RESPONSE TO ACUTE PAIN AMONG CHILDREN WITH AND WITHOUT SICKLE CELL DISEASE

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ABSTRACT

This study was designed to compare pain intensity during a clinical event (fingerstick) in children with Sickle Cell Disease (SCD) who have experienced recurrent episodic pain, against those children without SCD who have not experienced recurrent pain. A convenience sample of sixty-six 7-12 year old children was obtained, 33 with SCD from the sickle cell clinic and a matched (age, sex, ethnic origin) group of 33 children without SCD from the community. Pain intensity using the Coloured Analogue Scale (McGrath et al., 1996) and, medical fears using the Child Medical Fears Scale (Broome & Hellier, 1987) were measured following the fingerstick. The number of hospitalisations and the number of experiences with needles were examined for their relationship to pain intensity or medical fears. Multivariate analysis of variance revealed no significant differences in either pain intensity or medical fears between the two groups. There was a moderate, significant correlation between pain intensity and medical fears for the entire sample ($r=.269$, $p<.03$). Among children with SCD, those who had more than the median number of hospitalisations (6), reported lower medical fear scores ($p<.01$). This finding suggests adaptation on the part of these children to their chronic illness and to hospitalisations.

SOMMAIRE

Cette étude a été conçue pour comparer l'intensité de la douleur à une expérience douloureuse (piqûre au doigt) chez les enfants atteints d'anémie falciforme et qui ont subi des douleurs récurrentes, par rapport à des enfants ne souffrant pas d'anémie falciforme et qui n'ont pas subi de douleurs récurrentes. Un groupe de soixante-six enfants (facilement disponibles) âgés de 7 à 12 ans, a été établi, dont : 33 enfants souffrant d'anémie falciforme venant de la clinique par rapport à 33 autres enfants (du même âge, sexe et groupe ethnique) ne souffrant pas d'anemie falciforme et venant de la communauté. L'intensité de la douleur selon l'échelle analogue de couleurs (McGrath et al, 1996) et les préoccupations médicales selon l'échelle des préoccupations médicales chez l'enfant (Broome & Hellier, 1987) a été mesurée suite à la piqûre au doigt. Le nombre d'hospitalisations et le nombre d'essais avec les piqûres a été étudié avec leur relation à l'intensité de la douleur et aux préoccupations médicales. Des analyses polyvalentes de variables n'ont révélé aucune différence significatif que ce soit dans l'une ou l'autre intensité de douleurs ou préoccupations médicales entre les deux groupes. On a trouvé une corrélation moyenne et significatif entre l'intensité de la douleur et les préoccupations médicales pour tout l'échantillon ($r=.269$, $p<.03$). Toutefois, parmi les enfants souffrant d'anémie falciforme, ceux qui avaient plus que le nombre moyen d'hospitalisations (6), ont déclaré avoir moins de préoccupations médicales ($p<.01$). Ces resultats peuvent refleter une adaptation de la part de ces enfants vis-à-vis leur maladie chronique et les hospitalisations.

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Chapter I

Introduction and Statement of the Problem

It is only recently that chronic pain has been recognised as a public health problem. Estimates of pain prevalence reported in epidemiologic studies in the adult population, range between 10 and 40 per cent (Abbott, Gray-Donald, Sewitch, Johnston, Edgar, & Jeans, 1992; Bonica, 1990; Brattberg, Thorslund, & Wikman, 1989; Sternbach, 1986; Von Korff, Dworkin, & Le Resche, 1990). Chronic pain is a cause of suffering and disability for millions of people (Bonica, 1990). Numerous studies have been conducted on chronic pain in adults, however, chronic pain in children has not been widely researched.

Purpose

This study was designed to examine the response to acute pain in children who have experienced recurrent episodic pain (SCD), compared to children who have not experienced recurrent pain. Further aims of this study were to determine if there were differences in medical fears between the two groups and, if medical fears were related to pain intensity. In addition, the study was designed to examine other factors, such as the number of hospitalisations, the number of experiences with needles, to see the relation to pain intensity or medical fears.

Rationale

Chronic pain is generally defined as 'pain that persists beyond the normal time of healing.....' (Merskey, 1986, p. S5). There remains some disagreement on the definition of chronic pain and how it should be classified. The persistence of pain, to be classified as chronic pain, may be less than one month or more than six months (Bonica, 1953; Curro, 1987), however, Merskey et al. (1986) have defined three months as the most convenient point of division between acute and chronic pain. Von Korff et al. (1990) proposed a model of chronic pain that included three axes: time, severity, and impact. This model allows for flexibility in time, so that pain that either recurs in acute episodes or is persistent can be included. This is the only model that includes severity and dysfunction as components of chronic pain.

Following this definition, chronic pain from diseases can be experienced as episodes of pain alternating with pain-free periods, or by episodes of pain over a baseline of persistent pain (Sternbach, 1985). Several childhood chronic diseases are characterized by recurrent painful episodes, e.g. sickle cell disease (SCD), juvenile rheumatoid arthritis (JRA), and hemophilia. However, sickle cell disease has been considered the most intensely painful childhood disease (Gil, Thompson, Keith, Tota-Faucette, Noll, & Kinney, 1993; Platt, Thorington, Brambilla, Milner, Rosse, Vichinsky, & Kinney,1991; Shapiro, Dinges, Orne, Bauer, Reilly, Whitehouse, Kwaku, & Orne, M., 1995; Varni, Thompson, & Henson, 1987). The most widely known clinical manifestation of the disease is the recurrent episodes of vascular occlusion within the tissues which leads to organ damage and excruciating musculoskeletal pain; this is the principal cause of morbidity among these children (Platt et al.,1991). It is the pain component of the disease that keeps the child with SCD out of school and leads to repeated hospitalisations. Using the Von Korff et al

(1990) definition of chronic pain with the three axes of time, severity, and disability, SCD can be viewed as a condition leading to serious chronic pain.

Chronic pain has been an important area of research in adults, but has not been widely studied in children. Chronic pain from sickle cell disease (SCD) is characterised by acute episodes of pain alternating with pain-free periods. The acute pain episodes pose a major health problem. These episodes of pain may alter pain sensation via physiological mechanisms in the periphery (Woolf, 1991) as well as via cognitive and emotional factors (McGrath & Hillier,1996). The understanding of the impact of recurrent pain experienced by children with SCD is only beginning. There is little information regarding the consequences of the experience of recurrent pain in children. There have been studies on the consequences of chronic illness in children, but not specifically the pain component of the illness (Gil et al., 1991; Lavigne & Faier-Routman, 1992; Midence, Fuggle, & Davies, 1993; Pless & Satterwhite, 1972; Walker, Stein, Perrin, & Jessop, 1990). There have been studies specifically examining children with SCD and the consequences of that disease, but again, the pain component was not explicitly examined. While it may be believed that recurrent pain from frequent painful procedures may have lasting consequences (McGrath, personal communication in Atlanta, 1995; Johnston, 1996), there are no empirical data to support this claim. Still, based on clinical observations as well as some animal studies (Anand & Plotsky, 1995; Fitzgerald, Millard, & McIntosh, 1989), there is reason to suspect that children with SCD may be more sensitive to acute pain as a result of their recurrent and persistent experiences with pain. These children also often have fears of health care services (Alleyne & Thomas, 1994) which may increase their perceptions of pain (Fowler-Kerry & Lander, 1991; Ross & Ross, 1988).

It may be that nurses and health professionals believe that children with recurrent pain and frequent hospitalisations are less sensitive to acute pain and have fewer medical fears and thus, use this belief in their assessment and management of pain. This belief may result in the undertreatment of pain in these children. Nursing has an ethical obligation to relieve patients' suffering, therefore managing pain through clinical expertise and utilisation of research findings is imperative. Knowledge about the pain responses of children with SCD assists nurses to ensure proper pain management for these children, i.e. the development, assessment, and the reassessment of their pain management regimen.

Definitions

For purposes of clarification the following definitions will apply during the reading of the literature review.

Pain - "pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (IASP, Merskey, 1979, p.250). There are intensity, duration and sensation definitions associated with pain.

Perception of Pain - occurs when the intensity of pain goes beyond a threshold that distinguishes pain from no-pain.

Pain Threshold - the point at which sensations become unpleasant (point of discriminable pain). For example, heat application initially is felt as a warm sensation to a certain point then it becomes painful.

Pain Tolerance - upper limit of pain whereby the individual cannot endure the noxious sensation.

Acute Pain - pain which occurs as an automatic response to noxious stimulus.

Chronic Pain - any pain that lasts longer than 3-6 months (McGrath, 1990). For the present study, this definition will include recurrent pains of childhood, specifically sickle cell disease. Acute episodes of vaso-occlusive pain are characteristic of sickle cell disease. This recurrent acute pain can be defined as episodes of acute pain interspersed with pain-free periods (Turk & Melzack, 1992). This refers to pain from underlying recurrent or continued nociceptive input (Crue, 1985).

Pain response – refers to self-report of pain intensity. It is assumed that pain responses are the direct reflection of the perceived pain (McCaffery & Beebe, 1989).

Chapter 2

Review of the Literature

There are three main areas reviewed: physiological and pathological mechanisms of pain; psychological factors in pain; and multidimensional nature of children's pain experience. The concepts and findings found in the literature in relation to children who experience recurrent pain and pain intensity are delineated in this chapter.

Physiological and Pathological Mechanisms of Pain

Progress in pain research has increased knowledge of physiological and pathological mechanisms of pain transmission. The primary mechanisms involve the transmission and detection of a noxious stimulus, or the process of nociception. More complex mechanisms are involved in the perception of pain which broaden the experience beyond the detection of a noxious stimulus to an "unpleasant sensory and emotional experience" (Merskey & Bogduk, 1994, p. 210). The afferent signals initiated by a noxious stimulus can be modulated at many places in the peripheral and central nervous systems (CNS). (Melzack & Wall, 1965; McGrath, 1987; Woolf, 1991). This modulation alters the pain perception.

The nociceptive system has been referred to as being plastic, in that it has the capacity to respond differently to the same noxious stimulus. A person's pain is not determined solely by the intensity of a noxious stimulus, but also by situational and contextual factors. Thus, perception of pain is not directly related to the quality or extent of tissue damage (McGrath, 1987; Melzack & Wall, 1965).

The ability of the nervous system to be altered in response to certain stimuli has become an important area of research. Changes in the peripheral nervous system (PNS) which result in the interpretation of normal signals as painful in low threshold afferents has been reported by Woolf (1991). These changes occur due to inflammatory response from substantial tissue injury or damage to the nervous system (Woolf, 1989). Woolf describes four pathological pain symptoms that are a result of trauma in the peripheral afferents: 1) reduction in the threshold to elicit pain (allodynia), 2) increase in the response to noxious stimuli (hyperalgesia), 3) prolongation in the response to a transient stimulus (persistent pain), 4) spatial spread of the pain to the uninjured tissue (referred pain) (1991).

Woolf (1991) found that an alteration in the CNS, triggered by a peripheral injury, results in the misinterpretation of the signals in low threshold mechanoreceptors, such that low probability afferents acquire a high probability of activating a cell in the dorsal horn. These alterations of the spinal cord will alter somatosensory processing and account for the generation of pain in reaction to low-intensity stimuli. This capacity of the CNS for change may be responsible to a large extent for the generation of clinical pain states (Woolf, 1989). Research has shown that the arrival at the spinal cord of a burst of impulses in C-fibres can lead to prolonged and substantial receptive field changes (Brandt & Livingston, 1990; Cook, Woolf, Wall & McMahon, 1987). Consequently, even days after the initial injury, the

pain mechanisms may not be static but could be changing into new pathological modes of operation (Wall, 1984). It seems that recurrent, persistent pain can be a consequence of these changes within the nervous system (Woolf, 1989).

In summary, pain perception may not be determined solely by the intensity of a noxious stimulus, but rather may be modified as a result of an altered PNS or CNS interpreting normal signals in low threshold afferents in an abnormal way (Woolf, 1991).

Psychological Factors in Pain

A number of theories have been generated to explain the neural principle of pain, however these were incomplete in that they could not account for non-physical factors. Melzack and Wall (1965) proposed and later refined the Gate Control Theory of Pain in an attempt to provide an explanation for data that conflicted with the then current theories about pain (McGrath & Unruh, 1987). Their theory expanded the conceptualisation of pain from a sensory phenomenon to a multidimensional model that integrates motivational-affective and cognitive components with sensory-physiological ones (Melzack & Wall, 1965). The theory proposed a gate action to control nociceptive impulse modulation by the central nervous system, in particular from the cerebral cortex. This modulating mechanism in the substantia gelatinosa of the dorsal horn of the spinal cord acts like a gate that can increase or decrease the flow of nerve impulses from the periphery. Noxious stimuli from the periphery are subjected to the modulating influence of the gate before they elicit pain perception and response (Melzack & Wall, 1965). Just as the gate can be opened or closed by impulses going from the periphery to the brain, so the gate can be controlled by descending nerve impulses from higher neural centers. These descending fibres are

activated by situational factors (attention, anxiety, anticipation, beliefs, past experience) which can modify the activity of the sensory nerves that detect and transmit information about tissue damage (Melzack & Wall, 1988; McGrath, 1990). Furthermore, the Gate Control Theory has shown that psychological factors (meaning of the situation, past experiences, attention) and cognitive variables (influenced by sociocultural learning and experiences) are an integral part of pain processing and have an impact on the physiological processes involved in pain perception and response (Melzack & Wall, 1965; Bates, 1987). McGrath (1990) has adapted the Gate Control Theory to explain the physiological processes for the importance of other factors (psychosocial, behavioural, and psychological) relating to a child's pain.

Multidimensional Nature of Children's Pain Experience

The unidimensional concept of pain, that a certain level of noxious stimulation will consistently produce pain and that the strength of pain is directly proportional to the source of noxious stimulation, is no longer tenable. Rather, the neuronal responses stimulated by a constant noxious stimulus may be reduced by many environmental and internal factors (McGrath, 1990).

McGrath's (1990) model portrays situational factors (cognitive, behavioural, emotional) that modify children's pain perception (strength, duration, quality). These factors interact in a unique way between the child experiencing pain and the context in which the pain is experienced (McGrath, 1990; Ross & Ross, 1988). A noxious stimulus, such as an injection, can produce different strengths of pain for two different children. McGrath (1990) refers to situational factors as ones that are unique to a specific child, context, and time in which the pain is experienced. These

situational factors are divided by McGrath & Hillier (1996) into cognitive, behavioural, and emotional factors.

Cognitive, Behavioural, and Emotional Factors

Cognitive factors include children's understanding about the source of pain; the ability to control the event; the expectations about the quality and strength of pain sensations; the relevance of the situation; knowledge of simple pain control strategies (Beales, 1983; Beales, Keen & Holt, 1983; Ross & Ross, 1982).

Behavioural factors are defined as how children and adults behave in relation to the child's pain. These include overt physical behaviours; parents' and health providers' (adults) behaviour towards the child; the behavioural effects of chronic, persistent pain on children's lives, i.e. ability to attend school, participate in social activities with peers, assume family responsibilities; and the extent to which children require physical restraint during invasive procedures (McGrath and Hillier, 1996).

Emotional factors are defined as how children feel about their pain. Emotional reactions such as anxiety, fear, depression, frustration and anger are important influences on pain perception in children. Pain or fear of pain produces anxiety. Anxiety may also increase pain (McGrath and Frager, 1996).

These situational factors described by McGrath (1990) unfold over time for the child and play an important role in modifying children's pain perceptions. In addition to the situational factors there are factors which are relatively stable or constant for a child, which are typically classified as demographic.

Demographic Factors

Demographic factors which influence a child's response to a painful stimulus include: age and cognitive ability, gender, family learning and culture. Psychological experiential factors of previous pain and medical fears may also modify pain perception (Barr, 1983; Gaffney & Dunne 1986; Melzack & Wall, 1982; Merskey 1970; Zborowski, 1952).

Age and Cognitive Ability. The specific nature of a child's response to pain, changes with age. Within each developmental stage, the child's concept and perception of pain changes as cognitive and verbal skills mature. Investigation of children's pain by Gaffney and Dunne (1986, 1987) found that children's perceptions of pain are consistent with Piagetian stages. Gaffney and Dunne (1987) investigated the developmental progression of children's perceptions of pain in 680 children aged 5-14 years. Children were given a task which was designed to prompt children's ideas about such things as definitions and causes. The results of the study were that half of the children explained the causation of pain by referring to some form of self-causality. In addition, objective and abstract explanations of pain increased with age. Gaffney and Dunne (1986) used Piaget's three stages of cognitive developmental (preoperational, concrete operational, formal operational) to examine developmental changes. Children of the concrete operational stage began to generalise and abstract conceptualisations and were therefore able to form analogies or remark on the psychological effects of pain. The authors noted a gradual development of more complex and abstract ideas of pain rather than a sudden change in a child's perception of pain.

A study by Fradet, McGrath, Kay, Adams, and Luke (1990) found age was significantly related to self-report of pain (intensity) ($r = -0.24$, $p < 0.01$) and pain behaviour ($r = -0.39$, $p < 0.01$) in a sample of 171 children between 3-17 years of age who were having blood tests (venipuncture). Thirty-six per cent of children between 3 and 7 reported moderate or severe pain. Thirteen per cent of children over 7 years of age reported moderate or severe pain. However, school-age children seem to put the pain from needles in context as being necessary and report less pain intensity during venipunctures (Bournaki, 1997; Fradet et al., 1990; Jacobsen, & Redd, 1992; Manne, Lander & Fowler-Kerry, 1991) and, "rate pain intensity separately to some component of affective distress" (Goodenough,Warwick, Champion, Perrott, Taplin, van Bayer, & Ziegler, 1999, p. 180). Moreover, school-age children have begun to use more generalised conceptualisations and thus have a greater understanding of the painful procedures (Gaffney & Dunne, 1986), and therefore meaningfully rate pain intensity. Thus, children 7-12 years of age are cognitively similar and have a better understanding on the psychological effects of pain and can articulate this. In addition, this age group is less aware of the possible long-term implications of a chronic disease (as compared to older children) in which recurrent episodes of pain are a typical feature, and are more concerned with the immediate effects (Broome, Bates, Lillis, & McGahee, 1990; Gil, Williams, Thompson, & Kinney, 1991; Spirito, Stark, Grace, & Stamoulis, 1991). Thus, there is greater accuracy in the pain report.

Gender. Gender has been identified as an influencing variable in clinical pain experience. Painful procedures due to common health care practices such as venipunctures, immunisations, bone marrow aspirations, dental procedures and surgery have been studied and show gender variations in pain response. For example, school age girls have more behavioural distress than boys towards such painful

procedures (Fowler-Kerry & Lander, 1991; Fowler-Kerry & Day, 1993; Jay, Ozolins, Elliott, & Caldwell, 1983; Schechter, Berde, & Yaster, 1991;) and, report more pain (Goodenough, Kampel, Champion, Nicholas, Laubreaux, Ziegler, & McInerney, 1997). Parents of toddlers have rated their boys as less sensitive than girls to the pain of bumps, cuts or common hurts (Grunau, Whitfield, & Petrie, 1994). However, other studies have reported no gender differences in children's pain intensity scores (Fradet et al., 1990; Lander et al., 1991; Manne et al., 1992). This may be due to school-age children having increased opportunities for socialisation and, how this can influence sex-role identification (Davidson, 1980).

Gender variations in reported limitations in daily activities/school absences due to pain have been examined. Higher rates of school absences due to pain for girls were reported by Bille (1981), Fairbank, Pynsent, Van Poortvliet, & Philips, (1984) and Sparks (1978). A study by Shapiro et al. (1995) on sickle cell-related pain found girls reported more days with pain than did boys and the pain affected school attendance and sleep. These children were absent from school 21% of 3186 school days. Salminen, Pentti, & Terho (1992) found that girls (with SCD) reported significantly more limitations in their activities of daily living because of pain.

Gender variations in coping with pain (strategies) was noted by Reid, Gilbert, & McGrath (1994) who found among school age children that girls tend to cry, moan, or seek comfort when they have pain. On the other hand, boys respond differently and tend to report more behavioural- and cognitive-distraction and problem-solving abilities than girls. Considering the varied responses from the many studies, gender was matched in this study.

Culture and Family Learning. It is reasonable to expect that cultural affiliation is a variable affecting pain perception (Bates, 1993; Lipton & Marbach, 1984; Weisenberg et al., 1975; Zborowski 1952). One's perception and expression of pain, the meaning and attitude assigned to pain, and the care associated with pain experiences can be said to be culturally derived. Empirical evidence supporting this is based largely on a number of studies comparing cultural groups with clinical pain experience. The importance of culture in pain began with the work of Zborowski (1952) who articulated a framework for the study of culture and pain response. Zborowski studied the pain experience of 350 adults of Italian, Jewish, and Anglo-Saxon ethnicity and postulated that an individual's cultural origin has an important influence on their reaction to painful stimuli, and the meaning of the pain (1952). He found differences among the cultural groups and these included reported pain perception, expression of pain, and pain emotionality. However, the data collection was done through informal interviews (no questionnaire) and therefore open to biases of the author and the people interviewed. In addition, the unfamiliarity of the hospital environment in a foreign culture, the lack of support systems, and the dimension of time in the new country were overlooked.

The only clinical study that found statistically significant differences in pain intensity related to ethnicity was a study by Lipton and Marbach (1984). Four hundred and seventy-six subjects with facial pain were included in the study and categorised into five ethnic groups: Black Americans, Jewish, Irish, Italian, and Puerto Rican. The overall responses were relatively similar, with differences found in the emotionality of pain response and in the reported functional disruption due to pain. Variables shown by previous studies to influence pain response such as symptom history, psychological, social and cultural were controlled in the study. It

was found that differences in pain intensity was statistically different among the five groups. Bates (1993) also examined interethnic differences in reported perception of chronic pain intensity. She found that ethnic identity, locus of control style and age were significantly related to variation in reported pain intensity between ethnic groups.

Responses to pain differ not only between, but also within, ethnic groups (shared social and cultural heritage among members of a group, transmitted from one generation to another; Sue, 1991). Recognising the importance of intra-ethnic variation avoids the misinterpretation which can arise from stereotyping. More recently, studies have examined dimensions of clinical pain experience that vary intraculturally (Bates, 1993; Greenwald, 1991; Lipton & Marbach, 1984). Bates' study found that intra-ethnic group pain intensity variation showed differences in the degree of heritage consistency (degree of bond to one's ethnic group). One of the most important predictors of intraethnic variation is the degree of acculturation (cultural assimilation) to the society's predominant norms of health and illness (Harwood, 1981). In a study by Greenwald (1991), it was proposed that acculturation may have been a factor in his study on interethnic differences in pain perception. He conducted a study with 536 cancer patients of different ethnic backgrounds (95% born in the USA). He controlled for cancer site, stage and social background, and found no statistically significant relationships between ethnic identity and measures of pain sensation, contrary to the findings of Zborowski (1952). He did find some differences in affective pain components among ethnicities ($p = .01$). However,Greenwald's findings differed from Zborowski (1952) in that he found no significant relation between Jewish ethnicity and scores on any measure of pain, and that those of Italian origin did not express pain more freely (1991).

Very few studies address culture and children's pain. A study by Abu-Saad (1984) investigated a sample of of first generation Americans: Latin American, Arab-American and Chinese-American children, 9-12 years old in an attempt to find any differences in describing pain experiences in different terms between the groups. There were minimal cross-cultural differences found. No empirical data compare differences in pain experience and response patterns among children of various cultures.

It is commonly accepted that the way children respond to pain is influenced by parental attitudes, although there is a paucity of empirical studies on this topic. Studies by Pfefferbaum, Adams and Aceves (1990); Zeltzer and LeBaron (1985) found that when the experience of pain involves children and culture, parental expectations and the child's perceptions of those expectations may influence behaviour.

In addition, Canada particularly in contrast to South America, Asia, and Africa is unique in having universal access to health care and active SCD screening and treatment programmes. In recognising this, not only does cultural affiliation/family learning have an influence on the impact of pain, but also the health care system, as the experience may be different for children from outside of Canada. They may not have experienced the accessibility nor the expertise of health care.

In summary, it can be seen that both physiological mechanisms and psychological factors, and their interactions, can influence the perception of acute pain. These factors explain the wide variability in response among individuals. Repeated bouts of pain in association with a chronic illness may also lead to fears around medical procedures.

Factors of Past Experiences

The psychological sequellae of chronic or recurrent pain in children are related to how the recurrent pain is viewed or coped with as well as their experiences with the pain, i.e. successfulness of coping and response of hospital staff (McGrath, 1996). However, in spite of advances in our understanding of the physiological and psychological mechanisms, report of pain in children with recurrent pain varies widely. There are two psychological theories that explain the variations across individuals in their pain response.

Repeated Pain. Two contrasting models from the psychological literature have been proposed to explain differences in pain perception in patients with chronic/recurrent pain to noxious stimulation. The hypervigilence theory states that an individual who is exposed to repeated or constant noxious stimulation will become sensitised to pain and will report pain during low levels of stimulation (Fordyce, 1983). These patients would react to an acute stimulus with an exaggerated reaction and would have a decreased pain threshold and/or pain tolerance and judge the pain as more intense in comparison with others. In contrast, some patients may evaluate the acute pain stimulus within the context of their previous pain experience, by comparing new pains with the other multiple and often severe pains in their previous experience, and therefore under report. Rollman (1979) proposed the adaptation theory to explain this idea. This model predicts that chronic pain patients should have a higher pain threshold and tolerance levels than controls and rate the painful stimuli as lower than pain-free individuals.

Of the 13 experimental studies reviewed in the literature, six (Arntz, Merckelbach, Peters, & Schmidt, 1989; Cohen, Naliboff, Schandler, & Heinrich, 1983; Hapidou & DeCatanzaro, 1988; Lipman, Blumenkopf, & Parris,1987; Naliboff,

Cohen, Schandler, & Heinrich,1981; Yang, Richlin, Brand, Wagner, & Clark,1985) found those with chronic pain experience *increased* pain thresholds to various experimental pain stimuli. Seven other studies found that those with chronic pain experience a *decreased* pain threshold (Brands & Schmidt, 1987; Flor, Breitenstein, Birbaumer, & Furst, 1995; Langermark, Jensen, Jensen, & Olesen, 1989; Malow, Grimm, & Olson, 1980; Peters, Schmidt, & Van den Hart, 1989; Schmidt and Brands, 1986; Wilson, Chaplin, & Thorn, 1995). Such inconsistent and conflicting results can be explained by a difference in experimental paradigm (pain threshold versus pain tolerance level), a difference in the pathophysiology of the disease (underlying the pain), a difference between the qualities of pain stimulus (pressure-induced versus heat-induced pain) and, a difference in duration of the painful stimulus in these studies. In reviewing the above experimental studies an important difference seems to prevail. A difference between the pain perceptive qualities of pressure-induced versus heat-induced stimuli has been shown. The nature of the pain stimulus may trigger either a hypervigilant response or an adaptation response (Naliboff & Cohen, 1989). However, it remains difficult to explain the discrepancy in the literature.

All of these studies included adult subjects, there have been only two studies where children with chronic pain were examined (Hogeweg, Kuis, Huygen, De Jong-De Vos, Van Steenwijk, Bernards, & Oostendorp, & Helders, 1995; Walco, Dampier, Harstein, Djordjevic, & Miller, 1990)). In the study by Walco et al. (1990) these children had a chronic illness (SCD or JRA) in which recurrent pain was a typical feature. The pain stimulus or experimental pain method was direct pressure pain. The mechanism of pain response was the between-group approach whereby responses of children with recurrent painful conditions were compared to responses found in healthy children (comparison group). They found these children had significantly

lower pain thresholds ($F = 10.03$, $p<.0001$) than did their healthy peers when exposed to direct pressure pain (experimental). The study by Hogeweg et al (1995) expanded on Walco et al.'s study by comparing the pain threshold levels in patients with JRA, both with and without signs of articular inflammation to levels found in a control group of healthy children. They measured pain thresholds at 12 sites using a pressure algometer, whereas Walco et al. applied pressure (pressure algometer) at the finger joint only. Hogeweg et al. found the pain threshold of JRA patients to be significantly lower ($F = 33.8$, $p<.001$) than in their healthy peers, and it was also correlated to visual analogue scales. Means of quantifiying the response to the noxious stimulation in both studies were measured in seconds. In the study by Walco et al. (1990) an experimental pain stimulus was used and no matching was done on any sociocultural factors, which can influence the pain response. Both studies showed that children with recurrent pain have a decreased pain threshold.

In an effort to gain further knowledge on the consequences of the experience of recurrent pain, employing a clinical pain stimulus rather than an experimental pain stimulus, may be more clinically relevant especially since researchers seriously question the ethics of experimental pain in children (Cunningham, N., personal communication IASP 1993 workshop; McGrath, 1993). In addition, the clinical painful stimulus may be more reflective of the child's experience with pain.

Medical Fears. Fear is a distressing emotion. Research on school-age children's fearful events during hospitalisation has been limited (Drotar, 1981; Hart & Bossert, 1994; Wallander, Varni, Babani, Banis & Wilcox, 1988). The most difficult event of a child's hospital experience which has been reported is the fear of medical procedures (intrusive procedures, i.e. injections) and the pain these procedures inflict (Eland & Anderson, 1977; Fassler & Wallace, 1982; Fernald & Corry, 1981; Field,

Alpert, Vega-Lahr, Goldstein, & Perry, 1988; Menke, 1981; Saylor, Pallmeyer, Finch, Eason, Trieber, & Folger, 1987;). Children with medical fears have reported higher pain intensity to venipunctures (Broome, Bate, Lillis, & McGahee, 1990; Fowler-Kerry & Lander, 1991), and show more behavioural distress (Fradet et al., 1990; Jacobsen, Manne, Gorfinkle, Schorr, Rapkin, & Redd, 1990; Wong & Baker, 1988). Overall distress observed in children may be a combination of fear and pain, although reports of overall distress do not distinguish the two emotions. The studies that used overall distress in relationship to previous painful procedures (Fradet et al., 1990; Jacobsen et al., 1990; Jay et al., 1983; Manne et al., 1992) have reported children were less distressed over time, that is with greater exposure (children with cancer and healthy children). On the other hand, Katz, Kellerman, & Siegel, (1980) found that overall distress was not related to the number of prior procedures. Some studies (Broome and Hellier, 1987; Bournaki, 1997; Fradet et al., 1990; Manne et al., 1992) found that previous pain experiences did not correlate with children's self-report of medical fears. In addition, a study by Hart and Bossert (1994) on self-reported fears of hospitalised school-age children found no significant differences between children with a chronic or acute health status. These authors postulated that prior experiences with medically related events may not reduce fear in children.

All of these studies have examined either healthy children or children with cancer in relation to the fear of medical procedures. The current study examined children with a chronic illness who endure recurrent pain, the most frequent problem encountered in SCD and, causing 91 per cent of hospital admissions (Brozovic, Davies, & Brownell, 1987). Investigating pain response in these children may add to our understanding of their pain experience and ultimately reduce the level of stress that many of these children experience. The effect of having this type of chronic

illness on medical fears was examined, as well, the relationship between medical fears and pain intensity was explored.

Children with Sickle Cell Disease

Sickle cell disease (SCD) is a hemoglobinopathy affecting ethnic groups from areas such as West and East Central Africa, the Mediterranean region and the Indian Subcontinent. The gene frequency is highest in African populations (Shapiro, 1993) and second highest in North Americans of African ancestry. The sickle cell gene in North America was most likely introduced as a result of West African immigration (Khan & Dozy, 1980). This disease is not confined by race, although it is most common in Blacks in Canada, whose numbers are greatest in the cities of Montreal and Toronto. The original Black population in Canada came here via the underground railway (secretly transported) from the Southern United States. More recently, Black families have been immigrants from the Caribbean and Africa.

In Montreal and Toronto the Black population is estimated by the Canadian Sickle Cell Society to be 120,000 and 300,000 respectively (Esseltine, Baxter, & Bevan, 1988). The prevalence of SCD (SS or homozygous for sickle hemoglobin) in this population is 0.16 - 1.30 per cent (Miller, Baehner, & McMillan, 1984 as cited in Esseltine et al., 1988) and of sickle cell trait (AS or heterozygous for hemoglobin A and S) is 8.0 per cent.

Homozygous sickle cell disease (SS) is a chronic, as yet, incurable hereditary illness. It is a hemolytic anemia characterised by recurrent vaso-occlusive episodes of pain (Embury, 1986; Fabry & Kaul, 1991; Serjeant, Ceulaer, Lethbridge, Morris, Singhal, & Thomas, 1994). It occurs when the beta globin gene on each chromosone contains the classical sickle mutation (single point mutation) (Serjeant, 1985). The

altered hemoglobin is unstable and forms polymers when deoxygenated, producing the sickled red blood cells. These cells readily adhere to endothelium, cells aggregate and occlude local flow. If the collateral vessels, which normally protect the tissues distal to the occlusion are also occluded, ischemia, infarction, and then tissue necrosis result (Nagel, Fabry, Billett, & Kaul, 1987). The occlusion process is painful, and is often located in various parts of the body. The process is known as a painful vaso-occlusive episode and is the most frequent problem encountered in SCD resulting in 91 per cent of hospital admissions (Brozovic, Davies, & Brownell, 1987). It is the most common cause of acute morbidity in sickle cell disease and signals underlying marrow ischemia or necrosis (Mankad, Williams, & Harpen, 1990). Variability in frequency, intensity, duration, and quality is the distinguishing feature of sickle cell related pain. Children with SCD usually can anticipate many painful episodes over the course of their lives (Platt et al., 1991; Shapiro et al., 1989). The mean duration of painful episodes in school-aged children ranges from once every 2 – 8 weeks (Gil, Williams, Thompson, & Kinney, 1991; Hurtig & White, 1986). The pain rate (episodes per year) increases as the patients grow older, until 30 years and declines thereafter (Platt et al., 1991). Among patients less than 18 years of age, the pain rate is consistently higher (8-17 years of age).

The disease is characterised by other acute and chronic complications such as acute chest syndrome, aseptic necrosis of the hips or shoulders, sickle cell retinopathy, leg ulcers, and cerebral vascular accidents (Serjeant, 1985). The course of the disease itself is unpredictable in terms of patient well-being, quality of life, functional status, and outcome. The disease can be difficult to manage because of the complexity and the differing symptoms in each child. According to Shapiro (1993), the genetic and physiologic factors interact to determine to some extent, the severity

of the pain, which can be a marker of disease severity. The more severe and frequent the pain, the greater will be the impact on the child and family. Other markers of disease severity include those patients with Hb SS (homozygous for sickle hemoglobin) or Hb Sbeta-thalassemia (heterozygous for hemoglobin S and beta-thalassemia) who experience more episodes of pain than those with Hb SC (heterozygous for hemoglobin S and C) disease. The trajectory of this illness on the child is often uncertain. This fluctuation can threaten the family's on-going life-pattern and add emotional strain. High levels of maternal anxiety, overprotection, excessive feelings of responsibility, and guilt associated with the hereditary nature of SCD are some of the emotional issues contributing to the family's stressors (Anionwu & Beattie, 1981; Graham, Reed, Levitt, Fine, & Medallie, 1982).

Activities such as school attendance, are issues when some children experience frequent and severe painful episodes (Eaton, Haye, Armstrong, Pegelow, & Thomas, 1995; Shapiro et al., 1995). There have been few reports in the literature regarding the number of missed school days. Shapiro et al. (1995), in a recent study on the natural history of the pain and impact on sleep and school attendance, found children with SCD were absent from school 21% of 3186 school days, half of this time was due to reported pain. The absences on days without vaso-occlusive pain were due to medical problems i.e. infections, clinic visits, as well as the family's over-protectiveness whereby they may perceive their child as vulnerable and have the child remain at home for problems when in fact there was no need to (Shapiro et al., 1995). The average consecutive number of school days missed was 2.7 as reported by Shapiro et al. (1995).

Some of the difficulties in managing the pain in children with SCD arise from lack of knowledge among nurses and other health care professionals regarding factors

that influence pain perception and response (Seers, 1989; Thomas & Rose, 1991). As a consequence, the affected children may often be viewed as 'difficult', with health staff underestimating the degree of pain which they experience (Seers, 1989). In addition, the inadequate treatment available for the severe recurrent painful episodes adds to the negative experience of the patients. Often nurses and other health professionals mistrust the patients and suspect them of being drug dependent, thus the patients may experience difficulty in obtaining appropriate care (Alleyne & Thomas, 1994). Conversely, patients mistrust the health care professionals to act in their best interests. This can lead to avoidance of patients by the health professionals and avoidance of hospital by the patients, which may have serious consequences (Alleyne & Thomas, 1994). Life-threatening complications can develop suddenly and may be attended to too late. Patients who are frequent hospital visitors are viewed as 'difficult' and 'manipulative', yet these patients who are admitted frequently with painful episodes are at higher risk of early death (Platt et al., 1994). Thus, the knowledge of the pain perception and response of children with SCD is important for staff to understand.

Since these childrens' condition will continue to result in recurrent painful episodes and will require ongoing medical interventions, their perceptions about pain and hospitals will greatly affect how they cope in the future as adults with chronic recurrent pain.

Conceptual Framework

The conceptual framework used as the basis for this study includes two theoretical perspectives. These theoretical perspectives are enmeshed and both address a broader perspective of the pain experience. The first is the Gate Control

Theory of Pain postulated and developed by Melzack and Wall in 1965. Basically, the theory proposes that a neural mechanism acts as a gate to increase or decrease the flow of nerve impulses from the receptors by way of peripheral fibers to the CNS (Melzack & Wall, 1965, 1982). It has offered a physiological explanation for the psychological factors which impact on pain. However, there are other factors that come into play with persistent pain which were discussed in the previous section and will therefore be briefly summarised here. The arrival of nerve impulses at the spinal cord can initiate excitations and sensations by means of the gate control mechanism. These can lead to prolonged and substantial receptive field changes (Brandt & Livingston, 1990). The longlasting changes in response to certain stimuli can alter sensory processing and may be responsible for the generation of clinical pain states (Woolf, 1989).

The second theoretical perspective, which also describes an individual's pain experience as not determined solely by the intensity of a noxious stimulus, addresses the psychological aspects of pain as were found in the work of McGrath, (1990). This perspective also involves the idea of 'plasticity', where children can experience very different pains from the same type of tissue damage. McGrath's model (Appendix A) depicts situational factors responsible for this plasticity. Cognitive, behavioural, and emotional factors have been identified as components of a complex pain-modulation system (McGrath & Hillier, 1996). These factors influence one another and can "modify the child's pain through interactions that occur at spinal and supraspinal levels in the nociceptive system" (p.40, 1990).

Summary of the Review of the Literature

In summary, this literature review described a broad perspective of the pain experience. Pain response in patients suffering from clinical pain/disease-related pain varies widely irrespective of the type of painful stimulus or the pathophysiology of the disease. There are a number of physiological mechanisms and psychological factors, that can influence the perception of acute pain and explain the wide variability in response (McGrath & Hillier, 1996; Woolf, 1991).

There have been few studies on the effects of the consequences of the experience of recurrent pain in children. However, there was evidence to suggest that children with SCD exposed to repeated or constant noxious stimulation may report pain as more intense. This may be due to physiological changes in synapses (Woolf, 1991), which may support the hypervigilance model. One study by Walco and his colleagues (1990) has demonstrated that children with disease-related pain were more sensitive to acute pain, supporting the hypervigilance theory. In addition, consistent with this view is the incidence of increased medical fears which would explain the anxiety which increase pain perception.

Chapter 3

Methods

The purpose of this study was threefold: 1) to investigate the response to acute pain in children who have experienced unpredictable, severe recurrent episodic pain (SCD), compared to children who have not experienced recurrent pain; 2) to determine if there were differences in medical fears between the two groups and, 3) to determine if medical fears were related to pain intensity in children with SCD.

Hypotheses

The following hypotheses were proposed: children with SCD would report greater pain intensity to an acute painful event than healthy controls; children with SCD would report greater medical fears than healthy controls and, there would be a positive relationship between pain intensity and medical fears.

Design

A matched case-control design was used. This design allowed for a comparison of pain intensity in response to a painful clinical event (fingerstick) between children with and without SCD matched on age, sex, and race/ethnic origin. This procedure is normally done as a routine blood test for children with SCD, whereas the control group underwent the procedure for purposes of sickle cell trait screening. The matching of these important factors would control for potential confounders, reduce variability,

thereby allowing for better understanding on the direct effect of repeated, experienced pain.

Sample

Children with Sickle Cell Disease

A group of 36 Black children with sickle cell disease aged 7 to 12 years was recruited from a Sickle Cell Clinic in a metropolitan children's hospital. Children who met the following *inclusion criteria* were eligible:

1. 7 to 12 years of age.
2. diagnosed with SCD (SS, SC, or S-Beta Thal.) and no other chronic illness; experienced at least one painful vaso-occlusive episode within the last 12 months and more than 10 episodes in their lives.
3. demonstrated the ability to understand English or French.
4. one of the child's parents read, wrote and spoke English or French.
5. not in acute distress (not having a painful episode)
6. demonstrated the ability to use the selected pain scales.

Comparison Group

A comparison group was selected from the Côte des Neiges Black Community Center and the West Island Black Youth Camp. Selection criteria were the same, with the exception of #2: diagnosed with SCD, and were applied to children recruited from these settings. To ensure the child had no chronic disease, the mother was asked if her child had a condition that he/she was followed for on a regular basis.

These children were recruited into a pool from which a matched sample was drawn. Matching was done on age (within 12 months), sex, and ethnic origin (Canadian-born mother or not). It is acknowledged that even within these categories, there may be cultural distinctions, as the historical heritage, migration, and demographics may be

different for each person. In addition, since access to health care is universal in Canada and since there are active SCD screening and treatment programmes in Canada, the experience with the health care service may be different for children from outside of Canada.

Sample Size

The sample size required was based on the variance of the pain responses of the children, the statistical test, level of significance (alpha level set at 0.05) and power (0.80) selected for the Coloured Analogue Scale (CAS), and the anticipated effect size (Woods & Catanzaro, 1988). To calculate sample size, Colton's (1974) formula for comparing means from two independent groups was used. Colton's formula for independent groups assumes that the standard deviations of the two populations are equal, and that the sample sizes are equal in both groups. If u1 - u2 is the magnitude of the difference to be detected between the groups, the sample size needed in each group is determined by the following formula: $n = 2[(Z\alpha - Z\beta)\sigma/\mu 1 - \mu 2)]^2$.

A study by Walco et al. (1990), used the visual analogue scale (VAS), comparable to the CAS, to rate the intensity of the threshold stimuli. Although the current study used *pain intensity* following fingerstick, the Walco study was the only report of group differences and standard deviations on the VAS of pain levels, and so was used for sample size determination. Walco et al (1990) used the VAS with 140 children between the ages of 5 and 15 years to assess present pain. The mean and standard deviation of pain threshold levels as a function of health status revealed: for SCD: $M = 2.95$ ($SD = 1.13$) versus for healthy subjects: $M = 4.01$ ($SD = 1.24$). Substitution of these values into the formula, resulted in a sample size $n = 36$ per group.

The Child Medical Fear Scale (Broome & Hellier, 1987) is a 17-item scale and was used in a study to examine the fears of 82 hospitalised school-aged children (Hart and Bossert, 1994). The mean and standard deviation of responses of the CMFS were:

M = 1.83 (SD = .77). Application of these values into the formula, results in a sample size n = 13 per group. In the current study, it was predicted there would be a difference of 2 points on the Coloured Analogue Scale (20%) and a 20% difference on the Medical Fear Scale, based on Walco et al.'s study (1990), with an alpha of .05 and a power of at least .80, the sample size would be between 30 and 36 children per group. Since the Coloured Analogue Scale is the primary outcome, 36 per group was sought.

Measures

Coloured Analogue Scale (CAS) (McGrath, Seifert, Speechley, Booth, Stitt, & Gibson, 1996).

The CAS, validated by McGrath et al. (1996) has been modelled after the Analogue Chromatic Continuous Scale (ACCS) (Grossi, Borghi, Cerchiari, Puppa & Francucci, 1983). The CAS was used in this study to assess children's pain intensity. The CAS provides vivid gradations in colour, width and length. The CAS consists of a coloured stripe 10cm long and 2.5cm wide, containing no markings except for the anchor points at each end; NO PAIN or MOST PAIN. These words lie on a white background at the two extremities of the coloured stripe. The colour graduates from white (starting with no pain), through to a pale pink, to a dark red (corresponding to most pain). The coloured stripe lies on one side of a double-sided device. A 100-mm ruler is printed on the opposite side of the device, so the subjects' self-reports in colour can be converted into numerical scores from 0-100 mm. The child evaluated their pain intensity by positioning a transparent slider containing a narrow black line perpendicular to the coloured stripe. A study by Beyer, McGrath, & Berde (1990) examined concurrent self-reports of pain intensity (Oucher and ACCS) and behavioural responses (Children's Hospital of Eastern Ontario Pain Scale) (CHEOPS) (McGrath, Johnson, Goodman, Schillinger, Dunn, & Chapman, 1985) in 25 children aged 3-7 years following major surgery. The two self-report measures (Oucher and ACCS) were strongly and

significantly correlated (0.87-0.98). A study by McGrath et al. (1996) examined the validity of the CAS by evaluating the psychometric properties of the scale and comparing them to those of the Visual Analogue Scale (VAS) (Price, Bush, Long, & Harkins, 1994). The results showed equivalency of the psychometric properties and this is an accurate measure of children's perceived intensity. The CAS was also rated as easier to use and score than the VAS, making it more practical in the clinical area.

The Child Medical Fear Scale (CMFS) (Broome & Hellier, 1987). The CMFS was developed to measure medical fears. Broome defines medical fears as distressing emotions aroused from "any experience that involves medical personnel, or procedures involved in the process of evaluating or modifying health status in traditional health care settings" (Broome et al., p.361, 1990). The CMFS consists of 17 items that the child scores from 1 (not at all afraid) to 3 (very afraid). Higher scores indicate greater fear. Total scores range from 17 to 51. The scale has been used successfully with children aged 5 to 11 years. The content validity index for the CMFS is 78% (Broome et al., 1988). Criterion validity has been established by administering the CMFS concurrently with the Medical Fear Subscale of the Fear Survey Schedule for Children with a correlation of 0.71 (Scherer & Nakamura, 1968). Test-retest reliability is high, as well as the internal consistency (.93) of the overall scale.

Demographic Questionnaire

Standard information and medical data such as age, gender, country of birth, country of origin of mother, length of time in Canada, diagnosis, reason for hospitalisation, experience with needle procedures, and any chronic condition other than SCD were obtained from the questionnaire (see Appendix B).

Procedure

Subjects for the study group who met the inclusion criteria were identified by the clinic nurse and hematologist in the Sickle Cell Clinic. Mothers were informed that a research project was being conducted to learn more about pain in children with SCD and, their permission to have the researcher speak to them about participation in the study was obtained. The researcher then explained the study and sought consent.

The subjects for the comparison group were identified by the collaborative efforts of the members of the Sickle Cell Society, the Côte des Neiges Black Community Centre and the West Island Black Youth Camp.

Information meetings about the study were scheduled for those who agreed to participate and, a written consent form was signed at that time. As well, an appointment at the community centre for participation was assigned to the parent/child, and they were contacted the day before for confirmation.

The data collection included, demographic and hospitalisation data of the potential subjects for the study group and, were collected from the parents and child, and the child's health record. This took place either by phone call, during a clinic visit, or at the Sickle Cell Society. The potential subjects for the comparison group had the same data collected at the community centre.

The actual location of the investigation, for both groups, occurred in the community center where the office of the Sickle Cell Society is located. This occurred during the same week as the visit with the parents and the child, either in the community centre or the clinic.

The preparation session included the child receiving information as to what to expect during the fingerstick (acute painful event). The child was introduced to the self-report scale (CAS) to assess his/her comprehension of the concept of pain, and to provide him/her with experience on how to use the scale. The child then received the fingerstick. This was administered by the research assistant to the child sitting in a chair.

This was then followed by the child using the Coloured Analogue Scale (CAS) to assess his/her pain intensity.

When the child reported that he/she felt all right after the fingerstick, the Medical Fears Questionnaire was administered by the research assistant. The format was explained and the questions were administered orally to account for different reading levels, and the responses were marked by the child (Hart & Bossert, 1994) .

Data Analysis

All analyses were computed using the Statistical Package for the Social Sciences (SPSS Inc., 1998). The two groups were examined for equivalency on all variables (age, gender, country of birth, country of origin of mother, number of hospitalisations, number of needle procedures, chronic condition other than SCD, and family member with chronic pain). Pain intensity and medical fears were examined and descriptive univariate analyses were conducted to obtain means, range, and variance of the dependent variables. Variables within both groups (age, number of hospitalisations, number of previous experience with needles) were examined in relation to the dependent variables through regression analyses and correlational coefficients. To determine if there were significant differences in pain response and medical fears between the two groups, a multivariate analysis of variance (MANOVA) was performed using SCD as the independent variable and, pain intensity and medical fear scale as the dependent variables. Variables such as, number of hospitalisations, that differed between the two groups were included in the analysis (MANCOVA) as co-variates. Pearson's correlation coefficient was calculated on the relationship between pain intensity and medical fears.

Ethical Considerations

Children between the ages of seven and twelve years do not have the competence, legally and ethically, to give their informed consent. Considering the above, a parent or legal guardian was asked by the researcher to give their informed consent. Verbal assent was however, obtained from the child.

The Research Institute and Institutional Review Board of the Montreal Children's Hospital, as well as the Ethics Committee of McGill University were asked to evaluate the proposal and provide recommendations. Approval from the Quebec Minister of Health was obtained as per the Quebec civil code on research with children.

Children with SCD are confronted with many stresses, the most frequent being the painful vaso-occlusive crises. As a result, the most common concern related to studying this population has been that of the added stress of undergoing an acute painful procedure. However, this procedure is normally done during a routine clinic visit, thus eliminating any redundant procedures. The comparison group underwent the same procedure for purposes of sickle cell trait screening. The results of the sickle cell trait screening was distributed through the Sickle Cell Society. Appropriate follow-up in the Hematology Clinic at the Montreal Children's Hospital was offered to those whose results were positive. In addition, following an explanation of the study, any questions or concerns raised by the child and parents were addressed. Parents and children were also given the option to discontinue their involvement in the study at any time. Parents were assured that all information remained confidential.

Chapter 4

Results

Results of this study are presented in three sections. First, the subjects of the study groups are described. This is followed by a comparison of the two groups on selected background characteristics. Finally, to answer the research questions and test the hypotheses, the independent and dependent variables are examined in relation to each other.

Sample

Mothers of 38 children with sickle cell disease were approached to participate in the study. Five mothers of children with SCD refused to participate. Two of these did not participate because their child had been quite ill and hospitalised frequently within a short period of time. The remaining three did not participate due to a) father refused, b) the child already was exposed to too much, c) no stated reason. Therefore, 33 children with sickle cell disease, 7-12 years, who met the inclusion criteria participated in the study. Eighty-four per cent of the mothers in the sickle cell disease group were born in the Caribbean: 42% in the English West Indies and 42% in Haiti. Ninety-one per cent of the children were born in Canada (see Table 1).

Mothers of 43 potential subjects for the control group were identified by the collaborative efforts of the members of the Sickle Cell Society and, the Côte des Nieges Black Community Center and the West Island Black Youth Camp. Ten mothers of

children for the control group refused to participate, six of whom did not like the idea of being a research subject. The other four gave no stated reason.

Thus, 33 children participated in the comparison group. These children were matched on age, sex, and race/ethnicity. Ethnic origin was categorised into two groups, Canadian-born or immigrants (country of origin of mother only).

Participation rates for the two groups differed. In the sickle cell disease group it was 86% and in the control group the participation rate was 76%. The goal of obtaining 36 children per group was not met due to difficulty in recruitment. After several weeks of implementing various recruitment strategies, to no avail, the decision to stop at 33 subjects per group was made.

Table 1

Sample Characteristics

SCD	Controls
• 9.9 years old (2.0)	• 9.8 years old (2.1)
• 70% female	• 70% female
• 42 % West Indian 42% Haitian, 6% Canadian, Indian 6% Africa 3%	• 42% West Indian 42 % Haitian, 6% Canadian, Indian 6% Africa 3%

Selected Background Characteristics

Examination of the two groups for equivalency on demographic variables was conducted to ensure the identification of factors which could potentially contribute to differences in dependent variables between the two groups.

Demographic Variables

When compared on demographic profiles, there were differences between the two groups on the number of hospitalisations and the number of experiences with needles (see Table 2). The variables compared were age, number of hospitalisations, number of experiences with needles, child's birthplace, child with a chronic condition other than sickle cell disease, family member with chronic pain, and gender. The two groups were matched on age, gender, and race/ethnicity and thus, were the same on these variables. The two groups differed significantly on the number of hospitalisations ($p = .000$) and the number of experiences with needles ($p = .000$). The children in the control group had fewer hospitalisations ($M = 0.5$) and fewer experiences with needles ($M = 1.1$). In addition, the two groups differed significantly on the variable, child with a chronic condition other than SCD ($p = .01$). There were eight chronic conditions (asthma) for the control group and one chronic condition (asthma) for the SCD group. Since these conditions were minor and were not followed on a regular basis, these children were not excluded.

Table 2

Comparison of the SCD and Control Groups on Selected Demographic Variables

Variable	SCD Group N=33 M	SD	Control Group N=33 M	SD	ρ
Age	9.9	2.0	9.8	2.1	.86
Number of Hospitalisations	8.2	5.3	.52	1.3	.00
Number of Needles	10.0	11.3	1.1	2.7	.00

Categorical Data Variable		SCD Group N = 33 N (%)	Control Group N= 33 N (%)	X^2 (df)
Child's birthplace:	Canada	30 (90.9)	30 (90.9)	
	Other	3(9.0)	3(9.0)	2.1 (3)
Chronic Condition (not SCD)		1 (11.1)	8 (88.9)	6.3 (1)
Family Member with Pain		6 (18.8)	3 (9.1)	1.2 (1)
Sickle Cell Hemoglobinopathy	SS	24 (72.7)		
	SC	7 (21.2)		
	S beta.thal	2 (6.1)		
Sickle Cell Trait	AS		10 (30.3)	
	AC		2 (6.06)	

The most common type of sickle cell hemoglobinopathy found in the SCD group was homozygous sickle cell disease (SS), n = 22 (see Table 2). The control group

underwent the same procedure for purposes of sickle cell trait screening. The 33 children were screened and, twelve children were found to have the sickle cell trait (see Table 2).

Group Differences on Pain Intensity and Medical Fears

In order to answer the first two hypotheses, namely, if there were differences between children with SCD and healthy controls on pain intensity and medical fears, a multivariate analysis of variance (MANOVA) was performed with group as the independent variable and pain intensity and medical fears as the dependent variables. There was no significant multivariate main effect of group (SCD and control) F (2,63) =.14, p = 0.86. Number of hospitalisations was selected as the covariate because it was correlated (r = .66) with number of needles and thus it would be redundant to include both. Number of hospitalisations was selected as there would be a more accurate measure of pain experience since hospitalisations are probably more memorable than needles and were also verified with the Hospital Admissions Department. The results of this MANCOVA did not reach the predetermined significance level (F (2,62) = 2.7, p = .07). Since this MANCOVA approached significance, univariate results were examined. A univariate ANCOVA for pain intensity was not significant. A univariate ANCOVA for medical fears approached significance (F (1,63) = 3.4, p <.07). An examination of the means for the two groups suggested that the SCD group (M = 31.5) had more medical fears than the non-SCD group (M = 27.7).

Means, standard deviations and analysis of variance, on the two dependent variables (TMFS and CAS) in both groups are presented in Table 3 (and Appendix G). Comparisons of SCD and Control groups on certain demographic variables are presented in Appendix H.

Table 3

Means and Standard Deviations Between Pain Intensity and Medical Fears Among Children with and without SCD

	SCD Group N = 33		Control Group N = 33	
Variable	**M**	**SD**	**M**	**SD**
CAS (pain intensity)	3.16	2.86	3.40	3.03
TMFS	29.78	6.85	29.30	5.40

Analysis of Variance on the Dependent Variables: Pain Intensity & Medical Fears

Variables	df	F	p
Medical Fears	(1,64)	1.6	.75
Pain Intensity	(1,64)	.01	.74

Contrary to the above findings, there were three single items (in the MFS) that were different between the two groups of children. The two most feared items reported by children with SCD were: #8. 'I am afraid to throw up' (M = 1.9); #9. 'I am afraid of missing school if I'm sick' (M = 2.09). The most feared item reported by children in the control group was: #6. 'I am afraid of having my finger stuck'(M = 1.9). See Appendix I. for the list of all the items for the Medical Fear Questionnaire for each group.

Relationship Between Pain Intensity and Medical Fears

The third purpose was to determine if medical fears were related to pain intensity. Correlation matrices were examined to describe the magnitude of the association between the variables.

The strength of the relationship among the two dependent variables (pain intensity, medical fears) varied between the total sample and the two groups (see Table 4). Correlations for the total sample showed that there was a moderate significant correlation between pain intensity and medical fears ($r = .27$, $p<.03$). When data from children with SCD were analysed separately, the relationship between CAS and MFS was not significant ($r = .29$, $p<.1$). In addition, the relationship between CAS and MFS was not significant in the control group ($r = .25$, $p<.2$).

Table 4

Pearson's Correlation Coefficients for the SCD and Control Group

Total Sample

Variable	CAS	MFS	Age	# needles
CAS				
MFS	.269*			
Age	-.269*	-.142		
# needles	-.095	-.231	.021	
# hospitalizations	-.092	-.163	.302*	.620**

Pearson's Correlations for SCD Group

Variable	CAS	MFS	Age	# needles
CAS				
MFS	.291*			
Age	-.219	-.063		
# needles	-.086	-.374*	.028	
# hospitalization	-.148	-.369*	.606**	.441*

Pearson's Correlations for Control Group

Variable	CAS	MFS	Age	# needles
CAS				
MFS	.252			
Age	-.325	-.257		
# needles	-.165	.004	.180	
# hospitalization	.065	.059	.009	.573**

Note. Sample size for each of the correlation matrices n=33. *$p < .1$. **$p < .01$. Significance for all r coefficients was $p<.05$.

Relationship of Experience and Age on Dependent Variables

Since the conceptual framework suggests relationships between pain experience and pain perception and fears and age, is known to be related to both variables (Melzack & Wall, 1965; McGrath, 1987) these relationships were examined. Multiple regression analyses for both pain intensity and medical fears with number of hospitalisations, number of needles and age as independent variables, were performed (see Table 5). Only age was negatively related to pain intensity.

Table 5

Regression Analysis for Number of Hospitalisations, Number of Needles and Age on Pain Intensity

Variable	B	SE B	β	Sig.
Number of Hospitalisations	**1.2**	**.09**	**.02**	**.88**
Number of Needles	**-1.7**	**.05**	**-.06**	**.72**
Age	**-.38**	**.18**	**-2.1**	**.04**

Note. Adjusted R Square = .03.

Regression Analysis for Number of Hospitalisations, Number of Needles and Age on Medical Fears

Variable	B	SE B	β	Sig.
Number of Hospitalisations	**8.1**	**.18**	**.01**	**.96**
Number of Needles	**-.15**	**.10**	**-2.4**	**.14**
Age	**-.30**	**.38**	**-.10**	**.43**

Note. Adjusted R Square = .03.

Data from children with SCD were analysed separately from controls since the control group had such few hospitalisations. In this group an inverse

correlation between medical fears and the number of hospitalisations ($r = -.369$, $p<.04$) was found. This inverse relationship was unexpected, and a closer examination of the distribution of number of hospitalisations was warranted. The distribution showed a clear pattern of few or many hospitalisations with a median of six (see Appendix J.).

Using a median split on number of hospitalisations (6) within the SCD group only and age as covariate, those children who experienced less than six hospitalisations were more afraid ($M = 33.55$) compared to those who had experienced more than six hospitalisations ($M = 25.78$) (F (1,33) = 7.5, p <.05) (see Table 6). The results of ANCOVA for number of hospitalisations and pain intensity within SCD group was not significant (F (1,33) = .50, p = .50).

Table 6.
Analysis of Covariance for Number of Hospitalisations and Age within SCD Group

Group	Variables	df	F	Sig.
Age	TMFS	(1,33)	1.9	.17
# Hospital. (> 6)	TMFS	(1, 33)	7.5	.01

In summary, there were no significant differences in either pain intensity or medical fears between the two groups. Although the study sample was smaller (33 children /group) than the original calculation (36 per group), the power remained adequate (0.80) to confidently conclude the above statement. Thus, an increase in sample size (3 more /group) would not have yielded more meaningful results. However, certain extraneous variables did impact on the study outcomes.

Chapter 5

Discussion

The purpose of this study was to investigate response to acute pain in children who have experienced recurrent episodic pain (SCD), compared to children who have not experienced recurrent pain. Further aims of this study were to determine if there were differences in medical fears between the two groups and if medical fears were related to pain intensity. In addition, the study was designed to examine other factors, such as the number of hospitalisations and the number of experiences with needles, to see if they were related to pain intensity or medical fears. The goal was to provide an opportunity to examine the impact of recurrent pain experienced by children with SCD, and to provide nurses/health professionals with increased knowledge about these children's perceptions of pain and hospitals.

This chapter will provide a description and discussion of the following areas: the results of the research question (pain intensity); the medical fears of those children with SCD and the relationship between pain intensity and medical fears; additional factors relating to pain intensity and medical fears; implications for nursing; future research; and will conclude with the limitations of the study.

Pain Intensity

This study attempted to answer the question of whether there were differences in pain intensity to acute pain in children suffering from SCD and healthy controls. There were no significant differences between these two groups.

The two models of response to recurrent pain used to direct the study were the hypervigilance and the adaptation models. These competing theories predict the potential responses of patients with recurrent pain to nociceptive stimulation. The hypervigilance model (Fordyce, 1983) states that patients with recurrent pain would overreact and report pain during low levels of stimulation when receiving an acute painful stimulus. Several studies have provided evidence for hypervigilance in adult patients with chronic pain (Flor et al., 1995; Langermank et al., 1989; Malow et al., 1980; Malow & Olsen, 1981; Peters et al., 1989; Schmidt & Brands, 1986; Wilson et al., 1995). On the other hand, Rollman (1979) postulated that patients with recurrent pain would evaluate and compare acute painful stimuli within the context of their previous experience with pain. As well, several studies have provided evidence for adaptation in adult patients with chronic pain as compared to healthy controls (Arntz et al., 1989; Cohen et al., 1983; Hapidou et al., 1988; Lipman et al., 1987; Naliboff et al., 1981; Yang et al., 1985). The only study of pain intensity in children with SCD compared to others showed that they had increased pain sensitivity, supporting the hypervigilance theory (Walco et al., 1990).

The present study does not support the hypervigilance model nor the adaptation model with respect to pain, and differs from other relevant studies in four ways: a difference in experimental paradigm (pain threshold versus pain tolerance), a difference in the pathophysiology of the disease underlying the pain, a difference between the qualities of pain stimulus, and finally a difference in duration of the painful stimulus.

Experimental Paradigm. In most of the previous studies, the experimental pain measurements used were pain threshold (the point of first discernible pain) and pain tolerance (the upper limit of endurance). These indices have been criticised since their variation may be confounded by different sensory, affective, or cognitive factors (Boureau, Luu, & Doubrere, 1991). For example, pain threshold levels are related to sensory component of pain perception, whereas, pain tolerance reflects affective-motivational aspects. Those studies using pain threshold as the measurement, found patients had a higher pain perception threshold (Cohen et al., 1983; Naliboff et al. 1981 and Yang et al., 1985). However, a different picture emerges when pain tolerance is measured. Patients experiencing pain had a lower tolerance of the stimulus and a higher pain response (intensity) (Malow et al., 1980; Schmidt & Brands, 1986). The validity of indices such as pain threshold and pain tolerance as proxy measures of pain index is an important issue. The present study used the Coloured Analogue Scale (CAS) to assess the child's pain intensity to an acute painful stimulus and may reflect a different aspect of the pain experience, namely intensity, not threshold or tolerance.

Pathophysiology of the Disease Underlying the Pain. The majority of the studies conducted included adult subjects with chronic low back pain (reported as constant pain varying in intensity); myofascial pain dysfunction syndrome or temporal mandibular joint pain (TMJ) (characterised by tenderness and muscle tension due to emotional stress) (Malow et al., 1980). The few studies involving children, examined childhood diseases characterised by recurrent painful episodes e.g., SCD, JRA, and hemophilia (Hogeweg et al., 1995; Walco et al., 1990). The differences in the pathophysiology underlying the pain, that is the severity and the characteristics, found in the chronic pain patient populations may cause differences in the findings. Children with SCD experience recurrent attacks of acute severe pain and has been considered the most intensely painful childhood disease (Gil et al., 1993; Platt et al., 1991; Shapiro et al., 1995; Varni et al., 1987). The pain is vaso-occlusive in quality and is often located in various parts of the body. The quality, frequency and duration characterises the uniqueness of the pain. Furthermore, it may be that there is more of a psychological component involved with the disorders: TMJ and chronic low back pain, than with SCD.

Type and Duration of Pain Stimulus. Differences in the type of pain stimulus and the length of exposure to a painful stimulus may influence the pain response. That is, the nature of the experimental pain stimulus may trigger either a hypervigilant response or an adaptation response (Naliboff & Cohen, 1989). A wide variety of experimental pain stimuli have been developed. The more common experimental pain stimuli used include: cold pressor (Flor et al., 1995; Schmidt & Brands, 1986; Wilson et al., 1995), mechanical pressure (Gil et al., 1995; Malow et

al., 1981; Peters et al., 1989; Walco et al., 1990), radiant heat stimuli (Cohen et al., 1983; Lipman et al., 1987; Naliboff et al., 1981; Yang et al., 1985;), electrical stimulation (Arntz et al., 1989) and a clinically relevant pain produced by lumbar exercise (Fuller & Robinson, 1995). All of these except one are experimental pain methods. The study using the clinically relevant pain produced by the lumbar exercise showed no differences in the ratings of pain between the two groups (patients with clinical pain and the healthy controls). Whereas in the studies using the radiant heat stimuli, the electrical stimulation showed evidence for adaptation in patients with clinical pain as compared to healthy controls. The studies using mechanical pressure and the cold pressor stimuli showed evidence for hypervigilance in patients with clinical pain.

Another possible influence on the pain response is the length of exposure to a painful stimulus. Flor et al. (1995) found after a brief exposure (less than one second) there were no differences in pain intensity between patients with clinical pain and healthy controls. However, patients with clinical pain reported higher pain intensity than controls after a prolonged exposure (several seconds to minutes) to a painful stimulus. In the only study of prolonged pressure pain with children, Walco et al. (1990) found those children with SCD had a lowered threshold than their healthy controls. In contrast, this study employed a brief and clinically relevant painful stimulus and found no difference in the ratings of pain intensity between the two groups.

Taken together, all of these factors (experimental paradigm, pathophysiology of the disease, type and duration of pain stimulus) can account for the differences

between this study and other reports. It remains unclear whether children with SCD would adopt a hypervigilant or an adaptation response style if the stimulus was more relevant to their ischemic pain. Such that, ischemic pain, secondary to intravascular sickling in children with SCD, is unpredictable, severe and of longer duration. Whereas, the acute painful stimulus (fingerstick) is brief in duration and, the circumstances in which it is delivered is different. That is, it (fingerstick) may not evoke the emotional turmoil that may result from experiencing ischemic pain.

Recent studies have found changes in the central nervous system of an individual who experiences recurrent pain, are important contributors to the pain experience. The changes can influence how subsequent noxious stimuli are processed and how the pain is perceived. This study was unable to provide evidence for the manifestation of these changes, for example, hyperalgesia (noxious stimuli produce a pain that is much greater than normal). It may be that this mechanism is usually related to a single site, whereas the pain in SCD is more migratory. The lack of group differences of reported pain intensity in this study may also be due to the fact that the pain stimulus may have been too brief and the pain perceptive qualities different (sharp, stabbing). On the other hand, by employing a painful stimulus (fingerstick) that had been experienced as part of care versus an experimental pain stimulus, findings may be more relevant to their pain experience (i.e., pain history, duration, fear).

In spite of differences in paradigms, the two theoretical perspectives used as the basis for this study, the Gate Control Theory (Melzack & Wall, 1965) and McGrath (1990) would predict that children with a history of repeated pain

would respond differently compared to healthy controls. However, this study found no relationship between pain intensity and number of hospitalisations and number of needles, further suggesting that the acute painful stimulus (fingerstick) is not relevant enough to SCD to elicit differences between children with or without SCD.

This study suggests that the pain response in children with SCD was no different than controls which does not reflect psychological mechanisms. That is, the quality and intensity of pain are influenced by the unique past experiences of the child and by the meaning he/she gives to the painful situation (Melzack & Wall, 1996). This is not consistent with the Gate Control Theory in which both physiological mechanisms and psychological factors, and their interactions, can influence the pain response. Fear for example, is a conscious response to pain in children (McGrath, 1990) and can influence the perception of pain.

Differences in Medical Fears Between the Two Groups

The second purpose of this study was to determine if there were differences in medical fears between the two groups. This study found that children with SCD did not report different levels of medical fears than healthy controls. Because children with SCD were likely to have experienced more pain, the number of hospitalisations was used as a proxy measure of the number of severely painful crises. However, when the number of hospitalisations for painful episodes was covaried the results approached significance ($p = .07$). Children with SCD were more afraid than the healthy controls. This is contrary to what one would expect. That is, when the groups

are made more equal on hospitalisation experiences it is expected there would be less of a difference on medical fears between the two groups. A median split based on number of hospitalisations showed that children with SCD with more than six hospitalisations were less afraid than those with fewer hospitalisations (under six). Thus, there appears to be two distinct groups, those who have had few hospitalisations and who have much higher fear scores (M = 32.35) and those with many hospitalisations who have become less afraid than even controls (M = 27.06 vs M = 29.30). However, the analysis for the control group was not possible as there were no children in the control group who had more than six hospitalisations. Beyond a certain cut-off number of hospitalisations, fears appear to diminish. This may reflect adaptation on the part of children with SCD to their disease and to hospital admissions.

Previous research in children with chronic painful conditions supports a positive relationship between previous painful experiences and medical fears. Jacobsen et al. examined children with cancer and examined the number of venipunctures, the number of days since the last venipuncture and the time since diagnosis (1990). They found children who had undergone a greater number of venipunctures exhibited less overall distress. However, those findings were weakened once age and venous access were controlled. Jay et al.(1983) found that distress was less in children who had been diagnosed for a longer period of time and who received a greater number of bone marrow aspirates, even when effects for age were statistically removed.

Distress responses may be a combination of pain and fear, and these previous

reports of overall distress may reflect fear and distress as well as pain experienced. In this study, pain and fear were measured separately and it is difficult to compare them to distress: if the distress reflected fear, their results compare, if distress reflected pain, their results do not compare.

The findings of this study suggest that children with SCD who have greater exposure to painful events, have less medical fears than children with fewer experiences. This is contrary to prior research that found no relationship between previous pain experiences and children's self-report of medical fears (Manne et al., 1992) but consistent with the work of Jay et al (1983) and Jacobsen et al (1990) who found children were less distressed over time. Children who have some experience with pain from disease or treatment have been shown to be more afraid (Katz et al., 1980; McGrath & deVeber, 1986; McGrath & Hillier, 1989).

Children with a chronic illness, like SCD, need to adapt to more stresses compared to healthy children. Based on the change in medical fears after six hospitalisations, it would seem that the children with SCD in this study have adapted to their illness, at least in terms of medical fears. Coping strategies were not examined in this study, but they may be important in understanding the findings. Children with a chronic illness report coping as a strategy for adapting to common painful and stressful events (Olsen, Johensen, Powers, Pope & Klein, 1993). The relevance of the age of the child and their ability to use spontaneous coping strategies has been identified in the literature (Ellerton, Ritchie, & Caty,1994). Older children generally have a wider repertoire of coping skills to draw upon than their younger counterparts (below age six). It has been found that children of age 7 to 12 have

better coping styles than older children (adolescents) with SCD (Gil et al., 1993). It is also known that pain frequency and disease complications may change over time (increase with age). In this study, SCD children who have experienced more than six hospitalisations apparently have coping strategies that have become more effective over time.

It is noteworthy that, although children with SCD appear to have become capable of decreasing their fears with many hospitalisations, the same was not there for pain intensity and pain perception. It would be interesting to know what strategies children used that were successful in reducing fears and if these same strategies were or were not attempted to reduce pain. It could well be that fears are from within the child, and thus within his/her control, whereas pain is inflicted on the child either through disease processes or medical interventions, and thus are less amenable to modification by the child's own efforts. It may be important to examine adaptation at various times throughout the disease process and across hospitalisations.

There were two items from the medical fear questionnaire in which children with SCD reported more fear, namely, the fear of vomiting, and fear of missing school when sick. These results are not surprising. Children with SCD often experience epigastric pain associated with the painful crisis. The abdominal pain may be severe enough to cause nausea, vomiting, constipation and guarding (Serjeant, 1985). They may associate this with the onset of a severe vaso-occlusive episode. Second, school attendance is an issue when some children experience frequent painful episodes. Shapiro et al. (1995) found children with SCD were absent from school 21% of 3186 school days, due to reported pain. Although hospitalisation for pain

accounts for a large number of school absences, there are a number of children who miss school while dealing with the pain crisis at home (Eaton, Haye, Armstrong, Pegelow, & Thomas, 1995).

The healthy controls reported more fear of fingersticks. The fear of medical procedures (intrusive procedures) has been reported as the most difficult event of a child's hospital experience (Eland & Anderson, 1977; Fassler & Wallace, 1982; Menke, 1981). Children who do not have a chronic illness in which recurrent pain is a typical feature may place a different meaning on such medical procedures. The circumstances may be different for them, compared to the emotional turmoil that children with SCD may experience when dealing with yet another medical procedure. The findings support the idea that children with SCD are less afraid of procedural pain than those with less experience.

Relationship Between Pain Intensity and Medical Fears

The final purpose of the study was to examine the relationship between pain intensity and medical fears. There was a moderate, significant correlation between pain intensity and medical fears for the entire sample, but not within each group. This is likely due to smaller sample size as the strength of correlation was similar (total sample: $r = .269$; SCD: $r = .291$; control: $r = .252$). Contrary to prior research (Bournaki, 1997; Jay et al., 1983) where the findings showed no relationship between the variables fear (overall distress) and pain response, the findings in this study showed a relationship between pain intensity and medical fears indicating children with higher levels of fear reported more pain during the fingerstick. This

was consistent with a study conducted by Broome et al. (1990). They found a moderately positive relationship between medical fear scores and pain ratings, indicating that children with higher scores of fear reported more pain during the painful event. This finding is supported by the two theoretical perspectives, Gate Control Theory and McGrath's theory. It is well known that anticipation of pain can raise the level of anxiety, fear, and thereby the intensity of the perceived pain (Melzack & Wall, 1996). Situational factors (fears, past experiences) can activate the descending fibres and modify the activity of the sensory nerves thereby influencing the pain response (McGrath, 1989; Melzack & Wall, 1996). Certainly research has shown there are many factors involved in the child's experience of pain that may go between stimulus (fingerstick) and response, producing variability between the two. These factors are responsible for the plasticity and explain the complex gate control mechanisms that alter nociceptive activity (McGrath, 1989).

Additional Findings

Sufficient evidence supports a negative relationship between age and pain intensity or distress. Similar to previous findings (Fowler-Kerry & Lander, 1987; Fradet et al., 1990; Jacobsen et al., 1990; Manne et al., 1992) the results from this study showed that age was inversely correlated with pain intensity. These data suggest that younger children report more pain and greater distress during venipunctures. Consistent with Piagetian theory, children who are older (aged 7 and above), may have a more realistic understanding of the need for performing procedures and as a result experience less fear and pain.

Nursing Implications

Progress in pain research has made enormous advances in our understanding of children's pain perception as well as in pain management. However, pain assessment and management in children with SCD pose some of the most difficult challenges for health professionals. Nurses and health professionals are responsible for managing pain through clinical expertise and knowledge, and with the utilisation of research findings to maximise pain evaluation interventions for these children with SCD. This study was undertaken in response to the fact that little empirical data was available regarding the consequences of the experience of recurrent pain in children. Indeed, there have been studies on the consequences of chronic illness (SCD) in children, but the pain component was not explicitly examined. The findings from this study revealed new information about children's perceptions about pain and hospitals, and have several pertinent clinical implications.

First, children with SCD did not differ in their response to acute pain as compared to children without recurrent pain. However, it seems the acute pain is just as traumatic for the SCD children (that is not any less traumatic) as compared to healthy children. On the otherhand, this finding may suggest children with SCD (recurrent pain) may not over-report pain. They may not exhibit over-reactive behaviours such as, over-utilising health care services, or dramatically reducing their activity. Therefore, nurses and other health professionals, should not assume that SCD children have become habituated to painful procedures. Nor is the acute pain any less intense than children who do not experience recurrent pain. Neither can we assume that SCD children do not need pain management interventions. Children with SCD may have developed coping abilities in response to familiar painful events in situations specific to their care, however, coping with illness-related pain and other hospital-related stressors need to be examined (Spirito, Stark, & Tyc, 1994).

During such acute painful events or exacerbations of recurrent pain, these children may not be able to concentrate or learn effective pain management strategies. However, nurses can provide ongoing assessment to understand children's attempts to manage pain, as well as the processes that influence those coping efforts and, develop individualised pain management programs.

Second, SCD children with more prior hospitalisations are less fearful of medical procedures. Other equally important factors associated with hospitalisation need to be considered in order to understand what strategies these children use. Children with SCD are undergoing prolonged exposure to recurrent pain,

experiencing repeated exposure to medical procedures as well as experiencing more time in hospitals. They may have developed intense, warm, and trusting relationships with nurses and other health professionals, thereby, reducing their fears. In addition, children with a chronic illness, such as SCD, who experience frequent hospitalisations may have created a repertoire of coping skills to deal with the various stressors while hospitalised due to their longer history of illness and treatment exposure. Research suggests that the use of active-coping strategies, such as information seeking, may minimise fears associated with medical procedures (Peterson, 1989; Siegel, 1981). They may have learned to use cognitive (problem-solving, wishful thinking) and behavioural (social support) strategies that could reduce fear. A study by Spirito, Stark and Tyc compared chronically ill children with acutely ill/injured children on types of stressors encountered during hospitalisation, as well as the coping strategies used (1994). It was found that chronically ill children were less likely to use avoidant-coping strategies (wishful thinking) than acutely ill/injured children.

This study shows that beyond a certain cut-off number of hospitalisations, fears appear to diminish. However, particular attention should be given to children who have had few hospitalisations as they were found to be more fearful of medical procedures. The nurse needs to learn how they appraise the experience, as a basis for planning programs of interventions to help them cope and make the experience as least distressing as possible. There may be stressors other than painful procedures that may need to be identified and addressed in order to improve the hospital experience.

Third, considering the psychosocial staging (Erickson, 1963) for school-age children, it was expected that children with SCD have a greater amount of fear of missing school if ill. The pain experienced by these children can be highly disruptive, with frequent hospitalisations for pain each year (Hurtig & White, 1986; Shapiro, 1989). About 90% of hospital admissions of patients with SCD are for treatment with recurrent pain (Ballas, 1995; Brozovic, Davies, & Brownell,1987). Due to the lengthy hospitalisations, children often miss opportunities for new learning, must make up missed work, and may experience anxiety and social isolation (Eaton et al., 1995). Nurses may be instrumental in encouraging home management of sickle cell-related pain as a way to normalise daily functioning and an opportunity to provide home based schooling. In addition, the nurse can assess coping strategies and target specific interventions (tutorials in hospital and/or home) early enough to facilitate reintegration into the school system. Support groups for children and their parents may be used to provide both education and support.

Finally, children also showed fear of vomiting. Since epigastric pain is especially common in children with SCD, as part of the vaso-occlusive pain episode, the abdominal pain may be severe enough to cause vomiting (Serjeant, 1985). The nurse in collaboration with the child and family may need to find methods to alleviate the vomiting and/or coping mechanisms to reduce the fear of vomiting.

Future Directions

While the present findings show no difference in pain response between SCD children and healthy controls, further studies on the type of coping strategies employed by children with SCD may be useful to determine whether or not the

coping patterns are adaptive. In addition, long term follow-up studies are needed to trace changes in coping over time, due to increased pain and complications associated with the disease.

Future investigations using structured interviews to determine how children with SCD deal with their fears, and what they identify as fearful, would be useful. In addition, a prospective study to look at the coping process on admission, from which the health professionals would learn how to assist children with SCD in early admissions and what interventions to develop for them. Finally, a comparison study involving hospitalised children with SCD and, a healthy group of children admitted for short term acute illnesses, may be useful in looking at differences in coping with hospital related stressors.

Limitations

This study is based on a comparative design. Although this in itself is a strength, specific components contributing to the potential differences between the two groups, eg. coping strategies used to manage pain and the stresses of hospitalisation and, level of acculturation, were not measured or controlled. Coping strategies in response to painful procedures and hospitalisations were not examined and need to be taken into account as they may be important in understanding the findings. Children with a chronic illness may cope with pain differently than do their healthy peers (Spirito et al.,1994). Coping strategies may in fact be more significant in determining adaptation to SCD than pain frequency and disease complications (Gil et al., 1991).

Ethnic origin was categorised into two groups. In keeping the categories broad there is less problem with interpretation, but will not reveal specific cultural differences that might exist. Variations in the degree of acculturation to the society's predominant norms of health and illness have shown to influence intra-ethnic group pain intensity (Bates, 1993; Greenwald, 1991; Lipton & Marbach, 1984).

Convenience sampling, rather than random sampling, may limit generalisability of the results in this study. There is risk of selection bias since those in the study group represent those patients with SCD who are regular attenders of an outpatient sickle cell clinic and want to cooperate with the study. Therefore social desirability may have played a role in the SCD group. In addition, those in the comparison group may represent those individuals who have an interest in SCD and want more knowledge.

Finally, the study was carried out in a non-health care facility. Certain health care settings (ER, clinic) may promote anxiety, fears and may affect pain response of the child with SCD. There may be a complex interaction between the child and aspects of the health care environment.

However, there were three unique aspects of this study that were improvements over previous reports of the effects of recurrent pain on pain response. Although, most studies with children have focused on clinical pain, experimental pain methods used in adults have provided a means to standardise stimulus intensity and measure pain response with a precision that is not possible in clinical pain. However,

there are serious ethical considerations that preclude using experimental pain in children (McGrath, 1993). By using a procedure that is part of usual health care (fingerstick) as the painful, yet standardised (spring loaded lancet) stimulus, both ethical concerns and control of pain intensity were addressed. Secondly, the fingerstick is clinically relevant to children with SCD, and even healthy children may have experienced the procedure through blood tests. Finally, matching or controlling for race/culture, gender, and age may have allowed for a better understanding on the direct effect of repeated pain in the present study.

Conclusion

Our enhanced understanding, achieved through research of children's pain, has shown that pain is a complex, multidimensional experience involving sensory, affective, cognitive, social, and behavioural components (Melzack & Katz, 1994). In this study, the children with SCD and the healthy controls rated the pain as equally intense. However, there was a relationship in the group of children with SCD between the number of hospitalisations, the number of needles, and in medical fears. In addition, children with SCD who have had fewer hospitalisations have increased medical fears, whereas those who have many, regardless of age, have decreased medical fears. There were two contrasting models proposed i.e. the hypervigilence versus the adaptation. There is no evidence to support either one in terms of pain intensity. There was support for the adaptation model regarding medical fears, in that children with SCD who had many hospitalisations were less afraid. This relationship suggests adaptation on the part of these children to their chronic illness and to hospitalisations.

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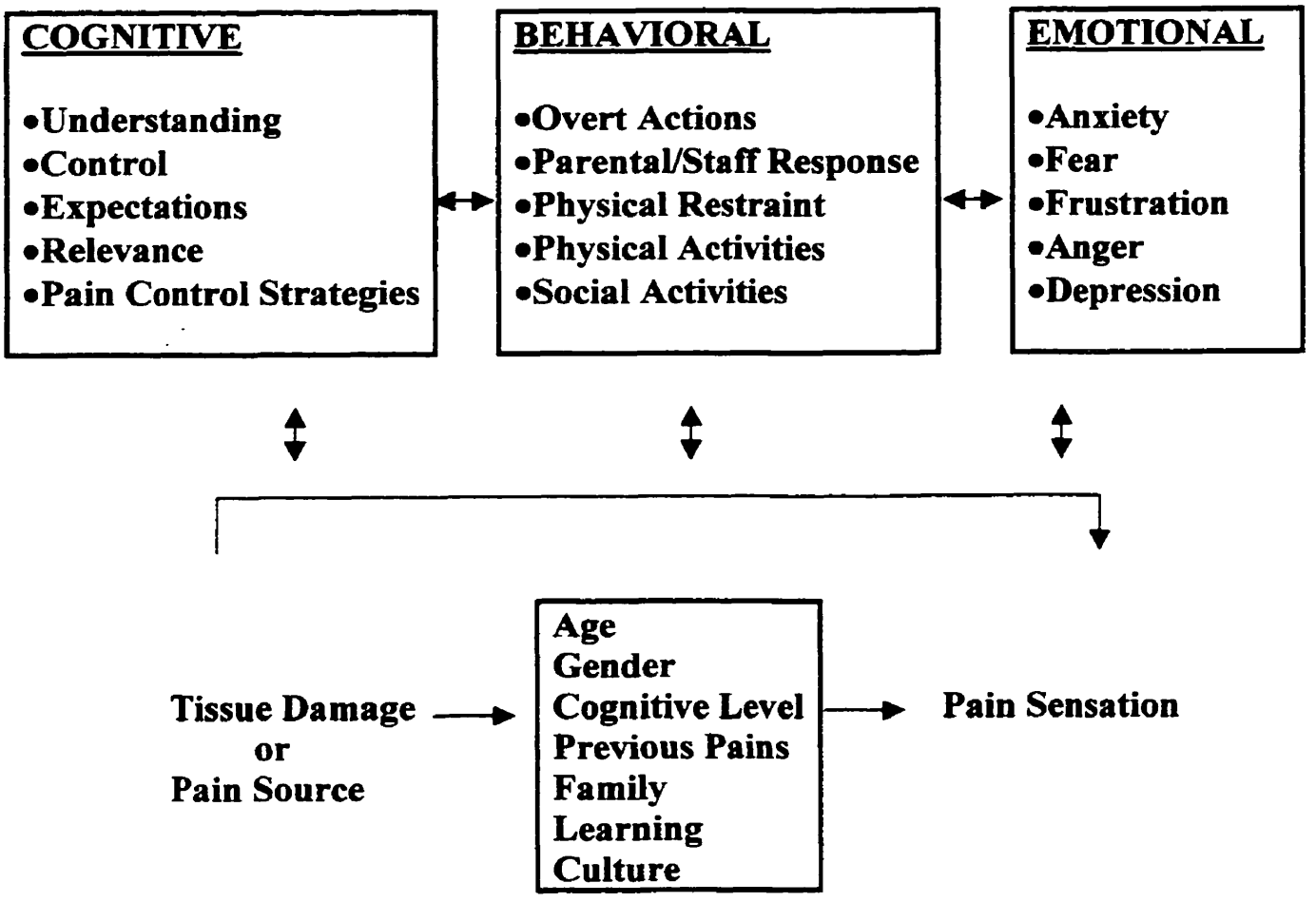
Appendix A

McGrath's Model: depicting situational, behavioral, and emotional factors

McGrath, P.A. & Hillier, L.M. (1996). Controlling children's pain. In R.J. Gatchel & D.C. Turk (Eds.), Psychological Approaches to Pain Management: A practitioner's Handbook. The Guilford Press, New York.



A model depicting the situational factors that modify children's pain perception

Appendix B

Parent Questionnaire

PARENT QUESTIONNAIRE

I.D. :_____ Date_____

1. Sex:_____

2. Birth Date (Day/Month/Year):_____ Birth Place:_____

3. Type of sickle hemoglobinopathy:_____

4. Previous hospitalisations(date/diagnosis):_____

_____

5. Number of blood tests(per year):_____

6. Experience with other needle procedures (yes/no) and how often:_____

7. Presence or absence of a painful condition in the family:_____

8. Medications child is presently taking:_____

9. Does your child have a condition that he/she is being followed for on a regular basis?

(Yes/no) _____

10. Country of origin: mother_____

father_____

grandmother - maternal/paternal_____

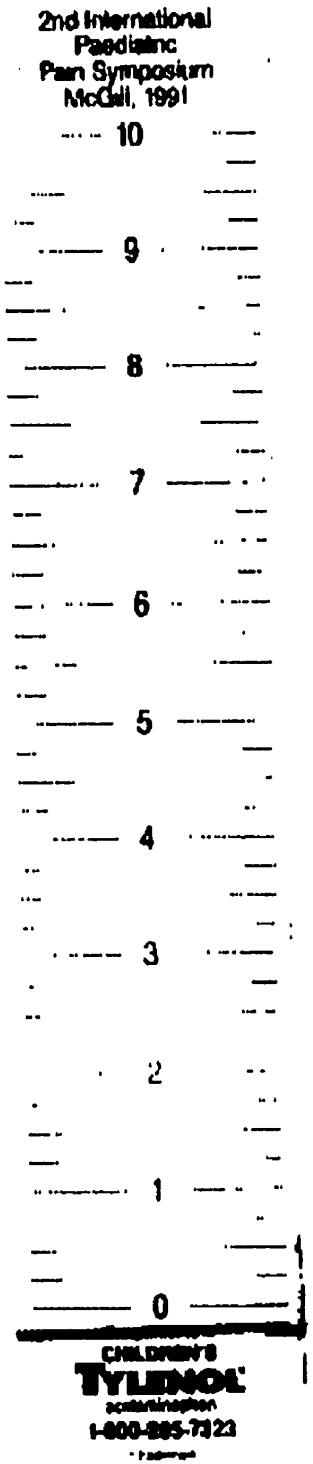
grandfather - maternal/paternal_____

11. Length of time in Canada:_____

12. At what age did your child begin school in Canada:_____

Appendix C

Coloured Analogue Scale (CAS)


2nd International
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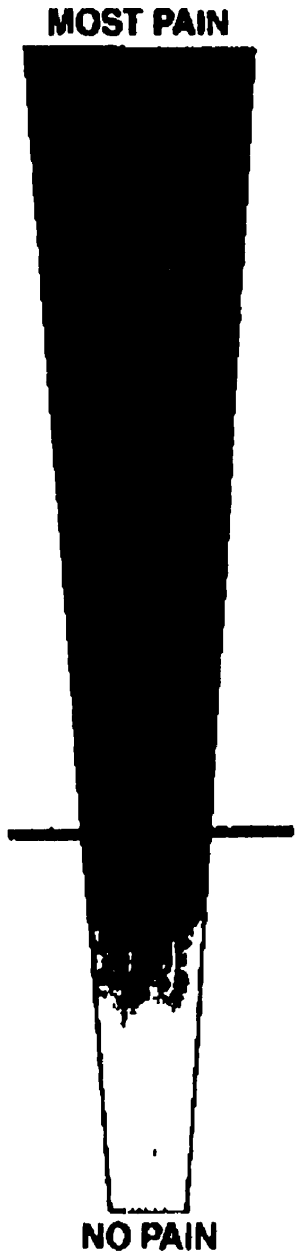
MOST PAIN
NO PAIN

Appendix D

Child Medical Fear Scale (CMFS)

Directions to child: I am going to ask you some questions about things that you may think about when you are sick, see a doctor or go to the hospital. I want you to tell me how afraid you are of each of the sentences I read to you. For instance, if I say "I am afraid of throwing up if I'm sick," I want you to tell me if you are not at all afraid, a little afraid or a lot afraid of throwing up when you are sick. Ok? Do you have any questions before we begin?

		not at all	a little	a lot
1.	I am afraid of hurting myself.	___	___	___
2.	I am afraid of going to the doctor's office.	___	___	___
3.	I am afraid of getting a shot.	___	___	___
4.	I am afraid of seeing blood come out of me.	___	___	___
5.	I am afraid of going to the hospital.	___	___	___
6.	I am afraid of having my finger stuck.	___	___	___
7.	I am afraid the doctor and nurse will not tell me what they are going to do to me.	___	___	___
8.	I am afraid to throw up.	___	___	___
9.	I am afraid of missing school if I'm sick.	___	___	___
10.	I am afraid I will cry when I get hurt.	___	___	___
11.	I am afraid if I went to the hospital I'd have to stay a long time.	___	___	___
12.	I am afraid my friends/family will catch something I have if I'm sick and play with them.	___	___	___
13.	I am afraid I might die if I go to the hospital.	___	___	___
14.	I am afraid of having the doctor or nurse look down my throat.	___	___	___
15.	I am afraid the nurse or doctor will tell me something is wrong with me.	___	___	___
16.	I am afraid of being away from my family if I go to the hospital.	___	___	___
17.	I am afraid of the doctor putting a tongue blade in my mouth.	___	___	___

Appendix E

Letters of Approval

Date: Fri, 17 May 1996 10:14:35 -0500 (CDT)
From: Marion E Broome <mebroome@csd.uwm.edu>
To: md28@musica.mcgill.ca
Subject: Re: children`s medical fears questionnaire

On Wed, 15 May 1996 md28@musica.mcgill.ca wrote:

> Hi Marion!
>
> I have a Master`s student working on a study of children with sickle cell
> disease and we want to uses your measure of children`s medical fears. May we
> have permission to do so? Even if you sent a response by email, we can print
> it and use it as official.
>
> Hope all is well and that I will see you in Vancouver.
>
> Bye for now,
>
> Celeste
>
> Celeste Johnston, RN, DEd
> McGill University School of Nursing
> Montreal, QC CANADA
>
I'd be happy for you to use the CMFS- do you have the revised version and
info on psychometrics? I am also currently funded by NINR to test
interventions with sickle cell patients and could administer it to our
kids and have some comparison data. Let me know where to send the info on

Appendix F

Explanation of the Study - Recruitment Form

Consent Forms

McGill

School of Nursing

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3506 University Street
Montreal, Quebec, Canada H3A 2A7

École des sciences infirmières

Université McGill
3506, rue University
Montréal, Québec, Canada H3A 2A7 Fax: (514) 398-8455

Response to acute pain among children with and without Sickle Cell Disease

School of Nursing, McGill University
Patricia Meredith, RN, BSc(N), MSc (cand) 343-0947
Karen Bradley, RN, MScN 934-4400 (2253)

Parental Consent Form

Explanation of the Study.

Children who have sickle cell disease have frequent bouts of pain and these experiences may change the way in which they feel pain. They may feel less pain because they have learned to deal with it or they may be more sensitive to pain because of fears about it. The purpose of this study is to find out if children who have sickle cell disease differ in their perception of pain from children similar to them, but who do not have sickle cell disease.

Participation in the Study

If I agree for my child to participate in this study:

1) We will meet at the Sickle Cell Society community center on Cote Des Neiges.
2) My child will receive a fingerstick.

If my child *does have sickle cell disease* this fingerstick is for routine complete blood cell count and will replace the fingerstick normally done in the hospital clinic.

3) My child will be asked to rate his/her pain intensity immediately following the fingerstick.
4) My child will be asked to rate his/her fears about hospitals, doctors, and other related subjects.
5) I will be asked to complete a one page questionnaire on the child's experience with pain and family origin (Canada or outside Canada) and any chronic illness or major hospitalizations.
6) This visit will take approximately 20 minutes.
7) There will be money for a month's bus pass provided.

Non-participation in the Study

If I do not participate in the study, my child and family will still receive the usual care by the hospital or school.

Withdrawal

I may withdraw my consent to be in the study at any time, with no change in the care that my child or family would normally receive in the hospital or school.

Risks

There are no known risks from participation in this study. There will be brief pain from the fingerstick. There will be the inconvenience of the time taken for the test.

Benefits

For children with sickle cell disease, there are no direct benefits from participation in this study, although results from the study may increase the knowledge of health care providers about their pain perceptions.

Confidentiality

My and my child's identity will be coded and the key to the code will only exist in a filing cabinet at the School of Nursing at McGill University with this consent form so that his/her name will not appear on any documents.

Results from the study may be presented at scientific or professional meetings, but my child's identity will not be known.

For more information contact Patricia Meredith at 343-0947 or Karen Bradley at 934-4400 (2253) or the Sickle Cell Society at 735-5100.

Consent Form

Response to acute pain among children with or wihtout Sickle Cell Disease

Patricia Meredith, RN, BSc(N), MSc(N) (cand) McGill University

Montreal Children's Hospital

The study has been explained to me and my questions have been answered to my satisfaction. The information on the risks and benefits of joining the research study have been explained to me. I have been assured that all information relating to my child's identity will be kept confidential.

My participation in this study is entirely voluntary, and I may withdraw at any time, and that this action will not in any way prejudice my child's present or future care in hospital or school.

I consent for my child_____to participate full in the study.

_____
Name of parent or guardian

_____
Signature (parent, guardian)

_____ _____
Signature of Person Who Obtained Consent Date

March 10/97

McGill

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3506 University Street
Montreal, Quebec, Canada H3A 2A7

École des sciences infirmières
Université McGill
3506, rue University
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Fax: (514) 398-8455

Response to acute pain among children with and without Sickle Cell Disease

School of Nursing, McGill University
Patricia Meredith, RN, BSc(N), MSc (cand) 343-0947
Karen Bradley, RN, MScN 934-4400 (2253)

Parental Consent Form

Explanation of the Study.

Children who have sickle cell disease have frequent bouts of pain and these experiences may change the way in which they feel pain. They may feel less pain because they have learned to deal with it or they may be more sensitive to pain because of fears about it. The purpose of this study is to find out if children who have sickle cell disease differ in their perception of pain from children similar to them, but who do not have sickle cell disease.

Participation in the Study

If I agree for my child to participate in this study,

1) We will meet at the Sickle Cell Society community center on Cote Des Neiges.
2) My child will receive a fingerstick.

If my child *does not have sickle cell disease* this fingerstick is to collect blood to determine if he/she has sickle cell trait and we will be informed of the results. There is another consent form for this test.

3) My child will be asked to rate his/her pain intensity immediately following the fingerstick.
4) My child will be asked to rate his/her fears about hospitals, doctors, and other related subjects.
5) I will be asked to complete a one page questionnaire on the child's experience with pain and family origin (Canada or outside Canada) and any chronic illness or major hospitalizations.
6) This visit will take approximately 20 minutes.
7) There will be money for a month's bus pass provided.

Non-participation in the Study

If I do not participate in the study, my child and family will still receive the usual care by the hospital or school.

Withdrawal

I may withdraw my consent to be in the study at any time, with no change in the care that my child or family would normally receive in the hospital or school.

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Réaction à la douleur aiguë chez les enfants qui sont atteints d'anémie falciforme (drépanocytose) et chez ceux qui ne sont pas atteints d'anémie falciforme

École des sciences infirmières, Université McGill
Patricia Meredith, I., B.Sc.I., M.Sc.I. (cand) 343-0947
Karen Bradley, I., M.Sc.I. 934-4400 (2253)

Formulaire de consentement des parents

Explication de l'étude

Les enfants souffrant d'anémie falciforme subissent des crises de douleurs fréquentes et ces expériences peuvent changer la façon dont ils sentent la douleur. Il se peut qu'ils ressentent moins de douleur parce qu'ils ont appris à l'endurer ou bien, ils pourraient être plus sensible à la douleur parce qu'ils en ont peur. Le but de cette étude est de trouver si les enfants qui sont atteints d'anémie falciforme perçoivent différemment la douleur comparativement aux enfants semblables à eux, mais qui ne souffrent pas d'anémie falciforme.

Participation à l'étude

Si je consens à ce que mon enfant participe à l'étude :

1) Nous nous rencontrerons au Centre communautaire de la Société d'anémie falciforme de Côte-des-Neiges.
2) Mon enfant recevra une piqûre dans le doigt.
   Si mon enfant *souffre d'anémie falciforme*, cette piqûre dans le doigt est un examen de routine sanguin complet qui remplacera la piqûre dans le doigt qui est normalement faite à la clinique de l'hôpital.
3) On demandera à mon enfant d'évaluer l'intensité de sa douleur immédiatement après l'administration de la piqûre dans le doigt.
4) On demandera à mon enfant de faire connaître ses préoccupations face aux hôpitaux, aux médecins et à d'autres sujets relatifs.
5) On me demandera de remplir un questionnaire d'une page sur l'expérience de l'enfant envers la douleur et l'origine familiale (Canada ou à l'extérieur du Canada) et toute autre maladie chronique ou hospitalisations majeures.
6) Cette visite durera environ 20 minutes.
7) On nous donnera de l'argent pour une passe d'autobus mensuelle.

Aucune participation à l'étude

Si je ne participe pas à l'étude, mon enfant et ma famille recevront les soins habituels de l'hôpital ou de l'école.

Renoncement

Je pourrai renoncer à mon consentement de participer à l'étude en tout temps, sans qu'il n'y ait changement dans les soins habituellement dispensés à mon enfant et à ma famille à l'hôpital et à l'école.

Risques potentiels
Il n'y a aucun risque pour les enfants participant à cette étude. Il y aura l'inconvénient du temps passé pour l'examen.
Avantages
Pour les enfants souffrant d'anémie falciforme, il n'y a pas d'avantages directs lorsqu'ils participeront à cette étude; néanmoins, les résultats de cette étude augmenteront les connaissances des professionnels des soins de santé sur leur perception de la douleur.
Confidentialité
Mon identité et celle de mon enfant seront codées et la clé du code se trouvera dans un classeur à l'École des sciences infirmières de l'Université McGill avec ce formulaire de consentement afin que le nom de l'enfant n'apparaisse sur aucun document.
Les résultats de l'étude pourraient être présentées à des rencontres scientifiques et professionnelles, mais l'identité de mon enfant ne sera pas divulguée.

Pour de plus amples renseignements, veuillez communiquer avec Patricia Meredith au 343-0947 ou avec Karen Bradley au 934-4400 (2253) ou avec la Société d'anémie falciforme au 735-5100.

Formulaire de consentement

Réaction à la douleur aiguë chez les enfants atteints d'anémie falciforme (drépanocytose) et chez ceux qui ne sont pas atteints d'anémie falciforme

Patricia Meredith, I., B.Sc.I., M.Sc.I. (cand) Université McGill

Hôpital de Montréal pour Enfants

L'étude m'a été expliquée et on a répondu à mes questions avec satisfaction. Les renseignements sur les risques et les avantages de participer à l'étude de recherche m'ont été expliqués. On m'a assuré que les informations concernant l'identité de mon enfant seront gardées confidentielles.

Ma participation à cette étude est entièrement volontaire, et je pourrai y renoncer à n'importe quel moment; cette action n'influencera aucunement les soins actuels ou futurs que mon enfant recevra à l'hôpital et à l'école.

Je consens à ce que mon enfant _____ participe entièrement à l'étude.

_____
Nom du parent ou du tuteur

_____
Signature (parent, tuteur)

_____ _____
Signature de la personne qui a obtenu le consentement Date

March 10/97

McGill

School of Nursing

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École des sciences infirmières

Université McGill
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Réaction à la douleur aiguë chez les enfants qui sont atteints d'anémie falciforme (drépanocytose) et chez ceux qui ne sont pas atteints d'anémie falciforme

École des sciences infirmières, Université McGill
Patricia Meredith, I., B.Sc.I., M.Sc.I. (cand) 343-0947
Karen Bradley, I., M.Sc.I. 934-4400 (2253)

Formulaire de consentement des parents

Explication de l'étude

Les enfants souffrant d'anémie falciforme subissent des crises de douleurs fréquentes et ces expériences peuvent changer la façon dont ils sentent la douleur. Il se peut qu'ils ressentent moins de douleur parce qu'ils ont appris à l'endurer ou bien, ils pourraient être plus sensible à la douleur parce qu'ils en ont peur. Le but de cette étude est de trouver si les enfants qui sont atteints d'anémie falciforme perçoivent différemment la douleur comparativement aux enfants semblables à eux, mais qui ne souffrent pas d'anémie falciforme.

Participation à l'étude

Si je consens à ce que mon enfant participe à l'étude :

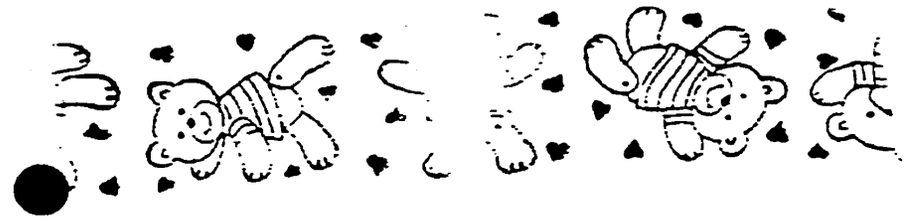
1) Nous nous rencontrerons au Centre communautaire de la Société d'anémie falciforme de Côte-des-Neiges.
2) Mon enfant recevra une piqûre dans le doigt.
   Si mon enfant *ne souffre pas d'anémie falciforme*, le but de cette piqûre dans le doigt est de prélever le sang pour déterminer s'il y a des traces d'anémie falciforme et on nous donnera les résultats. Il y a un autre formulaire de consentement pour cet examen.
3) On demandera à mon enfant d'évaluer l'intensité de sa douleur immédiatement après l'administration de la piqûre dans le doigt.
4) On demandera à mon enfant de faire connaître ses préoccupations face aux hôpitaux, aux médecins et à d'autres sujets relatifs.
5) On me demandera de remplir un questionnaire d'une page sur l'expérience de l'enfant envers la douleur et l'origine familiale (Canada ou à l'extérieur du Canada) et toute autre maladie chronique ou hospitalisations majeures.
6) Cette visite durera environ 20 minutes.
7) On nous donnera de l'argent pour une passe d'autobus mensuelle.

Aucune participation à l'étude

Si je ne participe pas à l'étude, mon enfant et ma famille recevront les soins habituels de l'hôpital ou de l'école.

Renoncement

Je pourrai renoncer à mon consentement de participer à l'étude en tout temps, sans qu'il n'y ait changement dans les soins habituellement dispensés à mon enfant et à ma famille à l'hôpital et à l'école.

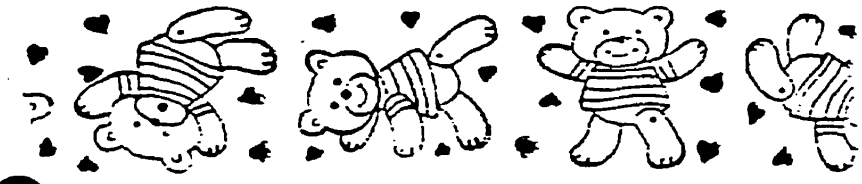


An important message for families with children with Sickle Cell Disease:

Sickle Cell Disease is a real concern for many families and their children. Children with Sickle Cell Disease have unexpected and frequent bouts of pain. A question that often arises is why do some children feel less pain and others feel more? Researching pain in children with Sickle Cell Disease will help to answer this question. Furthermore, it may also help you and your child understand the disease, learn to cope with future painful events and improve the quality of your child's health.

A research study will be conducted at the Montreal Children's Hospital in partnership with the Sickle Cell Society to learn more about pain in children with Sickle Cell Disease. We would like to invite the families to attend upcoming information meetings about the research. This will give you an opportunity to ask questions and to participate in the study so that together we can find new ways of coping with this painful disease.

McGill University - School of Nursing
Montreal Children's Hospital
Sickle Cell Society



Message important concernant les familles dont les enfants sont atteints d'anémie falciforme :

L'anémie falciforme préoccupe beaucoup de familles et leurs enfants. Les enfants qui sont atteints d'anémie falciforme subissent des douleurs inattendues et fréquentes. Une question qui revient souvent est pourquoi certains enfants ressentent moins ou plus de douleurs ? La recherche en douleur chez les enfants atteints d'anémie falciforme aidera à répondre à cette question. De plus, ceci vous aidera ainsi que votre enfant à comprendre la maladie, à apprendre à vivre avec la douleur et à améliorer la qualité de santé de votre enfant.

Une étude de recherche sera dirigée par l'Hôpital de Montréal pour Enfants en association avec la Société d'anémie falciforme pour mieux connaître la douleur que ressentent les enfants souffrant d'anémie falciforme. Nous aimerions inviter les familles à assister à des séances d'information qui se tiendront relativement à cette recherche. Vous aurez l'occasion de poser des questions et de participer à cette étude, afin qu'ensemble, nous puissions trouver de nouvelles façons d'affronter cette douloureuse maladie.

Université McGill - École des sciences infirmières
Hôpital de Montréal pour Enfants
Société d'anémie falciforme

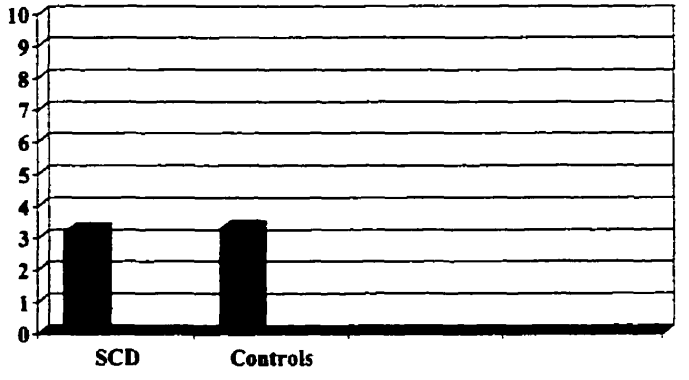
Appendix G

Means of Dependent Variables by Group

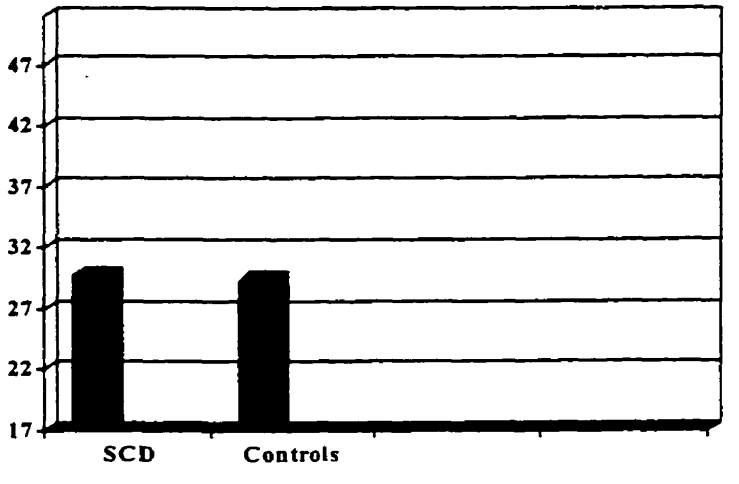
Figure I

Means of Dependent Variables by Group

PAIN INTENSITY



MEDICAL FEARS



Appendix H

Extraneous Variables

Table 1.

Comparison of SCD Group and Control Group on Demographic Variables

Variables	SCD Group N = 33 n (%)	Control Group N = 33 n(%)	X^2 (df)
Sex	(f) 23 (69.6) (m) 10 (30.3)	(f) 23 (69.6) (m) (30.3)	.00
Maternal Country of Origin (both groups)	(Canadian) 2(6.1), (not Can.) 31(94)		.00
Family Member with Pain	(yes) 6 (18.2) (no) 27 (82)	(yes) 3 (9.1) (no) 30 (91)	1.2
Child with Chronic Disease (not SCD)	(yes) 1 (3) (no) 32 (97)	(yes) 8 (24) (no) 25 (76)	6.3

Note: the df for all variables was 1.

Table 2.

Comparison of SCD Group and Control Group on Extraneous Variables

	SCD Group		Control Group		(T-Test) p
	N = 33		N = 33		
Variables	**M**	**SD**	**M**	**SD**	
Age	9.9	2.0	9.8	2.1	.86
# Hospitalisations	8.2	5.3	.52	1.3	.00
# Needles	10	11	1.1	2.7	.00
Time in Canada	17	8.6	21	9.7	.14

Table 3.

Analysis of Variance for Demographic Variables on Dependent Variables (CAS & MFS)

		CAS		MFS	
Variables	**df**	**F**	**p**	**F**	**p**
Time in Canada	1	.00	.99	2.1	.15
Maternal Country of Origin	4	.44	.78	.53	.72
Sex	1	.36	.55	.32	.57

Appendix I

Means and Standard Deviations on 17 Items of the

Medical Fear Questionnaire

Descriptive Data for Child Medical Fear Scale Items

Specific Fears	SCD Group N = 33 M	SD	Control Group N = 33 M	SD
1. I am afraid of hurting myself.	1.8	.7	1.9	.6
2. I am afraid of going to the doctor's office.	1.3	.5	1.6	.8
3. I am afraid of getting a shot.	2.1	.8	1.9	.8
4. I am afraid of seeing blood come out of me.	1.4	.6	1.4	.7
5. I am afraid of going to the hospital.	1.5	.7	1.5	.6
6. I am afraid of having my finger stuck.	1.3	.6	1.9	.7
7. I am afraid the doctor and nurse will not tell me what they are going to do to me.	1.8	.7	1.9	.8
8. I am afraid to throw up.	2.0	.8	1.5	.7
9. I am afraid of missing school if I'm sick.	2.1	.8	1.6	.7
10. I am afraid I will cry when I get hurt.	1.6	.7	1.4	.6
11. I am afraid if I went to the hospital I'd have to stay a long time.	2.1	.8	1.7	.8
12. I am afraid my friends/family will catch something I have if I'm sick and play with them.	1.8	.8	2.0	.8
13. I am afraid I might die if I go to the hospital.	1.7	.8	1.9	.9

14. I am afraid of having the doctor or nurse look down my throat.	1.4	.8	1.2	.6
15. I am afraid the nurse or doctor will tell me something is wrong with me.	1.9	.7	2.2	.8
16. I am afraid of being away from my family if I go to the hospital.	2.2	.8	2.2	.7
17. I am afraid of the doctor putting a tongue blade in my mouth.	1.5	.7	1.3	.7

*Note: Child scores 1 (not at all afraid) to 3 (very afraid).

Appendix J.

Relationship Between Number of Hospitalisations

and Medical Fear Scores

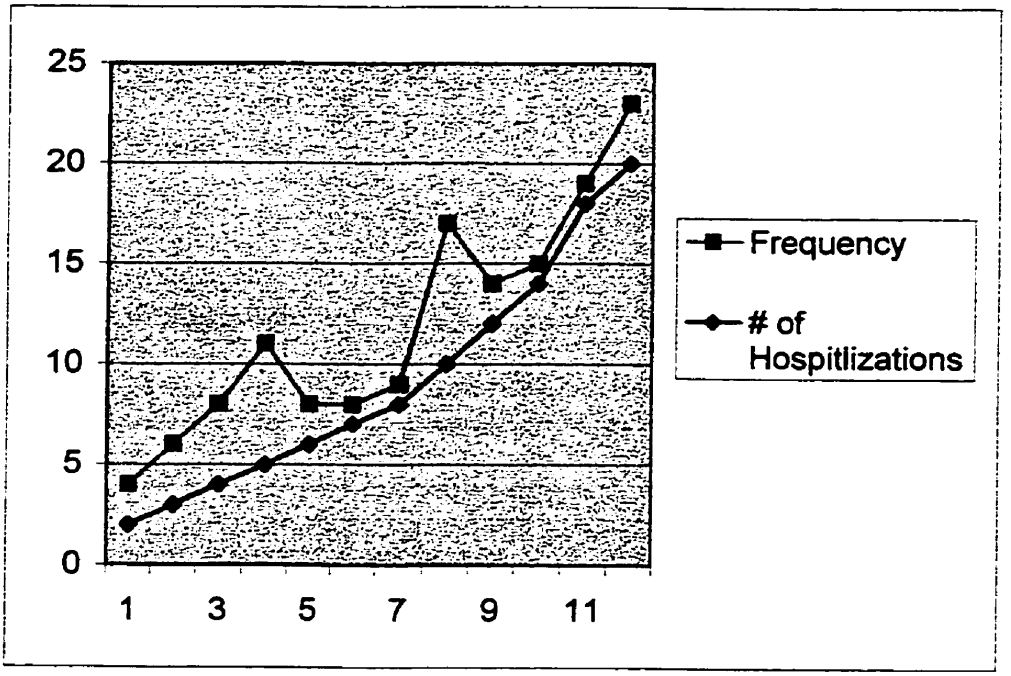


Figure 2. **Frequency of hospitalisations for children with SCD. Mean = 8.2**

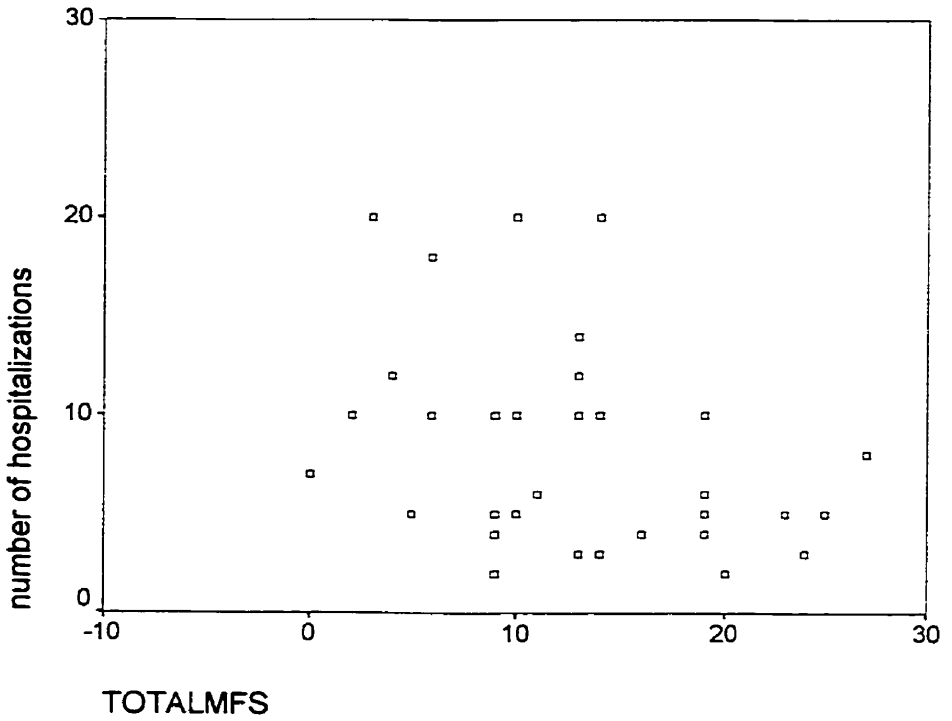


Figure 3. **Scatter plot shows SCD children with more hospitalisations have a lower score on medical fears (median of six).**