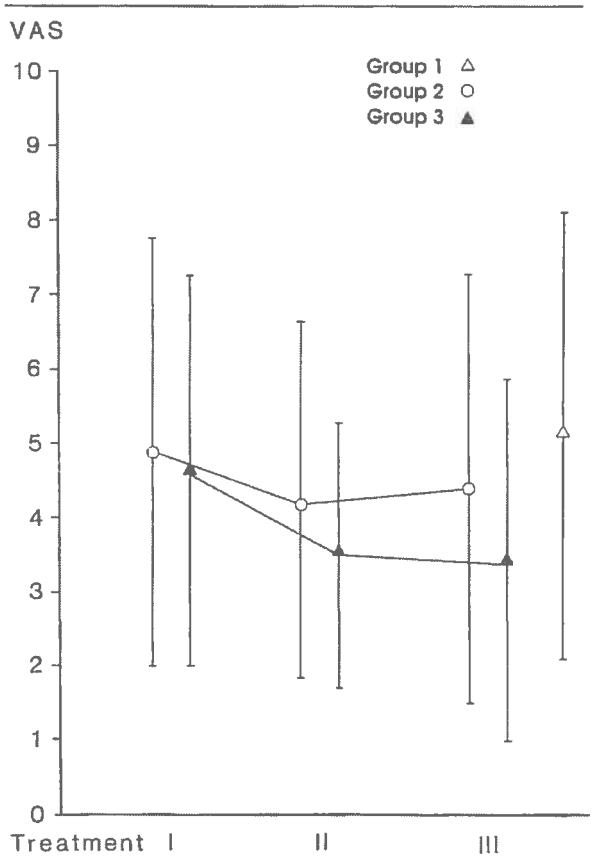

Figure 4. Children's Perceptions of Pain on a Visual Analogue Scale at T_1, T_2, and T_3

Interestingly, the children demonstrated a greater use of the full-scale range (see Figure 4) than the parents, nurses, and trained video observers (see Figure 3). All three groups of children may have hidden their reactions more or less during the procedures but afterward rated their own pain more realistically and honestly. The presence of the video camera during the procedures also may have inhibited their behaviors.

The adult ratings tend to fall on the lower half (i.e., less than 3) of the scale's range. If the VAS (which rates the child's perception of pain) and the adult scales (which rate the child's behavior and anxiety) are reasonably related and effectively scaled, then, presumably, VAS values above some arbitrary limit (e.g., 4.5) would tend to be associated with adult observations above some corresponding arbitrary limit (e.g., 2.5). Even if the VAS and adult scales are not being used to describe a shared perception of the experience, consistent usages among the groups would be expected. However, this was not the case. Of the 30 Group 2 observations, 16 high VAS values were associated with low adult average ratings of anxiety and noncooperation. In the 30 Group 3 observations, however, only six high VAS values were associated with low adult ratings (see Figure 5). The children in Group 2 received only one preparation program, whereas the children in Group 3 received three. Therefore, the reinforcement of information may explain the respective proportions of high VAS values. A large proportion of the high VAS values of the children in Group 1 also were associated with lower adult ratings. The children in the control group already were in treatment and were not specifically informed by the program nurse, but they had been informed in some unstructured way during the procedures and also had experienced the procedure previously.

The adult rating scales were selected based on the assumption that their full ranges would be used. However, the upper half of the adult scales went largely unused. Explaining the adults' consistent use of low values is difficult. The possibility that this might be a result of a faulty translation from the English language rating scale was tested by independently retranslating the scale definitions from Swedish back to English. No obvious connotative shifts were identified. At the planning stage of this study, no other published and tested scales were considered suitable. Cultural factors also must be considered. The usability of scales previously developed and tested in an American dental environment for a study in a Swedish pediatric clinic is open to question.

Frequency distributions resulting from the use of existing scales were necessarily nonparametric and, in the case of the adult scales, mainly limited to the range of integers 0–2. Measures of central tendency (e.g., mean, SD, median) are extremely difficult to interpret, especially when numbers are small and when underlying behavioral norms are not clearly differentiated among groups.

Another hazard that may be inherent in comparisons among groups is the possibility that the groups were not alike at the outset with respect to anxiety, noncooperation, or general temperament. This study was conducted based on the assumption that each group's characteristic psychological profile could best be defined by its performance at T_1 and that this would be taken into account when evaluating the results at T_2 and T_3. Although the mean adult scores at T_1 were consistently higher in Group 3 than in Group 2, the proportional reductions at T_2 and T_3 were nearly identical in the two groups. Conversely, VAS scores were consistently lower in Group 3 than in Group 2 and exhibited much greater proportional reduc-

Table 2. Percent Reduction of Mean Adult Ratings and VAS Scores Over Time

Variable	Mean Observed Score			Percent Reduction in Relation to Time 1	
	T_1	T_2	T_3	T_2	T_3
Mean Adult Rating (Range 0–5)					
Group 2	1.45	0.92	1.10	37	24
Group 3	1.95	1.15	1.50	41	23
VAS Scores (Range 0–10)					
Group 2	4.90	4.20	4.40	14	10
Group 3	4.60	3.50	3.40	24	26

VAS–visual analogue scale

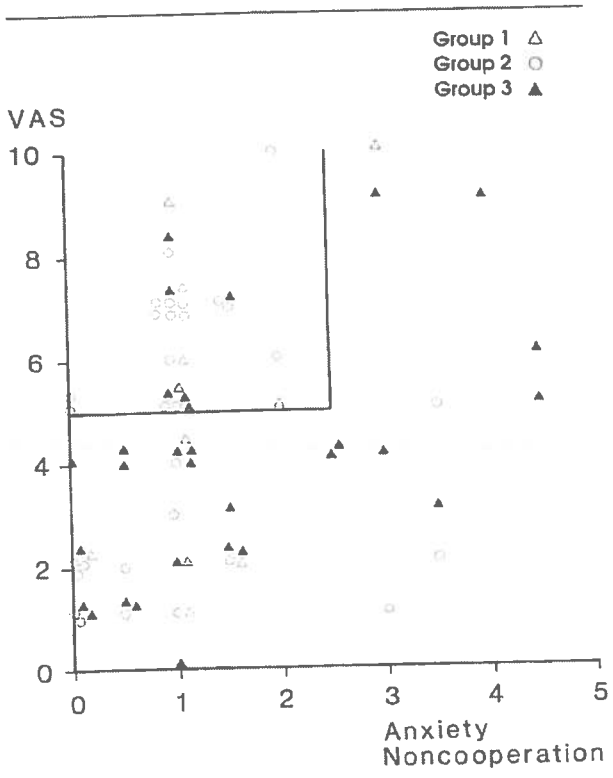

Figure 5. Children's Pain Ratings Compared to Adults' Ratings of Anxiety and Noncooperation

tions at T_2 and T_3 than at T_1 (see Table 2). This implies the possibility that the preparation program influenced the children's experience of pain at T_2 and T_3.

When the children were divided into age groups, it was evident that the adults rated children under 8 years of age as more anxious and less cooperative (see Table 1). These findings coincide with Mahaffy's (1965) results, which indicated that younger children had significantly higher distress ratings and cooperated significantly less than older children during blood tests and the administration of preoperative medication.

Does the long-term experience of LPs lead to higher or lower VAS, anxiety, and noncooperation ratings? In this study, the 10 children in the control group had undergone between 1 and 33 previous LPs ($\bar{X} = 14$). No statistically significant indicators of either negative or positive correlation between number of previous LPs and VAS or adult ratings were found.

Comments made by the children during treatment demonstrated much about their feelings and fears. Many expressed a greater understanding after the preparation program. In addition, the preparation program encouraged the children to express their feelings and anxieties. Conversely, a few indicated that they did not need more information after the first or second treatment, which raised the question of whether a child in this situation could become over-informed.

Some of the children who had been premedicated were frightened prior to the next treatment because they did not remember what had happened previously. This effect also has been observed in other studies and raises questions about the benefits of premedicating children in these situations. Månsson, Fredrizon, and Rosbert, (1992) found that children receiving preparation reacted similarly to those who had received premedication. Theoretically, this could provide a reason for not automatically using premedication when information alone is adequate; however, this decision should be made based on each child's special needs.

Conclusion

The results of this study indicate that a child's perception of pain does not necessarily agree with his or her display of anxiety and noncooperation as perceived by adults, including parents. The children's own ratings of pain often were high in relation to anxiety and noncooperation as judged by the adults. Although not statistically evident, the repeated information program may have affected the children's ratings of pain more than the adults' ratings. Regardless of the children's behavior during the LPs, it was interesting to observe the eagerness with which most of them participated in the VAS evaluations. The information process seemed to have many beneficial effects on the children's cooperation in stressful situations and also may have helped them express their feelings openly. Much more research is needed to define the importance of clinical contacts with children.

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