

answer the questions posed in appellate litigation, recent opinions clearly constitute an implicit invitation for relevant research. In particular, the courts have identified aspects of child witnessing—especially the circumstances under which child statements are elicited—that will be critical to judicial evaluation and admission of child evidence. Identification and explanation of the effects that interviewing and reporting conditions can have on the reliability of child witness reports will be of great interest to the courts. Authoritative summary statements of conclusions based upon this research will be particularly helpful to courts seeking to determine the conditions under which child witnesses will be allowed to testify and the conditions under which their reports to adult witnesses will be independently admissible. Researchers interested in guiding this evaluation process are likely to find their studies are eagerly received by the courts.

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# 9

## Understanding Children's Memories of Medical Procedures: “He Didn’t Touch Me and It Didn’t Hurt!”

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### MEDICAL PROCEDURES: A CONTEXT FOR STUDYING MEMORY AND EMOTION

All children in our society are subject to medical procedures sometime during the period from birth through 6 years-of-age to assess health status, prevent diseases or to diagnose and treat illness. Most healthy infants and young children experience annually body touch and handling by medical staff using a stethoscope, otoscope, a thermometer, a tongue depressor, and a hammer during routine pediatric examinations. Nearly every child will have experienced “the needle” prior to entrance in public school programs, as we strive for our national health goal that all young children be inoculated against common childhood diseases. During periods of acute illness or following accidental injury, a young child may be introduced to additional medical procedures if, for example, she or he required to give a urine or blood sample or have an X-ray taken. Approximately 10 to 15% of the children in our society, cutting across all ethnic and socioeconomic groups, have a chronic, sometimes life-threatening, disease that requires vigorous, repeated, and often very painful medical procedures (Hobbs, Pettin, Ireys, 1985).

Whether healthy or ill, a child’s encounter with a medical procedure presents a complex set of stimuli which may compel a child’s attention, elicit strong emotions, and evoke a broad range of coping strategies. A richly textured, highly personal event or scenario such as this is likely to be remembered. To date there are few research studies on children’s memory of medical procedures, and even fewer that explore the impact of the affective experience of medical procedures on a child’s subsequent memory of the event (Peterson, Harbeck, Farmer,

Zink, 1991). However, there are research data in three related fields that can be drawn upon for the design and interpretation of studies of children's memory of medical procedures. First, there are clinical vignettes and case studies in the pediatric literature reporting children's experience with illness, medical procedures, and hospitalization extending back at least 50 years (Bergmann & Freud, 1965; Jackson, 1942; Jessner, Blom, & Waldfogel, 1952; Levy, 1945; Pearson, 1941; Plank, 1971). The majority of this work has focused on unique defensive or protective functions of children's emotional responses to illness and is based on observations of individual children made by pediatric or psychiatric staff members in hospital settings. One particularly rich report in this genre is based on a diary kept by Joyce Robertson of her daughter's 3-day hospitalization for a tonsillectomy (Robertson & Freud, 1956). Details of Robertson's report will be reviewed later in this chapter as it describes the child's anticipation and memory of medical and surgical procedures over a 6-month time frame.

Second, investigators interested in children's memory of medical procedures may benefit from the findings of studies on the development of children's understanding of the causes of illness. Research was initiated in the early 50s by Nagy, a Hungarian psychologist, who documented what healthy and hospitalized children knew about body contents, function and dysfunction. Initially chronological age differences were sought (Gellert, 1962; Nagy, 1953; Williams, 1979); then children's explanations of illness causation and treatment were framed by the structural differences of Piagetian cognitive stages (Bibace & Walsh, 1980, 1981; Brewster, 1982; Carandang, Folkins, Hines, & Steward, 1979; Myers-Vando, Steward, Folkins, & Hines, 1979; Neuhauser, Amsterdam, Hines, & Steward, 1978; Perrin & Gerrity, 1981; Perrin, Sayer, & Willett, 1991; Potter & Roberts, 1984; Steward & Regalbutto, 1975; Sussman, Dorn, & Fletcher, 1987; Whit, Dykstra, & Taylor, 1979). Currently, emphasis on a child's domain specific knowledge including unique expertise with illness (Bearison, 1990; Eisner, 1989; Siegal, Patty, & Eisner, 1990) children's self-attributions with regard to their illness/injury (Moss, Steward, & Racusin, 1992), and attention to the beneficial effects of illness on social, emotional, and cognitive development (Nelms, 1989; Parmelee, 1986) are augmenting the age/stage-based developmental hypotheses.

Third, research on children's experience of pain, though lagging far behind research on adult pain (Bush & Harkins, 1991; Ross & Ross, 1988), is important, for pain may play a critical role in mediating children's memory of medical procedures. Pain has been defined by the International Association for the Study of Pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey, 1979). Ross and Ross (1982), in their interviews with nearly 1000 children, have demonstrated that children think about and remember their own painful experiences. The initial work on the clinical assessment of children's pain was conducted by pediatric nurses because of their concern about undermedication of postsurgical and burn patients (Eiland, 1974; Eiland & Anderson, 1977). Nursing

research also evolved from the pragmatic need to determine when to administer analgesic medication ambiguously ordered "PRN" (pro re nata) by children's physicians (Zeltzer, 1991). A wide variety of tools have been developed to assess the quality (Wilkie, Holzemer, Tesler, Ward, Paul, & Savedra, 1990) and quantity (Beyer & Wells, 1990; Kuttner & Lepage, 1989; Lollar, Smits, & Patterson, 1982; McGrath, 1987) of young children's self-report of pain and to code the behavioral (Jay, Ozolins, Elliott, & Caldwell, 1983) and biochemical distress that pain evokes (Gunner, Hertsgaard, Larson, & Rigatuso, 1992).

Careful studies of children's memory of medical procedures may contribute to three quite distinctive endeavors. First, children's memory of necessary but painful medical procedures can contribute to the growing research literature on children's event memory (Bearison & Pacifici, 1989). Second, the documentation of children's memory of medical procedures may enhance the clinical care of ill children as the information will enable medical staff who must administer necessary procedures to do a better job of preparation and follow-up with individual children (Jay, 1988; Melamed, 1991b). Third, the results of research on children's experience of medical procedures may provide an ecologically valid empirical data base from which to interpret reports from investigative or therapeutic interviews of children's memory of other emotionally charged events centered on the body such as their observation of domestic violence or their direct experience as victims of child physical and sexual abuse (Goodman, 1984; Melton, 1981).

In the next section I offer an operational definition of medical procedures and the relation of such procedures to stress. Then, I discuss characteristics of young children's memories and, finally, three models of the impact of distress on memory.

### What Are Medical Procedures?

We have defined a medical procedure as "any procedure conducted or supervised by medical personnel for the purpose of evaluating or modifying health status" (Steward & Steward, 1981). This definition includes three essential components—the what, the who, and the why. These components incorporate an inherent developmental perspective. The first component in our definition of medical procedure—"any procedure"—focuses on the child's sensorimotor experience of just what is happening as the medical equipment required for the procedure is brought into juxtaposition to his or her body. Medical procedures range widely and from the child's perspective include such activities as standing in stocking feet on the doctor's scales to be weighed and measured, feeling the cold stethoscope pressing on one's chest or back as the doctor listens to the heart and lungs, experiencing the prick of a needle and watching the bubble begin to develop just below the skin when a TB test is administered, or being physically restrained by tape and belts on an X-ray table as a big metal plate is lowered

overhead. Attention to the sensorimotor information predominates, regardless of the age of the individual receiving the procedure. The sight, sound, smell of the procedure and all kinesthetic, proprioceptive, and nociceptive (painful) experiences are often vivid, rarely verbalized, yet apparently rarely forgotten.

The second component of our definition of medical procedure—"conducted or supervised by medical personnel"—focuses on who is administering the procedure. For young children it is nearly always a medical staff member or a parent under medical staff direction who is responsible for administering a procedure, but increasingly for children as young as six, the child may self-administer a procedure under the direction of medical staff. For most children there are increasing choices, as they become developmentally appropriate, in the process of administration. For example, a child may be asked in which arm she or he prefers to receive an injection. This shift in the child's role from a passive to a collaborative or active participant is seen as contributing differentially to the child's cognitive and emotional experience of the procedure and may impact the child's memory of the experience as well. (Note that home remedies, such as a parental "kiss-to-make-it-well," or the kindergarten teacher's placement of an ice cube "between the pain and the brain" are not included in this definition. Nor is children's unsupervised self-medication, although these events merit study.)

The third component of our definition of medical procedure—"for the purpose of evaluating or modifying health status"—focuses on the reason for the procedure. In Piagetian terms, we believe that it isn't until an individual is a concrete operational thinker that medical procedures can be categorized accurately as diagnostic or treatment procedures. Young children, regardless of what they are told, sometimes confuse the two different purposes, believing that every procedure will "get me better." Adults who are poorly informed, or whose cognitive faculties are compromised by anxiety, illness, or both often confuse the purpose of medical procedures as well, giving rise to curative placebo effects following procedures that are solely diagnostic. Regardless of the mandate for informed consent, it is probably only the person able to mobilize formal operational thinking who can evaluate the probable physical and psychological impact of diagnostic or treatment procedures on their health status and subsequent quality of life.

### Are All Medical Procedures Stressful?

This question is not as simple to answer as it might first seem—and it is one that must ultimately be answered by the child who experiences the procedure, a point to which we return. I have developed a three dimensional, intersecting matrix in order to describe the relative distress that a child might experience with any particular medical procedure (Steward, 1988). The dimensions include the following: (a) the relative painfulness of a procedure (this may range from no pain to excruciating pain); (b) proximity of the equipment used in the procedure to the

body (this may range from diagnostic or treatment procedures that do not touch the body to those that penetrate body boundaries, e.g., breaking the skin or penetrating a body orifice); and (c) the cognitive congruence with the child's understanding of the need for the procedure (ranging from the procedure being consonant with the child's understanding to being totally incongruent and incomprehensible to the child). These dimensions have been drawn from the clinical literature and our own clinical observations of ill or injured children.

Our clinical observations suggest that it is likely that any procedure that falls at the upper extreme of any of the three dimensions will be experienced by a child as distressing. Of course, any procedure that hurts is distressing, and when the procedure needs to be repeated frequently, anticipatory fear and anxiety increase the stressfulness of the experience—even if a child understands why it is necessary. Invasive procedures that break body boundaries or place Q-tips, hands, tubes, or instruments into body orifices are stressful for they are experienced by children as unwanted, and apply described as invasive. Procedures that children don't understand, even if they are described as noninvasive and painless, can be very distressing to children. For example, if an X-ray of an arm can reveal a broken bone, and results in a cast being placed on the broken arm, it all makes good sense to the child. But shift the target of the X-ray or CT scan to the same child's head, and the child may become very agitated believing that the doctor is trying to read the bad thoughts in her mind.

Procedures that fall in the three dimensional space defined as painful, invasive, and incomprehensible appear to be cognitively and emotionally the most distressing for children. All procedures that involve a needle as the most salient feature, for example where it is used to take something out of the body (e.g., blood or spinal fluid) or to put something into the body (e.g., medication, live virus, etc.), fit that description. Further research is needed to determine if the contributions of the three variables are additive or multiplicative.

### YOUNG CHILDREN'S MEMORIES

Most of our work is with young children, ranging from infancy to 6 years-of-age, and therefore we have become particularly interested in the characteristics of early childhood memory. Nelson (1989), a pioneer in the study of event memory of young children, has identified the following features. First, a young child's memory is rarely deliberate. Second, the content of early childhood memories consists primarily of events that were directly experienced by the child. Third, most of the content of the young child's memory is inaccessible to retrieval later in life. Fourth, memory can be manifested in a variety of intentional behaviors, including verbal response. She notes, in addition, that the child may remember more than he or she can tell.

We have found it useful to place Nelson's characteristics of young children's

memory within a dual memory system, a developmental framework proposed by Pillemer and White (1989). The authors have described the first memory system, which is present at birth and continues to predominate into early childhood, as containing the memories that are organized and evoked by an infant's experiences of persons, location, and emotion. Situational and affective cues access these memories that are experienced through images, behaviors, or emotions. The first memory system is not verbally mediated, nor are the memories easily *transported* outside the original experiential stimulus context. The second, language-based memory system posited by Pillemer and White begins to develop in early childhood. Memories are accessible in this socially connected system through intentional retrieval efforts in contexts other than the original learning environment. Event representations are encoded in narrative form or processed into verbal symbolizations, and are brought into *socialized memory*.

The model of the dual memory system suggests that young children who experience medical procedures may store different facets of the experience in each of the two systems, depending on their cognitive development, language skill, and/or emotional distress. It may also be that even after the language-based memory system is well established, some facets of the memory of older children, adolescents, and adults for a specific medical procedure that evokes strong emotional responses will also be stored in the first memory system. Pillemer and White posit that the two systems function separately but both may continue to operate throughout the life span. The theory suggests that even after the language-based memory system is established, some experiences are powerful enough to leave a person speechless, and memories stored in the first system will not be easily retrieved by a simple verbal interview.

### Models of Memory and Distress

What is the impact of distressing emotional experiences on children's memories? There are two models that might be posited to predict differential memory of the event utilizing the variable of the relative distress of a medical procedure and a third model that factors self-evaluation of one's role in a stressful experience and the frequency of occurrence into the model. First, a simple linear model suggests that the more distressing the experience, the more a child would be able to remember it. Earlier, I identified three potential sources of stress from our clinical work with ill children (painfulness, invasiveness, and incongruence of a medical procedure with the child's understanding of his or her needs). This model predicts that children who experience more distress as a result of pain, invasiveness, and/or incongruence, also experience increased arousal and alertness which accompanies distress and thus are able to remember more about the events of a medical procedure than can children who were less distressed (Gold, 1987).

A second model suggests a cubic relationship such as the inverted U-shaped

curve. The cubic model predicts that if an experience is either of neutral valence (eustress) or extremely distressing it will be remembered less well than if the emotional experience is mid-range. Many link this model back to the work of Yerkes and Dodson (1908) in which they tested the relationship between the strength of the negative reinforcement and the number of trials needed by the dancer mouse to learn a visual discrimination task.<sup>1</sup> On the extreme left hand side of the curve fall experiences that are not experienced as sufficiently distressing for an individual to enlist perceptual or cognitive skills to appraise or cope. There is little to remember about the event. On the extreme right hand side of the curve there are intense emotional experiences. Easterbrook (1959) demonstrated experimentally that intense emotional experience limits the range of perceptual cues that an individual is able to process, a mechanism that inhibits an individual's performance and subsequently the ability to recall an event.

There are at least two data sets, one from adults in dangerous environments (Baddeley, 1972; Broadbent, Reason, & Baddeley, 1991), and another from traumatized children (Terr, 1991), which suggest that both the linear and the cubic models are too simple to be useful to explain the relationship between distress and children's memory of medical procedures. Research by Baddeley acknowledges the impact of perceptual narrowing on performance in dangerous environments described by Easterbrook, but suggests that an individual's performance in a dangerous situation will improve if she or he believes that performance on the task is important. Performance will deteriorate, as predicted by the cubic model, only if the task is deemed by the individual to be peripheral. A child's evaluation of the relative importance of his role during medical procedures—regardless of the specific assignment—may be dependent on the skill of parents and medical staff during the preparation phase to convey not only what the child is expected to do during the medical procedure (e.g., to hold the left arm very still), but why it is important that the child do it just that way (e.g., so the procedure can be done quickly, won't have to be repeated, will hurt less, etc.). Baddeley further predicts that with repeated experience in dangerous situations individuals inhibit anxiety, judge the experience as less dangerous and thereby reduce the amount of impairment to performance of peripheral tasks, and may remember peripheral tasks better.

Terr (1979, 1983, 1988, 1990, 1991) has focused on children's memory of extremely stressful, traumatic experiences in which, by definition, children are helpless. She has hypothesized that under these conditions it is the relative frequency of occurrence of a stressful event that differentially impacts a child's memory. Childhood trauma is defined as "... the mental result of one sudden

<sup>1</sup>It should be noted that in the original data set published by Yerkes and Dodson the U-shaped curve described the relationship between stress and performance when the discrimination tasks were moderately or very difficult, while a linear model described the relationship of stress to learning when the task was easy.

external blow or a series of blows, rendering the young person temporarily helpless and breaking past ordinary coping and defensive operations. . . . All childhood traumas originate from the outside. . . . Once the events take place, a number of internal changes occur" (p. 11). Terr (1991) has described two categories of trauma: (a) Type I disorders result from a one time occurrence, an unanticipated "single-blow," while (b) Type II disorders result from repeated exposure to extreme external events. Terr asserts that children's memories to Type I trauma are reported in "amazingly clear and detailed fashion" whereas memories of children suffering Type II trauma "appear to be retained in spots rather than in clear, complete wholes." Children's reports of events causing Type II trauma are characterized by a number of defensive strategies which might interrupt the memory such as denial and self-numbing, self-hypnosis and dissociation, and rage (which paradoxically is dealt with by extreme passivity).

A third model of the link between relative distress and memory, incorporating the work of Baddeley and Terr, resembles a graphic overlay of the linear and cubic models. The linear prediction of high memory performance about a highly stressful experience holds for a single traumatic event and/or one in which the child perceives him or herself to play an important role; repeated traumatic experiences that render the child helpless depress memory with the y axis dropping theoretically to total amnesia at the zero point. Terr typifies the child who has experienced a Type I trauma as repetitively reviewing the traumatic experience mulling the question, "How could I have avoided it?" This psychologically driven rehearsal of the child's behavior before and during the event may serve ego defensive purposes and suggests à la Baddeley a child's post hoc attempt to assign a significant role in the event to herself. The third model of stress and memory predicts that both rehearsal and role reassignment processes contribute to strengthen a child's memory of the event. The child who has experienced Type II traumas is existentially alert asking, "How will I avoid it next time?" The process of drawing attention away from the past event limits rehearsal and fails to assign a child an important role in the past traumatic event. The third model predicts that these experiences lead to a deterioration of memory about a past event. The current pediatric population offers a potential resource for testing empirically the usefulness of each of the three models for predicting or describing the link between experiences that are emotionally stressful and memory. Anna Freud (1952) asserted that it is not the severity of the injury or illness that is important in determining the relative stressfulness of that experience for a child, but rather the meaning of the illness to the child. Research results support Miss Freud's caution by documenting that parents share a common judgment about the relative stressfulness of specific medical procedures (Watt-Watson, Evernden, & Lawson, 1991), but children do not (Beyer, Berde, & Bounaki, 1991; Lehmann, Bendebba, & DeAngelis, 1990). Terr (1991) has extended that discussion by identifying some of the "internal changes" that a child must invoke to cope with repeated events that he judges to be traumatic, which interfere with

subsequent recall of the events. In order to test any of the models of the link between memory and emotion in the context of medical procedures, the assessment of a child's distress and judgments about the importance of the child's role in medical procedures must be made by the child. Of course, children's assessments may change over time. It is possible, for example, that with experience a child's judgment about the relative *dangerousness* of a particular medical procedure may diminish and future encounters may become less memorable. With maturity the judgment of the relative importance of his or her role is likely to be proportional to the child's participation in the administration of a procedure (such as when a diabetic child takes over the role of testing her own blood glucose). Memory may be enhanced with increased responsibility. It may be useful, both theoretically and clinically to collect judgments from adult observers (e.g., parents, medical staff, research assistants) about the child's distress, for discrepancies between adult and child judgment can provide another independent variable which may contribute to the predictive power of any of the models. However, adult judgments of child distress or importance should never be substituted for the child's judgment.

The biochemistry of distress and memory in children has not been studied extensively but clearly offers another set of variables anchored in the child's body. Stress can be measured most easily by assessing changes in cortisol levels in a child's blood or saliva. The stress system plays a critical role in setting the level of arousal, and interacts with other central nervous system elements that influence the retrievability and analysis of information, the initiation of specific action and the setting of the emotional tone (Chrousos & Gold, 1991). Jay and her colleagues (Jay & Elliott, 1990; Jay, Elliott, Katz, & Siegel, 1987) have explored simultaneously multiple measures of children's distress (e.g., self-report estimates of distress, behavioral observations of a child's distress, and cortisol levels) during medical procedures, but to my knowledge there has been no research on the incorporation of biochemical measures of stress into an optimal set of child stress variables to predict memory.

Finally, it should be noted that research on memory and emotion in the context of medical procedures can shed light on only a limited range of emotional experiences from neutral to negative at the time of encoding. Early versions of coding systems used to record children's behavior during invasive medical procedures included such categories as laughing and smiling. Those have been deleted in later versions because of infrequent use. Ross (1989, personal communication) reported that when children are asked to give advice to doctors, one of their common requests is that the doctors "don't be too jokey!" In a new study that is currently underway (Steward, Reinhart, Joye, & Steward, 1992), a colleague urged us to include the question, "Did you do anything fun with the doctor today?"—no child has yet answered "Yes." In addition, professional ethics preclude experimental manipulation of mood at postevent interviews, although note could be made of the child's mood by the interviewer.

## DOING RESEARCH ON CHILDREN'S MEMORY IN MEDICAL SETTINGS

### The Laboratory versus the Natural Setting

There is a lively debate occurring among memory researchers about the relative merits of the study of memory within the confines of the laboratory versus memory study in the setting of the "everyday" (Banaji & Crowder, 1989; Loftus, 1991). This is a discussion that was initiated more than a decade ago by Neisser (1978) and by Bronfenbrenner (1979). The discussion is not only about the relative amount of experimental control; it is, as Neisser (1991) pointed out, also about the interaction between research subjects and the setting. Neisser (1988) asserts that a person is always nested in an environment that contributes to and extends the complexity of the phenomena to be studied. For those interested in children's memory, research in the natural setting is important, for it has been documented that the capacities of children to perform and remember are often underestimated in a laboratory situation (Ceci & Bronfenbrenner, 1991).

Schneider and Pressley (1989), reviewing research on children's memory, observed that most researchers accept a memory model in which contextual and motivational variables are presumed to be important determinants of memory. But for the most part, these same researchers continue to study memory without regard to naturalistic situational or motivational states. Schneider and Pressley call for work on interindividual differences and intraindividual differences in children's memory performances in order to understand consistency across situations. For those of us who are interested more specifically in the impact of traumatic events on children's memories, research in the natural setting becomes even more compelling. Fabes and his colleagues (Fabes, Eisenberg, McCormick, & Wilson, 1988; Fabes, Eisenberg, Nyman, & Micalieau, 1991) assert that it is possible to study a range of children's emotion and experience in the natural setting, the circumstances of which would never pass a human Subject Review Committee, nor receive parental approval were they proposed for a laboratory setting. And unlike a child's participation in a laboratory setting, in a medical setting if a procedure is deemed necessary, a child may not refuse to participate.

### OBSERVATIONS ABOUT MEMORY IN THE MEDICAL SETTING

The medical setting offers more diversity than do laboratory settings. For example, the physical and psychosocial settings in which children experience a medical procedure may range from a calm, child-friendly private office of a beloved pediatrician to a chaotic, impersonal emergency room of a large metropolitan hospital or even to a child's hospital bed. A child may be surrounded by a three

generational delegation of family members, sit on a parent's lap throughout a procedure or be handed over to a medical staff person by a transportation worker of half hour's acquaintance to cope with the experience alone.

Many of us who have worked with children in medical settings have been impressed with what we believe to be the detailed and uncanny accuracy of children's memories of specific medical experiences. Children's memories of who, what, where, and when seem to be particularly vivid in the medical setting. For example, children can describe, and often name, the nurse who "doesn't do the shots good," the size of the needle used in a blood draw, exactly where a little girl was when her broken arm was set, and whether a boy's surgery was before or after Halloween. Children sometimes remember what happened to them in the hospital more accurately than their parents or their doctors (Beauf, 1979). Furthermore, many adults retain clear memories of their childhood accidents, injuries, and illnesses (Massie, 1985).

It is now possible to test hypotheses developed from the rich clinical vignettes of children's experience in medical settings: to document their experiences and subsequently to determine just how accurate, complete, and consistent their memories are. From a methodological perspective, by placing videocameras in pediatric settings, one can insure an objective record, an atheoretical flow, if you will, of events, actions, and language against which to compare children's later reports of events. It has been our experience that there has been little objection to making the video recordings when cameras are inobtrusively mounted (for example in one corner of the room) and when they don't take floor space or interrupt swift, but unpredictable movement of children, parents, or staff.

We have found that access to medical records (increasingly computerized, may still be necessary to clarify events that children experience and later report but that are not shown on camera. Sometimes in our work a doctor's body fills the screen and we would have miscoded a child's description of "the pump and the ribbon thing" if we had not found notation of a child's blood pressure in the medical record. We have found, however, that, as a rule, a child's medical record is far sparser than the video record. For example, medical staff rarely note in a child's medical record how many "tries" or persons were required to start an I.V. successfully, or the names of medical students or staff who were present for part or all of a medical or surgical procedure. Never does the medical record reflect the often subtle communication between medical staff and parent, or any but the most extreme expressions of emotional behavior of a parent or child.

The earliest work in the pediatric literature that speaks to the issue of children's memory of medical procedures can be found in clinical vignettes and case studies. For developmental psychologists, the carefully documented case study is the oldest method of collecting data on child behavior (Achenbach, 1978). There is renewed interest in the case study method for generating and testing hypotheses about mechanisms that, for example, contribute to cognitive development (Siegler & Crowley, 1991) and for tracking individual response to pediatric

human immunodeficiency viruses (Fletcher, Francis, Peguegnat, Raudenbush, Bornstein, Schmitt, Brouwers, & Stover, 1991). The limitations to generalizability of the findings of an observational study of an individual child are balanced by the opportunity to review a child behavior's longitudinally, usually in natural settings.

The observations reported next were selected from the diary that Joyce Robertson (Robertson & Freud, 1956) kept over a 26-week period about her daughter's tonsillectomy. These data are presented in the best tradition of the "baby biographies" written by parents such as Charles Darwin (1877) and Jean Piaget (1952, 1954). Robertson's piece provides an introduction (or reminder) to the reader who may be unfamiliar with young children's medical experiences and will serve as a template to identify some thematic issues with respect to children's anticipation, experience, and memory of the events and people surrounding medical and surgical procedures.

The classic theoretical paper on children's response to illness, "The role of bodily illness in the mental life of children," was written by Anna Freud in 1952. Robertson's work provided an important translation from theory to a clinical data base, and Anna Freud wrote an appreciative interpretive piece that was published along with the diary. Although neither Anna Freud nor Joyce Robertson focused explicitly on memory, each author had something to say about the link between the illness experience and the child's memory of those experiences.

### An Early Case Study

Joyce Robertson's (Robertson & Freud, 1956) diary about her 4-year-old daughter Jean's trip to the hospital for a routine tonsillectomy was begun 6 weeks before hospitalization. It includes daily entries until 3 weeks after the return home, and a brief addendum to summarize events from the 11th to the 20th weeks home. The results suggest that the anticipation and memory of the events of a 3-day hospitalization, which included brief medical and surgical procedures deemed successful and unremarkable from a medical perspective, filled Jean's life for 6 months.

It should be noted that this was no ordinary vignette. It is interesting and important for historical and psychodynamic reasons. First, just prior to Jean's hospitalization, her father, James Robertson (1953a), had completed an astonishingly poignant black and white, silent film entitled, "A Two Year Old Goes to the Hospital." The film, by documenting the surprise, terror, and subsequent depression of a toddler "abandoned" by parents to medical staff, challenged the wisdom of the then current practice in Great Britain and the United States of separating the young patient from the parent during hospitalization. Jean's father not only had begun a revolution that would impact a number of decisions about hospital care of young children (a revolution that is unfortunately not yet complete today), he also created some of the first materials to prepare children for

hospitalization (Connell, 1953; Robertson, 1953b). Thus Jean had easy access to the hospital stories of two children she named "Tonsil Boy" and "Laura."

Second, Jean had the benefit of an unusually sensitive, patient, and observant mother. Joyce Robertson faithfully recorded Jean's words and deeds reflecting her daughter's anticipatory distress, her behavior during the course of hospitalization and posthospital recovery. Mrs. Robertson was a participant-observer, for she was her daughter's fulltime and primary parental caretaker at home. In addition she stayed in her daughter's room throughout the hospitalization and arranged to provide all but the most technical of nursing care during her daughter's hospital stay. All of this occurred during a period of time when parents were typically allowed to visit their children in hospital *one hour a week!* Third, Anna Freud was a family friend. Miss Freud was so impressed by Joyce Robertson's diary notes that she changed her stance on the potential scientific contribution which could be gleaned from mothers as observers of their own children.

In spite of all these extraordinary features, 4-year-old Jean still had a rocky time. I rehearse briefly Jean's experience during three periods—the preparatory phase, the in-hospital phase and the posthospitalization phase at home.

*Preparation.* Even though Joyce Robertson had planned to wait to prepare Jean until a week before the surgery—recommendations that we still give today to mothers of preschoolers—Jean overheard during an outpatient visit her doctor's decision to schedule a tonsillectomy for 6 weeks hence. The very next day she began to give clues that she had some understanding of what might lie ahead for her and that she didn't like the idea at all! Her protest included a refusal to eat, then a refusal to use silverware, linking eating with the planned assault on her throat; initiation of knife play on herself, her mother, furniture; separation anxiety—taunting her sister that mother would stay in hospital with her, but requesting that Daddy stay too; the definition of operation as punishment and equation of medical staff with policemen and the hospital with prison; repeated discussion of, then rejection of, other children's illness/death and increased accident-prone behavior. Jean's troublesome behavior not only signaled the need for repeated clarification and expansion by her mother of up-coming events, she initiated preparatory activities herself by rummaging through her father's papers to find the stories of "Tonsil Boy" and "Laura," asking that they be read to her many times each day.

*Postsurgery.* Apparently Jean was fascinated by her lack of memory for an event that occurred in which her body was not only touched and handled, but actually had a piece cut out. She repeatedly marveled at her absence of memory. She had been well-prepared for the special sleep, for some pain following the surgery, and even for the experience of "not remembering." Postsurgery she verbalized again and again, "You were quite right, Mummy. My throat does

hurt a lot—but I didn't feel them come out." She repeatedly asked her mother to rehearse the scenario beginning with the preparatory pills and injection through the trolley trip, the funny smell, the surgery, the return to her room, and finally mother beside her reading a story. Following each rehearsal, Jean had many questions—sometimes about the doctor, other times about the special room, or the exact location of her tonsils ("were my tonsils in my nose too?")—which allowed her mother to elaborate the story.

My favorite episode in the story came when Jean demonstrated her accurate memory for a presurgery injection 3 days after surgery by speaking in "a friendly way to her Big Nurse, but then {she} shot a flying toy which hit the Big Nurse's leg." Six days postsurgery, while bouncing her head on and off a pillow, she asked her mother "Was it yesterday you kept telling me to lay my head on the pillow? I didn't want to—I wanted to sit up." The interchange to which Jean was referring between herself and her mother had occurred just half an hour after the surgery—a period most believed she would not remember.

*Posthospitalization.* Three features stand out in Joyce Robertson's rich description of the posthospital period. First, although Jean's memory for the exact spot on her leg where she received an injection continued to be accurate, she changed temporarily the identity of the medical staff member who administered the procedure, first claiming it was a student nurse. Two weeks later she spontaneously announced, "It was my Big Nurse who pricked my leg. I didn't like it. Why did she?" On the 15th day home she told her sister with "impish laughter" about the time she hit the Big Nurse's leg with the flying toy—"She hit me, so I hit her." On the 16th day she was playing doctors and said, "We must have a doctor, and you be the doctor. You must hurt her leg and then you must make her quite better." On the 18th day home she reported "I didn't like the Big Nurse pricking my leg. Which leg did she prick? Did she make a hole?"

Second, although Jean was spared the anxiety of being separated from her mother during hospitalization and commented both before and after her hospitalization on the sadness of children whose mothers did not visit or did not stay the night, she demonstrated marked ambivalence toward her mother. Mother had been a warm and comforting presence, yet at the same time she had delivered Jean to the hospital and did not protect Jean from the necessary painful procedures, the surgery and resulting sore throat. She could not protect her child from vomiting blood, or a bloody nose. And though the Robertsons had sufficient clout to insure mother's presence in the hospital, Jean wanted a bed for daddy as well. The first evening home Jean slapped her mother. In fact Joyce Robertson reported that "she slapped me hard saying, 'I don't like you because you took me to the hospital.'" The heightened ambivalence did not resolve immediately, as is seen on the 8th day home when Jean asked for 4 bedtime stories. Her mother began with Jean's own story and the child said, "Yes, I am cross with you for taking me to the hospital. I didn't want to go." Five minutes

later she cuddled round her mother's neck saying "I do like you Mummy. I do like you."

Third, Jean demonstrated a long distance vulnerability reflecting her continuing access to many detailed, but distressing memories of her illness experience. During the 11th week home, Jean's behavior suddenly deteriorated into temper tantrums, weepy and dependent demands for parental attention, etc. Her mother identified a series of external events which triggered her memories: the anticipated tonsillectomy of a friend, a trip away from her children by a mother whom Jean knew, and the arrangements for a Robertson family holiday. The occurrence most parallel to her own tonsillectomy was the tonsillectomy of a friend. Unfortunately, there were medical complications and the friend's return home from the hospital was delayed by a week. When the child finally was able to play again, Jean announced, "I thought you were dead." Robertson believed that the activities preholiday cued Jean's anxious prehospital memories, while the mother's absence raised Jean's worries again about being abandoned in the hospital. Jean's behavioral upset played itself out, with sensitive intervention by Robertson, by 20 weeks post hospitalization.

Anna Freud (Robertson & Freud, 1956), commenting on Jean's experience, said,

"... it is not the external danger, real and serious as it may be, which accounts for the traumatic value of an experience. Injections, loss of blood, surgical interventions, etc., are shown to remain manageable events unless they touch on and merge with id material which transforms them into experiences of being assaulted, emphytied out, castrated or condemned . . . I believe in a sliding scale between external and internal threats and fears . . . Mrs. Robertson helped her child . . . meet the operation on the level of reality, to keep the external danger in consciousness to be dealt with by a reasonable ego instead of letting it slip to those depths in which the rational powers of the ego become ineffective and primitive methods of defense are brought into action." (p. 436)

Clinical observation and research has been done to help children who must undergo medical procedures. Little of this work has been linked to memory research. The administration of medical procedures provides a temporal framework and many variables which memory researchers can use to develop their own theories and to enhance the medical care of children.

## THE CURRENT SCENE IN PEDIATRIC MEDICINE

Jean's story, written nearly 40 years ago, still has coinage today. It offers some nice examples of linkages between reality, affect, and memory for the young child and of a young child's fascination with her own metacognitive processes. Information given to a child in anticipation of a medical procedure is still re-

heard, supported, or challenged by actual experiences. A child's memory for a medical procedure as simple as an injection may be a mixed blessing. Memory may burden a child with fragments of negative affect as a result of sensory pain and loss of control. Anxious rehearsal of the event is easily triggered for months and sometimes years to come. Children whose lives are interrupted by negative memories may require sensitive parental or therapeutic intervention in order to lay the past experience down.

What has changed since Jean was hospitalized for a tonsillectomy? The patterns of pediatric illness have changed, as have the models of health care delivery, the team of health care professionals with whom the child and parents work, the constellation of the family, and advancing medical technology. I review these features of the current pediatric scene in the next section.

### Patterns of Illness

Haggerty (1986) asserts that the face of pediatrics has changed dramatically during the past 4 decades, with marked decreases in the numbers and percentages of children suffering from common infectious disease agents such as polio, measles, rubella, and mumps. The bulk of hospital pediatric care has shifted during the past decade to emergency treatment of accident/injury/abuse, and to the episodic readmissions of children with chronic, life threatening diseases such as asthma, congenital heart disease, diabetes, sickle cell anemia, etc. (Hobbs et al., 1985). It is a different group of children, with far more serious injury or severe physical disease, who are seen in medical centers today. The frequency of surgery to remove the tonsils and adenoids, which reached nearly ritualistic proportions for children of Jean Robertson's generation, has decreased dramatically. If that surgery were deemed necessary today it would probably be handled on an outpatient or 1-day surgery basis (Starfield, 1991). Paradoxically, nearly 80% of the children seen by the private pediatrician are brought by their parents with requests for the pediatrician's help with their children's school problems, parental divorce, sibling relationship or moving; not for medical reasons. In short, the children in the hospital are sicker, and the children in the private pediatricians office are more healthy than ever before in our history.

### The Biopsychosocial Model of Health Care Delivery

The model of health care delivery has changed. In most medical settings the biopsychosocial model of illness now dominates the delivery of children's medical care. The biopsychosocial model was introduced by Engel (1977) to supplant the biomedical model of illness, prevalent when Jean Robertson was a youngster, which argued that the physician's major effort should focus on the biologic aspects of physical illness. Engel proposed that biological, psychological, and

social variables all contribute to the predisposition, onset, course, and outcome of most illnesses. The biopsychosocial model increases the responsibility of the individual for health maintenance, emphasizes the link between health-risk behaviors and illness, and increases the possibility of participation by the patient with medical staff in diagnostic and treatment decisions during illness. Developmental variables fit nicely within this new model as do such concepts as locus of control, coping, and self-efficacy.

The biopsychosocial model differentiates *disease* from *illness*. Disease is defined as the biological pathophysiology that results in symptoms and signs that are commonly recognizable in everyone, everywhere, at any age, who is diagnosed with the disease. Disease belongs to the medical system. In contrast, illness refers to the experience of the individual, and thus belongs to the personal, family, and social systems. Parmalee (1986), who has been interested in the beneficial effects of illness on children's cognitive and affective development, pointed out that one can have a disease without feeling ill, or can feel ill without having a disease.

### Professionals Who Care for Children in Pediatric Settings

The introduction of the biopsychosocial model was accompanied by a parallel development of subspecialty training in pediatrics and psychology (Davidson, 1988). Developmental and behavioral pediatrics and pediatric psychology programs focus on the psychosocial health care needs of infants, children, and adolescents. There are new opportunities for training, consultation, and collaboration (and competition, as Davidson notes) between pediatricians and psychologists in the full range of health care delivery.

Until very recently most pediatric research has been on children's disease rather than on children's illness. The biopsychosocial model and the professionals who practice within that framework insure that in the future we will see clinical and research attention to both the pathophysiology of children's disease and to children's experiences of illness. Professionals from both developmental pediatrics and pediatric psychology may serve as excellent collaborators on teams interested in studying childhood memory and other related developmental phenomena within the context of the medical setting.

There are many participants in the delivery of contemporary pediatric medicine, especially in a university medical complex. As an outpatient, a child may meet an assortment of medical and graduate students, interns, residents, and faculty during a visit to a pediatric specialty clinic. A typical child who is an inpatient in our teaching hospital is visited by more than 50 "strangers" who come in their room in a 24-hour period (e.g., medical, psychological, and nursing staff and trainees, TV repair men, maintenance staff, relatives of other

pediatric patients, etc.). Studies of children's memory of experiences and events that occur in a medical setting could benefit from analysis of the interaction of these persons with the child and with one another.

### The Role of the Family

The contemporary American family is changing. Family constellations are now such that many children don't have a daddy with a big car to drive them to the hospital, or a full-time mother, as Jean Robertson did. Even though the biopsychosocial model envisions a much more active and responsible role for parents in the care of their sick children, and hospital policy has been liberalized so that a parent may stay in the hospital with his or her child, many children today must face medical and surgical procedures alone. Many of today's working mothers can't take the time off to meet the preventive health care needs of their young children, let alone stay full-time with their hospitalized children. In addition, the medical care of many children today is compromised by economic, ethnic, and language barriers between parents and medical staff. These changing demographic and relational features of the child's family potentially contribute to children's medical experience and to their memory. I describe next research on the involvement of parents as coaches in preparation for medical procedures, and the research on parent-staff-child interaction during medical procedures.

### New Technology

Advances in medical science and medical technology, while enormously important for the health care of children, mean that children are subjected to a new array of aggressive, invasive, radical, and repeated diagnostic and treatment procedures (Pruitt & Strickland, 1987). For young children with chronic diseases such as cancer these medical procedures are painful. Multiple procedures are administered during one outpatient clinic visit. Yet the routine use of potent analgesia/anesthesia is often medically contraindicated. At our medical center the typical child with acute lymphocytic leukemia receives approximately 2–4 bone marrow aspirations, 15–20 spinal taps, and countless venipunctures during diagnosis and treatment—a painful process that may last 12 to 36 months (C. Abildgaard, personal communication, December 28, 1991).

In contemporary pediatric care memory plays a very important role. Young pediatric patients are awake to experience and remember; unfortunately their memories often contribute to anticipatory anxiety before return visits—which can in turn elicit unpleasant experiences for the child such as nausea and vomiting, compounding the distress further. Misperceptions and misconceptions may also be woven into child's memory and unnecessarily traumatize or emotionally burden the child, making it even more difficult for a child to tolerate/cope with repeated procedures.

The interaction of the biopsychosocial model and modern technology plays out for children and adolescents as a double-edged sword. Some multistep pediatric treatment regimens involving data collection and analysis, judgment and subsequent behavior, are likely to be administered at home thereby increasing the importance of the role of the child and the family in the child's care. The emotional burden for the child may also be increased if she or he is made to feel responsible for the illness or given charge of the testing or treatment too early. Some believe that we have gone from the myth of the vulnerable child to the myth of excessive resilience. For example, children as young as 6 years diagnosed with Type I, insulin dependent diabetes mellitus, are now trained to monitor their own blood glucose (ideally 4 times/day) with small portable devices. For elementary aged children, parents supervise the administration of blood testing. Communication skills may be a mediating factor in joint control determining which "diabetic tasks" shift from the parent to the child as the child matures (Anderson, Auslander, Jung, Miller, & Santiago, 1990). Gudas, Koocher, and Wypij (1991) have studied compliance with children and adolescents who have cystic fibrosis. They remind us that increasing autonomy—particularly with regard to medical compliance—may be the wrong goal even for the chronically ill adolescent.

LaGreca (1990) has written about the growing interest in techniques for documenting the reliability of reports of pediatric compliance with medical regimens administered at home—a problem of double memory: (a) Did the child remember to do X? and (b) Did the child remember that he remembered? Memory errors at either point can compromise a child's health status with, for example, diabetic patients. Memory errors can be life-threatening if, for example, pediatric seizure patients or renal transplant patients forget a necessary medication or administer it twice. It is estimated that the overall adherence rate for pediatric regimens is approximately 50% (Lit & Cuskey, 1980), although that estimate masks differences between short-term vs. long-term regimens. Adherence is considerably higher for the former than the latter, and includes only patients willing to participate in compliance studies, biasing the data towards overestimation. LaGreca notes that verification of the double memory process is complex because of the long chain of command involved in instructions for the administration of a procedure (physician to parent to child). Parents may depend on a child's report and physicians may depend on a parent's report, with no independent source of information to confirm that the procedure was indeed remembered. A recent study that utilized independent parent and child reports assumed that a behavior in a diabetic regimen sequence had occurred if either parent or child remembered it (Freund, Johnson, Silverstein, & Thomas, 1991). Clearly it is strategically difficult to place observers in a child's home and school environment inobtrusively enough so that the observation process does not influence the child's behavior. I report shortly a study that employed independent observers in

a camp setting to establish the accuracy of children's memory of self-administered glucose/ketone testing and insulin injections.

In the next section I review clinical and research work focused specifically on the three temporal stages of medical procedures: (a) the preparation of children for medical/surgical procedures, (b) the "in vivo" experience of the procedure, and (c) the debriefing period. Next, I review a set of studies that report what children remember from a medical experience about body touch, persons and location. Finally, I identify several subject populations who might be of special interest to researchers curious about the long-term impact of childhood experience of medical procedures on adult memory.

## USING MEDICAL PROCEDURES TO STUDY CHILDREN'S MEMORY

The administration of contemporary medical procedures provides an opportunity to study children's memory of complex, personal events in natural settings such as hospitals, outpatient clinics, physicians private offices, and children's homes. The role that memory plays in the child's exposure to complex medical procedures can be studied, as suggested by the clinical case study of Jean Robertson, by linking the three temporal stages of the experience: preparation, experience, and debriefing. Preparation strategies can be understood as a seeding of the short-term memory for the event to come. Debriefing after a procedure provides an opportunity to seed long-term memory by assessing (and correcting or clarifying if necessary) the perceptions, cognitions, and emotions a child associates with the experience of medical procedures that he has just completed.

Measures of memory of medical procedures can include behavioral, verbal, and biochemical indices. For example, one can study children's memory of their preparation for medical procedures in the short range by observing how children cope during the administration of the procedure, and in the long range by observing their behavior at one or several points in time after the procedure is completed. Children can also be asked, postprocedure, to reflect on the correspondence or discrepancies between their preparation for and their experience of medical procedures. Those verbally mediated memories can be analyzed for accuracy, completeness, and consistency. In addition to observational and self-report measures of memory, it may be possible to document adequacy or lack of preparation, insufficient or inaccurate preparation by studying changes in biochemical/neuroendocrine stress responses, such as salivary or blood cortisol levels. Gunnar, Marvinney, Isensee, and Fisch (1989) identified "significant changes in demands that the organism is not immediately prepared to meet" as the basic stimulus to the neuroendocrine system. A rise in a child's cortisol level following the experience of a medical procedure signals the distress of an unprepared child. The magnitude of the change can be related to memory.

Multiple methods of assessing memory for medical procedures are necessary because children's willingness to verbally report their memories of medical procedures may be negatively influenced by self-conscious emotions such as embarrassment, shame, and guilt (Lewis, Sullivan, Stanger, & Weiss, 1989). Negative self-evaluations may be activated when medical procedures require relative states of dress/undress to expose sensitive or "private parts" of a child's body for careful examination, or when body touch and manipulation occur against a child's will (Beuf, 1979). Careful interview techniques need to be crafted to elicit memories of medical procedures if coercion, bribery, or threat was invoked to elicit a child's cooperation (Bussey, 1990).

There is little research on children's memory of medical procedures. The bulk of the clinical and research literature available on the topic of medical procedures with children is devoted to the preparation of children for a future event. There is relatively less information about the interaction of children, parents, and staff during medical and surgical procedures, and very little literature that reports the results of talking with children about what happened to them after their medical experience. Until very recently, there has not been much interest in children's perceptions of their medical experience. (However, see Bearison, 1990, for a new, powerful set of verbatim interviews with childhood cancer patients.) We believe that parents and medical staff (for very different reasons) have decided not to discuss with children their past medical experiences. This is quite striking in light of K. Nelson's (this volume) observation that most researchers studying event memories in young children have analyzed parent-child rehearsals of past events, but have done little with parent-child discussions of future events. Research in the pediatric setting inverts this emphasis. Students of childhood memory in medical and nonmedical settings need to be in conversation.

### Preparation and Memory

What is the impact of preparation for medical procedures on children's memory? Although there is a vast clinical literature on preparing children for hospitalization and medical procedures (Beuf, 1979; Peterson & Mori, 1988; Petrillo & Sanger, 1980; Plank, 1971; Steward & Steward, 1981), there has been very little test of the impact of that preparation on children's memory. Melamed (1991b) has called for more research on the role of children's memories in anticipating, preparing for, and forgetting painful experiences in order to improve the delivery of medical care for children. The clinical research literature on preparation of children for medical procedures can serve as a source for the identification of variables which the memory researcher can use to organize studies of children's memory of medical procedures. Variables prominent in the preparation literature that may impact both the efficacy of the preparation experience and memory of the child include children's cognitive level of development (Perrin et al., 1991; Rasnake & Linscheid, 1989), past medical experience (Eiser, 1989; Melamed,

1991a; Siegel et al., 1990), preferred coping styles (Fanurik & Zeltzer, 1991; Peterson, 1989; Smith, Ackerson, & Blotcky, 1989), choice of timing (Burstein & Meichenbaum, 1979; Melamed, Robbins, & Graves, 1982; S. A. Ross, 1984), sequencing of information (Peterson & Toler, 1986), and parental presence (Bauchner, Waring, & Vinci, 1989; Gonzalez, Routh, Saab, Armstrong, Shifman, Guerra, & Fawcett, 1989; Pinto & Hollandsworth, 1989; Shaw & Routh, 1982; Ross & Ross, 1988).

Three sets of clinical studies are reported here in some detail to highlight the potential impact on memory of differential preparation. None of these studies addresses the question of children's memory of medical procedures squarely, but each suggests a critical facet which could be studied. The first set of studies focuses on content of preparation; the second set looks at the source of preparation; and the third set presents the tailoring of preparation to enhance a child's natural coping strategies.

*Content of Preparation.* Claffin and Barbarin (1991) have done a small study on children's memory of preparation for medical procedures. They reverse the question about how memory is influenced by preparation, asking instead about children's memory of the preparation itself. Claffin and Barbarin interviewed a group of 43 children with cancer, ranging in age from 3 years to 18 at the time of diagnosis, about explicit information which the children remembered receiving about diagnosis, treatment, and prognosis. Children were clustered in 3 groups for the purpose of data analysis: (a) the youngest group included 18 children whose average age was 5.4 years at diagnosis and 7.4 years when interviewed, (b) the middle group included 15 children whose average age was 11.3 years at diagnosis and 12.1 years when interviewed, and (c) the oldest group included 10 children whose average age was 16.1 years at diagnosis and 17.3 years when interviewed. The authors were testing the hypothesis that if children received less information about the diagnosis and treatment of cancer—if the children were less well-prepared—the children would be "protected" from some of the negative impact of having cancer (e.g., they would experience fewer negative side effects of the chemotherapy, be less aware of parental worry, etc). Seventy-two percent of the children remembered having medical procedures explained to them. Differences in the quality and quantity of explanation were identified as a function of the age of the child, and as a function of the source of the information (parent vs. medical staff).

Children in the two younger groups remembered receiving less information, and less specific information than the oldest group. With one exception no child in the younger two groups remembered being given a rationale for the procedures, while 56% of the oldest group remembered receiving detailed information and rationales about treatment procedures. The age differences found in these children's memory of their preparation may have resulted from confounding the age of the child with source of information. Children in the younger two

groups were more likely to be prepared by parents, while the oldest group was more likely to be prepared by medical staff. In spite of differential preparation across all age groups children rated their experience of medical procedures as the most stressful of seven domains of illness-related stress about which they were questioned. No age differences were found in the number or kind of symptoms or treatment side effects, or children's awareness of parental distress related to the children's disease. Claffin and Barbarin concluded that withholding preparation information did not *protect* children with cancer from negative consequences of the treatment or disease process.

Unfortunately, there was no independent corroboration for any discrepancies between what the children were actually told by parents or medical staff and what children reported remembering. The authors noted further that all of the families studied had volunteered, and that these families and their children may have differed along a number of dimensions (adjustment of individuals within the family, severity of the course of the disease, and symptoms at the time of contact) from those who refused, including families who never told their children that they had been diagnosed and treated for cancer.

A study by Fernald and Corry (1981) links the impact of differential information given by medical staff to children during preparation to their subsequent thoughts and feelings. Staff prepared children for venipuncture or finger stick with one of two strategies: empathetic preparation—"I'll bet the alcohol feels cold. In a moment I'm going to stick you. You're probably feeling scared. You can cry if you want."—and directive preparation—"Act big and brave. Remain very still." Children prepared empathetically demonstrated fewer distress behaviors such as crying, wincing, and refusing to comply during the administration of the procedure. Even more important, after the procedure was completed children who were prepared empathetically had fewer negative self-reports. For example, only 5% felt angry after the venipuncture and only 5% felt the technician had tried to hurt them, whereas in the group of directive prepared children 58% were angry and 47% believed the lab technician had tried deliberately to hurt them.

Even this very brief differential preparation influenced the stress children experienced during the procedure and also influenced the amount of distress they felt subsequently—as reflected in at least two measures: anger and sense of victimization. It is likely that the memories that the two groups of children hold of a technically similar medical procedure differ. This difference may influence subsequent interactions with medical staff. K. Nelson (1989) suggested that young children's memory can be manifested in a variety of intentional behaviors, nonverbally as well as verbally. Children in the empathetically prepared group will be more likely to approach subsequent medical experiences with confidence and to trust new medical staff, while children who were directive prepared—fearful of revictimization—may act on their anger and behave aggressively toward medical staff, retaliating as Jean Robertson did against "big Nurse." Unfortunately,

nately, a recent study by Stern, Ross, and Bielas (1991) demonstrated a belief bias, or stereotype, by 4th-year medical student clerks about children described as being "in remission from cancer," such that they are more likely than healthy children to receive a less sensitive, more time-expedient approach when administered an injection. Such behavior by medical staff reinforces negative memories of an event which could contribute to a child's escalating cycle of anger and mistrust.

My colleagues and I are conducting currently a content analysis of mothers' preparation of their 3 to 6 year-old children for a wide variety of outpatient procedures. Seventy mothers completed a parental preparation questionnaire in the waiting room prior to a medical visit. Their children were interviewed after the medical visit. We found a striking discrepancy between the number of mothers who claimed that they prepared their children for a medical procedure (95%), and the number of children who confirmed after the procedure that they had been forewarned (33%). Why did two-thirds of the children *forget* that they had been prepared? And what was it that their mothers told them that they forgot? In order to investigate differences in the content of the information given the group of children who remembered being prepared and those who forgot, the mothers responses are being analyzed within a  $3 \times 3$  matrix. The cells of the matrix represent the interaction of three components of medical procedures—the what, the who, and the why—which we have identified from the clinical literature (Steward & Steward, 1981), and an adaptation of three attributional features that Seligman and his colleagues (Peterson & Seligman, 1984) find that people use to explain a negative event: (a) whether the self or another initiated the event, (b) the uniqueness of the event, and (c) the sensory and descriptive specificity of the experience. The third component parallels information from the empathetic preparation of Fernald and Corry. Although the study is limited to second order data—what the mothers told us they told their children, we will be able to triangulate the content of the mothers' reports of preparation, the children's memory of having been prepared, and the accuracy and completeness of children's memory of the procedures. Some of the things that mothers tell their children may not lead to memories of preparation *per se*, but the information given may alert the child so that his or her memories of the procedures are enhanced.

Finally, the selection and use of props is a critical feature of the content of most preparation programs designed for young children, and provides an interesting variable that may impact children's memory of medical procedures differentially. In the medical setting staff, who are not aware of the specific cognitive gifts and limitations which young children bring, often make mistakes in their use of props. One frequent mistake is the use of model, rather than real medical equipment. Models may be charmingly designed but they are ineffective or irrelevant to the preparation of young children for an upcoming medical or surgical event. DeLoache and her colleagues (DeLoache, 1987, 1990; De-

Loache, Kolstad, & Anderson, 1991) have demonstrated that for very young children it is difficult to make the connection between the model and the real thing. The model, rather than serving as a symbol for another thing, is seen and understood as an object in its own right. Thus toy models of hospital rooms with beautifully polished miniature wooden X-ray machines won't prepare a child for the icy cold sensation of the table, or the fact that everyone will scurry out of the room and leave them, naked and alone, while a huge piece of metal is slowly lowered over their body. I know of no empirical studies that test the impact on a child's memory of use of toy models vs. real medical equipment during medical preparation. As Fernald and Corry (1981) demonstrated, children report feeling tricked and angry when they are not well-prepared—emotions that are likely to enhance memory of the event and the person who prepared them.

*When Parents are the Source of Preparation Information.* Persons who prepare the child may influence differentially what a child will remember about a procedure. In the Clafin and Barbarin study reported earlier the age of the child and source of information were confounded. When parents serve as sources of information, younger children may remember less about the preparation period—not only because they have more cognitive and language limitations than older children—but also because the information from parents, while emotionally supportive, may contain less detail about process or equipment than information that a medical staff person might have given. In addition the authority of the informer may play a role in determining a child's willingness to accept preparation information. To date there have been no experimental studies that examine the differential influence of the source of preparation on children's memory. Results of such studies would contribute to the event memory literature, and would prove very useful in the design of preparation events for young children.

Parental preparation of their children for an examination that includes the use of a colposcope highlights a problem shared by many parents, who do not know exactly what their child is about to experience. Some parents wrongly assume that the colposcope is merely another name for the pelvic examination performed on adolescent and adult women that includes both digital penetration of the vagina and anus, the introduction into the vagina of a cold metal instrument, a speculum, to open the area for visual inspection, and the collection of tissue for a pap smear. In contrast, the colposcope is an instrument that provides a source of light and magnification, and includes a camera for the collection of evidentiary data for subsequent legal proceedings. The instrument stands about one foot away from the child and never touches the child's body. Even adults who understand the operation of a colposcope often withhold full information about the genital examination from children on the premise that they do not want to retraumatize an allegedly abused child—a premise tested and challenged by the Clafin and Barbarin study reported earlier. Children may be told only about the

spotlight and the camera. One mother reported to us that she told her child that the doctor would "look at her eyes, her nose, and her pretty face." After the medical examination was completed the child announced to our interviewer with considerable surprise and irritation in her voice that "the doctor looked at my peepee!" We hunch that a poorly prepared child is likely to remember and be forced to rework an event that a well-prepared child may be able to forget.

My colleagues and I are conducting currently a clinical interview study with allegedly abused children about the source and accuracy of their information prior to undergoing an examination using a colposcope. Immediately following the examination and again 1 week later the children are asked what information another child who is their same age and gender should be given about the procedure, and who should give them that information. The purpose of the study is to improve the preparation of children for this unusual procedure, and to lessen children's surprise and distress.

A second problem parents face as they prepare their children for medical procedures is that they may not anticipate the pain that their child will experience as a result of the procedure. A recent study by Wart-Watson et al. (1991) in a Canadian hospital focused on parents' perceptions of children's acute pain experience. Seventy-one parents of 62 children ( $92\% < 6$  years-of-age) hospitalized on short-term pediatrics wards rated their children's most painful procedures. They rated blood work ( $M = 46$ ), intravenous therapy ( $M = 74$ ) and lumbar punctures ( $M = 79$ ) as the most painful procedures. Fifty-eight percent of the parents claim that they were not told the procedure would be painful and 70% claimed that they were not told of any way they could alleviate the pain! Parents as well as their children may be surprised. Parents may transform their surprise into anger and frustration, which may fuel their own and their children's memory of the event in synergistic ways.

The behavioral interaction of parents and their children prior to medical procedures may contribute to a child's level of distress, which in turn will impact both the child's coping strategies during the procedure and their memory afterwards. Bush, Melamed, Sheras, and Greenbaum (1986) observed 50 mother-child dyads during a 5-minute period before medical procedures were administered to the children. They found that maternal agitation and maternal reassurance were each associated with increases in child distress. Distraction techniques, information giving, and low rates of ignoring by the mother were associated with low rates of child distress. Melamed and her colleagues (1991a) are studying crisis-parenting by examining cues that mothers give their children during the waiting period (e.g., anticipatory restraining and agitated maternal behavior) which might signal the child that a dangerous situation is about to occur, and maternal personality traits (e.g., especially state and trait anxiety) that may lead the child to develop anxiety rather than coping skills.

*Preparation and Children's Natural Coping Strategies.* One of the most controversial new research endeavors with respect to preparation of children for

medical procedures involves the pretesting of a child's natural coping strategies. If a child must endure repeated, painful medical procedures, what kind of help can that child be given? Two different research teams (Fanurik & Zeltzer, 1991; Siegel, 1991) have shown that by pretesting a child's strategies for withstanding pain, preparation for necessary medical procedures can be tailored so that the child's strategies can be enhanced. As a result medical procedures can be experienced as less painful. Fanurik and Zeltzer employed a "cold pressor" technique in which children were asked to lower one arm into a vat of very cold water and leave it there as long as they could tolerate it. After the child quit, each was interviewed to determine what they had done in order to keep their arm in so long.

The children's spontaneous strategies were categorized into two general groups. One group of children, *distractors*, used a strategy that involved mental distraction or escape. The other group of children, *attenders*, focused directly on the sensory experience—monitoring how cold it was, whether or not their arm was changing color, etc. Then each group was divided in half, creating a  $2 \times 2$  design in which half of the distractors and half of the attenders were taught mental distraction techniques. The remaining children, half distractors and half attenders, were instructed to focus directly on the sensations they experienced. The purpose was to see if children would benefit from learning other strategies, broadening their coping repertoire.

The results revealed that instruction in distraction techniques benefited the children who already spontaneously used that strategy by significantly increasing their cold pain tolerance, but did not improve the cold pain tolerance of the children who initially used the sensory focusing technique. The instructions to focus on the sensory input did not improve the performance of either group. Siegel (1991) trained children in a laboratory with a sensory pressure/pain stimulus, which he believed paralleled the sensation that children would experience in a bone marrow or spinal tap procedure. His strategy was to seek to enhance the child's self-efficacy while their hand was placed under a bar that exerted variable pressure on their fingers.

The debate about pretesting children's coping strategies to handle painful sensory stimulation is not limited to the cold pressor or variable pressure bar techniques, for there are other techniques that could be designed. The debate is an ethical one. Although pretesting provides useful sensory information about an upcoming medical procedure, and increases the clarity and importance of a child's role assignment, does painful pretesting increase to an unacceptable level the *pain burden* the ill child already has to carry? The debate might be framed differently, by asserting that when necessary painful experiences can be made less traumatic, then haunting memories of the necessary event may be less disruptive in young children's lives. A well-designed study could determine if children, pretested to determine natural coping strategies and prepared with skill training to enhance those strategies, remember fewer details about the medical procedure, and if those memories are less negatively toned than those of children left to cope with medical procedures on their own.

There are two notes of caution for the memory researcher who plans to focus on the impact of preparation on memory for medical procedures. The first has to do with the characteristics of children who experience medical procedures. The second has to do with the difficulty of keeping experimental groups *pure* in a clinical setting. The population of children available for study in medical settings is limited and rather uniquely defined. Preparation of children for medical procedures which occur during outpatient, well-child check-ups is usually done, if at all, by parents prior to arrival and thus may not be available for research observation. For those children attending specialty clinics, one should anticipate an interaction between the child's previous medical experience and preparation offered. We know clinically that it is very, very difficult to prepare a child a second time. Their memories of previous negative medical experiences interrupt and challenge a presentation that is made too simple or too true (Dahlquist et al., 1989; Melamed, 1991b).

The pediatric inpatient population is bimodal with respect to preparation at our medical center. The majority of children are not planned, scheduled admissions; rather children come into our hospital as a result of accident, injury, or poisoning. In fact, less than 25% of the children in our inpatient pediatric units have been prepared prior to admission for the experience of hospitalization or for the medical procedures that they will experience. Preparation, if it does occur, may be provided at any point in the 24-hour day, by one or several staff. For the researcher the problems of variable timing and the potential of multiple, overlapping (or conflicting) information offer significant problems. Another smaller group of children in our hospital are returning because of chronic illness, and previous negative experiences with medical staff, medical procedures experience and the constraints of hospitalization interact with attempts to prepare those children.

The second caution is a result of the fact that in front-line clinical settings the pragmatist often wins over the scientist. That is particularly true in medical settings where clinical trials are aborted if one diagnostic or treatment strategy appears to be superior to others. An example of that is found in research by Kuttner, Bowman, and Teasdale, (1988), who reported that there appeared to be "some contamination in the control group" between the beginning and end of a study in which different kinds of cognitive/behavioral strategies were taught during a preparation period to enhance a child's coping with painful medical procedures. This meant that children and their parents assigned to the control group were learning from children and their parents in the experimental group how to handle better the distress of medical procedures.

In sum, there are a number of factors from the preparation period that may impact both the experience and memory of the child. These include content and sources of the preparation, and informational and strategic preparation of the child for coping with pain. Research to date reveals that some children don't even remember being prepared. Studies are underway to determine how memory for

preparation is related to memory for the subsequent medical events. There is no *protective advantage* to withholding preparation information from children. Children may be forced to remember painful medical procedures if they are given incomplete, directive preparation as opposed to empathetic preparation (which allows children to anticipate both sensory and emotional contingencies) because children are likely to feel angry at and victimized by medical staff. Children may also be more distressed and thus remember more when they are prepared by parents who have limited information about the equipment that will be used, the relative painfulness of the experience, or are agitated and distressed themselves. On the other hand enhancing the skills of children who naturally use distraction/imagery may impact memory by shifting the perceptual and cognitive focus of the child away from the procedure and lowering the distress. The result should be that these children will remember less about the procedures.

### Experience of Medical Procedures and Memory

During medical and surgical procedures children's bodies are touched, handled, and sometimes, when necessary, hurt by medical staff in the process of diagnosis or treatment. There are two sets of variables that can be measured during the administration of medical procedures that enhance or interfere with memory: the child's experience of pain, and the psychosocial interaction amongst parent, child, and staff. There is vigorous new clinical research interest in both areas. Pain is a personal experience, with no simple physiological, neurological, or biochemical marker independent of the judgment of the individual (McGrath, 1987). Investigators who have studied childhood pain understand that the "unpleasant set of sensory and emotional experiences" (Merksey, 1979) may include feelings of fear, anxiety, loneliness, anger, and sadness. The fact that the experience of pain is associated with "actual or potential tissue damage" highlights the dynamic role of memory in the assessment of previous experience with medical procedures and of cognitive appraisal informed by that memory in anticipation of subsequent procedures (Merksey, 1979). Jay et al. (1985) believe that the complex set of sensory, emotional, and cognitive variables that are included in the childhood experience of pain is more parsimoniously conceptualized as *distress* (Jay et al., 1985).

A wide variety of pain scales has been developed to assess children's self-report of pain, including visual analogue scales, face scales, verbal scales often used with adults, as well as a range of physiological measures (Beyer & Wells, 1990; Bush, 1987; McGrath, 1987; Ross & Ross, 1988). Two recent studies have asked children to remember and rate the intensity of past painful episodes, and a third contrasted memories of two groups of children who differed on the organic vs. functional cause of their pain.

Beyer, Berde, and Bounnaki (1991) asked 46 3-7 year-olds "Can you remember a time when you had a hurt?" Children identified a total of 143 incidents

and rated them on a 0 to 5 photographic Oucher scale. Approximately half of the incidents (52%) were recalled spontaneously, the remaining incidents were prompted by parents or the interviewer. Thirty-eight percent of the children had previously experienced surgery, but none of those children spontaneously mentioned painful medical or surgical experiences associated with their surgery. Although pain scores varied widely for similar incidents (e.g., falls and needles both received ratings across the full range from 0 to 5), in general, less traumatic incidents were given lower pain scores than more traumatic incidents. Children remembered incidents that had occurred from a few minutes to 4 years prior to the interview.

Lehmann, Bendeiba and DeAngelis (1990) interviewed 91 3–8 year-olds asking them to remember two recent painful events. Children were interviewed on two occasions 7 days apart in order to estimate the consistency with which children would rank order the two experiences of pain they remembered and four others identified by the authors (shot, stomachache, cut, and a bump). Five scaling procedures were employed, including the simple question, "Which hurt more?" The 7 and 8 year-olds were more consistent than were the younger children, yet the authors cautioned against the use in clinical settings of past painful experiences as anchors for current pain estimates. Using an 80% agreement as their definition of consistency, they found that children over the age of 5 remembered pain intensity consistently in response to the verbal question, but the other scaling procedures created by the authors (which combined various directional, color and/or face cues) did not elicit consistent responses. The inconsistent responses to the multidimensional pain scales may be a reflection of a methodological problem, not a developmental one. Both the study by Beyer and her colleagues and the study by Lehmann and his colleagues suffer from the lack of independent confirmation from parents, medical staff, or medical records about actual occurrence of the painful events children reported.

Geist (1991) compared the descriptions of pain from the medical records of a group of 30 school-aged children diagnosed with an organic etiology for their stomach pain (inflamed bowel syndrome) and a group of 32 children diagnosed with "functional pain" (no known etiology for chronic abdominal pain). She identified a series of differences between the two groups of children in their memories about several dimensions of the pain and how children coped with it. For example, children with an organic cause for their pain had only vague memories about the onset of the pain, reported the pain to be of variable, unpredictable intensity, and complained that it awoke them from sleep. In contrast, the children with functional pain remembered exactly when the pain began, reported constant intensity and complained of problems falling asleep. The children with functional pain also reported, rather suspiciously, that exercise aggravated the pain, rest alleviated it, and they avoided going to school when in pain. The active role that the children with functional pain had in the construction of their description of the event, and the secondary gain which apparently resulted

from the functional pain may have contributed to sharper, clearer memories when they reported the pain to their physicians. The provocative findings from this retrospective study call for replication.

There is a link between children's experience of pain and how they cope with it. The observation of coping strategies that children actually use during brief but repeated painful treatment for chronic or life-threatening diseases suggests that even very young children can use modeling, "thought-stopping" techniques, and coping skills training to reduce their anxiety (Jay et al., 1987; Koocher, 1985; Peterson & Mori, 1988; D. M. Ross, 1984; Zeltzer, Jay, & Fisher, 1989; Zeltzer & LeBaron, 1986). However, it is rare for young children to initiate stress-reducing strategies unless they are specifically cued by supportive adult coaches. This phenomenon will be very familiar to those who conduct research on the role of retrieval cues in young children's memory (Ritter, Kaprive, Fitch, & Flavell, 1973; Smith, Ratner, & Hobart, 1987).

A child may exhibit behavioral distress at different points in the process of administration of a medical procedure. For example, our (Steward, Steward, Joye, & Reinhardt, 1991) research with 79 3–6 year-olds, and work by Blount and his colleagues (Blount, Sturges, & Powers, 1990) reveal that children may manifest more distress behavior in anticipation of the insertion of the needle in bone marrow, spinal tap, or venipuncture than after the needle is in. Blount and his colleagues found that children exhibited an increase in demonstrative distress (crying, screaming, etc.) and a decrease in apprehensive distress (request for emotional support, verbal fear etc.) from the prepainful to the painful phase. We have found that different procedures elicit different profiles of behavioral distress. In our study children's memories of their distress behavior did not match the behavior we observed. For example, 66% of the 36 children who cried did remember, but 17% of the 43 children who did not cry also reported crying; only 5% of the 25 children who asked for help or emotional support remembered and reported that while 4% falsely reported the same behavior.

Several research teams are now focusing on the psychosocial interaction between the child patient, the medical staff and the parent during the process of medical procedures. Blount and his colleagues (Blount, Corbin, Sturges, Wolfe Prater, & James, 1989) studied audiotape recordings of 23 pediatric oncology patients prior to, during, and after bone marrow aspiration and lumbar puncture procedures with the primary goal of establishing which adult vocalizations most often preceded or followed child distress and coping. They found that children's coping with necessary medical procedure has been enhanced by adult commands to cope, humor, and nonprocedural talk.

The pride felt by both the child and the parent when the child-parent team handles a painful session better this time than last time, with less overt distress and more sense of control, may well contribute to enhancement of positive memories of their teamwork, and concomitant decrease in memories of the painful procedures. On the other hand, memories of the painful procedures may