HOW CHILDREN COPE WITH ARTHRITIS: THE RELATIONSHIP OF COPING STYLE TO REPORTED PAIN, AND CAREGIVER'S INFLUENCE

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How Children Cope With Arthritis: the Relationship of Coping Style to Reported Pain, and Caregiver's Influence.

by

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Abstract

Children with juvenile arthritis (JA) are subject to chronic pain. The literature suggests that style of coping may influence amount of pain experienced, and that parents' beliefs may influence their child's choice of coping skills. Fifteen youth with JA and their primary caregivers participated in a semi-structured interview. Pain experience was measured with the Varni/Thompson Pediatric Pain Questionnaire, and an instrument to measure youth arthritis coping skills adapted from the Vanderbilt Pain Management Inventory was titled The Children's Arthritis Coping Inventory, which consisted of two sub-scales representing inner-directed and outer-directed coping. No relationship was found between youth reports of frequency of uses of inner and outer directed coping skills. There was a non-significant negative relationship between a child's use of outer-directed coping and reported pain ($r = -0.33_{14}$), and a positive relationship between inner-directed coping and pain ($r = 0.67_{14}$, $p < .01$). The use of proportionately more inner than outer directed coping was also significantly related to reported pain ($r = 0.66_{14}$, $p < .01$, while primary use of outer coping was not ($r = -0.13_{14}$). Parents did accurately estimate the magnitude of their child's experienced pain, and type of coping skill used. Hypotheses of parental beliefs influencing their child's coping skill use were not fully supported, as there were non-significant positive relationships between (a) parents estimates of the child's coping and (b) their opinion of what skills are best to use, with those their child did report ($r = 0.12_{14}$, $r = 0.30_{14}$ respectively). Trends suggested in these results were encouraging given the small sample size. Use of information on both adaptive (negatively related to pain) and maladaptive (positively related to pain) types of coping is suggested for application in the design of child chronic pain management programs.

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I understand I am the last graduate of Memorial University of Newfoundland's Clinical Psychology program - one which prepared clinicians for a province greatly in need of their service. I sincerely hope that my position as the final graduate is only a temporary one.

Table of Contents

List of Tables

Table No. Page

List of Figures

How Children Cope With Arthritis: the Relationship of Coping Style to Reported Pain, and Caregiver's Influence

Improvements in perinatal care, parent education, and community health have resulted in increased viability of ill children. One consequence of these improvements is that more children experience the challenge of coping with long term illness or disability. It has been estimated that at least 10% of all children live with some type of chronic illness (Eiser, 1990).

One chronic childhood illness is juvenile arthritis (JA). Persistent musculoskeletal pain and physical disability characterize many forms of this condition. One puzzling irregularity is that children with the same degree of JA disease can experience different amounts of difficulty with pain and daily functioning (Sherry, Bohnsack, Salmonson, Wallace & Mellins, 1990). Some understanding of the influencing factors may be gained through investigation of the coping skills children develop to manage this chronic illness. It is possible that a child's disease experience is affected by coping style, which may in turn be related to the health attitudes of their care-givers. This study will examine youths' coping skills with respect to juvenile arthritis, and the relationship between a care-giver's beliefs and their child's coping style.

A review of the relevant literature begins with the areas of juvenile arthritis, the nature of children's pain, and the history of child pain research.

Juvenile Arthritis

Juvenile Arthritis (JA) comprises the heterogeneous group of more than 80 conditions that cause arthritis in children (Cassidy, Levinson, & Brewer, 1989). One diagnostic class of JA that has been the focus of behavioural medicine is connective tissue disease. The more homogeneous conditions in this class include juvenile rheumatoid arthritis, systemic lupus erythematosus, dermatomyositis, vasculitis, and scleroderma.

Of these, juvenile rheumatoid arthritis (JRA) has received much study, as it is the most common connective tissue disease in children (Varni & Jay, 1984). This is estimated to be the diagnosis for over 50% of children with rheumatic disease (Lovell & Walco, 1989). A discussion of the etiology and symptomatology of JRA can illustrate the experience of pain and physical dysfunction.

JRA was officially adopted by the American College of Rheumatology in 1972 as the accepted diagnostic term for childhood idiopathic, peripheral, inflammatory arthritis. The current American College of Rheumatology classification criteria for JRA are: (a) age of onset before 16 years, (b) arthritis in one or more joints defined as swelling or effusion, or the presence of two or more of the following signs: limitation of range of motion, tenderness or pain on motion, or increased heat; (c) duration of disease greater than six weeks, and (d) exclusion of other forms of juvenile arthritis. The accepted classification criteria for JRA and other childhood arthritic conditions continue to be the subject of much debate (Fink, 1995; Fink, 1996; Hochberg, 1995; Hochberg, 1996; Malleson, 1996; Miller, 1996).

Juvenile rheumatoid arthritis involves an imbalance of the autoimmune system. Arthritic symptoms are initiated by an immune response to some causative agent, resulting in the destruction of synovial tissue, the connective tissue membrane that lines the joints. Inflammation through increased synovial fluid and blood flow results in the characteristic arthritic symptoms of redness, swelling, heat, and pain. Pannus, a granulation tissue, accumulates within the joints and produces fatty acids known as prostaglandins. These and other substances destroy the peripheral cartilage and bone of the joints. Pain can thus result from pitted cartilage, osteoporosis, fibrosed capsules and ligaments, or large necrotic nodules. Systemic features of JRA can include fatigue, irritability, anorexia, weight loss, fever, and rash, as well as visual, pulmonary, haematological or cardiac complications. Should the disease progress without remission, deformity, dislocations of the joints, growth failure, or blindness and other systemic deterioration can occur (Ansell, 1990; Prokop, Bradley, Burish, Anderson & Fox, 1991; Rendle-Short, Gray, & Dodge, 1985).

JRA is also sub-classified by onset type: pauciarticular, polyarticular, and acute febrile. *Pauciarticular* onset (oligoarthritis or monoarthritis) is the most common subtype of JRA, occurring in 40% to 50% of all cases. It is characterised by arthritis in four or fewer joints, little involvement of most other organs, but a significant risk of visual impairment. This form typically begins in children under 10 years old, with initial involvement most frequently in the knee or other large joints. It is predisposed to periods of remission and relapse, with later involvement of other joints and occasional progression to polyarticular disease. *Polyarticular* onset indicates simultaneous involvement of five or more joints, and occurs in 30% to 40% of those affected. There typically is no fever or rash at onset, and little systemic involvement of other organs. This form typically affects children older than 10 years, often with symmetrical involvement of joints. There is also a tendency toward remission and relapse, with occasional progression to deformity and growth failure. *Acute febrile*, or systemic onset occurs in approximately 20% of patients. It is exhibited through high grade intermittent fever and predominant systemic manifestations, with minimal joint symptoms. Fifty percent suffer recurrent attacks that eventually subside, while the remainder develops the polyarticular form (Rendle-Short et al., 1985; Varni & Jay, 1984).

JRA is rare under the age of one year and has a bimodal onset distribution peaking in the age groups of 1-3 and 8-12 years (Neuberger & Neuberger, 1984; Varni & Jay, 1984). Early onset is considered to worsen prognosis (Rendle-Short et al., 1985). Girls are affected twice as often as boys, although the female preponderance is less marked than in adult arthritic conditions.

It has proven difficult to determine accurately the number of youth who suffer from JRA. Some epidemiological studies do not distinguish different connective tissue diseases, or are conducted using disparate diagnostic criteria. Reported incidence estimates for a given period are questionable, as JRA can be insidious in onset, making accurate early detection difficult (Lawrence et al., 1989; Neuberger & Neuberger, 1984). Efforts to establish valid prevalence estimates are also subject to confound, through (a) misrepresentation in self report studies by patients who may lack a definite diagnosis, (b) samples that include other related musculoskeletal disorders, and (c) samples representing inconsistent mixtures of individuals with conditions that are active, inactive, or in remission. Conservative estimates may occur because of a lack of diagnosis or poor sampling, while overestimates may result from inclusion of other disorders. Composite data from several North American and European prevalence studies suggest an acceptable estimate of 50 active JRA cases per 100,000 children (Gewanter & Baum, 1989; Lawrence et al.; Lovell and Walco, 1989; Neuberger & Neuberger).

This relatively low prevalence has hampered research efforts into this disease. Many studies that have focused solely on JRA have been conducted in large urban catchment areas such as Los Angeles (Varni, Thompson, & Hanson, 1987; Varni, Wilcox & Hanson, 1988), Cleveland (Coulton, Zborowsky, Lipton & Newman, 1987) and Cincinnati (Howe et al., 1991). Even in such studies, sample size is often small (e.g. Rapoff, Lindsley & Purviance, 1991, *N* = 31; Varni, Wilcox et al., *N* = 23). Where possible, it is preferable to study a homogeneous group. As necessary, a broader group who share salient similarities can be accepted. In this case, an alternative is to include participants with diagnoses in the connective tissue disease subclass (Berry, Hayford, Ross, Pachman & Lavigne, 1993), or rheumatic disease in general (Timko, Baumgartner, Moos & Miller, 1993). Despite other varied symptoms, the common experience of chronic musculoskeletal pain in the connective tissue disease subclass of JA appears sufficiently prevalent and disabling to warrant inclusion in the present study.

The Experience of Pain: History, Research, and Measurement

Pain was once considered to have solely physical cause and mediation. Sternbach (1968) identified a linear model of pain experience that assumed that tissue damage is necessary for pain, and that equivalent physical damage results in similar pain. This was known as the specificity theory (Melzack & Wall, 1983). There is no longer an insistence upon a linear and causal relationship between physical damage and pain, as the individual's subjective experience is acknowledged to influence pain perception. Contemporary pain theories are more comprehensive, as in Dolgin and Jay's (1989) definition of pain as "a complex psychophysiological phenomenon involving sensory, neurochemical, cognitive, affective and motivational components that interact to produce a behavioural response to tissue damage or irritation, and that may be influenced by antecedent and consequent stimulus conditions" (p. 384). Pain is thus viewed as ultimately verifiable only by the sufferer, who both defines and determines the presence of his or her own pain (Prokop et al., 1991).

Although the experience of pain is unique to the individual, there are distinguishable types. Duration of symptoms may be classified as either chronic, lasting more than six months, or acute, tending toward isolated and occasional short term bouts (Prokop et al., 1991). Discomfort may be decreasing, continuous, or increasing in intensity. The underlying causative condition may be distinguished as either benign, or resulting from a malignant disease process. Pain can also be considered organic, with related tissue damage, or psychogenic, when tissue damage is not apparent (Sarafino, 1990).

Acute pain is often related to an identified cause, with an eventual return to normal functioning. This experience seldom presents major problems in treatment, or results in serious psychological dysfunction. Conversely, chronic pain presents frequent and challenging hurdles to functioning and adjustment. The result may be lengthy periods of stress, as in JA, with its often chronic and unpredictable course (Lovell & Walco, 1989).

Until the 1970's, there appeared to be little interest in research of children's pain experiences. This was illustrated through Eland and Anderson's review of medical literature from 1970 to 1975 (Eland & Anderson, 1977). They located 33 articles concerning pediatric pain, and within these there was little emphasis on assessment or treatment. Historically, children's pain was often under-treated (de Lima, Lloyd-Thomas, Howard, Sumner, & Quinn, 1996), partially stemming from a common misconception that young children, infants, and neonates did not have the neurological maturity to experience pain, and had no memory for pain (Schechter, 1989). The specific consequences of under-treatment of pain are now acknowledged. Yaster and Deshpande (1988) explain that

> pain is intimately associated with the stress response. It causes elevations in heart rate and blood pressure, and the release of adrenal stress hormones. The metabolic consequences of these

> pain-induced endocrine changes are widespread and include protein wasting, mobilization of substrate from energy stores, electrolyte imbalance, and impaired immune function. (p.421)

It appears reasonable to postulate that *physiological* consequences of untreated pain are likely to be of greater significance for children who suffer illness characterized by chronic, rather than acute pain. Varni, Rapoff, et al. (1996) also found significant *emotional* correlates of untreated pain. In a sample of 160 youth with chronic pain, higher patient-perceived pain intensity was associated with higher depressive and anxiety symptoms, lower self-esteem, and increased behaviour problems.

It is encouraging that since Eland and Anderson's (1977) review there has been a great increase in basic and applied research of children's pain. Comprehensive literature on established pain measurement tools and techniques is readily available (P.A. McGrath, 1990a, 1990b, 1995; P.A. McGrath & Brigham, 1992; P.J. McGrath & Unruh, 1987).

Of particular interest to this study is the Varni/Thompson Pediatric Pain Questionnaire (PPQ; Varni &

Thompson, 1985). The PPQ has been credited as "the most comprehensive assessment of pain associated with JRA" (Lovell & Walco, 1989, p. 1018). It was adapted from Melzack's (1975) McGill Pain Questionnaire for adults. The PPQ was designed to be developmentally appropriate and sensitive to the cognitive conceptualizations of youth. Since publication, the PPQ has been validated for use with children as young as five years of age (Varni et al., 1987), and has been widely used. This instrument will be incorporated in the present study (see Appendix A).

Varni's research group has used the PPQ to create an empirical model of factors that predict and influence functional status in children with JRA (Varni, Wilcox, Hanson & Brik, 1988). Through regression analyses, the variables of musculoskeletal pain, disease activity, child psychological adjustment, and family psychosocial adjustment were found to have a predictive relationship with functional status. With a similar aim, the present study will question the relationship of coping skill use with expressed pain.

Coping With Pain

All children who live with a painful chronic disease experience a certain amount of related stress. Despite similar physical demands, some children report less pain and functional disability than others. This may be a function of different personal coping styles. P.A. McGrath (1995) also notes that childrens' nociceptive systems are plastic, in that at different times they can respond quite differently to the same amount of tissue damage, or to similar disease states. This may be in response to the numerous cognitive, behavioural, emotional and experiential variables which influence the pain experience.

Use of coping skills has been conceptualized as an expression of control over personal health. The concept of control may be central to positive rehabilitation and adjustment to chronic disorders (Pitts, 1991). Those who believe that they can exert some control in response to a stressful event appear to adjust better than those who do not (Taylor, 1990).

Rationale for the success of pain coping strategies is found in the Gate Control Theory (GCT, Melzack & Wall, 1965), which incorporates the sensory, affective, and cognitive dimensions of pain. Melzack and Wall proposed that pain is not the product of a linear system, but the outcome of a dynamic process. A simplified description of their theory is that central nervous system (CNS) structures in the dorsal horn of the spinal cord interact to form a gating mechanism that regulates the transmission of neural impulses from pain receptors. This gate is thought to 'open' or 'close' in response to the interaction of physical and psychological variables. The individual experiences an increased or decreased awareness of pain, with "pain signals from the periphery being evaluated in terms of prior experience, and current attentional and emotional states" (May, 1991, p.94).

Since the inception of the GCT, these researchers have further specified the influences on pain perception (Melzack and Katz, 1990; Melzack & Wall, 1983). Beyond the 'gating' mechanism, they identified CNS structures that modulate the pain experience in response to factors in three psychological dimensions. The *sensory-discriminative* dimension is characterised by perceptions of the onset, location, magnitude, and duration of pain. The *motivational-affective* dimension appears to play a role in pain processing, through the tendency toward pain aversion and the drive toward escape or attack to reduce pain. Suggestion or placebos appear to affect this system. Finally, they propose a *cognitive-evaluative* dimension, by which thought processes act selectively on the sensory and motivational dimensions. The cognitive-evaluative dimension is determined by experience, cultural values, emotional state, attention and suggestion. These three psychological dimensions of pain appear to interact with each other, CNS structures, and the gate control mechanism to modify the neural pain message. The message is then projected to the motor nerve system, where the experience is then registered.

This expanded theory is supported by the findings that behaviours, cognitions, and emotional states can affect pain. *Physical* factors that appear to heighten the pain response are greater extent of injury, increased readiness of the brain to respond with pain signals, excessive muscle tension, and inappropriate activity levels that cause physical stress or further injury. Physical factors that appear to temper the pain response include analgesic chemicals, appropriate activity levels, and counterstimulation such as heat, progressive muscle relaxation, and massage. *Emotional* factors that appear to intensify the pain experience include worry, tension, anxiety, anger, and depression. Emotional factors with a positive effect include relative emotional stability, feelings of relaxation or rest, and positive emotions such as happiness or joy. Negative *cognitive* influences include focusing on the pain, and boredom. Conversely, productive distraction and increased interest in life activities appear to help decrease the pain perceived.

Such findings suggest that pain management can be influenced by the wide range of coping choices available to the individual. Coping has been defined as "the process of managing external or internal demands that are perceived as taxing or exceeding a person's resources" (Taylor, 1990, p. 44), or responses designed to eliminate, minimize, or tolerate these demands. Many authors have shown or pointed to the utility of instructing children in cognitive, behavioural, and emotional strategies to cope with pain (e.g. Duckro & Cantwell-Simmons, 1989; Moore, Geffken, & Royal, 1995), and more specifically the chronic musculoskeletal pain characteristic of JRA (Johnson & Repp, 1984; Rennebohm & Correll, 1984; Varni & Bernstein, 1991). However, there is little information on the *spontaneous* development of such skills. Many studies have examined youths' spontaneous coping responses to aversive medical procedures (Hubert, Jay, Saltoun & Hayes, 1988; Peterson, Harbeck, Chaney, Farmer & Thomas, 1990; Woodgate & Kristjanson, 1995), but few assess natural responses to chronic pain.

Ross and Ross (1984) interviewed 994 children between the ages of five and twelve years. Health experiences of the participants varied widely, ranging from those in perfect health to those with chronic conditions requiring regular medical attention, such as recurrent abdominal pain or headaches, joint disorders, leukemia, hemophilia, and sickle cell anemia. Open-ended questions were used to determine children's pain knowledge, behaviours, and use of coping strategies or skills. The authors expressed concern with the children's general lack of knowledge about pain and how to cope with it. Only 21% of subjects (n = 213) reported self-initiated use of coping skills. Identified skills included distraction with internal or external activity, physical distraction (i.e., clenching fists), thought-stopping, relaxation/imagery, and fantasy. Of note is one sub-group of children with various forms of juvenile arthritis. They were found to exhibit "a combination of coping strategies that consisted of knowing the physical pain-free limits, keeping within them, and refusing to allow oneself to become depressed about the limitations of activity" (Ross & Ross, p. 187).

Stimulated in part by this evidence, one prediction of the present study is that children with JA naturally develop responses to cope with their pain.

Typology of Coping Skills

Research in the area of coping skills has resulted in numerous theoretical constructs. The literature contains many "inconsistencies of terminology that present major difficulties in the conceptualization and evaluation of different strategies" (Fernandez, 1986, p. 141). Different terms have been used to refer to the same coping strategies. In their review of children's coping in the medical setting, Rudolph, Dennig, and Weisz (1995) summarize many of the commonly used coping terms, or constructs (see Table 1). As did Fernandez (1986), Rudolph et al. experienced difficulty in their meta-analysis of this literature. Description of some of these commonly used coping constructs illustrates the parallels in terminology. Billings & Moos (1981) categorized coping responses according to the individual's *choice of action*:

1. An *approach* response involves any active attempt to deal with the threat. "Active or approach strategies include cognitive attempts to change ways of thinking about the problem and behavioral attempts to resolve events by dealing directly with the problem or its aftermath" (Ebata & Moos, 1991, p. 34). Approach strategies can include defining the situation, information gathering, problem solving, redefining situations with a positive emphasis, seeking support or guidance from a variety of sources including one's family or peers, and direct action.
2. An *avoidant* response is considered passive. "Avoidant

Table 1

Definitions of Selected Key Coping-Related Constructs

Term	Definition
Behavioural vs. cognitive coping	*Behavioural* = external modes of coping (e.g., observable actions) *Cognitive* = internal modes of coping (e.g., subjective thoughts)
Problem- vs. emotion-focused coping	*Problem-focused* = efforts to eliminate or alter a distressing situation *Emotion-focused* = efforts to regulate emotional consequences of stress
Primary vs. secondary control coping	*Primary control* = efforts to influence objective events or conditions *Secondary control* = efforts to maximise one's fit to current conditions
Approach vs. avoidance	*Approach* = active efforts to confront a stressful event *Avoidance* = attempts to avoid a stressful event
Information seeking vs. information avoiding	*Information seeking* = efforts to acquire information about the stressor *Information avoiding* = efforts to avoid information about the stressor
Active vs. passive coping	*Active* = willingness to encounter information *Passive* = tendency to avoid or deny stress
High monitoring vs. low monitoring	*High* = scanning for threat-relevant information *Low* = ignoring threat-relevant information

Note. Adapted from "Determinants and consequences of children's coping in the medical setting: Conceptualisation, review, and critique," by K.D. Rudolph, M.D. Dennig, & J.R. Weisz, 1995, Psychological Bulletin, 118, p. 332.

strategies include cognitive attempts to deny or minimize threat, and behavioural attempts to get away from or avoid confronting the situation or to relieve tension by expressing one's emotions" (Ebata & Moos, 1991, p. 34). Avoidant responses manage tension through indirect attempts to avoid thinking about a stressor or its implications, acceptance or resignation to an existing situation, seeking alternate rewards through sources of pleasure or diversion, expressing feelings openly, or acting out.

Brown and Nicassio's (1987) construct distinguished coping as either *active* or *passive* in nature, drawing parallels between active and approach responses, and between passive and avoidant responses. Lazarus & Folkman (1984) developed the Problem Versus Emotion-Focused Coping model which classifies coping responses according to their function. A *problem-focused* coping effort is an attempt to modify the stressor. *Emotion-focused* coping efforts serve to regulate the emotional state that can accompany the stressor. Ebata and Moos (1991) suggested that approach coping is often problem-focused while avoidance coping tends to be emotion-focused.

What now appears to be required is a framework for the meaningful comparison of coping strategies. In response to construct confusion, Rudolph et al. (1995) proposed integrating the various coping typologies into two categories which

> best captured the parallels among the systems (although there is clearly not a one-to-one correspondence among the systems): (a) outer-directed coping modes, including behavioural, problem-focused, primary control and information-seeking or approach coping; and (b) inner-directed coping modes, including cognitive, emotion-focused, secondary control, and passive or avoidant coping (p. 352).

In light of identified difficulties in this area, Rudolph et al.'s (1995) proposed construct of *outer-directed* vs. *inner-directed* coping constructs will be the focus of the present study.

The Utility of Different Coping Styles

One issue addressed in the coping literature concerns which types of response are most beneficial. Letham, Slade, Troup, & Bentley (1983) proposed that approach coping can be considered adaptive, while avoidant coping is maladaptive. They hypothesized that the emotional-motivational component of pain is fear of pain. Like any other fear, it is likely to be reduced if confronted, and increase if avoided. They proposed that an 'avoidance spiral' can develop, leading to a decrease in physical and social activity. An individual with this avoidant coping style may develop an 'invalid' personal identity, experience physical atrophy, and not have an opportunity to test their ability to deal with pain. May (1991) asserts that if avoidance is the individual's response to pain, the

> perception of pain will remain high due to secondary consequences, reinforcements for illness behaviour and lack of opportunity to test out recovery. If confrontation is the response, the secondary consequences will be minimized, reinforcements will serve to increase well behaviour and the individual will have an opportunity to test out recovery (p.95).

Brown & Nicassio (1987) assessed 361 adults with arthritis to explore the relationship between coping strategies and psychological adjustment. They employed the Vanderbilt Pain Management Inventory (VPMI), which is based on the active/passive coping construct. Findings indicated that use of active coping skills was positively related to an internal health locus of control and feelings of self-efficacy, and negatively associated with pain, functional impairment, depression, and helplessness. Use of passive coping skills was positively related to external health locus of control, low self-efficacy, and a greater degree of pain, functional impairment, depression and helplessness. VPMI subscales were found to predict levels of adjustment six months later. The VPMI has since been used in a study of the role of pain and coping strategies in predicting depression in adults with rheumatoid arthritis (Brown, Nicassio, & Wallston, 1989). Cross-sectional findings revealed that passive coping, pain, and their interaction independently contributed to higher levels of depression.

Brown & Nicassio (1987) theoretically support the adaptive benefits of active/approach coping, based on the premise that

> irrespective of their type, coping strategies may be classified as adaptive or maladaptive based on their relationship to indices of pain and psychosocial functioning. Specifically, patients may use active or adaptive pain coping strategies when attempting to control their pain or to function in spite of their pain. Alternatively, patients may use passive or maladaptive pain coping strategies when relinquishing control of their pain to others, or when allowing other areas of their life to be adversely affected by pain (p. 54).

In their 1991 study of healthy and distressed adolescents, Ebata and Moos hypothesized that coping style may be a factor that moderates the relationship between threatening personal stressors and psychological adjustment. They assessed 190 adolescents: controls, and those with rheumatic disease, conduct disorder, or depression. Self-report forms were completed by mail or through telephone interview. Subjects were asked to select the most important problem they had faced in the previous year, and indicate how they chose to cope by completing the Coping Responses Inventory (Moos, 1989). This inventory is based on the approach/avoidance coping construct. Areas of psychosocial functioning such as psychological well-being, distress, and problem behaviours were assessed through additional established instruments.

Ebata and Moos (1991) found no group differences in the use of approach coping responses. Teens with depression and conduct disorder, however, showed more avoidant coping than controls or those with rheumatic disease. It was found that reliance on avoidance coping is associated with poorer long-term psychological adjustment, but they concluded that both approach and avoidance coping "may be effective in particular situations, with certain stressors, or at specific stages of the coping process" (p. 51).

A more comprehensive impression of the efficacy of approach/avoidant coping style is found in the series of meta-analyses conducted by Suls and Fletcher (1985). They examined the relative usefulness of avoidant and non-avoidant (approach) coping strategies in reducing pain, stress, and anxiety. Their sample included 43 published research reports in which attention (approach) and avoidant coping strategies were operationalized. The sample included a mixture of child and adult studies. Twenty-nine of the studies were considered short-term, in which outcome variables (i.e., pain, stress or anxiety) were measured immediately after occurrence of the stressor. The remaining 14 studies were considered long-term, where there occurred an interval of at least three days between stressor and assessment of outcome.

The majority of these studies included an acute medical procedure stressor, but some assessed coping with chronic pain conditions. In general, Suls and Fletcher (1985) found that in the early stages of the stressful experience avoidance was associated with more positive adaptation. This was true for a period of up to two weeks following stressor onset. Approach strategies were associated with more positive outcomes for longer term threats.

Rudolph et al. (1995) limited their review of coping in the medical setting to studies of children. They agreed that the efficacy of coping responses varied at different stages of the stressor. They found that if assessment occurred during the 'preparation stage' (prior to the onset of a stressor) outer-directed types of coping predicted better outcomes and adjustment. If assessment occurred during the 'encounter stage' (during experience of stressor), inner-directed coping was more productive.

Expanding on Rudolph et al.s' (1995) conclusion, it can be argued that the experience of acute pain often occurs as an 'encounter', as acute episodes are often unpredictable. This would encourage the use of inner-directed coping. On the other hand, the experience of chronic pain may become more predictable with time, allowing the child to 'prepare' for an episode with a familiar coping skill.

As pain from JA represents a long term stressor, these reviews suggest that outer-directed/approach coping responses are likely to be adaptive and show the greatest efficacy in personal management of this pain. It is thus hypothesised in the present study that children with JA who use primarily outer-directed coping skills will report less pain than those who use either primarily inner-directed coping, or none at all.

Measurement of Coping

It has been suggested that coping questionnaires targeting the behaviours of a specific clinical population are more useful than general measures (Taylor, 1990). One difficulty in this area of study is the lack of an instrument to measure coping as it pertains to juvenile arthritis. In preparation for this work, instruments were identified which assessed coping responses in youth (Ebata & Moos, 1991; Patterson & McCubbin, 1987), but none were specific to youth coping with chronic arthritic or musculoskeletal pain. In response, a goal of this study was to modify an existing adult measure of arthritic coping skills for use with youth.[1]

The target instrument for this modification was the Vanderbilt Pain Management Inventory (VPMI), developed in 1987 by Brown and Nicassio for use with adult rheumatoid arthritis patients. It is a self-report questionnaire which measures the frequency of use of 18 behavioural and cognitive coping strategies to deal with moderate to severe episodes of pain.

The item content of the initial 27 item questionnaire was developed in consultation with pain professionals, and responses were made on a five point likert scale of frequency. During the study, established instruments were

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[1] Following completion of this study, it was discovered that a new instrument to assess pediatric pain coping skills was published in late 1996 (Varni, Waldron et al., 1996). Their sample consisted of 187 children and adolescents experiencing musculoskeletal pain associated with rheumatological disease. The instrument was titled The Waldron/Varni Pediatric Pain Coping Inventory (PPCI). It was found to be a conceptually valid and internally reliable measure. In a strikingly similar vein as the present study, Varni et al. developed the PPCI "to further the understanding of the demonstrated individual differences in pediatric pain perception, pain behaviour, functional status, and to potentially give empirical direction in the development and further refinement of cognitive-behavioural pediatric pain treatment techniques" (p.142). The PPCI consists of 41 items, many of which parallel those in the CACI, the coping skills instrument adapted for this study.

also used to collect information on pain, functional impairment, helplessness, health locus of control, and general self-efficacy (Brown & Nicassio, 1987).

Of the original 368 participants, data from 259 were randomly selected to assess the factor structure of the VPMI. A confirmation of these factors with 101 of the participants was conducted six months later. At time 1, results suggested a two factor model which accounted for approximately 30% of the variance. Twenty-one items met the criteria of loading significantly on only one factor, with either no relationship or a negative relationship to the other factor. At time 2, further validity was established through chi-square (χ^2 $(120, N = 101) = 142.6$, $p > .05$) and goodness-of-fit indices ($GFI = 0.87$). The factors were negatively correlated ($r = -.29_{99}$, $p > .05$), and were found to have internal consistency ($\alpha = 0.71$ (active) and 0.82 (passive)).

Brown and Nicassio (1987) used these factors as VPMI subscales, labelled as active coping and passive coping. Of the original 27 questions, 11 passive coping and 7 active coping items were retained in the final two scales (see

Appendix B).

The VPMI was thus chosen as a statistically sound model to modify for use with JA patients. The parallels between symptomatology in juvenile and adult arthritis provide rationale for retaining basic item content. The primary alteration of the VPMI consisted of minor rewording to maintain the original item content, while ensuring comprehension by youth. Subscales of the VPMI were not maintained as it is likely that youth will show differing patterns of coping skill use. In lieu, two subscales were theoretically derived from the original 27 items. This was achieved through consultation with professionals in children's health, using Rudolph et al.'s (1995) definitions of outer-focused and inner-focused coping. Five questions did not meet the criterion of 86% agreement, while 10 were considered outer-focused and 12 inner focused (see Appendix B). The final instrument has been titled The Childrens' Arthritis Coping Inventory (CACI; see Appendix C).

Children's Health Orientations

Instructing children in cognitive and behavioural pain management strategies has proven effective as a therapeutic intervention. Resources are not available to offer such programs to all children in chronic pain, yet it appears that some children with arthritis may be independently initiating these strategies (Ross & Ross, 1984). It is of value to examine factors that influence this skill development.

The catalyst to use coping skills in response to pain may be a function of an individual's health orientations. Bush and Iannotti (1985, p. 70) define health orientations as "the whole set of personal beliefs, attitudes, perceptions, expectations, values, motivations, and psychological constructs that relate to health and illness". Numerous influences on the development of children's health orientations and behaviours have been identified, such as cognitive development, parents, siblings and peers, school experiences, and the media.

One weakness with much of the research in this area lies in the focus on individual variables. While such studies are necessary, they fail to develop a comprehensive picture of the influences on health beliefs and behaviours.

An improvement can be found in the multivariate nature of Bush and Iannotti's (1988) hypothesised Children's Health Belief Model (CHBM). This model was developed to portray and study children's conceptual systems of health and illness within a realistic personal and social context. The CHBM accomplished this by integrating salient elements of the four most influential conceptual systems that have been used to explain how children acquire and develop health orientations and behaviours, as none of these theories appeared individually adequate (Bush, Davidson & Iannotti, 1985). These systems were Cognitive Development Theory (Inhelder & Piaget, 1958), The Health Belief Model (Rosenstock, 1966), Behavioral Intention Theory (Fishbein & Ajzen, 1975), and Social Learning Theory (Bandura, 1977; see Table 2).

Literature concerning children's health choices suggested parental influence on use of tobacco and abusable substances, but had not fully examined all areas of health

Table 2

Principal Variables Associated With Children's Conceptual Systems of Health and Illness.

	Conceptual Systems				
Variables	**CHBM**	**CDT**	**HBM**	**BIT**	**SLT**
DEVELOPMENTAL					
Age	x		x	x	x
Cognitive Stage	x	x			
ENVIRONMENTAL					
Family Behaviour/Attitudes	x	x		x	x
Peer Behaviour/Attitudes	x	x		x	x
School/Media Influence	x	x		x	x
Availability	x		x		x
INDIVIDUAL					
Cognitive/Affective					
Perceived Vulnerability	x		x	x	
Health Salience/Values	x		x	x	x
Health Locus of Control	x		x		x
Self-Concept/Esteem	x	x			x
Risk Taking	x		x		x
Competency					
Knowledge	x				x
Decision-Making Skills		x			x
Coping Skills		x			x
Behavioral Capability		x			x
Personality		x			
Autonomy	x	x			x
Trauma	x				x
Health Status/Stress	x		x		

Note. CHBM = Child Health Belief Model; CDT = Cognitive Development Theory; HBM = Health Belief Model; BIT = Behavioral Intention Theory; SLT = Social Learning Theory. Adapted from "The development of children's health orientations and behaviours: Lessons for substance use prevention." by P.J. Bush & R. Iannotti, 1985. In C.J. Jones & R.J. Battjes, (eds.). *Etiology of Drug Abuse* (monograph 56). Washington, DC: National Institute on Drug Abuse, (DHHS pub. no. ADM 85-1335), p. 48.

or illness related behaviours. In response, Bush and Iannotti's works have explored how the variables of the CHBM affect children's use of medications for common illnesses, and the origins and stability of medicine-taking beliefs and behaviours (Bush & Iannotti, 1985, 1988, 1990).

For the present study, the salient variables tested concern the effect of the primary caregiver on health beliefs and resulting health coping behaviours. Although it has often been predicted that the health beliefs of children should resemble those of their primary caretaker, early studies did not support this (Campbell, 1975a, 1975b; Mechanic, 1964). Bush and Iannotti (1988) concluded that "these studies suggested that children's attitudes and beliefs about illness are more the result of general social accretion that keeps pace with cognitive developmental stages than the result of direct interpersonal learning from a primary caretaker" (p. 345). More recent studies reviewed by Bush & Iannotti suggested that parents do have a strong influence on their children's health behaviours and behavioural intentions, but to a somewhat lesser degree on their health orientations.

Bush and Iannotti (1988) examined predictors of medicine use for five common illnesses - cold, fever, upset stomach, nervousness, and trouble sleeping. They sampled 270 children between the ages of 8-14, and their primary caregivers (93% mothers). Children were privately interviewed at school, while caregivers were contacted by telephone. Bush and Iannotti used original and standardised instruments to measure the *modifying*, *readiness*, and *behaviour* variables of the hypothesised CHBM (see Figure 1). Of these, some were relevant to only child or parent, while 14 variables were measured in both. For 10 of these common variables there were significant correlations between mothers' and children's reports, including both health behaviour variables of medicine use and physician visits (see Figure 1). Health beliefs relative to the use of medicines for common health problems were as likely to be correlated between mothers and children as were behaviours or expected behaviours. Primary readiness and modifying variables suggest many of the health related beliefs were derived at least in part from primary caretakers.

Bush and Iannotti (1990) further examined their 1988 data set. Their two primary hypotheses were "1) CHBM variables predict children's expectations to take medicines and 2) caretaker health beliefs and expectations increase the ability of the CHBM to explain children's states of readiness and expectations to take medicines" (p. 71). Separate regression analyses were performed first with children's response variables, then with the inclusion of caretaker variables to examine any increased ability of parental influence to predict medication use. With caretaker variables in the regression, overall R^2 increased by a small but significant amount (0.67-0.69, $F_{13,256} = 2.88$, $p < 0.01$). Although the CHBM without caretaker variables explained a sufficient amount of variance for the purposes of predicting medication use, caretaker variables are valuable to help explain the origin of child readiness variables.

The role of family influence is also outlined by Tinsley (1992) in her review of studies examining the varied influences on children's health attitudes and behaviours. She concluded that the aggregate of results provides support for the hypothesis of intergenerational similarity in health

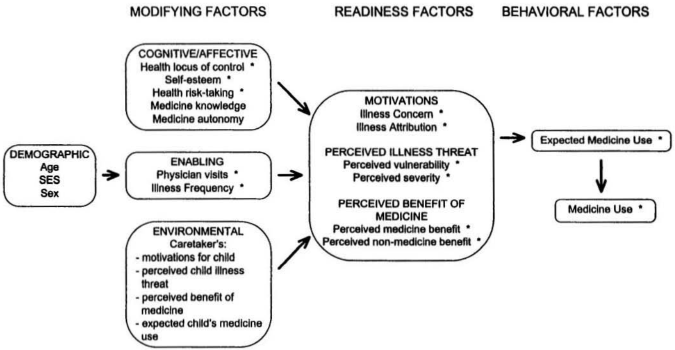

Figure 1. Children's Health Belief Model. * = p. < 0.01 in correlation of mother's and child's reports. Arrows indicate hypothesised causal relationship pathways. Adapted from " A Children's Health Belief Model", by P.J. Bush & R.J. Iannotti, 1990, Medical Care, 28, p. 71.

orientations and behaviours. These were thought to "underscore that the family clearly constitutes an important social unit for the production of children's health related attitudes and behaviours, although just as clearly, the relations among these variables have yet to be adequately explored" (p. 1051). She proposed that "parents create supported learning situations in which their children can extend their skills and knowledge to a higher level of competence" (p. 1045).

An additional question in this area concerns variation in the strength of parental influence as children age, with conflicting evidence in the literature. Campbell (1975a) found that intergenerational similarity between illness ideas was higher between older than younger children and their mothers. Dielman et al. (1982) also found age of the child to be a factor, through a study of parents' own health behaviours and their children's utilisation of illness prevention resources. A positive relationship occurred only when the children were mature enough to initiate their own health decisions. Conversely, the more recent work of Bush & Iannotti (1988) found parental modelling to be strongest in pre-school and primary age children, with a reduced influence past elementary school when there is increased exposure to peers and other societal influences, and more complex cognitive development. Their data indicated that children's health beliefs were relatively stable by age nine or ten, and neither the pattern of means nor the correlations suggested that the relationship with parental beliefs is stronger for older children.

The following studies indicated that influencing a child's beliefs may not always produce tangible behaviours. Pratkanis, Breckler, and Greenwald's (1989) results support only a modest relationship between children's health attitudes and their actual behaviours. This appears to change with maturity as, in general, a stronger relationship exists between adult health orientations and their behaviours (Wallston & Wallston, 1984) with substantial association demonstrated between parental health beliefs and their health behaviour *on behalf of* their children (Tinsley & Holtgrave, 1989). Dielman et al.(1982) found that parents *demonstrate* health care behaviours more frequently than they *express* or *discuss* actual beliefs. They contended that parent's health beliefs influence children's preventative health behaviour only indirectly. It appears that children may be learning primarily from a combination of their parent's own health behaviours and the parent's care-taking behaviours directed toward them.

The examination of the intergenerational transmission of health beliefs is much debated and suffers from a lack of methodological consistency between studies. Although age related trends are somewhat inconclusive, it appears that parents do have a role in influencing their children's development of health orientations and behaviours. Iannotti & Bush (1986) argued that even when children are young, mothers daily provide them with many health messages or indicate concern for their health. It is plausible that should caregiving demands increase through a child's development of chronic illness, so may the frequency of these health messages. This may place children with chronic pain in a position to be more influenced by parents' beliefs and behaviours of health management and pain coping. One aim of this study is to explore the relationship between the primary caregivers' beliefs regarding which coping skills are most effective for their child to use, and those their child reports using.

The Present Study: An Overview

This study was undertaken to investigate variables related to the use of coping skills by youth with chronic musculoskeletal pain. Initially it was intended to survey children with a diagnosis of juvenile rheumatoid arthritis. Local population estimates of children with JRA were made by health professionals, and appeared to support this aim. Also, based on the population of Newfoundland and Labrador, one might expect to identify upwards of 250 youth with a diagnosis of JA. Prospective statistical power analyses (Cohen, 1992) for the current study suggested a sample size of 85 participant families. This number was chosen to accommodate a predicted medium effect ($p < .05$) for a multiple regression analysis with three independent variables, and correlational analysis. Unfortunately, fewer children with confirmed diagnoses were identified than predicted. Some explanations for this discrepancy include:

(a) during the period between estimate and eventual data collection a cohort of youth had passed the maximum age for inclusion, (b) many children were younger than the established minimum age, (c) previously identified families had relocated (d) other differential diagnoses were being considered, and (e) other present medical conditions or personal stressors were likely to present confounds. Geographical isolation, and the relatively small population of Newfoundland and Labrador were undoubtedly also limiting factors.

Peterson, Mason, Nelson, O'Fallon, and Gabriel (1996), found that the incidence rate of JRA per 100 000 population dropped from 15.0 to 7.8 over the 33 year period of 1960-1993. The decrease was most marked for pauciarticular and systemic onset sub-types. They suggested that this change may represent a natural cycle, or be influenced by environmental factors. Perhaps the region of Newfoundland and Labrador is also at a low point in a natural epidemiological cycle. The medical criteria for inclusion in this study were thus broadened to include children with a diagnosis of any juvenile arthritis, connective tissue disorder and a history of related musculoskeletal pain. The revised aim was to assess the responses of 40 youth and their primary caregiver(s). All reasonable efforts were made to meet this goal, however, complete data was obtained from only 16 participant families. Small sample size reduced the range of appropriate analyses, statistical power, and possible generalizations. Revisions were made to the hypotheses and analyses in order to best answer the proposed questions, while in so far as possible maintaining sound statistical principles.

One intent of this study was to use multiple regression analysis to assess whether coping skills had a predictive relationship with expressed pain. Also planned were correlational analyses, a measure of internal consistency, and descriptive statistics. The limited sample ruled out multiple regression to explore a possible predictive relationship. In lieu, correlation between youth coping style and reported pain are presented. Small sample size also prevented comparisons of the child and adolescent groups.

To facilitate assessment of coping skills related to juvenile arthritis, a goal of this study was to modify an existing adult instrument to be valid and developmentally appropriate. The construct used to re-structure the Vanderbilt Pain Management Inventory was outer-directed vs. inner-directed coping. The resulting scale was titled the Childrens' Arthritis Coping Inventory (CACI).

Analysis of the CACI and its subscales was also hampered. Combined with the small sample size, the small number of items in the CACI (22) and its' subscales (10 and 12) contraindicates the internal consistency analysis of Cronbach's alpha. Also for this reason, a complete correlation matrix of scale items is not presented. Correlation of subscales are reported, but interpretation must cautiously focus on comparisons with the CACI total coping score. Relationships of CACI subscales with other variables will be reported only for purposes of identifying interesting trends and questions for further study.

As discussed earlier, one puzzling aspect of JA is that children with the same degree of disease can experience different amounts of difficulty with pain and daily functioning, and an explanation may lie in understanding the coping skills children develop to help control their pain. The evidence reviewed suggests that children with JA who use outer-directed coping skills are likely to report less pain than those who use either inner-directed coping, or none at all. This study investigated the type and number of coping skills youth were using, and how the type of action chosen related to expressed pain. It would have been interesting to have been able to assess developmental differences through a comparison of child and adolescent responses.

A final question concerned the role of the family, specifically parents' estimates of their child's coping and parents' opinions as to which coping skills are most effective, and how these relate to the skills their child reports using.

Hypotheses and Analyses

The modified hypotheses and analyses of the current study were as follows:

Hypothesis 1. Correlational analyses of the two CACI sub-scales will show (a) a negative relationship of the subscales with each other, and (b) a positive relationship of each subscale with the total score.

Hypothesis 2. Youths' reported pain will show a positive correlation with inner-directed coping skills, and a negative correlation with outer-directed coping skills.

Hypothesis 3. A parent's estimate of which coping skills their child uses will have a positive correlation with their child's reported behaviours.

Hypothesis 4. A parent's estimate of which coping skills they believe to be most effective for arthritis pain management will have a positive correlation with their child's reported coping skill use.

Method

Participants

Fifty-three families of youth (aged 6-18 years) with a diagnosis of JA were identified, with sixteen (30%) providing complete data. One additional set of data was discarded as the child was unable to estimate frequencies reliably. Ten families who chose not to participate in the study returned demographic information forms to allow comparison for representativeness of the sample. The total of 26 families who provided demographic data amount to 49% of those contacted.

Eleven participant families were surveyed through personal interview, while five provided data entirely by mail. Youth participants were divided into child (ages 6-11) and adolescent (ages 12-18) groups. A large proportion of youth participants were in the age clusters of 8 to 9 years (n = 6, 38%) and 16 to 18 years (n = 4, 25%). Demographic and medical characteristics of the youth are provided in Tables 3 and 4 respectively. Eighty-eight percent (*n* = 14) of families included two parental figures, with two single parent homes. Families were composed on

Table 3

Participant and Non-Participant Demographics

Variable	Participant Families	Non-Participant Families
Age of Youth		
Mean	12 yrs. 6 mos.	12 yrs. 11 mos.
SD	4 years	4 years
Range	6 yrs. 7 mos. - 18 yrs. 7 mos.	5 years 6 months - 17 years
Youth's Sex		
Female	n = 9 (56%)	n = 9 (90%)
Child	n = 6	n = 3
Adolescent	n = 3	n = 6
Male	n = 7 (44%)	n = 1 (10%)
Child	n = 1	n = 0
Adolescent	n = 6	n = 1
Age Group		
Child	n = 7 (44%)	n = 3 (30%)
Adolescent	n = 9 (56%)	n = 7 (70%)

Table 3 (continued)

Participant and Non-Participant Demographics

Variable	Participant Families	Non-Participant Families
Family Members In the Home		
Total		
Mean	4.3	4.3
SD	0.9	0.8
Females		
Mean	2.2	2.6
SD	0.9	1.0
Males		
Mean	2.1	1.7
SD	0.9	0.8
Mother's Age		
Mean	37.9 years	37.4 years
SD	3.9 years	4.7 years
Father's Age		
Mean	40.4 years	40.9 years
SD	4.5 years	5.6 years
Parents In Home		
2 parents	n = 14 (87.5%)	n = 9 (90%)
1 parent	n = 2 (12.5%)	n = 1 (10%)
Family Income		
Mean	\$ 58 300[a]	\$ 51 200[b]
SD	31 010	45 740

[a] $N = 12$. [b] $N = 6$

Table 4
Youth Arthritis Characteristics

Variable	Participant Families	Non-Participant Families
Age At Diagnosis		
Mean	6 yrs. 6 mos.	8 yrs. 8 mos.
SD	4 yrs. 7 mos.	5 yrs. 2 mos.
Range	2 yrs.-17 yrs.	2 yrs.-15 yrs.
Time Since Diagnosis.		
Mean	6 yrs. 4 mos.	4 yrs. 2 mos.
SD	3 yrs. 1 mo.	4 yrs. 7 mos.
Range	18 mos. - 11 yrs. 6 mos.	6 mos. - 13 yrs. 6 mos.
Disease Onset Type[a]		
Pauciarticular JRA	n = 5	-
Polyarticular JRA	n = 6	-
Systemic JRA	n = 1	-
Dermatomyositis	n = 1	-
Disease Activity		
Remission	n = 1	-
Quiescent	n = 3	-
Mild	n = 4	-
Moderate	n = 4	-
Severe	n = 0	-
Prescribed Medication		
Yes	n = 14	-
No	n = 2	-

[a] *N* = 13 as Physician Report Form data was not provided for all youth participants. - = information not available for non-participant families.

average of four people. Adult questionnaires were completed by mothers in 12 cases, fathers in one, and both parents in three. Additional demographic data for both participants and non-participants are included in Table 3.

Questionnaires

Physicians' Report Form. The Physician's Report Form (Appendix D) is a brief questionnaire compiled for this study. It was used to record basic medical data related to arthritis. This consisted of (a) the date at which the information was obtained, (b) whether medications were currently prescribed, (c) a measure of youth's pain through a visual analogue scale, (d) a measure of global arthritis activity through The Disease Activity Index (DAI, Varni, Wilcox, Hanson, & Brik, 1988); (e) youth's arthritis onset subtype, and (f) approximate date of diagnosis.

Varni-Thompson Pediatric Pain Questionnaire (PPQ). Administered through a semi-structured interview, the PPQ provides a comprehensive assessment of youth pain experience (Varni, Wilcox, Hanson, & Brik, 1988). There are separate child, adolescent, and parent forms to allow for crossvalidation. Three primary assessment tools are used to measure pain: (a) visual analogue scales (VAS); these are 10 cm ratio scales anchored with facial expressions or pain descriptors to indicate pain intensity; (b) body outlines with coloured or numerical indicators to record the location and relative intensity of the youth's pain, and (c) pain descriptors to tap sensory, affective and evaluative qualities (Varni & Bernstein, 1991). Varni et al.(1988) have found that in children with JRA who are over 5 years of age, VAS reports of pain correlate highly with both parental ($r = 72_{23}$, $p < .001$) and physician ($r = .85_{23}$, $p < .001$) ratings. An additional section recorded the youth and family's pain history through questions on symptomatology, past and present treatments for pain, and potential socio-environmental influences.

The supplementary demographic information required for sample comparisons in this study was requested at the end of the parent's PPQ form (see Appendix A).

Core features of the PPQ have solid empirical support. It is P.J. McGrath's (1990) view that "semi-structured interviews should be incorporated into all clinical pain assessments for children. These provide a basic framework that can then be complemented by quantifiable scales" (p. 19). The PPQ administration and content satisfy both criteria. The Visual Analogue Scale (VAS) has been found to fulfil the requirements of reliability, validity, minimum inherent bias, and versatility (P.A. McGrath, 1986).

Complete forms of the three available versions of the PPQ (Child, Adolescent, and Parent) were used[2] (Varni and Thompson, 1985; see Appendix A). To address the hypotheses of the current study, only the PPQ visual analogue scale pain reports were used to assess pain experience and create a composite pain score. Additional PPQ data have been reserved for possible use in future reports.[3] Adolescents and adults provided six discrete estimates of the youth's

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[2] Copies and written permission to use the unpublished PPQ in this study were obtained from Dr. J.W. Varni.

[3] Although data were collected using the PPQ body outline, responses proved difficult to summarise reliably. Primary difficulties included (a) identifying number of affected joints in multiple joint body areas such as hands, feet, and spine; (b) comparing child and adolescent responses as the child task was less detailed and discrete, and (c) the body outline measure did not clearly represent overall severity of pain, which was the desired data (i.e. 10 mildly affected small joints are not necessarily as painful or debilitating as one severely effected large or weight bearing joint).

pain, while children provided four (see PPQ, Appendix A). These represented pain experienced over a two week period. A composite pain score was calculated from the mean of these estimates for each participant. Multiple pain measures and a composite figure was necessary to obtain a reasonable estimate of the youth's typical pain experience. A single measure may have risked an unrepresentative report measured on an atypically good or bad day. Daily pain diaries for a longer period would have been preferable. This method was not chosen because the risk of non-compliance and incomplete data was judged too great.

The Children's Arthritis Coping Inventory (CACI). The CACI was developed for this study from Brown and Nicassio's (1987) Vanderbilt Pain Management Questionnaire (VPMI). The primary alteration of the VPMI consisted of minor rewording of items so as to maintain the original item content, while ensuring comprehension by young participants. One Child/Adolescent and two Parent forms of the CACI were created, with the Child/Adolescent form incorporating client-centred language. Youth and Parent forms (see Appendix C) were identical except for initial instructions.

Youth reported their actual coping skill use. Parent forms (P1 and P2) asked parents to *estimate* how often their child used each coping skill (P1), and their *opinion* of how often it would best serve their child to use each skill (P2).

Two subscales were derived by using Rudolph et al.'s (1995) suggested definitions of outer-focused and inner-focused coping. Alphabetically ordered CACI items were independently grouped into these two subscales by the author and six psychologists working with children and adolescents. The criterion for inclusion in a subscale was item agreement by six of the seven judges (86%). Of the original 27 items, 10 were regarded as outer-directed coping and 12 as inner-directed coping. Five items were not included in either subscale as they obtained less than the required agreement (see Appendix E).

The original CACI likert scale provided a choice of frequency from 1-5. To allow data analysis of composite coping scores to be more representative of actual presence or absence of behaviour, obtained scores were transformed to a 0-4 range. To examine frequency of use, all 27 original CACI items were administered to youth and parents. In the calculation of total, inner-directed, and outer-directed coping scales only the 22 items which met the inter-rater agreement criteria were included (see Appendix E).

Materials

A pre-test was administered to ensure young children's ability to estimate frequency using a likert scale. Materials for this test consisted of fifteen colour samples mounted on white cardboard, five each of red, blue, and green. These were obtained from commercial paint samples, and colour saturation ranged equivalently from light to dark. Each set had a random presentation order indicated on the back of the squares (see Appendix F).

A supplementary likert chart was used as a visual aid for all child age group participants. This consisted of an 18 cm x 66 cm standing cardboard display featuring black figures on a white background. It included 1.5 cm numerals from one to five, each paired with a corresponding 7 cm pie chart graded by quarters (i.e., 1 = empty circle, 5 = whole circle). Children were provided with Crayola markers to use in completing questionnaires. Adolescents and adults were provided with pencil or pen, but did not use supplementary visual aids.

Procedure

Recruitment. Participants were solicited from the clinical populations of four pediatricians in the province of Newfoundland and Labrador. These physicians provided primary medical follow-up for youth with arthritis from all areas of the province. This project was initially discussed with a pediatrician from The C.A. Janeway Child Health Centre[4] to aid in developing inclusion criteria. It was further discussed with each physician in person, or through an introductory letter followed by phone calls.

Physicians identified families who met criteria for inclusion. Letters soliciting participation were mailed to identified families by the child's physician or support staff (see Appendix G). Parents were given the option of responding to the researcher by telephone or mail. Six weeks later a support staff employee of the C.A. Janeway

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[4] The pediatric tertiary care facility of The Health Care Corporation of St. John's.

Child Health Centre identified those families who had not made contact, and mailed them a brief reminder letter (see Appendix G). A letter from the researcher was included, to clarify some common questions participants had raised, and to provide families of adolescents with the option of participating entirely by mail. All correspondence included a form requesting anonymous demographic information from those who chose not to participate in the study (see Appendix G), in order to determine whether the participant sample was representative of the population.

Participation Through Interview. Families who indicated an interest in participating were given an appointment for the interview session. The researcher travelled to conduct interviews in the eastern, central, and western regions of the province. Participants were given the choice of meeting in their home, in a university setting, or at the C.A. Janeway Child Health Centre.

Data were collected from the youth and the parent(s) who indicated being primarily involved in their care. Prior to data collection, time was taken to develop rapport with the family. An explanation of the study was given, with verbal and written informed consent obtained from parents and youth (see Appendix H). To ensure confidentiality, once post-test data was received and matched, all data was identified only by a subject number. The parent(s) and youth completed the instruments in separate but adjacent areas to minimise interference or response bias.

1. Parents. Parents were asked to complete the PPQ adult form and two copies of the CACI, one concerning which coping strategies their child used, and the second identifying which coping strategies the parent(s) believed to be most effective for children with arthritis. The researcher introduced test materials to the parent(s), answered any questions, and allowed privacy to complete the questionnaires. Completion time of these three instruments ranged from 30 to 60 minutes. Parents were offered any additional required assistance following their child's participation.

2. Children. All child age group participants were asked to complete the Child version of the PPQ and the Youth form of the CACI. This data was gathered through a semi-structured interview, and completion time varied from 20 to

30 minutes. The supplementary likert chart was explained and offered for use.

3. Children Younger Than Eight Years. Young children were asked to complete the materials described above. As the CACI likert scale required the judgement of greater and lesser amounts, a pre-test was performed by children younger than eight years. This was to ensure comprehension of the task and consistent responses. Colour blindness was ruled out by questioning the parent and ensuring the child's ability to visually discriminate red, blue, and green. The child was asked to choose a preferred colour from these three. The chips of the chosen colour group were arranged before the child in a pre-determined random order (see Appendix F), and he/she was asked to place the chips in order of intensity, i.e. "Which square is the most red?, Which is the least red?", etc.. The child was given the opportunity to make corrections once the order was initially chosen. If errors were made, the interviewer explained the correct order. On such occasions, the task was repeated with a second colour group. If further errors were made, the session proceeded normally, but the data was discarded.

The pretest was only required for the two youngest children, and in one case clearly indicated that the child did not understand how to consistently estimate greater and lesser amounts.

4. Adolescents. Adolescents were asked to complete the Adolescent version of the PPQ and the Youth version of the CACI through semi-structured interview. If there was no arthritic discomfort in writing, and it was clear the task was understood, the adolescent was permitted to complete some items independently. The researcher remained nearby to provide any necessary clarification. Completion time varied from 30 to 60 minutes.

Debriefing. Families were thanked for their participation and given an informal debriefing. A suitable time for a follow-up telephone call was then established.

Post-Measure. One week later, youth and parent were contacted and asked to complete copies of the PPQ visual analogue scales (pain post-measure) independently. Families were provided with a return envelope for these scales. Families were mailed further debriefing information upon the interviewer's receipt of the post-measures (see Appendix I) and encouraged to contact the interviewer should they have additional questions. They were given the option of receiving a summary of results.

Participation By Mail. Families with adolescents were also eligible to participate entirely by mail, as adolescents were able to complete questionnaires independently. Families who chose this option were mailed questionnaires, instructions outlining the procedure, and return envelopes. When participants had received the materials, the researcher contacted them by telephone to discuss issues of consent and any questions. They were asked to return the initial questionnaires and consent form immediately following completion, and to separately mail the PPQ visual analogue scales (pain post-measure) data one week later. The follow-up debriefing letter was mailed to participants once their initial data had been received.

All 16 participant families indicated a preferred physician, who was asked to complete the Physician's Report Form within one week of the initial family data collection. Physicians will also be provided with a summary of the study results.

Results

All data analyses were performed with Microsoft Excel software. A required alpha level of *p* <.01 was uniformly applied, necessary conservatism in light of sample size and number of analyses performed.

<u>Comparison of Participants to Non-Participants.</u> Although the initial criteria were broadened to include children with any JA connective tissue disease, 94% (15/16) of the participant children had a diagnosis of JRA, forming a fairly homogeneous participant group. Ten non-participant families returned demographic information forms. Two-tailed t-tests indicated no significant demographic differences between the participants and non-participants (df = 16-24, see Table 3) in a comparison of most family characteristics. For the non-parametric variables of youth sex and age group, chi-square analyses were not significant (χ^2 (1, N = 16) = 0.02, χ^2 (1, N = 16) = 0.08, respectively). It is of interest that mean age of the two groups of youth was roughly the same (12 years 6 months vs. 12 years 11 months) but participant children were roughly two years younger at

diagnosis, and had suffered arthritis for two years longer.

Hypotheses

Hypothesis 1. As previously outlined, division of the CACI into two subscales representing outer-directed and inner-directed coping styles was achieved through a theoretical analysis by experienced professionals. Interrater agreement on each item ranged from 50 to 100%, with an average agreement for the total scale of 88%. The minimum agreement for inclusion of any one item in a subscale was six out of seven, or 86%, and was met for 22 of the original 27 items (see Appendix E).

Participants reported the use of coping skills, at a mean rate of 39.4 (*SD* = 6.9) for the total 22 CACI sub-scale items. This represents a mean use for each item of 1.79, or "sometimes". Use of the 12 items of the inner-directed coping sub-scale were reported at a mean of 19.6 (*SD* = 5.3) and the 10 outer-directed items a mean of 19.9 (*SD* = 5.3). These scores show mean use for each inner item as 1.6 and for each outer item as 1.99. This indicates that in general youth do report the use of both inner-directed and outer-directed coping strategies "to lessen the pain or bad feelings" (see Appendix C).

It was hypothesised that the two CACI sub-scales would have a negative relationship with each other, but positive relationships with the Total coping scale score. Correlation of the inner- coping scale with the outer-coping scale showed $r = -.13_{14}$. The hypothesis of a significant negative relationship was thus not supported. Correlation of each sub-scale with the total coping scale was $.66_{14}$, ($p < .01$, see Table 5). This supported the original hypothesis.

Hypothesis 2. It was predicted that youth reported pain would show a significant positive correlation with inner-directed coping skills, and a significant negative correlation with outer-directed coping skills. Youth pain was found to be significantly associated with inner- coping style ($r = .67_{14}$, $p < .01$), while the relationship of pain with outer- coping was not significant, but suggested a negative association ($r = -.33_{14}$). Data suggested a non-significant but positive relationship between reported youth mean pain and total coping score ($r = .26_{14}$).

Data showed that all children were reporting the use of both outer-directed and inner-directed coping skills. This mix may cloud relationships of coping style with reported pain. A relative 'surplus' inner-directed coping score was obtained by subtracting the youths' outer-directed sub-scale score from the inner score. The remainder, an indication of proportionately more or less inner-directed coping was correlated with reported pain. For this analysis, $r = 0.66_{14}$ ($p < .01$), indicating a positive relationship between reported pain and the use of greater relative proportions of inner-directed coping skills.

The opposite analysis of deriving the surplus of outer-directed skills (outer scale score minus inner scale score) showed a negative but non-significant relationship ($r = -0.13_{14}$). These results thus partially support the proposed hypothesis.

Hypothesis 3. It was hypothesised that a parent's estimate (P1) of which coping skills their child uses will have a significant positive correlation with their child's reported behaviours. As seen in Table 5, however, this prediction was not supported ($r = .12_{14}$). Parents did appear

Table 5

Relationship of Youth and Parent Coping Reports

Variable		1	2	3	4	5	6	7	8	9
1. Youth Total		-								
2. Youth Inner-Directed		*.66	-							
3. Youth Outer-Directed		*.66	-.13	-						
4. Parent 1 Total	(P1)	.12	.21	-.06	-					
5. Parent 1 Inner	(P1)	.14	.32	-.15	*.94	-				
6. Parent 1 Outer	(P1)	.08	.04	.06	*.91	*.70	-			
7. Parent 2 Total	(P2)	.30	.13	.27	.51	.47	.48	-		
8. Parent 2 Inner	(P2)	.42	.51	.04	.33	.39	.21	*.69	-	
9. Parent 2 Outer	(P2)	.08	-.23	.33	.43	.32	.48	*.81	.13	-

Note. Parent 1 = estimate of how frequently their child uses different coping skills; Parent 2 = opinion of desired frequency of most useful coping skills.

to estimate reasonably the mean *amount* (P1) of coping efforts their child made (P1, see Table 6). It is also illustrated that parents provided a marginally better estimate of their child's use of inner-directed coping skills, than of outer-directed ones ($r = .32_{14}$ versus $r = .06_{14}$, see Table 5).

Hypothesis 4. It was hypothesised that a parent's opinion (P2) of which coping skills they believe to be most effective for arthritis pain management will have a significant positive correlation with their child's reported coping skill use. As seen in Table 5, this prediction was not supported. Parents' coping skill *opinions* (P2) concerning coping skill effectiveness, however, were more strongly associated with the child's *actual use* than were their *estimates* of coping skill use (P1, see Table 5). Table 6 indicates that parents believe that children with arthritis would benefit from using a greater amount of outer-directed coping more frequently (*M* = 27.1, or "often") than the children currently do (*M* = 19.9, "sometimes").

Table 6

Comparison of Youth and Parent Coping Reports

Pain and Coping Reports/Estimates	Mean	Standard Deviation
Pain		
Youth	2.8	2.4
Parent	2.8	2.7
Physician	2.0	2.7
Total Coping		
Youth	39.4	6.9
Parent		
P1 (estimate)	36.4	15.5
P2 (opinion)	45.6	8.2
Inner-Directed Coping		
Youth	19.6	5.3
Parent		
P1 (estimate)	19.8	9.2
P2 (opinion)	18.5	4.9
Outer-Directed Coping		
Youth	19.9	5.3
Parent		
P1 (estimate)	16.6	7.6
P2 (opinion)	27.1	6.0

Note. *N* = 11 for physician's pain rating, for all other data *N* = 16.

Additional Observations

As is shown in Table 6, average pain estimates by youth and parents were relatively low, with means of 2.8 out of 10 on the visual analogue scales. Parents showed a reasonable degree of accuracy in estimating the pain their child was experiencing ($r = .81_{14}$, $p < .01$, see Table 7). This is an even stronger relationship than Varni, Wilcox et al.'s (1988) report of parent and child pain report correlations ($r = .72_{23}$). Table 8 outlines the relationships between individual and composite parent-child pain reports. Many of these are significant, as would be expected by the significant composite score relationship. Table 8 also illustrates an interesting trend in that the relationship between parent and child pain reports are stronger at time 2 (post-test) than at time 1.

Physicians reported a lower mean pain estimate of 1.98 (*SD* = 2.7), as compared to the 2.8 reported by both youth (*SD* = 2.4) and parents (*SD* = 2.7, see Table 6). Although the physician ratings are lower, this is not a meaningful comparison as physician ratings were only available for 11 participants, and could not be obtained within the proposed time frame of one week post-testing. This discrepancy is

Table 7

Relationship of Reported Pain With Youth's Coping

	1	2	3	4	5
1. Youth Pain Report	-				
2. Parent Pain Estimate	.81*	-			
3. Youth Total Coping	.26	.05	-		
4. Youth Inner Coping	.67*	.46	.66*	-	
5. Youth Outer Coping	-.33	-.40	.66*	-.13	-

* $p < 0.01$

Table 8

Relationship of Parent and Youth Pain Reports

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Youth Now T1	-													
2. Y. Avg. T1	.79*	-												
3. Y. Worst T1	.90*	.80*	-											
4. Parent Now T1	.56	.32	.42	-										
5. Par. Avg. T1	.66*	.53	.74*	.80*	-									
6. Par. Worst T1	.43	.23	.61	.67*	.92*	-								
7. Youth Now T2	.60	.48	.75*	.65*	.95*	.89*	-							
8. Y. Avg. T2	.50	.86*	.47	.55	.58	.40	.55	-						
9. Y. Worst T2	.58	.77*	.75*	.51	.83*	.81*	.80*	.69*	-					
10. Parent Now T2	.60	.45	.69*	.65*	.83*	.82*	.84*	.62*	.69*	-				
11. Par. Avg. T2	.35	.27	.43	.71*	.74*	.83*	.66*	.61	.67*	.85*	-			
12. Par. Worst T2	.40	.23	.57	.60	.84*	.93*	.78*	.32	.86*	.77*	.83*	-		
13. Youth Mean	.82*	.89*	.93*	.58	.88*	.78*	.87*	.74*	.91*	.79*	.65*	.74*	-	
14. Parent Mean	.54	.37	.64*	.80*	.95*	.96*	.88*	.56	.82*	.90*	.90*	.93*	.81*	-

Note. * = $p < 0.01$; T1 = pain measures provided at interview; T2 = pain measures provided one week later; Avg. = average.

also likely contributed to by the often lengthy period of time since the youth's last physician visit.

Youth as a group report using the two types of coping skills with similar frequencies (see Table 6). For a ranked list of frequency of youths' reports of all 27 individual coping skills, see Table 9. It is interesting to note a general tendency for outer-directed coping skills to be reported more frequently, with a number of inner-directed among the least frequently used skills.

Table 9

Frequency of Use of Individual Coping Skills

Coping Skill	Freq.	Type
Wish that the pain would stop.	3.0	I
Watch television.	2.7	D
Lie down to rest.	2.6	O
Participate in a hobby or some activity that I like.	2.6	O
Try to think about something else/distract myself.	2.4	D
Relax my muscles.	2.4	O
Exercise or do physical therapy.	2.3	O
Ignore the pain.	2.3	I
Stay busy or active.	2.2	O
Take a warm bath or rub on ointments.	2.1	O
Think that I can handle the pain all by myself.	2.1	I
Not think of things that bother me.	2.1	I
Tell others how much the pain hurts.	2.0	O
Let out my feelings when I am angry, sad, or fed up with the pain.	2.0	O
Take medicine to make the pain go away quickly.	1.8	O
Not move around or do other things that I know will make the pain worse.	1.8	D
Think about nice things or pleasant times.	1.8	I
Read or look at books for a while.	1.6	O
Think about where the pain is and how much it hurts.	1.5	I
Keep my feelings inside when I feel angry, sad, or fed up with the pain.	1.4	I
Depend on others to help me with everyday things.	1.3	D
Wish my doctor or parents would give me better pain medicine.	1.3	I
Think that the pain is getting me down.	1.2	I
Wonder if I did something to make the pain worse.	1.2	I
Think I can't do anything to cope with the pain.	1.1	I
Not go out with my friends or family as much.	0.8	I
Ask my parents to call or take me to a doctor or nurse.	0.4	O

Note. Values from adjusted likert scale: 4 = very often, 3 = often, 2 = sometimes, 1 = rarely, 0 = never. I = inner-directed coping, O = outer-directed coping, D = dropped (item not included in final subscales analyses); freq. = frequency of reported use.

Discussion

Sample Characteristics. Although statistical analyses show no significant differences between participants and non-participants, some trends indicate potential influencing factors. Of all 26 participant and non-participant children, we see that the sample roughly fits the expected 2:1 female to male ratio. In the participant group the sex ratio was more closely 1:1, for which there presents no obvious explanation. Although mean age of the two groups of youth was roughly the same (12 years 6 months vs 12 years 11 months), the distribution differs in that the participant children were roughly two years younger at diagnosis, and have suffered arthritis for two years longer. If children are developing skills or strategies to cope with their disease, an additional two years may result in a more extensive or refined skill pattern.

Another possible sample bias may be related to disease severity. Anecdotal evidence from physicians and allied health professionals suggested that some children in the province experience severe JRA. However, no children with severe arthritis as measured by the Disease Activity Index, participated in the study, and participants reported a mean pain experience of only 2.8/10.0. It is likely that the level of pain, disability, and resulting medical interventions would be higher for youth with severe arthritis. Perhaps parents of children with severe JA did not volunteer in order to spare their child any additional difficulty or inconvenience. This is supported by a comment from the parent of a child with moderate JRA. She chose to participate only after the mail-in option was offered. She reported this was partly because of distance, but primarily because of her perceived need to shelter her child from additional "interventions". Varni et al.'s (1987) procedure of gathering data during a regular medical clinic visit may serve both to reduce the family's inconvenience, and to allow for more reliable physician pain estimates.

Youth Coping Skills. The literature suggests that outer-directed coping skills should prove adaptive when coping with chronic pain, and that inner-directed skills are likely maladaptive under the same circumstances. Results of the present study indicated that youth with JA are using a combination of both to deal with chronic pain. All participants were naive in the sense that they had not received specific cognitive-behavioural pain management instruction. It is likely, however, that their coping skills have been influenced by exposure to multidisciplinary health care management.

The development of Varni, Waldron et al.'s (1996) pain coping instrument (PPCI) is encouraging as it confirms the need for this type of investigation. In future study it will now be possible to assess construct validity of the CACI through comparison of youth's responses to both instruments.

The predicted relationships of inner-directed coping (positive) and outer-directed coping (negative) to reported pain were supported, although outer-directed coping not significantly so. The degree of a 'surplus' of inner-directed coping was significantly related to pain, but 'surplus' outer-directed coping was not. The data appears to support the adaptive nature of outer-directed coping as related to less reported pain, and the maladaptive nature of inner-directed coping as related to greater reported pain. It appears that use of outer-directed coping may not greatly impact (reduce) the pain experience, but that proportionately more inner-directed coping may serve to focus or heighted the experience of pain. This pattern of results is reminiscent of Ebata & Moos (1991) findings with avoidant and approach coping (see P. 26).

There are likely, however, many potential confounding factors in these relationships. One example is individual pain threshold. As a group, youth with JA have been shown to have significantly lower general pain thresholds than their healthy peers, even in the absence of active or even detectable inflammation (Hogeweg et al., 1995). In Hogeweg et al.s' study, youth exhibited an enhanced sensitivity to noxious stimuli in all measured body areas, suggesting a change in the natural pain processing system through JA. It is also likely that between youth there also exists individual variability in pain threshold. These factors could not be measured or accounted for in the present study, but may not have been of great importance as general levels of reported pain were low (see Table 6).

Parents Influence. The hypotheses that child coping reports would be positively related to parental coping estimates and opinions concerning effective pain management were not supported. It is interesting, however, that parents provided better mean estimates of 'covert' inner-directed coping skills than the presumably more observable outer-directed ones. This is the opposite of what the researcher would have predicted. This tendency is surprising, as parents also reported the opinion that outer-directed skills are more effective for pain management. Perhaps parents believe that their children could be making more effective pain management efforts.

In general, parents appear to be aware of what *type* of coping skills (inner versus outer) their child is using. Weaker correlations may have resulted if parents and youth responded to different 'specific' inner or outer skills. As parents' coping 'opinion' means and correlations show stronger relationships than coping 'estimates', this indicates that parents beliefs are having an important influence on their child's use of pain coping skills.

Additional Observations. Table 9 provides a ranked list of how frequently youth report using all 27 original coping skills. It is interesting that the most frequently reported skill, at a rate of "often", is "wish that the pain would stop" (*M* = 3.0). In itself, this highlights the chronic and intrusive nature of arthritic pain. This also supports the need for additional behavioural medicine programs for youth. An alternative non-medical focus may be of benefit as "ask my parents to take me to a doctor or nurse" was the least frequently reported, nearly "never" (*M* = 0.4).

In reviewing Table 9 it is of note that negatively connoted items tended to be reported less than the positively connoted items. It is possible that although the study was anonymous, youth may have felt some expectation to report 'positive' behaviours, or those they have been told by adults they 'should' be doing.

In the context of variables associated with chronic pain, the scope of this study was limited. It should be acknowledged that these youth must also cope with the emotional, familial, social, recreational, academic and occupational repercussions of juvenile arthritis. Details of these additional difficulties were provided spontaneously by families, or through the history section of the PPQ. Problems were highlighted primarily during the severe periods or flare-ups. In general, young children appeared less troubled than adolescents. Younger children did report the experience of a sense of rejection with respect to physical activity (e.g. not being included by peers in gym class). Adolescents indicated negative emotions and experiences concerning: (a) negative body image, primarily regarding thinness and joint deformity, (b) the possibility of having to abandon valued hobbies or career aspirations (e.g. one talented artist was beginning to have increased problems with pain and stiffness in his hands and wrists), and (c) concerns about future parenthood (e.g. fears of passing the disorder on to offspring). Obviously, many questions and salient variables remain to be addressed in this field.

Application. This study has primarily concerned the etiology of coping skills for arthritic pain - a limited look at how children acquire health orientations and behaviours. Also needed is research concerning the practical application of such empirical data so as to provide information on how positive pain management changes can be encouraged. As Varni, Waldron et al. (1996) also concluded, "by identifying maladaptive as well as adaptive coping strategies, future cognitive-behavioural therapy treatment research can target cognitive and behavioral responses to clinical pain which may exacerbate emotional adjustment problems, as well as promote adaptive coping strategies" (p.149).

In order to maximize therapeutic benefits, parents will also need to receive intervention. Even though direct parental influence on coping skill use does not receive strong support in this study, the reviewed literature does identify parents as an important influence. Parents are likely to serve different therapeutic roles as their children age. For example, when children are in the pre-operational stage of cognitive development, skills may need to be reinforced by parents through consistent practice, modelling, and behaviour modification. At older ages characterized by concrete operational and formal operational cognitive development, youth have an advanced understanding of health salience, cause and effect relationships, generalising to and from others, and rational thought. At these stages parents may play a different role in introducing skills and initiating discussion regarding coping choices and resulting health effects.

Also, to more fully explore the influences on the health beliefs and behaviours of children with chronic illness, variable of the complete Child Health Belief Model could perhaps be tested in this context. Such information would be valuable in designing a comprehensive chronic pain treatment plan.

As youth are health care consumers with a long future, the optimal time for intervention is in childhood. Improvements in their personal health care management and quality of life can only be positive, to the individual, the family, and to society.

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Appendix A

Varni-Thompson Pediatric Pain Questionnaire:

Child, Adolescent, and Parent Forms,

(With Supplementary Demographic Data Form)

VARNI/THOMPSON

PEDIATRIC PAIN QUESTIONNAIRE

Form C

Name: ____________________

Age: ____________________

Date: ____________________

What words would you use to describe pain or hurt?

____

____

____

From the words listed below, circle the ones that best describe the way it feels when you hurt or are in pain.

cutting
beating
burning
scraping
pricking
pinching
stinging
fearful
hot

pounding
squeezing
pulling
aching
cruel
unbearable
cool
pins & needles
spreading

tingling
throbbing
sickening
uncomfortable
warm
sad
sore
sharp
punishing

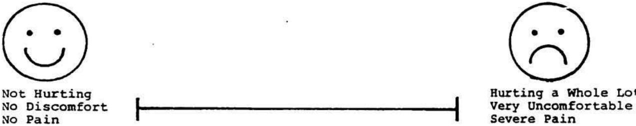
tiring
horrible
biting
cold
miserable
itching
flashing
jumping
scared

deep
stabbing
screaming
tugging
stretching
terrible
pressing
tight
lonely
bad

From the words you circled, which three words best described the pain you are feeling right now?

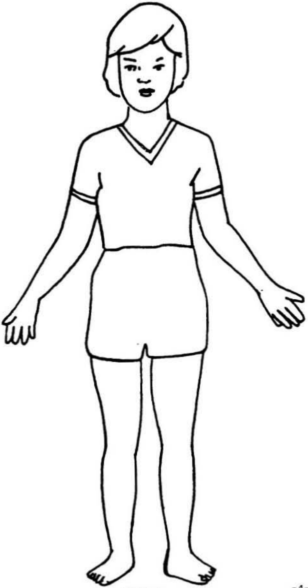
Put a mark on the line that best shows how you feel now. If you have no pain or hurt, you would put a mark at the end of the line by the happy face. If you have some pain or hurt, you would put a mark near the middle of the line. If you have a whole lot of pain or hurt, you would put a mark by the sad face.

Put a mark on the line that best shows what was the worst pain you had this week. If you had no pain or hurt this week, you would put a mark at the end of the line by the happy face. If the pain or hurt you had was some hurting, you would put a mark by the middle of the line. If the worse pain you had was a whole lot of pain or hurt, you would put a mark by the sad face.



No Hurt	A Little Hurt	More Hurt	A Lot of Hurt
☐	☐	☐	☐

Pick the colors that mean No Hurt, A Little Hurt, More Hurt, and A Lot of Hurt to you and color in the boxes. Now, using those colors, color in the body to show how you feel. Where you have no hurt, use the No Hurt color to color in your body. If you have hurt or pain, use the color that tells how much hurt you have.



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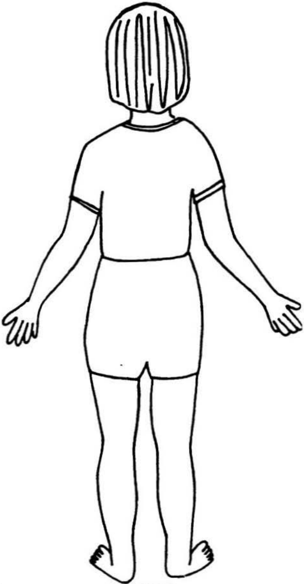


BACK

VARNI/THOMPSON

PEDIATRIC PAIN QUESTIONNAIRE

Form A

Pediatric Pain Questionnaire

Form A

The purpose of this questionnaire is to help us to obtain a comprehensive history of your pain problems. All information obtained from this questionnaire and in interviews will remain strictly confidential. If you do not wish to answer a particular question, for any reason, please write "Do not wish to answer" in the space provided. Please print or write clearly.

Today's Date: ____________________

Your Name: ____

Age: ____________________ Date of Birth: ____________________

Grade in School: ____________ Place of Work: ____________________

Address: ____________________________________

____

Phone Number: ______________

When did your present pain problem begin? Please also explain the symptoms, exact locations of pain and whether the pain has been on or off over the months and years?

What was your reaction to the pain at that time? Please explain.

Were any major changes in your life occurring then?
Please explain.

Is your current pain constant or does it apear to come and go?

Is your pain accompanied by nausea, vomiting, dizziness, feeling faint, anxiety, rapid breathing or other symptoms? If so, please list the symptoms.

If your pain were suddenly to disappear, how would it change your life?

How would it change your family relationships?______________________

Assuming that the pain continues, what kinds of things do you think you should do <u>now</u>, which will help you later on?

Is there anything else you would like to tell us about your pain and the effect it has on yourself or your family?

What words would you use to describe your pain?

From the words listed below, circle the ones that best describe the way it feels when you hurt or are in pain.

cutting
beating
burning
scraping
pricking
pinching
stinging
fearful
hot

pounding
squeezing
pulling
aching
cruel
unbearable
cool
pins & needles
spreading

tingling
throbbing
sickening
uncomfortable
warm
sad
sore
sharp
punishing

tiring
horrible
biting
cold
miserable
itching
flashing
jumping
scared

deep
stabbing
screaming
tugging
stretching
terrible
pressing
tight
lonely
bad

From the words you circled, which three words best describe the pain you are feeling right now?

What day of the week do you have the most pain?

What week of the month do you have the most pain?

What season or month do you have the worst pain?

Have you ever noticed something that tells you that you are about to experience a pain episode? (e.g., stiffness, particular thoughts or statements, physical sensations or irritability).

How many hours a day do you have pain now?

How long does a single pain episode last? (minutes, hours)?

What do you call your pains? (For example, "headache", "joint pain", "stomachache", "backache", etc.) Please list them in order of severity, #1 being the most severe pain.

Pain Problem #1: ____________________

Pain Problem #2: ____________________

Pain Problem #3: ____________________

On a scale of 0-10, (0=no pain, 10=severe pain), how severe is your pain at the following times of the day?	6 a.m. ______ 9 a.m. ______ 12 noon ______ 3 p.m. ______	6 p.m. ______ 9 p.m. ______ 12 a.m. ______ 3 a.m. ______

What is the worst time of the day? ____________________

What is the best time of the day? ____________________

Are you currently taking medication for pain? Yes______ No______
If yes, please complete the following information.

Medication	Dose	#Times/day	When	How Effective (0=not effective, 10=very effective)

What medications or other treatments have you tried in the past?
On a scale of 0-10 (0=not effective, 10=very effective) how effective has each one been?

____

____

____

____

____

What do you currently do, besides taking medication, to relieve your pain?

Does your pain seem worse when you are?

	YES	NO		YES	NO
tired			angry		
anxious			busy		
bored			lonely		
happy			arguing		
unhappy			upset		

Are there any other situations in which your pain is worse?
If yes, what are they?

Does your pain interfere with any of the following? Please circle the most correct number.

	Never	Rarely	Sometimes	Often	Always
Enjoying the family	1	2	3	4	5
Eating/appetite	1	2	3	4	5
Seeing friends	1	2	3	4	5
Sports	1	2	3	4	5
Sleeping	1	2	3	4	5
Watching T.V.	1	2	3	4	5
Reading	1	2	3	4	5
Schoolwork	1	2	3	4	5
Attending school	1	2	3	4	5
Going to the movies	1	2	3	4	5
Favorite activities	1	2	3	4	5
Unliked activities	1	2	3	4	5

Comments?____

____

____

____

During the past three months, did your pain limit you from doing things which you wanted to do?

1. _____ Yes
2. _____ No

If yes, please explain ____

____

____

____

During the past three months of the school year, how often did your pain keep you from going to school?

0. _____ None
1. _____ 1 day only
2. _____ 2-3 days
3. _____ 4-7 days
4. _____ more than 1 week
5. _____ more than 2 weeks
6. _____ more than 3 weeks
7. _____ more than 1 month

During the past three months, how often did your pain limit you from vigorous activities such as running, bicycling, lifting heavy objects, or participating in strenuous sports?

0. _____ None
1. _____ 1 day only
2. _____ 2-3 days
3. _____ 4-7 days
4. _____ more than 1 week
5. _____ more than 2 weeks
6. _____ more than 3 weeks
7. _____ more than 1 month

During the past three months, how often did your pain limit you from moderate activities such as climbing several flights of stairs, bending, walking several blocks, lifting or stooping?

0. _____ None
1. _____ 1 day only
2. _____ 2-3 days
3. _____ 4-7 days
4. _____ more than 1 week
5. _____ more than 2 weeks
6. _____ more than 3 weeks
7. _____ more than 1 month

During the past three months, how often did your pain limit you from mild activities such as walking one block, climbing one flight of stairs, sitting, or standing?

0. ______ None
1. ______ 1 day only
2. ______ 2-3 days
3. ______ 4-7 days
4. ______ more than 1 week
5. ______ more than 2 weeks
6. ______ more than 3 weeks
7. ______ more than 1 month

Please rate how much pain you are having at the present time by placing a mark somewhere on the line.

Not Hurting		Hurting a Whole Lot
No Discomfort	____	Very Uncomfortable
No Pain		Severe Pain

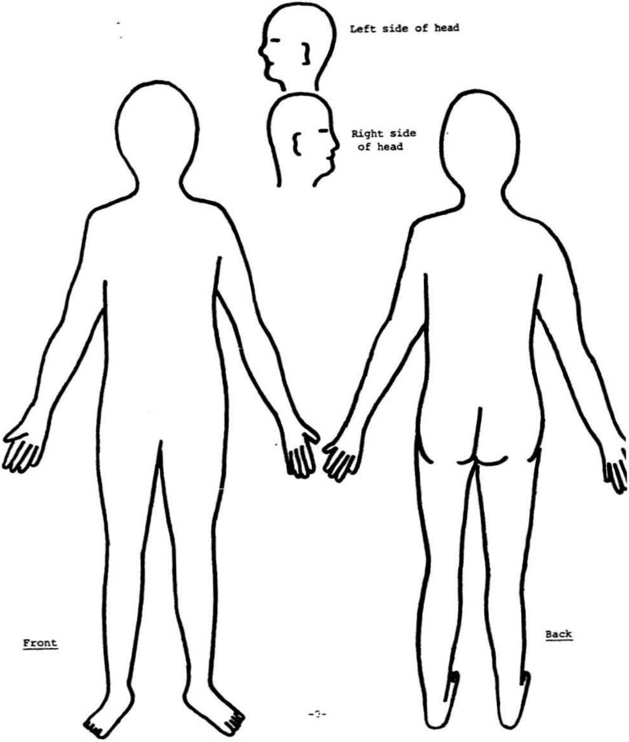
Please rate how much pain you have on an average each day by placing a mark somewhere on the line.

Not Hurting		Hurting a Whole Lot
No Discomfort	____	Very Uncomfortable
No Pain		Severe Pain

Please rate how severe the worst pain you had in the past week (7 days) by placing a mark somewhere on the line.

Not Hurting		Hurting a Whole Lot
No Discomfort	____	Very Uncomfortable
No Pain		Severe Pain

there is more than one painful place, mark them "1", "2", "3", etc., starting with the most painful place as "1".



VARNI/THOMPSON

PEDIATRIC PAIN QUESTIONNAIRE

Form P

Pediatric Pain Questionnaire

Form P

The purpose of this questionnaire is to help us to obtain a comprehensive history of your child's pain problems. All information obtained from this questionnaire and in interviews will remain strictly confidential. If you do not wish to answer a particular question, for any reason, please write "Do not wish to answer" in the space provided. Please print or write clearly.

Today's Date: ______________

Your Name: ______________________

Address: __________________________

____

Phone Number: ______________

Relationship to child of person completing this form: ______________

Child Information

Name: ____________________

Age: ________ Date of Birth: ______________

Sex: ________

Grade in School: __________

Home Information

Please list the name, age and sex of all individuals living in the home.

Name	Age	Sex

Please list any health problems that your child has.

If anyone else in the family has health problems please list the person and the health problem. Example: son with asthma, husband with arthritis.

Please list all severe or chronic family illnesses that your child has been aware of.

Family member	Dates	Type of Illness	Outcome

Please list all severe and/or chronic pain problems experienced by other family members that your child has observed.

Family member	Dates	Type of Pain	Outcome

Are there currently any major life stresses in the family situation (e.g. divorce, separation, difficult financial burden, illness)? If yes, please list.

When did your child's present pain problem begin? Please also explain the symptoms, exact locations of pain and whether the pain has been on or off over the months and years?

What was your reaction to the pain at that time? Please explain.

Were any major changes in yours or your child's life occurring then? Please explain.

Is your child's current pain constant or does it appear to come and go?

Is your child's pain accompanied by nausea, vomiting, dizziness, feeling faint, anxiety, rapid breathing or other symptoms? If so, please list the symptoms.

When your child has pain how do you react? Please explain.

If your child's pain were suddenly to disappear, how would it change his/her life?

How would it change your life?

How would it change family relationships?

Assuming that the pain continues, what kinds of things do you think your child should do <u>now</u>, which will help him/her later on?

Is there anything else you would like to tell us about your child's pain and the effect it has on your child, yourself or the family?

____

____

____

____

What words would you use to describe your child's pain?

____

____

____

Please circle any of the words listed below that you feel describe your child's pain.

cutting
beating
burning
scraping
pricking
pinching
stinging
fearful
hot

pounding
squeezing
pulling
aching
cruel
unbearable
cool
pins & needles
spreading

tingling
throbbing
sickening
uncomfortable
warm
sad
sore
sharp
punishing

tiring
horrible
biting
cold
miserable
itching
flashing
jumping
scared

deep
stabbing
screaming
tugging
stretching
terrible
pressing
tight
lonely
bad

What day of the week does your child have the most pain? ____________

What week of the month does your child have the most pain? ____________

What season or month does your child have the worst pain? ____________

Have you ever noticed something that tells you that your child is about to experience a pain episode? (e.g., stiffness, particular thoughts or statements, physical sensations or irritability).

____

____

____

How many hours a day does your child have pain now? ____________

How long does a single pain episode last (minutes, hours)? ____________

What do you label your child's pains as? (For example, "headache", "joint pain", "stomachache", "backache", etc.) Please list them in order of severity, #1 being the most severe pain.

Pain Problem #1: ____

Pain Problem #2: ____

Pain Problem #3: ____

On a scale of 0-10, (0=no pain, 10=severe pain), how severe is your child's pain at the following times of the day?

6 a.m.	______	6 p.m.	______
9 a.m.	______	9 p.m.	______
12 noon	______	12 a.m.	______
3 p.m.	______	3 a.m.	______

What is the worst time of the day? ______________________________

What is the best time of the day? ______________________________

Is your child currently taking medication for pain? Yes______ No______
If yes, please complete the following information.

Medication	Dose	#Times/day	When	How Effective (0=not effective, 10=very effective)

What medications or other treatments have been tried in the past? On a scale of 0-10 (0=not effective, 10=very effective) how effective has each one been?

____

____

____

____

____

What do you currently do, besides giving medication, to relieve your child's pain?

____

____

____

Does your child's pain seem worse when he/she is?

	YES	NO		YES	NO
tired	_______	_______	angry	_______	_______
anxious	_______	_______	busy	_______	_______
bored	_______	_______	lonely	_______	_______
happy	_______	_______	arguing	_______	_______
unhappy	_______	_______	upset	_______	_______

Other situations in which your child's pain is worse? Please describe.

____

____

____

Does your child's pain interfere with any of the following? Please circle the most correct number.

	Never	Rarely	Sometimes	Often	Always
Enjoying the family	1	2	3	4	5
Eating/appetite	1	2	3	4	5
Seeing friends	1	2	3	4	5
Sports	1	2	3	4	5
Sleeping	1	2	3	4	5
Watching T.V.	1	2	3	4	5
Reading	1	2	3	4	5
Schoolwork	1	2	3	4	5
Attending school	1	2	3	4	5
Going to the movies	1	2	3	4	5
Favorite activities	1	2	3	4	5
Unliked activities	1	2	3	4	5

Comments?____

During the past three months, did your child's pain limit him/her from doing things which he/she wanted to do?

1. _____ Yes
2. _____ No

If yes, please explain ______________________________

____

____

____

During the past three months of the school year, how often did your child's pain keep him/her from going to school?

0. _____ None
1. _____ 1 day only
2. _____ 2-3 days
3. _____ 4-7 days
4. _____ more than 1 week
5. _____ more than 2 weeks
6. _____ more than 3 weeks
7. _____ more than 1 month

During the past three months, how often did your child's pain limit him/her from <u>vigorous</u> activities such as running, bicycling, lifting heavy objects, or participating in strenuous sports?

0. _____ None
1. _____ 1 day only
2. _____ 2-3 days
3. _____ 4-7 days
4. _____ more than 1 week
5. _____ more than 2 weeks
6. _____ more than 3 weeks
7. _____ more than 1 month

During the past three months, how often did your child's pain limit him/her from <u>moderate</u> activities such as climbing several flights of stairs, bending, walking several blocks, lifting or stooping?

0. _____ None
1. _____ 1 day only
2. _____ 2-3 days
3. _____ 4-7 days
4. _____ more than 1 week
5. _____ more than 2 weeks
6. _____ more than 3 weeks
7. _____ more than 1 month

During the past three months, how often did your child's pain limit him/her from mild activities such as walking one block, climbing one flight of stairs, sitting, or standing?

0. _____ None
1. _____ 1 day only
2. _____ 2-3 days
3. _____ 4-7 days
4. _____ more than 1 week
5. _____ more than 2 weeks
6. _____ more than 3 weeks
7. _____ more than 1 month

Please rate how much pain you think your child is having at the present time by placing a mark somewhere on the line.

Not Hurting		Hurting a Whole Lo
No Discomfort	____	Very Uncomfortable
No Pain		Severe Pain

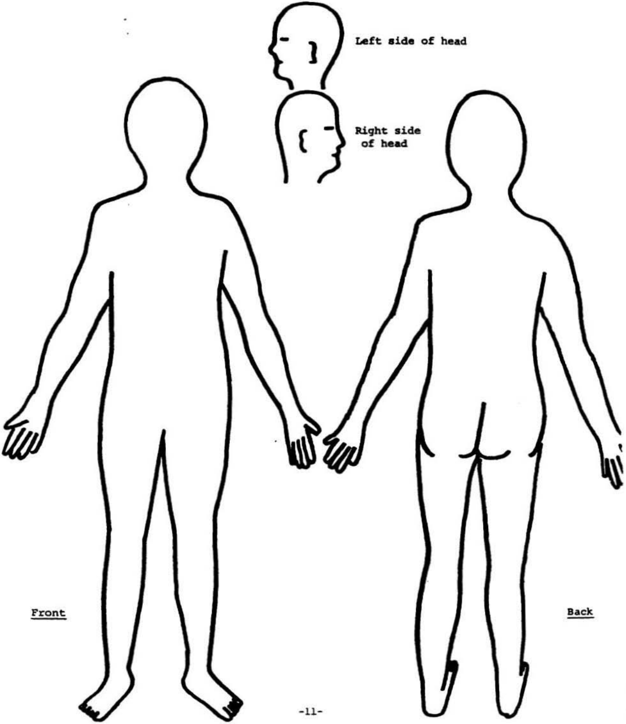
Please rate how much pain you think your child has on an average each day by placing a mark somewhere on the line.

Not Hurting		Hurting a Whole L
No Discomfort	____	Very Uncomfortabl
No Pain		Severe Pain

Please rate how severe the worst pain your child had in the past week (7 days) by placing a mark somewhere on the line.

Not Hurting		Hurting a Whole L
No Discomfort	____	Very Uncomfortabl
No Pain		Severe Pain

having pain now. If there is more than one painful place, mark them "1", "2", "3", etc., starting with the most painful place as "1".



Appendix B

Comparison of Item Content and Sub-Scales of The Vanderbilt Pain Management Inventory and The Children's Arthritis Coping Inventory

Comparison of Item Content and Sub-Scales

VPMI		CACI	
1. Wishing doctor would prescribe better pain medication.	P	1. Wish my doctor or parents would give me better pain medicine.	I
2. Thinking the pain is wearing one down.	P	2. Think that the pain is getting me down.	I
3. Telling others how much the pain hurts.	P	3. Tell others how much the pain hurts.	O
4. Praying for relief.	P	4. Wish that the pain would stop.	I
5. Restricting social activities.	P	5. Not go out with my friends or family as much.	I
6. Depending on others for help with daily tasks.	P	6. Depend on others to help me with everyday things.	**
7. Thinking one cannot do anything to cope with the pain.	P	7. Think I can't do anything to cope with the pain.	I
8. Taking medication for purposes of immediate pain relief.	P	8. Take medicine to make the pain go away quickly.	O
9. Calling a doctor or nurse.	P	9. Ask my parents to take me to the doctor or a nurse.	O
10. Focusing on the location and intensity of the pain.	P	10. Think about where the pain is and how much it hurts.	I
11. Suppressing angry, depressed or frustrated feelings.	P	11. Keep my feelings inside when I feel angry, sad, or fed up with the pain.	I
12. Lying down to rest.	*	12. Lie down to rest.	O
13. Avoiding activities or movements which make the pain worse.	*	13. Not move around or do other things that I know will make the pain worse.	**
14. Taking a hot bath or using rubbing ointments.	*	14. Take a warm bath or rub on ointments.	O

Comparison of Item Content and Sub-Scales (Continued)

VPMI		CACI	
15. Wondering whether one has done anything to cause or exacerbate the pain.	*	15. Wonder if I did something to make the pain worse.	I
16. Watching television.	*	16. Watch television.	**
17. Engaging in physical exercise or physical therapy.	A	17. Exercise or do physical therapy.	O
18. Ignoring the pain.	A	18. Ignore the pain.	I
19. Staying busy or active.	A	19. Stay busy or active.	O
20. Clearing mind of bothersome thoughts.	A	20. Not think of things that bother me.	I
21. Reading.	A	21. Read or look at books for a while.	O
22. Participating in leisure activities.	A	22. Participate in a hobby or some activity that I like.	O
23. Distracting attention from the pain.	A	23. Try to think about or do something else or distract myself.	**
24. Thinking one can handle the pain by oneself.	*	24. Think that I can handle the pain all by myself.	I
25. Relaxing the muscles.	*	25. Relax my muscles.	O
26. Imagining pleasant situations.	*	26. Think about nice things or pleasant times.	I
27. Expressing angry, depressed, or frustrated feelings.	*	27. Let out my feelings when I am angry, sad, or fed up with the pain.	**
P = factor loaded as passive coping A = factor loaded as active coping * = dropped, did not meet inclusion criteria		O = outer-directed coping skill I = inner-directed coping skill ** = dropped, did not meet inclusion criteria	

Appendix C

Children's Arthritis Coping Inventory (CACI)

Youth Form (CACI-Y)

Parent Form (CACI-P1, CACI-P2)

CACI - Y

These questions deal with what you do to cope with the pain from your arthritis. Coping is what you do to lessen the pain or bad feelings you may have about it, or just what you normally do when it happens. Everyone copes differently; maybe you do some of these things, or none at all. Please read the sentences carefully, and circle the number that matches how often you choose to do each thing when bothered by your pain.

1) **Wish my doctor or parents would give me better pain medicine.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

2) **Think that the pain is getting me down.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

3) **Tell others how much the pain hurts.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

4) **Wish that the pain would stop.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

5) **Not go out with my friends or family as much.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

6) **Depend on others to help me with everyday things.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

7) **Think I can't do anything to cope with the pain.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

8) **Take medicine to make the pain go away quickly.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

9) **Ask my parents to call or take me to a doctor or nurse.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

10) **Think about where the pain is and how much it hurts.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

11) **Keep my feelings inside when I feel angry, sad, or fed up with the pain.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

12) **Lie down to rest.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

13) **Not move around or do other things that I know will make the pain worse.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

14) **Take a warm bath or rub on ointments.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

15) **Wonder if I did something to make the pain worse.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

16) **Watch television.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

17) **Exercise or do physical therapy.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

18) **Ignore the pain.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

19) **Stay busy or active.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

20) **Not think of things that bother me.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

21) **Read or look at books for a while.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

22) **Participate in a hobby or some activity that I like.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

23) **Try to think about something else or distract myself.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

24) **Think that I can handle the pain all by myself.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

25) **Relax my muscles.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

26) **Think about nice things or pleasant times.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

27) **Let out my feelings when I am angry, sad, or fed up with the pain.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

CACI - P1

These questions concern what your child does to cope with the pain from his or her arthritis. We define coping as what they do to lessen the pain or bad feelings they may have about it, or just what they normally do when it happens. Everyone copes differently; maybe she/he does some of these things, or none at all. Please read the sentences carefully, and circle the number that matches how often you think your child chooses to do each item when bothered by arthritic pain.

1) **Wish my doctor or parents would give me better pain medicine.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

2) **Think that the pain is getting me down.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

3) **Tell others how much the pain hurts.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

4) **Wish that the pain would stop.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

5) **Not go out with my friends or family as much.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

6) **Depend on others to help me with everyday things.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

7) **Think I can't do anything to cope with the pain.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

8) **Take medicine to make the pain go away quickly.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

9) **Ask my parents to call or take me to a doctor or nurse.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

10) **Think about where the pain is and how much it hurts.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

11) **Keep my feelings inside when I feel angry, sad, or fed up with the pain.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

12) **Lie down to rest.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

13) **Not move around or do other things that I know will make the pain worse.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

14) **Take a warm bath or rub on ointments.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

15) **Wonder if I did something to make the pain worse.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

16) **Watch television.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

17) **Exercise or do physical therapy.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

18) **Ignore the pain.**

1	2	3	4	5
NEVER	RARELY	SOMETIMES	OFTEN	VERY OFTEN

19) **Stay busy or active.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

20) **Not think of things that bother me.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

21) **Read or look at books for a while.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

22) **Participate in a hobby or some activity that I like.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

23) **Try to think about something else or distract myself.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

24) **Think that I can handle the pain all by myself.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

25) **Relax my muscles.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

26) Think about nice things or pleasant times.

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

27) Let out my feelings when I am angry, sad, or fed up with the pain.

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

CACI - P2

I'd like you to answer these questions once more. Please read the sentences carefully, and this time circle the number that matches how often you think it would best serve your child to choose to do each item when bothered by arthritic pain. In other words, which responses do you feel are best, and how frequently.

1) **Wish my doctor or parents would give me better pain medicine.**

1............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

2) **Think that the pain is getting me down.**

1............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

3) **Tell others how much the pain hurts.**

1............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

4) **Wish that the pain would stop.**

1............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

5) **Not go out with my friends or family as much.**

1............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

6) **Depend on others to help me with everyday things.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

7) **Think I can't do anything to cope with the pain.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

8) **Take medicine to make the pain go away quickly.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

9) **Ask my parents to call or take me to a doctor or nurse.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

10) **Think about where the pain is and how much it hurts.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

11) **Keep my feelings inside when I feel angry, sad, or fed up with the pain.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

12) **Lie down to rest.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

13) **Not move around or do other things that I know will make the pain worse.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

14) **Take a warm bath or rub on ointments.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

15) **Wonder if I did something to make the pain worse.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

16) **Watch television.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

17) **Exercise or do physical therapy.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

18) **Ignore the pain.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

19) **Stay busy or active.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

20) **Not think of things that bother me.**

1.............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

21) **Read or look at books for a while.**

1.............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

22) **Participate in a hobby or some activity that I like.**

1.............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

23) **Try to think about something else or distract myself.**

1.............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

24) **Think that I can handle the pain all by myself.**

1.............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

25) **Relax my muscles.**

1.............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

26) **Think about nice things or pleasant times.**

1.............................. 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

27) **Let out my feelings when I am angry, sad, or fed up with the pain.**

1............................ 2 .... 3 .... 4 5
NEVER RARELY SOMETIMES OFTEN VERY OFTEN

Appendix D

Physician's Report Form

Patient Name______________________ Today's Date__________

Date of last appointment (if applicable)___________________

Are JA related medications currently prescribed? Yes No

At your most recent encounter with this patient, please rate your perception of the patient's pain by placing a mark at a point along the line.

No Pain ____ Severe Pain

Please indicate your impression of the patient's present disease activity:

1............	2............	3............	4............	5
Severe	Moderate	Mild	Quiescent	Remission

(Quiescent = no physical or laboratory signs, on medication; Remission = quiescent for two months without medication)

Please indicate onset type of Juvenile Arthritis for this patient (check one):

1) Pauciarticular JRA (__)

2) Polyarticular JRA (__)

3) Systemic JRA (__)

4) Other Connective Tissue Disease(__)
Please specify___________________________________

____

Approximately when was this child first diagnosed with JA?

____

Appendix E

Division Criteria and Rater Responses For Outer-Directed and Inner-Directed Coping Constructs

Thanks for taking a few minutes to help me with this project. I've given you a list of some things that children with arthritis pain do to make themselves feel better. I would like you to divide these items into two scales, as many coping theories indicate that there are often two distinct coping styles. There are a number of paradigms for classifying coping responses, but these tend to be confusing and often contradictory. In a review of children's coping with medical situations, Rudolph, Dennig, and Weisz (1995) proposed two categories which seem to best capture the parallels among the various paradigms. They are summarised as follows:

1) **Outer-directed coping modes**: Strategies are behavioural, problem-focused, information seeking, active, or approach oriented.

2) **Inner-directed coping modes**: Strategies are cognitive, emotion-focused, passive, or avoidance oriented.

Indicate whether you think each action represents outwardly directed or inwardly directed coping by ticking the appropriate column. If you have any questions, I can be reached at 758-3633 or 834-3292.

Thanks again,

Janet Kavanagh

Rater Responses

What A Child With Arthritis Chooses To Do When In Pain	Outer Directed	Inner Directed
Ask my parents to call or take me to a doctor or nurse	7	0
Depend on others to help me with everyday things	2	5
Exercise or do physical therapy	7	0
Ignore the pain	1	6
Keep my feelings inside when I feel angry, sad, or fed up with the pain	0	7
Let out my feelings when I am angry, sad, or fed up with the pain	5	2
Lie down to rest	6	1
Not go out with my friends or family as much	1	6
Not move around or do other things that I know will make the pain worse	4	3
Not think of things that bother me	0	7
Participate in a hobby or some activity that I like	7	0
Read or look at books for a while	6	1
Relax my muscles	6	1
Stay busy or active	6	1
Take a warm bath or rub on ointments	7	0
Take medicine to make the pain go away quickly	6	1
Tell others how much the pain hurts	7	0
Think about nice things or pleasant times	1	6
Think about where the pain is and how much it hurts	0	7
Think I can't do anything to cope with the pain	0	7
Think that I can handle the pain all by myself	1	6
Think that the pain is getting me down	0	7
Try to think about something else or distract myself	2	5
Watch television	5	2
Wish my doctor or parents would give me better pain medicine	1	6
Wish that the pain would stop	0	7
Wonder if I did something to make the pain worse	1	6

Appendix F

Order of Colour Sample Presentation For Children's Likert Scale Comprehension Task

Red[5]	4, 1, 5, 3, 2
Blue	1, 4, 3, 5, 2
Green	3, 1, 4, 2, 5

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[5] Numbers one to five indicate colour samples of increasing intensity, i.e. one is lightest, 5 is darkest.

Appendix H

Letters to Solicit Subject Participation, and Supplementary Demographic Information Form

(JA Study Questionnaire)

Dear Parent,

I am writing to tell you about a study of children who have arthritic conditions. The focus of this study is the pain children experience and how they cope with it. Mrs. Janet Kavanagh, the researcher, has asked me to help find families who are interested in taking part. This project forms part of her Master's degree program in Clinical Psychology at Memorial University of Newfoundland. It has been approved by myself, as well as by M.U.N., The Janeway Child Health Centre, and The Health Care Corporation of St. John's. I am her Janeway sponsor, and she is being supervised at M.U.N.'s Psychology Department by Dr. Christine Arlett.

If you decide to take part, Janet will need to meet once with you and your child. You will both be interviewed, and asked to fill out questionnaires about pain and coping with pain. The questionnaires will take into account your child's age, and Janet will help with completing them. One week later you will be asked to answer another brief questionnaire on pain, and mail it to her. All information you provide will be kept **strictly private and confidential.** At the end of the study we plan an informal workshop to give you the results and to talk about ways to help children cope with pain and illness.

In any case, if you decide not to take part please take a few minutes to complete the enclosed questionnaire, and mail it to us in the provided envelope. We will be happy to answer any questions you may have, so please feel free to contact Mrs. Janet Kavanagh at 834-3292. You may call out of interest, before you decide whether or not to take part.

Yours sincerely,

Chaker Hobeika, MD., FRCP.(C)

Dear Parent,

A few months ago I wrote to tell you about a study of children who have arthritic conditions. Some families have not yet had the opportunity to respond. The focus of this study is the pain children experience from arthritic conditions and how they cope with it. Mrs. Janet Kavanagh is the researcher, and this project is the final requirement for her Master's degree program in Clinical Psychology at Memorial University of Newfoundland. It has been approved by myself, as well as by M.U.N., The Janeway Child Health Centre, and The Health Care Corporation of St. John's. I am her Janeway sponsor. She is being supervised at the M.U.N. Psychology Department by Dr. Christine Arlett, who is also a psychologist at the Janeway.

Many of the parents who received letters had additional questions about the study. To assist you in making your decision whether or not to participate, I am enclosing a letter from Mrs. Kavanagh which addresses some commonly raised questions. We will be happy to provide any other information you may need. In any case, we would like to hear from all families before you decide whether or not to take part. Please feel free to contact Mrs. Janet Kavanagh at 834-3292. If you live outside the St. John's area you may make this a collect call.

Yours sincerely,

Chaker Hobeika, MD., FRCP.(C)

Dear Parents,

Thank you for taking a few moments to consider the study I am conducting. Since Dr. Hobeika first wrote to you I have found that many families would like more information before making a decision. For your interest, I'd like to clarify some of the most common questions and comments:

"We'd like to participate, but live too far from St. John's" - This is a common problem, as the 46 families who received letters live in all areas of the province. To help more families participate, we have altered the study to allow children age 12 years and older to participate by mail. These families can call to ask for the questionnaires to be mailed, and complete them at their convenience. Also, if you and your child will be coming to St. John's at any time during the next few months, I can arrange to meet with you at short notice. I will also be travelling to Corner Brook in order to meet with families in that area.

"Why did you send us a questionnaire about marital status and income if this study is about the children?" In a study it is impossible to interview all of the possible participants. One purpose of any study, however, is to be able to use the results to provide information about the group in general. In order to make these general conclusions, it is necessary to make sure that those families who chose not to participate are **on average** the same as those who do. One way to do this is to compare their demographics, such as number of children, marital status, etc. just as Statistics Canada would in a census. This is my only use for this information, and you can provide it anonymously.

"Is there a support group for children's arthritis?" All of the parents I have interviewed are interested in forming a support group for families and children. Such groups exist in some other provinces, and are able to act as a source of information and education about these conditions, and introduce families who can share experiences and support each other. I have volunteered to help establish such a group at the end of this study, and to combine it with the informal workshop I had planned. In the meantime I will contact the Arthritis Society and children's arthritis support groups in other areas for information which may be useful to you. **Even if you do not wish to participate in this study, please let me know if you would like to receive information about this group when it is being formed.**

Here again, are the general details of this study. If you decide to take part in person, I will need to meet once with you and your child. You will both be interviewed, and asked to fill out questionnaires about pain and coping with pain. The questionnaires will take into account your child's age, and I will help with completing them. One week later you will be asked to answer another brief questionnaire on pain, and mail it to me. For those who participate by mail, I will talk briefly with you and your child by phone before you complete the questionnaires, and will call to remind you of the brief questionnaire one week later. You will then return the material to me by mail in a provided envelope. All information participants provide will be kept **strictly private and confidential**.

In any case, if you decide not to take part please take a few minutes to complete the enclosed questionnaire, and mail it to us in the provided envelope. I will be happy to answer any questions you may have, and can be contacted at 834-3292. You may call out of interest, before you decide whether or not to take part. Please feel free to make this a collect call if you live outside the St. John's area. I very much appreciate your time and interest, and look forward to hearing from you.

Sincerely,

Mrs. Janet Kavanagh

JA Study Questionnaire

Please take a few minutes to complete the following questions and return them to us in the enclosed envelope. This information is confidential, and very important to our study. Thanks very much!

1. Please list the age and sex of all family members living in your home:

Age	Sex (M/F)

2. How old was your child when he/she first developed JA? ______ How old is he/she now? ________

3. Is this child male or female? (please circle)

4. What grade in school will this child be attending in September? ______

5. Parent(s) occupation(s):____________________________

6. Parent(s) education:____________________________

7. Marital status of parent(s) in the home:

Married ___
Separated ___
Common Law ___
Other ___

Divorced ___
Single Parent ___
Widowed ___

8. Gross family income ___________

Appendix H

Consent to Participate Form

DEPARTMENT OF PSYCHOLOGY AND FACULTY OF MEDICINE
MEMORIAL UNIVERSITY OF NEWFOUNDLAND
ST. JOHN'S, NEWFOUNDLAND A1B 3V6

CONSENT TO PARTICIPATE IN BIO-MEDICAL RESEARCH

TITLE: How Children Cope With Juvenile Rheumatoid Arthritis: Caregiver's Influence, and the Effect of Coping On Expressed Pain

INVESTIGATORS: Mrs. Janet Kavanagh, B.Sc., M.Sc. Candidate, Department of Psychology.

SPONSORS: Dr. Christine Arlett, Associate Professor, Department of Psychology and
Dr. Chaker Hobeika, Associate Professor, Faculty of Medicine, C.A. Janeway Child Health Centre.

You and your child or ward have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment.

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Information section

1. **Purpose of study:** This is to provide you with more information about our proposed study. We are interested in learning more about the pain experiences of youth who have Juvenile Rheumatoid Arthritis or other rheumatic conditions. We are also interested in what they choose to do to make the pain easier to cope with, and the opinions of their parents or guardian. This study is part of the researcher's Master's degree program in Clinical Psychology at Memorial University of Newfoundland.

2. **Description of procedures and tests:** In this study, Janet Kavanagh will be your researcher. During your interview session several things will take place. Janet will meet first with both parent and child, to get acquainted. The parent and child will then go to separate rooms, or at least where they cannot hear each other. Janet will give the parent three questionnaires - one about pain and two about coping. She will explain how to fill these out, and if there are no further questions, will leave the parent alone to complete them. If the parent has any difficulty or questions, Janet will provide assistance after the child has finished his/her questionnaires.

Janet will begin the session with young children by testing their understanding of greater and lesser amounts. This will be done by having the child put light and dark colours in the correct order. This step is not necessary for older children and adolescents. All youth will be asked to fill out one questionnaire on pain, and one on coping skills. They will be asked to use pencils or markers to do this. Janet will work through all questions with the youth. In the case of adolescents, if they have no writing difficulties, and understand the instructions, they may go ahead and complete some questions on their own. Janet will stay with them in case they have any problems. Once they have finished, Janet will check with the parent to see if any help is needed.

Once the questionnaires are complete, Janet is free to answer some questions about the study. A letter explaining the study will be provided for you to keep. Janet will give each of you another brief questionnaire about pain. You will need to fill this out one week from your interview, and mail it to us in an envelope provided. Janet will arrange to telephone you to remind you of this. We will also need to ask your child's doctor a few brief questions about his/her arthritis, and will show you the form your doctor will fill out.

3. **Duration of subject participation:** The researcher will need to meet once with your child and an adult who is their primary caregiver. This interview and questionnaire session should take no more than two hours. One week later you will both be asked to answer another brief question on pain, and send it to us by mail in a provided envelope. This should take no more than five minutes.

4. **Foreseeable risks, discomforts, or inconveniences:** It is possible that focusing attention on pain and illness may temporarily increase your child's discomfort. It can also be the case, however, that an opportunity to talk openly about illness experiences can help reduce stress. Should your child pay more attention to their pain as a result of this study, this effect is likely to be short lived.

5. **Benefits which the subject may receive:** After the study is complete, Janet will be offering a workshop for parents, to thank you for your help. This will be an informal meeting of parents, to give you the results of the study, and provide information on ways that children can learn to cope with pain.

6. **Alternative procedures or treatment for those not entering the study:** This study is in no way intended to replace any of your child's usual medical care, therefore an alternative for those who choose not to participate is not needed.

7. **Liability Disclaimer Statement:** Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I, ______________________________, the undersigned, agree

to my participation and to the participation of

___________________________ (my child, ward, relative) in

the research study described.

Any questions have been answered and I understand what is involved in the study. I realise that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

_____________________________________ ___________________

(Signature of Participant) (Date)

_____________________________________ ___________________

(Witness Signature) (Date)

____

(Signature of Minor Participant)

Age _______

Relationship to Participant Named Above_____________________

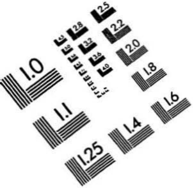
<u>To be signed by investigator:</u>

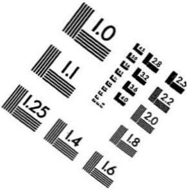
To the best of my ability I have fully explained to the participants the nature of this research study. I have invited questions and provided answers. I believe that the participants fully understand the implications and voluntary nature of this study.

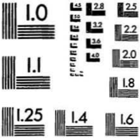
_____________________________________ ___________________

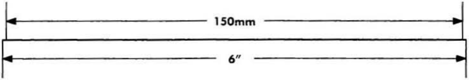
(Signature of Investigator) (Date)
Telephone Number: 834-3292

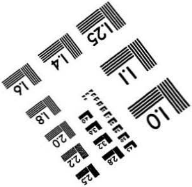
IMAGE EVALUATION
TEST TARGET (QA-3)











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