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B. SIGNIFICANCE OF STUDY

A guiding principle of medical social work is to assist families in adjusting to both the foreign environment of the hospital and to the event which brought them to the hospital setting. Research that sheds light on the dynamics of illness may assist social workers in providing better service to families which have to adjust to the problems of coping with chronic illness.

When a child is diagnosed as having a chronic illness parents often deal with only the concrete problems of their children. Their child's physical and emotional needs tend to take precedence over the parents individual and couple needs. Often, as a result of this focus on the ill child, the family as a whole suffers. A preoccupation with the child's problems not only poses a threat to the parents marriage and to family functioning in general, it can also impinge on the child's developmental tasks.

Parents who are over-involved make it difficult for the child to develop autonomy and eventually separate from their parents. Within the context of chronic and severe illness, this is perhaps a major factor in a child's lack of normal emotional and social adjustment.

The undersigned recommend to the Faculty of Graduate Studies
and Research acceptance of the thesis

"A STUDY OF SELECT STRESSORS
AFFECTING FAMILIES OF CHILDREN SUFFERING
JUVENILE CHRONIC ARTHRITIS"

submitted by Gill Reilly, B.S.W.

in partial fulfilment of the requirements for
the degree of Master of Social Work

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ABSTRACT

This study attempted to determine the relationship between the variables pain, anxiety, family coping strategies and family functioning in a group of 24 families each containing a child with Juvenile Chronic Arthritis. A control group, with children matched for age and sex, provided a comparison on all the variables except pain. Self-report questionnaires were administered to the subjects in both groups. The results were mixed, but no differences were found between groups on the family functioning variable. The concept of the family of a chronically ill child as being at greater risk of breakdown is not supported by this study. Further research is needed regarding the type and number of coping strategies used by adequately functioning families which contain a chronically ill child. Thus increasing our understanding of the complex process of acquiring and using resources to better resist and adjust to the demands of chronic illness.

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I wish to express my appreciation to Carleton University and the Children's Hospital of Eastern Ontario for the resources provided from the inception to completion of this project. In particular I would like to thank Dr. Patrick McGrath who gave so generously of his time and expertise. Without his direction this piece of research could not have been possible. I wish also to extend my sincere gratitude to Drs. John Latter and James McKee whose patients in the Rheumatology Clinic formed the basis of this study. The Department of Social Work and its personnel at the hospital deserve a special thanks for the direction, resources and moral support offered throughout the duration of this project.

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I INTRODUCTION

A. STATEMENT OF PURPOSE

The purpose of the proposed investigation was to determine the relationship between the variables pain, anxiety, family coping strategies and the level of family functioning experienced by families containing a child suffering Juvenile Chronic Arthritis. It is assumed that the type and degree of illness has an effect on family functioning through the mechanisms of anxiety and coping strategies. It is further assumed that the additional component of pain, which always occurs to some degree in arthritis, may create unique stresses upon the patient and his/her family. A control group of families containing a healthy child was used to compare differences between the two groups on all the variables except pain and chronic illness. Parents in both groups completed three self report questionnaires covering the variables of anxiety, family coping strategies and family functioning. The children in both groups completed one self report questionnaire on the variable anxiety, in addition children in the experimental group were asked to complete a pain diary over a two week period.

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A social worker who understands how an illness impacts on the family can better help families move through these difficulties and learn ways to help their child compensate for his/her illness in constructive ways (Roy, 1976).

Family functioning is considered to be an important predictor of individual adjustment. Therefore the ability of the family to cope with various stresses imposed on the system by chronic illness becomes critically important to the well being of both the child and the family unit.

An investigation of the relevant theory, literature and published studies revealed some serious gaps in the existing knowledge. Melzack and Wall (1982), whose work has expanded our understanding of pain, worked exclusively with adults. Very little research has been done in regard to the childhood pain experience (Beales, 1982). The studies that do exist have been mostly concerned with psychogenic pain rather than with pain produced by physical disease. As well, these studies focus on the actual pain itself including the psychological and cognitive factors that impact on the child's adjustment to that experience. Research on the impact of chronic illness on the family has had much the same emphasis. Most studies have concerned themselves with the individual

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adjustment of family members. Very few have focused on the effects of chronic illness on family functioning. These studies have been, for the most part, conducted by medical personnel or psychologists and necessarily reflect the specific orientation, interest and concern of these professions. These concerns center on the control and management of pain or on the effect of chronic illness on individual psychological adjustment. It is largely for these reasons that the family as a unit has been ignored. Social workers with their comprehensive perspective which includes emotional, family, social and environmental issues, are particularly well equipped to contribute to the further understanding of the multidimensional problem of chronic illness in relation to family life.

Since the overwhelming majority of children belong to and live within some type of family system there is clearly a need to widen our focus to include the family as a whole in our understanding of the impact that various stresses, concomitant with chronic illness, have on family adjustment. The family is the main socializing element in a child's life. It has the added function of being the locus of support and encouragement for all its members, both children and adults alike. There are numerous

variables which all affect, to some degree, the complex and multi-faceted nature of family functioning. The existing literature, however, supports the thesis that the degree of stress generated by a negative experience and the manner in which a family manages that stress has a significant bearing on the level of family functioning demonstrated by that family. It is for this reason that the concept of stress has been separated into its two key components: anxiety and family coping strategies.

Families that function poorly can not provide for the evolving needs of their members. The ramifications of this inadequacy are felt by society as a whole. The children of these families often exhibit behavior problems in school or in their community. This can have serious economic implications in terms of social services needed to correct the child's earliest learning experience.

II LITERATURE REVIEW AND THEORETICAL FRAMEWORK

A. CONCEPT OF PAIN

Many attempts have been made to define the term pain, but a suitable working definition has yet to be found. The link between pain and injury seems so clear that it is generally believed that tissue damage always results in pain and conversely that pain always indicates tissue damage. While in general this principle holds true, a number of studies conducted with wounded soldiers on the battle field and civilians who have undergone surgery indicate that the link between pain and injury is highly variable (Melzack and Wall, 1982). One study conducted by Beecher, (1959) showed that 65% of soldiers who are severely wounded and 20% of civilians who undergo major surgery reported little or no pain within hours after their ordeal. In contrast, Loeser (1980) found that in 70% of people who suffer from chronic low back pain, no injury was detectable. It would therefore seem that any definition which unequivocally links pain to tissue damage is spurious.

Definitions of Pain:

In 1978 the Subcommittee on Taxonomy of the International Association for the Study of Pain defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey, 1979, p. 250). The most attractive feature of this definition is the loose association between injury and pain and the inclusion of the emotional dimension of the pain experience. Melzack and Wall (1982) point out that the major drawback of this definition is the term 'unpleasant' which does not properly explain the complex and multiple dimensions of the 'unpleasantness' of pain. Many of these dimensions have not yet been determined by pain research (Melzack and Wall, 1982). According to Melzack and Wall the diversity of the pain experience explains why a suitable definition of the term has not yet been formulated.

To understand the complexity of the pain experience these writers feel that an understanding of the 'language of pain' is essential. They feel the word pain "represents a category of experiences, signifying a multitude of different, unique experiences having different causes, and

characterized by different qualities varying along a number of sensory and affective dimensions" (Melzack and Wall, 1982, p.71). These dimensions include somato-sensory and negative-affective components that evoke behavior aimed at eliminating the condition that produced them. They go on to add that any noxious input that does not elicit negative affect and aversive drive cannot be called 'pain'. Accordingly, emotional pain does not fall within this definition since it does not evoke activity in the somatic afferent system (Melzack and Wall, 1982).

In formulating this definition of pain Melzack and Wall, who confined their studies on pain to adults, do not expand on the factors of age, intellectual and developmental level of the individual experiencing pain. Bland and Anderson remark that the elusive nature of pain makes assessment more difficult in children than in adults since children are always physically, emotionally and cognitively in a stage of flux (Bland and Anderson, 1977). They go on to add that it is not appropriate to talk about the childhood experience of pain in a global way. Infants, toddlers, preschoolers, younger and older children all respond differently to pain. Beales (1982)

supports this position in regard to pediatric pain by noting that the perception of pain in children is greatly influenced by such psychological processes as cognition and attention which are rooted in the level of cognitive development attained by a particular child at a particular point in time in his development.

Pain in children as well as adults is important as a warning of tissue damage and as a device to deter self-destructive behavior. The link between pain and injury, however, is just as tenuous in childhood pain as in adult pain. As well different individuals often experience different degrees of pain to the same pathology. Or, a given injury can produce different levels of pain at different times with the same individual. There have been reports of younger children experiencing less severe pain than adolescents with the same pathology (Beales, 1982). By the same token, lower levels of pain have also been found among children with Juvenile Chronic Arthritis than among comparable adults with Rheumatoid Arthritis (Beales, 1982).

Theories of Pain:

Pain is a phenomenon that has interested mankind from the earliest days. In an attempt to understand the complexities of this phenomenon a number of theories have been developed. A theory, essentially, is an attempted solution to a problem and is based on whatever facts are available at that time. As new facts are made available to researchers a given theory is either supported, altered or rejected. Over the years this has happened to numerous theories as new information was uncovered in the progression of the sciences of anatomy, physiology, biology and psychology. The most widely accepted of these theories of pain is the specificity theory.

Put forward in its most simplistic form by Descartes in 1664 it was developed during the 1800's by physiologist Johannes Muller to form the basis of modern-day specificity theory. During the present century it has been expanded further. In essence, specificity theory states that pain is transmitted by specific pain receptors in body tissue via pain fibres and a pain pathway to a pain center in the brain (Melzack and Wall, 1982). The fact that this Theory depicts a fixed, straight-through

conceptual nervous system, which imputes a direct, invariant relationship between a psychological sensory dimension and a physical stimulus dimension has led recent researchers to challenge the entire theory (Melzack and Wall, 1982). To call a receptor a 'pain receptor' implies a direct connection from the receptor to a pain center where pain is felt. This means that stimulation of that receptor must always elicit pain and only the sensations of pain. It also implies that the information concerning the sensation occurs entirely at the receptor level and this information is transmitted to the brain. Recent experiments conducted by Melzack and Wall (1965) and Melzack and Casey (1965) have refuted this traditional concept (Beales, 1982). It is now clear that nociceptive signals triggered by tissue damage are modulated at various synaptic levels on their way to the brain and that the brain itself can exercise control over the selection of sensory inputs from lower levels of the central nervous system (Beales, 1982).

The human brain is under a constant barrage of sensory inputs and pain producing signals have to compete with all other signals for conscious awareness. For this reason an athlete injured during a game is often unaware of the

injury until the game is over. However, if pain is anticipated or feared nociceptive signals are more likely to overcome the competition and an actual pain experience occurs. Interpretation of the source of nociceptive signals and the situation as a whole can determine the ability of the signals to create an actual pain experience (Beales, 1982). It is for this reason that children often experience pain differently than adults.

Children and Pain

Children learn early in life to associate pain with visual damage to their bodies, but internal injuries and the sensations produced by these injuries are much less obvious. Few studies of children's concepts of health and illness have been conducted. However, a recent one by Bibace and Walsh (1980) suggest that such concepts may develop in accordance with Piaget's stages of cognitive development (Perrin and Genity, 1980). This means that children must reach the level of formal-logical thought (at around 11 years) to have a concept of their internal structure and be able to interpret internal signals in 'physiologic' terms. In 1979 Beales found that among children with Juvenile Chronic Arthritis those under the

age of 11 were much less aware of the significance of internal pathology than were those in the 12-17 years age bracket. This latter age group rated their internal structure at least as important as their external surface (Beales, 1979).

A child who can not visualize internal pathology often dismisses the sensations emanating from within as relatively unimportant. The nociceptive signals therefore often not overcoming the competition from other sources. In the case of Juvenile Chronic Arthritis, children in the 6-11 age group are often only concerned with the external appearance of their joint (swelling or redness).

Fantasies about the internal appearance of damaged joints are generally more frequent among adolescents (Beales, 1982).

The same internal sensations have different significance for children at different ages as their goals and lifestyles change. In adolescence the significance of a chronic disabling disease takes on new proportions as it impinges on career choice, physical attractiveness and freedom from parental control. It is likely that the age variation in the cognitive appraisal of nociceptive

signals has much to do with the lower levels of pain reported by 6-11 year olds with Juvenile Chronic Arthritis in comparison with patients ages 12-17 (Beales, 1979).

Recent studies have shown that the closer a child comes to adulthood the closer his joint pain comes to the levels experienced by Rheumatoid Arthritis patients (Beales, 1979). It is important to realize, however, that age is not the only variable influencing the interpretation of and sensitivity to nociceptive signals emanating from internal tissue damage.

In children pain is closely linked with anxiety and fear and can be a major event in the child's life which has profound influence on later reactions to pain. It can bring out feelings of guilt, helplessness, anger and a tendency to regress (Stoddard, 1982). This anxiety can be caused by the trauma itself, as in the case of children suffering serious burns or it can be caused by the familial attitude towards illness.

Familial factors in the Recognition of Pain

Parental anxiety is easily transmitted to children causing them to pay greater attention to pain producing internal sensations (Beales, 1982).

Such parents are preoccupied with health and illness. This preoccupation tends to be transmitted from generation to generation and to some degree varies from culture to culture (Beales, 1982). Zborowski (1952) found a significant difference in the ways Italians, Jews and Irish Americans experienced, thought about and related to pain. This difference being rooted in attitudes towards illness can influence the priority given to pain-producing signals. In this way cognitive processes can dictate the frequency and severity of pain experienced by the child. Cognitive appraisal of the pain source can also affect the level of suffering by attaching a positive or negative 'meaning' to it.

Sensory experience that has a neutral or positive affect attached to it can not be considered pain. Pain only occurs when a sensation is linked to negative affect. If a feeling of heat or pressure inside the body is associated with ~~fears of~~ internal pathology the negative

affect attached to the sensation is likely to be more extreme. Depending on the particular interpretation a child makes of sensations emanating from within his body, he may experience these sensations as either negative or positive, unpleasant or pleasant, painful or producing no pain at all.

In a study of pain among children with Juvenile Chronic Arthritis all children reported "burning", "sharp" or "aching" feelings. Yet some children reported no pain at all while the 6-11 age group reported lower levels of pain than did the 12-17 age group (Beales, 1982). Younger children were able to largely ignore their pain because the "pain and its associations did not generate much thought" (Beales, 1982, P. 162). With teenagers, however, the pain reminded them of their illness thus increasing their level of pain (Beales, 1982).

CONCLUSION RE: PAIN

Although very little hard data is available on the childhood experience of pain, particularly pain produced by physical disease, it is clear that psychological and familial factors play a significant part in how a child experiences pain, and in how he responds to that experience. The 'problem of pain' is clearly an extremely complex area of the human experience and a great deal more research must be done before any conclusive answers can be offered to health care professionals who work with patients and families living with this problem.

Nevertheless, if our understanding of the impact of pain on families is to be increased we must base present studies on the most useful definition and theory of pain that are available to us.

The definition of pain to be used in this study is the one put forward in 1978 by the subcommittee on taxonomy of the International Association for the Study of Pain. The subcommittee defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey, 1979, p.250). The loose association between pain and injury and the

inclusion of the emotional dimension makes it particularly useful when dealing with chronic pediatric pain that is associated with physical disease (Melzack & Wall 1982). This study is concerned with the relationship between pain experienced by children and level of family functioning, as such the emotional component of the pain experience is particularly relevant. For this reason an analysis of the dimension of stress is included in the research. Without the element of negative affect or aversive drive, burning, aching or sharp feelings in the joints will not impinge on family life in any meaningful way and hence, cannot be said to influence the family's response to the child's condition.

Understanding the childhood experience of pain in terms of cognitive and attentional processes is particularly cogent when one looks at the differences between the childhood and the adult experience. This approach also offers a method to trace the linkage between the child's experience and the family's reaction to the child's experience and vice versa.

B. Concept of Chronic Illness

Chronic illness, by its range and variation, impinges upon family life at every point. The stress imposed upon the family unit demands a degree of adaptation and coping which the average family will never experience. As a result psychosocial problems are more likely to arise in children and adolescents with a chronic illness, as well as in their parents and siblings, than in the normal population (Rusk & Novey, 1957; McAnarney, Pless, Satterwhite, Freedman, 1974; Leichtman, Freedman, 1975; Gayton, Freedman, Tavormina and Tucker, 1977; Satterwhite, 1978; Lavigne and Ryan, 1979; Cairns and Lansky, 1980; Heisler, Freedman, 1981; Miller & Spitz, 1982). To understand the implications this has for family functioning we must begin with an understanding of the disease process itself.

Some Facts About Chronic Illness:

Chronic illness has been defined as a condition which lasts more than three months (Bergman, Lewiston & West, 1979). It's most striking feature is that it is not cured, but managed.

Recent estimates, made in the United States, of the prevalence of chronic illness in children under 18 years of age in the general population range between 10% and 20% (Bergman, Lewiston & West, 1979). These children now spend most of their time at home and in the community, the major burden of their care being carried by their families and community personnel such as social workers and teachers (Travis, 1976).

A Brief Review of Studies on Impact of Chronic Illness on the Child and Family

Numerous studies have been conducted in an attempt to evaluate the impact of chronic illness on the child and his/her family. McAnarney, et. al. (1974) found that children with arthritis were identified as having more psychological problems than the control group. As well,

Pless and Roghmann (1971) and Cytryn, Moore and Robinson (1973) found an increased incidence of psychiatric disorders or behavior problems in pediatric patients. Richardson and Friedman (1974) noted significant psychosocial problems in 13 of 17 teenagers with epilepsy particularly in the realm of behavior and school problems. In an overview based on five surveys concerned with the impact of chronic illness on child and family, Satterwhite (1978) found that two out of three studies suggested that more of the ill children than controls showed indices of maladjustment.

When studying the siblings of a chronically ill child La Vigne & Ryan (1979) concluded that, when considered collectively, these siblings were more likely to experience adjustment or behavioral problems than healthy children. The illnesses, however, seemed to differ in the extent to which they precipitated adjustment problems. The siblings of patients undergoing plastic surgery showed the highest level of psychopathology. Breslau, Weitzman & Messeuger (1981) found siblings of children with various disabling diseases scored higher than controls in the area of fighting and delinquency. Conversely Harder & Bowditch (1982) in a study of 19 subjects who had a sibling with

cystic fibrosis found no negative effects of this chronic illness. In this study many of the subjects offered evidence of personal growth and increased family cohesion.

In a study to explore the emotional adjustment and marital relationships of parents of children with chronic, life-threatening illness, Cairns and Lansley (1980) tested parents of both pediatric cancer patients and hemophilic children. They found that both groups suffered more distress than a normal group, but less than marriage counsellees. Parents of cancer patients showed higher levels of stress than parents of hemophiliacs. However, the divorce rate among these parents was no different than the divorce rate of the population at large. Similar results were found by Beglerter, Burry and Harris (1974) in a study of parents of children with cystic fibrosis. Gayton, Freedman, Tavormina and Tucker (1976) conducted a psychological evaluation of 43 families each with a child with cystic fibrosis. They found that 32% of fathers and 22% of mothers obtained scores which suggested emotional disturbance. Their results, however, did not indicate an increased incidence of emotional disturbance in the children with cystic fibrosis.

Factors Relating to Child's Adjustment

The conflicting results of these studies underscore the importance of understanding the social and emotional variables which affect the child's and his family's adjustment to chronic pediatric illness. The type and severity of the illness clearly have a large impact on the psychological distress and the need for the child and the family to adapt their lifestyle to meet the patient's needs and limitations. Dr. Pless in his article "Effects of Chronic Illness on Adjustment" (1983) suggests that one of the best ways to predict maladjustment in a child is to examine these specific areas: a) features of the disease, b) characteristics of the child as a person, and c) social influences, especially the family. All three of these areas interrelate with one another and none of them can be viewed in isolation.

The social significance or functional consequences of an illness are useful factors in predicting the impact the disease will have on emotional adjustment. The characteristics of the child's illness determines the extent to which he can participate in age appropriate activities. To be forced to

watch passively while contemporaries run and jump or socialize freely with others can have a negative effect on the development of a child's self-concept (Pless, 1983) and emerging autonomy (Wright, 1960). It has been noted that when chronic pain is coupled with chronic illness as in the case of arthritis, regressions in the child's behavior can occur which go beyond what may be expected from the illness itself (Eland and Anderson, 1977). This compounds the difficulty a child will have in making a satisfactory emotional adjustment. Restrictions placed on a child by his disease will effect an older child or adolescent differently than a younger child because of the different goals that are inherent in each developmental stage of growth.

The adolescent who has been recently diagnosed with a chronic illness must go through stages of loss of the previous 'healthy' self. The concerns they have are different from their parents' concerns as they struggle with issues of separation and individuation, sexual adequacy and career goals. To form a firm identity the adolescent must be able to incorporate his illness into his self-image and accept whatever limitations are imposed on him by his illness (Leichtman & Freedman, 1975).

Impact of Degree of Disability on the Child and Family:

Many studies have supported the hypothesis that the more severe the disability the more difficulty a child has in adjusting to his illness (Pless, 1983) but it appears now that this might not be the case. In a study of children with Chronic Juvenile Arthritis, McNarney, et. al. (1974) found that 42% of those with mild disabilities were maladjusted as compared to 38% of those with severe disabilities. Both of the groups, however, were more maladjusted than their healthy peers. Several others have found this same phenomena in a wide range of disorders.

For the chronically ill child or adolescent who does not appear or feel ill, but who must have frequent contacts with medical practitioners, the acceptance of his disability as part of his self-image may be particularly difficult. Barker, Wright and Gonick (1953) introduced the concept of 'marginality' in which it is suggested that a child suffering from a chronic illness, but with no visible signs of that illness, suffers the uncertainty of not knowing if his role is that of a healthy or disabled person. This leads to greater psychological stress than having a disability which is clearly pronounced and must

be accepted. As well, children with clearly pronounced disabilities are supported in their view of themselves by others who also recognize and make allowances for their condition. Viewed within the context of family systems theory, which emphasizes the importance of circular feedback loops, the psychological stress suffered by any handicapped children must necessarily spill over into the family as a whole thus having a reciprocal effect on the entire group. In other words, if one member of a family is stressed, every member of the family is affected to some degree.

The Interaction Between the Child, Family, Illness and the Environment

When one considers the characteristics of a child as a person, the process that will likely have the greatest influence on a child's adjustment is negative changes in self-concept. Self-concept does not begin and end with the child himself, but is a dynamic situation resulting from the interaction between the severity of the chronic illness, the child himself and external forces such as the family. The family, after all, is the major social support system for the child.

An illness which imposes limitations on a child's activities will have a deleterious effect on that child's development. Without opportunities to meet age appropriate challenges a chronically ill child cannot develop mature behavior. Weakness or physical disability can prevent a child from engaging in the necessary activities for psychological and emotional growth. The stage of development of the child when he encounters a particular stress is of prime importance in his ability to assimilate that experience constructively into his character development. This in turn affects his perception of his disability and his reaction to it. Benjamin S. Bloom (1964) states that environmental changes in a child's life when he is in a stage of rapid growth has a much more debilitating effect on the child than when he is in a period of slow growth.

Infancy and childhood are periods of the most rapid growth in children and it is during this period that chronic illnesses, particularly Arthritis, are usually diagnosed. A child who cannot function normally on a physical level will, for many reasons, create greater stress on the family system. Family systems theory, with its emphasis on the interaction between a

person and a group is a particularly useful model for understanding the reciprocal influence between the child, his illness and the family (Family Systems theory is discussed in detail in Section C).

The child's concept of the illness and its implications is also greatly influenced by the parents concept of disease (Hersher & Freedman, 1981). The child can sense fear, anger or denial even when not verbalized by the parents and thus his attitude towards his illness is shaped. Parents who suffer from high levels of anxiety can have a deleterious effect on a child's sense of autonomy by making him fearful to separate to the extent that limitations allow. Conversely, parents who are not able to accept their child's illness may minimize the illness beyond realistic levels thus conveying the message that the child must be normal. In this way, the family can be seen as a strong influence on how a child adjusts to his illness. As well, the family is usually the major component in the child's social support system. As such, the ability of the family to cope with the various stresses imposed on the system by chronic illness and other factors becomes critically important to the well being of the child and the family as a whole.

resources to include: 1) The skills to maintain family stability and manage individual anxiety, 2) to procure support from the community, interpersonal relationships and the extended family, and 3) to become actively involved in an attempt to reduce the potency of the stressor event through both individual and collective family efforts. While McCubbin's analysis underscores the importance of Hill's B factor, family resources, it is his understanding of the value of the community in the management of family stress which carries it beyond Hill's work.

A family's community provides the norms and expectations of how best to manage the stressor event. Through interpersonal relationships it can offer social support as well as providing the context within which the family may unite in an effort to deal directly with the stressor event. While the studies analyzed by McCubbin concerned themselves with the specific stress of family separation, it is reasonable to assume that one can generalize these findings to include other types of stress, such as illness. Sociologists have long proclaimed man's need for a community within which to base his security and sense of identity. This factor has special significance today when one considers that the majority of urban families are

he states, figure largely in producing stress reactions and therefore stress must be defined in terms of transactions between individuals and situations rather than viewing either factor in isolation. To understand the interaction between these two factors it is useful to look at the component parts of each factor.

Stress and the Family

The concept of family burden becomes important when attempting to understand the stresses imposed on a family when one member becomes ill. There are several aspects to this concept which bear heavily on the family's ability to adapt successfully to a chronic illness. These are: 1) generic features of the illness; 2) the psychological burden; 3) community support; 4) environmental issues.

Generic Features

The generic features of the illness are those factors that place demands on the family that are different from those expected in the care of a well child (Pless, 1983). It is assumed that the extra duties imposed on a family with a chronically ill child will in many cases add significantly to their stress level.

Each illness has its own particular set of demands. For Juvenile Chronic Arthritis these demands depend on the type of Arthritis the child has and the severity of the disease. One fourth of the children suffer from acute systemic Still's Disease, another fourth suffer from oligoarticular arthritis which affects less than four joints. The remaining 50% of children suffer from Polyarticular arthritis which affects many joints. This last type of arthritis is the one most likely to lead to crippling (Travis, 1976).

During flareups of this disease, which may occur several times a year, demands on the parent's reserves of energy and patience are great. Some children awake crying several times a night and require medication or bathing to relieve the pain. Others require bathing first thing in the morning to relieve stiffness of joints. Involvement of various joints can lead to destructive bone changes which create deformity. This type of functional impairment can cause serious limitation of motion. If walking is too painful the child may have to be carried. During the prolonged illness the mother often spends much time holding and lifting the child. Pain is always a significant factor and can exacerbate the parent's sense

of helplessness, anger and frustration. These stresses are often associated with difficulties in the parent's emotional adjustment and marital relationships (Cairns and Lansky, 1980; Lavigne and Ryan, 1979; Gayton, Freedman, Tavormina and Tucker, 1978).

Psychological Burden:

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The psychological burden carried by the family depends on several factors, but pivots on the perceived impact of the demands which are inherent in the generic features of the illness. Venters (1981) found in her study of 100 families living with a chronically ill child that two useful strategies were employed by those families who appear to cope most successfully with the inherent stresses. One was to give specific illness related hardships more of a positive than a negative interpretation. The second involved defining the illness situation within a previously existing religious and/or medical-scientific philosophy of life. Because one's perceptions constitute one's reality, these coping strategies could significantly reduce a family's psychological burden.

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Venters findings support the work done by Rueben Hill on Family Stress theory which began in the late 1940's. In Hill's (1949) ABCX model the crisis or "event" (A) interacts with the family's crisis-meeting resources (B) which interacts with the definition the family gives to the "event" (C), this in turn produces the crisis itself (X). Family resources and the definition of the crisis lie within the family itself while the "event" (A) lies outside the family system. The coping behaviors found by Venters fall within Hills B and C determinants.

It seems reasonable to argue that one of the factors that contribute to a family's crisis meeting resources are the personality factors mentioned by Lazarus and operationalized by the personality development of the parental dyad.

It is generally agreed among developmental psychologists that the progressive experiences of normal living strengthens and develops the personality enabling it to withstand greater stress as it achieves greater maturity. Being overwhelmed by stress before the personality is fully developed can leave an individual particularly vulnerable to certain types of stress (Travis, 1976).

This concept of "emotional vulnerability" is useful in explaining some families lack of ability to cope with the stress of a chronically ill child (Beales, 1982, Travis, 1976).

A parent who was overwhelmed by symptoms similar to the child's illness in his own early childhood would have greater difficulty in dealing with the stress as the old painful experience is reactivated. In other words, an individual may be incapable of dealing with a small amount of stress to which he is vulnerable, whereas he could cope with a large amount of a different type of stress.

Community Support

Further development of Family Stress Theory has uncovered another important factor in a family's ability to cope successfully with stress. McCubbin (1979) analyzed three studies of coping and adaptation in the face of family separations in an attempt to understand some of the discrepancies between observations of family behavior under stress and family stress theory literature. His effort revealed the tripartite aspect of coping behavior. These three aspects reveal the need for the family's

resources to include: 1) The skills to maintain family stability and manage individual anxiety, 2) to procure support from the community, interpersonal relationships and the extended family, and 3) to become actively involved in an attempt to reduce the potency of the stressor event through both individual and collective family efforts. While McCubbin's analysis underscores the importance of Hill's B factor, family resources, it is his understanding of the value of the community in the management of family stress which carries it beyond Hill's work.

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highly mobile and the support offered by the extended family is often not available to them. One would expect this to be an event of greater deprivation for families which include the added stress of a child suffering a chronic illness. There is clearly a need for community services to identify these families and to link them to those structures within the community that can provide them with the necessary supports.

Environmental Issues:

In Hill's research on families of American servicemen (1949) he discusses how no crisis-precipitating event is the same for any given family. Its impact, he discovered, varies according to the number of separate hardships that accompany the event for a particular family. In other words, the number and severity of stresses which a person is subjected to at any given time affect one's ability to cope with new ones. Thus the multiple stresses which are a part of daily living for the very poor affect their ability to cope with a chronically ill child (Travis, 1976). A parent who must cope with unemployment, shiftwork or single parenthood will be rapidly drained of energy needed to give on-going care to a sick child. The

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same holds for parents who must cope with more than one seriously ill member of their family at a given time. The result of too many or too severe stresses is breakdown of the individual or the family unit (Travis, 1976).

While parental roles are less clear-cut in contemporary society than in the past, the mother is still considered the primary care giver of the preschool child. In families where the father offers support and security to the mother, she is better able to offer the child the confidence and encouragement he needs to meet the on-going crises that are part of his illness. A single mother who must by herself cope with the physical, financial and emotional burdens of a chronically ill child is particularly vulnerable to these stresses. And in particular need of help by members of the health care team (Travis, 1976).

One final aspect of the family burden is the stage in life a family is in when a chronic illness is diagnosed in their child. The family as a unit is constantly changing as it moves through a life cycle on its own. The needs of a young family are very different from a "middle aged" or "old" family. Therefore the ability of the family system

to meet the needs of a chronically ill child depends to some extent on the stage of the family life cycle (Travis, 1976). When the needs of the child seriously conflict with the needs of the parents greater stress can be anticipated. For example, a young couple with their own needs to have an active social life would experience greater stress under the restraints imposed by a chronically ill child than would another couple in a more settled stage of life.

CONCLUSION RE: CHRONIC ILLNESS

Taken collectively, children with chronic physical disorders comprise between 10% and 20% of the North American population. A large number of studies have provided evidence that these children are at an increased risk of developing psychosocial problems. When viewed in the context of family systems theory it follows that the families of these children will also reflect adjustment problems. Given the stresses of living on a daily basis with the increased needs of these children the remarkable aspect is that most families manage to adjust to these problems and cope adequately with the illness. It is, however, the significant minority that need to be looked at closely if health care professionals are to learn how to meet their needs effectively.

C. Concept of the Normal Family

Definitions of Normality

Over the years the term 'normality' has been defined in many different ways. Offer and Sabshin (1966), in an overview of theoretical and clinical concepts of mental health identified various definitions of normality from the clinical and social science literature. Pulling together the various viewpoints they put forth four major perspectives on normality: 1) Normality as health: if no family member is diagnosed as being emotionally ill then the family is considered healthy. 2) Normality as utopia: normality is seen as an ideal with an emphasis on self actualization. 3) Normality as average: those families who fall in the center of a bell shaped curve, in terms of their functioning, are seen as 'normal'. 4) Normality as Process: This approach views normal behavior in the context of multiple circular processes in trans-actional systems over time. Family systems theory supports this approach to defining normality since normal functioning is viewed in terms of a transactional system that operates overtime and within the limits of specific family rules. For the purposes of this study the normal family will be defined in terms of normality as Process and viewed within a family systems perspective.

In an attempt to define and understand normal family processes recent family systems theorists have expanded on general system theory concepts developed in the past to describe marital and family dynamics. Some of the more recent concepts have been developed by practitioners observing both clinical and non clinical families. They identified and defined three separate family processes that could be measured which were intrinsically involved in family functioning.

Family Processes

One family process has to do with the degree to which an individual is separated from or connected to his/her family system (Olson, Russell, Sprenkle, 1982). The process is referred to as family cohesion and is defined as "the emotional bonding that family members have toward one another". (Olson, Russell, Sprenkle, 1982, P. 70). Levels of cohesion range from very low (disengaged) to low moderate (separated), to moderate high (connected) and finally very high enmeshed. It is hypothesized that the middle range of cohesion (separated and connected) is the optimal functioning range. In the middle range it is felt that the individual members of a family can experience the

balance between being connected to and independent from the family unit. When cohesion is very high overidentification between members takes place which prevents individuation and thus personal growth of family members. At the other extreme the lack of cohesion prevents family members from forming attachments and commitment to their family unit.

The second family process identified is family adaptability which focuses on the extent to which the family system is flexible and able to change with the evolving needs of its members. Family adaptability is defined as "the ability of a marital or family system to change its power structure, role relationships and relationship rules in response to situational or developmental stress" (Olson, et al 1982, p.71). Levels of family adaptability range from very low (rigid), to low moderate (structured) to moderate high (flexible) and finally very high (chaotic). As with cohesion, it is hypothesized that the healthiest families operate in the middle range area of adaptability. The process focuses on the ability of a family system to change and thus to grow. In general systems theory this process is referred to as morphogenesis (Jackson, 1957) and provides the

flexibility to adapt to internal and external demands. Internally a family's flexibility is challenged repeatedly as it evolves over the course of its life cycle. External crisis events stress the family as well, and require adaptational shifts and reorganization (Speer, 1978) if the family is to survive as a unit.

Reaction to crisis events, then, is heavily influenced by the family organization - its on-going interactional patterns. Thus one family may become overwhelmed while another family copes in response to the same crisis. It is this ability to change that most clearly distinguishes between functional and dysfunctional families.

The third process identified by theorists is family communication. Communication is considered a facilitating dimension that is crucial in allowing families to move along the cohesion and adaptability dimensions. Within family system theory all behavior is seen as communication, transmitting interpersonal messages. Every communication is seen as having two functions: 1) a "content" aspect conveying factual information or feelings; and 2) a "relationship" aspect, which in conveying how the information is to be taken defines the

nature of the relationship (Walsh, 1982). The process of defining relationships is stabilized by the establishment of family rules. Positive communication patterns enable families to share their changing needs, especially as they relate to cohesion. Negative communication patterns restrict family members movement in the cohesion and adaptability dimensions through the lack of understanding of each members needs.

Family rules organize family interaction and function by prescribing and limiting members behavior, thus stabilizing the system. These 'rules' are norms within the family communicated for the most part non-verbally and occur in repetitious sequence creating the family's pattern of behavior which fulfills its need for homeostatic balance (Jackson, 1957).

Within this context dysfunctional families would be those whose transactional patterns reflect either too high or too low a degree of both cohesion and adaptability. Thus the 'family rules' cannot evolve over the course of the family's life cycle to allow for its members changing needs. Furthermore, individual dysfunction is viewed as a relationship problem that reflects the family's

I chose to operationally define the degree of pain through the use of a pain diary to be filled out by the child. In the case of children under the age of nine parents were asked to assist them when necessary.

2) The Family Functioning Variable

For the purposes of this study the normal family will be defined in terms of Normality as Process (Offer and Sabshin (1966)) and viewed within a family systems perspective. Family systems theory supports this approach to defining normality since normal functioning is viewed in terms of a transactional system that operates over time and within the limits of specific family rules.

Normal family functioning will be operationalized through the use of Olson, Portner and Bell's Family Adaptability and Cohesion Evaluation Scale and defined as those families which demonstrate on this scale flexible separations and flexible togetherness. This form of definition contains a margin which allows families in different stages of

individuals within the family system are easily stressed into dysfunction and have difficulty recovering. At the high end of the scale individuals are more flexible, adaptable and independent of surrounding emotionality and are thus better able to cope with life stresses. The stresses inherent in living with a chronic illness would be particularly difficult for families which function at either end of the cohesion or adaptability dimension since they would lack the correct balance of separateness/connectedness and flexibility/structure.

CONCLUSION - CONCEPT OF THE NORMAL FAMILY

Defining normality as process allows us to view the family within the context of its own state of the life cycle. For example, families with young children might be expected to demonstrate a higher degree of cohesiveness and more structure than families with adolescent children. In this sense there is no absolute degree of cohesiveness or adaptability that should be maintained over a twenty year period. Communication skills, however, would be expected to remain a fairly constant variable. Positive communication skills are relayed from parents to children providing them with a model for developing certain cognitive capacities such as remaining task oriented and communicating ideas and feelings clearly and directly. These patterns would be expected to be present throughout the family life cycle.

Olson, et al (1982) have developed a model which allows us to operationalize the concept of the normal family. Their circumplex model of Marital and family systems:III attempts to locate families along the two important dimensions of cohesion and adaptability. Too much or too little of either of these dimensions is considered to be detrimental to family functioning. A third dimension, communication, is considered to

be a facilitating dimension which allows families to move along the other two dimensions.

There are several other theoretical models which can be used to measure family functioning. I have chosen Olson's model for the following reasons: It is relatively easy to apply; Olson is a well respected researcher in his field; this model is derived from general systems theory, the theoretical approach which is most useful when attempting to understand dynamic relationships.

III METHODOLOGY

A. Statement of Problem and Hypotheses

The long and often unpredictable duration of Juvenile Chronic Arthritis guarantees many family changes as it runs its course. For about half the children the disease remains active for approximately three years, for the other half the duration and course of the illness remains unpredictable

(Travis 1976). This study is concerned with how families cope with this illness in regard to 4 specific variables:

- 1) pain,
- 2) family functioning,
- 3) anxiety,
- 4) family coping strategies.

1) The Pain Variable

The degree of pain experienced by the child.

The recurrent pain experienced by children with Juvenile Chronic Arthritis over a period of months or years must have an impact on the family system.

Although no supporting literature has been uncovered, it seems logical to assume that recurrent pain will produce a unique stress that many families will have

difficulty managing. For the purposes of this study, pain was defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage". (Merskey, 1979). This definition was chosen because it makes a loose association between pain and injury and because it includes an emotional dimension.

The emotional dimension is particularly important when attempting to understand the experience of pain within the framework of family dynamics. Zborowski (1952) suggests that familial attitudes towards illness can influence the priority given to pain-producing signals. Beales (1982) mentions numerous studies which have looked at the role of parental anxiety in exacerbating the pain experience in children. The majority of these studies found an exaggerated concern towards health among parents of children suffering non-organic headache, limb pain and abdominal pain. Beales suggests that the child's condition seems to be linked to parental anxiety and concern about health that is passed from one generation to another.

I chose to operationally define the degree of pain through the use of a pain diary to be filled out by the child. In the case of children under the age of nine parents were asked to assist them when necessary.

2) The Family Functioning Variable

For the purposes of this study the normal family will be defined in terms of Normality as Process (Offer and Sabshin (1966)) and viewed within a family systems perspective. Family systems theory supports this approach to defining normality since normal functioning is viewed in terms of a transactional system that operates over time and within the limits of specific family rules.

Normal family functioning will be operationalized through the use of Olson, Portner and Bell's Family Adaptability and Cohesion Evaluation Scale and defined as those families which demonstrate on this scale flexible separations and flexible togetherness. This form of definition contains a margin which allows families in different stages of

their life cycle to be included in the central or optimal functioning area of the matrix (Olson, Russell, Sprenkle 1982).

Anxiety and Coping Strategies in Connection with
Stress - The Intervening Variables:

Anxiety and the family's coping strategies, as discussed earlier, are considered to be key components in the creation of and/or management of stress. As Spielberger (1976) points out, the perception of threat is central to the experience of anxiety. As well, the level of anxiety experienced is largely determined by how that threat is interpreted. This underscores the importance of measuring anxiety as well as coping strategies when attempting to understand the impact that stress has on family functioning.

In following Spielberger's lead it seems logical to suggest that physical pain is usually perceived as a threat to one's body, therefore the degree of pain experienced is likely to vary directly with one's anxiety. As well, if one is generally concerned with

one's health, it is likely to be reflected by one's level of anxiety. Spielberger's comment on how a threat is interpreted has a direct link to a family's coping strategies. Venter's (1981) study indicates the importance of coping strategies in a family's successful management of the stresses associated with chronic illness.

Anxiety will be operationalized through the use of two scales which measure trait anxiety 1. The Self-Evaluation Questionnaire. 2. The How-I-Feel Questionnaire (Spielberger 1973). Family coping strategies will be operationalized by a scale which will look at various types of strategies which may be utilized by a family. F. Copes: Family Coping Strategies (McCubbin, Laren, Olson 1982).

Hypotheses

- 1) The two groups will have similar scores on the family coping strategies scale.
- 2) The experimental group will have higher anxiety scores than the control group.

- 3) More families in the control group will score in the 'balanced' levels of family functioning than in the experimental group.
- 4) The level of pain experienced by the child will show a negative relationship to family functioning.
- 5) The level of pain experienced by the child will show a positive relationship with the level of anxiety reported by both the child and his/her parents.
- 6) The level of pain experienced by the child will show a negative relationship with the number of family coping strategies reported by the parents.
- 7) The level of family functioning will show a negative relationship to the level of anxiety experienced by the parents.
- 8) The level of family functioning will show a positive relationship with the number of family coping strategies reported by the families.
- 9) There will be a negative relationship between anxiety and number of coping strategies.

B. Design:

A case-control design was used:

- 1) to compare families which contain a child suffering Juvenile Chronic Arthritis (the experimental group) with families which do not contain a child suffering a chronic illness (the control group) on the variables of anxiety, family functioning and family coping strategies.

A Quantitative-descriptive design was used:

- 2) to determine the relationship between the level of family functioning and the variables of pain, anxiety and family coping strategies within the experimental group.

C. Population and Sample:

This study was composed of families of children and adolescents seen at the Arthritic Clinic of the Children's Hospital of Eastern Ontario who meet the following criteria.

- 1) The child was between 6 and 16 years of age.
- 2) Subjects were comfortable speaking English.
- 3) Child was living with natural or adoptive parents.
In the case of adoption this has taken place at least two years previously.
- 4) These families included two parents to control for the additional stresses that are part of single parenting.
- 5) Child was currently being seen at the clinic.
- 6) Child was diagnosed as having Arthritic diseases.
- 7) Diagnosis was made at least six months previously.

To this author's knowledge this scale has not been used to measure coping strategies of families containing a child suffering a chronic illness. Nevertheless, it was expected to adapt well to the present study since it is conceptually based on traditional family stress theory. This theory has been used as the basis for other studies attempting to measure family coping strategies in families containing a chronically ill child and was found useful (Venters 1981). For the purposes of this study coping strategies are defined as the general family response intended to minimize the hardships and stress of living with chronic illness.

4) Circumplex Model of Marital and Family Systems.

Family Adaptability and Cohesion Evaluation Scales.

This scale measures both the adaptability and cohesion dimensions of family functioning. There are four levels of family cohesion ranging from extreme low cohesion (disengaged) to extreme high cohesion (enmeshed). The two moderate or balanced levels of cohesion have been labelled separated and connected. There are also four levels of family adaptability

Sampling Procedure:

Approximately 90 families were being seen at the hospital Rheumatology clinic at the time of this study. Of these families 45 met the above mentioned criteria. A letter explaining the proposed study and asking for their participation was sent to these families. (Appendix G). Twenty-five families agreed to participate. A similar letter was sent to families of the control group. (Appendix H). A follow up phone call was made by the researcher to each family who was sent a letter to ask if they would participate in the study. In the case of families who were in the control group they were asked if any member of the immediate family suffered from a chronic illness. For the purposes of this study chronic illness was defined as any illness lasting three months or longer.

D. Procedure:

When families agreed to participate in the study informed consent (Appendix A) was sought from both the child and his family. An appointment was then set up at the convenience of the family to explain and present the measures. This appointment took place either at the hospital or at the family's home.

A telephone call was made at the end of the first and second week to each family to facilitate compliance in pain diary recordings. Each family was provided with two stamped addressed envelopes to send their pain diary to the hospital at the end of the first and second week.

At the end of the interview each participating family was debriefed to answer any questions they may have had concerning the procedure and instruments used.

E. Instruments:

At the initial meeting the following measures were presented:

- 1) The Trait Anxiety Inventory (Spielberger, 1973, Spielberger, Gorsuch and Lushene, 1970).

This scale measures anxiety characteristics. This self-report measure comes in two formats, the How I Feel Questionnaire (Appendix F) for use with children (defined here as those not yet in high school) and the Self-Evaluation Questionnaire (Appendix B) for use with adolescents (defined here as those in high school) and Adults. Both formats reflect proneness to anxiety or generalized cross-situational anxiety.

The How I Feel Questionnaire was administered to the child by the researcher.

Each parent and adolescent administered the Self-Evaluation Questionnaire to themselves.

Both the adult and the child scale have good internal reliability (.78-.92). The test-retest reliability for the trait scale in adults was .73 for males and .77 for females over 104 days. For children, these reliabilities were .65 for males and .71 for females over 42 days. Extensive evidence for content, criterion and construct validity of these scales is provided in the test manuals (Spielberger 1973, Spielberger et al, 1970).

- 2) Pain Diary (Richardson, McGrath, Cunningham, Humphreys 1983)

The children were asked to keep a record of their pain over a two week period in a pain diary (Appendix C). The child was to record the intensity of his pain on a scale from 0-5 twice each day, before breakfast and again before dinner. He/she also

indicated any other symptoms experienced, any medication taken for the pain and possible causes for the intensity of the pain such as "Walked too far today" or "lack of sleep".

The particular version of pain diary to be used in this study has been administered successfully at the Children's Hospital of Eastern Ontario. It adapted well for use with children suffering Juvenile Chronic Arthritis.

3) F - Copes: Family Coping Strategies.

(McCubbin, Larsen & Olson, 1982)

This scale measures five separate aspects of family coping strategies conceptually based on Family stress theory put forward by R. Hill and H. McCubbin. There are nine items grouped under Acquiring Social Support that measure a family's ability to actively engage in acquiring support from relatives, friends, neighbors and extended family. Eight items, grouped under Reframing, assess the family's capability to redefine stressful events in order to make them more manageable. Four items, grouped under Seeking Spiritual Support, focus on the family's ability to

acquire spiritual support. Four other items grouped under Mobilizing Family to Acquire and Accept Help measure the family's ability to seek out community resources and accept help from others. The category Passive Appraisal assesses the family's ability to accept problematic issues minimizing reactivity. The scale is in a format for use with adults and adolescents.

The construct validity of this scale is good. The test-retest reliability for the scale was .81. The factors "Reframing" and "Passive Appraisal" at .61 and .75 show slightly lower scores in comparison with the other factors which suggests that the more concrete behavioral items provide more response consistency over time than those factors which relate to more cognitive adjustment.

This scale was administered to parents only.

To this author's knowledge this scale has not been used to measure coping strategies of families containing a child suffering a chronic illness. Nevertheless, it was expected to adapt well to the present study since it is conceptually based on traditional family stress theory. This theory has been used as the basis for other studies attempting to measure family coping strategies in families containing a chronically ill child and was found useful (Venters 1981). For the purposes of this study coping strategies are defined as the general family response intended to minimize the hardships and stress of living with chronic illness.

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This scale measures both the adaptability and cohesion dimensions of family functioning. There are four levels of family cohesion ranging from extreme low cohesion (disengaged) to extreme high cohesion (enmeshed). The two moderate or balanced levels of cohesion have been labelled separated and connected. There are also four levels of family adaptability

(rigid) to extreme high adaptability (chaotic). The two moderate or balanced levels of adaptability have been labelled flexible and structured.

For each dimension, the balanced levels are hypothesized to be most viable for healthy family functioning and the extreme areas are generally seen as more problematic for couples and families over time.

This scale was derived from families which did not contain a chronically ill child. It is therefore possible to speculate that families which do contain a chronically ill child will score somewhat differently, particularly on the cohesion dimension. In other words, the norms for families which contain a chronically ill child will differ from the norms of families that do not have this particular problem to deal with.

Because the scale was designed to measure family dynamics, the items attempt to focus on system characteristics and focus on all the family members currently living at home. For the purposes of this

study, each parent was administered the scale and their scores combined and located on the matrix according to instructions.

Previous researchers have suggested the interaction dimensions of 'cohesion', 'positive communication' and 'satisfaction' with the family unit as among the more important determinants of family survival during periods of conflict (Glasser and Glasser 1970).

These three indicators are utilized by the Circumplex Model of Marital and Family Systems.

Reliability: This scale has excellent internal reliability. Cronbach Alpha on the Cohesion factor was .87. For the Adaptability factor .78 and for the total scale .90.

The test-retest reliability is good. The Pearson correlation for the 50 items on the original scale was .84; it was .83 for cohesion and .80 for adaptability. Detailed evidence for construct validity is provided in the test manual.

F. Scoring of Instruments

1. Anxiety Inventory Scoring:

How I Feel Questionnaire:

a) The STAIC Trait Score (C-2)

This self-report measure consists of 20 items which are assigned values from 1-3 using a scoring key. The total score is calculated by adding these values (range 20-60).

b) The STAIC Trait T-score (C-2)

This is a normalized T-score derived by converting the above score to a T-distribution (mean = 50, S.D. = 10) using the appropriate norms.

Self-Evaluation Questionnaire

a) The STAI Trait Anxiety Score (X-2)

This self-report measure consists of 20 items which are assigned values from 1-4 according to a scoring key. These values are summed for an overall trait anxiety score ranging from 20-80.

b) The STAI Trait T-score (X-2)

This is a normalized T-score derived by converting the above score to a T-distribution (mean = 50, S.D. = 10) using the appropriate norms.

2. F-Copes Scoring:

A sum score is obtained for each sub-scale and total scale by simply summing the items.

Norms are available for each sub-scale and the total scale.

3. Pain Diary Scoring:

Pain Index - This is a measure of total pain activity in a week. It is a sum of all 14 ratings (2 per day, 7 days).

This value is prorated if there is more or less than 14 ratings per week. This value is not calculated if there are less than 10 ratings (more than 4 missing data points).

Pain is defined as one or more sequential intensity ratings of joint pain on any one day. Whenever there is continual pain activity on successive days, new pain is counted each day.

4. Circumplex Scale of Marital and Family Systems

Scoring Procedure:

Cohesion dimension - First, sum the two groups of items.

The first group of items are the negative items (3, 9, 15, 25, 29). The second group are all the positive items.

Subtract the first group sum from the constant of 36 and add the second sum which will give the total score for cohesion (range 16-80).

Adaptability dimension - The first group are negative items (12, 24, 28). The second group are positive items. Subtract the first sum from the constant 18 and add the second sum to which were given the total score (range 15-70).

The final 30 item scale contains 16 cohesion items and 14 adaptability items. There are two items for the following eight concepts related to the cohesion dimension:

emotional bonding, family boundaries, coalitions, time, space, friends, decision-making and interests and recreation. There are two or three items for the six concepts related to the adaptability dimension:

assertiveness, leadership, discipline, negotiation, roles and rules.

5. Limitations of Study:

Since the study population was not a random sample of all arthritic families, but contained only English speaking, two parent families who live close to the City of Ottawa and who were being seen at the clinic during the study period, generalizability of findings extends only to the participants. As well, it must be acknowledged that

self-report data is subject to perceptual bias and therefore can be inaccurate. A possible limitation of this study is that while the Family Functioning scale is well validated, it was not created for use with families having to deal with the specific demands of chronic illness. For example, one might expect a family with a chronically ill child to demonstrate more cohesiveness than a family with healthy children who do not require the same amount of parental involvement in their daily living. This might place a family outside the 'balanced' level of family functioning while in fact it reflects optimal functioning under the specific circumstances.

By including only two parent families in the study it is likely that a more traditional approach to solving marital conflict was reflected. As well, each parent can act as a resource for the other in minimizing illness hardships. It might be expected then that both Family coping strategies and Family Functioning scores would have been higher than if single parents had been included in the population.

G. DATA ANALYSIS

1. T-tests were done to determine any differences between the two groups on the anxiety, family functioning and family coping strategy scales. Table 1 indicates table testing significance of group difference.
2. A simple chi-square and phi coefficient was computed to show the degree of relationship between both groups and family functioning.
3. Correlational analysis was done to determine the relationship between all the variables in the experimental group. See Tables 2 and 3.
4. Table 4 indicates number of parents on or above 50% range on subscale norms in family coping strategies. A test for significance of difference between two proportions was done to reveal possible differences between mother and father's coping strategies in the experimental group and between groups.

IV RESULTS

A. Demographic and Background Statistics

Forty-eight families participated in this study with 24 families in each of the two groups. All children had two adults caring for them in the home. In four cases there had been a remarriage with the mother retaining custody of the children. In the control group the average length of marriage was 19 years with a range between 9 and 25 years. The experimental group had an average length of marriage of 17 years with a range between 4 and 27 years.

In the control group the mean age of fathers was 46 years, mothers 41 years and children 14 years. In the experimental group the mean age of fathers was 44 years, mothers 40 years and children 14 years.

An effort was made to roughly match the groups in terms of socio-economic status. The families were placed in three categories defined as follows: Category 1: one or both parents being "professionals" i.e. lawyers, teachers, diplomats, business executives who owned their own homes. These families were considered well off because of the

intellectually and culturally enriched lives they lead as well as not suffering any obvious economic deprivations. Category 2: middle class and working class families, this category also contained three farm families. These families seemed to live on a more modest scale, but were financially secure and owned their own homes. Category 3: those families who lived in modest apartments, in Ottawa Housing Projects or who rented small homes outside the city.

Eight families in the control group and seven in the experimental group fell within Category 1. Twelve families in the control group and 15 in the experimental group fell within Category 2. Seven families in the control group and two families in the experimental group fell within Category 3.

Average number of siblings in both groups was two with a range of zero to five. In the experimental group the average length of illness was 3.2 years, with a range from 8 months to 9 years.

The test results were analyzed in four ways. First, within the experimental group a Pearson correlation was

applied to discover the relationship between the variables. Second, student t-tests were run on comparisons between the experimental and control groups on the variables anxiety, family coping strategies and family functioning. Third, a simple chi-square and phi coefficient was used to show the degree of relationship between both groups and family functioning. Fourth, to test the significance of the difference between parents within the experimental group and between each group of parents on the P-Copes subscale of Family Coping Strategies, an analysis of two proportions was used.

Table 1 illustrates the results of the comparisons between families of children with arthritis and families with healthy children on the variables anxiety, family coping strategies and family functioning. Mothers, fathers, adolescents and children in the experimental group were all found to have significantly higher anxiety scores than their counterparts in the control group.

There were no significant differences found between groups on the variables family coping strategies or family functioning.

Hypothesis 1 states that the two groups will have similar scores on the family coping strategies scale. This hypothesis was supported.

Hypothesis 2 states the experimental group will have higher anxiety scores than the control group. Significant differences were found between the two groups with the strongest difference between the children and the weakest difference between the adolescents.

Hypothesis 3 states more families in the control group will score in the 'balanced' levels of family functioning than in the experimental group. This was true in regard to actual numbers, but to test the significance of the results two statistical procedures were performed. A t-test was carried out on each dimension of the scale between the two groups. With alpha tabled at .05 no difference was found between the two groups. Then a simple chi-square was applied to determine the degree of relationship between the variables 'balanced' and 'not balanced' levels between the two groups. The difference was found to be not significant $\chi^2(1) = 1.05, ns$. When the scores of families were separated into those families

with children and those families with adolescents, certain interesting differences emerged.

All nine experimental group families with children had scores which showed high cohesion, only one family scored low adaptability. In the control group 45% of the families had scores which showed high cohesion and 33% of the families showed low adaptability. In the adolescent subgroup 33% of the experimental families had scores which showed high cohesion. Forty-six percent of the families showed low adaptability. In the control group only 20% of families showed high cohesion and as with the experimental group 46% showed low adaptability.

Table 2 describes the results of the correlations between pain and select variables in the experimental group. A detailed description of the table follows.

Hypothesis 4 states that there will be a negative relationship between pain and family functioning. A Pearson r was used to determine the relationship between pain and each of the family functioning dimensions: cohesion and adaptability. No relationship was found.

Hypothesis 5 states there will be a positive relationship between pain and mother, father, adolescent and child anxiety. These results were mixed. No relationship was found between pain scores and parental or child anxiety although a rather strong but not significant negative relationship was found between children's pain and father's anxiety. A significant relationship was found between adolescent pain and anxiety.

Hypothesis 6 states there will be a positive relationship between pain and family coping strategies. Parents' scores were combined to arrive at a family score. This hypothesis was not supported. No relationship was found.

Table 3 describes the correlations between anxiety and select variables in the experimental group. A Pearson r demonstrated the relationship between anxiety and each of the family functioning dimensions.

Hypothesis 7 states there will be a negative relationship between anxiety and level of family functioning. A negative relationship was found between father's anxiety and both of the family functioning dimensions, cohesion $p < .01$; adaptability $p < .001$.

Hypothesis 8 states there will be a positive relationship between family functioning and family coping strategies. Parents scores on each variable were combined to arrive at family scores. This hypothesis was not supported. No relationship was found.

Hypothesis 9 states there will be a negative relationship between anxiety and family coping strategies. This hypothesis was not supported.

Table 4 indicates the degree to which each parent utilizes each of the strategies in the Family Coping Strategies subscales. More mothers than fathers in both groups scored on or above the 50% range on each of the subscales. As can be seen there was a significant difference between mothers and fathers in the importance placed on specific strategies. Mothers in both groups placed a significantly greater importance on the strategies of acquiring social support and mobilizing family to acquire and accept help than did fathers. Within the experimental group mothers placed a significantly greater importance on Passive Appraisal than did fathers in the same group or either parent in the control group.

Table 1.

Comparisons Between Families of Children With Arthritis and Families With Healthy Children.

Variable	Family Member	Experimental Group $\bar{X}$	Control Group $\bar{X}$	Student's t Score
Anxiety	Mother ^a	38.20	34.12	1.82 ^{**}
	Father ^a	37.75	34.20	1.65 [*]
	Adolescents ^a	40	35.86	1.40 ^{ns}
	Child ^c	36.11	27.88	2.52 ^{***}
Family Coping Strategies	Mother ^a	92.85	88.79	1.11
	Father ^a	80	82.04	1.16
Family Functioning Cohesion:	Mother ^a	66.41	67.41	.55
	Father ^a	61.33	60.30	.24
Adaptability:	Mother ^a	49.75	52.12	1.42
	Father ^a	47.41	48.58	.016

a: N=48, b: N=30, c: N=18

* $p < .10$, ** $p < .05$, *** $p < .025$ one-tailed.

TABLE 2.

Correlations Between Pain and Select Variables in Experimental Group

Pain	Family Cohesion	Functioning Adaptability	Number of Coping Strategies	Anxiety		
				Mother	Father	Adolescent Child
Pain Scores ^a (Children and Adolescents)	.070	.039	.237	.096	.073	
Pain Scores ^b (Adolescents Only)	.046	-.022	.016	.316	.141	.582 ^a
Pain Scores ^c (Children Only)	.048	.167	.157	-.022	-.616	.318

^a $p < .05$

a: n=21, b: n=14, c: n=7.

Table 3.
Correlations Between Anxiety and Select Variables in Experimental Group

Anxiety	Family Cohesion	Functioning Adaptability	Number of Coping Strategies
Anxiety Scores ^a (Children and Adolescents)	-.410	-.211	-.032
Anxiety Scores ^b (Children Only)	.176	.390	.416
Anxiety Scores ^c (Adolescents Only)	-.288	-.258	.334
Anxiety Scores ^a Mothers	-.090	-.210	-.132
Fathers	-.576 [*]	-.663 ^{**}	.105

a: n=24, b: n=9, c: n=15

* $p < .01$; ** $p < .001$

This study as well as previous ones show a strong relationship between adolescent pain and anxiety. This finding can be useful to the social worker by alerting him/her to the need of teenagers to come to terms with their illness in order to develop a healthy self-image.

By not showing any significant differences between groups, this study emphasizes that most families cope with stresses of chronic pediatric illness adequately. In the majority of cases intervention by social workers is not necessary. For those families who have more difficulty coping, the findings of this study can also be helpful. They can be used as a starting point in the exploration of issues that can assist social workers in helping clients deal with their stress in a constructive manner.

Table 4

Difference Between Two Proportions.
 Number of Scores on or above 50% on
 F-Copes Subscale Norms.

Subscale	Experimental Group			Experimental and Control Group		
	Mother ^a Z	Father ^a Z	s Score	Mother ^b Z	Combined Fathers ^b Z	s Score
Acquiring Social Support	.54	.88	5.62 ^a	.50	.18	5.33 ^a
Reframing	.54	.45	0.88	.75	.58	1.79
Mobilising Family to Acquire and Accept Help	.33	.04	3.95 ^a	.25	.06	3.80 ^a
Seeking Spiritual Support	.41	.25	1.69	.37	.33	0.66
Passive Appraisal	.58	.29	3.00 ^a	.45	.31	2.02

a: n=24, b: N=48.
 z ± 1.96, p < .05.

C. DISCUSSION

Many previous studies suggest that chronic pediatric illness creates greater stress on the family unit. This additional stress is reported to often manifest itself in negative psychosocial consequences for both the children and parents in these families. Pless & Pinkerton (1975), Venters (1981) and Harder & Bowditch (1982) all found that long term family responses are more varied, with some families reporting greater closeness and familial strength being achieved after a family member became chronically ill. The results of this study indicate that families with a chronically ill child do in fact suffer a higher level of stress manifested by higher anxiety scores than do families in the control group. This additional stress, however, does not appear to impinge on the adequacy of family functioning.

The particular population of arthritic patients who with their parents took part in this study, did not, for the most part, suffer from an extreme form of this disease. None of the children were seriously disabled, all were ambulatory, only one was on crutches at the time of the study. Of the 21 subjects who complied with the pain diary (14 adolescents, 7 children) three indicated no pain at all over the two week testing period and the highest score of 108 out of a possible 140 was given by the child on crutches. The mean score of this combined group was 42 (children $\bar{X} = 42.57$; adolescents $\bar{X} = 40.92$). These pain scores, perhaps because they are relatively low, had no correlation to the other variables except in one instance, adolescent anxiety. Nevertheless they have some interesting characteristics when the scores are separated into a children's subgroup (those in elementary school) and an adolescent subgroup (those in high school). Beales (1982) suggests that younger children experience less pain than adolescents due to the age variation in the cognitive appraisal of nociceptive signals. The age variation was not apparent in the present study where the mean score of the children was somewhat higher than that of the adolescents. When the scores of these two subgroups are examined together four of the six highest scores were

given by children between the ages of eight and eleven. Another, strong but not significant, negative correlation was found between childrens' pain and fathers anxiety ($r = -.616$; $df = 5$). The most likely reason for this unusual finding is that the childrens pain scores while higher than the adolescents, are still too low to affect parental anxiety.

It is interesting to note that no relationship was found between childrens' pain and their anxiety where previous research (Stoddard, 1982) has found that in children pain is closely linked with anxiety. This is likely due to the low degree of pain reported by these children as well as the cause of the pain i.e. arthritis disease as opposed to the trauma experienced by a burn victim. Adolescents on the other hand, showed a significant relationship between pain and anxiety ($r = .582$; $p < .025$). This finding supports previous research (Beales, 1977) that adolescent pain has greater significance since it reminds the teenager of his illness and the effect it might have on physical attractiveness and career choice.

This study attempted to discover what if any relationship exists between the type or extent of coping strategies

used by a family to deal with chronic pediatric pain. The issue is how families with the unique stress of living with a child who suffers recurrent bouts of pain utilize internal and/or external family resources to cope with this event. No relationship was found between pain and number or type of coping strategies used by the families in this study, perhaps due to the low pain scores.

However, one interesting trend seems to exist. Of the 14 families which utilize the coping strategy passive appraisal more frequently than 50% of the subscale norms, 12 of these families had children with the highest pain scores. A possible explanation for this finding is the sense of helplessness a parent must experience when a child suffers recurrent pain that a parent is unable to alleviate. As well, it should be noted that while fathers used this strategy to some degree it was only the mothers who scored in the upper 50% of the subscale norms. This trend is different from previous findings (Olson & McCubbin, 1983) which found that both parents use this strategy equally sparingly.

The correlation between anxiety and family functioning showed a significant negative relationship between

father's anxiety and both the cohesion and adaptability dimension of family functioning. Previous research (Patterson & McCubbin, 1983) indicates that one of the hardships often experienced by families of chronically ill children is strained intrafamily relationships because of a coalition which exists between the mother and the sick child. This could lead to the father's perception of low cohesiveness and adaptability and conceivably contribute to increased anxiety. The difficulty with a correlational analysis is that it does not determine direction or causality. A more conclusive interpretation of these results is difficult without further exploration of possible extraneous factors contributing to the fathers' anxiety and whether the anxiety is causing the lack of cohesion or the reverse. The same problem exists in regard to children's anxiety and perceived lack of family cohesion. The reason for this relationship is difficult to interpret without further exploration of possible causal factors. Although there was a mild trend towards a negative relationship between mother's, children's and combined children's anxiety and number of coping strategies no significant relationship was found. More research is needed to determine whether or not the number of coping strategies used by a family will help to reduce anxiety or if use of specific strategies is more effective.

As a group, mothers, fathers and children in the experimental group showed significantly higher anxiety levels than did members of the control group. Lazarus (1980) points out that stress must be defined in terms of transactions between individuals and situations. It follows then that the added stress of chronic illness would manifest itself in higher anxiety levels among all members of the family. The strongest difference between groups was found among the children perhaps indicating the relative lack of extraneous forces which might impinge on one's anxiety score. The weakest difference was between adolescent groups indicating that many other factors apart from chronic illness may create anxiety for a teenager. It should be noted that the higher anxiety scores obtained by the experimental group while indicating a statistically significant difference between groups are not high enough to be clinically significant (anxiety scale mean = 50). This may be a function of the particular illness being studied as well as the degree of seriousness of the illness experienced by each child. A note of caution should be introduced at this point. Due to the mixed results achieved by this study there is a reasonable likelihood that type one error has occurred. In the

majority of cases alpha was tabled at .05, the occasional finding came in at the .025 or .001 level. Nevertheless, one must suspect the significance of all the results. More research needs to be done before conclusive statements can be made.

There were no differences between groups on the variables of family functioning or family coping strategies. Several factors could have influenced the similarity between groups in regard to family functioning. First, the previous studies which found dysfunctional individual and family functioning in relation to chronic illness dealt with illnesses which were either fatal or generally more severe than Juvenile Chronic Arthritis. Second, although the experimental group was more stressed than the control group, their stress fell well short of pathological levels which might be expected to affect level of family functioning. Third, none of the families in the study contained problems of sexual or drug abuse or psychiatric illness. All these factors contribute to these families' "normalcy" and to the lack of difference between groups. However, when one separates the children from the adolescents in each group and looks at each family's placement within the circumplex model then some interesting trends begin to emerge.

Previous research (Olson and McCubbin, 1983) indicates that cohesion and adaptability within a family varies over the life cycle. These two characteristics are at their highest during the early years of marriage and child bearing, reach a low point during the adolescent and child launching years and rise again once the children have left home. The present study largely supports these findings, but also indicates that a chronically ill child does exert an influence on family cohesiveness.

The findings indicate that both the experimental and control group families are moving through the expected phases of a family's life cycle which further supports the 'normalcy' of both groups of families. It is important to note however, that both the children and adolescent subgroups of experimental families show a higher level of cohesiveness than do control group families. It would appear from these findings that chronic illness does play a role in creating greater cohesiveness within families.

Since the number of experimental families which scored high cohesion dropped from 100% in the child subgroup to 33% in the adolescent subgroup one is tempted to assume that families with chronically ill children are able to

move towards greater separation and individuation as the children grow up. This is clearly true in some cases, but we cannot assume from this study that 66% of families will allow their children to grow up and away. The families in this study represent a cross-sectional view of families with arthritic children and as such the findings cannot be generalized to a larger population. Those families that do not evolve will likely be the ones that cause problems for their individual members.

The literature and previous studies dealing with the psychological and psychosocial aspects of chronic pediatric illness suggest that families which contain a chronically ill child are often at greater risk than healthy child families in terms of family functioning and emotional disturbance in individual members. Although it seems reasonable to conceptualize chronic illness as a stressor, this does not mean that families can not utilize successful coping strategies to develop healthy adaptations to the illness. Pless and Pinkerton (1975) as well as Venters (1981) suggest that in some instances the presence of chronic illness promotes personal growth. It is clear from the present study that the concept of chronically ill children as significantly disturbed and

their families as having a greater risk of breakdown than families with healthy children is not true of this population of arthritic children.

Interestingly, no significant differences were found between the families with an Arthritic child and the families with a healthy child on any of the variables except anxiety. Even in the case of anxiety the individual members of the experimental group families had scores well within the 'normal' or 'healthy' range. Some interesting questions emerge from the strong negative correlation between father's anxiety and family cohesion and adaptability. What factors are present which create such a difference in score between fathers and mothers? Do these scores relate to the role fathers play within the family or do they relate to the type of coping strategies used by fathers rather than mothers? What effect do different coping strategies, if they exist, have on family functioning? These are just a few of the questions that should be answered in the future.

One of the results of this study indicates a higher level of anxiety in families of children with Chronic Arthritis. This knowledge can be used by a medical social

worker as a cue in helping families identify the sources of their anxiety and perhaps finding better coping strategies for dealing with it.

The finding that mothers of children with JCA use the strategy of passive appraisal more frequently than mothers of the control children or fathers in either group can be used as a cue to exploring the value of this particular coping strategy. The literature suggests that the more active strategies are generally considered most helpful to individuals coping with stress, but perhaps this is not always the case.

The same holds true for the finding that fathers of JCA children who experience high anxiety also perceive their families as less cohesive and adaptable than do fathers with lower anxiety. This can be used as a starting point in examining the role of these fathers in their family.

Is there a coalition between mother and child that excludes the father? Whether or not this is the case, an exploration of other possible factors which may contribute to a sense of alienation would prove useful.

This study as well as previous ones show a strong relationship between adolescent pain and anxiety. This finding can be useful to the social worker by alerting him/her to the need of teenagers to come to terms with their illness in order to develop a healthy self-image.

By not showing any significant differences between groups, this study emphasizes that most families cope with stresses of chronic pediatric illness adequately. In the majority of cases intervention by social workers is not necessary. For those families who have more difficulty coping, the findings of this study can also be helpful. They can be used as a starting point in the exploration of issues that can assist social workers in helping clients deal with their stress in a constructive manner.

APPENDIX A

INFORMED CONSENT

I understand that a study is being conducted by The Children's Hospital of Eastern Ontario to investigate the problem of Juvenile Chronic Arthritis. This study will attempt to determine some of the factors involved in living with this illness and how families cope with the various stresses. This study is being conducted by Gill Reilly (MSW candidate, Carleton University) and by Doctors John Latter and James McKee of the Rheumatology clinic.

The children and parents involved in this study will be asked to fill out several questionnaires under the direction of the researcher. In addition, children in the experimental group will be asked to keep a Pain Diary for a two week period. This involvement will require one appointment lasting less than two hours and will be scheduled at your convenience.

There are no known negative effects of the procedures in this study. All discussions between the researcher and the child and family will be kept confidential. In the event any parts of this study are submitted for publication, complete anonymity of the subjects is assured.

You may withdraw from this study at any time without affecting the availability of future treatment from the hospital. Any questions or comments you may have may be directed at any time to Mrs. Reilly at 741-4857, Dr. Latter or Dr. McKee at 737-7600.

I agree to participate in this study.

Child's signature: _____

Mother's signature: _____

Father's signature: _____

Witness: _____ Date: _____

APPENDIX B

SELF-EVALUATION QUESTIONNAIRE

STAI FORM X-2

NAME _____ DATE _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OTHER	ALMOST ALWAYS
21. I feel pleasant _____	①	②	③	④
22. I tire quickly _____	①	②	③	④
23. I feel like crying _____	①	②	③	④
24. I wish I could be as happy as others seem to be _____	①	②	③	④
25. I am losing out on things because I can't make up my mind soon enough _____	①	②	③	④
26. I feel rested _____	①	②	③	④
27. I am "calm, cool, and collected" _____	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them _____	①	②	③	④
29. I worry too much over something that really doesn't matter _____	①	②	③	④
30. I am happy _____	①	②	③	④
31. I am inclined to take things hard _____	①	②	③	④
32. I lack self-confidence _____	①	②	③	④
33. I feel secure _____	①	②	③	④
34. I try to avoid facing a crisis or difficulty _____	①	②	③	④
35. I feel blue _____	①	②	③	④
36. I am content _____	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me _____	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind _____	①	②	③	④
39. I am a steady person _____	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests _____	①	②	③	④

PAIN DIARY

APPENDIX C

NAME _____

WEEK BEGINNING _____

FILL IN THIS FORM AT BREAKFAST AND DINNER EACH DAY

	INTENSITY RATING	OTHER SYMPTOMS	MEDICATION	POSSIBLE CAUSE
BREAKFAST				
DINNER				
BREAKFAST				
DINNER				
BREAKFAST				
DINNER				
BREAKFAST				
DINNER				
BREAKFAST				
DINNER				
BREAKFAST				
DINNER				
BREAKFAST				
DINNER				

INTENSITY RATING

0-NO PAIN

1-PAIN - I AM ONLY AWARE OF IT IF
I PAY ATTENTION TO IT

2-PAIN - BUT I CAN IGNORE IT AT TIMES

3-PAIN - I CAN'T IGNORE IT BUT I CAN DO
MY USUAL ACTIVITIES4-PAIN - IT'S DIFFICULT FOR ME TO CONCENTRATE
I CAN ONLY DO EASY THINGS

5-PAIN - SUCH THAT I CAN'T DO ANYTHING

APPENDIX C

INSTRUCTIONS FOR PAIN DIARY

1. Be sure to fill your pain diary at breakfast and dinner each day.
2. Fill in the diary for how you feel at the time.
3. INTENSITY RATING: Use the numbers from the Intensity Rating chart at the bottom of this page to show how you feel at the time. Be sure to mark 0 if you have no pain.
4. OTHER SYMPTOMS: Write in anything else you feel at the time such as stiffness, visual disturbance, loss of appetite...etc. If you feel nothing else, draw a line through the space.
5. MEDICATION: Please write in the name and amount of any medicine you have taken since the last time period. If none was taken draw a line through the space.
6. POSSIBLE CAUSE: Write in anything you think might have caused the pain at this time, such as change in weather, a particular activity or fatigue etc. If you don't know, draw a line through the space.

APPENDIX D

F-COPES

Hamilton I. McCubbin, Andrea S. Larsen & David M. Olson

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

RESPONSE CHOICES				
Strongly Disagree ¹	Moderately Disagree ²	Neither ³ Agree Nor Disagree	Moderately Agree ⁴	Strongly Agree ⁵
1. Sharing our difficulties with relatives. 2. Seeking encouragement and support from friends. 3. Knowing we have the power to solve major problems. 4. Seeking information and advice from persons in other families who have faced the same or similar problems. 5. Seeking advice from relatives (grandparents, etc.) 6. Asking neighbors for favors and assistance. 7. Seeking assistance from community agencies and programs designed to help families in our situation. 8. Accepting that we have the strength within our own family to solve our problems. 9. Accepting gifts and favors from neighbors (ex. food, taking in mail, etc.) 10. Seeking information and advice from the family doctor. 11. Facing problems "head-on" and trying to get solutions right away. 12. Watching television. 13. Showing that we are strong. 14. Attending church services. 15. Accepting stressful events as a fact of life. 16. Sharing concerns with close friends. 17. Knowing luck plays a big part in how well we are able to solve family problems. 18. Accepting that difficulties occur unexpectedly. 19. Doing things with relatives (get-togethers, dinners, etc.) 20. Seeking professional counseling and help for family difficulties. 21. Believing we can handle our own problems. 22. Participating in church activities. 23. Defining the family problem in a more positive way so that we do not become too discouraged. 24. Asking relatives how they feel about problems we face. 25. Feeling that no matter what we do to prepare, we will have difficulty handling problems. 26. Seeking advice from a minister. 27. Believing if we wait long enough, the problem will go away. 28. Sharing problems with neighbors. 29. Having faith in God				

FACES II ITEMS

APPENDIX E

by

David H. Olson, Joyce Portner, and Richard Bell

1. Family members are supportive of each other during difficult times.
2. In our family, it is easy for everyone to express his/her opinion.
3. It is easier to discuss problems with people outside the family than with other family members.
4. Each family member has input in major family decisions.
5. Our family gathers together in the same room.
6. Children have a say in their discipline.
7. Our family does things together.
8. Family members discuss problems and feel good about the solutions.
9. In our family, everyone goes his/her own way.
10. We shift household responsibilities from person to person.
11. Family members know each other's close friends.
12. It is hard to know what the rules are in our family.
13. Family members consult other family members on their decisions.
14. Family members say what they want.
15. We have difficulty thinking of things to do as a family.
16. In solving problems, the children's suggestions are followed.
17. Family members feel very close to each other.
18. Discipline is fair in our family.
19. Family members feel closer to people outside the family than to other family members.
20. Our family tries new ways of dealing with problems.
21. Family members go along with what the family decides to do.
22. In our family, everyone shares responsibilities.
23. Family members like to spend their free time with each other.
24. It is difficult to get a rule changed in our family.
25. Family members avoid each other at home.
26. When problems arise, we compromise.
27. We approve of each other's friends.
28. Family members are afraid to say what is on their minds.
29. Family members pair up rather than do things as a total family.
30. Family members share interests and hobbies with each other.

APPENDIX F

HOW-I-FEEL QUESTIONNAIRE
STAIC FORM C-2

NAME _____ AGE _____ DATE _____

DIRECTIONS A number of statements which boys and girls use to describe themselves are given below. Read each statement and decide if it is *hardly-ever*, or *sometimes*, or *often* true for you. Then for each statement, put an X in the box in front of the word that seems to describe you best. There are no right or wrong answers. Do not spend too much time on any one statement. Remember, choose the word which seems to describe how you usually feel!

1.	I worry about making mistakes	☐ hardly-ever	☐ sometimes	☐ often
2.	I feel like crying	☐ hardly-ever	☐ sometimes	☐ often
3.	I feel unhappy	☐ hardly-ever	☐ sometimes	☐ often
4.	I have trouble making up my mind	☐ hardly-ever	☐ sometimes	☐ often
5.	It is difficult for me to face my problems	☐ hardly-ever	☐ sometimes	☐ often
6.	I worry too much	☐ hardly-ever	☐ sometimes	☐ often
7.	I get upset at home	☐ hardly-ever	☐ sometimes	☐ often
8.	I am shy	☐ hardly-ever	☐ sometimes	☐ often
9.	I feel troubled	☐ hardly-ever	☐ sometimes	☐ often
10.	Unimportant thoughts run through my mind and bother me	☐ hardly-ever	☐ sometimes	☐ often
11.	I worry about school	☐ hardly-ever	☐ sometimes	☐ often
12.	I have trouble deciding what to do	☐ hardly-ever	☐ sometimes	☐ often
13.	I notice my heart beats fast	☐ hardly-ever	☐ sometimes	☐ often
14.	I am secretly afraid	☐ hardly-ever	☐ sometimes	☐ often
15.	I worry about my parents	☐ hardly-ever	☐ sometimes	☐ often
16.	My hands get shaky	☐ hardly-ever	☐ sometimes	☐ often
17.	I worry about things that may happen	☐ hardly-ever	☐ sometimes	☐ often
18.	It is hard for me to control my anger	☐ hardly-ever	☐ sometimes	☐ often
19.	I get a funny feeling in my stomach	☐ hardly-ever	☐ sometimes	☐ often
20.	I worry about things that I don't know	☐ hardly-ever	☐ sometimes	☐ often

APPENDIX C

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario

Dear Parents,

We are writing to you to request your assistance in a research project being conducted at the Rheumatology Clinic of the Children's Hospital of Eastern Ontario. In an effort to better understand the stresses which families of Arthritic children must cope with on an on-going basis, and to improve the services offered to new families in our clinic, we would appreciate your meeting with Mrs. Gill Reilly (MSW candidate, Carlton University) to fill out several questionnaires.

Mrs. Reilly will be conducting the research project which will begin in early September and finish mid-October. She will be contacting you by phone in the near future and at that time will request an appointment to meet with you at your convenience.

Thank you for your interest and cooperation.

With best personal regards,

Dr. John Laffer
Rehabilitation Medicine

Dr. James McKee
Rheumatology Clinic

APPENDIX M

Children's Hospital of Eastern Ontario
Hôpital pour enfants de l'est de l'Ontario

Dear Parents:

We are writing to you to request your assistance in a research project being conducted at the Rheumatology Clinic of the Children's Hospital of Eastern Ontario. Your child's chart was selected at random from the current hospital files. In order to complete our research we need to include families which do not have a chronically ill child. We are asking that you and your child be a member of our control group.

This research project is investigating the problem of Juvenile Chronic Arthritis. We would like to determine some of the factors involved in living with this illness and how families cope with the various stresses. This study is being conducted by Mrs. Gill Reilly (MSW candidate, Carleton University) and by Doctors John Latter and James McKee of the Rheumatology Clinic. Your participation in this study will be greatly appreciated.

The children and parents involved in this study will be asked to fill out several questionnaires under the direction of Mrs. Reilly. This involvement will require one appointment lasting approximately one hour and will be scheduled at your convenience. All discussions between your family and the researcher will be kept in confidence.

Mrs. Reilly will be contacting you by phone in the near future and at that time will ask for an appointment to meet with you and your child.

Thank you for your interest and cooperation.

Dr. John Latter
Rheumatology Clinic

Dr. James McKee
Rheumatology Clinic

K. REFERENCES

Barker, R.C., Wright, B.A. & Gonick, M.A. (1953):

Adjustment to physical handicap and illness: a survey of the social psychology of physique and disability. Social Science Research Council Bulletin. New York: Social Science Research Council.

Beales, J.G. (1979): Effect of disease concepts on experience of pain, depression or anxiety in children with juvenile chronic polyarthritis. Annals of the Rheumatic Diseases, 36(3), 288.

Beales, J.G. (1982): The assessment and management of pain in children. In A.P. Goldstein & L. Krasner (eds); Child Health Psychology, Concepts and Issues. Toronto: Pergamon Press.

Beecher, H.K. (1959): Measurement of Subjective Responses. New York: Oxford University.

Beglerter, M.L., Burry, V.F. & Harris, D.J. (1976):

Prevalence of divorce among parents of children with cystic fibrosis and other chronic diseases. Social Biology, 23(3), 260-264.

Bergman, A.S., Lewiston, N.J. & West, A.M. (1979): Social work practice and chronic pediatric illness. Social Work in Health Care, 4(3), 265-274.

Beyerman, K. (1982): Flawed perceptions about pain. American Journal of Nursing, 2, 302-304.

Bibace, R. & Walsh (1980): Development of children's concepts of illness. Pediatrics, 66, 912-917.

Block, A.R. (1981): Investigation of the response of the spouse to chronic pain. Psychosomatic Medicine, 43(5), 415-422.

Bloom, Benjamin, S. (1964): The child's response to illness. In G. Travis; (1976): Chronic Illness in Children, it's Impact on Child and Family. California: Stanford University.

Blumer, D. (1982): Chronic pain as a variant of depressive disease: The pain - prone disorder. Journal of Nervous and Mental Disease, 170(7), 381-406.

Bond, M. (1978): Psychological and psychiatric aspects of pain. Anaesthesia, 33, 355-361.

Bowen, M. (1978): Theory in the practice of psychotherapy. In Family Therapy in Clinical Practice. (pp. 88-102) New York: Aronson.

Breslau, N., Weitzman, M. & Messenger, K.P. (1981): Psychologic functioning of siblings of disabled children. Pediatrics, 67, 344-353.

Cairns, N.U. & Lansky, S.B. (1980): MMPI indicators of stress and marital discord among parents of children with chronic illness. Death Education, 4(1), 29-41.

Chodoff, P. (1964): Stress defenses and coping behavior: observations in parents of children with malignant disease. American Journal of Psychiatry, 120, 744.

Coyne, L.C. & Lazarus, R.S. (1980): Cognitive style, stress perception, and coping. In I.L. Kutash & L.B. Schlesinger (eds). Handbook on Stress and Anxiety: Contemporary Knowledge, Theory and Treatments. (pp. 144-158). San Francisco: Jossey-Baso.

- Cytryn, L., Moore, P. & Robinson, M. (1973): Psycho-
logical adjustment of children with cystic fibrosis.
In E.J. Anthony & C. Koupernik (eds); The Child in His
Family: The Impact of Disease and Death.
(pp. 37-48). New York: John Wiley & Son.
- Deutsch, C.P. & Goldston, J.A. (1960): Family factors in
home adjustment of the severely disabled. Marriage
and Family Living, 5, 95-103.
- Eland, J.M. & Anderson, J.E. (1977): The experience of
pain in children. In A.K. Jacox (ed); Pain: A Source
Book for Nurses and Other Health Professionals.
(pp. 453-473). Boston: Little Brown.
- Endler, N. & Edwards, J. (1982): Stress and personality.
In L. Goldberger & S. Breznitz (eds); Handbook of
Stress: Theoretical and Clinical Aspects.
(pp. 36-48). New York: Erce Press.
- Gayton, W.F., Freedman, S.B., Tavormina, J.F. & Tucker,
F. (1977): Children with cystic fibrosis: psycho-
logical test findings of patients, siblings and
parents. Pediatrics, 59(6), 888-894.

Glasser, P. & Glasser, L. (1970): In Families in Crisis.

(pp. 290-301). New York: Harper and Row.

Harder, L. & Bowditch, B. (1982): Siblings of children with cystic fibrosis: perceptions of the impact of the disease. Pediatrics, 10(4), 116-120.

Hart, F.D. (1968): Control of pain in the rheumatic disorders. British Medical Journal, 3, 635-640.

Hersher, A.B. & Freedman, S.B. (1981): Social and psychological considerations in chronic disease: with particular reference to the management of seizure disorders. Journal of Pediatric Psychology, 6(3), 239-251.

Hill, R. (1949): Families Under Stress. Connecticut: Greenwood Press.

Isaacs, J. & McElroy, M.R. (1980): Psychosocial aspects of chronic illness in children. Journal of School Health, 6, 318-321.

Jackson, D.D. (1957): The question of family homeo-
tasis. Psychiatric Quarterly, 31, 79-90.

Kolb, L.C. (1982): Attachment behavior and pain com-
plaints. Psychosomatics, 23, (4) 413-425.,

Lavigne, J.V. & Ryan, M. (1979): Psychological adjustment
of siblings of children with chronic illness.
Pediatrics, 63(4), 616-627.

Leichtman, S.R. & Freedman, S.B. (1975): Social and
psychological development of adolescents and the
relationship to chronic illness. Medical Clinics of
North America, 59(6), 1319-1328.

Loeser, J.D. (1980): Low back pain. In J.J. Bonica (ed);
Pain. (pp. 363-377). New York: Raven Press.

Marlick, M. (1979): The impact of severe illness on the
individual and family: an overview. Social Work in
Health Care, 5(2), 117-129.

May, R. (1977): The Meaning of Anxiety.
New York: Norton.

McAnarney, E.R., Pless, I.B., Satterwhite, B. & Freedman, S.B. (1974): Psychological problems of children with chronic juvenile arthritis. Pediatrics, 53(4), 523-528.

McCubbin, I.I., Larsen, A.S. & Olson, D.H. (1982): In Family Inventories. (p. 130). St. Paul: Family Social Science.

Melzack, R. & Casey, K.L. (1968): Sensory, Motivational and central control determinants of pain: a new conceptual model. In D. Kenshalo (ed); The Skin Senses. (pp. 423-443). Springfield: Thomas.

Melzack, R. & Wall, P.D. (1965): Pain mechanisms: a new theory. Science, 150, 971-979.

Melzack, R. & Wall, P.D. (1982): The Challenge of Pain. New York: Basic Books.

Merskey, H. (Chairman) and IASP subcommittee on Taxonomy. (1979): Pain terms: a list with definitions and notes on usage. Pain, 6, 249-252.

Miller, J.J. & Spitz, P.W. (1982): The social function of young adults who had arthritis in childhood. Journal of Pediatrics, 90, 528-532.

Offer, D. & Sabshin, M. (1965): Normality: Theoretical and Clinical Concepts of Mental Health. New York: Basic Books.

Olson, D.H. & McCubbin, H.I. (1983): Families, What Makes Them Work, Beverly Hills: Sage Publication.

Olson, D.H., Portner, J. & Bell, R. (1982): In Family Inventories (p. 90). St. Paul: Family Social Science.

Olson, D.H., Russell, C.S. & Sprenkle, D.H. (1982): Circumplex model of marital and family systems: VI. theoretical update. Family Process, 22, 69-83.

Olson, D.H., Russell, C.S. & Sprenkle, D.H. (1980): Marital and family therapy: a decade review. Journal of Marriage and Family, 42, 973-993.

- Patterson, J.M. & McCubbin, H.I. (1983): Chronic illness: Family stress and coping. In C.R. Figley & H.I. McCubbin (eds), Stress and the Family Vol. II, Coping with Catastrophe. (pp. 21-36). New York: Brunner/Mazel.
- Perrin, E.C. & Genity, P.S. (1980): There's a demon in your belly: children's understanding of illness. Pediatrics, 72, 233-236.
- Peterson, E.T. (1972): The impact of adolescent illness on parental relationships. Journal of Health and Social Behavior, 13(4), 429-437.
- Pilowsky, I. & Spence, N.D. (1976): Is illness behavior related to chronicity in patients with intractable pain? Pain, 2, 167-173.
- Pless, I.B. & Pinkerton, P. (1975): Chronic Childhood Disorder. London: Henry Kimpton.
- Pless, I.B. & Roghmann, R.J. (1971): Chronic illness and its consequences: observations based on three epidemiologic surveys. Journal of Pediatrics, 79, 351-359.

Pless, I.B. (1983): Effect of chronic illness on adjustment. In P. Firestone, P. McGrath & W. Feldman (eds), Advances in Behavioral Medicine with Children and Adolescents. (pp. 1-16). New York: L. Erlbaum Associates.

Richardson, D.W. & Freedman, S.B. (1974): Psychosocial problems of the adolescent patient with epilepsy. Clinical Pediatrics, 13, 121-126.

Richardson, G., McGrath, P., Cunningham, S.J. & Humphreys, P. (1983): Validity of headache diary for children. Headache, 23, 184-187.

Roy, R. (1976): Social work and chronic pain. Health and Social Work, 6(3), 54-62.

Rusk, H.A. & Novey, J. (1957): The impact of chronic illness on families. Marriage and Family Living, 5, 193-197.

Russell, C.S. (1979): Circumplex model of marital and family systems: III empirical evaluation with families. Family Process, 18, 29-43.

Satterwhite, B.B. (1978): Impact of chronic illness on child and family: an overview based on 5 surveys with implication for management. International Journal of Rehabilitation Research, 1(1), 7-17.

Speer, D.C. (1978): Family systems: morphostasis and morphogenesis, or is homeostasis enough? Family Process, 4(3), 259-272.

Spielberger, C.D. (1971): Trait-state anxiety and motor behavior. Journal of Motor Behavior, 3, 265-279.

Spielberger, C.D. (1973): Preliminary Test Manual for the State-Trait Anxiety Inventory for Children ("How I Feel Questionnaire"). Palo Alto: Consulting Psychologists.

Spielberger, C.D. (1976): The nature and measurement of anxiety. In C.D. Spielberger & R. Diaz-Guerrero (eds); Cross Cultural Anxiety. (p. 4). Washington, D.C.: Hemisphere.

Stein, R. & Jessop, D.J. (1982): A non-categorical approach to chronic childhood illness. Public Health Reports, 7(4), 354-362.

Stoddard, P.J. (1982): Coping with pain: a developmental approach to treatment of burned children. American Journal of Psychiatry, 139, 736-740.

Travis, G. (1976): Chronic Illness in Children, its Impact on Child and Family. California: Stanford University.

Venters, M. (1981): Familial coping with chronic and severe childhood illness: the case of cystic fibrosis. Social Science and Medicine, 15A, 289-297.

Walsh, P. (ed.), (1982): Normal Family Processes. New York: The Guildford Press.

Wepman, B.J. (1979): Pain as an interpersonal device. Psychosomatics, 20(8), 561-562.

Wright, B. (1960): Physical Disability: A Psychological Approach. New York: Harper and Row.

Zborowski, M. (1952): Cultural components in response to pain. Journal of Social Issues, 8, 16-30.

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