

THE ARTHRITIC PAIN EXPERIENCE OF CHILDREN WITH JUVENILE
RHEUMATOID ARTHRITIS

BY

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ABSTRACT

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This study was designed to investigate the experience of having arthritic pain from the children's perspective. Previous research on how Canadian children perceive and manage arthritic pain and how it affects their daily lives is nonexistent. Therefore the purpose of this qualitative descriptive study was to explore and describe the arthritic pain experience of school age children with juvenile rheumatoid arthritis (JRA) and to understand the impact/influence of various factors on the construction of that experience.

Ten children, aged 10 to 13 years, with either early (at 2 to 4 years) or late (at 7 to 11 years) onset arthritis participated in this study. Descriptive data were obtained during two open-ended indepth interviews with the children in their homes. Using content analysis, data were analyzed for themes and their elements. An analytical framework of themes and their elements was developed that reflected the children's descriptions of and explanations for arthritic pain in the context of their day to day

in the context of their day to day living with arthritis, both in the past and currently.

The children perceived pain to be synonymous with arthritis and the mediating factor in how they functioned. They described arthritic pain in relation to distinguishing factors: intensity, duration, and frequency. Intermittent arthritic pain was attributed to cessation of medications, arthritis "flare-ups," inactivity, and activity. A current concern for most children was pain attributed to activity because it meant limitations in activities with peers. The children identified strategies they used to manage pain and cope with pain's unpredictability.

The findings of this study were discussed in relation to selected research studies that either supported or refuted the findings of this study. Implications for nursing practice and research were addressed.

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CHAPTER I: INTRODUCTION

Introduction to Problem and Purpose

This study is an exploration of the experience of arthritic pain for school age children with juvenile rheumatoid arthritis (JRA). A qualitative descriptive approach which sought to understand human experience from the perspective of the children was used.

Pain is a complex, multidimensional, subjective experience that is difficult to define, describe, measure, and control (Beyer & Byers, 1985; Jerrett, 1985). Because pain is subjective and personally experienced, children with similar illnesses or injuries do not seem to experience similar intensity of pain nor do they respond in similar ways (McGrath, 1987). Likewise, severity of illness or injury does not correlate with pain intensity (Beales, 1982). Other factors such as age, cognitive development, anxiety, past pain experiences, and meaning influence children's perceptions of and responses to pain (Beales, Keen, & Holt, 1983a; Beyer & Byers, 1985; Jeans, 1983; Ross & Ross, 1984b; Schultz, 1971; Thompson & Varni, 1986; Wilkinson, 1983).

Until recently, there was little interest in children's pain. Understanding of children's pain was derived from clinical observations, assumptions, intuition, personal beliefs, and generalizations from

the adult literature (Beyer & Byers, 1985; Eland & Anderson, 1977; Jerrett, 1985). Although children's pain research has increased in the past decade, major gaps still exist in our understanding of pain. Most research has focused on acute pain experiences of healthy and/or hospitalized children (Abu-Saad, 1984a, 1984b, 1984c; Gaffney & Dunne, 1986; Jeans, 1983; Jerrett, 1985; Ross & Ross, 1984b; Savedra, Tesler, Ward, Wegner, & Gibbons, 1981; Schultz, 1971; Tesler, Wegner, Savedra, Gibbons, & Ward, 1981).

These research studies have clearly demonstrated that children over the age of seven are able to describe pain, express their feelings about pain, and identify coping strategies used when in pain. Some evidence also exists that children's perceptions of and responses to pain change in some predictable fashion throughout childhood (Beales et al., 1983a; Gaffney & Dunne, 1986; Jeans, 1983).

Few studies have investigated pain associated with juvenile rheumatoid arthritis (Beales et al., 1983a; Laaksonen & Laine, 1961; Scott, Ansell, & Huskisson, 1977). Lacking is research that investigates children's perceptions of and responses to arthritic pain.

For most children, their pain experiences are limited to acute episodes associated with mild traumas

of childhood and the occasional medical/surgical procedure, e.g. injections, sutures. However, for the children who have juvenile rheumatoid arthritis, pain is assumed to be a concomitant facet of the illness (Singsen, Johnson, & Bernstein, 1983).

Arthritis refers to inflammation of the connective tissue of a joint and is characterized by swelling, heat, tenderness, pain or limitation of movement (Brewer et al., 1977). For the diagnosis of JRA to be confirmed, children under age sixteen must have arthritis of one or more joints for at least six weeks. JRA is an unpredictable chronic illness characterized by remissions and exacerbations of unknown duration and severity (Calabro & Londino, 1986). Although its etiology is unknown, JRA occurs most frequently between the ages of one and three, and eight and twelve years (Calabro & Londino, 1986; Williams, 1981). More girls than boys are affected (Beales, 1984).

Although pain is a prominent feature of rheumatoid arthritis (RA) with adults (Skevington, 1986), little is known about the pain experience of children with JRA. Previous research is sparse and inconclusive. Presently there is no common understanding that these children do have pain. In spite of this, health professionals working with these children argue about the extent, presence or absence of arthritic pain.

Disagreement, according to Beyer & Byers (1985), "appears to arise over the meaning of various behaviors as they relate to pain" (p.153). A common behavior observed by the researcher and others (Ansell, 1983; Brewer, Giannini, & Person, 1982; Cassidy, 1982) is that, unlike adults with rheumatoid arthritis, few children with JRA complain of pain. Because children rarely complain, health professionals seldom ask them whether or not they are experiencing pain. Rather health professionals assume that children unless they are complaining, have mild or no pain.

How Canadian children with JRA perceive and manage arthritic pain (if pain exists) and how pain affects their daily lives, has not been documented in the literature to date. Because pain is subjective and personally experienced, only the children who experience it can describe it and articulate the meaning it has for them. It is the children's perspective that is missing from most of the literature.

Therefore, this study investigated the arthritic pain experience of children, age eight to thirteen years, since JRA occurs more frequently in this age group.

Statement of Problem and Purpose

The general problem which this study addressed is the dearth of knowledge about the experience of arthritic pain for children with JRA. Specific questions which guided this study were:

What is the experience of arthritic pain for children with JRA?

1. Do children with JRA experience arthritic pain?

2. How do they perceive arthritic pain?

3. What is their interpretation of it?

4. How does it affect their daily lives?

5. How do they cope with it?

The purpose of this study was to explore and describe the arthritic pain experience of school age children with juvenile rheumatoid arthritis, and to understand the impact/influence of various factors on the construction of that experience.

Definition of Terms

The following terms are defined to clarify their use in this study:

Arthritic pain: Any pain associated with JRA that occurs during the course of the illness.

Children: Girls and/or boys age eight to thirteen years.

Meaning: Significance or sense of pain from the child's perspective as it is experienced within the context of her/his day to day living.

Pain: "Whatever the experiencing [child] says it is, existing whenever she/he says it does" (McCaffery, 1972, p. 11).

Assumptions

This study is based on the following assumptions:

1. Children with JRA are capable of describing what pain is for them, when asked.
2. Children with JRA are capable of giving subjective meaning to their pain experience.
3. Children with JRA are willing to talk with the researcher about their pain experiences.

Limitations

This study recognizes the following limitations:

1. Data collection is dependent upon the ability of the researcher to establish rapport and gain trust with the children and upon the researcher's interviewing skills (Field & Morse, 1985).
2. Depth and richness of the data is conditional upon the availability of informants and time allotted for data collection.
3. Generalizability of findings is restricted to the children participating in this study.

4. Sample is limited to children who had been diagnosed with JRA for a minimum of two years.

Organization of this Thesis

This thesis is organized in the following way. Chapter II is a review of the literature, which provides the theoretical background for this study's problem and purpose. Chapter III is the methodology, including how the children's accounts were constructed. Chapter IV presents the children's accounts of their experience with arthritic pain. Chapter V is a discussion of this study's findings in relation to other selected research studies. Chapter VI is the summary and conclusions.

CHAPTER II: LITERATURE REVIEW

Introduction

The purpose of this literature review is to place this study in the context of previous experiential and research based literature. Furthermore, this literature provides the theoretical background for this study's problem and purpose: to describe the experience of arthritic pain for school age children with juvenile rheumatoid arthritis.

Although children's pain research has increased in the past decade, non acute pain research in children is a neglected area. A review of the literature reveals a paucity of research studies that investigate how children themselves perceive non acute pain, how it affects their daily lives, and how they manage this pain. Specifically, nothing is known about the arthritic pain experience of Canadian school age children with juvenile rheumatoid arthritis (JRA). In this chapter, the literature reviewed pertains to school age children's acute pain experiences and children's arthritic pain experiences.

The literature will be further reviewed in chapter V where the findings of this study will be discussed in relation to other research studies.

School Aged Children's Pain Experience

In this section, literature on what is generally known about children's acute pain experiences will be presented. A review of the literature related to children's pain reveals that most research has focused on measurement of acute pain. Researchers agree that children's pain is difficult to define, describe and measure (Beyer & Byers, 1985; Jerrett, 1985). Methodological difficulties related to measurement arise because of the subjectivity of pain, developmental changes of growing children and other influencing factors (Lavigne, Schulein, & Hahn, 1986; McGrath, 1987).

Despite methodological difficulties related to quantifying pain, recent research has shown that children over the age of seven can communicate verbally about their pain experiences in terms of location, quality, and feelings; and identify coping strategies that they use when in pain (Gaffney & Dunne, 1986; Jeans, 1983; Ross & Ross, 1984; Savedra et al., 1981; Schultz, 1971; Tesler et al., 1981).

Pain as an Experience

Pain is conceptualized in the literature as a complex subjective experience with sensory, cognitive, and affective dimensions (Wilkinson, 1983; Lavigne et al., 1986). As an experience, it includes both

perception and response. Perception, according to Berelson & Steiner (1964), is the process by which individuals organize and interpret sensory stimulation into a meaningful picture of the world. Researchers (Canam, 1980; Strong, 1957) stress that the way individuals perceive themselves in relation to their situations influences how they respond.

According to Piaget & Inhelder (1969), children perceive the world from a unique perspective that is different from adults. The literature suggests that children both perceive and respond to pain differently than do adults (Beales, 1982; Thompson & Varni, 1986), but there is no agreement that children's conceptualizations of pain follow Piaget's discrete stages of cognitive development.

However, there is some evidence of increasing abstraction of pain concepts with increasing age and maturation. Several researchers (Beales, 1983b; Gaffney & Dunne, 1986; Jeans, 1983) have found developmental trends in children's concepts of pain. In a study of 54 healthy children, 5-13 years, Jeans (1983; personal communication, 1987) examined the developmental process in children's pain perceptions. Children's own drawings and interviews were used. She found that between the ages of eleven and thirteen, children's concept of pain moves from a primarily physical idea to incorporate a

more psychological component. Her findings indicate that children's perceptions change in accordance with increasing age and maturation.

Gaffney & Dunne (1986) argue that children's pain perceptions are consonant with Piaget's stages of cognitive development. As a part of a larger qualitative descriptive study in Ireland, Gaffney & Dunne (1986) studied developmental changes in children's pain definitions. Their sample consisted of 680 school children 5 to 14 years with a minimum of 30 boys and girls per year of age. Their sample was divided into three groups: 5 to 7, 8 to 10, and 12 to 14 years to correspond to Piaget's stages of cognitive development. Using an open-ended questionnaire, children were asked to complete this sentence, "Pain is..." (p.106). The questionnaire was administered in school, either verbally to younger children or in written form to older children. Data from the three groups were analyzed for themes and sorted into categories. Categories were binary variables for chi-square analysis to determine significant differences between groups. Results indicated that the children's definitions of pain change from concrete, i.e. "a thing, something," to semi-abstract, i.e. "sensation or feeling," to more abstract, i.e.

physiological or psychological definitions as children increase in age.

Other researchers (Ross & Ross, 1984; Savedra et al., 1981) have found no well defined developmental/age trends in children's descriptions of pain.

Factors Influencing Pain

Most authorities agree that children's pain is influenced by numerous developmental and psychological factors (McGrath, 1987; Thompson, & Varni, 1986; Wilkinson, 1983). Some of those most frequently mentioned are developmental changes, previous pain experience, anxiety/fear, parental attitudes, and meaning (Beales, 1982; Craig, 1983; Willis, Elliott, & Jay, 1982; Wilkinson, 1983). How these factors influence pain is not well understood because research is sparse and inconclusive. An awareness, however, of influencing factors is necessary when studying children's pain.

The literature indicates that because pain is a subjective experience influenced by numerous factors, children's behavioral responses vary. Some authorities point out that children over eight years of age rarely complain of pain (Schultz, 1971; Whaley & Wong, 1983). In a survey study of 74 school children 10 to 11 years of age, Schultz (1971) found that children rarely cried when in pain, rather they tried to appear brave and in

control. Similar findings were reported by Savedra et al. (1981) in their study of healthy and hospitalized children, 9 to 12 years of age. Schultz suggests this lack of emotional expression is the result of children's growing need to maintain control.

McGrath (1987) in her review of children's pain literature, stresses that children's overt behavioral responses are not direct indicators of the quality and intensity of their pain. She further emphasizes that "their behavioral responses are influenced by developmental factors and learning and reflect the totality of their pain experience, the sensory aspects and emotional aspects intrinsic to that experience" (p. 150). Therefore, she cautions against using observations of children's overt behaviors as the sole indicator of their pain. To understand children's overt behaviors, Lavigne et al. (1986) stress that children's subjective experiences should be assessed by asking children themselves about their pain.

The literature clearly indicates the need for research that investigates the qualitative aspects of children's non acute pain experiences to understand their subjective experience and the meaning pain has for them (Jeans, 1983; Lavigne et al., 1986).

Children's Arthritic Pain Experience

In this section, literature related to juvenile rheumatoid arthritis and arthritic pain in children will be reviewed.

Juvenile Rheumatoid Arthritis

The literature related to chronic illness in childhood indicates that the presence of a chronic illness or onset of one during the school age years has implications for developing children (Perrin & Gerrity, 1984; Whaley & Wong, 1983). Juvenile rheumatoid arthritis (JRA) is one such illness that may affect children's physical, social, educational, and emotional growth (Jacobs, 1982; Petty, 1982). According to Petty (1982), JRA is a painful connective tissue disease affecting one or more joints. Although its etiology is unknown, children acquire JRA most frequently between one and three years, and eight and twelve years (Calabro & Londino, 1986; Williams, 1981). More girls than boys are affected (Beales, 1984). Since JRA is a non-reportable disease in Canada, accurate incidence/prevalance statistics are unavailable. (Petty, personal communication, 1987).

For the diagnosis of JRA to be confirmed, children under sixteen must have persistent arthritis in one or more joints for 6 weeks (Jacobs, 1982). Arthritis is defined as "swelling of a joint or limitation of motion

with heat, pain, or tenderness" (Brewer et al., 1977, p. 195).

JRA is a variable chronic illness involving remissions and exacerbations of unpredictable severity and duration (Calabro & Londino, 1986). Prognosis is also variable. In general, most children experience insidious onset arthritis followed by flare-ups and partial remissions; some have persistent arthritis for 5 years or longer; still others have an acute onset involving one or more joints with a complete remission after a few months or years (Brewer et al., 1982).

Arthritic Pain

While pain is a feature of arthritis (Brewer et al., 1977; Petty, 1982), little is known about the pain experience of children with JRA. According to some authors (Ansell, 1983; Brewer et al., 1982; Cassidy, 1982), few children with JRA complain of pain. The literature indicates a scarcity of research that investigates children's arthritic pain experiences.

Two quantitative studies conducted in Finland and England compared joint pain intensity in children with arthritis and adults with arthritis. Laaksonen & Laine's (1961) study was conducted because these researchers observed that children's joints were not as painful as adults. The sample consisted of twenty-four children, 4 to 14 years (8 under 8 years) and thirty

adults, 18 to 51 years. In each group, 95 matched joints were examined for pain using multiple measures such as swelling, active inflammation, range of motion exercises; and pain on movement, on palpation and on weight bearing. These researchers concluded that children experience less joint pain than adults because children react differently to pain.

Similarly, Scott, Ansell & Huskinsson (1977) studied arthritic pain in 100 children, 2 to 17 years and adults. A visual analogue scale (VAS) for pain and 4-point descriptive scale for disease activity and severity were used. The findings indicated that children's scores were lower on the VAS than were adults with similar disease activity and severity. These researchers reported that 11% of children, mostly under 5 years could not complete the VAS.

The findings of these early studies contribute little to understanding children's arthritic pain experiences because they fail to consider developmental differences between children, 2 to 17 years, and adults. These developmental differences and other factors would have influenced how children perceived and responded to pain.

More recently, other British researchers have investigated children's perceptions of arthritic pain and arthritis (Beales, Holt, Keen, & Mellor, 1983a;

Beales, Keen, & Holt, 1983b). Beales et al. (1983a) studied pain perceptions of 39 children with arthritis. The purpose was to explore whether the meaning which children attributed to sensations from damaged joints influenced the level of pain experienced. Sample consisted of two groups: twenty-four 6-11 year olds and fifteen 12-17 year old children. The children varied with respect to joints involved, systemic disease and prognosis. Semi-structured interviews were conducted in the children's homes. The term "pain" was never mentioned. Initially, children selected words that described how their joints felt from a predetermined word list, and then described what the sensations meant to them. Lastly, the children rated unpleasantness and severity of pain on two visual analogue scales. The findings indicated that all children experienced some sensation, e.g. aching, from their arthritic joints. Furthermore, children 12 to 17 years perceived arthritic pain as more severe than did children 6 to 11 years. Children 6 to 11 years did not perceive the aching, sharp, or burning sensations as representing internal pathology, whereas 12 to 17 year old children perceived the sensations as representing internal pathology and reminded them of their restrictions. These researchers concluded that the more children associate joint sensations with internal pathology and

restrictions in activities and ambitions, the more likely children might experience those sensations as pain.

Likewise, Beales et al. (1983b) interviewed 75 children with arthritis, 39 children 6 to 11 years and 36 children 12 to 17 years. Open ended questions (3), children's own drawings, and a visual analogue scale to rate feelings about arthritis were used. Responses to questions: "what he imagined his arthritis to be, how it affected his body, and how it made his body different from that of children who did not have arthritis" (p.482) were categorized. These categories were subjective feeling, surface appearance, motor ability, and internal pathology. Most 6 to 11 year olds drew pictures representing visual structures, while 12 to 17 year olds' pictures represented internal pathology. Their findings showed that children 6 to 11 years perceived arthritis in terms of immediate concrete signs, rather than internal pathology, whereas children 12 to 17 years perceived arthritis in terms of internal pathology and their restrictions as a result of "severe internal damage."

Summary

The literature reviewed has shown that school age children can verbally communicate about their pain experiences. But their perceptions of and responses to

pain are influenced by numerous factors. Research that investigates the experience of having arthritic pain from the children's perspective is scarce. This scarcity supported the need for further study on the qualitative aspects of children's arthritic pain experiences. Therefore, a qualitative study that explored 8 to 12 year old Canadian children's self-statements about arthritic pain, its affect on their daily lives, and how they manage this pain seemed warranted if we were to understand arthritic pain from their perspective.

CHAPTER III: METHODOLOGY

Introduction

The purpose of this study was to explore and describe the experience of arthritic pain for school age children with JRA and to understand the impact/influence of various factors on the construction of that experience. According to Field & Morse (1985), "when there is little information available on a topic, a descriptive qualitative study is appropriate" (p. 14). Therefore, since nothing is known about Canadian children's arthritic pain experience, a qualitative descriptive approach guided the collection and analysis of the data. In this chapter, the process used to collect and analyze the data will be described under the following headings: selection of informants, ethical considerations, data collection, and data analysis.

Selection of Informants

The sampling technique used in this study can be described as purposeful; that is, informants have had a range of experiences with the phenomenon under investigation (Diers, 1979). Thus, the ten children selected have had JRA for two to ten years and also have had sufficient experience with arthritis to know whether pain was a facet of their experience.

Criteria for Selection

Criteria for selection required that informants:

- (a) were between eight and twelve years of age,
- (b) had confirmed juvenile rheumatoid arthritis for a minimum of two years,
- (c) spoke and understood English, and
- (d) resided in the Lower Mainland or on Vancouver Island.

The rationale supporting these criteria was as follows: The first three criteria determined that informants have had sufficient experience with JRA and were able to talk about it. The age range of eight to twelve years coincided with the second onset peak of JRA. In addition, children's cognitive abilities and language skills are adequately developed by age eight. Therefore, they are able to communicate verbally about their pain experience. However, as the study progressed, the age criterion was adjusted to include additional informants age thirteen. The reason for this adjustment will be explained subsequently in the section entitled "Characteristics Of Informants." The fourth and final criterion was the researcher's preference because of time and financial constraints.

The final sample consisted of ten children, aged 10 to 13 years old, who met this study's criteria.

Setting

The sample was obtained from a Vancouver community agency where adults and children are treated for arthritis.

Selection Process

The process by which this sample was obtained will now be described. Early in the research process, it became evident that agency personnel, in addition to parents, acted as gatekeepers for the study population of children. Gatekeepers, according to Becker (1970 cited in Bodgan & Taylor, 1975, p. 31), are those individuals "who have the power to grant access" to the study population. In other words, the researcher had to obtain permission from those in charge before initiating any contact with the study population (Bodgan & Taylor, 1975), children with JRA.

Agency Personnel as Gatekeepers

The approval of the University of British Columbia's Behavioral Science Screening Committee, the Agency's Research Committee, and the Director of the Pediatric Program were obtained prior to contacting the pediatric nurse clinician and social worker to discuss the availability of children who met this study's criteria. Since another pain study with children was in progress at this agency, a decision was made that informants would not be children who had participated

in that study. Subsequently, the social worker and nurse clinician selected twelve potential informants who had been diagnosed as having JRA for a minimum of two years.

As required by the agency, the nurse clinician made initial phone contact with the parents to ascertain their interest in this study and to obtain verbal permission for the researcher to contact them. Three parents did not return the nurse clinician's phone calls, thus indicating to her that they were not interested. These parents were not contacted again.

Parents as Gatekeepers

When verbal permission was obtained from parents, the researcher sent them an introductory letter (Appendix A) and parental consent (Appendix B). This letter and consent introduced the researcher; explained the nature and purpose of the study, method of data collection, procedures involved, time commitment, expectations of the children; and requested permission for their children's voluntary participation. Approximately one week after parents received the letter/consent, the researcher phoned to ascertain the parents' and children's understanding of the study.

Parents' and children's responses varied. The parents' comments made it evident that they had shared the letter with their children and had spent time

discussing the study. Most parents were enthusiastic about their children's participation, but stressed that the children themselves decided to participate. A couple of parents perceived this study to be an opportunity for their children to talk about a difficult topic. Several parents expressed their children's concerns that (a) they would not know what to say and/or (b) they would not know how to draw their affected joints (see Appendix A). In response to the first concern, parents were reassured that, as the researcher was interested in their children's own view of arthritic pain, there were no right or wrong answers. Because the children were anxious about drawing their affected joints, the researcher decided to delete the drawing from this study. Some parents regarded this decision as the researcher's willingness to compromise on behalf of their children. All parents who were contacted by the researcher agreed to their children's participation. During the phone conversations, arrangements were made for consent signing and the first interviews.

Characteristics of Informants

Initially, nine informants were interviewed. Following the first interviews with the youngest informants, aged eight, it was apparent that while they had confirmed JRA, they did not have current JRA

experience. One informant had been in remission for four years; the other informant, according to her mother, had been pain free and in remission for one year. As would be expected, these two informants did not remember what it was like to have JRA and specifically did not remember arthritic pain. Therefore, they were eliminated from this study. Since no additional eight to twelve year old informants were available, the age criterion was adjusted to include additional informants aged thirteen.

The final sample consisted of five girls and five boys who ranged in age from 10.75 to 13.33 years (average 12.5 years). One informant resided in Vancouver; the others resided in smaller communities within a 150 kilometer radius of Vancouver. All spoke and understood English. All informants except one had 1 to 3 siblings; one informant had no siblings.

Informants' arthritis varied with respect to onset, duration, number of and specific joints involved, and degree of disability. The informants had had JRA for 2 to 10 years (average 5.9 years). Age at onset was between 2 and 4 years for three girls and two boys, and between 7 and 11 for two girls and three boys. Of the 10 informants, four had pauciarticular JRA (4 or fewer joints), five had polyarticular JRA (five or more joints), and one had systemic JRA. Five

informants had no visible disabilities, whereas five informants had visible disabilities. According to two informants, aged 12.5 years, they had had no signs of JRA for 1 to 2 years. Nevertheless, they were included in the final sample because their accounts provided another facet of the JRA experience, remission, which contributed to the richness of the data obtained.

Ethical Considerations

As previously stated, approval from the University, the Agency's Research Committee, and the parents was obtained before data collection. The manner by which the children's rights were protected will now be addressed.

1. An introductory letter (Appendix A) and parental consent (Appendix B) sent to parents explicitly stated the nature and purpose of the study, method of data collection, procedures involved, time commitment, expectations of the children, and the risk/benefits. The parents discussed the study with their children and allowed them to decide whether to participate or not.
2. The researcher verbally explained the study to the parent(s) and the children prior to obtaining their written consents.
3. The children's consent (Appendix C) was a simplified version of the parental consent. The

children's consent, which the researcher read to the children, and the parental consent clearly stated that the children could ask questions, refuse to answer questions, and could stop the talks at any time. A request to tape interviews (talks) was also included.

4. Parents were assured that no risk was involved because the researcher would terminate the interview if the children appeared tired, were reluctant to answer questions, or asked to withdraw from the study.

5. Parents (9 mothers, 1 father) and children were provided with a copy of their signed consents.

6. The identities of parents/children were kept confidential by coding the tapes and transcribed data by numbers, not names. These codes were known only to the researcher.

7. Access to tapes was restricted to the researcher, her thesis advisors, and a typist.

8. Consents and tapes were kept locked.

9. Scholarly writing, which will result from this study, will not identify children or parents by name.

Data Collection

Data collection and analysis were conducted concurrently. These two processes were interwoven until data collection was completed. However, for the sake of clarity, data collection will be described first.

Data were collected through a series of 19 open-ended interviews in the children's homes, during a five month period (April - August, 1987). Interviews ranged in length from 30 to 60 minutes. Most frequently, interviews were conducted in the early evening or on weekends because of family commitments (school, work schedules) and the time the researcher required for travel.

Setting/Interview Environment

An informal period preceded each first interview. During this time, the study was further explained and consents were signed. Parents (10 mothers and 5 fathers), children and pets met the researcher. An informal, relaxed, but professional atmosphere prevailed, as the researcher and children became acquainted. Since these children had never participated in a study, they asked questions about the researcher's background and about what they themselves had to offer. In answer to the children's questions, the researcher tried to convey to the children that they were the experts, and therefore that they had something important to contribute to this study (Ross & Ross, 1984a). This was accomplished by talking directly to the children during this informal period.

All interviews were audiotaped. Several children offered to assist in setting up the cassette tape

recorder and PZM microphone. None of the children appeared intimidated by the recording equipment as they either owned a tape recorder or had used one in school. In fact, initially, a couple of children were more knowledgeable than the researcher in the use of this equipment. This working together provided the children with another opportunity to share their knowledge and thus gain the confidence to function effectively in the researcher's presence.

Most children appeared comfortable, but reserved. Judging from parents' comments, such as "my son is afraid he might not know what to say," the researcher anticipated that the children and, to some extent, their parents might be apprehensive once the taped interviews began. Therefore, the objective was to create an atmosphere conducive to openness. The extent to which this objective was met will now be described.

Although the parents' presence at interviews had not been addressed in the introductory letter (Appendix A), this issue was anticipated and did occur. This situation was managed by honoring whatever decision parents and/or children had made. As a result, 6 parents (5 mothers, 1 father) chose to stay, whereas 9 parents (5 mothers, 4 fathers) did not.

Most parents were silent participants, in that they gave their children non-verbal support. On

occasion, however, parents would clarify or contradict what their children were saying. The researcher managed this type of dialogue between parents and children by redirecting the conversation to the children, thus, reassuring them that their perspectives were sought.

The researcher's overall impression was that the parents were interested in their children's participation but supported their children in different ways. One mother suggested that the interview be conducted in the child's bedroom to ensure privacy and a quiet environment. Several parents reassured their children that they were in the next room or outside. Still others left the living room because of other family responsibilities, and to restrict younger siblings and family pets from interrupting the interviews.

The Open-Ended Interview

Cannell & Kahn (1968) describe an interview as "a conversation with a purpose" (p. 526). In this study the purpose was to collect descriptive data on the children's experience of having arthritic pain. To initiate this conversation once the tape recorder was started, a few warm-up questions were used. These questions pertained to favorite activities and family life. All informants found these questions easy to

answer. The purposes of these questions were (a) to instill confidence in the informants that they could answer questions, (b) to obtain some demographic data (number/age of siblings, age/grade of informants), and (c) to check the quality of the tape recording. The informants had been previously told that, after these questions, the tape would be stopped and replayed. This brief replaying of the tape did not seem to have any adverse affects on the informants because they were familiar with their recorded voices. However, it provided a few moments of relaxation before the tape was restarted and the open ended indepth interviews began.

Construction Of Informants' Accounts

The construction of informants' accounts (descriptive data) was accomplished by exploring in depth the experience of arthritic pain from the informants' perspectives. This process involved a dynamic interaction between the researcher and informants, with both taking active roles. The researcher's role, as suggested by Field & Morse (1985), was "to guide the interviews and keep the informants on topic" (p.66). First interviews began with a broad question: What is it like for you to have arthritis? The informants' responses to this question provided the direction for the interview. Other

questions evolved during the interactive process of constructing the children's accounts. In addition, general questions which evolved from the review of the literature and from the researcher's previous experience with children who had arthritis were used. The children's responses were explored using several techniques: reflecting, clarifying, probing, validating, and summarizing. These techniques allowed the informants' stories to unfold naturally. As the researcher became more relaxed and confident with interviewing, specifically listening, giving encouragement (Ummm, tell me more, etc.), and asking the right questions, a richer quality of data was obtained.

The Second Open-ended Interview

Permission to return for a second interview was obtained following each of the first interviews. The purposes of the second interviews with the same informants were (a) to clarify and validate informants' responses from the first interviews, within the accounts and across the accounts, and (b) to further explore the unfolding stories until similar or same responses were heard.

Although the original plan was to interview ten informants twice, second interviews were conducted with nine informants. One informant was not interviewed a

second time because the researcher felt the parents and child had willingly consented to participate at a very inconvenient time for them.

Because of time constraints and a delay in obtaining additional informants, the second interviews were started before the first interviews were finished. The interval between first and second interviews among informants varied from one week to two months because of other commitments. The variable interval, however, did not seem to have any effect on the informants' accounts as they forgot about first interviews and did not think about second interviews. The only differences were their own experiences between interviews. None of the informants asked to change their accounts. Rather their stories (accounts) were consistent, suggesting to the researcher that these accounts represented reality for them. Second interviews ranged in length from 15 minutes to 45 minutes. Following each interview, additional data in the form of field notes were recorded either on audiotape or in a notebook.

Data Analysis

As previously mentioned data analysis and data collection began simultaneously. The two processes were interwoven until data collection was completed. Then the final phase of data analysis was completed

over a period of months. The process by which data were analyzed will now be described.

Initial Phase

The initial phase of data analysis commenced with the first interview and ended when data collection was completed. After each taped interview, each tape was played to gain a sense of how the children described arthritic pain. Then each taped interview was transcribed verbatim onto computer discs. While transcribing the tapes and, subsequently, while reading the transcripts, the researcher looked for recurring themes within and across transcripts.

These recurring themes were noted by color codes in the margin of each transcript. All pieces of data related to each theme were identified, cut, sorted, and put into manilla envelopes according to each theme. The researcher discussed these recurring themes with her thesis advisors.

Final Phase

The final phase of data analysis commenced after data collection was completed. The researcher reread the transcripts while listening to the tapes. Using the themes already identified, the researcher analyzed each theme to describe the elements that were a part of each them. These themes and their elements were organized to provide an analytical framework. That is,

they were organized to show their interrelationships and together described the experience of having arthritic pain. This framework was discussed with thesis advisors.

In the process of writing an outline and organizing the data for chapter IV, analysis continued. Discussing the themes and their elements with friends and thesis advisors helped to clarify the researcher's thinking. Throughout the process of writing chapter IV, analysis continued. The process of data analysis continued until the researcher's analysis and the children's descriptions provided a vivid picture of their experience with arthritic pain.

Summary

This chapter on methodology described the process used to select informants, protect the children's rights, collect and analyze the data. In the next chapter, the informants' (children) accounts will be presented.

CHAPTER IV: THE CHILDREN'S ACCOUNTS

Introduction

In this chapter, the children's accounts of their experience with arthritic pain will be presented. Although each child provided an unique account of her/his daily life with arthritic pain, it is the children's shared experience, unless otherwise stated, that will be presented.

The children's accounts revealed that all children were familiar with arthritic pain. Thus, they did not find it unusual that they might be asked to discuss this topic. But because the researcher did not want to suggest to the children that they should have pain, all first interviews began with this general question: What is it like for you to have arthritis? In responding to this question, all children spontaneously brought up the topic of pain.

R: Can you tell me what it is like for you
to have arthritis?

C: Sometimes, it is painful.

C: Well, it doesn't really bother me much
right now. But a year ago, it really used
to hurt in the morning.

Their responses showed that all children had or did

have intermittent pain that they associated with arthritis. Furthermore, these children equated pain with arthritis and talked about pain and arthritis interchangeably. This notion will be explained later. Therefore, the reader must assume that when the children talk about arthritis, they are also referring to pain.

When the children talked about arthritic pain, they discussed this pain in the context of current and past experience with arthritis. Much of the time, they compared their current experience with their past experience. Thus, the past was viewed as the standard by which they assessed their current pain experience.

The children's accounts showed that the onset of pain changed their lives. Although the 5 children with early onset arthritis (at 2 to 4 years) did not remember their lives before pain, 5 children with late onset arthritis (at 7 to 11 years) recalled the change. Before the onset of pain, they explained that they were free of pain and free to be active.

C: It was just normal, like it is
now [remission]. I didn't have any pain.
I could do things.

C: I was pretty active....Now I am sore a lot.
One child who was a former skater further explained her change in activity this way.

C: I really like skating. I was practicing for my solo, that's when I hurt myself....It really changed cause I can't do the things I like any more...I can't skate any more because of my knees....It just hurts whenever I do something really active.

As a result of this significant change, the children expressed that when in pain, they are limited in activities. Therefore, they perceived pain to be the mediating factor in how they functioned.

This chapter is about this significant event, pain, that changed their lives. Four themes make up this chapter: description of arthritic pain, making sense of arthritic pain, affect on daily lives, and coping with unpredictable arthritic pain.

Description Of Arthritic Pain

In this section, the factors that distinguish arthritic pain will be described. These factors relate to intensity, frequency, and duration. Factors that influence pain will be addressed in the next section.

The children distinguished between arthritic and non arthritic pain. Arthritic pain was perceived to be more intense than other kinds of pain. For example,

one child described the taking of blood specimens as "a pinch," whereas this child referred to arthritic pain as "a punch or a kick." Another child further emphasized the intensity of arthritic pain compared to that of other kinds of pain.

R: What are other kinds of hurting?

C: One is my arthritis hurt. The other one is just a different hurt.

R: What is different about it?

C: It doesn't hurt as much. My arthritis hurt is very painful.

Not only did several children perceive a difference in intensity between arthritic and non arthritic pain; several children also stressed that pain intensity varied between their joints. One child explained.

C: The pain up here (pointing to upper body) I think is lighter, like my shoulders and wrists, but the pain that's in my knees is really heavy. It is like it is worse!

R: Oh, I see. Why do you think that?

C: I imagine that because they have different feelings, like my shoulders have different feelings than my knees. My knees get stiff and they have to have the cracks out and I have to move them up and down but with my shoulders, I just have to move them a little

and the cracks come out....My hips sometimes they get really stiff so my mum stretches them so they get better then too.

R: I understand better now. What about your neck?

C: That never bothers me. I don't hardly know I have arthritis in my neck.

Not only did pain intensity vary between joints, but the children said intensity varied within joints over time. The children identified two types.

One type was acute and brief. According to six children, it came suddenly and without warning. Several children described this pain as "sharp" "shooting." Others used analogies such as "shocks," "a spear," and "getting stung from a bee in my knee." The duration was brief. "It is just bang! Then off! Then bang!" Six children described this pain in graphic detail. For example:

C: If it is hurting really a lot and I step on it [ankle], that when I usually get that shooting pain...it sort of shoots through my ankle...then it is just sore.

C: All of a sudden it is like something stabs into my knees, just like a pain, and then it will stop, and I will get it again in a

couple....Like a spear, but I don't get it often, but it has happened.

C: Sometimes it would get really stiff, then there would be shooting pain. Sometimes when I am bending my knee just lately, it just locks in and really, really hurts [emphasizes the intensity in his voice] for 5 seconds and then it stops!...It is like getting your finger cut off, just total pain.

As these quotes illustrate, this type was characterized by a sudden onset, high intensity, and a brief duration. It occurred either when the children were active or inactive, but less frequently than the other type described by the children.

In contrast, the other type was a long term ache. The children used word descriptors such as "hurts," "sore," "stiff," and "bug" to describe this type of pain. It occurred frequently either during or following periods of inactivity or activity.

C: I get sore in the joints and it is hard to move my joints and it really hurts.

C: After a lot of jumping, running, I get sore, then go stiff.

This type began as gradual soreness that seemed to change over time.

C: ...it started to get gradually a little
sorer...after skating, my ankles would
be really sore.

As indicated, this type was characterized by a gradual onset, lower intensity and a longer duration.

The children's choices of unique word descriptors, analogies, and graphic descriptions show that pain intensity varies over time.

C: Pins and needles, throbbing, you can feel
the joint beating like your heart.

C: ...the pounding in my ankle sort of slows
down and it becomes like a stomach ache...
sort of like when you are hungry and your
stomach growls.

C: Bubbling...boiling...kind of jingling, kind of
weird...The pressure comes up like my skin
is about to explode.

Arthritic pain was intermittent and unpredictable.
The children said it was less frequent currently than
it was in the past.

C: It [pain] comes whenever it wants to.

C: It used to hurt all the time...a long time ago when I first got it. It doesn't hurt all the time now. It doesn't hurt any more...Like right now. Well, I say now cause whenever I do exercises or anything if I just don't do anything. It just doesn't hurt forever. But when I start to do stuff, it starts to hurt.

As indicated, pain was recurring, but perceived to be more frequent and longer lasting in the past. Judging from their comments, duration was also variable and unpredictable.

C: Sometimes it lasts a long time and sometimes it just goes away.

C: It goes away in a minute...a half an hour or sometimes a day.

While their comments indicated that arthritic pain was unpredictable, the children also knew from experience when pain would probably occur and therefore, what factors influenced and changed pain. These factors will be discussed in the next section.

In summary, the children described arthritic pain as feelings located inside their joints that varied in intensity. Distinguishing factors were as follows: arthritic pain was perceived to be more severe than

other kinds of pain; the intensity of pain varied between joints and also within joints over time. The children identified two types, an ache and an acute pain. Arthritic pain was also described as intermittent and unpredictable. But the children knew from experience that certain factors influenced pain. In the next section, the children interpretation of this event, pain, will be presented.

Making Sense of Arthritic Pain

The children viewed their entire pain experience within the context of arthritis as an unpredictable event, from the onset of the first pain episode to the present. In searching over time for information about this mysterious event, they constructed their own explanations to explain the pain. This section is about their search for information and their interpretation of arthritic pain.

As previously mentioned, the onset of pain was a significant event for all children because it changed their lives by limiting their functioning. According to several children who remembered the circumstances at onset, pain alerted them that something unexplainable was happening. For no apparent reason, their joints started to hurt.

C: I woke up in the morning. When I bent down to get something, I fell under my chair. I

had to hold onto my chair to bend down. My knee started hurting and I couldn't bend down. I told my mum the next afternoon. Not only were the children mystified by the unexplainable pain, but because they had no visible signs of pain, they had to convince both their parents and physicians to take their complaints of pain seriously.

C: When I first started having pain, they [several doctors] put it off as "growing pains." The not knowing was the worst part. I did not know what was going on.

C: It was wintertime in grade 5, I would be out in the snow playing. My legs would get tired. My ankles and knees would start hurting. I would come in and my mom would think they were "growing pains" or that I had bashed my knee, but I said no. And it started to get gradually a little sorer so my mum took me to the doctor. The doctor knew I had arthritis so my mum was stunned, like she didn't know what it meant...I didn't really understand cause I was only ten.

Although the diagnosis of arthritis meant something to the doctors and to some extent to their parents, the diagnosis meant nothing to the children because it did not explain the pain. The children had many questions. Several children mentioned that they questioned why pain [arthritis] happened to them.

C: ...how could I get arthritis just by falling on the ice cause I have known a lot of people who have fallen on the ice and they didn't get arthritis.

C: Why me? I always used to wonder why I had to get it and I thought maybe my brother would get it, but it is just strange. Well, why would it have to happen to me, why couldn't it happen to someone else?

Because of their concern for their loss in functioning, they tried to make sense by seeking information that would explain their pain. Two sources of information were television commercials and health professionals. Several children said they watched television commercials to acquire information.

C: When I first found out I had it, I didn't know much about it. I had seen commercials on T.V. advertising for creams for it and I'd keep on watching it and I

thought that I would have to go into a wheelchair and I was kind of scared.

Although television commercials provided information, the children's lack of understanding coupled with their pain only intensified their reactions of fear, shock, and sadness.

C: It is pretty sad....It is sort of scary to think that a 13 year old has it....I thought older people would get it, not someone my age.

R: Other children have told me the same thing. That arthritis is only...

C: For older people. That's what I thought till I got it. I was shocked! Me! I am only 9, 10 years old. I got over it [the shock] but there are times I still want to skate.

Not only did some children seek information from television, but all children sought information from health professionals, particularly physicians. The children learned about arthritis. What the physicians told the children about arthritis helped to explain what was happening to their joints, but it still did not explain the pain.

C: The doctors have told me that it is like when your joint thing has separated and it is not

totally locked and the fluid of arthritis comes in and fills in that joint thing.

In seeking information about pain over time, the children tried to make sense of pain by equating pain with arthritis. That is, the presence of pain meant the presence of arthritis; absence of pain meant the absence of arthritis. One child explained it this way:

C: I don't pay much attention to my arthritis.

R: Ummm.....

C: Sometimes, I think that I don't even have arthritis.

R: Tell me more about that.

C: What do you want to know?

R: I want to know when you don't think you have arthritis, what that is like?

C: It is just like you don't have arthritis when it is not hurting.

R: Ummmm... But when you do have hurting

C: You know you have arthritis.

Although the children tried to make sense of pain by equating it with arthritis, this diagnostic label did not explain the pain. In the absence of information about pain, the children constructed their own explanations. Their interpretation is as follows.

The children tried to make sense of current pain by using past pain as a standard by which they

evaluated their current experience. Past pain was viewed to be more frequent, longer lasting, and more severe than they currently experienced. Such was their view whether they were explaining pain at onset or more recent pain episodes. Furthermore, the unpredictability of pain made making sense of it more difficult.

The children did not seem to blame themselves for pain. Rather they tried to make sense of intermittent pain by linking it to factors that influenced pain. The attributing factors were cessation of medications, disease "flare-ups," inactivity, and activity.

Four children explained that cessation of medications influenced pain. That is, pain occurred when they forgot to take medications or when their medications were being adjusted.

C: Sometimes I forget my pills and my mom reminds me. Because if I forget and I put it off too long I get sore.

Another child tried to make sense of this pain by explaining what she believed happened to her body without medications.

C: My body was adjusting to all this medication and then all of a sudden, no medications. [The body said] where did it go?...I felt lousy. I was drowsy, tired, and dizzy.

All children also explained that pain had occurred in the past when they had "flare-ups" of arthritis. They described this pain as intense, continuous, unrelenting and restrictive.

C: Last summer I was good. I was really loose and walked all over the place. But when my flare-up came, I couldn't walk as far as I could, everything was really sore and it didn't want to go away.

Similarly, the children attributed past pain to inactivity. Most significantly, the children knew by experience that prolonged inactivity changed the intensity of pain. The most severe pain/stiffness attributed to inactivity occurred upon rising which the children commonly referred to as morning stiffness. Currently, two children experienced it; but all children "remembered what it was like" because it meant limitations in daily home routines as well as in physical activities with peers. One child explained.

C: Well, it doesn't really bother me much right now. But a year ago, it really used to hurt in the morning. I couldn't get up and I couldn't do any sports.

R: Can you tell me what that was like?

C: Well, it really hurt (face grimace - hands on knees)...[now] my knees aren't stiff in

the morning and they don't hurt all the time. Two children explained why morning stiffness occurred.

R: Do you have any pain at night?

C: No, I don't cause I just sleep, but sometimes when I get up, it is sore for me to walk cause I am nice and comfey in bed, crunched up. I have to get loose which is hard sometimes.

C: When you first get up, it hurts because you forgot about it cause you were sleeping. When you get up, it hurts. Then you start to remember what it is like.

Not only did the children attribute past pain to inactivity and disease "flare-ups," the children also attributed past and current pain to activity. Eight children explained that pain occurred currently when they were active.

C: I didn't have any pain at all, then I would start running for at least 10 to 20 minutes and I would start to feel pain.

C: It just hurts whenever I do something active.

C: When I am active, it starts hurting. It always happens then.

According to the children, "active" denoted any joint movement, but most frequently referred to activities such as walking, running, or playing games.

Furthermore, the children explained that activity changed the intensity of pain over time. In other words, the children knew the more active they were, the more intense their pain.

C: If I have a sore ankle and I go and run on it, it will hurt more...

C: ...it started to get gradually a little sorer...after skating, my ankles would be really sore, I couldn't stand up.

While the children attributed pain to certain factors that influenced it, they also tried to make sense of the variation in intensity between joints, and within joints over time by explaining what was happening inside their joints.

C: ...they have different feelings, like my shoulders have different feelings than my knees.

C: I participated in every sport I could. My ankle killed. Tremendous pain, like there is some kind of blockage, I guess and it won't let the pain out until it (pause) when

it does, it really kills.

C: [Pain is] fluid that is hitting your bones
or it is going through very fast.

C: ...when my knees hurt when I walk, I think
that my joints have a red dot in them that
is trying to eat my bone and trying to make
me not walk any more.

Thus, these children tried to make sense of pain by
attributing it to external factors and disease
"flareups," but also thinking about what was happening
inside their joints that would change pain and limit
their activities.

In summary, the children viewed arthritic pain as
an unpredictable event, from onset of first pain
episode to the present time. In trying to make sense of
intermittent pain over time, they had come to terms
with pain by constructing their own explanations.
While they didn't always have pain, they tried to make
sense of pain by (a) equating it with arthritis,
(b) using past pain as a standard to evaluate current
pain (c) attributing it to cessation of medications,
disease "flare-ups," inactivity, and activity, and (d)
by imagining what was happening inside their joints to
cause pain and limit their functioning. For these

children currently, being "active" meant pain; pain meant limitations. The next section is about arthritic pain as it relates to the children's activities with peers.

Affect on Daily Lives

What was a current concern for most children was pain attributed to activity because of its meaning for them. Pain meant limitations in activities with peers. The children knew their limitations. Sometimes, when pain free, they chose to exceed their limits and move through pain. This section is about their limitations and their choices.

The children set their own limits.

C: I like my teachers not to know too much about arthritis so they don't let me do stuff, but enough about it to know, I have my own limits.

C: I refuse to be babied, I refuse to be pushed. Whether or not they participated in activities with peers depended upon the choices they made. Pain was a deterrent.

C: I can't do sports. I can't play with my friends. Whatever they do, I can't. I can't play soccer with them or baseball. If I try to do something, it hurts.

Although pain was a deterrent, other factors influenced their choices. These were past experience and the desire to participate in activities as do their peers.

R: How do you decide whether you will take P.E. or not?

C: If it is something I can do, then I will try and do it. But like last year, I didn't take gym because they just did stuff like soccer, basketball, and volley ball. I can't do volleyball because of my wrists cause that hurts when I get banged with that [ball].

C: I can't participate in sports and things like basketball, running and Sport's Day.

R: Because of?

C: Like I hurt my ankle, so if I run at all my ankle always hurts.

As indicated, past experience influenced their choices. The children knew from experience what sports influenced pain. Gymnastics and ball games were frequently mentioned. These were the sports in which all children desired to participate.

When pain free, the children made choices. Some children chose to participate in badminton, tag, discus, and sometimes, in trampoline. These activities were within their limits.

Some children chose to modify sports. Some modifications involved the cooperation of their peers.

C: I like P.E. because a lot of times they play baseball and I have a runner for me. He stays at the base, I hit it [ball], and he runs for me.

At other times, the children themselves made the necessary modifications.

C: Well, I can sort of join basketball cause I did in cottage games. Yes, I can join basketball cause I am right under the net and the boy passes it [ball] to me and I just shoot and it goes in [the basket].

C: Throwing the discus, the javelin...I don't have to bend down. I just bring my arms back and swing them forward and then let it go and then it works.

These quotes illustrate how the children and their peers chose to modify activities so that they could participate.

Some children chose to test their limits by participating in activities that they knew might eventually result in pain.

C: I have been skateboarding for about two weeks and it just started hurting now.

R: So it doesn't hurt every time you do it?

C: No, just if I keep doing it for a long time,
it will eventually, probably get sore.

C: I like dancing so I will go to all the
dances and just see what happens. Sometimes
it hurts and sometimes it doesn't hurt.

Although the children tried to participate as much as
possible, much of the time, pain limited their
activities.

C: I can run, but after a while it get sore
and I have to stop.

C: I really wanted to go out and play, but I
would have to sit on the stage cause we
had all the ropes out, the trampoline, and
we would have the apparatus out. I would
sit there...I really wanted to go out and
play...But I couldn't cause it [ankle] would
start hurting.

The children expressed that they felt sad and strange
when unable to participate as did their peers.

C: It bugs me because I can't do a lot of things
like the other kids do...

C: It is really upsetting because I can't do a

lot of sports at school.

C: It makes me feel like I am really strange.

When the children felt left out, different and wanted to participated in an activity, they frequently chose to exceed their limits and move through pain.

C: One day I felt so left out that I went and did it [gymnastics]...

C: I had Sport's Day. I participated in every sport I could. My ankle killed!

C: I tried to play soccer with a real soccer ball. I was the goalie cause I thought I would be protected....the ball ran against my knee and it hurt so.

As previously mentioned, the children knew from experience that prolonged activity resulted in severe pain. Thus pain meant limitations.

C: I was at a dance so it started bothering me. I was dancing alot...It [pain] was in my ankle...like a pounding...like I couldn't really walk with it so I sort of limped along.

C: Sometimes I can't do what I want to do. What

everyone else is doing because I can't walk
sometimes because of my ankles.

To summarize, all children yearned to participate in physical education (P.E.), particularly in sports such as basketball, volleyball, and track and field both in school and in other activities with peers after school. For these children, however, activity meant pain and pain meant limitations in activities at a crucial period in their lives when these children were striving to participate in the same activities as their peers.

In the next section, how these children managed arthritic pain and incorporated it into their daily lives will be discussed.

Coping with Unpredictable Arthritic Pain

These children had experienced intermittent, recurring arthritic pain for 2 to 10 years. Thus, they had come to terms with their pain. As they explained, they had "learned to lived with it." "I deal with it the best I can. That's the only thing I can do." By living with arthritic pain, they had learned to manage their pain and seek assistance when necessary. Furthermore they had learned to cope with unpredictable pain by incorporating it into their day to day living.

C: If they [doctors] don't find a cure, find
something like Aspirin or Naproxen or

something that will work, it is just going to be there, so you might as well get on with it.

In this section, how the children managed arthritic pain and coped with its unpredictability will be addressed.

The children managed pain using a variety of strategies. While the children indicated that health professionals recommended strategies, their accounts clearly showed that they themselves decided which of those strategies were more effective for them and as well, they developed their own strategies. Thus, the children used a combination of both physical and psychosocial strategies to manage pain.

Physical strategies involved direct action. Taking medications was the most frequently mentioned physical strategy for controlling pain.

C: My Naproxen which I take, helps.

C: I am on Aspirin, it usually helps. I take 2 in the morning, 3 at lunch and 3 at night.... I tried a lot of medications but most gave me stomach aches. These are coated Aspirin so I don't get stomach aches.

As indicated, all children were knowledgeable about what and when "pills"/"medicines" were taken. Most parents, however, assisted in administering them.

R: What medications are you on?

C: Entrophen 10, Palaform, Naproxen, Vitamin C, Multi-vitamins, Entrophen 5, and Methyltreaxate.

R: Who gets them ready for you?

C: My Dad or Mom.

R: Do your medications help your hurting?

C: Sometimes.

The children were prescribed 1 to 10 medications daily; two children also mentioned they were on Gold injections. One child explained how he encouraged his mother to administer Gold injections to him.

R: What medications are you on?

C: Plaquinol, Tolectin, eye drops, I forgot the name of the eye drops and Gold. I get needles...my Mom gives them to me....I got them at the family doctor. I thought it was a real drag that every week, I had to go there, so I said to my Mom why don't you let them teach you how to do it and they did. Now she is giving them to me.

Because this child's mother administered his weekly Gold injection, this child was able to incorporate this weekly medical regimen into his daily life. This is one example of how treatment was modified in the children's families so that life became as normal as possible.

Although the children knew from experience that cessation of medications resulted in pain, as previously mentioned, they also learned from experience that while medications helped control pain, they did not necessarily eliminate it.

C: After I started taking medicine for about 5 months, I didn't feel any pain, but it was still there.

R: How did you know it was still there?

C: Cause I would bend down, it would be a little sore...

When taking medications did not entirely eliminate the pain, the children used additional strategies.

Eight children reported that they soaked in a warm tub in the mornings, either currently or in the past, to relieve pain (stiffness).

C: Take my pills, then have a bath.

R: You also mentioned some stiffness. Did a warm bath help get rid of stiffness?

C: It just helped to soothe it so I could move it [ankle] a bit more.

R: Did it get rid of the hurting?

C: A bit.

C: I'd soak in the tub for a half an hour because I was so sore, well not sore, but stiff....

That was before I got my waterbed. Now I am fine.

As indicated, sleeping on a waterbed was seen as very effective in eliminating night pain and morning stiffness. Five children slept on waterbeds; three children credited waterbeds with eliminating pain/stiffness attributed to prolonged inactivity. Two children provided rationale for sleeping on a waterbed.

C: A waterbed helps a lot.

R: Why do you think it helps?

C: On a normal bed, I can't move my knees around. They get really stiff when they are in one place for a long period of time.

C: It is warm. You can't move around easy, but it...fits the shape cause you just sink in. The combination of buoyancy and warmth seem to soothe the children's sore, stiff joints.

Although health professionals suggested the application of heat, not all children found this effective.

C: They [health professionals] say to put heat on it [joint]. That doesn't usually help. Ice is better.

Six children found ice more effective in relieving swelling and pain.

R: When your [joints] hurt, what helps?

C: I stop pain by putting ice on it.

However, two children felt that the cold made pain worse.

R: Some boys and girls tell me that using ice helps.

C: Well, it doesn't help me. I don't bother with it. Like you take these peas and you put them on and that makes them hurt more and they get all frozen like....Actually I go to my room and lie on my waterbed.

C: I think the cold makes my pain worse.

When I go in a warm pool [physio], I always feel better afterwards.

The children's statements reflected that not only did these children know from experience what strategies were effective for them, but they also provided the rationale for their decisions when they differed from health professionals' suggestions.

Two children indicated that application of creams helped to soothe painful joints.

R: You mentioned something called A5-35 last time.

C: A5-3-5.

R: Could you tell me what that is?

C: It is a cream. It is like Absorbine Junior.
It is for aching muscles.

R: What does it do?

C: Well, it feels like heating and then it helps.
Massaging was also soothing.

C: I just move the cap [knee] around. That
sometimes slows, makes it not hurt so much.

As would be expected, most of these strategies
were carried out at home. Because the children spent
much of their time outside the home, i.e. at school,
these children developed other strategies that they
used either at school or at home.

Six children found that "resting" such as "sitting
down," "putting a painful joint up," and "relaxing" was
helpful.

C: I stop pain by relaxing [hands when writing].

C: Usually if I get off my feet or my ankle and
just rest them for awhile, it [pain] usually
goes away.

They emphasized, however, that it took time for pain to
resolve.

C: I just sit down, but it [pain] still doesn't
go away, it still takes maybe 45 minutes for
it to go away.

In contrast, two children stressed that "sitting down" made pain worse.

C: Sometimes I just slow down and I keep on walking. Sometimes just sitting down makes it worse, right. I just stretch my knees out.

C: I was at a dance so it started bothering me. But if I sit down for awhile and relax it and I let it stay still, then it stiffens up again so I keep moving it while I am sitting down. Some of these children seemed caught in a double bind, as sitting down to rest a joint resulted in stiffness (pain), whereas continuing the activity, also resulted in pain. But as indicated, a few children dealt with this predicament either by slowing down or by frequently changing positions.

Eight children talked about changing positions and exercising the joint.

C: I always sit with my legs out, then my legs cramped stretched. I have to bend them. It stops the pain.

C: My left knee would hurt in the day time if I twisted it wrongly. So I would be limping a bit. It [pain] would go away after awhile, but it doesn't usually until I am sitting on

the couch watching T.V., going up and down
with my knee and then it goes away.

These quotes represent the wide range of physical strategies used by the children to relieve their pain. The most frequently mentioned direct action strategies were taking medications and warm baths, sleeping on a waterbed, icing, changing positions and resting their joints. Not only did the children use physical strategies, but they also used a number of psychosocial strategies.

The children's accounts showed that all children cognitively managed pain by distraction, that is, "forgetting about it," and thinking about other things, not only when in pain, but also when pain free.

C: Forget about it....If I sometimes think about something else, it sometimes goes away.

C: I try to keep my mind off it [pain] as much as possible. I will think of spring days.

C: I just ignore it or try to ignore it.

C: I just try to forget about it cause it is over with.

One child distracted herself by using imagery.

C: I try to think about pain in funny ways so I

forget about it....When I am sore, I just think about the little men inside of me trying to get out with picks and forks digging. When I am not, I just don't think about it [pain]. Several children ignored pain by "reading," "watching T.V.," and "listening to music."

C: I will sit down and read a book and get all caught up in the book and not think about it [pain].

C: If my hips are hurting, I can't walk. I just sit and watch T.V.

Positive thinking was another strategy used by several of the children. By maintaining a positive attitude, these children tried to remain positive and accepting of their situations.

C: It can be a perfectly nice day and I can be up in spirits, but when I start getting pain, I slowly float downward. If it comes on really suddenly, I really go down in the dumps [voice trails off]. I try to keep my happiness. If I start getting it [voice raised], I keep pushing. I deal with it the best I can.

"Wishing" away pain was mentioned by one child.

C: I wish it [pain] would go away, you know,

cause it is very painful. I am sitting there going please go away, you know. And um sometimes it's sore a lot and I wish it wasn't really there. I try to overlook it.

"Hoping" for a cure was also frequently mentioned. That is, hope for a future free of pain.

C: I am still hoping that maybe it will go one day, but there is a bit of a doubt that I will always have it so I am trying to live with it the best I can....I do not want to keep my hopes up, but I am still hoping that maybe there will be a cure.

Most children, while they hoped for a cure, also believed that pain, would eventually be resolved at age "sixteen," "eighteen," "twenty," or at "puberty."

Despite the wide range of strategies that the children used to manage pain, no strategy was effective all the time. Rather, the children knew that "sometimes there is not much you can do" or "nothing helped." While the children seemed powerless at times to alleviate pain, they nevertheless had a supportive network that gave them support and assistance when necessary.

All children found their parents supportive. The children stressed that parents assisted them to live as normally as possible. Not only did parents assist with

pain management, but also with activities of daily living that were affected by pain.

C: [Parents] they feel I am like the rest of the kids and they know I can do almost what other kids do, so if I can't they will try to help me.

Although eight children mentioned that they rarely required assistance with activities of daily living at home, two children stressed that their parents' assistance was essential to their functioning, especially in the mornings.

R: What happens when you get up in the morning?

C: I feel stiff and sore, it is hard for me to get up off the bed....My Mom sort of maneuvers me into the bathtub cause I can't move as well as I can after my bath....My Mom helps me to get dressed sometimes...Then I go do my exercises. My Mom stretches my shoulders and bends my knees....And then my Mom drives me to school.

C: Some days my arthritis is real bad so I get my Dad to carry me...My Dad built a trailer and I just drive my scooter up on it and my Mom drives me to school.

As indicated, parents acted as facilitators in assisting their children to function not only at home, but also to attend school.

Another child commented that parental support meant doing activities together as a family. Once again, the family acted as a facilitator in helping this child to normalize within the protective environment of the family.

C: I like to ski. I can do that with my family.

When I was younger, the first time I started skiing was with my Dad. I thought I couldn't do it. I felt sorry for myself. Well, I have arthritis and I can't do anything. Everybody would take pity of me. Then my Dad like he didn't get mad at me, he just left me there and I did it myself. I was sort of proud of myself and I loved it.

To summarize, these quotes illustrate how parents assisted their children to live as normally as possible.

Not only were parents supportive, most children found their friends supportive. While most friends did not know much about arthritic pain they understood that the children were limited in activities because of pain.

C: They know I can't do a lot of sports and

sometimes I will have to stop what I am doing.

C: If the kids are skateboarding and I am sitting there wishing my arthritis would go away so I can do skateboarding, they [friends] know I am depressed about something. So they stop skateboarding and they come over and talk to me about something. And then I get up and walk with them while they are skateboarding and they talk to me. And they tell me to throw the ball so they can catch it while they are stateboarding so that makes me feel better.

Furthermore, most children indicated that friends provided assistance when needed.

C: I think it is important that my friends help me with the things I can't do.

C: Sometimes they [friends] help me, like at a party, and we have to walk awhile, then they usually help me walk. Some don't know I have arthritis.

C: My friend helps me up a lot of times if we are out on the field cause I can't bend my hands back to lift myself up.

While most children talked about supportive relationships with friends, five children also stressed the importance of knowing others who have pain.

C: Some of my friends have it so they sort of know what it feels like to have pain.

R: What kind of things would you talk about?

C: Well, they know that I have arthritis. I told them what kind of pain I have and usually they tell me what kind of pain they have. But they still go and run and do everything they can.

C: Cause I know what they are going through and they know what I am going through.

These quotes show that knowing others with pain provided the children with a common bond of understanding. This common bond of knowing what each other was experiencing without having to explain or hide their feelings or their pain, encouraged these children to be themselves.

In contrast, the children's accounts showed that sometimes the children passively accepted pain. That is, they rarely complained.

C: If I have pain at school, I just grin and bear it.

Several children explained why they don't complain.

C: I don't complain because it hurts. I don't

really tell anyone, cause if it hurts, it hurts. And I always think it is going to go away anyway.

These quotes, above and below, suggest that the children have learned to manage their own pain, but also they wanted to be believed when they said they have pain.

C: I don't complain cause I have lived with it for so long. I hate being a complainer because if you complain a lot (pause) you have heard of the boy who cried wolf....I don't want to do that. I want people to trust me. (pause) When I do tell my Mom it's pain, she knows that I am having really bad pain.

To summarize, the children tried to manage their pain on their own but when this was not effective they sought support and assistance from their parents.

C: If it is really bad. I go Mom, "I need some ice or something." She will try and help me as much as possible.

C: I just tell my Dad or Mom that it hurts.
That's it.

When the children knew that their efforts and those of their parents failed to alleviate severe pain,

then medical treatment was required to eliminate their unmanageable pain.

The children talked about two kinds of treatment. One kind involved physiotherapists.

C: Last summer I was really loose and I walked around all over the place. But when my flare-up came, I couldn't walk as far as I could. Everything was really sore and it didn't want to go away. So I had to go to physio and get exercises and serial casting. The other kind involved physicians, either for medication changes or most frequently, for joint aspiration and injection of steroids.

C: You can be put on these other pills, but I tried it and I had a reaction to them so they decided to inject my joint. The children sometimes referred to this treatment as having their joints "injected" and "drained."

C: ...they [doctors] injected my left knee...with Cortisone.

R: And that was because of?

C: They were all swollen and it was really hurting me. And that made them go down again.

Most children stressed that they had experienced this treatment at least once and for some children,

frequently. It was either done at the centre or in the hospital.

C: I had the fluid taken out three months ago out of my knees and just last month, I had it taken out of my wrists and my ankles. The knees I had done at the centre and the other two, I had done at the hospital.

R: And you had it taken out because?

C: Because of stiffness and pain.

One child described the treatment as she experienced it.

C: I went over to the hospital and went to [physio] therapy. They [doctors] drained my knees and it hurt, the big needle. But after that, it hurt while they were doing it, but when I got back to the room, I was kind of bending down, crouching down. It felt good cause they took a lot out. I was just moving around and it was a lot better.

Most children found this treatment eliminated pain in their joint(s). Thus, for an unpredictable interval they were pain free and free to be "active."

C: Now I got my ankles and wrists drained, I can do most things.

C: I had the injections in January and then a

couple of months after that, it [pain] just started to come on slowly.

When pain free, the children coped with pain's unpredictability by living as normally as possible. By normalizing within their limits, they caught up with what they had missed when pain limited their functioning. Furthermore, they coped by focusing on the present. It seemed they lived moment to moment. Although pain was intermittent and unpredictable, they knew from experience that certain factors influenced arthritic pain. Hence, knowing this they learned to incorporate in their daily lives, intermittent, unpredictable pain.

Summary

In this chapter, the children's accounts of their experience with arthritic pain were presented. This study found that these ten children with early and late onset arthritis experienced intermittent, recurring pain that limited their activities with peers at a crucial period in their lives when they were striving to participate in the same activities as their peers.

This study found that these children discussed arthritic pain within the context of their past and current experience with arthritis. Past experience with pain influenced their perception of current arthritic pain. Past arthritic pain was viewed to be more

severe, more frequent, and longer lasting than currently experienced. Likewise, these children differentiated between arthritic pain and non-arthritic pain. Arthritic pain was perceived to be greater in intensity than externally induced pains. All children described arthritic pain as feelings located in their joints that hurt. Frequency and duration were unpredictable. In addition, pain intensity varied between their joints and within joints over time.

The children described two types of arthritic pain. One type was described as brief, but excruciating. The other type was described as gradual, beginning as an ache and increasing in intensity with increasing activity. The children also used a variety of unique word descriptors, analogies and graphic descriptions to show that arthritic pain varies in intensity over time.

This study found that these children viewed arthritic pain as an unpredictable event, from onset of the first pain episode to the present. Pain was perceived to be synonymous with arthritis and the mediating factor in how the children functioned. Absence of pain suggested absence of arthritis; presence of pain suggested presence of arthritis. The children tried to make sense of pain by attributing it

to absence of medications, disease "flare-ups," inactivity, and activity.

All children viewed their limitations in activities with peers similarly. That is, both girls and boys longed to participate in sports such as baseball, basketball, volleyball, and track and field in P.E. This study found that these children knew their limitations. They chose whether or not to participate in sports and risk pain. Factors influencing their choices were past experience and desire to participate with their peers.

By living with arthritic pain for 2 to 10 years, these children had learned to manage their own pain and seek assistance when necessary. This study found that with the support of their parents, peers and others, these children developed a wide range of strategies to manage pain. In conclusion, this study also found that when these children were pain free, they coped with pain's unpredictability by living as normally as possible. As one child stated: "the best cure for kids with arthritis [pain] is just forgetting they have it."

In the next chapter, the findings of this study will be discussed in relation to the findings of other selected research studies.

CHAPTER V: DISCUSSION OF FINDINGS

Introduction

The purpose of this chapter is to discuss the findings of this study in relation to previous research findings. Some of the research based literature discussed in Chapter II will also be discussed in this chapter. In addition, other research which either supports or contradicts these findings will be reviewed. Previous research from the children's perspective is limited. This chapter is organized in the same manner as Chapter IV, but only the major findings in each section will be discussed here.

Description of Arthritic Pain

The children in this study were able to describe arthritic pain in relation to location, intensity, duration, and frequency. The findings of the current study to be discussed in this section are consistent with previous research on children's pain.

Several previous studies investigated how school age children describe acute pain (Gaffney & Dunne, 1986; Jeans, 1983; Ross & Ross, 1984; Savedra et al, 1981). Savedra et al. (1981) studied 114 healthy children's and 100 hospitalized children's, 9 to 12 years, descriptions of acute pain. Using a short answer/forced choice questionnaire, children were asked

about causes, words to describe pain, feelings when in pain and purpose of pain. The written questionnaires were administered to the entire grade at one time and separately to hospitalized children between the 2nd. and 7th. day of hospitalization. The researchers found differences in healthy and hospitalized children's descriptions of pain. Healthy children listed external causes related to everyday occurrences such as being hit, falling, etc. whereas hospitalized children listed physical internal causes related to illnesses or treatment. In addition, the children in both groups selected words, from a predetermined list, that described pain along sensory, affective, and evaluative dimensions. Limitations: The questionnaire used was not clearly described. While a forced choice written questionnaire may be easier to administer to groups of children, it allows little opportunity for the children to explain or elaborate on their answers. Furthermore, the quality of the children's answers may be influenced by their comprehension and writing skills.

Similarly, in an extensive descriptive study, Ross & Ross (1984) investigated school age children's knowledge and understanding of acute/chronic pain. The sample consisted of 974 American children, 9 to 12 years, with/without health problems. Children were assigned to 4 major groups; the first 3 groups were

representative of an urban school age population in California. The 4th. group consisted of 6 subgroups of children with chronic pain. Semi-structured taped interviews were conducted with the children individually in schools, hospital or clinics. A basic set of open-ended questions developed for this study was asked of all children. Additional questions related to specific painful conditions were asked of each subgroup, for example, children with headaches. Test/retest reliability was established by interviewing 24 children twice within 10 days by two interviewers naive to the study. The answers were almost identical. Interviews were audiotaped. Data were analyzed according to predetermined categories. Interrater reliability was 98.7%. The findings suggest that the children had little opportunity to learn about pain. The children's pain definitions were unidimensional, with 80.9% stressing general discomfort and 12.2% related to specific pains such as stomach aches. The children used a number of word descriptors such as "stabbing, burning, squeezing, jabbing, dull, and agonizing" (p. 184) as well as analogies and graphic illustrations. These researchers also found that a few children described pain by discriminative comparisons and quantification.

Similarly, the current study found that children were able to distinguish pain intensity between arthritic and non arthritic pain, between their joints and within joints over time. In addition, the children used a variety of word descriptors, analogies and graphic illustrations that shows pain varies over time. Another finding of the current study was that the children described about two types of arthritic pain distinguishable by intensity and duration. One type was a long term ache described as "sore," by the majority of children and the other was an acute brief pain described by six children using word descriptors such as "sharp" and "shooting," analogies such as "like a spear," and graphic illustrations that reflected the intensity of this pain.

Previous research on arthritic pain from the children's perspective is scarce. One study discussed in chapter II was conducted by Beales et al. (1983a) in Ireland. The 39 children, 6 to 17 years, who participated were asked to select words from a predetermined word list that described how their joints felt. All of the children reported some feeling from their involved joints. All 39 children reported an "aching" feeling in their joints, whereas 50% of 6 to 11 year olds and 53% of 12 to 17 year old children reported reported a "sharp" sensation such as "cut,"

"pricked," "smacked," or "pinched." Few of the children in the current study used the same word descriptors as did the children in Beales's study to describe their pain. The difference in words used by the children in Canada and children in Ireland to describe arthritic pain may be a function of culture or the result of limitations imposed by a forced choice predetermined word list used in Beales et al.'s study.

To summarize, the findings of the current study are consistent with previous research that has demonstrated that children describe pain in a variety of ways.

Making Sense of Arthritic Pain

This study found that the children viewed their entire pain experience as an unpredictable event, from the onset of the first pain episode to the present. The onset of pain and subsequent diagnosis of arthritis changed their lives. This change represented a loss in functioning. The children who remembered the onset of pain talked about being mystified by the unexplainable pain. The children recalled initial reactions of shock, fear, and sadness. Several children questioned "why me"? They did not blame themselves for pain.

This study found that even children search for information that will explain their pain. Lacking information, children construct their own explanations.

The children in this study attributed intermittent pain episodes to immediate happenings in their environment that they experienced and could explain such as cessation of medications, disease "flare-ups," inactivity, and activity. This finding is similar to that of Ross & Ross (1984) who found that children attributed specific pain experiences to immediate causes such as accidents (36.3%), environmental factors (11.3%) and illnesses (11.3%).

Children at this age, 11 to 13 years, are beginning to conceptualize unseen events such as pain that are beyond their immediate concrete environment. The finding of this study is congruent with Jeans (1983) and Gaffney & Dunne (1986). Jeans found that between the age of 11 and 13 years, children's conceptualizations of pain move from concrete to semi-abstract ideas. Similarly, Gaffney & Dunne (1986) found that children's pain definitions change from concrete, i.e. "a thing, something," to semi-abstract, i.e. "sensation or feeling," to more abstract as children increase in age. Children in the current study conceptualized pain as feelings located inside their joints that varied in intensity over time. The children also explained what was happening inside their joints to cause pain in concrete terms such as "some kind of blockage."

As previously mentioned, children in Beales et al. (1983a) study were asked what the feelings in their joints meant to them. Children 6 to 11 years did not perceive these feelings as representing internal damage, but children, 12 to 17 years reported that the feelings "reminded them of their disabling condition, i.e. represented the unpleasant implications of their arthritis" (p.63). Feelings in their joints were interpreted as damage in the joint. In contrast, none of the children in the current study perceived the different feelings in their joints to be the result of severe internal damage. None of the children mentioned the term "damaged." Children in the current study attributed pain to external factors such as inactivity and activity and to the disease itself. While the children wondered about what was happening inside their joints, they nonchalantly explained the internal happenings in concrete terms and did not dwell on this aspect of pain.

This current study also found that children's view of arthritic pain changes over time. These children viewed past pain to be more painful, more frequent, and longer lasting than what they experienced currently. The children used their past pain experiences as a standard by which they evaluated pain currently. The

current findings are consistent with the findings of recent research on children's perceptions of pain.

Lollar, Smits & Patterson (1982) found differences in children's perception of pain when children rated their own pain experiences against their past pain experiences. Two hundred and forty children, 4 to 19 years, participated in this study. The children were asked to rate their pain experiences using The Pediatric Pain Inventory, a projective instrument, developed by these researchers. This instrument consists of 24 pictures representing a range of potentially pain evoking situations in 4 settings: common activities of daily living, recreational, medical, and psychosocial. Some pictures project more severe pain than others and some project pain of greater duration. The subjects were asked initially a series of forced choice demographic questions to obtain information on number of hospitalizations, illnesses, and school attendance related to illness. As part of the study, the children were asked to rate the pictures on the perceived intensity and duration of the pain. Intensity of pain was measured by sorting the 24 pictures according to a 3 color scale, with red, yellow, and green representing respectively "much," "some," and "little" pain. Children were then asked to choose the pain intensity group that represented the

most pain that they had experienced. Differences were found among children who described their own pain experiences as "much," "some," and "little." The children who reported little past pain experience rated all categories of current pain as more painful than did children who reported much or the some level of past pain.

In contrast, Jerrett, (1985) argues that the more recent the pain experience, the more intense the perception of pain. This finding may be explained by looking at the ages of the children in Jerrett's study. The children who participated were between 5 and 9 years old and were attending an ENT clinic. Young children with acute pain such as ear aches may have forgotten about past pain, only remembering the current acute pain episode, whereas the children in this current study interpreted past pain as more severe because of the impact it had on their lives. The significance of intermittent pain, that is, the change in their functioning may have influenced their perception of pain. Furthermore, the children's interpretation of current arthritic pain as less severe than past pain is a positive strategy for dealing with long term pain.

According to McGrath (1987), children judge each new pain against past pain experiences. She suggests

that as the diversity and intensity of the pain experiences increase, than pains that are more common tend to be perceived as less severe and unpleasant. This suggests that known pain is perceived differently from unknown pain.

The finding of the current study that children interpret current pain as less painful, less frequent, and of shorter duration than in the past may be a function of the intensity of their own pain experiences, their age, and their concept of time. This finding also suggests that these children are optimistic about their current pain experiences.

Affect on Daily Lives

The literature related to growth and development shows that school age children are driven to compete in physical activities with their peers and to be accepted by them (Collins; 1984; Erikson, 1963). Empirical research dealing with peer relations has been mainly concerned with aggression and prosocial behavior (Hartup, 1984). Little research has examined peer interactions and their relationship to physical activities.

In an extensive study, Medrich, Rosen, Rubin, & Buckley (1982) interviewed 764 American children in sixth grade about what activities they did with their peers. The children were asked, "What do you like to do

when you are with your friends"? These researchers found that children spend the most time with friends participating in active interactions. Team sports were mentioned more frequently by boys (45%) than girls (28%) whereas girls more often mentioned social activities and playing. Much of what children do at this age involves physical activities with peers.

Maloney & Petrie (1972) examined 567 Canadian school children's attitudes toward achievement in sports. They found that boys were more achievement orientated in sports than girls. In contrast, girls were more interested in playing fairly than in winning.

The findings of both these studies support the current findings. All children in the current study longed to participate in physical activities such as baseball, volley ball, track and field in school and with their peers after school. Whether or not the children chose to participate and risk pain may be explained in relation to these previous research studies and knowledge about developmental tasks of middle childhood.

Previous research that has investigated the effect of pain (excluding cancer pain) on children's physical activities with peers is scarce. Schultz (1971) in a study of 74 school children and Gaffney & Dunne (1986) in a study of 680 school children in Ireland reported

that boys viewed pain to be a hindrance to their activities. Neither of the researchers, however, elaborated on this finding. It is difficult to comment on this sex related finding without further data, except to say that societal sex stereotyping in the 70's and a segregated school system in Ireland in the 80's may have influenced these separate, but similar findings.

In contrast, both girls and boys with either early or late onset arthritis in the current study viewed their limitations in activities similarly. Girls as well as boys had an overwhelming desire to participate in team sports. These current findings may reflect sociocultural changes in sex stereotyping and the importance of physical education, especially achievement in sports, in our schools today. The emphasis on participation and achievement in sports and the inherent drive of the school age children to strive for skill mastery and peer acceptance may explain why these children in the current study chose to risk pain to participate in activities with their peers.

Coping with Unpredictable Arthritic Pain

Children in the current study used a variety of strategies, both physical and psychosocial, to manage pain. This finding is consistent with previous

research that investigated children's coping strategies with pain (Jeans, 1983; Ross & Ross, 1984; Tesler et al., 1981).

As a part of a study (Savendra et al. 1981) previously mentioned, Tesler et al. (1981) found differences in coping strategies used by hospitalized and healthy school children. Two hundred and fourteen children were asked to respond to the question "What helps you feel better when you have pain"? The number of responses increased with age of children. Hospitalized children identified medications, needles, the application of heat/cold to pain site, distraction, and presence of parent more frequently than did school children. In contrast, school children managed pain by resting, sleep, and relaxation more frequently than did hospitalized children. Overall, the most frequently mentioned strategy was taking medications such as Aspirin.

Similarly Jeans (1981) in a study of 54 healthy Canadian children, 5 to 13 years reported that the number of strategies increased with age. By age 11, children reported using psychological as well as physical strategies. On the other hand, Ross & Ross (1984) found that only 213 out of 994 children, 9 to 12 years, reported using self-initiated coping strategies to manage pain.

The findings of the current study suggest that the number and variety of both self-initiated physical strategies and psychosocial strategies are a function of their past experience with pain.

Ross & Ross (1984) reported also that children with chronic conditions such as headaches, arthritis, etc. seemed to have the ability to take painful events in stride, view them in a realistic but optimistic manner and then move on. This current study supports this finding. With the assistance of their parents, friends and others, children in this current study coped with pain's unpredictability by living as normally as possible.

Normalizing, according to Strauss (1975), is a strategy used by an individual with chronic illness to live as normally as possible, despite symptoms, disease and treatment regimen. Children in this study normalized by knowing their own pain free limits and by remaining within them. That is, they selected alternate activities or modified activities to decrease the difference between them and their peers, while still maximizing their capabilities.

Normalizing is a coping strategy identified in the data of recent qualitative studies (Anderson & Chung, 1982; Edwards, 1987; McLaughlin, 1982). These studies, except one (McLaughlin, 1982) dealt with parents'

attempts at creating as normal as possible a life for their children within the confines of chronic illness. Similarly, according to the children in this study, parents assisted them to live as normally as possible.

The findings of this current study were found to be consistent with the research reviewed.

CHAPTER VI: SUMMARY AND IMPLICATIONS

Summary

This study has explored and described school aged children's experience of having pain associated with juvenile rheumatoid arthritis (JRA). Little has been written about the experience of arthritic pain from the children's perspective. Therefore, this qualitative descriptive study was conducted to explore and describe how children perceive and manage arthritic pain and how it affects their daily lives.

Literature related to children's acute pain and arthritic pain experiences was reviewed. This literature provided the theoretical background for this study's problem and purpose. The literature suggests that children perceive and respond to pain differently than do adults. It is evident from the literature that what is known about children's arthritic pain has been obtained by observing children's overt behaviors and by comparing children with adults who have arthritis. The literature reviewed demonstrated the need for research that investigates the qualitative aspects of children's arthritic pain experience to understand how children themselves describe their experience and the meaning pain has for them.

Data were collected during two open-ended taped interviews with ten children in their homes. Questions evolved from the data during the process of constructing the children's accounts with them.

Data analysis occurred concurrently with and after data collection. Taped interviews were transcribed verbatim onto computer discs. Using content analysis, data were analyzed for themes and their elements. An analytical framework evolved that showed their interrelationships. This framework provided the structure for presenting the children's descriptions of and explanations for arthritic pain within the context of their day to day living with arthritis, both in the past and in the present.

This study found that these school age children with arthritis experience intermittent pain that limits their activities with peers. The children's view of arthritic pain changes over time. The children evaluated their current pain against past pain experiences. Past pain was viewed to be more painful, more frequent, and longer in duration than current pain. The children described arthritic pain in relation to distinguishing factors and explained pain in relation to attributing factors. The children used a number of physical and psychosocial strategies to manage pain and cope with pain's unpredictability. The

findings of this study suggest that these children have an optimistic outlook and realistic attitude toward pain and their ability to manage it and to cope with its unpredictability.

The findings of this study were discussed in relation to the previous limited research with children.

Implications for Nursing Practice

A number of conclusions can be made from the findings of this study that have implications for nursing practice. First, children can understand pain within the context of past and current experience with arthritis. Thus by providing children with opportunities to talk about pain early in their illness experience, i.e. at onset of the first pain episode and frequently over time, nurses can help children deal effectively with pain. The opportunity to express their concerns may help to allay fears related to searching for information from multiple sources.

The second conclusion is that children try to make sense of what they don't understand by constructing their own explanations. Therefore, it is essential for nurses to provide information about arthritic pain. Furthermore, nurses need to understand the children's perspective which includes how they view pain and its meaning for them.

The third conclusion is that school age children with arthritic pain have common concerns about how intermittent pain limits their activities, especially in physical education, at a critical period in their lives when they are striving to participate as do their peers. When given the opportunity, children set their own limits, but may exceed their limits in order to participate as do their peers. Therefore, nurses need to assist children to participate as normally as possible.

The fourth conclusion is that children with arthritis have an optimistic outlook and realistic attitude toward pain. They have learned to manage their own pain and cope with its unpredictability by using a variety of physical and psychosocial strategies. Therefore, it is important that nurses assess children's strategies and assist them to choose strategies that help them to cope with long term pain.

Finally, this researcher concludes that by talking to children with arthritis about pain, we as nurses are not suggesting to them that they should have pain, but we are acknowledging to them, that they are the experts in terms of their pain and its meaning for them.

Implications for Nursing Research

During the research process, the researcher became aware of the dearth of knowledge about the arthritic

pain experience of children with arthritis. Given this study's findings and the scarcity of previous research on children with recurring pain, any of the findings could be investigated further.

The sample for this study was limited to children who had been diagnosed with arthritis for a minimum of two years. A study that measured pain intensity and explored the qualitative aspects of children's pain, at onset, and at different periods during the illness course would help to understand how children view arthritic pain over time.

A study on parents' and siblings' perceptions might be helpful to find out their concerns and their coping strategies.

While this study investigated school age children's arthritic pain experiences, a phenomenological study on adolescents' perceptions of arthritic pain might be useful in understanding their pain experiences and the meaning it has for them from their perspective.

To conclude, little arthritic pain research from the children's perspective has been done. This Canadian study is only a beginning. Further research, both qualitative and quantitative, is necessary before we as nurses will begin to understand what it is like for children with arthritis to have pain.

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APPENDICES

Appendix A

Introductory Letter To Parents

Dear _____

My name is Barbara Riding and I am a pediatric nurse. I am also a graduate student in the School of Nursing at The University of British Columbia, Vancouver. For my thesis, I am interested in learning how children with juvenile rheumatoid arthritis (JRA) experience pain. Specifically, I am interested in their view of pain, the meaning it has for them, its effect on their daily lives, and what they find helpful in dealing with pain.

Therefore, this letter is to request your permission for your child's voluntary participation in this study. If you and your child agree to participate, I will talk with your child for 30 to 60 minutes in your home at a convenient time. I would also like to tape our interview so I will not have to write notes. Initially, your child will be asked a few questions about herself (himself) and about arthritis, then she (he) will be asked to draw a picture of her (his) affected joint(s) and to explain the drawing. Subsequently, your child will be asked to describe pain, how pain affects her (his) daily life, the meaning it has for her (him) and what she (he) finds helpful in dealing with pain. If you and your child agree, I may ask to talk with your child again at a later date.

Although I will ask questions, your child's answers will guide the interview. There are no right or wrong answers as only your child knows what pain is for her (him). I will terminate the interview if your child appears tired, is reluctant to answer questions, or your child/you ask to withdraw from this study.

All information that your child and you share with me will be kept strictly confidential as your identities will never be revealed in any way. The tapes will be coded by numbers, not by name, and will be shared only with my thesis advisors who are also experienced pediatric nurses. At the completion of this study, all tapes will be erased by me. Publications which result from this study will not in any way identify your child. Your child will not receive any direct benefit from this study, but her (his) participation will help health professionals understand how pain affects the daily lives of children with JRA.

In approximately five days I will phone you to answer any questions and to discuss further my study.

I would appreciate your child's participation and contribution to my study. Please share this letter with your child. However, if you and your child should choose not to participate, your decision will in no way affect the care and treatment your child receives or will receive in the future.

Thank you for your consideration of this request.

Sincerely yours,

S. Barbara Riding, RN, BScN

Appendix B

Parent's Consent Form

I consent/do not consent to my child's participation in this Descriptive Study on the Experience of Pain for Children with Juvenile Rheumatoid Arthritis to be conducted by Barbara Riding, a graduate student in The School of Nursing, The University of British Columbia, Vancouver. I have read the introductory letter from Barbara as well as discussed her study with her. I understand the nature and purpose of this study and all procedures required of my child.

I also understand that:

- (a) my child's participation is voluntary.
- (b) refusal to participate will in no way affect the care and treatment which my child receives or will receive in the future.
- (c) a maximum of two interviews with my child will be conducted in my home. These interviews will be approximately 30 to 60 minutes in length.
- (d) the interviews will be tape recorded.
- (e) my child does not have to answer any questions which she(he) does not want to answer and she(he) may withdraw from the study at any time.
- (f) Barbara will terminate the interview if my child appears tired, is reluctant to answer questions, or asks to withdraw from the study.
- (g) my child's identity will be kept confidential as tapes will be coded by numbers and shared only with Barbara's thesis advisors.
- (h) at completion of this study all tapes will be erased by Barbara.
- (i) my child or I may contact Barbara at any time during this study, if there are questions or concerns. Her telephone number is 261-2456.

I acknowledge receipt of a copy of this consent form and introductory letter.

Signature: _____

Child's Name: _____

Date: _____

Telephone Number: _____

Please provide your address, if you wish a summary of this study when it is completed.

Appendix C

Child's Consent Form

Barbara Riding, a nurse, has explained to me that she would like to talk to me about what it is like to have arthritis and pain (hurt). I understand she would like to learn how I describe pain, what I think about when I have pain, how pain affects my activities and what helps when I have pain.

I also understand that:

- (a) there are no right or wrong answers.
- (b) I do not have to answer any questions which I do not want to answer.
- (c) I can also ask questions at any time.
- (d) I can stop our talks at any time.

I have agreed that Barbara may tape our talks.

Signature: _____

Date _____

POSITIONS HELD:

Staff Nurse (Casual),
B.C. Children's Hospital,
Vancouver, B.C.

Vacation Relief Nurse Clinician,
Pediatric Rheumatology Program
Arthritis Society and B.C. Children's
Hospital, Vancouver, B.C.

Sessional Lecturer (Teaching
Assistant), School of Nursing,
University of British Columbia,
Vancouver, B.C.

Nurse Consultant,
Lister Hall Student Residence,
University of Alberta, Edmonton, Alta.

Head Nurse, Staff Nurse,
Hospital for Sick Children,
Toronto, Ont.