The Spontaneous Coping Strategies of Children who live with Chronic Pain

A thesis presented in partial
fulfilment of the requirements for the degree
of Master of Arts in Psychology
at Massey University

KAREN ELAINE RAMSAY
1994

Abstract

The spontaneous coping strategies of children who experience chronic disease-related pain have received little research attention. Ten children aged between 7 and 13 years were interviewed. The interview data was analysed using the grounded theory method of qualitative data analysis. The participant children described using a variety of cognitive and behavioural coping strategies in order to manage their pain. The children also described changes over time in the types of coping strategies that they utilized. Most children also described subjective habituation to pain. A local theory was generated from the data which describes the changing process over time of the children's getting used to living with pain. Children's ways of being changed over time, along with their appraisals of pain and their use of coping strategies. Similarities between this process and strategies that have been found to be adaptive in the adult chronic pain literature were noted. Strategies that were pervasively described were cognitive-behavioural distractions and behavioural interventions. Coping strategies that have not been previously documented among children were also found. "Keeping going" was a purposefully used coping strategy, as was seeking social support and minimizing pain. The implications of these findings including the contexts which impact on use and effectiveness of the children's coping strategies are discussed.

Acknowledgements

I would like to express my gratitude to those who have made this research project possible:

My thesis supervisors, Ms. Cheryl Woolley and Mr.Malcolm Johnson of the Psychology Department, Massey University, who were encouraging of my ideas and whose knowledge and wisdom guided the research process and helped to refine the final presentation.

Dr.Mandy Morgan, Psychology Department, Massey University, for her guidance on qualitative methods of research and data analysis, during the planning stages of the project.

Ms.Jo Walton of the Nursing Department, Massey University, for her valuable comments towards the end of the data analysis.

Dr.Mike Corkhill, Paediatric Rheumatologist, Hutt Hospital, for his support in finding research participants. The nursing staff and paedatric consultants in the paediatric outpatients and paediatric wards of Hutt and Wellington Hospitals for their support.

The children who participated in the research, and who taught me far more than I expected to find. I am especially grateful for their willingness to talk about themselves and their pain. The parents of participating children for their support and interest in the research project.

Bob Ramsay, for his support and belief in my abilities. Sarah and Sam, who were very understanding of the time that I spent away from parenting them. Leigh Tierney for always being there for us.

Table of Contents

List of Tables and Figures

PART ONE

Introduction

Overview of Introduction

Children's experience of chronic pain is a relatively uninvestigated area, and there is a dearth of literature on the coping strategies that children may utilize in response to chronic pain. There exist however, a variety of bodies of literature that bear relevance to the topic, and a broad review is undertaken in the introduction to this study in order to cover multiple aspects of children's likely responses to chronic pain. The body of literature which describes children's experience of pain is discussed, and also literature that describes children's use of coping strategies in response to acute pain. Relevant concepts of coping that arise from the adult coping literature as well as factors that have been suggested to influence the use of coping strategies in children are reviewed. Literature which describes psychosocial aspects of chronic pain in children is surveyed, along with salient literature which is relevant to the use of coping strategies in children's chronic pain. Lastly, the reasons for choosing qualitative methodology are reviewed, and some advantages and disadvantages of the grounded theory method of data analysis discussed.

It is necessary to define the different categories of pain. Varni(1983) has identified four primary categories of pediatric pain, and the category of relevance to the present report is pain associated with a disease state (e.g. arthritis, haemophilia or malignant processes). In addition to these categories, pain in children is classified as either acute, chronic, or recurrent (P.A.McGrath,1990). Acute pain is defined as relatively brief, caused by a well-defined noxious stimulus, and usually with sudden onset. Chronic pain has been defined as pain that has a less well defined stimulus, and persists beyond the usual time period required for healing (P.A.McGrath,1990). Recurrent pain is similar to chronic pain, but with no obvious physical stimulus, and children otherwise appear healthy. In keeping with the adult literature, chronic pain in the present report is pain that has persisted for a minimum of six months. The participant children all experienced disease-related pain, as in the category provided by Varni(1983), and the terms long-term disease-related pain, and chronic disease-related pain are used interchangeably.

CHAPTER ONE

Children's Experience of Pain

DETERMINANTS OF PAIN IN CHILDREN

Children's experience of pain has received increased research attention in the past decade (Ross & Ross,1988), and several beliefs which contributed to the misinterpretation of children's pain have been found to be inaccurate (Schecter, Berde & Yaster,1993). In particular, it was erroneously assumed that young children and infants did not feel pain, that children have no memory for pain, and that their pain produces no harmful effects. Consequently pain in children had been undertreated and mismanaged, (Schecter, 1989).

The earlier divergent evidence has been firmly replaced with a convergence that children feel pain from the neo-natal period onward (Craig & Grunau,1991), and have the neurological mechanisms to feel discomfort during the third trimester of pregnancy (Anand & Hickey,1987, cited in Schecter et al.1993). Societal attitudes such as biases against pain expression, believing that pain is somehow character building, and relationships between suffering and cleansing incorporated in some religious belief systems have tended to perpetuate the misinterpretation and undertreatment of pain in children (Ross & Ross,1988; Schecter et al.1993).

Physical and Psychological Factors that Influence Pain Perception

The development and acceptance of the gate-control theory of pain (Wall & Melzack,1984) provided a neurological explanation for the transmission of pain, which acknowledges that both descending impulses from the higher cerebral centres and ascending impulses activated by innocuous stimuli, modify the neural input from the site of tissue damage. The descending input from higher cerebral centres offers an explanation as to why intrapersonal factors (e.g. emotion, fear, rational thought, memory of past experiences), and environmental factors (e.g. distraction, situational and cultural variables) can influence the perception of pain and its intensity.

P.A. McGrath (1993) noted further that several converging lines of evidence *"suggest that children's pain is even more plastic than adults, so that environmental and psychological factors may exert a more powerful influence on children's pain perceptions"* p.39. Plasticity of pain refers to the way in which pain perception is not rigidly related to the degree of tissue damage. Factors other than the neural input from tissue damage modify the perception of pain, so that children (and adults) can experience differing degrees of pain from the same type of tissue damage. Children can experience pain where there is no obvious signs of tissue damage, and can be injured without experiencing pain (P.A.McGrath,1993; Ross & Ross,1988).

P.A.McGrath(1993) proposed a model of key psychological factors which influence children's perceptions of pain in a mutually interactive way that incorporates situational factors (e.g. perception of control and expectations); behavioural factors (e.g. parental response, overt distress and coping style); emotional factors (e.g. fear, anger and frustration); along with relatively stable child characteristics (sex, age, cognitive level, previous pains, family learning and culture). Ross and Ross (1988) described a social ecology model of pain, which incorporated situational, environmental and child factors similar to P.A. McGrath(1993) cited above, and conceptualised a mutually reciprocal transactional process between all of the factors and the physiological tisue damage in which the child's reactivity to pain is not only a consequent of the environment (and other factors), but also an influence on it.

Age and Perception of Pain in Children

Research has begun to investigate some of these determinant factors and results have not always been consistent. It seems clear that some of this inconsistency arises from the interactive nature of the psychological, situational and environmental determinants which impact greatly on the perception of pain in children. For instance, Haslam (1969) found that pain threshold increased with age (5-18 years), and Lander & Fowler-Kerry(1991) similarly found a negative correlation between age and degree of pain associated with venipuncture in children aged between 5 and 17 years.

However, it is often noticed clinically that younger children report fewer post-operative pain symptoms, and a study reported by Leikin, Firestone & P.J.McGrath (1988) confirmed this clinical impression. Studies of pain emanating from different procedural sources (i.e., injections and surgery) are compared with caution as it may be that age differences in pain following surgery are due to younger children's greater physiological resiliency in response to surgery. Alternatively , older children's cognitive advancement allows for greater understanding of pathological processes and implications of disease or surgery, so that intensity of pain experienced may be increased (Beales, Keen & Lennox-Holt, 1983; Craig & Bennett-Branson, in press).

P.A.McGrath(1990) found that in "healthy" children, the reported strength and unpleasantness of routine, mild injuries generally decreased with age, although the number of reported pains increased. It was also described that children at the same chronological age who had greater experience of painful procedures (children with chronic arthritis having intramuscular gold injections), may perceive subsequent immmunisation boosters as less painful than their age-mates who had not had the same degree of procedural pain, (P.A.McGrath, 1993). It may be that greater experience of pain is likely to alter the child's perception, although this has not generally been investigated as yet.

Definitions of pain threshold and pain tolerance are important when reviewing this

area of research. Pain threshold refers to the point at which the stimulus is first experienced as painful, while pain tolerance is the point at which the stimulus can no longer be endured (P.J.McGrath & Unruh,1987). Pain threshold has generally been found to increase with age. However, other factors such as understanding of the implications of the pain, possibly increased experience of pain, and socio-cultural expectations of children in relation to age impact on this finding. P.A. McGrath (1993) stated that *"we do not know the true impact of children's sex, age, and cognitive level on their 'hurting'."*p.42.

Gender and Perception of Pain in Children

The findings of the impact of the child's sex on perception of pain are even more divergent than that of age. For example, Ross and Ross(1984a) found no significant differences between boys and girls reporting of pain experiences and descriptions of pain responses in their large scale interview study. However other studies have revealed sex-related differences, although each of these studies tapped into different aspects of pain perception (Grunau & Craig,1987; Savedra, Gibbons, Tesler, Ward & Wegner,1982). For instance, Grunau and Craig(1987) found that infant boys cried sooner and with significantly more cry cycles than infant girls during heel lance procedures, whereas Savedra et al.(1982) found differences in the selection of words used to describe pain, with girls selecting more psychologically and emotionally orientated words than boys. Most recently, it has been suggested that any differences that emerge in relation to sex are likely to be dissimilarities in expressions of pain which are the result of socialization practices (Fowler-Kery & Lander, 1991; P.A.McGrath, 1993), and this factor therefore interacts with age, social environment and culture.

In summary, research investigating the impact of age and sex of the child has been reviewed as examples of the interactive nature of the determinants of children's pain. Some aspects of tissue damage are predictably related with perception of pain (e.g. spatial extent and location). However as well as the nature of tissue damage, children's perception of pain depends on contextual factors internal to the child, for example, age, gender, emotions, feelings of control, and also contextual factors external to the child, both situational and environmental/cultural. These factors will be further discussed below in relation to children's use of coping strategies. The next section reviews what has been a major missing link, the viewpoint of the child.

THE CHILD'S VIEW OF PAIN

Ross & Ross (1984b) noted that there had been little input from children within the increasing body of clinical and research literature which offered guidelines for managing pain in children. However, more recently several lines of research have

begun to document children's views of their experience and understanding of pain. Children's understandings and conceptualisations of pain are a valuable source of information about their experience of pain and should not be equated with the actual experience because there may be an age lag between the understanding/experience, and the ability to express that experience, especially in younger children (Gaffney,1993).

Children's Definitions of Pain

Gaffney & Dunne(1986) have provided convincing evidence that children's definitions of pain alter developmentally in a manner consistent with Piagetian stages (Piaget & Inhelder,1969). Children in the preoperational age group (approximately 18 months up to 6 years) were more likely to attend to the perceptually dominant features of a painful experience. They were more likely to say *"Pain is...in your tummy, it hurts you;....it is in your belly."*(Gaffney & Dunne,1986,p.111). They did not understand the relationship between pain and illness, or the value of pain as an early warning system.

During the concrete operational period (approximately 7 to 10 years) there was some retention of earlier definitions (which is consistent with Piagetian stages), and a move toward more generalised and abstract definitions of pain that were less passive. Pain was now understood to occur within the body, and the localisation of internal pain was more likely to be differentiated and no longer globally ascribed to the tummy. Children began mentioning the psychological effects of pain, and they might mention that pain could make people feel miserable, unhappy, or angry (Gaffney & Dunne,1986).

The capacity for introspection and abstract thinking allowed the children of the formal operational period (11 years upwards) to offer definitions of pain that included a physical and psychological component, and often also included psychosocial factors (both inter- as well as intra-personal). For example, `pain may make you grumpy and spiteful, as well as sad and depressed'. Pain was conceptualised as something that had to be coped with, dealt with, or borne, which Gaffney and Dunne(1986) interpreted as a shift to a more active view of pain, as opposed to the passive view of the children of the preoperational stage. *"The ability to reflect on pain in an abstract, non-perceptually dominated way also allows the positive, biologically useful aspects of pain to be recognised"* (Gaffney & Dunne,1986,p.113). Anxiety about the significance of pain, and the implications of the pain in relation to illness was also noted by Gaffney(1993), and is discussed below.

Ross and Ross(1984a) did not find developmental themes in children's definitions of pain, and the definitions which they found tended to be brief, unidimensional, and emphasised the sensory dimensions of pain. However Ross and Ross(1988) suggested

that differences in questioning format led to different results, in particular the specificity of questions in their own study. Ross and Ross(1988) proposed that they would also have found developmental transitions in definitions of pain if they had asked similarly open questions to Gaffney & Dunne(1986). Preliminary results of a replication study by Ross and Ross(1988) show the same Piagetian developmental transitions as those found by Gaffney & Dunne(1986), lending support to the conclusion that there are developmental themes in children's definitions of pain. However, regardless of developmental stage, children described the most aversive aspect of pain to be its unpleasant sensory qualities, followed by the disruption of play and other activities of everday life (Gaffney,1993). Children were also concerned that pain may never go away (Ross & Ross,1988).

Pain Descriptors and Expression of Pain

The behavioural expression of pain alters with chronological age and developmental level. Grunau, Johnston & Craig(1990) described the cluster of facial behaviours of the neonate in response to pain, for example, brow bulging, eyes squeezed shut, taut tongue and mouth open. Pain expression becomes a full-bellowed angry cry in infancy, and then alters as the child learns familial and cultural beliefs as to how one should experience and cope with pain. Individual differences in pain expression can well be understood in light of the previous discussion of interacting psychological and situational factors. Furthermore, Grunau et al.(1990) found substantial individual differences in newborns' response to painful stimuli, and it seems likely that there are differences in temperament, expressivity, or possibly degree of pain sensitivity present at birth.

There is a lack of data on children's pain language compared to the vast amount of adult data. However, children as young as three years of age have described pain as shooting and hurting (Hahn,1986, cited in Ross & Ross,1988). In a series of studies designed to construct a word list for use with children and adolescents to describe pain quality, Tesler,Savedra,Ward,Holzemer & Wilkie (1988) reported an additional 31 words not in the McGill Pain Questionnaire, that 50% or more children selected to describe pain.

Language and vocabulary used to describe pain has been found to be age-related and followed a similar pattern in both sexes (Gaffney,1988; Wilkie et al.1990), which is in keeping with the developmental sequence described above. Gaffney(1988) found that the five year olds used six pain descriptor words, but by age 14 the boys used 44 words and the girls 61 words. The use of analogies in describing pain also increased with age, from 5.7% of 5-7 year olds, to 42.1% of 8-10 year olds, and to 70.1% of 11-14 year olds. It has also been suggested that the use of analogy depends on the content of

the question as well as the age/developmental stage (Ross & Ross,1988). Furthermore, children's descriptions of pain may vary with the demand characteristics of the situation, in particular recency of a hospitalisation experience (P.J.McGrath & Unruh,1987; Savedra et al.1982), and most of the studies have investigated "healthy" children from school samples. However, Tesler et al.(1988) found no significant differences in selection of words for pain between children previously hospitalised, as compared to children with no previous hospitalisations.

The overall implications of children's language of pain in relation to the present study are that up to the age of seven or eight years children are limited in their ability to describe pain (Gaffney,1988), and after this age children begin to use qualitative and affective words (8-10 year olds), with increasingly more complex words, and increasing use of analogy as children get older (11-14 year olds).

Children's Reports of the Causality of Pain

Gaffney & Dunne(1987) found that children's understanding of the causality of pain progressed developmentally in keeping with Piagetian stages (Piaget & Inhelder, 1969). Objective and abstract explanations increased significantly with age, and "transgression" explanations of pain were offered by 44% of the children in their study. Examples of transgression explanations are varied, e.g., `go out with no coats'; `watches T.V. too long'; and failure to comply with rules. Transgressions involving eating were common (Gaffney & Dunne,1987). During the concrete operational period transgressional explanations appeared to exist alongside other more objective explanations for pain, as the children became aware of multiple rather than single causes for pain (Gaffney,1993). Trauma explanations and psychological explanations increased in the formal operations group, although transgression explanations could still be retained.

Earlier studies reviewed by Ross & Ross(1988) found a high percentage of causality attributed to illness-related pain, and trauma or malfunctioning parts of the body. In contrast, Gaffney & Dunne(1987) proposed that because they found that "transgression" or "moral" explanations of pain could co-exist with the more objective causes such as trauma and illness, it may be that different types of questioning tend to elict either "moral", or "illness" explanations, and this could account for the discrepant findings. Preliminary findings of a Ross and Ross(1988) study show many of the same causality trends documented by Gaffney and Dunne(1987), except that pain as punishment for transgressions involving eating was seldom mentioned. Recognition of psychological causes of pain was reported in all studies (Ross & Ross,1988), and an interesting gender difference was found by Gaffney and Dunne (1987) in that girls cited psychological factors as causes of pain more frequently than boys.

Memory for Pain in Children

Memory for pain has not been established under about six months, but P.J. McGrath and Unruh (1987) suggested that this may reflect a lack of appropriate methodology, and furthermore, that the assumption that infants do not learn from painful experiences has led to the tendency to undermedicate infants. The long-term effect of painful experiences in infancy is a cause for concern, as feelings of helplessness, hopelessness, and a tendency for poor coping with later pain have been suggested (P.J.McGrath & Unruh,1987).

Studies have found that children aged five years and upwards have good memories for pain (Lander, Hodgins & Fowler-Kerry,1992; Ross & Ross,1988). Lander et al.(1992) in a study of venipuncture pain, found that children's recall of affective aspects of pain was superior to their recall of sensory pain. However, they suggested that this may reflect the type of scales used to measure pain. Postulated relationships between predictions of pain, actual experience of pain, and accuracy of recall, extrapolated from findings of research with adults, were not generally supported by the findings of Lander et al.(1992). In particular, the underprediction of pain did not necessarily lead to over-reacting to pain, and inaccuracy of recall.

In summary, a developmental progression consistent with Piagetian stages has been found in children's definitions of pain, children's language of pain, and children's attributions of causality of pain. Children have been found to have good memories for pain. Most of the research has been undertaken with "healthy" children, recalling painful episodes and describing their current conceptualisations of pain in terms of previous experiences. Children who have long-term disease-related pain have been a neglected group, yet they have current and ongoing experience of pain about which they are likely to be thinking, and drawing conclusions.

PSYCHOLOGICAL INTERVENTIONS

An outline of coping strategies that have been taught to children is included in preparation for the discussion of strategies that children have been found to develop spontaneously. A variety of psychological strategies have been taught to children, and there is some evidence that teaching coping strategies to children is helpful in assisting them to cope with painful syndromes, and painful procedures (P.J.McGrath & Unruh,1987;1993). The major strategies can only briefly be noted, with the understanding that there is an increasing literature of outcome research which will expand our views on effective intervention as this field develops.

Behavioural interventions that have been documented are: operant conditioning; film modelling procedures; relaxation training; biofeedback; art and play therapy; group therapy; and family therapy (P.A.McGrath,1990; P.J. McGrath & Unruh,1987;1993; Ross & Ross,1988). There have been criticisms of operant

conditioning because it may be that instead of feeling less pain, the child is learning to complain less (Ross & Ross,1988).

Cognitive interventions that have been documented are: distraction techniques which divert the child's attention; visual imagery; thought-stopping; hypnosis and hypnotherapy; music therapy; and psychotherapy (P.A.McGrath,1990; P.J.McGrath & Unruh,1987;1993; Ross & Ross,1988). Distraction is the most common cognitive intervention (P.A.McGrath,1990), and parents tend to use this in response to the bumps and bruises of childhood play. A variety of external distractors have been used in relation to children's pain, e.g. toys, bubbles, music, video games, and also internal distractors, e.g.deep breathing. Age of the child was found to be an important determinant of the success of a music distractor in 4.5 to 6.5 year olds (Fowler-Kerry & Lander,1986).

Providing accurate, developmentally appropriate explanations in language that the child understands is an important intervention which has been documented in relation to procedural pain (P.J.McGrath & Unruh,1993), and chronic pain (P.A.McGrath, 1990). Harrison(1991) found that children aged 6-12 years who were prepared with a picture book/explanation story prior to venous blood sampling, experienced less pain during blood sampling and were less disturbed by the procedure. Non-pharmacological physical interventions such as massage, applying pressure, and applications of heat and cold have been taught to children and are an extension of naturally occurring responses to pain (P.A.McGrath,1990).

Combinations of strategies are often utilized, and it is important to note that the effectiveness of psychological interventions does not indicate that the pain being experienced was any less "real". The choice of interventions has often rested with the particular biases of the health professional (P.A.McGrath,1990) and furthermore, certain types of pain have become matched with certain interventions. Factors unique to each child (described above) need to be considered when selecting interventions, in addition to the basis of the pain (P.A.McGrath,1990). It is of paramount importance to find out from the children what they may already be doing in order to manage their pain. What has been effective in the past for them and what sort of preferences do they have? The clinical necessity of obtaining an in-depth picture of each child prior to imposing a clinician favoured intervention on him or her, has been discussed by Ross & Ross(1988). It may be that the child has spontaneously developed coping strategies that can be supported and extended, thus returning feelings of being in control to him or her.

In summary, the variety of coping strategies that have been taught to children have been outlined. It is necessary to find out what coping strategies children may have spontaneously developed, and obtain information about their understanding of their pain as part of the assessment prior to teaching interventions.

CONCLUSION

Psychological aspects and contextual factors that impact on children's perception of pain have been discussed and literature which describes children's understandings of pain reviewed. Strategies that have been taught to children in order to help them cope with pain have been outlined. Subsequent chapters review the literature that has documented the spontaneous coping strategies of children in response to acute pain.

CHAPTER TWO

Children's Spontaneous Strategies for Coping With Pain

Children's spontaneous strategies for coping with pain have been researched from several different perspectives, but still comprises a relatively small body of literature. Studies include: Children's responses to hospitalisation stressors and painful pre-surgical procedures (e.g. LaMontagne,1984;1987; Savedra & Tesler,1981); Children's spontaneous strategies for coping with acute painful medical and dental procedures (e.g. Brown, O'Keefe,Sanders & Baker,1986; Curry & Russ,1985); Research in which "healthy" school-children have been asked to recall their experience of pain, and what they might do in order to manage acute pain (e.g. Ross & Ross,1984a); Children's spontaneous strategies for coping with acute post-operative pain (Bennett-Branson & Craig, in press). There has been no published research into the coping strategies of children who experience chronic disease-related pain. Therefore the above related body of research must be drawn upon for a discussion of children's coping with pain.

CONCEPTUAL ASPECTS OF COPING IN CHILDREN

The literature on coping during childhood and adolescence lacks the convergence in conceptualisation and measurement that has evolved in the adult coping literature (Compas,1987). However, in spite of the divergent lines of research, and different methodologies, the present author found several unifying concepts underpinning children's coping research.

There was general acceptance of Lazarus & Folkman's (1984) definition of coping: *"We define coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person"* (p.141). While acknowledging that this definition arises from adult literature, and there is a paramount necessity to consider the developmental backdrop in relation to children's coping, most of the studies and review articles utilized definitions similar to the above as a starting point, (e.g., Brown et al.1986; Craig & Bennett-Branson,in press; Curry & Russ,1985; Siegel & Smith,1991).

Inherent in the Lazarus & Folkman (1984) definition is the idea that coping involves an effortful behavioural and/or cognitive response, and that appraisal of the stressor is the initiating part of the coping response. According to Lazarus & Folkman's(1984) conceptualisation, primary appraisal refers to evaluating the significance of any event to the person's well-being, and secondary appraisal refers to evaluating the resources available for mastery. Reappraisal is described as part of primary appraisal and refers

to re-evaluation of an original stress appraisal because of information changes and/or effective coping. Jensen, Turner, Romano & Karoly (1991) noted in a review of the literature on coping with chronic pain that existing measures often confound coping, appraisals, and adjustment.

Appraisal has rarely been addressed in the children's coping with pain literature but it needs to be addressed because it seems likely that the child's level of development impacts on appraisal of the pain stressor. Peterson(1989) suggested that cognitive distortions in younger children influence appraisal, and that children's cognitive abilities may limit their capacity to define a painful event in terms of the time it lasted and the severity of pain. Furthermore, the meaning that the child ascribes to the pain influences appraisal (Siegel & Smith,1991). This is discussed below in relation to chronic pain.

Implicit also within the Lazarus & Folkman(1984) definition is that coping efforts are either intrapsychic so that the individual manipulates his/her cognitions,(i.e., cognitive strategies), or direct action in which physical acts are employed to prepare for, or to manage the stressor(i.e., behavioural strategies). Strategies may be intended to change the problem situation (problem-focussed coping), alter the meaning of the situation, or change one's emotional reaction to it (emotion-focussed coping, Lazarus & Folkman,1984).

In summary, coping is conceptualised as a situation-specific process that includes appraisal of a stressor, initiation of effortful coping strategies, and coping outcome. In relation to children a developmental overlay is required.

CLASSIFICATION OF CHILDREN'S SPONTANEOUS STRATEGIES FOR COPING WITH PAIN

Acceptance of the Lazarus & Folkman(1984) conceptual model implies that a process approach is taken as a theoretical framework for coping. That is, the appraisals, coping responses or strategies, and re-appraisals constitute a dynamic and changing process that varies depending upon the demands of the specific situation (Folkman,1984). Several studies in the pediatric pain coping literature paid lip service to the process model extrapolated from the adult literature but subsequently hypothesized and found support for global coping styles, or a trait approach (La Montagne, 1984;1987; Peterson 1989).

There is inconsistency in the children's coping literature and both process and trait frameworks have been utilized. In particular, there has been support in the literature on hospitalisation and painful stressors for a global coping style of passive/information-avoiding versus active/information-seeking (Knight et al.1979; La Montagne 1984;1987; Peterson & Toler 1986; Siegel,1988). However, there are theoretical

and measurement problems with this conceptualisation. For instance, a child who appears passive may be purposefully absorbed in counting the tiles on the ceiling, or listening to music, but (s)he would be coded as avoidant. That is, because active coping has been conceptualised as a willingness to encounter information (e.g.playing with medically relevant toys, or asking questions about the painful procedure), being psychologically active (e.g. using imagery or distraction) does not comply with the active conceptualisation, since it does not involve observable action (Keefe, Salley & Lefebvre,1992).

The single dimension of information-seeking versus information-avoiding does not allow for the complexities inherent in the coping process. For instance, the use of emotionally-focussed strategies as opposed to problem-focussed strategies is likely to be situation-specific rather than global. Internal versus external aspects of coping have mostly been ignored within this conceptualisation of a global style.

The tendency to classify children's coping with painful procedures along a continuum from active/information-seeking to avoidant/information denying has led to research results in which successful coping has been equated with information-seeking, and unsuccessful coping with information avoiding (Peterson & Toler,1986; Siegel,1981, as cited in Siegel, 1988). The present author contends that this has been an untimely adoption of a trait framework within the literature on children's coping with pain which has led to some unfortunate consequences and unnecessary labelling of children. For instance, there has been debate about whether children should be provided with preparatory information because it may be antithetical to their global style. Yet at this time few studies have researched children's responses across a variety of amxiety-provoking and stressful situations. We cannot therefore assume that a global style along an information-seeking to information-avoiding continuum adequately represents children's coping responses.

The definitions of successful and unsuccessful coping are an issue in the above formulation. That is, successful in whose eyes? Coping outcome has often been measured in terms of the child's co-operation with a procedure and/or ward personnel, or independent observer's reports of overt behaviours (studies reviewed by Peterson,1989), and less often in terms of self-report of the child. Furthermore, the use of particular coping strategies should not be confused with coping outcome.

Most recently, Craig and Bennett-Branson(in press) concluded that:

> *The weak predictive validity of several of the coping style measures suggests that either the measures have been unsatisfactory, despite the several approaches that have been used, or global classification of coping predispositions is too general for prediction of differences in coping outcome. Recent work in the pediatric literature indicates the relevance of examining variability in the situation-specific strategies for coping with pain.* (p.6).

The current trend in the pediatric pain literature is to follow the lead of the adult coping literature (e.g.Aldwin & Revenson,1987), that a particular coping strategy is not inherently adaptive or maladaptive, nor is any particular coping strategy globally superior to other strategies (Craig & Bennett-Branson,in press; Siegel & Smith,1991). That is, a coping strategy that is effective in one painful or stressful situation may not necessarily be effective in a different painful situation, or with other aspects of the pain. Craig and Bennett-Branson(in press) therefore suggested that it is likely to be beneficial for individuals to have a variety of coping strategies that they are able to adapt to particular situations. However, elsewhere these authors also noted that greater coping effort does not necessarily imply better outcome, and it may be that a variety of alternative strategies are attempted in response to more severe pain (Bennett-Branson & Craig,in press) The findings of specific studies investigating children's coping strategies are reviewed in the next section.

REVIEW OF STUDIES

There is no consensus about the numbers of children who spontaneosly utilize coping strategies in response to acute pain. Several researchers have found that children spontaneously utilize coping strategies in response to acute pain at relatively low rates (e.g., Brown et.al.1986; P.A.McGrath,1990; Ross & Ross,1984a). However, research evidence has been equivocal. Conceptual anomalies, such as trait versus process approach, differences in classifying coping strategies, and methodological variations have contributed to the divergence in research conclusions. For instance, both Branson & Craig(1988) and Ross & Ross(1988) suggested that the wording of the questions may have resulted in underestimation of the use of spontaneous self-management (i.e., the wording created a response set directed toward other help rather than self-help). Recent findings suggest that children spontaneously employ a variety of coping strategies,and higher numbers of children may do so than earlier reported (Branson & Craig,1988; Branson,McGrath,Craig,Rubin & Vair,1990; Curry & Russ,1985; Bennett-Branson & Craig, in press).

Curry & Russ(1985) constructed categories of coping which they had integrated from reviewing the adult coping and cognitive-behavioural literature. Children's coping responses to dental treatment were then assessed using both direct observation during the procedure and a post-procedure semi-structured interview with each child, then were analysed in terms of the *a priori* categories. Coping categories were subdivided into behavioural and cognitive, and three behavioural and six cognitive categories of coping strategies were identified. Every subject (n = 30 children, aged 8-10 years) reported using at least two cognitive coping strategies and was observed eliciting at least one behavioural coping strategy during treatment, and the average

child in the sample employed a varied repertoire of cognitive and behavioural coping strategies (Curry & Russ,1985).

Brown et al.(1986) utilized an imaginally reconstructed (dental) pain situation alongside other imaginal non-painful stressful situations and documented children's written responses from a large sample (n = 487) of "healthy"school children aged 8 – 18 years. Coping strategies arising from the dental pain situation were classified post-hoc into either coping strategies or catastrophizing cognitions.

The coping strategies described by the children were categorized as: positive self-talk (e.g. I can take this); attention diversion; relaxation, deep-breathing; and thought-stopping. Positive self-talk was used most often by all age groups, and its frequency of use increased with age. Catastrophizing cognitions were: focussing on negative affect or pain (e.g. this hurts); thoughts of escape or avoidance; fear of unlikely consequence; fear of response to dentist or vice versa (e.g. what if he's a meany?). Focussing on negative affect or pain was the most frequent catastrophizing reported by all age groups. Across all of the age groups, 37% of the sample were classified as copers, and twice as many 16-18 year olds reported predominantly coping cognitions as did 8-9 year olds. Older children reported using a greater number of different types of strategies.

There are several issues in relation to the Brown et al.(1986) study. Firstly, these authors assumed that certain coping strategies were successful or unsuccessful. For example, the strategies labelled as coping were assumed to be successful and the strategies labelled as catastrophizing were assumed to be unsussessful when no outcome measures were reported. This error has been maintained in subsequent reviews (e.g., Siegel & Smith,1991). Coping outcome has been inferred from the type of strategies reported but the effectiveness of coping strategies can only be demonstrated through their association with good or poor outcome. *"At any age, active coping strategy use does not necessarily imply adaptive outcome"* (Craig & Bennett-Branson,in press,p.14).

The findings of Brown et al.(1986) werehowever, an important illustration that children do use catastrophizing cognitions as has been demonstrated in the adult literature. The finding in the adult literature has been that the use of catastrophizing coping strategies is associated with less effective coping with chronic pain (Williams & Keefe,1991). However, to date there has been little documentation of the effectiveness of children's spontaneous strategies for coping with pain, although some documentation of outcomes of coping strategies utilized to manage hospitalisation stressors noted that less successful outcome was associated with catastrophizing (Siegel,1988).

Secondly, utilizing only written responses across a wide age range of children without any verbal back-up must be questioned in view of children's cognitive and academic capabilities. It is misleading to compare responses that require written

construction of children aged 8-9 years, with children aged 14-16, or 16-18 years. However, younger children's construction of oral language is far in advance of what they are able to construct in written responses. For this reason, Ross & Ross(1984) suggested that oral language responses should always be utilized where children are required to construct answers. It is possible therefore that the less advanced written expression skills of the younger children led to underreporting of their coping strategies in the Brown et al.(1986) study.

The studies by Brown et al.(1986) and Curry and Russ(1985) provided initial classification systems that are representative of the sorts of cognitive and behavioural coping strategies that have been documented as being utilized by children experiencing acute pain. However,because the starting point of the classifications has been the adult coping literature, it is possible that important facets of children's coping with pain are not being documented. Varni & Walco(1991) have cautioned against the tendency to apply downward the perception and experience ofadults to children. One strategy that does not fit easily into the above classification systems is that of fantasy, although it could possibly be construed as diversionary thinking within the Curry & Russ(1985) classification. The use of fantasy has been documented as a coping strategy that children spontaneously utilize by both Ross and Ross(1984a),and Siegel(1981,as cited in Siegel,1988).

As part of a semi-structured interview investigating children's experience of pain, Ross & Ross(1984) tapped into children's self-initiated coping strategies. Only 213 out of 994 children aged between 5 and 12 years reported using such strategies. Distraction with internal or external activities was used by 93 children, and physical procedures such as clenching one's fist were used by 91 children. Only 29 children used the variety of strategies including thought-stopping, relaxation/imagery, and fantasy.

Bennett-Branson and Craig(in press) utilized a classification system which was integrated from previous research (Branson & Craig,1988; Brown et al.1986; Curry & Russ,1985), which consisted of five cognitive strategy subtypes, seven behavioural strategy subtypes, and four varieties of catastrophizing cognitions. The findings were that children can generate at least one behavioural strategy in response to an open question, and many children generated more than one (mean of 2.28 strategies). Endorsement of supplied examples of behavioural strategies was higher than generated examples of behavioural coping. The mean number of cognitive coping examples generated was 1.02, and mean endorsement ofcognitive strategies was 3.12. The mean number of catastrophizing thoughts generated by the children was 1.05.

All children were experiencing in- vivo post-operative pain (24 hours after surgery), and most had tonsillectomies. Coping outcome was measured in terms of multiple components and several key relationships were found. The stronger the perceived self-efficacy, the less pain was experienced. A greater number of catastrophizing thoughts

was positively related with higher pain component scores. Also, increased behavioural coping frequency was positively related with increased severity of pain. Possible interpretations of this relationship were that children employ a greater variety of strategies when the sensory component of pain becomes more severe, or that better copers may successfully employ fewer strategies(Bennett-Branson & Craig, in press). It is important to note that other factors were involved in this relationship. Complex age/develpmental relationhips were also found, and are discussed below.

CONCLUSION

Conceptual and classification aspects of children's strategies when coping with pain have been discussed. The review of studies shows that findings remain equivocal about the rate of children's use of coping strategies in response to acute pain, although recent research suggests that most children can generate one or two behavioural strategies, and many children can generate a cognitive strategy (Bennett-Branson & Craig,in press). Similar contextual factors are likely to impact on the children's use of coping strategies, as they impact on their perception and experience of pain. These are discussed in the next chapter.

CHAPTER THREE

Factors that Influence the Use of Coping Strategies when Children Experience Pain

COGNITIVE DEVELOPMENT

It is clear from the foregoing that the child's level of cognitive development is likely to influence both appraisal and the use of coping strategies. As noted previously, appraisal has rarely been addressed, but the evidence reviewed above found a developmental progression in:

(1) children's definitions of pain (Gaffney & Dunne,1986);
(2) children's reports of the causality of pain (Gaffney & Dunne,1987);and
(3) the pain descriptors and symptom reporting of children (Wilkie et.al.,1990), all of which appear to impact on appraisal.

Age-related differences in appraisal were also documented by Bennett-Branson & Craig (in press), although there was an uneven gender distribution in their sample of subjects. Children aged 10 years or over (mostly girls) described their post-operative pain in a qualitatively different manner, including more complexity of detail than the younger children, and were more likely to include affective or evaluative words or to provide an analogy explaining the quality of the pain experienced. Craig and Bennett-Branson(in press) supported the view that developmental shifts in children's understanding of pain impact on both appraisal and the type of strategies that children naturally employ when coping with pain

However, there is inconsistency in the findings, especially in relation to the type of coping strategies children utilize. For example, Savedra and Tesler(1981) found no statistically significant patterns in coping strategies by age group (6-9 years and 10-12 years) in children hopsitalised for surgery, in contrast to La Montagne (1984;1987), who did find age-related effects on coping strategies, with older children using more active modes of coping. The body of research on painful procedures has provided beginning evidence that a developmental progression occurs in children's spontaneous utilization of coping strategies. Younger children at the Piagetian pre-operational cognitive development stage (Piaget &Inhelder,1969), have been found to use predominantly behavioural coping strategies (Reissland,1983). As children's cognitive development progresses through the concrete operational stage, and on to formal operations, an increasing use of cognitive coping strategies has been found (Brown et.al.,1986; Curry

& Russ,1985; Reissland,1983). The convergence of this finding occurred in spite of the use of different methodologies, and different classification of coping strategies.

Recently therefore, the consensus has been that, as children progress through their cognitive development,they supplement (but do not replace) the predominant use of behavioural coping strategies with an increasing use of cognitive coping strategies (Craig & Bennett-Branson,in press). However, Bennett-Branson and Craig,in press) documented an intriguing finding when they found that the above described age differences in predominant coping strategies emerged in children's generated responses to an open-ended question, but not when children were asked to endorse their use of cognitive coping strategies as supplied by the interviewer. Explanations offered for this finding were: that younger children use cognitive coping strategies but lack the memory retrieval or verbal production ability to generate for the interviewer examples of their cognitive coping; or, alternatively that the lack of age differences in the supplied response situation reflected a response bias, e.g.a desire to please adult researchers (Bennett-Branson & Craig, in press). Therefore, although it seems likely that children use an increasing frequency of cognitive coping strategies as their cognitive development progresses, the inherent problems of research with children may have distorted this finding. Again, all of the research pertains to acute painful episodes, either painful procedures, or post-operative pain, and it is possible that children who experience long-term pain will offer alternative insights.

In terms of coping outcome, the developmental trends do not always suggest that youger children are more vulnerable. For example, younger children reported less distress, were perceived by their parents to be in less distres9s, and returned to normal activities more quickly following tonsillectomy and adenoidectomy than did older children and adults (Leikin et al.1988). This trend was also documented by Bennett-Branson & Craig (in press), and these researchers suggested that as the medical literature offers no clear pathophysiological reason to expect greater pain in older children and adolescents following tonsillectomy, it is possible that variations in coping processes are involved. The appraisals of older children and adolescents may have incorporated all of the unpleasant after-effects of surgery, such as nausea,disorientation, taste of old blood, in their characterisations of pain, and therefore perceived themselves to be in greater pain than younger children.

MEANING ASCRIBED TO THE PAIN

The importance of the meaning that the child ascribes to the pain was first documented by Beales et al.(1983), and bears direct relevance to children who experience long-term pain. Older children with juvenile chronic arthritis, aged 12–17years, unanimously reported the sensations they experienced "reminded them" of their disabling condition and unpleasant internal pathology. Thus, they were more inclined to interpret diffuse

joint sensations as pain. The majority of younger children in the study, aged 6–11 years described similar sensations but did not appear to associate the joint sensations with anything markedly unpleasant. This finding has clear implications for children coping with the recurring pain of any chronic illness. It seems that older children have the cognitive capacity to include consideration of internal pathology and the degree of harm that may be reflected by their pain, as well as having an awareness of the possible consequences of the pathology that is brought to their attention by the pain. Pain may then be experienced more intensely, for instance the pain arising from cancer and its treatment (Beales,1979, cited in Lavigne, Schulein & Hahn,1986).

COGNITIVE STYLE AND TEMPERAMENT

Appraisal of the painful stressor is also influenced by cognitive style (Lazarus & Folkman,1984). For instance,Leikin et al.(1988) proposed that Type A behaviour patterns originated in childhood and found that children identified as exhibiting Type A behaviour underreported a wide variety of symptoms, including pain. This was not likely to be effortful coping but an inherent tendency to suppress symptoms which impacts on appraisal.

The issue of whether children exhibit global coping styles,or more situation-specific coping strategies, is unable to be resolved because of the lack of cross-situational research investigating children's coping strategies (Siegel &Smith,1991). At present, the situation- specific model described above, with a developmental overlay, seems to represent the most useful integration of the literature. However, Lazarus & Folkman(1984) noted that there is both stability and change in coping. That is, although coping is a situation-specific process, individuals may have preferred modes of coping. Children's preferred styles of coping (while not being construed as global styles), are likely to influence the sorts of coping strategies that they utilize in response to their appraisal of a painful stressor.

CONTROLLABILITY

Perceived controllability of the pain is thought to influence the child's use of coping strategies (Siegel &Smith,1991). However there is little research pertaining to pain in children. Some related research has investigated children's reports of control-related strategies for coping with chronic illness in pediatric oncology patients (Worchel,Copeland & Barker,1987). These researchers differentiated between behavioural-control strategies, cognitive-control strategies, decisional-control strategies, and information-control strategies. Results suggested that behavioural control is the best predictor of emotional adjustment and that the quality of behavioural control strategies utilized is more important than the quantity of strategies

in chronically ill children with cancer (Worchel et al.(1987). Cognitive and decisional control were also significant predictors of adjustment and no effect was found for informational control. This was in contrast to previous findings in the literature on hospitalisation stressors, (reviewed by Siegel,1988), where an increased number of strategies was found to predict adjustment, along with an information-seeking style. The issue of children's perceived controllability of chronic pain remains to be explored. There are likely to be complex interactions between situation-specific factors, socio-environmental influences, personal resources such as cognitive development and perceived self-efficacy, as well as previous experiences.

PERCEIVED SELF-EFFICACY

Perceived self-efficacy differs from perceived controllability of the pain and refers to the person's confidence in his/her ability to initiate and carry out an available coping response (Siegel & Smith,1991). The adult literature suggests that individuals who have perceived high control over the situation and who have the highest self-efficacy pertaining to their ability to use that control, have the better coping outcomes (Litt,1988). However, perceived self-efficacy has seldom been referred to in the children's pain literature.

The recent findings of Bennett-Branson and Craig (in press) supported the relationship between stronger perceived self-efficacy and less experience of pain with a sample of children. Furthermore, children who reported higher levels of post-operative pain were likely to also report using more behavioural strategies to try and manage their pain, experienced more catastrophizing thoughts, and perceived themselves as less able to perform recovery-enhancing behaviours (i.e., lower self-efficacy). Therefore it seems that perceived self-efficacy is relevant to children's pain coping strategies. These correlational findings would indicate that complex interactions take place between the factors that influence children's use of coping strategies and caution against any over-simplification of the relationships.

Bandura (1977) proposed that judgements of self efficacy in pain or other situations are based on four sources of information:

(1) previous performance that is related to the present situation;
(2) vicarious experiences, that is, observing others cope calmly with similar situations;
(3) social persuasion, that is, others telling the child he will be able to manage. However this needs to realistic.
(4) physiological state, that is, anxiety and arousal.

If the child's heart and respiratory rates start to increase markedly, he may begin to doubt that he can cope. An increase in state anxiety has been found to occur when children are undergoing painful procedures (Brown et.al.,1986), and this has the

above-mentioned physiological concomitants, which have been implicated in diminishing the sense of efficacy. All four sources of information are likely to be relevant in children's judgements of their self-efficacy in relation to managing chronic pain.

PREVIOUS EXPERIENCE

Previous experience with painful events can have either positive or negative effects on children's subsequent coping (Siegel & Smith,1991). Children who have had earlier adverse experiences with painful procedures are likely to experience a conditioned anxiety response when confronted with subsequent procedures. This sensitizes them to the subsequent pain-producing situation, and interferes with adaptive coping attempts. On the other hand, children who have had positive experiences in the past, and been given the opportunity to develop feelings of control during the painful procedures, are more likely to have developed adaptive coping strategies, approach the situation with confidence in their own efficacy, and need little in the way of preparation (Faust & Melamed,1984; Siegel & Smith,1991; Craig & Bennett-Branson,in press). It is clear that the control needs of the child should always be addressed, whatever the situation.

TYPE, DURATION, FREQUENCY OF PAIN

There are situation-specific factors which are likely to impact on children's coping. These include the type, duration, frequency, and severity of the pain (Siegel & Smith,1991). However, there is no data as to how this constellation of factors affects the use of coping strategies in children's pain.

CULTURE AND GENDER

Cross-cultural variations in acceptable reactivity to pain have been well documented, and undoubtedly influence the use of coping strategies. For example, Chinese children reportedly expect little discomfort during tonsillectomy with local anaesthetic spray and open their mouths co-operatively for the procedure (Brown,1972, cited in Ross & Ross,1988), an operation that would never be performed without general anaesthetic in western culture. The importance of the sex of the child to pain reactivity varies cross culturally also, and research has been inconclusive on this factor. There is some clinical evidence that boys in western society respond to the pressures for the male to be brave and tolerate moderate pain better than girls(Ross & Ross,1988). The recent research evidence of Bennett-Branson and Craig (in press), also found that pain severity was significantly predicted by gender, with boys reporting lower pain levels than girls.

PRESENCE OR ABSENCE OF PARENTS

The presence or absence of primary caregivers (usually the mother) during painful medical procedures has been a controversial issue in regard to children's responses to pain in clinical practice (P.J.McGrath & Unruh,1987). Research results have also been equivocal as to whether parents' presence is associated with calm children, agitated children, or has no influence (Craig & Bennett-Branson,in press). In terms of the children's use of coping strategies, it seems likely that rather than the mere presence of the parent, it is the interactions between the parent and child that have an impact on the coping process.

Mothers' interactions with children have been found to alter with increasing age of the child, from calming and physical comforting with babies under one year of age to the increasing use of distraction with older children (Craig & Grunau,1991). It has also been found that as children get older they less frequently initiate parents' involvement in their own coping with pain (Peterson & Toler,1986). This is in keeping with findings that effective parenting entails parents progressively turning over control to their children, in pace with the children's increasing capacity for self-control (Ross & Ross,1988). However, Bush and Harkins(1991) suggested that in situations where children are experiencing pain, parents' behaviours may fail to keep pace with their children's increasing coping competencies.

Children's own views have also been documented by Ross & Ross(1988), and 99.2% of children aged 5 to 12 years felt that the thing that helped most, regardless of the kind of pain, was to have one or both parents present, although children acknowledged that often the parents could not actually do anything. The literature which relates children's coping with painful procedures to parental presence or absence, and in particular to specific qualities of the parent-child interaction, has pointed out that children often learn coping skills through familial and cultural socialization practices. However, the actual mechanisms of transmission have received little research attention (P.J.McGrath & Unruh,1987).

FAMILY AND CULTURAL SOCIALIZATION PRACTICES

Parents own coping history, parental coping styles, childrearing practices, anxiety level of parent, and age of child are some of the specific variables that have been suggested to impact on the interaction of parental influence and children's coping during painful procedures (Ross & Ross,1988; Craig & Bennett-Branson,in press). Parental anxiety is believed to have a disorganizing effect on effective parenting behaviours (Melamed,Siegel & Ridley-Johnson,1988).

There is beginning evidence that parents' own coping styles determine the manner in which parents help their children cope with stressful procedures (Craig & Bennett-

Branson,in press). There is some support for the supposition that parents who have a history of being calm and supportive, and who have modelled effective coping behaviour in relation to their own pain, are likely to elicit similar reactions in their children. Previous learning within the family and cultural context partly determines the range of coping strategies that a child is likely to exhibit in response to a painful stressor. There is direct training by parents as to the manner in which the child is expected to behave. Contingent social reinforcement however, exerts a much stronger influence and is more pervasive than direct training (Ross & Ross,1988). Children's expressions of pain and coping attempts may be rewarded by parents in a broad spectrum of ways. Observational learning occurs whenever the child voluntarily observes the behaviour of others and its consequences to them, and encodes the sequence. Learned pain reactivity may be appropriate or inappropriate,and this is also dependent on the age of the child. That is, children may encode and utilize sequences of pain behaviour within the family context that are deemed inappropriate for their age by their peer group. Potent models are parents, siblings, and peers, and there is continuous interaction between all types of learning. It is likely that coping strategies are learned along with pain behaviours, and there is a body of literature that suggests that families provide powerful models for responses to pain symptoms (P.J.McGrath &Unruh,1987).

Two studies have attempted to unravel some of the mechanisms of transmission of coping strategies within families. Dunn-Geier et al(1986) operationally defined coping outcome as degree of interruption to daily activites in adolescents coping with chronic arthritis. Adolescents were defined as "non-copers" when they had missed three or more days of school each month for the past two months because of pain, and were continuing to miss school. "Copers" did not have a school absence problem. Differences between the "copers" and "non-copers" were investigated in terms of mother-child interaction, child personality, and family characteristics. Children's overt behaviours were observed, but cognitive coping strategies were not examined. Adolescents defined as "non-copers" exhibited significantly more negative behaviour (e.g. anger, refusal) than adolescents defined as "copers", during a painful 15 minute exercise task.

During the painful exercise task, mothers of the "non-coping" adolescents more frequently discouraged coping behaviour and generally intruded more on any type of behaviour that the adolescent exhibited, than did mothers of "coping" adolescents. The finding that mothers of "non-coping" adolescents tended to be more actively involved or overprotective when their child was in a pain-oriented situation lends some support to the family dysfunction hypothesis in the maintenance of chronic pain in children. However, it should be noted that it was not possible to determine from the Dunn-Geier et.al.(1986) whether the maternal behaviour was a cause or effect of the child's

non-coping behaviour. Also, it shoud be noted that the focus was on relating coping outcomes to parent-child interactions, rather than investigating the coping process.

Bennett-Branson and Craig (in press) investigated parental influence on children's post-operative coping, in terms of global influences and situation-specific influences. Parents perceived themselves to have transmitted a variety of coping strategies to their children as part of their general parenting style over the years. Although this was commonly reported to be verbal, these authors cautioned that because socialization entails a considerable amount of unwitting, non-verbal mechanisms of influence, parental perceived mechanisms of transmission may only provide one part of the overall picture. No age group differences were reported by parents in the mechanisms of transmission of coping, contrary to the evidence described above that parental efforts to influence children are contingent upon age (e.g.,Peterson & Toler,1986). However, the older children in the Bennett-Branson & Craig (in press) study were more likely to recall that their parents had attempted to prepare them specifically to expect and cope with post-operative pain. These authors suggested that children have inherent capabilities for coping, as well as those learned within familial, cultural, and specific-situational contexts. However, further behavioural observations of parent-child interactions would strengthen the present parent influence findings.

CONCLUSION

There are many complex and interracting factors which theoretically impact on children's coping with pain. Research evidence, mostly pertaining to acute pain, is beginning to support some previous theoretical assumptions,and cast doubt on others. Cognitive-developmental level, perceived self-efficacy, cognitive style, meaning ascribed to the pain, family socialization practices, and possibly gender, impact on children's use of coping strategies. There are inconsistencies in the research findings. There is a lack of data on the impact of such factors as severity and duration of pain, and of particular relevance to the present study, long-term experience of pain. The following chapter will review the psycho-social aspects of long-term experience of pain in children and some preliminary evidence in relation to their use of coping strategies.

CHAPTER FOUR

Chronic Pain in Children and Use of Coping Strategies

PSYCHOSOCIAL ASPECTS OF CHRONIC PAIN IN CHILDREN

Chronic pain evoked by disease, injury, or life-threatening illness impacts differently on the child and family than acute pain. The role of the family in maintaining or alleviating chronic pain has received attention in the literature (e.g. Lavigne,Schulein & Hahn,1986; Payne & Norfleet,1986), and there is some relevance to chronic pain caused by disease (P.J.McGrath & Unruh,1987). The implications of the disease as well as the child's concept of illness are intricately related with the child's experience of pain, and psychosocial adjustment of the child and family. P.A.McGrath(1990) stated that:

> *Children perceive a chronic pain, such as arthritic joint pain in relationship to a certain context. The context is defined by their frame of reference – that is, their age and cognitive level, their previous pain experiences against which they evaluate each new pain, the significance of the disease to their lives, their expectations for obtaining eventual pain relief, and their ability to control the pain by themselves(p.310).*

Many of the above factors have been identified in the research on children's coping with acute pain, but the contextual factors, in particular the significance of the disease and the meaning the child ascribes to the pain in relation to the disease are of major importance in children's experience of chronic pain (Beales et.al.1983; P.A.McGrath,1990), and seem likely to impact on the use of coping strategies. Children with chronic illness and/or life-threatening medical conditions have issues of loss to deal with, such as not having a healthy body, feeling different from their peers, and the possibility of death. The perception of what their pain means in relation to these issues impacts on appraisal and the perception of pain severity. These appraisals impact on the use of coping strategies. The individuality and uniqueness of each child should never be overlooked, as well as the likelihood of intra-individual variation in emotional responses, depending on the situational and familial factors at the time.

Developmental trends in keeping with Piagetian cognitive-developmental stages have been found in children's concepts of illness (Beales et al.1983; Brewster,1982;Eiser,1985). For example, Beales et al.(1983) found that 7 to 11 year old children with juvenile chronic arthritis tended to see their illness in terms of concrete signs and defined arthritis in terms of its effects on their bodies,e.g. it made their knees ache. For the majority of the 7 to 11 year old children, these signs of illness were an adequate explanation of the disease. Most of the 12 to 17 year old children recognized

that these outward signs were related to internal pathology. This was discussed above. It has been suggested in relation to post-operative pain, that older children's increased understanding of the pathological implications draws attention to the pain, and pain may then be experienced more intensely, thus reducing the positive effect of children's reported increased use of cognitive coping strategies as they get older(Bennett-Branson & Craig, in press).

Findings have been inconsistent as to whether chronically ill children's concepts of illness are similar to that of healthy children of a comparable age, or altered by their personal long-term experience. Eiser (1985) concluded that illness was not likely to influence a child's concept of illness in any simple way. Also, there is a need to consider variations in the demands of the illness when predicting how chronic illness affects the child's cognitions. Koocher(unpub) suggested that developmentally advanced reasoning occurs in relation to the child's own specific illness, but does not generalize to other illness/injury situations.

Children who experience chronic pain resulting from disease or injury have far more to contend with than the pain, although this may be a paramount issue. Social isolation from peers because of restricted activity has also been found to be an issue of concern. P.A.McGrath(1990) noted that the nature of children's physical and emotional distress in response to chronic pain from physical illness has not been well documented. Lack of sleep because of pain may lead to tiredness, listlessness and being easily distracted. Children may be angry, frightened or depressed, or may suppress their emotions in order to protect their parents from further anxiety. Varni & Walco(1988)stated:

> *Pediatric chronic pain ... is typically characterized by the absence of an anxious component, with a constellation of reactive features such as compensatory posturing, lack of developmentally appropriate behaviours,depressed mood, and inactivity or restriction in the normal activities of daily living. These chronic pain behaviours may eventually be maintained independently of the original pain sensations and tissue damage, being reinforced by socio-environmental influence (p.146).*

Clinical reports vary from assuming that children's pains from chronic diseases are managed effectively, to the niggling doubt that their pain may not have been recognized, in much the same manner that the ability of neonates to feel pain was unrecognized (P.A.McGrath,1990). Furthermore, research on the psychosocial functioning of children with chronic illness and pain has often relied solely on mothers' reports, neglecting the rich, firsthand experiences of the children themselves (Timko,Stovel, Moos & Miller,1992). An exception to this was a study by Bennett-Branson, Malleson & Craig(unpub), discussed below, in which children recorded weekly pain and coping diaries. The majority of the children were experiencing pain,

and the intermittent type of pain experienced in chronic juvenile arthritis was evidenced by large within-subject variability in daily pain intensity. Although the group of children were generally well adjusted to their chronic illness, this did not mean that they did not experience pain. However we are lacking qualitative documentation about the context of their adjustment to pain.

Timko et al.(1992) focussed on children with juvenile rheumatic disease and investigated their psychosocial adjustment. Results supported previous findings that patients are more isolated than healthy peers, and that difficulties occurred primarily in social functioning, and also in the domains of psychological adjustment and family environment. Contrary to previous findings, Timko et al.(1992) found that more severe functional disability put the patient at higher risk of poor psychosocial adaption and that having little or no disability may reduce the risk of poor adaptation so that it is similar to that of healthy children. Previous research had suggested that the less disabled children had higher expectations for personal achievements than seriously disabled children, and consequently had difficulties adjusting to the realities of their functional abilities (McAnarney et al.1974, cited in P.A.McGrath,1990). There is consistency in the literature however, that the attitudes and behaviour of the child's family are of major importance in assisting the child to adjust to arthritis (P.A.McGrath,1990; Timko et.al.1992; Ungerer et al.1988).

An important finding documented by Timko et al.(1992) was that children with juvenile arthritis are more concerned about acceptance by peers than about physical impairments imposed by their illness. That is, feelings of "differentness" become a major concern for children, especially after the age of about 10–12 years. This is in keeping with the major developmental task of adolescence, which is to gain independence from one's family, and gain acceptance from one's peers. The concern about feeling different because of chronic illness, pain and functional disability is thought to occur regardless of the disease entity, and Timko et al.(1992) regarded their findings as generalizable to other chronic childhood disorders. *"There are many more commonalities than differences in the adjustment of children with chronic health problems"* Timko et al.(1992,p.75). Following this lead, the present research addresses the coping strategies and pain experience of children with chronic pain caused by various long-term illnesses.

CHILDREN'S COPING STRATEGIES AND CHRONICITY OF PAIN

Currently, there is an absence of published research into the coping strategies that are developed by children who experience chronic pain. Recent publications include informative review chapters on children's chronic pain experiences as well as the assessment and management of chronic pain states in children (e.g.,P.A. McGrath,1990;

P.J. McGrath & Unruh,1987); Walco & Varni,1991). P.A.McGrath (1990;1993) suggested that most children and adolescents who live with chronic pain related to disease or injury usually have few pain-coping strategies, although no research evidence was cited. Alternatively P.J.McGrath and Unruh(1987) stated that *"it is quite clear that most children who have chronic or recurrent types of pain cope quite well. However there is a small group of children who do not cope"*(p.290). Again, no research evidence was cited, and coping outcome was being described rather than what these children actually do in order to manage their pain.

There is no published research evidence about the types of coping strategies that children with chronic pain utilize, frequency or order of use of these strategies, nor the factors which may predict their use. There is agreement in the literature that previous experience with a painful procedure can have either a positive or negative effect on the use of coping strategies at subsequent procedures (e.g. Siegel & Smith,1991). Whether previous experience has a subsequent positive effect is dependent upon a number of factors. Of major importance is the child's perceived control over the painful situation and sense of self-efficacy at utilizing control and control-related strategies. The behaviour of parents and professionals present also exerts an influence. Children's experience with chronic pain is repeated (often daily) episodes of pain, but we do not know how repeated episodes of chronic pain influence children's coping strategies.

The findings of two studies overlap into the area of children's coping strategies and chronicity of pain. The Dunn-Geier et al.(1986) investigation into mother-child interactions, family characteristics, child personality, and coping outcomes, documented overt behavioural differences between "coping" and "non-coping" adolescents when completing a painful exercise task. However, the variety of use of coping strategies was not investigated. There is a pressing need to investigate this group of children and adolescents further, and find out in an exploratory way what sorts of coping strategies they perceive themselves as utilizing in order to manage ongoing pain.

In a study of children with cancer under-going acute medical procedures, Smith, Ackerson & Blotcky (1989) found the opposite interaction from that predicted. Children's coping styles were matched with either a "consistent" or an "inconsistent" intervention strategy, and it was expected that children with interventions consistent with their coping style would report less pain. However, these children reported higher levels of pain than the children using inconsistent intervention strategies. For example, children who had a repressor (i.e.,avoiding) style were provided with information, and reported less pain than children whose style was sensitizing (information-seeking) who were provided with information. Aside from endorsing the discussion above regarding the weak predictive validity of global coping styles in children, and the need to consider the situation-specificity of strategies for coping with pain, chronicity of pain

appeared to influence preferred coping strategies. Previous exposure to painful episodes was found to be a confounding variable that had a greater impact on the preferred coping strategies than did matching the child's coping style with a "consistent" pain management strategy.

The findings of Smith et al.(1989) suggest that children's strategies for coping with pain may alter and develop with chronicity. Furthermore, in regard to teaching coping strategies to children, Smith et al.(1989) stated that *"these results suggest that the greatest influence may be on the children's choice of strategy they might use on their own"* (p.417). The importance of finding out from children what coping strategies they may have already developed prior to teaching coping strategies, has again been stressed.

One unpublished study has investigated children's spontaneous strategies for coping with joint pains in chronic arthritis (Bennett-Branson et al.unpub). Coping strategies were classified using the coding system described above (Bennett-Branson & Craig, in press). Open-ended interview questions focussed on pain quality, pain intensity and coping strategies. A pain and coping daily diary was also recorded by each subject for a week,and was analogous to the interview. On average, participants reported 2.6 examples of behavioural coping to manage chronic joint pain (range = 0-14) from the interview data, and 2.1 (range = 0-6) from the weekly diaries. Fourteen of the 38 participants reported at least one cognitive coping example and 28 reported none during the interview. Weekly diaries revealed an average of 4.2 cognitive coping examples(range = 0-7). A larger percentage of participants reported using cognitive coping strategies in the diary data than in the interview data.

Cognitive reappraisal, cognitive distraction, and thought-stopping were the three types of cognitive coping most commonly recorded in the diaries. For both interview and diary data, the most frequently reported behavioural coping subtypes were behavioural distraction, rest or restricted movement, and application of heat or cold. Overall,concrete behavioural activities were most frequently cited as coping strategies. The researchers reported that very few children reported spontaneously using imagery strategies, physical muscle relaxation, or deep breathing techniques that have been shown in the pediatric psychology literature to be extremely helpful in diminishing recurrent pain.

Although the Bennet-Branson et al.(unpub) study found that on average, children with chronic joint pain utilize at least one or two behavioural coping strategies, there was a wide range in the quantitative results (e.g., 0–14 examples of behavioural coping per subject on interview, and 0–6 in the diaries). The wide range, along with the zero quantity of examples reported by some children add strength to the imperative that we must qualitatively investigate the context surrounding children's use of coping strategies, and explore the use of strategies from the child's perspective. The large number of children who reported no use of cognitive coping strategies parallels the

acute pain research. However, again there is the problem of untamgling less frequent use versus less developed metacognition in youger children. They may also find it more difficult to generate descriptions of cognitive strategies. The present author suggests that there was an additional confound in the Bennett-Branson et al.(unpub) study, because the wide age range of 6–19 years is likely to have confounded the coping strategies of children with those of young adults, and there was no analysis of data in relation to age/developmentalstage. However, the findings of Bennett-Branson et al.(unpub) strongly suggest that children who experience chronic disease-related pain do develop coping strategies.

CONCLUSION

There is beginning evidence which suggests that children who experience chronic disease-related pain do develop coping strategies. There is a dearth of literature about these children's use of coping strategies, and the context of children's coping with long-term pain. The implications from the literature reviewed are that children's concepts of illness, the meaning ascribed to the pain in relation to the significance of the disease, and age/cognitive developmental stage are likely to impact together on the use of coping strategies. Family socialization processes and family responses to the child's chronic illness/pain are also likely to impact on the coping process.

CHAPTER FIVE

Rationale for Using a Qualitative Approach

The first part of this chapter presents the rationale for choosing a qualitative research approach and grounded theory as the method of data analysis. The second section describes some disadvantages of the research method that has been chosen. Finally, criteria for judging qualitative research that have been addressed in the present study, are reviewed.

RATIONALE

There are broad underlying philosophical differences as well as surface methodological differences between qualitative and quantitative research methods (Bryman,1988). In spite of these differences the epistemological poles of qualitative and quantitative approaches may be viewed as a continuum of differing forms of the analytic practice of re-representation in science (Henwood & Pidgeon,1992; Miles & Huberman,1984). From this perspective, the researcher needs to closely examine the suitability of the research method, both in relation to the research questions being asked and with understanding of the epistemological stance underlying the proposed method. Decisions on methodology are therefore pragmatic as well as epistemological (Henwood & Pidgeon,1992).

A qualitative approach was chosen for the present study for several reasons, the major one being the ability of the approach to explore meaning and to represent reality through the eyes of the participants (Bryman,1988). It has already been noted that the perceptions of the children have generally been missing from the pediatric pain literature. Furthermore, current taxonomies for classifying children's strategies for coping with pain have often resulted from the downward application of knowledge of pain coping strategies in adults (e.g.Curry & Russ,1985), and subsequent confirmatory non-qualitative research with children in acute pain (overviewed by Branson & Craig,1988). However, Kirk & Miller(1986) suggested that when confirmatory research goes smoothly, everything comes out precisely as expected and discovery of non-confirmatory instances is prevented.

The present researcher therefore chose not to use current classification systems and a quantitative content analysis, firstly, because of the initial extrapolation from adult research; secondly, because they have been further developed in relation to acute pain in children. Children's experience of and coping with chronic pain may differ greatly from acute pain. Finally, and most importantly, because a wealth of data and the

complex detail of children's coping with chronic pain was likely to be lost. A priori, theory driven, quantitative methodology would not have allowed for the exploration and discovery of undocumented coping strategies, nor the beginning generation of theory specific to children's coping with long-term pain.

Neither should prior theory be ignored, and the grounded theory approach encourages post hoc comparison with related literature (Glaser & Strauss,1967; Strauss & Corbin,1990). More recently the grounded theory approach has also included the early reviewing of literature as a component of "theoretical sensitivity" (Strauss & Corbin,1990), after having been criticized for its former tenet of only allowing for comparison with related literature relatively late in the research process (Henwood & Pidgeon,1992). The above review of the children's coping with acute pain literature provided an initial orientation to the related field of children's coping with long-term pain, and enhanced the theoretical sensitivity of the research and concurrent data analysis.

Taken overall, the body of quantitative data on acute pain in children suggests that there is a wide variation in children's use of coping strategies. The only study on children's use of coping strategies in long-term arthritic pain (Bennett-Branson et.al.unpub) also revealed a wide individual range in the children's use of coping strategies. It is a matter of urgency that rather than continuing to replicate the wide individual range in use of coping strategies (or possibly document further "inconsistent" findings in frequency), that qualitative exploration is undertaken into what is happening for these children. The children's viewpoints and their own perceptions of what sort of things they do to help their pain, as well as how they perceive different situations and contexts interacting with their use of coping strategies, define the paramount research issues requiring qualitative methods of data collection and analysis. The present study does not profess to measure coping outcomes in a quantitative sense (i.e.external observer measures), although the children's perspectives on how effectively different samples of their strategies help with their pain will be explored.

In quantitative research methods, the feelings and concerns of the subjects are often of secondary concern in order to maintain the objectivity and detachment of the research. However, by utilizing a qualitative approach, the child participants can be consulted as knowledgeable experts. Therefore, the power differentials between adult researcher and child "subject" are reduced and the child participant is interacted with in terms of being a co-investigator with important knowledge to offer. The research interview therefore becomes a growth enhancing experience as the children take on the role of expert when describing their experiences. The personal involvement of the researcher allows for the child's strengths to be emphasized, rather than the accumulation of knowledge for its own sake (Lather,1988).

Grounded theory refers to a set of techniques for analysing qualitative data, with the ultimate aim of developing an inductively derived grounded theory about a phenomenon (Strauss & Corbin,1990). The method was developed from the implications of the symbolic interactionist view of human behaviour (Chenitz & Swanson, 1986), which proposes that the individual achieves a sense of self through social interaction, and that the reality or meaning of a situation is created by people and leads to action and the consequences of action. Henwood & Pidgeon (1992) suggested that there are occasions in psychology when existing theory is incomplete, inappropriate, or entirely absent. They suggest that the grounded theory method should be utilized more in psychology rather than relying entirely on research which either confirms or disconfirms pre-set theory. The current absence of theory pertaining to children's coping with long-term pain lends support to the choice of grounded theory as the method of data analysis in the present study.

Other attributes of grounded theory methodology are also relevant. The underlying procedure is that of constant comparative analysis, wherein each piece of data is constantly compared with all other pieces of data for similarities and differences in meaning. The hierarchy of categories and concepts are also constantly compared, so that the full diversity and complexity of data is explored (Strauss & Corbin,1990). Furthermore, there is a generative focus underlying the exploratory and descriptive purpose, and propositions may be stated about the relationships between the concepts and categories (Chenitz & Swanson,1986; Henwood & Pidgeon,1992). A study which utilizes grounded theory methodology can be reported at the descriptive level of analysis or at the theoretical process level (Chenitz & Swanson,1986), although Becker(1993) contends that the descriptive and discovery modes of research differ in intent rather than levels of analysis. The present study was initially conceived with an exploratory and descriptive intent, but as data analysis informed subsequent data collection and vice versa, the generation of "local" theory evolved.

DISADVANTAGES OF THE QUALITATIVE APPROACH

It is necessary to acknowledge the disadvantages of the qualitative approach utilized. The reliance on language as the tool for understanding has potential disadvantages. We use language every day to communicate, but we may have less awareness of things that we do not usually communicate verbally (Jaeger & Rosnow,1988). Although children's verbal ability is usually far in advance of their written ability, their capacity for metacognition has a developmental aspect (Garbarino & Stott,1989), and is difficult to assess. Metacognition refers to being able to think about one's own thinking. In relation to the present research, and indeed all studies of children's self-reported coping strategies, it may be easier for children to generate descriptions of what they do (behaviours) than what they think about (cognitions).

In order to represent the perspective of the participants it is necessary to be aware of the potential for misunderstanding when using language (a greater potential when the research participants are children), and use the technique of negotiating meaning during the research interview. Thus, meanings are checked out with the participants. Reactivity to being studied occurs in qualitative research as it does in quantitative research, although this has not always been recognized (Bryman,1988).

A criticism of grounded theory is that it espouses a form of "inductive positivism" (Stanley & Wise,1983). This is resolved by ensuring that any emergent theoretical account is the result of constant interplay between data and conceptualisation (Henwood & Pidgeon,1992). The interrelating of concepts arises from this interplay between data analysis, conceptualization, and further data collection. In this way premature closing or fixing of theory when new insights arise is persistently avoided (Henwood & Pidgeon,1988), and theoretical sampling seeks out and investigates negative instances.

CRITERIA FOR JUDGING QUALITATIVE RESEARCH

The philosophical paradigm which underpins qualitative research challenges the distinction between knower and known and therefore the criteria for judging the quality of research which have evolved from the positivist paradigm are inappropriate (Henwood & Pidgeon,1992). The rigour of qualitative research, however, has been ensured by the development of a diverse range of criteria appropriate to judging the quality of qualitative research, without stifling the researcher's theoretical imagination (e.g. Henwood & Pidgeon,1992; Marshall & Rossman,1989; Stiles,1990).

No single one of these criteria can be considered an adequate test on its own, and there are no methodological criteria capable of guaranteeing the absolute accuracy of the research (Henwood & Pidgeon,1992; Stiles,1990). A combination of criteria appropriate to the field of study and specific methodology can, however, show that the findings of a qualitative study are trustworthy. The following criteria are a selection of those proposed by Stiles(1990), apppropriate for qualitative research in general, and Henwood & Pidgeon(1992), with more specific reference to grounded theory methodology. Each of these criteria are relevant, and have been addressed in the present research, in order to ensure the trustworthiness of the findings.

Testimonial validity (Stiles,1990)

This involves checking with the participants that the researcher has understood what they have said. Several limitations have been noted with this, and Henwood & Pidgeon(1992) proposed a similar criterion which addressed some of the limitations, that of sensitivity to negotiated realities. The present research utilized a mixture of

these criteria, by negotiating realities with the children during the interviews, and then a validity check of the overall findings at a later date.

Triangulation (Stiles,1990)

Triangulation means seeking information from multiple sources of data, multiple methods, and multiple prior theories, and assessing convergences. Marshall & Rossman(1989) stated that *"Triangulation is the act of bringing more than one source of data to bear on a single point"* 144, and that the transferability of a study can be enhanced by fulfillment of this criteria.

Coherence (Stiles,1990). Keeping close to the data (Henwood & Pidgeon,1992)

This criteria refers to both the degree of coherence in the shared story, or emergent theory, and the internal consistency of the building blocks of data. Do the pieces of data fit well into the emergent theory? Definitions summarizing why the data have been labelled in a certain way are an important part of this criteria (Henwood & Pidgeon,1992), as are researchers' disclosures of expectations and biases (Stiles,1990).

Consensus among researchers (Stiles,1990)

This is a pragmatic criterion, and because of flaws related to conformity pressures does not ensure validity on its own. Interpretations from people other than the researcher can, however, enhance the trustworthiness of the research (Stiles, 1990).

Catalytic Validity (Stiles,1990).

This refers to the ability of the research interpretation, and the action of being a research participant to empower the participant to change, focus, and become energized. *"If a theory is right, then it will have an impact on the people whose experience is being described"* (Stiles,1990, p.33).

Theory integrated at different levels of abstraction (Henwood & Pidgeon,1992)

The synthesis and conceptual analysis of data are able to be integrated at different levels of generality, so that the threads at the most basic level of analysis relate to the overall theory as meaningfully as do the more general relationships. That is, the theory "works" (Glaser,1978).

Theoretical sampling and negative case analysis (Henwood & Pidgeon,1992)

This criteria refers to the deliberate attempt in grounded theory to explore negative instances which do not fit the emerging conceptual system. This may be viewed as a particular manifestation of the method of constant comparative analysis, and *"serves as*

a device for challenging initial assumptions and categories, and for modifying and elaborating theory where necessary" (Henwood & Pidgeon,1992, p.107).

SUMMARY

This chapter has discussed the reasons for choosing the grounded theory approach in the present study and some disadvantages of the approach were acknowledged. The ability of the approach to represent reality through the eyes of the children, to explore the contexts of children's use of coping stategies, and to serve their interests as research participants, were among the major reasons for choosing the approach. The lack of theory in the area of children's coping with long-term pain was an additional reason for the choice of grounded theory methodology, because it offers the choice of generating theory from the qualitative data, should that theory begin to emerge. Lastly, criteria for judging the quality of qualitative research and grounded theory studies in particular have been presented.

CHAPTER SIX

The Present Study

The first part of this chapter reviews the reasons for undertaking the study, the aims of the study, and the prior assumptions with which the researcher entered the field of study. The second part of the chapter describes the research method that was used and the grounded theory technique of data analysis.

AIM

The aim of the present study is to explore the spontaneous coping strategies developed by children who experience chronic, disease-related pain. The impact of contextual and situational variables on children's use of coping strategies, and the children's perceptions of the effectiveness of the coping strategies they use will be explored. The intention is to increase the knowledge base of how long-term repeated experience of pain impacts on children's use of coping strategies.

At present there is minimal documentation of the coping strategies which children may develop to manage chronic pain, nor of the impact of chronic pain on the lives of affected children. The significance of the study therefore arises from this lack of documentation. There is a great need to discover what strategies these children spontaneously develop and use, to provide more effective and appropriate support to children who experience chronic pain. The ultimate aim of the study is to generate a theory of children's coping with chronic pain that is "local" to the participant children, but will have bearing on the coping strategies of other children who experience chronic pain.

PRIOR ASSUMPTIONS

The knowledge base (or theoretical sensitivity) of the researcher implicitly impacts on the analysis of data. The researcher must therefore acknowledge the assumptions and expectations with which the field is entered. The present writer entered the field of researching children's coping with chronic pain, acknowledging the following assumptions. These are both as a result of reviewing the literature, and of personal experience of supporting children in pain.

(1) Children are inherently capable of utilizing effortful coping strategies when they experience pain. However, contextual variables impact on their use of coping strategies in a largely unknown way. Repeated experience of pain is a particularly unexplored context.

(2) The coping paradigm proposed by Lazarus & Folkman(1984) provides the most useful model of the coping process, which, in relation to children, requires a developmental overlay. Coping strategies are therefore viewed as part of the coping process (refer Chapter Two). There is both stability and change in the coping process,i.e. coping is situation-specific, but individuals also have preferred styles. The present research concentrates on coping strategies, but in qualitatively exploring children's experiences of pain, appraisals and perceived outcomes must also be included.

(3) Although categories and codes will arise directly out of the data, the distinction that exists in the current body of literature between cognitive and behavioural strategies cannot be avoided. That is, clearly cognitive strategies pertain to children's purposeful thought processes, and behavioural strategies to purposeful activities initiated by the children. Strauss and Corbin(1990) noted that the names of some categories will come from the pool of concepts resulting from the researcher's own discipline and reviewing of literature.

Method

PARTICIPANTS

Ten children, ranging in age from 7.5 years to 13 years were interviewed. Five of the children experienced long-term pain from chronic juvenile arthritis, and five of the children experienced long-term pain from a variety of other chronic diseases. Their varying pain histories are reviewed along with the profile of their interviews in the next chapter. Three of the children were female, and seven of the children were male.

The participants were a convenience sample of children who were currently attending a juvenile arthritis clinic, and were under the care of the Paediatric Rheumatology Consultants, Lower Hutt Hospital. Children under the care of the Paediatric Consultants at Wellington Hospital who fitted the criteria, were also approached. The criteria for selection were that the children had experienced a minimum period of six months pain, and were aged between 7 and 14 years. These criteria were employed because the accepted definition of chronic pain is to have experienced pain for a period of at least six months (refer Chapter One). The reasons for the age limits were that children younger than seven years would be less likely to be able to verbalize what they do. The cognitive development of children older than 14 years borders on adult mechanisms (Piaget & Inhelder,1969), and the purpose is to explore children's coping with pain.

Other criteria for selection included children who were willing to talk about their

pain, and whose parents were also willing for them to do so. Willingness to talk about pain was indicated by:

(1) children actively choosing to participate in the study;
(2) both parents and children having read the study information sheet and discussed together what was involved; and
(3) the researcher verbally checking with the children that they knew what was expected of them as participants.

Criteria for exclusion included:

(1) any indication of distress by the children . Interviewing would then be discontinued;
(2) worsening of condition and/or increase of pain prior to the interview or during the interview.

Two children who had been contacted were therefore excluded prior to interviewing, because of an exacerbation of their condition.

MEASURES

The questions guiding the semi-structured interview are outlined in Appendix 1. Points to note are that the initial, warm-up questions were intended to help establish rapport with the children, while also serving as a way of reducing their reactivity to the research process. It was assumed that the more comfortable the children became with the interviewing situation, the more likely it was that they would disclose thoughts and perceptions.

Triangulation of data within interviews was addressed by asking children about coping strategies from three broadly different approaches. Most of the middle part of the interview focussed on what sort of things the children thought or did themselves when experiencing pain. It was suggested they pretend to be watching themselves experiencing pain as though they were watching a television programme. They were then asked to describe what they could see themselves doing and thinking. This was a technique described by Smith et al.(1989). Later in the interview children were asked what they would advise their best-friend to do if they were experiencing pain, and this is referred to as the best-friend question in the report. Towards the end of the interview children were shown an outline of a child who was described as experiencing pain (refer Appendix 1), and asked what they could advise this person to do. This is referred to as the projective question in the present report.

The content and structure of the interview was reviewed with a Senior Lecturer in Clinical Child Psychology prior to commencement of the study. Pilot interviews were conducted with two children (aged 7 and 12 years), to test and further develop the content of the interview. All interviews were recorded on a small audio-tape recorder.

Two self-report measures were utilized to assess the severity of pain which children had been experiencing. These were the Facial Affective Scales (FAS, Appendix 2), and the Visual Analogue Scale (VAS, Appendix 3), both adapted from the Children's Pain Inventory (P.A.McGrath,1990). To assess the severity of pain, using the VAS scale, children were instructed to put a mark on the line which represented the amount of pain they were feeling now; when their pain was at its' worst; at its' smallest; and how much pain they felt most of the time. To assess the affective aspects of pain, that is, how the pain made them feel emotionally, children were asked to point to the face on the FAS scale which showed how they felt deep down inside in relation to each line they had marked.

PROCEDURE

Participants were recruited through the Outpatient Departments at Wellington and Hutt Hospitals. Initial contact was made with the parents, and permission sought to approach their child about participating in the study. If permission was given to approach the the child, a full verbal explanation was then given by the researcher to each child and parents together about the study, and questions invited from them. A study information sheet (Appendix 4) was then given to each family by the researcher. After a minimum of 24 hours, the family were then contacted. If parents and children agreed for the child to take part an interview time and place was then established. Children and parents each signed their respective consent forms (Appendix 5), prior to commencement of the interview. Interviews took place from May through until November 1993.

Eight of the interviews took place in the homes of the children and two took place in hospital wards. In most instances the children were interviewed alone, although because of being in hospital, a parent was present during one of the interviews. Children had the option of terminating the interview at any time, and a paramount concern was that the children feel as comfortable as possible during the interviewing process. To this end, paints, paintbrushes, felt-tipped pens, drawing paper, and play-dough were taken by the researcher to each interview. Children were established with an activity at the commencement of the interview and continued to paint or play at their leisure while talking. The tape-recorder was played back to them near the beginning of the interview so that they could hear how they sounded (although some children chose not to hear themselves on tape).

In keeping with the exploratory nature of the research, the open questions required the children to generate answers. The inconsistencies between using supplied response versus generate questions, which has been found to impact on research results (Bennett-Branson & Craig, in press; Ross & Ross,1984b), was less of an issue because the meanings of the children's responses were negotiated with the children. An indication that the children felt comfortable with the interviewing process and able to

participate in negotiating meanings, occurred when the children contradicted the researcher's reflected information or prompts, and clarified their own meaning. Children's leads were followed rather than strictly adhering to the structure of the interview.

Cautions were taken to ensure that children were not distressed by the interview:

(1) The research project was approved by the Massey university Human Ethics Committee and the Ethics Committee of the Wellington Area Health Board.
(2) The strategies within the interview enabled the children to think back to painful episodes without becoming re-involved in their pain (e.g. watching themselves as if looking at television).
(3) Children were closely observed during the interview for any signs of distress.
(4) Children did not talk about pain for all of the interview and the researcher guided the conversation on to other topics several times during each interview, in order to provide appropriate breaks from the topic of pain.
(5) After the interviews, the researcher paid attention to how children were feeling, and whether they felt satisfied with the interview process.

A prime concern was that the children were left feeling pleased with themselves, that they had made an important contribution to the dissemination of knowledge about children's ways of managing pain, and that their self-esteem was enhanced by the research process (Ross & Ross,1984b). To enhance this children were consulted as knowledgeable experts throughout the interview, and their ability to pass on information positively affirmed. Children were presented with a personal certificate acknowledging their contribution and thanking them at the completion of the interview (Appendix 6). Interviews typically lasted for an average of 45 minutes, and some lasted for an hour.

Follow-up took place approximately one to two weeks later, when the researcher telephoned the child's parents to ensure that there had been no harmful effects to the child from the interview process. Some of the children chose to talk to the researcher at this follow-up because they had things to tell me about what was happening in their lives. This would appear to indicate that a friendship or rapport had been established during the interview process.

Several months later all of the participants and their parents received a Summary of Findings letter (Appendix 7), and telephone calls were made two weeks later, to assess the reactions of child participants and their parents to the findings and analysis of data. The summary outlined the general findings and overviewed the emergent theory in a way that it was hoped children of varied ages would understand. It was intended that parents explain the letter to children and discuss their joint reactions.

Grounded Theory Method of Data Analysis

All of the interviews were transcribed in full by the researcher and listened to in their entirety several times to elicit phrases and voice expressions that might have been missed. This was a staggered process, and initially four interviews were transcribed and open-coding techniques applied. A further four interviews were conducted and analysed, and the theory began to emerge. The final two interviews served to refine and confirm the emergent theory.

OPEN CODING

During open coding, sentences, and parts of sentences which described incidents were separated out and analysed, using the method of constant comparative analysis. That is, each incident was compared and contrasted with every other incident by asking questions about each one: What is this? What does it represent? (Strauss & Corbin,1990). Incident was compared with incident for similarities and differences, and the phenomena were labelled, often using the words that the children used. Similar phenomena were grouped together and given the same name. The resulting "laundry list" of codes were labelled as substantive codes, and each interview was initially coded separately. Thus a separate list of substantive codes resulted. The data became fractured into small fragments, so that its properties and dimensional locations could be identified in preparation for reconnecting the data into categories.

AXIAL CODING

During this stage, the substantive codes were connected into categories which have similar properties. Each substantive code was examined for similarites and differences in the conditions and contexts in which it arose, the strategies or mechanisms by which it was carried out by the child (e.g. thinking or doing), and the consequences of those strategies (Strauss & Corbin,1990). Axial codes represented the "best fit" of substantive codes, grouped together in terms of the properties of conditions, strategies, and consequences. This "weaving back together" of the fractured data took place across the entire corpus of data, i.e. included all of the substantive codes from all of the interviews. It was, however, a staggered process, as the data from subsequent interviews were included.

SELECTIVE CODING

During this stage of coding, the core category emerged from the data, which was a phenomenon that was reflected over and over again in the data. This phenomenon

emerged as being both a condition for and a consequence of the use of coping strategies in children who experience chronic pain. The axial codes were further integrated into a more abstract level of analysis using a similar basis to that used in axial coding. That is, the causes, contexts, contingencies, consequences, covariances,and conditions were the properties with which the axial codes were compared with each other in order to group them into the selective codes (Glaser, 1978). The relationships within and between the axial codes, the selective codes and the core category were able to be examined and defined through the application of these properties (the six C family of theoretical codes according to Glaser,1978).

The core category was contributed to by all of the other categories and codes, and identifiying the core category was the crucial step in integrating the data. The emergent theory was a result of constant interplay between conceptual analysis, and returning to the data for verification. Interviews were reviewed in their entirety, as well as the fragmented data, and there was continual movement through the phases of coding at this stage. As the theory became clarified, and data analysed from the final two interviews served to confirm the "local theory", substantive codes were able to be collapsed into each other and refine the constituent parts of the theory.

A list of substantive, axial and selective codes is attached to the report (Appendix 8), but it is important to note that these codes do not relate to each other in a linear way. All of the codes relate to each other in a non-linear fashion, and the core category serves to integrate the corpus of data. The criteria of consensus among researchers was applied to the interpretation and analysis of data. The interpetations and substantive codes were reviewed by a Senior Lecturer in Clinical Child Psychology, of five of the interview transcripts, and there was agreement as to what each of the incidents within those transcripts represented. The overall integration of data was also reviewed by the Senior Lecturer, and there was consensus.

SUMMARY

The aims of the study have been reviewed, and the method for collecting and analysing data has been described. The purpose of the study is to explore the spontaneous coping strategies of children who experience chronic, disease-related pain. The following chapter will profile the children, their histories of pain, and their responses to the interview. Subsequent chapters describe the emergent theory, the integration of data, and the descriptive detail that supports the emergent theory.

PART TWO

The Results

CHAPTER SEVEN

Profiles and Pain Histories of Children

The first section of this chapter describes the medical diagnosis and outlines the history of pain of the individual children. Their reactions to the interview are noted. The second section describes the results of the VAS scale and FAS scale measurements.

PROFILES OF PARTICIPANT CHILDREN

Children were given code numbers in order to ensure their confidentiality.

C1 was a male, aged 10.5 years. He had a genetically determined skin condition, Epidermolysis Bullosa, which is a severe, chronic blistering disorder of the skin. He has experienced painful daily debriding of his skin with accompanying painful bathing procedures for all of his life. Debriding blisters, bathing, and re-bandaging can take anywhere from one to three hours depending on how severely damaged his skin is currently. He also does daily painful stretching exercises with his hands to keep then as mobile as possible. His condition has generally improved for the past two years, since a team of volunteers were trained to do the debriding and bathing. This enabled his parents to remove themselves from the roles of inflicting pain on their child. He still requires continuous bandages to his legs, feet, and buttocks. The reaction of C1 to the interview was to enjoy the games we played, and generally to minimize his pain which he said that he had got used to.

C2 was a male, aged 12 years. He had experienced three months of continuous pain in his thigh until diagnosed with Leukaemia, and then three months of variable intermittent pain up until the time of the interview. He responded enthusiastically to the interview, which took place in hospital. He also described getting used to the pain.

C3 was a female, aged 12 years. She had experienced two years of intermittent pain from Cholecystitis. A Cholecystectomy had been performed three months prior to the interview, and she had a deep vein thrombosis in her leg which was not resolving. She was currently experiencing aching pain in her leg, undertaking painful exercises, and weekly blood tests. She enjoyed drawing throughout the interview, and said that she had got used to pain.

C4 was a male, aged 12 years, who had experienced long-term pain from Chronic Juvenile Arthritis since he was aged 2 years. He had no periods of remission from aged 5 years until approximately 18 months prior to the interview. He still experiences aches, but is currently walking (after having used a wheelchair), and is attending school. He spoke quietly, but clearly and assertively described his episodes of pain and his use of coping strategies. He also described increased tolerance for pain (having got used to it), and acceptance of his pain and condition.

C5 was a male, aged 10.5 years. He had experienced long-term pain from Chronic Juvenile Arthritis since aged 4 years, but also suffered from congenital Nephrogenic Diabetes Insipidus. The management of this condition involved his eating a salt-free diet, and drinking 20 litres of fluid per day. He experienced joint pain on most days, and described the variable severity of his pain, and how pain limited his activity. He described getting used to pain over time, and as he had got older.

C6 was a male, aged 7.5 years. He had experienced long-term pain from Chronic Juvenile Arthritis since age 5. He now has continuing joint pain in his ankles. He also sustained a head injury 18 months prior to the interview, and was experiencing some cognitive developmental delay, evidenced in his academic work at school. He talked in a bright, alert manner, and displayed an interest in the research process. He requested to telephone the interviewer for several days after the interview because he "had found a new friend" (reported by his mother). The cognitive developmental delay may have impacted on his descriptions of coping strategies.

C7 was a male, aged 8 years. He had a sudden onset of Chronic Juvenile Arthritis 9 months prior to the interview. He had been experiencing severe pain for most of the time since onset and was becoming increasingly reliant on a wheelchair.

C8 was a male, aged 13 years. He had Haemophilia, so had life-long experience of joint pain. He was able to clearly disclose his feelings about his pain and condition, as well as his use of coping strategies. He described increased tolerance for pain.

C9 was a female, aged 11 years. She had experienced long-term pain from Chronic Juvenile Arthritis for 2 years. Initially her pain level was very severe, although this settled to intermittent variable aches in the 6 months prior to the interview. She had an exacerbation of more severe pain in the period between initial contact and the interview. She gave clear, full descriptions about her coping strategies, and her feelings about the episodes of pain. She said that she had got used to pain.

C10 was a female, aged 10 years who had experienced back pain for the previous 18 months. A probable diagnosis had recently been established of Scheuermann's Disease, which develops at puberty, and consists of deformities of the vertebrae. She clearly described having got used to pain.

In summary, these profiles of the children were presented to give an indication of each child's history of pain, and an impression of each child as an individual. All of the children described using a variety of coping strategies, and the contexts of their use are described in subsequent chapters.

VAS SCALE AND FAS SCALE RESULTS

The results of the children's self-reports of the severity of their pain (VAS scale), and the affective aspects of the pain, that is, how each sort of pain made them feel (FAS scale), are presented in Table 1. The numbers reported from the VAS Scale are

TABLE 1: RESULTS OF ASSESSMENT OF PAIN IN DIFFERENT INSTANCES.

A: VAS SCALE (in millimetres)

Participant	Now	Worst	Smallest	Mostly
C1	0	162	21	0 1(a)
C2	0	165	9	165(b)
C3	2	62	1	5 1(a)
C4	6	154	3	152(b)
C5	44	102	9	70
C6	6	6	1	19
C7	1	151	8	21
C8	61	162	14	66
C9	6	138	2	24
C10	39	106	12	71

B: FAS SCALE (in millimetres)

Participant	Now	Worst	Smallest	Mostly
C1	7	5	4	9
C2	7	6	3	4
C3	8	6	3	4 7(a)
C4	4	2	8	6(b)
C5	5	2	1	1
C6	4	7	8	9
C7	3	5	3	9
C8	9	6	8	3
C9	5	2	9	3
C10	1	2	5	1

(a) Pain felt "most of time" currently

(b) Pain felt "most of time" during exacerbation

generated from measuring the child's point of marking the line in millimetres, with 0 representing almost no pain, and 165 representing the strongest possible pain (refer Appendix 2). The numbers on the FAS Scale represent nominal data, and the faces are not ranked in any way (refer Appendix 3).

In spite of differences in diagnoses, location of pain, and length of time since onset, the VAS scores which children recorded were consistent. That is, they recorded low scores for the smallest pain and also for the pain being felt "now", high scores for the worst pain (although there was some variation in these instances), and low to medium scores for the pain felt "mostly". C2 and C4 recorded two scores for the pain that they felt mostly, because both children wanted to indicate that differences existed between "mostly during a period of remission", and "mostly during a period of exacerbation". There was a similarity between the two children's scores, in spite of very different histories of pain (refer Table 1).

In general the scores on the VAS scales indicated that the children were able to self-report the severity of their pain in a reliable manner. The scores recorded by C6 did not appear consistent with the severity of pain that he described in different instances, and it is likely that the developmental delay described above impacted on his scores.

There was little evidence of patterns in the faces that children chose on the FAS scale. There was one reasonable consistency because face numbers 2, 5, and 6 were chosen as representing how children felt when their pain was at its' worst, and four of the children chose face number 2 in relation to this worst instance of pain. Often two or three children chose the same face for similar instances of pain (refer Table 1). However there was generally little consistency in the results. It should be noted that children were not rating the severity of their pain on this scale, but how specific severities of pain influenced them emotionally. Children's perceptions of their affective responses to pain are therefore represented in these results, and it seems clear that children respond differently to the affective components of their pain.

In summary, the results of the VAS scale indicated that children reliably reported the severity of their pain in different instances, and that all of the children had experienced severe pain. Furthermore, all of the children were experiencing an ongoing level of pain. Except for the instance of worst pain, the faces chosen on the FAS scale varied widely, and this was interpreted as indicating the children's differing emotional responses to pain.

SUMMARY

Qualitative and quantitative findings indicate that the participant children experienced different severities of pain, and had varying lengths of time since onset. All of the children reported having ongoing episodes of pain, and they described using a variety of coping strategies. The conceptual analysis and the descriptive data is presented in subsequent chapters.

CHAPTER EIGHT

The Core Category: Getting Used to Living With Pain

CONCEPTUAL ANALYSIS

The conceptual analysis which draws together all of the data will be presented first, and the descriptive and explanatory detail will be presented in subsequent chapters. Although this is the reverse of the order in which the data was inductively analysed, it is hoped that in this way clarity of presentation will be achieved.

"Getting used to pain" was described by almost every child interviewed, and began as a substantive code during the open-coding stage of analysis. Although not an effortful coping strategy, "being used to pain" was a pre-existing condition for the use of many coping strategies, and getting used to pain was also a consequence of the use of coping strategies. For instance, the coping strategy of using positive self-talk entailed the belief and self-knowledge that the child was used to pain, and so could handle it, and the consequence was feelings of control and a furthering of their sense of self-efficacy in that they did indeed manage.

Getting used to pain runs through all of the selective codes, and influences the way in which coping strategies are utilized, and is a part of the way in which the children perceive pain, and their current way of being. The core category of "getting used to living with pain" therefore has three major aspects. Firstly, there is the increasing tolerance for the same degree of pain severity (which almost all of the children described). Secondly, there is the experience of pain and coping which informs subsequent utilization of coping strategies. Thirdly, there are the continual lifestyle adjustments which the children initiate on a daily basis in order that their living with pain be as near "normal", or as similar to their age-mates as possible. Hence **"getting used to living with pain"** became the core category, to denote the pervasive lifestyle aspects, as well as increasing tolerance for pain.

Subsequent data collection and conceptual analysis confirmed that **getting used to living with pain** is a Basic Social Process (BSP), which occurs among these children. A core category can be considered a BSP if it accounts for changes which occur over time, remains intact even when conditions vary it considerably, and if the BSP discovered in the data can account for a large part of the variation in the behaviours (Fagerhaugh,1986). Figure I summarizes the overall conceptual analysis, and represents the way in which **getting used to living with pain** interacts with the use of coping strategies, and underpins the children's ways of being.

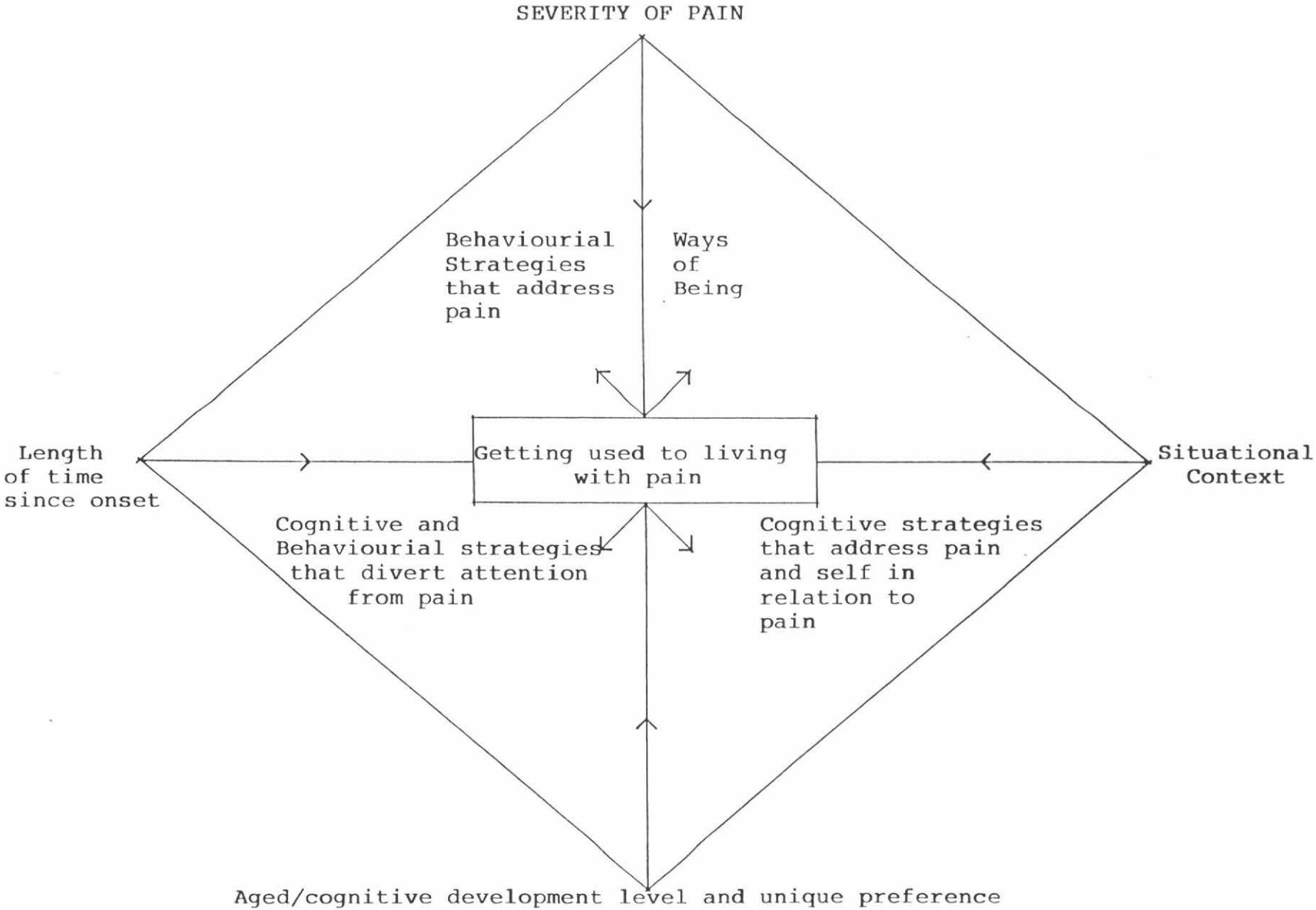


FIGURE 1: THE BASIC SOCIAL PROCESS OF GETTING USED TO LIVING WITH PAIN

Each of the constituent triangles represents a selective code, and the central crossing arrows indicate that there are initiating and consequential relationships between the selective codes, while the central position of the BSP of **getting used to living with pain** denotes that it runs through and links all of the codes. The following four chapters each describe these selective codes using the children's data: behavioural strategies that address pain; cognitive strategies that address pain; cognitive and behavioural strategies that divert attention from pain; and ways of being. Children's descriptions of their "ways of being" were closely intertwined with their getting used to pain and their use of coping strategies, so that this selective code is representative of children's perceptions of their feeling states in response to coping with pain. It also describes stages of the process of **getting used to living with pain.**

The changing nature of the process is represented by the inward arrows from the outer points of the diamond, and each outer point of the diamond represents a context which the children perceived as impinging both on their use of coping strategies at any particular point in time, and the overall process of their **getting used to living with pain**. These contexts arise from the participant children's data, and have not been imposed from prior literature. The remainder of this chapter will review the children's descriptions of the impact of these contexts, and also how they described the BSP of **getting used to living with pain**. The centrality of the process and the impact of the contexts will be further authenticated in subsequent chapters as the children's data on coping strategies and ways of being is presented.

GETTING USED TO LIVING WITH PAIN

- **getting used to pain**
- **experiential learning**
- **lifestyle adjustments**

Increasing tolerance for pain was directly described by the children. For exanple:

> *"They gave me hundreds and hundreds of blood tests down there, I had to have them, which now I wouldn't mind having."* C2(12 years)

indicated that his tolerance for injection pain had increased with repeated experience over six months since onset.

> *"If you're used to having pain, it's much easier, but if you're not then it's hard."* C5(10.5 years).

> *"It wouldn't hurt me so much, 'cause I'm used to pain."* C1 (10.5 years).

C9 (11 years) said that the sore had not changed, but *"Well I've sort of got used to it now"*

There was a clear overall message from the children that the same intensity of pain, distressed them less over time, as they became used to it. This was a difficult message that they were trying to convey, but they found ways of clarifying it. For example:

> *"Like it hurts the same, and it's the same, but it doesn't feel like it ... but I feel better, like the pain doesn't, but I do."* C10 (10 years).

Getting used to pain informs subsequent utilization of coping strategies, and is also a consequence of the use of coping strategies. Variations of this relationship are described throughout the findings. For instance, in relation to regulating activity and self-management of interventions (refer Chapter Nine). A specific example was described by C3 (12 years), of getting used to pain interacting with the subsequent use of coping strategies:

> *"It's getting better (blood tests) ... To-day when it went in, it was just a little bit, and I can't feel the pain now". "I'm sort of getting used to it." "Like before I was real shaking and nervous, but now I'm alright. I'm just a little bit nervous, but not as much."*

C3 was also able to describe the differences in her thinking (i.e. cognitive coping strategies) as she became used to the blood tests. Before she had got used to the pain of blood tests she described catastrophizing,*"How bad the hurt was going to be"* Now that she was used to them, she described calming self-talk and acceptance*"I was sort of saying it would happen if it was going to happen, so don't worry about it."*

Another child described the learning of coping strategies from previous experiences of pain:

> *"Well I've learned how to, like when it hurts I know what to do, like I'll go and lie in bed or things like that, I know what to do."* C10 (10 years).

Lifestyle adjustments in the form of continuing, small, everyday things that the children did as they got used to living with pain were not initially addressed within the semi-structured interview. However, the children described many such adjustments which became a part of their lives, while allowing them to continue with similar activities to their age mates. These were sometimes parent assisted and/or parent initiated, but as time went by the children described taking over these adjustments and having them become an integral part of their daily self-management plan in living with pain. These adjustments often relate to the use of coping strategies, and are further clarified when specific coping strategies are discussed in the following chapters.

For instance, a parent of one of the children had approached the school and asked if she could regulate her own activity level according to her level of pain (i.e. her own perceived need), rather than contingent upon the classroom timetable. There was a couch in the classroom and C10 (10 years) has remained fully participant in classroom

ties in spite of a year of continuing and variable pain because she rests on the
. when she feels she needs to.
onitoring of pain levels in order to intervene at an appropriate point was an
day lifestyle adjustment that most of the children described. This underpins their
coping strategies.

first when I have it I keep on going, but if it gets um, like harder for me, I just try and ax it ... Just by lying down it relaxes, like I don't have to sit up." C10 (10 years).

aisals and decisions to intervene were not made solely on the severity of pain,
s it was extremely acute and severe, but also on the other contexts of situation and
of interest in current activity, knowledge of pathological process and
ological necessity of intervening, age and length of time since onset (i.e., learning
previous pain experiences)

THE CONTEXTS

se of coping strategies and ways of being (including expression of pain) were
nced by the contexts of:

everity of pain,
ge/cognitive developmental and unique preferences of child,
ngth of time since onset of painful condition ,
ie current situation.

oncept of the interactive influence of different contexts is implicated, and different
ns of use of coping strategies and different ways of being can be superimposed
gure I, depending on the variation of the contexts. The list of codes in Appendix 8
iews the coping strategies and ways of being that constitute the selective codes in
e I. Examples of some of the specific variations described by the children are
ated throughout the descriptive data, and some common patterns described in
ter Thirteen.
ierefore, although each of the segments in Figure I denotes a selective code of
g strategies, or ways of being, the strategies that were actually utilized by the
en depended on the ever-changing contexts within which they operated, as did
ways of being. Inherent within this conceptualisation is the idea that the children
nce their environment and contexts, as well as being affected by it. This message
omes through within the children's data. The process of **getting used to living pain**, and its constituent parts (i.e. coping strategies and ways of being) are
ore impacted on by the contexts described. Other contexts may also be relevant in
idual cases, but the contexts included are those which appeared repeatedly in the
en's data, and are referred to in the descriptive findings in subsequent chapters.

Some descriptive data which links the contexts with the overall process of **getting used to living with pain** are presented below in order to add strength to the conceptualisation.

The contexts do not impact singly, but are interactive. For example, age and length of time since onset were often described together by the children:

> *"You get to cope with it a lot more when you get older, 'cause you've had it for your life, so you know what to do."* C5 (10.5 years).

The children referred to their experience of pain over time giving them the knowledge to manage their pain and initiate coping strategies:

> *"I mean you have to get better (at managing) with experience. Um well, I can't say how I found out, 'cause you live with it, that's how you find out."* C8 (13 years).

The same child described crying less as he got older and more used to the pain.

Age and cognitive developmental influence on the use of coping strategies was therefore evident within individual children's recollections of how things had changed with them. For example less use of expressions of distress. This also applied when the data was viewed across children. For example, only the youngest child did not describe cognitive strategies, C6 (7 years). Children also described getting used to pain alongside increasing age, as well as with repeated episodes. For example:

> *"Well, I hardly notice it, 'cause I am used to it (pain). I mean when I was little ... I used to scream in pain"* C8 (13 years).

The descriptions by the children that increasing age, as well as time since onset, impacted on their getting used to pain was supported by the analysis of negative instances, because it was the two youngest children who did not describe getting used to pain, C6 (7.5 years), C7 (8 years).

Each child described a variety of coping strategies and had a combination of strategies which they currently preferred. For example, C2 (12 years) currently preferred a variety of cognitive attention diversion strategies, although he described using other strategies as well. Children's current preferences changed over time as part of the process of getting used to living with pain and this is evident in the corpus of descriptive data.

Length of time since onset was also associated with minimizing pain symptoms and being aware of low-grade or "niggling" pain for a lot of the time, without feeling the need to do anything about it. This was in contrast to when they were younger (and nearer the time of onset). They were sure that children "not used to pain" would have cried, complained, or intervened.

"Like I was just thinking the other day, if I gave the pain I was feeling at the moment to someone else, they'd probably be sitting down and crying ... but because I'm used to it, it is hidden so I'm not crying or anything. I don't feel I need to cry or anything like that, but I was thinking because people aren't used to it, if I gave it to them, they wouldn't be used to it and they would (cry)". C8 (13 years).

Those children who had experienced pain over very long periods (all or most of their lives) therefore described pain they experienced almost every day as:

"a little bit" C1; C5; both 10.5 years.

"I've just got a sore back ... but like its not too bad" "Tingles a bit" C4 (12 years).

"Niggling" C8 (13 years).

The corollary of this minimizing of everyday pain was that, taken across children, some of the children who had experienced life-long continuing/intermittent pain offered fewer examples of coping strategies akin to the classifications that have been presented in the acute pain literature. Instead they offered a qualitatively different attitude toward their pain and condition. Managing their pain was incorporated as part of their broader lifestyle, with the intention being to live their lives as near "normally" as possible, be as little different from their peers as possible. They had "got used to pain", and were carrying on with their lives.

One child who had a painful genetic condition provided the extreme example of this. C1 (10.5 years) described two or three behavioural strategies, and two cognitive strategies which addressed the pain (minimizing pain and positive self-talk), and befitting the expert he is at his own pain management, found it difficult to convey the intricacies of his daily living with pain to the present researcher. Age and the importance of not feeling different from about 10 years onwards may also have impacted on this (refer Chapter Twelve).

Children described how the severity of pain impacted on which coping strategies they used, and with experience at using coping strategies, the ones that they chose to use could effectively reduce the severity of pain. For instance C3 (12 years) described how "concentrating on other things" was used when doing painful exercises with her leg and for the acute pain of blood tests, but that for less severe pain, resting and distraction (watching T.V.) was an adequate coping strategy.

"It's not as sore as the other blood tests and stuff. I just sit down and watch T.V. It sort of helps."

Many children described how "keeping going" with an activity was used as a coping strategy for less severe pain. This had to be altered if the pain became more severe:

"If I have a little bit of pain I don't really notice it, I just keep going and it goes away, and if I have a lot of pain I do something about it" C5 (10.5 years).

Situational contexts which impacted were related to:

(1) feelings of differentness,
(2) feelings of not wanting to bother people,
(3) the degree of interest in a current activity,
(4) and linking through these aspects, how "used to pain" the children perceived themselves to be.

For instance, children were aware that school activities distracted from pain, and children mentioned that they felt less pain at school because there was" *too much to do*"C9 (11 years), C 10 (10 years). Also that they didn't tell the teacher because she was too busy," *unless it's really, really, sore*". C9 (11 years).

The interactive decision about the need to intervene (and/or express pain) was balanced between severity of pain and current social context, and was clearly described by an older child:

"Well it would be just as sore if I was at home. I could probably show it more, but I still don't have to show it at all. But when I'm with someone else you don't want to burden them, and say I have to go home 'cause I'm sore, so you don't want to go and ask them, but if it was really bad I would. But if I was at home it might be different, I might say I need Factor 8 now." C8 (13 years).

A situational context which impacted on one child's use of coping strategies was being in a hospital ward. He described how initially he was too shy and unfamiliar with the situation to ask for medication for pain relief, but increased familiarity with the situation made it easier to ask for help:

"I don't even mind asking to go on the computer, but I used not to even ask for a pain killer, too shy." C2 (12 years).

Vicarious learning about the "rules" for being a good patient enabled him to manage the situation in order to manage the pain:

"It's easier to ask now, 'cause you know them (the staff) and you try to get to know them as well, and be nice and that, helpful and friendly and don't ring your bell too much, otherwize you're very unpopular. 'Cause the little boy (name) would keep his finger on it for minutes and minutes and minutes ..."

Multi-faceted aspects of coping with pain and being in hospital are evident in this statement.

The children's diagnoses, their understanding of the implications of their condition

and possible outcomes operated as a situational context, which impacted on their use of coping strategies. For example, C8 (13 years) described how, with increasing age, he had become more aware of the implications of Haemophilia. He now utilized prevention strategies and did not do things that would cause pain and bleeds. Also, not knowing the diagnosis, what was happening, and possible outcomes had contributed toward the use of catastrophizing as a coping strategy (e.g., C3 and C10, described in Chapter Ten).

SUMMARY

This chapter has presented the conceptual analysis that draws together the data from the children's interviews. The BSP of **getting used to living with pain** links the data, and accounts for a large part of the variation in behaviours described by the children. Children described an increasing tolerance for pain, as well as daily lifestyle adjustments as they became more used to pain. The contexts which impact on the changing process of getting used to living with pain and its constituent coping strategies and ways of being have also been discussed. These included severity of pain, length of time since onset, age/cognitive developmental level, and situational contexts. The following chapters describe the selective codes which are constituent of the process of **"getting used to living with pain"**, and relationships between the codes are described in terms of the children's data.

CHAPTER NINE

Behavioural strategies that address pain

These were behavioural actions that the children described purposefully initiating in response to pain, or to prevent pain from occurring.

Axial Codes:

- REGULATING ACTIVITY
- PHYSICAL INTERVENTIONS
- SHOWING DISTRESS

REGULATING ACTIVITY

- **Stopping and resting**
- **Changing position**
- **Keeping going**

All of the children described stopping what they were doing, resting, and trying out various body positions.

> *"Just lay in different places to see if it would go away."* C5 (10.5 years).

Children from 10 years of age upwards described making conscious decisions about stopping and resting, in light of the current severity of pain, their previous experiences, the current social situation, and "how used to pain" they were. Not stopping, thatis, keeping going with an activity, was then a conscious decision made in the light of previous experiences, that less severe pain may be relieved by continuing the activity. Alternatively, they felt that it was socially inappropriate for them to stop some activities. Feelings of differentness also impact on this decision, and are described in Chapter Twelve.

> *"Sometimes I'll bend over and it will hurt and I'll just try to go on, but then it'll hurt more after I'll keep on doing stuff, and I'll have to lie down."*C10 (10 years).

A preceeding condition for regulating activity was often cognitive working through, in the form of working out what previous activity may have "caused" the pain, or through experience deciding to regulate activity as a way of preventing exacerbations of pain from occurring.

"I think it's because I've been doing too much the day before. ... I just rest for the next couple of days until it gets back to normal." C5 (10.5 years).

*" also I don't really do anything that makes them have bleeds."*C8 (13 years).

One child who was younger than 10 years of age described regulating his activity, with less reference to the decision making process, and without describing causal attributions for the pain. For example:

"If I get it, I stop and go inside sometimes." "I have to have the long, long, longest sit down." C6 (7.5 years).

C6 and the other child under 10 years, C7 (8 years), described resting, but did not describe keeping going.

Lying down, and re-positioning were considered effective by most children, and a major strategy for children who had long-term joint pain from arthritis. For example:

"If you lie down, it's easier than sitting up." "So I just put my hands in the cushion, and they'd feel so much better." C4 (12 years).

In response to the projective question:

" He's a dope, he should lie down." C7 (8 years).

Lying down was described as a strategy that was often used by all of the children.

The consequences of regulating activity, as well as relieving pain, were feelings of being in control and able to manage pain and their condition. The regulation of activity also then led on to strategies which diverted the child's attention from the pain (both cognitive and behavioural) and also cognitive strategies that addressed the pain. For instance, having managed their pain by stopping, resting, and possibly initiating a physical intervention, children then often engaged in a distraction, and/or in positive self-talk by telling themselves "I know what to do, I can manage the pain." Some combinations of strategies are described in Chapter Thirteen.

Another consequence of knowing when to stop, rest, and what position was best (i.e. the overall ability to regulate their activity), was the belief that children who are not used to pain find it difficult to stop and rest, or to know when to stop. In response to advising their "best friend" what to do when they experience pain, most children described stopping, resting, and re-positioning. However, many of the children went on to say that friends of theirs would not be able to do that.

"But he wouldn't do nothing,yeah, he's that kind of boy that can't really stay, that can't really do nothing for a day 'cause he's so used to not having pain, that he would just get up and start running around and that." C5 (10.5 years).

"I mean, they'd probably just try to play sport again and probably make it worse ... and they wouldn't think about trying to make it better by calming down, even if I told them to because they're so used to playing." C8 (13 years).

The children often provided examples of friends who had not stopped when they had acute injuries. The knowledge that they themselves knew what to do in order to alleviate their pain and manage their condition (i.e. all the forms of regulating activity plus using other coping strategies), strengthened their belief that because they were used to pain they could handle it, and resulted in further positive self-talk and feelings of self-efficacy. "I'm used to it, so I know what to do" was a commonly repeated theme (refer previous chapter).

The basic social process of **getting used to living with pain** therefore ran through regulating activity, because it was through repeated experience of pain that the children were able to make comparisons of severity, and know at what point to stop and rest. This point was likely to change over time, as the children increasingly minimized their pain, and also became able to rely on their experiential knowledge that they could participate in appropriate activities while tolerating some degree of pain, yet intervene when needed.

The stopping and resting point varied for each child, partly contingent on judgements of current severity of pain, but also on length of time since onset, increasing tolerance for pain, and also on the desire to complete the activity. There was a trial and error learning aspect to keeping going with activities, yet knowing at what point to stop. Some children who were earlier on in the process of **getting used to living with pain** described testing their limits, and attempting to participate in activites in spite of inducing quite severe exacerbations of pain. For instance, C9 (11 years) wanted to run the cross-country, and completed several practise runs.

"It really, really hurt afterwards." Eventually, she decided that she would try walking it. *"I'd rather walk than not do it at all".*

The children described maintaining a lifestyle balance of participating in age-appropriate activities at a non-harmful (if slightly hurtful) level, and adjusting those activities where necessary, and stopping if need be. The children clearly indicated the need to participate in a normal lifestyle, and described adjustments they had made in order to do so. For example, C4 (12 years) described going on a school camp, and being able to use his special bike on the tramp:

" I went on my bike. The track was just wide enough."

This sort of adjustment also required input and support of parents. Children would tolerate an increase in pain in order to participate in activities, e.g. getting a sore bottom from the bike.

A more specific version, and part of not letting pain interrupt daily life, was the belief that pursuing a current interest/activity could supersede pain, up to a point. The children described maintaining a balance between stopping activity in order to reduce pain, and keeping going with what they were interested and involved in, which they recognized acted as a distractor until the activity finished, or sometimes the pain became too severe and intervention became necessary. These were often goal-directed activities, for example, playing netball:

> *" Well, if it's not too sore, then I can play, but I just put some support on it." "I just take some medicine after the game."* C9 (11 years).

C8 (13 years) played an accordion in a small orchestra, and continued to play, although he felt pain at times:

> *"It would hurt your arm, but I don't really care about that. ..." In relation to playing computer games: "but I just get pain, and then after my go, I do something about it."* C5 (10.5 years).

> *"Like sometimes I'll go up the road (on bike) and it'll be real sore,but I'll keep on going and it'll go away and I'll forget about it."* C10 (10 years).

Children were also aware of the need to maintain regular, paced activity, and keeping themselves fit at a level that was appropriate for them.

> *"Its (the bike) been such a help, like its brought my leg muscles up such a lot."* C4 (12 years).

In summary, the axial code of regulating activity consisted of the substantive codes of stopping and resting, changing position, and keeping going. Children described making decisions about regulating activity, and maintaining a balance between participating in everyday activities (keeping going) while tolerating a level of pain and stopping and intervening when pain became too severe. **Getting used to living with pain** was an integral part of their use of coping strategies, as well as the perceived outcomes, i.e. relief of pain, and knowing what to do in order to relieve pain. Sometimes they tested their limits as part of the experiential learning process, and this was likely to occur relatively soon after onset of their condition, or when pain had been less severe for some time. There was a general opinion among the participant children, that children who are not used to pain don't know when to stop and rest, and the overall consequence of this group of strategies resulted in children perceiving themselves as knowing what to do to manage pain, and feelings of having some control over pain.

PHYSICAL INTERVENTIONS

- **heat/cold**
- **medication**
- **help-seeking**
- **self-management**

Physical interventions were things that the children described doing themselves, and included massaging, rubbing the sore part, application of heat or cold, taking medication, and help-seeking. The contexts of increasing age, and length of time since onset (i.e.experience) influenced the degree to which children self-managed these interventions, rather than being parent assisted. For instance, children described learning self-management of physical interventions by experiencing parent initiated physical interventions:

> *" and then Mum would massage my wrists, and so now that I can move around a lot better, I can do that myself."* C4 (12 years).

The process of learning to self-manage physical interventions in the above instance included being mobile enough to use the intervention, as well as the experiential learning process, which takes place in the context of age and length of time since onset. C4 thought that massaging was especially effective at relieving pain:

> *" What would work the best would be massaging, I reckon it is a real good thing."* C4 (12 years).

Massaging was also learned by observing the physiotherapist.

The physical interventions of heat applications and massaging were described most often by children with long-term arthritic pain, used regularly by them, and thought by them to be very effective at relieving pain. As well as relief of pain, the interventions again offered a sense of control over the pain, i.e. that there were things that they could do to help themselves:

> *" I can lie in the bath, and I can put a hot water bottle on it. Sometimes that helps. Baths are really good for it."* C5 (10.5 years).

The substantive code of help-seeking is included for discussion with physical interventions because very often the process of physically seeking help (mostly from parents) resulted in a parent assisted physical intervention, e.g. offering analgesic medication, massaging, and advice. However, seeking help from parents (and friends) also provided an entire gamut of physical and psychological support, as well as parent assisted coping strategies. Strategies involving parents were both child initiated and

parent initiated, but the child initiated help-seeking will mainly be reported on, and the following are examples:

C2 (12 years) *"Ask my Mum to come in and that 'cause she used to read books to me to keep my mind off it." Mum provided distraction.*

C4 (12 years): his parents took turns at turning him at night to relieve pain and help him get comfortable when he was unable to turn himself. They provided re-positioning and massaging. *"I'd call out to them." "It didn't feel so bad when they were with me."* C4 indicated that he felt emotionally supported when his parents were with him, as well as the physical care which they provided.

C5 (10.5 years): Mum could rub the sore part, taught him coping strategies, and provided nurturance. *"Tells me not to do too much the next day ... and she can give me a cuddle and she can rub it."*

C10 (10 years): *"Sometimes I take something, like a disprin, Mum gives it to me." "She can, well usually she cuddles me."* C10 later described how being cuddled was one of the best things for her when she was sore, and as well as her Mum, her teacher, and also one of her mother's friends would cuddle her.

C8 (13 years): Mother administered intravenous medication at home. *"Well she doesn't really comfort me or anything now because I can take care of myself."* C8 indicated that the need for physical comforting had changed over time, but had been important for him earlier.

C9 (11 years) valued parental advice and at the same time parental leeway for making her own decisions about activities. At school, she told her friends about being sore, rather than the teachers, and described feeling socially supported by her friends. *"they help me and stuff. ... Well if I've got a sore ankle and I can't walk, they act like a sort of crutch so I don't have to walk on my leg."*

From the above examples, it can be seen that help-seeking was closely linked with experiential learning of physical interventions and coping strategies, i.e. parents taught coping strategies either verbally, or by example when children sought help. Children added to and developed their repertoire of coping strategies as they adapted parent's advice to suit their own needs, and in the light of their experiential learning (refer also Chapter Eleven).

The other paramount theme involved the children describing a feeling of emotional safety and support when parents or significant others were present, regardless of age. The contextual factor of age was applicable however, because up until approximately 11 years of age, physical cuddling was very important, and after this age, the presence

of the parents remained important, but actual physical nurturance in the form of cuddling was not described. The oldest child, C8 (13 years), quoted above summarized his increasing independence from "comforting", but there was still a need for Mum to be present. Unique preferences and situational contexts also impinged on physical comforting. C9 (11 years) felt emotionally supported by Mum at home, but sought help and received both emotional and physical support from her friends at school. Peers, siblings, and cousins were an increasing source of social support for several of the 12 years olds (e.g.C2, C4 and C9), and the autonomy and independence of C8 was related to his self-management of his condition.

A specialized form of help-seeking was information-seeking. This was not frequently referred to by the children, and the two children who described it did so in the context of relatively recent onset, and acute episodes in hospital.

" Ask the Doctors questions ... lots, until I know what I want to know." C2 (12 years).

" Doctors told me and I didn't really understand then, so I asked Mum and asked the Nurses." C3 (12 years).

Asking questions was a way of regaining control, by increasing their knowledge about what was happening to them. Several other children described the provision of information, rather than seeking it out. Parents were often the providers of information, and they interpreted the information that was provided by professionals for the children.

Asking questions was described as not relevant by the children, as pain became long-term, and a part of their lives. Children had knowledge of their conditions, knew what to do about pain and how to manage their condition. Therefore, they did not perceive asking questions as important. However, children also remembered back to needing accurate information during acute flare-ups, and nearer the time of onset. The link between not knowing what is happening (i.e. lack of information), and catastrophizing is described in the next chapter.

Most of the children described consultation and joint decision-making with their parents in regard to the need for analgesic medication, which was often described alongside help-seeking and rest, e.g.

" Rest, sit up on couch, and have some tablets." C6 (7.5 years).

" Ask Mum for some Panadol."

This statement was made by many of the children, while some of the older children took analgesic medication when they perceived it necessary themselves.

The extreme case of the substantive code of self-management was provided by C8

(13 years) who has Haemophilia. He continually self-monitors his level of pain in order to check for the occurrence of a bleed, and particularly in the mornings prior to school, he decides if his pain is at its' usual "niggling" level, or if it is severe enough to indicate a bleed. He then makes a decision as to whether Factor Eight is required or not. If it is he asks his mother to administer it, and if not, then he goes with that decision until after school. Occasionally he miscalculates in the mornings, or his symptoms alter during the day, but he continues on with the day, and gets Factor Eight after school. His long-term experiences with his symptoms, and awareness of pathological processes enable him to clearly differentiate between harmful pain (bleeding) and non-harmful pain (arthritic joint pain):

> *" Well you know that this one won't be a bleed because it is just sore, but um you can just tell because what happens is you can't bend it, I mean you can't straighten it because it is bent ... (getting full up) with blood and everything, so you know then."* C8 (13 years).

The consequences of his effective self-management were a reduction in severe exacerbations of pain because bleeds were pre-empted and a massive reduction in hospital visits and days off school. He had missed three days from school in the previous 18 months, and was living as near "normal" a life as possible. *"I used to miss heaps of school ... now I hardly miss any."* Feelings of being different to peers were reduced, but some ambivalence was described between managing so well and the consequent invisibility of pain to others:

> *" But they still don't know that I have to be injected. They just think that nothing is really wrong because I don't look different or anything like that ... I used to find that hard when I was younger, but I'm pretty used to it."*

Changes in the importance of feelings of difference related to age were described by C8, and are discussed in Chapter Thirteen.

Other 11 and 12 year olds self-managed analgesic medication, and made decisions based on clearly described different severities of pain.

> *" Just take medicine, and sometimes I do exercises, depending on how sore it is. If it's not that sore, then I exercise it and if it is quite sore then I rest it."*C9 (11 years).

Self-management therefore encompassed physical interventions, regulating activity, decisions about what interventions are appropriate, and indeed overall daily lifestyle and activities for the children from approximately 11 years upwards. This did not happen instantly, but was part of the process of **getting used to living with pain.** That is, increasing self-management was engendered by increasing experience with the pain/condition, having supportive parents who trusted their children's decisions, as well as being able to talk through decisions with parents at times and an increasing

cognitive-developmental level. The process of moving toward self-management was referred to by a younger child, C5 (10.5 years) in relation to taking breaks from activity:

> *" Mum decides ... yeah, but I can decide as well."* Describing how he massages gel onto his hip: *"I do that every morning and every night and sometimes at lunchtime."*

Another aspect of physical interventions was that some interventions advised or initiated by professional helpers caused increased pain at the time, although the children were aware as they got older of the need for the intervention. That is, they described tolerating the increased pain of the intervention, in order to help their condition in the long-term. This was mainly physiotherapy exercises to increase mobility (C1, C3, C4), cold packs for bleeds (C8), and intravenous injection procedures (C2, C8).

> *" Yeah, and it sort of makes it just throb more and hurt, but its helping." "I just do them and don't worry about it, I don't really know how."* C3 (12 years).

> *"Not as far as I feel like it, I stretch it until it hurts quite a bit." C1* (10.5 years).

Age and being used to pain were relevant contexts when tolerating the pain of "helpful interventions", and C8 (13 years) remembered back to how it had seemed when he was younger:

> *" 'Cause when they say put an ice pack on it to make it feel better, you don't think of it feeling better, 'cause it actually makes it feel worse ... it just makes it throb more and hurt, but it's helping. The Doctors should say put it on so it helps in the long-term or something, they shouldn't say its going to help, 'cause when I was little I didn't understand why they said that, 'cause they said it would help me and it made me hurt more."*

Being used to pain, increased tolerance for pain, and expecting pain were described by one child with arthritis who had cracked his knee in a car accident.

> *" like I knew that it was really, really sore, but I didn't know it was cracked. I just thought since I had arthritis it would just hurt much more than it would normally hurt and so I didn't really think too much of it. ... The physiotherapist up there (visiting Auckland) kept wanting me to, um urging me to get up and walk and I had a walking frame and I found I could do a few steps, and I was so excited that I kept on practising and practising, and so all the weight was on my cracked knee."* C4 (12 years).

This example illustrates that these children can and do experience severe pain, and have a greatly increased tolerance for that pain, especially in the context of trying to maintain or regain mobility.

In summary, the axial code of physical interventions included massaging,

application of heat, and taking medication. The behavioural strategies of help-seeking and self-management were also included because of the close links that occurred as a consequence of help-seeking and self-management. Overall consequences were similar to regulating activity in many respects, i.e. experiential learning, knowing what to do, and feelings of being in control. Feelings of being socially supported also resulted from help-seeking. Children also described tolerating the increased pain of some interventions in order to manage their condition as effectively as possible and ensure optimum outcomes. For instance the exercises undertaken by children with arthritis in order to regain and maintain mobility.

SHOWING DISTRESS

- **crying, screaming**
- **complaining**

Children described crying or screaming in response to very severe and/or acute pain, and there was also an age, time since onset, and being used to pain aspect to showing their distress.

> *" I mean when I was little with my ankles and things, I used to scream in pain, 'cause the bedclothes, even that just draped over was too much weight and I couldn't sleep all night, but now I'm used to it. I mean I still know it's sore, but I'm just used to it, that is all."* C8 (13 years).

Showing distress was therefore described in relation to being younger, less used to pain, and in relation to initial acute episodes and severe exacerbations of long-term pain. Feeling scared was also associated with showing distress:

> *" I just really started to cry, it was just so painful." C4 (12 years) was describing his scariest pain, a severe exacerbation of arthritic pain. "I was trying to keep calm, like I was crying. ... It was really sore, and stung."* C3 (12 years), during acute painful dye procedure.

Children were aware of changes over time in their expressions of distress, i.e. that they felt less need to show distress as they got older and became used to pain.

> *" Well I've sort of got used to it now. I don`t complain as much."* C9 (11 years).

The consequences of crying, screaming, or complaining were that nurturance and help was provided by parents, special attachment figures, and professionals. C9 described how she complained less in response to a similar degree of pain (the sore hadn't changed, she had got used to it), but she also described alternative ways in which she

sought out social support (refer above). The advice of C9 for a best friend who was in pain indicated the importance which she placed on social support :

> *" They could go and talk to someone." Seeking out social support provided the nurturance and contact, that had previously resulted from complaining and showing distress.*

SUMMARY

The axial code of showing distress differs from the codes of regulating activity and physical interventions, but there are close relationships. Showing distress was described as a response to extremely severe pain and/or acute onset, and was also related to age and time since onset. Showing distress resulted in nurturance and physical interventions being provided by parents and others, which was also provided in response to help-seeking. Help-seeking replaced showing distress as children became more used to living with pain. However it is important to note that showing distresss was a response to extremely severe pain at all ages, and of feeling scared by the severity and unknown aspects of the pain. Regulating activity and initiating physical interventions resulted in feelings of being in control over the pain, knowing what to do about pain, and feelings of being socially supported. Conscious decisions were made about regulating activity, either to stop and rest or keep going with an activity. **"Keeping going"** was a purposefully used strategy that served as a distraction from pain, and also to keep children involved with their social world.

CHAPTER TEN

Cognitive Strategies that Address Pain and Self in Relation to Pain

Children actively thought about pain, and these thinking strategies altered, were refined, or were influenced in some way as the children became more used to pain.

Axial Codes:

- COGNITIVE WORKING THROUGH
- POWERFUL SELF-TALK
- POSITIVE SELF-TALK
- STRATEGIES THAT ALTER APPRAISAL
- CATASTROPHIZING

COGNITIVE WORKING THROUGH

- **Causes**
- **Making it better**
- **Preventing pain**

The children described thinking through various aspects of the pain in a way that allowed them to cognitively manage the painful situation. The most common version of this, which was described by most of the children (and all of the children aged over 10 years), was thinking through what had made their pain worse or better. Also, if they were feeling pain, what they could do in order to make the pain better. In particular, the children attributed causes and exacerbations of pain in terms of previous activities and even if aware of pathological processes, their prior activity level was more likely to be cited as a cause for pain, i.e. what they had been doing prior to the exacerbation was a more salient cause for them. This had the consequence of bringing the pain into the realm of being able to be controlled, because a known occurrence or activity had caused the pain, so they could then think through ways of alleviating pain relevant to the known cause. Cognitive working through was therefore closely linked with subsequently regulating activity (rest, positioning, and sometimes keeping going), and physical interventions.

" Well, in the week-ends I'm O.K., because I'm not walking around at school, like we have to run around a lot and so, well not all days, but most of the days I get quite sore." C9 (11 years).

" I think its (sore) because I've been doing too much the day before. ... Oh, I just rest for the next couple of days until it gets back to normal." C5 (10.5 years) demonstrated the link with regulating activity.

C4 (12 years) had participated in activities with his cousins, slept on the floor in a sleeping bag, and the next day he had a sore back which he attributed to the cold (thinking through the cause of the pain). Consequently, the next day, he applied the physical intervention of warmth to his back.

" Just a litte (sore) to-day because when I was out at the farm I slept in a sleeping bag on the floor ... and it was quite cold, and I've just got a sore back."

Some older children began to add an awareness of pathological processes to their causal attributions, but their main focus was on what they might have done, and be able to do differently in order to alleviate pain, or prevent pain from occurring.

" Well, both of them are sore after I've played netball, but if it's sore before ... the left one is sorer than the right one ... it's much weaker than the other one."

C9 (11 years) indicated that she was aware of the internal pathology, that one leg was weaker than the other one, alongside the activity related cause of pain. C9 also employed prevention strategies by having a hot bath before and after participating in exercise. The cognitive working through expanded over time, as the children used their experiential knowledge of previous episodes to include planning how to prevent similar exacerbations in the future.

C8 (13 years) described relatively advanced understanding of pathological processes and this was an important facet of his self-management of his condition. Along with this he described an awareness that emotional upsets that were unrelated to condition could cause pain and a flare-up of his condition. This indicated that he had thought through antecedent events, whether emotional or physical and noted the relationship to increased pain and a flare-up of his condition. He also indicated that he thought that the degree of emotional upset influenced the severity of pain experienced:

" Well if I'm feeling bad on that particular day, they can get quite sore and they can have a bleed. Like, when my Dad died, about a week after, I was having bleeds every day for seven days a week, you know every day, but now it's not so bad. I don't normally get them for that sort of thing ... but if something happened, like if something happened to one of the dogs or something like that you know, I'd get a sore arm the next day."

Other children showed some awareness of the impact of emotional factors on their experience of pain, for example:

> *" Like, when I got up a few months ago, or a year ago, I could get really nervous and I'd get so nervous I'd make it even sore, I'd get all hyped up and that."* C10 (10 years).

In summary, cognitive working through allowed for the children to work out their own understandings of causes and exacerbations of pain, to adjust their daily activities in order to prevent pain, and to initiate strategies in order to relieve pain. There were close relationships with the behavioural strategies of regulating activity and physical interventions (including information-seeking and the provision of information), and also with distraction strategies (refer Chapter Eleven). Cognitive working through was a pivotal strategy in the children's **getting used to living with pain**, as they initiated coping strategies in light of the understandings gained from working through of previous and current experiences of pain.

POWERFUL SELF-TALK

- **Fighting self-talk**
- **Encouraging self-talk**
- **Calming self-talk**

Many children described thinking about themselves and their abilities in a powerful way, i.e. that they were not going to "give in" to the pain. The substantive codes of fighting self-talk, calming self-talk, and encouraging self-talk collapsed into this code, and examples are:

> *"beat it"; and "don't let it get you too much"* (C5, C7, C8).

> *" Never give up"* was a central theme for C2 and C4, who were both 12 years old, yet had very different pain histories (C2 had more recent and relatively acute pain over the previous six months, and C4 had a long history of chronic and acute exacerbations of arthritic pain).

> *" Don't give up, 'cause when you do give up I'd say it would probably get worse, 'cause you're letting it take control instead of really fighting back."*C4 (12 years).

Powerful and encouraging self-talk was clearly related to the need to feel as though they had some control over the pain (i.e. not letting it take control over them), and the consequence of this sort of self-talk was feelings of being able to take control over the pain.

"When you can't think of anything else, think that you are going to beat it, and also it's not going to take control of you." C2 (12 years).

POSITIVE SELF-TALK

Children who had very long-term pain (most or all of their lives), described a form of self-talk that resulted from their being used to pain and their increased tolerance for pain, which led them to say to themselves:

" I can handle more pain than other people." C1 (10.5 years).

"I'm, used to pain, so I don't need to cry or anything." C8 (12 years).

Positive self-talk was a general way in which children told themselves that they could handle pain, and positively appraised their abilities to manage pain, and therefore addressed secondary appraisal. A pre-existing condition and also a consequence of this positive self-talk, was acceptance of their pain and chronic disease. The ability to continue with everyday activities, although at some level they were feeling pain. was the overall consequence of the use of positive self-talk and increased tolerance for pain. Pain was treated as less of an issue, and as part of their lifestyle. That is, there was a relationship between positive self-talk and acceptance as a way of being (refer Chapter Twelve).

STRATEGIES THAT ALTER THE APPRAISAL OF PAIN

- **Minimizing pain**
- **Positive re-frames**

Again it was children who had experienced very long-term pain who described this group of coping strategies. The most common way of altering the appraisal was to minimize pain (and examples of this data have been presented above in relation to the process of getting used living with pain). Repeated experience of pain and getting used to pain was a pre-condition for use of this strategy, and also a consequence. There were links with tolerance of pain, and acceptance that pain was a part of their lifestyle. Minimizing pain was useful in relation to "niggling" every day pain, and along with the use of positive self-talk and increased tolerance for pain, allowed for participating in everyday activities.

Another form of altering the appraisal was described as effective in very severe pain by one child:

"Sometimes when it was really bad, I would keep on thinking that it doesn't hurt and things like that, and it would still hurt, but even just thinking about that, it wouldn't hurt so bad." C4 (12 years).

This statement indicated an awareness that thinking about pain differently could alter the sensation of pain, and this awareness also underpinned the use of minimization by these children who had experienced very long-term pain.

Another child used positive re-framing, which addressed the impact of the pain, rather than appraisal of the severity of pain. C8 (13 years) described how the affected painful joints had altered over time from his ankles to his arms, while his hips and knees had not been affected:

> *"But it just went from my ankles to my arms, which is quite good, 'cause hips and knees are more important."*

C8 was highlighting the positive aspects of the impact of his painful condition, rather than the negative aspects. C8 also employed several other positive re-frames throughout the interview, especially in relation to enjoying activities which his condition allowed him to participate in, and not liking activities which would have been risky. Later on in the interview, he also indicated that he was aware of his own re-frames:

> *" But I don't think I'd enjoy it, playing sport 'cause I'm not used to doing it, but if I'd been born without Haemophilia I'd probably like sport because I'd be used to doing sport."*

The variations of powerful self-talk, positive self-talk, and strategies that altered appraisals of pain, all addressed different aspects of appraisal. That is, the self-talk strategies addressed secondary appraisal, because the children were telling themselves that they had the resources available for mastery. Children altered the primary appraisal of pain, by telling themselves, that the pain was less severe, or that the impact was less disabling. These strategies all led to feelings that the children were able to tolerate and accept pain, and ultimately to lifestyle adjustments to their pain and condition.

CATASTROPHIZING

- **Thinking how bad it is**
- **Thinking it will never end**

Catastrophizing was used to summarize substantive codes which indicated that children were thinking that the pain was never going to get better, being frightened and scared, and *"How bad the hurt was going to be."* C3 (12 years). In terms of similarity of conditions and consequences, catastrophizing doesn't clearly fit in with the selective code of cognitive strategies that address pain. However, in terms of the basic social process of **getting used to living with pain** useful comparisons and theoretical links

can be made by including catastrophizing at this point. Furthermore, catastrophizing thoughts do address pain and impact on appraisals of pain.

This catastrophic thinking was described by three children , who had all had relatively recent acute onset of their conditions, with severe pain. Two of the children had recently had acute episodes in hospital. Stemming from the contexts that these children described, catastrophizing occurred during initial severe pain experiences (i.e. early after onset), when the outcome was unknown and/or a feared outcome seemed to be happening, and there was lack of information provided to the child.

"I didn't know much about it, I didn't know what it was and I was scared and nervous, and I didn't know how to handle it." C10 (10 years).

If I don't get better, I'll be here for ever and ever trying to get better." C2 (12 years).

Children were able to describe changes in their thinking over time since onset, and also as they got used to pain.

" Sometimes I used to (think bad thoughts), but I don't now." C2 (12 years).

"Like before I was real shaking and nervous ... thinking how bad it was going to be." Now C3 (12 years), tells herself: *"I was sort of saying it would happen if it was going to happen, so don't worry about it."*

C3 had described how her thinking had changed from catastrophizing in relation to blood tests,to calming self-talk. C2 had moved on from catastrophizing thoughts to "thinking about positive outcomes". Another child, C9 described the experiential learning of cognitive and behavioural strategies that replaced catastrophic thinking over time. The variations of self-talk that altered the appraisals of pain (described above), therefore tended to replace catastrophic thinking, as children became used to living with pain, and as they learned more about what to do.

A very severe and extreme form of catastrophizing was described (separately) by the parents of two of the children with arthritis. These children had told their parents, with serious intent, that they wanted to die to get rid of the pain. In both instances, there was extremely severe, unrelenting constant pain, and a lack of relief from pain.

One of these children (C7, 8 years), told his mother several times that he wanted to die, approximately three months after initial onset. As well as the severity and unremitting nature of the pain, there was a lack of information from professionals combined with uncertainty about the future (information from parent). Hospital treatment and medical interventions were initiated. At the time that he was interviewed by the present researcher, approximately nine months after initial onset, C7 was utilizing a variety of coping strategies, and he did not describe catastrophizing thoughts. At the telephone follow-up, approximately one year after initial onset, his

mother reported that he was increasingly tolerant of pain, and accepting of his pain and condition, and this was associated with an increasing religious belief.

The other child C5, (10.5 years) had told his mother that he wanted to die, several years previously, when he was about 6 years old. His pain was also extremely severe and unremitting. Counselling from a psychologist had been sought at the time. At the time of the present interview, C5 did not describe any catastrophizing thoughts, and described using coping strategies and increasing self-management of his pain and condition. However, in response to the projective question he said: "I just reckon he's had enough. ... Yeah, I reckon he can't cope any more." which indicated that C5 knew what it was like to have "had enough", although he didn't describe this as a current response for himself.

The contexts of severity and frequency (i.e. constancy) of pain, along with length of time since onset were particularly relevant to catastrophizing, which was a part of the process of getting used to living with pain. Catastrophizing thoughts altered over time, and were replaced by other coping strategies, but could be revisited if very severe and unremitting exacerbations occurred.

SUMMARY

The cognitive strategies described in this chapter either addressed pain, or the self in relation to the pain. The process of getting used to living with pain was evident throughout the descriptions, and while catastrophizing was likely to occur earlier in the process, strategies that altered appraisal of the pain and positive self-talk occurred later in the process. Cognitive working through altered and expanded as the children became more used to pain, and also in relation to age and cognitive developmental stage. Powerful forms of self-talk occurred throughout the process.

The context of severity of pain was especially relevant, and catastrophizing could occur at any stage in the process, if pain became extremely severe and unrelenting. Catastrophizing was related to feelings of loss of control over the pain, whereas the other strategies resulted in feelings of being in control of pain, and managing their lifestyle.

CHAPTER ELEVEN

Cognitive and Behavioural Strategies that Divert Attention from Pain

The children described many variations of coping strategies which relieved their pain through diverting their attention from pain. Very often the children were aware of the cognitive influence over pain of undertaking a distracting activity, and said they did it to "keep their mind off the pain". Sometimes the cognitive influence was not mentioned, hence the distinction between cognitive-behavioural distraction and behavioural distraction in these axial codes.

Axial Codes:

- BEHAVIOURAL DISTRACTION
- THINKING ABOUT SOMETHING ELSE
- THINKING ABOUT GETTING BETTER
- NOT THINKING ABOUT IT

BEHAVIOURAL DISTRACTION

- **Alternative activities**
- **Squeezing muscles**
- **Involving others**

Only the very youngest child, C6 (7.5 years) did not describe the "keeping my mind off pain" aspect of distracting activities. He did, however, describe finding alternative activities which followed on directly from regulating activity and resting. Older children also described initiating alternative activities to those which were deemed to be exacerbating pain, with less reference to the cognitive influence over pain, i.e. the purposeful strategy in these instances was to alter the hobby, and these sorts of alternative activites have been included in the axial code of behavioural distraction.

Alternative activities were less physically active interests, initiated alongside resting the body. Examples were: playing with lego, playing with cars (C6, 7.5 years); drawing (C7, 8 years; C10, 10 years); walking (C8, 13 years; C9, 11 years); and companionship with friends (described by most participants). Companionship with friends was described as very important by every child, and having friends who altered their

activities to accommodate the needs of the child experiencing pain resulted in them feeling socially supported. When children had life-long experience of their condition and pain, their interests were already centred around less pain-producing activities with their friends. For example, C8 and C1 both described board games with friends, and liking non-physical activites. However, when the initial onset had been within the previous one to two years, a common pattern was for children to participate in physical activities with their friends (e.g. biking, running around at school) and to stop their activity if the pain became too severe. Their friends would also stop and participate with them in an alternative activity that was less physically strenuous. For example:

"Sometimes they come home with me and keep me company." C 10 (10 years).

The consequence of both of these patterns of initiating alternative activities was that the children maintained similar activities to their peers, they kept up their friendships and social contacts, and they avoided extreme exacerbations of pain. Pain was relieved by finding alternative interests to physical activity. There are links with regulating activity (as a pre-condition for initiating alternative activity), and also with acceptance. The contexts of time since onset and being used to living with their painful condition also interact.

Two of the children described behavioural things which they did themselves, or involving others, which acted as a distraction from the pain. One child described how he would clench his teeth, and another how she squeezed Mum's hand.

"Well I bite my jaw hard together like that until your face goes like that, without touching it like ..." and he made a screwed up face (C7, 8 years).

*"Try and squeeze my stomach to get rid of it (the pain)"*C7;

"Squeezing Mum's hand, that sort of took the pain away." C3 (12 years).

These strategies involved tensing muscles, and were related to relatively recent, acute onset of pain, and also painful procedures, i.e. blood tests. Concentrating on something else was described at the same time as muscle tensing strategies, and the children thought that together they relieved pain.

COGNITIVE BEHAVIOURAL DISTRACTION

- **Watch television**
- **Play computer games**
- **Musical instrument**
- **Reading**
- **Involving others**

These were interests and activities which the children purposefully used in order to "keep their mind off pain". The activities involved doing something (i.e. a behavioural activity), and having to think about it. Almost every child described purposefully using activities in this way, the negative instances being the youngest child (described above), and the child who has been described earlier, who currently minimized his pain to such a degree, that few other strategies were necessary.

The types of cognitive-behavioural distraction which the children described were: watching television; playing computer games; reading; and playing a musical instrument. C4 (12 years) talked about playing computer games:

> *"That just took my mind off completely while I was playing (computer) games, and then once like I had finished the game, I'd kind of start feeling the pain again. It's as though the pain had completely gone while I was playing ..."*

Other examples were:

> *"It (playing the computer) definitely takes your mind off it because if you're really desperate to finish that level and to get past everything, you'll really concentrate and um, it takes my mind off the pain. So does watching television."* C5 (10.5 years).

> *"Watch T.V. or something to keep my mind off the pain."*C2 (12 years).

Some distractions were considered more effective at relieving pain than others, and this was related to the salience of the distraction for the particular child. The components of this salience were the child's level of interest in the activity, and the concentration involved when doing it. Some of the children therefore thought that computer games were more effective than other distractors for relieving their pain:

> *"Oh and another thing that really helped was videos. We would get videos for me and they'd really help, but I found the computer helped more than the video. ... Maybe that I was more interested in it (the computer), or whether you had to concentrate more on the game than on T.V."* C4 (12 years).

In relation to television programmes:

> *"Yeah, it (the television) does help, 'cause it takes your mind off it, but if it's not very good on T.V., it doesn't take your mind off it at all."*C8 (13 years).

A further aspect of salience of the distraction, was the cognitive developmental level of the child, as well as unique interests. The oldest child (C8, 13 years) described similar distractions to the other children, but also treated them as though they were a bit similar to "doing nothing", indicating a need for goal-directed distractions.
C8 described playing the accordion:

"It keeps your mind off things 'cause it's a hobby, because I can't play sport or anything ... 'cause you have to work towards something and that's the best thing." Further on in the interview: *"Otherwize, what else would I do? I'd play on the computer, and watch T.V., and do nothing."*

Although playing the accordion provided a distraction from pain, as well as goal-directed interests, (he helped with a junior ensemble, and had joined a senior orchestra), and consequent feelings of being useful, sometimes it exacerbated his condition and induced pain. However, the need to have an enjoyable, goal-directed hobby that was his own unique interest (and reasonably low-risk), over-rode pain that he experienced when playing the accordion.

In a similar way, most children described "keeping going" with various physical activities (refer above, to regulating activity), which then acted as a cognitive-behavioural distraction in itself, but if pain was not relieved, or became too severe, then stopping:

"Yeah, like sometimes I'll go up the road and it'll be real sore, but I'll keep on going and it'll go away and I'll forget about it. ... It just depends how sore it is." C10 (10 years).

Severity of pain, previous experiences and getting used to pain therefore impacted on the type of cognitive-behavioural distraction and behavioural strategy utilized. The children made conscious decisions about which strategy was likely to be most effective, in view of the severity of pain, and whether keeping going would act as a distraction and relieve pain, or whether the severity of pain warranted stopping. They also decided when to intitiate other strategies, including cognitive-behavioural distractions. C3 (12 years) utilized watching television and sitting down when her pain was perceived as less severe, and a combination of strategies, which included other cognitive distractions when the pain was more severe:

"No (doesn't need to concentrate on other things), 'cause it's not that sore, it's not as sore as the other blood tests and stuff. I just, with my leg, sit down and watch T.V., it sort of helps."

One child described how parental teaching had enhanced his experiential learning about how behavioural distractions influenced his thinking and relieved pain:

*"Playing can definitely take my mind off it, 'cause when I go to school, like if I've got a sore stomach or something, Mum always tells me it will go away 'cause I won't be thinking about it, and it does."*C5 (10.5 years).

The children perceived the consequences of this group of strategies as relief of pain.

"Well, I just usually read a book or something ... 'cause I don't want to think about it, or I listen to music or something like that. ... It helps because I'm not thinking about it." C9 (11 years).

There was variation between the children in how effective they perceived cognitive-behavioural distraction to be, and how much they relied upon distractions as coping strategies. Other consequences were that attention was diverted from the pain, and from ruminating on disabling effects of pain and condition, or thinking about possible undesirable outcomes. Feelings of "normality", of participating in similar activities to other children (e.g. playing computer games) and feelings of usefulness as though working towards goals were also described.

Distractions involving others were activities that entailed attending to others (i.e. cognitive), or doing things with other that involved behavioural activity as well. Often help-seeking was related to these strategies. As well as diverting attention from pain, and relieving pain, other consequences were feelings of being nurtured and socially supported. Parents, friends, and other people who were "special" to the children provided these distractions. Examples were parents reading to the children, the sharing of jokes and humour, and talking to friends and family:

> *"Another really good thing in bearing the pain was Mum would read to me, and it just got my mind off the pain."*C4 (12 years).

> *"Ask my Mum to come in and that, 'cause she used to read books to me to keep my mind off it."*C2 (12 years).

The sharing of humour was especially important and effective for C2:

> *"Also one of my Mum's friends used to come up, she used to have these funny letters from her cat ... we used to read the letters from the cat." "Also jokes help with the pain."*

Talking to people was seen as an effective distraction by several of the children, and the importance of social interaction for C9 and C10 has already been described. Triangulation of findings in relation to this was further evident, because in response to what she would advise her "best friend" to do when in pain, C9 (11 years) said:

> *"They could go and talk to someone. They could go and watch television, um read a book."*

Jokes and talking to people were viewed by C10 as both effective for herself, and as a way of helping a friend in pain:

> *"Sometimes, like when my back was sore ... she told me when she was at home the other night, that her brother tripped up and stuff, and it was really funny."* Later in the interview: *"I'd remind them (friend in pain) of some of the funny things that happened at school. ... Like take their mind off being sore, like talk to them or tell them jokes or something."*C 10 (10 years).

C3 (12 years) combined two distraction strategies involving her Mum, when having her usual blood tests, that she described as having got used to:

"When I have my blood tests I sort of have to concentrate on something else, like talk to my Mum or something." and at the same time she squeezed Mum's hand. *"Dad or Mum's best friend" would be able to substitute for her Mum if need be.*

In summary, children made conscious decisions about which sorts of cognitive-behavioural distractions were likely to take their minds off pain and thus relieve pain, in the light of current pain severity and previous experiences. Along with the contexts of severity and time since onset, cognitive-developmental level, unique preferences, and situational contexts also impacted on decisions about which distractions were utilized. That is, the process of **getting used to living with pain** encompassed and explained variations in use of distraction strategies. Current situational context and activity may also act as a distraction in itself. Along with diverting attention from pain and condition, distraction involving others resulted in children feeling socially supported.

THINKING ABOUT SOMETHING ELSE

- **Thinking about desired events/visualisation**
- **Using imagination/fantasy**
- **Counting/concentrating**

This was an almost exclusively cognitive group of strategies, in which the children described purposefully directing their thinking on to things and events away from the pain. There was often a relationship with lying down and resting their bodies, and then the children subsequently used these thinking strategies.

Children described thinking about going places and doing things that they really wanted to do:

*"Think of going somewhere, simply going somewhere that you really want to go, and then keep your mind on it."*C2 (12 years).

"Think of something nice ... going back to England." "Like the movies." C7 (8 years).

The explanation which C7 then offered for how pain was relieved by thinking about nice things suggested that he was able to induce an altered state of consciousness:

"Dunno, it kind of goes me off to sleep."

Some children more clearly described their ability to extend this kind of thinking into visualization, often to places that they had previously visited. C10 (10 years) described this as daydreaming:

"Sometimes I just close my eyes and sort of, like when my back's sore I close my eyes and try to go to sleep but I can't, but it feels like I'm asleep but I'm daydreaming. ... Mostly I

daydream about seeing my Aunty 'cause sometimes I think about my Aunty 'cause she lives in Australia. Like I used to live with her, and then we came over here."

C9 (11years) could clearly see herself on the rides in Disneyland, where she had been prior to the onset of her illness. There was also some imaginative thinking involved for her:

"I imagine I'm going to win a million dollars. ... Go to Disneyland or something. ... I just think about being in places like Disneyland, and. ... I think about being on the rides in Disneyland."

C9 described spontaneously using different levels of trance through her visualizations, and also said that she used this technique each time it was sore.

C7 (8 years) also used fantasy, and had spontaneously developed a way of inducing trance. His mother had taught him a deep-breathing, relaxation technique which he mentioned several times. He had extended that technique to include hand rituals which he had learned from watching the "Karate Kid", and although he found it difficult to describe, the deep-breathing, hand rituals, and fantasy centred around the "Karate Kid" enabled him to induce a trance to relieve his pain. Another technique he sometimes used when he was sore was to *"imagine watching violent movies."*

Several children described focussing on something to the point of inducing trance. For two of the children, the point of focus was the posters on their bedroom walls. For example, while lying down in her bedroom to relieve pain, C10 (10 years) said:

"Sometimes I draw, or I count how many posters are on my wall. ... I just forget about lying on my bed and feel like I'm standing up counting them and putting them up on my wall."

C3 (11 years) counted the posters on her wall while she was doing painful exercises, and thus was able to continue with her exercises. The cognitive focus was therefore elsewhere, and painful exercises (and/or blood tests) were continuing at a less focussed level, i.e. attention was diverted from the pain and focussed elsewhere.

In summary, this group of strategies, "thinking about something else" had the effect of diverting the children's attention away from their bodies and their pain, and children focussed their attention on pleasurable events, fantasy, or more tangible points of focus. These strategies were often used alongside behavioural strategies, such as resting. The children indicated that the effectiveness of these strategies occurred because it stopped them from thinking about the pain. Several children also described varying levels of trance. Half of the total number of subjects (five children) contributed to these descriptions, whereas almost all of the children described cognitive-behavioural distractions. The five children who described these strategies had all experienced onset of their conditions within the previous two years, rather than having life-long painful symptoms.

THINKING ABOUT GETTING BETTER

Three of the children described focussing their thoughts on getting better. Their attention was diverted from the pain, onto positive outcomes of their condition. There was little similarity of external context between these three children, and length of time since onset had varied widely, as did their ages. None of these children had inherited genetic disorders. The contexts which the children described were, that this strategy was employed in relation to very severe, unremitting pain, or there was an element of acute exacerbation and/or acute onset associated with unknown causes and outcomes, so that this strategy was an alternative to catastrophizing. That is, the context in which the strategy was employed was similar to that of catastrophizing, but the way of thinking and the perceived consequences of the strategy were very different. The consequences of the strategy of thinking about getting better were that attention was diverted away from the pain and the possiblity of negative outcomes, and the focus on positive outcomes contributed to feelings of control over illness, as well as the children attributing feeling less pain, or tolerating pain, to their own efforts.

C2 (12 years) believed that his thinking about getting better contributed to the effectiveness of the chemotherapy in the remission of his leukaemia, as well as which he had been taught a visualization technique (by one of his school-teachers), in relation to the "bad cells disappearing". He referred to earlier severe pain, when he hadn't known about visualization:

> *"I used to think of it (the pain) going away and that, and used to think the medicine was getting me better." Also, "Getting better, getting out of hospital, going to use my roller blades and stuff like that"* were recurrently used strategies described by C2.

Thinking about getting better was related to acceptance, tolerance for pain, and religious belief for C4 (12 years):

> *"Well I really feel like, I've got it (arthritis), there's not much I can do about it, so let's just bear the pain and get better soon. ... Like I believe in God, and I've always believed that God would cure me and so it hasn't been much of a problem."*

In response to the advice to the best-friend question, C7 (8 years said): *"He could think he's going to get rid of arthritis and he could think he's going to beat it, and other things."* which suggested that thinking about getting better was associated with attempts at being in control over pain and condition.

In summary, thinking about getting better was described in similar contexts to that of catastrophizing, i.e. severe, unrelenting pain, and/or acute onset. Instead of the feelings of loss of control associated with catastrophizing, thinking about getting better represented attempts at regaining and maintaining control. Consequences were that children attributed feeling less pain, and/or positive outcomes to their own efforts.

NOT THINKING ABOUT IT

Children described a cognitive strategy which included "keeping their minds off pain", and "not thinking about it", which indicated that they had spontaneously developed their own variations of the cognitive technique of thought-stopping. This was a first response and initial choice of strategy when tracking into their "worst pain" for two of the children, although many of the children included this as a strategy. There was a close link with the cognitive strategies described above, and the children often described moving on from "not thinking about it" to "thinking about something else". Not thinking about the pain was viewed by the children as providing some relief of pain, i.e., children said that thinking about it makes it worse, and not thinking about it makes it go away.

> *"Usually not think about it, think about something else." "Also, keep your mind off it and try and take control over it." "Keep your mind off it whatever you do, 'cause when you think about it, it's worse, much worse, ten times worse."* C2 (12 years).

> *"I just don't think about it."* C3 (12 years) when legs sore and aching.

These same two children also described infromation-seeking in similar contexts to not thinking about it (refer Chapter Nine), and the relevance of this is elaborated in the Discussion.

Advice to best friends was often not to think about it, although C8 said that for himself, he just tolerates pain:

> *"Well, I can't really say, because I'd just, I just take it. I tell them to keep their mind off it is really all I can say."* C8 (13 years).

> *"Don't think about it (the pain), and to go and do something else."*C9 (11years) in response to projective question, and in relation to herself: *"Ignore it (the pain), so it doesn't come back."*

As well as perceiving that this strategy helped to relieve the pain, some children described feelings of being in control related to their ability to "ignore" or "not think about" the pain. There was a relationship between children's descriptions of using this strategy and length of time since onset, with all of the children who described this strategy in relation to themselves having experienced onset of their conditions within the previous two years. C8 (who had an inherited genetic condition) provided an indication of the changing process over time, when he said that he "just takes it", i.e. he tolerates pain, but he would advise a friend with sudden onset to "keep their mind off it".

SUMMARY

The common thread which linked these strategies was that pain was relieved by the children's attention being diverted from the pain, and that feelings of being in control over the pain were related to ignoring the pain, rather than addressing it as in the previous chapter. Children were almost always aware of the thinking (i.e.cognitive) influence over pain, and purposefully initiated strategies upon which to focus their thinking, and which held their attention and interest. Cognitive-behavioural distraction was utilized by almost all of the children, and was associated with all of the stages of **getting used to living with pain**. The cognitive attention diversion strategies were described by children who had onset of painful conditions within the previous two years. The process of **getting used to living with pain** was evident, as tolerating pain and minimizing pain was described by children who had experienced very long-term pain, although they recognized the value of thought-stopping type strategies for other children. The experiential process of **getting used to living with pain** linked the use of attention-diversion strategies to behavioural strategies of regulating activity and resting, and children developed their own preferred distraction strategies in view of what they found to be most effective.

CHAPTER TWELVE

Ways of Being

This selective code consisted of children's descriptions of how they perceived themselves to "be". The content of the semi-structured interview did not initially intend to address these issues, but the early analysis of data indicated that these "ways of being" interacted with the use of coping strategies, both as conditions for the use of coping strategies and consequences of the children's use of coping strategies. Subsequent data collection and analysis confirmed the necessity of including **ways of being** as an integral part of the process of **getting used to living with pain**, because of the interactions with the use of coping strategies and also because these ways of being represent feeling states that are constituent of that process. As with any process, children found their own unique order of visiting and re-visiting the stages, or feeling states, and the order presented here was the most common, taken from an integration of the data. The children's perceptions of coping outcomes also contribute to these feeling states, and there is some overlap with perceptions of effectiveness from previous chapters.

Axial Codes:

- SCARED/AVOIDING
- UNDERSTANDINGS
- CONTROL FEELINGS
- ACCEPTANCE
- FRUSTRATED

SCARED/AVOIDING

- **Not wanting to remember**
- **Scared**

These feeling states were described in relation to acute onset of very severe pain, remembering back (or not wanting to remember back) to very severe episodes, and unknown or feared causes and outcomes. There was a close relationship with catastrophizing, lack of information, and severe pain. Some children clearly stated that

there were severely painful episodes that they did not want to remember, while other children said that they could not remember severely painful episodes:

*"I can't remember 'cause it was quite a while ago." "I can't remember it."*C1 (10.5 years).

"When it happened (the embolus causing pain), the night after the operation. Just that night, I don't want to think about it." C3 (12 years).

Another child described how she had used avoiding as a way of being, because of her fear that she had a terminal condition inherited from her father, until it was confirmedthat she did not have this condition:

*"When, before I didn't know what it was, I thought I had the thing my Dad had, but I didn't like people reminding me about it, I just liked to forget about it and go on until they did know what it was."*C10 (10 years).

Being scared, frightened and nervous was closely related to not wanting to think about it, because the pain and possible causes of the pain were too frightening to think about:

*"When I came home from hospital, a week later it was sort of blotchy, huge, swollen (her leg). I couldn't really walk on it properly. I was really scared because I didn't know what was happening. ... Like I had an idea that I had to go back in to hospital and I didn't want to believe that."*C3 (12 years).

Children described how they became less nervous and less scared over time as they became more experienced at managing their pain (got used to living with it), and were provided with accurate information:

"Over the last few months I've gone better with it, I know how to handle it and I know more about it. Like a few months ago, or like a year, I didn't know much about it, I didn't know what it was and I was scared and nervous and I didn't know how to handle it ..."
C10 (10 years)

C10 then went on to describe how she uses coping strategies, and the same pain feels different because she knows what to do:

"Like it hurts the same and it's the same, but it doesn't feel like it, but it is ... I feel better but like the pain doesn't, but I do."

These statements exemplify the process of **getting used to living with pain**. Children who had experienced life-long pain didn't remember back to being scared, but retrospectively described the need for accurate information at earlier stages of their illness, especially in relation to pain-producing interventions.

In summary, there were two major aspects to this way of being, firstly there was being scared and frightened because of extreme severity and/or acute onset of pain,

along with not knowing what was happening. Secondly, not wanting to think about it (i.e.. avoiding), was an extension of the coping strategy of not thinking about it, and served to divert the children's attention from thinking about how scared they were, and the severity of pain. As well as being associated with relatively early onset, not remembering was a useful life-long strategy which served to remove the children from thinking back to severely painful episodes, so that this stage could be re-visited in a different way. That is, children's way of being at a later time could be to "not remember", without the associated feeling state of being scared. For example, C1 used appraisals which altered the perception of pain in relation to his current pain (refer to acceptance stage), while "not remembering" back to previous severe pain.

UNDERSTANDING OF PAIN/CONDITION

- **Expression of pain**
- **Understandings of causes**
- **Psychological implications**

Understandings of the causes of pain altered over time, and as understanding and knowledge increased, being scared, nervous and catastrophizing decreased.

Expression of pain

Using pain descriptors and describing their pain sensations enabled the children to communicate with parents and professionals about their pain, and thus was closely linked with help-seeking, and increased understanding as information and help was provided in response to expressions of pain. The range of responses from parents to communications about pain were nurturing, physical and behavioural interventions, and the seeking of professional consultation. Some children described coping strategies that had been taught to them by their parents.

Children clearly distinguished between different severities of pain, used descriptive adjectives to do so, and described variability in their pain:

> *"No it doesn't happen every day, sometimes it can happen for days in a row and all that, but other times it doesn't really. ... It's not sore every day, but it does get very sore."*
> C5 (10.5 years)

Extreme severity was often described as "really, really sore", and C10 (10 years), described the difference between the sort of pain that she was able to "keep going" with, and more severe pain that required intervention:

> *"Like most of the time with a little bit of pain, I do that (keep going). When I get really sore, the pain, the pain comes in, the pain strikes out in my back ... and I get really sore."*

Children described different severities and intensities of pain over time, and in different instances:

*"Well it's just the same really, or sometimes it gets worse than other times. It was really, really sore about a week ago."*C9 (11 years).

Children used words to decribe different pain sensations:

*"Crushing, pushing."*C2 (12 years).

"wouldn't be just short, sharp kind of ... and it feels as if it's getting pushed out of place." C4 (12 years) was describing very severe pain.

"I just tell her it's aching, or I'm getting shoots up the back of my leg ... shoots of pain going up the back of my leg." C9 (11 years).

One child used an analogy for earlier pain from cholecystitis:

*"like a knife digging into you, or something."*C3 (12 years).

Children sometimes described pain in terms of the severity of pain inhibiting their mobility and limiting their activities:

*"Like if I'm, walking somewhere, sometimes it just comes and it really hurts, and I couldn't walk."*C9 (11 years).

"The next day when it was really sore, and I couldn't walk around." C2 (12 years).

Several children who had severe arthritis had limited mobility and did not describe pain in this way. The youngest child (C6, 7.5 years) used less descriptive terms, and did not describe different severities in retrospect, but was able to describe *"sometimes I have sore bits"*,and clearly demonstrated which of his ankles was currently the most sore.

The tendency for children with long-term pain to increasingly use minimizing descriptions has already been described, and this was part of increasing tolerance for pain. Some children described how they filtered their expression of pain, i.e. they could choose to minimize, not express, or describe fully the extent of their pain, depending on the social context they were in. They described having developed a knowledge of context, and whether it is appropriate to express pain to this person in this context:

*"I don't ever tell the teacher unless it's really, really sore, and like if I can't do something, if she sets us something to do, and I can't do it ... then I just go and tell her."*C9 (11 years).

*"If someone asked me how my arm was and it felt like that (niggling, everyday sore), I'd say it was fine, 'cause what else can you say?"*C8 (13 years).

Negotiated meaning around this statement indicated that it was easier to say "fine", than to enter into explanations of the continuing everyday pain that he was used to and could tolerate, but that was still pain.

Understandings of causes

Children's increasing knowledge about causes of their pain came from information provided to them by parents and professionals, and their own experiential knowledge of what sorts of activities had exacerbated their pain in the past. Increased understanding of antecedent exacerbating events (and pathological processes in some children) led to self-management of physical interventions, regulating activity, resting and the use of other coping strategies. Cognitive working through often mediated this relationship. Feelings of being in control and "knowing what to do" resulted from the cognitive working through, increased understanding, and initiation of coping strategies. Much of this data has been described alongside the related coping strategies (refer cognitive working through), but some examples of causal links will be quoted.

> *"Well I think it's the joints when they get tightened up, squeezes too hard ... I lie down. Try and squeeze my stomach to get rid of it."* C7 (8 years), indicated some idea of internal pathological process, and using behavioural strategies to try to relieve pain.

C8 (13 years) described his experiential learning related to cognitive working through of his symptoms:

> *"I mean if it was a hot day it would feel better, but it's actually doing a lot more damage. Your feet get hot and that makes it bleed and they swell up, but if it was a cold day you probably wouldn't get any problems, but I'd feel every little bit that was sore because it was cold."*

A consequence of increased knowledge and understanding from experiential learning was also the initiation of prevention strategies:

> *"I don't do anything that really makes them have bleeds."*

C8 also illustrated the learning process over time:

> *"Well I wasn't as much aware of my problem (when younger). I can only think that, 'cause Mum hasn't really told me, but I saw it in a school report of J1. It's really old, no J2, I think, and it says he takes a big interest in physical education and loves physical education, but now I'd never think of doing that because of the risk it would have."*

Several of the children with arthritis described using hot baths and showers prior to undertaking their daily activity, as a way of loosening up so that their joints did not become painful during the day,i.e. a prevention strategy:

*"I have a shower in the morning to get me going and at night to rest. ... Sometimes when Mum goes to work in the morning I get up at 6.30 and muck around, and run a bath, and stay in that 'till 7 o'clock, and then I start getting ready for school."*C5 (10.5 years).

Children showed varying degrees of awareness of pathological processes, but as has been described earlier, the main thrust of their concern was in sorting out what activities may exacerbate or alleviate their pain,i.e. aspects that were able to be controlled by them. There was less emphasis on the internal pathology which was much less directly accessible to them. In all of these instances, children had been given information about their diagnosis. However, in the instance where diagnosis had been uncertain, there was greater concern with pathology. Accurate information about likely outcomes was more important than the mechanisms of pathology to the children.

Understandings of psychological implications

Children's understandings sometimes extended to include an awareness that pain may be exacerbated by emotional upsets (described earlier), and also that the experience of pain has an effect on the person's interpretations of events around him. For instance the response of C8 (13 years) to the projective question was:

"If you saw them like that you'd probably say, what's the matter? But I'd probably get mad if someone said what's the matter and it's obvious what the matter is. You're sore aren't you. But it's just normal for people to say what's the matter, and probably what I told you before I'd just tell them to take it easy and that. But you don't normally talk to them because they don't listen when they're sore like that, you just wait until they calm down if they're crying or something."

There was an awareness that people in pain may not be able to listen, may react differently than they usually would, and that it is important to judge whether to approach the person, or give them space.

C2 (12 years) described how situational factors had come to be associated with pain for him:

"I hate Room Nine because I associate that with pain, 'cause I was always in there when I had the osteomyelitis pain."

C2 was referring back to a time when he had severe, unrelenting pain and the diagnosis was uncertain, and from his present understandings described the psychological implications of the context in which that pain was experienced.

In summary, the children's increasing understanding and experiential knowledge of how pain became exacerbated, and what to do to prevent or relieve pain, initiated increased use of coping strategies, and led on to feelings of being able to control pain.

CONTROL FEELINGS

- **Feelings of being in control**
- **Limitations to control**
- **Had enough**

Knowing what to do, and describing the effectiveness of coping strategies which they utilized indicated that the children felt they had moved on from the scared early stage of the process of **getting used to living with pain**. Whereas lack of control, uncontrolled pain, unknown outcomes and fear characterized the earlier stage, feelings that they knew what to do, and had ways of "beating it" characterized this stage.

Some children also described realistic limits to the amount of control they had over pain, alongside their feelings of being in control:

> *"Yeah, you're the boss, the pain's not the boss. But you feel sometimes that it is the boss, 'cause you want it to stop, but it just keeps going."* C8 (13 years).

C9 (11 years) described feelings of being in control over the pain, but the worst pain for her was:

> *"The one that comes up the back of my leg, 'cause you don't know when it's coming."*

The unpredictability of the pain reduced her feelings of being in control over it, and one of her ways of maintaining control was to:

> *"Ignore the pain so it doesn't come back."*

Feelings of being in control resulted from the use of many of the coping strategies described and data quoted in previous chapters: powerful self-talk; positive self-talk; regulating activity, rest; and self-management of physical interventions. The most common thread that linked through all of the interviews was that children regained and maintained control over the pain by cognitive working through of previous pain experiences, increasing understanding of their pain and condition, and the use of several coping strategies which they had found to be effective. That is, knowing what to do, and having had effective experiences at doing it, most clearly resulted in feelings of being in control. This was also related to being used to pain:

> *"If you're used to having pain it's much easier, but if you're not then its' hard ..." "(it's easier) 'Cause you're used to the pain ... yeah you get to cope with it a lot more when you're older 'cause you've had it for your life so you know what to do."* C5 (10.5 years) then went on to describe resting, taking panadol, and using distractions such as computer games and watching television.

Awareness that there were limits to their control over pain arose from the severity and unpredictability of some exacerbations, which could not be attributed to antecedent events.

Had enough

A stage of having had enough is tentatively included which could occur when a child was in the process of becoming used to pain, but the pain became so severe, constant and unrelenting that their efforts at control were to no avail. C5 implied that he knew what it was like to have "had enough" (refer to section on catastrophizing), but neither he nor the other children directly described this. A feeling state of "having had enough" and "not coping anymore" may also have belonged to the realms of "not wanting to remember". The sense that I gained from the children was not that they had not developed and utilized coping strategies, but that the pain had become too overwhelming at times since they had got more used to pain. For instance, C7 (8 years) described using a variety of coping strategies, both cognitive-behavioural distraction, and cognitive attention diversion. However, he had told his mother in the past that he wanted to die to get rid of the pain, and most recently his mother described that he was again becoming overwhelmed by the pain, although at the same time had been telling his physiotherapist about the variety of coping strategies that he could use to manage pain. The analysis of negative instances illustrated the impact of all of the contexts. He had relatively recent onset (within the previous year), had very severe, constant pain, was one of the two youngest children in the sample, and had not described getting used to pain. Situational contexts were also impinging, because there was a lack of extended family in this country, a parental separation, and he did not know what future level of physical activity he might regain.

The "not wanting to remember" aspect of these very painful and difficult times for the children were likely to have contributed to the lack of descriptive data. The data is scant for this stage of "having had enough", and partly comes from the parents. However, in view of the parent provided data revealing that two of the children had said in the past that they wanted to die because they had had enough of the pain, the importance of documenting this becomes obvious.

In summary, feelings of being in control of pain resulted from the previous stage of increased understanding and experiential knowledge, as well as relationships with increased use of coping strategies which were all a part of the process of **getting used to living with pain**, so that children felt that they knew what to do about pain, and could handle it. Realistic limitations to feelings of control were also described alongside the feeling that children knew what to do and could control pain. Extreme feelings of loss of control (having had enough) could occur when children's efforts at coping became overwhelmed by the severity and unremitting nature of their pain.

ACCEPTANCE

This was related to increasing tolerance of everyday pain, along with the increased feelings of control engendered by the perceived effective use of coping strategies. Several children indicated that living with pain was part of their lives, and there was a continuing level of pain that they tolerated while they carried on with as near normal life as possible. All of the children described increased tolerance for pain over time (i.e. they got used to pain), along with increased experience at using coping strategies. Because of the intermittent and variable nature of the pain which many of the children experienced, their acceptance included this variability of not quite knowing how severe their pain was going to be each day, and of limiting their activities in order to prevent exacerbations of pain.

A close link was described earlier between increased tolerance for pain leading to positive self-talk, i.e. the child telling himself that he can manage pain because he is used to it, and subsequent feelings of being in control leading to acceptance. That is, acceptance of pain lead to the effective use of coping strategies and further acceptance.

In summary, acceptance was closely linked with the perception of knowing what to do to relieve pain, having effectively done it, and therefore knowing that they could manage pain. Increased tolerance for pain, that is, being used to pain also contributed to acceptance. Children also described being transitional between acceptance, and being frustrated with both the pain and aspects of their condition which impacted on their lifestyle.

FRUSTRATED

- **Feelings of differentness**
- **Limited activity**
- **Reactions of adults**

Children described aspects of living with pain that frustrated and annoyed them, although they described having got used to pain. That is, an integral part of the overall process of **getting used to living with pain** was that frustrations and annoyances existed alongside acceptance and tolerance for pain. These were individual and unique for different children (and not always explicitly described). However, some themes emerged.

Feelings of differentness

Several children indicated that they felt different from other children because they were used to pain, knew what to do to manage pain, and were somehow "tougher" than other children. They indicated that they felt it was acceptable for them to be different in

this way, but not too different. Feelings of not wanting to be different from others therefore impacted on decisions about expressing pain, and also at what point to stop and rest during a group activity with peers. There were close links between regulating activity and feelings of differentness. One child clearly described how he balanced the decision as to whether his pain was severe enough to stop and intervene, or keep on going so as not to be different from his peers, or a burden to others. Changes over time, perceived to be in relation to his age were also described by him:

> *"But when I'm with someone else, you don't want to be a burden to them, and say I have to go home 'cause I'm really sore, so you don't want to go and ask them, but if it was really bad I would." "Well if it was really bad, when I was litle I used to hide it, but now I don't care, I just tell them it's sore. But it's quite hard because if we're out at Petone or something and then if you have to come all the way back to get treatment it's a bit of a pain."*
> C8 (13 years).

Other children were less articulate about these feelings, although it was a theme for most of the children that they wanted to do as many things similarly to their peers as possible. The overall finding of the interview with C1 (10.5 years) was that his major coping strategy was to lead as normal a life as possible and to appear as little different from his peers as possible. He achieved this by minimizing pain and increased tolerance for pain. C9 (11 years) balanced the activity that was being required of the class with the severity of pain she was feeling, and then decided whether it was necessary to tell the teacher and be exempted from an activity, i.e. if there was a need to be treated differently from her classmates.

C7 (8 years) indicated some feelings of being different, and how his lifestyle had changed over the nine months since the onset of his condition:

> *"Well sometimes, I just don't feel used to going outside any more, so I don't do it."*

This was referring to lunchtime activities at school, and the alternative to going outside was activities such as story-writing and maths. As well as the physical limitations of his condition, C7 was getting less used to peer-interactive playground activities. The interview did not assess the degree to which he needed a wheelchair, and the availability of ramps.

Feelings of differentness were often addressed with the help of supportive parents, e.g.the father of C4 accompanied him on a school camp and tramp, and the parents of C1 were helping him to organize friends to visit to play board games in the school holidays.

Limited activity

Having to limit their activity in order to prevent pain or to relieve pain (and/or to manage their condition) was described by most of the children, and this has been

described under the coping strategy of regulating activity. Most often, limiting their activity was described matter-of-factly, although there was reference to balancing stopping with not feeling too different. Sometimes, frustrations also arose directly from having to alter or stop a desired activity. C9 (11 years) felt *"annoyed.."*when the pain came back quite severely the previous week because she had wanted to run in the school cross-country. Because her pain had been better for several months, she had tested her body to see what would happen, and it was a source of frustration that she was unable to run.

C2 (12 years) also described transitional feelings between knowing he had to limit activities, and wanting to do things. Relatively soon after his onset of pain and diagnosis of leukaemia, he wanted to go roller-blading:

> *"but Mum went no, no, no, next thing you know you'll be in hospital with a broken leg or something. But if she keeps thinking like that I'll never get to go."*

It was a source of frustration for C3 (12 years) that she had been unable to continue with her Jazz Ballet, and six months later, at the time of feeding back her reactions to the follow-up letter she had become more frustrated by this. She had recommenced Jazz Ballet, but in a limited way and was unable to sit examinations or dance at her previous standard.

For C8 (11 years) his source of frustration was *"feeling useless"* because he was unable to help his mother enough around the home.

Reactions of adults

Adults who misunderstood the children's conditions and over-dramatized them, or professionals who provided them with misinformation, or lack of information, were a source of frustration for some of the children. It was only two of the older children who described these events and frustrations, but they are included as examples of what can happen in the lives of children experiencing pain.

One child described that earlier in the course of his diagnosis and treatment (prior to his getting used to pain), he had intravenous lines replaced several times, and was told there was nothing to ease the pain:

> *"Yeah they used that emla cream (topical anaesthetic cream) after I got told by another patient. They wouldn't tell me about it. I said is there anything to make it go numb or something and they said no, no, no, and then I found out from this other sick boy ..."*
> C2 (12 years).

A frustration for C8 (13 years) with Haemophilia was that as he increasingly self-managed his condition, had minimal school absences, and tolerated an everday level of pain, his pain had become invisible.

"Yeah it gets sore, but it's inside so no-one can see it." "But they don't know what happens once you get home, I mean how much you've got to ..."

He found it acceptable for peers not to be aware of what went on for him, but misunderstandings by school-teachers frustrated him. In one instance a woodwork teacher had initially over-dramatized his condition, and told the class at the beginning of the Form I year

"If you touch this boy he could die" "and then now he thinks it totally nothing and he's changed it" and the teacher continually asks C8 why he is not wearing regulation shoes.

In summary, children experienced frustrations alongside acceptance, and the most common frustrations were limitations to their activity, feelings of being different from their peers, and misunderstanding by adults or misinformation provided by them. To balance the description of misunderstanding by adults, another child (C10, 10 years) described how important "cuddles" were for her when she was sore, and her school-teacher cuddled her when she was sore at school.

SUMMARY

Ways of being are feeling states which the children described, and they also represent the stages that constitute the process of **getting used to living with pain**. Other feelings states also existed, but those included above were found across children and represent an integration of the children's data. Individual coping strategies cannot be viewed as specifically occurring at certain stages of the process. This is because of the other contexts which impacted on the children's use of coping strategies, as well as the situation-specificity of their use. However, some strategies were more likely to occur in relation to certain contexts, and at earlier or later stages in the process of **getting used to living with pain**. The following chapter discusses some of the predominant patterns of use of coping strategies that were associated with various stages of the process of **getting used to living with pain**.

CHAPTER THIRTEEN

Integration

This chapter will integrate some of the patterns of use of coping strategies that were found to be associated with different stages of the process of **getting used to living with pain** The data has already been presented in relation to the use of specific coping strategies, so the following integration will be relatively brief. The early, middle, and later stages described in this chapter denote the manner in which the ways of being overlap as the process evolves. For instance, control feelings occur in the middle stages and are maintained in the later stage. The impact of contexts has been addressed throughout the findings, but the context of severity of pain impacts markedly on the process, and has been included in this discussion. The second part of the chapter will document the feedback of participant children and their parents to the summary of findings (refer Appendix 7).

EARLY STAGE

The earlier stages of the process occurred around the time of acute onset, and some children's data did not contribute to this because they had experienced pain for all of their lives. Coping strategies that were likely to be utlized included showing distress, catastrophizing, not thinking about it, beginning to cognitively work through events (which altered and expanded with subsequent experiential knowledge), learning to regulate activity, and physical interventions. Information-seeking was described sometimes (and could occur alongside not thinking about it), but the need for accurate information was retrospectively described more often. Children began to use cognitive-behavioural distraction strategies relatively early in the process, and not thinking about it was also likely to occur early. Feeling scared and frightened was described as their "way of being" at this stage. Attempts at regaining control were also likely to occur,i.e. "think you`re going to beat it".

The example provided by C3(12 years), illustrates the sort of coping strategy search and experiential learning of coping strategies that occurred in this early stage:

> *"The second time I went in I had the hurt. I had this needle put in my foot 'cause they had to put dye up my leg and it really hurt in my foot. ... Yeah, you could feel the dye going up and it was really cold and I was really scared then too. ... I was trying to keep calm, 'cause like I was crying. It was really sore and stung ... I would just say it will all be over in a minute, so I was squeezing Mum's hand and that sort of took a little bit of the pain away ... I did that when I have my blood tests too ... Yeah, and when I have my blood tests I sort of have to concentrate on something else, like talk to my Mum or something."*

Being scared, initiating cognitive and behavioural coping strategies, and experiential learning about their effectiveness informing the subsequent use of coping strategies is also illustrated in the above quotation.

MIDDLE STAGES

The middles stages of the process of **getting used to living with pain** included increased understanding of their pain and condition, experiential knowledge about the antecedents of exacerbations of pain, and feelings of knowing what to do and being able to control pain. As feelings of being in control increased, feelings of loss of control decreased, and catastrophizing was not likely to occur at this stage. Coping strategies that were likely to be utilized were, regulating activity and increasing self-management of physical interventions. Children also increasingly used all of the cognitive-behavioural distraction strategies and cognitive strategies which diverted their attention from the pain. Children said they had become used to pain, and described increased tolerance for pain. Help-seeking altered as children more clearly described different severities of pain to their parents, became increasingly tolerant of everyday "little bits" of pain, and matured or became older. Expressions of behavioural distress therefore became less, both in relation to increasing tolerance and increasing age, and were replaced by seeking nurturance and social contact.

C10(10 years), described what she currently does in order to manage pain that is too severe to keep going:

> *"like putting a sad face on and going up and telling Mum and then going down to my bedroom and lying on my bed and watching T.V. ... Sometimes I'll go back up to Mum and say it's really sore and she'll give me someting for it and it'll go away, sometimes it doesn't ... watching T.V. takes my mind off the pain. ... Sometimes I draw or count how many posters are on my wall ... I just forget about lying on my bed and feel like I'm standing up counting them and putting them on my wall."*

LATER STAGES

The later stage of the process included acceptance of their pain and condition, and also the acknowledgement of frustrations. There was a lifetyle attitude that their "way of being" was to tolerate a "little bit" of pain most days of their lives, and to live their lives as near normally as possible within the necessary adjustments to their activities. For example:

> *"But now I'm used to it, so it's just sore, I mean I know it's sore, But I'm just used to it, that's all."* C8(13 years).

Positive self-talk, minimizing of pain, and using positive re-frames were likely to be used as cognitive coping strategies which addressed pain. Cognitive-behavioural distractions, regulating activity, self-management and cognitive working through continued to feature as coping strategies. Although children felt as though they were able to be in control over pain, they were also aware of limits to the amount of control they had, which arose from experience with severe exacerbation. In one instance, there was a low number of coping strategies described, and reliance on minimizing pain, increased tolerance for pain, positive self-talk, and getting on with life.

The contexts that impacted on the process have been described alongside the relevant data. However, severity of pain had a notable impact on which coping strategies were likely to be utilized, and this was described by the children. Acute exacerbations of pain that were extremely severe and constant also impacted on the overall process, i.e. both the use of coping strategies, and the child's way of being. Behavioural distress and catastrophizing could re-occur. Children could also become overwhelmed, have "had enough", and parents described a despondent way of being. Two of the children had experienced this way of being, according to data provided by their parents.

Children also described the effectiveness of coping strategies during this later stage, in relation to very severe "worst" pains, particularly the use of strategies which altered the appraisal of pain, cognitive-behavioural distractions, regulating activity, re-positioning, and physical interventions. For example C4(12 years) described a combination of strategies related to worst pains which included **"thinking that it doesn't hurt"** playing computer games, re-positioning, massaging, and asking parents to read to him (quoted in previous chapters).

SUMMARY

Patterns of use of coping strategies that were likely to occur at various stages of the process of **getting used to living with pain** have been described. Some strategies, e.g. showing distress, catastrophizing, not thinking about it, and sometimes information-seeking were likely to be used near the time of onset. Other strategies occurred increasingly, and in a more informed way (knowing what to do) throughout the process,e.g. regulating activity, cognitive working through, use of cognitive-behavioural distractions and cognitive attention diversion. Other strategies tended to be used later in the process, e.g. strategies that altered appraisal and minimized pain, along with acceptance of pain and condition. Increased tolerance for pain (getting used to pain as the children described it), occurred from the middle stages onwards, and contributed to acceptance and a further sense of self-efficacy that children had the ability to utilize strategies and could manage their pain. Catastrophizing could re-occur

if pain became sufficiently severe and unrelenting. As with any continually changing basic social process, children found their own unique way of visiting and re-visiting the stages, depending on current contexts, including age/developmental stages and severity of pain.

The Responses of Participants to the Summary of Findings

The findings were conveyed to the parents and children in a summary letter (refer Appendix 7). It was intended that parents explain and discuss the letter with children, but in order to increase children's understandings, the detail of conceptual analysis was simplified and overviewed. Eight of the ten families were able to be contacted for a response to the summary of findings. Responses were sought from both children and parents.

All families responded positively, and made very positive comments about the depth of the findings, for example: "Felt that you've sorted it out well." Children said that they identified what they did themselves with what was stated in the summary. For example: "Some of the things were me, sort of." They were able to select out several parts that they especially identified with, and taken together, all of the coping strategies were suported by their responses. The use of distraction, keeping going, and testing their limits were specifically mentioned by the children, as was the need for parental support. Children again reiterated that they get used to pain.

Parents also stated that the children get used to pain, and get used to managing pain. Parents said that the coping strategies described were typical of the sorts of things their children did. For example, "Pretty typical for her." One mother emphasized that in the many years that she has had experience of her own child and other children with chronic pain, they do seem to develop their own "coping mechanisms ... each child intuitively gets on to their own thing." Other parents said that their children's ways of coping had changed since early onset. Parents also identified that lack of information had been an issue early after onset, and that professionals tended to communicate with the parents and not the children.

In summary, the descriptive findings and overview of the conceptual analysis were supported by the responses of the children and parents to the summary of findings. The conceptual depth of the changing process over time was not able to be conveyed in the summary of findings letter. However, the changes in children's coping strategies over time was supported by parents of children with long-term pain.

SUMMARY

An overall integration of the process of **getting used to living with pain** was described in the first section. The second section reviewed the responses of children and parents to the summary of findings. Children and parents supported the findings. Together the results chapters provide in-depth descriptive data and a conceptual analysis of children's use of coping strategies when they experience long-term disease-related pain. A local theory was generated from the children's data which describes and explains the process of **getting used to living with pain**. The following chapter discusses these findings and the local theory in relation to the existing pediatric pain literature and adults' chronic pain literature.

PART THREE

Discussion, Summary and Recommendations

CHAPTER FOURTEEN

Discussion

This chapter discusses the present findings in relation to previous literature on children's coping with chronic pain. In view of the dearth of literature on children's use of coping strategies when they experience chronic pain, the adult chronic pain literature is drawn upon in support of the process of getting used to living with pain that has been generated from the data. Firstly, the participant children's descriptions that they get used to pain are discussed in terms of subjective habituation. In the second section the changing process of **getting used to living with pain** is supported by several lines of research with adults and one study with children. The use of some specific coping strategies are also discussed in terms of selected pediatric adult pain literature. The third and final section presents the conclusions of the present study as it relates to the above literature.

GETTING USED TO PAIN

Almost all of the children described increased tolerance for pain. This has been termed subjective habituation to pain in adult pain research (Arntz, Dreessen & Merkelbach, 1991). Furthermore, children were able to describe how increased tolerance for pain was confounded with increasing age. That is, they described pain as bothering them less, both as they got used to it (subjective habituation) and as they got older. Similarly, P.A. McGrath(1993) described increased tolerance for injection pain in children who had previously experienced intramuscular gold injections. However, increased tolerance for chronic disease-related pain in children has not previously been reported. These findings are in contrast to the suggestion by P.J. McGrath & Unruh (1987), that habituation to pain does not occur in children.

In relation to acute pain, children's ability to tolerate pain has been found to increase with age (Lander & Fowler-Kerry, 1991), and there has been a recent suggestion that increasing age may be confounded with familiarity with an acute painful stimulus (Lander et al. 1992). The present findings are consistent with the suggestion of Lander et.al.(1992), and provide insight into children's experience of chronic pain and their response to repeated experience of pain. Of particular relevance to the Lander & Fowler-Kerry (1991) finding that the ability to cope may improve with repeated exposure to venipuncture, several children in the present study described subjective habituation to venipuncture, as well as changes in the types of coping strategies used after repeated exposure to this procedure.

It is important to note that the children were not directly questioned about being

used to pain, but that the phrase "getting used to pain" (or similar) was always generated by them. The analysis of negative instances should also be briefly noted, and the two children who did not generate descriptions of subjective habituation to pain (and also were not specifically asked about habituation), were the youngest two in the sample, aged 7.5 and 8 years. However, they both described lifestyle adjustments as part of the process of getting used to living with pain.

In summary, most of the children noted subjective habituation to pain, which they described as "getting used to pain", and included the chronic daily pain that they experienced, as well as repeated painful procedures such as venipunctures. Pain was easier to bear, both as they got used to it and as they got older. These findings are a new insight into children's experience of chronic pain, and are consistent with some recent findings in relation to acute painful procedures in children.

THE BASIC SOCIAL PROCESS OF GETTING USED TO LIVING WITH PAIN

The content of the "local" theory which describes the process of how children who experience chronic pain get used to living with pain, builds directly on the preliminary suggestion of Smith et al.(1989) that children's coping strategies may change over time with repeated exposure to pain. In the present study, children did describe some individual preferences or coping styles, but also clearly described changes over time in the coping strategies that they utilized as they got more used to pain. The conceptual analysis of the contexts and contingencies of coping strategy use further supported the children's descriptions that their use of coping strategies changed over time.

In the Smith et al.(1989) study, preferred coping style (i.e., information-seeking or avoiding) was related to how long the children had their cancer, with avoiders tending to have been diagnosed for six months or less. In the present study, all of the children had experienced pain and been diagnosed for longer than six months. However, avoiding strategies, e.g. "not thinking about it" were described during the early and middle stages of the process. Quantitative time spans could not be reported because this was a combination of current and retrospective information described by the children. In contrast to Smith et al.(1989), information-seeking was also described during early/acute stages, and could occur **alongside** avoiding strategies.

Children retrospectively described the need for accurate information during earlier stages, particularly in relation to painful interventions that were supposed to "help". These findings are consistent with the suggestion of Smith et al.(1989), that in spite of using avoiding strategies during the early stages after onset of a painful condition, children are likely to benefit from the provision of accurate information both about their condition, and about their pain. In terms of the present findings, children moved

through the stages of the process as they regained a sense of control and perceived that they knew what to do. This resulted from their experiential learning, and the provision of information (when it was provided). Feeling scared, and catastrophizing about the severity of pain and possible outcomes of the condition decreased with the provision of accurate information and successful experiences at using coping strategies that relieved their pain.

The integration of data presented in Chapter 13 provided an overview of what coping strategies were likely to occur at different stages of the process in a broad sense, with the caution that the use of coping strategies is situation-specific and that children could re-visit the stages of the process in their own unique way, depending on contextual variables. In particular, the inductively generated theory and its constituent data described how the process of **getting used to living with pain** (i.e. the subjective habituation, the experiential learning, and the lifestyle adjustments), both informed the use of coping strategies and was a consequence of the use of coping strategies. This conceptualisation has broken new ground, and the present writer (in keeping with grounded theory methodology) undertook a late review of the adult chronic pain literature, in view of the lack of literature on children's coping with chronic pain.

Progression From Cognitive Diversion To Cognitive Attention Strategies

The progression from using predominantly avoidant and attention diversion strategies in the early and middle stages of the process, to strategies that addressed the pain (e.g. altering the appraisal and positive self-talk) with increased time since onset and in the later stages of the process, has been described in Chapter 13. Although outcomes were not measured in the present study, the theory which was inductively analysed from the children's data described a similar process in the "change in use of coping strategies over time", as was found to have positive adaptational outcomes in recent-onset and chronic adult pain patients by Holmes and Stevenson(1990). These authors found that **recent-onset** adult pain patients were more positively adapted when they employed primarily avoidant coping strategies. Adult **chronic** pain patients were more positively adapted when they employed primarily attentional coping strategies (e.g.,reappraisal, information-seeking).

Contrasts from the adult findings were also evident because as noted above, information-seeking could occur **alongside** avoiding strategies relatively soon after onset. Also in contrast to the findings of Holmes and Stevenson (1990), information-seeking was not evident in the children's data as a later part of the process.

Consistent with the findings of Holmes and Stevenson(1990), cognitive strategies that diverted attention from pain (e.g., not thinking about it), were perceived as particularly effective when the meaning ascribed to the pain and possible outcomes

were too frightening to contemplate or dwell on, for example an unknown but feared diagnosis of a terminal genetic condition, or relatively newly diagnosed leukaemia. The perception that these cognitive attention diversion strategies relieve pain is described in Chapter Eleven.

During the later stage of the process, acceptance was described as the children's way of being (refer Chapter 12). This was clearly related to both the use of cognitive strategies that altered the appraisal of pain and also a perceived consequence of these strategies, which is in keeping with the findings of Holmes and Stevenson(1987), in relation to adaptational outcomes in adult chronic pain patients.

These findings extend the data provided by Bennett-Branson et al.(unpub). These authors found that cognitive reappraisal, cognitive distraction and thought-stopping were the three types of cognitive coping most frequently recorded. However, in the theory generated from the present study, thought stopping was likely to occur at an early stage of the process, cognitive distraction during early and middle stages of the process, and cognitive reappraisal during the later stage of the process and in relation to acceptance of their pain and condition. These changes over time in children's preferred use of coping strategies cautions against typecasting children as having global coping styles, such as information-seeking or information avoiding (e.g.Peterson & Toler,1986).

Help-seeking,Social Support and Acceptance

Turner, Clancy & Vitaliano (1987) noted the importance of viewing coping with chronic pain (in adults) as a process, with different coping strategies used at different phases, although the detail of such a process has not yet been described. These authors found that seeking social support was more likely if adults had not experienced pain before, and suggested that seeking social support may be most useful in the early stages of coping with a pain problem, when uncertainty and anxiety were likely to be higher. Furthermore, acceptance of a pain problem and not believing that the pain required them to hold back from doing what they wanted was positively associated with problem-focussed coping and less seeking of social support. Turner et al.(1987) postulated that acceptance of the pain leads to less distress and thus less need for information or support.

In the children's process of **getting used to living with pain**, help-seeking and seeking social support were similarly described as being utilized in the early stages. It was then that being scared and not wanting to think about the pain problem was also described, along with some information seeking. However, seeking social suppport remained important for children throughout the middle stages of the process, and sometimes replaced the "showing distress" mode of help-seeking. Children's help-

seeking depended on contextual factors (e.g. severity of pain, specific situational context, and age), and tended to be replaced with self-management as they became older, more used to pain, and knew what would help from previous experience. Seeking social support has not been well documented among children. In the present study, children described seeking social contact with their friends and siblings as a specific coping strategy in response to pain.

Acceptance was found to be a later stage in the process of the children's **getting used to living with pain**, and was associated with less distress and less need for information. This is consistent with the findings of Turner et al.(1987). However, the acceptance stage described by the children was less clear-cut than Turner et al.(1987) implied in relation to adult chronic pain patients. That is, although acceptance was associated with less distress in the children's ways of being, frustrations could still exist alongside acceptance, for instance feelings of being different from their peers. The participant children's data also indicated that acceptance was associated with participating in as near normal activities as possible, as well as using cognitive strategies that addressed the pain (refer Chapter Ten). This appears similar to Turner et al.'s(1987) description of adults who believe that they don't have to hold back, and utilize problem-focussed coping in association with acceptance.

In contrast to Turner et al.(1987), children described the importance of feeling supported by their families throughout all the stages of the process of **getting used to living with pain**. This was particularly so during severe exacerbations. The preferred sort of social support was described as altering with age, and the presence and companionship of parents, siblings, and friends replaced "cuddling" and comforting as children got older. Two children described the importance to them of seeking social contact with friends as a specific coping strategy in response to pain. It is interesting to note that these were two of the three females in the sample. Although no conclusions can be drawn from these small numbers, Affleck et al.(1992) found that requesting emotional support was a more prominent tactic among adult women than adult men with chronic arthritis.

Consistent with the present findings, Jamison & Virts(1990) reported that adult chronic pain patients who described their families as supportive, reported significantly less pain intensity, less reliance on medications, and greater activity levels than adult chronic pain patients who described lack of support. This was in contrast to previous suggestions that a supportive family could be detrimental to chronic pain patients and interfere with adaptive coping, particularly if showing distress was reinforced. In the present study children perceived nurturance and support as being of major importance, not necessarily contingent upon expressions of distress. Ross and Ross(1988) similarly noted the importance of the presence of parents during acute painful procedures.

Feelings of Control

The situational appraisals of children that they were able to initiate strategies that could effectively control pain parallel Bandura's (1977) concept of efficacy expectancy (Folkman, 1984). Increased efficacy expectancy was described by the children over time, as they became increasingly adept at using the coping strategies they had developed, and experienced some relief of pain from the strategies they used. In Bandura's(1977) terms, "personal mastery experiences" raised the children's beliefs that they were able to initiate coping strategies that would relieve their pain. This was referred to as **increased perceived self-efficacy** in the present report.

Cognitive working through of antecedent events, regulating activity, physical interventions, and cognitive-behavioural distractions were particularly linked to perceived self-efficacy. Children's feelings that they were able to control pain arose from previous effective use of coping strategies (and also finding out what strategies were less effective for them), as well as increased knowledge about antecedent exacerbating causes. These findings are consistent with those of Bennett-Branson and Craig (in press), that stronger perceived self-efficacy has a positive relationship with less reported pain in children. The present findings also extend the knowledge base by describing the way in which increased perceptions of self-efficacy facilitated children's use of coping strategies.

These findings are also consistent with Folkman's(1984) conceptualisation that appraisals of control can alter as an encounter unfolds. The overlap between appraisal and use of coping strategies, and how they interact with each other, described by Folkman (1984) was evident in the present descriptive data and conceptual analysis. For example, children described how they were less scared by the pain because they had found ways of managing it, so then it seemed less sore (refer Chapter 12). Experiential learning to use coping strategies which relieved pain and increased perceived self-efficacy impacted on subsequent appraisals and use of coping strategies. Increasing tolerance for pain also impacted on both appraisals and use of coping strategies. The adult findings of Litt(1988) support the concept that perceived self-efficacy plays a mediating role in the increasing tolerance of a pain stressor.

The changing process of **getting used to living with pain** that was generated from the children's data, was consistent with Folkman's(1984) concept that the process of coping changes over time. Changes in the use of coping strategies interacted with changes in appraisals and the perceived consequences of feeling as though they were able to control pain, and all facilitated the children's moving through the stages of the process (refer Chapters 12 and 13).

Children described feelings of being able to control pain alongside the expression of realistic limitations to the amount of control that they perceived over the pain (refer Chapter 12). According to Folkman(1984), there is a greater risk of maladaptive

outcomes when the appraisal of control does not match reality. Again, the findings in the present study were that children described a mode of operating that has been documented in the adult coping literature as likely to be adaptive. That is, feelings of being able to control pain were described alongside an awareness that there were limits to their control.

Feelings of being able to control pain were not described in the early stage of the process, but increased in the middle stages, and were part of the impetus that moved children on from the early stage. Extreme feelings of loss of control over the pain were documented in relation to very severe and constant pain, but there was limited data to draw from.

Keeping Going as a Coping Strategy

"Keeping going" was described by almost all of the children, and as children's tolerance for their everyday pain increased, and they got older, keeping going became a part of their lifestyle. As well as a distractor from the pain, keeping going functioned to keep children involved with peers and social interactive activities, and so reduced or prevented avoidance behaviour. Feelings of differentness were also reduced by participating in activities and keeping going. Some of the older children were able to describe how the decision to keep going involved balancing "not wanting to appear different in the current situation" against the need to address the current severity of pain.

A prominent component of pain behaviour that has been found to occur in adults who experience chronic pain is that of avoidance (Philips,1987). Avoidance refers to extensive withdrawal from social interactions, as well as inhibiting movement, stimulation, and leisure pursuits. Philips(1987) proposed a model that described how cognitions produced avoidance behaviour, which in turn was a major contributor to chronic pain problems. It was suggested that the graded exposure to activity and social interaction (i.e. non-avoidance) entailed in behavioural treatment programmes was an important determinant of positive outcomes from treatment. The children in the present study generally did not describe this level of avoidance behaviour.

The children did however, describe graded exposure to activity, which they regulated themselves in view of their experiential learning of the point at which they should stop. The concept of regulating activity included keeping going, as well as stopping and resting, and keeping going served to maintain children's involvement and exposure to their world of school and extracurricular activities (similar to the exposure segment of behavioural treatment programmes for adult chronic pain patients). Keeping going is a coping strategy that has not yet been documented in any of the taxonomies of children's coping with pain, presumably because the taxonomies have not been based on children who experience chronic pain. Keeping going was utilized as a purposeful coping strategy because children made a conscious decision to use keeping going as a distractor,

or to stop and intervene (i.e. use an alternative strategy, refer to Chapters 9 and 10). P.A. McGrath (1993) suggested that parents who expected their children to live as normally as possible despite their chronic painful condition may assist their children in experiencing less pain.

Avoiding the pain problem and not wanting to think about it was described previously, as an early part of the process of getting used to living with pain. This was different from the extensive avoidance described among adults with chronic pain. However, children described some withdrawal from activities during the early stage of the process and during severe exacerbations. The analysis of negative instances should also be reported, and the one child who did not describe "keeping going" (and also did not use the phrase getting used to pain), also described withdrawal from peer interactive social activities at school. This child had relatively recent onset, and was experiencing severe and constant pain, and was one of the children who had told his mother in the past that he wanted to die (parent information). At the time of the interview he described using a variety of coping strategies. His mother reported that he was becoming increasingly accepting of his pain and condition at the first follow-up. However, most recently, when contacted for the purpose of feedback of findings, his mother was worried about his increasing withdrawal, and he was again becoming overwhelmed by the pain, and the unknown prospects for future physical activities.

One of the ten children therefore evidenced avoidance behaviour, as opposed to keeping going and maintaining peer interactive social contact. Avoidance behaviour could occur relatively soon after onset (within the first year), partly in response to lack of information and not knowing what the likely outcome would be in terms of the level of activity the child might regain. It could also occur as part of the despondence of having had enough of the pain. There was a lack of data around these concepts of despondence and avoidance. Most of the data described the concepts of experiential learning of coping strategies, getting used to pain, regulating activity (keeping going or stopping and resting), and an increased sense of self-efficacy that the children increasingly knew what to do and how to manage the pain. The overall process was one of re-integration into the peer interactive social world. The brief outline of the negative case analysis serves to explicate the theory further, in terms of both the process, and the contexts that impact on the process. In particular the contexts of severity, age, and time since onset were all impacting on the negative case, where "keeping going" was not described, and increasing avoidance was.

Impact of Contexts

The severity of pain had a major impact on the children's use of coping strategies, and different strategies were described as being used for different severities of pain. The impact of severity of pain on the use of coping strategies in chronic pain patients, both

adults and children has generally been neglected (Siegel & Smith,1991). Affleck, Urrow, Tennen & Higgins (1992) found complex relationships between severity of pain, use of coping strategies and positive mood in adults with rheumatoid arthritis. Severity of pain was found to be a moderating variable between use of specific coping strategies and outcome. Specific correlational relationships cannot be extrapolated from the present study, but the theory generated from the children's data conceptualises severity of pain as a moderating variable, both in terms of children deciding which coping strategies are likely to be most effective, their use of coping strategies, and impacting on current ways of being of the children and their movement through the stages of the process. Severity of pain impacted in conjuction with other contexts.

Children described age/developmental changes in their use of coping strategies, in particular reductions in showing distress, and an increase in self-management of physical interventions and coping strategies which they had learned through experience and further developed. No clear change from using behavioural strategies to the increasing use of cognitive stratgies could be extracted from the data. Children used both cognitive and behavioural strategies, and supplemented one with the other. Only one child did not describe using cognitive strategies, and he was 7.5 years old, and experiencing some developmental delay. The 8 year old child in the sample described cognitive strategies that diverted his attention from the pain.

Changes over time in use of coping strategies were described in relation to other contexts as well as age/cognitive development,that is, the overall process of getting used to living with pain (refer Chapter 8). In general therefore, the present findings are supportive that there are age/cognitive developmental trends in children's appraisals of pain and use of coping strategies (Craig & Bennett-Branson,in press). However, these trends are more complex than previously suggested, and long-term experience of pain impacted particularly on appraisals and use of cognitive coping strategies. Children retrospectively described appraising their pain differently when they were younger.

The limited age range of children in the present study does not allow for any conclusion about an age-related progression from behavioural to cognitive strategies. A child as young as 8 years of age utilized cognitive coping strategies, in contrast to the 7.5 year old who did not. Increased time since onset interacted with increasing age and was associated with alteration in the type of cognitive strategies utilized. The progression from cognitive strategies that diverted attention from the pain, to cognitive strategies that addressed the pain by altering the appraisals of pain and altered appraisals of efficacy at managing the pain, has been discussed above. It is important to note that catastrophizing, which is a strategy that addresses the pain (refer Chapter 10), is not included in this formulation.

The findings of the present study were consistent with the pediatric pain literature

that children can use catastrophizing in reponse to pain (e.g.Brown et al.,1986; Bennett-Branson & Craig,in press). However, the contexts of severity and constancy of pain, recency from time of onset, as well as unknown outcomes and fear of outcomes had not previously been described (refer Chapter 10).

Cognitive-Behavioural Distraction

The findings described the prevalence of use of cognitive-behavioural distractions throughout the process, and by almost all of the children. This is consistent with the pediatric pain literature, although it has previously been referred to as behavioural distraction (Bennett-Branson et al.(unpub; Bennett-Branson & Craig,in press). The consistencies in these findings dictate that the context of children's use of cognitive-behavioural distraction strategies should be further discussed.

In the present study, children described how their level of interest in the distractor and their degree of concentration influenced the degree of relief from pain. Children preferred to use different distractors, and this was related to their own interests, previous experience with their own range of distractors, and cognitive-developmental level. The concept of salience of the distractor encompassed their different preferences. However, severity of pain also impacted on the choice of strategy, and the effectiveness of the distractor. In some instances, pain became too severe, and other interventions (such as analgesic medication) were added to the distraction strategy. Watching televison was generally viewed as effective in relatively mild pain, and several children thought that playing computer games was effective at relieving more severe pain, although individual preferences were evident. Several children described cognitive distractions (concentrating on other things and visualization) as effective in relieving relatively severe pain. The importance of the salience of the distractor and the impact of severity of pain has not been addressed in the pediatric pain literature.

Cognitive working through, physical interventions, and regulating activity (either resting or keeping going), were frequently used alongside cognitive-behavioural distractions. The general relationships were that use of cognitive-behavioural distractions occurred throughout the process, although increased markedly in the middle stages, and were described with the authority of experience from the middle stages onwards. There were links with increasing tolerance for pain (subjective habituation), increased perceived self-efficacy that children felt they had the ability to initiate strategies to effectively relieve pain, and increased feelings of being able to control pain. That is, the increasing use of cognitive-behavioural distraction strategies facilitated the children's moving through the stages of the process of getting used to living with pain.

Recent findings reported in the adult pain literature bear direct relevance to the present finding of pervasive use of distraction strategies, and subjective habituation in

the present study. Arntz et al.(1991) found that distraction was related to ongoing habituation of experimentally induced pain. These authors suggested that attention-diverting techniques would be a powerful ingredient of psychological treatment programmes for chronic pain patients. In keeping with this sugggestion, almost all of the participant children described using cognitive-behavioural distraction strategies, and their increasing expertise at finding and using distractions which suited them has been described.

A difference from the results with adult experimentally induced pain, is that eventually (during the later stage of the process), although the children continued to use cognitive-behavioural distractions, their increased tolerance for pain engendered the use of strategies which did attend to the pain by altering the appraisals of pain, with perceived adaptive consequences (i.e., acceptance),as discussed above.

Children With Chronic Pain Do Use Coping Strategies

The findings from the present study were therefore similar in some respects to the Bennett-Branson et al.(unpub) study, which investigated the coping strategies of children with chronic arthritis. In both studies there was daily variation in the severity of pain described by the children, and all children who reported pain described active efforts to exert control over pain. However, increased tolerance, or subjective habituation to the daily experience of chronic pain was not described by Bennett-Branson et al.(unpub).

There was a wide variation in numbers of coping strategies utilized by individual children in the Bennett-Branson et.al.(unpub) findings. Similarly, there was variation in the use of coping strategies in the present study, which was explained in terms of the changing process over time, and the contexts. The exploration of contexts in the present study was able to explain one child's relatively reduced reported number of coping strategies. The perceived effectiveness of his use of minimization and positive self-talk, along with subjective habituation and a few behavioural strategies, were described alongside acceptance of his pain and condition and continued graded exposure to life's activities (i.e., adjustments to allow participation were a part of his lifestyle). There was apparently less need for a large variety of coping strategies during the later stage of the process of getting used to pain because of the effectiveness of the few strategies used, and acceptance of the pain and condition. The present study supports the suggestion of Bennett-Branson and Craig(in press), that perceived effectiveness of the coping strategies which the children have at their disposal may be more important to adaptational outcome than numbers of coping strategies reported. This is also related to the stage of the process.

There were similarities and differences in the codes of coping strategies resulting from the present study to the taxonomy of coping strategies used by Bennett-Branson

et al.(unpub), which was previously used in studies of coping strategies in acute pain in children (Bennett-Branson & Craig,in press; Branson, McGrath, Craig, Rubin & Vair,1990). It should be noted that the codes described within the selective code of "ways of being" are not coping strategies (refer Appendix 8). Specific differences were that minimizing of pain, a strategy which altered appraisal and was an important strategy in the daily lives of children who accepted their pain and condition, was not included in the Bennett-Branson et al.(unpub) taxonomy. Cognitive reappraisal in the Bennett-Branson et al.(unpub) and Branson et al.(1990) taxonomies referred to statements such as: "I think after this I'll feel better"; "I think about the good things about being in hospital", but did not actually address the appraisal of pain.

Similarly, the generalized form of positive self-talk which several of the children used ("I am used to pain, so I can handle it"), was not documented by Bennett-Branson et al.(unpub), although positive self-talk (I can take this), has been documented in relation to dental pain (Brown et al.1986). The use of visualization and fantasy has rarely been documented as a spontaneous coping strategy in children, although Ross & Ross(1984a) reported a small number of children who described using fantasy. Olness(1989) has documented the effectiveness of inducing altered levels of consciousness as a strategy to relieve pain in children. However, it has not been documented that children have spontaneously developed the ability to induce trance. The few children who used visualization in the present study appeared to describe different levels of trance and its effectiveness for them (refer Chapter Eleven).

Other important differences from the taxonomies of coping strategies resulting from the pediatric acute pain literature have been noted above, in particular "keeping going", and seeking social support. The findings of the present study differ also from the description of children with chronic pain offered by P.A.McGrath(1993), which suggested that most of these children did not know any coping strategies that they could integrate into their daily lives and that consequently there was a lack of control over pain and an increase in emotional distress. However, the children described by P.A.McGrath had been referred to a pain clinic, in contrast to the present sample of children who were not pain clinic referred. The lack of use of coping strategies and lack of control described by P.A.McGrath(1993), may not be representative of the population of children who experience chronic pain, but rather of a select sample of children who have been pain clinic referred because of problems. The children who participated in the present study had a variety of pain histories and severities (refer Chapter 7). Some aspects of P.A.McGrath's(1993) description of children with chronic pain were evident in the present findings. These were the need for age-appropriate information about their pain and the possiblity of a despondent stage (having had enough). However, having had enough did not necessarily mean the children did not use coping strategies (refer Chapter Twelve).

In contrast to the description by P.A.McGrath(1993), the participant children did describe a variety of coping strategies which they utilized singly and in combination. They described feelings of being in control, that they "knew what to do" and cognitively worked through aspects of their pain in order to plan preventive strategies, and use strategies that relieved pain.

CONCLUSION

There is support in the adult chronic pain literature for the process of **getting used to living with pain**, described in relation to the participant group of children who experience chronic pain. The coping process is viewed as changing over time, and the present study has generated a description of the process of coping with chronic pain that is clearly relevant to children. There were important differences from adult findings in chronic pain, for example, the need for social support continued throughout the process with children, alongside the later stage of acceptance, which differed from adults where seeking social support was found to lessen as acceptance increased.

In general however, there was a surprising consistency in the changes over time of the predominant coping strategies used by the children, and changes over time that have been described as having adaptive outcomes in adults. The predominance of avoiding and cognitive diversion strategies in the early and middle stages of the children's process, and the use of strategies which attended to the pain by altering appraisals in the later stages, were both examples of strategies which have been found to have adaptive outcomes in adult chronic pain patients at similar stages.

In spite of the children's overall inherent ability to utilize coping strategies that have been found to be adaptive in adult chronic pain patients, children's coping should not be viewed as a miniature version of adult coping. Children did have different needs, and there were age/cognitive developmental influences on their appraisals and use of coping strategies, as well as the influence of time since onset. In particular, the need for age-appropriate information about their pain and condition was documented and this need could occur alongside avoiding strategies. Feeling scared,frightened and catastrophizing was reduced by the provision of accurate information relatively soon after onset.

The present findings also supported and extended some of the findings in the pediatric pain literature,in particular a preliminary syggestion that children's coping strategies do change over time with repeated exposure to pain. These changes were described in the present findings and highlight that children should not be viewed as having global and unchanging coping styles. Several strategies were described by the participant children that have not previously been described in the pediatric literature. Of particular relevance to children who experience chronic pain, the strategy of keeping going served as a distractor, and also functioned to keep them involved and

exposed to peer interactive social activities. Minimizing pain has not been previously documented in children, and generalized positive self-talk not referred to in relation to chronic pain in children. Both of these strategies were closely related to acceptance of pain and condition. The ability to self-induce trance through the use of visualization has not previously been documented.

Subjective habituation to pain was clearly described by most of the children, and this extends prior suggestions that children habituate to some repeated painful procedures. However,the pervasiveness of children's subjective habituation to chronic pain has not previously been reported. There was an increasing age and increasing time since onset aspect to habituation.

The use of distraction strategies with awareness of the cognitive influence on relieving pain was described in all stages of the process,although perceived positive effect of strategies varied between children,and children developed their own preferred distraction strategies. At all stages of the process of **getting used to living with pain**,children initiated active coping efforts, and their coping strategies changed over time since onset,and in relation to other contextual variables.

The final chapter presents a summary of the overall findings,some implications for future research, and for clinicians and parents of children who have long-term pain.

CHAPTER FIFTEEN

Summary and Recommendations

The first section of this chapter overviews the main findings. The second part describes some limitations of the present study, and the third section makes recommendations for future research. Lastly, some implications of the present findings for clinicians and parents of children with chronic disease-related pain are discussed.

SUMMARY OF FINDINGS

Children who experience chronic disease-related pain utilize a variety of coping strategies in order to manage and relieve their pain. A theory was generated from the children's data which describes how their appraisals of pain, and their use of coping strategies changes over time. The changes over time in their use of coping strategies and ways of being were described as the process of **"getting used to living with pain".** An integral part of the process consisted of the children's descriptions that they got used to pain (i.e., they described subjective habituation to pain). Other major aspects of the process were experiential learning of coping strategies, and life-style adjustments. Children moved through the stages of the process as their feelings of being able to control pain increased in response to mastery experiences, as their knowledge about pain relieving strategies increased, and as they became more used to pain.

Several contexts were therefore found to impact on their use of coping strategies, and their current way of being, or stage in the process. Severity of pain had a major impact, as did age, length of time since onset, and situational context. The participant children used similar coping strategies to those that have been described in the pediatric pain literature, although some inconsistencies were noted and discussed. Several coping strategies that have not been documented previously were described in the data. The lack of prior documentation of these strategies may be related to the lack of research on children's coping with chronic pain.

Consistencies were also found between children's use of coping strategies at varying stages of the process, and strategies that have been found to be adaptive in adults with chronic pain at similar stages. There were also inconsistencies which have been discussed. The children described using some strategies that are taught to adults in treatment programmes for chronic pain, and as one of the parents put it, they intuitively find their own way. Although the children found personalized coping strategies that suited them, the experiential learning process was not an easy one, and children described different needs from adults.

LIMITATIONS OF THE STUDY

Limitations of the study were that the sample of participants was limited by the availability of children with chronic disease-related pain. As a consequence, there were fewer children in the lower age range of 7 to 9 years old, and most of the children were aged between 10 and 12 years. Age/cognitive developmental differences which individual children described retrospectively were therefore less able to be viewed across the sample. Furthermore, the exploration of negative instances was somewhat limited by the availability of children and the small sample size.

A limitation which always exists when attempting to gain children's viewpoints is the problem of metacognition and verbal ability. That is, the younger children in particular may have had difficulty thinking about their own thinking, and furthermore applying verbal descriptions to their thinking. Several of the older children were very clear in their descriptions of their thinking.

Lastly, although a qualitative approach was taken in order to provide the viewpoints of the children, the single interview constituted a "snapshot in time" approach. Children retrospectively described changes over time in their responses to pain, their thinking about pain, and their use of coping strategies. Children's descriptions were therefore reliant on memory as well as current experience of pain.

IMPLICATIONS FOR FURTHER RESEARCH

At present the theory is local to the participant children, although some consistency was found with literature on adult chronic pain patients. Some aspects of the theory have a depth of supportive data, and in other areas the data has less depth. It is particularly important to further explore the stage of having had enough, or despondence, because this is likely to be when children have been labelled as exhibiting "maladaptive coping outcomes", rather than being viewed as part of an overall process in which the contexts impacting on the child have combined to overwhelm his coping efforts. Research which looks more closely at the contexts could more fully describe the strategies which enable children to succesfully negotiate this stage. Furthermore, the combination of contexts which precipitate a return to this stage (as well as the context of severity of pain) may be clarified. For instance, the context of loss or the accumulation of stressful life events may be significant.

A larger sample size would more clearly document the extent of a stage of despondence. Aspects of the theory which have a greater depth of supportive data would also benefit from exploration, refining and verification with a larger sample children who experience chronic disease-related pain. The suggested trends in relation to contexts (refer to Figure I), could be further documented in a large scale study.

Longitudinal multiple case study research which follows individual children's use

of coping strategies and assesses coping outcomes over time is recommended. Qualitative and quantitative data should be collected. The use of weekly pain coping diaries at intermittent intervals would reduce the reliance on memory, and these would be supplemented by periodic interviews to collect qualitative data.

In summary, there is a need to further document children's use of coping strategies and also explore adaptational outcomes in chronic disease-related pain. The process of **getting used to living with pain** that was described should be investigated in relation to other groups of children with chronic pain.

IMPLICATIONS FOR CLINICIANS AND PARENTS

Recommendations for clinicians and parents are that children's use of coping strategies cannot be viewed in isolation from contextual factors. That is, the current severity and constancy of the child's pain, their age, time since onset, and situational influences all need to be considered. Prior to teaching any coping interventions to children, there is a paramount necessity to find out from children both what strategies they may already be utilizing or have a preference for, and what other contextual factors are impacting on their experience of pain and their use of coping strategies. In chronic disease-related pain with children it may be that the current severity of pain is such that pharmacological interventions should be initiated alongside psychological interventions. Furthermore, situational factors such as additional social support for the child may be need to be addressed, for instance, involvement in peer social interaction.

Another paramount issue is to explore children's fears about their pain and condition. Providing children with accurate, age-appropriate information about their pain and condition, listening to their fears and concerns, and providing honest answers to their questions seems basic. However, many of the children interviewed had not had this courtesy paid to them, and information was almost always relayed through their parents. Children's moving on from being scared by their pain was facilitated both by their experiential learning of coping strategies, and increased knowledge which arose from both their own expertise and from information provided to them by others. At a later stage in the process, children did not view information about their condition as relevant, and were more interested in living with their pain, and getting on with their lives. It should be noted again, however, that stages could be re-visited in relation to current contexts. Therefore, being aware of each child's current needs is important.

An awareness of children's age/cognitive developmental level and their preferences in use of coping strategies is important if coping strategies are going to be taught to children. For instance, younger children may not be able to use the cognitive diversionary strategies that were described by older children (mostly from 10 years of age upwards). Investigation of unique preferences is always warranted, and coping strategies already being used by children may be able to be extended, so that their own

strengths are built upon. The prevalence of the use of distraction strategies suggests the usefulness of these techniques, and children's preferred distractions can be incorporated into a pain management plan at any age. It is also important to be aware that children may have the ability to use visualization and induce trance to relieve pain.

A further implication is that supportive, caring, parenting may need to be supplemented with a firm approach. That is, children are encouraged to regulate their activity in a responsible way, resting when necessary and keeping going when they are able. They therefore maintain involvement in peer interactive social activities and keep themselves physically active within their capabilities, yet do not suffer severe exacerbations from having over-extended themselves. There is a further need then to trust the judgements of the children, and not be over-solicitous when they are testing their limits.

Clinicians need to be aware that children who experience long-term disease-related pain subjectively habituate to pain. They still feel pain, but it bothers them less. This has implications for allowing children to keep going, and remain involved in activities (i.e., again trusting the judgements made by the children). This information also has relevance in instances where level of disease activity is assessed in relation to the severity of pain reported by children. Furthermore, it seems likely that children's severity and frequency of pain in chronic disease may have been underestimated by clinicians and researchers, because of the child's capacity to subjectively habituate to pain, and to initiate coping strategies that have been found to be adaptive in adult chronic pain patients. The parents of the participant children were already aware that their children had got used to pain, yet still felt pain.

SUMMARY

Clinicians and parents should be aware that children make active efforts to cope with their chronic pain, and these coping efforts can be supported. In particular, the provision of accurate information early after onset is important, and the provision of social support is important at all stages. The form that social support takes will vary with age.

Children's abilities to develop coping strategies must be acknowledged. To date, pain management programmes for children have been well intentioned but one blind spot has been that children have not had the opportunity to contribute their expertise at managing pain. Finally, the importance of listening to the concerns of the children and employing them as "consultants" in helping to devise their own pain management programmes has a promise that has not hitherto been tapped into sufficiently.

REFERENCES

:., Urrows,S., Tennen,H. & Higgins,P.(1992). Daily coping with pain from rheumatoid itis: patterns and correlates. *Pain*,**51**, 221–229.

:.M. & Revenson,T.A.(1987). Does coping help? A re-examination of the relation of ıg and mental health. *Journal of Personality and Social Psychology*, **53**, 333–348.

, Dreessen,L. & Merckelbach,H.(1991). Attention, Not Anxiety, Influences Pain. *ıour Research and Therapy*,**29**, 41–50.

,A.(1977). Self-efficacy: Toward a Unifying Theory of Behavioral Change. *Psychological w*,**84**, 191– 215.

:., Keen,J.H. & Holt,P.J.L.(1983). The Child's Perception of the Disease and the :ience of Pain in Juvenile Chronic Arthritis. *Journal of Rheumatology*, **10**, 61–65.

H.(1993). Common Pitfalls in Published Grounded Theory Research. *Qualitative Health rch*,3, 254–260.

3ranson,S.M. & Craig,K.D.(in press). Postoperative Pain in Children: Developmental amily Influences on Spontaneous Coping Strategies. *Canadian Journal of Benavioural :e.*

3ranson,S.M.,Malleson,P.N. & Craig,K.D. (1993). *Pain, Coping and Health Status in Older en and Adolescents with Chronic Arthritis*. Manuscript submitted for publication.

S.M. & Craig,K.D.(1988). Children's Spontaneous Strategies for Coping with Pain: A w of the Literature. *Canadian Journal of Behavioural Science*, **20**, 102–112.

S.M.,McGrath,P.J.,Craig,K.D., Rubin,S.Z. & Vair,C.(1990). Spontaneous Strategies for ıg with Pain and Their Origins in Adolescents Who Undergo Surgery. In D.C.Tyler & ne (Eds.), *Advances in Pain Research Therapy*, Vol, 15. New York: Raven Press.

.A.B. (1982). Chronically Ill Hospitalized Children's Concepts of Their Illness. *rics*,**69**, 355–362.

M., O'Keeffe,J., Sanders,S.H. & Baker,B.(1986). Developmental Changes in Children's ition to Stressful and Painful Situations. *Journal of Pediatric Psychology*, **11**, 343–357.

A.(1988). *Quantity and Quality in Social Research*. London: Unwin Hyman.

& Harkins,S.W.(1991). Conceptual Foundations: Pain and Child Development. In sh & S.W.Harkins (Eds.), *Children in Pain: Clinical and Research Issues From a ɔpmental Perspective* (pp. 1 –30). New York: Springer Verlag.

N.C. & Swanson,J.M. (Eds.).(1986). *From Practice To Grounded Theory: Qualitative Research rsing*. Menlo Park, California: Addison Wesley.

B.E.(1987). Coping With Stress During Childhood and Adolescence. *Psychological in*, **101**, 393–403.

D. & Bennett-Branson,S.M.(in press). Postoperative Pain in Children: Developmental rs, Psychological Processes and Parental Influence. In K.M.Prkachin & H.Merskey . *The Control Of Postoperative Pain*. Waterloo,Ont: University of Waterloo Press.

D. & Grunau,R.V.E.(1991). Developmental Issues: Infants and Toddlers. In J.P.Bush & Harkin (Eds.), *Children in Pain: Clinical and Research Issues From a Developmental :ctive* (pp.171–193). New York: Springer Verlag.

.. & Russ,S.W.(1985). Identifying Coping Strategies in Children. *Journal of Clinical Child ɔlogy*,**14**, 61–69.

:ier,B.J., McGrath,P.J., Rourke,B.P., Latter,J. & D'Astous,J. (1986). Adolescent Chronic the Ability to Cope. *Pain*, **26**, 23–32.

985). *The Psychology of Childhood Illness*. New York: Springer-Verlag.

Fagerhaugh,S.Y.(1986). Analyzing Data for Basic Social Processes. In W.C.Chenitz & J.M.Swanson(Eds.), *From Practice To Grounded Theory: Qualitative Research in Nursing* (pp. 121–132). Menlo Park, California: Addison Wesley.

Faust,J. & Melamed,B.G.(1984). Influences of arousal, previous experience, and age on surgery preparation of same day surgery and in-hospital pediatric patients. *Journal of Consulting and Clinical Psychology*, **52**, 359–365.

Folkman,S.(1984). Personal Control and Stress and Coping Processes: A Theoretical Analysis. *Journal of Personality and Social Psychology*, **46**, 839–852.

Fowler-Kerry,S. & Lander,J.(1991). Assessment of Sex Differences in Children's and Adolescents' Self-Reported Pain from Venipuncture. *Journal of Pediatric Psychology*,**16**,783–793.

Gaffney,A.(1988). How Children Describe Pain: A Study of Words and Analogies Used By 5–14-Year-Olds. In R.Dubner,G.F.Gebhart & M.R.Bond (Eds.). *Proceedings of the Vth World Congress on Pain* (pp. 341 – 347). Elsevier Science Pubs.

Gaffney,A.(1993). Cognitive Developmental Aspects of Pain in School-Age Children. In N.L.Schecter, C.B.Berde & M.Yaster (Eds.), *Pain in Infants, Children and Adolescents* (pp. 75–85). Baltimore, Maryland: Williams & Wilkins.

Gaffney,A. & Dunne,E.A.(1986). Developmental Aspects of Children'st Definitions of Pain. *Pain*, **26**, 105–117.

Gaffney,A. & Dunne,E.A.(1987). Children's Understanding of the Causality of Pain. *Pain*, **29**, 91–104.

Garbarino,J. & Stott,F.M.(1989). *What Children Can Tell Us: Eliciting, Interpreting, and Evaluating Information from Children*. San Francisco: Jossey-Bass.

Glaser,B.G.(1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. Mill Valley, California: Sociology Press.

Glaser,B.G. & Strauss,A.((1967). *The Discovery of Grounded Theory*. Chicago: Aldine.

Grunau,R.V.E. & Craig,K.D.(1987). Pain Expression in Neonates: Facial Action and Cry: *Pain*, **28**, 395–410.

Grunau,R.V.E., Johnston,C.C. & Craig,K.D.(1990). Neonatal Facial and Cry Responses to Invasive and Non-invasive Procedures. *Pain*, **42**, 295–305.

Harrison,A,(1991). Preparing Children for Venous Blood Sampling. *Pain*, **45**, 299–306.

Haslam,D.R.(1969). Age and the Perception of Pain. *Psychonomic Science*, **15**, 86–87.

Henwood,K.L. & Pidgeon,N.F.(1992). Qualitative Research and Psychological Theorizing. *British Journal of Psychology*, **83** 97–111.

Holmes,J.A. & Stevenson,C.A.Z.(1990). Differential Effects of Avoidant and Attentional Coping Strategies on Adaptation to Chronic and Recent-Onset Pain. *Health Psychology*, **9**, 577–584.

Jaeger,M.E. & Rosnow,R.L.(1988). Contextualism and its implications for psychological inquiry. *British Journal of Psychology*, **79**, 63–75.

Jamison,R.N. & Virts,K.L.(1990). The Influence of Family Support on Chronic Pain. *Behaviour Research and Therapy*, **28**, 283–287.

Jensen,M.P., Turner,J.A., Romano,J.M. & Karoly,P.(1991). Coping with Chronic Pain: A Critical Review of the Literature. *Pain*, **47**, 249–283.

Keefe,F.J.,Salley,A.N. & Lefebvre,J.C.(1992). Coping with Pain: Conceptual Concerns and Future Directions. *Pain*, **51**, 131–134.

Kirk,J. & Miller,M.(1986). *Reliability and Validity in Qualitative Research*. Beverley Hills: Sage.

Knight,R.B.,Atkins,A.,Eagle,C.J.,Evans,N.,Finkelstein,J.W., Fukushima,D.,Katz,J. & Weiner,H.(1979). Psychological stress, ego defenses, and cortisol production in children hospitalized for elective surgery. *Psychosomatic Medicine*,**41**, 40–49.

Koocher,G.P.(1993,June). *Development of Children's Conceptions of Death and Illness.* Paper presented at the meeting of the Cancer Society, Wellington, N.Z.

La Montagne,L.L.(1984). Children's Locus of Control Beliefs as Predictors of Preoperative Coping Behavior. *Nursing Research,* **33**,76–80.

La Montagne,L.L.(1987). Children's Preoperative Coping: Replication and Extension. *Nursing Research,* **36**, 163–167.

Lander,J. & Fowler-Kerry,S.(1991). Age Differences in Children's Pain. *Perceptual and Motor Skills,* **73**, 415–418.

Lander,J.,Hodgins,M. & Fowler-Kerry,S.(1992). Children's Pain Predictions and Memories. *Behaviour Research and Therapy,* **30**, 117–124.

Lavigne,J.V.,Schulein,M.J. & Hahn,Y.S.(1986). Psychological aspects of painful medical conditions in children. II. Personality factors, family characteristics and treatment. *Pain,* **27**, 147– 169.

Leikin,L.,Firestone,P. & McGrath,P.J.(1988). Physical Symptom Reporting in Type A and Type B Children. *Journal of Consulting and Clinical Psychology,* **56**, 721–726.

Litt,M.D.(1988). Self-efficacy and perceived control: Cognitive mediators of pain tolerance. *Journal of Personality and Social Psychology,* **54**, 149–160.

Lazarus,R.S. & Folkman,S.(1984). *Stress, Appraisal, and Coping.* New York: Springer.

McGrath,P.A.(1987). An Assessment of Children's Pain: A Review of Behavioural Physiological and Direct Scaling Techniques. *Pain,* **31**, 147–176.

McGrath,P.A.(1990). *Pain in Children: The Perception, Assessment, and Control of Children's Pain.* New York: Guildford Press.

McGrath,P.A.(1993). Psychological Aspects of Pain Perception. In N.L.Schecter, C.B.Berde & M.Yaster (Eds.), *Pain in Infants, Children, and Adolescents: An Overview* (pp.39–63). Baltimore, Maryland: Williams & Wilkins.

McGrath,P.J. & Unruh,A.M.(1987). *Pain In Children And Adolescents.* Amsterdam: Elsevier.

McGrath,P.J. & Unruh,A.M.(1993). Psychological Treatment of Pain in Children and Adolescents. In N.L.Schecter, C.B.Berde & M.Yaster (Eds.), *Pain in Infants, Children, and Adolescents: An Overview* (pp.219–236). Baltimore, Maryland: Williams & Wilkins.

Marshall,C. & Rossman,G.B.(1989). *Designing Qualitative Research.* Newbury Park: Sage.

Melamed,B.G.,Siegel,L.J. & Ridely-Johnson,R.(1988). Coping Behaviors in Children Facing Medical Stress. In T.Field, P.McCabe & N.Schneiderman (Eds.), *Stress and Coping Across Development* (pp. 109–137). Hillsdale, New Jersey: Erlbaum.

Miles,M.B. & Huberman,A.M.(1984). *Qualitative Data Analysis: A Sourcebook of New Methods.* Newbury Park: California: Sage.

Olness,K.(1989). Hypnotherapy: A Cyberphysiologic Strategy in Pain Management. *Pediatric Clinics of North America,* **36**, 873–884.

Payne,B. & Norfleet,M.A.(1986). Chronic Pain and the Family: A Review. *Pain,* **26**,1–22.

Peterson,L.(1989). Coping by Children Undergoing Stressful Medical Procedures: Some Conceptual, Methodological, and Therapeutic Issues. *Journal of Consulting and Clinical Psychology,* 57, 380–387.

Peterson,L. & Toler,(1986). An Information Seeking Disposition in Child Surgery Patients. *Health Psychology,* **5**, 343–358.

Piaget,J. & Inhelder,B.(1969). *The Psychology of the Child.* London: Routledge & Kegan Paul.

Philips,H.C.(1987). Avoidance Behaviour And Its Role In Sustaining Chronic Pain. *Behaviour Research and Therapy,* **25**, 273–279.

Reissland,N.(1983). Cognitive Maturity And The Experience Of Fear And Pain In The Hospital.

Social Science and Medicine,**17**, 1389–1395.

Ross,D.M. & Ross,S.A.(1984a). Childhood Pain: The School-Aged Child's Viewpoint. *Pain*, **20**, 179–191.

Ross,D.M. & Ross,S.A.(1984b). The Importance of Type of Question, Psychological Climate and Subject Set in Interviewing Children about Pain. *Pain*, 19, 71–79.

Ross,D.M. & Ross,S.A.(1988). *Childhood Pain: Current Issues, Research, and Management*. Baltimore: Urban & Schwarzenburg.

Savedra,M.,Gibbons,P.,Tesler,M.,Ward,J. & Wegner,C.(1982). How Do Children Describe Pain? A Tentative Assessment. *Pain*, **14**, 95–104.

Savedra,M. & Tesler,M.(1981). Coping Strategies Of Hospitalized School-Age Children. *Western Journal of Nursing Research*, **3**, 371–384.

Schecter,N.L.(1989). The Undertreatment of Pain in Children: An Overview. *Pediatric Clinics of North America*, **36**, 781–794.

Schecter,N.L., Berde,C.B. & Yaster,M.(Eds.).(1993). *Pain in Infants, Children and Adolescents*. Baltimore, Maryland: Williams & Wilkins.

Siegel,L.J.(1988). Measuring Children's Adjustment to Hospitalization and to Medical Procedures. In P. Karoly (Ed.), *Handbook of Child Health Assessment* (pp.265–302). New York: Wiley.

Siegel,L.J. & Smith,K.E.(1991). Coping and Adaptation in Children's Pain. In J.P. Bush & S.W. Harkins (Eds) *Children in Pain: Clinical and Research Issues From a Developmental Perspective* (pp.149–170). New York: Springer-Verlag.

Smith,K.E., Ackerson,J.D. & Blotcky,A.D.(1989). Reducing Distress During Invasive Medical Procedures: Relating Behavioural Interventions to Preferred Coping Style in Pediatric Cancer Patients. *Journal of Pediatric Psychology*, **14**, 405–419.

Stanley,L. & Wise,S.(1983). *Breaking Out: Feminist Consciousness and Feminist Research*. London: Routledge & Kegan Paul.

Stiles,W.B.((1990). *Narrative in Psychological Research*. (Visiting Fellowship Series No.1). Massey University: Psychology Department.

Strauss,A.L. & Corbin,J.(1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, California: Sage.

Tesler,M.,Savedra,M.,Ward,J.A.,Holzemer,W.L. & Wilkie,D.(1988). Children's Language of Pain. In R.Dubner, G.F.Gebhart & M.R.Bond (Eds.), *Proceedings of the Vth World Congress on Pain* (pp.348–352). Elsevier Science Pubs.

Timko,C.,Stovel,K.W.,Moos,R.H. & MillerJ.J.(1992). Adaptation to Juvenile Rheumatic Disease: A Controlled Evaluation of Functional Disability With a One-Year Follow-Up. *Health Psychology*, **11**, 67–76.

Turner,J.A.,Clancy,S. & Vitaliano,P.P.(1987). Relationships Of Stress, Appraisal And Coping, To Chronic Low Back Pain. *Behaviour Research and Therapy*, **25**, 281–288.

Ungerer,J.A.,Horgan,B.,Chaitow,J. & Champion,G.D.(1988). Psychosocial Functioning in Children and Young Adults With Juvenile Arthritis. *Pediatrics*, **81**, 195–202.

Varni,J.W.(1983). *Clinical Behavioral Pediatrics: An Interdiscipinary Biobehavioral Approach*. New York: Pergamon.

Varni,J.W. &Walco,G.A.(1988). Chronic And Recurrent Pain Associated With Pediatric Chronic Diseases. *Issues in Comprehensive Pediatric Nursing*, **11**, 145–158.

Walco,G.A. & Varni,J.W.(1991). Chronic and Recurrent Pain: Hemophilia, Juvenile Rheumatoid Arthritis, and Sickle Cell Disease. In J.P.Bush & Harkins,S.W.(Eds.), *Children in Pain: Clinical and Research Issues From a Developmental Perspective* (pp.297–325). New York: Springer-Verlag.

Wall,P.D. & Melzack,R.(Eds.).(1984). *Textbook of Pain*. New York: Churchill Livingstone.

Wilkie,D.J.,Holzemer,W.L.,Tesler,M.D.,Ward,J.A.,Paul,S.M. & Savedra,M.C.(1990). Measuring Pain Quality: Validity and Reliability of Children's and Adolescent's Pain Language. *Pain*, **41**, 151–159.

Williams,D.A. & Keefe,F.J.(1991). Pain beliefs and the use of cognitive-behavioral coping strategies. *Pain*, **46**, 185–190.

Worchel,F.F., Copeland,D.R. & Barker,D.G.(1987). Control-Related Coping Strategies in Pediatric Oncology Patients. *Journal of Pediatric Psychology*, **12**, 25–38.

CONTENT OF SEMI-STRUCTURED INTERVIEW

Introductory statement, appropriate to age of child e.g. "... important things you could tell adults about children and their pain ..."

Warm/up open questions about family, brothers, sisters

home ... school ... where live?
what like to do? what activities able to join in?
friends? grandparents? TV programmes/movies/heroes?
favourite places? holidays?

Move on to history of pain. (or feelings in joints).

Can they describe the sensation? How it feels?
How long since started? When started? How Often? How long does it last each time?

Assessment of usual intensity and severity of pain.

Do they have any particular words for their hurt? Miss much school?
Does the pain (or whatever word they use) make a difference to ... (whatever favourite activities child has talked about?) What sorts of things are different when you are in pain? What sorts of things are different when you are not in pain?

Can you use words to describe what your pain usually feels like?

Faces scale	mostly like?	worst pain?
Visual Analogue Scale	like now?	littlest pain?

First look at coping strategies

Tell me about your scariest pain (hurt)?

To help me to think about what you were thinking or doing at the time, I would like you to close your eyes and imagine everything that happened, just like you are running a T.V. programme through your head? ...

Now what kinds of things did you think or do that made it hurt less, or made you feel better?

Have you done that at other times?

Are there things that you try and think about (as a further prompt).....try not to think about?

Are there any other sorts of things that you do yourself to try and make the pain feel better? ***Need to track into response ... find out more about each specific strategy.*** How long do you do that for? How many times a day/week would you say that you do that?, Every day? How long do you do it for? Does it take long to work? Do some things that you do work better than others? Which used most often.

What sorts of things make a difference to how well they work? Does where you are make a difference? Does what is happening in the room at the time change things? Does who you are with make any difference? What do they do that makes a difference? Are there people you like to be with?

Extent of information seeking?

How much to you know about your illness ? (about what causes the pain/makes the pain happen?) How di dyou find out these things that you know about your illness and your pain?

Acknowledge child's knowledge and cleverness at learning about illness and managing pain. Maybe use this as a lead to ask about what other things they do well or use their "cleverness on".

Other Ways of looking at feelings of control.

Do they feel they are the boss of the hurt?
Who do they think is the boss of the hurt?

What do they do to become the boss of the hurt?

Typical day (see as a look at other coping strategies, and way of tracking out of pain at appropriate time).

Second look at coping strategies.

If your best friend (possibly brother/sister...use earlier information) started having pain like yours, what would you tell them to do? What sorts of ways would you teach them to help make their pain better?

Track out of pain, e.g. talk about activity, or whatever child is doing, or talk about siblings, friends from above scenario.

Third look at coping strategies (projective technique).

Show drawing of child in pain.

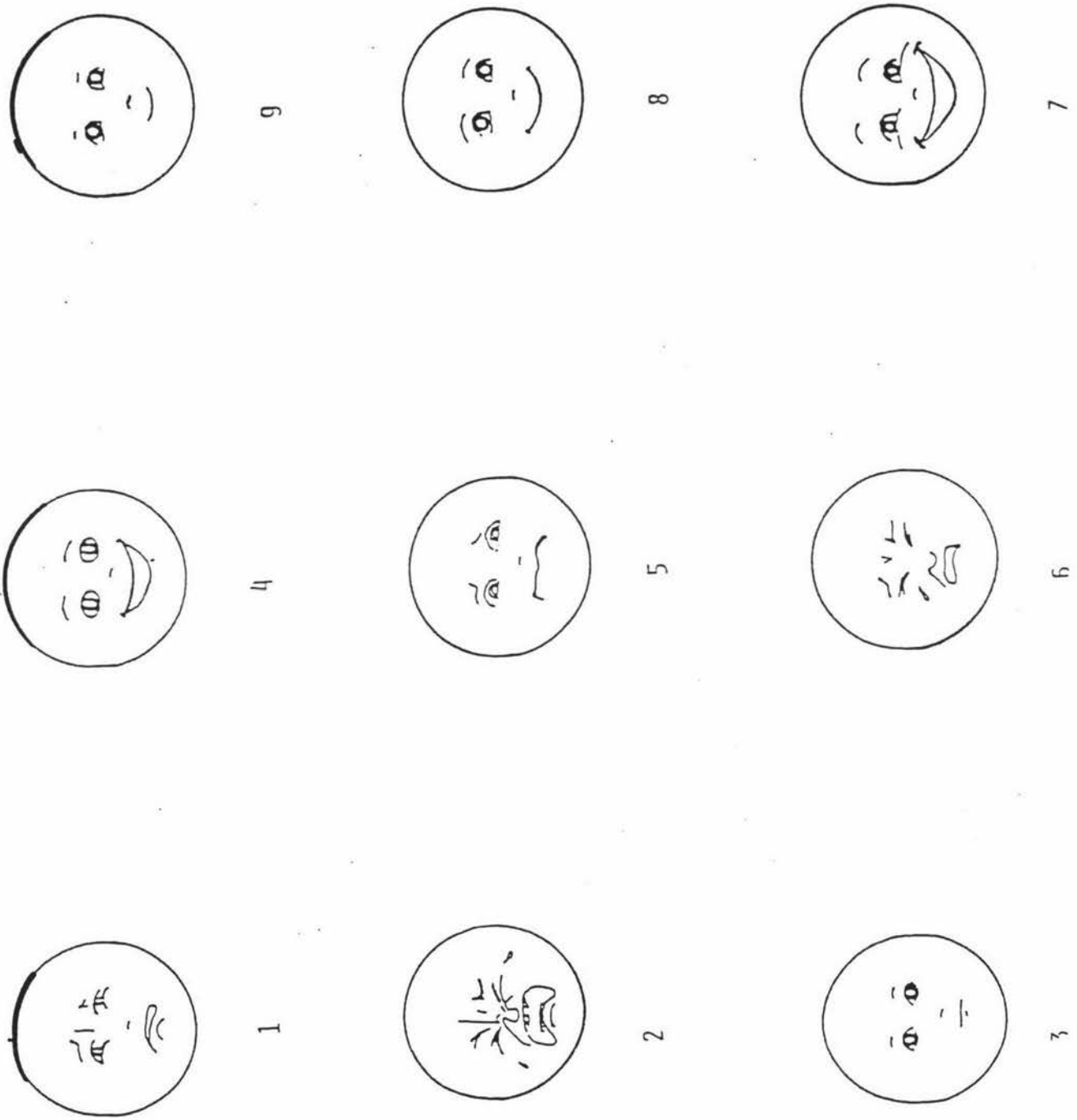
This is a boy/girl about the same age as you, and they have a lot of hurt right now. What do you think that (s)he could do to make the hurt feel better? Are there things that (s)he could do? Are there things that (s) he could think about?

Debriefing

How do you feel now? Is there anything that you want to ask me?

Know lots of helpful things .....good at managing things.

FACIAL AFFECTIVE SCALE (FAS)



(adapted from P.A. McGrath, 1990)

VISUAL ANALOGUE SCALE (VAS)

Child's code:_____

1. Put a mark on the line that shows how much pain or hurt you have now.

not strong strongest possible

Face:_____

2. Put a mark on the line that shows what your worst pain or hurt is like.

not strong strongest possible

Face:_____

3. Put a mark on the line that shows what your smallest pain or hurt is like.

not strong strongest possible

Face:_____

4. Put a mark on the line that shows what your pain or hurt is like most of the time.

not strong strongest possible

Face:_____

MASSEY
UNIVERSITY

Private Bag 11222
Palmerston North
New Zealand
Telephone 0-6-356 9099
Facsimile 0-6-350 5611

FACULTY OF
SOCIAL SCIENCES

DEPARTMENT OF
PSYCHOLOGY

INVESTIGATION INTO THE SPONTANEOUS COPING STRATEGIES OF CHILDREN WHO EXPERIENCE CHRONIC PAIN

INFORMATION SHEET FOR PARENTS AND CHILDREN

INVESTIGATOR: Karen Ramsay
- Graduate Psychology Student, Massey University
- Paediatric Staff Nurse, Wellington Hospital
- Registered General Obstetric Nurse
- BA Social Sciences

Contact Phone Number: [redacted]

Karen is undertaking this research as part of her Masters' degree in Psychology. She has also worked with children as a Paediatric Nurse in Wellington Hospital for several years.

PURPOSE OF RESEARCH: Pain in children has been increasingly researched during the past decade, in particular focussing on assessment of pain in children, and various methods of managing pain for the children. This investigation intends to address two neglected areas, firstly that of chronic pain in children, whereas much of the research has looked at acute pain. Secondly, the child's point of view, rather than a adult interpretation of what the child may be experiencing or how that child attempts to manage his/her pain.

WHAT THE INVESTIGATION INVOLVES: Children whose parents agree for them to be approached, will have an explanation given to them about the investigation and its purpose, in the presence of their parent. Children and parents will have at least a day to discuss the investigation together, and should approach the investigator if there is any further information that they require. The child and his/her parent or guardian each need to sign a consent form if they wish the child to participate.

Once consent forms are signed, each child will be interviewed on their own by the investigator for approximately one hour, or less, depending on the age of the child, and how they are feeling. The interview will be informal, and will ask the children to discuss aspects about the severity, duration, and frequency with which they experience pain, and what sorts of things they do themselves to make the pain feel less hurtful. The interview will be tape-recorded for later analysis, and the tapes coded so that the identity of each child remains confidential. The tapes will be destroyed after the project has been written up.

WITHDRAWAL: Children are free to withdraw at any stage of the investigation, and their parents are free to withdraw them also, with no ill feeling on the part of the investigator.

AVAILABILITY OF RESEARCH RESULTS: A summary of the findings will be provided to each child participant and their parents/guardian. Children will not be able to be identified from any of the summary findings, or thesis. A copy of the thesis will be held at Massey University, and one at Ward 18, Hospital.

MASSEY
UNIVERSITY

Private Bag 11222
Palmerston North
New Zealand
Telephone 0-6-356 9099
Facsimile 0-6-350 5611

FACULTY OF
SOCIAL SCIENCES

DEPARTMENT OF
PSYCHOLOGY

PARENT CONSENT FORM

INVESTIGATION INTO THE SPONTANEOUS COPING STRATEGIES OF CHILDREN WHO EXPERIENCE CHRONIC PAIN

INVESTIGATOR: Karen Ramsay
- Graduate Psychology Student, Massey University
- Paediatric Staff Nurse, Wellington Hospital
- Registered General Obstetric Nurse
- BA Social Sciences

Contact Phone Number: [redacted]

VENUE: Wellington Hospital, or homes of children.

AIM OF INVESTIGATION: To find out what sorts of things children who have experienced pain a lot, do themselves in order to manage pain. Other children who experience pain should benefit from these findings, because clinicians will learn of the many ways that children have developed to manage pain, rather than relying on pain research with adults. From the children's information, it should be possible in the future to build on children's strengths when teaching them coping strategies.

Inconvenience will be minimal, and your child will be asked to spend an hour or less in an informal, tape-recorded interview with the investigator.

Participating children are assured of confidentiality by the investigator, and they will not be able to identified in the research report/thesis.

STATEMENT BY PARENT OR GUARDIAN

I have read the consent form and have had the opportunity for discussion with Karen Ramsay.

I understand that the procedures have been approved by the Wellington Area Health Board Ethics Committee.

I have discussed this investigation with my child and I am satisfied that she/he fully understands it, and that her/his consent is freely given.

I know that I may withdraw my agreement at any time and I understand that this withdrawal will in no way interfere with my child's treatment in the hospital.

I agree for my child to take part in this investigation.

Signature of Parent
or Guardian_____ **Date**_____

STATEMENT BY WITNESS

I have discussed this consent form with the parent of the child patient, and I am satisfied that she/he fully understands it and that her/his consent is freely given.

Signature of Witness_____ **Date**_____

MASSEY
UNIVERSITY

Private Bag 11222
Palmerston North
New Zealand
Telephone 0-6-356 9099
Facsimile 0-6-350 5611

FACULTY OF
SOCIAL SCIENCES

DEPARTMENT OF
PSYCHOLOGY

CHILDREN'S CONSENT FORM

INVESTIGATION INTO THE SPONTANEOUS COPING STRATEGIES OF CHILDREN WHO EXPERIENCE CHRONIC PAIN

AIM OF INVESTIGATION: Children who have had a lot of pain have got important things to tell adults. Karen Ramsay would like to ask children some questions, and listen to what children can tell her.

To help Karen remember what the children say, a tape recorder will be used. No-one else will know which children were talking, and the things that Karen finds out will be written so that on-one can tell who the children were.

STATEMENT BY CHILD

I have read the consent form and talked about it with my parent(s) or guardian, and had a talk about it with Karen Ramsay.

I know that I am free to change my mind if I do not want to talk to Karen Ramsay, and that it will not make any difference to the way that I am looked after in hospital.

I would like to take part in this investigation.

Signature of Child_____ **Date** _____

Signature of Investigator_____ **Date**_____

STATEMENT BY WITNESS

I have discussed this consent form with the child patient and I am satisfied that she/he fully understands it and that her/his consent is freely given.

Signature of Witness_____ **Date**_____

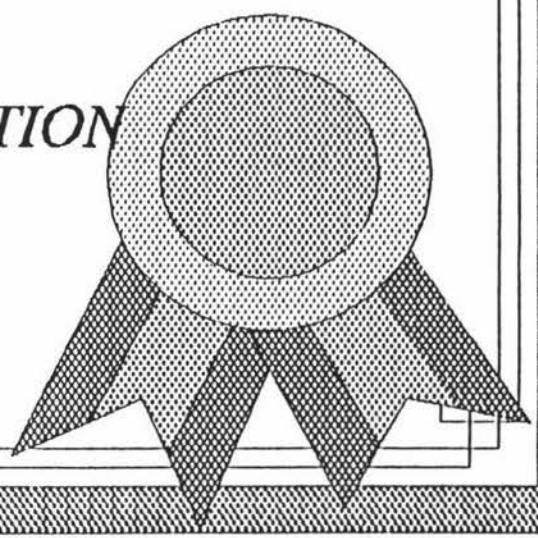
CERTIFICATE OF SPECIAL KNOWLEDGE

THIS IS TO CERTIFY THAT ..... IDENTIFIED HIS SPECIAL KNOWLEDGE AND TALKED ABOUT THIS KNOWLEDGE TO HEALTH PROFESSIONALS SO THAT THEY MIGHT LEARN SPECIAL THINGS THAT ..... KNOWS.

THIS CERTIFICATE IS AWARDED IN APPRECIATION OF YOUR PARTICIPATION AND FOR TEACHING US WAYS OF HELPING CHILDREN.

Signed

Health Researcher. Massey University



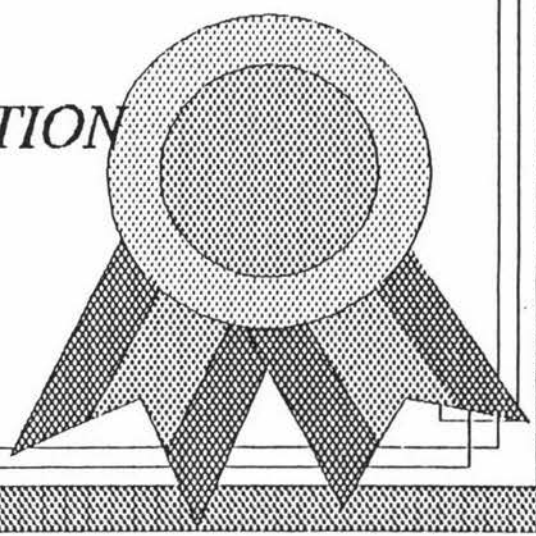
CERTIFICATE OF SPECIAL KNOWLEDGE

THIS IS TO CERTIFY THAT ..... IDENTIFIED HER SPECIAL KNOWLEDGE AND TALKED ABOUT THIS KNOWLEDGE TO HEALTH PROFESSIONALS SO THAT THEY MIGHT LEARN SPECIAL THINGS THAT ..... KNOWS.

THIS CERTIFICATE IS AWARDED IN APPRECIATION OF YOUR PARTICIPATION AND FOR TEACHING US WAYS OF HELPING CHILDREN.

Signed

Health Researcher. Massey University



SUMMARY OF FINDINGS LETTER

MASSEY
UNIVERSITY

Private Bag 11222
Palmerston North
New Zealand
Telephone +64-6-356 9099
Facsimile +64-6-350 5673

FACULTY OF
SOCIAL SCIENCES

DEPARTMENT OF
PSYCHOLOGY

[redacted] 1993.

Dear

I hope you can read this together as a family so that you can talk together and make sure everyone is satisfied that they understand the ideas I would like to share with you in this letter.

Earlier on in the year you took part in an interview as part of the research for my Master's Thesis. It is investigating the coping strategies used by children who experience long-term pain. I would like to share the outline of my findings with you, and ask both children and parents for their reactions to this outline.

All of the children described using a variety of coping strategies. The children described both behavioural strategies (i.e. doing things), and cognitive strategies (i.e.thinking things). Behavioural strategies were resting, changing their position, and applying physical interventions such as heat, massage, and medication. The children used their previous experience of pain to make decisions about regulating their level and type of activity, both to relieve present pain and in order to prevent pain from occurring. The children described a knowledge of their own body reactions, and reported undertaking a realistic amount of activity to keep themselves physically fit without harming themselves. They seemed to have learned through experience, their own unique balance of maintaining regular activity at a non-harmful (although sometimes mildly hurtful) level, a strategy which is taught to adults who experience chronic pain. Some children whose pain was of a more recent onset, or had been less severe for some time described trying out activities which may cause a flare-up, as a way of learning for themselves how far they can go without things being too painful.

Distraction, or purposefully diverting attention from the pain was a commonly reported cognitive-behavioural coping strategy by all children. Video games, reading books, watching T.V., playing musical instruments and drawing were the main distractors. Children from 8 years upwards described an awareness of the cognitive influence on pain ("keeps my mind off it"), and also that their degree of involvement and interest in the distraction affected the

effectiveness of relief of pain. Video games were considered most effective by several of the children.

Examples of thinking strategies that effectively relieved pain through diverting attention were: thinking about something else (several variations on this)including imagining events that they hoped would happen and imagining themselves to be in a different, pleasant scene (visualisation) ; not thinking about pain; and thinking about getter better.

Examples of thinking strategies to deal with the pain were: positive self-talk ("I am used to pain, so I can handle it"); thinking through the causes of flare-ups, and what would be likely to relieve the pain; thinking about the pain in a way that changes the meaning of it, for instance, that "it is not so sore", or finding postive aspects to the present location of the hurt, because it could be worse if it was somewhere else.

The children described that what they did when they experienced pain, and the techniques they used was influenced by the following things:

1. the severity and location of the pain;
2. the specific situation which they were in at the time;
3. their age and their own preferred ways of managing;
4. the length of time since onset of their painful condition.

Taking these four aspects into consideration, the children described an increasing ability to tolerate pain over time. i.e. that they "got used to pain". This does not mean that they don't feel pain. They most certainly do feel pain, and can describe and make clear comparisons of severity and intensity. However the "everyday" sort of pain that each child experiences is judged by them, and they make frequent decisions in view of their current situation/activity (e.g. at school, with friends) and the severity of the pain, as to what strategy is needed. They also decide if "keeping going" will not be harmful, and act as a distractor in itself. They often ignore everyday "niggling" pain, while being aware of it in the background, and said that when they were younger or less experienced at handling it, they would have become upset (crying) but not ignored it.

An overall process of "getting used to living with pain" happened over time. This involved a lifestyle adjustment where the children balanced maintaining as near everyday activities as their age-mates as possible. while dealing with their pain as necessary by using their choice of the strategies described above, and increasing experience at using their preferred strategies. This was combined with an increasing tolerance for pain.

Children also described how they filtered the way they expressed their pain, depending on the situation, severity of pain, their age, and how "used to pain" they were. Crying and distress was therefore described as belonging to "when I was younger", and when the pain was very severe. Also expressions of distress (e.g. crying) became less over time.

Catastrophizing (e.g. thinking the pain was never going to end, and how bad it was, or was going to be) was reported by a few of the children. This sort of thinking was reported around the time of an initial, acute and severe onset, and also when they did not know what was happening, and feared the worst. A lack of age appropriate, relevant information provided to the children and parents appear to contribute to catastrophic thinking. Severe, constant, and unremitting pain also resulted in catastrophic thinking.

Another major theme was the importance of parents, siblings, and friends when children were feeling pain. They not only helped the children with physical interventions,but provided comfort, support, and distractions. Feelings of being in control over the pain were reported by most children, and they described powerful forms of self-talk, for instance "beat it", "never give up".

In summary, the children described many ways of coping with pain, and demonstrated that their experiences with pain helped them choose the coping strategies they felt would be helpful. The children whom I inteviewed had become or were becoming experts in the management of their pain, with the support of their parents. Again there were influencing factors, in particular age, with the older children remarkably self-managing, and the younger children being helped by parents to manage.

Although this may seem like quite a long letter, it doesn't convey the many rich and complex ways the children described for dealing with their pain. I would like to thank you and your parents for you help, and will contact each family by telephone in the near future.

Yours sincerely,

Karen Ramsay.