ACUTE PAIN IN CHRONICALLY ILL CHILDREN: PSYCHOLOGICAL ASSESSMENT AND INTERVENTION

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ABSTRACT

Five separate studies are reported on two groups of chronically ill children: children with end-stage renal failure who had received renal transplants and children with insulin dependent diabetes mellitus (IDDM). Assessment studies of both these groups investigated psychosocial factors influencing children's anxiety, pain and distress during venipunctures. Behavioural, cognitive and physiological measures of pain were used as well as standardized and structured interview questionnaires. The assessment studies involved 21 renal transplant children and 62 children with IDDM.

The results found a revised version of the Observation Scale of Behavioural Distress to be a valid and reliable measure of children's distress during venipuncture. The predictor variables for children's distress in the transplant sample were the child's self-concept for social acceptance and the child's usual anxiety over injections. In the diabetic sample, the presence of emotional/conduct disorder, the child's usual anxiety over bloodtests and parent's rating of the child's usual anxiety over bloodtests were the three predictor variables for children's distress. Other significant psychosocial variables are discussed. Bloodtests were reported to be the most stressful aspect of the medical treatment by parents of children with renal transplants and by diabetic children.

A pilot study is reported of cognitive-behavioural and hypnotic intervention with children in the transplant clinic. Cognitive-behavioural intervention was found to be effective in reducing distress during venipuncture in children aged four to seven years, following renal transplantation. With older children aged 6-16 years, both cognitive-behavioural and hypnotic intervention were effective in reducing diabetic children's distress. However, control groups appeared to improve following baseline observations, possibly as a result of non-specific factors such as attention and therapist presence. The results are discussed in relation to the literature on acute pain in children.
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CHAPTER 1
INTRODUCTION

Interest in the assessment and management of pain has increased dramatically over the last five years, concurrent with advances in our understanding of the plasticity (i.e. the capacity to respond differently to the same noxious stimulus) and complexity of pain processing (P.A. McGrath, 1990). Further advances in our understanding of internal pain-inhibitory systems and the factors that trigger them have revolutionized traditional approaches to pain control. Pain is no longer regarded as simply and directly proportional to the nature and extent of an injury. We now realize that children's pain is plastic and that it can be alleviated by many different interventions (P.A. McGrath, 1990). Research has focused on the assessment and treatment of pain, from a multidimensional perspective. The conceptual framework adopted in the present research stems from a social learning perspective; pain experience is viewed as the outcome of factors within the child interacting with the influence of his/her social and nonsocial environments.

Health professionals are becoming more concerned about the assessment and management of acute pain in infants and children (McGrath and Hillier, 1989). Much progress has been made regarding acute pain in children associated with invasive medical procedures. These involve penetration of tissue or body orifices,
for diagnostic or treatment purposes (Anderson and Masur, 1983). Such invasive procedures constitute a significant threat for many children, particularly chronically or terminally ill children who have to undergo invasive procedures on a regular basis. There is a need for controlled systematic research into the effectiveness of various interventions with children. Most of the treatment outcome studies have been conducted in the area of distress related to bone marrow aspirations and spinal taps in children with cancer, although cancer is a relatively rare childhood disease. More work is required in evaluating and intervening with children undergoing more common procedures such as injections and venipunctures. Chronically ill children, such as those with diabetes, chronic renal failure, cystic fibrosis and those with growth deficiency problems, who encounter frequent venipunctures could, it is suggested, benefit from psychological intervention. Few reports confirming this proposition can be found in the literature however. Unfortunately, the amount of research carried out on pain management for children undergoing invasive medical procedures does not match the magnitude of the clinical problem.

Nevertheless, many interesting interventions have been developed to help children cope with invasive procedures, such as hypnosis, preparation, cognitive-behavioural and operant behavioural approaches. Techniques such as participant modeling, imagery, and in-vivo systematic desensitization have been used successfully with children (Ayer, 1973; Katz, 1974; Dash, 1981; Poster and
Betz, 1983; Ross, 1984) however, these have not been empirically validated.

While the literature documents both hypnotic and behavioural methods as being effective in reducing behavioural distress during invasive medical procedures (e.g. Zeltzer and LeBaron, 1982; Kuttner, 1984; Jay, Elliott, Katz and Siegel, 1987), few comparative studies have been carried out, particularly for acute pains involving venipunctures.

1.1. RATIONALE AND AIMS

The present research was designed to address, in part, these issues and is a study of psychological assessment and intervention of acute pain associated with blood tests, in two groups of chronically ill children:

1. Children with insulin-dependent diabetes mellitus (IDDM)
2. Children who had received renal transplants because of end-stage renal failure.

These two groups were selected as the literature revealed little research into the assessment and amelioration of acute pains experienced by these children; they were accessible to the researcher; and cooperation was obtained from medical and nursing staff in the respective paediatric clinics. As injections and venipunctures are the most common procedures which children
undergo, and are viewed by most children as a separate, critical and stressful event among all possible medical procedures encountered during hospitalization (Lewis, 1978), this was an important area to investigate. The present thesis involved five experimental studies on acute pain:

1. An assessment study of children aged 6-16 years who had received renal transplants.
2. A pilot treatment study of children aged 6-16 years who had received renal transplants.
3. A treatment study of children aged 4-7 years who had received renal transplants.
4. An assessment study of children with IDDM aged 6-16 years.
5. A treatment study of children with IDDM aged 6-16 years.

These groups of children were studied concurrently in different settings. The young transplant study of children aged 4-7 years developed from the assessment and pilot treatment study with older children.

1.2. HYPOTHESES

1.2.1. Studies Involving Children Aged 6-16 Years.

On the basis of the literature on childhood pain, the following hypotheses were formulated for the present studies:
Validity of Distress Scores

Children's distress scores were expected to positively correlate with global scores, anticipatory scores, usual anxiety over medical procedures and with behaviour categories of the behaviour checklist.

Assessment of Acute Pain and its Concomitants

1. That children who cope less well with bloodtests will have the following on the basis of standardized questionnaires:
   a) a poor self concept
   b) be more likely to be depressed
   c) be more likely to be anxious
   d) have an external locus of control
   e) have an external health locus of control
   f) have emotional or behavioural problems

2. That children who cope less well with bloodtests will have parents who:
   a) are more anxious, and
   b) have an external locus of control

3. A number of additional variables were investigated (e.g. demographic variables, coping strategies, coping style, child's understanding of illness and treatment, parental management of child's pain). The following hypotheses were made. That children who cope less well with bloodtests will
have:

a) less understanding of bloodtests, illness and treatment
b) previous unpleasant experiences with needles
c) anticipatory anxiety prior to clinic
d) other fears
e) other family members with fears

However, two-tailed hypotheses were formulated about the relationship between other variables (e.g. physiological measures of anxiety) and children's distress, given inconclusive or contradictory findings in the literature.

Intervention for Acute Pain

1. Psychological interventions of hypnotherapy and cognitive-behavioural management will be more effective in reducing pain, anxiety and distress during bloodtests, than standard medical practice (control group).

2. The two treatments will be no different in terms of overall effectiveness, but may be differentially effective for children of different ages and sex.

3. Hypnotic susceptibility and treatment effectiveness will be positively correlated in the hypnosis group.

1.2.2. Study Involving Young Children Aged 4-7 Years.
Cognitive-behavioural management will be effective in reducing pain, anxiety and distress during bloodtests as compared to baseline scores.
CHAPTER 2
THE NATURE OF PAIN

Pain is a complex and ubiquitous phenomenon (Melzack and Wall, 1983; Turk, Meichenbaum and Genest, 1983) and an unpleasant sensory and emotional experience (McGrath and Hillier, 1989). It presents numerous conceptual, experimental and practical difficulties. Pain has often been referred to as a mystery, a puzzle and a challenge, due to the poor correlation between tissue damage and reported discomfort (McGrath, 1990). Many researchers regard pain as determined in part by psychological factors which are unrelated to trauma or disease. Acute pain, for example, is greatly influenced by anxiety and rarely exists in the absence of any emotion (Chapman, 1976). From the observer's perspective, the emotional aspect of pain cannot be meaningfully separated from the sensory experience. The consensus view is that pain is no longer regarded as unidimensional, as simply and directly related to the extent of tissue damage, but as a multidimensional phenomenon with sensory-discriminative, motivational-affective, and cognitive-evaluative aspects (Melzack and Wall, 1965; Chapman, 1977). There is a dynamic interrelationship among these dimensions, such that a change in one affects the other, resulting in a change in the processing and experience of the noxious sensory input.

The challenge of pain is to understand the diverse aspects of pain perception and to provide adequate relief for different
types of pain. Knowledge about pain perception and factors which influence pain provides a base for designing interventions to ameliorate pain. The recognition that pain is influenced by many environmental and psychological factors led to increased interest in nonpharmacological methods of intervention, such as cognitive-behavioural methods, hypnosis and biofeedback for relieving pain.

The formal study of pain as a sensation is relatively new. The International Association for the Study of Pain (IASP) was founded in 1973 in order to integrate the various disciplines required for solving the puzzle of pain and in 1975 the IASP Journal Pain was established, which provided a scientific forum on information about pain. There are currently three journals devoted exclusively to research on painful conditions: Pain, the Journal of Pain and Symptom Management, and the Clinical Journal of Pain. There are now four textbooks on various aspects of children's pain which have been published in recent years (McGrath, 1987; McGrath and Unrah, 1987; Ross and Ross, 1988; McGrath, 1990) and entire journals on painful conditions. Childhood pain has been extensively reviewed by several authors (e.g. Eland and Anderson, 1977; Anderson and Masur, 1983; Bush, 1987; Jay, 1988; Zeltzer and LeBaron, 1986; Ioannou, 1991). Eland and Anderson's (1977) review of pain highlighted the relatively cursory attention paid to childhood pain in contrast to that associated with adults. Of 1,380 articles reviewed, only
33 dealt with paediatric pain; 30 dealt with pain as a tool for
differential diagnosis and only three articles contained data on
assessment and amelioration of children's pain. Since this
paper, research on pain assessment and measurement in children
has increased dramatically.

Over the past 15 years there has been a burgeoning literature on
pain in children which has resulted in dramatic changes in our
understanding of how pain is experienced and modified.
Traditionally, it was believed that pain occurs when a noxious
stimulus producing tissue damage activates the system. The level
of pain experienced was thought to be proportionately related to
the intensity and nature of the noxious stimulus. However it is
known that the sensory system for pain is complex and that pain
can be modified by the nociceptive system (the sensory system for
pain). For example, there are endogenous (internal) opioid or
morphine-like systems that can be activated by psychological and
environmental factors to suppress pain. Research has recently
focused on how pain perception, pain behaviour and attitudes vary
throughout childhood and how these may be influenced by factors
such as age, sex, learning and previous experience (McGrath,
1990). Childhood pain should be viewed from a number of
perspectives, but essentially within a developmental framework.
In terms of management, more research is being conducted nowadays
on relieving pain in infants and children undergoing invasive
medical procedures, pain associated with surgery, and, painful
The earlier neglect of research into childhood pain was due to several unsubstantiated beliefs and ethical concerns:

1. The assumption that children were unable to communicate their pain in a reliable way.
2. The assumption that children did not perceive pain in the same manner as adults.
3. Ethical concerns about experimental studies with children.
4. The lack of objective and consistent criteria for assessing pain.
5. The assumption that pain was simply related to the extent of tissue damage.
6. That the ability to discriminate pain is learned and that this process has not yet occurred in infancy.

(Ross and Ross, 1988; McGrath, 1990)

2.1 DEFINITIONS OF PAIN

There are a number of definitions of pain in the literature. The following definition by Melzack (1973) underscores the complexity of the pain experience:
Pain is not a single quality of experience...the word "pain" represents a category of experiences, signifying a multitude of different, unique events having different causes, and characterized by different qualities varying along a number of sensory and affective dimensions. (Melzack, 1973, pp45-46).

The lack of a single commonly accepted definition has been a major impediment in understanding pain (Bohica, 1979). In nursing journals, the most frequently quoted definition of pain is: "Pain is whatever the experiencing person says it is, existing whenever he says it does" (Meinhart and McCaffery, 1983, p.11). The definition reflects a pragmatic management attitude towards pain, which relies on the sufferer's self-report and which avoids any epistemological problems.

In the psychological literature, one of the most frequently quoted definitions of pain is that postulated by Sternbach (1968), where pain is described as:

.....an abstract concept that refers to (1) a personal, private sensation of hurt; (2) a harmful stimulus that signals current or impending tissue damage; (3) a pattern of responses which operate to protect the organism from harm. (p.12)

Sternbach's (1968) definition includes a subjective sensation component, but fails to clarify the cognitive component of pain. The experience of pain conveys more than a signal that tissue damage is occurring. For example, the same level of tissue damage can be experienced and expressed in markedly different ways by different individuals.
A satisfactory definition of pain must include a cognitive component which recognizes the meaning of pain for the individual. How the definition will account for the interaction between the components remains a problem as "the relative contributions of sensory stimulation, emotions and cognitions to the experience of pain remain unresolved, and continue to be a center of controversy among theoreticians" (Turk, 1978, p.200).

The Task force on Taxonomy of the International Association for the Study of Pain (IASP) defined pain as:

An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Note: Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. (Merskey, 1986, p.6217).

This definition takes into account the subjective nature of pain and conveys a multidimensional perspective. It suggests that learning about pain and how to respond to painful situations occurs during childhood. Pain threshold and tolerance are additional considerations. Pain threshold represents the point at which a stimulus is first experienced as painful, while pain tolerance refers to the point at which the noxious stimulus can no longer be endured (Wolff, 1983).

2.2 THEORIES OF PAIN

Concern about the prevention and treatment of pain and disease in
infants and children can be traced to ancient writings. Indeed, the origins of our contemporary understanding of pain may be traced back to ancient times. The evolution of man's understanding of pain from ancient times to about 1950 can be divided into three major periods, according to changes in the conceptualization of pain. The first two periods, the primitive and prescientific, were noted for nonempirical progress. The subsequent early scientific period was noted for important theoretical advances. For detailed discussions of the historical perspective on pain, see McGrath and Unruh (1987), Ross and Ross (1988) and McGrath (1990).

2.2.1 Primitive Period

For ancient people, inexplicable pains which were not related to apparent physical injury were regarded as afflictions caused by offended gods or as bodily invasions from evil spirits. Treatment involved supplicating the offended gods or exorcising the evil spirits. The headache, for example, was believed to be due to the presence of an evil demon in the skull and treated by trepanning, an operation in which a hole was made into the skull with a sharp instrument. The view of pain as a problem which could be managed with methods other than supplicating to the gods or exorcising demons, marked the beginning of the prescientific period.
2.2.2. Prescientific Period

By the 5th and 4th centuries B.C. the ancient Greeks had become increasingly interested in the physiology of pain and whether the heart or the brain was the center of all sensation. Alcmaeon (a disciple of Pythagoras, 566-497 B.C.) and Anaxcgoras (500-428 B.C.) believed that the brain was the center of all sensation including pain (Procacci and Maresca, 1984). Plato (about 400 B.C.) argued that pain was caused by an external event or intrusion into the body. According to him, both pain and pleasure were the result of an interaction of earth, fire, air and water, with the soul housed in the body. The ancient Egyptians believed that the heart was the center of all pain sensation. Herophilus (335-280 B.C.) and Erasistratus (310-250 B.C.) later provided evidence that the brain was part of the nervous system with connecting nerves related to sensation and movement (Procacci and Maresca, 1984).

The predominant belief about pain during the prescientific period was shaped by Aristotle (384-322 B.C.) who viewed pain as an emotion felt in the heart. He regarded the heart to be the center of sensory perception and the most important organ in the body. Pain was not however, thought to be one of the sensations such as sight, smell or touch. Aristotle believed that pain was produced by an increased sensitivity to touch due to the hardness or softness, warmth or coldness of the heart. Aristotle also described what could now be considered as psychogenic pain.
Galen (130-200 A.D.), a Greek physician who worked in Rome, studied the central and peripheral nervous systems extensively. He classified nerves into three groups: nerves for sensory function referred to as soft nerves; nerves for motor function described as hard nerves; and a third group of nerves which relayed pain messages. Galen believed that the brain was the center of sensation (Procacci and Maresca, 1984).

The view that the heart was the center of sensory perception persisted for almost twenty-three centuries, to the detriment of the pain field, despite impressive evidence to the contrary, particularly that proposed by Galen and Avicenna. Primitive man distinguished between pain having obvious external causes and internal disease related pain for which there was no obvious explanation (Fairley, 1978). This categorization of pain became increasingly more refined in the prescientific period.

There are well documented records of attempts to alleviate pain in early civilizations (Bonica, 1983). Pains related to physical injury were treated with physical or pharmacological methods. Remedies for reducing pain related to injury or sickness during the 10th century have been summarized by Avicena, an Arabic physician (980 to 1036 A.D.), (McGrath and Unruh, 1987; McGrath, 1990). These included many remedies similar to those used today, such as drugs, herbal preparations, therapeutic physical treatments and mental relaxation techniques.
2.2.3. Early scientific period

The early scientific period extends from the early 17th century to the middle of the 20th century. It was most notable for the theoretical advances that were made. Early 20th century theories of pain were based on stimulus-response models which regarded pain perception as a direct function of neural stimulation caused by tissue damage. There was therefore a hypothesized proportional relationship between level of tissue damage and the intensity of pain experienced. Within this neurophysiologically based model, there are two theories of pain: the specificity theory and the pattern theory.

Specificity theory

The specificity theory of pain (von Frey, 1894; cited in Ross and Ross, 1988) was essentially similar to that of Descartes, who two centuries earlier had adhered to the Galenic view in attributing pain to sensory input. According to Descartes, pain was a specific sensory modality, with its own central pain center and peripheral receptors. The transmission of pain was similar to pulling a rope and causing a bell to ring (Feuerstein and Skjei, 1979).

The specificity model postulates that there are pain receptors, a specific set of peripheral nerve fibres known as A delta and C fibres. The crucial assumption is the existence of modality specific centers in the central nervous system, with independent
connections to pain receptors at peripheral sites (Ross and Ross, 1988). When the pain receptors are activated by intense chemical or physical stimulation, they transmit impulses along specific peripheral nerve tracts, A delta (myelinated) and C (unmyelinated) fibres. These fibres were thought to synapse and ascend via the anterolateral spinothalamic tract to the higher brain centres and thalamus, where these impulses are registered as pain. The locus of the pain centre has been a source of controversy (Melzack and Wall, 1983). The current view is that rather than a pain center, there is a complex interaction among multiple structures which involve most of the brain (Melzack and Wall, 1983).

The specificity theory has been criticized on a number of grounds, including its inability to explain some of the characteristics of clinical pain (Dubner, 1980) and intra and inter-individual differences in response to identical noxious stimuli; its failure to account for pain where there is no noxious stimulus involved; its implication of a simple relationship between stimulus intensity and the magnitude of pain perception; and the failure of specificity theory based somatic therapies (e.g. nerve blocks) to eradicate pain (Melzack and Wall, 1983). Despite the above criticisms, specificity theory still has its supporters (Kerr and Wilson, 1978; Perl, 1971). While the theory has been dismissed as "a simplistic S-R view of pain" by Weisenberg and Tursky (1976, p.115) its significance in
the developing pain field is acknowledged as an impetus to experimental and clinical research (Melsack, 1973).

Pattern theory
The shortcomings of specificity theory led to alternative formulations by Goldscheider (1894), Nafe (1934), Livingstone (1943), Sinclair (1955), Weddell (1955), and Noordenbos (1959), cited in Ross and Ross (1988), collectively referred to as pattern theory. This theory proposes that pain results from the summation of spatial and temporal patterns of input. Pain perception is therefore based on stimulus intensity and central summation, but there were no specific pain receptors hypothesized in the peripheral nervous system. Pattern theories and specificity theories are similar in viewing peripheral stimulation as essential for pain perception. However, they differ on how sensory input is coded and transmitted to the cerebral cortex. Only pattern theory allows for the possibility of central modulation of sensory input (Noordebos, 1959; Melsack and Wall, 1962).

The theory's concepts of input control and central summation have received empirical support (Melsack and Wall, 1983). It has however, been criticized on a number of points: it has not considered the complexity of pain; it fails to explain certain problems of pain (e.g. phantom limb pain); and some pattern theorists have ignored the evidence of receptor-fiber
specialization, for example, A-delta and C fibers (Liebeskind and Paul, 1971). It also fails to adequately account for pain mechanisms (Melzack, 1973). Notwithstanding these criticisms, pattern theory has outpaced specificity theory.

2.2.4. Current Scientific Period

Bonica (1953) formalized the current status of knowledge on pain with his classic text, The Management of Pain. Of significance was his introduction of the concept of chronic pain, which affected the patient psychologically as well as physically. Bonica's (1953) advocacy of a multidisciplinary approach in the management of chronic pain problems set the stage for a shift from a unidimensional to a multidimensional view of pain. Other workers had also questioned the unidimensional concept of pain (Beecher, 1956, 1959) and emphasized the psychological component of pain, particularly the importance of attention (Barber, 1959; Kolb, 1962). The next major advance was the gate-control theory developed by Melzack and Wall (1965).

Gate-Control Theory

The gate-control theory proposes that:

Neural mechanisms in the dorsal horns of the spinal cord act like a gate which can increase or decrease the flow of nerve impulses from the peripheral fibres to the spinal cord cells that project to the brain. Somatic input is therefore subjected to the modulatory influence of the gate before it evokes pain perception and response...the gate is profoundly influenced by descending influences from the brain (Melzack and Dennis, 1970, p.2).
This theory suggests that sensory information is selected at various levels of the central nervous system and that the brain controls and influences this process. Pain occurs when the number of nociceptive impulses arriving at neural areas exceeds a certain level. Also, the perception of pain involves a complex balance between peripheral (physiological) and central (psychological) input. Psychological factors are viewed as comparable in importance to physiological factors.

The degree to which the gate inhibits or facilitates nociceptive transmission is determined by two factors. The first involves the relative activity in large (A-beta) and smaller (A-delta and C) fibers. Small fiber activity tends to facilitate nociceptive transmission by activating the gating mechanism, while large fiber activity inhibits it by closing the gate. Small fiber activity also activates the T cells that project the nociceptive information to the neural areas of the brain responsible for pain experience. The second set of factors are the cognitive, behavioural, and affective factors, which can modulate the somatic input relayed from the dorsal horn in ways not fully understood. According to this theory, central nervous system mediation is a significant factor in pain perception.

The theory is unique for its comprehensive elaboration of neurophysiological mechanisms of pain and its inclusion of cognitive-motivational aspects that account for avoidance of pain.
(Weisenberg, 1977). The theory attempts to account for the variability between a painful stimulus and pain perception. However, the exact mechanism involved in gate control has not yet been clarified (Weisenberg, 1977). It is nevertheless an important theory as it "ties together many of the puzzling aspects of pain perception and control ...(and) has had a profound influence on pain research and the clinical control of pain" (Weisenberg, 1977, p.1012). A further refinement of the theory was Wall's (1979) proposal that pain be viewed as a drive to promote recovery from injury. The gate-control theory stimulated new approaches to pain management, particularly those based on cognitive behavioural interventions (Melzack and Wall, 1983; Turk, 1978) and has helped to bridge the gap between laboratory research and clinical investigations (Chapman, 1978).

Behavioural Conceptualization of Pain
The behavioural approach conceptualizes pain as an overt behaviour that can be influenced by the same principles of learning and conditioning as other behaviours. Fordyce (1978) classified pain behaviours as either operant or respondent. Pain behaviour was classified as operant (chronic) if it was contingent on its consequences and not upon antecedent stimuli of tissue damage or irritation. It is in this area of chronic pain where behavioural techniques have had greatest application. Pain behaviour was considered respondent and therefore acute, if its onset and frequency was directly related to antecedent stimuli of
tissue damage or irritation from trauma or disease.

In the cognitive-behavioural literature pain has been conceptualized as a trimodal construct involving an interaction of behavioural, cognitive-affective and physiological responses, produced by tissue damage or irritation; however, it may also be produced and maintained by antecedent and consequent conditions (Sanders, 1979). Behavioural (overt) pain responses refer to observable verbal and nonverbal behaviours such as crying, screaming and physical resistance. Cognitive-affective (covert) responses refer to the perceptions, imagery and thoughts associated with pain, such as during invasive procedures. Physiological responses may include autonomic and biochemical reactions, such as elevated blood pressure and heart rate. Assessment and intervention of pain should take into account the interaction of behavioural, cognitive-affective and physiological responses.

2.3. TYPES OF PAIN CHILDREN EXPERIENCE

Most children will experience a diverse number of pains, from cuts, bruises, scrapes, broken bones, headaches, toothaches, burns and injections. Some children will experience pain produced by major injuries and accidents, pain related to surgery and pain related to diseases (e.g. cancer, hemophilia and sickle cell anaemia). Other pains include: 1) referred pain (pain felt in one
part of the body but originating from an injury in another site); 2) causalgia pain (intense pain sensations produced by normally nonpainful stimuli); and 3) phantom limb pain (felt in a limb that has been amputated).

Varni (1983) categorized children’s pain into four categories: specific disease states, recurrent pain, physical injury or trauma, and medical/dental procedures. Ross and Ross (1982, 1985) proposed seven categories best representing pain experiences described by children in their studies: common pain experiences, psychophysiological pain, acute pain, chronic pain, treatment related pain, competency pain and vicarious pain experiences. These are described in detail in Ross and Ross (1988). One of the most helpful distinctions in pain diagnosis and treatment is the differentiation of pain states into acute, chronic and recurrent pain.

2.3.1. Acute Pain

Acute pain is produced by a noxious or tissue-damaging stimulus, is relatively short in duration and usually provides an important adaptive function that something is wrong. Acute pain often exists in the presence of emotions such as anxiety, fear or anger. The concurrent fear component of acute pain distinguishes it from chronic pain.

All children will at some time experience some acute pain from
necessary medical and dental treatments, such as injections for immunization and local anaesthetics. Other children will receive invasive procedures as part of medical treatment for serious injury or a disease. Children with chronic illness such as cancer, diabetes, and arthritis will inevitably experience repeated invasive medical procedures as part of their treatment. Children with growth hormone deficiency, those who have sustained burns, undergone surgery, or required lengthy hospitalization, will also experience a variety of acute pains during treatment. These treatments include diagnostic and therapeutic procedures, blood sampling procedures and medication administrations.

Children experience three forms of acute pain: 1) pain caused by minor accidents that occur during normal activities; 2) pain caused by intense physical trauma such as appendicitis and severe earaches; and 3) pain caused by invasive medical or dental procedures (McGrath, 1990). The situational and emotional factors involved in acute pain differ significantly depending on the context. Pain which occurs during normal activities or from usual childhood illnesses does not cause serious anxiety or fear as it is accepted as part of growing up. However, in a medical or dental setting, children often feel they have no control, they may not understand the need for a particular treatment, they may not know what to expect and they may not know any coping strategies for anxiety and pain. These situational factors can lead to increased fear and anxiety and consequently higher levels
of pain. Unlike adults, children frequently use affective descriptors to describe their acute pain with words such as "pounding", "cutting", "aching" and "crushing" (Ross and Ross, 1988).

Children's concepts of their illness will also affect levels of pain perception. Although the noxious stimuli that evoke pain may be similar, the level of pain children experience can be very different. The management of acute pain in children therefore requires an assessment of the context in which each pain occurs.

2.3.2. Chronic Pain

In contrast, chronic pain tends to be associated with disease, and may be constantly present over a number of months. A pain is chronic if it persists beyond the usual course of a disease or healing time for an injury (Bonica, 1980). Chronic pain may warn of trauma or disease in the early stages, but generally it does not serve a useful protective role. Chronic pain has proved to be refractory to conventional medical treatment (Chapman, 1976) and is a major health problem for adults (McGrath, 1990). Children experience less chronic pain than adults. Common chronic pains for children are associated with diseases such as hemophilia, arthritis and sickle cell anaemia. The goals of treatment are the preservation of joint function and the control of pain. Unlike adults, most children with cancer do not experience
chronic pain. Paediatric cancers (i.e. the acute leukemias and lymphomas) are not extremely painful, but can produce pain during active phases of the disease.

Children may develop chronic pain as a consequence of anxiety and depression, where pain becomes the somatic expression of their underlying emotional distress (McGrath, 1990). Children can also develop chronic pain from their anxiety about a disease, fears of dying, anxiety about unnecessary treatments and frustrations about being different from other children (McGrath, 1990). Some depression is, however, inevitable in a child who has experienced pain for a year or more (Masek, Russo and Varni, 1984). McGrath and Hillier (1989) describe children with chronic pain as being unable to express their feelings and recognize stress-inducing situations. The pain that is experienced is real and not imagined and can become a method of coping with stress, by avoiding an aversive situation. It can also be reinforced by secondary gain (e.g. attention by parents, teachers, friends).

Management of chronic pain must begin with an understanding of the source of tissue damage, children’s perceptions of their illness and the situational and emotional factors that exist for a particular child.

2.3.3. Recurrent Pain

Recurrent pain syndromes include frequently occurring episodes of
headaches, abdominal pain or limb pains in otherwise healthy and pain free children which persist beyond a three month period. Approximately 30% of children and adolescents may experience recurrent abdominal pain or headaches (Apley, 1975; McGrath, 1983; McGrath and Hillier, 1989). There are several common features of recurrent pain syndromes:

1. Children experience severe episodes in the absence of a well defined organic etiology.

2. Pain may be triggered by a variety of external or internal factors, particularly stressful events.

3. Children are healthy and pain free in between episodes.

4. There is often a history of similar pain in one of the child's parents.

5. Specific etiology is unknown, but does not necessarily indicate a psychological etiology.

It is essential to study the family as well as the child with recurrent pain, since the prevalence of similar pains for other family members is high and findings suggest that parents of children with recurrent pain are more anxious and depressed than control parents (Hodges, Kline, Barbero and Flanery, 1985; Hodges, Kline, Barbero and Woodruff, 1985). It is not sufficient to examine the sensory aspects of recurrent pain (quality,
intensity, duration, location, frequency). Many different situational, emotional and familial factors can be implicated, but are unique for each child (McGrath and Hinton, 1987).

There is clinical evidence to suggest that children are likely to develop emotional and psychological difficulties the longer they endure recurrent pain, particularly if they do not understand their syndrome and do not have strategies to cope with the painful episodes (McGrath, 1987a). They are also likely to develop another type of recurrent pain in adolescence. Many questions remain unanswered about the etiology and management of recurrent pain in childhood. It is not clear how frequent painful episodes affect children’s development and their pain perceptions and coping abilities as adults. Assessment must consider the sensory aspects of recurrent pain and the relevant situational, emotional and familial factors.

2.4. ENDOPHINS

Research into endogenous pain suppressing mechanisms has developed rapidly over the last two decades (Fields, 1985; Hammond, 1985). The discovery of opiate receptors and endogenous opioids (endorphins) in the same region of the brain from which stimulation produced analgesia could be elicited, and the reversal of this analgesia by the opiate antagonist naloxone, established the idea of an endogenous opioid mediated analgesia
system (McGrath, 1990). The function of endorphins for pain control has been studied by blocking the opioid receptor with naloxone and subsequently examining the effects on pain perception. There is evidence from animal studies that various factors such as stress, fear, pain intensity and duration are all important for activating endogenous endorphin mediated analgesic systems (McGrath, 1990). Research into endogenous opioids increased as studies sought to clarify the role of the endorphins in chronic pain (Terenius and Wahlstrom, 1979). Most research into endorphins has involved adult and animal studies. The critical features of nociception (specificity, convergence, inhibition, summation and descending control) have important implications for managing paediatric pain (McGrath, 1990). (For detailed reviews of nociceptive processing, see McGrath, 1990; Melzack and Dennis, 1978; Ng and Bonica, 1980; Wall, 1988).

2.5. COPING STRATEGIES

Coping strategies refer to cognitive or behavioural actions which the child uses to modify pain. Pain is a stressor that disrupts the child’s sense of equilibrium (Ross and Ross, 1988). The way in which the child deals with stressors is called coping style. According to Lazarus and Folkman (1984), coping styles evolve from a variety of intrapersonal sources, such as personality or developmental level and the child’s experience of previous stresses, the history of success or failure in dealing with them, and early social experiences and relationships. Thus, coping
strategies are the specific techniques the child uses to diffuse the stressor’s effects (Ross and Ross, 1988). Coping strategies can be either internally or externally directed. Externally directed coping strategies have been categorized as direct actions on the self or environment which include avoidance behaviour, and active preparations against harm. Internally directed coping strategies have been referred to as intrapsychic coping processes, characterized by cognitive processes such as attention, reappraisal and wish fulfilling fantasy (Lazarus, Averill and Opton, 1974). Similar categories have been developed by other researchers (e.g. Murphy, 1974; White, 1974). Pearlin and Schooler (1978) identified three functions of coping: (1) eliminating or modifying conditions that contribute to the problem; (2) perceptually controlling the meaning of the experience; and (3) keeping the emotional consequence of the problem within manageable limits. It may be difficult to eliminate or modify the situation because it is not possible for the child to escape or avoid the situation which gives rise to pain. An example would be children with severe burns who are required to undergo debridement as part of the healing process. Pharmacological agents may be useful in modifying the experience of pain in other situations. In many painful situations we help children cope via the latter two functions. Some strategies may be more problem focused while others are focused on regulating emotions (Lazarus and Folkman, 1984). Strategies used to regulate emotions may interfere with problem solving strategies and vice
versa. Some behaviours which may be regarded as distress (crying or screaming) are used as coping strategies by children. Thus, behaviours do not have to be "adaptive" or "successful" to be considered a coping strategy.

The problem of "method variance" in obtaining information on children’s coping strategies has been discussed by Ross and Ross, 1988). For example, the wording of a question may create a certain response set and may account for some differences found in studies. Other sources of variation in children’s responses to questions on pain include the location (e.g. hospital, school) of and the perceived purpose of the interview. Occasional use of coping strategies such as distraction have been reported in studies where children were asked general questions about what would help a child feel better when in pain (Abu-Saad, 1984a, 1984b; Savedra, Gibbons, Tesler, Ward and Wegner, 1981, 1982; Gaffney, 1983). Jeans and Gordon (1981), Reissland (1983) and Ross and Ross (1982) provide most of the information on children’s coping strategies, where they distinguish between self-help and others’ help. The following coping strategies have been identified:

1) Direct action (externally directed) coping strategies.
These include escape strategies for children confronted with potentially aversive experiences (Ross and Ross, 1982) and postponement/avoidance frequently used by children undergoing
painful treatment procedures (Ross and Ross, 1982). Ross and Ross (1982) reported on the following escape strategy by a six year old boy:

I heard my mom say we soon had to go to the doctor and I'd heard a lot of bad things about the doctor so I hid in my cupboard but she started yelling and getting real mad so I came out.

An example of a postponement/avoidance strategy was given by Savedra (1980) cited in Ross and Ross (1988):

When they come for me I tell them it's the kid in the other bed. (Boy, aged 6, burn dressing).

2) Cognitive (internally directed) coping strategies.

The following cognitive coping strategies used by children have been identified in various studies:

a) Attention diversion
b) Imagery
c) Incompatible emotive imagery

a) Attention diversion

Attention diversion was widely used by children of all ages (Ross and Ross, 1982; Gaffney, 1983; Reissland, 1983; Hilgard and LeBaron, 1984). Children appeared to know that attending to an external stimulus or internal activity could increase their pain tolerance:

I counted the tiles on the ceiling till I couldn't count any higher, then I started over and did it again. (Six year old girl, having a shot, Ross and Ross, 1982).
b) Imagery

Imagery was used to transform the context of pain, while the pain was acknowledged as in this example by Ross and Ross (1982):

I pretended I was in a space ship and the pressure was making my ears hurt and I was the only one that could get it back to earth. (nine year old girl, painful ear procedure).

Incompatible emotive imagery

Incompatible emotive imagery involves engaging in imagery/fantasy that is incompatible with the painful experience:

I look at the animals on my pillow; just think about them walking about 'cause if I don't think (about the animals) I think of my tummy, but when I'm thinking it goes way. (Reissland, 1983).

There are some reports of developmental changes regarding coping strategies, with older children using them more often than younger children (Jeans and Gordon, 1981; Reissland, 1983). No sex differences have been reported. Brown, O'Keefe, Sanders and Baker (1986) found an increase with age in the total number of coping strategies used in a hypothetical dental injection situation, with positive self-talk ("Be brave", "It's not so bad", and "I can take this") being the most frequently used strategy and attention deployment being the second most common strategy. They also found that many children did not report coping strategies. Worchel, Copeland and Barker (1987) reported the quality of coping strategies to be more important than
quantity in paediatric oncology patients. Ross and Ross (1982) found that some children used another strategy if one did not work. They found two types of coping style in their study: one that confronted pain and refusing to become depressed, found in a small group of children with juvenile arthritis, and another involving an unusual ability to cope with unpleasant events optimistically and realistically. This latter style was found in a group referred to as “the Blithe Spirits” (Ross and Ross 1984a):

You can make it awful or you can make it OK. (Girl, aged nine).

Just go in there and have fun with the fun things and tell yourself it won’t be long. (Boy, aged nine).

In some studies, healthy children and not chronically ill children were interviewed. It is necessary however, to conduct research with chronically ill children who have had experience of painful procedures to understand the influence on verbal reports. The coping strategies children report in interview studies may differ from those used in a stressful medical situation (Eiser, 1990).

Siegel (1983) studied coping strategies in children hospitalized for minor elective surgery who also experienced several potentially stressful procedures (e.g. bloodtest, preoperative injection). He found that successful copers used more coping
strategies and had more accurate information about why they were in hospital, than unsuccessful copers. Table 2-1 lists the coping strategies reported by children in this study. These self generated coping strategies are important as they can serve as a base for planning interventions.

Hyson (1983) studied coping behaviours in children undergoing a routine physical examination. Coping behaviours were classified according to White's (1974) strategies of adaptation, which involve information seeking (looking, asking questions), comfort seeking (contact with mother, familiar objects), and autonomy (attempts to control, structure, or protest). Information seeking behaviours were the most common among children of all ages just before the examination, while autonomy behaviours were more common during the actual examination. Pidgeon (1981) found that the preschool child maintains a vigilant orientation in the hospital and suggested that preparation procedures should include information about the actions and intentions of hospital personnel and the identification of objects and persons in the hospital environment. Caty, Ellerton and Ritchie (1984) conducted a content analysis of the coping strategies reported in 39 case studies of hospitalized children aged 20 months to 10 years of age. Younger children were found to display greater numbers of behaviours in the action/inaction dimension using Lazarus's stress and coping paradigm. Older children exhibited more information seeking reflecting their greater cognitive ability.
### TABLE 2-1 Categories of Coping Strategies

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>DEFINITION OF COPING STRATEGY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Distraction</strong></td>
<td>indicates that he/she does something to divert his/her attention away from the procedure by focusing on some aspect of the immediate environment (e.g. looking at a picture on the wall, counting floor tiles)</td>
</tr>
<tr>
<td><strong>External</strong></td>
<td>indicates that he/she does something to divert his/her attention away from the procedure by focusing on some part of the body or sensation unrelated to the procedure (e.g. concentrates on heart beating)</td>
</tr>
<tr>
<td><strong>Imagery</strong></td>
<td>indicates that he/she thinks about or imagines some pleasant event, activity or situation to divert attention away from the procedure (e.g. thinks about playing an electronic game, imagines self at school, thinks about being at a party)</td>
</tr>
<tr>
<td><strong>Reinterpret sensations</strong></td>
<td>indicates an attempt to reinterpret or alter by some cognitive process (other than by distraction) the sensory stimulation produced by the procedure (e.g. thinks about it as being cool or as pressure rather than as hurting, burning or stinging)</td>
</tr>
<tr>
<td><strong>Fantasy</strong></td>
<td>imagines he/she is some imaginary character who does not feel pain (e.g. Superman) or pretends that some magical event is happening (e.g. waving a magic wand) to make the pain disappear</td>
</tr>
<tr>
<td><strong>Mental rehearsal</strong></td>
<td>indicates some attempt to prepare for the experience by mentally planning how he/she will confront it</td>
</tr>
<tr>
<td><strong>Information Seeking</strong></td>
<td>indicates an attempt to ask questions or gather information relevant to the medical procedure</td>
</tr>
<tr>
<td><strong>Relevant</strong></td>
<td>indicates an attempt to ask questions or gather information that is unrelated to the medical procedure</td>
</tr>
<tr>
<td><strong>Positive self-statements</strong></td>
<td>indicates thinking about positive aspects of the procedure, reassures self that he/she can tolerate the procedure; thinks about how he/she had handled successfully previous procedures; makes self-reinforcing statements for doing well during the procedure; thinks about the experience (i.e. &quot;the Dr. is doing this to help me&quot;, &quot;it doesn't hurt so bad, I can get through this OK&quot;)</td>
</tr>
<tr>
<td><strong>Negative self-statements</strong></td>
<td>indicates thinking about distressing aspects of the current procedure and problems in tolerating it (e.g. thinks about how much it was hurting and wanting it to stop)</td>
</tr>
<tr>
<td>Strategy</td>
<td>Description</td>
</tr>
<tr>
<td>----------</td>
<td>-------------</td>
</tr>
<tr>
<td>Catastrophizing</td>
<td>Indicates thinking about distressing or bad things that might happen or have occurred in the past (e.g., thinks about the last time it really hurt)</td>
</tr>
<tr>
<td>Affective</td>
<td>Indicates that he/she thought about or actually displayed some affective response (i.e., cried, yelled, got angry) as a means of tension or stress reduction</td>
</tr>
<tr>
<td>Affective</td>
<td>Indicates an attempt to reduce emotional distress by specifically controlling or inhibiting feelings such as trying not to cry or yell</td>
</tr>
<tr>
<td>Relaxation</td>
<td>Indicates that he/she engaged in some activity or thought about something with the specific intent of relaxing or making self feel calm</td>
</tr>
<tr>
<td>Seeking help/ emotional support</td>
<td>Indicates that he/she thought about asking or actually asked someone for help, comfort, sympathy, or emotional support, such as asking the nurse to hold his/her hand or thought about mother being in the room to call for help or comfort if needed</td>
</tr>
<tr>
<td>Physical activity</td>
<td>Indicates that he/she attempts to place a part of the body in a certain position (i.e., holds arm rigid) or that he/she engages in a particular physical activity (i.e., holds breath, massages arm) for the specific purpose of reducing discomfort</td>
</tr>
<tr>
<td>Active acceptance</td>
<td>Engages in any activity or thinks about engaging in an activity with the specific purpose of immediately terminating the procedure (e.g., escaping from the room, pushing the doctor away, verbalizing that he/she wants the procedure stopped)</td>
</tr>
<tr>
<td>Passive acceptance</td>
<td>Indicates some decision that presumes that nothing could be done to change the situation or to make it better or less stressful in some way</td>
</tr>
<tr>
<td>No strategy reported</td>
<td>Indicates that he/she did not engage in any activity or did not think about anything</td>
</tr>
</tbody>
</table>

(From Siegal & Smith, 1989)
The assessment of coping strategies in children, while still in its infancy, suggests some consistency in that older children use a greater number of coping strategies and tend to use more cognitive strategies than younger children. These findings are to be expected given the differences in cognitive developmental level as children mature and have more opportunities to have tried different coping strategies. Relating coping strategies to outcome in specific painful situations would further our understanding of adaptive and less adaptive strategies. It is unknown whether children have more global coping styles, such as information avoiding or seeking. The goal of any intervention is to teach children effective coping strategies and/or match interventions to children's preferred coping strategy. Few studies have investigated this issue.

The child's evaluation of the pain experience will affect the coping process. Factors influencing the child's perception of pain include the child's developmental level, specific child factors, and social and non-social environmental factors. These are discussed in the following chapter.
CHAPTER 3
FACTORS THAT MODIFY CHILDREN'S PAIN PERCEPTIONS

Various factors modify children's pain perceptions, such as age, sex, cognitive level, parental behaviour and previous pain experiences. Much research has attempted to identify the diverse factors that modify pain perception (Beecher, 1956, 1959; Hilgard, 1969; Johnson, Dabbs and Leventhal, 1970; Johnson, Leventhal and Dabbs, 1971; Melzack, 1976). These factors are discussed in detail by Ross and Ross (1988), and Mcgrath (1990). Table 3-1 depicts the factors influencing children’s pain perceptions.

**TABLE 3-1** A model depicting the factors that modify children’s pain perceptions. Pain produced by a noxious stimulus depends on relevant situational and emotional factors, which are influenced by a child’s sex, age, cognitive level, previous pain experience, learning and culture. (From Mcgrath, 1990, p.22).
Any attempts at understanding the complexity of pain must take into account inter- and intra-individual variability in pain reactivity that occur in situations in which the degree of aversive stimulation is the same for all individuals. Pain experienced by a child is not only produced by a noxious stimulus, but is influenced by the factors listed in Table 3-1, all of which must be considered when assessing pain and designing therapeutic interventions.

The somewhat simplistic view of pain as a trait, an enduring aspect of the individual's personality, regards how a child reacts on one occasion as predictive of how he will react on another. Ross and Ross (1988) cogently argue that it should more appropriately be regarded as a state, determined by internal and external factors. A number of child and environmental variables are implicated in pain reactivity. These have been classified into two groups by Chapman (1985): (1) predisposing factors, which include the child's age, sex, personality, observational and cultural learning; and (2) situational factors which are relevant to the immediate pain situation, which are further divided into situation-specific child factors, social environmental factors and nonsocial environmental factors. Situation-specific child factors include variables which are relevant to the context in which the pain is experienced (e.g. state anxiety, cognitive style and feelings of control). Social environmental factors include other people present and their
effect on the child (e.g. presence of mother and paediatric personnel). Nonsocial environmental factors are those elements of a setting which exert an influence on the child (e.g. strange machines and high noise level).

The premise is that pain reactivity is the result of factors within the child and complex social transactions that may influence his/her perception of pain. This conceptualization represents the culmination of two theoretical developments. The first was von Frey’s specificity theory (Foster, 1901), the unidimensional, antecedent-consequent model of pain (described in Chapter 2). The pain perceived by the child involves a sensory dimension only that reflects the intensity of the noxious stimulus (see Table 3-2).

Beecher’s (1959) two-component model included sensory and reactive dimensions and the contribution of the environment to account for inter- and intra-individual differences in pain reactivity. The model recognizes that there is no predictable relationship between the degree of trauma and pain experienced. The two component model is depicted in Table 3-2.

Gate-control theory (Melzack and Wall, 1965) suggests pain reactivity is multidimensional, influenced by cognitive, personality, learning and cultural variables with environment clearly involved. There is no suggestion that the influence of
environment is bidirectional. Instead, child factors interact with environmental factors, each remaining relatively constant within this interaction (see Table 3-2).

Ross and Ross (1988) postulate that the social ecology model formulated by Whalen and Henker (1976) on hyperactive behaviour in the classroom setting extends the gate control theory and has important implications for the management of pediatric pain (see Table 3-2). The model involves a reciprocal transactional process in which the child’s behaviour is not only a consequence of the environment but also influences it. Thus, what may be a consequent at one point in time, may become an antecedent at a subsequent point (Whalen, Henker and Dotemoto, 1980).

The social ecological approach offers great potential in understanding inter- and intra-individual differences in pain reactivity. There is evidence from interview data (Ross and Ross, 1984), clinical data (Lewis, 1978; Stoddard, 1982), and supporting statements (Bland and Anderson, 1977; McCaffery, 1969), that as a result of differential management, the paediatric setting can function as a provocation ecology that mediates increased anxiety, distress and pain or as a rarefaction ecology that reduces these responses. Whalen and Henker’s (1980) construct of provocation and rarefaction ecologies has direct relevance to effective management of paediatric pain (Ross and Ross, 1988).
Table 3-2 Increasing Complexity in Models of Pain Reactivity

<table>
<thead>
<tr>
<th>Model</th>
<th>S (Noxious stimulus)</th>
<th>R (Pain perceived by child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unidimensional</td>
<td>Intensity of stimulus</td>
<td>Has sensory dimension only</td>
</tr>
<tr>
<td></td>
<td>input is the only</td>
<td>variable</td>
</tr>
<tr>
<td></td>
<td>variable</td>
<td></td>
</tr>
<tr>
<td>Two-Component</td>
<td>Physiological + psych-</td>
<td>Has sensory + reactive dimensions, with reactive possibly more important</td>
</tr>
<tr>
<td></td>
<td>ological input with</td>
<td></td>
</tr>
<tr>
<td></td>
<td>environmental influence implied</td>
<td></td>
</tr>
<tr>
<td>Gate-Control</td>
<td>Physiological + psych-</td>
<td>Is multidimensional: sensory-discriminative, motivational-affective, + cognitive evaluative aspects</td>
</tr>
<tr>
<td></td>
<td>ological input with</td>
<td></td>
</tr>
<tr>
<td></td>
<td>environmental influence clearly involved</td>
<td></td>
</tr>
<tr>
<td>Social Ecology</td>
<td>Physiological, psych-</td>
<td>Is multidimensional: sensory-discriminative, motivational-affective, + cognitive evaluative aspects</td>
</tr>
<tr>
<td></td>
<td>ological, social, +</td>
<td></td>
</tr>
<tr>
<td></td>
<td>nonsocial environmental components all merge as</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$S_1$</td>
<td></td>
</tr>
</tbody>
</table>

The influence of $R_1$ on $S_1$ $S_2$ in turn effects changes it to $S_2$ changes in $R_1$ so that it becomes $R_2$

The influence of $R_2$ on $S_2$ $S_3$ in turn effects changes it to $S_3$ changes in $R_2$ so that it becomes $R_3$ and so on.

(From Ross and Ross, 1988; p 77).

The predisposing and situational variables influencing children's pain are discussed in this Chapter within a social ecology framework according to Chapman's classification of predisposing variables and situational factors. It should be noted that many
determinants of the predisposing factors are also determinants of the situational variables, that there may be an overlap of categories, and that all categories have a concurrent influence on children's pain reactivity.

3.1. PREDISPOSING FACTORS

3.1.1 Age

There is a lack of agreement about when infants perceive pain. Consequently, prescribing and administering medications for pain relief in infants is inconsistent. Clinical surveys suggest that neonates (infants less than one month of age) and infants, receive invasive procedures without analgesia, or surgery without anaesthesia or postoperative analgesics. Although most anaesthetists believe neonates feel some pain, they are reluctant to prescribe analgesics (Purcell-Jones, Dorman and Sumner, 1988). This reluctance is probably based on the assumption that infants do not feel much pain because they have an immature nervous system. Clinical studies and objective assessments show that neonates and infants do experience pain, because of their cries, facial expressions, physiological reactions and overt distress behaviours. There is evidence that pain causes physiological stress, which hinders optimal recovery (e.g. Williamson and Williamson, 1983; Anand, Sippell and Aysley-Green, 1987). Adequate pain control in infants and children is essential during surgery and in the postoperative period, not only to prevent
needless suffering, but also to promote recovery following surgery.

Age is an important variable because the meaning that the child attributes to pain varies as a function of his/her cognitive development (Gaffney, 1983). The meaning that the child attaches to the pain experience can enhance or attenuate pain tolerance. Younger children have been shown to exhibit more distress than older children during highly painful procedures. For example, Jay, Ozolins, Elliott and Caldwell (1983) found distress levels in children under the age of seven years were 5-10 times higher than older children. This distress is probably due to the meaning of pain for the child, their immature cognitive processes and difficulty in understanding cause and effect, which may result in distorted conceptions and misattributions about pain and illness (Simeonsson, Buckley and Monson, 1979; Willis, Elliott and Jay, 1982). For example, some children believe it is possible to bleed to death from bloodtests (Sheridan, 1975), and perceive pain and illness as punishment for bad thoughts and behaviour and transgression of the rules (Perrin and Gerrity, 1981).

3.1.2 Cognitive Level

Children's understanding of pain is related to their level of cognitive or intellectual development. There is evidence that children are able to recognize the multidimensional and
ubiquitous nature of pain, from an early age (McGrath, 1990).
Children understand the concept of pain, through their own experiences. From the young child's point of view, "pain is what hurts". Even very young children can describe the emotional and suffering aspects of pain in addition to the physical aspects. Many children describe experiences such as teasing or the death of a close relative as painful. As children become older, they are able to describe the physical and emotional aspects of pain in more sophisticated and abstract language.

McGrath (1990) is currently evaluating differences in children's pain perceptions according to their age, sex and health status (healthy children versus children with cancer, arthritis or headaches). Children are asked to describe pain, including their most and least painful experiences, and keep a pain diary over a one month period. A seven year old boy described pain as "something very bad and unuseful"; a nine year old girl defined pain as "hurt - it gives you bad feelings"; a 14 year old girl's perception of pain was "a feeling of hurt physically or mentally by someone or something".

Ross and Ross (1988) and Eiser (1990) cogently argue that the child's view of pain parallels the developmental sequence of other health-related concepts such as health and illness (Bibace and Walsh, 1980; Perrin and Gerrity, 1981), hospitalization and related procedures (Redpath and Rogers, 1984) and death (Lonetto,
According to Piaget's (Piaget and Inhelder, 1969) theory of cognitive development, children progress through a series of cognitive stages from a sensorimotor level of cognitive development (birth to two years) to a preoperational level (two to seven years) to a concrete operations level (eight to ten years) and then a formal operational stage (11 - 16 years).

During the sensorimotor stage, infants and toddlers become aware of their environment through exploration. Although language is limited, there is some evidence that some children at this period can generate pain descriptors (Hahn and McLone, 1984). In the preoperational stage, children are egocentric and cannot grasp the idea that their perception may be different from others. The child may think his/her pain is as obvious to others as it is to him/her. Events are interpreted in terms of immediate perceptions. Cause and effect are not understood and pain is often perceived as a punishment. Children at the concrete stage begin to differentiate themselves and others. More importantly, they begin to differentiate their internal from their external states and between the cause of illness and its effects. The
cause is viewed as a person, object or action that is external to the child and that is perceived as bad or harmful to the body. Children become aware of the subjectivity of their own thoughts. They understand the cause of pain and are able to express pain. Thinking is concrete rather than abstract.

Children at the formal operational stage are able to think in more abstract terms and may thus attribute illness to physiological or psychological causes.

Developmental trends have been reported in studies on children's beliefs about pain (Schultz, 1971; Jeans and Gordon, 1981; Gaffney and Dunn, 1986). For example, Schultz (1971) found younger children were more likely to attribute colour and shape to different types of pain than older children. Jeans and Gordon (1981) found that children's concepts of pain changed from a physical understanding to a more abstract one in children aged five to 13 years of age. Gaffney (1984) investigated children's definitions of pain in 600 children aged five to 14 years where they were asked to complete ten sentences about pain. Responses were analyzed for three age groups: 5-7, 8-10, and 11-14, corresponding to Piagetian developmental stages. Gaffney and Dunn (1986) classified three types of definitions in the children's responses listed in Table 3-3 which shows that children's concrete concepts of pain gradually decreased with age, with semi-abstract and abstract concepts increasing with age. Younger
children were found to have a more passive perspective of pain, which shifted with age to include a degree of perceived control.

TABLE 3-3 Children’s Definitions of Pain

Definition 1: Concrete definitions. Pain is "a thing", "something", "it"; pain is defined by a location in the body or by its unpleasant physical properties; something that hurts, or the association with illness or trauma.

Definition 2: Semiabstract definitions. Pain is described in terms of feeling or sensation, without specific elaboration to a body part. Pain is not a thing that hurts, but is a hurting feeling or sensation. Children use synonyms to describe qualities of pain, such as "ache" or "cramp", or describe pain associated with sickness.

Definition 3: Abstract definitions. Pain is described in physiological, or psychophysiological terms. Children refers to the physiological substrate or purpose of pain-pain as damage that sets off nerves. Pain is also emotional, such as worry, anxiety, or depression.

(From McGrath, 1990; summarized from Gaffney and Dunne (1986, p.109)).

A second trend in Gaffney’s (1984) data was of increasing thematic elaboration and use of analogies with age, reflecting a growing awareness of more abstract aspects of pain. Ross and Ross (1988) postulate that whether children use analogies or not may depend more on the nature of the question than on developmental level.

Ross and Ross (1984a) in contrast, did not find age or sex
differences in their study of children aged five to twelve years. Pain definitions tended to be brief and unidimensional by emphasizing the sensory dimension of pain. There was no trend toward thematic elaboration with increased age.

Gaffney and Dunn (1986) suggest two methodological differences between their study and previous research which has not reported developmental patterns: 1) in their study children were classified into cognitive age; 2) a higher age ceiling of 14 years was used, which allowed better assessment of formal operational responses. The authors also used a coding system that included multiple responses (McGrath, 1990).

Lollar, Smits, and Patterson (1982) interviewed 240 children and adolescents aged four to 19 years of age and found that children with little pain experience rated pains depicted in pictures as more painful than children with extensive pain experience. This has implications for chronically ill children who have repeated painful procedures. Savedra et al (1982) found children who were hospitalized described pain differently than non-hospitalized children. Ross and Ross (1984a) interviewed 994 children aged five to 12 years about their pain experiences and coping strategies. Children attributed pain to specific causes such as illness, accidents, surgery and aggressive actions of others. Interestingly, there was very little evidence that children perceived pain as a punishment. Also, children’s responses were
not consistently related to their age or sex.

In summary, children’s cognitive level determines how they understand pain and thus how they perceive pain. It behoves us to consider the child’s developmental level when assessing and managing children’s pain. Young children at the preoperational stage of cognitive development may perceive painful situations as more threatening and fearful than younger infants or older children (Jeans, 1983). Younger children are less able to understand the purpose of invasive medical procedures and therefore the significance of the pain. Also, they may be less able to develop or consistently use coping strategies for pain.

3.1.3 Previous Pain Experience

Children’s frame of reference for evaluating pain experiences changes as they grow older and experience new pains that vary in quality, intensity and duration. Common pains related to mild tissue damage such as cuts and bruises, may be perceived as less unpleasant as children mature. However, children at the same cognitive level who differ in pain experience may perceive pain differently. For example, children who have received many intramuscular injections may find these less painful than children who have had little experience of injections. McGrath (1990) argues that the effect of age, cognitive level and previous experience all interact with children’s emotional response to pain.
The effects of previous experience are unclear. This issue has been addressed by various investigators regarding children's distress during bone marrow aspirations (Katz, Kellerman and Siegel, 1980; Jay et al, 1983). The question is whether children habituate or get "used" to painful procedures over time. Katz et al (1980) reported that children did not habituate to procedures over time, however, Jay et al (1983) did find that patients became less distressed over time. Habituation was found to take as long as two years (at least 12 procedures) for children under seven years. Little is known about habituation to other medical procedures. There is some evidence that burned children show less rather than more tolerance of painful stimuli as their treatment progresses (Savedra, 1976). Early uncontrolled pain may contribute to feeling of helplessness and hopelessness and poor coping (Seligman, 1975).

3.1.4 Previous Learning Experiences

Pain reactivity is influenced by a combination of learning experiences which include: direct training, contingent social reinforcement, avoidant learning and vicarious learning experiences (Ross and Ross, 1988).

Direct training

Direct training involves direct, explicit and usually situation specific instructions about dealing with pain, such as acceptable
ways of expressing discomfort and how much discomfort justifies a complaint. Direct training precedes the child's response to the pain situation, which may or may not be followed by parental action (Ross and Ross, 1988).

Contingent social reinforcement

Contingent social reinforcement exerts a stronger influence on the child's pain reactivity than direct training. It involves the early shaping by parents and others through the process of contingent social reinforcement. Parental reaction to the child's expression of pain varies from little interest in minor pain events and a pragmatic sensible approach, to over solicitous attention to similar events. With the former, the child's reactions to minor pain events are kept in perspective with corrective feedback as to how to react. Children who are reinforced for pain expression with privileges and proximity are likely to show increasing pain awareness. Ross and Ross (1988) discuss the possible motivations of this parental behaviour. Parents may, for instance, obtain "tertiary gains" from their child's pain (Boken, Ries and Katon, 1981). Also, parental overreactivity to the child's pain may be part of a general style of overprotective and overanxious parental behaviour (Apley, 1975).

Acquired patterns of overreactivity to minor aversive stimulation can persist into adolescence and adulthood (Chapman, 1985).
Further, learning acquired through contingent social reinforcement is strengthened by observational learning (Craig, 1983).

Observational learning

Observational learning is the principal mode for acquiring new patterns of behaviour (Bandura, 1969). This learning involves the child voluntarily observing the behaviour of others and its consequences. The effect of these vicarious learning experiences may be either strengthened or weakened depending on whether the model is reinforced or criticised and if the model has high status or is viewed as powerful by the child. The powerful role of familial models, particularly parents in the etiology of children's pain conditions and complaints, has been documented (e.g. Craig, 1978; Violon and Giurgea, 1984).

There is evidence also, that the number of familial models is important; children with more models have more pain complaints than children with fewer models. References to "the painful family" (Apley, 1975) and the "pain-prone family" (Craig, 1980) can be found in the literature, with early influences of familial pain models predisposing individuals to frequently report pain in later years (Edwards, Zeichner, Kuczmiczky and Boczkowski, 1985).

Familial models demonstrating inability to cope with pain can
also affect health locus of control beliefs (Lau, 1982) leading children to believe that their pain is not under their internal control. This can lead to feelings of helplessness (Seligman, 1975) and an external locus of control about health (see Chapter 4 for a discussion of locus of control).

Peer models are an important source of observational learning with regards to pain tolerance and reactivity (Jaremco, Silbert and Mann, 1981), particularly in middle childhood and adolescence. Observational learning is strengthened when the model is perceived as similar (Bandura, 1969), for example, when the child and model are undergoing the same medical procedure, or are of the same sex or age. If the model is perceived as powerful or has high status, the effects are further enhanced.

Avoidant learning
Avoidant learning occurs when pain is used to avoid anxiety provoking situations, by a process of contingent reinforcement. For example, the child may enjoy staying home in order to miss a test at school. For the overprotected child, the gains may generally outweigh the losses. It is irrelevant that the child's pain may be mild or nonexistent. These learning sequences can become more entrenched through observational learning (e.g. Turkat, Guise and Carter, 1983). Children may observe their parents or peers rewarded for using real or imagined pain as an excuse, and thus are influenced by such maladaptive pain
behaviour.

Cultural learning
The family and culture are the primary models for children's development of pain behaviours and attitudes. There are cross-cultural and intra-cultural variations in acceptable pain reactivity (Ross and Ross, 1988) which reflect a process of observational learning. The cross-cultural variations are often quite remarkable. For example, Eskimo children learn to respond to pain with laughter (Christopherson, 1966), while young Chinese children learn to view surgical intervention and the insertion of acupuncture needles positively (Caperauld, 1972). In contrast, American children view hospitalization and invasive procedures as distressing, require prior preparation and mother's presence (Peterson and Ridley-Johnson, 1980; Peterson and Mori, 1988).

Thus, as a consequence of culturally transmitted attitudes, the same event may be transformed into what Ross and Ross (1988) describe as a "provocation" or "rarefaction" ecology. There have, however, been few studies investigating the influence of culture on pain expression in children.

3.1.5 Demographic Variables

Demographic variables include the child's age, sex and ordinal position. Parental behaviour to pain complaints differs depending
on the child's age, sex and birth order (McGrath, 1990). They may provide more reassurance and support to younger children, but encourage independence in older children. Boys may be encouraged to suppress pain complaints, while girls may be reinforced for pain complaints. The higher pain sensitivity reported for first-born children may be attributed to differences in parental responses (Johnson, Dabbs and Leventhal, 1970; Vernon, 1974). The empirical findings on the relationship between age and sensitivity to aversive stimulation in infants is far from conclusive (Ross and Ross, 1988). However, several studies suggest an increase in pain threshold with age, in school aged children and adolescents although these results must be viewed cautiously because of the various factors influencing pain (Ross and Ross, 1988). Developmental level is likely to be more important in understanding differences in pain reactivity rather than chronological age as this influences the child's perception of the pain experience (Piaget and Inhelder, 1969).

There is no conclusive evidence of sex differences in pain reactivity. Jay et al (1983) did not find any sex differences in a paediatric oncology population. Girls had higher distress scores in each age group, but these differences were not statistically significant. Other workers (Katz et al, 1980; Hilgard and LeBaron, 1984) have found sex differences however. Hilgard and LeBaron (1984) found girls showed minor but
significant higher observed and self-reported pain during cancer related treatment. Differences were attributed to cultural norms discouraging expression of anxiety and fear in boys. Studies with adults (e.g. Notermans and Tophoff, 1967) fail to show sex differences for pain threshold, although they often show differences in pain tolerance in favour of males (e.g. Weisenberg, 1977). Research studies support the view that physiologically men are as responsive as women to pain, but display less overt distress because of learning. Little research has paid attention to ordinal position in children and sensitivity to pain (Ernst and Angst, 1983).

3.2 SITUATIONAL FACTORS

More attention has recently been given to situational and emotional factors that exert a profound effect on pain. These variables include situation-specific child factors (the child’s coping strategies, the child’s perceived level of control, understanding of the painful stimulus, the relevance of the pain to the child’s life) and environmental factors (parental anxiety and behaviour and presence or absence of mother).

Children not adequately prepared for a potentially painful procedure are likely to be fearful and distressed because of the lack of predictability and control and thus will experience more pain. Their fear and anxiety may generalize to medical personnel, all medical procedures including noninvasive ones and to the
hospital itself. Children will generally experience less pain when prepared in an age appropriate way.

Parents may expect their children to cope with invasive procedures like "little adults" and thus place undue stress on them. However, children are not little adults and should be helped to cope with these procedures in an age appropriate manner (McGrath, 1990).

There is evidence from animal behavioural studies that situational variables such as attention, predictability and relevance can directly modify the physiological responses produced by a noxious stimulus (Dubner, Hoffman and Hayes, 1981; Hayes, Dubner and Hoffman, 1981). Psychophysiological experiments with adults in which subjects rate the painfulness of noxious stimuli in different contexts, have found that it is possible to control the effects of situational factors on reducing pain (Dworkin and Chen, 1981; P.A. McGrath, 1983). The precise mechanism by which situational variables modify nociceptive processing is unknown, but may activate descending pain-suppressing systems, which modulate neuronal activity at spinal cord and medullary levels (McGrath, 1990).

3.2.1 Situation-Specific Child Factors

Situation-specific child factors include cognitive style, state
anxiety and self-efficacy.

Cognitive style
Assessment of individual coping styles is important before planning intervention. Most psychological interventions are based on the assumption that preparation is helpful for all children. However, some children become more distressed during preparation and respond by closing their eyes and covering their ears to avoid receiving information about forthcoming stressful procedures (Ross and Ross, 1984). Three cognitive styles have been described in the adult literature which all describe a similar construct: repression-sensitization, (Byrne, 1964), minimization-vigilant focusing (Lipowski, 1970), and monitor-distractor (Miller, 1979). Sensitizers, vigilant focusors and monitors actively seek information, and focus on details and practice coping skills. In contrast, repressors, minimizers and distractors avoid information and use denial, repression and rationalization about the stressful event. The implications of such coping styles for intervention have been discussed by Shipley, Butt, Horwitz and Farbry (1978) who suggested extensive preparation for sensitizers and no preparation for repressors, except preparations which would support their defenses.

The literature contains only a few studies on coping style in children. Burstein and Meichenbaum (1979) found two classes of "copers" in children undergoing surgery: a "low defensive" group
who engaged in the "work of worrying" by playing with stress-related toys before hospitalization; and a second "high defensive" group who avoided stress related toys. The low-defensive group showed less distress and better post-surgical emotional adjustment than the high-defensive group. In another study, Knight, Atkins, Eagle, Evans, Finkelstein, Fukushima, Katz and Weiner (1979) found children who used a mixed pattern of defenses and intellectualization coped better with hospitalization and surgery than children who used denial and displacement. Research therefore suggests that children who actively seek information are able to cope better with a stressful medical situation (Siegel, 1981; Peterson and Toler, 1986).

Internal-external locus of control is another cognitive dimension (Neuhauser, Amsterdam, Hines and Steward, 1978), and refers to a person's perception of whether events are controlled by oneself (internal) or by external forces such as luck and fate (external). Children who have high internal locus of control perceive themselves as being more in control of the healing process (Neuhauser et al, 1978). Jay et al (1983) did not find a correlation between locus of control and children's distress levels during bone marrow aspirations.

Three types of control have proven effective in the paediatric setting: behavioural, decisional and cognitive control (Ross and
Ross, 1988). Behavioural control may involve the child providing a signal when he wants the aversive stimulation to stop. Decisional control involves providing the child a choice in the pain situation. Cognitive control refers to the child’s belief that he is in control of himself or the situation. Ross and Ross (1988) suggest the child only needs to perceive himself as being in control for this to be effective. Thompson (1981) reported that behavioural control increases pain tolerance but does not reduce pain intensity. Turk et al (1983) concluded that perception of control usually resulted in higher pain tolerance, pain threshold, or both. However, it has been suggested that it is the reduction of uncertainty that is important (Averill, 1973).

Further research is required to investigate coping styles in children, for painful and less painful medical procedures and their implications for psychological intervention. Personality characteristics in relation to pain have not been studied in children.

State anxiety
State anxiety is a transitory emotional state that fluctuates over time and varies in intensity (Spielberger, Gorsuch and Lushene, 1970). This construct is discussed in detail in Chapter 8 and will therefore only be briefly presented here. State anxiety increases in response to stressful situations or events,
resulting in the increased activation of attentional mechanisms (Melzack, 1973). Clinical evidence suggests that state anxiety usually intensifies the pain experience while reduction of state anxiety reduces it. Katz et al (1980) reported age and sex differences in state anxiety. Younger children exhibited more diffuse verbal and physical expressions of anxiety than older children, who exhibited fewer such behaviours. Girls showed more distress than boys, however these differences could be attributed to cultural attitudes discouraging boys from expressing pain.

Self-efficacy
Self-efficacy refers to the child’s perception of his/her abilities in specific situations (Bandura, 1981). It overlaps with some of the variables previously discussed in this chapter. As each situation occurs, the child re-evaluates his/her self-efficacy. Perception of self-efficacy is based on four sources of information (Bandura, 1981): (1) previous performance; (2) vicarious experiences; (3) social persuasion (i.e. others telling the child that he/she can manage a situation); and (4) physiological state. A child’s judgement of his/her capabilities will significantly influence his/her coping with pain (Ross and Ross, 1988).

3.2.2 Environmental Social Factors

The child’s pain reactivity may be influenced by the behaviour of others in the situation including the parents, paediatric
personnel as well as other adults and children (Ross and Ross, 1988).

Parental anxiety and behaviour
This is an important variable to assess as parental attitudes and expectations may mediate children’s perceptions and reactions (Jay, 1988). Parental anxiety and parental presence have been discussed in the literature in relation to children’s distress during medical procedures. Maternal anxiety may heighten the child’s pain perception. Jay et al (1983) found parental anxiety to be one of three variables most highly predictive of children’s distress during bone marrow aspirations. She suggested that children who cope more effectively have parents who do not reinforce pain behaviours, or display their own personal anxiety, who are supportive and expect them to cope well (Jay, 1988). Zabin and Melamed (1980) found children who had lower hospital and surgery related anxiety had parents who tended to use modeling, positive reinforcement and reassurance in stressful medical situations.

The empirical and clinical findings on the effect of mother’s presence on children’s reactions during invasive medical procedures is equivocal and mixed (Shaw and Routh, 1982; Venham, 1979; Frankl, Share and Fogels, 1962). "Mother" refers to either or both parents, but is used here as it is usually the mother who accompanies the child. Some studies have provided evidence that
parental presence can exacerbate, disinhibit or reinforce children's distress during less painful procedures such as bloodtests and injections (Shaw and Routh, 1982; Gross, Stern, Levin, Dale and Wojnilower, 1983). The importance of preparing parents for the sight of noxious procedures has been emphasized (e.g. Hahn, 1983) to avoid parental anxiety which could be transmitted to the child.

Parental presence may conversely be a discriminative stimulus for coping. In a study by Ross and Ross (1984a) 99% of 720 children aged nine to 12 years reported that having their parent present was what helped the most, regardless of the type of painful experience. Other studies have reported mother's presence to be helpful, although it was not ranked as most helpful (Abu-Saad, 1984a; Savedra et al, 1982; Tesler, Wagner, Savedra, Gibbons and Ward 1981). Mother's presence exerts an important effect which can be explained by several theories: (1) attachment theory (Ainsworth, 1964) which suggests mother's presence helps the child cope with novel or stressful experiences; (2) affiliation theory (Schacter, 1959); and (3) social ecology theory (Bronfenbrenner, 1979) which propose that the mother acts as an intermediary between the child and paediatric personnel and is seen by the child as a resource having some control over events.

It is unclear what specific parenting behaviours intensify children's responses to medical stressors. It is likely that what
the parent does during the medical procedure is very important. Bush, Melamed, Sheras and Greenbaum (1986) investigated mother-child patterns of coping with anticipatory medical stress and found that mothers who supported their children's coping skills rather than emphasising emotional expression had children who coped better. Further research is required to examine the effect of parental presence on behavioural, cognitive-affective and physiological responses.

Paediatric personnel
Ross and Ross (1988) outline the factors relevant to paediatric personnel. Lack of trust in paediatric personnel may contribute to increased pain reactivity. Children may feel betrayed if told a procedure would not hurt and it did. Paediatric personnel should avoid claims such as this that may not be guaranteed. Ross and Ross (1988) suggest statements about the temporal duration of pain should be made cautiously. Thus, length of time should be defined in terms of a routine familiar to the child. What the child says must be taken seriously. It is important that medical staff show warmth, involvement and treat the child as an individual (Ross and Ross, 1988).

Other adults and children.
Other adults and children can have a significant influence on the child's behaviour. For example, the child can become anxious if he/she sees distressed adults or hears them make fear-arousing
remarks. Similarly, seeing other children crying or screaming for no apparent reason is very likely to have a negative effect, while a child coping model of the same age and sex will have a positive effect. Ross and Ross (1988) recommend that behaviour of paediatric personnel should be explained to the observing child, particularly in high anxiety areas such as paediatric intensive care units.

3.2.3 Environmental Nonsocial Factors

In order to make the paediatric environment a "rarefaction ecology", it is necessary to ensure the child's needs are met. Olds (1978) asserts these involve the need to feel comfortable, the need to feel in control and the need to feel purposefully active. These environmental nonsocial factors are only one part of the pain equation, but the simplest to change. What is required is an administration that understands the needs for such environmental changes and is willing to allocate funds for them, and personnel who understand the need for these facilities from the child's point of view (Ross and Ross, 1988).

The paediatric environment can be more comfortable for the child if child orientated, with furniture, equipment, rooms and other spaces on an appropriate scale. Structural changes to reduce noise would make the environment less stressful. Empirical data on these paediatric environmental variables are scarce however.
The sense of being in control partly depends on feeling competent (Bandura, 1981). The child should be provided with his/her own space and encouraged to do as many things for him/herself as possible, such as having access to toys, being able to find his/her way around the clinic without help and making decisions. Finally, the paediatric setting should allow the child freedom to explore and play, as the need for play is strong in the medical setting (Piaget and Inhelder, 1969; Crocker, 1978), particularly during waiting times in the treatment sequence.
CHAPTER 4

ASSESSMENT AND MEASUREMENT

Effective management of pain in children depends on accurate assessment (Beales, 1983; Varni, 1983). While a distinction between assessment and measurement is not always made in the literature, McGrath and Unruh define measurement as "the application of some metric to a specific element, usually intensity of pain" (McGrath and Unruh, 1987, p. 74), whereas assessment encompasses not only different dimensions of pain, but also the factors which influence pain perception (Savedra and Tesler, 1989). An obstacle to developing clinical pain measurement procedures is the issue of whether pain can be measured at all. Some theorists and clinicians assert that clinical pain cannot be measured. Bonica (1984) states that only minimal advances have been made in pain measurement. The lack of progress is attributed to the problem of definition. Wolff (1980, p.174) states that:

The lack of a generally accepted scientific definition of pain still hampers us...measurement is always made difficult if one is not quite sure what one is actually measuring.

Characteristics specific to children further compound difficulties with assessment. Different developmental stages have their own unique problems (Jeans, 1983) such as changes in perception of pain and children's understanding about pain. Thus,
additional research design considerations are required for younger children, for example, ensuring that instructions are understood by each child.

There is at present no method of measuring paediatric pain directly. Investigators have chosen to study pain indirectly via subjective reports, observing pain related behaviours and defining physiological correlates. The major dependent variables assessed during acute clinical situations have been the child’s experience of anxiety, pain and distress. These can be very difficult to assess and distinguish and led a number of investigators to use the term distress to refer to both anxiety and pain in acute situations (Katz et al, 1980; Jay and Elliott, 1984; Jay, Elliott, Ozolins, Olson and Pruitt, 1985). The relation between anxiety and the sensory components of pain has been reviewed by Sternbach (1968), and, Hilgard and Hilgard (1983).

Clinical pain is conceptualized as a complex multifaceted experience involving subjective, behavioural and physiological components, lending itself (not without methodological difficulties) to specific assessment and measurement procedures. The subjective component of pain requires verbal or nonverbal input from the child. Included here are a diversity of assessment techniques such as direct questions, self-rating scales, graphic procedures such as pain drawings, and projective tests.
Behavioural assessment measures incorporate parameters that are thought to be indicative of pain and that are measured objectively. Observational procedures are used to determine the presence or absence of pain related behaviours and their intensity. Physiological measures are objective indices of pain-related parameters but are not measures of pain per se. Behavioural, cognitive and physiological measures are all essential to provide an adequate assessment of pain and anxiety because of the multidimensional nature of pain (Varni, 1983; Hilgard and LeBaron, 1984; Le Baron and Zeltzer, 1984). There is no evidence, however, that any one response system reflects pain more than any other. One difficulty is that measures may not necessarily correlate between or even within response systems (Lang, Melamed and Hart, 1970; Jay, Elliott, Katz and Siegel, 1984).

An example of this discordance between measures would be a child reporting low anxiety or pain by pointing to a happy face, which may be inconsistent with the child's behaviour during the procedure (e.g. crying and screaming). This discrepancy does not necessarily suggest that the measures lack validity (Syrjala and Chapman, 1984), but rather should be regarded as representing different facets of the complexity of pain (Ross and Ross, 1988). Advantages and disadvantages of self-report and observer ratings have been discussed in the literature (Glennon and Weiss, 1978) as well as the tendency for observers to rate adolescents' pain
lower than they do themselves (Hilgard and LeBaron, 1982; Winer, 1982) suggesting that older children and adolescents learn to control their overt behaviours while still feeling anxious.

Thus, the crucial question in paediatric pain assessment is which measure or measures will provide the most accurate and objective information about the child’s pain experience. The choice of assessment methods will depend on the child’s age and cognitive level, the nature of the pain (i.e. acute, recurrent or chronic), and whether the data are required for clinical or research purposes. If the latter, multidimensional assessment is recommended. It is important to note that some methods will be more appropriate for certain children and pain conditions. Before considering medical or psychological intervention, it is important to assess the intensity of pain and anxiety; what makes the child’s pain better or worse; the child’s coping strategies; the meaning of pain for him or her; and, the social and environmental factors which may influence the experience of pain.

McGrath (1990) discusses the criteria required for an accurate pain measure for children. It must be reliable; that is it must produce consistent pain scores when children have the same pain, regardless of factors such as sex, age, cognitive level and time of testing. Second, it must be valid and thus measure a specific dimension of a child’s pain such as intensity or quality. Third,
the method should be bias-free, providing the same information regardless of the biases of the person administering it or the child using it. Fourth, the measure should be applicable to the assessment of acute, recurrent or chronic pain, in a variety of medical and dental situations. Difficulties arise in paediatric pain measurement because the influence of developmental factors on children's perceptions and expressions of pain are still unclear. Current research therefore is concerned with the adequacy of a pain measure according to the child's age, sex, cognitive level, previous pain experience and the type of pain.

Methods for assessing children's pain within the behavioural, cognitive and physiological categories are summarized in Table 4-1. The next section reviews behavioural, cognitive-affective and physiological assessment of acute pain in children. Emphasis is given to methods which meet the criteria of reliability and validity, which assess multiple dimensions of pain, and methods appropriate for assessing acute pain in particular but also recurrent and chronic paediatric pains. (For assessment methods relating to infants see Craig McMahon, Morrison and Zaskow, 1984; Grunau and Craig, 1987).

4.1. BEHAVIOURAL ASSESSMENT

Three types of technique have been reported to measure behavioural, overt pain responses in the assessment of paediatric pain: a) behavioural observation scales, b) global rating
scales, and c) indirect measures.

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<th>Methods for Assessing Pain in Children.</th>
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<tr>
<td><strong>Behavioural assessment</strong></td>
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<td>Behavioural rating scales</td>
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<tr>
<td>Procedural Behavioural Rating Scale (Katz, Kellerman and Siegel, 1980)</td>
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<td>Observation Scale of Behavioural Distress (Jay and Elliott, 1984)</td>
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<td>Procedure Behaviour Checklist (LeBaron and Zeltzer, 1984)</td>
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<td>Children’s Hospital of Eastern Ontario Pain Scale (McGrath, Cunningham, Johnson, Goodman, Schillinger, Dunn and Chapman, 1985)</td>
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<td>Expressive Pain Interaction Coding System (Russell, 1984)</td>
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<td><strong>Global rating scales</strong></td>
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<td>Visual Analogue Scales</td>
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<td>Pain thermometers</td>
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<td>Face interval scales</td>
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<td>Photographic scale</td>
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<td>Poker Chip Tool</td>
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<td>Pain Colour matching</td>
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<tr>
<td>Interviews (supplied and generate formats)</td>
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<td><strong>Graphic procedures</strong></td>
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<td><strong>Projective methods</strong></td>
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<td>Eland Projective Tool (Eland, 1974)</td>
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<td>Pediatric Pain Inventory (Lollar, Smits and Patterson, 1982)</td>
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Physiological assessment

Cardiac rate
Palmar sweat index
Blood pressure
Biochemical assessment


These are the most reliable observation scales for assessing behavioural distress (Jay, 1988) and are not subject to the cognitive distortion by the child that may occur with self-report (Syrjala and Chapman, 1984). They consist of a checklist of operationally defined behaviours indicative of anxiety and pain (e.g. crying, screaming, muscle tension, anxiety and pain verbalized). Observers record the occurrence of these behaviours during a stressful procedure for a specified time and may also rate their intensity. Several scales have been reported in the literature. The first three observational scales described below have been developed on a paediatric oncology population, to measure distress during bone marrow aspirations and lumbar punctures.

Procedural Behaviour Rating Scale

Katz et al (1980; 1981) developed the Procedure Behaviour Rating Scale (PBRS) which originally consisted of 25 operationally defined behaviours, later revised to 11 items. These behaviours were exhibited by young oncology patients prior to, during, and after BMA's. High inter-rater reliability data was reported
(r = .85), but little validity data. The scale does not discriminate intensity of distress, but only documents the occurrence or nonoccurrence of the 11 behaviours during the aversive medical procedure. Consequently, a child who screams and cries may be given an identical rating to one who exhibits a variety of behaviours at a milder intensity. However, because of the simplicity of the scale, it tends to yield a high interrater reliability, at the expense of the quality of behaviour that is observed.

Observation Scale of Behavioural Distress

Jay and Elliott (1984) developed the Observation Scale of Behavioural Distress (OSBD), an 11 item revision of the PBRS which included two methodological refinements: a) continuous recording in 15 second intervals within each of the four phases of the medical procedure, rather than once for occurrence or nonoccurrence over one phase, and b) a weighting scale of severity of distress. The behaviours are weighted on a 4-point scale, in which 4 indicates maximal anxiety or pain. The behaviours and their respective intensity weights are cry (1.5), scream (4), physical restraint (4), verbal resistance (2.5), requests emotional support (2), muscular rigidity (2.5), verbal pain (2.5), flail (4), nervous behaviour (1), and information seeking (1.5).

The OSBD was found to be a reliable and valid scale in measuring

Elliott et al. (1987) later revised the OSBD to eight items (information seeking, cry, scream, restraint, verbal resistance, emotional support, verbal pain and flail). Three items (verbal fear, nervous behaviour, and muscular rigidity) were eliminated because they occurred infrequently, did not correlate with other behavioural categories or to total OSBD scores. The validity of the OSBD was supported by significant correlations with nurse ratings of distress, fear ratings, anticipated pain and heart rate and blood pressure at two time periods (Elliott et al., 1987). Even when scored without methodological refinements (interval recording and severity weights), the OSBD was found to have reasonably good validity. Reliability of the OSBD was high ($r=.98$) for two observers. In addition, the mean agreement between two observers as to whether or not each of the 11 behaviours occurred within each 15-second interval was 84%.

The OSBD is more complex than the PBRS and Procedure Behaviour Checklist described next and therefore provides more precise information about children's distress. It is also a robust scale which is likely to be useful for assessing children's distress associated with other invasive medical procedures.

Procedure Behaviour Checklist
LeBaron and Zeltzer (1984) developed the Procedure Behaviour
Checklist (PBCL) based on the PBRS, but consisting of eight behaviours. The scale was developed partly to refine the two previous scales, which contained categories of behaviour suggestive of coping rather than distress, such as information seeking (LeBaron, 1988, personal communication). The categories for this scale are: muscle tension, screaming, crying, restraint used, pain verbalized, anxiety verbalized, verbal stalling and physical resistance. The PBRS is a reliable and valid scale for assessing children's distress behaviour. There was also evidence of concurrent validity in that significant correlations were found between observer's ratings of the children's pain and anxiety made during three phases of the BMA procedure and their total PBCL scores.

Although these scales have been developed to measure distress during BMA's and lumbar punctures, they would also be useful for assessing procedure related distress during venipunctures, injections and debridement for burns. The OSBD has been used successfully for assessing distress in children undergoing X-ray procedures (Bradford, 1990).

Children's Hospital of Eastern Ontario Pain Scale

McGrath, Cunningham, Johnson, Goodman, Schillinger, Dunn and Chapman (1985) developed the Children's Hospital of Eastern Ontario Pain Scale (CHEOPS) for use with young children to assess postoperative pain. It assesses six categories of behaviour:
crying, facial expression, pain-related and non pain-related verbalisations, torso activity, tactual responses and lower limb responses. The observation schedule requires 5 seconds of observation time, followed by 25 seconds of recording time, a practice that contributes to higher reliability coefficients. Behaviours in each category are assigned a numerical value according to whether the child’s behaviour is regarded as positive (0); neutral, representing no pain (1), mild pain (2), moderate pain (3), or severe pain (4). The scale was found to have good interrater reliability with agreement for all categories exceeding 80%. However, the coefficients may be spuriously high in view of the gross nature of the rating required. Although the CHEOPS is a promising tool for assessing children’s behavioural responses when in pain, it does require further validation.

Expressive Pain Interaction Coding System
Russell and his colleagues (Russell, 1984; Russell, Strassberg and Speltz, 1986) developed the Expressive Pain Interaction Coding System (EPICS) to provide an objective base for the social learning analysis of children's pain responses. The scale consists of 29 categories of behaviour with a sequential, 6-second time sampling scoring system, which includes recording of concomitant facilitating and inhibiting responses from the child’s immediate social environment.
The EPICS provides an empirical basis for assessing potential controlling social stimuli as well as permitting a variety of discrete behaviours to be sampled. Preliminary evidence of the scales' interrater reliability and content, construct and concurrent validity has been provided (Russell, 1984). While the EPICS is one of the most objective and sophisticated observation instruments developed for assessing paediatric pain, its main drawback is that it is complex and expensive. It requires extended observer training, expensive videotape equipment, and requires time consuming data analysis (Ross and Ross, 1988). It is therefore more appropriate for empirical investigations than clinical use.

Further scales have been developed for children undergoing dental treatment (Melamed, Hawes, Heiby, and Glick, 1975; Melamed, Weinstein, Hawes and Katin-Borland, 1975; Venham, Gaulin-Kremer, Munster, Bengston-Audia and Cohan, 1980), surgery (Melamed and Siegel, 1975) and nonmedical situations (Glennon and Weisz, 1978).

The advantages and disadvantages of behavioural scales have been discussed in the literature. The advantages of behavioural scales are that: 1) target behaviours or variables can be operationally defined and are reliably observable; and 2) cost effectiveness of the intervention can be shown by documenting behaviours which affect the efficient running of a clinic (Seltzer and LeBaron,
The disadvantages are: 1) behavioural checklists do not differentiate between pain and anxiety responses (Sacham and Daut, 1983); 2) behavioural expressions of pain and anxiety reflect a number of individual differences (Ross and Ross, 1984; Abu-Saad, 1984), which are presumed to indicate distress, but may be adaptive coping responses for some children (Zeltzer and LeBaron, 1986); 3) they are less useful for adolescents who are likely to display fewer overt pain responses (Jay, Elliott and Varni, 1986); and 4) observers' characteristics such as experience and attitude can affect observation scores (Ross and Ross, 1988). Disadvantages of relying solely on a behavioural checklist have been discussed by LeBaron and Zeltzer (1984). The difficulties concerning the validity of behaviours selected as indicators of pain can be circumvented by selecting a cluster of behaviours rather than a single behaviour and by including subjective and physiological measures. Thus, when the behaviour observation procedure is used in conjunction with other measures of pain it becomes a useful assessment tool about the child's pain experience (Ross and Ross, 1988).

4.1.2. Global Rating Scales.

These are similar to scales used with adults, and enable direct comparisons between observer and child reports (Katz et al, 1980; Hilgard and LeBaron, 1982; LeBaron and Zeltzer, 1984). Global
rating scales are completed by an observer who generally knows
the child well, who makes a single judgement about an aspect of
the child's pain-relevant behaviour during an invasive procedure
such as a bone marrow aspiration. Commonly used observer scales
are based on Likert ratings, for example, on a 1 to 5 continuum
(1 = no distress; 5 = extreme distress). These ratings may be used
for clinical as well as experimental purposes. Although
subjective and gross, several studies have shown high
correlations between behaviour observation scales and observer
ratings of behavioural distress (e.g. Katz et al, 1980; LeBaron
and Zeltzer, 1984). Such results could however be an indication
of observer skill rather than of rating scale strength.
Generally, global ratings are subject to rater variability as a
result of differences in attitude, experience and culture. For
example, less experienced nurses have assessed pain as more
severe than experienced nurses (Jacox, 1980; Lenburg, Burnside
found nurses from different cultures varied markedly in their
global assessment of severity of pain. Subjective rating scales
are discussed in more detail in the section to follow on
cognitive-affective assessment.

4.1.3. Indirect Measures.

These may include recording behaviours presumed to be indicative
of pain or absence of pain. For example, documenting "well"
behaviours such as the time the child spends playing or does not request medication (Fordyce, 1976), or extent of school absenteeism. These are recorded by an observer, usually the parent or nurse. Indirect measures may not be valid however, as children may play despite experiencing pain and may be reluctant to request further medication for fear of needles, which is stronger than the pain itself (Eland and Anderson, 1977); because medication may be an indication that the child is not getting better; or because the child associates oral medications with an unpleasant taste and vomiting. The main difficulty with indirect measures is that there are no behavioural indicators solely accounting for paediatric pain (Craig and Prkachin, 1983). Behaviours suggestive of pain such as increased or decreased activity may in fact be adaptive coping mechanisms and are well documented in the literature (Eland and Anderson, 1977; McCaffery, 1969). Ross and Ross (1988) provide illustrations of this point:

Move around a lot if it hurts and just think about the moving parts. (Boy, aged 7 years).

Keep very, very still, it's the only way to be sure not to get a shot. (Boy, aged 8 years).

4.2. COGNITIVE-AFFECTIVE ASSESSMENT

Cognitive-affective assessment procedures include verbal self-report, self-report rating scales, questionnaires, graphic procedures and projective techniques. The purpose of these
procedures is to obtain information about the child's subjective pain experience.

4.2.1. Verbal Self-Report

"The single most reliable indicator of how much pain a person is experiencing is the subject's verbal report" (Jacox, 1980, p.86). Although verbal self-reports are the most frequently used pain estimation procedure, their value is controversial because of their subjective nature. Notwithstanding this, self-reports provide information about a child's perception of his/her own pain and anxiety, cognitions, imagery and emotional reactions. Their advantage is of obtaining information from the child who is experiencing the pain (Ross and Ross, 1984; Hilgard and LeBaron, 1982, 1984). They convey more information about the intensity, quality and individual differences of pain than is usually the case with behavioural or physiological measures. However, investigating the subjective component of a child's pain has inherent weaknesses. Children may exaggerate or mitigate the intensity of pain due to the demands of the situation. Reasons for mitigating pain are interesting. For example, the child may have learned during the process of socialization to inhibit or attenuate complaints of pain, a behaviour characteristic of victims of child abuse (Ross and Ross, 1988). Fear in the paediatric setting may also inhibit pain complaints (Eland and Anderson, 1977) because of anxiety about loss of privileges, or
fear of shots (Ross and Ross, 1982). Children may also exaggerate pain in order to obtain analgesics more promptly for fear of increased pain. It is possible to determine the extent to which self-reports are biased by conducting a comprehensive pain assessment with an evaluation of situational, familial and emotional factors.

Ross and Ross (1988) suggest ways of minimizing error and maximizing quality in verbal reports. Because the child may be afraid to admit pain, questions should be prefaced with an accurate explanation for asking the question, together with reassurance that the child's admission of pain will not lead to noxious consequences. Questions can be presented in an open-ended format which requires the child to generate answers (e.g. "What does your pain feel like?") or a supplied format that requires only a yes or no response (e.g. "Is your stomachache a stabbing pain?"), (Ross and Ross, 1984a, 1988). While the generated format is more time consuming than the supplied format, it avoids the difficulty of bias in response and yields information of greater value. Problems in self-report can also be partly mitigated by combining the data with behavioural and physiological measures.

It is essential to ascertain the meaning words have for the child before obtaining verbal reports. Words commonly used to refer to pain such as pain, ache, hurt and ouch, have different meanings
for children (Ross and Ross, 1982b). These words are often used interchangeably on the assumption that they convey equal intensity of pain (Ross and Ross, 1988). It is sometimes easier for the child to describe pain if asked to compare it with a different pain such as an earache, or an earlier episode of the same pain.

The issue of the accuracy of the child's long term memory and its relationship to sensory pain matching described above is discussed by Ross and Ross (1988). Clinical (Hahn and McLone, 1984) and empirical evidence (Ross and Ross, 1982b) suggest that preschool and school aged children can recall noxious events accurately and in detail, particularly if the child's mood at the time of recall is similar to his/her mood of the previous event (Bartlett, Burleson and Santrock, 1982). As pain events of childhood are often associated with negative affect, this increases the accuracy of sensory pain matching by the child.

Obtaining details from children about the duration of pain can be facilitated by using prompts with temporal anchors: "Was the pain there at breakfast? Was it still there at lunch?" (Ross and Ross, 1988). Enquiring about the temporal pattern (e.g. continuous or intermittent) could be demonstrated by using tangible objects. For example, Scott (1978) used a sheet of paper with two rows of light bulbs. The continuous pain row consisted of yellow lighted bulbs; the intermittent pain row contained alternating lighted and unlighted bulbs. For children who have
difficulty in verbally reporting their pain, tangible objects such as dolls can be used as a medium for communication.

7.2.2. Self-Report Rating Scales

Self-report rating scales are the most common approach to the assessment of pain (Ross and Ross, 1988) and have varied across studies from impressionistic to quantifiable (Zeltzer and LeBaron, 1986). Examples of quantifiable scales include visual analogue scales (Abu-Saad and Holzemer, 1981; Abu-Saad, 1984a; Varni, Thompson, and Hanson, 1987), numerical scales (Hilgard and LeBaron, 1982; Zeltzer and LeBaron, 1982), picture assortment (Lollar, Smits and Patterson, 1982), and questionnaires (Varni et al, 1987). Impressionistic scales include drawings and projective tests. There are three main categories of self-report rating scales: (1) the visual analogue scale; (2) the graphic rating scale; and (3) the numerical rating scale. These scales are shown in Figure 4-1 and discussed below together with several derivatives of them.
Visual Analogue Scale

Although visual analogue scales have often been used with adults, they are also used with children. The visual analogue scale (VAS) is a 10-cm vertical or horizontal line with labels at either end such as "no pain" and "severe pain". The child's task is to place a mark on the line to indicate his/her level of pain or anxiety. The score (range 1-10) is obtained by measuring the number of centimeters from "no pain" to the child's choice on the line.

Variations of this would be a numerical scale (e.g. 0 - 7) with similar descriptions at either end (Hilgard and LeBaron, 1982, 1984). Research with adults has found that 10 cm is the optimum length for the line (Revill, Robinson, Rosen and Hogg, 1976) and that a horizontal line is easier to use than a vertical one (Scott and Huskisson, 1976). Children's preferences for rating
scales has been subject to limited empirical study, with conflicting results. Ross and Ross (1982b) found children preferred a horizontal MRS, others have found that preschool children preferred a vertical facial scale (Beyer, 1985) and older children preferred a vertical pain thermometer (Szyfelbein, Osgood and Carr, 1985).

Ross and Ross (1988) advocate that a practice session is essential to help the child understand the scale. What may be important however is the way the scale is presented and the instructions given to the child. The consensus is that children above five years of age can use the VAS in a reliable and valid manner to rate different acute pains, regardless of their sex, age, or health status (McGrath, 1990; Abu-Saad and Holzem'er, 1981).

The strengths of the VAS include: (1) its usefulness for children with limited language skills, as the choice points are not labeled; and (2) there is an unlimited number of choice points between the end points. The VAS is statistically more superior to the graphic rating scale (Syrjala and Chapman, 1984) as parametric statistics can be used to analyze data from the former but not the latter. The main limitation of the VAS is that it requires the rater to conceptualize pain intensity linearly (Kremer, Block and Gaylor, 1981). Children unable to understand the VAS should have less difficulty with the graphic rating scale.
or the numerical rating scale.

Graphic Rating Scales
The graphic rating scale (GRS) consists of a series of words along a continuum of increasing value, such as "no pain", "mild pain", "moderate pain" and "severe pain". This scale developed because of dissatisfaction with the VAS, however, no empirical data on the most useful terms for children are available. The GRS has been used more frequently with children than the VAS, possibly because it is more structured. Children aged 5 years and older have used the scale effectively (McGrath et al, 1985).

Ross and Ross (1988) outline some of the methodological difficulties with the GRS. For example, it classifies the child's pain experience according to the descriptions provided. However, neither the descriptors nor their placement at equal distances along the line necessarily reflects the child's interpretation. A description such as "moderate" may not have the same meaning for a child that it does for an adult. Some researchers have suggested individualized scales for children, whereby each child shows where on a line he/she would place the words and then rates his/her pain accordingly (e.g. Hoft and Parker, 1984). In addition to inter-individual differences in interpretation of the scale, some of the points may not lie on the same dimension and would thus complicate comparisons across children. Also, the descriptors may not express exactly what the child is
Numerical Rating Scales

Numerical scales are the most frequently reported scales in the paediatric literature. They consist of numbers reflecting increasing severity of pain (or anxiety). There are a number of permutations of these, including the pain thermometer, "faces" scales and tangible objects such as poker chips. These are noted for their simplicity and clarity. Both the pain thermometer (Katz et al, 1980; Jay et al, 1983) and "faces" scales (LeBaron and Zeltzer, 1984; Kuttner, 1984) are the most popular assessment methods used with children (Jay, 1988).

The numerical rating scales (NRS) consist of a straight line numbered 0 to 10 or 0 to 100, with anchor points from the VAS such as "no pain" and "extreme pain". The NRS approximates the VAS but allows the child to respond orally (Syrjala and Chapman, 1984) although it is essential that he/she has a concept of number. The advantages of using numbers is that they permit more definable choices than the GRS, they increase the sensitivity of the instrument and do not require the researcher to measure the child’s responses on the line.

Pain thermometer

The pain thermometer is a visual representation of a thermometer on a numerical scale (0-10, or 0-100) where 0 represents no pain.
and 10 or 100 represents pain as bad as it can be. The child is asked to indicate on the thermometer how much the procedure hurt. The pain thermometer has been used in studies of children with cancer (Jay et al, 1987), and burns (Szyfelbein et al, 1985).

Face Interval Scales
Face interval scales usually consist of about five faces representing differing degrees of pain or anxiety, from smiling (no anxiety or pain) to crying (intense anxiety or pain). The child is asked to point to the face which shows how much pain or "hurting" they felt, or how scared they felt, during the medical procedure. Face scales operate on the same principles as the GRS. Several investigators have used face interval scales with children (Kuttner and LePage, 1983; McGrath et al, 1985; Rogers, 1981). The faces represent a global index of how the child perceives his/her pain (Ross and Ross, 1988). The advantages of face interval scales are that the facial expressions are familiar, the child is required only to point to his/her choice, and the task is interesting (Ross and Ross, 1988). Evidence of the scale's reliability and validity was provided by McGrath et al (1985) in a study of healthy children and child oncology patients aged 5 years and over. The actual value of affect depicted by each of nine faces was determined by the children who used two cross-modality matching responses, VAS and brightness matching, to rate the intensity of positive or negative affect represented by each face. Interestingly, the results showed that
the intervals on this nonmetric scale were unequal. However, using nine faces may require greater discrimination from the child than five faces and may also be more confusing.

Photographic Scale

The Oucher (Beyer, 1984) is a second derivative of the GRS. It is a photographic scale consisting of two separate scales. The scale for younger children involves a series of six colour photographs of the face of a young preschool child which are arranged vertically from "no hurt" to "the biggest hurt you can have". A numerical rating scale from 0 to 100 is used for older children. This is also arranged vertically. The pictorial scale has good instructions, particularly regarding the practice trials during which the child is asked to rate pains he/she has had. Like other pictorial scales, the Oucher is useful for children with language difficulties (Ross and Ross, 1988). Some evidence of test-retest reliability and content and construct validity has been provided with children in the 4 to 12 year old range (Beyer, 1984, 1985; Beyer and Aradine, 1986).

The Oucher poses some difficulties. The manual describes the photograph as a boy, however there are no indications as to the child's sex. It would be preferable to treat the photograph as the same sex as the child. Little attention has been given to the issue of photographs versus cartoon faces. The latter would appear to be more clear cut in terms of the expressions depicted.
However, children may be able to identify more with photographs. Another difficulty concerns the placement of faces at equal intervals adjacent to the numerical scale. There is no empirical basis for such placement even though children may order faces correctly (Ross and Ross, 1988).

Poker Chip Tool
The Poker Chip Tool was developed by Hester (1979) and consists of four white poker chips which represent degrees of pain. The child is asked whether a procedure hurt. A response of "no" is scored 0; if the response is "yes" the child is given the chips and told, "These are pieces of hurt - one chip is a little bit of hurt, and four chips are the most hurt you could ever have. Did you have one, two, three, or four pieces of hurt?" The score is the number selected by the child. Molsberry (1979) modified the Poker Chip Tool by using red chips for pain, with a white chip for no pain; the instructions were improved; and a practice session was included. Unfortunately, reliability and validity data are limited for both forms. Hester (1979) in a study of 24 children aged 4 to 8 years undergoing immunization injections, found that the Poker Chip Tool scores were highly correlated with children's verbal and behavioural responses to the injection, suggesting some evidence of concurrent validity. Molsberry (1979) found evidence of construct validity in the tool's measurement of postoperative pain in children aged 4 to 7 years.
An advantage of the Poker Chip Tool is that it is easy to use and is appropriate for children with limited language ability. It poses a number of methodological problems. The word "hurt" has been used in the instructions on the assumption that most 4 to 8 year old children do not understand the meaning of pain but do understand the word "hurt". As discussed in Chapter 2, children do understand the concept of pain (Bibace and Walsh, 1980; Gaffney, 1983; Ross and Ross, 1984a). The scale also requires that the child understands number concepts of 1 to 4, which may not be true for some preschool children. Grading the poker chips in size, from very small to very large may be helpful, as size concepts are mastered earlier than number concepts (Piaget and Inhelder, 1969). Further, preschool children may not see their hurt as "bits of hurt" but as a more global hurt.

There is evidence that children as young as five years can understand and use a rating scale (Zeltzer, LeBaron, Richie and Reed, 1988) with clear instruction and practice (Ross and Ross, 1988) and are able to think conceptually about the differences between pain and anxiety (LeBaron and Zeltzer, 1984). Generally, studies have shown self-report to be valid for children over the age of 6 years (Abu-Saad and Holzemø, 1981; Jay et al, 1983; Hilgard and LeBaron, 1982; LeBaron and Zeltzer, 1984) but problematical and less reliable for younger children. The difficulty is in translating personal experience into visual representations such as those used on a numerical scale, or
verbal representations (no pain, mild pain, severe pain) useful in assessing adult pain.

McGrath, Cunningham, Goodman and Unruh (1986) review some of the measurement procedures described in this chapter. The self-report rating scales have considerable potential for measuring pain in children. Reliability and validity data are however weak in most instances. Ross and Ross (1988) argue that the specifications delineating one scale from another must be maintained in order to evaluate a particular scale, otherwise it is uncertain whether the child is using the words, numbers or faces to respond to. For an excellent review article on paediatric pain assessment within a developmental cognitive-biobehavioural framework, see Thompson and Varni (1986).

Pain Colour Matching
Studies with children and adolescents on a variety of colour choice tasks have found that when asked to choose from an array of colours that best represented pain, red tended to be picked for intense pain, oranges or orange-reds for mild pain, and yellows for least intense pain (Abu-Saad, 1984a; Bland, 1981; Jeans and Gordon, 1981; Savedra et al, 1982; Scott, 1978). These studies confirmed Stewart’s (1977) original work on pain colour matching with adults. One exception, however, was Abu-Saad’s (1984b) study on a group of Arab-American children who selected black and blue before red to depict intense pain. While these
studies represent an interesting approach to assessment of pain, no reports have been provided on their reliability and validity. Vair (1981) asked children what their choices represented, but other studies failed to do so. Eland (1974) found red, black and purple were the most common colours selected by children to depict pain. In a later study (Eland, 1981) she constructed the Eland Colour Tool consisting of eight crayons from which children construct their own colour scale to represent different levels of "hurt" from "no hurt at all" to "worst hurt". The crayons are also used to colour a body outline, emphasizing different areas of pain.

While colour scales are useful for young children they seem to be unappealing to some older children and adolescents (Savedra et al, 1982).

4.2.3. Interviews

Interviews have had a minor role in pain assessment because of the beliefs that children cannot provide reliable and valid information about their pain experiences. Formats can be structured or semi-structured. There are several structured interviews which assess children's knowledge about pain. For example, Schultz (1971) in a study of 74 children aged 10 and 11 years found the predominant meanings attached to pain were fear of bodily harm, death and anxiety. Tesler, Ward, Savedra, Wegner and Gibbons (1983) extended this research to assess children's
coping strategies used during painful experiences. Ross and Ross (1984a) describe three critical components for an accurate interview based on semi-structured interviews with 994 school children: 1) the type of questions used; 2) the psychological climate in the interview situation and; 3) the child's perception of his/her role and capabilities. A comprehensive interview should contain both generate and supplied format questions used in several questionnaires.

Questionnaires
Although the following structured interview and pain questionnaires were developed to assess chronic pain, they are presented here because they are comprehensive, reliable and valid and contain questions useful in assessing multidimensional aspects of acute pain. For a specific questionnaire on acute pain see McGrath (1990). Unfortunately, no reliability or validity data is provided on this questionnaire used in her pain management programme.

The McGill Pain Questionnaire
The McGill Pain Questionnaire (MPQ) was developed by Melzack (1975) and although designed for adults, is described here because children aged 12 and older are able to use it (Jeans, 1983). It is considered to be one of the best pain assessment instruments because it is comprehensive, and assesses both physiological and psychological dimensions of pain. Evidence of
the reliability and validity of the MPQ has been provided by Reading (1983). The MPQ contains 20 sets of words which describe the sensory, affective, and evaluative qualities of pain, including a category containing miscellaneous pain descriptors. The questionnaire also contains descriptors that describe the pattern of pain (e.g. continuous, steady); anterior and posterior drawings of the body on which the patient marks the location of his/her pain and whether it is external or internal; a rating of present pain intensity on a 5 point scale; questions about factors which exacerbate or minimize pain; and a comparison of present pain with other types of pain.

The Varni/Thompson Paediatric Pain Questionnaire

The Varni/Thompson Paediatric Pain Questionnaire (PPQ) consists of visual analogue scales, colour coded rating scales, and verbal descriptors relating to the sensory, affective and evaluative aspects of children’s chronic pain (Varni et al, 1987). The questionnaire was evaluated on 25 children aged 4–19 years with juvenile rheumatoid arthritis and was found to be reliable and valid (Varni et al, 1987). It is completed independently by the child, parent and physician. It also provides information about the child’s and family’s pain history, interventions to relieve pain, symptomatology and socio-environmental situations that may influence pain. The PPQ is useful for clinical settings because it does not take long too complete. There are questions regarding factors which may precipitate, maintain or exacerbate the pain.
yielding information which would be valuable when planning intervention. Although used for assessing chronic pain, the instrument contains some questions relevant to acute pain.

The Children's Comprehensive Pain Questionnaire
The Children's Comprehensive Pain Questionnaire (CCPQ) assesses multiple dimensions of children's recurrent or chronic pain (McGrath, 1986). It consists of generate and supplied format questions about the sensory dimensions of children's pain (i.e., intensity, quality, duration, location and frequency), emotional factors and situational factors. The questionnaire includes a checklist of pain descriptors, facial scales, and VAS to assess pain intensity and range of intensity, the level of pain associated affect, and the child's feelings concerning his/her pain. There are also questions concerning coping strategies and pain related secondary gains. Validity and reliability studies with 300 children aged 5-16 years indicate the questionnaire and structured interviews provide a comprehensive and accurate assessment for many dimensions of children's chronic pain. The CCPQ is sufficiently brief for clinical purposes. One strength of the questionnaire is its utilization of different question formats. A child who finds one format difficult is able to provide information with another format. An example is the use of VAS which younger children and those with difficulty verbalizing would find easier to use than questions requiring a verbal response.
Cognitive-functional analysis

An alternative way of assessing cognitive-affective pain responses is to undertake a cognitive-functional analysis (Meichenbaum, 1976; Meichenbaum and Turk, 1976). This involves asking the child to report thoughts, images, feelings and fantasies, while imagining a stressful procedure, during the painful procedure itself, or to "think out loud" during rehearsal. This process can be very helpful in identifying dysfunctional thoughts, misconceptions, and positive and negative coping strategies, which may then be used to plan psychological intervention. The method may be useful with older adolescents who are able to express themselves verbally but less useful for children. Cognitive approaches are discussed more fully in Chapter 6 with reference to intervention of pain.

4.2.4. Graphic Procedures

Pain maps

Pain maps were developed by Keele (1948) to obtain graphic reports from adults of their pain. They have been used in several studies of hospitalized children which have provided evidence of concurrent validity (Eland, 1983; Vair, 1981). The procedure involves giving the child an anterior and posterior outline of the human body on which he/she marks the specific pain site with an X, or shades an area for diffused pain. For intensity of pain the child uses colours when shading the affected area. There is
no quantitative scoring system for the pain map, which is instead examined visually for accuracy and intensity of pain. The advantages of the pain map include its brevity and ease of administration and evaluation in the paediatric setting. It is useful for assessing chronic pain where repeated measures are required. Pain maps are also useful for identifying changes in the distribution of pain or unexpected pain developments (Ross and Ross, 1988).

Pain drawings
Children with limited verbal skills often find graphic procedures an excellent way of communicating information that would otherwise be difficult to verbalize (Ventafridda, Rogers and Valera, 1984). Even if the child is quite verbal, it can be easier to communicate more effectively through drawings (DiLeo, 1977) and has led some clinicians to use this approach to obtain information about the child's pain. Developmental aspects of children's concepts of pain have been studied as reflected in their drawings (Jeans and Gordon, 1981). Drawings of self-inflicted pain decreased with age while drawings of other inflicted pain increased with age. Pain drawings have also differentiated between children who have been prepared for needle procedures and those who have not (Sturner, Rothbaum, Visintainer and Wolfer, 1980). Villamira and Occhiuto (1984) also found drawings differentiated between children with acute and chronic orthopaedic pain. Unfortunately, descriptions of the method of
collecting data in this way have rarely been provided and thus make replication difficult. An exception is a study by Unruh, McGrath, Cunningham and Humphreys (1983; p.387) on migraine and tension headaches who instructed children to "draw a picture of your pain. If we could actually see your pain, what would it look like?" and to draw a second picture "of you when you are in pain". The drawings were subsequently categorized on the basis of content. Although no evidence of reliability was found there was some support for construct validity, in that the drawings differentiated between children with migraine headaches and those with tension headaches on the basis of content and dominant colour. No studies have compared the reliability and validity of information inferred from children's pain drawings with responses on standardized questionnaires and self-report in structured interviews (McGrath, 1990). Pain drawings are particularly useful for projecting affective and cognitive information about pain (Vair, 1981) and helping the clinician understand the child's perception of his/her pain as well as fantasies. Thus, drawings provide a qualitative measure for assessing children's pain level.

4.2.5. Projective Tests

Other assessment methods reported in the paediatric pain literature, include projective techniques (Eland, 1974; Scott, 1978; Lollar et al, 1982). Scott (1978) investigated colour, shape, texture, pattern and time sequences in the child's
perception of pain. Children in outpatient clinics and school settings were shown two cartoon sequences of a child experiencing self-inflicted pain caused by an accidental hammer blow and pain caused by a shot. Some developmental trends were reported in the children's perceptions of pain, however, test-retest reliability data are lacking.

Eland Projective Tool
Eland (1974) developed the Eland Projective Tool designed to help young children convey their feelings about the intensity of pain. It consists of five pictures of a dog cartoon character in five situations. Four of these pictures depict the animal in a series of painful situations familiar to children (e.g. hit on head by swing, paw caught in car door). The fifth picture shows the animal in the same painful situation that the child is experiencing (an injection). The child is asked to rank the pictures from the picture of the event that hurts least to the one that hurts most. The picture replicating the child's situation is inserted by the child in the ranked series. No consistency was found in the ordering of the pictures.

Pediatric Pain Inventory
The Pediatric Pain Inventory (PPI) developed by Lollar et al (1982) is a more refined structured projective test which assesses how children perceive pain experienced by themselves and their parents. The PPI consists of 24 pictures in groups of six,
with each group relevant to one of four pain-evoking situations: medical, recreational, psychosocial, and common activities. The child rates the pictures for intensity and duration of the perceived pain. The child’s parents complete the PPI as they perceive the situations in relation to him/her. Reliability and validity were found to be sufficiently high to warrant the test’s continued development. Preliminary findings were based on 240 children aged 4 to 19 years. A significant difference was found between children’s perceptions of their own pain intensity and how adults perceived the children’s pain intensity, with adults tending to underestimate children’s pain. This is consistent with other reports in the literature (Eland and Anderson, 1977; Ross and Ross, 1982).

While projective techniques are useful for assessing pain in young children and for cross-cultural developmental studies, few have been systematically evaluated (McGrath, 1990). However, these methods may be helpful as part of a comprehensive assessment to provide information about the child’s understanding of pain and methods for coping with pain.

4.3. PHYSIOLOGICAL ASSESSMENT

There is both clinical (Eland and Anderson, 1977) and empirical evidence (Malamed, Yurcheson, Fleece, Hutcheson and Hawes, 1978; Shapiro, 1975) that physiological responses may be elevated by
psychological factors such as fear, pain, expectancy and social reinforcement. Physiological measures which have been found to relate to pain experience include increased pulse rate, systolic and diastolic blood pressure, skin resistance, respiration rate, and muscular tension (Sanders, 1979; Sternbach, 1968).

Although physiological measurement is useful in assessing pain and anxiety, there are a number of methodological problems in such assessment which make interpretation difficult. One problem is the variability of response and the individual differences in response elicited by painful stimuli (Sternbach, 1968). Further, the behavioural (overt), cognitive (covert) and physiological systems do not tend to correlate highly with one another and it is not clear which measure most reflects anxiety or pain (Epstein, 1976). Attempts to establish that any autonomic indices are correlates of pain have yielded equivocal results (Owens, 1984), with the exception of thermography investigations (electro-optical procedures of translating variations in skin surface temperature into visual images, (Nerlinger, 1976)). While pain states are characterized by a nonspecific arousal pattern that includes increases in cardiac rate, blood pressure, respiration depth and pupil dilation, they are also indicative of physiological conditions and psychological states that are unrelated to pain (Wallenstein, 1982). Thus, it is unclear whether the physiological changes children experience prior to and during noxious stimulation are suggestive of their pain.
experience or their general emotional distress.

Clinical and experimental observations highlight the need for physiological as well as self-report measures for older children and adolescents, who may be highly anxious but do not exhibit their distress overtly (Jay et al, 1983; Hilgard and LeBaron, 1982, 1984). Barrios, Hartmann and Shigetomi (1981) provide a brief overview on physiological assessment in children. A selected group of measures of physiological arousal are described below.

4.3.1. Cardiac Rate

Cardiac rate has been extensively studied in a diversity of paediatric populations and settings and is a potentially important dependent variable in the study of paediatric pain. The advantage of the measurement technique is that it is relatively unobtrusive and does not produce pain or discomfort. Changes in cardiac rate are bidirectional, they increase to strong stimuli and decrease to mild stimuli. Studies with infants undergoing routine medical procedures (heel lance, immunizations and circumcision) have yielded contradictory findings. Some studies have reported increases in cardiac rate to noxious stimulation (Owens and Todt, 1984; Johnston and Strada, 1986) while others have found both increases and decreases in cardiac rate (Williamson and Williamson, 1983; Dale, 1986).
Studies with older children have focused on pulse rate as an index of anxiety during invasive procedures, however the results are not clear. Shapiro (1975) found cardiac rate increases and self-reported needle avoidance were positively correlated in children undergoing routine immunizations. Johnson, Kirchoff and Endress (1975) found that pulse rate discriminated between sensation versus procedural preparation treatment groups in children undergoing cast removal. Cardiac rate and blood pressure both proved reliable and valid indices of anxiety in children having a BMA (Jay et al 1984) and discriminated between treatment conditions (behaviour therapy versus control versus valium). However, in a study of pre and post-operative anxiety, cardiac rate failed to correlate with other measures of anxiety and to discriminate between treatment groups (Peterson and Shigetomi, 1981).

4.3.2. Palmar Sweat Index

The Palmar Sweat Index has been found to be a useful measure of anxiety related to surgery and dental procedures (Melamed and Siegel, 1975; Melamed, Yurcheson, Fleece, Hutcherson and Hawes 1978). It involves the use of a plastic impression method that allows measurement of sweat gland activity in the finger (Johnson and Dabbs, 1967). Melamed and Siegel (1975) found the palmar sweat index to be a useful measure of children’s pre and postoperative anxiety. McNair, Dropleman and Russman (1967)
describe the procedure in detail which is simple and painless. Shapiro (1975) employed an electrodermal measure similar to the Palmar Sweat Index. Tape bands were attached to the child's left index finger for three minutes after which raters judged the darkness of the finger print on a 10-point scale. This method is however more subjective than the analysis of Palmar Sweating, although inter-rater reliability was demonstrated. The Palmar Sweat Index can be sensitive to nonrelevant sources of sweat production, such as room temperature, and highlights the problem of extraneous variables in natural clinical environments (Barrios et al, 1981). In Shapiro's (1975) study, for example, palmar sweat was completely masked by room temperature. The validity of sweat indices must therefore be questioned because of their sensitivity to nonemotional influences on sweat production (Barrios et al, 1981).

4.3.3. Blood Pressure

Blood pressure is one indicator of sympathetic activity and typically involves measuring systolic and diastolic pressures:

"Systolic blood pressure is the pressure in the arteries recorded at the point of systole or when the heart pumps blood into the circulatory system. Diastolic blood pressure is considered the basic systemic pressure in the absence of systole" (Haynes, 1978, p.358).

Systolic and diastolic blood pressure are differentially sensitive to transient stimuli. For example, diastolic blood pressure is less sensitive than systolic blood pressure to
transient stimuli and therefore provides a measure of general systemic condition. It may be more useful in detecting long-term changes in cardiovascular tone. Systolic blood pressure is more reactive to the effects of environmental manipulations such as relaxation instructions and exposure to feared stimuli. It sometimes provides a better index of cardiovascular response to environmental stimuli than diastolic blood pressure (Haynes, 1978).

The traditional method of measuring systolic and diastolic blood pressure is of a manually operated occlusion cuff and a stethoscope for auditory detection of Korotkoff sounds while the brachial artery is occluded. Korotkoff sounds can be detected when the occlusion cuff inflated to a pressure between 80 and 120 mm/Hg between the diastolic and systolic blood pressure. The traditional method of recording blood pressure, is however moderately unreliable (Haynes, 1978). Variables which can affect the validity of the measures include interpretative errors, cuff size and placement, rate of cuff inflation and internal instrument errors. Insufficient attention has been paid to assessing error in psychophysiological research involving indirect measurement of blood pressure. One difficulty is that the percent of error in blood pressure measurement sometimes approximates the percent of change to be expected from the experimental manipulation.
The assessment of blood pressure has been used in studies with children undergoing invasive medical procedures. Jay et al. (1983) found pulse rate and blood pressure to be reliable indices of children's distress levels prior to bone marrow aspirations.

4.3.4. Biochemical Assessment

Biochemical assessment of changes accompanying stress and anxiety has been reported in the literature (Mason, 1975; Selye, 1976). There are highly sensitive laboratory procedures (e.g. radioimmunoassays and chromatography) which can measure biochemical variables linked to the neuroendocrine system (Katz, Varni, and Jay, 1984). These are costly however and involve some pain. Endogenous opiates (endorphins and encephalins) have been identified as important in pain modulation, acting in pain pathways in the brain and spinal cord (Varni, Katz and Dash, 1982). The discovery of endogenous opiates has generated a great deal of research into pain modulation (Terenius and Wahlstrom, 1979). The release of endogenous opiates into the blood can result in an analgesic effect which may persist for two or three hours. Biochemical assessment provides an objective index of pain and has the potential to throw some light on individual differences in pain reactivity (Ross and Ross, 1988).

Olness, Wain and Ng (1980) reported a pilot study of blood endorphin levels in five children using self-hypnosis to control
pain related to treatment-induced and clinical pain. The radioimmunassay revealed no detectable levels of B-endorphin immunoactivity in the pre or post-pain plasma samples. Either these children tolerated the procedures better than most children or hypnotic analgesia is not mediated through opiate receptor sites. Goldstein and Hilgard (1975) suggested that hypnosis-related relaxation may diminish endorphin levels rather than increase them. Katz, Sharp, Kellerman, Harston, Hershman and Siegel (1982) reported a positive but not significant relationship between self-report of pain and B-endorphin immunoactivity level in cerebrospinal fluid (CSF) in leukemic children undergoing lumbar punctures. The findings suggested that beta-endorphin in spinal fluid is reactive to stress, increasing as a child experiences and perceives higher levels of distress. Interestingly, differences were also found between girls and boys in endorphin concentration that could throw light on documented differences in pain thresholds and tolerance (Maccoby and Jacklin, 1974).

In a study of acutely burned children, Szyfelbein et al (1985) found self-reports of pain experienced during highly painful medical procedures were inversely related to plasma B-endorphin immunoactivity and body weight and also varied with the extent of the burned injury. Szyfelbein et al (1985) offer possible explanations to account for the discrepant results including the
disparity in B-endorphin immunoactivity measures (plasma versus CSF). They suggest that circulating plasma levels of beta-endorphin may reflect a concurrent central response to stress that involves endogenous opioid systems and that may lead to stress induced analgesia. Major differences in design and procedural differences in timing of obtaining scores are also important. Although complex, biochemical assessment is relevant in assessing children's reactions to pain and could further our understanding of individual differences in pain response and in the selection of specific interventions for specific children.

Summary
Effective management of pain in children depends on accurate assessment, preferably of behavioural, cognitive and physiological responses because of the multidimensional nature of pain. The choice of assessment methods depend on the child's age, sex, cognitive level, previous pain experience and the type of pain (e.g. acute, recurrent or chronic). There are a diversity of methods for assessing pain in children, not without methodological considerations. These methods include behavioural assessment, cognitive-affective assessment, graphic procedures, projective methods and physiological assessment. Physiological measurement is weak in paediatrics. Although it is the most unbiased measure of children's stress responses, few investigators have studied physiological responses to pain experience. While a number of promising observation scales have
been developed to assess distress associated with specific medical procedures, there is a need for scales which can be adapted for a variety of procedures. An accurate pain measure should fulfil the four criteria of reliability, validity, minimal inherent bias and versatility. Of the existing assessment methods, VASs and numerical scales (e.g. pain thermometer and faces interval scales) offer the most versatility for evaluating acute, chronic and recurrent pain in children above 5 years of age.
CHAPTER 5

PSYCHOLOGICAL INTERVENTION

Psychological interventions for paediatric pain have been categorized by Varni (1983) into: a) pain perception regulation methods which involve altering the child’s perception of pain through self regulatory processes as hypnosis, guided imagery, meditation, relaxation and biofeedback, and, b) pain behaviour regulation methods (e.g. contingency management) which identify and modify socioenvironmental factors which may influence pain expression. Pain perception regulation is the primary treatment modality for acute pain in children, while pain behaviour regulation is utilized in the treatment of chronic pain. Interventions are aimed at reducing anxiety as well as pain since behavioural distress usually involves both of these components. Most studies of pain perception have used a combination of techniques which tend to capitalize on children’s fantasy and imagery following progressive relaxation or hypnotic induction (Fielding, 1986).

This chapter is in two parts. The first section describes types of psychological intervention for acute pain, followed by a review of the literature for various invasive procedures. Interventions for chronic pain are not discussed, with the exception of operant techniques as these can be applied to acute pain as part of a wider management programme.
5.1. TYPES OF INTERVENTION

There are various psychological interventions for acute pain which can be categorized into behavioural and cognitive approaches. These are presented in Table 5-1 and discussed below followed by an overview of the issues in using these with children undergoing various invasive procedures. Physical interventions are not discussed but a comprehensive review of them is given by Ross and Ross (1988) and McGrath (1990).

TABLE 5-1 Interventions for acute pain in children

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5.1.1. Behavioural Interventions

Relaxation

Progressive relaxation is a training procedure developed for adults by Jacobson (1938) involving tensing and relaxing various muscles of the body. Many relaxation procedures for children are revisions of this technique. Common relaxation techniques for children are deep breathing exercises and progressive muscle relaxation. Specific relaxation instructions depend on the child's age, cognitive level and pain source (McGrath, 1990). Children under the age of seven years generally require concrete relaxation instructions to reduce pain, such as blowing out fears with soap bubbles or going floppy like a rag doll. The use of relaxation training for pain control is rarely discussed in the paediatric literature, although it is frequently reported in the adult literature (Anderson and Masur, 1983). Some children are able to use relaxation techniques on their own without prior teaching, although it is difficult to distinguish the influence of observational learning from this ability (Bandura, 1969).

Progressive muscle relaxation, meditation, yoga and biofeedback are widely used to alleviate anxiety, distress and pain for both adults and children. However, the precise mechanism by which relaxation reduces pain is not known. Specific procedures for teaching children relaxation can be found in the literature (e.g. Gardner and Olness, 1981; Cautela and Groden, 1978; Benson, 1984; Morris and Kratochwill, 1991). Relaxation is often a component of hypnotherapy or desensitization training. It has been used in the

The benefits of teaching relaxation as a preventative strategy have been explored by Setterlind and his associates (Setterlind, 1982; Setterlind and Unestahl, 1978) in two school programmes for children in Grades 4 to 12 (i.e. ages 9 - 17 years). They compared four modes of presentation of relaxation training: taped instructions, oral instructions, personal relaxation to music and personal relaxation without music. The results showed oral instructions were clearly superior to the other modes of presentation. In addition, there were interesting sex differences in response to relaxation training. That is, girls reported being sad less often and less easily frightened as well as having more positive feelings about relaxation. Boys reported fewer headaches and stomachaches. Because the results were so positive, relaxation training is now a regular component of the physical education programme in Swedish schools.
A relaxation strategy developed for children is a six-second exercise called the quieting reflex (Stroebel, 1982). It was developed to counteract the fight or flight syndrome caused by stressful experiences. There are four steps to the quieting reflex. The first involves the child identifying the stress (e.g. "I am really scared and upset about having an injection"). The next is to decide whether his/her body will be a help or not and then think about the problem causing stress. The third step requires the child to smile inwardly with his/her eyes and mouth. The fourth step requires the child to inhale smoothly to the count of three while imagining that the inhaled air is coming up through the holes in the soles of his/her feet. The destined effect of this imagery is a feeling of warmth and heaviness rising through the body. As the child exhales, he/she lets his/her body go limp so that the warmth and heaviness flows down to the feet. The child then practices the quieting reflex whenever stressed, worried or annoyed.

Relaxation is not an ideal analgesic however as its effects are not long lasting and has to be repeated twice a day for successful results (Ross and Ross, 1988). There are no studies evaluating the efficacy of relaxation training alone to control children’s pain. It is unlikely that relaxation in the absence of a cognitive-behavioural approach would be adequate in controlling children’s pain (McGrath, 1990).
Operant techniques

Operant techniques involve behaviour regulation methods which modify a child's behaviour during medical procedures. These techniques involve contingency management procedures such as positive reinforcement, shaping, extinction and time-out. The basic premise is that overt behaviour is governed by its consequences. Behaviours which are reinforced are more likely to occur, while those not reinforced will occur less frequently. Children's pain behaviours (crying, screaming, seeking reassurance) may be reinforced by increased attention, sympathy or comfort. These behaviours may actually increase children's pain. While solicitous behaviours are desirable in the early stages of trauma, they are not helpful to the child if they persist. Varni (1983) suggests responding positively to the child when he/she engages in "well" behaviours, defined as adaptive or positive behaviours. This does not imply that the child's pain behaviour be ignored but that attention is not paid to behaviours which provide secondary gains that have a powerful effect on subsequent pain.

McGrath (1990) cogently suggests that parents who reward their child's pain by increased attention and encourage dependence, increase the child's passivity, decrease control over the situation, impair his/her ability to learn independent coping strategies, and increase the aversiveness of the procedure. Such situational factors exacerbate children's anxiety, pain and
distress.

The use of operant techniques to reduce pain is similar for children and adults (see Fordyce 1978; Masek et al, 1984) and involve: 1) identifying all pain behaviours (verbal and nonverbal); 2) assessing the responses of significant persons (familial, medical, school, peer) to the child's pain; 3) modifying the responses of these significant persons in order to minimize maladaptive pain behaviours and maximize adaptive behaviours for coping with pain; and 4) rewarding positive coping behaviours, for example, by promising a child a badge or trophy (positive reinforcement) if he or she keeps still during the next medical procedure. Operant techniques need to be used carefully in stressful situations, so that the child does not feel upset and disappointed for not coping well and earning the reinforcement. Interventions must therefore be designed to ensure the child experiences feelings of self-efficacy and mastery. Operant techniques have been used successfully in studies for various pain conditions including migraine (Ramsden, Friedman and Williamson, 1983), burns (Varni, Bessman, Russo and Cataldo, 1980) and acute pain associated with insulin-dependent diabetes (Lowe and Lutzker, 1979).

One criticism of operant methods is that they teach the patient to complain of pain less rather than experience less pain and thus teach a stoic attitude to discomfort. However, operant
conditioning methods do not have as their main goal the direct modification of pain, but rather, excessive pain behaviours such as constant crying and resistance (Fordyce et al, 1985). Another criticism concerns the lack of evidence of operant methods compared with behavioural interventions such as relaxation training or biofeedback for pain control (Ross and Ross, 1988). However, when combined with cognitive-behavioural strategies, operant techniques have been found to be effective (Jay, 1988). Cognitive-behavioural methods are described later in this chapter.

Modeling
Modeling refers to observational learning in which children observe another child coping successfully with an invasive procedure without negative consequences (Bandura, 1969). Modeling is often used in conjunction with operant and desensitization techniques. Modeling can reduce anxiety, pain and distress associated with finger pricks, injections, bone marrow aspirations, lumbar punctures, and dressing changes for burns (McGrath, 1990). Participant film modeling has been shown to be more effective than standard film modeling in providing information and reducing distress in children and adolescents who were fearful of dentists (Klingman, Melamed, Cuthbert and Hermecz, 1984). In participant modeling the child observes the model participating increasingly with the feared stimulus, then practices what the model performed as well as receiving
corrective feedback and information about the feared stimulus from the therapist (Morris and Kratochwill, 1991). Filmed modeling has been used preventatively for healthy children in classroom settings to increase their medical knowledge and attitudes towards paediatric personnel (see Elkins and Roberts, 1985; Klinzing and Klinzing, 1977). The purpose of these studies was to reduce fears about common medical events. Many studies demonstrate the efficacy of filmed modeling, which is the most commonly investigated technique, but not the most commonly used procedure (Peterson and Ridley-Johnson, 1980) possibly because practitioners are not in touch with the literature. Models similar to the observer increase observational learning (Bandura, 1969). Consequently, many films have models of the same sex, age and race as the child observer. Findings suggest that regardless of the type of modeling procedure used (filmed, videotaped or puppet) a model is an effective preparation for children (Peterson and Mori, 1988).

There is some evidence, however, to suggest modeling is contraindicated for young "experienced" children who have previous experience of invasive procedures (Melamed and Siegel, 1980; Melamed, Dearborn and Hermecz, 1983) who may be sensitized by viewing modeling preparation (Faust and Melamed, 1984). Children who are experiencing medical or dental procedures for the first time generally benefit from the film presentation (Klinzing and Klinzing, 1977; Melamed and Siegel, 1980. Ginther
and Roberts (1982) did not find a reduction in children's dental fears regardless of whether they had prior experience of dental procedures or not. There were also no differences according to the type of model (mastery versus coping) which raises interesting questions about the distinction between these models. Zachary, Friedlander, Huang, Silverstein and Leggott (1985) found similar results on stress relevant and irrelevant filmed models for children in the dental setting.

Not only does modeling provide the child with information about the details of the procedure, but also specific coping skills such as imagery, relaxation and distraction (Jay, 1988), thus maximizing intervention effects. There is some evidence that mastery models which display no anxiety and cope effectively with the stressor are less effective than coping models, which exhibit anxiety and express concern about forthcoming stress, but cope successfully with it. In general, identification is facilitated more easily with coping models (Meichenbaum, 1971).

Ross and Ross (1988) argue that some disappointing findings on filmed modeling can be attributed to procedural shortcomings rather than difficulties in the use of models. These include timing of modeling, problems of single trial exposure, and individual differences in requiring prior information. No attention has been paid to the value of using models dissimilar to the child, which could possibly have a powerful effect. There
is evidence to suggest that multiple models are more powerful in naturalistic settings than a single model (e.g. Craig, 1980). Another consideration would be to have multiple film presentations for "experienced" children, who generally do not benefit from filmed modeling prior to their hospital experience. Repeated exposure to the film should help reduce the fears of these children. For excellent reviews on film modeling see Siegel (1987) on dental fears and Thelen, Fry, Fehrenbach and Frautschi (1979) on filmed modeling generally.

Systematic Desensitization

Desensitization is a procedure which involves gradually exposing individuals to the feared object or situation in hierarchical steps, until anxiety eventually decreases. The feared stimulus is systematically paired with a response that is incompatible with anxiety, such as relaxation (Wolpe, 1982). The principle underlying the desensitization process is known as reciprocal inhibition. Desensitization has been used frequently in treating children's fears and phobias, including fear of the dark, animals and anxieties about school (Barrios et al, 1981; Morris and Kratochwill, 1991). Often, desensitization is one component of a cognitive-behavioural programme (e.g. Jay et al, 1987). The procedure involves identifying the anxiety provoking components of the invasive treatment, a programme of gradual exposure to reduce the aversiveness of the situation, and teaching the child coping strategies to increase relaxation, control and
understanding of the treatment

Systematic desensitization is helpful for children who have developed conditioned fears about repeated invasive treatments, although there are practical limitations to its use. The intervention requires a period of time in which the child can be gradually exposed to the medical equipment, treatment environment and medical personnel (Jay, 1988). Unfortunately, there is often little or no time to prepare children prior to invasive medical procedures, such as suturing procedures in accident and emergency departments of hospitals. By the time children are referred for
psychological intervention, they have developed conditioned anxiety responses. Desensitization may be more useful in treating healthy children’s fear of routine scheduled procedures such as immunizations or dental procedures, or chronically ill children who have scheduled procedures which allow time to prepare the child.

Art and Play therapy

Art and play therapy can alleviate children’s distress during hospitalization or prior to invasive procedures. They can be used for both assessment and therapy to help children cope with stress, anxiety, pain and fear. Essential information about children’s emotional reactions to painful procedures or painful diseases can be obtained in a natural and familiar context. Artwork can provide relaxation and reduces stress. Unlike other interventions, play therapy is the only behavioural method restricted to younger children (McGrath, 1990). It represents a natural outlet for emotional expression and can provide a method of familiarizing children with frightening instruments, providing information to children about their disease or treatment procedure and practicing coping skills (see for example, Caty Allerton and Ritchie, 1984). The interpersonal element during procedures can also be emphasized, in that paediatric personnel are not being deliberately unkind or punitive. Play can be a part of a multidimensional intervention package (Jay et al, 1987). Play therapy enables the child to shift from a passive recipient of painful treatment, to the paediatric personnel who
administer it, by playing "doctor" on a doll or teddy. Single case examples of the use of play therapy for coping with pain can be found in the literature (e.g. Tucker, 1982; Adams, 1976) as well as reports of play therapy programmes and therapeutic techniques (Adams, 1976; Linn, 1977; Petrillo and Sanger, 1972) and guidelines on non-directive play therapy (Axline, 1969).

Although play therapy has long been used clinically, it has not been empirically validated, possibly because it tends to be conducted in a treatment setting rather than a research one.

5.1.2. Cognitive Interventions

Cognitive interventions include hypnosis, cognitive coping strategies, thought stopping and cognitive-behavioural interventions. Many of these have been used successfully to treat acute, chronic and recurrent pains (for reviews, see Anderson and Masur, 1983; Turk, 1978; Turk and Meichenbaum, 1984). Although there is an overlap between different cognitive interventions, there are characteristics unique to each method. Most cognitive methods require the patients to become completely absorbed in a thought or image, so that they attend to or perceive pain less intensely. It is likely that cognitive methods can also reduce pain perception by activating endogenous opioid and nonopioid pain suppressing systems (McGrath, 1990).

Hypnosis

Definitions of hypnosis have followed the various theories attempting to explain hypnotic phenomena over the years.
Competing theories were pursued in the 1960's and 1970's, however differences in them are being resolved with the acknowledgement that each approach contributes to different features of hypnosis. Acknowledging this controversy over what hypnosis is, the present study adopts an operational definition described by Kilstrom (1985, p385-386):

Hypnosis may be defined as a social interaction in which one person (designated the subject) responds to suggestions by another person (designated the hypnotist) for experiences involving alterations in perception, memory and voluntary action.

Hypnosis with children has been described as an intense involvement in imagination (Hilgard, 1970; Hilgard and LeBaron, 1984). Children respond readily to hypnosis because of their imaginative involvement (Krickson, 1958; Ambrose, 1961; Gardner, 1974) and consequently are excellent hypnotic subjects. In fact, hypnotizability peaks between the ages of 9 - 12 years (London, 1965; Morgan and Hilgard, 1978/1979). The relationship between imaginative involvement and hypnotizability is well established in adults (Hilgard, 1970) and recently in children (Lebaron, Zeltzer and Fanurik, 1988). The precursors of hypnotic behaviour are believed to be pretend or make-believe play beginning at age two or three years, referred to as "protohypnosis" (Hilgard and LeBaron, 1984).

Imaginative involvement and hypnotizability in children are probably related to several aspects of cognitive and emotional development described by Gardner (1974): 1) a capacity for
focused attention, immersion and absorption in the present; 2) concrete literal thinking; 3) love of magic, limited reality testing, and readiness to alternate between reality and fantasy; 4) intensity of feeling states; and 5) openness to new ideas and experiences.

Hypnotherapy has special value in reducing pain and discomfort (Gardner and Olness, 1981; Hilgard and Hilgard, 1983; Zeltzer and LeBaron, 1986; Hart, 1991; Ioannou, 1991a). For an excellent review of hypnosis for children in pain see Zeltzer and LeBaron (1986). The main application of hypnosis in paediatrics has been in the control of acute pain in children with cancer, described later in this chapter. Imaginative involvement and dissociation are essential components of the hypnotic experience. Some studies which do not refer to their approach as hypnotherapy nevertheless share some features with hypnosis, such as use of imagery. It is not clear how hypnotic techniques such as fantasy and dissociation differ from cognitive-behavioural techniques such as emotive imagery (Lazarus and Abramovitz, 1962), guided imagery and attention distraction (Turk, 1978). Some techniques are referred to as hypnosis by some authors and behavioural by others, depending on the authors' theoretical orientation. It is necessary to delineate intervention procedures to avoid confusion and misleading terminology (Jay, 1988).

**Hypnotic susceptibility**

It is widely accepted that children make better hypnotic subjects
than adults. Hypnotic responsiveness in children can be measured
by the Children's Hypnotic Susceptibility Scale (CHSS) or the
Stanford Hypnotic Clinical Scale for Children (SHCSC). The CHSS
(London, 1963) consists of 22 items including visual, auditory
and sensory hallucinations. The scale's disadvantage is that it
requires 45-60 minutes to administer. The SHCSC (Morgan and
Hilgard, 1979) only requires 20 minutes to administer and is
therefore of more practical value to the clinician and
researcher. The SHCSC includes two forms, one for children aged
6-16 years and a modified form for younger children aged 4-8 years
(see Appendix ?). The modified form includes an active
imagination induction, avoiding eye closure which many young
children resist, and six test items. The form for older children
includes an eye-fixation induction (face on thumb-nail) with
relaxation, and the following seven test items: hand lowering,
arm rigidity, visual and auditory hallucination, dream,
age-regression and post-hypnotic response. This last item is
omitted in the modified version. There is some evidence for the
validity of the scale which correlated .67 with the longer
Stanford Hypnotic Susceptibility Scale, Form A modified for use
with children. The SHCSC is of value because the child's
responses may help the clinician select appropriate methods, it
demonstrates to the child how responsive he or she is, and the
child's hypnotic responsiveness on the scale can be related to
clinical outcome. This helps the clinician assess whether
improvements are due to hypnotherapy or to non-specific aspects
of treatment (Zeltzer and LeBaron, 1986). The existing scales do
not extend to children under the age of four years however.

Scales have been criticized for being biased in that normative
studies on the SHCSC and the CHSS have used subjects only from
the middle socio-economic class. Children from diverse social
and cultural backgrounds should be included in normative samples.
Lastly, research regarding correlates of hypnotic responsiveness
including locus of control, anxiety and self-concept is
required.

Hilgard and Hilgard (1983) have documented the clear relationship
between the degree of hypnotizability and response to hypnotic
analgesia and anaesthesia. Hypnoanaesthetic effects are not
simply due to placebo or relaxation (Hilgard, 1980, Orne, 1980).
Hypnotizability would appear to be more relevant to the relief of
acute pain when the alteration of physiological responses is the
focus of treatment (Orne, 1980). It is less important for
chronic pain, since it is changes in social motivational aspects
(e.g. motivation, expectation, attitude, attribution) which are of
more concern (Hart, 1991). J. Barber (1980) and other clinicians
influenced by the late Milton H Erickson assert that
hypnotizability is clinically irrelevant to pain control
providing indirect, permissive and naturalistic suggestions are
used. However, J. Barber (1980) has recently altered his view in
line with Price and Barber (1987) who found that the sensory
aspects of pain control are determined by hypnotizability when
hypnosis is used, while the affective (i.e. emotional) aspects
of pain are not. Notwithstanding this, the bulk of clinical
research supports a positive relationship between hypnotizability and the response to hypnotic treatment for acute pain (Wadden and Anderton, 1982).

The repeated finding of studies on hypnotic responsiveness is of a modest curvilinear relationship with age, with a peak in middle childhood followed by a slight decline into adulthood (London and Cooper, 1969). Changes in responsiveness with age are explained in terms of a decline in imaginative skills. London and Cooper (1969) in their standardization sample of 250 children aged 5-16 found large standard deviations for all age-groups, suggesting wide variations in children's responses at all ages. The data did, however, show children to be more responsive to hypnosis than adults. While early research on norms suggested hypnotizability to be limited in preschool children, more recent clinical and research data has indicated that very young children respond positively to hypnosis (LaBaw, 1973; Gardner, 1977; Kuttner, 1984; Kuttner, Bowman and Teasdale, 1988).

Children are said to have a better capacity than adults to control pain when using hypnosis (Wakeman and Kaplan, 1978). Hypnotherapy is effective in helping children reduce pain associated with the illness itself (such as cancer, sickle cell anaemia, and fractures), invasive medical and dental procedures (such as injections, bone-marrow aspirations, lumbar punctures, change of dressings and debridement for burns), with migraine, tension headache and rheumatic pain, analgesia for minor
surgical procedures, and with terminally ill children.

Gardner and Olness (1981) describe several methods of hypnoanalgesia in their book *Hypnosis and Hypnotherapy with Children*, an excellent and comprehensive text on paediatric problems. These hypnoanalgesic techniques can be used in combination, and involve suggested dissociation either directly or indirectly:

1. Direct suggestions for hypnoanalgesia, for example, "just imagine painting numbing medicine on your hand". Imagery of a pain switch-box can be used to show how pain is transmitted by nerves from different parts of the body to the brain, which then sends a pain "message" back to the body. The child can then imagine a switch-box that can turn off incoming nerve signals.

2. Distancing suggestions such as moving the pain away from the self by imagining that the body part does not belong to oneself, transferring the pain to another part, and moving the self away from the pain by imagining, for example, being in the mountains.

3. Suggestions for feelings antithetical to pain such as comfort, laughter or relaxation.

4. Distraction techniques such as story telling, focusing on the procedure or injury by asking the child to describe these in detail, and focusing on a less uncomfortable experience such as cold instead of pain.

5. Directing attention to the pain itself. This may be employed for children who cannot be distracted from the pain but for whom subtle suggestions for change can be given.

6. Reinforcement of pain control by self-hypnosis, which may include the use of audiotapes or parents acting as therapeutic coaches.

Other hypnotic techniques for pain control such as time distortion can be found in the adult literature (Hilgard, 1980; J.Barber, 1986) but can be adapted for children. The choice of
induction method will depend on the therapist's style and creativity and the child's age and development, interests, hypnotic talent, needs and preferences. Prior to the initial induction, the therapist should obtain information from the child including his/her likes and dislikes, favourite activities as well as clarify ideas about hypnosis and misconceptions. Methods are likely to be symptom orientated focusing on removal of pain and distress, and encouraging mastery and self-efficacy, the child's involvement and control, and active participation.

Children enjoy fantasy inductions which capture their attention and imagination. This involvement in fantasy then permits the child to disengage from some aspect of the environment (such as a bone marrow aspiration) by dissociation. Children respond differentially to hypnosis at different age levels (Zeltzer and Lebaron, 1986). Preschool children are not able to internalize imaginative involvement and therefore respond to hypnosis in an active way. Older children can experience hypnosis in an internalized way, focusing their attention on fantasies and images. By adolescence this is enhanced by a greater verbal and cognitive ability. While adolescents will respond to any adult induction method, formal inductions are not necessary with children (Erickson, 1958). Preschool children respond best to active play-orientated inductions. Props are very helpful such as soap bubbles, toys or puppets, which all require the child's eyes to be open. Children, unlike adults, tend to be fidgety and distractable during hypnosis, and may open and close their eyes.
or refuse to close them at all. It is their absorption in the images and fantasy which indicates the level of responsiveness. Children's involvement in fantasy can be assessed by enquiring whether an experience felt real or whether they just thought about it. Eye closure is not necessary to induction and has been found the most difficult item for children (London and Cooper, 1969).

Induction techniques

Induction techniques have been described in detail in the literature (Gardner and Olness, 1981; Hilgard and Lebaron, 1984; Karle and Boys, 1987; Gibson and Heap, 1990; Ioannou, 1991b). Gardner and Olness (1981) list induction techniques by age. Induction methods include visual, auditory and movement imagery, story telling, ideomotor techniques, progressive relaxation, distraction and utilization methods. These can be used in combination. Induction methods with children are permissive and encourage children's active involvement, participation and mastery; authoritarian methods are not recommended with children. Induction methods can be mechanical or ideomotor (e.g. eye fixation or hand levitation) or imagery and fantasy techniques (e.g. riding on a magic blanket, favourite place/activity, television fantasy). The ideomotor techniques are helpful in enhancing imaginative involvement. Focusing the child's attention on sensory details of the experience such as what he or she can see, feel, or hear enhances dissociation further. Hypnotic stages like induction, deepening, treatment and ego strengthening (used
with adults), may sometimes be indistinguishable from one another. Indeed, this is evident with storytelling techniques which form the entire therapeutic procedure. Therapeutic suggestions may be delivered directly or indirectly by story or metaphor and using age appropriate language. Therapeutic suggestions can also be delivered through the "hypnotic hero" (Tilton, 1984), in other words, the child's favourite hero. Gardner (1974) suggested that young children may follow directions more easily if they appear to come from a revered hero. Young or immature children seem to respond best to story telling techniques rather than more formal hypnotic methods. Story telling can be helpful for young children experiencing invasive procedures which may be painful or frightening (Gardner and Olness, 1981; Kuttner et al, 1988). The story may be a favourite one (Kuttner, 1984) or a personalized story (Elkins and Carter, 1981; Levine, 1980; Callow, 1988) or one that utilizes therapeutic metaphor (Crowley and Mills, 1985/6). Therapeutic suggestions for well-being and analgesia can be embedded or interspersed in the story. The technique is more than a distraction. Gardner and Olness (1981) have commented on the narrowed focus of attention and alterations in sensation which are also observed in the hypnotic state.

Theories of Hypnosis
While the efficacy of hypnotherapy for the control of clinical and experimental pain has been demonstrated, the nature of hypnotic analgesia is still a subject for controversy (Hilgard
and LeBaron, 1984). The physiological mechanisms responsible for hypnotic analgesia are unknown. There are a number of theories which try to explain hypnosis and two general and contradictory theories of the hypnotic process. According to the traditional view (Hilgard, 1977), hypnosis is a special or altered state of consciousness, often referred to as a "trance" or "state". Hilgard (1977) formulated the neodissociation theory of hypnotic analgesia (sometimes referred to as the theory of alternative cognitive controls), based on the concept of the "hidden observer", which perceives pain at an unconscious level. As there are no consistent physiological or behavioural responses that distinguish a hypnotic "state" from deep relaxation the "non-state" theory was proposed as an alternative paradigm (T.X. Barber, 1963; Wagstaff, 1981). This theory suggests that subjects behave in accordance with their motivations, attitudes and expectations about hypnosis rather than entering an altered state of consciousness. For an excellent discussion of the various theories of hypnosis, see Fellows (1990).

**Self-Hypnosis**

The child who uses self-hypnosis for pain control experiences mastery over his/her pain which induces a feeling of self-efficacy (Bandura, 1981). Self-hypnosis also reinforces therapeutic suggestions (Gardner and Olness, 1981). There is a substantial body of research on the effectiveness of self-hypnosis for pain control in children and adolescents (e.g. Gardner and Olness, 1981; Hilgard and LeBaron, 1984; McGrath and
de Veber, 1986; Olness, MacDonald and Uden, 1987). Children as young as three years old are able to use self-hypnosis with assistance (Kohen, Olness, Colwell and Heimell, 1984) although children over five or six can use it independently. Few children however, practice self-hypnosis beyond about 6 weeks because they become bored or forget to practice (Kohen et al, 1984).

Cognitive Coping Strategies
While there is unequivocal clinical (Ross, 1984) and empirical evidence (Jay, 1988; McGrath and deVeber, 1986; Peterson and Shigetomi, 1981; Siegel, 1988) that children and adolescents can be taught cognitive coping strategies for the attenuation of pain, there are few instances of paediatric personnel teaching children and adolescents in clinical situations. There are coping strategies that children use spontaneously (see Chapter 2) prior to and during painful procedures (see also Gaffney, 1983; Ross and Ross, 1982b) which are often used in combination with taught cognitive coping strategies. The general procedure for teaching cognitive coping strategies to children has been outlined by Ross and Ross (1988). Why these strategies help in the attenuation of pain remains unknown. Ross and Ross (1988) discuss possible explanations, including the relevance of a consequent enhancement of self-efficacy (Bandura, 1981) accompanying an ability to use coping strategies. This increase in self-efficacy possibly eliminates feelings of helplessness in the painful situation (Seligman, 1975). However, the type of strategy used is important. Not all coping strategies are effective. For example,
distraction alone is not effective for reducing severe pain (McCaul and Malott, 1984).

The strategies described below are those that influence children's perception of pain through the medium of the child's cognitions (Ross, and Ross, 1988) and include attention-diversion, self-instruction and imagery.

Attention Diversion
Distraction is the most common cognitive method used with children in mild to moderate pain. It does not only passively divert children's attention away from pain, but alters their perception of pain (McGrath, 1990). By focusing attention elsewhere during a painful procedure, the child will have less attention for the pain, and as a result, experience less pain (Ross and Ross, 1988). Common distraction strategies for children have been listed by McGrath (1990): singing, describing a favourite place, toy, or cartoon, playing video games, watching a special cartoon, describing a novel object (auditory or visual), deep breathing, coughing (during injections) and hand squeezing. The choice of distraction method is critical to the success of cognitive intervention, and depends on the child's age and interests. Young children require external concrete objects to absorb their attention such as pop-up books or soap-bubbles (Kutner, 1984). Older children can be distracted by external or internal activities. The selected distraction task should be one
that requires some concentration and attentional capacity for it to be effective (McCaul and Malott, 1984). An internal distraction may include counting backwards, reciting a poem or singing songs. An external distraction involves focusing on a feature of the environment, such as counting tiles on the ceiling.

Attention diversion has been used in several studies with leukemic children undergoing bone marrow aspirations. Jay et al (1987) used internal attention diversion (breathing exercises) as part of a multicomponent cognitive-behavioural package. Ruttner (1984) in a well designed experiment, used soap bubbles and pop up books as attention diversion stimuli. LeBaron and Zeltzer (1982) asked children to count the stripes on their mothers blouse. The success of these methods is likely to be due to the child's active rather than passive participation.

**Self-Instruction**

The aim of self-instruction is for the child to coach him/herself during an invasive procedure. It is most helpful for children who have some knowledge of the forthcoming procedure and what the pain will be like. The child can be instructed to think about the pain treatment one step at time (Ross and Ross, 1988). The child then concentrates on internal self-instruction, giving him/herself advice ("Just relax"), encouragement ("You're doing great"), and reassurance ("You're past the worst part") (Ross and Ross, 1988). Self-instruction can be combined with other
cognitive coping strategies. Siegel and Peterson (1980) used self-instruction as part of a treatment package for children undergoing dental treatment, while Nocella and Kaplan (1982) used reassuring self-talk, for example, "If I get scared or worried I tell myself this is a good dentist, I'm doing good, I can handle this, I'm terrific". Jay et al (1987) included positive coping statements in their treatment package for paediatric cancer patients.

Imagery

"Imagery" refers to the process of concentrating on the image of an experience or situation as a specific method for distraction and attention (McGrath, 1990). It is more than just thinking about a situation. Rather, children are often asked to describe specific details of an experience, such as colours, sounds and textures. They are encouraged to become immersed in their imagery as if it were occurring in the present. This type of absorption in imagery occurs during hypnosis as already described. Imagery is also a method for producing physiological changes to relax the body (McGrath, 1990). Children's ability to use imagery and hypnosis to alter psychophysiological functioning has been documented (Olness, 1986). The mechanism by which imagery reduces pain is not yet understood. Children can become absorbed in a variety of images to help them cope with painful procedures, such as a favourite place, activity, pet animal or favourite television programme. Children as young as three years old can use imagery effectively to control their pain (Kuttner,
Ross and Ross (1988) describe three types of imagery: 1) context transformation; 2) stimulus transformation; and 3) incompatible imagery. Transformative imagery alters the meaning of pain for the child. In context transformation the child does not ignore the pain, but instead, focuses on transforming the pain situation into a more desirable one. An example is imagining the dentist is the enemy and the child a secret agent and the dentist is torturing the child to get secret information (Ross and Ross, 1982b). In stimulus transformation, the child transforms the instrument that is causing the pain into something more exciting and positive. For example, a needle can be viewed as a silver knight which slays the enemy (Ross and Ross, 1982b). Incompatible imagery has been described above as imagining being in a pleasant scene, engaged in an activity that is inconsistent with pain (Ayer, 1973).

Emotive imagery has also been described by Lazarus and Abramovitz (1982) and is a technique that involves ascertaining the child's superhero or fantasy character and weaving these images into the medical situation. The purpose is to encourage mastery, provide distraction and transform the meaning of pain for the child (see Jay et al, 1985; Elliott and Olson, 1983).
Thought-Stopping

Thought-stopping is a coping technique which involves substituting positive thoughts for more negative ones (Wolpe and Lazarus, 1966). This is helpful for children who have anticipatory anxiety about forthcoming medical procedures. Information about the positive aspects of the event are obtained which is condensed into simple positive statements that can be repeated by children. Whenever children begin to think negatively about the procedure, they interrupt this thinking with positive statements.

Thought-stopping has been effective in reducing anxiety in hospitalized children undergoing regular bloodtests and in children with learning difficulties during dental treatments (Ross, 1984). Two disadvantages with the technique are that it does not effect any change in the quality of negative thoughts about the situation and it does not provide any information to help the child cope effectively should his or her fears be realized (Ross and Ross, 1988). However, Ross (1984) developed a thought-stopping procedure which eliminated these disadvantages. The procedure involved assembling positive and reassuring facts, condensing and memorizing them (e.g. "A needle in my arm is quick, I have good veins. The girl who does it is nice. The doctor has to know how my blood is. It won't hurt as much if I think hard about something nice"), and repeating them whenever anxiety arousing thoughts occurred. While there have not been any controlled studies into the efficacy of this procedure,
clinical reports suggest it can decrease children's anticipatory anxiety prior to impending invasive procedures as well as anxiety during treatment (Ross and Ross, 1988).

Cognitive-Behavioural Intervention

Cognitive-behavioural interventions can include a number of strategies such as distraction, stress inoculation, cognitive restructuring and coping skills training. The focus of therapy is not only on behaviour, but on the patient's cognitions, self-statements, expectancies and images (Meichenbaum and Turk, 1976; Turk and Meichenbaum, 1984; Turk, Meichenbaum and Genest, 1983). Cognitions are believed to be important in determining patients' stress reactions; thus, the aim of intervention is to modify maladaptive cognitions (Meichenbaum, 1976).

Cognitive-behavioural strategies are frequently multimodal (involving a number of interventions), the rationale being that individuals can respond to different components of the intervention (Turk, 1978). It is best to develop an intervention "package" with a maximum probability of success and thereafter to carry out studies to isolate the effective components in it. Comprehensive pain management programmes are likely to involve cognitive-behavioural interventions that are required to modify the situational, psychological and sensory components of the child's pain experience (McGrath, 1990). The recognition that pain is a multidimensional concept has led to a multidisciplinary approach to its management. As described in previous sections,
there is considerable overlap between various cognitive and behavioural techniques, particularly with imagery. In contrast to adults, however, there are only a few accounts of cognitive-behavioural interventions with children in the literature (Peterson and Shigetomi, 1981; Nocella and Kaplan, 1982; Siegel and Peterson, 1980, 1981; Elliott and Olson, 1983; Jay et al, 1987). These are briefly discussed in the next section.

5.2. INVASIVE MEDICAL PROCEDURES

The following section is a review of psychological interventions for acute pain in children associated with surgery, burns, dentistry, bone marrow aspirations, lumbar punctures and injections.

5.2.1. Surgery

Preparation for surgery or hospitalization has been shown to be effective in reducing pre- and post-surgical distress and post-surgical pain (Melamed and Siegel, 1975). Preparation is a generic term including a range of interventions such as doll play, hospital tours, and modeling films. The purpose is to provide children with information about the forthcoming medical procedure, encourage emotional expression and establish a trusting relationship with hospital staff (Vernon, Foley, Sipowicz, and Schulman, 1965). It is predicated on the belief that surgery and hospitalization are stressful and painful
experiences which may lead to transient or long term psychological disturbance, especially if the child is not sufficiently prepared (Melamed and Siegel, 1980).

Preoperative instruction is the most frequently used method of preparation for children. It involves helping the child understand the purpose and meaning of the procedure, correcting misconceptions, and helping the child master the experience (Melamed and Siegel, 1975). Preparatory information is either sensory or procedural (Johnson et al., 1975). Sensory information provides details concerning sensations the child will experience during the procedure, such as smells and kinesthetic awareness. Procedural information describes the steps of the procedure. A combination of procedural and sensory preparation is the most effective (Anderson and Masur, 1983). Puppet therapy (Cassell, 1965) and play therapy (Dimock, 1960) have been used as preparatory methods for surgery. These techniques enable children to carry out the "work of worrying" (Janis, 1958), to act out, express their fears, while also providing information about medical procedures.

Early research studies investigating preoperative preparation suffer from a number of methodological flaws such as uncontrolled variables and inadequate measurement, which make interpretation difficult (Melamed and Siegel, 1975). Results are therefore equivocal in showing differences between prepared and unprepared children on a number of measures. More controlled and sophisticated outcome studies can be found in the recent
literature however (Melamed and Siegel, 1975; Melamed, Meyer, Gee, and Soule, 1976; Wolfer and Visintainer, 1975). Filmed modeling has been used most frequently in preparing children for surgery. Melamed and Siegel (1975) conducted a well controlled study on the efficacy of filmed modeling in reducing children's anxiety over elective surgery. Children were shown either a peer modeling film "Ethan has an operation", or a control - unrelated film. Children who viewed the modeling film showed fewer anxiety related behaviours and medical concerns at preoperative and postoperative assessment.

Peterson and Shigetomi (1981) found a combination of coping techniques (deep muscle relaxation, imagery distraction and self instruction) and filmed modeling to be more effective than modeling or coping techniques alone in preparing children for surgery. Previous work suggested that older children benefit from a longer time interval between preparation and surgery, while younger children benefit from preparation closer to the procedure (Dimock, 1960; Melamed et al, 1976). Wolfer and Visintainer (1975) found any preparation to be better than routine hospital practice although the effects of intervention did not generalize beyond surgery.

Research into preparing children for surgery has largely focused on minor (short stay) surgery such as tonsillectomies. For extensive reviews of this area see McCue (1980) and Peterson and Mori (1988). There is a need, however, to develop methods on
preparation for the chronically sick child undergoing surgery. For example, little attention has been paid to preparing chronically ill children undergoing kidney, liver or heart and lung transplants.

5.2.2. Burns

The problem of pain relief for burns has received little attention in the literature (Bonica, 1980). The burned child poses a difficult management problem to hospital personnel. In addition to the pain caused by injury, the child must undergo highly painful treatment of their wounds involving hydrotherapy, debridement and dressing changes. Such procedures have been reported as the most painful aspects of hospitalization for burned victims (Savedra, 1976). Burned children do not habituate to these treatments, rather they tend to become less tolerant of them over time (Savedra, 1976). Factors influencing expectation of pain have been discussed by Beales (1982) and include beliefs about therapy and recovery, and, exposure to the sight of instruments and the injured area. Respondent and operant conditioning play an important part in children's pain behaviour (Fordyce, 1976; Varni et al 1980). The child learns to experience pain in the presence of particular conditioned stimuli.

The misunderstanding of the experience of pain by medical staff, fear of creating addiction in children and lack of knowledge of narcotic analgesics often lead to undermedication of children's
Perry and Heidrich (1982) surveyed 151 U.S. burn units and found that children were frequently undermedicated even though their level of pain was assessed as being the same as adults (i.e. moderate to severe). Pain was rated as most severe by staff who provided most analgesia before the procedure and by staff who had spent less time on the job.

Crasilneck, Stirman, Wilson, McCranie and Fogelman (1955) first demonstrated the effectiveness of hypnosis in the management of burned victims. The majority of studies however, consist of a series of case studies rather than controlled research. Wakeman and Kaplan (1978) conducted a methodologically sound study of hypnosis for burns in children and adults and found that children (aged 7-18 years) did significantly better than adults in managing pain regardless of burn size (0-30% or 31-60%) and used significantly less medication. Although hypnotic susceptibility was probably the significant predictor variable, it was unfortunately not assessed. Elliott and Olson (1983) developed a stress management programme to reduce distress in burned children undergoing painful treatment of their injuries. The package included the following components: attention-distraction, relaxation, emotive imagery, and reinforcement. The intervention was moderately effective for three of the four children and the presence of the therapist was essential as distress levels increased when the therapist was absent.

Kelly, Jarvie, Middlebrook, McNeer, and Drabman (1984) evaluated
a multicomponent behavioural package involving cartoon viewing and a star feedback chart in two severely burned children. The results suggested decreases in pain behaviour during physical therapy, but cartoon viewing without the star chart produced only slight decreases in pain behaviour.

Other methods which may be effective for pain relief for burn related pain include filmed modeling and training in specific coping techniques (e.g., Melamed and Siegel, 1975; Peterson and Shigetomi, 1981; Turk, 1978). Modifying the child's beliefs about the healing process and the role of burn treatments, involving the child in therapy and achieving distraction from the pain source, have all been suggested as important in increasing compliance with medical procedures (Beales, 1982). Empirically based treatment of burned children is difficult from a clinical and methodological perspective, as pain responses tend to increase over time such that stable baselines cannot be obtained (Kelly et al., 1984). Other difficulties regarding research include the stressful nature of observing children's suffering, which may partly explain why little research has been conducted in this area (Kelly et al., 1984). For a recent review of children's burns see Miller, Elliott, Funk and Pruitt (1988).

5.2.3. Bone marrow aspirations and lumbar punctures

Children with cancer frequently undergo bone marrow aspirations (BMA's) and lumbar punctures (spinal taps), both highly painful and distressing procedures. Studies have shown the behavioural
distress associated with these medical procedures is virtually ubiquitous in paediatric cancer patients, particularly in young children (Katz et al, 1980; Jay et al, 1983). These procedures are often perceived as worse than the disease itself. Bone marrow aspirations involve the insertion of a needle into the hip bone (posterior ileac crest) in order to withdraw bone marrow to be examined for the presence or absence of cancer cells. Lumbar punctures are similar and involve inserting a needle into the spinal column, spinal fluid is then withdrawn to be examined for cancer cells. Sometimes chemotherapeutic drugs are injected into the spinal column for therapeutic purposes. Hypnosis is the most frequently used intervention for acute procedure related distress and pain in paediatric cancer patients. While formal hypnotic procedures have not been reported to be effective with children under the age of six years undergoing BMA’s and lumbar punctures (Hilgard and Morgan, 1976), older children have been found to be responsive (Zeltzer and LeBaron, 1982; Kellerman, Zeltzer, Ellenberg, and Dash, 1983). Recently, Kuttner (1988) has provided support for the efficacy of hypnotic pain reduction (story techniques) for children as young as three years old. This work is important as children under age six have been documented as being in most need of psychological intervention (Jay et al, 1983).

In a controlled study of 36 children aged six to 11 years, Katz et al (1980) found hypnosis to be more helpful for girls and supportive play to be more helpful for boys. Hilgard and LeBaron
(1982, 1984) found hypnosis effective in reducing self-reported pain in 24 children undergoing BMA's. Hypnotic treatment was individualized but followed a standard pattern in which imaginal rehearsal played a prominent part.

Case studies and uncontrolled reports provide support for the efficacy of hypnosis in reducing procedural anxiety and pain in children with cancer (Labaw, Holton, Tewell and Eccles, 1975; Gardner, 1976; Zeltzer, 1980; Ellenberg, Kellerman, Dash, Higgins, and Zeltzer, 1980; Olness, 1981). The methodological shortcomings of many reports on hypnosis have been described as follows: 1) objective measures of distress are rarely used; 2) lack of control groups; and 3) hypnotic procedures are vaguely specified (Jay, 1988). Two controlled outcome studies have however, been reported in the literature (Zeltzer and LeBaron, 1982; Kuttner et al 1988). Zeltzer and LeBaron (1982) conducted a controlled outcome study comparing the efficacy of hypnotic techniques with a supportive counselling and distraction intervention in 33 paediatric cancer patients (aged 6-17 years). The hypnosis intervention consisted of imagery and fantasy individualized for each child such as exciting or funny stories with questions requiring imagination. For example, the child could be asked to "notice the elephant about to squirt water on us" (p.1033) and to describe what he or she saw. The distraction (non-hypnotic intervention) included deep breathing and focusing on aspects in the room rather than on fantasy, such as squeezing the mother's hand and counting flowers or stripes on her blouse.
at critical points during the procedure. Kuttner et al (1988)
reported on an interesting and well controlled study on the
efficacy of a hypnotic treatment (imaginative involvement) and a
behavioral treatment (distraction) compared to an attention
placebo control condition in reducing behavioural distress in 48
children aged 3-10 years undergoing BMA's. Imaginative
involvement consisted of a favourite story (for children aged 3
years to 6 years 11 months), or fantasy adventure (for children
aged 7-10 years) during which direct and indirect suggestions for
comfort and pain reduction were interwoven with procedural and
sensory information. The distraction treatment included physical
objects such as pop-up books, puppets, soap bubbles, and squeezy
toys. Imaginative involvement was found to be most effective for
younger children (aged 3-6 years), while older children were
helped by both imaginative involvement and distraction.
Jay and colleagues (Jay et al, 1985; Jay, Elliott, Katz and
Siegel, 1987) developed a cognitive behavioural package for
children undergoing BMA's and lumbar punctures. The package is
partly based on a stress inoculation model described by
Meichenbaum (1976) and Turk (1978) which involves providing
information about the stressful event, teaching coping skills
such as distraction and relaxation, and practicing coping skills.
The cognitive-behavioural intervention consisted of five
components: filmed modeling, breathing exercises, positive
reinforcement, emotive imagery and behavioural rehearsal. The
intervention was found to be effective in reducing behavioural
distress in paediatric cancer patients in a pilot study (Jay et
al, 1985) and further validated in a more recent comparative study (Jay et al, 1987).

5.2.4. Dental procedures

Behavioural interventions for anxiety related to dentistry have been reviewed by several investigators (Melamed, 1979; Winer, 1982; Siegel, 1988). Three intervention approaches have been used for dental fear: information approaches, coping skills training and modeling techniques (Siegel, 1988).

Information approaches
These provide the child with information about the dental procedure such as information about its purpose, procedural information, sensory information and information about specific coping strategies (Cohen and Lazarus, 1979). Siegel and Peterson (1980) found an informative treatment as effective as a cognitive-behavioural one for children with no previous experience with dental restorations. Children were provided with sensory and procedural information or taught coping skills including relaxation, pleasant imagery, and calming self talk. Compared to a placebo group, both groups showed better adjustment on behavioural and physiological measures.

Coping skills training
Coping skills training involves training in the use of self-control procedures (Melamed, Klingman and Siegel, 1984).
Perceived control is important as it may influence the level of pain experienced by an individual (Thompson, 1981; Corah, 1973).

Nocella and Kaplan (1982) taught coping skills to young children aged five to 13 years with prior dental experience scheduled to have dental restorations or extractions. Coping strategies included identification of anxiety provoking events, deep breathing exercises, muscle relaxation, in-vitro desensitization (imagining using coping strategies at next dental visit) and positive self-statements ("I'm doing good, I can handle this"). The coping skills group had significantly fewer anxiety related and disruptive behaviours during dental procedures compared to attention-control and no treatment groups.

Modeling procedures
Controlled studies support the efficacy of modeling procedures in reducing anxiety related behaviours in children during dental treatment, especially children with no prior experience of the dental setting (Melamed, 1979; Melamed and Siegel, 1980; Melamed et al, 1975; Melamed et al, 1978). Some studies however, have not found modeling helpful for children with previous dental treatment or for children who viewed a mastery versus coping model (Ginther and Roberts, 1982) or covert modeling (Chertok and Bornstein, 1979). The efficacy of modeling depends on such factors as the use of coping versus mastery models, previous experience with dental treatment, and age of the child (Melamed, 1979).
Other approaches
Ayer (1973) found imagery effective in reducing injection fears in three children requiring dental extraction. Children held their mouths open and imagined they were barking dogs. They were also reinforced for cooperative behaviour and given control over the procedure. Neiburger (1978) gave suggestions to paediatric dental patients that a teeth cleaning instrument would tickle and make some children laugh. Such suggestions given for limited effect can be helpful and are described in detail by Hilgard and LeBaron (1984). Also, descriptions of hypnotherapeutic procedures for dental fears can be found in the literature (Gardner and Olness, 1981; Crasilneck and Hall, 1975; Hilgard and LeBaron, 1984).

5.2.5. Injections and venipunctures
Injections are critical and stressful events for most children and are viewed as a bodily invasion (Lewis, 1978). Some investigators noted children perceive injections and venipunctures as the most anxiety provoking experiences in the hospital (Eland and Anderson, 1977; Fernald and Corry, 1981; Foster, 1983; Ross and Ross, 1984a). Medical and injection phobias have not been extensively studied in children. Agras, Sylvester, and Oliveau (1969) found a prevalence rate of 14% of needle phobias in a population of 20 year olds. Little data exists on prevalence of injection phobias in children, but one could expect a higher proportion of children who would be fearful
of needles, given their immature cognitive processes and misconceptions about invasive procedures (Willis et al, 1982). Fradet, McGrath, Kay, Adams and Luke (1990) reported moderate to severe distress from blood drawing in 23% to 54% of children aged three to 17 years in a sample of 196 children. The child’s age and the parent’s prediction of distress were a valuable indice of distress.

Prior preparation is the most common method of intervention for injections. Preparations involve some or all of the following: providing information about the procedure, letting the child handle equipment, having the child practice on a doll, introducing the child to medical personnel, and discussion of fears (Jay, 1988). Fernald and Corry (1981) studied empathic versus directive preparations for blood tests in 39 children aged three to nine years. The empathic group were told "it’s going to hurt a little bit" and "I don’t mind if you cry" while the directive group were told to "be big, brave, not cry and hold still". The children in the directive group cried more in anticipation of the needle and many felt the technician had intentionally tried to hurt them. In contrast, Hedberg and Schlong (1973) found children who were not given instructions were more likely to faint or vomit in a mass inoculation clinic, than children who were given stern instructions to "stand on their feet and not be silly".

In a study of 111 healthy children aged four to seven years,
Rodin (1983) found medical preparation games (venipuncture sorting board game, activity book and story book) more effective than non-medical games or no games in reducing children's anxiety during venipunctures. The study is limited by its reliance on behavioural indicators of distress and the absence of self-report from the child and parent. Also, there are no reports of inter-rater reliability or standardized assessments of parental anxiety.

There is little consensus on how best to prepare a child for injections. While preparation is helpful it does not directly teach the child a coping skill (Varni et al, 1982). Techniques used successfully with children include participant modeling, hypnosis, imagery, cognitive-behavioural strategies, and in-vivo systematic desensitization (Ayer, 1973; Katz, 1974; Dash, 1981; Poster and Betz, 1983; Ross, 1984a; Rainwater, Sweet, Elliott, Bowers, McNeill and Stump, 1988). While empirical validation of these techniques is required, these uncontrolled studies provide a useful source for further research into managing children's anxiety of injections.

There have been a number of efforts to reduce the pain associated with needles by improving the techniques themselves, such as spraying a skin coolant, Frigiderm, on the injection site immediately prior to the injection (Eland, 1981) or the application of a topical anaesthetic (lidocaine and prilocaine) to reduce venipuncture pain (Moller, 1985). The disadvantage of
the latter is its comparatively long application time. The use of
the Syrijet 11 otherwise known as the "Mizzy Gun" by children and
staff has been a promising development by Dyment, Doering and
McHugh (1978). It is a method of performing BMA's that achieves
local anaesthesia without the use of a needle and is
significantly less painful than the traditional method of
infiltration. Not surprisingly, this approach is preferred by
children. Diabetic children have available to them a number of
devices for measuring blood glucose via finger pricks (see
Chapter 6), however some are known to be more painful than others
(e.g. the autolet). The child can try out various devices until a
suitable one is found that causes least distress and discomfort.

Although injections and venipunctures are the most common
invasive procedures which children undergo, little attention has
been paid to these, particularly in chronically ill children.
Further work is required in this area, because of the large
number of children who undergo injections and venipunctures for
immunization, preoperative sedation and monitoring and treatment
of illness.

The next chapter reviews the literature on acute pain and
psychological aspects of chronically ill children with an
emphasis on children with chronic renal failure and children with
diabetes mellitus, the two groups studied in the present
research.
CHAPTER 6
CHRONIC ILLNESS IN CHILDREN

The increasing number of children surviving with life threatening illnesses as a result of advances in paediatric medicine have provided new areas of clinical practice and research (Fielding, 1986). Further, the social consequences of paediatric conditions has provided a fertile area for future investigation and intervention (La Greca, 1990). There is an increasing interest in the role of psychological factors in health and illness, encompassed by the common terms such as behavioural pediatrics, paediatric psychology, health psychology and behavioural medicine. It is estimated that the prevalence of chronic illness in children is around 10% (Pless, 1968; Pless and Douglas, 1971), however the impact of these chronic diseases can have profound effects on the psychological adjustment of the child and family (Fielding, 1986).

Many of the problems faced by chronically ill children involve not only coping with the disease but also the associated medical treatments. The focus of clinical and research practice with chronically ill children has been in the study of psychosocial adjustment of chronically ill children and their families, ways of communicating with chronically ill children (children's concepts of illness, preparation for hospitalization and medical procedures) and psychological management of the consequences of illness (e.g. adherence to medical regimens). This chapter will consider these issues with an emphasis on children with chronic
renal failure and insulin dependent diabetes mellitus as these are the client groups that the present research has studied. Discussion is later devoted to specific aspects of these chronic conditions, which are not relevant to other childhood illnesses. Also included is an account of studies of pain management. Issues relating to preparation for hospitalization, surgery and medical procedures are not discussed as these have been covered in preceding chapters.

6.1. PSYCHOSOCIAL ADJUSTMENT

Chronic illness has been defined by Mattsson (1972, p801) as:

....a disorder with a protracted course which can be fatal or associated with a relatively normal life span despite impaired physical or mental functioning. Such a disease frequently shows a period of acute exacerbations requiring intensive medical attention.

Chronic medical conditions of childhood are diverse and include many physical disabilities such as diabetes, chronic kidney disease, juvenile rheumatoid arthritis, asthma, cystic fibrosis and hemophilia. Although many paediatric diseases have a low incidence, together they affect a significant proportion of children. The most common condition is asthma (approximately 2% of the population under 18 years). Other common illnesses include epilepsy (1%), cardiac conditions (0.5%), cerebral palsy (0.5%), and diabetes mellitus (0.1%) (Fielding, 1986).

A chronic illness in childhood is generally assumed to be a major
life stressor (Siegel, Smith and Wood, 1991). These illnesses and their medical management place systematic stresses on the children and their families. Among other things, these children must cope with frequent and invasive medical procedures, repeated hospitalizations and clinic visits (which may involve travelling over a long distance), surgery, physical discomfort associated with the illness, periodic exacerbation of symptoms, bodily disfigurement, side effects of medication, and for some a shortened life expectancy (Mattson, 1972). Chronic disease can also seriously disrupt a family’s routine and life-style. Many conditions require adherence to complex, long-term medical regimes that may involve medication taking, dietary and activity restrictions, dialysis for children with chronic kidney disease (Siegel et al 1991) and frequent self-injections. Children who are poorly adjusted and/or have poor compliance with treatment (usually associated with adverse psychosocial circumstances) may be excluded from some treatment programmes, such as heart and lung transplantation because they are considered an "at risk" group (Whitehead, Helms, Goodwin, Martin, Lask, Serrano, Scott, Smyth, Higenbottam, Wallwork, Elliot and De Leval, 1991).

Physical changes that can occur as a result of the disease process and/or treatment, (such as growth failure, facial hair and weight gain as a result of steroids), or loss of hair as result of chemotherapy and radiation treatment, can reduce the child’s self-esteem and interfere with peer socialization. Frequent school absences disrupt peer relationships and academic
achievement (Siegel et al, 1991).

The chronically ill child also poses a potential strain on other family members such as siblings who have been reported to have a significant degree of behaviour problems, psychosomatic problems and underachievement at school (Tritt and Esses, 1988). However, effects of a chronic illness on the psychological adjustment of siblings are poorly understood and vary with age, sex and type of illness (Drotar and Crawford, 1985). Studies have also reported increased incidences of depression, anxiety, marital conflict and psychosomatic problems in the parents of chronically ill children (Steinhauer, Mushin and Rae-Grant, 1974; Sabbeth and Leventhal, 1984).

Early researchers in this area concluded that many chronically ill children were seriously maladjusted compared to healthy children and showed low self-esteem and immaturity and that their families tended to cope poorly (Korsch, Pine, Grushkin and Negrete, 1971; Mattson, 1972; Fless and Pinkerton, 1975). The research on which these conclusions were based had a number of methodological problems however, including subjective evaluations, retrospective reports, clinical case material, uncontrolled investigations and the use of measures with questionable reliability and validity (Fielding, 1986; Siegel et al 1991). Recently, better designed studies have suggested that children with chronic illnesses are much less deviant than initially reported (Kellerman, Zeltzer, Ellenberg, Dash and

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Rigler, 1980; Cadman, Rosenbaum, Boyle and Offord, 1991), are better adjusted than children with psychiatric problems (Malhotra and Malhotra, 1990) and are no different from healthy controls when they reach adulthood (Pless, Cripps, Davies and Wadsworth, 1989). Other studies have failed to find increased psychopathology in children with chronic illnesses such as cystic fibrosis (Bywater, 1981; Drotar, Doershuk, Stern, Boat, Boyer and Mathews, 1981). The discrepancy in these studies could reflect differences in the nature, stage and severity of the illness under investigation (Garralda, Jameson, Reynolds and Postlethwaite, 1988).

Despite these optimimistic reports, problems of adjustment do occur in many families, requiring psychological assessment and intervention. Although chronic illness can be a life stressor, the specific disease itself does not appear to be the primary cause of difficulties in adjustment. It has been suggested that feelings such as anxiety and depression are best considered as normal responses to stressful experiences associated with long-term illness and/or treatment regimes, rather than psychiatric disorders (Varni, 1983). Furthermore, there does not appear to be a consistent relationship between severity of illness and adjustment. There are many potential factors which could have an impact on the child’s overall adjustment, including age of onset, severity of illness, the course of the illness (i.e. stable, progressive, relapsing), visibility of the disease, coping skills of the child and family, family dysfunction and
life-threatening nature of the disease (Drotar and Bush, 1985; Pless and Pinkerton, 1975). The above factors are relevant to any chronic childhood disease and have led researchers to regard the psychosocial aspects of chronic illness within a noncategorical framework (Stein and Jessop, 1984; Pless and Perrin, 1985).

Fielding (1985) cogently argues that underlying recent studies is the erroneous assumption of chronic illness as a unitary phenomenon with a similar impact in a group of children at a given point in time. She suggests two reasons to support her argument: firstly, it is likely that chronic illnesses will have different levels of severity and different psychological effects and secondly, the illness and reaction of the child and family follow a fluctuating rather than stable course. For example, Zeltzer, Kellerman, Ellenberg, Dash and Rigler (1980) found adolescents with different illnesses experienced different impacts.

There have been recent attempts to study chronically ill children longitudinally by monitoring their adjustment to illness over time (Kovacs, Iyengar, Goldston, Stewart, Obrosky and Marsh, 1990). Studies investigating psychosocial variables relating to adjustment need to consider a number of variables such as age, type and severity of the disease, onset of the disease, developmental level and treatment regime. For example, age has been found to be important in several studies (Koocher, O'Malley, Gogan and Foster, 1980; Hudson, 1984) suggesting the importance
of developmental stage on adjustment. In one study of paediatric cancer patients, early age of onset, diagnosis and treatment were related to psychological adjustment later in life (Koocher et al., 1980). Haemophilic adolescents over the age of 15 years (Klein and Nimorwicz, 1982) and adolescents on haemodialysis (Hudson, 1984) had greater levels of depression and psychological distress than younger children with these illnesses.

6.1.1. Assessment

The assessment of the chronically ill child is very complex. An assessment may be used to provide information about the child’s psychosocial functioning, the child’s current medical status, and how these may interact so that appropriate interventions can be delivered. Assessment can also be used to document the effectiveness of medical and psychological intervention or to identify the strengths and vulnerabilities that may affect the child’s adjustment. Siegel et al (1991) discuss assessment issues in more detail. There are a variety of standardized questionnaires on a number of psychological constructs that would be useful in assessing adjustment in the chronically ill child. These include anxiety, depression, behaviour problems, self-esteem, locus of control (discussed in Chapter 8) as well as hospital related fears, family adaptability and cohesion, parenting stress and coping strategies (Karoly, 1988). One difficulty with these assessments is that many do not include chronically ill children in the normative samples and therefore
the appropriateness for children with such conditions must be
questioned.

Given that a child’s understanding of his or her illness is often
essential to adjustment and sometimes to medical management
(including coping with medical procedures), an assessment of the
child’s cognitive level is important. While age is often used
inappropriately as a measure of cognitive development, there are
tools for individualized assessment (Burbach and Peterson,
1986).

6.1.2. Children’s concepts of illness

A number of studies have documented the relationship between
cognitive-developmental level and concepts of illness in children
with and without chronic illnesses (Bibace and Walsh, 1980;
Neuhauser, Amsterdam, Hines and Steward, 1978; Perrin and
Gerrity, 1981; Simeonsson, Buckley and Monsoon, 1979). These
studies suggest that children’s concepts of illness evolve in a
systematic and predictable sequence consistent with Piaget’s
(1929) theory of cognitive development (see Chapter 3), ranging
from global phenomenological concepts characteristic of
preoperational thought to more sophisticated psychophysiological
concepts characteristic of formal logical thought (Bibace and
Walsh, 1980).

Bibace and Walsh provided the most clearly defined system so far
in the literature, involving six stages of cognitive development. Perrin and Gerrity (1981) evolved a similar model. These are presented in Table 6-1. A synthesis of findings from studies on children’s concepts of physical illness are summarized in Table 6-2. The data suggest there is a clear relationship between chronological age/cognitive maturity and children’s concepts of illness. For a systematic review and critique of the cognitive-developmental literature on children’s concepts of physical illness, see Burbach and Peterson (1986) and Eiser (1984; 1990). Unfortunately, a number of studies investigating children’s concepts of illness suffer from methodological weaknesses which make conclusions difficult. These include (a) poor description of samples, assessment instruments and procedures; (b) lack of control over observer bias, expectancy effects, and other confounding variables; and (c) little attention to reliability and validity issues.

The growing research interest in this area stems partly from efforts to improve communication between children and health professionals concerning the prevention and treatment of chronic illness. With some medical conditions such as diabetes, accurate knowledge of illness is required for active participation in medical management. Eiser and Patterson (1983) investigated children’s knowledge of health and illness in 57 diabetic children with a matched control group. They found that generalized beliefs about illness concepts were not affected by health status and that diabetic children did not differ from
<table>
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<tr>
<th>Age Group</th>
<th>Study</th>
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</tr>
</thead>
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<tr>
<td>4-7 Years</td>
<td>1 Prelogical</td>
<td>2 Concrete: rigid response with precocious quality — little comprehension by children</td>
</tr>
<tr>
<td>7-11 Years</td>
<td>4 Formalization</td>
<td>5 Generalized principles: beginning use of underlying principles — greater dynamism of causal agents or illnesses</td>
</tr>
<tr>
<td>11 Years &amp; Over</td>
<td>6 Physiologic — Formal</td>
<td>6 Physiologic — Logical</td>
</tr>
<tr>
<td>Author</td>
<td>Preoperational (Approx. 2-6/7 years)</td>
<td>Concrete Operations (Approx. 7-11/12 years)</td>
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<tr>
<td>Liben &amp; Malek (1980)</td>
<td>Phenomenizing contagion</td>
<td>Contamination; internalization</td>
</tr>
<tr>
<td>Klois (1985)</td>
<td>Descriptive stage</td>
<td>Explanatory stage</td>
</tr>
<tr>
<td>Zwooster (1982)</td>
<td>Lack of understanding; apomoristion; finalism</td>
<td>Physicalism; autophysical reasoning</td>
</tr>
<tr>
<td>Campbell (1973a, 1973b)</td>
<td>More likely to accept sick role; less likely to see themselves as sick in the face of illness</td>
<td>Increasing denial of sick role; more likely to see themselves as sick in the face of illness particularly in milds</td>
</tr>
<tr>
<td>Geier (1986)</td>
<td>Self-blame</td>
<td>Self-blame/increasing objectivity</td>
</tr>
<tr>
<td>Gist &amp; Patterson (1980)</td>
<td>Overestimation of contagion concept/illness as a form of immanent justice</td>
<td>More appropriate use of contagion concept; less likely to use immanent justice explanations</td>
</tr>
<tr>
<td>Magy (1951)</td>
<td>Inept at understanding the cause of illness; all illnesses caused by infection</td>
<td>All diseases/illnesses/infections caused by one type of germ</td>
</tr>
<tr>
<td>Hasbauer, Amstad</td>
<td>Use external rather than internal cues to determine illness</td>
<td>Use external rather than external cues to assess illness; increasing control over illnesses</td>
</tr>
<tr>
<td>Purrin &amp; Carcitty (1981)</td>
<td>Global</td>
<td>Concrete rules; internalization</td>
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</tbody>
</table>

(From Ribeau & Putschar, 1986)
healthy children in their definitions of health or knowledge about the cause and prevention of illness. The exception was the greater knowledge that diabetic children had about diabetes. More research is required into children's concepts of illness with chronically ill children.

Misconceptions about illness may interfere with effective intervention and communication. Young children's concepts of illness frequently involve punishment, guilt and self-blame (Perrin and Gerrity, 1981). In an early survey conducted by Beverley (1936) 90% of hospitalized children with diabetes and cardiac defects responded to the question, "Why do children get sick?" with "Because they are bad". Hospitalized children have also ascribed illness to misdeamenors and hospitalization as punishment or rejection (Brewster, 1982). However, in much of this earlier literature concepts of illness causality were confounded with other aspects of hospitalization such as the stresses of illness and hospitalization (Perrin and Gerrity, 1981).

There has been little investigation into children's concepts of treatment and prevention, although what is available suggests these concepts follow a similar developmental sequence (Perrin and Gerrity, 1981; Fielding, 1986) and that as children get older they develop an internal health locus of control and thus understand that they can improve and maintain their own health (Parcel and Meyer, 1978).
Implications for communicating with children about health care have been summarized by Fielding (1986).

1. Determining the child’s developmental level is important when planning effective intervention and developing modes of information giving to chronically ill children. Medical staff could be misled by a child’s age or verbal ability, thus assuming greater understanding than is actually the case. This could be particularly problematic during stressful medical procedures, if the child has misconceptions about illness and treatment.

2. These fears or misconceptions in younger children are also best understood within a developmental framework, such as fears of bleeding to death from injections and attempts made to alter these. It has been suggested that children learn best when concepts are taught at the current level of reasoning or one stage beyond (Bibace and Walsh, 1980).

3. Explanations of illness to children at different developmental stages should also be presented at an appropriate level. For example, for young children who cannot conceptualize internal body parts, explanations should be at a concrete level which could include play, drawing, and metaphor (Varni, 1983) as well as simple books, story techniques and demonstrations on a doll (see Rodin, 1983 for books and games designed to prepare children for venipunctures). For older children at the formal operational stage, details about physiology and anatomy could be
given.

(4) Issues of personal control need to be considered. As children grow older they can be expected to take more responsibility for their health and treatment (e.g. self-injecting insulin). However, the child's developmental stage more so than age should be taken into account. Understanding the child's developmental level can assist clinicians in developing appropriate expectations for adherence to medical treatments. Younger children are more likely to adhere better to treatments if they receive contingent reinforcement rather than discussing general benefits of adherence. Children at the concrete operational stage are more likely to benefit from explanations about the advantages of adhering to treatment (Siegel et al, 1991). Adherence to medical treatments is discussed further in the next section below.

A final issue concerns children's preferences for avoiding or obtaining information regarding illness or medical procedures (Peterson and Toler, 1986). These investigations suggest that children differ in how much information they prefer. Where a medical treatment requires active participation and adherence by the child, it would be difficult not to provide detailed information. There is some evidence that information given to children with an avoidant coping style can also be beneficial (Smith et al, 1989). Further studies are required with a variety of chronic illnesses to clarify this issue.
6.1.3. Adherence to medical regimens

A significant number of children fail to adhere to medical treatments with estimates ranging from 10% to 60% in paediatric practice (La Greca, 1988). Non-adherence to treatment is therefore a crucial area of concern for child health. Considerable attention has been given to investigating factors that contribute to non-adherence to treatment in diverse paediatric populations and, to some extent, on methods for improving adherence to treatment. The aim of these efforts is to improve the health status of chronically ill children (La Greca, 1988). Studies attempting to assess adherence are faced with several methodological problems, one of which concerns how to operationalize adherence (La Greca, 1988). It is a difficult concept to assess as it is not known what constitutes an adequate level of compliance or adherence and furthermore, results may be biased in that subjects who are not adherent are less likely to participate in such studies (Cluss and Epstein, 1985).

A variety of assessment methods have been used to assess adherence, including patient or parent monitoring, interviews and clinical outcome or health status (Varni, 1983; Johnson, Silverstein, Rosenbloom, Carter and Cunningham, 1986; Meichenbaum and Turk, 1987). Of these, self or parent reporting is thought to be the most efficient means of obtaining information, although adherence tends to be overestimated (Parrish, 1986).

A number of factors have been correlated with adherence,
including the complexity and duration of treatment, beliefs about
the medical condition and treatment, level of knowledge and
relationship with health care provider (Siegel et al, 1991), the
child's developmental status, the role of the family, individual
differences (e.g. in coping style, levels of adjustment and
biological functioning), and the quality of medical care
(LaGreca, 1988), disease chronicity, long-term regimes and
complexity of treatments (Varni, 1983) and few or no immediate
consequences for adherence.

Treatments for chronic illnesses such as diabetes, chronic renal
failure or cystic fibrosis are complex and require adherence over
a long period of time (Fielding, 1986; Siegel et al, 1991).
Adherence is likely to be poor for such treatments, but can be
enhanced by attempts to fit the regime to the patient's lifestyle
rather than the other way round (Meichenbaum and Turk, 1987). The
consequences of non-adherence can be very serious. Diabetic
children can suffer from ketoacidosis and possibly coma for
failing to adhere to medical treatment. Knowledge and skill are
necessary but not sufficient conditions to ensure adherence. For
some children, adhering to treatment may result in aversive
consequences, such as nausea and hair loss with chemotherapy or
increased weight and body hair due to steroids given after renal
suggest that external positive reinforcers may be necessary to
increase motivation to adhere to treatments. Indeed, a functional
analysis approach may be particularly helpful to identify
antecedents and consequences of non-adherent behaviour (Varni, 1983).

In adolescents with diabetes, self-efficacy beliefs have been noted to be the strongest predictors for adherence (McCaul, Glasgow and Schafer, 1987), while negative interactions with parents were associated with less adherence to diet and glucose monitoring (Schafer, Glasgow, McCaul and Dreher, 1983). Family instability (e.g. parents divorced) was associated with less adherence in children who had renal transplants (Beck, Fennell, Yost, Robinson, Geary and Richards, 1980).

Adherence is likely to change over time, particularly for chronic conditions, and adherence to one aspect of treatment is not necessarily related to adherence for another (Johnson et al 1986). For example, a diabetic child may always self-inject insulin at the appropriate time, but refuse to carry out finger pricks or adhere to an appropriate diet. Adherence therefore needs to be assessed over time and for different components of the medical treatment. Where non-adherence is due to anxiety over the medical regime itself, such as the pain associated with finger pricks for diabetics, pain management procedures described in the preceding chapters should be employed. If however, non-adherence is due to misconceptions about treatment, appropriate verbal and written information should be given which is specific and repeated over time if necessary. For some children, behavioural management including peer reinforcement has
improved adherence to diet in children on renal dialysis (Magrab and Papadoupoulou, 1977) and urine glucose testing in diabetic children (Epstein, Beck, Figueroa, Farkas, Kazden, Daneman and Becker, 1981). It has been suggested that nonadherence to long-term treatments should be expected in the absence of systematic behavioural intervention (Varni and Wallender, 1984). Interventions for nonadherence involve educational approaches, support and supervision, and behavioural interventions (self-monitoring, visual cues or reminders, reinforcement procedures, modeling) (La Greca, 1988). The most consistent intervention success (although not without limitations) has been achieved with reinforcement procedures, often used in conjunction with other procedures above. The most successful interventions are those that combine intensive education, parental involvement, self-monitoring and reinforcement procedures (Epstein et al., 1981). However, studies are limited by a reliance on single-subject designs, small samples, subject selection procedures that exclude nonadherent patients, short-term interventions with limited follow-up, and failure to establish a relationship between adherence and improved health outcome (La Greca, 1988).

Future research into adherence to treatments should consider multiple aspects of adherence, particularly for more complex treatments, view adherence as varying along a continuum, and explore the relationship between adherence and treatment outcome (La Greca, 1988). The Health Belief Model (Becker, Radius,
Rosenstock, Drachman, Shuberth and Teets, 1978) initially developed from data on adults, offers a multivariate model of health behaviour which has been applied to adherence issues in paediatric populations to a limited extent. It consists of several social-psychological variables known to predict medical adherence. According to this theory, individuals who are most adherent are those who: (1) maintain strong perceptions of their vulnerability to a particular illness; (2) perceive the illness as serious; (3) believe that treatment will produce positive results and are not hindered by obstacles to implementing treatment (e.g. financial cost or restriction on daily activities). However, a variety of other factors may further modify adherence, including the quality of the doctor-patient relationship, social support available, age and personality. Whilst some promising results have emerged for children with chronic illnesses (e.g. La Greca and Hanna, 1983) little attention has been given to children's health beliefs. Furthermore, the applicability of this model for developing adherence interventions remains unclear.

6.2. END-STAGE RENAL FAILURE

End-stage renal disease (ESRD) is relatively rare in children, affecting 20-50 children under the age of 15 years per million child population in European countries with the largest population (Trompeter, 1990). Chronic renal failure refers to renal function that is less than 30%, whilst end-stage renal...
failure is a condition requiring dialysis treatment or renal transplantation. The etiology of renal disease varies across countries, but is generally congenital and hereditary rather than acquired in origin (Korsch and Fine, 1985). The majority of cases (50%) are caused by reflux nephropathy or pyelonephritis (inflammation of the renal pelvis and kidney) and renal dysplasia or anatomical defect. Acquired glomerulonephritis (an inflammatory process of the glomerulus which filters blood in the kidney to remove waste) accounts for about 30% of the cases (Trompeter, 1990).

Recent figures from the European Dialysis and Transplant Association (1987, personal communication) show improved survival rates for children with end-stage renal failure (children on haemodialysis, peritoneal dialysis and those with functioning grafts) as a result of advances in dialysis and organ transplantation. Reports based on transplantation centres in Britain suggest at least an 80% survival of first cadaver (deceased donor) kidneys at one year and higher rates for live related donor grafts (Trompeter, 1990). However, in spite of improved techniques many children and their families remain under considerable strain caused by complex treatments, anxieties about the child's future (e.g. bone disease and growth retardation), repeated hospital attendances and admissions, difficulties in accepting the illness and treatment, poor growth and urinary incontinence and occasional life-threatening episodes (Reynolds, Garralda, Jameson and Postlethwaite, 1986). There is also
uncertainty about the course and prognosis of the disease (Korsch and Fine, 1985).

6.2.1. Medical Treatment

Treatments for end-stage renal failure involve either haemodialysis or peritoneal dialysis for children not yet transplanted. Haemodialysis is the perfusion of an "artificial kidney" with blood that removes certain metabolic substances retained by the body because of reduced renal function. A vascular access is required for this procedure which may be carried out three times a week for 4-6 hours. Peritoneal dialysis involves inserting fluid into the patient's peritoneal cavity so that substances retained in the blood because of reduced kidney function diffuse into the peritoneal cavity and can be removed. The procedure requires a permanent indwelling peritoneal catheter that can be accessed regularly possibly three times a week for 10-12 hours. An adaptation of peritoneal dialysis is continuous ambulatory peritoneal dialysis (CAPD) which has been likened to a wearable artificial kidney. The advantage of CAPD is that it does not require machines, dialysis proceeds continuously and the patient is totally mobile. The use of plastic bags minimize the number of connections (Korsch and Fine, 1985). Children who receive transplants take immunosuppressant drugs daily to prevent rejection which may have side effects, hospital attendances are required for bloodtests and physical examinations and admissions for complications to surgery (Trompeter, 1990). Furthermore, children and their
families are faced with the uncertainty that the graft may fail at any time.

6.2.2. Psychosocial Adjustment

Studies have reported on the psychosocial adjustment of children in end-stage renal failure and the effects of the disease on siblings and parents. Much of the literature reports on the psychological effects of both dialysis and transplantation on children, rather than chronic renal failure itself (Reynolds et al, 1986). Psychological problems have been reported in children with end-stage renal failure, including problems in social adjustment, low self-esteem and high levels of anxiety (Garralda et al 1988) as well as anxiety, depression and psychosomatic problems in the parents (Fielding, Moore, Dewey, Ashley, McKendrick and Pinkerton, 1985). A double-fold increase in psychological problems has been reported in adolescents who have had a transplant compared to younger children (Klein, Simmons and Anderson, 1984). However, earlier studies were methodologically weak, based on anecdotal reports, lacking standardized assessment measures and little information on reliability and validity of assessment procedures (Fielding et al, 1985). Of interest are the findings by Korshe and Fine (1985), that one year after transplantation most children and families returned to pre-illness adaptation with continued support from a health care team.

Significant morbidity can result from non-compliance with the
therapeutic regime. For example, non-compliance is a major cause of allograft loss in the adolescent transplant recipient (Fine, 1985). A number of studies have looked at adherence to treatment in children with end-stage renal failure (Fielding, 1989; Hudson, Fielding, Jones and McKendrick, 1987). Hudson et al, 1987 reported a significant relationship between adherence and social desirability and shorter duration on dialysis. Further, non-compliance with immunosuppressive drugs has been reported to be more common post-transplantation in children with psychiatric problems (Korsch, Fine and Negrete, 1978).

Organ transplantation is being used increasingly for life-threatening diseases of childhood (Bradford and Tomlinson, 1990). The survival rate for children who received transplants at a leading centre in Britain between November 1968-December 1987 was 79% after 14 years, compared with 94% for those transplants since October 1983 after four years (Rigden et al, 1989). In the light of these figures there is a recognition amongst clinicians for regular psychosocial reviews to enhance children’s adjustment in the short and long term (for psychological guidelines on the management of paediatric organ transplantation, see Bradford and Tomlinson, 1990).

6.2.3. Preparation for medical procedures

There have been few reports in the literature of attempts to prepare children with end-stage renal failure for painful medical
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<tr>
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<th>Intervention</th>
<th>Outcome Measures</th>
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<tr>
<td>Lira and Nisit (1976)</td>
<td>10 children on haemodialysis</td>
<td>Systematic training Days to including social reinforcement and corrective feedback</td>
<td>Prepared group learned faster than group taught by traditional methods</td>
<td></td>
</tr>
<tr>
<td>Usbert, D'Marzio, Pecchini, Pacoraro and Del Canton (1984)</td>
<td>45 children (4-15 years)</td>
<td>Hypnosis versus control group undergoing renal biopsy. Control group sedated one hour before biopsy. Hypnosis involved imagery and positive suggestions for relaxation.</td>
<td>Hypnosis group needed less time than control group for biopsy and were more cooperative</td>
<td></td>
</tr>
<tr>
<td>Karle and Boys (1987)</td>
<td>16 year old</td>
<td>Hypnotherapy for acute pain associated with physiotherapy for severe contractures, Imaginary pain switch technique.</td>
<td>None</td>
<td>Subjective description of a reduction in pain and increased feelings of mastery.</td>
</tr>
</tbody>
</table>
treatments and none investigating psychosocial variables in relation to children's distress during such treatments. This is surprising, given the complex nature of treatments and the frequent invasive medical procedures necessary during the course of disease. Children must cope with needles associated with haemodialysis, injections and regular venipunctures following transplantation. There is evidence that children find the needles in dialysis distressing (Brookes, 1983). Unfortunately, the few studies in the literature have either involved single case design, uncontrolled reports or have been methodologically weak because of subjective outcome reports and lack of reliable and valid outcome measures. Clearly, this is an area for further study and requires controlled group outcome studies on different psychological interventions for preparation and pain management. Table 6-4 presents some studies on preparation for medical procedures. Although these studies have inherent methodological difficulties as described above, they are nevertheless interesting initial attempts in this area.

### 6.3. INSULIN DEPENDENT DIABETES MELLITUS

Diabetes Mellitus is a chronic metabolic disease characterized by inadequate insulin production by the pancreas (Johnson, 1988). There are two types of diabetes: Type 1 or insulin-dependent diabetes mellitus (IDDM) involving complete pancreatic failure requiring daily injections of insulin and Type 2 or non-insulin dependent diabetes mellitus (NIDDM) where the pancreas continues to produce some insulin. The onset of IDDM occurs in childhood,
while NIDDM is an adult disorder often managed by diet and weight loss (Johnson, 1988). NIDDM differs in etiology and management and will not be discussed further here. IDDM is a relatively rare disease which affects approximately 1 per 1,000 children under the age of ten (Farquhar and Campbell, 1980). Diagnosis tends to occur in two age periods, 5-6 years and 11-13 years, although onset can occur at any time from infancy to early adulthood. Incidence is similar for both girls and boys. Onset symptoms include thirst, fatigue, frequent urination, hunger and weight loss despite excessive eating. Because the pancreas is not producing enough insulin, this prevents utilization of blood sugar. The body breaks down body fats into fatty acids, which are then converted by the liver to ketone bodies. Because insulin is important in the inhibition of the breakdown of fats, fatty acids and ketones accumulate in the bloodstream. If the kidney cannot eliminate sufficient amounts of ketones, a very serious condition called ketosis or ketoacidosis results, which if untreated, could lead to coma and death (Johnson, 1988).

The child with diabetes is faced with a relatively complicated treatment regimen. Daily demands include insulin injections, glucose tests, and dietary restrictions. The child must learn to adjust insulin needs to prevent hypoglycaemia (excessively low blood glucose) and hyperglycaemia (excessively high blood glucose). The child must also learn to understand the effects of stress, exercise and illness on blood glucose levels. A variety of serious complications can occur, usually 15-20 years after
onset affecting neural, visual and kidney functions, which can be delayed or prevented by keeping blood glucose levels at near normal levels. Hypoglycaemia, if left untreated, can rapidly lead to cognitive disorientation, convulsions and coma (Johnson, 1988). The goal of treatment is therefore to keep blood glucose levels as close to normal as possible.

6.3.1. Psychosocial Adjustment

While early research focused on variables within the diabetic patient (e.g. personality), current approaches regard health and adjustment as the result of the interaction between the disease, the patient and the environment (Johnson, 1988). Studies have found some diabetics manifest emotional or psychological difficulties (Close, Davies, Price and Goodyer, 1986) while others have not found disruptions to adaptation (Jacobson, Hauser, Wertlieb, Wolfsdorf, Orleans and Vieyra, 1986). Psychiatrically diagnosable reactions in children with IDDM are more likely among those whose parents are of low socioeconomic status and with marital distress (Kovacs, Feinberg, Paulauskas, Finkelstein, Pollock and Crouse-Novack, 1985). Others have found that children’s adjustment shortly after onset of IDDM as measured by levels of depression, anxiety and self-esteem, were predictors of later adjustment. Mother’s adjustment shortly after diagnosis was a strong predictor of the children’s long-term adjustment. Mother’s symptoms over time were not related to medical aspects of IDDM including compliance with the medical
regime and metabolic control (Kovacs et al 1990).

6.3.2. Metabolic Control and Adjustment

Psychological state and metabolic control are clearly linked, although the nature of the relationship is unclear. Research into psychosocial correlates of glycaemic control has been variable in outcome. It is likely that extremely poor diabetic control is linked to overt behavioural and emotional disturbance (Mazze, Lucido and Shannon, 1984). Mild psychiatric disorder appears to be associated with good rather than poor metabolic control (Close et al 1986). One possible explanation is that poor control somehow protects the child from psychological difficulties (Fonagy, Moran and Higgitt, 1989).

A great deal has been written about the characteristics of families of children with poor metabolic control. Some studies have shown that diabetics from less than ideal family circumstances are in worse diabetic control than their counterparts from better adjusted families (Gath, Smith and Baum, 1980; Johnson, 1980). The former families are more likely to contain parental conflict, to lack support for the child and to be low in cohesion (Fonagy et al, 1989).

In another study Mazze et al (1984) state variables such as anxiety, depression and quality of life were significantly correlated with control, however the direction of the relationship was not clear. Close et al (1986) found an
association between depression, poor self-esteem, a greater external locus of control and good glycosylated haemoglobin levels, suggesting maintaining good glycaemic control is stressful.

Other psychosocial correlates of metabolic control include health locus of control, parental continuity and consistency of expectations (Johnson, 1988). Children who participate early or assume more responsibility for diabetes care tend to be poorly controlled (Fonagy, Moran, Lindsay, Kurtz and Brown, 1987). Although there is a tendency to encourage children to manage their diabetes independently as early as possible, this may be misguided.

Smith, Mauseth, Palmer, Pecoraro and Wenet (1991) found diabetic adolescents who were in better metabolic control reported more conflict regarding family relationships and issues of independence than adolescents with poorer control. Adherence and stress have been found to relate directly to metabolic control.

It is possible that maladjustment may negatively influence the course of the disease. Anxiety and depression for example, may make the individual feel unable to manage diabetes and result in inadequate compliance with treatment. Alternatively, emotional disorders may directly affect metabolic control and consequently the stress hormones which may lead to glucose and free fatty acid accumulation in the blood (Tarnow and Silverman, 1981-82). Thus,
the relationship between health and psychological adjustment appears to be interactive. Psychosocial variables may influence metabolic control directly through the influence of stress hormones, or indirectly, through adherence behaviours (Johnson, 1988). The individual's health may also affect how they feel about themselves and their illness. However, findings concerning psychosocial variables are inconsistent across studies, the strength of the relationship between stress and health is weak and major life events are only one type of stress, which may not be representative of the daily stresses experienced by families (Johnson, 1988).

6.3.3. Locus of Control

Other investigators have studied children's perception of control over their disease rather than affective state. Those with an internal locus of control who perceive a functional relationship between their own action and health outcome, might be expected to make greater efforts to control their diabetes and consequently adhere to the medical regimen. "Internal" diabetic adult patients have been found to know more about diabetes than "externals" (Lowery and DuCotte, 1976). In children, the relationship between health status and locus of control is influenced by the sex of the child. That is, in girls an internal locus of control was positively associated with adequate metabolic control, while the inverse was true for boys (Hamburg and Inoff, 1982). However, perceived locus of control may be the result of health status as well as its cause (Johnson, 1988). In a longitudinal study of
over 200 children, youngsters who tested their blood glucose more often and who ate more frequently were in better diabetic control (Johnson, 1990). On the whole external locus of control appears to protect children from poor control (Connell, 1986). A number of investigators have attempted to apply the health beliefs model to problems of adherence in diabetes (Marteau and Johnston, 1986), however the results have been disappointing. For example, Marteau and Johnston (1986) found that parents who recognised that diabetes is a severe disorder were more likely to have a child in poor metabolic control.

6.3.4. Developmental issues

There is evidence that children's knowledge and skills about diabetes increase with age (Gilbert, Johnson, Spillar, McCallum, Silverstein and Rosenbloom, 1982). Age can also be a determinant of what the child learns. For example, eight and nine year old girls benefitted more from a modeling film teaching children how to self-inject insulin than younger children of either sex (Gilbert et al, 1982). There is evidence that adolescent's management behaviours differ markedly from those of younger children. Adolescents are less compliant despite being more knowledgeable about diabetes (Johnson et al, 1982) and being given greater responsibility for diabetes management (Allen, Tennen, McGrade, McCabe, Affleck and Ratzan, 1983). Mother and child attitudes to diabetes management have been reported to be stronger predictors of adherence than knowledge about the disease.
However, the factors that may interfere with adherence to diabetes management (e.g. forgetting, schedule conflicts, social interference) have received little investigation. Estimates of nonadherence range from 20 to 80 percent (McNally, MacIver, Jowett and Hearnshaw, 1987).

6.3.5. Preparation for Medical Procedures

Children with IDDM are required to undergo three types of invasive medical procedures as part of the management of their disease: insulin injections (once or twice daily), finger pricks (for testing immediate blood glucose levels) and venipunctures (blood tests) for assessing blood glucose levels over the last six to eight weeks. It is not unusual for children to become anxious about one or more of these procedures. Improved diabetic control has been attempted through the use of insulin infusion pumps which are worn externally, closely mimic pancreatic function (Schade, Santiago, Skyler and Rizza, 1983) and overcome the problem of self-injecting insulin. However, this method does not accurately approximate pancreatic function and therefore the child must be motivated to carry out blood glucose tests frequently in order to make decisions about the rate of infusion required. For children who may be anxious about finger pricks this could be problematic. While useful for some individuals, the pump is not considered an ideal treatment for most patients (Johnson, 1988).
In a survey by Kosub and Kosub (1982) diabetic children of elementary to high school age rated injections as one of the top three stressors in their medical management. Anxiety over needles has been reported to interfere with children’s diabetic care (Fonagy et al, 1989) although the extent of needle phobias in diabetic clinics is not reported. Children’s anxieties over bloodtests appear to influence whether doctors carry out venipunctures or not. Marteau and Johnston (1986) found that only 31% of 60 required blood samples were taken from children with diabetes, despite an intention to take samples regularly. Doctors’ attributions for not taking blood were mostly to some aspect of the child, such as the child’s refusal, or psychological or physical difficulty in the child.

There are surprisingly few reports of pain management with diabetic children (and none on psychosocial variables influencing children’s distress during medical procedures). The available literature includes single case studies and uncontrolled reports, or studies with inadequate measures. Gardner and Olness (1981) reported on a single case of a six year old boy with diabetes with a fear of needles. Hypnotherapy was used involving a pain switch to master his fear of insulin injections. The authors suggested the use of hypnotherapy to enhance mastery in diabetics will indirectly affect morbidity from the disease. For example, children actively participating in their therapy may be more compliant about other aspects of treatment such as glucose and urine testing and consequently have fewer complications.
Gilbert, Bennett-Johnson, Spillar, McCallum, Silverstein and Rosenbloom (1982) investigated the effects of a peer-modeling film on anxiety reduction and skill acquisition in 28 diabetic children aged six to nine years learning to self-inject insulin at a summer camp. Subjects were randomly assigned to view a peer-modeling film of children learning to self-inject or another film on nutrition. The measures used were the "state" portion of the State-Trait Anxiety Inventory, a Behaviour Profile Rating Scale, and global ratings of cooperation and anxiety, and a Behavioural Skills Test to assess children’s accuracy and skill in self-injecting. The results showed the peer-modeling film failed to reduce anxiety, however, there was no evidence that children were anxious in the first place. The oldest girls showed greater skill in self-injection than those viewing the control film. Although a modeling film may be helpful to newly diagnosed diabetics in reducing anxiety, children with a history of receiving insulin injections may not be sufficiently anxious to be assisted by this procedure. It is possible that for these children the utility of peer modeling was in skill acquisition (Gilbert et al, 1982).

Rainwater, Sweet, Elliott, Bowers, McNeill and Stump (1988) examined the effectiveness of systematic desensitization in the treatment of needle phobias for 25 patients with IDDM aged from seven to 20 years. Imaginal and in-vivo desensitization was used, depending on the procedure (finger prick, venipuncture, or self-injections). Of the 38 fear responses treated, 92% responded
favourably in an average of less than four sessions. The advantage of desensitization as a treatment approach is that it can be taught to other medical personnel as well as it leading to increased compliance to complex medical regimens involving needles. Systematic desensitization was found to be effective for treating all three forms of needle phobia. At one year follow-up 93% of children with fears of venipuncture were successfully treated, 86% for injection fears and 100% of children who had anxieties over finger sticks. However, there was little evidence of treatment generalization for children treated for more than one fear. The study’s weakness is in failing to adequately describe evaluation measures and the reliance on self-report. Physiological and behavioural assessment of distress would have added considerably to the methodology.

Summary
Chronic illness in childhood can have profound effects on the child and family and is generally assumed to be a life stressor. Amongst other things, chronically ill children must cope with frequent invasive medical procedures, repeated hospitalizations and clinic visits, surgery, and for some a shortened life expectancy. Many conditions require adherence to complex long-term medical regimens that may include medication taking, dietary restrictions and frequent injections. While earlier studies reported that many chronically ill children were seriously maladjusted compared to healthy children, recent better designed studies have found much less deviance. However, problems
of adjustment do occur, for example in children with end-stage renal failure and children with IDDM, requiring psychological assessment and intervention. Since children’s understanding of illness is often essential to adjustment and sometimes to medical management, this has been one of many important areas for investigation. Considerable attention has also been given to investigating non-adherence to medical regimens in diverse paediatric populations. There have been few reports of psychological interventions for pain management in children with end-stage renal failure and children with IDDM and none investigating psychosocial variables related to these children’s distress during medical procedures.
CHAPTER 7

ASSESSMENT OF ACUTE PAIN IN CHILDREN FOLLOWING RENAL TRANSPLANTATION

7.1. PILOT STUDY

Ten children were seen in the pilot study from May to September 1987, on alternate weeks. The purpose of the pilot study was to:

1. Assess the duration of the child and parent interviews.
2. Assess how many children and parents could be interviewed within the time constraints of the clinic.
3. Determine whether any standardized questionnaires needed omitting or including.
4. Discover whether the structured child and parent questionnaires required further modification.

The results of the pilot study are as follows. The child and parent interviews took 30-45 minutes to complete in general, which meant that two subjects could be expected to be seen in one clinic. Interviews were sometimes delayed or interrupted by various aspects of clinic routine, such as consultations with the doctor and parent's taking blood samples to laboratories. These aspects of the clinic were therefore accommodated during the study. If questionnaires were not completed because of scheduling difficulties, where possible they were done so when the child and parent next attended clinic.
Some revisions were included in the assessment protocol:

1. The addition of the Birleson Depression Inventory, as some children in the pilot study appeared to be depressed, and also did not cope well with stressful medical procedures.

2. Minor revisions to the child and parent structured questionnaires which involved deleting some questions, the answers to which were obtained more reliably from medical notes. A question about stressful life events from The Parenting Stress Index (Abidin, 1983) was added to the parent structured interview questionnaire, in place of an open ended question about stresses on the family.

The measures for pain, anxiety and distress were found to be satisfactory during the reliability phase of the study, which preceded the pilot study and were therefore not changed. As few alterations to the assessment procedure resulted, the data was thereafter included in the final sample.

7.2. METHOD

7.2.1. Subjects

Twenty-one children aged 6-16 years who had received renal transplants because of end stage renal failure, took part in the assessment study. They attended the paediatric renal transplant out-patient clinic at Guy’s Hospital, London. On arrival at the clinic, the child and parent were approached by the researcher
and invited to participate in a study about children's experiences with bloodtests. The purpose of the study was explained in terms the child would understand:

This is a study about how children in the clinic cope with bloodtests. I am interested in the kinds of things which make some children cope well and others not cope so well. I would like to talk to you both about the sorts of things that are easy and difficult about bloodtests and your experiences here. I would like to observe and understand which parts are easy or difficult for each child. This will help me to find out the best ways of helping children in the clinic cope with bloodtests so they don't get as bothered by them. We can talk about these things while you are waiting to see the doctor. I will need to ask you some questions before the bloodtest. Would it be alright to talk to me about your experiences with bloodtests?

Informed consent was obtained from the child and parent and parent's completed a consent form. Children who were identified by medical staff as not coping with bloodtests were initially approached by the researcher. Children attending without a parent were generally not approached as it was necessary to complete parent questionnaires simultaneously and obtain parent ratings of child distress. One girl who did not cope well with bloodtests took part in the study although her parent was absent from the clinic. No child or parent refused to take part, but one adolescent boy refused to answer some questionnaires. This did not come as a surprise as he had suffered from depression, poor self esteem and difficulty in coping with his illness. Other missing data resulted from insufficient time during clinic, some parents finding the Rotter Locus of Control scale difficult to complete (see next chapter), parents not attending clinic regularly and changes in clinic appointments. There were 16
(84.2%) mothers and 3 (15.8%) fathers interviewed in the present study.

7.2.2 Criteria for Selection

Following the study’s approval by Lewisham and North Southwark Committee on Ethical practice in February 1987 (see Appendix I), children were selected according to the following criteria:

1. They were aged between 6-16 years.
2. The child and parent spoke English.
3. The child was accompanied by a parent.

At the time of the study there were several Greek children who did not speak English, attending the clinic. They were excluded from the study as it was essential to understand and speak English to complete questionnaires in the assessment study. The subjects in the study were predominantly Caucasian; four were Asians and one mixed Oriental and Caucasian. A clinic list was provided by medical staff before the study began, which included each child’s date of birth. This made it possible to select children according to age.

7.2.3 Sex

There were 12 (57.1%) boys and nine (42.8%) girls in this study. When the study began in 1987 there were 99 children listed as attending the outpatient clinic. Of these 62 were boys and 37 girls, which reflects the fact that more boys than girls are
affected. Sex differences in observed and self-reported levels of pain and anxiety have been reported in early studies, with females showing higher levels (Katz, Kellerman and Siegel, 1980; Hilgard and LeBaron, 1982). Other studies have not found any sex differences (Katz, Kellerman and Siegel, 1982; LeBaron and Zeltzer, 1984). As a result, some studies (e.g. Kuttner, 1984) have not controlled for sex differences. Sex was included as a variable to be investigated here as the above studies have focused on highly painful medical procedures in the paediatric cancer population, however, little is known about sex differences with less painful medical procedures.

7.2.4 Age

Children were aged between six years ten months and 16 years and 11 months. Mean age was 12.3 years (SD = 3.0 years). The mean age of boys was 11 years and eight months, with a range of six years ten months to 16 years and eight months. The mean age of girls was 12 years and eight months, with a range of eight years and three months to 16 years and 11 months.

Various studies have used differential distinctions for age, thus the criterion for separating age groups has been inconsistent. Katz et al (1980) divided their sample into three age groups. Hilgard and LeBaron (1982) and LeBaron and Zeltzer (1982) used age 10 years of age as a division of younger and older children, finding that children over this age were better at controlling
their distress during bone marrow aspirations. The finding was of a divergence between self-reported pain and observed pain. Jay, Ozolins, Elliott and Caldwell (1983) used three age groups in their sample - two to six years, seven to 12 years and 13 to 20 years. They noted that age and stage of cognitive development was associated with the child's understanding of the meaning of pain.

Other studies such as those by Kuttner (1984) have used Piagetian developmental stages as a guide for assessing effects of age. According to Piagetian theory (Piaget and Inhelder, 1969) the preoperational stage of development is approximately from two to six years; the concrete operational stage is from approximately seven years and the formal operational stage from age 12 to 16 years. In order to assess differences according to age, children in the present study were divided into younger and older groups according to Piaget's developmental stages: six to 11 (young), and 12-16 (old) and thus according to middle and adolescent years.

7.2.5 The Clinical Setting

The paediatric renal transplant clinic occurred every Wednesday morning. It was situated on the ninth floor of Guy's Hospital Out-Patient Department. Only children who had received renal transplants attended this clinic for regular monitoring of their height, weight, blood pressure, urine analysis and bloodtaking. Regular blood tests checked full blood count, creatinine, urea
and electrolytes, bicarbonate and calcium. The main objective was to monitor the progress of the new kidney and to check for rejection which was diagnosed by a rise in the level of plasma creatinine. Children were placed on a medical regime involving cytotoxic immunosuppressants and corticosteroids and other immunosuppressants to suppress rejection of the new kidney. Details of this medical regime and description of drugs affecting the immune response are provided in Appendix II.

Children attended the clinic regularly according to their health status and when they had received the transplant. Most children attended every two to four weeks, two children attended daily, and one every twelve weeks. Blood was taken every time the child attended clinic. Children with end stage renal failure who were not yet transplanted or newly diagnosed children with chronic renal failure attended other clinics during the week.

The transplant clinic consisted of a relatively small waiting area with a small extended play area. Toys and educational activities were provided by a hospital teacher who was usually present. Fold up chairs attached to one wall provided further waiting space with a bench at the end of the corridor. A treatment room was situated adjacent to the waiting room. There were three consultation rooms.

The treatment room where bloodtests occurred was exceptionally small. It contained a couch and chair at the far end, a weighing
chair, a height instrument, a chair at the other end and a wide
shelf attached to one wall on which nurses wrote in files and
kept bloodtaking equipment. The room permitted two children and
two nurses comfortably at one time. When two parents were also
present, which was usually the case, the room was full. It was
uncomfortably full when the researcher was also present! The door
to the treatment room was usually left open, but closed when an
anxious child was having blood taken. This was to prevent
children in the waiting area hearing the child’s distress which
was inevitable as sound carried.

The staff office which also contained children’s medical notes
was situated beyond a corridor close to two in-patient renal
wards. Adjacent to the staff office was a small store room, which
also contained two chairs. This was kept locked at all times.
Both these rooms were used during the assessment and intervention
study. These were not ideal, however, as interruptions were
common in the staff room and the store room had to be locked
immediately after use. Another difficulty which later led to the
researcher carrying out interviews in the waiting area, was the
anxiety parents expressed at “losing their place” while waiting
to see the paediatrician for review. While nursing staff were
informed as to the whereabouts of children and parents when
interviewed away from the treatment room and waiting areas,
parents needed reassurance that they would be called as usual.
Carrying out interviews in the waiting area helped to reduce this
anxiety.
Children did not have appointment times at the clinic although they were booked to attend particular weeks. Upon arrival at clinic, children signed their name in the diary and waited to be called by one of the nurses for routine monitoring and a bloodtest, which occurred at every visit. Children had to wait for up to one hour for the result of the bloodtest analysis (creatinine) before being called by the Consultant Paediatrician for consultation and review of medication. Clinic size varied from week to week, although it was usual to have 24 children attend the paediatric transplant clinic on a Wednesday morning, but could be as high as 40. The two or three nurses on duty took blood and carried out routine assessments as described above. There was little change in staffing during the study, with the exception of one nurse who was replaced in January 1988. There was a Consultant Paediatrician and Senior Paediatric Registrar reviewing children in the clinic. Families sometimes travelled a considerable distance to the clinic. While most children lived in the Thames area, two children lived in East Anglia and one in Wessex.

7.2.6 Measures

Assessment of pain, anxiety and distress.

The following assessments were used to measure pain, anxiety and distress during routine bloodtests:

1. Global ratings of anxiety, pain and distress.
2. Behavioural checklist.
3. Physiological measures (heart rate and blood pressure).

1. Global ratings of anxiety, pain and distress.
These were completed by the nurse (usually performing the medical procedure), as well as the child and parent immediately following the bloodtest. This is a numerical Likert 10 point scale with 0 representing no anxiety or pain and 10 representing extreme anxiety or pain. The scale was anchored with a smiling face at 0 and a sad face at 10. The child, parent and observer were asked to select the number which best represented the child’s anxiety or pain during the procedure. Nurses were also asked to rate their own anxiety during bloodtesting.

2. Behavioural checklist.
A revised version of the Observational Scale of Behavioural Distress (OSBD) (Jay et al, 1983; Jay and Elliott, 1984) previously described in Chapter 3, was used as a more objective measure of behavioural distress, which includes both anxiety and pain (see Appendix III). While categories remained the same, eight of these were reworded so that medical staff could more easily understand the checklist. The categories used were taken from the PBCL (LeBaron and Zeltzer, 1984). The behavioural categories in the revised OSBD were as follows with OSBD categories in brackets where appropriate: muscle tension (muscular rigidity), crying (cry), screaming (scream), anxiety verbalised (verbal fear), pain verbalised (verbal pain), restraint used (physical restraint), verbal stalling (verbal resistance), physical resistance (flail), requests emotional
support, nervous behaviour and information seeking.

The revised OSBD was scored by recording the occurrence of behaviours during three phases of the medical procedure (before, during and after), as described by LeBaron and Zeltzer (1984) for the PBCL, and not four as on the OSBD. It was not possible to observe children in the waiting room immediately before the bloodtest, as nurses were busy in the treatment room. During the reliability phase of the study (described later in this section), it became evident that children did not tend to become anxious in the waiting room, but rather at the sight of the medical instruments in the treatment room. It was therefore not necessary to include observations of children in the waiting room.

The phases of the medical procedure were as follows:
Phase 1 included preparation and cleansing of the venipuncture site and usually began after the child's weight, height and blood pressure were taken. It included anticipatory anxiety and/or anticipatory pain before the insertion of the needle.

Phase 2 began with the insertion of the needle into the vein and bloodtaking and therefore measured anxiety and pain experienced during the procedure.

Phase 3 began with the removal of the needle and the placing of cotton wool and plaster over the puncture. It measured pain and anxiety following the procedure.
**TABLE 7-1 - Observational Scale of Behavioural Distress - revised**

**Definitions of Behavioural Categories**

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Definition</th>
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<tbody>
<tr>
<td>1. Muscle tension</td>
<td>Includes any of the following behaviours: eyes shut tight, tense or stiff body, clenched jaw or fists, gritted teeth, contraction of any observable part of body, from or pinched expression.</td>
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<td>2. Crying</td>
<td>Shed tears or sobs</td>
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<td>3. Screaming</td>
<td>Raises voice at high pitch with verbal or nonverbal expressions</td>
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<td>4. Anxiety verbalised</td>
<td>Says &quot;I'm scared&quot; or &quot;I'm afraid&quot; or other statements about anxiety</td>
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<tr>
<td>5. Pain verbalised</td>
<td>Makes comments about pain or discomfort, e.g. &quot;you're hurting me&quot;, &quot;that hurt&quot;, &quot;ouch&quot;</td>
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<tr>
<td>6. Restraint used</td>
<td>Has to be physically restrained or held</td>
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<tr>
<td>7. Verbal stalling</td>
<td>Try to delay or terminate procedure, e.g. &quot;stop I'm not ready&quot;, &quot;I want to tell you something&quot;, &quot;I don't want a bloodtest&quot;</td>
</tr>
<tr>
<td>8. Physical resistance</td>
<td>Withdraws hand or arm, will not sit still, kicks legs, thrashes limbs around.</td>
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<tr>
<td>9. Requests emotional support</td>
<td>Asks parent to accompany, provide physical or verbal comfort, e.g. &quot;hold my hand&quot;</td>
</tr>
<tr>
<td>10. Nervous behaviour</td>
<td>Expressions of anxiety or discomfort, e.g. groans, winces, tremors, clenches, bites lips, hyperventilates</td>
</tr>
<tr>
<td>11. Information seeking</td>
<td>Asks for information about the medical procedure, e.g. &quot;what's that for?&quot;, &quot;what are you doing now?&quot;, &quot;will it be over soon?&quot;</td>
</tr>
</tbody>
</table>

Based on the OSBD (Jay et al, 1983; Jay & Elliott, 1984) and PBCL (LeBaron and Zeltzer, 1984)
Nurses completed the revised OSBD by noting the presence of behaviours and rating their intensity according to a 5-point Likert scale (1= very mild, 5= very intense). Absent behaviours were simply not recorded rather than being represented by 0, to save time. Unlike the OSBD, behaviours were recorded once for each phase, rather than at intervals. The checklist was completed after the bloodtest. The scoring system generated a total intensity score and intensity scores for the three phases of the medical procedure for each child. The entire medical procedure lasted about five minutes, except in the case of highly anxious or resistant children, when more time was needed. Operational definitions of the OSBD categories are provided in Table 7-1.

3. Physiological (cardiovascular) measures:
(a) Heart Rate.

Heart rate was taken in the waiting room and during the three phases of the medical procedure. Heart rate was measured by a heart speedometer (model 8519 - Computer Instruments Corp.) with a pulse sensor clipped to the child’s earlobe. Measurement involved the ear lobe being illuminated by a light in the pulse sensor with a barrier cell in the sensor measuring the amount of light reflected in the ear lobe. The amount of light varies with each pulse, as it is absorbed by the blood pigment (haemoglobin) which increases in volume during the heartbeat and then decreases again until the next pulse arrives. The signal produced is processed by a micro-processor, which measures the time between the individual beats and extrapolates this to give the heart rate
in beats per minute.

This particular instrument was chosen in preference to one which required the child to place his or her finger over a sensor for a few reasons. Firstly, children who received kidney transplants often had an artery and a vein in one arm joined together surgically (i.e. a fistula). A pulse taken from that same arm would be incorrect as an artifactual "buzz" or echo could be felt there. Some children had blood taken from the fistula, while others did not. The instrument was simple and relatively unobtrusive to use. The rationale for its use was provided, that is, when we are scared or excited our heart beats faster and by measuring heart rate it was possible to assess how a child felt during a bloodtest and to indirectly ascertain whether he or she was coping well or not.

There are two methodological difficulties in measuring heart rate with these children. The first concerns the use of beta blocking drugs in this clinic, which often stabilized heart rate. Thus, one would not expect to see a significant change in heart rate during the medical procedure in children taking such drugs. The second difficulty concerns the potential intrusiveness of the instrument, which could result in elevated heart rate. For example, one child did not like the instrument and refused to have it attached to her ear. In general, however, the instrument did not appear to be overly intrusive and all other children agreed to use it. Furthermore, it became a source of curiosity,
particularly for the older children.

(b) Blood pressure.
Systolic and diastolic blood pressure (see Chapter 4) was taken routinely before the bloodtest by nurses to monitor children's physical health status. Where possible blood pressure was taken before and after bloodtests. However, because of workload and size of the clinic, this proved to be too demanding for medical staff and was therefore not done consistently. It was sometimes practically difficult for nurses to obtain both systolic and diastolic blood pressures, because of poor veins or behavioural distress in the child, which resulted in further missing data.

7.2.7 Psychosocial Variables.

Structured interview questionnaires
The child and parent were given a structured interview questionnaire about a number of procedure related variables, such as anticipatory anxiety and pain, parental and staff management of the child's pain, what helps the child cope better or less well with pain, the child's coping strategies for pain, and the child's understanding of his or her illness and treatment. Open ended questions were subsequently coded according to common responses. The coded version of the child and parent structured interview questionnaires are included in Appendix IV and V. Demographic variables were also collected including the child's age at diagnosis, months since transplant, social class and birth order. Information was obtained from the child's medical notes
regarding the number of bloodtests prior to baseline and cytotoxic and immunosuppressant drugs. The child structured questionnaire was completed with the researcher. The parental questionnaire was either given to the parent to complete along with the standardized questionnaires described below, or completed with the researcher depending on time constraints.

Standardized Questionnaires
(a) Child
The following standardized questionnaires were given to each child:


(b) Parent
The parent was given the following standardized questionnaires:
2. Rotter Locus of Control Scale (Rotter, 1966). (Appendix XII).


(c) School

The child’s school was contacted with the parent’s permission. Teachers were asked to complete the Rutter Teacher Questionnaire (Rutter, 1967) regarding the child’s emotional and behavioural adjustment in school. (Appendix XIV).

A detailed description of the above mentioned standardized questionnaires, the issues underlying their construction and methodological considerations are discussed in the next chapter.

7.3 RESULTS

7.3.1 Inter-Rater Reliability

Before commencement of the study, two experienced nurses in the paediatric transplant clinic were trained in observing children’s behavioural distress during routine bloodtests for 26 children. Definitions of behavioural categories were supplied for the revised version of the OSBD (see next section). While one nurse performed the medical procedure, the other observed. Both subsequently completed the global and checklist ratings. The observation of these procedures was immediately followed by discussion and clarification of behavioural categories, protocol, behavioural issues and personal reactions. It was noted that the nurse performing the medical procedure was less
sensitive to facial cues of behavioural distress because her
attention was on the needle itself, whereas the observing nurse
was less sensitive to subtle muscle tension and resistance.
However, this made little difference to inter-rater
reliability.

The results of observer inter-rater reliability for global
ratings according to Spearman Rank correlations were as follows:
.93 for anxiety (p=<.05); and .87 for pain (p=<.05). Pearson
correlations for total distress scores revealed good inter-rater
reliability (r= .99; p<.001). Reliability of the revised OSBD was
calculated using the agreements disagreements method (Haynes,
1978). The formula for this method is as follows:

\[
\text{Reliability} = \frac{\text{Number of agreed events}}{\text{agreed events} + \text{disagreed events}} \times 100
\]

This was calculated for the three phases of the medical
procedure, where an event refers to an observed behaviour in one
particular phase. The results for the three phases were: Phase 1
= 95% agreement; Phase 2 = 92% agreement; and Phase 3 = 95%
agreement. The results show satisfactory inter-rater reliability
as 80% or above is considered to be a satisfactory level (Haynes,
1978).

7.3.2. Descriptive Statistics

Variables which were categorized are presented in this section as
well as responses to the child/parent structured interview
questionnaires. Generate format questions yielded descriptive data not subjected to statistical analysis, but are presented below. Responses were categorised accordingly. Some supplied format questions are also included where appropriate. The percent presented is the valid percent based on actual responses.

Demographic characteristics

Social class

Social class was determined by the father’s occupation in two parent families and by mother’s in single parent families, according to the Classification of Occupations and Coding Index (1980). Table 7-1 shows the majority of children were from social class 2, although there was missing data on nine children.

<table>
<thead>
<tr>
<th>Social class</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>16.7</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>50.0</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>33.3</td>
</tr>
</tbody>
</table>

Birth order

Table 7-2 shows there was a preponderance of first born children in the study.
TABLE 7-2 Birth order of sample

<table>
<thead>
<tr>
<th>Birth order</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>13</td>
<td>65</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

Child and Family Health

A subjective measure of children's health status was obtained from parental interview. According to parents seven (36.8%) children were described as being in "good" health, nine (47.4%) in "adequate" health and three (15.8%) in "poor" health. Attempts were made to obtain a medical measure of the child's medical status (plasma creatinine), however there was missing data on over half the sample which prevented meaningful analyses. Family illness (e.g. renal problems or diabetes) was present for eight (42.1%) families.

Anticipatory Anxiety

The majority of children did not experience anticipatory anxiety prior to attending the clinic (i.e. unusual behaviour or symptoms, such as changes in eating or sleeping patterns, crying, nausea etc): 14 (73.7%) did not experience anticipatory anxiety while 5 (26.3%) of the sample did, suggesting either the procedures were not overly distressing or that children were habituating to them as routine procedures, or both.
Previous experience

Seventeen children (81.0%) reported having had unpleasant experiences with needles in the past. These included experiences with injections, finger pricks and complications with dialysis.

Problems with injections were commonly reported:

When I had this transplant going into theatre, they had to give me an injection in my hand. The syringe bent over and went out of place. It was very painful. I screamed and cried on the way to theatre...the worse thing was no one believed me that it hurt (girl aged 16).

Frequency of Bloodtests

Table 7-3 presents frequency of bloodtests that children experienced when seen for assessment. Most children attended the transplant clinic regularly each month.

<table>
<thead>
<tr>
<th>Frequency of bloodtests</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every 1-2 days</td>
<td>3</td>
<td>15.0%</td>
</tr>
<tr>
<td>weekly</td>
<td>3</td>
<td>15.0%</td>
</tr>
<tr>
<td>fortnightly</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>every 3 weeks</td>
<td>3</td>
<td>15.0%</td>
</tr>
<tr>
<td>once month</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>every 1-3 months</td>
<td>5</td>
<td>26.3%</td>
</tr>
</tbody>
</table>

Parent presence

Fifteen parents (78.9%) said they were usually present during their child’s bloodtest, two (10.5%) said they were not and a further two (10.5%) said they were sometimes present. Fifteen parents (78.9%) said they would be willing to wait in the
waiting room while their child had their bloodtest, while four (21.1%) were not. Parents were asked whether their child was better, no different or worse if they were present. Six parents (33.3%) felt the child was better, seven (38.9%) no different and five (27.8%) worse.

Parental management of bloodtests/needles

Table 7-4 presents the management strategies used by parents to help their child cope with bloodtests and other needles (e.g. intramuscular injections and injections prior to X-ray). Most parents used emotional support (e.g. reassuring child, holding child’s hand) or did not offer help because they felt they did not need to.

<table>
<thead>
<tr>
<th>Parent strategy</th>
<th>Freq/Bt</th>
<th>Percent</th>
<th>Freq/N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not help</td>
<td>7</td>
<td>36.8%</td>
<td>7</td>
<td>50.0%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>7</td>
<td>36.8%</td>
<td>3</td>
<td>21.4%</td>
</tr>
<tr>
<td>Combination</td>
<td>3</td>
<td>15.8%</td>
<td>3</td>
<td>21.4%</td>
</tr>
<tr>
<td>Distraction</td>
<td>1</td>
<td>5.3%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Relaxation</td>
<td>1</td>
<td>5.3%</td>
<td>1</td>
<td>7.0%</td>
</tr>
</tbody>
</table>

Parent communication to child about pain/anxiety

Parents often dealt with their child’s distress by telling the child to cry if he/she wanted to or by providing information or reassurance. The “other” category included distraction, telling the child not to cry, to be a big boy/girl or be strong and the use of humour and meditation. Providing reassurance, support or comfort when hurt or worried was the most common management of
distress reported by children.

TABLE 7-5 Parent communication to child about pain/anxiety

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>7</td>
<td>36.9%</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Reassure/provide</td>
<td>4</td>
<td>21.1%</td>
<td>6</td>
<td>31.6%</td>
</tr>
<tr>
<td>information</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cry if wants to</td>
<td>4</td>
<td>21.1%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Relax</td>
<td>2</td>
<td>10.5%</td>
<td>3</td>
<td>15.0%</td>
</tr>
<tr>
<td>Reward coping</td>
<td>2</td>
<td>10.5%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Encourage talking</td>
<td>0</td>
<td>0.0%</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>No response</td>
<td>0</td>
<td>0.0%</td>
<td>4</td>
<td>21.1%</td>
</tr>
</tbody>
</table>

Examples:

They'd try to comfort me and make me relax, make jokes, try to make me forget about it [the transplant] so I don't get too tensed up...they talked it over and wanted to know how I felt (girl aged 16).

They both say "think of something else". It's impossible not to think about it. You know you're going to have it done. How can you think of something else? (girl aged 11).

Staff management of bloodtests

Parents described the most common ways in which staff helped children to cope with bloodtests. References to general competence in taking blood were made the most.
TABLE 7-6 Staff strategies for helping children cope with bloodtests

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competence</td>
<td>6</td>
<td>31.6%</td>
</tr>
<tr>
<td>Talk to child</td>
<td>5</td>
<td>26.3%</td>
</tr>
<tr>
<td>Sympathetic</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Information</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>Encourages control</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>Combination</td>
<td>1</td>
<td>5.3%</td>
</tr>
</tbody>
</table>

What helped child cope better

The factors influencing what helped children cope better with bloodtests are presented in Table 7-7.

TABLE 7-7 Factors influencing coping according to parents and children

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>7</td>
<td>36.9%</td>
<td>7</td>
<td>33.4%</td>
</tr>
<tr>
<td>Successful</td>
<td>5</td>
<td>26.3%</td>
<td>3</td>
<td>14.3%</td>
</tr>
<tr>
<td>Venipuncture</td>
<td>2</td>
<td>10.5%</td>
<td>4</td>
<td>19.0%</td>
</tr>
<tr>
<td>Feeling happy</td>
<td>2</td>
<td>10.5%</td>
<td>2</td>
<td>9.5%</td>
</tr>
<tr>
<td>Nurse</td>
<td>2</td>
<td>10.5%</td>
<td>4</td>
<td>19.0%</td>
</tr>
<tr>
<td>Parent presence</td>
<td>2</td>
<td>10.5%</td>
<td>1</td>
<td>4.8%</td>
</tr>
<tr>
<td>Nothing</td>
<td>1</td>
<td>5.3%</td>
<td>4</td>
<td>19.0%</td>
</tr>
</tbody>
</table>

"Other" responses provided by parents included nurses' positive mood, relaxation, meditation and time. Children also found imagery helpful:

I've got an imaginary friend, a dinosaur. I pretend I'm Rambo and I go "uh" and it [the needle] goes in. I imagine I'm sitting on the dinosaur's back and spears are hitting me (boy aged 13).
What made child cope less well

Factors which parents and children felt interfered with coping with bloodtests are presented in Table 7-8. Unsuccessful venipunctures were the most commonly reported problem for children while the second most common for parents. "Other" reasons according to parents were if the nurse was not cheerful, and if the child had to go to school afterwards and for children, using nonpreferred veins.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unwell/unprepared</td>
<td>6</td>
<td>33.3%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Unsuccessful</td>
<td>5</td>
<td>27.8%</td>
<td>9</td>
<td>42.9%</td>
</tr>
<tr>
<td>venipunctures</td>
<td>3</td>
<td>16.7%</td>
<td>3</td>
<td>14.3%</td>
</tr>
<tr>
<td>Different nurse</td>
<td>2</td>
<td>11.2%</td>
<td>4</td>
<td>19.0%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>5.6%</td>
<td>1</td>
<td>4.8%</td>
</tr>
<tr>
<td>Parent absent</td>
<td>1</td>
<td>5.6%</td>
<td>4</td>
<td>19.0%</td>
</tr>
<tr>
<td>Nothing</td>
<td>1</td>
<td>5.6%</td>
<td>4</td>
<td>19.0%</td>
</tr>
</tbody>
</table>

Worst part of bloodtest

Children were asked what the worst part of the bloodtest was for them. The following table shows most children found the insertion of the needle most stressful.
TABLE 7-9 Worst part of bloodtest

<table>
<thead>
<tr>
<th>Factors</th>
<th>Freq</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insertion of needle</td>
<td>8</td>
<td>38.1%</td>
</tr>
<tr>
<td>Removal of needle</td>
<td>5</td>
<td>23.8%</td>
</tr>
<tr>
<td>Bloodtaking</td>
<td>3</td>
<td>14.3%</td>
</tr>
<tr>
<td>Seeing needle</td>
<td>2</td>
<td>9.5%</td>
</tr>
<tr>
<td>When it hurts</td>
<td>1</td>
<td>4.8%</td>
</tr>
<tr>
<td>Creatinine result</td>
<td>1</td>
<td>4.8%</td>
</tr>
<tr>
<td>Nothing</td>
<td>1</td>
<td>4.8%</td>
</tr>
</tbody>
</table>

Preference to look at needle or look away

Of 19 children who responded, 12 (63.2%) preferred to look at the needle during the bloodtest and monitor the procedure, compared to six (31.6%) who preferred to look away and distract themselves. Only one child (4.8%) had no preference. Reasons for looking at the needle were they knew when the needle was coming and they liked to see what was done. Reasons for not looking were that it was worse if they looked, and, not liking needles.

Child's cognitions during bloodtest

Three children (27.3%) reported they did not think of anything during their bloodtest, while two (10.2%) children had expectations of pain or unsuccessful venipunctures. Six (54.6%) reported other cognitions which involved imagery, hoping the venipuncture would be successful, positive self-talk and thoughts about getting the bloodtest over with. (An example of the use of imagery was provided by a 13 year old boy).
In my mind I say it's not going to hurt, Superman is going to get you through it. Mr Rex you can help me through all this because you're a big dinosaur, so I don't have to get injured on your back. They [the nurses] miss with their spears.

Child's coping methods

The most commonly reported coping methods by children were deep breathing and relaxation, although a number of children did not report any coping strategies at all (see Table 7-10). Other strategies included monitoring the bloodtests, distracting self from bloodtest, biting on fingers and making a fist. Parents reported talking and deep breaths and relaxation as helpful strategies. "Other" strategies not classified included using humour and "mind over matter."

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td>6</td>
<td>31.7%</td>
<td>7</td>
<td>33.4%</td>
</tr>
<tr>
<td>Nothing</td>
<td>5</td>
<td>26.3%</td>
<td>4</td>
<td>19.0%</td>
</tr>
<tr>
<td>Talks</td>
<td>4</td>
<td>21.0%</td>
<td>1</td>
<td>4.8%</td>
</tr>
<tr>
<td>Deep breaths/relaxation</td>
<td>4</td>
<td>21.0%</td>
<td>6</td>
<td>28.6%</td>
</tr>
<tr>
<td>Imagery</td>
<td>0</td>
<td>0.0%</td>
<td>3</td>
<td>14.3%</td>
</tr>
</tbody>
</table>

Examples of coping strategies:

I try to breathe and not to think too much and relax inside (girl aged 14).

I have an imaginary friend, Rambo, my superhero. I think I can fly like superman. When the needle goes in I just think hard about it and concentrate on something specific. After that I make my mind go blank (boy aged 13).
I breathe in deeply and think about my animals, like funny things you've seen them doing, like the parrot peeping into a hole (boy aged 10).

Children's understanding of bloodtests

Table 7-11 presents children's understanding of bloodtests according to parent ratings and children's responses to being asked what bloodtests are for and why they needed to have them.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding</td>
<td>1</td>
<td>5.3%</td>
<td>7</td>
<td>35.0%</td>
</tr>
<tr>
<td>A little</td>
<td>2</td>
<td>10.5%</td>
<td>2</td>
<td>10.0%</td>
</tr>
<tr>
<td>Moderate</td>
<td>11</td>
<td>52.9%</td>
<td>6</td>
<td>30.0%</td>
</tr>
<tr>
<td>A great deal</td>
<td>5</td>
<td>26.3%</td>
<td>5</td>
<td>25.0%</td>
</tr>
</tbody>
</table>

Children's descriptions of the purpose of bloodtests were categorized according to the following classifications: no understanding (shows complete lack of understanding); a little understanding (general understanding of the need to assess kidney function or health); moderate understanding (involving the need to test for creatinine for kidney function); and a great deal of understanding (including awareness of the need to test creatinine and other investigations). Table 7-11 shows that although the majority of parents felt their child had at least a moderate understanding of bloodtests, they actually overestimated children's knowledge.
Children's understanding of their illness

Table 7-12 presents children's understanding of their illness according to parent ratings and children's own responses to a question about telling a child of the same age what was wrong with them (now and before the transplant). This variable is coded like the previous one: no understanding (child has no concept of illness); a little (child refers to kidney problems); a moderate amount (understands that kidney has failed); and a great deal of understanding (referring to chronic renal failure and/or necessity for transplant). Of interest is the overestimation by parents of children's understanding of their illness. Most children in contrast, had little understanding of their chronic illness.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>Percent</td>
</tr>
<tr>
<td>No understanding</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>A little</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>A moderate amount</td>
<td>5</td>
<td>26.3%</td>
</tr>
<tr>
<td>A great deal</td>
<td>12</td>
<td>63.2%</td>
</tr>
</tbody>
</table>

Children's understanding of treatment

Table 7-13 presents children's understanding of their treatment according to their responses to a question about what they would tell a child of their age concerning how their illness would be treated. Parent ratings of their child's understanding are also included. The following classifications of understanding were
used based on children's responses: no understanding (no understanding of specific treatments); a little understanding (child refers to drugs/other treatment aspects but not transplant or dialysis); a moderate understanding (child refers to either transplant or dialysis) and a great deal of understanding (child refers to two or more of the following: transplant, dialysis and drugs). Once again parents were found to overestimate their child's understanding.

<table>
<thead>
<tr>
<th>TABLE 7-13 Children's understanding of their treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factors</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>No understanding</td>
</tr>
<tr>
<td>A little</td>
</tr>
<tr>
<td>A moderate amount</td>
</tr>
<tr>
<td>A great deal</td>
</tr>
</tbody>
</table>

Treatment child finds most difficult

The following table shows the treatment children found most difficult and parent's view of the most difficult treatment for children. Bloodtests was the procedure parents felt to be most difficult for children and the second most difficult reported by children after clinic visits.
## TABLE 7-14 Treatment child finds most difficult

<table>
<thead>
<tr>
<th>Factors</th>
<th>Child</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>Percent</td>
</tr>
<tr>
<td>Clinic visits</td>
<td>6</td>
<td>28.6%</td>
</tr>
<tr>
<td>Bloodtests</td>
<td>4</td>
<td>19.0%</td>
</tr>
<tr>
<td>Nothing</td>
<td>3</td>
<td>14.3%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>14.3%</td>
</tr>
<tr>
<td>Taking drugs</td>
<td>2</td>
<td>9.5%</td>
</tr>
<tr>
<td>Travelling</td>
<td>2</td>
<td>9.5%</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>1</td>
<td>4.8%</td>
</tr>
<tr>
<td>Everything</td>
<td>0</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

## Treatment parent finds most difficult

Table 7-15 presents the treatment parents reported to be most difficult for them to cope with and children's responses of what they believed their parents found difficult. Parents reported that they found travelling to clinic the most difficult with drugs being of least concern. Interestingly, children underestimated the amount of difficulty their parents experienced (see "nothing" category).

## TABLE 7-15 Treatment parent finds most difficult

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>Percent</td>
</tr>
<tr>
<td>Travelling</td>
<td>5</td>
<td>26.3%</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>Child in pain</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>Everything</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>Nothing</td>
<td>2</td>
<td>10.5%</td>
</tr>
<tr>
<td>Bloodtests</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>Clinic visits</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>Drugs</td>
<td>0</td>
<td>0.0%</td>
</tr>
</tbody>
</table>
Arguments over treatment

Five children (25.0%) said they argued with their parents over treatment (e.g. over drugs and diet) while the majority did not. This was consistent with parent reporting.

Anxiety about transplant

Eight children (38.0%) reported being worried or very worried about their transplant, with six (28.6%) not being worried, one (4.8%) having mixed feelings, two (14.3%) being relieved/excited and four (19%) described other feelings, for example:

"I didn't want another one. I preferred to have been dead after the last one. I felt sentimental after all the suffering and everything. I still wish I hadn't got it" (boy aged 13)

Ten children (52.6%) felt their parents had been worried or very worried about their transplant. Interestingly, ten (52.7%) parents reported the same about their own feelings, two (10.5%) had mixed feelings, two (10.5%) hoped for the best, two (10.5%) were pleased about the transplant, and three (15.8%) described other feelings.

Dialysis

Fourteen children (70.0%) had been dialysed, of these, approximately two children (15.4%) had peritoneal dialysis, six (46.2%) had haemodialysis and five (38.5%) had both. The problems reported with dialysis included: difficulties in coping with dialysis, infection, leaks, tubes falling out, blockages, potassium problems and problems with blood pressure.
Children's fears

Parents were asked whether children had any fears or phobias other than needles. Eight parents (42.1%) said their child did while 11 (57.9%) said they did not. Children had a number of fears reported by parents: the dark, dogs, spiders, wasps, small rooms, snakes, and multiple fears. Twelve parents (66.7%) reported fears or phobias in the family. Injection fears in parents were more common than other fears (58.3%).

Impact of child's illness and treatment on family

The following table shows the impact that the child's illness had on the family according to parents and children. This was a difficult question for younger children who believed there was no impact on the family. "Other" categories including "spoiling" the child and uncertainty about the future.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disruption/restriction</td>
<td>7</td>
<td>38.9%</td>
<td>1</td>
<td>5.9%</td>
</tr>
<tr>
<td>Worry</td>
<td>7</td>
<td>38.9%</td>
<td>4</td>
<td>23.5%</td>
</tr>
<tr>
<td>Affected siblings</td>
<td>1</td>
<td>5.6%</td>
<td>1</td>
<td>5.9%</td>
</tr>
<tr>
<td>No effect</td>
<td>0</td>
<td>0.0%</td>
<td>7</td>
<td>41.2%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>16.8%</td>
<td>4</td>
<td>23.5%</td>
</tr>
</tbody>
</table>
7.3.3. Inferential Statistics

Summary statistics
The means, standard deviations, minimum and maximum values for variables analysed in this section are presented in Appendix XV. Definitions (variable labels) can be found in Appendix XVI. Variables with N less than 10 were excluded from statistical analyses and are therefore not presented in the table. Unless otherwise indicated one-tailed correlation coefficients were used for inferential statistics in this section for variables expected to be positively or negatively correlated.

Spearman correlation coefficients were used rather than Pearson because most of the data did not have normal distributions and because the former were more conservative than the latter. Kendall coefficients were used for variables involving two responses (e.g. yes or no). Missing data was ignored rather than using a correction.

Total Distress Scores
The revised OSBD total scores were positively correlated with the following measures: child state anxiety (\( \rho = .38; p < .05 \)); child external locus of control (\( \rho = .42; p < .04 \)); nurse global anxiety ratings (\( \rho = .86; p < .001 \)); nurse global pain ratings (\( \rho = .69; p < .001 \)); parent ratings of the child's usual anxiety over bloodtests (\( \rho = .66; p < .01 \)); the child's rating of usual anxiety over injections (\( \rho = .66; p < .001 \)); the child's rating of anticipated anxiety (\( \rho = .64; p < .02 \)) and pain (\( \rho = .53; \))
p<.05) during the bloodtest; and the number of bloodtests experienced (rho = .41; p<.04).

Total distress scores were negatively correlated with self-concept scores for social acceptance (rho = -.54, p < .01), (i.e. low distress scores were associated with high self concept for social acceptance) and parent’s rating of child’s understanding of bloodtests (rho = -.66; p<.01) (i.e. low OSBD distress scores were associated with increased understanding of bloodtests). The main significant correlations are presented for phases 1 to 3.

Phase 1
Significant correlations for phase 1 included: child external locus of control (rho = .48; p<.02); nurse global anxiety (rho = .80; p<.001) and pain ratings (rho = .57; p<.01); and negatively correlated with self-concept for social acceptance (rho = -.50; p<.01) and parent’s rating of child’s understanding of bloodtests (rho = -.65; p<.01). Thus, distress was associated with increased understanding.

Phase 2
Distress scores for phase 2 correlated with child state (rho = .39; p<.04) and trait (rho = .40; p<.04) anxiety; Rutter teacher scores (rho = .46; p<.05); nurse global anxiety (rho = .87; p<.001) and pain ratings (rho = .74; p<.001); and the number of bloodtests experienced (rho = .48; p<.02). Distress scores were negatively related to self-concept for cognitive competence (rho
Phase 3
Distress scores for phase 3 positively correlated with child state anxiety (\(\rho = .42; p < .03\)); nurse global anxiety ratings (\(\rho = .63; p < .01\)) and nurse global pain ratings (\(\rho = .56; p < .01\)); and negatively correlated to self-concept for social acceptance (\(\rho = -.49; p < .01\)).

Correlations between distress scores for each of the three phases of the medical procedure and standardized questionnaires were not significant as expected, with one exception for phase 2 where the child's self-concept score for social acceptance (\(\rho = -.54; p < .01\)), again showing (as for total scores) a relationship between low distress and high social acceptance scores.

Reliability measures
Total distress scores were also significantly correlated with the following nine behavioural categories: muscle tension (\(\rho = .68; p < .001\)); crying (\(\rho = .51; p < .01\)); screaming (\(\rho = .75; p < .001\)); anxiety verbalized (\(\rho = .67; p < .001\)); pain verbalized (\(\rho = .66; p < .001\)); restraint used (\(\rho = .51; p < .01\)); verbal stalling (\(\rho = .51; p < .01\)); physical resistance (\(\rho = .68; p < .001\)); and nervous behaviour (\(\rho = .68; p < .001\)), adding further reliability to the scale. Correlations between total distress scores and requests emotional support and information seeking were not significant.
The behavioural categories were correlated with global scores and anticipatory ratings. Muscle tension correlated positively with nurses global ratings of the child's anxiety (rho = .85; p<.001) and the child's rating of anticipatory anxiety (rho = .75; p<.01). Pain verbalized correlated with nurses global rating of the child's pain (rho = .69; p<.01). These provide further substantial validity to the OSBD.

Global ratings
Children's global ratings of pain significantly correlated with parent's global ratings of their pain (rho = .67; p<.01), and nurse's global ratings (rho = .66; p<.001), showing that pain was being assessed to a similar degree by children, parents and nurses. The child's usual anxiety over bloodtests correlated with parent's global rating of anxiety (rho = .73; p<.01) and the child's global rating of anxiety (rho = .68; p<.01) indicating some stability in the child's distress over procedures.

The child's usual anxiety over injections correlated with parents' global rating of pain (rho = .64; p<.01); child's rating of anxiety (rho = .68; p<.01); child's rating of pain (rho = .72; p<.01); and parent's rating of pain (rho = .69; p<.01). There was also a relationship between the child's global anxiety rating and usual anxiety over dialysis needles (rho = .86; p<.01). Thus, if a child was anxious about injections or dialysis, the child was likely to be anxious about bloodtests.

Age and sex differences
Total distress scores (the summation of distress scores across
the three phases of the medical procedure) were subjected to a 2 (age) x 2 (sex) analysis of variance to determine age and sex differences in children's expression of behavioural distress. The main effects were not significant ($F(2,20) = 0.20, p < .83$).

Distress scores for the three phases of the procedure were also scrutinized, but these were also not significant. (Phase 2 = $F(2,20) = 0.38, p < .69$; Phase 3 = $F(2,20) = 1.06, p < .37$). However, there was a trend towards significance in phase 1 (anticipatory phase) for a 2-way interaction between age and sex ($F(1,20) = 3.70, p < .07$).

Scores for the eleven behavioural categories were subjected to a 2 (age) by 2 (sex) analysis of variance to determine age and sex differences in children's expression of behavioural distress. The results were not significant for ten of the behavioural categories. A significant 2 way interaction between age (young/old) and sex was found ($F(1,19) = 4.42, p < .05$) for nervous behaviour however, although the main effects were not significant.

Children's description of the purpose of bloodtests positively correlated with age ($\tau = .57; p < .01$; one tailed) showing increasing understanding with age as would be expected. Children's understanding of their illness correlated with parent ratings of their understanding ($\rho = .48; p < .02$). However, concepts of the purpose of bloodtests and treatment did not correlate with parent ratings of children's concepts.
Nurse variables
An analysis of variance and correlations were conducted separately to assess whether children's distress scores and global ratings were influenced by the nurse performing the medical procedure. The results were not significant.

Nurse's global ratings of their own anxiety positively correlated with children's total distress scores (rho = .63; p < .01) as well as distress scores for phase 1 (rho = .63; p < .01) and phase 2 (rho = .65; p < .01) but not phase 3. Nurse's own anxiety scores also correlated with nurse global anxiety scores for the child (rho = .70; p < .01), nurse global ratings of pain (rho = .67; p < .01) and child global ratings of anxiety (rho = .62; p < .01). These results suggest performing blood tests on anxious children is stressful for staff.

Fears and phobias
Kendall correlations were conducted on children's fears and phobias. Significant correlations were found for parent's rating of whether children had fears or phobias other than needles, with age (months) (tau = .35; p < .05). A further correlation of younger versus older children found that children under 11 years of age to have more fears reported by parents (tau = .54; p < .01). Fearful children (according to parents) had higher nurse global anxiety ratings (tau = .41; p < .05); nurse global pain
ratings (tau = .41; p<.05); parent global anxiety ratings (tau = .35; p<.05); parent rating of child’s anticipatory anxiety (tau = .43; p<.01); parent rating of own anticipatory anxiety (tau = .38; p<.05); parent rating of child’s anticipatory anxiety during bloodtests (tau = .33; p<.05); parent’s rating of child’s anticipatory pain during bloodtests (tau = .34; p<.05); child’s rating of anticipatory anxiety (tau = .39; p<.05); and child’s rating of parent’s anticipatory anxiety (tau = .37; p<.05).

Children’s ratings of whether they had other fears and phobias other than needles significantly correlated with: parent’s ratings of child’s anticipatory anxiety (tau = .48; p<.01); parent ratings of own anticipatory anxiety (tau = .44; p<.05); child’s rating of own anticipatory anxiety (tau = .38; p<.05); presence of fears in other family members according to parent (tau = .39; p<.05); and child’s usual anxiety over injections (tau = .44; p<.05). Children who had other family members with fears or phobias reported higher global anxiety scores (tau = .31; p<.05).

Child’s anticipatory anxiety prior to attending clinic
The child’s anticipatory anxiety prior to attending clinic (such as difficulties in sleep, anxiety etc) was positively correlated with the following: nurse global pain rating (tau = .45; p<.01); child global anxiety rating (tau = .31; p<.05); child global pain rating (tau = .36; p<.05); parent rating of child’s
anticipatory anxiety (tau = .41; p<.01); parent rating of own
anticipatory anxiety (tau = .41; p<.01); child’s rating of
anticipatory anxiety (tau = .33; p<.05).

Rejections and Number of Transplants
The number of rejection episodes a child had was not associated
with other variables. However, the number of transplants a child
had was negatively correlated (two-tailed) with the child’s
global anxiety rating (tau = -.48; p<.01), thus suggesting lower
experienced anxiety.

Previous Experience
There was a significant relationship between children’s previous
unpleasant experience with needles and parent’s rating of the
child’s anticipatory anxiety prior to the medical procedure (tau
= .41; p<.05); with parent’s own anticipatory anxiety (tau = .47; p<.01) and with parent’s rating of the pain they
anticipated their child would experience during the procedure
(tau = .31; p<.05).

Prediction of Distress - Multiple Regression Data
A stepwise multiple regression analysis was used to determine
the predictor variables for children’s total distress scores.
Results suggested that the child’s self-concept for social
acceptance ( F (1,16) = 6.50 ; p<.05) and child’s usual anxiety
over injections ( F (2,15) = 7.16; p<.01) were the two predictor
variables for children’s total distress scores.
Physiological data

Heart rate (high) taken in the waiting room negatively correlated (two-tailed) with parent’s rating of the child’s anticipatory anxiety prior to the procedure (rho = -.81; p<.002); with parent’s rating of their own anxiety prior to the procedure (rho = -.80; p<.002); and with parent’s global pain rating (rho = -.78; p<.02). Heart rate taken during phase 3 of the medical procedure (removal of needle) negatively correlated with parent’s rating of their own anticipatory anxiety prior to the procedure (rho = -.64; p<.02). Heart rate taken during phase 1 and 2 of the procedure did not correlate with global ratings or anticipatory ratings.

Systolic blood pressure taken immediately after bloodtests positively correlated with total distress scores (rho = .67; p<.02) and with phase 1 (rho = .65; p<.02) and phase 2 (rho = .64; p<.02) but not phase 3. Diastolic blood pressure taken both before and after bloodtests was not significant with total distress scores, global ratings or anticipatory ratings. The results suggest systolic blood pressure to be more useful than heart rate as a physiological measure of anxiety and distress. Heart rate taken in the waiting room, before, during and after the medical procedure did not correlate with systolic and diastolic blood pressure.

Non-adherence to treatment

Children who said they argued over treatment with parents had
higher parent ratings of their anticipatory anxiety prior to the procedure (tau = .40; p < .01); higher parent ratings of their own anticipatory anxiety prior to the procedure (tau = .44; p < .005); and were likely to report high global anxiety scores themselves (tau = .39; p < .01) as well as pain scores (tau = .43; p < .01). Children who said they argued over treatment had parents with high trait anxiety (tau = .41; p < .01).

Variables not related to children's distress
Variables which were not related to children's total distress scores included: parent and child state and trait anxiety scores, child internal health locus of control, Rutter parent questionnaire total score, Rutter teacher questionnaire total score, parent and child external locus of control, parent internal locus of control, the child's self-concept scores for cognitive competence, athletic competence, physical appearance, behavioural conduct, and global self-worth, the number of coping strategies used, parent ratings of child's anticipatory anxiety and pain, child's rating of parent's anticipatory anxiety, months since diagnosis, months since transplant, number of drugs taken by child, social class, ethnicity, birth order, child's physical health status, frequency of blood tests, number of transplants experienced by the child, family illness, the child's usual anxiety over dialysis needles and dental needles, whether parents were willing to wait in the waiting room during the medical procedure, child's anticipatory anxiety prior to attending clinic, number of kidney rejections, whether children
had been dialyzed, parent rating of child's understanding of his/her illness, child's understanding of illness and treatment, child's previous unpleasant experiences with needles, whether child's illness and treatment interfered with the child's activities and physiological measures of heart rate.

7.4 DISCUSSION

The present study found that children's self-concept for social acceptance and usual anxiety over injections were the two predictor variables for total distress scores during routine bloodtests. Children with low distress scores tended to have high self-concept scores for social acceptance (i.e. the degree to which a child feels accepted by peers and others). The revised Observation Scale of Behavioural Distress (OSBD) positively correlated with nurse ratings of the child's anxiety and pain, parent ratings of the child's usual anxiety over bloodtests and child's rating of usual anxiety over injections. The scale correlated with nine of the eleven behavioural categories.

"Requests emotional support" and "information seeking" did not correlate with distress scores since they occurred infrequently, suggesting that for this group of children they could be omitted from the scale. Although the OSBD was developed for use with paediatric cancer patients (Jay et al, 1987), it was found to be a valid measure assessing children's distress during venipunctures, considered to be less painful procedures.

Hypotheses about the relationship between certain psychosocial
variables and children's distress were partly confirmed for child state anxiety, child external locus of control and self-concept for social acceptance. In addition, children with emotional/conduct disorder or high trait anxiety tended to have higher distress scores during the medical procedure. The results failed to show a relationship between global self-concept scores, depression and health locus of control in the children. Distress scores also did not correlate with parent state and trait anxiety or locus of control, as expected. There could be two explanations for these findings. Firstly, these variables may be less relevant for mildly painful medical procedures than for more painful procedures such as bone-marrow aspirations. Also, the psychosocial variables influencing children's distress may vary according to chronicity of illness (life-threatening versus non life-threatening) and severity of medical procedure (e.g. bone-marrow aspirations versus bloodtests). Secondly, the small sample size may have not permitted an adequate assessment of these variables. Further studies with larger groups of children could help to clarify whether these psychosocial variables influence children's distress during mildly painful procedures.

There were no age and sex differences in children's expressions of distress. However, there were no children below the age of six years in the present study. Other studies have found differences according to age (Jay et al, 1983; Katz et al, 1980) however these included much younger children in their samples. There is evidence that distress levels drop dramatically between the ages
of six and seven years, suggesting a cognitive-developmental factor underlying children's distress. This is consistent with children's development of concepts of pain. That is, children aged seven years have a more logical and realistic understanding of medical procedures, which may function to reduce anxiety. Although mean self-report scores were relatively low, some children in the present study were still anxious about bloodtests despite numerous procedures in the past. Indeed, there was a positive relationship between the number of previous bloodtests and behavioural distress. Many older children may not express their distress overtly by crying, screaming and physical resistance. It is therefore important to obtain information from older children about their pain. Anecdotal evidence from the study suggested that many children used to be more anxious about bloodtests immediately after their transplant but coped better with time. These children stated that they would have benefitted from help with bloodtests early on in treatment. Jay et al (1983) suggested habituation and adjustment to procedures are related to interpersonal factors such as relationship with medical staff. In the present study, children sometimes had a clear preference for one nurse to carry out the procedure, although children's distress was not related to the nurse performing the procedure. There was evidence that distress in children during bloodtests caused stress in medical staff and was related to higher self-reported anxiety in nurses performing the procedure.
Parents reported bloodtests to be the most stressful treatment in the child's medical regimen and the second most stressful for children after clinic visits. Bloodtests were, however, of least concern to parents. Unlike other studies of severe pain (Katz et al, 1980; Zeltzer and LeBaron, 1982; Jay et al, 1983) the majority of children did not experience anticipatory anxiety prior to clinic (changes in eating, sleeping, crying, nausea) suggesting that bloodtests were not overly stressful or that children had habituated to them. Children who were anxious about attending clinic tended to have higher global anxiety and pain ratings associated with bloodtests. If a child was anxious about injections or dialysis, he/she was likely to be anxious about bloodtests. Difficulties relating to adherence to treatment were associated with higher self-report of anxiety and pain as well as high trait anxiety scores in parents.

Previous experience and observational learning had an impact on children's distress. Children with previous unpleasant experiences with needles had higher anticipatory anxiety and parent anticipatory anxiety prior to bloodtests. However, in contrast, children who had experienced more than one transplant reported significantly lower self-reported anxiety during bloodtests. One possible explanation may be that repeated traumatic invasive procedures facilitated habituation to
relatively milder stressful procedures. Many children had fears or phobias and there was a relationship between fears and age. That is, children under the age of 11 years had more fears reported by parents than older children. Children with other fears and with other family members with fears tended to have higher self and observer ratings of anxiety and distress. Injection fears were common in the parents, suggesting children may have learned similar fears through observational learning.

According to children, unsuccessful venipunctures was the most common problem in not coping with bloodtests. Insertion of the needle was reported to be the most stressful part of the procedure. Children in the study tended to have either a monitor or distractor coping style described in the literature (Miller, 1979). The majority of children had a monitor style of coping with bloodtests, preferring to observe the needle and procedure closely in order to know “when the needle was coming”. Other children preferred to look away during the procedure and distract themselves. This type of coping style could be related to locus of control (Nowicki and Strickland, 1973) and health locus of control (Parcel and Meyer, 1978), however this was not found to be significant in this study.

The most frequently reported coping strategy was deep breathing or relaxation. A few children used imagery spontaneously which could possibly be described as self-hypnosis. This included superhero imagery, transforming the meaning of pain and images
of mastery. Children already using coping strategies effectively should be encouraged to continue using them. However, for children with no coping strategies, parental intervention can be helpful. Most parents in the study used emotional support or did not help their child during bloodtests because they felt they did not need to. The child's pain or distress at other times was managed by providing reassurance, comfort or information.

There was evidence of increasing understanding of bloodtests and treatment with age, consistent with other studies of children's development of health related concepts (Bibace and Walsh, 1980; Perrin and Gerrity, 1981). An interesting finding was parent's overestimation of children's understanding of both bloodtests and illness. While half the sample of children had from a moderate to a great deal of understanding of bloodtests (of the need to test kidney function), a third had no understanding at all. The concept of illness was even more difficult. Many children only had a little understanding that they had a kidney problem. While children's understanding of health related concepts is expected to increase with age (Burbach and Peterson, 1986; Ross and Ross, 1988; Eiser, 1990) individual differences in understanding were noted in the present study. That is, some older children and adolescents appeared to have no understanding of bloodtests. This was not consistent with a "stage" view of children's development of concepts of illness and treatment. Indeed Eiser (1990) argues that developmental changes in
concepts of illness may be the result of experience and do not need to be explained in terms of stages of development. The stage model has been criticized because of its failure to acknowledge the role of experience, social and cultural factors and in explaining how children pass from one stage to another.

Physiological measures of children’s pain, anxiety and distress yielded puzzling results. Heart rate failed to positively correlate with children’s distress during bloodtests. Rather, high heart rate in the waiting room was associated with low parent ratings of child’s anticipatory anxiety, and own anticipatory anxiety, and parent rating of the pain children experienced during bloodtests. These results are counter-intuitive and suggest either that parents were not accurate at rating their child’s distress or that heart rate was not a reliable measure of distress. Interestingly, systolic blood pressure taken immediately after bloodtests proved to be a more reliable indicator of children’s distress before and during the procedure. Heart rate and systolic and diastolic blood pressure did not correlate with one another. The lack of concordance between behavioural, cognitive and physiological measures of pain has been documented (Epstein, 1976).

The present study represents a first attempt to study psychosocial variables related to children’s distress during routine bloodtests following renal transplantation. Parent and child reports confirmed the child’s illness was stressful and
imposed restrictions on the family. Invasive medical treatments impose further stresses on the child which are likely to be more acute with younger children, and children beginning complex medical regimens immediately after renal transplantation. Further assessment studies are required with larger groups of children, possibly focusing on the time shortly after renal transplantation when the child and family are adjusting to further invasive medical treatments on a regular basis. While a body of research is accumulating into the assessment of pain in children, those with end-stage renal failure have not received as much attention as other chronic illnesses such as childhood cancer. Specific chronic illnesses need to be assessed separately as the factors influencing pain perception may vary according to type and severity of chronic illness as well as situational, emotional and child specific factors.
8.1. STAIT TRAIT ANXIETY INVENTORY (STAI)

The State-Trait Anxiety Inventory (STAI) provides measures of anxiety for adolescents and adults (Spielberger, Gorsuch and Lushene, 1970). It is the most researched and best standardized inventory on anxiety, and was therefore used in this research. Cattell (1966) and Cattell and Scheier (1963) introduced the concepts of state and trait anxiety, which were later elaborated by Spielberger (1972).

State anxiety is conceptualized as a transitory anxiety response which varies from moment to moment and is situationally determined (Spielberger, 1972). It is characterized by subjectively perceived feelings of tension, apprehension, worry, nervousness and arousal of autonomic nervous system activity. In contrast, Trait anxiety is a relatively stable tendency to respond anxiously to a wide range of stimuli, especially those perceived as threatening (Spielberger, Gorsuch and Lushene, 1970; Spielberger, 1972). Individuals with a high Trait anxiety are likely to experience more intense elevations in State anxiety in a stressful situation. Assessment of State and Trait anxiety is nevertheless independent.

The STAI (Form Y), consists of two 20 item self-report scales for measuring State (S anxiety) and Trait (T anxiety) anxiety. The S
anxiety scale evaluates how subjects feel "right now, at this moment", while the T anxiety scale assesses how subjects "generally feel". The STAI has been used to assess anxiety in psychiatric, medical, surgical and psychosomatic patients (Spielberger et al, 1983). Although the STAI was originally developed for use with adolescents and adults, it has been extended to children (described in the next section).

Administration.
The STAI was presented to the parent or adolescent as a self-evaluation questionnaire. Form Y-1 (state anxiety) was presented first before the child's bloodtest, following questions concerning anticipatory anxiety. Form Y-2 was then completed, sometimes after the child's bloodtest, depending on the clinic schedule. The S anxiety scale is sensitive to conditions under which the test is administered and was therefore given first, particularly as subjects were more likely to be anxious before rather than after bloodtesting. In contrast, the T anxiety scale is thought to be relatively impervious to conditions under which it is given (Spielberger et al, 1973).

In responding to the STAI S-anxiety scale (eg "I feel calm, I feel secure, I am tense, I am strained"), subjects were asked to blacken the number on the test form for each item statement which best described the intensity of their feelings: 1) not at all; 2) somewhat; 3) moderately so; 4) very much so. Parents and adolescents were asked to indicate how they generally felt on the
T anxiety scale (eg "I feel pleasant, I feel nervous and restless, I feel satisfied with myself") by rating the frequency of these feelings: 1) almost never; 2) sometimes; 3) often; 4) almost always.

Scoring.
Each STAI item is weighted from 1 to 4 (1= low anxiety; 4= high anxiety). Scoring weights for anxiety - present items (eg "I feel frightened", "I feel upset") are the same as the blackened numbers on the test form. The scores for anxiety - absent items (eg "I feel calm", "I feel relaxed") are reversed. Total scores for both State and Trait anxiety can vary from 20 to 80.

Norms, reliability and validity.
The test development and validation process is described in detail by Spielberger et al (1970). Spielberger et al (1983) report normative data for Form Y for working adults, high school students, college students and military recruits. Norms for Form X are also reported for male psychiatric patients, general medical and surgical patients and young prisoners. The internal consistency of the Trait-anxiety scale, represented as coefficient alpha, ranges from .89 to .91 for male and female samples of working adults, high school and college students and military recruits. The alpha ranges for State-anxiety are .86 to .95. The stability of the STAI scales (Forms X and Y) was assessed for test-retest intervals which ranged from 1 hour to 104 days. Test-retest correlations for the Trait-anxiety scale ranged from .65 to .86, compared to .16 to .52 for the
State-anxiety scale. The low level of stability found for the State-anxiety scale is expected because state anxiety reflects situational factors that exist at the time of testing. The stability of the STAI as measured by test-retest correlations is therefore high for the T-anxiety scale and low for the S-anxiety scale, as expected for a measure assessing anxiety resulting from situational stress.

Spielberger et al (1983) provide evidence of the concurrent, convergent, divergent and construct validity of the STAI scales. They refer to research findings relating to six areas: contrasted groups; correlations between the S-anxiety and T-anxiety scales; correlations of the T-anxiety with other trait anxiety measures; correlations of STAI with other measures of personality; correlations of the STAI scales with academic aptitude and achievement; and the effects of stress on S-anxiety scores. The STAI was found to discriminate between anxious patients and normals; the median correlation for the State and Trait anxiety scales for seven samples is .65. The T-anxiety scale correlated with other widely used trait anxiety scales at the time it was being developed (i.e. .75 with the IPAT Anxiety Scale and .80 with the Taylor Manifest Anxiety Scale).

Buros (1978) states that the reliabilities of the STAI are nearly as high as those expected for intelligence scales. It demonstrates expected differences among groups of people and its State form generates nonrandom factor structures when used over...
time. In addition it is a valid and efficient way to assess individual differences in both anxiety proneness and phenomenological experiences of anxiety in patient and normal populations. The only main criticism is its openness to faking which would be a problem if used in personnel selection.

8.2. STATE-TRAIT ANXIETY INVENTORY FOR CHILDREN (STAIC).

The State-Trait Anxiety Inventory for Children (STAIC) is similar in development and structure to the STAI described above. It was particularly developed to measure anxiety in nine to 12 year old children, however, it may also be used with younger children with average or above reading ability (Spielberger, 1973). For example, it has been used successfully with third grade (8 year old) children (Papay and Hedl, 1978) as well as first (6 year old) and second grade (7 year old) children when the scale was read to them and their responses recorded by the researcher (Papay, Costello, Hedl, and Spielberger, 1975). The STAIC consists of two separate self report scales for measuring state anxiety (A-State) and trait anxiety (A-Trait). The A-State scale, designated C-1, consists of 20 statements concerning how children feel "right now, at this very moment" such as "calm", "upset" and "pleasant". Children are asked to decide how they feel by choosing one of three words: "very calm", "calm" or "not calm". The A-Trait scale designated C-2 also consists of 20 statements, but children respond to these by indicating how they generally feel. Thus, to statements such as "I worry about making
mistakes" and "I feel like crying", children decide whether it is true for them "hardly ever", "sometimes" or "often".

The STAIC items are similar in content to the STAI, but have been simplified for use with young children. Like the STAI, the A-State scale measures transitory anxiety states, while the A-Trait scale is a more stable measure of individual differences in anxiety proneness. Children with a high A-Trait score are expected to score high on the A-State scale in threatening situations. Indeed, stressful situations normally evoke high elevations in A-State. Generally, children with high A-Trait tend to have high A-State scores because they perceive situations as more threatening or dangerous than children with low A-Trait (Spielberger, Edwards, Lushene, Montuori and Platsek, 1973).

Administration.

The STAIC is referred to as the "How I Feel Questionnaire" when presented to the child. In this study, the STAIC A-State scale was presented first, followed by the A-Trait scale. The questionnaire was read aloud to the child, who gave his or her responses. Some children had difficulty in understanding certain adjectives, asking the researcher to explain further. This was done using alternative words and giving examples of situations where the child might experience such feelings.
Scoring.

Each STAIC item is a 3-point scale, which provides A-State and A-Trait scores ranging from 20 to 60. The A-State items are scored 3 for anxiety present items, and 1 for anxiety absent items. For example, very worried=3; worried=2; and not worried=1; and very calm=1; calm=2 and not calm=3. The A-Trait items are scored for frequency of occurrence. For example for item 3 ("I feel unhappy") the child decides if the statement is hardly ever, sometimes or often true. These are scored 1, 2 and 3 respectively.

Norms, reliability and validity.

Development of the STAIC is described by Spielberger (1973). Extensive norms are available, based on two large samples of elementary school children in Florida - 1554 fourth, fifth and sixth grade (9 - 11 year old) students. The A-State scale was always given first, followed by the A-Trait scale. Both samples included 35 to 40 percent of black children because one school selected for study had predominantly black students. Small sex differences were found for the A-Trait scale. The mean STAIC A-Trait scores were slightly higher for girls than for boys, particularly in the fourth and fifth grades. Differences in mean STAIC A-State scores for boys and girls were minimal.

Spielberger (1973) provided test-retest reliability coefficients for the STAIC for 246 fourth, fifth, and sixth grade children. Test-retest correlations for the A-Trait were moderate,
(males= .65; females= .71) which are attributed to both limitations in the psychometric properties of the scale and unstable personality characteristics in the children at these ages. Correlations for A-State were low as expected (males= .31; females= .47) because the measure is sensitive to unique situational factors at the time of testing. Evidence for internal consistency of the STAIC scales is given: the alpha coefficients for the A-State scale for males were .82 and for females .87; for the A-Trait scale the alpha coefficients were lower, .78 for males and .81 for females. Evidence for internal consistency of the STAIC scales is therefore good; and moderate for stability (test-retest reliability) of the A-Trait scale. Interestingly, the subscales of the STAIC are generally less internally consistent and stable compared to the STAI scales (Spielberger et al, 1970).

Evidence for concurrent validity of the STAIC A-Trait scale was provided by its correlation with the Children's Manifest Anxiety Scale (Castaneda, McCandless and Palermo, 1956) and the General Anxiety Scale for Children (Sarason, Davidson, Lighthall, Waite and Ruebush, 1960), the two most widely used measures of trait anxiety in children. The STAIC A-Trait scale correlated .75 with the CMAS and .63 with the GASC in a sample of 75 children (Platsek, 1970, as in Spielberger et al, 1973). Further evidence for the construct validity of the A-State scale is given based on a sample of over 900 fourth, fifth and sixth grade students given the scale under normal conditions (standard) and then test
conditions (according to how they would feel before an examination in an important subject).

Mean scores were higher in the test condition than the normal condition, and furthermore, individual items significantly discriminated between these conditions for males and females. In an unpublished study, Gorsuch (1971) as in Spielberger et al (1973) investigated the relationship between A-Trait and a number of factors in a sample of 428 fourth and fifth grade elementary children in Tennessee. A significant negative correlation was found between IQ (measured by the IPAT-CPQ) and A-Trait; scores were significantly higher for girls than boys and for children from lower socio-economic backgrounds. There was no relationship between STAIC A-Trait scores and race or grade.

The STAIC has been used in a number of experimental studies with children; for assessing anxiety in 12 to 15 year olds with reading difficulties or emotional problems (Finch, Kendall, Dannenburg and Morgan, 1978; Finch, Kendall and Montgomery, 1976; Finch, Montgomery and Deardoff, 1974); for investigating the effects of stress associated with school integration for black and white elementary children (Edwards, 1972 as in Spielberger, 1973); for investigating the effects of success and failure for ninth grade children; for the assessment of distress of chronically ill children undergoing invasive medical procedures (Jay et al, 1983); for assessing the psychological effects of illness in adolescence (Kellerman et al, 1980) and in
8.3. THE RUTTER PARENTAL SCREENING QUESTIONNAIRE.

This is a children's behaviour questionnaire which is completed by parents, concerning the child's emotional and behavioural adjustment over the last 12 months. The Rutter Scale A questionnaire was developed in parallel with Scale B questionnaire for completion by teachers (Rutter, 1967), for children in the middle age range (i.e. 9 - 12 years). It was used in this study to screen children likely to show emotional or behavioural disorder.

It's usefulness is in differentiating neurotic and antisocial disorder, but it provides only a crude measure which for clinical purposes needs to be supplemented by further information. Other difficulties with this scale have been described by Rutter (1970):

1) While information on the child's behaviour is provided by the parent, a child's behaviour can differ markedly at home and school.

2) The questionnaire was developed on nine to 12 year olds only, although later studies on the Isle of Wight investigated the use of the scale with infant school children and children in their last year of compulsory schooling.

The scale contains 31 items listed as minor health problems which most children have at some time, and a series of descriptions of
behaviour often shown by children, which are divided into three sections. The first section on health problems consists of eight problems (eg complains of headaches, has stomach-ache or vomiting etc) which requires the parent to place a cross in the box representing frequency over the last year. There is a three-point rating scale: "never", "occasionally, but not as often as once per week" and "at least once per week" which are scored 0, 1 and 2 respectively. In the second section referring to habits, there are five questions (eg "Does he/she stammer or stutter?") to which the parent responds "No", "Yes-mildly" or "Yes-severly". These are weighted 0, 1 and 2 as in the first section. The third section contains 18 descriptions of behaviour identical to those on the teacher's questionnaire described in the next section. The parent decides whether each statement "doesn't apply" , "applies somewhat" or "certainly applies". Again these are scored 0, 1 and 2 respectively. The total maximum score produced on this questionnaire is 60.

Children obtaining a score of 13 or above are recognised as showing appreciable emotional or behavioural problems. They are further distinguished as neurotic or antisocial as follows:

1) A "neurotic" subscore is obtained by adding the scores of the following items: B ("has stomach ache or vomiting"), G ("had tears on arrival at school or refused to go into the building"), V ("is there any sleeping difficulty"), 6 ("often worried, worries about many things"), and 15 ("tends to be fearful or afraid of new things or new situations"). Children with a
neurotic score which exceeds the antisocial score are defined as "neurotic".

2) An "antisocial" subscore is obtained by adding the scores of items III ("does he/she ever steal things"), 3 ("often destroys own or others' property"), 13 ("is often disobedient"), 17 ("often tells lies") and 18 ("bullies other children"). Children with an "antisocial" score exceeding the neurotic score are defined as "antisocial". Children with equal neurotic and antisocial scores remain undifferentiated.

Evidence of good retest and inter-rater reliability is discussed by Rutter (1970) and was obtained during a larger epidemiological survey in Aberdeen. Retest reliability of the Rutter parent questionnaire was obtained from 83 mothers who rated their nine to 13 year old children twice with a two month interval. The product-moment correlation between total scores was .74. Inter-rater reliability between fathers and mothers of 35 nine to 13 year old children was .64.

The discriminative power of the questionnaire was tested by comparing scores of children in the general population with those of children from psychiatric clinics. Children in the general population sample consisted of a random sample of 99 boys and 99 girls aged nine to thirteen years who lived in Aberdeen. Children in the clinic sample consisted of a consecutive series of 72 boys and 48 girls attending the Maudsley Hospital. The best
discrimination between clinic and non-clinic children was established by a score of 13 or more; 70.8 per cent of boys and 66.6 per cent of girls in the clinic sample obtained scores of 13 or more compared to 15.1 per cent of boys and 8.1 per cent of girls in the non-clinic sample.

Further validation of the scale is provided by data discriminating neurotic children from antisocial children on the basis of clinical diagnoses (from case notes) and questionnaire diagnoses (Rutter, 1970). Agreement between clinical and questionnaire diagnoses was found in about 80 per cent of the antisocial and neurotic children. The Isle of Wight studies of 10 and 11 year old children (Rutter, 1970), showed that 54.5 per cent of children diagnosed as having psychiatric disorder scored 13 or more on the scale compared to 6.0 per cent of children in the general population. In addition, the agreement between final psychiatric diagnosis of neurotic or antisocial disorder and scale diagnosis agreed in 78 per cent of cases. There is therefore good evidence of the scale's validity in indicating whether the child shows psychiatric disorder and discriminating between neurotic and antisocial disorders.

The Rutter Parental Screening Questionnaire has been used in numerous studies assessing psychiatric adjustment in children with chronic renal failure (Garralda et al, 1988); the relationship between blood lead, intelligence, reading attainment and behaviour in 11 year old children (Silva, et al, 1988); investigating the relationship between attainment and adjustment.
in children (Rutter, Yule, Quinton, Rowlands and Yule, 1975); perinatal problems (McGee, Silva and Williams (1984); psychological problems in Ugandan children (Minde (1975) and investigating the effects of father absence of children in naval families (Totterman, 1989).

Methodological issues to be considered include the scale’s restriction to children in the middle age range and that the behaviour of children changes over time (Butler and Golding, 1986). In addition, parent’s own feelings and mood may influence the way they complete the questionnaire. Lastly, there may also be cross cultural differences regarding the way children’s behaviours are accepted or perceived as deviant. That is, in some countries some behaviours may be more acceptable than others.

8.4. RUTTER TEACHER QUESTIONNAIRE.

The Rutter Teacher Questionnaire is a children’s behaviour questionnaire for completion by teachers concerning behaviour in a school situation and is very similar in content and scoring to the Rutter Parent Questionnaire described above. It is a good screening device for behavioural and emotional disorders for children in the middle age range, and is a valid discriminator between neurotic and antisocial conditions. Rutter (1967) describes the development of the scale on seven - 13 year old children from eight different schools.

The teacher scale consists of 26 statements regarding the child’s behaviour to which the teacher decides whether the statement
"doesn't apply", "applies somewhat" or "certainly applies". These are weighted "0", "1" and "2" respectively. The 26 items provide a total score of 52. A score of nine or more points indicates some disorder. Children obtaining a neurotic score exceeding the antisocial score are designated "neurotic", while those with an antisocial score exceeding the neurotic score are designated as "antisocial". The neurotic subscore is obtained by adding the scores of the following items: 7 ("often worried, worries about many things"), 10 ("often appears miserable, unhappy, tearful or distressed"), 17 ("tends to be fearful or afraid of new things or situations"), and 23 ("has had tears on arrival at school or has refused to come into the building in the past 12 months"). The antisocial subscore is obtained by adding the scores of items 4 ("often destroys or damages own or others' property"), 5 ("frequently fights or is extremely quarrelsome with other children"), 15 ("is often disobedient"), 19 ("often tells lies"), 20 ("has stolen things on one or more occasions in the past 12 months"), and 26 ("bullies other children").

Rutter (1967) reports good retest reliability and inter-rater reliability for the scale. Retest reliability of 0.89 was obtained on 80 seven year old children rated twice by four teachers with a two month interval between ratings. The inter-rater reliability from ratings of 70 children was 0.72. The discriminative power of the questionnaire was tested by comparing scores of children in psychiatric clinic samples with those of children in the general population. The best discrimination
between clinic and non-clinic children was obtained with a total score of nine or more. About 80 per cent of boys and 60 per cent of girls obtained scores of nine or above compared with about 11 percent of boys and 3.5 percent of girls in the general population. Similar results were obtained with further samples adding support to the scale's validity in differentiating children attending psychiatric clinics.

A further test of validity is the scale's discrimination between neurotic and antisocial children. Comparisons were made between teacher questionnaire scores and clinical diagnoses of neurotic or antisocial disorder based on clinic case notes. The percentage agreement was about 90 per cent for antisocial children and 80 per cent for neurotic children. These results were confirmed with additional samples used for cross-validation. Richman (1964) as in Rutter (1967) reported similar findings with a slightly modified version of the scale with a group of epileptic children attending a special school.

Rutter (1967) discusses the scale's limitations, which are much like those described for the parent scale:

1. It is a crude measure of disorder and for clinical purposes needs to be supplemented by further information from the teacher.

2. It does not identify children with monosymptomatic disorders.
3. It is less efficient in distinguishing children with less common disorders such as anorexia nervosa and obsessional disorders or disorders manifested outside the school setting. Interestingly, the overlap between disorders perceived by teachers and parents is very small (Rutter and Graham, 1966). The validity of the teacher scale depends on the teacher's observational skills and on opportunities to observe the child in various situations.

8.5. THE DEPRESSION SELF-RATING SCALE FOR CHILDREN (DSRSC).

The Depression Self-Rating Scale for Children (DSRSC) was developed to measure moderate to severe depression in childhood (Birleson, 1981). It is an 18 item self report questionnaire which consists of statements about the child's mood over the past week. The items (eg "I look forward to things as much as I used to"; "I sleep very well") are scored on a scale of 0-2. The child is asked to indicate whether he or she has felt each statement most of the time, sometimes or never over the past week. Sometimes is scored 1 and most or never is scored 0 or 2 depending on the positive or negative tone of the response. The depression scale includes measures of mood, cognitive aspects of depression, physiological and somatic complaints (Birleson, 1981). Although the total score is 36, children who score 13 or more are considered to be possibly depressed.

The operational definition of depressive disorder in childhood given by Birleson (1981) is as follows:
"i) Evidence of recent expressed unhappiness, sadness, misery or weepiness.

ii) A history of behaviour change lasting at least two weeks but less than one year.

iii) Evidence of recent impairment in social relationships and/or decline in school performance.

iv) The presence of two or more of the following symptoms: sleep disturbance, appetite disturbance, loss of usual energy or interest, reduction in activity, expression of self-deprecating ideas, suicidal threats or behaviour, increased irritability, new somatic complaints, wandering behaviour, and depressive delusions and hallucinations."

(p.76).

The above four criteria had to be met for a diagnosis of depression to be made. The scale was developed on four groups of children: 17 children aged seven to 13 years attending a child psychiatric clinic who were diagnosed as depressed according to the operational definition, a matched control group, and comparison groups of 20 children from a residential school for maladjusted pupils and 19 children from a normal school.

Independent ratings by three child psychiatrists of behavioural vignettes of the clinic children agreed with those of the investigator using the operational definition in 85% of cases and thus provided clinical validation of the definition. The scale
was subjected to an item analysis. Those items which discriminated the depressed children from the psychiatrically disturbed and normal children formed the final depression scale. The scale however requires further testing on other groups of depressed and psychiatrically disturbed children. A satisfactory level of test-retest reliability of 0.80 was found as assessed on the maladjusted group. Individual items correlated between 0.65 and 0.95. The split-half reliability coefficient found an internal consistency of 0.86. The scale was found to have high internal consistency, factorial validity and stability. While this study did not provide irrefutable evidence for the clinical validity of the diagnosis of depression in childhood, it did provide construct validity for the concept. Birleson (1981) suggested a replication was required using larger numbers of subjects although he estimated approximately only 2% to 5% of clinic cases may meet the operational definition criteria.

It would appear that the scale measures moderate to severe depression in childhood. It has been used in a number of studies including those assessing psychiatric adjustment in children with chronic renal failure (Garralda et al, 1988) and those investigating emotional difficulties in children with diabetes mellitus (Close et al, 1986). An advantage of the scale is its brevity compared to the Children’s Depression Inventory (Birleson, 1981).

The conceptual and methodological difficulties involved in evaluating depression rating scales for children are fully
discussed by Birleson, Hudson, Buchanan and Wolff (1987).
Self-rating scales have intrinsic limitations which have not been studied well in children (Kazdin and Petti, 1982). These difficulties include:

1) Whether children are able to answer honestly and reliably. Children over the age of seven years should be able to make judgements about their feelings and behaviour (Piaget, 1954). They may not, however, describe these in adult terms (Birleson, 1981). Self-report is influenced by mood and may not be a reliable measure when compared with performance. On the other hand, observer reports may be unreliable.

2) No single symptom of depression is unique to the condition with many features of depression overlapping with anxiety states and stress reactions.

3) Rating scales which correctly identify individuals with depression tend to also falsely identify subjects without depression (Galen and Gambino, 1975).

4) While self-rating scales are likely to mirror overlaps of moderate to severe depression with mourning and severe stress reactions, they are unlikely to delineate diagnostic subgroups.

5) Research has suggested that young children have difficulty in reporting depression, tending to overestimate it and that age increases the expression of depressive symptoms (Kazdin, French, Unis and Esveldt-Dawson, 1983). This has implications for how we
evaluate children's scores.

One difficulty regarding diagnosis of depression is that the symptoms overlap with those of other diagnostic categories. There is only modest agreement between self-report, clinical interview and research measures of depression in childhood (Kovacs and Beck, 1977). Birleson et al (1987) describe a clinical validation of the DSRSC on 155 children aged eight to 14 years referred to a child psychiatric clinic, based on standard psychiatric interviews, global mood assessments and clinical diagnosis. The DSRSC is helpful although imperfect in the identification of depression in childhood but cannot be expected to be a complete diagnostic tool as it does not include an assessment of other symptoms, the history of the disorder or its context. There is evidence that the DSRSC can tap an internal dimension of depression and that children can evaluate their feeling states. The instrument needs further testing on a non-clinical population before it can be used as a screening tool. Its value is in validating diagnosis in clinical and research populations and in assessing change in treatments for depression in children.

8.6. ROTTER LOCUS OF CONTROL SCALE.

Locus of control is a cognitive dimension which is concerned with the individual's attitudes about being able to control his or her own destiny. Individuals with an internal locus of control express strong belief in personal choice and being able to influence their own future. Individuals with an external
locus of control see themselves as being controlled by external factors such as fate, luck or chance. Rotter (1966) describes the concept of locus of control within a social learning framework. Locus of control was originally developed as a general measure of personality (Rotter, 1954) based on early instruments by Phares (1957) and James (1957) but has been modified to deal specifically with health issues (Wallston, Wallston, Kaplan and Maldes, 1976). The scale covers different areas such as general, social and political attitudes, achievement and affection.

The Rotter Locus of Control scale (I-E scale) is a 29 item, forced-choice test which includes six filler items intended to make the purpose of the test more ambiguous. Each item in the scale consists of a pair of alternative choices lettered a or b as follows for question 2:

a. Many of the unhappy things in peoples's lives are partly due to bad luck (external).

b. People's misfortunes result from the mistakes they make (internal). (p.11)

Subjects are required to choose the one statement which they more strongly believe to be true. The letter preceding the external choice is underlined in the appendix. The score is the summation of external choices. The items deal with the subject's belief about the world and expectations about how reinforcement is controlled. The test is consequently a measure of what Rotter (1966) refers to as a generalized expectancy, which may correlate
with the value the subject places on internal control. The individual items are not, however, concerned with a particular preference for internal or external control.

Rotter (1966) reports relatively stable internal consistency estimates for the scale, based on data obtained in a series of samples of University psychology students, groups of prisoners and a national stratified sample of 10th, 11th and 12th grades (i.e. ages 15 - 17 years). Test-retest reliability of the scale is satisfactory. It correlates reasonably well with other methods of assessing generalized expectancy for internal-external control such as questionnaire, interview assessments and ratings from a story completion test. Evidence for discriminant validity is provided by the low correlation with variables such as intelligence, social desirability, and political liberalness. A series of studies provide evidence of construct validity of the I-E scale and strong support for the hypotheses that an individual with an internal locus of control is likely to: (a) be more alert to those aspects of the environment which provide useful information for his future behaviour; (b) take steps to improve his environmental condition; (c) place greater value on achievement reinforcements; and (d) be resistant to subtle attempts to influence him (Rotter, 1966).

The scale has been used in numerous studies with adults. Jay et al (1983) studied locus of control amongst other variables in parents of paediatric cancer patients but did not find an
reliability data and is also difficult to administer to large groups. Lastly, the Crandall et al (1965) scale is developed for the academic achievement situation, and its forced-choice content may prove difficult for younger and less bright children.

Nowicki and Strickland (1973) constructed a more reliable, methodologically sound instrument to measure generalized locus of control of reinforcement. The Nowicki-Strickland Locus of Control scale consists of 40 questions answered “yes” or “no” constructed on the basis of Rotter’s definition of locus of control. The scale items describe reinforcement situations across interpersonal and motivational areas such as achievement, dependency and affiliation. An example of an achievement item is: “Do you believe that if somebody studies hard enough he or she can pass any subject?” The external response to this item is “No”.

The preliminary form of the test was made up of 59 items given to a sample of 152 children ranging from the third to ninth grades. Internals performed significantly better than externals on achievement test scores even when IQ was controlled (t=3.78; df=48). Test-retest reliabilities for a six week period were 0.67 for the 8-11 year old children and 0.75 for the 12-15 year old group. The 40 item scale was given to a large number of children (N=1,017) from grades three to twelve. The results showed:

1) Students’ responses became more internal with age.
2) Biserial item correlations were moderate but consistent for all ages.
3) The scale was found to have satisfactory internal consistency and test-retest reliability.
4) The Scores were not related to social desirability.
5) Internality was found to relate to higher occupational level, particularly for boys.
6) Locus of control scores were related to achievement, especially in boys.

Although the Nowicki-Strickland scale has been revised to produce shorter yet reliable versions of the 40-item scale, more reliability and validity data is required. It has also been revised for use with adult subjects. The scale has been used in a number of studies, the results of which add support to the validity of the scale.

8.8. CHILDREN'S HEALTH LOCUS OF CONTROL SCALE.

This instrument developed by Parcel and Meyer (1978) consists of 20 statements about health related issues that children respond to by Yes (agree) or No (disagree). Children were told the questionnaire was about a number of beliefs which children have about their health. They had to decide if they agreed or disagreed with each statement for example, "Good health comes from being lucky", by placing a circle around their answer. Children’s responses were scored in an internal or external direction. A score of two was given to each internal response and
a score of one was given to external responses. Multiple or missing responses were assigned a value of 1.5. The items were adapted in part from the Adult Locus of Control Scale (Wallston, Wallston and Kaplan and Haides 1976) and from statements in elementary grade health education textbooks. Seventeen items are worded in an external direction and three in an internal direction.

The instrument was developed from studies with children aged seven to 12 years which provided evidence of acceptable levels of reliability, internal consistency and construct validity. The preliminary instrument of 30 items showed there were no significant differences in scores according to sex, consistent with results obtained with the Nowicki-Strickland Children's Locus of Control Scale (Nowicki and Strickland, 1973). However, CHLC scores tended to become more internal with age as represented by grade. Lefcourt (1966) extensively reviewed the literature on locus of control stating that older children are more internal and that natural changes such as age influence I-E scores. The suggestion is that locus of control changes with developmental stages and could be related to other developmental stages (Parcel and Meyer, 1978). A relationship between ethnicity, socioeconomic status and locus of control was found, consistent with other studies. The findings were that black children of lower socioeconomic status tended to be more external than children in a mixed race group with a higher socioeconomic status (Parcel and Meyer, 1978).
Results obtained from the revised instrument were consistent with the above preliminary findings regarding sex, age and ethnicity. Kuder-Richardson coefficients showed a moderately high internal consistency for first and second administrations ($r = .72$ and .75) given on a six-week test retest interval. These compare favourably with estimates of internal consistency via split-half method for the NSCLC ($r = .63$). There was a significant but not high correlation between the CHLC and the NSCLC for the total group and each grade in the study. Validity studies show that the CHLC scale is associated with locus of control. Further studies are needed however to show that it is predictive of health behaviour (Parcel and Meyer, 1978). While the scale items have face validity for health, use of another measure of locus of control can provide further discriminant validity. Some studies have assessed locus of control and health related behaviours (e.g. Dabbs and Kirsch, 1971; Kellerman et al, 1980; Wallston, Maides and Wallston, 1976). Additional studies are required to substantiate findings for the CHLC scale and to assess its use particularly with chronically ill children.

Parcel and Meyer (1978) suggest three general forms in which the CHLC will facilitate the application of learning theory to studying children's health behaviour: (1) determining the relationship of health locus of control to particular health behaviours; (2) determining which social learning experiences reinforce an internal or external locus of control; and (3)
determining the effects of planned learning experiences on health locus of control in children. The application of social learning theory to children's health behaviour has particular relevance for health education. For example, if an internal locus of control is necessary for children to take more responsibility for health related behaviour, then planned learning experiences which would reinforce an internal health locus of control would be essential, which would also take developmental factors into account.

8.9. HARTER SELF-CONCEPT SCALES

The self-concept occupies a prominent role in numerous theories of human behaviour (Harter, 1988b). In the literature self-concept is considered as a global, unitary construct as opposed to a multi-dimensional, more differentiated aggregate of self evaluations. There are a number of conceptual models of self-concept, each of which dictates a particular measurement strategy. Unidimensional models (Coopersmith, 1967; Piers and Harris, 1969) are based on the assumption that self-concept is a unitary construct assessed by tapping a range of content areas, which are given equal weight to provide a single score. Multidimensional models (Harter, 1985, 1988b; Harter and Pike, 1984) identify particular domains of self-evaluation that are assessed separately. Self-concept can be conceptualized, along a continuum of approaches that are not necessarily mutually exclusive (Harter, 1988b). Issues in the assessment of
self-concept in children have been elaborated by Harter (1986, 1988b) as well as the causes, correlates and functional role of global self-worth in mediating the child’s affective state and motivational orientation (Harter, 1989).

The assumption underlying the construction of the Harter Self-Concept Scale was that a multi-dimensional scale would provide a richer and more differentiated picture than unidimensional instruments providing only a single self-concept score (e.g., the Coopersmith Self-Esteem Inventory, 1967). It is based on the assumption that children do not view themselves as equally adequate in all domains. It is for this reason that in the present research the Harter scale was selected. The rationale for a multi-dimensional self-concept scale has been discussed in detail by Harter (1982; 1985).

Empirical findings (e.g., Rosenberg, 1979) suggest self-concept undergoes developmental change, such that young children shift their focus from behavioural characteristics of the self to trait-like constructs during middle childhood, and then to abstract psychological constructs during adolescence. Changes in the structure, content and question format of the various instruments described pose certain methodological problems when assessing developmental changes in self-concept at the individual level, where longitudinal or cross-sectional designs are employed. Scores may be confounded by changes in the nature of the instrument itself. Harter (1988b) has attempted to deal with...
this measurement issue by designing instruments which are as similar as possible across age periods, but which are responsive to developmental changes. Another issue is the stability of the construct itself. There is evidence that on domain-specific measures, self-concept changes considerably over time, even within a period of days or weeks (see Harter, 1988b).

Harter (1988b) in her exhortation of the issues involved in the assessment of self-concept, elucidates factors which influence children’s scores. One factor is the social reference group children use to compare themselves to. This could be explored by asking children which group of children they were thinking about when answering particular questions and also about the criteria they employ in making self-judgements. Harter (1985) suggests it is also of value to enquire about the determinants of a child’s sense of adequacy or competence. Other factors which influence children’s judgements of competence or adequacy are comparison with past performance, comparison with ones ideal self and the feedback received from significant others. Children may be less cognizant of the determinants of global self-worth judgement. Harter (1985; 1986; 1988b) has identified two important antecedents of a child’s sense of global self-worth drawing on the work of James (1892) and Cooley (1909) both cited in Harter (1988b): the degree to which one is successful in domains believed to be important, and, one’s perceptions of the attitudes which others hold toward the self.
Harter developed a number of self-concept scales for children which tap children's judgements about specific domains, and (for older children and adolescents) ask about self-worth itself, that is, the overall value that is placed on the self as a person. Thus, her approach integrates multidimensional and unidimensional models of assessing the self-concept. The following scales were developed for children and adolescents taking into account developmental changes in the structure and content of the self, and are described below:

1. The Pictorial Scale of Perceived Competence and Social Acceptance for Young Children
2. The Self-Perception Profile for Children
3. The Self-Perception Profile for Adolescents

1. The Pictorial Scale of Perceived Competence and Social Acceptance for Young Children

This was designed to be a downward extension of the Perceived Competence Scale for Children (Harter, 1982) and is not viewed as an index of self-concept because of the structure of the scale. Rather, it is a scale of the child's perceived competence and social acceptance. The scale consists of four subscales: (1) Cognitive Competence, (2) Physical Competence, (3) Peer Acceptance, and (4) Maternal Acceptance. There are separate versions of the scale for Preschool (kindergarten) children and one for first and second grades. The latter was used in the present research for children aged six and seven years.
Judgements across these four domains are not yet clearly differentiated. Two factors were identified from factor analyses for both age groups. These were General Competence and Social Acceptance (see Harter and Pike, 1984). General Competence included cognitive and physical competence, while Social Acceptance involved both peer and maternal acceptance. Young children were able to make reliable judgements about the four domains when pictorially depicted as concrete behaviours, but were unable to make judgements about their self-worth, because they do not have a verbalizable concept of their self-worth, as assessed by self-report measures. In fact, global self-worth does not emerge until approximately the mental age of eight.

The theory, rationale, construction and psychometric properties of the scale have been discussed by Harter and Pike (1984). The final version of the scale was piloted on 90 preschool children. Internal consistency reliabilities were found to be high for both competence scales (0.75) and acceptance scales (0.89) with a reliability of 0.89 for the total scale. The item means and standard deviations showed some variability suggesting individual differences in perceived competence and social acceptance. Harter and Pike (1984) discuss the convergent, discriminant and predictive validity of the scale. The reasons children gave for their judgements were consistent with their responses on the items and suggest their ratings are valid in the sense that these are based on specific behavioural referents. An interesting finding was that young children's judgements are not very
accurate when compared with teacher ratings (there is a teacher rating scale which parallels the child scale), with children tending to rate themselves positively. This is thought to reflect a blurring of the boundaries between reality and the wish to be competent or accepted, rather than to socially desirable responses.

The scale consists of a booklet of pictures (separate versions for boys and girls) and an individual sheet on which to record the child’s responses. There are 24 items, six items in each of the four subscales. Within each subscale, half of the items depict the competent child on the left and the other half on the right.

Instructions are standardized and given at the beginning of the booklet. The child is shown a sample item at the beginning of the booklet and given the following instructions:

"I have something here that’s kind of like a picture game and it’s called WHICH BOY (GIRL) IS THE MOST LIKE ME. I’m going to tell you about what each of the boys (girls) in the picture is doing.

Sample: In this one (examiner points to picture on the left), this boy (girl) is usually kind of happy, and this boy (girl) is usually kind of sad. Now, I want you to tell me which of these boys (girls) is the most like (Child’s Name)."

Following this, the researcher points to the circles directly below the picture to help refine his or her choice further. For example, if the child points to the sad picture, the researcher would ask:
Are you always sad? (pointing to the larger circle)

Or are you usually sad? (pointing to the smaller circle)

In some pictures there is a target child central to the description designated by an arrow which requires the researcher to point to that particular child.

Scoring.
Scores range from 1, for the least competent choice, to 4 for the most competent choice which are based on the child’s selection of circles under the pictures. These are recorded on the individual scoring sheet for each domain, the total of which is divided by six to provide a mean subscale score. A self-concept score of 1 is considered low; a score of 2.5 is medium; and a score of 4 is high. This scoring system applies to all of the Harter Self-Concept Scales.

2 The Self-Perception Profile for Children

This scale is a revision of the Perceived Competence Scale for Children (Harter, 1982), which was designed to assess children’s judgments of their competence, as well as a global perception of their worth as a person. The revised scale taps children’s perceptions of themselves rather than competence in the form of actual skills. The resulting individual scores across the various domains provide the most accurate profile of the child’s self-concept. The scale is appropriate for children aged eight to 12 years, but not younger, as children under the age of eight.
have not yet formed a global concept of themselves (Harter, 1988b). There is a further questionnaire for children aged eight to 12 years assessing competence in domains deemed important by the child. There is also a teacher rating scale of the child’s actual behaviour which parallels the Self-Perception Profile for Children. The scale contains six separate sub-scales tapping five specific domains and a global self-worth scale: (1) Scholastic Competence, (2) Social Acceptance, (3) Athletic Competence, (4) Physical Appearance, (5) Behavioural Conduct, and (6) Global Self-Worth. Each subscale contains six items, making up a total of 36 items. A practice item is included which is not scored. The subscale items are presented in the above order and thereafter repeat themselves throughout the instrument.

The questionnaire entitled "What I am Like" is introduced as a survey. The scale is administered orally for children aged eight and nine years, however, children over the age of ten years can read the items for themselves. The present researcher asked older children if they wished to read the questionnaire themselves or have it read to them. Generally most children preferred to have the questionnaire read to them. The scale contains a structured alternative format in which the child is presented with the following type of question:

Some kids find it hard to make friends

BUT

Other kids find it's pretty easy to make friends.

The child first decides which type of child is most like him or her, and then whether this is really true or sort of true for him
or her. This type of question avoids socially desirable responses by legitimizing either choice.

Scoring.
A detailed scoring key is provided in the back of the manual. Generally, the procedure is to score each item on a scale from 1 to 4, where score 1 represents low perceived competence and a score of 4 indicates high perceived competence. Thus, in the above example, the child who finds it hard to make friends and feels it is really true for him would receive a 1. The child who feels it is sort of true would receive a 2. The child who feels it is sort of true for him that it's pretty easy to make friends would receive a 3, and the child for whom this statement is really true would receive a 4. Scoring of subscales is as described for the previous pictorial scale, providing a total of six subscale means which define a child's profile.

Psychometric properties.
Harter (1985) discusses the psychometric properties of this scale based on four separate samples of children from 3rd grade through to 8th grade, with a total sample of 1543 children. Acceptable reliabilities for internal consistency were found based on Cronbach's Alpha, ranging from 0.71 for Behavioural Conduct to 0.86 for Athletic Competence. The means fluctuate around the value of 3.0 just above the midpoint scale. Differences were found associated with sex and grade level for certain subscales. Factor analyses revealed that individual domains define their own factor and there are no cross-loadings greater than 0.18.
Furthermore, there is a tendency for intercorrelations among subscales to be higher for younger children (3rd and 4th grades) than older children. Several clusters were found between Scholastic Competence and Behavioural Conduct; between Social Acceptance, Athletic Competence and Physical Appearance; and also between Physical Appearance and Global Self-worth. The implications of these correlations are discussed by Harter (1985). Interestingly, the two domains found to be most highly predictive of global self-worth for older children and adolescents are physical appearance and peer social acceptance.

The scale in its present form is unsuitable for children with learning difficulties, however, as the factor structure and interpretation of subscales is quite different (Silon and Harter, 1985). It is also not appropriate for children below age eight as the question format is not understood by younger children. Harter (1985) discusses additional considerations concerning children’s social comparison processes, the bases on which children are making their self-judgements, the determinants of a child’s competence and global self-worth and suggests methods of enquiring into these. There is an additional short questionnaire which taps competence in domains deemed important however, as this was not used in the present study it will not be discussed further.
3 The Self-Perception Profile for Adolescents

This scale is an upward extension of the Self-Perception Profile for Children. The language of certain items has been altered in the adolescent scale and three further subscales have been added reflecting the concerns of adolescents. The scale consists of the following nine subscales: (1) Scholastic Competence, (2) Social Acceptance, (3) Athletic Competence, (4) Physical Appearance, (5) Job Competence, (6) Romantic Appeal, (7) Conduct/Morality, (8) Close Friendship, and (9) Global Self-Worth. The original six domains of the Self-Perception Profile for children have been kept parallel across the child and adolescent versions. Many items are identical. There are five items in each subscale which are scored from 1 to 4 as described for the Self-Perception Profile for Children and the Pictorial Scale for Perceived Competence and Acceptance. The Self-Perception Scale for Adolescents consists of 45 items.

Psychometric Properties

Reliabilities for internal consistency for all nine subscales based on Cronbach's Alpha range from .74 to .93. These are based on four samples of adolescents from 8th to 11th Grade. The subscale means fluctuate around the value of 2.9, which is above the midpoint of the scale. With regard to subscale differences across samples, Close Friendship followed by Job Competence were consistently rated the highest while Romantic Appeal and Physical Appearance were rated the lowest. Sex differences were found with girls consistently rating their Athletic Competence, Physical
Appearance and Global Self-Worth lower than boys. In contrast, girls saw themselves as more adequate than boys in the area of Close Friendships.

Factor analyses showed that each of the eight specific subscales define their own factor with no cross loadings greater than .30. These therefore provide a differentiated and meaningful profile of self-perceptions for adolescents. Across all samples Physical Appearance was consistently and highly related to self-worth (r's in the range of .66 to .73) suggesting attractiveness is important to one's sense of self-worth. Intercorrelations among subscales show that Scholastic Competence, Social Acceptance, Close Friendships, Romantic Appeal and Behavioural Conduct were moderately correlated with self-worth. However, Athletic and Job Competence were less highly related to self-worth. For additional considerations to administering this scale see Harter (1988).
CHAPTER 9

INTERVENTION WITH CHILDREN SUFFERING ACUTE PAIN FOLLOWING RENAL TRANSPLANTATION: A PILOT STUDY.

Seven children were seen in this pilot study from May to December 1987 at Guy’s Hospital, London. These children took part in the assessment study described in Chapter 7 at the same paediatric renal transplant clinic. As interrater reliability, measures, and the paediatric setting have already been described in Chapter 7, these details will not be repeated.

The purpose of this pilot study was to:

1. Test two intervention scripts, hypnotic and cognitive-behavioural interventions for children aged 6-16 years, and ensure that they were both distinct from one another and of similar duration.

2. To see if the interventions could be delivered immediately before bloodtests and be accommodated into the clinic’s routine.

3. To see if the Stanford Hypnotic Clinical Scale for Children SHCSC (Morgan and Hilgard, 1978/1979) could be included in the same preparation session prior to the medical procedure.
9.1. METHOD

9.1.1. Subjects

Seven subjects took part in the pilot study: six girls and one boy who had received renal transplants because of end-stage renal failure. Children's ages ranged from 9 years eight months to 16 years 11 months, with a mean of 13 years 5 months. Three girls were Asian while the remaining three girls and boy were Caucasian. Children who either reported high distress (e.g. over 5 on the 10-point global rating scale) or were observed to show high distress levels by nurse observer (global ratings or behaviour checklist) were invited to take part in this intervention study aimed at helping children cope better with routine bloodtests.

The pilot subjects were assessed on the SHCSC before hypnotic or behavioural interventions. As described in Chapter 5, the scale takes 15-20 minutes to administer. The scale is presented as set out in Appendix XVII and follows a standardized script. The hypnotic and behavioural interventions were of similar duration to each other (approximately twenty minutes). Thus, the child's total intervention took about 40 minutes. The interventions were conducted prior to the child's bloodtest in a small room close to the in-patient renal wards (see Chapter 7). The SHCSC was administered first, followed by either a hypnotic or cognitive-behavioural intervention. Children were randomly allocated to one of these interventions.
Parents were present during the intervention if the child wanted them to be. Usually only one parent attended clinic with the child. The child was always asked his/her preference. Younger children tended to want their parent present while older children and adolescents did not. The interventions are described below:

9.2 PSYCHOLOGICAL INTERVENTIONS

9.2.1 Hypnotic intervention

The hypnotic intervention followed a standardized script, although fantasy was individual to each child. The intervention is partly based on work by Hilgard and LeBaron (1984), Gardner and Olness (1981) and Benson (1984; 1988). The phases of the hypnotic intervention were: the induction, progressive relaxation, deepening, treatment, and de-hypnotization. The child was prepared for the hypnotic intervention with a brief discussion of hypnosis (see Chapter 5) which was adapted to the child's age and understanding followed by a discussion of the word "relax" as a feeling of "letting go" when the therapist holds the child's wrist and lets it drop gently, or "feeling loose like a rag doll" (Gardner and Olness, 1981, p.352).

The hypnotic intervention is described below:

Induction

Induction of hypnosis involved either eye fixation on a smiling face on the child's thumbnail, television viewing or eye fixation on a coin. The choice of induction method partly depended on the
child's interests and his/her response to the SHCSC induction; for example, if the child had difficulty with eye fixation on the thumbnail television viewing was selected. The suggestions for "a" and "b" below were continued until the child closed his/her eyes and were therefore adapted to the child, but nevertheless followed a similar format:

a) Eye fixation on thumbnail

I want you to relax as you did a few minutes ago....just by looking at that face on your thumbnail.....and as you look at that face...you will feel so relaxed again you will probably want to close your eyes....just close your eyes when you are ready....as it is easier to imagine things with your eyes closed...just keep watching that little face as you listen to my voice....and let your whole body go floppy and relaxed.....your eyelids too are relaxing....as you listen to my voice....very soon they will feel so heavy that they will begin to close by themselves....let them close when they feel like it....that's lovely.

b) Eye fixation on coin

Hold the coin in one hand like this (between thumb and forefinger) and just look at it.....and listen to my voice....in a while your fingers will get a little tired of holding it....and the coin will fall down onto the floor....it will be safe there.....you can get it later.....when the coin falls just let your eyes close.

c) Television viewing

Close your eyes and imagine you are watching your favourite television programme....one that you know you will enjoy watching....as you are watching your programme...you are getting more and more interested in it....if it's a good one you can pretend that you are taking part in it.....what programme are you watching?....as you are watching your programme...let yourself relax.....you can carry on watching your programme while you listen to my voice.
Relaxation

Suggestions for progressive relaxation were given to the child:

Now let yourself relax completely...breathe nice and steadily...start by letting your eyelids relax...so with every breath you take and every word I say...your eyelids feel more and more relaxed and heavy...so heavy that if you tried to open them it would be too much trouble...then let that comfy relaxed feeling spread up over your forehead...across the top of your head...down your face...and into the muscles of your neck...that's lovely...any little noise in the background...like the telephone ringing...or people talking...is just helping you to relax more deeply.

Now let that comfy feeling of relaxation spread right to the top of your head...down into the tips of your fingers and the tips of your toes...letting the relaxation spread into your neck and shoulders...into your arms and hands...into the muscles in your chest...your back and tummy...pushing away any worries or butterflies...and as you're letting all the muscles in your tummy unwind and relax...so you are getting a lovely calm happy feeling...that's spreading into your legs...feet...and toes...as you relax your whole body you almost feel as though you're body doesn't belong to you...but that's a safe and comfortable feeling...it doesn't matter if you are carefully listening to my voice or not...because you can still hear every word...let your mind relax in the same way that you're letting your body relax.

Deepening

The child imagined a favourite activity or place which could later be fantasized during the bloodtest. The imagery was intensified such that the child’s attention was drawn to the sensory experience of the fantasy. Suggestions for well being and comfort were given. During the medical procedure, the child was encouraged to imagine this again. The purpose of the fantasy was to provide a dissociative experience from the child’s pain during the medical procedure. For example:
Imagine you are standing at the top of 10 steps leading down to a lovely beach....it may be a beach that you have been to....or one of your imagination....the sun is shining....it is as warm as you like it to be...the sea is blue and clear....and you can hear the waves gently lapping on the shore....as I count from 10 to 1 just walk down those steps....and as you walk down them let yourself drift deeper into relaxation....so that by the time you get to the bottom....you will feel very relaxed...as relaxed as you want to be....are you ready?....10..9..8..7..6..5..4..3..2..1..that's lovely.....now that you are on the beach...you can do what you like to help you to relax even better...perhaps you would like to go for a swim....or go water skiing....or eat an ice cream....what are you doing?.....(the researcher asks questions about what the child can see, hear, smell, taste etc. and the imagery is intensified).

Treatment
The treatment phase included direct suggestions for hypnoalgesia, rehearsal and post-hypnotic suggestions.

a) Direct suggestions for hypnoanalgesia

Imagery of a pain switch-box (see Chapter 5) was used to show how pain is transmitted by nerves from different parts of the body to the brain, which send a pain message back to the body. A picture was drawn to illustrate this. The child was invited to imagine a pain switch as follows:

Now because of your good imaginative ability....better than many adults....you can learn to turn off your pain switch whenever you have a bloodtest or injections....so you won't feel as much pain or feel as scared....I want you to imagine your pain switch....it could be like an on/off switch....or a remote control....or a dimmer switch....what does yours look like?...good....I wonder where you switch is....it might be in your head....or the top of one arm....or around your wrist....where is yours?....now imagine the veins from your arms (or legs if the child has blood taken from his/her legs) going to the switch....what colour are the veins?....now imagine you are turning off your switch so the pain messages won't get through to your switchbox....just
Imagine turning off the pain switch to the veins in that left arm....now give it a pinch...and now try pinching the right arm....what does it feel like?...does it feel different?...good...(if the child says no, explain that sometimes it takes a little while to learn how to do this).... you can turn the switch back to normal now.

When you have bloodtests from now on....you will find you automatically turn off your pain switch.....as soon as the nurse has found a vein....and wipes your skin with a swab...you will keep your pain switch turned off until the bloodtest is over....and you have placed cotton wool or a plaster on your skin.

b) Rehearsal method

The bloodtest was rehearsed in imagination including the pain switch-box and favourite place or activity fantasy. Suggestions for coping and mastery were given as well as preparing the child for unsuccessful venipunctures. The rehearsal went as follows:

Now let's imagine your bloodtest together...imagine you had your blood pressure taken....now imagine being in your favourite place or doing your favourite activity...and you keep on thinking about these right the way through...and now roll up your sleeve on your left arm....imagine the nurse is looking for a vein and finds one...you turn off your pain switch...the nurse cleans your arm with a swab...pretend the pen I touch you with is the swab (researcher touches child's arm lightly with a ballpoint pen)...and you carry on thinking about - (name child's favourite place or activity).....feeling calm and comfortable...and now imagine the nurse is inserting the needle into the vein...as I touch you with the pen again.....and maybe it doesn't work first time...but you don't let this bother you...you carry on using your imagination to help you stay calm...and now the nurse is taking blood from that arm...and now she has finished...and you are holding cotton wool over that arm...perhaps you stick a plaster on it....you might have been surprised to notice how much easier your bloodtest could be just by using your imagination in this way...and now you can turn your pain switch back to normal....feeling calm and relaxed again.
c) Posthypnotic suggestion

Posthypnotic suggestions were given for coping and mastery during the bloodtest, and for using the pain switch-box and fantasy as follows:

When you go to have your bloodtest soon....you can practice just what you have done in imagination.....you will be able to relax as soon as you enter the treatment room....where you will be weighed and measured and have your blood pressure taken as usual.....you can relax even deeper by looking at your thumbnail or taking a deep breath....and then you will do everything else automatically....without even thinking about it....imagining something you like doing or thinking about your favourite place while you are having your bloodtest....turning off your pain switch as soon as the nurse has found a vein and starts to clean your arm....you may be surprised and pleased at how well you can cope with bloodtests and other needles from now on no matter which nurse you see....and even if it doesn't work first time....because you are learning new ways of coping with needles....and the more you practice using your imagination to help you stay calm and relaxed....the better you get at it....even when I'm not there .....the more relaxed you are the easier it will be for the nurse to find a vein first time.

Now carry on relaxing for awhile....when you feel you have got what you want from this session to help you cope better with your bloodtest....take a deep breath....and open your eyes....you will then feel wide awake....calm and relaxed....with a nice warm feeling inside.....and feeling very pleased with the progress you have made today.

9.2.2. Cognitive-Behavioural Intervention

This intervention was also standardized. The use of imagery, often used in cognitive-behavioural approaches was avoided, so that the present intervention was distinct from the hypnotic one. The cognitive-behavioural approach was adapted from Jay et al's (1985) work with paediatric cancer patients and Meichenbaum's (1985) stress inoculation method. It is described
in the order that it was carried out.

Positive Incentive
The child was given a certificate (see Appendix XVIII) with his/her name on it for doing the best he or she could during the bloodtest and for keeping still and practicing breathing exercises. The child was told that keeping still enabled the nurse to find his/her vein more easily and the procedure would be over more quickly. The rationale described by Jay et al (1985) is that keeping still enables medical staff to perform the procedure more quickly with fewer unsuccessful venipunctures and the breathing exercises function as an active diversion, promote some relaxation, and reduce overt behavioural distress such as crying and screaming. The certificate was given to the child regardless of how well he or she coped with the medical procedure. Some children find invasive medical procedures distressing enough; to have withheld the certificate may have caused disappointment and upset.

Breathing exercises
Breathing exercises were taught to the child to promote relaxation and increase feelings of self-efficacy. The child was given a rationale for relaxation and breathing exercises: that taking deep breaths and relaxing would help him/her feel calmer and less scared. It was explained that relaxation and tension are incompatible states and that if the child was relaxed, the bloodtest would not hurt as much when the needle was inserted and removed. The child practiced deep breaths during the
preparation session and then during the bloodtest especially at
the point of insertion and withdrawal of the needle. Younger
children were encouraged to go floppy like a rag doll during the
rehearsal and bloodtest. This image was used as it had already
been included in the SHCSC.

Take a deep breath and fill your lungs right up and then
slowly let the breath out....and as you breathe out relax
your chest....pay attention to breathing out very slowly
each time you breathe out...spread your relaxation right
down your body...starting from you face and head....relax
your forehead...eyes...cheeks...let the relaxation spread
over the top of your head and into your neck....breathe in
and out...and relax your shoulders, arms and hands....now
let the relaxation flow into your back....chest...tummy....
take a deep breath and breathe out....and relax your
legs...feet....and .....toes....as you breathe out...focus
on the word RELAX....just breathe in and out deeply several
times until you feel comfortable all over.

When you have your bloodtest soon....take deep breaths in
out as the needle goes in and is taken out....as breathing
out helps to keep you relaxed and comfortable.

Distraction

Distraction was either internal or external. An example of
internal distraction was counting backwards from 100 and
external distraction, focusing on pictures on the wall, counting
tiles on the ceiling or the stripes on mother's blouse. The child
chose an internal or external distraction which he/she later used
during the medical procedure.

Cognitive conceptualization and reconceptualization

a) Conceptualization phase

The child was asked to recall thoughts and behaviour which make
the bloodtest worse (referred back to structured interview questionnaire) so that these could be modified.

b) Skill acquisition and reconceptualisation

This step involved clarifying misconceptions about the procedure or the child's body such as having little blood left in the body after the bloodtest, providing information about the procedure and making a short list of positive coping statements to be repeated during bloodtesting. For example, "If I take some deep breaths, I will feel calmer and it will soon be over". Information about the purpose of bloodtests was provided in an age appropriate manner. For example, "the nurses need to take a little blood from you to make sure your new kidney is working properly and to keep you well."

Behavioural rehearsal

The medical procedure was rehearsed in three stages with real medical equipment. The procedure involved in-vivo desensitization (via exposure to medical instruments), role play, providing information about the procedure, clarifying misconceptions, providing a coping model, practicing coping skills and emphasizing the interpersonal element. The procedure was rehearsed three times as in Jay et al's (1985) study:

a) The child rehearses the procedure on a doll
b) The child rehearses the procedure on the researcher
c) The child rehearses undergoing the procedure
The first stage was omitted for older children and adolescents.

a) The child rehearses the procedure on the doll.
During this first phase, the child pretended to be the nurse and gave the doll a bloodtest with toy and real medical equipment. Both sex dolls were available for the child to play with. The child was encouraged to follow the usual medical procedure, such as taking blood pressure, finding a "good" vein, applying an imaginary tourniquet, cleansing the venipuncture site, inserting the needle (into the doll), bloodtaking, placing cotton wool over the site and applying a plaster with a smiling face sticker.

During rehearsal, the doll was used to provide a coping model, that is, admitting to feeling anxious or scared, but modeling coping behaviours and positive coping statements such as "I'm a big boy, I can manage even if I am scared." The doll was coached to sit still and practice the breathing exercises. Positive statements and breathing exercises were modeled at stressful points of the procedure, such as the insertion and removal of the needle.

The interpersonal element in the medical situation was emphasized, that nurses performing bloodtests were trying to keep them well and did not intend to hurt them.

b) The child rehearses the procedure on the researcher.
During this phase, the child rehearsed the procedure using toy and real medical equipment on the researcher, who modeled coping
behaviours (breathing exercises and distraction) and statements selected by the child (e.g. "I'm scared but I know I can manage it. I'll do my breathing exercises so I won't be so scared. It will be over quickly if I keep still."

c) The child rehearses undergoing the procedure. During this phase, the child rehearsed undergoing the bloodtest with toy and real medical equipment and practicing coping skills. The child was coached to sit still, practice breathing exercises, distraction and positive statements. The child was encouraged to anticipate difficulties with venipuncture, such as the needle not being successfully inserted first time.

**Medical phase**

During the medical phase the child was reminded by the researcher about hypnotic or cognitive-behavioural coping strategies, particularly during stressful points of the procedure. The intervention was reinforced by the researcher who accompanied the child at a subsequent medical procedure (intervention 2). There was no prior preparation before the bloodtest on this occasion. At the child's next bloodtest, follow up observations without the researcher present were carried out, to assess the child's ability to practice coping strategies independently.

**9.3 RESULTS**

Raw data are presented in Appendix XXVII. However, as there were only seven pilot subjects, statistical analysis would not have
been meaningful and was therefore not carried out.

9.4 DISCUSSION

There were three aims of the present study, which are discussed in turn with reference to whether the pilot showed the methods to be feasible.

(1) This pilot study of seven children successfully tested hypnotic and cognitive-behavioural interventions for helping children cope with regular bloodtests in the renal transplant clinic. The omission of imagery from the cognitive-behavioural intervention made this approach distinct from the hypnotic one. Using scripts ensured that the interventions and duration of interventions remained standardized.

(2) The interventions were accommodated into the clinic routine, by seeing children shortly after arrival at the clinic. Children were seen in a small room adjoining the transplant wards and then returned to the waiting room to be called for routine bloodtests.

Nurses were informed of the child's whereabouts before intervention. Thus, it was impossible for nurses to be "blind" as to whether children had intervention or not, although they were not aware of the specific intervention children received.

(3) The pilot study showed that the SHCSC could be included in the same preparation session prior to the medical procedure. It was given to the child first and was followed by either the
hypnotic or cognitive-behavioural intervention. However, some children (and parents) were anxious about "losing their place" for routine bloodtests during the preparation and were consequently concerned about the concomitant delay in seeing the Paediatrician. It would have been possible in a larger study to give the SHCSC on a separate occasion to reduce the intervention time.

However, it was not possible to carry out an intervention study with larger numbers of children as planned, for several reasons. Firstly, few children volunteered to take part in this intervention study as they felt they were coping with routine bloodtests, although observer ratings of distress were sometimes high. Thus, it was highly likely that only a small sample would have been obtained during the time scale of the present research. It is interesting that only one boy agreed to take part in this pilot study and could reflect cultural and sex differences in expression and experience of pain.

Secondly, nurses completing the behaviour checklist and global ratings became uncooperative with the study, which made it difficult to proceed. This could have been due to several reasons: low morale amongst nurses due to wage disputes in the Health Service at the time; perceiving their participation in the study as additional work; not understanding the aims of the study, although these had been explained at the beginning of the research; interpersonal difficulties in having a researcher who
was not part of the transplant clinical team; and the researcher being from another Health Authority. The latter may have been more important as relationships between the researcher and medical staff in another study within the same Health Authority, differed markedly and were extremely positive (see Chapters 11 and 12). This may have also been helped by the researcher's clinical contribution to that clinic as well as being considered a member of the multidisciplinary team.

The next chapter describes cognitive-behavioural intervention with younger children in the renal transplant clinic.
CHAPTER 10
COGNITIVE-BEHAVIOURAL MANAGEMENT OF ACUTE PAIN IN
YOUNG TRANSPLANTS

INTRODUCTION

The purpose of the present investigation was to evaluate the efficacy of a behavioural intervention in reducing pain and anxiety during routine bloodtests following renal transplantation. The study, an extension of the research described in Chapters 7 and 9 developed following a request from the Paediatric Transplant Sister to help the youngest children in the clinic cope with bloodtests. These young children were felt by medical staff to be in greatest need of psychological intervention for these procedures.

The study was conducted from January to June 1988. Approval for the study was granted by Lewisham and North Southwark Committee on Ethical Practice in January 1988 (see Appendix XIX).

10.1 METHOD

10.1.1. Subjects

The subjects were 12 children aged four to seven years who had received kidney transplants who attended the paediatric renal transplant clinic at Guy's Hospital, London. The youngest children in the clinic were selected from the clinic list, as older children (aged six to 16 years) were taking part in a
larger assessment study by the researcher (see chapter 6). Sample size was consequently restricted.

10.1.2. Selection criteria

Criteria for inclusion in the study required that:
1 The child was aged between three and seven years of age.
2 The child was not mentally handicapped.
3 The child and parent spoke English.

No parent refused to allow his or her child to take part. Two children were excluded from treatment because one showed no distress at baseline and usually coped well and the other was returned to the care of her local health authority before she was due for intervention. There were therefore ten children in the treatment group, nine of whom were boys.

10.1.3. Design

A repeated measures pre/post staggered baseline design was used. It was staggered in that baselines were at different points in the treatment sequence. Repeated measures were taken at pre-treatment, post-treatment and follow-up for each child. Follow-up observations were made without the researcher present, on average ten weeks after the treatment session. Although a multiple baseline design was preferred this was not possible due to pressure of work on nursing staff.
10.1.4. Assessment Instruments

The major dependent variables assessed during acute clinical situations has been the child's experience of anxiety and pain. Children's anxiety, pain and distress during bloodtests were evaluated in two ways:

1) Global ratings.

(a) Global ratings of the child's anxiety and pain were made by nurses (usually performing the procedure) and parents. This involved a 10-point Likert scale with 0 representing no anxiety or pain and 10 representing extreme anxiety or pain, as described in Chapter 6.

(b) A simple "faces" rating scale was used with the children. They were shown three fear faces (smiling face, neutral face and sad face) and asked to point to the one that best showed how "scared" they felt or how much "hurting" they felt during the bloodtest. Faces scales were chosen as these are one of the most popular assessment methods used with young children (Jay, 1988).

2) The behavioural checklist (revised OSBD), (Jay et al, 1983; Elliott et al, 1987) described in Chapter 6 was used as an objective measure of distress.

10.1.5. Reliability

Two nurses were trained in making observations according to global ratings and the behaviour checklist. One nurse had been trained previously by the researcher for the assessment study.
(see Chapter 6) and was therefore more experienced in behavioural observation. The results of nurse inter-rater reliability according to Spearman Rank Correlations for N=10 were: .82 (p<.01) for global ratings of anxiety and .51 (NS) for global ratings of pain. Further analysis of the reliability checks revealed the less experienced nurse had difficulty assessing pain whereas the experienced nurse had more difficulty recording behaviours during Phase 1 and was therefore not observing details of the child’s behaviour. It should be noted that during the study, over 80% of ratings were completed by the more experienced nurse. Pearson correlations for total distress scores were found to be high between both nurses (r= .93, p<.001); between the experienced nurse and researcher (r= .96, p<001); and between the less experienced nurse and researcher (r= .98, p<001).

Reliability of the revised OSBD was calculated by the agreements disagreements method (Haynes, 1978). This was calculated for the three phases of the medical procedure. The results were: Phase 1 = 70% agreement, Phase 2 = 80% agreement, and Phase 3 = 94%. The overall agreement was 81%, which suggests a satisfactory level of agreement (Haynes, 1978). A higher frequency of behaviours occurred in Phase 1, thus reflecting greater problems of anticipatory anxiety. High frequency behaviours are probably more difficult to observe and record reliably, which may account for the lower agreement for Phase 1. Correlations between the experienced nurse and the researcher were .88 (p<.01) for anxiety and .84 (p<.01) for pain. Percentage agreement for the three phases were: Phase 1 = 75%, Phase 2 = 84% and Phase 3 =
95%. Correlations between the less experienced nurse and the researcher were .55 (NS) for anxiety and .52 (NS) for pain. Percentage agreement for the three phases were: Phase 1 = 85%, Phase 2 = 80% and Phase 3 = 98%.

10.1.6. Procedure

Upon arrival at the clinic, parents were approached by the researcher and asked to take part in a study aimed at helping the youngest children in the clinic cope with regular bloodtests. Informed consent was obtained. Details were collected from medical notes regarding the number of previous bloodtests prior to baseline to assess habituation. The average number of bloodtests experienced by children (N=10) prior to baseline was 197, with a range of 64-361. The number of venipuncture attempts were recorded for each observation as nurses and parents reported that this significantly influenced children’s coping with the procedure and that venipunctures were often unsuccessful with younger children.

Behavioural intervention

A multicomponent intervention was used because children may respond to different components of an intervention (Turk, 1978). The intervention was based on cognitive behavioural methods (Jay et al, 1985; Kuttner, 1984) with paediatric cancer patients. Children received the intervention, lasting approximately 20 minutes, shortly before their bloodtest (see accompanying video.
of this intervention with a young diabetic child). They were seen individually and accompanied by a parent. Parents were encouraged to act as coaches during preparation and the procedure itself.

The intervention included the following components:

1) Breathing exercises.
A simple breathing exercise was taught to each child to promote relaxation and to provide distraction and encourage a sense of mastery over the medical procedure (Jay et al, 1985). It was explained this special way of breathing would help them feel calm and brave as they could blow away their fears. Parents were encouraged to practice the breathing exercises with their child in play. Three images were developed by the researcher and used to enhance relaxation and capture the child’s attention and imagination. These images are presented as follows:

1. Taking deep breaths and filling an imaginary balloon while slowly breathing out.
2. Blowing imaginary soap bubbles.

**Image 1**

Pretend you are a party balloon. What colour balloon would you like to be? Take a deep breath and blow the balloon right up. Slowly let the air out and pretend you can hear the hissing sound as the air slowly comes out of the balloon. Let all the air out and then start all over again. Fill the balloon right up, make it big and then let the air out very slowly.
The soap bubble image was preceded with a brief play session with real soap bubbles. This was selected for those children who found it difficult to imagine or whose attention span was short. This "concrete prop" has been found to be helpful for young children undergoing invasive medical procedures (e.g. Kuttner, 1989; Sokel, Lansdown and Kent, 1990).

Pretend you have some blow bubbles...dip the wand in the bottle and blow very slowly...watch the bubbles float up in the air....how many bubbles can you see?...are they all the same size?....take a deep breath and blow again....see how the bubbles come out all different sizes...watch the colours changing...take another deep breath and this time blow very gently and slowly...see how many bubbles you can make this time.

Pretend you have a birthday cake right there in front of you...It's a really super birthday cake with magic candles....How many candles are there?....Take a deep breath and blow out all the candles.....Now they are lighting up again, just like magic....Take another deep breath and blow them out again....Make sure you blow out every candle....Keep on taking deep breaths and blow out the candles until they are all out.

During the bloodtest, the researcher held up one hand and invited the child to imagine the fingers were candles and to pretend to blow them out. A similar method, which is described by Hilgard and LeBaron (1984) is referred to as a hypnotic technique.

The breathing exercises were practiced several times with the child during the session and were individualized and adapted to the child's own responses. One of the above three images was selected for each child, however, another was tried if the child was not sufficiently interested in a particular image or as stated, whose attention span was limited. All three breathing
exercises involve imagery and deep breathing and are therefore very similar. The advantage of the second image is its play based "concrete" element which in developmental terms is most appropriate for young children.

2) Positive incentive
Children were shown commercially available badges of favourite children's story characters and told they were given to children who were brave during bloodtests. In order to get their badges they had to sit still and practice their breathing exercises. Children were told it was alright to cry or scream. They were asked to do the best they could. The procedure has already been described in Chapter 9.

The children were also given smiling face stickers following bloodtests usually applied to their plaster. These proved to be very popular with both children and medical staff and helped interpersonal relationships between them. Once children received their stickers, they forgot about their bloodtest and any distress experienced.

3) Superhero imagery
A story was made up incorporating the child's favourite Superhero. During the medical procedure children were asked what their hero would do in a similar situation. They were encouraged to be brave like their superhero. Thus, emotive imagery was used as a cognitive strategy to inhibit anxiety and produce feelings of self-assertion (Lazarus & Abramovitz, 1962) and to promote
feelings of mastery rather than avoidance (Jay et al, 1985).

4) Behavioural rehearsal

Behavioural rehearsal involved play with specially prepared soft dolls, and toy and real medical equipment. The procedure was practiced three times as in Jay et al's (1985) study:

(a) The child rehearses the procedure on a doll.
(b) The child rehearses the procedure on the researcher.
(c) The child rehearses undergoing the procedure.

(a) The child rehearses the procedure on a doll.

The child could choose whether to play with toy or real medical equipment first. Highly anxious children tended to choose toy equipment, only progressing onto real equipment when more confident.

The child was shown how difficult it was to insert the needle if the doll resisted. This was presented as a game, which children found amusing.

Misconceptions about bloodtests (e.g. of punishment or losing all blood) were corrected. Children were told their bodies would make more blood. Information as to the purpose of the bloodtest was provided, if the child had little or no understanding about this: that nurses needed to take some blood to make sure the new kidney was working properly and to keep them well. Nine of the
ten children in this study said they did not know why they had to have bloodtests.

Finally, the interpersonal element was emphasised, that nurses were their friends, were trying to keep them well and did not want to hurt them. A few children believed the nurses deliberately tried to hurt them.

(b) The child rehearses the procedure on the researcher.
The child then rehearsed the procedure on the researcher, with the real needles covered. Breathing exercises, imagery and positive statements were modeled as above.

(c) The child rehearses undergoing the procedure.
Finally, the child practiced undergoing the procedure with toy and real medical equipment, but without insertion of needles which were kept covered. Real medical equipment was not used if the child chose not to play with this. The child was reminded to sit still and practice breathing exercises, while the researcher pretended to carry out the bloodtest.

One child had a younger brother present during this preparation. It was not possible to exclude him because of sibling rivalry for attention. The brother was therefore included in the behavioural rehearsal component of the intervention and in order to prevent behavioural difficulties, he was also provided with badges after the bloodtest!

At the end of the preparation the child and parent returned to the clinic waiting room, to be called by the nurse for routine
monitoring of weight, height, blood pressure, urine analysis and blood test. The researcher accompanied the child into the treatment room and reminded him or her about the breathing exercises, superhero imagery and positive incentive.

10.2. RESULTS

The results from this intervention study suggested significant reductions in children's anxiety and pain responses, according to both nurse and parent global ratings and a behaviour checklist. The study should be regarded as a preliminary report, however, because only ten children took part. Changes in global ratings were examined using the Wilcoxon paired test (one tailed).

Table 10-1 shows Wilcoxon Z scores for nurse and parent global ratings of anxiety and pain showing significant change following intervention. There were no significant differences according to children's self-report. The implications of this finding are discussed in the next section.

**TABLE 10-1 Differences in global ratings of anxiety and pain pre vs post, pre vs follow-up intervention and post vs follow-up (N=10)**

<table>
<thead>
<tr>
<th></th>
<th>ANXIETY</th>
<th>PAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nurse Ratings</td>
<td>Parent Ratings</td>
</tr>
<tr>
<td>Pre &amp; Post</td>
<td>-2.37 ***</td>
<td>-2.01 **</td>
</tr>
<tr>
<td>Pre &amp; FU</td>
<td>-1.42</td>
<td>-1.12</td>
</tr>
<tr>
<td>Post &amp; FU</td>
<td>-.14</td>
<td>-.40</td>
</tr>
</tbody>
</table>

* p < .05  ** p < .025  *** p < .01
At follow-up children's pain responses were still significantly reduced compared to baseline according to nurse ratings. However, nurses ratings of anxiety and parents' ratings of anxiety and pain were not significantly different at follow-up compared to pre-treatment levels. Spearman correlations of nurse and parent ratings at baseline, showed high agreement for anxiety (\(\rho = .72, p < .01\)) but not pain (\(\rho = .40, \text{NS}\)) although it should be noted that nurses received training in observation and parents did not. Figures 10-1 and 10-2 show the mean nurse and parent ratings of pain and anxiety at baseline, post-intervention and follow-up.

Changes in revised OSBD intensity scores were analysed by t-tests (one tailed). Table 10-2 shows intensity scores pre and post-intervention and pre-intervention and follow-up for the three phases of the medical procedure. It shows highly significant differences in scores for Phases 1 and 2 and differences continuing at follow-up. There were no differences for Phase 3. Children exhibited greatest distress during Phase 1, thus exhibiting a great deal of anticipatory anxiety, followed by high distress levels during the actual procedure, and thereafter a reduction in behavioural distress on removal of the needle.
Global Rating

Fig 10.1: Mean Note Ratings of Pain and Anxiety

Fig 10.2: Mean Parent Ratings of Pain and Anxiety

Fig 10.3: Mean OASD Distress Scores
TABLE 10-2 Differences in OSBD intensity scores pre and post intervention and follow-up (n=10)

<table>
<thead>
<tr>
<th></th>
<th>PHASE 1</th>
<th>PHASE 2</th>
<th>PHASE 3</th>
</tr>
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<tbody>
<tr>
<td>Pre &amp; Post</td>
<td>4.57</td>
<td>3.79</td>
<td>1.45</td>
</tr>
<tr>
<td>Pre &amp; FU</td>
<td>2.68</td>
<td>2.48</td>
<td>1.40</td>
</tr>
<tr>
<td>Post &amp; FU</td>
<td>- .33</td>
<td>.22</td>
<td>-1.0</td>
</tr>
</tbody>
</table>

* p < .05  ** p < .025  *** p < .005

There was a low frequency of behaviours in Phase 3 with therefore little room for significant change. The mean intensity score at pre-intervention of 41.7 reduced to 14.3 at post-intervention, which represents over 60% reduction in children's distress levels. The mean intensity score of 14.7 at follow-up suggests this reduction has been maintained. Further, total intensity scores reduced significantly following intervention (t= 4.14, p < .005) and remained significantly different to baseline levels at follow-up (t= 2.54, p < .025), suggesting a reduction in intensity of children's distress. Figure 10-3 shows the mean OSBD distress scores for baseline, post-intervention and follow-up.

Kendall correlations were used to assess the relationship between venipuncture attempts, anxiety and pain. Positive relationships were found between the number of venipuncture attempts and elevated anxiety, according to nurse ratings (tau = .56, p < .05), and parent ratings (tau = .63, p < .02) at baseline, and
parent ratings of pain at baseline (τ = .54, p < .05). This correlation ceased at post-intervention and follow-up, suggesting children were beginning to cope better with unsuccessful venipunctures.

10.3. DISCUSSION

The results from this preliminary study suggest that the behavioural intervention described above helped to reduce children's anxiety, pain and behavioural distress. These young children experienced most anxiety before the actual procedure. The intervention helped reduce children's anticipatory anxiety and anxiety during the actual procedure.

There could be four explanations for these findings, other than a true intervention effect. One is the possibility of observer bias influencing nurse ratings, as they knew when a child was receiving preparation for bloodtests. It was necessary, however, to inform nurses that the child was with the researcher, because of clinic routine. Presenting observers with a counter expectancy rationale has been found to have no effect on reliability of observations (Elliot and Olson, 1983). Jay et al (1985) found no difference in reliability of observations during intervention versus no intervention periods in their study.

A second explanation may be placebo or expectancy factors influencing reductions in distress. This would need to be
clarified by group outcome studies.

A third explanation may be that children had habituated to bloodtests. It should be noted however, that Spearman correlations failed to show significant associations between the number of previous bloodtests prior to baseline and parent and nurse ratings of pain and anxiety. At baseline, children were therefore still showing high distress levels after numerous previous experiences of these procedures. Not until the follow-up phase was a significant negative association noted between the number of previous bloodtests and parent ratings of pain (\( \rho = -0.74, \ p = <.05 \)) with pain scores decreasing with experience.

A fourth difficulty involves inferring changes from a single baseline measure with a small sample size. A child's distress may vary from one procedure to another in response to a variety of individual, psychosocial and environmental factors, such as the child's disease activity, clinical waiting time and medical staff performing the procedure. A multiple baseline design would control for this difficulty in variability in children's responses.

Interestingly, children's self-report was found to be unreliable. That is, some children pointed to the smiling face or neutral face when their behaviour clearly showed they had been distressed (e.g. crying or screaming). It is not clear whether children were unable to understand concepts of anxiety and pain or were simply
responding to contextual demands. Other researchers have also found self-report in children under age five to be unreliable (e.g. Jay & Elliott, 1983). While self-report is important in telling us about the child's experience of pain, this can be problematical in this age group. This does not mean that self-report methods cannot be used with younger children, but rather that other quantitative scales for pain could be used, such as poker chips and colour scales (see Chapter 3 on assessment of pain). It should be noted that five of the ten children in the study were aged four years and that three children (aged four, five and seven years) were developmentally delayed according to their medical notes, which could account for these results. The developmental delay often found in children with chronic renal failure has been documented (Rissoni, Broyer and Guest, 1988).

Effective intervention must include parents, as the relationship between parental anxiety and children's distress during invasive medical procedures is highly correlated (Jay et al, 1983) and since parental presence may be a stimulus for coping and relaxation (Ross and Ross, 1984a). Anxiety may not necessarily constitute the main difficulty inhibiting parental support. The nature of the clinic environment (e.g. treatment room size) can exert a significant effect on interpersonal relationships. In this study, parents were often present in the treatment room, although space was a great problem. It is feasible that some parents may feel their presence is intrusive to medical staff; some may be confident the nurse can manage without their
presence; and others may feel unsure about their role in the medical context. Parents' uncertainty about their role has been referred to in the literature (Bradford and Tomlinson, 1990). In this study, some parents who coached their child well during the behavioural component of the intervention, surprisingly provided little or no support during the actual medical procedure. Parents may need to be given permission and encouragement by staff to accompany their anxious child and provide active support. Some parents may benefit from training in pain management methods and in anxiety management for themselves.

Although the present study did not address the effective components of the behavioural package, it is worth describing the children's responses to it, which suggested the importance of the doll play. The highly anxious children observed at baseline tended to play more aggressively with the dolls, performing numerous venipunctures on them, in an attempt to deal with their own anxiety. These anxious children preferred to play with real medical equipment. Some children were disappointed they could not insert the real needles into the researcher and that the dolls did not bleed! At the end of the study, four children asked if they could play with the dolls again. None of the children asked for more badges, although when they received them, they were very proud of them and of the attention received from medical staff.

The reductions in distress persisted longer than expected, given that no further intervention was given. This could have been due
to a change in the parents' behaviour and/or further doll play by children at home. A number of parents reported that their child continued behavioural rehearsal at home with dolls and toy equipment. The doll play was considered by parents to have been very helpful and most enjoyed by the children. Active participation by the child has been found to increase the effect size obtained by psychological preparation (Saile, Burgmeier and Schmidt, 1988).

It behoves us to demonstrate the efficacy of psychological intervention in order to prove its value. Cooperation from medical staff is however vital to the success of any intervention study in clinically based research. This was fully given by the two paediatricians in the clinic. While nursing staff involved in the study had positive views on intervention with the youngest children in the clinic because it made their task easier and less stressful, they questioned the efficacy of the intervention when reductions in behavioural distress did not appear to last beyond follow-up. Issues concerning generalization were not intended for study in the present research, but are extremely important and need to be addressed in future studies. Training nurses and playstaff in pain management techniques would be one way of ensuring generalization. There was no time, however, in the nurse's busy schedule to prepare children using the intervention described, at least in the centre studied, but could be more easily given by hospital playstaff who are often trained in preparatory play with children. Whether the play component alone
is sufficient to reduce behavioural distress requires further investigation.

The present study demonstrated the efficacy of a psychological approach in helping reduce behavioural distress in young children undergoing regular bloodtests following renal transplantation, notwithstanding the four alternative explanations described above. Future studies could include a larger group of children and multiple baseline and follow-up assessments to control for variability in children's pain responses. Comparative group outcome studies could control for placebo or expectancy factors. Some attempt to isolate the effective components of the behavioural package would be fruitful. The issue of generalisation could also be addressed by future research. It is not always possible to have access to large numbers of children in a special population. This difficulty could be overcome by multicentre research. Further work is required on methods of pain management because of the increasing numbers of children having renal transplants who are required to undergo repeated venipunctures as part of their treatment.
CHAPTER 11

ASSESSMENT OF ACUTE PAIN IN CHILDREN WITH INSULIN DEPENDENT DIABETES MELLITUS

11.1 PILOT STUDY

The studies described in the present Chapter and following Chapter originally developed from a seminar given to paediatric medical staff at Addenbrooke's Hospital on pain in children. Interest was expressed by paediatricians at the meeting in having the researcher conduct research in the paediatric diabetic clinic, as a number of children found needles difficult. The Diabetic Clinic staff felt the aims of the present study and the study described in the next chapter were important and were therefore cooperative throughout the four years of its duration.

Nine children were seen in the pilot study from May to November 1987. This study and the next described in Chapter 12 were approved by Cambridge Health Authority Ethical Committee in April 1987 (see Appendix XX). The purpose of the pilot study was to:

1. Assess the duration of the child and parent interviews.

2. Assess how many children and parents could be interviewed within the time constraints of the clinic.

3. Determine whether any standardized questionnaires needed omitting or including.

4. Discover whether the structured child and parent
questionnaires required further modification.

The child and parent interviews took approximately 30 minutes each to complete. The interviews were conducted in a very large waiting room as space was a problem in the clinic. To take part in the assessment study, it was necessary that the child was scheduled for a bloodtest (venipuncture). This was ascertained by asking the paediatrician at the start of the clinic (with reference to medical files) who was expected to have blood taken for analysis. Children had appointment times at clinic, however it was common for two or three children to have the same appointment time. On arrival at the clinic, children reported to the receptionist and were then called by the staff nurse for height and weight measurement and urinary analysis. Children due for bloodtests were routinely sent to the Phlebotomy Clinic before the consultation with the paediatrician. On average 12 children attended clinic each week, however, some weeks the clinic was smaller and others a little larger. It was inevitable that some children and parents would have a lengthy wait (e.g. one hour) before their consultation.

There were practical difficulties in conducting the research in a clinical setting. These included parents and children not always arriving at clinic on time, scheduling difficulties and failing to attend clinic. Another concerned carrying out interviews which were sometimes interrupted by consultations with the doctor. The pilot study involved finding an optimal system of
conducting the interviews accommodating clinic routine. It was generally only possible to see one child and parent in one afternoon's clinic. However, the pilot study showed that it was possible to increase this by asking parents to complete their questionnaires on their own, thus allowing more time to interview other children. Research time was inevitably wasted, by some of the above factors described, particularly children failing to attend, or no children due for bloodtests in a particular afternoon's clinic. If questionnaires were not completed at the first baseline assessment, they were done so at the next clinic visit.

The pilot study led to some revisions of the assessment protocol as for Chapter 7:

1. The addition of the Birleson Depression Inventory.
2. Minor revisions to the child and parent structured interview questionnaires. These included the addition of a question on stressful life events (Abidin, 1983).
3. Parents completing questionnaires while the researcher interviewed their child.

The pilot data were included in the final sample, as there were few alterations to the assessment procedure.
11.2 METHOD

11.2.1. Subjects

Subjects were 62 children and adolescents with Insulin Dependent Diabetes Mellitus (IDDM) who attended the Diabetic Paediatric out-patient clinic at Addenbrooke’s Hospital, Cambridge. Sixty one children were Caucasian, while only one was Asian. This reflects the predominantly white population in the Cambridgeshire District, which the Paediatric Diabetic Clinic served. Only one subject, an adolescent boy and his mother refused to take part in the study because of the time demands involved. The high compliance rate could well have been influenced by the incentives given to children for being interviewed! For example, each child or adolescent was offered several choices of Rupert Bear (diabetic mascot) badges, pencils, rubbers and pens. No child refused to complete the questionnaires. Fifty three mothers (85.5%) and nine fathers (14.5%) were interviewed. When both parents attended the clinic with their child, only one was invited to take part in the study. Usually, the parent who regularly attended the clinic with their child volunteered.

11.2.2. Procedure

The researcher approached children and parents when they arrived at the Diabetic Clinic, and invited them to take part in a study about children’s experiences with bloodtests. The study was described to the child and parent as in Chapter 7 for the transplant assessment study. Children known to medical staff as
disliking bloodtests were initially approached by the researcher, when they were scheduled for routine bloodtests, otherwise children who met the selection criteria were asked if they would take part in the study.

11.2.3. Criteria for selection

Children were selected according to the following criteria:
1. They were aged between 6-16 years.
2. The child was accompanied by a parent.
3. The child was scheduled for a bloodtest (venipuncture) on the day of initial contact.

11.2.4. Sex

There were 23 (37.1%) boys and 39 (62.9) girls in the present study. When this study began, there were approximately 90 children listed as attending the clinic aged between 3 years and 17 years, although a small group of children (about 10%) did not attend regularly. As described in Chapter 7, little is known about sex differences in children's expression of pain with less painful medical procedures, therefore sex was included as a variable in this study.

11.2.5. Age

Children's ages ranged from 6 years 0 months to 16 years and 9 months with a mean age of 11 years 0 months (SD = 37 months). As
with the assessment study with transplant children, age was divided into young (6-11 years) and old (12-16 years) according to Piagetian developmental stages, in order to assess differences according to age. There were 38 (61.3%) young children and 24 (38.7%) older children in the study.

11.2.6. Diagnosis

Children in the clinic were diagnosed as having Insulin Dependent Diabetes Mellitus from birth to 15 years 8 months. Mean age for diagnosis was 6 years and 9 months (SD = 44 months) often following symptoms of polyuria, polydipsia and hypoglycaemia.

11.2.7. The Clinical Setting

The Paediatric Diabetic Out-Patient Clinic was held weekly on Tuesday afternoons at Addenbrooke's Hospital. The medical staff consisted of a Senior Paediatric Registrar (J.C., a Consultant paediatrician in the latter six months of the study), Specialist Sister in Diabetes, Staff nurse, Auxiliary nurse and Dietician. Another Senior Paediatric Registrar usually shared the clinic caseload, however, because of staff turnover was replaced approximately every six months. J.C. was the consistent paediatrician for the entire duration of the present study. The Specialist Sister and Staff nurse were also consistent staff members during the study.

The Diabetic Clinic used two medical consulting rooms, two
adjoining rooms for weight, height and urine analysis, two small examination rooms, a Sister's office with small waiting area, and a large waiting room at reception. Interviewing in the waiting room made it easier for medical staff to know where individual children were. Fortunately, the waiting room was sufficiently large, including a further small waiting area near the Sister's office, to enable interviews to take place relatively undisturbed.

Bloodtests were usually carried out in the hospital Phlebotomy Clinic, situated close by on the same floor. However, the paediatrician preferred to conduct bloodtests herself on the younger children who were known to be fearful, presumably because it would be less disruptive than in the busy Phlebotomy Clinic. The Diabetic Clinic and Phlebotomy Clinic environments differed in several respects. For example, the paediatrician carried out bloodtests in the context of the medical consultation, usually at the beginning. A "butterfly" needle was used for bloodtaking.

The Phlebotomy Clinic was staffed by three phlebotomists who carried out bloodtests on both children and adults for various clinics in the hospital. There were three treatment rooms which were exceptionally small. The rooms were open plan and did not have doors. There was also a small waiting area. Because of the open plan design of this clinic, distressed children were heard clearly by other children and adults in the waiting area or in the other treatment rooms. Often two phlebotomists were involved
in taking blood from the more anxious children. Unlike the paediatrician, Phlebotomists preferred to use a larger needle because they felt venipunctures were more successful with this than the butterfly needle.

Children had bloodtests in the Diabetic Clinic every 3-6 months. They were frequent (every three months) if the child’s diabetes was poorly controlled. Once a year children had an "annual review" around the child’s birthday. This was rather like a "service" which included assessment of: retinal changes in the child’s eyes (from age 10 years); injections sites and state of sites, hypoglycaemic episodes over the last month, hospital admissions in the last year, changes in family history of diabetes, and assessment of insulin regime and diet. It also included a plan of action usually involving one or more of the following: education session, blood sugar profile at home and in hospital, change in method of testing, changes in insulin regime, changes in diet or psychological intervention (e.g. psychological management of failure to adhere to medical treatment).

The annual review required taking more blood than usual for a range of biochemistry analyses: glycosylated haemoglobin (HBA1), lipids (triglyceride and cholesterol), thyroid function (T4 and TSH), thyroid antibodies thyroglobulin, thyroid microsomal antibodies and renal function (urea and creatinine). Urinary analyses investigated glucose output and protein output. Routine
bloodtests taken every 3-6 months, investigated glycosylated hemoglobin only (HBA1).

11.2.8. Dependent Measures

The assessments used to measure pain, anxiety and distress included self-report measures, the revised OSBD, and psychophysiological measures of arousal (see Chapter 7). Indices of metabolic control were also taken. Forty-one (66%) children were seen for one baseline assessment and 21 (34%) for two assessments.

Self-report measures
Global ratings of anxiety and pain were completed by the paediatrician or phlebotomist performing the bloodtest, the child and the parent (if present). The global ratings consisted of a 10 point scale with 0 representing no anxiety or pain and 10 extreme anxiety or pain. A smiling face anchored one end (0) and a sad face the other (10). The child, parent and paediatrician/phlebotomist were asked to select the number which best represented the child’s anxiety and pain during the bloodtest.

Behavioural checklist
The revised version of the OSBD previously described in Chapter 7 was used as an objective measure of the child’s behavioural distress. The checklist was scored during three phases of the medical procedure. This generated a total intensity score as well
as distress scores for each of the three phases of the procedure (see Chapter 7 for a detailed description and definitions of behavioural categories).

Physiological Measures
Heart rate was measured in the waiting room and then during the three phases of the procedure. A heart speedometer (model 8519 - Computer Instruments Corp.) was used to measure heart rate during the medical procedure (for a full discussion see Chapter 7).

Metabolic control
Glycosylated hemoglobin values are the most widely used, single index of diabetic control (Spevack, Johnson, Harkavy, Silverstein, Shuster, Rosenbloom and Malone, 1987). Glycated (or glycosylated) haemoglobin (HBA1) comprises a series of minor haemoglobin components (HBA1a, HBA1b and HBA1c) formed by the non-enzymatic adduction of glucose and glucose-derived products to normal haemoglobin (HBA). The level of HBA1 (expressed as a percentage of total HBA) reflects the integrated glycaemic level and therefore the mean blood glucose concentration over the preceding 6-8 weeks (McCance and Kennedy, 1991).

Glycated haemoglobin (HBA1) taken at the clinic visit, was used as a measure of metabolic control in the present study. Bloodtest results were obtained from the medical file when the child next attended the clinic. Addenbrooke's Hospital Biochemistry department measured glycated hemoglobin using an iron exchange chromatography method which measures all fast hemoglobins as a
percentage of the total (normal range = 5.5-8.5). This normative range was based on a sample of 50 males and 50 females aged 18-60 years undergoing blood transfusions at Addenbrooke's Hospital. The range in non-diabetic patients is approximately 5-9%, with levels in poorly controlled diabetic patients ranging up to approximately 20% (McCance and Kennedy, 1991). Although no normative data were available on younger patients, this range was applied by the Biochemistry department to children. For the purposes of statistical analysis, children with scores below 10% were classified as having good control, while those with scores above 10% were classified as having poor control consistent with other studies (e.g. Close et al, 1986).

From March 1990, the Biochemistry Department at Addenbrooke's Hospital adopted a different method of calculating glycated hemoglobin using high performance liquid chromatography, with the use of finely divided resins and high flow pressures, permitting faster and more precise separation of HbAlc and HbA1. This produced a different normative range (4.9-6.3), not comparable to the previous range obtained by the ion exchange method. The original method was changed because it was labour intensive and because of heavy workload. As the majority of data collected in this study was in the old range, it was necessary to convert new HbAlc values to HbA1 values. This was carried out by the Biochemistry Department using a simple mathematical formula.
Psychosocial variables.

Structured interview questionnaires and standardized questionnaires comprised the main part of this assessment study. These questionnaires investigated psychosocial variables in relation to behavioural distress.

(a) Structured interview questionnaires

The child and parent were given a structured interview questionnaire with similar content to the one described in Chapter 7 (see Appendices XXI and XXII). That is, questions focused on anticipatory anxiety and pain, what helped the child cope better and less well with bloodtests, the child's existing coping strategies, the child's understanding of the purpose of bloodtests and understanding of diabetes and its treatment. Demographic variables were also collected including social class, birth order, the child's age at interview and age at diagnosis. The number of previous bloodtests prior to interview were recorded from the medical notes as well as the number of hospital admissions and glycosylated hemoglobin results at each contact with the child. There were generate and supplied format questions. The generate format questions were coded for statistical analysis following a frequency analysis of the data. The results are presented under descriptive data later in this chapter.

Inter-rater reliability (between the researcher and an independent rater, K.B.) for open ended questions on the child.
and parent structured interview questionnaires revealed a satisfactory agreement of 88%, using the agreements disagreements method. However, most of the data (approximately 55 cases) was entered into the computer for statistical analysis by K.B. who coded open ended questions according to the researcher's categories. Nevertheless, these results suggest the data was being coded according to the researcher's classification system.

(b) Standardised questionnaires

Standardized questionnaires were given to children and adolescents, parents and the child's schoolteacher (see Chapter 8 for details of standardized questionnaires including their reliability and validity).

(a) Child
Each child was given the following standardized questionnaires:
1. State Trait Anxiety Inventory for Children.
2. Child Health Locus of Control Scale
3. Nowicki Strickland Locus of Control
4. Birleson Depression Inventory
5. Harter Self-concept Scale

(b) Parent
The parent was given:
1. State Trait Anxiety Inventory
2. Rotter Locus of Control Scale
3. Rutter Parental Questionnaire
Teachers were asked to complete the Rutter Teacher Questionnaire regarding the child's emotional and behavioural adjustment in school.

The procedure for administering the questionnaires and collecting measures was as follows: Firstly, children and parents were asked about their anticipatory anxiety, they completed the "state" section of the State-Trait Anxiety Inventory, and the child's heart rate was taken in the waiting room. The researcher then accompanied the child and parent to the Phlebotomy Clinic or paediatrician's consulting room during bloodtesting and measured the child's heart rate before, during and after the bloodtest. The phlebotomist/paediatrician then completed global and behavioural checklist ratings immediately after the bloodtest. Global ratings of the child's anxiety and pain during the bloodtest were also completed by the child and parent. The child structured interview questionnaire and standardized questionnaires were next completed with the researcher. Adolescents however, completed standardized questionnaires independently while completing the structured interview questionnaire with the researcher. Parents usually completed both structured interview questionnaires and standardized questionnaires on their own, unless they required help.
11.3. RESULTS

11.3.1. Inter-rater Reliability

Prior to the pilot study, the researcher trained a phlebotomist (W.C.) and Senior Paediatric Registrar (J.C.) to observe children's behavioural distress and assess their pain and anxiety according to global ratings and the revised OSBD (as described in Chapter 7). Discussions took place after assessments regarding clarification of behavioural categories, protocol and personal reactions. Initially two phlebotomists were trained simultaneously, however one left the clinic after nine children had been observed. The data from the second phlebotomist is thus not presented. As noted in the study described in Chapter 7, the person performing the bloodtest was less sensitive to subtle facial cues from the child because her attention was focused on the needle, while the researcher was less cognizant of subtle muscle tension in the arms and resistance. This did not affect inter-reliability however. Because the paediatrician and phlebotomist worked in two separate clinics, it was not possible to obtain simultaneous ratings on the same children. Thus, the researcher trained the phlebotomist and paediatrician separately in their respective clinics.

The results of inter-rater reliability (N=10) for Spearman correlations between researcher and paediatrician were .87 for anxiety (p<.001) and .77 for pain (p<.001); correlations between the researcher and phlebotomist were .85 for anxiety (p<.001) and .77 for pain (p<.001). The number of agreements between the two
observers and researcher as to whether the 11 behaviours occurred during the three phases of the procedure were divided by the total number of agreements plus disagreements. Percent agreement for the three phases of the medical procedure (see Chapter 7) between the researcher and paediatrician were as follows: Phase 1 = 93%; Phase 2 = 96%; Phase 3 = 94%; and Total Score = 94%. The percent agreement between the researcher and phlebotomist was also high: Phase 1 = 92%; Phase 2 = 93%; Phase 3 = 89%; and Total Score = 91%.

During the last year of the study (March - September 1990), video recordings were taken of children undergoing routine bloodtests in the Diabetic Clinic (N=15) for further inter-rater reliability checks. The phlebotomist, paediatrician and researcher rated each child's behaviour. These checks between the paediatrician, phlebotomist and researcher were not carried out at the beginning of the study because of time constraints. Table 11-1 shows satisfactory inter-rater reliability according to Spearman correlations for global ratings of anxiety and pain made by the paediatrician, phlebotomist and researcher.
TABLE 11-1 Inter-Rater Reliability for Global Ratings of Anxiety/Pain.

<table>
<thead>
<tr>
<th></th>
<th>Phleb</th>
<th>Res</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paed</td>
<td>.79**</td>
<td>.94**</td>
</tr>
<tr>
<td>Phleb</td>
<td>.82**</td>
<td>.83*</td>
</tr>
</tbody>
</table>

* p < .01 ** p < .001

Table 11-2 presents Spearman correlations for distress scores for the three phases of the medical procedure and for total distress scores according to paediatrician, phlebotomist and researcher ratings. These also show satisfactory agreement between raters of children’s behavioural distress.

TABLE 11-2 Spearman Correlations of Paediatrician (JC), Phlebotomist (WC) and Researcher (R) Ratings of Distress Scores.

<table>
<thead>
<tr>
<th></th>
<th>JC/R</th>
<th>JC/WC</th>
<th>WC/R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1</td>
<td>.99**</td>
<td>.97**</td>
<td>.99**</td>
</tr>
<tr>
<td>Phase 2</td>
<td>.98**</td>
<td>.98**</td>
<td>.96**</td>
</tr>
<tr>
<td>Phase 3</td>
<td>1.00**</td>
<td>.99**</td>
<td>.99**</td>
</tr>
<tr>
<td>Total</td>
<td>.99**</td>
<td>.99**</td>
<td>.99**</td>
</tr>
</tbody>
</table>

* p < .01 ** p < .001

The percent agreement for the 11 behavioural categories for the
three phases of the medical procedure and for total scores is presented in Table 11-3. These results are particularly interesting in showing trained raters continued to observe children's distress reliably over time. Observers' level of accuracy may have been helped by regular feedback from the researcher throughout the study, following global and behaviour checklist ratings.

<table>
<thead>
<tr>
<th>TABLE 11-3. Percent agreement for behaviour categories according to Paediatrician (JC), Phlebotomist (WC) and Researcher (R).</th>
</tr>
</thead>
<tbody>
<tr>
<td>JC/R</td>
</tr>
<tr>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Phase 1</td>
</tr>
<tr>
<td>Phase 2</td>
</tr>
<tr>
<td>Phase 3</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

11.3.2 Descriptive Statistics

Variables which were transformed into categorical data are presented in this section. Generate format questions in the child and parent structured interview questionnaires yielded descriptive data which were not subjected to statistical analysis. Responses to supplied format questions are also included where appropriate. The percent presented is the valid percent based on actual responses. Variables with responses from less than half the sample (N=30) are not included as the results.
would be statistically meaningless.

Demographic characteristics

Social class

Social class was determined by the father's occupation in two parent families and by mother's in single parent families according to the Classification of Occupations and Coding Index (1980). Table 11-4 shows slightly more children were represented in social class 2.

<table>
<thead>
<tr>
<th>Social class</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>13</td>
<td>25.0%</td>
</tr>
<tr>
<td>2</td>
<td>19</td>
<td>36.5%</td>
</tr>
<tr>
<td>3</td>
<td>15</td>
<td>28.8%</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>9.6%</td>
</tr>
</tbody>
</table>

Birth order

Table 11-5 shows a larger number of first born children in the sample.

<table>
<thead>
<tr>
<th>Birth order</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>28</td>
<td>47.5%</td>
</tr>
<tr>
<td>2</td>
<td>20</td>
<td>33.9%</td>
</tr>
<tr>
<td>3</td>
<td>10</td>
<td>16.9%</td>
</tr>
<tr>
<td>4</td>
<td>1</td>
<td>1.7%</td>
</tr>
</tbody>
</table>
Child and Family health

A subjective measure of children's diabetic control was obtained from parental interview. According to parents 42 (71.2%) children were in good metabolic control, 11 (18.6%) were in adequate control and 6 (10.2%) were in poor control.

Frequency of Bloodtests

The following table presents how often children experienced bloodtests (venipunctures) in the diabetic clinic according to parent estimates. These were consistent with child reports.

<table>
<thead>
<tr>
<th>Bloodtests</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3 months</td>
<td>3</td>
<td>5.4%</td>
</tr>
<tr>
<td>3-6 months</td>
<td>25</td>
<td>44.6%</td>
</tr>
<tr>
<td>&gt;6 months</td>
<td>28</td>
<td>50.0%</td>
</tr>
</tbody>
</table>

Frequency of Finger Pricks

Table 11-7 shows how often children carried out finger pricks for glucose monitoring according to parent estimates. These were consistent with child reports.

<table>
<thead>
<tr>
<th>Finger pricks</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;10 a week</td>
<td>37</td>
<td>67.3%</td>
</tr>
<tr>
<td>10-20 a week</td>
<td>11</td>
<td>20.0%</td>
</tr>
<tr>
<td>20-30 a week</td>
<td>7</td>
<td>12.7%</td>
</tr>
</tbody>
</table>
Anticipatory anxiety

The majority of children (91.7%) reported that they did not experience anticipatory anxiety (i.e. changes in eating or sleeping patterns, crying, nausea etc.) prior to attending the clinic.

Previous experience

According to parents 33, (57.9%) children had previous unpleasant experiences with needles consistent with children’s reports (58.3%).

Parental management of bloodtests/needles

Parent strategies for helping children cope with bloodtests and other needles are presented in Table 11-8. A number of parents did not offer help during bloodtests or other needles (e.g. finger pricks and injections). The most common strategy that was used involved talking to the child.

<table>
<thead>
<tr>
<th>Parent strategy</th>
<th>Freq/Bt</th>
<th>Percent</th>
<th>Freq/N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t help</td>
<td>17</td>
<td>29.3%</td>
<td>23</td>
<td>38.3%</td>
</tr>
<tr>
<td>Talk</td>
<td>16</td>
<td>27.6%</td>
<td>14</td>
<td>23.3%</td>
</tr>
<tr>
<td>Parent presence</td>
<td>9</td>
<td>15.5%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Combination</td>
<td>6</td>
<td>10.3%</td>
<td>4</td>
<td>6.7%</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>8.6%</td>
<td>5</td>
<td>8.3%</td>
</tr>
<tr>
<td>Distraction</td>
<td>3</td>
<td>5.2%</td>
<td>2</td>
<td>3.3%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>2</td>
<td>3.4%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Be firm</td>
<td>0</td>
<td>0.0%</td>
<td>4</td>
<td>6.7%</td>
</tr>
<tr>
<td>Play it down</td>
<td>0</td>
<td>0.0%</td>
<td>3</td>
<td>5.0%</td>
</tr>
<tr>
<td>Rehearse</td>
<td>0</td>
<td>0.0%</td>
<td>5</td>
<td>8.3%</td>
</tr>
</tbody>
</table>
Staff management of bloodtests

Staff strategies for helping children cope with bloodtests according to parents are presented in Table 11-9 and show more responses referring to the doctor/phlebotomist's general competence in carrying out the procedure as helpful.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competent</td>
<td>21</td>
<td>51.2%</td>
</tr>
<tr>
<td>Talk to child</td>
<td>6</td>
<td>14.6%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>14.6%</td>
</tr>
<tr>
<td>Combination</td>
<td>5</td>
<td>12.2%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>3</td>
<td>7.3%</td>
</tr>
</tbody>
</table>

Parent presence

Forty two (68.9%) parents said they were usually present during their child's bloodtest, consistent with children's reports. Twenty seven (48.2%) felt their child was no different if they were present, 21 (37.5%) felt their child coped better and only 8 (14.3%) felt their child coped worse in their presence. However, 34 (56.7%) children said they coped better when their parents were present, 15 (25.0%) felt they were no different and 11 (18.3%) felt they coped worse. Most parents were willing to wait in the waiting room during the bloodtests if asked. That is, fifty two (83.9%) said they were willing to wait there, while 10 (16.1%) were not willing because of concerns about how their child would cope.
What helped child cope better

The factors influencing coping with bloodtests are presented in the next table. The child's positive attitude was most referred to by parents, while most children felt that either nothing or distraction helped them to cope better with bloodtests.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's pos att</td>
<td>9</td>
<td>16.7%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>16.0%</td>
<td>9</td>
<td>15.3%</td>
</tr>
<tr>
<td>Nothing</td>
<td>7</td>
<td>13.0%</td>
<td>19</td>
<td>32.2%</td>
</tr>
<tr>
<td>Parent presence</td>
<td>6</td>
<td>11.1%</td>
<td>8</td>
<td>13.6%</td>
</tr>
<tr>
<td>Explanation</td>
<td>6</td>
<td>11.1%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Parental calmness</td>
<td>5</td>
<td>9.3%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Distraction</td>
<td>5</td>
<td>9.3%</td>
<td>16</td>
<td>27.1%</td>
</tr>
<tr>
<td>Combination</td>
<td>2</td>
<td>3.7%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Positive staff attitude</td>
<td>2</td>
<td>3.7%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Not waiting</td>
<td>3</td>
<td>5.6%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Speed</td>
<td>0</td>
<td>0.0%</td>
<td>3</td>
<td>5.1%</td>
</tr>
<tr>
<td>Reassurance</td>
<td>0</td>
<td>0.0%</td>
<td>4</td>
<td>6.8%</td>
</tr>
</tbody>
</table>

In addition, children were asked whether carrying out injections themselves was easier, or having other people administer injections on them. Forty-five (76.3%) children felt injecting themselves was easier while 14 (23.7%) felt it was worse.

What made child cope less well

Table 11-11 presents the factors children felt made them cope less well with bloodtests. Many children felt nothing in particular interfered with their coping.
TABLE 11-11 Factors which interfere with coping

<table>
<thead>
<tr>
<th>Factors</th>
<th>Freq</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nothing</td>
<td>27</td>
<td>46.6%</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
<td>22.3%</td>
</tr>
<tr>
<td>Sight of needle</td>
<td>5</td>
<td>8.6%</td>
</tr>
<tr>
<td>Unsuccessful</td>
<td>3</td>
<td>5.2%</td>
</tr>
<tr>
<td>venipunctures</td>
<td>5</td>
<td>8.6%</td>
</tr>
<tr>
<td>Big needle</td>
<td>1</td>
<td>1.6%</td>
</tr>
<tr>
<td>Pain</td>
<td>2</td>
<td>3.2%</td>
</tr>
<tr>
<td>Unwell</td>
<td>2</td>
<td>3.4%</td>
</tr>
</tbody>
</table>

Child’s coping strategies

Child and parent responses indicated that a number of children had no coping strategies. For those children who did, deep breaths or relaxation were most often reported, as shown in Table 11-12.

TABLE 11-12 Child’s coping strategies according to parents and children

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nothing</td>
<td>15</td>
<td>24.2%</td>
<td>19</td>
<td>32.2%</td>
</tr>
<tr>
<td>Other</td>
<td>24</td>
<td>38.7%</td>
<td>16</td>
<td>27.1%</td>
</tr>
<tr>
<td>Deep breaths/relaxation</td>
<td>5</td>
<td>8.1%</td>
<td>11</td>
<td>18.6%</td>
</tr>
<tr>
<td>Tenses</td>
<td>2</td>
<td>3.2%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Distraction</td>
<td>1</td>
<td>1.6%</td>
<td>10</td>
<td>16.9%</td>
</tr>
<tr>
<td>Looks</td>
<td>0</td>
<td>0.0%</td>
<td>3</td>
<td>5.1%</td>
</tr>
</tbody>
</table>

Information obtained directly from children indicated that 19 (32.2%) had no coping strategies, 30 (51.0%) reported one
strategy, 8 (13.6%) had two and two children (3.2%) had three or four strategies.

Example of coping strategies:

I take a breath and then breathe out...and breathe in when the needle goes in and breathe out when the needle is coming out (boy aged 7).

Worst part of bloodtests

Table 11-13 presents children's description of the worst part of bloodtests for them. The insertion of the needle was perceived to be the most stressful.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Freq</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insertion of needle</td>
<td>38</td>
<td>66.7%</td>
</tr>
<tr>
<td>Sight/size of needle</td>
<td>5</td>
<td>8.8%</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>8.8%</td>
</tr>
<tr>
<td>Removal of needle</td>
<td>3</td>
<td>5.3%</td>
</tr>
<tr>
<td>The pain</td>
<td>3</td>
<td>5.3%</td>
</tr>
<tr>
<td>Drawing blood</td>
<td>3</td>
<td>5.3%</td>
</tr>
</tbody>
</table>

Preference to looking at needle or away

Children's cognitive style of coping with bloodtests was assessed by asking whether they preferred to look at the needle or look away during the procedure. Thirty (53.6%) children said they looked away during the procedure, while 17 (30.4%) preferred to look. Only nine (16.1%) had no preference. Reasons for their preference included monitoring the procedure (29%), distracting oneself from the procedure (29%), fear of loss of control (6.5%), don't know (16.1%) and other reasons (19.4%).
Child’s cognitions during bloodtests

Children were asked what specific thoughts they had during bloodtests. The following table shows children’s cognitions during bloodtests. Children commonly reported either no specific thoughts or distracting thoughts.

<table>
<thead>
<tr>
<th>Cognitions</th>
<th>Freq</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nothing</td>
<td>15</td>
<td>32.6%</td>
</tr>
<tr>
<td>Distraction</td>
<td>15</td>
<td>32.6%</td>
</tr>
<tr>
<td>Positive self-talk</td>
<td>6</td>
<td>13.0%</td>
</tr>
<tr>
<td>Imagery</td>
<td>5</td>
<td>10.9%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>6.5%</td>
</tr>
<tr>
<td>Expectations of pain</td>
<td>2</td>
<td>4.3%</td>
</tr>
</tbody>
</table>

Examples:

- Sometimes my mind goes blank. Sometimes I think about things like Dracula drinking blood out of a straw (boy aged 8).

- I think the best thing is “John don’t be afraid”, just get it over and done with quickly (boy aged 7).

- I think good things like when I’m playing with my dad (boy aged 6).

Parent communication to child about pain

Parent’s usually managed their child’s pain or distress by encouraging the child to talk about his/her feelings or providing emotional support or reassurance.
TABLE 11-15 Parent communication about pain

<table>
<thead>
<tr>
<th>Response</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encourages to talk</td>
<td>24</td>
<td>42.9%</td>
<td>12</td>
<td>22.6%</td>
</tr>
<tr>
<td>Provides emotional</td>
<td>22</td>
<td>39.3%</td>
<td>28</td>
<td>52.8%</td>
</tr>
<tr>
<td>support</td>
<td>7</td>
<td>12.5%</td>
<td>5</td>
<td>9.4%</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0.0%</td>
<td>4</td>
<td>7.5%</td>
</tr>
<tr>
<td>Plays it down</td>
<td>0</td>
<td>0.0%</td>
<td>4</td>
<td>7.5%</td>
</tr>
<tr>
<td>Nothing</td>
<td>0</td>
<td>0.0%</td>
<td>4</td>
<td>7.5%</td>
</tr>
</tbody>
</table>

Examples:

I praise her if she’s brave about a cut and don’t make too much fuss. If something is wrong I try to find out what is wrong (mother of a 6 year old girl).

I let her have a good cry. She is usually able to cope afterwards. I don’t tell her not to be a baby (mother of an 11 year old girl).

I like her to talk about her worries. She can solve them herself and she does talk to me about things that worry her. If she knows we can sort things out, she won’t worry so much (mother of a 15 year old girl).

Examples of children’s responses:

They tell me to be a big girl and grow up (girl aged 8).

Mum says stop moaning, you’ve got to get on with it (girl aged 15).

They [the parents] say it’s better if you let it out in the open (boy aged 9).

Children’s understanding of bloodtests

The next table shows children’s understanding of the purpose of bloodtests and parent ratings of their child’s understanding.

Classification of understanding was as follows: no understanding (no concept of purpose of bloodtests); a little understanding...
(vague idea bloodtests investigate the child's metabolic control/health); a moderate amount (testing blood sugar); a great deal (tests blood sugar over 6-8 weeks). In general, parents over-estimated children's understanding of bloodtests.

TABLE 11-16 Children's understanding of bloodtests

<table>
<thead>
<tr>
<th>Response</th>
<th>Child Freq</th>
<th>Child Percent</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding</td>
<td>15</td>
<td>25.9%</td>
<td>1</td>
<td>1.8%</td>
</tr>
<tr>
<td>A little</td>
<td>17</td>
<td>29.3%</td>
<td>9</td>
<td>16.4%</td>
</tr>
<tr>
<td>A moderate amount</td>
<td>13</td>
<td>22.4%</td>
<td>24</td>
<td>43.6%</td>
</tr>
<tr>
<td>A great deal</td>
<td>13</td>
<td>22.4%</td>
<td>21</td>
<td>38.2%</td>
</tr>
</tbody>
</table>

Children's understanding of finger pricks

Classification of children's responses for this variable was similar to the above: no understanding (no concept of purpose of finger pricks); a little understanding (vague idea they investigate child's metabolic control/health); a moderate amount (test blood sugar); a great deal (test blood sugar for immediate reading on metabolic control). Parents again over-estimated children's understanding regarding finger pricks.

TABLE 11-17 Children's understanding of finger pricks

<table>
<thead>
<tr>
<th>Response</th>
<th>Child Freq</th>
<th>Child Percent</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding</td>
<td>3</td>
<td>5.2%</td>
<td>1</td>
<td>1.8%</td>
</tr>
<tr>
<td>A little</td>
<td>9</td>
<td>15.5%</td>
<td>3</td>
<td>5.5%</td>
</tr>
<tr>
<td>A moderate amount</td>
<td>29</td>
<td>50.0%</td>
<td>11</td>
<td>20.0%</td>
</tr>
<tr>
<td>A great deal</td>
<td>17</td>
<td>29.3%</td>
<td>40</td>
<td>72.7%</td>
</tr>
</tbody>
</table>
Children's understanding of their illness

Table 11-18 presents children's understanding of their illness according to parent ratings and children's responses to a question about telling a child of the same age what was wrong with them. This variable is categorized as follows: no understanding (no concept of diabetes); a little understanding (vague reference to insulin or bodily dysfunction); moderate understanding (pancreas not producing enough insulin); and a great deal of understanding (pancreas not producing enough insulin and the need to inject it). Parents most frequently stated that their child had a great deal of understanding of their diabetes, while more children indicated having a little understanding.

<table>
<thead>
<tr>
<th>Response</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding</td>
<td>0</td>
<td>0.0%</td>
<td>7</td>
<td>11.5%</td>
</tr>
<tr>
<td>A little</td>
<td>4</td>
<td>6.5%</td>
<td>25</td>
<td>41.0%</td>
</tr>
<tr>
<td>A moderate amount</td>
<td>23</td>
<td>37.1%</td>
<td>12</td>
<td>19.7%</td>
</tr>
<tr>
<td>A great deal</td>
<td>35</td>
<td>56.5%</td>
<td>17</td>
<td>27.9%</td>
</tr>
</tbody>
</table>

Children's understanding of their treatment

The following table presents children's understanding of their treatment regimen and parent ratings of their child's understanding. Children's concepts of their treatment were categorized according to which treatments were referred to (i.e. bloodtests, finger pricks, insulin injections, diet) as follows:
no understanding (no concept of treatment involved); a little (vague understanding of treatment, mentions one of treatments); a moderate amount (mentions two treatments); a great deal (mentions three or more treatments). Once again, parents over-estimated their child's understanding.

**TABLE 11-19 Children's understanding of their treatment**

<table>
<thead>
<tr>
<th>Response</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding</td>
<td>0</td>
<td>0.0%</td>
<td>11</td>
<td>18.0%</td>
</tr>
<tr>
<td>A little</td>
<td>6</td>
<td>9.7%</td>
<td>13</td>
<td>21.3%</td>
</tr>
<tr>
<td>A moderate amount</td>
<td>26</td>
<td>41.9%</td>
<td>17</td>
<td>27.9%</td>
</tr>
<tr>
<td>A great deal</td>
<td>30</td>
<td>48.4%</td>
<td>20</td>
<td>32.8%</td>
</tr>
</tbody>
</table>

Children's fears
Twenty five (42.4%) parents reported their child had fears or phobias other than needles while 34 (57.6%) said they did not. Children tended to have one other fear rather than several fears (79.4%). Half the parents (50.8%) reported fears or phobias in the family, with injection phobias being the most common (48.3%).

Treatment child finds most difficult
Table 11-20 shows the treatment children found most difficult and parent's view of the most difficult treatment for children. Parents felt that diet was the most difficult aspect of the treatment regimen for children, while children reported bloodtests to be most stressful.
TABLE 11-20 Treatment child finds most difficult

<table>
<thead>
<tr>
<th>Response</th>
<th>Child Freq</th>
<th>Child Percent</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bloodtests</td>
<td>19</td>
<td>33.9%</td>
<td>7</td>
<td>11.3%</td>
</tr>
<tr>
<td>Diet</td>
<td>11</td>
<td>19.6%</td>
<td>16</td>
<td>25.8%</td>
</tr>
<tr>
<td>Finger pricks</td>
<td>9</td>
<td>16.1%</td>
<td>15</td>
<td>24.2%</td>
</tr>
<tr>
<td>Insulin injections</td>
<td>6</td>
<td>10.7%</td>
<td>10</td>
<td>16.1%</td>
</tr>
<tr>
<td>Clinic attendance</td>
<td>4</td>
<td>7.1%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>5.4%</td>
<td>4</td>
<td>6.4%</td>
</tr>
<tr>
<td>More than one</td>
<td>2</td>
<td>3.6%</td>
<td>6</td>
<td>9.7%</td>
</tr>
<tr>
<td>No problems</td>
<td>2</td>
<td>3.6%</td>
<td>4</td>
<td>6.5%</td>
</tr>
</tbody>
</table>

Treatment parent finds most difficult

The following table shows that diet was the most difficult aspect of the child's treatment for parents to cope with. Children felt their parents were most concerned about insulin injections.

TABLE 11-21 Treatment parent finds most difficult

<table>
<thead>
<tr>
<th>Response</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>21</td>
<td>38.9%</td>
<td>8</td>
<td>20.5%</td>
</tr>
<tr>
<td>More than one</td>
<td>8</td>
<td>14.8%</td>
<td>3</td>
<td>7.7%</td>
</tr>
<tr>
<td>Finger pricks</td>
<td>7</td>
<td>13.0%</td>
<td>3</td>
<td>7.7%</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>13.0%</td>
<td>2</td>
<td>5.1%</td>
</tr>
<tr>
<td>Injections</td>
<td>4</td>
<td>7.4%</td>
<td>10</td>
<td>25.6%</td>
</tr>
<tr>
<td>Child's moods</td>
<td>3</td>
<td>5.6%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>No problems</td>
<td>2</td>
<td>3.7%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Bloodtests</td>
<td>1</td>
<td>1.9%</td>
<td>8</td>
<td>20.5%</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>1</td>
<td>1.9%</td>
<td>2</td>
<td>5.1%</td>
</tr>
</tbody>
</table>

Arguments over treatment

About half the parents in the study (49.2%) reported difficulties
over adherence to treatment and consequent arguments. Twenty-five (41%) children reported difficulties. Despite this, 83.6% of children carried out their own finger pricks, and 83.9% their own insulin injections (according to parents). According to children, 30.5% did not carry out finger pricks regularly and 8.6% did not carry out insulin injections regularly.

Impact of child’s illness and treatment on family

The following table shows the impact of the child’s diabetes and treatment on the family. Parents more frequently referred to a multiple effect while children most often believed there was no effect.

<table>
<thead>
<tr>
<th>Response</th>
<th>Parent Freq</th>
<th>Parent Percent</th>
<th>Child Freq</th>
<th>Child Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple effect</td>
<td>26</td>
<td>43.3%</td>
<td>3</td>
<td>6.3%</td>
</tr>
<tr>
<td>No effect</td>
<td>9</td>
<td>15.0%</td>
<td>19</td>
<td>39.6%</td>
</tr>
<tr>
<td>Diet</td>
<td>7</td>
<td>11.7%</td>
<td>6</td>
<td>12.5%</td>
</tr>
<tr>
<td>Worry</td>
<td>7</td>
<td>11.7%</td>
<td>7</td>
<td>14.6%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>10.0%</td>
<td>4</td>
<td>8.3%</td>
</tr>
<tr>
<td>Clock conscious</td>
<td>2</td>
<td>3.3%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Affected siblings</td>
<td>2</td>
<td>3.3%</td>
<td>5</td>
<td>10.4%</td>
</tr>
</tbody>
</table>

Examples:

It’s been quite hard on the siblings, particularly her elder sister. She feels Claire gets more attention and gets away with more (mother of 6 year old girl).

We can't leave her for the weekend. No one else does them [insulin injections] in the family. They are afraid of hurting her.
According to most parents, their child's diabetes did not interfere with daily activities (83.9%) although for a small group it did (16.1%).

Annual review and glycosylated haemoglobin
Thirty-six (66.7%) children had a medical "annual review", 18 (33.3%) did not and there was missing data on eight children. Thirty-two (51.6%) children had poor glycaemic control (i.e. haemoglobin values over 10%) while 30 (48.4%) had good control (i.e. haemoglobin values less than 10%).

Doctor/phlebotomist
Thirty-two (51.6%) children were seen by the paediatrician and 30 (48.4%) by the phlebotomist for bloodtaking during the baseline assessments.

Emotional and conduct disorder
Twenty-one (34.4%) children were classified as having emotional/conduct disorder according to the Rutter Parental Screening Questionnaire. Of these children, four (22.2%) were antisocial and 14 (77.8%) neurotic. However, 10 (18.9%) children were classified as having a disorder according to the Rutter Teacher Questionnaire. Of these, three (33.3%) had an antisocial disorder and six (66.7%) a neurotic disorder. Of the 46 children who completed the Birleson Depression Inventory, seven (15.2%) were found to be possibly depressed.
11.3.3 Inferential Statistics

Summary statistics
The means, standard deviations, minimum and maximum values for variables analysed in this section are presented in Appendix XXIII and variable definitions in Appendix XVI. Variables with N less than 30 were excluded from analyses and are therefore not presented as statistically the results would have little meaning. In general, Pearson product moment correlation coefficients were used for data from a normal distribution, Spearman rank order correlation coefficients for data with values below 10, and Kendall correlations for data where one variable contained two values (i.e. yes/no responses). One-tailed tests were used when the direction of significance was expected, except where otherwise indicated. Generally, only significant correlations are reported.

Total Distress Scores
Children's total distress scores correlated with the following:
with Rutter parent scores (r = .43; p < .001); with emotional and behavioural disorder according to Rutter parent scores (tau = .29; p < .005); Rutter teacher scores (r = .37; p < .005); with the child's external locus of control (r = .24; p < .03); depression (r = .31; p < .02); parent rating of child's usual anxiety over bloodtests (rho = .57; p < .001); child's usual anxiety over bloodtests (rho = .58; p < .001) and insulin injections (rho = .22; p < .05); child's anticipatory anxiety prior to attending the clinic (tau = .22; p < .05); parent rating of child's anticipatory
anxiety prior to bloodtesting (rho = .35; p < .01); anxiety (rho = .35; p < .01) and pain (rho = .26; p < .03) parents anticipated their child would experience during bloodtesting; and parent rating of whether the child’s anxiety was increasing over time (rho = .56; p < .01).

Total distress scores were negatively correlated with the child’s global self-concept (r = -.26; p < .03); the child’s age (r = -.28; p < .02); with birth order (rho = -.31; p < .01); child’s understanding of illness (rho = -.33; p < .04); whether the child carried out insulin injections according to parents (tau = -.18; p < .01); and according to self-report (tau = -.19; p < .05); and the number of finger prick sites according to parents (r = -.36; p < .01), these being associated with lower distress scores. Parent’s own anxiety about dental injections was negatively related to children’s distress scores.

Phase 1
Distress scores during Phase 1 of the medical procedure correlated with a number of scores including Rutter parent scores (r = .53; p < .001); emotional/conduct disorder according to these scores (tau = .31; p < .005); Rutter teacher scores (r = .39; p < .005); parent rating of child’s usual anxiety over bloodtests (rho = .56; p < .001); the child’s self-report of usual anxiety over bloodtests (rho = .50; p < .001); child’s expected anxiety during bloodtest (rho = .38; p < .01); parent rating of child’s anticipated anxiety during bloodtest (rho = .45; p < .001);
parent's own anticipatory anxiety (\(\rho = .53; p<.001\)); and negatively related to global self-concept (\(r = -.28; p<.02\)).

Phase 2
Distress scores for phase 2 correlated with similar variables, including child state (\(r = .29; p<.01\)) and trait anxiety (\(r = .24; p<.03\)); child external locus of control (\(r = .26; p<.02\)); the child's emotional/conduct disorder according to Rutter parent scores (\(\tau = .28; p<.01\)); total Rutter parent scores (\(r = .24; p<.03\)); Rutter teacher scores (\(r = .30; p<.01\)); depression (\(r = .44; p<.001\)); parent rating of child's usual anxiety over bloodtests (\(\rho = .59; p<.001\)); the child's self-report of usual anxiety over bloodtests (\(\rho = .56; p<.001\)); parent rating of child's anticipatory anxiety prior to attending the clinic (\(\tau = .25; p<.025\)); child rating of expected anxiety during bloodtest (\(\rho = .42; p<.001\)); parent rating of child's anticipatory anxiety prior to bloodtesting (\(\rho = .56; p<.001\)).

Phase 3
Variables correlating with distress scores in phase 3 included: child state (\(r = .29; p<.01\)) and trait anxiety (\(r = .24; p<.03\)); child external locus of control (\(r = .26; p<.02\)); Rutter parent (\(r = .22; p<.04\)) and teacher scores (\(r = .26; p<.03\)); depression (\(r = .28; p<.03\)); parent rating of the child's usual anxiety over bloodtests (\(\rho = .53; p<.001\)); the child's self-report of usual anxiety over bloodtests (\(\rho = .56; p<.001\)).
Validity measures

Total revised OSBD distress scores (the summation of the distress scores across the three phases of the medical procedure) correlated with phase 1 (preparation for venipuncture) (r = .96; p<.001), phase 2 (insertion of needle and bloodtaking) (r = .91; p<.001), and with phase 3 (removal of needle and recovery) (r = .77; p<.001) of the medical procedure. Table 11-23 presents Spearman correlations between total OSBD distress and scores for the three phases of the medical procedure with the OSBD behaviour categories. The table shows significant correlations with all but two (i.e. requests emotional support and information seeking) of the behavioural categories. Screaming did not occur during bloodtests.

<table>
<thead>
<tr>
<th>Behaviours</th>
<th>Total Scores</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscle tension</td>
<td>.95 **</td>
<td>.89 **</td>
<td>.88 **</td>
<td>.79 **</td>
</tr>
<tr>
<td>Crying</td>
<td>.42 **</td>
<td>.43 **</td>
<td>.39 **</td>
<td>.41 **</td>
</tr>
<tr>
<td>Screaming</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Anxiety verbalised</td>
<td>.73 **</td>
<td>.73 **</td>
<td>.69 **</td>
<td>.46 **</td>
</tr>
<tr>
<td>Pain verbalised</td>
<td>.51 **</td>
<td>.48 **</td>
<td>.47 **</td>
<td>.49 **</td>
</tr>
<tr>
<td>Restraint used</td>
<td>.58 **</td>
<td>.56 **</td>
<td>.57 **</td>
<td>.42 **</td>
</tr>
<tr>
<td>Verbal stalling</td>
<td>.51 **</td>
<td>.56 **</td>
<td>.44 **</td>
<td>.33 **</td>
</tr>
<tr>
<td>Physical resistance</td>
<td>.57 **</td>
<td>.57 **</td>
<td>.56 **</td>
<td>.56 **</td>
</tr>
<tr>
<td>Requests emotional support</td>
<td>.26</td>
<td>.19</td>
<td>.20</td>
<td>.21</td>
</tr>
<tr>
<td>Nervous behaviour</td>
<td>.54 **</td>
<td>.50 **</td>
<td>.55 **</td>
<td>.31 **</td>
</tr>
<tr>
<td>Information seeking</td>
<td>.15</td>
<td>.22</td>
<td>.06</td>
<td>.20</td>
</tr>
</tbody>
</table>

** p<.001
Global ratings

Table 11-24 shows Spearman correlations between global
doctor/phlebotomist, child and parent ratings with distress
scores.

<table>
<thead>
<tr>
<th></th>
<th>Distress Scores</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total Scores</td>
<td>Phase 1</td>
<td>Phase 2</td>
<td>Phase 3</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Parent</td>
<td>Phase 3</td>
<td>Phase 2</td>
<td>Phase 1</td>
</tr>
<tr>
<td>Doctor/Phleb</td>
<td>Parent</td>
<td>Phase 3</td>
<td>Phase 2</td>
<td>Phase 1</td>
</tr>
<tr>
<td>Child</td>
<td>Parent</td>
<td>Phase 3</td>
<td>Phase 2</td>
<td>Phase 1</td>
</tr>
<tr>
<td>Parent</td>
<td>Parent</td>
<td>Phase 3</td>
<td>Phase 2</td>
<td>Phase 1</td>
</tr>
<tr>
<td>Pain</td>
<td>Parent</td>
<td>Phase 3</td>
<td>Phase 2</td>
<td>Phase 1</td>
</tr>
</tbody>
</table>

* p<.01 ** p<.001

The behavioural categories also correlated with anticipatory
type ratings in that muscle tension correlated with child’s
anticipated anxiety during bloodtest (rho = .38; p<.01); crying
with parent rating of the pain they anticipated their child would
experience during the bloodtest (rho = .33; p<.01); screaming
with child’s anticipated anxiety during bloodtest (rho = .33;
p<.01); anxiety verbalized with child’s anticipated anxiety
during bloodtest (.40; p<.001), with parent rating of child’s
anticipatory anxiety (rho = .39; p<.01), and parent rating of
anxiety they anticipated child would experience during bloodtest
(rho = .39; p<.01); restraint used with child’s rating
anticipated anxiety during bloodtest (rho = .36; p < .01); nervous behaviour with child rating of parent anticipatory anxiety (rho = -.39; p < .01), with parent rating of child's anticipatory anxiety (rho = .42; p < .01) and parent rating of anxiety they anticipated the child would experience during bloodtest (rho = .42; p < .001). These all add further validity to the OSBD

Global ratings

Table 11-25 presents Spearman correlation coefficients of global anxiety ratings between the doctor/phlebotomist, child and parent and shows that anxiety was being assessed to a similar degree by children and parents, and parents and medical staff but not by children and medical staff.

<table>
<thead>
<tr>
<th></th>
<th>Doctor/phleb</th>
<th>Child</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor/phleb</td>
<td>1.00</td>
<td>.26</td>
<td>.41*</td>
</tr>
<tr>
<td>Child</td>
<td>.26</td>
<td>1.00</td>
<td>.44**</td>
</tr>
<tr>
<td>Parent</td>
<td>.41*</td>
<td>.44**</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* p < .01 ** p < .001

Table 11-26 shows correlation coefficients for global pain ratings between the doctor/phlebotomist, child and parent. It suggests that pain was being assessed to a similar degree by children, parents and medical staff.
The child's usual anxiety over bloodtests correlated with:

<table>
<thead>
<tr>
<th></th>
<th>Doctor/phleb</th>
<th>Child</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor/phleb</td>
<td>1.00</td>
<td>.35 *</td>
<td>.36 **</td>
</tr>
<tr>
<td>Child</td>
<td>.35 *</td>
<td>1.00</td>
<td>.47 **</td>
</tr>
<tr>
<td>Parent</td>
<td>.36 *</td>
<td>.47 **</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* p < .01  ** p < .001

The child's usual anxiety over bloodtests correlated with:
anxiety (rho = .49; p < .001) and pain (rho = .44; p < .001) ratings
by medical staff; the child's anxiety rating (rho = .50; < .001); and, parent's rating of anxiety (rho = .57; p < .001). The child's
usual anxiety over finger pricks correlated with the child's
experienced anxiety during the bloodtest (.32; p < .01). Anxiety
over insulin injections was associated with parent ratings of the
child's anxiety (rho = .40; p < .01). However, the child's anxiety
over dental injections did not correlate with any global
ratings.

Age and sex differences

Total revised OSBD distress scores were subjected to a 2 (age) by
2 (sex) way analysis of variance to determine age and sex
differences in children's expression of behavioural distress. The
results indicated a significant main effect for age (young versus
older children) (F (1, 61) = 4.32, p < .04). There was a trend
toward significance in phase 1 for age (F (1, 61) = 3.85, p < .06)
and for phase 2 (F (1, 61) = 3.36, p < .07).
Scores for the eleven behavioural categories were subjected to a 2 (age) by 2 (sex) way analysis of variance to determine age and sex differences in children's expression of distress. The results showed a significant age main effect for muscle tension \( F(1,61) = 5.16; p < .03 \) and restraint used \( F(1,61) = 5.02; p < .03 \), and a trend toward significance for verbal stalling \( F(1,61) = 3.50; p < .07 \).

**Physician/phlebotomist variables**

An analysis of variance was conducted to assess whether children's distress scores were affected by whether they saw the paediatrician or phlebotomist for bloodtaking. The results were non significant for total scores \( F(1,61) = 3.05, p < .09 \), phase 1 \( F(1,61) = 2.78, p < .15 \), phase 2 \( F(1,61) = p < .10 \) or phase 3 \( F(1,61) = p < .09 \). Global and anticipatory ratings were not related to paediatrician or phlebotomist variables.

**Fears and phobias**

Kendall correlations were conducted on children's fears and phobias. There was no significant relationship between parent's rating of whether children had other fears with age (months) or age (young/old), and with anxiety and pain ratings by medical staff, children and parents, and the child's anticipatory ratings. Children's description of other fears correlated with age (months) \( (\tau = .27; p < .005) \) and age (young/old) \( (\tau = .26; p < .025) \); with parent rating of their own anxiety prior to bloodtest \( (\tau = -.23; p < .025) \); and with usual anxiety over

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dental injections (tau = -.31; p<.01).

Child’s anticipatory anxiety prior to attending clinic
The child’s anticipatory anxiety prior to attending clinic (i.e. difficulties in sleep, anxiety etc.) was positively associated with: global anxiety ratings by doctor/phlebotomist (tau = .32; p<.025); global anxiety ratings by the child (tau = -.23; p<.05); child pain ratings (tau = .28; p<.025); parent’s rating of the anxiety they anticipated their child would experience during the bloodtest (tau = .23; p<.05); and, parent’s rating of the child’s usual anxiety over bloodtests (tau = .30; p<.025).

Parent anxiety
There was a negative correlation between parents willing to wait in the waiting room with parent state anxiety (tau = -.24; p<.025); parent trait anxiety (tau = -.26; p<.005); and parental anticipatory anxiety (tau = -.28; p<.01). Thus, parents willing to wait had lower anxiety scores.

Previous experience
There was a significant relationship between children’s previous unpleasant experience (according to parents) with needles and parental anticipatory anxiety (tau = .23; p<.05) and the child’s report of unpleasant experience and pain rating (tau = -.21; p<.05).

Child’s understanding of bloodtests, finger pricks, illness and
treatment were non significant, although concepts of diabetes were. Children’s understanding of these variables correlated with one another with the exception of understanding of finger pricks and diabetes, as presented in Table 11-27.

TABLE 11-27 Spearman correlations of children’s understanding of bloodtests, finger pricks, diabetes and treatment

<table>
<thead>
<tr>
<th></th>
<th>B/tests</th>
<th>Finger pricks</th>
<th>Diab</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bloodtests</td>
<td>1.00</td>
<td>.35 *</td>
<td>.46 **</td>
<td>.52 **</td>
</tr>
<tr>
<td>Finger pricks</td>
<td>.35 *</td>
<td>1.00</td>
<td>.25</td>
<td>.43 **</td>
</tr>
<tr>
<td>Diabetes</td>
<td>.46 *</td>
<td>.25</td>
<td>1.00</td>
<td>.61 **</td>
</tr>
<tr>
<td>Treatment</td>
<td>.53 *</td>
<td>.43 *</td>
<td>.61 **</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* p<.01  ** p<.001

Interestingly, parent ratings of their child’s understanding of bloodtests (rho = .24; p<.04), diabetes (rho = .31; p<.01) and treatment (rho = .43; p<.001) correlated with one another, while ratings of finger pricks did not.

The following table presents Spearman correlations of children’s understanding of bloodtests, finger pricks, illness (diabetes) and their treatment with age (months) and Kendall correlations for age (young/old), suggesting increasing understanding with age with the exception of finger pricks.
TABLE 11.28 Correlations of children's understanding of 
bloodtests, finger pricks, illness and treatment with age

<table>
<thead>
<tr>
<th></th>
<th>Age (months)</th>
<th>Age (young/old)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bloodtests</td>
<td>.42 **</td>
<td>.41 ***</td>
</tr>
<tr>
<td>Finger pricks</td>
<td>.13</td>
<td>.12</td>
</tr>
<tr>
<td>Illness</td>
<td>.58 **</td>
<td>.48 ***</td>
</tr>
<tr>
<td>Treatment</td>
<td>.38 *</td>
<td>.31 *</td>
</tr>
</tbody>
</table>

* p < .01  ** p < .001  *** p < .0005

Glycosylated haemoglobin and pain perception
Glycosylated haemoglobin was not found to be relevant to children's anxiety, pain and distress scores.

Prediction of distress
A stepwise multiple regression analysis was used to determine which predictor variables in combination with each other determined children's total distress scores. The results suggested that parent rating of child's usual anxiety over bloodtests (F(1,22) = 23.33; p < .0001); the child's usual anxiety over bloodtests (F(2,21) = 17.83; p < .0001); and the presence of emotional/conduct disorder according to teacher reports (F(3,20) = 15.35; p < .0001) were the three predictor variables for children's total distress scores.

Physiological data
Heart rate did not correlate with anticipatory ratings or global ratings of anxiety and pain, or with child state and trait
anxiety. However, the child's heart rate during phase 1 of the medical procedure (anticipatory phase) correlated (two-tailed) with parent trait anxiety ($r = .34; p<.02$). Interestingly, heart rate increased significantly during insertion of the needle and bloodtaking compared to that in the waiting room ($t(58) = -7.37, p < .0001$). However, there were no significant differences in heart rate for the other phases of the procedure.

Non-adherence to treatment
Arguments over treatment did not correlate with global or anticipatory ratings or distress scores. Whether the child did finger pricks was not significantly related to global ratings. Insulin injections done regularly negatively correlated (two-tailed) with parent rating of pain they anticipated their child would experience ($tau = -.26; p<.05$). Thus, parents had lower expectations of experienced pain during bloodtests, possibly because they felt their child coped with needles.

Cognitive style
Kendall correlations (two-tailed) on children's preference to inject themself or have others inject them found a significant association with external health locus of control ($tau = .22; p<.05$) and a negative correlation with internal health locus of control ($tau = -.19; p<.05$). Thus, children preferring to inject themselves were likely to have higher internal health locus of control scores.
Variables not related to children’s distress

The following variables were not related to children’s total distress scores: child state and trait anxiety, child external and internal locus of control, child external and internal health locus of control, parent state and trait anxiety, parent external and internal locus of control, the child’s self-concept for social acceptance, cognitive competence, physical appearance, athletic competence, behavioural conduct and global self-worth, glycosylated haemoglobin, heart rate, the child’s sex, social class, months since diagnosis, presence of family illness, the child’s understanding of treatment, the number of bloodtests or admissions prior to baseline, life events, frequency of bloodtests and finger pricks, child’s usual anxiety over finger pricks and dental injections, child’s age when self-injecting, number of coping strategies, annual review, doctor or phlebotomist taking blood, child’s rating of parent’s anticipatory anxiety, child rating of the pain expected during the bloodtest, child’s preference to monitor or distract during bloodtest, arguments over treatment, previous experience, child’s fears and presence of fears in the family.

Nonsignificant parent ratings with total distress scores included: parent rating of their anticipatory anxiety, parent presence during bloodtests, parent’s willingness to wait in the waiting room, parent rating of number of insulin injection sites, parent rating of child’s compliance with finger pricks and insulin injections, parent’s view of illness interfering with activities, and parent self-rating of bloodtests and injections.
11.4 DISCUSSION

Hypotheses about psychosocial variables and children's total distress were confirmed for emotional and conduct disorder, depression, child external locus of control, and global self-concept. Child state and trait anxiety were relevant to children's distress during and immediately after bloodtests. Health locus of control, parent state and trait anxiety and parent locus of control were not associated with children's distress scores. Depression in chronically ill children has been reported in the literature but suggested to be a normal response to stressful experiences associated with long-term illness and or treatment regimens (Varni, 1983; Close et al, 1986).

Three variables found to be predictive of children's distress during routine bloodtests in a diabetic clinic were the parent rating of the child's usual anxiety of such procedures, the child's reported anxiety over bloodtests, and, the presence of emotional/conduct disorder. Children who carried out their own insulin injections and varied finger prick sites enjoyed lower distress scores. However, this may have been possible for children with lower anxiety levels about needles. Taking responsibility for diabetic management may increase self-efficacy and consequently significantly influence a child's coping with pain (Ross and Ross, 1988). There was no significant
relationship between adherence problems to finger pricks and insulin injections with children’s anxiety, pain and distress scores. Rather, children who took responsibility for their insulin injections had parents who expected their children to experience less pain and distress during bloodtests.

The revised version of the Observation Scale of Behavioural Distress (OSBD) was found to be a valid and reliable measure of children’s distress during routine bloodtests. It correlated with parent and child self-report measures of anxiety and pain, observer reports, anticipatory ratings and the child’s usual anxiety over bloodtests. Like the previous assessment study described in Chapter 7, the behavioural categories “requests emotional support” and “information seeking” did not correlate with total distress scores since they occurred infrequently and could therefore be omitted from the scale with less painful procedures.

Age differences were found in children’s expression of behavioural distress, with younger children under the age of 11 years displaying more muscle tension and requiring physical restraint during bloodtests. These findings are consistent with other studies that have found age differences in children’s distress levels (Katz et al, 1980; Jay et al, 1983). However, while there were no sex differences found here in children’s
expression of distress, other studies have reported mixed findings (Katz et al, 1980; Jay et al, 1983; Hilgard and LeBaron, 1982).

Just over half the children in the study had previous unpleasant experiences with needles, often when newly diagnosed. Children with previous unpleasant experiences with needles had parents with higher anticipatory anxiety prior to the medical procedure. This was possibly due to anticipation of difficulties over the procedure rather than to parent state or trait anxiety, which had been found not to be significant. Children also tended to report higher experienced pain during bloodtests. Interestingly, there was no relationship with other fears and distress, possibly because it was common for children to have fears. This is consistent with Ollendick and King’s (1991) assertion that children experience a variety of "normal" fears over their development.

Bloodtests were found to be the most difficult aspect of the diabetic treatment regimen by children. The insertion of the needle was found to be the most stressful aspect of the bloodtest by children. Children’s preference to look at the needle during
bloodtesting or away from it identified two groups of children, "monitors" and "distractors", described by Miller (1979). Monitors felt they coped better by monitoring the procedure because they felt more in control, while distractors felt they coped better by focusing attention elsewhere. Although a number of children had no coping strategies, some children used cognitive strategies for coping with bloodtests, consistent with those described by Siegel (1989) such as positive self-talk, relaxation, imagery and distraction techniques. Such coping strategies could be helpful for other children in the diabetic clinic who do not cope well with needles.

Children with a preference to inject themselves, as opposed to others carrying out invasive procedures on them, had an internal health locus of control. Thus, these children felt they could make decisions about their own health care (Parcel and Meyer, 1978). Many children referred to issues of cognitive control regarding their choice, that is, that they felt more in control of the situation and the discomfort if they administered injections or finger pricks themselves. Such control increases pain tolerance, pain threshold or both (Thompson, 1981; Turk, Meichenbaum and Genest, 1983; Ross and Ross, 1988a). It is likely that the reduction of uncertainty was the important factor (Averill, 1973).

Just over half the sample of children felt their parent's presence helped them to cope better, although when asked what
helped them cope better. Frequent responses included nothing or distraction. Other studies have also reported parental presence to be helpful (Ross and Ross, 1984b; Abu-saad, 1984; Gaffney, 1983). Parents usually managed their child’s pain or distress in painful and other situations by encouraging the child to talk or by providing emotional support or reassurance. However, children’s reports suggested attempts by some parents to reinforce a stoic attitude to discomfort, while other more anxious parents were observed by the researcher to encourage an inappropriate degree of pain expression. The possible motivations of this behaviour have been described by Ross and Ross (1988) and appeared to be due to a general style of overprotective and overanxious parental behaviour (Apley, 1975), often more common in the parents of newly diagnosed children.

Interestingly, children’s understanding of bloodtests, finger pricks and treatment were not related to distress levels during bloodtests, although concepts of diabetes were. Development of these concepts nevertheless were found to increase with age consistent with other reports (Bibace and Walsh, 1980; Perrin and Gerrity, 1981; Burbach and Peterson, 1986) with the exception of finger pricks. Parents overestimated children’s understanding of finger pricks, but were more accurate with understanding of bloodtests, knowledge about diabetes and its treatment. One difficulty in interpreting these findings concerns the comparison of responses obtained from a generate format which were subsequently coded (child’s responses) with a supplied format.
used for parents. The responses may not be directly comparable and further, it is difficult to know what parents are basing their assumptions on regarding children's concepts.

Physiological measures of heart rate did not correlate with children's anxiety, pain and distress scores. There were significant changes in heart rate during the procedure compared to that in the waiting room. The results on heart rate are similar to those found by Peterson and Shigetomi (1981). The lack of concordance between behavioural, cognitive and physiological systems has been referred to earlier (Epstein, 1975). Jay (1988) suggests using multiple physiological measures as described in Chapter 7, other measures such as blood pressure may be more valid and reliable indicators of distress. Metabolic control, as measured by glycosylated haemoglobin, was not found to relate to children's distress. No other studies have addressed the relationship between metabolic control and pain perception, and it thus requires further study.

The present assessment study represents a first attempt to study the psychosocial variables influencing diabetic children's distress during routine bloodtests. Further studies are required to identify children most likely to cope poorly with routine painful procedures, an essential aspect of the treatment regimen. This has implications for clinical practice, in that these children could be offered intervention early on, preferably when newly diagnosed. Treatment issues are discussed in the next chapter.
CHAPTER 12

COGNITIVE-BEHAVIOURAL AND HYPNOTIC TREATMENT OF ACUTE PAIN IN CHILDREN WITH INSULIN DEPENDENT DIABETES MELLITUS

12.1. PILOT STUDY

Seven children were seen in the pilot study from May 1987 to May 1988 at Addenbrooke's Hospital, Cambridge. These children had also taken part in the assessment study described in the previous chapter. The present intervention study was an extension of this study. The aims of the present pilot study were identical to those described in Chapter 9 for the renal transplant intervention study:

1. Test two intervention scripts, hypnotic and cognitive-behavioural intervention for children aged 6-16 years, and ensure that they were both distinct from one another and of similar duration.

2. To see if the interventions could be delivered immediately before bloodtests and be accommodated into clinic routine.

3. To see if the Stanford Hypnotic Clinical Scale for Children SHCSC (Morgan and Hilgard, 1978/1979) could be included in the same preparation session prior to the medical procedure.

Of the children who took part in the pilot study, three were seen for hypnotherapy and four for cognitive-behavioural intervention. The scripts for both interventions were found to be satisfactory.
and were not altered. As discussed in Chapter 9, the omission of imagery in the cognitive-behavioural condition maintained clarity between the two interventions. Standardizing interventions by using scripts ensured that they were delivered in the same way for each child in a particular group and that the duration was also similar. Both interventions lasted approximately 20 minutes.

Children were seen for intervention on arrival at clinic, following routine measurement of height and weight and urinary analysis. An examination room in the clinic was used which contained a couch and chair. It was necessary to inform the staff nurse that the child was being seen prior to his/her bloodtest, so that this could be incorporated into the clinic routine. When the intervention was completed the researcher accompanied the child to either the phlebotomist or paediatrician for routine bloodtests. It was necessary to inform nursing staff of children taking part in the study, so that the researcher could be alerted when they arrived at clinic.

The SHCSC (see Appendix XVII) was included in the intervention session prior to the medical procedure and was always given before hypnotic or cognitive-behavioural intervention. The SHCSC took 20 minutes to administer and thus total intervention time was approximately 40 minutes.

The pilot data were included in the final sample, as the interventions were found to be satisfactory.
12.2. METHOD

12.2.1. Subjects

Subjects were 36 children and adolescents with IDDM who attended the Diabetic Paediatric Out-patient clinic at Addenbrooke’s Hospital, Cambridge from May 1987 to March 1991. These children and adolescents had previously taken part in the assessment study described in Chapter 11. One adolescent girl in the cognitive-behavioural group became uncooperative, saying she preferred to cope with bloodtests in her own way. This reduced the final sample to 35. No other child refused treatment once they volunteered for this part of the study. All subjects were Caucasian. There were 23 girls and 13 boys in the sample. The mean age of the children was 136 months (SD = 37 months; range = 72 - 203 months).

12.2.2. Criteria for selection

Children seen in the assessment study (see Chapter 11) who had moderate to high levels of self-reported, parent or observer reported anxiety and/or pain (e.g. 5 or over on the 10-point global scale) were invited to take part in the present study which aimed to look at different ways of helping children cope with bloodtests in the clinic.

12.2.3. The Clinical Setting

This has been previously described in Chapter 11.
12.2.4. Dependent Measures

The assessment measures used consisted of self-report measures of anxiety and pain (global ratings), the revised version of the OSBD, and psychophysiological measures of arousal (heart rate). These measures have been described in Chapters 7 and 11 and are therefore not presented again. The assessment measures evaluated the children's cognitive, behavioural and physiological responses, consistent with the trimodal conceptualization of pain proposed by Sanders (1979). Indices of metabolic control were also taken (glycosylated hemoglobin) (see Chapter 11).

12.2.5. Design

The study consisted of three experimental conditions (Hypnosis, Cognitive-Behavioural intervention, waiting treatment - Control) delivered in the context of a multiple baseline repeated measures design. Children were randomly allocated to one of the three conditions controlling for age. Control children later received either hypnotic or behavioural intervention. The intervention conditions had an ABBA design as follows:

A  Initial assessment (Baseline)
B  Intervention (Hypnosis or Cognitive-Behavioural preceded by SHCSC) plus assessment (Intervention 1)
B  Intervention reinforced during medical procedure plus assessment (Intervention 2)
A  Final follow-up assessment (without researcher present)
There was an AABBA design for the control group which involved an additional baseline prior to intervention:

A Initial assessment (Baseline 1)
A Second assessment (Baseline 2)
B Intervention (Hypnosis/Cognitive-Behavioural preceded by SHCSC) plus assessment (Intervention 1)
B Intervention reinforced during medical procedure plus assessment (Intervention 2)
A Final follow-up assessment (without researcher present)

Repeated dependent measures were taken at baseline assessment(s) intervention 1, intervention 2 and final assessment. It was not possible to have the control subjects wait for treatment after five observations (true control group), because of ethical and practical considerations. Some children had been referred to the study by the paediatrician because of needle anxiety. Children usually waited up to four to six months for intervention within the present design. To have waited for five observations meant a delay of 15 - 24 months which would have extended the present study by a further two years. The study design was therefore limited by the difficulties of conducting research in a clinical setting.

12.2.6. Intervention Procedures

All interventions were conducted by the researcher 45 minutes
prior to the medical procedure. The SHCSC was given first, followed by either hypnotic or cognitive-behavioural intervention. The researcher accompanied children to either the Phlebotomy Clinic or paediatrician's consulting room during blood testing and assisted children with hypnotic or cognitive-behavioural coping strategies as necessary. Global ratings were completed immediately after the procedure by the child and parent. The paediatrician or phlebotomist performing the procedure also completed global ratings of anxiety and pain and the OSBD.

At the next scheduled bloodtest (intervention 2), the researcher accompanied the child and reinforced the hypnotic or cognitive-behavioural intervention. There was however, no preparation prior to the bloodtest. Global and OSBD ratings were again collected. At the subsequent procedure (final assessment), the researcher did not accompany the child. The purpose was to evaluate whether children were able to continue using coping strategies in the researcher's absence and whether some generalization had taken place. Dependent measures were repeated with the exception of heart rate because of the researcher's absence. On this last occasion the child and parent were asked to generate and supply type format follow-up questions about intervention. For example, the child was asked what was most helpful about the training session given, whether he/she expected it to help, what he/she does now to cope with bloodtests, his/her present anxiety over finger pricks and insulin injections, and
whether learning new coping strategies with bloodtests had helped him/her in any way (see Appendix XXIV). Parents were asked similar questions about their child (see Appendix XXV).

The psychological interventions used in the present study have been presented in detail in Chapter 9 and are thus summarized briefly here:

Hypnotic intervention
This followed a standardized script, although fantasy was individualized for each child. The components of hypnotherapy were:

1. Induction (either eye fixation on thumbnail or coin, or television viewing)
2. Relaxation
3. Deepening (imagery of favourite place or activity)
4. Treatment (direct suggestions for hypnoanalgesia, rehearsal and post-hypnotic suggestion)

The script was identical to that used for transplant children, but minor adaptations were made for the diabetic clinic. For example, the word "nurse" was altered to refer to the doctor or phlebotomist taking blood in the diabetic clinic, and "wipes your skin with a swab" was altered to "cleans your arm with a spray".
Cognitive-behavioural intervention

This intervention was also standardized. Imagery, often used in cognitive-behavioural approaches (e.g. emotive imagery and imagery during breathing exercises) was avoided so that the intervention remained distinct from the hypnotic one. The components of the cognitive-behavioural intervention were as follows:

1. Positive incentive (certificate, see Appendix XXVI)
2. Breathing exercises
3. Distraction
4. Cognitive conceptualization and reconceptualization
5. Behavioural rehearsal

The phlebotomist and paediatrician were blind as to which treatment group children had been allocated and were not aware of the intervention components used in the present study. While it was likely that they would be able to ascertain whether a child had received intervention prior to a bloodtest because of coaching by the researcher in specific hypnotic or cognitive-behavioural strategies, they were often inaccurate about whether children had been prepared or not. For example, some children who were being observed for the first time who were not yet in the treatment study, were believed by raters to have received preparation.
12.3. RESULTS

12.3.1. Inter-rater reliability

The results of inter-rater reliability checks have been reported in Chapter 11 and show high agreement between the paediatrician, phlebotomist and researcher for dependent measures (global ratings and the revised OSBD).

Differences between groups at baseline
A one way analyses of variance (ANOVA) followed by a Scheffe multiple comparison test was carried out to see whether groups differed at baseline in total distress scores. The Scheffe test determines which population means are different from one another and has more stringent criteria for declaring significant differences than other methods such as the t-test. The results revealed that hypnosis and cognitive-behavioural groups differed significantly (i.e. had higher distress scores) from combined control groups and the no treatment group ($F(3,61) = 8.43$, $p<.0001$). A further analysis of groups, separating the control groups, revealed a significant difference in means between hypnosis, cognitive-behavioural and control hypnosis groups from control cognitive-behavioural and no treatment group as presented in Table 12-1 ($F(4,61) = 7.62$, $p<.0001$). However, hypnosis and behavioural groups did not differ from one another.
TABLE 12-1 Mean OSBD distress scores by group at baseline

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypnosis</td>
<td>19.00</td>
</tr>
<tr>
<td>Behavioural</td>
<td>18.17</td>
</tr>
<tr>
<td>Control hypnosis</td>
<td>17.45</td>
</tr>
<tr>
<td>Control Behavioural</td>
<td>6.33</td>
</tr>
<tr>
<td>No treatment</td>
<td>3.26</td>
</tr>
</tbody>
</table>

Intervention Effects

A repeated measures multivariate analysis of variance (MANOVA) was conducted for intervention conditions for distress scores across the dependent measures. Although these revealed a significant effect over time ($F(3,48) = 5.84, p<.002$) on repeated measures (i.e. a reduction of distress scores), there were no significant differences between hypnosis and cognitive-behavioural interventions in total distress scores or scores for the three phases of the medical procedure. This suggests both cognitive and imagery techniques are helpful in reducing children’s distress associated with venipuncture. Figure 12-1 and 12-2 show the mean distress scores for hypnosis and cognitive-behavioural groups at baseline, first and second intervention and follow-up. The control groups differed from the treatment groups for phase 3 over time, with the control behavioural group having lower distress scores ($F(1,8) = 2.71, p<.05$). This is probably due to this group having lower scores at baseline compared to all groups.
Mean Total Distress Scores

Fig 12.1: Hypnagogic-Group Mean Distress Scores

Fig 12.2: Cognitive-Behavioral-Group Mean Distress Scores
Post-hoc t-tests were conducted to examine differences between groups in detail. There were no differences between total distress scores for the control conditions (standard medical practice) with intervention scores of the treatment groups. Also, there were no differences for the three phases of the medical procedure for these observations. These findings suggest that children who had not yet received intervention were becoming less distressed by the second baseline (control condition) and that their distress scores were not significantly different to those of children who had received intervention. There were also no differences between hypnosis and control hypnosis groups at baseline, post intervention, second intervention and follow-up. However, behavioural and control behavioural groups differed in treatment distress scores which were lower for the control group during phase 2 of the first intervention \( t(15) = 2.39, p < .03 \), and phase 2 of the second intervention \( t(12) = 2.23, p < .05 \). Since the control behavioural group had significantly lower distress scores at baseline, this finding is not surprising. There were no differences at follow-up as the behavioural group continued to improve.

Hypnosis and control behavioural groups differed at second intervention total score \( t(12) = 2.49, p < .03 \) the latter having lower scores and for phase 1 \( t(13) = 2.42, p < .03 \) and phase 2 \( t(12) = 2.63, p < .02 \) of this intervention. Again, this finding can be expected given the lower baseline scores for the control behavioural group. There were no differences at follow-up as the
hypnosis group continued to improve.

Control hypnosis and control behavioural groups were significantly different from one another as described above, the latter group having lower total distress scores ($t(10) = 2.59$, $p < .03$) and lower distress scores for phase 1 at baseline ($t(10) = 2.92$, $p < .02$). However, the groups did not differ at the control observation, post intervention or second intervention or follow-up. Figures 12-3 and 12-4 present the mean distress scores for first and second baseline, first and second intervention and follow-up. Figure 12-5 shows all treatment and control group distress scores, which suggest a reduction in scores after the first intervention, an increase in scores for the hypnosis and control hypnosis groups at second intervention, followed by a decrease again by follow-up.

Age and Sex Differences by Group

A one-way ANOVA with a Scheffe multiple comparison test examined age differences by group. There were no significant age differences between groups. An analyses of variance found no age by sex differences for treatment scores, second intervention and follow-up scores for hypnosis and behavioural groups. However there was a significant main effect for age for the control groups ($F(1,9) = 17.85$, $p < .004$) for the second intervention and follow-up ($F(1,10) = 82.72$, $p < .0001$). This may have been largely due to the overrepresentation of younger children in the control groups (n=11).
Mean Total Distress Scores

Fig 1.2.3: Control Hypnosis Group Mean Distress Scores

Fig 1.2.4: Control Cognitive Behavioral Group Mean Distress Scores

Baseline 1 | Baseline 2 | Intervention 1 | Intervention 2 | Follow-up

Phase 3 | Phase 2 | Phase 1 | Total
Mean Total Distress Scores

Fig 12.5: Treatment Groups and Control Groups Mean Distress Scores.
Global ratings

There were significant differences in global ratings between the control condition (standard medical practice) and cognitive-behavioural and hypnosis conditions. These were observed for medical staff anxiety ratings ($t(16) = 2.19, p<.04$), and pain ratings ($t(16) = 2.33, p<.03$) for the hypnosis and control behavioural groups. Also different (i.e. lower) were anxiety ratings ($t(15) = 2.70, p<.02$) as well as pain ratings ($t(15) = 4.50, p<.0001$) by medical staff for cognitive-behavioural and control cognitive-behavioural groups. However, these results were likely to have been due to lower scores in the control cognitive-behavioural group at pre-intervention.

MANOVAS were conducted on global ratings of anxiety and pain across repeated measures. Although there was an effect with time for child, parent and medical staff anxiety ratings for all groups, pain ratings were not significantly different over time.

Differences in global ratings of anxiety and pain across repeated measures for child, parent and paediatrician/phlebotomist ratings are discussed below under treatment and control groups.

**Hypnosis group**

Table 12-2 presents Wilcoxon matched pairs signed ranks test $Z$ scores for differences in repeated measures of global ratings for the hypnosis group.
TABLE 12-2  Differences in global ratings of anxiety (Hypnosis group) pre-intervention (Pre), intervention 1 (Int 1), intervention 2 (Int 2), and follow-up (FU).

<table>
<thead>
<tr>
<th></th>
<th>Child</th>
<th>Parent</th>
<th>Observer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre vs Int 1</td>
<td>-1.51</td>
<td>-1.90</td>
<td>-1.07</td>
</tr>
<tr>
<td>Int 1 vs Int 2</td>
<td>-0.70</td>
<td>-0.59</td>
<td>-1.30</td>
</tr>
<tr>
<td>Int 2 vs FU</td>
<td>-1.68</td>
<td>-1.12</td>
<td>-2.03 *</td>
</tr>
<tr>
<td>Pre vs Int 2</td>
<td>-1.07</td>
<td>-1.86</td>
<td>-1.22</td>
</tr>
<tr>
<td>Pre vs FU</td>
<td>-2.05 *</td>
<td>-2.17 *</td>
<td>-2.37 **</td>
</tr>
<tr>
<td>Int 1 vs FU</td>
<td>-1.60</td>
<td>-0.77</td>
<td>-2.52 ***</td>
</tr>
</tbody>
</table>

* p<.05  ** p<.025  *** p<.01

Child and medical staff pain global scores were not significantly different from each other across repeated measures. However, parent ratings of pain differed from baseline at first intervention (z = -2.10, p<.05), second intervention (z = -2.13, p<.025) and at follow-up (z = -2.13, p<.025).

**Behavioural group**

Although child and parent anxiety scores did not differ significantly across repeated measures, medical staff ratings of anxiety differed from first intervention to follow-up (z = -2.10, p<.05). Child, parent and observer pain scores did not differ significantly over time.

**Control groups**

Control hypnosis global anxiety ratings by medical staff were significantly lower at first intervention from baseline (z = -2.02, p<.04). Child anxiety ratings (z = -2.02, p<.04) and pain
ratings (z = -2.02, p < .04) were lower at first intervention from the control condition. Parent anxiety ratings differed at follow-up from the control condition (z = -2.02, p < .04).

Control cognitive-behavioural child anxiety ratings were significantly lower at follow-up from baseline (z = -2.02, p < .04) and from the control condition (z = -2.02, p < .04). However, parent and medical staff ratings did not differ for either anxiety or pain ratings.

Hypnotic Susceptibility
An ANOVA was conducted on age and sex differences in children’s responses on the Stanford Hypnotic Clinical Scale for Children (SHCSC). The results were not significant. Spearman correlations of hypnotic susceptibility scores and total distress scores for post intervention, second intervention and follow-up were conducted by treatment group. High SHCSC scores were associated with low total distress scores at follow-up (rho = -.58; p < .04) and during the medical procedure at follow-up (rho = -.62; p < .03) for the hypnosis group; with phase 1 following the first intervention (rho = -.54; p < .04) and phase 2 (rho = -.56; p < .05) and 3 (rho = -.68; p < .02) of the second intervention for the cognitive-behavioural group. SHCSC scores were also negatively correlated with total distress scores at follow-up for the control cognitive-behavioural group (rho = -.89; p < .02).

Spearman correlations of SHCSC scores with global ratings were not significant, except for the control cognitive-behavioural
group. Parent ratings of the child’s anxiety following the first intervention were negatively related to SHCSC scores. Interestingly, 29 (82.9%) children in the present study had high scores (i.e. 5-7) on the SHCSC. There was also an overrepresentation of children with high SHCSC scores in each group.

**Parent and Child Ratings of Interventions**
Parents and children were asked follow-up questions about the intervention received, mostly as simply descriptive information that would hopefully provide useful clinical information.

**Most helpful aspect of intervention**
The following table shows the most helpful aspect of intervention according to children and parents. Children found distraction to be the most helpful (cognitive-behavioural and hypnotic interventions) followed by relaxation (cognitive-behavioural and hypnotic interventions) and imagery (hypnosis). Parents were often not sure about the most helpful aspect, possibly because they were not present during the intervention. Parents of older children and adolescents tended not to be present because of the child’s choice. The most frequent aspect of intervention cited by parents was relaxation (contained in both cognitive-behavioural and hypnotic interventions).
### TABLE 12-3 Most helpful component of intervention according to children and parents

<table>
<thead>
<tr>
<th>Component</th>
<th>Child</th>
<th></th>
<th>Parent</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>Percent</td>
<td>Freq</td>
<td>Percent</td>
</tr>
<tr>
<td>Distraction</td>
<td>11</td>
<td>27.5%</td>
<td>4</td>
<td>10.8%</td>
</tr>
<tr>
<td>Don't know</td>
<td>9</td>
<td>22.5%</td>
<td>12</td>
<td>32.4%</td>
</tr>
<tr>
<td>Relaxation</td>
<td>7</td>
<td>17.5%</td>
<td>7</td>
<td>18.9%</td>
</tr>
<tr>
<td>Imagery</td>
<td>7</td>
<td>17.5%</td>
<td>3</td>
<td>8.1%</td>
</tr>
<tr>
<td>Combination</td>
<td>3</td>
<td>7.5%</td>
<td>7</td>
<td>18.9%</td>
</tr>
<tr>
<td>Reward</td>
<td>1</td>
<td>2.5%</td>
<td>1</td>
<td>2.7%</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>2.5%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0.0%</td>
<td>2</td>
<td>5.4%</td>
</tr>
</tbody>
</table>

**Expectation of intervention**

There was no relationship to distress scores at post-intervention with child and parent expectations of whether they believed the intervention would be helpful or not according to Wilcoxon tests.

**Child’s present coping strategies for bloodtests**

At follow-up, children and parents reported the coping strategies in Table 12-4. Distraction was the most frequently reported strategy which children continued to use during bloodtests.

### Table 12-4 Present coping strategies according to children and parents

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Child</th>
<th></th>
<th>Parent</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>Percent</td>
<td>Freq</td>
<td>Percent</td>
</tr>
<tr>
<td>Distraction</td>
<td>14</td>
<td>35.0%</td>
<td>4</td>
<td>18.2%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>9</td>
<td>22.5%</td>
<td>2</td>
<td>9.1%</td>
</tr>
<tr>
<td>Combination</td>
<td>6</td>
<td>15.0%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Imagery</td>
<td>4</td>
<td>10.0%</td>
<td>4</td>
<td>18.2%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>7.5%</td>
<td>6</td>
<td>27.3%</td>
</tr>
<tr>
<td>Relaxation</td>
<td>2</td>
<td>5.0%</td>
<td>4</td>
<td>18.2%</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>5.0%</td>
<td>1</td>
<td>4.5%</td>
</tr>
</tbody>
</table>
Effect of intervention

Children and parents were asked whether intervention had helped in any way. Most children (64.3%) felt it had, 17.9% felt it helped a little, while 17.9% felt it had not made any difference. Parent reports showed most felt intervention had been helpful (64.3%), 7.1% felt it helped a little and 28.6% felt it had not made any difference. No child or parent reported that the intervention received had made the child cope less well with bloodtests.

Those children and parents who felt that intervention had helped referred mostly to a reduction in anxiety (rather than pain) in the child and/or parent. Their responses are presented in the next table.

Table 12-5 Effect of intervention on child and family according to child and parent reports

<table>
<thead>
<tr>
<th>Effect</th>
<th>Child Freq</th>
<th>Percent</th>
<th>Parent Freq</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less anxious</td>
<td>8</td>
<td>47.1%</td>
<td>8</td>
<td>44.4%</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>29.4%</td>
<td>5</td>
<td>27.8%</td>
</tr>
<tr>
<td>Pain reduction</td>
<td>2</td>
<td>11.8%</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>More relaxed</td>
<td>2</td>
<td>11.8%</td>
<td>5</td>
<td>27.8%</td>
</tr>
</tbody>
</table>

Generalization of intervention

Spearman correlations were conducted to assess generalization of intervention for bloodtests to coping with finger pricks and insulin injections. The results were not significant for child or parent ratings between usual anxiety over these procedures.
(obtained at the assessment interview) and ratings of anxiety at follow-up.

Glycosylated haemoglobin and distress
Kendall correlations of metabolic control with children’s distress scores post-intervention, second intervention and follow-up were not significantly related.

12.4 DISCUSSION

The present study did not find evidence to support the hypothesis that cognitive-behavioural and hypnotic interventions would be more effective in reducing pain, anxiety and distress during bloodtests than standard medical practice (control groups). There were no significant differences in distress scores between the control condition (pre-intervention) and with intervention scores in the hypnosis or cognitive-behavioural groups. However, this may have been due to the depressed scores in the control behavioural group before treatment. There were differences in global self-report scores between the control condition and cognitive-behavioural and hypnosis interventions, however, these were possibly due to the lower scores in the control behavioural group at the beginning of the study. These findings deserve some comment as they are contrary to expectation. One explanation may be that children in the control groups improved during the second baseline (pre-intervention) as a function of non-specific aspects of the assessment process, which involved spending time with the
child and parent in talking about coping with painful procedures. Since children in the control groups received intervention following the second baseline, one cannot predict whether they would have continued to improve. Another explanation is that therapist presence was an important factor in the reduction of children's distress. This would be consistent with findings from other studies (e.g. Elliott and Olson, 1983).

The results did confirm the hypothesis that the two interventions would be equally effective in reducing children's behavioural distress during routine bloodtests. This is consistent with the literature on children's pain, that is, that both interventions are effective for mild pain compared to more severe pain associated with treatments such as bone-marrow aspirations and lumbar punctures (Jay, 1988). Interestingly, children over the age of six years have been helped by both imaginative involvement and distraction techniques in a study by Kuttner et al (1988). However, in the present study it is unclear whether improvements were due to the interventions themselves or to non-specific aspects such as therapist presence and attention.

Although the control behavioural group had lower distress scores in phase 2 of the first and second intervention than the cognitive-behavioural group, the former group had significantly lower distress scores at pre-intervention from the other treatment groups. There were also differences between the
control behavioural group and the hypnosis group at second intervention, the control behavioural group having lower total distress scores and lower distress scores during phase 1 and 2 of the medical procedure. Again, this was likely to be a function of significantly lower scores in the behavioural group to start with. Although the control groups had significantly different mean distress scores at pre-intervention from each other, they did not differ over time for any of the observations, suggesting a large improvement in the control hypnosis condition over time. Although there were no age or sex differences between groups, this was confounded by the over-representation of younger children in the control groups.

The expected relationship between hypnotic susceptibility and pain control was partly confirmed not only for hypnotic but also cognitive-behavioural and control behavioural groups. That is, high scores were associated with lower distress scores. However, there were only a few significant correlations, possibly because of the small sample size. Further research with a larger sample is required.

The results from subjective reports of the child’s anxiety and pain suggested global pain scores to be unreliable as a measure of children’s pain experience. Child and medical staff pain scores did not alter significantly across repeated measures for the hypnosis group, neither did child and parent pain and anxiety scores for the behavioural group. Parent and medical staff
ratings for the control behavioural group did not differ for either anxiety or pain. These results may be due to the difficulty in distinguishing pain from anxiety noted in the literature (Katz et al., 1980; Jay and Elliott, 1984; Jay et al., 1985).

One might hypothesize that diabetic children would habituate to medical procedures over time, given that they are required to self-inject daily, carry out glucose testing several times each week and undergo regular venipunctures for blood tests. However, many children were found to have high distress levels for blood tests in particular, which were the focus of the present study, despite numerous previous procedures. Regarding the mechanisms of change, self-efficacy theory (Bandura, 1977) and exposure (habituation) models (Lader and Mathews, 1968; Watts, 1979) do not explain why diabetics remain anxious over needles, despite regular insulin injections and/or blood testing for many months or years before treatment. Many children have had multiple modeling experiences with the clinic diabetic sister or other diabetic educators (e.g. at summer camp) before treatment. The answer might be explained by the fact that diabetic children experience daily repeated exposure to the feared stimuli without a concomitant reduction in anxiety. This is consistent with Mark’s (1981) observations about non-responsiveness to “exposure” outside of the treatment situation. Exposure in itself is unlikely to be sufficient in reducing anxiety. What is likely to be important is the development of coping strategies and
modifying the social, situational and emotional aspects of the pain experience.

The study was limited by not having a control group which did not receive intervention. This could have helped to distinguish treatment effects from habituation effects. The ethical difficulties in not providing intervention for children known to experience anxiety and distress during venipunctures prevented this research design. Some of these highly distressed children had been referred to the programme by the paediatrician. An alternative would have been to have had a minimal treatment attention control group. It is likely that while some children do habituate to medical treatments over time there are others who do not. For example, there were several older adolescents in the clinic whose anxiety had increased rather than decreased over time. Clinical observations in the diabetic clinic suggested that newly diagnosed children adjusting to the medical treatment regimen often experienced anxiety over one or more of the needles involved in their management, but that this decreased with minimal behavioural intervention (e.g. relaxation, distraction, positive self-statements) involving the child and family or by suggesting other ways of injecting or using alternative instruments for glucose testing. This intervention did not appear to be sufficient for children with emotional difficulties however, or children who required more intensive individual an/or family intervention. Indeed, emotional/conduct disorder was found to be one of the predictive variables for children's distress...
scores in the assessment study described in Chapter 11. Providing psychological intervention for such children is essential in helping them to cope with the diabetic treatment regimen.

Another limitation included the small sample size in the treatment groups and particularly in the control groups. Since the main interest was to compare the control observations with the treatment observations of the cognitive-behavioural and hypnotic groups, the two control groups were combined for this purpose thus increasing the sample size to match the intervention groups. The design was determined by the duration of time involved in conducting the assessment and treatment studies in a clinical setting.

While no one treatment was found to be superior to another in the present study, the treatment of choice for a particular child would depend partly on the child's age, cognitive development, interests, talents (i.e. hypnotic susceptibility) and existing coping strategies. Although the study design required random allocation to treatments, in clinical practice attempts should be made to individualize intervention to each child (Zeltzer and LeBaron, 1986). For example, some children allocated to the hypnosis groups may have benefitted more from behavioural methods. There were a few younger boys in the study with lower SHCSC scores, who found it difficult to focus on imagery for any length of time and who were highly distractable. A play-based intervention would have been preferable, such as that contained
in the cognitive-behavioural intervention. In contrast, there were some children who showed a rich imaginative ability in the behavioural groups who may have responded better to the hypnosis intervention. Generally, children found distraction techniques to be most helpful followed by relaxation and imagery techniques. Distraction techniques were still being used at follow-up. No attempt was made to isolate the effective components of the interventions, but this could be done in future studies. Clearly, children could have responded to any one or a combination of components. The results also showed that preparation for bloodtests did not affect children’s coping with finger pricks and insulin injections. This is consistent with findings by Rainwater et al (1988), thus underscoring the need to intervene separately for specific fears. Diabetic children’s anxiety, pain and distress experienced as part of their treatment regimen has not received much attention. This study represents a first attempt to compare cognitive-behavioural and hypnotic or imagery based interventions in helping children cope with bloodtests, perceived by diabetic children to be the worst part of their treatment. Further studies are required with larger samples into managing diabetic children’s distress during regular invasive medical procedures.
The present thesis began in Chapter 1 with hypotheses about psychological assessment and intervention of acute pain in children with end-stage renal failure who had received renal transplants and children with insulin-dependent diabetes mellitus. Five experimental studies were reported on assessment and intervention with these two groups of chronically ill children. A summary of the main findings is provided below according to assessment and intervention issues which are discussed in relation to the hypotheses presented in Chapter 1.

13.1 PSYCHOLOGICAL ASSESSMENT

13.1.1. Validity of Distress Scores

Hypothesis:

Children’s distress scores were expected to positively correlate with global scores, anticipatory scores, usual anxiety over medical procedures and with behaviour categories of the behaviour checklist.

The revised version of the Observation Scale of Behavioural Distress (OSBD) was found to be a valid and reliable measure of children’s distress during venipunctures for bloodtests in both children who had received renal transplants and in diabetic children. The scale correlated with global ratings, anticipatory ratings, with the child’s usual anxiety over bloodtests and with the behavioural categories. Although developed for use with paediatric cancer patients (Jay et al, 1983; Jay et al, 1987),
it was found to be applicable in assessing children's behavioural distress during venipunctures, considered to be a mildly painful procedure. Two of the behavioural categories (i.e. "requests emotional support" and "information seeking") were not found to correlate with total distress scores because their frequency was low. This was found for both assessment studies with children with renal transplants and diabetic children, suggesting that for venipunctures these categories could be omitted from the scale.

13.1.2. Assessment of acute pain and its concomitants in children aged 6-16 years.

Hypotheses:

1) That children who cope less well with bloodtests will have the following on the basis of standardized questionnaires: (a) a poor self-concept; (b) depression; (c) anxiety; (d) an external locus of control; (e) an external health locus of control; (f) emotional or conduct problems.

Hypotheses about psychosocial variables influencing children's behavioural distress were confirmed for child state anxiety, child external locus of control and self-concept for social acceptance in the renal transplant paediatric sample. In addition, children with emotional/conduct disorder and high trait anxiety had high distress scores during the second phase of the medical procedure (i.e. insertion of the needle and blood withdrawal). Diabetic children experienced more distress during venipunctures if they had emotional/conduct problems, depression, and an external locus of control. Child state and trait anxiety were relevant to distress during the second phase of the medical procedure. Health locus of control was not relevant for either
sample.

2) That children who cope less well with bloodtests will have parents who: (a) are more anxious; and (b) have an external locus of control.

Children's distress scores did not correlate with parent's state and trait anxiety or locus of control for either study.

3) That children who cope less well with bloodtests would also have: (a) less understanding of bloodtests, illness and treatment; (b) previous unpleasant experience with needles; (c) anticipatory anxiety prior to attending the clinic; (d) other fears; and (e) other family members with fears.

Low distress scores were associated with increased understanding of bloodtests, but not of illness and treatment in children with renal transplants according to parent ratings. Diabetic children's understanding of bloodtests, finger pricks, and treatment was not related to distress levels, although development of these concepts did appear to increase with age. There was also evidence of increasing understanding of bloodtests and treatment with age with the transplant children.

While the effects of previous experience with stressful medical procedures was not relevant for diabetic children, it was mixed with the transplant sample. While previous unpleasant experiences with needles was associated with higher child and parent anticipatory anxiety prior to bloodtests, previous experience with transplantation appeared to help children habituate to relatively milder stressful medical procedures such as venipunctures.
Anticipatory anxiety prior to attending the clinic was relevant to children’s anxiety and pain scores in the renal transplant population, but not to diabetic children’s distress scores.

Children with other fears or with other family members with fears tended to have higher self-reported, observer and parent ratings of anxiety and distress in the transplant but not diabetic sample.

Other Psychosocial Variables

Prediction of distress

Children’s self-concept for social acceptance and usual anxiety over injections were the two predictor variables accounting for total distress scores in transplanted children. In the diabetic sample, three variables were found to be predictive of diabetic children’s distress during bloodtests: parent ratings of the child’s usual anxiety over bloodtests, the child’s self-report of usual anxiety over bloodtests and the presence of emotional/conduct problems.

Age and sex differences

There were no age or sex differences in the transplant assessment study, however, there were age differences in children’s expression of behavioural distress in the diabetic children. Children under the age of 11 years displayed more muscle tension and required physical restraint more often than older children, consistent with other studies (Katz et al, 1980; Jay et al, 1983).
Bloodtests

Bloodtests were reported to be the most stressful aspect of the child’s treatment regimen by parents of children with renal transplants and by diabetic children and the second most stressful by transplant children. Unsuccessful venipunctures was the most frequently reported problem in not coping with bloodtests both for transplant and diabetic children. Insertion of the needle was the most stressful part of the procedure.

Cognitive style

Both studies identified a monitor versus distractor cognitive style with a minority having a mixed style (both monitor and distractor). Reasons for monitoring the procedure included issues of control and the reduction of uncertainty. Although this cognitive style was not associated with locus of control in the transplant children, it was in the diabetic children, possibly because of the larger sample size. Diabetic children who preferred to inject themselves were found to have an internal health locus of control, which possibly increases pain tolerance.

Coping strategies

The most frequently reported coping strategy used during bloodtests by transplant children was deep breathing or relaxation. Although a number of diabetic children had no coping strategies, some used relaxation and distraction techniques.
Adherence to treatment

Difficulties relating to adherence to treatment in transplant children were associated with higher self-report of anxiety and pain as well as high trait anxiety scores in parents. In diabetic children, there was no relationship between adherence problems and children's distress scores.

Concepts of medical procedures, illness and treatment

Parents overestimated children’s understanding of bloodtests in the transplant sample. Many transplant children had only a little understanding of their illness and individual differences were found in understanding, which were inconsistent with a stage view of concepts of illness. Parents of diabetic children overestimated children’s understanding of bloodtests, finger pricks, illness and treatment.

Physiological measures of anxiety, pain and distress

Heart rate was not found to correlate with other behavioural and cognitive measures of distress for either study, although diabetic children’s heart rate during the bloodtests correlated with parent trait anxiety. Systolic blood pressure taken immediately after bloodtests correlated with children’s distress before and during the medical procedure in children with renal transplants. Heart rate and systolic and diastolic blood pressure did not correlate with one another. Glycosylated haemoglobin in diabetic children was not relevant to coping with bloodtests.
13.2 PSYCHOLOGICAL INTERVENTION

13.2.1. Intervention for acute pain in children aged 6-16 years.

Hypotheses:

1) Psychological interventions of hypnotherapy and cognitive-behavioural management will be more effective in reducing pain, anxiety and distress during bloodtests than standard medical practice (control group).

This hypotheses was not confirmed for diabetic children, partly because of the lower distress scores in the control behavioural group at baseline.

2) The two treatments will be no different in terms of overall effectiveness, but may be differentially effective for children of different ages and sex.

There were significant differences in distress over time for both hypnotic and cognitive-behavioural groups, which were equally effective in reducing children’s distress. Non-specific factors may have been responsible for improvements. Global scores for anxiety for all groups decreased over time, however pain scores did not. There were no age or sex differences in treatment responsiveness by group.

3) Hypnotic susceptibility and treatment effectiveness will be positively correlated in the hypnosis group.

Correlations of hypnotic susceptibility and treatment effectiveness were significant for both hypnosis and cognitive-behavioural groups, although most children were highly hypnotizable.
13.2.2. Intervention for acute pain in children aged 4-7 years.

Hypothesis:
Cognitive-behavioural management will be effective in reducing pain, anxiety and distress during bloodtests as compared to baseline scores.

This hypothesis was supported in this preliminary study of younger children. In particular, the intervention helped to reduce children's anticipatory anxiety and anxiety during the actual medical procedure.

13.3 LIMITATIONS OF STUDIES

As with many research studies, the present studies suffered from several limitations which are discussed below and include sample size, research design and methodology.

13.3.1. Assessment Studies

Children with renal transplants
This assessment study suffered from a small sample size and the reliance on mainly one baseline assessment.

Children with insulin dependent diabetes mellitus
Although this was a better study in terms of sample size, it relied on only one physiological measure (i.e. of heart rate). Additional measures such as blood pressure or the palmer sweat index might have been taken as well. It would have been desirable to have had multiple baselines on all children, to control for
variability in children’s distress responses.

13.3.2. Intervention studies

Children with renal transplants

Unfortunately, the pilot treatment study did not lead to further research due to inadequate staff cooperation. However, if it had continued, it would have been more helpful to have used newly transplanted children, as they are more likely to experience distress over venipunctures. The intervention study was planned to include a control group which would not have received intervention until after five observations, so that the effects of standard medical practice could have been adequately assessed. This design was possible because bloodtests were far more frequent than those in the diabetic clinic.

The intervention study with young transplanted children suffered from not having a control group, the small sample, and a lack of multiple baselines and adequate self-report from children. The study included all of the younger children in the clinic, although a few six year old children were involved in the assessment study described above. It would have been necessary therefore to have carried out a multicentre study in order to increase the sample size. Other methods of self-report that could have been used include colour scales and the “Oucher” photographic scale.

Children with insulin dependent diabetes mellitus

The main difficulties with this intervention study included the
lower distress scores in the control cognitive-behavioural group at baseline, which did not adequately permit a comparison of the control condition with the treatment conditions. Controlling for level of distress scores when allocating to groups would have been desirable. Also, a control minimal treatment group may have been a better alternative to the present design, however, there were difficulties in fitting the present research design into the time constraints involved. Such a group would have required a team of researchers which was not possible for the present research.

13.4. IMPLICATIONS FOR CLINICAL PRACTICE

The present research holds several implications for clinical practice, discussed below.

13.4.1 Assessment of children's pain

The revised version of the OSBD can be used to reliably and validly assess children's behavioural distress during venipuncture. Although Jay (1988) recommends the development of alternative scales to assess children's distress during venipuncture, the present studies showed that it is possible to successfully adapt a scale from one particular paediatric population to two others. However, the importance of obtaining information from the child about their experience rather than relying solely on observable behaviour cannot be overemphasized. In both clinics studied it was not common practice for medical
staff to ask children about their pain experiences. Asking children (and parents) how much anxiety and pain is experienced during bloodtests will let staff know whether intervention is required. There are a number of self-report measures described earlier which can be used. For research purposes, the addition of physiological measures such as systolic blood pressure taken immediately after the procedure can be a useful additional assessment measure.

13.4.2. Staff training in psychological interventions of pain

Staff training in pain management techniques is essential for repeated invasive medical procedures which chronically ill children undergo. One difficulty presented by clinical research is who will continue pain assessment and management when the researcher has completed his or her work. Teaching hospital playstaff cognitive-behavioural methods, such as those described in Chapter 10, would be feasible and could be interwoven into a preparation programme. However, preparation of children (e.g. provision of information, doll play and modeling films) requires less training than hypnosis or cognitive-behavioural interventions and is more cost-effective in terms of professional training costs (Jay, 1988). Teaching hypnosis to other staff is also restricted by membership rules of the British Society of Experimental and Clinical Hypnosis, whose membership includes clinical and educational psychologists, doctors and dentists.
Teaching nurses pain management techniques is also important however, particularly in accident and emergency departments, where acute pain must be managed promptly. The use of distraction, imagery and storytelling techniques are some methods that could be usefully applied there. The International Association for the Study of Pain is developing a teaching programme for nurses on pain management. This would be invaluable for all nurses working with children in a paediatric setting.

13.4.3. Psychosocial factors and distress during medical procedures

The assessment studies with transplant and diabetic children suggested children with high state and trait anxiety, external locus of control, emotional/conduct disorder and depression predisposed some children to cope less well with venipunctures. Offering such children psychological intervention for these difficulties appears essential. The present research also suggested that children with high global self-concept and high self-concept for social acceptance (accepted by peers and others) are likely to cope better.

13.4.4. Development of health related concepts

A particularly striking finding was the overestimation by parents of children’s understanding of bloodtests and finger pricks. Why do a number of parents overestimate their child’s understanding of these procedures? This could be an artifact of comparing coded responses from generate format questions with
supplied format questions, or could be due to parent’s not considering their child’s developmental stage. Parents who believe their child possesses more understanding of the purpose of bloodtests, for example, may have difficulty in accepting why a child has difficulties or fears about that particular procedure or treatment. Clarifying children’s understanding of procedures, illness and treatment is important in managing chronic illness and should also involve parents.

13.4.5. Development of susceptibility scales for preschool children

The existing hypnotic susceptibility scales do not extend to younger children. In order to link treatment outcome with hypnotic susceptibility, it is necessary to have scales for measuring hypnotic responsiveness, "protohypnosis", in children under the age of four years.

13.5 CLINICAL CONSIDERATIONS

Having presented the theoretical background to acute pain in children and several experimental reports of chronically ill children, the reader may wonder how to select an appropriate assessment and intervention approach. One question is whether assessment methods are required for clinical or research purposes. More sophisticated and multiple methods are required for research purposes, including self-report, behavioural and physiological.
The type of medical procedure is likely to influence the intervention that is selected. Preparation may be used for less painful procedures, while cognitive methods which provide the child with active coping skills are recommended for more distressing procedures such as bone-marrow aspirations and lumbar punctures. Children who receive repeated invasive procedures over a prolonged period are likely to require more sophisticated interventions than children having less frequent and milder procedures (Jay, 1988). Other considerations include the child's existing coping strategies, if any, and the child's age and cognitive style.

A pain management programme evolves from a theoretical perspective in which the child's pain is multifaceted, usually initiated by tissue damage caused by invasive medical procedures, but modified by emotional, situational and child specific factors. An adequate assessment is required to identify the factors that alleviate or intensify pain. Intervention can then be focused on the factors that modulate pain perception. Interventions must be selected according to the child's pain (acute, chronic or recurrent), the child's age or cognitive level and the emotional, behavioural, situational and familial factors identified in the pain assessment (McGrath, 1990).

A multidimensional pain treatment programme offers the child a flexible repertoire of coping strategies. Since children may respond to different aspects of a treatment programme (Turk,
such a programme provides more opportunities for successful management. Also, the same strategy may not always be effective for the same pain, since its quality and strength may vary. Providing children with a rationale for controlling pain is important as well as encouraging a sense of self-efficacy and mastery.
CHAPTER 14
FUTURE DIRECTIONS AND RESEARCH

The past decade has been marked by advances in the assessment and intervention of childhood pain. Special attention has been given to children requiring repeated invasive procedures and children with chronic diseases (McGrath, 1990). Special paediatric pain clinics have been formed recently around the world, but mostly in Canada and the United States. In Britain, a paediatric pain clinic exists at the Hospital for Sick Children, Great Ormond Street provided by clinical psychologists. These clinics share a common goal, that is, to provide a multidisciplinary approach for children's pain assessment and management. Berde, Sethna, Masek, Fosburg and Rocklin (1989) describe these clinics and provide useful recommendations for their development.

Although many questions remain about children's pain, much is known about how children perceive pain and how their pain can be modified. Many of the earlier myths about children's pain have been refuted. The child's concept of pain gradually evolves from the simple and concrete to the more sophisticated, complex and abstract, and from the prelogical to the logical in predictable Piagetian shifts (Gaffney, 1983; Gaffney and Dunne, 1986). The child demonstrates an increasing competence for self-report of pain and may acquire a diversity of coping strategies. Children's ability to cope independently with pain increases as does concern for maintaining control.
Recent research has emphasized the plasticity and complexity of children's pain. The traditional assumption that children's pain was simply and directly related to the nature and extent of tissue damage is no longer tenable. A child's pain may be modified by many environmental and internal factors. There is an increasing awareness in the paediatric field to consider which intervention is appropriate for which child. An example is the preparation procedure developed by Peterson and Toler (1984) which allows the child to decide at given points in the information session the type of information he/she would like next. However, we do not know enough about which interventions are maximally effective for reducing different types of pain.

Unfortunately, there is often a discrepancy between the scientific accumulation of knowledge about pain and the application to clinical practice (McGrath, 1990). Establishing a paediatric pain management programme from a multidisciplinary perspective is essential, as well as regional guidelines for hospitals in pain management to ensure that pain control is given adequate priority.

The role of age, previous experience and coping style requires further investigation in predicting how well children cope with pain. The area of physiological measurement remains underdeveloped, despite the importance of assessing children's physiological responses to stressful procedures. Self-report measures of anxiety and pain remain problematic for children.
under the age of seven years, underscoring the need for further refinements of assessment measures with young children.

Invasive medical procedures constitute a significant threat for chronically ill children who undergo them regularly as part of a complex treatment regimen. There are many creative interventions for helping children cope with such procedures including various types of preparation, hypnosis, cognitive-behavioural techniques and operant approaches. However, few of these have been empirically validated and most research has focused on children with cancer undergoing bone marrow aspirations and lumbar punctures.

Many research papers conclude with recommendations for further research in their particular area of study. More work is required into acute pain associated with venipunctures and injections. Controlled studies are required with children with end-stage renal failure before and after transplantation in reducing distress over dialysis and bloodtests. Diabetic children are likely to require intervention soon after diagnosis when adjusting to bloodtests, finger pricks and insulin injections. Other under-researched areas include the discomfort associated with cardiac catheterization, catheterization prior to micturating cystograms, and venipuncture for children receiving other organ transplants such as liver, and, heart and lung transplants. Accident and emergency departments carry out painful procedures on children including suturing, treatment of burns and
managing injuries sustained during road traffic accidents. These departments require interventions that are effective and can be delivered rapidly, such as distraction, imagery and simple coping strategies. Another exciting area that has received no attention with children is the effect of hypnotic suggestion delivered under anaesthesia, on the child's post-operative recovery and level of acute pain and discomfort. This would need to be investigated jointly with the child's anaesthetist who takes responsibility for the child’s management of pain post-operatively. Given that children are generally highly responsive to suggestion, this has important implications for recovery and could be cost-effective, in that children may be discharged from hospital earlier. Lastly, further research is required into the optimum intervention for a particular child. Because pain is multidimensional, a multidimensional approach may be most useful for the alleviation of acute pain in children undergoing regular invasive medical procedures.
# APPENDICES

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28 April 1987

Ms Chrissi Ioannou
Senior Clinical Psychologist
Department of Child and Family Psychiatry
2 Brookside
CAMBRIDGE
CB2 1JE

Dear Ms Ioannou,

Dr Rees and I have looked at your application:

"Evaluation of psychological intervention to reduce pain and anxiety, for children undergoing repeated invasive medical procedures. The study will be concerned with children attending the Renal Transplant Clinic."

and feel that it is in order for you to proceed.

I will place this before the full Committee at its next meeting for their consideration and ratification.

Yours sincerely,

[Signature]

Ian Macdonald
Chairman of Ethical Committee
APPENDIX II

Medical Regimes: Paediatric Transplant Clinic, Guy's Hospital, London.

The transplant clinic followed a treatment regime as follows:

Children with first grafts, which were either cadaver (from a deceased person) or live related (from a living person) received steroids, cyclosporin A and azathioprine, if they had no present or past history of cytotoxic antibodies. Children with a history of cytotoxic antibodies received steroids, cyclosporin A, fresenius ATG and azathioprine. Some children received low dose aspirin, antibiotic therapy and drugs to deal with hypertension (eg chlorpromazine).

Drugs affecting the immune response.
The most commonly used drugs in the paediatric transplant clinic, were:

1. Cytotoxic immunosuppressants (azathioprine).
2. Corticosteroids and other immunosuppressants (prednisolone, cyclosporin).

1. Cytotoxic immunosuppressants.
"These drugs are used to suppress rejection in organ transplant recipients and are also used to treat a variety of auto-immune and collagen diseases. They are non-specific in their action and careful monitoring of peripheral blood counts is required, with dose adjustments for marrow toxicity."
Azathioprine is widely used for transplant recipients and is also used to treat a number of autoimmune conditions, usually when corticosteroid therapy alone has provided inadequate control" (British National Formulary, 1991; p.286).

2. Corticosteroids and other immunosuppressants.

(a) Prednisolone.
Prednisolone is a corticosteroid and powerful immunosuppressant. Corticosteroids are used to prevent organ transplant rejection, and in high dose they treat rejection episodes. Prednisolone is also widely used in oncology, to treat acute lymphoblastic leukemia, Hodgkin's disease and the non-Hodgkin lymphomas. It may also cause useful disease regression in hormone sensitive breast cancer and have a role in the palliation of symptomatic end stage malignant disease.

(b) Cyclosporin.
"Cyclosporin is a fungal metabolite and potent immunosuppressant which is virtually non-myelotoxic but markedly nephrotoxic. It has found particular use in the field of organ and tissue transplantation, for prevention of graft rejection following bone marrow, kidney, liver, pancreas, heart-lung transplantation, and for prophylaxis of graft-versus-host disease" (British National Formulary, 1991; p.286).
APPENDIX

BEHAVIOUR SCORING SHEET

Child........................................... Observer...........................................
Clinic........................................... Date..............................................

1. **GLOBAL RATINGS**

Please rate how much anxiety and pain you believe the child experienced during
the blood sampling procedure on the following 10 point scale:

A. **ANXIETY**

| Rating | No anxiety | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Extreme anxiety |
---|---|---|---|---|---|---|---|---|---|---|---|---|

B. **PAIN**

| Rating | No pain | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Extreme pain |
---|---|---|---|---|---|---|---|---|---|---|---|---|

2. **OBSERVATION SCALE OF BEHAVIOURAL DISTRESS** - Revised

Please note any behaviours observed before, during, and after the procedure and
then rate their intensity according to this 5 point scale:

| Very mild | 1 | 2 | 3 | 4 | 5 | Very intense |
---|---|---|---|---|---|---|

| Behaviour | Before/rating | During/Rating | After/Rating |
---|---|---|---|
1. Muscle tension | | | |
2. Crying | | | |
3. Screaming | | | |
4. Anxiety verbalised | | | |
5. Pain verbalised | | | |
6. Restraint used | | | |
7. Verbal stalling | | | |
8. Physical resistance | | | |
9. Requests emotional support | | | |
10. Nervous behaviour | | | |
11. Information seeking | | | |
### APPENDIX IV

**TRANSPLANT PARENT CODED QUESTIONNAIRE**

<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>1. SEX</th>
<th>Child’s sex</th>
<th>Male 0 Female 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. AGE_M</td>
<td>Age (months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. PARENT</td>
<td>Parent interviewed</td>
<td>Mother 0 Father 1</td>
<td></td>
</tr>
<tr>
<td>4. GROUP</td>
<td>Hypnosis 0</td>
<td>Behavioural 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Control H 2</td>
<td>Control B 3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No treatment 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. PRATCAAA</td>
<td>How anxious do you think your child is at the moment about his/her bloodtest?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. PRATAAA</td>
<td>How anxious do you feel about your child’s bloodtest?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. PANX</td>
<td>What are your anxieties?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 no anxieties</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 creatinine result</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 problems in taking blood</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 creatinine result and other difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 child upset</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. PTRATCAAB</td>
<td>How anxious do you think your child will be during the bloodtest?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PRATCAPB</td>
<td>How much pain do you think your child will experience during the bloodtest?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. DAGEN</td>
<td>Child’s age at diagnosis (months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. SEG</td>
<td>Social class (see Office of Population Censuses and Surveys (1980))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. B_ORDER</td>
<td>Birth order</td>
<td></td>
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</table>
13. CHEALTH  Child's present health (diabetic control)
   1 poor
   2 adequate
   3 good

14. FILLNESS  Family illness (i.e. diabetes, cancer etc)
   1 Yes
   0 No

15. TILLNESS  Type of family illness
   1 renal problems
   2 diabetes
   3 cancer
   4 other
   5 more than one

16. DRUGS  Number of drugs

17. LESCORE  Life event score

18. FREQBT  Frequency of bloodtests
   1 every day/other day
   2 weekly
   3 fortnightly
   4 every three weeks
   5 once month
   6 between 1-3 months

19. How anxious or distressed does your child become over the following procedures?

PRCUAB  a. Bloodtests (venipunctures)
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PRCUAI  b. Injections
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PRCUADW  c. Dialysis needles
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PRCUADI  d. Dental injections
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety
20. PRNEEDLE Has your child ever had an unpleasant experience with needles or difficulties in coping with needles at any time?

1 yes
0 no

21. PRIDCA Has your child’s anxiety increased or decreased over time?

1 decreased
2 same
3 increased

22. PDHCB How do you help your child cope with bloodtests?

1 dont help
2 distraction
3 relaxation
4 emotional support
5 combination of strategies

23. PDHCH How do you help your child cope with other needles (finger pricks, insulin injections)?

1 dont help
2 distraction
3 relaxation
4 emotional support
5 combination of strategies

24. PDSHCB How do staff help your child cope with bloodtests?

1 talk to child
2 general statement about competence
3 relaxation
4 offer emotional support
5 sympathetic/friendly
6 information giving
7 encourage child to take control
8 combination of strategies

25. PDSHCN How do staff help your child cope with other needles?

1 talk to child
2 general statement about competence
3 relaxation
4 offer emotional support
5 sympathetic/friendly
6 information giving
7 encourage child to take control
8 combination of strategies

- 419 -
26. PPB
Are you usually present during your child's bloodtest?
1 yes 0 no

27. PCCBW
Does your child cope better or worse if you are present?
1 better 2 no different 3 worse

28. FWR
Would you be willing to wait in the waiting room while your child has their bloodtest?
1 yes 0 no

29. PCCB
What helps your child cope better?
1 nothing 2 if feeling happy 3 which nurse has 4 successful venipunctures 5 parent presence 6 if nurse cheerful 7 relaxation 8 other

30. PCCLW
What makes your child cope less well?
1 unsuccessful venipuncture 2 different nurse 3 if nurse not cheerful 4 if feeling unwell 5 if parent not present 6 has to go to school afterwards

31. PCCM
What coping methods does your child use to manage the bloodtest? Other needles?
1 talks 2 deep breaths/relaxes 3 puts it out of mind 4 tries to be brave 5 uses humour 6 mind over matter 7 nothing 8 other

32. FCDA
What do you tell your child about expressing feelings about pain or anxiety? Has this changed as he/she has got older?
33. PRCUB

How much do you think your child understands what bloodtests are for?

0 no understanding
1 a little
2 a moderate amount
3 a great deal

34. PRCPF

Does your child have any fears or phobias other than needles?

1 yes
0 no

35. PDCF

If yes, how many fears?

1 one other fear
2 2 or more fears

36. PDFF

Does anyone in the family have fears or phobias, including needles?

1 yes
0 no

37. PDFMF

If yes, who?

1 mother
2 father
3 sibs
4 both parents

38. PDSP

What type of fears or phobias?

1 needles
2 other

39. CAA

In the last 24 hours prior to your clinic visit, have you noticed any unusual behaviour or symptoms in your child, such as changes in eating or sleeping patterns, crying, nausea etc?

1 yes
0 no
40. How anxious do you become yourself when undergoing the following:

PSRB a. Bloodtests
No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PSRI b. Injections
No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PSRDI c. Dental injections
No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

41. POA (If anxious) What are your anxieties about these procedures?
1 the pain
2 the needle
3 invasiveness
4 other

42. ATM Child's age at transplant in months

43. NT Number of transplants?

44. REJ Any rejections with the present transplant?
1 yes
0 no

45. CAT How worried was your child about the transplant?
1 very worried
2 worried
3 not worried
4 mixed feelings
5 relieved/excited
6 other

46. PAT How worried were you and your partner?
1 very worried
2 worried
3 mixed feelings
4 hoped for the best
5 pleased about transplant
6 other

47. DIALYSIS Has your child been on dialysis?
1 yes
48. PROBDIAL Problems with dialysis?
   0 no
   1 difficulty to cope with
   2 infection
   3 leaks
   4 tubes came out
   5 blockages
   6 potassium problems
   7 problems with blood pressure

49. PARGT Are there arguments or disagreements at home over treatment?
   0 yes
   0 no

49. PRCDT What part of the treatment does your child find most difficult? (eg bloodtests, drugs)
   1 bloodtests
   2 taking drugs
   3 travelling
   4 missing school
   5 clinic attendance
   6 everything
   7 hospitalization
   8 other

50. PRODT What part of the treatment do you find most difficult?
   1 travelling
   2 hospitalization
   3 child in pain
   4 bloodtests
   5 clinic attendance
   6 everything
   7 other
   8 nothing

51. Has your child's illness and its treatment interfered with any activities such as school, hobbies? Does it stop him/her doing anything in particular?

PCITIABT Before the transplant?
   0 yes
   0 no
<table>
<thead>
<tr>
<th>PCITIAPT</th>
<th>After the transplant?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 yes</td>
</tr>
<tr>
<td></td>
<td>0 no</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>52. PRCUI</th>
<th>How well does your child understand about his/her illness?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 not at all</td>
</tr>
<tr>
<td></td>
<td>1 a little</td>
</tr>
<tr>
<td></td>
<td>2 a moderate amount</td>
</tr>
<tr>
<td></td>
<td>3 a great deal</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>53. PRCUT</th>
<th>How well does your child understand about his/her treatment?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 not at all</td>
</tr>
<tr>
<td></td>
<td>1 a little</td>
</tr>
<tr>
<td></td>
<td>2 a moderate amount</td>
</tr>
<tr>
<td></td>
<td>3 a great deal</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>54. PRCIF</th>
<th>What effect do you think your child’s illness and treatment has had on your family (on you and your partner, on siblings) before the transplant and after?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 disruption of family life</td>
</tr>
<tr>
<td></td>
<td>2 stress</td>
</tr>
<tr>
<td></td>
<td>3 stress/restriction</td>
</tr>
<tr>
<td></td>
<td>4 worry</td>
</tr>
<tr>
<td></td>
<td>5 take each day as it comes</td>
</tr>
<tr>
<td></td>
<td>6 child spoilt</td>
</tr>
<tr>
<td></td>
<td>7 uncertainty</td>
</tr>
<tr>
<td></td>
<td>8 affected siblings</td>
</tr>
</tbody>
</table>
APPENDIX V

TRANSPANT CHILD CODED QUESTIONNAIRE

<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. CRAA</td>
<td>How anxious are you about your bloodtest today?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>2. CRPAA</td>
<td>How anxious or worried do you think your parent is about your bloodtest?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>3. CRAADB</td>
<td>How anxious do you think you will be during the blood- test?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>4. CRAPDB</td>
<td>How much pain do you think you will experience?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>5. CFREQBT</td>
<td>How often do you have bloodtest?</td>
</tr>
<tr>
<td></td>
<td>1 every day/other day 2 weekly 3 fortnightly 4 every 3 weeks 5 once month 6 1-3 months</td>
</tr>
<tr>
<td>6. CUABT</td>
<td>How anxious do you get about bloodtests?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>7. CUAI</td>
<td>How anxious do you get about injections?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>8. CUADN</td>
<td>How anxious do you get about dialysis needles?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>9. CUADI</td>
<td>How anxious do you get about dental injections?</td>
</tr>
<tr>
<td></td>
<td>No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety</td>
</tr>
<tr>
<td>10. CRNEEDLE</td>
<td>Have you ever had an unpleasant or bad experience with needles (at home or hospital)?</td>
</tr>
</tbody>
</table>

- 425 -
11. CPPB Is your mother/father usually with you when you have a bloodtest?
   1 yes
   0 no

12. CCBW Is it better or worse if he/she is with you?
   1 better
   2 no different
   3 worse

13. CDE Is there anything that makes the bloodtest easier?
   1 nothing
   2 if feeling happy
   3 which nurse does bloodtest
   4 successful venipuncture
   5 parent presence
   6 looking at bloodtest
   7 looking away from bloodtest
   8 other

14. CDW Is there anything that makes it worse?
   1 unsuccessful venipunctures
   2 different nurse
   3 parent absent
   4 nothing
   5 other

15. CCS Some children find a special way of coping with needles. What do you do to cope better or what have you tried?
   1 talking
   2 deep breaths/relaxation
   3 look
   4 don't look
   5 imagery
   6 nothing
   7 other

16. NCS Number of coping strategies

17. CDWPB What is the worst part of a bloodtest?
   1 when needle inserted
   2 when needle comes out
   3 bloodtaking
4 pain
5 sight of or size of needle
6 creatinine result
7 nothing

18. CPL  Do you prefer to look or look away?
0 look away
1 look
2 either

19. CRP  Any idea why?
1 like to see what is done
2 worse if look
3 worse if do not look
4 dislikes needles
5 other
6 knows when needle inserted

20. CCDB  What sort of things do you think about?
1 nothing
2 imagery
3 expectations of pain
4 hopes venipuncture will be successful
5 positive self-talk
6 other

21. CDPCA  What does your mother or father say to you when you are hurt or worried?
1 nothing
2 provides reassurance/support/comfort
3 encourages child to talk about/express feelings
4 tells child to relax
5 tells child to think of other things
6 other

22. CDPB  What are your blood tests for?
0 no understanding
1 general understanding kidney related
2 test creatinine/kidney function
3 creatinine and awareness of other investigations

23. CFP  Some children have fears or phobias about certain things...are there things you are afraid of and that you avoid?
1 yes
0 no
24. CDFP  How many fears?
1 one other fear
2 2 or more fears

25. CPPF  Does anyone else in the family have fears or phobias?
1 yes
0 no

26. CDFMFP What fears?
1 needles
0 other

27. COAT  How worried were you about your last transplant?
1 very worried
2 worried
3 not worried
4 mixed feelings
5 relieved
6 other

28. CDPAT How worried was your mother/father about your transplant?
1 very worried
2 worried
3 mixed feelings
4 hoped for best
5 pleased
6 other
7 don’t know

29. CARGT  Are there arguments or disagreements at home over treatment?
1 yes
0 no

30. CDF  What part of treatment do you find the most difficult or dislike the most?
1 bloodtests
2 taking drugs
3 travelling
4 clinic visits
5 hospitalization
6 nothing
7 other
31. CRPDT  What part of treatment do you think your mother/father find most difficult?

1 bloodtests
2 taking drugs
3 travelling
4 clinic visits
5 hospitalization
6 worrying
7 nothing
8 other

32. Has your illness and its treatment interfered with any activities such as school and hobbies.

CITIABT Before transplant?

1 yes
0 no

CITIAPT After transplant?

1 yes
0 no

33. CUILL If a child your age asked you what wrong with you before your transplant, what would you say?

0 no understanding
1 vague understanding
2 moderate understanding
3 great understanding

34. CUTREAT If a child your age asked you how your illness would be treated, what would you say?

0 no understanding
1 vague understanding
2 moderate understanding
3 greater understanding

35. CDEIT What effect do you think your illness and treatment has had on your parents and brothers and sisters?

1 no effect
2 disruption
3 worry
4 affected sibs
5 other
APPENDIX VI

THE STAIT-TRAIT ANXIETY INVENTORY FOR CHILDREN (STAIC)

HOW-I-FEEL QUESTIONNAIRE

STAIC FORM C-1

NAME ................................ AGE ...........
DATE ........................................

DIRECTIONS: A number of statements which boys and girls use to describe themselves are given below. Read each statement carefully and decide how you feel right now. Then put an X in the box in front of the word or phrase which best describes how you feel. There are no right or wrong answers. Do not spend too much time on any one statement. Remember, find the word or phrase which best describes how you feel right now, at this very moment.

1. I feel [ ] very calm [ ] calm [ ] not calm
2. I feel [ ] very upset [ ] upset [ ] not upset
3. I feel [ ] very pleasant [ ] pleasant [ ] not pleasant
4. I feel [ ] very nervous [ ] nervous [ ] not nervous
5. I feel [ ] very jittery [ ] jittery [ ] not jittery
6. I feel [ ] very rested [ ] rested [ ] not rested
7. I feel [ ] very scared [ ] scared [ ] not scared
8. I feel [ ] very relaxed [ ] relaxed [ ] not relaxed
9. I feel [ ] very worried [ ] worried [ ] not worried
10. I feel [ ] very satisfied [ ] satisfied [ ] not satisfied
11. I feel [ ] very frightened [ ] frightened [ ] not frightened
12. I feel [ ] very happy [ ] happy [ ] not happy
13. I feel [ ] very sure [ ] sure [ ] not sure
14. I feel [ ] very good [ ] good [ ] not good
15. I feel [ ] very troubled [ ] troubled [ ] not troubled
16. I feel [ ] very bothered [ ] bothered [ ] not bothered
17. I feel [ ] very nice [ ] nice [ ] not nice
18. I feel [ ] very terrified [ ] terrified [ ] not terrified
19. I feel [ ] very mixed up [ ] mixed-up [ ] not mixed-up
20. I feel [ ] very cheerful [ ] cheerful [ ] not cheerful
APPENDIX VI

HOW-I-FEEL QUESTIONNAIRE

STAIC FORM C-2

NAME..........................AGE...........
DATE................

DIRECTIONS: A number of statements which boys and girls use to describe themselves are given below. Read each statement and decide if it is hardly-ever, or sometimes, or often true for you. Then for each statement, put an X in the box in front of the word that seems to describe you best. There is no right or wrong answers. Do not spend too much time on any one statement. Remember, choose the word which seems to describe how you usually feel.

1. I worry about making mistakes
   [ ] hardly-ever [ ] sometimes [ ] often

2. I feel like crying
   [ ] hardly-ever [ ] sometimes [ ] often

3. I feel unhappy
   [ ] hardly-ever [ ] sometimes [ ] often

4. I have trouble making up my mind
   [ ] hardly-ever [ ] sometimes [ ] often

5. It is difficult for me to face my problems and bother me.
   [ ] hardly-ever [ ] sometimes [ ] often

6. I worry too much
   [ ] hardly-ever [ ] sometimes [ ] often

7. I get upset at home
   [ ] hardly-ever [ ] sometimes [ ] often

8. I am shy
   [ ] hardly-ever [ ] sometimes [ ] often

9. I feel troubled
   [ ] hardly-ever [ ] sometimes [ ] often

10. Unimportant thoughts run through my mind
    [ ] hardly-ever [ ] sometimes [ ] often

11. I worry about school
    [ ] hardly-ever [ ] sometimes [ ] often

12. I have trouble deciding what to do
    [ ] hardly-ever [ ] sometimes [ ] often

13. I notice my heart beats fast
    [ ] hardly-ever [ ] sometimes [ ] often

14. I am secretly afraid
    [ ] hardly-ever [ ] sometimes [ ] often

15. I worry about my parents
    [ ] hardly-ever [ ] sometimes [ ] often

16. My hands get sweaty
    [ ] hardly-ever [ ] sometimes [ ] often

17. I worry about things that may happen
    [ ] hardly-ever [ ] sometimes [ ] often

18. It is hard for me to fall asleep at night
    [ ] hardly-ever [ ] sometimes [ ] often

19. I get a funny feeling
    [ ] hardly-ever [ ] sometimes [ ] often
20. I worry about what others think of me
   [ ] hardly-ever  [ ] sometimes  [ ] often
APPENDIX VII
CHILDREN'S HEALTH LOCUS OF CONTROL QUESTIONNAIRE

NAME

DIRECTIONS
Below are a number of beliefs children have about their health. Please read each statement and decide whether you agree or disagree by underlining or placing a circle around your answer.

1. Good health comes from being lucky. Agree/Disagree
2. I can do things to keep from getting sick. Agree/Disagree
3. Bad luck makes people get sick. Agree/Disagree
4. I can only do what the doctor tells me to do. Agree/Disagree
5. If I get sick, it is because getting sick just happens. Agree/Disagree
6. People who never get sick are just plain lucky. Agree/Disagree
7. My mother must tell me how to keep from getting sick. Agree/Disagree
8. Only a doctor or a nurse keeps me from getting sick. Agree/Disagree
9. When I am sick I can do things to get better. Agree/Disagree
10. If I get hurt it is because accidents just happen. Agree/Disagree
11. I can do many things to fight illness. Agree/Disagree
12. Only the dentist can take care of my teeth. Agree/Disagree
13. Other people must tell me how to stay healthy. Agree/Disagree
14. I always go to the nurse right away if I get hurt at school. Agree/Disagree
15. The teacher must tell me how to keep from having accidents at school. Agree/Disagree
16. I can make many choices about my health. Agree/Disagree

17. Other people must tell me what to do when I feel sick. Agree/Disagree

18. Whenever I feel sick I go to see the school nurse right away. Agree/Disagree

19. There are things I can do to have healthy teeth. Agree/Disagree

20. I can do many things to prevent accidents. Agree/Disagree
APPENDIX VIII

NOWICKI-STRICKLAND LOCUS OF CONTROL SCALE FOR CHILDREN

INSTRUCTIONS

Please answer YES or NO to the following questions:

1. Do you believe that most problems will solve themselves if you just don't fool with them? YES/NO

2. Do you believe that you can stop yourself from catching a cold? YES/NO

3. Are some kids just born lucky? YES/NO

4. Most of the time do you feel that getting good grades (marks) means a great deal to you? YES/NO

5. Are you often blamed for things that just aren't your fault? YES/NO

6. Do you believe that if somebody studies hard enough he or she can pass any subject? YES/NO

7. Do you feel that most of the time it doesn't pay to try hard because things never turn out right anyway? YES/NO

8. Do you feel that if things start out well in the morning that it's going to be a good day no matter what you do? YES/NO

9. Do you feel that most of the time parents listen to what their children have to say? YES/NO

10. Do you believe that wishing can make good things happen? YES/NO

11. When you get punished does it usually seem its for no good reason at all? YES/NO

12. Most of the time do you find it hard to change a friend's opinion? YES/NO

13. Do you think that cheering more than luck helps a team to win? YES/NO

14. Do you feel that it's nearly impossible to change your parent's mind about anything? YES/NO

15. Do you believe that your parents should allow you to make most of your own decisions? YES/NO

16. Do you feel that when you do something wrong there's very
little you can do to make it right? YES/NO

17. Do you believe that most kids are just born good at sports? YES/NO
18. Are most of the other kids your age stronger than you are? YES/NO
19. Do you feel that one of the best ways to handle most problems is just not to think about them? YES/NO
20. Do you feel that you have a lot of choice in deciding who your friends are? YES/NO
21. If you find a four leaf clover do you believe that it might bring you good luck? YES/NO
22. Do you often feel that whether you do your homework has much to do with what kind of grades (marks) you get? YES/NO
23. Do you feel that when a kid your age decides to hit you, there's little you can do to stop him or her? YES/NO
24. Have you ever had a good luck charm? YES/NO
25. Do you believe that whether or not people like you depends on how you act? YES/NO
26. Will your parents usually help you if you ask them to? YES/NO
27. Have you felt that when people were mean to you it was usually for no reason at all? YES/NO
28. Most of the time, do you feel that you can change what might happen tomorrow by what you do today? YES/NO
29. Do you believe that when bad things are going to happen they just are going to happen no matter what you try to do to stop them? YES/NO
30. Do you think that kids can get their own way if they just keep trying? YES/NO
31. Most of the time do you find it useless to try to get your own way at home? YES/NO
32. Do you feel that when good things happen they happen because of hard work? YES/NO
33. Do you feel that when somebody your age wants to be your enemy there's little you can do to change matters? YES/NO
34. Do you feel that it's easy to get friends to do what you want them to? YES/NO

35. Do you usually feel that you have little to say about what you get to eat at home? YES/NO

36. Do you feel that when someone doesn't like you there's little you can do about it? YES/NO

37. Do you usually feel that it's almost useless to try in school because most other children are just plain smarter than you are? YES/NO

38. Are you the kind of person who believes that planning ahead makes things turn out better? YES/NO

39. Most of the time, do you feel that you have little to say about what your family decides to do? YES/NO

40. Do you think it's better to be smart than to be lucky? YES/NO
APPENDIX IX

BIRLESON DEPRESSION INVENTORY

NAME

INSTRUCTIONS. Please answer as honestly as you can. The statements refer to how you have felt over the past week. There are no right answers, it is important to say how you have felt. Thank you.

Most Sometimes Never

1. I look forward to things as much as I used to.......................... .... .... ....
2. I sleep very well......................... .... .... ....
3. I feel like crying............................ .... .... ....
4. I like to go out to play............. .... .... ....
5. I feel like running away............. .... .... ....
6. I get tummy aches............................ .... .... ....
7. I have lots of energy......................... .... .... ....
8. I enjoy my food............................. .... .... ....
9. I can stick up for myself.............. .... .... ....
10. I think life isn't worth living........ .... .... ....
11. I am good at things I do.................... .... .... ....
12. I enjoy the things I do as much as I used to.......................... .... .... ....
13. I like talking with my family...... .... .... ....
14. I have horrible dreams..................... .... .... ....
15. I feel very lonely......................... .... .... ....
16. I am easily cheered up............... .... .... ....
17. I feel so sad I can hardly stand it.................................. .... .... ....
18. I feel very bored............................. .... .... ....
APPENDIX X
THE PICTORIAL SCALE OF PERCEIVED COMPETENCE AND ACCEPTANCE FOR
YOUNG CHILDREN

SAMPLE QUESTION

ITEM 1
This boy is usually kind of happy. Are you:
Not too good at numbers OR Sort of good
1 2

ITEM 2
This boy has lots of friends to play with.
Do you have:
A whole lot of friends OR Pretty many
6 3

ITEM 3
This boy isn't very good at swinging by himself.
Are you:
Not too good at swinging
1 2

ITEM 4
This boy's mom usually doesn't let him eat dinner at friend's houses. Does your mom:
Hardly ever let you eat over OR Sometimes
1 2

ITEM 5
This boy knows lots of things in school. Do you:
Know a whole lot of things OR Pretty many things
4 3

ITEM 6
A few kids share their toys with this boy. Do: A few kids OR A whole lot of kids
1 2
This boy is pretty good at climbing. Are you:  
Really good at climbing OR Pretty good  
4 3

This boy's mom takes him to a lot of places  
he likes to go. Does your mom take you:  
A whole lot of places you like to go OR Pretty many places  
4 3

This boy isn't very good at climbing. Are you:  
Sort of good OR Not very good at climbing  
2 1

This boy's mom doesn't take him to very many places  
he likes to go. Does your mom take you:  
A few places OR Not very many places you like to go  
3 1

This boy isn't very good at reading by himself.  
Are you:  
Not very good at reading by yourself OR Sort of good  
1 2

This boy has pretty many friends to play  
games with. Do you have:  
A lot of friends to play games with OR Pretty many  
4 3

This boy is pretty good at reading by himself.  
Are you:  
Pretty good OR Really good at reading by yourself  
3 4

This boy has pretty many friends to play  
games with. Do you have:  
A lot of friends to play games with OR Pretty many  
4 3

This boy isn't very good at bouncing the ball.  
Are you:  
Not too good at bouncing the ball OR Sort of good  
1 2

This boy is pretty good at bouncing the ball.  
Are you:  
Pretty good OR Really good at bouncing the ball  
3 4

This boy's mom cooks a few of the foods he likes.  
Does your mom:  
Hardly ever cook the foods you like OR Sometimes  
1 2

This boy is pretty good at writing words.  
Are you:  
Rather good at writing words OR Pretty good  
4 3

This boy doesn't have very many friends to play  
with on the playground. Do you have:  
Hardly any friends OR A few  
1 2

This boy is pretty good at shipping. Are you:  
Really good at shipping OR Pretty good  
4 3

This boy has lots of friends to play with  
on the playground. Do you have:  
Pretty many OR A whole lot of friends  
3 4

This boy isn't very good at shipping. Are you:  
Sort of good OR Not too good at shipping  
2 1
This boy's mom reads to him a little. Does your mom read to you:

- Hardly ever
- Sometimes
- Pretty much
- A whole lot

This boy isn't very good at spelling words. Are you:

- Not too good at spelling words
- Sort of good
- Pretty good
- Really good at spelling words

This boy usually gets asked to play with the other kids. Do you:

- Always get asked to play
- Usually
- Sometimes
- Hardly ever get asked to play

This boy can't run very fast. Are you:

- Not very fast
- Sort of fast
- Pretty fast
- Really fast

This boy's mom usually lets him stay overnight at friend's houses. Does your mom let you stay over:

- A whole lot
- Pretty much
- Sometimes
- Hardly ever

This boy is pretty good at adding numbers. Are you:

- Really good at adding
- Pretty good
- Sort of good
- Not very good at adding

A few kids want to sit next to this boy. Do:

- Hardly any kids want to sit next to you
- A few
- Pretty many
- A whole lot of kids want to sit next to you

This boy is pretty good at jump rope. Are you:

- Really good at jump rope
- Pretty good
- Sort of good
- Not very good at jump rope

This boy's mom likes to talk with him a lot. Does your mom talk with you:

- A whole lot
- Pretty much
- Sometimes
- Hardly ever
THE SELF-FERCEPTION PROFILE FOR CHILDREN

What I Am Like

Name __________________________ Age ________ Birthday _____________________ Group

Boy or Girl (circle which)

SAMPLE SENTENCE

<table>
<thead>
<tr>
<th>Really True for me</th>
<th>Sort of True for me</th>
<th>Other kids would rather watch T.V.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(a)</td>
</tr>
<tr>
<td></td>
<td>Some kids would rather play outdoors in their spare time</td>
<td>BUT</td>
</tr>
</tbody>
</table>

1. Some kids feel that they are very good at their school work BUT Other kids worry about whether they can do the school work assigned to them.

2. Some kids find it hard to make friends BUT Other kids find it's pretty easy to make friends.

3. Some kids do very well at all kinds of sports BUT Other kids don't feel that they are very good when it comes to sports.

4. Some kids are happy with the way they look BUT Other kids are not happy with the way they look.

5. Some kids often do not like the way they behave BUT Other kids usually like the way they behave.

6. Some kids are often unhappy with themselves BUT Other kids are pretty pleased with themselves.

7. Some kids feel like they are just as smart as as other kids their age BUT Other kids aren't so sure and wonder if they are as smart.

8. Some kids have a lot of friends BUT Other kids don't have very many friends.
<table>
<thead>
<tr>
<th></th>
<th>Really True for me</th>
<th>Sort of True for me</th>
<th>Sort of True for me</th>
<th>Really True for me</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.</td>
<td>Some kids wish they could be alot better at sports</td>
<td>BUT Other kids feel they are good enough at sports.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Some kids are happy with their height and weight</td>
<td>BUT Other kids wish their height or weight were different.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Some kids usually do the right thing</td>
<td>BUT Other kids often don’t do the right thing.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Some kids don’t like the way they are leading their life</td>
<td>BUT Other kids do like the way they are leading their life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Some kids are pretty slow in finishing their school work</td>
<td>BUT Other kids can do their school work quickly.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Some kids would like to have alot more friends</td>
<td>BUT Other kids have as many friends as they want.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Some kids think they could do well at just about any new sports activity they haven’t tried before</td>
<td>BUT Other kids are afraid they might not do well at sports they haven’t ever tried.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Some kids wish their body was different</td>
<td>BUT Other kids like their body the way it is.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Some kids usually act the way they know they are supposed to</td>
<td>BUT Other kids often don’t act the way they are supposed to.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Some kids are happy with themselves as a person</td>
<td>BUT Other kids are often not happy with themselves.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Some kids often forget what they learn</td>
<td>BUT Other kids can remember things easily.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>Some kids are always doing things with alot of kids</td>
<td>BUT Other kids usually do things by themselves.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
21. Some kids feel that they are better than others their age at sports
   Other kids don't feel they can play as well.
22. Some kids wish their physical appearance (how they look) was different
   Other kids like their physical appearance the way it is.
23. Some kids usually get in trouble because of things they do
   Other kids usually don't do things that get them in trouble.
24. Some kids like the kind of person they are
   Other kids often wish they were someone else.
25. Some kids do very well at their classwork
   Other kids don't do very well at their classwork.
26. Some kids wish that more people their age liked them
   Other kids feel that most people their age do like them.
27. In games and sports some kids usually watch instead of play
   Other kids usually play rather than just watch.
28. Some kids wish something about their face or hair looked different
   Other kids like their face and hair the way they are.
29. Some kids do things they know they shouldn't do
   Other kids hardly ever do things they know they shouldn't do.
30. Some kids are very happy being the way they are
   Other kids wish they were different.
31. Some kids have trouble figuring out the answers in school
   Other kids almost always can figure out the answers.
32. Some kids are popular with others their age
   Other kids are not very popular.
<table>
<thead>
<tr>
<th>#</th>
<th>True for me</th>
<th>Sort of True for me</th>
<th>True for me</th>
<th>Sort of True for me</th>
</tr>
</thead>
<tbody>
<tr>
<td>33.</td>
<td>Some kids <em>don't</em> do well at new outdoor games</td>
<td><strong>BUT</strong> Other kids are <em>good</em> at new games right away.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34.</td>
<td>Some kids think that they are good looking</td>
<td><strong>BUT</strong> Other kids think that they are not very good looking.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35.</td>
<td>Some kids behave themselves very well</td>
<td><strong>BUT</strong> Other kids often find it hard to behave themselves.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36.</td>
<td>Some kids are not very happy with the way they do a lot of things</td>
<td><strong>BUT</strong> Other kids think the way they do things is <em>fine</em>.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Susan Harter, Ph.D., University of Denver, 1985
What I Am Like

<table>
<thead>
<tr>
<th>Number</th>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
<th>Sample Sentence</th>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>a)</td>
<td></td>
<td></td>
<td>Some teenagers like to go to movies in their spare time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td>Some teenagers feel that they are just as smart as others their age</td>
<td>BUT</td>
<td>Other teenagers would rather go to sports events.</td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td>Some teenagers find it hard to make friends</td>
<td>BUT</td>
<td>Other teenagers aren't so sure and wonder if they are as smart.</td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td>Some teenagers do very well at all kinds of sports</td>
<td>BUT</td>
<td>Other teenagers don't feel that they are very good when it comes to sports.</td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td>Some teenagers are not happy with the way they look</td>
<td>BUT</td>
<td>Other teenagers are happy with the way they look.</td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td>Some teenagers feel that they are ready to do well at a part-time job</td>
<td>BUT</td>
<td>Other teenagers feel that they are not quite ready to handle a part-time job.</td>
</tr>
<tr>
<td>6.</td>
<td></td>
<td></td>
<td>Some teenagers feel that if they are romantically interested in someone, that person will like them back</td>
<td>BUT</td>
<td>Other teenagers worry that when they like someone romantically, that person won't like them back.</td>
</tr>
<tr>
<td>7.</td>
<td></td>
<td></td>
<td>Some teenagers usually do the right thing</td>
<td>BUT</td>
<td>Other teenagers often don't do what they know is right.</td>
</tr>
<tr>
<td>8.</td>
<td></td>
<td></td>
<td>Some teenagers are able to make really close friends</td>
<td>BUT</td>
<td>Other teenagers find it hard to make really close friends.</td>
</tr>
<tr>
<td>9.</td>
<td></td>
<td></td>
<td>Some teenagers are often disappointed with themselves</td>
<td>BUT</td>
<td>Other teenagers are pretty pleased with themselves.</td>
</tr>
<tr>
<td>10.</td>
<td></td>
<td></td>
<td>Some teenagers are pretty slow in finishing their school work</td>
<td>BUT</td>
<td>Other teenagers can do their school work more quickly.</td>
</tr>
<tr>
<td>11.</td>
<td></td>
<td></td>
<td>Some teenagers have a lot of friends</td>
<td>BUT</td>
<td>Other teenagers don't have very many friends.</td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td>Some teenagers think they could do well at just about any new athletic activity</td>
<td>BUT</td>
<td>Other teenagers are afraid they might not do well at a new athletic activity.</td>
</tr>
</tbody>
</table>

**SAMPLE SENTENCE**

Name: [Blank]
Age: [Blank]
Birthday: [Blank]
Month: [Blank]
Day: [Blank]
Group: [Blank]
### Differences Between Teenagers

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
<th>Opposite Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>Some teenagers wish their body was different</td>
<td>Other teenagers like their body the way it is.</td>
</tr>
<tr>
<td>14</td>
<td>Some teenagers feel that they don't have enough skills to do well at a job</td>
<td>Other teenagers feel that they do have enough skills to do a job well.</td>
</tr>
<tr>
<td>15</td>
<td>Some teenagers are not dating the people they are really attracted to</td>
<td>Other teenagers are dating those people they are attracted to.</td>
</tr>
<tr>
<td>16</td>
<td>Some teenagers often get in trouble for the things they do</td>
<td>Other teenagers usually don't do things that get them in trouble.</td>
</tr>
<tr>
<td>17</td>
<td>Some teenagers do have a close friend they can share secrets with</td>
<td>Other teenagers do not have a really close friend they can share secrets with.</td>
</tr>
<tr>
<td>18</td>
<td>Some teenagers don't like the way they are leading their life</td>
<td>Other teenagers do like the way they are leading their life.</td>
</tr>
<tr>
<td>19</td>
<td>Some teenagers do very well at their coursework</td>
<td>Other teenagers don't do very well at their coursework.</td>
</tr>
<tr>
<td>20</td>
<td>Some teenagers are very hard to like</td>
<td>Other teenagers are really easy to like.</td>
</tr>
<tr>
<td>21</td>
<td>Some teenagers feel that they are better than others their age at sports</td>
<td>Other teenagers feel they can play as well.</td>
</tr>
<tr>
<td>22</td>
<td>Some teenagers wish their physical appearance was different</td>
<td>Other teenagers like their physical appearance the way it is.</td>
</tr>
<tr>
<td>23</td>
<td>Some teenagers feel they are old enough to get and keep a paying job</td>
<td>Other teenagers do not feel they are old enough, yet, to really handle a job well.</td>
</tr>
<tr>
<td>24</td>
<td>Some teenagers feel that people their age will be romantically attracted to them</td>
<td>Other teenagers worry about whether people their age will be attracted to them.</td>
</tr>
<tr>
<td>25</td>
<td>Some teenagers feel really good about the way they act</td>
<td>Other teenagers don't feel that good about the way they often act.</td>
</tr>
<tr>
<td>26</td>
<td>Some teenagers wish they had a really close friend to share things with</td>
<td>Other teenagers do have a close friend to share things with.</td>
</tr>
<tr>
<td>27</td>
<td>Some teenagers are happy with themselves most of the time</td>
<td>Other teenagers are often not happy with themselves.</td>
</tr>
<tr>
<td>28</td>
<td>Some teenagers have trouble figuring out the answers in school</td>
<td>Other teenagers almost always can figure out the answers.</td>
</tr>
<tr>
<td>Number</td>
<td>Question</td>
<td>Teenagers agreed</td>
</tr>
<tr>
<td>--------</td>
<td>----------</td>
<td>------------------</td>
</tr>
<tr>
<td>29.</td>
<td>Some teenagers are popular with others their age</td>
<td>Some teenagers are not very popular</td>
</tr>
<tr>
<td>30.</td>
<td>Some teenagers don't do well at new outdoor games</td>
<td>Other teenagers are good at new games right away</td>
</tr>
<tr>
<td>31.</td>
<td>Some teenagers think that they are good looking</td>
<td>Other teenagers think that they are not very good looking</td>
</tr>
<tr>
<td>32.</td>
<td>Some teenagers feel like they could do better at work they do for pay</td>
<td>Other teenagers feel that they are doing really well at work they do for pay</td>
</tr>
<tr>
<td>33.</td>
<td>Some teenagers feel that they are fun and interesting on a date</td>
<td>Other teenagers wonder about how fun and interesting they are on a date</td>
</tr>
<tr>
<td>34.</td>
<td>Some teenagers do things they know they shouldn't do</td>
<td>Other teenagers hardly ever do things they know they shouldn't do</td>
</tr>
<tr>
<td>35.</td>
<td>Some teenagers find it hard to make friends they can really trust</td>
<td>Other teenagers are able to make close friends they can really trust</td>
</tr>
<tr>
<td>36.</td>
<td>Some teenagers like the kind of person they are</td>
<td>Other teenagers often wish they were someone else</td>
</tr>
<tr>
<td>37.</td>
<td>Some teenagers feel that they are pretty intelligent</td>
<td>Other teenagers question whether they are intelligent</td>
</tr>
<tr>
<td>38.</td>
<td>Some teenagers feel that they are socially accepted</td>
<td>Other teenagers wished that more people their age accepted them</td>
</tr>
<tr>
<td>39.</td>
<td>Some teenagers do not feel that they are very athletic</td>
<td>Other teenagers feel that they are very athletic</td>
</tr>
<tr>
<td>40.</td>
<td>Some teenagers really like their looks</td>
<td>Other teenagers wish they looked different</td>
</tr>
<tr>
<td>41.</td>
<td>Some teenagers feel that they are really able to handle the work on a paying job</td>
<td>Other teenagers wonder if they are really doing as good a job at work as they should be doing</td>
</tr>
<tr>
<td>42.</td>
<td>Some teenagers usually don't go out with the people they would really like to date</td>
<td>Other teenagers do go out with the people they really want to date</td>
</tr>
<tr>
<td>43.</td>
<td>Some teenagers usually act the way they know they are supposed to</td>
<td>Other teenagers often don't act the way they are supposed to</td>
</tr>
<tr>
<td>44.</td>
<td>Some teenagers don't have a friend that is close enough to share really personal things with</td>
<td>Other teenagers do have a close friend that they can share personal thoughts and feelings with</td>
</tr>
</tbody>
</table>
APPENDIX XI

STATE-TRAIT ANXIETY INVENTORY (STATE)

NAME ............................................. DATE ..........................

VISIT: Pre, Post, FU. AGE ............... SEX: M ...... F .....

DIRECTIONS:

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the number to the right of the statement to indicate how you feel right now, that is at this moment. There is no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

1. I feel calm
2. I feel secure
3. I am tense
4. I feel strained
5. I feel at ease
6. I feel upset
7. I am presently worrying over possible misfortunes
8. I feel satisfied
9. I feel frightened
10. I feel comfortable
11. I feel self-confident
12. I feel nervous
13. I am jittery
14. I feel indecisive
APPENDIX XI cont.

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am relaxed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel content</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am worried</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel confused</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel steady</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel pleasant</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

STATE TRAIT ANXIETY INVENTORY (TRAFT)

NAME ........................................ DATE  .................

VISIT: Pre, Post, 1Y.

Directions:

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the number to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give answer which seems to describe how you generally feel.

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel pleasant</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel nervous and restless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel satisfied with myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish I could be as happy as others seem to be</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>25</td>
<td>I feel like a failure</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26</td>
<td>I feel rested</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27</td>
<td>I am &quot;calm, cool and collected&quot;</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28</td>
<td>I feel that difficulties are piling up so that I cannot overcome them</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29</td>
<td>I worry too much over something that really doesn't matter</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30</td>
<td>I am happy</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31</td>
<td>I have disturbing thoughts</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32</td>
<td>I lack self-confidence</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33</td>
<td>I feel secure</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>34</td>
<td>I make decisions easily</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35</td>
<td>I feel inadequate</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36</td>
<td>I am content</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37</td>
<td>Some unimportant thought runs through my mind and bothers me</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>38</td>
<td>I take disappointments so keenly that I can't put them out of my mind</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>39</td>
<td>I am a steady person</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>40</td>
<td>I get in a state of tension or turmoil as I think over my recent concerns and interests</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
APPENDIX XII

ROTTER LOCUS OF CONTROL SCALE

INSTRUCTIONS

This is a questionnaire to find out ways in which certain important events in our society affect different people. Each item consists of a pair of alternatives lettered a or b. Please select either a or b for each number, which you more strongly believe to be true. This is a measure of personal belief; obviously there are no right or wrong answers.

1.a. Children get into trouble because their parents punish them too much.

   b. The trouble with most children nowadays is that their parents are too easy with them.

2.a. Many of the unhappy things in people’s lives are partly due to bad luck.

   b. People’s misfortunes result from the mistakes they make.

3.a. One of the major reasons why we have wars is because people don’t take enough interest in politics.

   b. There will always be wars, no matter how hard people try to prevent them.

4.a. In the long run people get the respect they deserve in this world.

   b. Unfortunately, an individual’s worth often passes unrecognised no matter how hard he tries.

5.a. The idea that teachers are unfair to students is nonsense.

   b. Most students don’t realise the extent to which their grades are influenced by accidental happenings.

6.a. Without the right breaks one cannot be an effective leader.

   b. Capable people who fail to become leaders have not taken advantage of their opportunities.

7.a. No matter how hard you try some people just don’t like you.

   b. People who can’t get others to like them don’t understand how to get along with others.

8.a. Heredity plays the major role in determining one’s personality.
b. It is one's experiences in life which determine what they're like.

9.a. I have often found that what is going to happen will happen.

b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

10.a. In the case of the well prepared student there is rarely if ever such a thing as an unfair test.

b. Many times exam questions tend to be so unrelated to course work that studying is really useless.

11.a. Becoming a success is a matter of hard work, luck has little or nothing to do with it.

b. Getting a good job depends mainly on being in the right place at the right time.

12.a. The average citizen can have an influence in government decisions.

b. This world is run by the few people in power, and there is not much the little guy can do about it.

13.a. When I make plans, I am almost certain that I can make them work.

b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.

14.a. There are certain people who are just no good.

b. There is some good in everybody.

15.a. In my case getting what I want has little or nothing to do with luck.

b. Many times we might just as well decide what to do by flipping a coin.

16.a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.

b. Getting people to do the right thing depends upon ability, luck has little or nothing to do with it.

17.a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.

b. By taking an active part in political and social affairs the people can control world events.
18.a. Most people don't realise the extent to which their lives are controlled by accidental happenings.
   b. There really is no such thing as "luck".
19.a. One should always be willing to admit mistakes.
   b. It is usually best to cover up one's mistakes.
20.a. It is hard to know whether or not a person really likes you.
   b. How many friends you have depends upon how nice a person you are.
21.a. In the long run the bad things that happen to us are balanced by the good ones.
   b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.
22.a. With enough effort we can wipe out political corruption.
   b. It is difficult for people to have much control over the things politicians do in office.
23.a. Sometimes I can't understand how teachers arrive at the grades they give.
   b. There is a direct connection between how hard I study and the grades I get.
24.a. A good leader expects people to decide for themselves what they should do.
   b. A good leader makes it clear to everybody what their jobs are.
25.a. Many times I feel that I have little influence over things that happen to me.
   b. It is impossible for me to believe that chance or luck plays an important role in my life.
26.a. People are lonely because they don't try to be friendly.
   b. There's not much use in trying too hard to please people, if they like you, they like you.
27.a. There is too much emphasis on athletics in high school.
   b. Team sports are an excellent way to build character.
28. a. What happens to me is my own doing.
   b. Sometimes I feel that I don't have enough control over the direction my life is taking.

29. a. Most of the time I can't understand why politicians behave the way they do.
   b. In the long run the people are responsible for bad government on a national as well as on a local level.
APPENDIX XIII

RUTTER PARENTAL SCREENING QUESTIONNAIRE

SCALE A (2)

TO BE COMPLETED BY PARENTS

Name of child:.................. Boy/Girl Date of birth........

Address:.................................................................

HOW TO FILL IN THIS FORM

The questionnaire asks about various kinds of behaviour that many children show at some time. Please give the answers according to the way your child has been during the PAST 12 MONTHS.

HEALTH PROBLEMS

Below is a list of minor health problems which most children have at some time. Please tell us how often each of these happens with your child by putting a cross in the correct box.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Occasionally</th>
<th>Never but as often as once per week</th>
<th>At least once per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Complains of headaches</td>
<td></td>
<td>[ ] [ ] [ ]</td>
<td></td>
</tr>
<tr>
<td>B. Has stomach-ache or vomiting</td>
<td></td>
<td>[ ] [ ] [ ]</td>
<td></td>
</tr>
<tr>
<td>C. Asthma or attacks of wheezing</td>
<td></td>
<td>[ ] [ ] [ ]</td>
<td></td>
</tr>
<tr>
<td>D. Wets the bed or pants</td>
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<td>[ ] [ ] [ ]</td>
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<tr>
<td>E. Soils or loses control of bowels</td>
<td>[ ] [ ] [ ]</td>
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<td>F. Has temper tantrums</td>
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(That is, complete loss)
of temper with shouting angry movements, etc.) [ ] [ ] [ ]

G. Had tears on arrival at school or refused to go into the building [ ] [ ] [ ]

H. Truants from school [ ] [ ] [ ]

HABITS - Please place a cross in the box by the correct answer

1. Does he/she stammer or stutter? [ ] No [ ] Yes, mildly [ ] Yes, severely

II. Is there any difficulty with speech other than stammering or stuttering [ ] No [ ] Yes-mild [ ] Yes-severe

If "Yes", please describe the difficulty............................

III. Does he/she ever steal things [ ] No [ ] Yes-occasionally [ ] Yes frequently

If "Yes" (occasionally or frequently)
does it involve
[ ] minor pilfering of pens, sweets, toys, small sums of money, etc.
[ ] stealing of big things
[ ] both minor pilfering and stealing of big things

is stealing done
[ ] in the home [ ] on own
[ ] elsewhere [ ] with other children or adults
[ ] both in the home and elsewhere [ ] sometimes on own, sometimes with others

IV. Is there any eating difficulty? [ ] No [ ] Yes-mild [ ] Yes-severe

If "Yes", is it
[ ] faddiness
[ ] not eating enough
[ ] eating too much
[ ] other, please describe.................................
V. Is there any sleeping difficulty?  
[ ] No  [ ] Yes-mild  [ ] Yes-severe

If "Yes", is it difficulty in  
[ ] getting off to sleep  
[ ] waking during the night  
[ ] waking early in the morning  
[ ] other, please describe .................................................................

-----------------------------------------------------------------------------------------------------------------------

Below are a series of descriptions of behaviour often shown by children. After each statement are three columns - "Doesn't Apply", "Applies Somewhat", and "Certainly Applies". If your child definitely shows the behaviour described by the statement place a cross in the box under "Certainly Applies". If he or she shows the behaviour described by the statement but to a lesser degree or less often, place a cross under "Applies Somewhat". If, as far as you are aware, your child does not show the behaviour, place a cross under "Doesn't Apply".

Please put one cross against each statement.

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<th>Doesn't Apply</th>
<th>Applies Somewhat</th>
<th>Certainly Applies</th>
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<td>1. Very restless, has difficulty staying seated for long</td>
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<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>2. Squirmy, fidgety child</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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<tr>
<td>3. Often destroys own or others' property</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. Frequently fights or is extremely quarrelsome with other children</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. Not much liked by other children</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. Often worried, worries about many things</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>7. Tends to be own - rather solitary</td>
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<td>[ ]</td>
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</table>
8. Irritable. Is quick to 'fly off the handle' [ ] [ ] [ ]

9. Often appears miserable, unhappy tearful or distressed [ ] [ ] [ ]

10. Has twitches, mannerisms or tics of the face or body [ ] [ ] [ ]

11. Frequently sucks thumb or finger [ ] [ ] [ ]

12. Frequently bites nails or fingers [ ] [ ] [ ]

13. Is often disobedient [ ] [ ] [ ]

14. Cannot settle to anything for more than a few moments [ ] [ ] [ ]

15. Tends to be fearful or afraid of new things or new situations [ ] [ ] [ ]

16. Fussy or over-particular child [ ] [ ] [ ]

17. Often tells lies [ ] [ ] [ ]

18. Bullies other children [ ] [ ] [ ]

ARE THERE ANY OTHER PROBLEMS?

Signature:

Mr./Mrs. ..............

THANK YOU VERY MUCH FOR YOUR HELP
APPENDIX XIV

RUTTER TEACHER QUESTIONNAIRE

SCALE B (2)

TO BE COMPLETED BY TEACHERS

Name of Child: .................... Boy/Girl
School: ................

Address of Child: ........................................

Date of Birth: ................
Form: ...........................

Below are a series of descriptions often shown by children. After each statement are three columns: "Doesn't Apply", "Applied Somewhat" and "Certainly Applies". If the child definitely shows the behaviour described by the statement place a cross in the box under Column 2 "Certainly Applies". If the child shows the behaviour described by the statement but to a lesser degree or less often place a cross in the box under Column 1 "Applies Somewhat". If, as far as you are aware, the child does not show the behaviour, place a cross in the box under Column 0 "Doesn't Apply".

Please complete on basis of child's behaviour IN THE PAST 12 MONTHS.

Put ONE cross against EACH statement. Thank you.

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<td>2. Truants from school</td>
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<td>3. Squirmy, fidgety child</td>
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<td>4. Often destroys or damages own or others' property</td>
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</tbody>
</table>
5. Frequently fights or is extremely quarrelsome with other children  
6. Not much liked by other children  
7. Often worried, worries about many things  
8. Tends to be on own - rather solitary  
9. Irritable, touchy. Is quick to 'fly off the handle'  
10. Often appears miserable, unhappy, tearful or distressed  
11. Has twitches, mannerisms, or tics of the face or body  
12. Frequently sucks thumb or finger  
13. Frequently bites nails or fingers  
14. Tends to be absent from school for trivial reasons  
15. Is often disobedient  
16. Cannot settle to anything for more than a few moments  
17. Tends to be fearful or afraid of new things or new situations  
18. Fussy or over-particular child  
19. Often tells lies
20. Has stolen things on one or more occasions in the past 12 months
   [ ] [ ] [ ]

21. Unresponsive, inert or apathetic
   [ ] [ ] [ ]

22. Often complains of aches or pains
   [ ] [ ] [ ]

23. Has had tears on arrival at school
    or has refused to come into the building in the past 12 months
   [ ] [ ] [ ]

24. Has a stutter or stammer
   [ ] [ ] [ ]

25. Resentful or aggressive when corrected
   [ ] [ ] [ ]

26. Bullies other children
   [ ] [ ] [ ]

Is there anything else unusual about this child's behaviour? - or are there any other comments you would like to make?

Signature:

Mr/Mrs/Miss

Date

THANK YOU VERY MUCH FOR YOUR HELP
### TABLE Summary statistics (Chapter 7)

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### APPENDIX XVI

#### VARIABLE DEFINITIONS

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<tr>
<td>CRPAA</td>
<td>Child's rating of parent's anticipatory anxiety prior to bloodtest</td>
</tr>
<tr>
<td>CUABT</td>
<td>Child's usual anxiety over bloodtests</td>
</tr>
</tbody>
</table>
VARIABLE DEFINITIONS cont’d

CUADI  Child’s usual anxiety over dental injections
CUADN  Child’s usual anxiety over dialysis needles
CUAI   Child’s usual anxiety over injections
DAGEM  Child’s age at diagnosis in months
DRUGS  Number of drugs child is receiving
FIGRANXC Second intervention global rating anxiety child
FIGRANXN Second intervention global rating anxiety nurse/doc
FIGRANXP Second intervention global rating anxiety parent
FIGRPAIC Second intervention global rating pain child
FIGRPAIP Second intervention global rating pain parent
FIGRBA  2nd intervention glycosylated haemoglobin
FIGRA  2nd intervention heart rate after
FIGRB  2nd intervention heart rate before
FIGRD  2nd intervention heart rate during
FIGRWR  2nd intervention heart rate waiting room
FIGSBDT  2nd intervention OSBD total scores
FIGSBD1  2nd intervention OSBD phase 1
FIGSBD2  2nd intervention OSBD phase 2
FIGSBD3  2nd intervention OSBD phase 3
F2GRAC  Follow-up global rating anxiety child
F2GRAD  Follow-up global rating anxiety doctor
F2GRAP  Follow-up global rating anxiety parent
F2GRPC  Follow-up global rating pain child
F2GRPF  Follow-up global rating pain parent
F2GRH  Follow-up glycosylated haemoglobin
F2OSBDT Follow-up OSBD total scores
F2OSBD1 Follow-up OSBD phase 1
F2OSBD2 Follow-up OSBD phase 2
F2OSBD3 Follow-up OSBD phase 3
MONTHSTX Months since transplant
NT    Number of transplants
OBSSRAB Observer’s self rating of anxiety during bloodtests
OSBDAN OSBD anxiety verbalised
OSBDC  OSBD crying
OSBDES OSBD requests emotional support
OSBDIS OSBD information seeking
OSBDMT OSBD muscle tension
OSBDBH OSBD nervous behaviour
OSBDBP OSBD physical resistance
OSBDPV OSBD pain verbalised
OSBDRU OSBD restraint used
OSBDS  OSBD screaming
OSBDVS OSBD verbal stalling
PARLOC E Parent external locus of control
PARLOC I Parent internal locus of control
PARTAAP Parent trait anxiety
PARATAA Parent rating of own anticipatory anxiety prior to bloodtest
PARCIAA Parent rating of child’s anticipatory anxiety prior to bloodtest
VARIABLE DEFINITIONS cont'd

to bloodtest
PRATCAAB Parent rating of child’s anticipated anxiety during bloodtest
PRATCAPB Parent rating of child’s anticipated pain during bloodtest
PRCUAB Parent rating of child’s usual anxiety over bloodtests
PRCUADN Parent rating of child’s usual anxiety over dialysis needles
PRCUAI Parent rating of child’s usual anxiety over injections
FSRB Parent self-rating of anxiety over bloodtests
FSRBI Parent self-rating of anxiety over dental injections
PSRI Parent self-rating of anxiety over injections
RUTPART Rutter parent questionnaire total score
RUTTREAT Rutter teacher questionnaire total score
SCATHCOM Self-concept for athletic competence
SCBEHCON Self-concept for behavioural conduct
SCCOGCOM Self-concept for cognitive competence
SCGLOBAL Global self-concept
SCPHYSAP Self-concept for physical appearance
SCSOCACC Self-concept for social acceptance
SHSCC Stanford hypnotic clinical scale for children
TGRANKC Treatment global rating anxiety child
TGRANKW Treatment global rating anxiety nurse/doctor
TGRANXP Treatment global rating anxiety parent
TGRPAINC Treatment global rating pain child
TGRPAINF Treatment global rating pain nurse/doctor
TGRPAINP Treatment global rating pain parent
THBA Treatment glycosylated haemoglobin
THRA Treatment heart rate after
THRB Treatment heart rate before
THRD Treatment heart rate during
THWR Treatment heart rate waiting room
TOSBDT Treatment OSBD total scores
TOSBD1 Treatment OSBD phase 1
TOSBD2 Treatment OSBD phase 2
TOSBD3 Treatment OSBD phase 3
APPENDIX XVII

STANFORD HYPNOTIC SUSCEPTIBILITY SCALE FOR CHILDREN

STANDARD FORM (AGES 6-16)

Discussion of preconceived ideas that child and/or parent may have about hypnosis should precede administration of the scale. Be sure the meaning of the word "relax" is understood. If necessary, explain it in terms of "letting go" as when the hypnotist holds the child's wrist and lets it drop gently, or "feeling loose like a rag doll."

INTRODUCTION

I'm going to help you learn some interesting things about imagination today. Most people say that it's fun (fascinating). I will ask you to think of some different things, and we will see how your imagination works. Some people find it easier to imagine some things than other things. We want to find what is most interesting to you. Listen very carefully to me, and let's see what happens. Just be comfortable in the chair (bed), and let's imagine some things now. Please close your eyes so you can imagine these things better.... Now I'd like you to picture yourself floating in a warm pool of water... What is it like?... And now can you picture yourself floating on a nice soft cloud in the air?... What is that like?...

That's fine - just open your eyes... Now I'd like to show you how you can feel completely relaxed and comfortable, because that makes it easier to imagine things, too... I'm going to draw a little face on my thumbnail.*... Here it is... Hypnotist draws face on own thumbnail with red felt pen. Let's put one on your thumb. Do you want to do it or shall I? Hypnotist or child does so. That's a good face! Now please hold your hand up in front of you like this - assist child so that hand is in front, thumbnail facing him, with elbow not resting on anything - and look at the little face (thumbnail) as you listen to my voice. Just keep watching the little face (thumbnail), try to think only about the things I talk about, and let your body relax completely.... Let your whole body feel loose and limp and relaxed... Relax completely... just let all the muscles in your

Notes: The text for the Standard Form contains both italicized and nonitalicized material. The sentences in italic type are instructions to the hypnotist. Those in roman type are verbal instructions to the child.

*If drawing a face on thumbnail seems awkward for the older child, eliminate it and have him simply stare at the thumbnail. Substitute "thumbnail" for "little face" as indicated.
body relax... relax completely... Be as relaxed as you were while you were imagining that you were floating in the pool of water, or floating on a cloud... Feel your body becoming more and more relaxed... more and more relaxed... Your eyelids, too, are relaxing. They are starting to feel heavy. As you keep watching the face (thumbnail), your eyes feel heavier and heavier... Your eyes are starting to blink a little, and that's a very good sign. That means you're relaxing really well. Just keep watching the face (thumbnail), your eyes feel heavier and heavier... Your eyes are starting to blink a little, and that's a very good sign. That means you're relaxing really well. Just keep watching the face (thumbnail) and listening to my voice... Already your eyelids feel heavy. Very soon they feel so heavy that they will begin to close by themselves... Let them close whenever they feel like it. And when they close, let them stay closed... Even now, and your whole body is feeling so nice, so comfortable, completely relaxed...

If child shows convincing evidence at any time of inability to relax, or unwillingness to let eyes close or remain closed, go to Modified Form.

Now I'm going to count from one to ten, and you will find your body becoming even more relaxed... You will continue to relax as you listen to the counting... one... more and more relaxed, such a good feeling... two... three... more and more relaxed all the time, feeling so good... four... five... six... even more relaxed... and your eyes are feeling heavier, heavier... It feels so good just to let go and relax completely... seven... eight... nine... VERY relaxed now... ten...

If child is still holding hand up: Just let your hand relax completely, too... Let it relax comfortably on your lap (the bed)... That's fine...

If eyes have not closed: Now please let your eyes close, and just relax completely. Just let your eyes close and keep them closed while you listen to me....

For all children: And now as we go on, it will be very easy for you to listen to me because you are so relaxed and comfortable. If you can keep your eyes closed, you can imagine some things better, so why don't you let them stay closed. You'll be able to stay relaxed and talk to me when I ask you to... You are feeling very good... Just keep listening to what I tell you and think about the things I suggest. Then let happen whatever you find is happening... Just let things happen by themselves...

If eyes open at any time, request child gently to close them: Because imagination is easier that way.
1. Hand Lowering

Please hold your right (left) arm* straight out in front of you, with the palm up. Assist if necessary. Imagine that you are holding something heavy in your hand, like a heavy rock. Something very heavy. Shape your fingers around the heavy rock in your hand. What does it feel like?... That's good... Now think about your arm and hand feeling heavier and heavier, as if the rock were pushing down... more and more down... and as it gets heavier and heavier, the hand and arm begin to move down... down... heavier and heavier... moving... down, down, down... moving... moving... more and more down... heavier and heavier... Wait 10 seconds; note extent of movement. That's fine. Now you can stop imagining there is a rock in your hand, and let your hand relax... It is not heavy anymore...

Score + if hand lowers at least 6 inches at end of 10 seconds.

2. Arm Rigidity

Now please hold your left (right) arm straight out, and the fingers straight out, too... That's right, your arm straight out in front of you, fingers straight out, too... Think about making your arm very stiff and straight, very, very stiff... Think about it as if you were a tree and your arm is a strong branch of the tree, very straight and very strong, like the branch of a tree... so stiff that you can't bend it... That's right... Now see how stiff your arm is... Try to bend it... Try... Wait 10 seconds. That's fine... Now your arm is no longer like a branch of a tree. It is not stiff any longer... Just let it relax again...

Score + if arm has bent less than 2 inches at end of 10 seconds.

3 and 4. Visual and Auditory Hallucination (TV)

It is easier to imagine what I am going to ask you to do if you keep your eyes closed.

What is your favourite TV programme? For the occasional child who does not watch TV, substitute favourite movie and modify the instructions appropriately. Record response.

You can watch that programme right now if you want to, and I'll tell you how. When I count to three, you will see a TV in front of you, and you can watch (name of programme)... Ready? One... two... three... do you see it?

*Either arm may be used for items 1 and 2; if, for example, one arm is immobilised, use other arm for both items.
If yes

That's all right... Sometimes it takes a little while to catch on to how to do this... Just wait a little while, and I think you'll start to see it pretty soon.

Wait 5 seconds. There, what do you see now? What are you hearing? If sees or hears, question as above.

Is the picture clear?... Is it black and white, or is it in colour? What's happening? Can you hear the programme?

... Is it loud enough? What are you hearing?... Finally:

Now the programme is ending...

... The TV is disappearing...

... It's gone now... very good.

If still no

That's okay. Just forget all about the TV... We'll do something else... Just relax and keep listening to my voice...

Visual: Score + if child sees a programme with sufficient detail to be comparable to actual viewing.

Auditory: Score + if child reports hearing words, sound effects, music, etc.

5. Dream

Do you dream at night when you are asleep? If puzzled, explain that a dream is like seeing things going on even when you are asleep. I'd like you to think about how you feel when you are just ready to go to sleep at night, and imagine that you are about to have a dream... Just let a dream come into your mind, a dream just like the dreams that you have when you are asleep...

When I stop talking, in just a moment, you will have a dream, a very pleasant dream, just like the dreams you have when you are asleep at night... Now a dream is coming into your mind... Wait 20 seconds...

The dream is over now, and I'd like you to tell me about it. Record verbatim, probing as necessary for thoughts or images.

That's fine. You can forget about the dream now, and just relax... Just relax completely and let your whole body feel good...

Score + if child has an experience comparable to a dream, with
some action.

6. Age Regression

Now I’d like you to think back to some very special time when you were younger than you are now. Some time that happened last year, or maybe when you were even younger than that... a special trip, perhaps, or a birthday party. Can you think of such a time? What was it? Record target event. All right... now I’d like you to think about that time... Think about being younger and smaller... In a little while, you are going to feel just like you did on that day when (specify target event). I am going to count to five and at the count of five you will be right back there again... one... two... three... four... five... You are now there... Tell me about it... Where are you? How old are you?... Look at yourself and tell me what you’re wearing. Continue as appropriate and record responses.

That’s fine... Now you can stop thinking about that day and come right back to today, in this room, with everything just as it is. Tell me how it seemed to be back at (target event)... Was it like being there, or did you just think about it? How real was it? Did you feel smaller?... That’s fine. Just relax completely again now.

Score + if child gives appropriate answers to questions and reports some experience of being there.

7. Posthypnotic Response

That’s it... very relaxed... feeling so good, so comfortable... so relaxed... In a moment I will ask you to take a deep breath and open your eyes and feel wide awake, so we can talk a little about the things we have done today... However, while we are talking, I will clap my hands two times, like this - demonstrate. When you hear me clap, you will immediately close your eyes and go right back to feeling just the way you do now... completely relaxed... You’ll be surprised at how easy it is to let your eyes close, and let your whole body relax completely again, when you hear the handclap... relaxed and comfortable, just as you are now... All right, then... now take a deep breath and open your eyes... That’s fine... Maybe you’d like to stretch just a little so you’ll feel alert... You’ve done very well at imagining these things... Which of the things that I asked you to think about was the most fun? After approximately 20 seconds, clap hands. Note response.

Score + if child closes eyes and exhibits characteristics of relaxation.

Do you feel relaxed? Do you feel as relaxed as you did before, before I asked you to open your eyes?... That’s fine. Now I’m
going to count from five to one, and when I get to one, you will
open your eyes and feel wide awake again, and you will know that
our imagining things together is over for today. Okay, then...
five... four... three... two... one... very good. How do you
feel now? Let's talk a little about the other things we did
today. *Remind child of specific items so that he recalls all
suggestions.* Now I'm going to clap my hands again, and this time
it will not make you drowsy and relaxed. *Clap hands, record
response, and be sure that the child is fully alert.*

Termination

You've done very well today. What was the most fun of the things
I asked you to do? Is there anything else you'd like to talk
about?... If there isn't, then we're all through.
Ms. Chrissi Ioannou,
Hon. Senior Clinical Psychologist,
Brookside Family Consultation Clinic,
2 Brookside,
Cambridge CB2 1JE.

Dear Ms Ioannou,

Dr Rees and I have looked at your application:

evaluation of psychological assessment and intervention to reduce pain and anxiety in young children undergoing regular invasive medical procedures in the Renal Transplant Clinic

and feel that it is in order for you to proceed.

I will place this before the full Committee at its next meeting for their consideration and ratification.

Yours sincerely

Ian Macdonald
Chairman of Ethical Committee
26 January 1987

Ms C Ioannou
Child Clinical Psychology
2 Brookside
CAMBRIDGE
CB2 1JE

Dear Ms Ioannou

Psychological Intervention for Children undergoing Painful Medical Procedures

I refer to your recent application to the District Ethical Committee regarding the above project and am pleased to inform you that this project was approved by the Committee at its meeting on 23 January 1987.

Furthermore, whilst I am sure that every effort is already made to preserve the confidentiality of any patient information used in this study, could you please ensure that the team of investigators are aware that everyone who has access to patient information appreciates the importance of maintaining confidentiality, particularly in respect of the use of computers and the statutory regulations laid down in the Data Protection Act 1984.

Yours sincerely

Professor I H Mills
Chairman
District Ethical Committee
### APPENDIX XXI

#### DIABETIC PARENT CODED QUESTIONNAIRE

<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <strong>SEX</strong></td>
<td>Child's sex</td>
</tr>
<tr>
<td>2. <strong>AGE_M</strong></td>
<td>Age (months)</td>
</tr>
<tr>
<td>3. <strong>PARENT</strong></td>
<td>Parent interviewed</td>
</tr>
<tr>
<td>4. <strong>GROUP</strong></td>
<td>Hypnosis 0, Behavioural 1, Control H 2, Control B 3, No treatment 4</td>
</tr>
<tr>
<td>5. <strong>PRATCAA</strong></td>
<td>How anxious do you think your child is at the moment about his/her blood test?</td>
</tr>
<tr>
<td>6. <strong>PRATAA</strong></td>
<td>How anxious do you feel about your child’s blood test?</td>
</tr>
</tbody>
</table>
| 7. **PANX**   | What are your anxieties?  
|               | 1 hate needles  
|               | 2 whether it will hurt him/her  
|               | 3 hba/ blood result  
|               | 4 child upset  
|               | 5 other |
| 8. **PRATCAAB**| How anxious do you think your child will be during the blood test? |
| 9. **PRATCAPB**| How much pain do you think your child will experience during the blood test? |
| 10. **DAGEM** | Child's age at diagnosis (months) |
| 11. **SEG**   | Social class (see Office of Population Censuses and Surveys (1980)) |
| 12. **B_ORDER**| Birth order |
13. CHEALTH  Child's present health (diabetic control)
   1 poor
   2 adequate
   3 good

14. FILLNESS  Family illness (i.e. diabetes, cancer etc)
   1 Yes
   0 No

15. TILLNESS  Type of family illness
   1 Diabetes
   2 Other

16. LESCORE  Life event score

17. FREQBT  Frequency of bloodtests
   1 <3 months
   2 3-6 months
   3 >6 months

18. FREQFP  Frequency of finger pricks
   1 <10 week
   2 10-20 a week
   3 20-30 a week

19. How anxious or distressed does your child become over the following procedures?

PRCUAB  a. Bloodtests (venipunctures)
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PRCUAFF  b. Finger pricks
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PRCUAI  c. Insulin injections
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

PRCUADI  d. Dental injections
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

20. PRNEEDLE  Has your child ever had an unpleasant experience with needles or difficulties in coping with needles at any time?
   1 yes
   0 no
21. PRIDCA Has your child’s anxiety increased or decreased over time?
   1 decreased
   2 same
   3 increased

22. PDHCB How do you help your child cope with bloodtests?
   1 don’t help
   2 talk
   3 parent presence
   4 emotional support
   5 distraction
   6 other

23. PDHCN How do you help your child cope with other needles (finger pricks, insulin injections)?
   1 don’t help
   2 talk
   3 distraction
   4 be firm
   5 other

24. PDSHCB How do staff help your child cope with bloodtests?
   1 talk to child
   2 general statement about competence
   3 emotional support
   4 combination strategies
   5 other

25. PDSHCN How do staff help your child cope with other needles?
   1 talk to child
   2 general statement about competence
   3 emotional support
   4 combination strategies
   5 other

26. PPB Are you usually present during your child’s bloodtest?
   1 yes 0 no

27. PCCBW Does your child cope better or worse if you are present?
   1 better
   2 no different
   3 worse
28. PWR  Would you be willing to wait in the waiting room while your child has their bloodtest?

1 yes
0 no

29. PCCB  What helps your child cope better?

1 nothing
2 distraction
3 parental presence
4 successful venipunctures
5 other

30. PCCLW  What makes your child cope less well?

1 nothing
2 if unwell/unprepared
3 unsuccessful venipunctures
4 other

31. PCCM  What coping methods does your child use to manage the bloodtest? Other needles?

1 none
2 deep breaths/relaxes
3 distraction
4 tenses up
5 other

32. PCPA  What do you tell your child about expressing feelings about pain or anxiety? Has this changed as he/she has got older?

1 encourages child to talk/express feelings
2 provide emotional support
3 other

33. PRCUB  How much do you think your child understands what bloodtests are for?

0 no understanding
1 a little
2 a moderate amount
3 a great deal

34. PRCUFP  How much do you think your child understands what finger pricks are for?

0 no understanding
1 a little
2 a moderate amount
35. PRCFP  Does your child have any fears or phobias other than needles?
   1 yes
   0 no

36. PDCF  If yes, how many fears?
   1 one other fear
   2 2 or more fears

37. PDFF  Does anyone in the family have fears or phobias, including needles?
   1 yes
   0 no

38. PDFMF  If yes, who?
   1 mother
   2 father
   3 siblings
   4 other

39. PDSP  What type of fears or phobias?
   1 needles
   2 other

40. CAA  In the last 24 hours prior to your clinic visit, have you noticed any unusual behaviour or symptoms in your child, such as changes in eating or sleeping patterns, crying, nausea etc?
   1 yes
   0 no

41. How anxious do you become yourself when undergoing the following:

   PSRB  a. Bloodtests
      No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

   PSRI  b. Injections
      No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

   PSRDI  c. Dental injections
      No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety
42. POA  (If anxious) What are your anxieties about these procedures?
   1 the pain
   2 the needle
   3 other

43. Which of these does your child do him/herself?
   a. finger pricks
      1 yes
      0 no
   b. insulin injections
      1 yes
      0 no

44. PAGEDM At what age did your child start taking control over diabetic management (i.e. injections, diet)
   Months=

45. Which sites does he/she use for:
   a. finger pricks number fingers=
   b. insulin injections number sites=

46. PCFP Does he/she carry out finger pricks regularly?
   1 yes
   0 no

47. PCII Does he/she carry out insulin injections regularly?
   1 yes
   0 no

48. PARGT Are there arguments or disagreements at home over finger pricks or injections?
   1 yes
   0 no

49. PRCDT What part of diabetic management does your child find most difficult? (eg bloodtests, finger pricks, injections, diet)
50. PRODT What part of diabetic management do you find most
difficult?

1 bloodtests  
2 finger pricks  
3 injections  
4 diet  
5 more than one  
6 clinic attendance  
7 hypos  
8 other

51. PCITIA Has your child's diabeties and its treatment
interfered with any activities such as school,
hobbies? Does it stop him/her doing anything in
particular?

1 yes  
0 no

52. PRCUI How well does your child understand about his/her
diabetes?

0 not at all  
1 a little  
2 a moderate amount  
3 a great deal

53. PRCTUT How well does your child understand about his/her
treatment?

0 not at all  
1 a little  
2 a moderate amount  
3 a great deal

54. PRCIF What effect do you think your child's diabetes and
its treatment has had on your family (on you and
your partner, on siblings)? What difference has it
made having a diabetic child?

1 no effect  
2 diet  
3 clock conscious  
4 worry
1 no effect
2 diet
3 clock conscious
4 worry
5 affected sibs
6 multiple affect
7 other
APPENDIX XXII

DIABETIC CHILD CODED QUESTIONNAIRE

VARIABLE NAME

1. CRAA  How anxious are you about your bloodtest today?
           No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

2. CRPAIA How anxious or worried do you think your parent is about your bloodtest?
           No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

3. CRAADB How anxious do you think you will be during the blood test?
           No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

4. CRAFTDB How much pain do you think you will experience?
           No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

5. CFRQBT  How often do you have bloodtest?
           1 <3 months
           2 3-6 months
           3 >6 months

6. CFRQFP  How often do you have finger pricks?
           1 <10 week
           2 10-20 a week
           3 20-30 a week

7. CUAABT How anxious do you get about bloodtests?
           No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

8. CUAAFP How anxious do you get about finger pricks?
           No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

9. CUAII  How anxious do you get about insulin injections?
           No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

10. CUADI  How anxious do you get about dental injections?
11. CRNEEDLE Have you ever had an unpleasant or bad experience with needles (at home or hospital)?
   1 yes
   0 no

12. CPPB Is your mother/father usually with you when you have a bloodtest?
   1 yes
   0 no

13. CCBW Is it better or worse if he/she is with you?
   1 better
   2 no different
   3 worse

14. CDE Is there anything that makes the bloodtest easier?
   1 nothing
   2 relax
   3 parent present/offers emotional support
   4 distraction
   5 other

15. CDW Is there anything that makes it worse?
   1 nothing
   2 unsuccessful venipunctures
   3 sight of needle
   4 noise
   5 if unwell
   6 other

16. CCS Some children find a special way of coping with needles. What do you do to cope better or what have you tried?
   1 nothing
   2 deep breaths/relaxation
   3 distraction
   4 look
   5 other

17. NCS Number of coping strategies

18. CDWPB What is the worst part of a bloodtest?
   1 when needle goes in
   2 when needle comes out
19. CPL
Do you prefer to look or look away?
0 look away
1 look
2 either

20. CRP
Any idea why?
1 when look - see what's done - know when it's coming
2 when look away - hurts less
3 other
4 don't know

21. CCDB
What sort of things do you think about?
1 nothing
2 positive self talk
3 imagery
4 distraction
5 expectations of pain
6 other

22. CDPCPA
What does your mother or father say to you when you are hurt or worried?
1 nothing
2 provides reassurance/support/comfort
3 encourages child to talk about/express feelings
4 other

23. CDPB
What are your blood tests for?
0 no understanding
1 vague idea they investigate child's control/health
2 testing blood sugar
3 how blood sugar is over a period of time/several weeks

24. CDPFP
What are your finger pricks for?
0 no understanding
1 vague idea they investigate child's control/health
2 test for blood sugar
3 test blood sugar there and then (see if
25. CFP
Some children have fears or phobias about certain things...are there things you are afraid of and that you avoid?
1 yes
0 no

26. CDFP
How many fears?
1 one other fear
2 2 or more fears

27. CFFP
Does anyone else in the family have fears or phobias?
1 yes
0 no

28. CDFMFP
What fears?
1 needles
0 other

29. COPP
Do you do finger pricks yourself?
1 yes
0 no

30. COII
Do you do insulin injections yourself?
1 yes
0 no

31. CAGRDM
How old were you when you started injecting yourself?
Age in months

32. CFPS
Which sites do you use for finger pricks?
Number of sites =

33. CIIS
Which sites do you use for insulin injections?
Number of sites =

34. CFPR
Do you carry out finger pricks regularly?
1 yes
0 no
35. CIIR  Do you carry out injections regularly?
    1 yes
    0 no

36. CARGT  Are there arguments or disagreements at home over finger pricks or injections?
    1 yes
    0 no

37. CIOS  Which are easier - bloodtests and injections given by others, or giving injections yourself?
    1 self
    0 others

38. CDF  What part of treatment do you find the most difficult or dislike the most?
    1 bloodtests
    2 finger pricks
    3 insulin injections
    4 diet
    5 more than one
    6 clinic attendance
    7 other

39. CRPDT  What part of treatment do you think your mother/father find most difficult?
    1 bloodtests
    2 finger pricks
    3 insulin injections
    4 diet
    5 more than one
    6 clinic attendance
    7 other

40. CITIA  Has your illness and its treatment interfered with any activities such as school and hobbies?
    1 yes
    0 no

41. CUILL  If a child your age asked you what diabetes was, what would you say?
    0 no understanding
    1 vague answer about insulin/bodily dysfunction/cant have sugar
    2 pancreas not producing enough insulin
    3 pancreas not producing enough insulin and need to inject it
42. CUTFREAT  If a child your age asked you how diabetes would be treated, what would you say?
   0 no understanding
   1 vague understanding of treatment- mentions one of below
   2 mentions two treatments
   3 mentions three or more treatments
      (blood tests, insulin injections, finger pricks and diet, exercise)

43. CDEIT  What effect do you think your illness and treatment has had on your parents and brothers and sisters?
   1 no effect
   2 diet effect
   3 worry
   4 affected sibs
   5 other
## APPENDIX XXIII

### TABLE Summary statistics (Chapter 11)

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APPENDIX XXIV

CHILD TREATMENT CODED FOLLOW-UP QUESTIONS

1. CFU1 Which of the things we did was most helpful?
   1 relaxation
   2 distraction
   3 rehearsal
   4 reward
   5 imagery
   6 other
   7 none

2. CFU2 Did you think that what we did would help?
   1 yes
   0 no

3. CFU3 What do you do to cope with your bloodtests now?
   1 relaxation
   2 distraction
   3 rehearsal
   4 reward
   5 imagery
   6 other
   7 none

4. CFUFP How anxious do you get now over finger pricks?
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

5. CFUII How anxious do you get now over insulin injections?
   No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

6. CFU5 Has learning new ways of coping with bloodtests helped you or your family in any way?
   1 yes
   0 no

7. CFU5A In what way?
APPENDIX XXV

PARENT TREATMENT CODED FOLLOW-UP QUESTIONS

1. PFU1 What do you think was most helpful about the training session given?
   - 1 relaxation
   - 2 distraction
   - 3 rehearsal
   - 4 reward
   - 5 imagery
   - 6 other
   - 7 none
   - 8 combination
   - 9 don't know

2. PFU2 Did you think the preparation session would help?
   - 1 yes
   - 2 sort of
   - 3 no

3. PFU3 What do you think your child does now to cope with bloodtests?
   - 1 relaxation
   - 2 distraction
   - 3 rehearsal
   - 4 reward
   - 5 imagery
   - 6 other
   - 7 none

4. PFUFPP How anxious does your child become now over finger pricks?
   - No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

5. PFFII How anxious does your child become now over insulin injections?
   - No anxiety 0 1 2 3 4 5 6 7 8 9 10 Extreme anxiety

6. PFU5 Has learning new ways of coping with bloodtests influenced your child or family in any way?
   - 1 yes
   - 0 no

7. PFU5a In what way?
   - 1 child/parent less worried
   - 2 hurts less
3 more relaxed
4 no difference
5 coped well before
6 other
ADDENBROOKE'S HOSPITAL
PAEDIATRIC DIABETIC CLINIC

FIRST CLASS
BLOODTESTING CERTIFICATE

Awarded to __________________________

Dated this ______ day of ______ 19

Signed

Chrissi Ioannou
Senior Clinical Psychologist

ames
APPENDIX XXVII TRANSPLANT DATA

The VARIABLES are listed in the following order:

Line 1: SEX AGE_M PARENT GROUP PRATCA PRATCAA PRATCAAB PRATCAPB PRATCAAI
       PRATCAU PARENT GROUP PRATCA PARENT GROUP PRATCAAI
Line 2: PCCBM PWR PCGB PCCBM PCCBM PCCBM PCCBM PCCBM PCCBM PCCBM
       PCCBM PCCBM PCCBM PCCBM PCCBM PCCBM PCCBM PCCBM PCCBM
Line 3: CRPDI DRUGS SEG BORDER CHEALTH FILLNESS TILLNESS FREQBT PRCUAB
       PRCUAI PRCUADN PRCUDI PRIEDGET PRCUAI PRCUAI PRCUAI
Line 4: PRCUI PRCUT PRCIPPY CHAA CHM CHAA CHAA CHAA CHAA CHAA CHAA
       CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA
Line 5: CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA
       CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA
Line 6: CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA
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Line 7: CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA
       CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA
Line 8: CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA
       CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA CHAA

Number of cases read = 21
### APPENDIX XXVII

**RAW DATA (CHAPTER 10)**

**Nurse and Parent Ratings for Anxiety and Pain - Pre Treatment, Post Treatment and Follow Up for N=10**

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**RAW DATA: Intensity Scores for 3 Phases of Blood Test (pre, post and follow-up) n=10**

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RAW DATA (CHAPTER 10) cont'd

RAW DATA: TOTAL INTENSITY SCORES, PRE, POST AND FOLLOW UP TO TREATMENT n=10 AND NO OF BLOODTEST AND VENIPUNCTURES

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APPENDIX XXVII DIABETIC DATA

62 cases, each consisting of
276 variables (including system variables).

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| CFFP: | 1 1 4 9 1 1 3 5 7 3 4 5 7 2 3 2 1 2 2 2 4 2 3 1 3 2 |
| BTFRION: | 1 1 1 3 8 3 2 4 2 2 1 5 4 3 2 9 3 0 0 3 2 9 3 1 1 1 |
| CHILDLI: | 28 13 12 99 9 1 5 1 1 2 0 9 29 40 7 2 8 3.7 2.7 2.5 999 999 999 999 |
| SCHROMAC: | 999 999 7 0 0 3 0 0 1 0 0 5 0 4 4 1 1 2 2 2 7.7 0 |
| THBA: | 0.90 9.90 8.60 1 1 1 2 8.0 1 2 2 5 5 5 99 3 3 1 1 8 4 10 2 1 1 |
| PUTIA: | 0 2 2 0 1 99 2 1 1 2 1 1 999 2 2 1 9 0 4 3 2 3 3 2 7 2 |
| HHR: | 80 106 80 85 92 92 82 70 71 76 63 75 78 73 69 4 3 0 |
| CONULT: | 7 6 2 8.60 1 8 1 8 0 1 1 1 2 4 1 9 6 5 2 3 4 5 2 |
| BCSOBDL: | 8 5 2 1 5 8 20 1 7 9 8 9 6 9 9 81 0 0 1 1 0 0 0 3 0 0 2 0 |
| BOSEDAM: | 0 9 0 2 2 4 |
|       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| SEX   | 0.750 | 0.061 | 0.568 | 0.350 | 0.338 | 0.338 |
| PDCF  | 0.278 | 0.067 | 0.067 | 0.100 | 0.100 | 0.100 |
| CFFP  | 1.099 | 0.119 | 0.760 | 0.000 | 0.100 | 0.100 |
| BTPRIOR | 0.841 | 0.203 | 0.203 | 0.039 | 0.310 | 0.6 |
| CHILDLI | 23.118 | 0.131 | 0.609 | 0.373 | 0.131 | 11.3 |
| SCROMANC | 999 | 999 | 999 | 999 | 999 | 999 |
| PCITIA | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 |
| BHRB  | 96.104 | 99.999 | 99.999 | 99.999 | 99.999 | 99.999 |
| COSBDT | 999 | 999 | 999 | 999 | 999 | 999 |
| BOSBDES | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 | 0.000 |

|       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |       |
|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| SEX   | 0.104 | 0.022 | 0.564 | 0.464 | 0.464 | 0.464 |
| PDCF  | 9.112 | 7.471 | 4.033 | 2.626 | 2.626 | 2.626 |
| CFFP  | 1.094 | 0.123 | 0.334 | 0.334 | 0.334 | 0.334 |
| BTPRIOR | 1.112 | 0.663 | 0.320 | 0.542 | 0.542 | 0.542 |
| CHILDLI | 26.126 | 5.689 | 4.009 | 5.246 | 8.157 | 3.784 |
| SCROMANC | 999 | 999 | 999 | 999 | 999 | 999 |
| THBA  | 7.670 | 8.800 | 0.111 | 999 | 4.192 | 5.035 |
| PCITIA | 0.919 | 0.049 | 0.512 | 0.100 | 0.100 | 0.100 |
| BHRB  | 119.126 | 99.999 | 99.999 | 99.999 | 99.999 | 99.999 |
| COSBDT | 999 | 999 | 999 | 999 | 999 | 999 |
| BOSBDES | 2.400 | 6.820 | 1.951 | 5.119 | 12.690 | 90.901 |

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- The table format is used to organize and present the data clearly.
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Support for cooperative networks through the display of social media and

Page references have been added in order to facilitate the reader's

Social media networks have been added to direct readers to the

Acknowledgements
geometric approach to the population

of individuals of a given species. The
ideas on the evolution of populations
are based on the concept of the
relationship between the genetic
constituents of a population and the
environmental factors that affect
them. This relationship is

represented graphically in the
following figure.

Figure 1: Geometric Approach to Population Evolution

- The figure shows a population divided into two groups, A and B, each
  representing a different genetic composition.
- Group A is composed of individuals with a high genetic susceptibility to
  environmental factors, while group B is composed of individuals with a
  lower susceptibility.
- The population evolves over time as a result of the interaction between
  the genetic composition and the environmental factors.
- The genetic composition of the population changes due to factors such as
  mutation, selection, and genetic drift.

In conclusion, the geometric approach to population evolution provides
an effective tool for understanding the genetic dynamics of populations.

References:

Figure 1 [Graphical representation of the geometric approach to population evolution]