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The Ohio State University, 1987
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U-M-I
PSYCHOLOGICAL ADJUSTMENT IN JUVENILE RHEUMATOID ARTHRITIS

DISSERTATION

Presented in Partial Fulfillment of the Requirements for
the Degree Doctor of Philosophy in the Graduate
School of the Ohio State University

By

Janet R. Meltzer, B.A., M.A.

* * * * *

The Ohio State University
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ACKNOWLEDGEMENTS

I would like to thank my adviser, Dr. Thomas Linscheid for his valuable contributions throughout the research. I also wish to thank my committee members, Dr. Charles Wenar, Dr. Robert Bornstein and Dr. Steve Beck for their thoughtful suggestions and comments. In particular, Dr. Bornstein's support and encouragement as well as assistance with the statistical analyses and critique of the manuscript are greatly appreciated. The study would not have been possible without the consistent cooperation and support of the Rheumatology Clinic staff at Columbus Children's Hospital. Special thanks go to the children and their parents who served as subjects in the study. I sincerely appreciate the support and encouragement provided by my parents. Finally, I am very grateful to my husband Seth for his continual love, support, understanding and patience throughout this research and all of my endeavors.
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### TABLE OF CONTENTS

**ACKNOWLEDGEMENTS**..............................................................ii

**VITA**..................................................................................iii

**LIST OF TABLES**.................................................................vi

**CHAPTER**

I. **INTRODUCTION**.................................................................1

II. **REVIEW OF THE LITERATURE**...........................................5

   Psychological Adjustment of Chronically Ill Children and Adolescents..........................5

   The Relationship Between Illness Characteristics and Adjustment..............................6

   The Relationship Between Individual-Child Characteristics and Adjustment...............10

   The Relationship Between Family Functioning and Adjustment.................................11

   Juvenile Rheumatoid Arthritis......................................................16

   Psychological Factors in Juvenile Rheumatoid Arthritis............................................18

III. **STATEMENT OF THE PROBLEM**..........................................35

IV. **METHODOLOGY**...............................................................40

   Subjects.................................................................................40

   Instruments...........................................................................42

   Procedure...............................................................................46

   Statistical Analyses...............................................................47

V. **RESULTS**............................................................................49

VI. **DISCUSSION**.......................................................................81

**REFERENCES**..........................................................................103
APPENDICES

A. Child Behavior Checklist..........................109
B. Piers-Harris Self-Concept Scale..................110
C. Family Environment Scale..........................111
D. JRA Questionnaire..................................112
E. Letter to Subjects..................................113
F. Consent Forms........................................114
# LIST OF TABLES

<table>
<thead>
<tr>
<th>TABLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Demographic and Illness Characteristics of the JRA Sample</td>
<td>50</td>
</tr>
<tr>
<td>2. JRA and National Norms: Piers-Harris Self-Concept Scale</td>
<td>51</td>
</tr>
<tr>
<td>3. JRA and National Norms: Child Behavior Checklist</td>
<td>51</td>
</tr>
<tr>
<td>4. Correlation Coefficients Among Adjustment Measures</td>
<td>53</td>
</tr>
<tr>
<td>5. Summary of ANOVA of Self-Esteem by Age of Onset and Agegroup</td>
<td>56</td>
</tr>
<tr>
<td>6. Summary of ANOVA of Self-Esteem by Duration of Illness and Agegroup</td>
<td>58</td>
</tr>
<tr>
<td>7. Summary of ANOVA of Social Competence by Duration of Illness and Agegroup</td>
<td>59</td>
</tr>
<tr>
<td>8. Summary of ANOVA of Total Behavior Problems by Duration and Agegroup</td>
<td>60</td>
</tr>
<tr>
<td>9. Spearman Correlation Coefficients for Severity Measures</td>
<td>62</td>
</tr>
<tr>
<td>10. Summary of MANOVA and ANOVA's of Adjustment by Disease Activity</td>
<td>64</td>
</tr>
<tr>
<td>11. Summary of MANOVA and ANOVA's of Adjustment by Marital Status</td>
<td>67</td>
</tr>
<tr>
<td>12. Summary of MANOVA and ANOVA's of Adjustment by Developmental Stage</td>
<td>68</td>
</tr>
<tr>
<td>13. Summary of ANOVA of Externalizing Problems by Agegroup and Type of JRA</td>
<td>70</td>
</tr>
<tr>
<td>14. JRA and Normative Family Environment Scale Scores</td>
<td>71</td>
</tr>
<tr>
<td>15. Multiple Regression Analyses: FES Subscale Scores</td>
<td>73</td>
</tr>
</tbody>
</table>
16. Pearson Correlation Coefficients Between FES Subscale Scores and Adjustment .................................. 75

17. Multiple Regression Analyses: FES Subscale Scores and Illness Variables ......................................... 77

18. Multiple Regression Analyses: FES Composite Scores and Illness Variables ..................................... 79
Chapter I
INTRODUCTION

Due to advances in medical treatment, the number of children living with chronic medical conditions has been steadily increasing in recent years (Magrab, 1984). Although incidence rates for most chronic diseases have remained relatively stable, the life expectancy for children with such conditions has increased substantially during the last few decades (Pless, 1984). With greater numbers of chronically ill children surviving into adolescence and adulthood, there has been a growing interest in the impact of chronic physical illness on a child's long-term development and overall psychological adjustment.

There is an extensive body of literature which describes the challenges to normal psychosocial adjustment posed by a chronic illness in childhood. Some theoretical discussions have focused on the ways in which a chronic illness hinders the achievement of critical developmental tasks necessary for healthy adjustment, resulting in an increased risk for intellectual, social and emotional difficulties (Brown, 1982; Coupey & Cohen, 1984; Magrab, 1984; Perrin & Gerrity, 1984; Weitzman, 1984). Others have described the dynamic interaction between a child's chronic illness and his/her family's functioning, emphasizing both the impact of family functioning on the child's
psychological adjustment to illness as well as the impact of a chronically ill child on the family's structure, organization and functioning (e.g. Minuchin et al., 1978; Sabbeth, 1984; Sargent, 1983).

In spite of numerous theoretical discussions and clinical descriptions which suggest that chronically ill children are more vulnerable to psychological adjustment problems, empirical evidence of greater psychopathology and maladjustment has been equivocal. Several large scale epidemiologic studies comparing the social and psychological functioning of large subgroups of chronically ill and healthy children (Pless & Roghmann, 1971; Pless, Roghmann & Haggerty, 1972; Rutter, Tizard & Whitmore, 1970) have reported that those with chronic illnesses have an increased risk of experiencing significant psychological or social problems when compared with their healthy peers. Numerous investigations of specific illnesses have also documented a greater frequency of psychological adjustment problems among chronically ill as compared to healthy children (Gayton & Freedman, 1973; Koocher, O'Malley, Gogan & Foster, 1980; Swift, Seidman & Stein, 1967). However, other studies have challenged the hypothesis that chronically ill children are a psychologically deviant population by reporting no differences in psychosocial adjustment between chronically ill and healthy children (e.g. Kellerman, Zeltzer, Ellenberg, Dash & Rigler, 1980; Tavormina, Kastner, Slater & Watt, 1976; Zeltzer, Kellerman, Ellenberg, Dash & Rigler, 1980). Numerous explanations for the contradictory nature of the literature have been cited including conceptual problems (e.g. varying definitions of what behavior constitutes "adjustment" or "psychopathology") as well as methodological
flaws (e.g. use of unstandardized, subjective measures, inadequate control or comparison groups, heterogeneous illness samples).

As a result of the contradictory and inconclusive nature of this literature, researchers have more recently proposed a reformulation of the model that guides research investigating psychological adjustment in children and adolescents with chronic illness. In a discussion of this literature, Drotar (1981) argues that previous research in this area has been dominated by a personality-focused paradigm, with a counterproductive emphasis on differences between chronically ill and healthy children. Rather than continuing to focus on whether children with chronic illness exhibit greater psychopathology than healthy children, Drotar suggests that the focus of research should instead be aimed at identifying those variables which differentiate children who are well-adjusted despite a chronic illness from those who are not. In a discussion of the literature on psychological adjustment in chronic childhood illness, Pless (1983, 1984) notes that a search for factors that increase the risk for maladjustment in this population has characterized most of the recent research in this area. The types of variables most frequently investigated fall into three broad categories: illness-related variables (e.g. severity, duration), individual child characteristics (e.g. age, sex, socioeconomic status, personality traits, coping strategies, cognitive development) and family functioning/social support system.

Numerous recent studies have examined the impact of these variables on children's psychological adjustment in a variety of specific illness groups including pediatric cancer (e.g. Koocher et al., 1980; O'Malley,
Foster, Koocher & Slavin, 1980), cystic fibrosis (e.g. Johnson, Muyskens, Bryce, Palmer & Rodman, 1985; Lewis & Khaw, 1982), hemophilia (e.g. Bruhn, Hampton & Chandler, 1971), diabetes (e.g. Hauser, Jacobson, Wertleib, Brink & Wentworth, 1985; Koski & Kumento, 1977; Wertleib, Hauser & Jacobson, 1986), chronic renal disease (e.g. Klein & Simmons, 1977; Klein, Simmons & Anderson, 1984) and sickle cell anemia (e.g. Lemanek, Moore, Gresham, Williamson & Kelley, 1986; Hurtig & White, 1986). Unfortunately, although more children suffer from arthritis than from each of the aforementioned illnesses (Gortmaker & Sappenfield, 1984), little empirical information is available concerning the psychological adjustment of children and adolescents with arthritis. A recent, comprehensive review of the literature regarding psychological factors in rheumatoid arthritis (Anderson, Bradley, Young & McDaniel, 1985) concluded that in contrast to the extensive psychological literature on rheumatoid arthritis in adults, there have been only a handful of empirical studies within the psychological literature on juvenile rheumatoid arthritis. Among the few studies which have examined psychological adjustment in children with arthritis, none have included systematic, multivariate investigations of factors which may increase the risk of psychological adjustment problems in this group.

The purpose of the present study was to identify those variables that mediate psychological adjustment in children and adolescents with juvenile rheumatoid arthritis. Utilizing several standardized, objective psychological measures, the relationship between psychological adjustment and illness-related variables, individual-child variables and family functioning variables was investigated.
Chapter II

REVIEW OF THE LITERATURE

Psychological Adjustment of Chronically Ill Children and Adolescents

In spite of the massive and rapidly growing literature investigating psychological adjustment of chronically ill children, few conclusive findings have emerged. As previously mentioned, this has been attributed to the methodological deficiencies of much of the early work in this area as well as the wide discrepancies between studies with regard to how "adjustment" is conceptualized and measured and what specific psychological constructs are examined. Even more recent, well-controlled studies have yielded inconsistent findings with regard to the prevalence of psychopathology and maladjustment among chronically ill children as well as the impact of particular mediating variables on psychological adjustment. The present review of the literature will be limited to those studies of chronic illnesses other than arthritis that are particularly relevant to the present study due to similarities in design, measures, and variables studied. Investigations of the relationship between psychological adjustment and illness characteristics, individual-child characteristics and family functioning will be reviewed with a particular emphasis on those studies that have utilized the Child Behavior Checklist (Achenbach & Edelbrock, 1983) and the Piers-Harris Self-Concept Scale (Piers & Harris, 1969) as indices of
adjustment. A comprehensive review of the literature concerning psychological factors in juvenile rheumatoid arthritis will follow.

The Relationship Between Illness Characteristics and Psychological Adjustment

Numerous theoretical discussions have hypothesized that certain clinical characteristics of chronic illness (severity, duration, age of onset, prognosis) may increase the risk for adjustment problems (e.g. Pless, 1983, 1984; Pless & Pinkerton, 1975; Steinhausen, Musin & Rae-Grant, 1974). Although a direct, linear relationship has generally been assumed to exist between severity of illness and increased risk for psychological maladjustment, numerous studies of both homogeneous and heterogeneous chronic illness groups have reported no relationship between various indices of severity and adjustment. Drotar (1981) found that adjustment, as measured by parent and teacher ratings of behavior on the Louisville Behavior Checklist, was not related to severity of illness in a study of 91 children with cystic fibrosis. In a study which will be discussed in detail in the following section, Kellerman et al. (1980) reported no relationship between physician ratings of severity, number of hospitalizations, visible signs of illness or life expectancy and measures of self-esteem, anxiety and health locus of control in a sample of 168 adolescents with a variety of chronic illnesses. O'Malley et al. (1980) studied the relationship between severity of illness and a global rating of adjustment based on pencil and paper measures of self-esteem, social adjustment, depression, anxiety and a standard psychiatric interview in 116 long-term pediatric cancer survivors. Severity was based on a composite score derived from
ratings of degree of visibility of impairment and degree of functional impairment (interference with activities of daily living and ability to work or attend school). The authors found that degree of visible/functional impairment did not differentiate well-adjusted from poorly adjusted cancer patients. In a study of 24 children with constitutional short stature, Gordon, Crouthamel and Riehman (1982) found no relationship between adjustment (as measured by parent ratings of social competence and behavior problems on the Child Behavior Checklist); self-reported self-esteem on the Piers-Harris Scale; and severity of illness (degree to which child's height was below the mean). Similarly, in their study of 85 early adolescents with cystic fibrosis, Simmons, Corey, Cowen, Kennan, Roberston and Levison (1985) reported no relationship between parent ratings of social competence and behavior problems on the Child Behavior Checklist and severity of illness based on pulmonary function and number of hospitalizations. However, there was a significant correlation between self-esteem scores on the Tennessee Self-Concept Scale and pulmonary function for males, but not for females. Such findings suggest that even when a relationship between severity of illness and adjustment is found, it may be mediated by other variables such as gender. The findings also underscore the need to define "adjustment" as a multifaceted construct certain aspects of which (e.g. self-esteem) may be more or less influenced by particular variables. Other studies have also demonstrated the influence of mediating variables on the relationship between severity of illness and adjustment as well as the differential impact of severity on various aspects of adjustment. In a study of 81 latency aged children with a
variety of chronic illnesses (respiratory, neurologic, renal, endocrinological, hematologic, neuromuscular) Stein and Jessop (1984) reported that functional impairment was related to days absent from school and psychological maladjustment measured by parent ratings. However, the strength of this relationship was less for children from intact families than from nonintact families, suggesting that family characteristics may also mediate the relationship between severity of illness and adjustment. In their investigation of psychosocial functioning in girls with Turner's Syndrome, McCauley, Ito and Kay (1986) reported that the number of external physical anomalies was related to lower self-esteem on the Piers-Harris Scale but there was no relationship between severity of physical anomalies and parent/teacher ratings of social competence and behavior problems on the Child Behavior Checklist.

Further complicating the relationship between severity of illness and psychological adjustment is the frequently cited (although unreplicated) finding of a study by McAnarney, Pless, Satterwhite and Friedman (1974) of 42 children with juvenile rheumatoid arthritis which will be discussed in greater detail in the following section. These authors reported a curvilinear relationship between severity (degree of functional impairment -- none, mild, moderate, severe) and several measures of adjustment, with nondisabled children displaying greater maladjustment than those with moderate to severe disabilities who in turn, appeared more maladjusted than mildly disabled children. This relationship remained intact even when duration of illness, family factors and parents' education were controlled.
In summary, the relationship between severity of illness and adjustment appears to be complex and due to the lack of consistency between studies with regard to how severity and adjustment are defined, it is difficult to draw definitive conclusions. However, it is clear that the assumption that greater severity is predictive of greater maladjustment has not received clear empirical support.

Far fewer studies have examined the relationship between other illness-related variables and adjustment. The impact of age of onset on adjustment has been examined in several studies. In their study of 115 pediatric cancer survivors, Koocher et al. (1980) reported that age of onset was the best predictor of psychological adjustment, with early onset (infancy, early childhood) associated with better overall adjustment (composite score based on paper and pencil instruments and psychiatric interview). Duration of time since diagnosis was also predictive of good adjustment. Ryan and Morrow (1986) examined self-esteem in a sample of 125 diabetic adolescents divided into an early disease onset group (diagnosed prior to five years of age) and a later onset group (diagnosed at or after age five). Although no group differences were found in self-esteem based on age of onset alone, when gender was taken into account, an interaction was reported, whereby females with an early disease onset had significantly lower self-esteem than males with an early disease onset. The relationship between prognosis and adjustment has been examined by Kellerman et al. (1980) and Zeltzer et al. (1980) in their studies of 168 chronically ill adolescents. These authors reported a significant relationship between type of prognosis (stable, uncertain, improved, deteriorated) and
measures of trait anxiety. A stable prognosis was associated with lower anxiety scores than other prognoses. However, there was no association between prognosis and self-esteem as measured by the Rosenberg Self-Esteem Scale. Such findings once again highlight the need to view adjustment as a complex, multifaceted process requiring multimethod, multitrait measures.

The Relationship Between Individual-Child Characteristics and Adjustment

The relationship of adjustment with age and sex has been reported in numerous studies of chronically ill children with no consistent findings. Some studies have reported no relationship (e.g. Gordon et al., 1982; Kumar, Powars, Allen & Haywood, 1976; Stein & Jessop, 1984) while others have reported a significant association between gender and adjustment (e.g. Kellerman et al., 1980; Simmons et al., 1985; Zeltzer et al., 1980) or age of the child and adjustment (Hurtig & White, 1986). In several recent studies the primary focus has been the relationship of adjustment with age and sex of the child. As previously mentioned, Ryan and Morrow (1986) examined the association between gender, age of onset and self-esteem in 125 diabetic adolescents and found that females who developed diabetes before the age of five had significantly lower self-esteem scores than early onset male diabetics. Noting that most studies of adjustment in chronic childhood illness do not control for age and developmental stage differences, Hurtig and White (1986) compared the psychosocial functioning of 31 latency aged (8-11 years) and 19 adolescent (12-16 years) sickle cell anemia patients. Adjustment measures included the Child Behavior Checklist, Piers-Harris Self-Concept Scale and California Test of Personality (CTP). The authors
reported increasing social adjustment problems with age on the CTP (particularly for males) but found no age group differences in the personal adjustment domain when compared to national norms. No differences were found between the self-esteem scores of both age groups and the national norms for either males or females. However, adolescent males displayed significantly more behavior problems (both internalizing and externalizing) than adolescent females or the latency group as a whole when compared to national norms for the CBCL. The interaction between age, gender and adjustment in these two studies also suggests that the relationship between various individual-child characteristics and adjustment is complex and interactive in nature.

The Relationship Between Family Functioning and Adjustment

In contrast to the overall lack of consistency between the findings of studies examining the association between illness-related variables, individual-child characteristics and psychological adjustment, the impact of family functioning on the adjustment of chronically ill children is considered by many to be very powerful (e.g. Drotar, 1981; Pless, 1983, 1984; Pless, Roughmann & Haggerty, 1972; Pless & Satterwhite, 1973; Stein & Jessop, 1984). In a series of studies comparing the psychological adjustment of chronically ill and healthy children, Pless and colleagues (Pless et al., 1972; Pless & Satterwhite, 1973) reported that family functioning, as measured by the Family Functioning Index (FFI), was the most powerful predictor of adjustment, more so than any clinical characteristics of the illness.
More recent studies have examined the relationship between family functioning and adjustment in a variety of specific chronic illness samples. Lewis and Khaw (1982) examined family functioning and adjustment in three groups of children: 31 with cystic fibrosis, 26 with asthma and 27 healthy controls matched for age, sex and race. Family functioning was measured by means of the Family Adaptability and Cohesiveness Evaluation Scales (FACES) an instrument which categorizes families according to levels of cohesion and adaptability, with extreme scores in either direction indicating poor functioning. Adjustment was assessed by parent ratings on the Behavior Problem Checklist and self-reported self-esteem on the Piers-Harris Scale. The three groups did not differ in terms of family adaptability, cohesion or self-concept, although the chronic illness groups had significantly more behavior problems than healthy controls. Multiple regression analyses of the three groups together revealed a highly significant relationship between family functioning and adjustment problems, with extremes of adaptability and cohesion predictive of increased behavior problems and lower self-esteem. The authors concluded that family functioning is an important mediator of adjustment to chronic illness and may be a better predictor of adjustment than the presence of a chronic illness. A more comprehensive investigation of the relationship between family functioning and adjustment has been described by Johnson, Muyskens, Bryce, Palmer and Rodnan (1985) in their study of 15 children with cystic fibrosis. Several indices of family functioning were utilized including the Family Environment Scale (FES), Family Hierarchy Test and independent observer ratings of videotaped family interaction based on
the Beavers-Timberlawn Family Systems Rating Scale. Adjustment was measured by means of parent ratings of social competence and behavior problems on the Child Behavior Checklist. Family size and composition, duration of illness, parents' age and amount of illness among other family members were all controlled. The authors reported several significant correlations between family characteristics and the child's adjustment. As measured by the FES, degree of family conflict was positively correlated with total number of behavior problems. An emphasis on family organization correlated negatively with total number of behavior problems. Parental sharing of power as assessed by observer ratings correlated positively with higher levels of social competence. No significant relationship was found between FES scores and severity of illness. Although the sample size was small, thus limiting the generalizability of the findings, the use of multitrait, multimethod measures of family functioning provides a more comprehensive picture of which family variables may be most strongly associated with psychological adjustment in chronically ill children.

As part of a four year prospective study of family functioning and adjustment in newly diagnosed diabetic children and adolescents, Hauser and colleagues (Hauser et al., 1985; Wertleib et al., 1986) have reported cross-sectional findings from the first year of the study. Hauser et al. (1985) examined the association between family functioning as measured by the Family Environment Scale (FES) and self-esteem as measured by the Perceived Competence Scale in a group of 30 diabetic and 30 acutely ill (e.g. appendicitis, pneumonia) 9-16 year olds. Although there were no group differences in perceived competence and a
significant group difference on only one of the 10 FES scales (diabetic families were more achievement-oriented), there were striking group differences in the relationship between family environment and perceived competence, particularly when controlling for age and socioeconomic status. In the diabetic group, greater family emphasis on independence, organization and social-recreational activities were strongly correlated with higher levels of perceived competence. In contrast, in the acute illness group, greater family emphasis on achievement, intellectual-cultural activities and expressiveness were predictive of higher levels of perceived competence. The authors suggested possible explanations for these groups differences (e.g. diabetic adolescents are especially sensitive to issues of independence and group activities with the family). Nevertheless, the findings highlight the importance of family functioning as a mediating variable in the adjustment to illness. As part of the same study, Wertleib et al. (1986) have reported findings concerning the relationship between family functioning as measured by the Family Environment Scale (FES) and behavior problems as measured by parent ratings on the Child Behavior Checklist in a sample of 46 diabetics and 29 acutely ill 9-16 year olds. When controlling for socioeconomic status, no significant group differences were found in total severity of behavior problems, internalizing or externalizing symptomatology or any of the 10 FES scales. In both groups high levels of family conflict were positively correlated with increased behavior problems (total, internalizing and externalizing) although the relationship was stronger for the diabetic group. However, other relationships between family and adjustment variables were group
specific. For diabetics, family emphasis on organization and social-recreational activities was predictive of fewer behavior problems. Greater moral-religious emphasis within the family was positively correlated with more internalizing symptoms. In contrast, for the acute illness group, low levels of family cohesion were associated with increased behavior problems (especially externalizing symptoms). Family emphasis on achievement and control predicted higher levels of total behavior problems and both internalizing and externalizing symptomatology. The authors note that these findings will need to be integrated with future data from this longitudinal study to clarify the implications of differential patterns of relationships between family functioning and adjustment in chronically ill and acutely ill adolescents.

In summary, family factors are clearly important mediators of adjustment and appear to influence adjustment in different ways in different illness groups. Although derived from only two studies with small sample sizes (Johnson et al., 1985; Wertleib et al., 1986) several consistent findings have been reported regarding the relationship between family functioning as measured by the Family Environment Scale and behavior problems as assessed by the Child Behavior Checklist. Higher levels of family conflict were strongly correlated with a high frequency of total behavior problems and a greater emphasis on family organization was predictive of fewer total behavior problems. Family organization was also positively correlated with higher levels of self-esteem in two of the studies. In the two studies of diabetic children an emphasis on social-recreational activities within the family was
predictive of higher self-esteem and fewer total behavior problems.

**Juvenile Rheumatoid Arthritis**

Juvenile rheumatoid arthritis (JRA) is the most common rheumatic disease of childhood, with prevalence estimates as high as 250,000 in the United States alone (Arthritis Foundation, 1983; Petty, 1982). Rheumatic diseases are a group of illnesses that affect muscles, ligaments, tendons and joints. Other common rheumatic diseases of childhood include rheumatic fever, scleroderma and systemic lupus erythematosus. The term arthritis refers to inflammation of a joint and occurs in many different diseases, all of which belong to the broader category of rheumatic disease. Contrary to popular belief, JRA is not a childhood version of adult onset rheumatoid arthritis which affects as many as seven million people (Williams, 1981). The only common denominator is that chronic inflammatory joint swelling occurs in both (Williams, 1981). In particular, the prognosis is much better in the case of JRA which frequently ends in remission unlike the typically progressive nature of adult rheumatoid arthritis (RA).

The diagnosis of JRA requires that there be continuous swelling, pain, warmth and redness of one or more joints for a period of at least six weeks (Williams, 1981). The etiology of JRA remains uncertain. The disease has its onset before age 16 with peak onset periods in the age groups of one to three years and eight to twelve years (Williams, 1981).

There are three subtypes of JRA which vary according to clinical characteristics, frequency, sex distribution and prognosis. **Systemic onset JRA** accounts for 20% of all JRA cases and has an equal male:female incidence. This subtype is characterized by an abrupt onset with high
intermittent fever that is often accompanied by a rash. Arthritis may or may not be present at the onset but usually occurs within six months. The number of joints involved is variable. The prognosis in this subtype is fair, with some patients experiencing a remission without permanent joint damage with others developing a more disabling arthritis. **Polyarticular onset JRA** is characterized by arthritis in five or more joints. This subtype affects 30% to 40% of all JRA patients. The small joints of the hands and fingers are usually affected and in many cases hips, knees, ankles and elbows are also affected. The female: male sex ratio is 4:1. Within the polyarticular subtype when the onset occurs in early childhood the joint prognosis is fair to good. In contrast, the more common onset in late childhood carries a poorer prognosis with progressive, debilitating arthritis developing in over 50% of patients. **Pauciarticular onset JRA** occurs in 40% to 50% of all cases and is characterized by arthritis in fewer than five joints (usually large joints of the knees, ankles and elbows). Within this subtype girls outnumber boys 4:1 and the prognosis is quite good. However, among those girls (20% - 40%) in whom pauciarticular JRA has its onset during early childhood, a chronic inflammation of the iris typically occurs which can result in severe visual impairment. Fortunately, this type of inflammation can usually be detected early with frequent ophthalmologic examinations permitting early treatment.

A major component of the treatment for JRA is designed to control the inflammatory disease and thereby reduce or eliminate pain and stiffness and prevent or limit disability. High doses of aspirin is the most frequently utilized anti-inflammatory medication and is effective in the
majority of children with JRA. Non-steroidal anti-inflammatory medications are also frequently utilized in the treatment of JRA. In more difficult to manage, progressive cases of JRA more potent medication such as steroids and gold salt injections may be utilized, although they carry the potential for severe side effects. In conjunction with pharmacological treatment, therapeutic exercise to increase range of motion and strength is an important component to the overall management of JRA. In some cases splinting and even surgical joint replacement may be necessary to restore function and reduce pain.

**Psychological Factors in Juvenile Rheumatoid Arthritis**

In a recent review of the literature on biobehavioral factors in JRA, Varni and Jay (1984) point out that studies investigating psychosocial aspects of JRA have been strongly influenced by work conducted with adult rheumatoid arthritis. The latter has been dominated by two major areas of investigation: 1) investigations of personality characteristics of patients with rheumatoid arthritis in an effort to identify a typical personality profile and 2) investigations of life events and psychosocial stressors preceding the onset of arthritis in an effort to identify possible precipitants (p. 548).

With few exceptions, the psychological literature on JRA is also dominated by a search for psychosocial precipitants and typical personality characteristics or manifestations of psychopathology. The once widely held belief that emotional factors play a prominent role in the etiology of adult rheumatoid arthritis (Moos, 1964; Baum, 1972) led to several investigations of psychosocial stress as a precipitating factor in the etiology of JRA. In an early descriptive study, Blom and Nichols
(1954) presented data from their work with 28 children with JRA who were being seen for inpatient or outpatient psychotherapy. The authors reported that in one-third of the cases, the onset of symptoms of JRA seemed to be correlated with an emotionally charged life event. Additionally, one-quarter of the sample experienced a recurrence or exacerbation of symptoms when reexposed to a conflict situation similar to that which occurred at the time of onset. However, as noted in reviews of the literature (Anderson, Bradley, Young & McDaniel, 1985; King & Hanson, 1986), due to the anecdotal nature of the findings, lack of adequate controls, subjective measure of life events (based on a clinical impression of history provided by the mother) and unreliable nature of retrospective data, the results are of questionable validity. Nevertheless, similar findings were reported by Heizel (1972) using the Coddington Life Events questionnaire, a modified version of the Holmes-Rahe Social Readjustment Rating Scale. The 45 JRA patients in the study obtained a mean "life change unit" score for the year prior to the onset of the disease that was twice that of the matched control subjects during the year prior to their test administration. The life events which occurred more often among the JRA patients included parental divorce or separation, birth of a sibling, moving to a new school and hospitalization for symptoms unrelated to JRA. The author concluded that children who develop JRA tend to have recently experienced a cluster of changes in their world "higher in amount and intensity than the average child". The author therefore proposes that JRA is a psychosomatic disease which has certain "specific trigger events" such as object loss and hospitalization. Although a more objective measure of life events
was utilized as was a control group, the retrospective nature of the data may reduce the validity of the findings.

Similar findings regarding stressful life events as precipitating factors in the onset of JRA have been reported by Rimon, Belmaker and Epstein (1977) and Henoch, Batson and Baum (1978). In a study conducted in Finland, Rimon et al. (1977) interviewed 54 children with JRA and found that 37% of these patients had experienced a "significant psychodynamic problem" during the year prior to the onset of JRA. The two most frequently cited problems were parental divorce or separation (18.5%) and hospitalization of a parent (11%). The authors identified two distinct subgroups of JRA patients -- a "major conflict group" characterized by the onset of JRA symptoms following the experience of a psychosocial stressor and no family history of JRA and a "no conflict group" which did not experience any apparent psychosocial stressor prior to disease onset and in which there was a significant family history of arthritis. Unfortunately, numerous methodological problems including the lack of control groups, unstandardized measures and anecdotal presentation of the data limit the validity of the findings (Anderson et al., 1985; King & Hanson, 1986; Varni & Jay, 1984).

On the basis of medical records and personal interview data obtained from parents of 88 children with JRA, Henoch et al. (1981) also reported a high incidence of parental divorce, separation or death among JRA patients (28%) as compared to matched controls (11%). Adoption also occurred three times more often in the JRA sample. The authors concluded that there appears to be a strong relationship between stressful life events and the onset of JRA. Although this study did include a random
pediatric sample as a control group, the validity of the results is weakened by some of the same methodological problems that were identified in previously cited studies including the lack of a standardized instrument and the retrospective nature of the data.

In summary, the literature reviewed thus far has consistently demonstrated a relationship between stressful life events and the onset of JRA. Although there appears to be a more than coincidental temporal association between stressful life events and JRA, due to the lack of methodological rigor of many of these studies and retrospective nature of the data, such a relationship should be regarded cautiously at this point. Prospective studies utilizing more objective, standardized measures and appropriate control groups could provide more definitive data concerning the role of stressful life events in the etiology of JRA. However, the consistency with which parental divorce and separation were cited as the most frequent psychosocial stressor associated with the onset of JRA suggests that families of children with JRA may experience significant levels of marital and family conflict and dysfunction.

Another group of studies have investigated the personality characteristics of children with JRA. In their descriptive study of 28 JRA patients involved in psychotherapy, Blom & Nichols (1954) reported that these children were characterized by a marked disturbance in mood (primarily depression), primitive-aggressive fantasies, severe hospitalization-separation difficulties and an inability to express feelings. Mother-child relationships were described as overly interdependent and father-child relationships as overshadowed by the
intensity of the former. Mothers were described as guilty, depressed, unable to express feelings openly and reporting "deep deprivation" in childhood. The anecdotal reporting of these findings together with the subjective assessment of personality characteristics and the failure to discuss the implications of using a psychotherapy sample of JRA patients renders the conclusions of questionable validity.

Cleveland, Reitman and Brewer (1965) also investigated the personality characteristics of children with JRA. Thirty patients, 6-16 years of age were administered the Rorschach Test, Draw-A-Person Test and selected subtests from the Wechsler Intelligence Scale for Children. Mothers were administered the Rorschach and Sentence Completion Test and were interviewed regarding their child's developmental history and their own attitudes. The results were compared to similar test data obtained in a separate study of 25 asthmatic children. No evidence was found for a typical personality profile characteristic of JRA patients.

In addition to examining the role of psychosocial stress in the etiology of JRA, Rimon et al. (1977) investigated personality characteristics and psychopathology in patients hospitalized for JRA. Measures included a psychiatric symptom profile derived from observations made by a psychiatrist, psychologist and general medical staff during the child's hospitalization. A personality rating scale was also completed by a nurse and a semi-structured psychiatric interview was conducted with the JRA patients and their families. The authors reported that 39% of the patients had suffered from some kind of emotional disturbance severe enough to necessitate contact with a physician or child guidance clinic prior to the onset of JRA. Among the
sample of 54 JRA patients overt psychopathology was observed in 31% during the course of hospitalization (e.g. depression, anxiety, psychomotor restlessness). In addition, over one-half of the children were reported to display a personality profile marked by shyness, unresponsiveness, passivity, aloofness, feelings of inferiority and difficulty expressing feelings. Unfortunately the authors did not make explicit the behavioral correlates of these personality characteristics, although they state that unspecified personality tests confirmed the profile in many of the cases. Furthermore, the study failed to discuss the implications of selecting a hospitalized sample of JRA patients, particularly the impact that a 50 day average duration of hospitalization might have on the patient's mood and behavior. The lack of control groups further weakens the validity of the findings.

Rimon et al. (1977) also examined, by means of semi-structured psychiatric interview, characteristics of the parent-child relationships of the 54 hospitalized JRA patients. The authors note that contrary to previous findings (Blom & Nichols, 1954; Cleveland et al. 1965), no uniform patterns of dysfunction were found in the mother-child relationship and problems of any sort were found in only one-third of the cases. In contrast, the father-child relationship was reported to be dysfunctional in almost one-half of the cases, most of which were characterized as superficial and aloof or excessively close. However, only 20 fathers of the 54 JRA patients were actually interviewed and most of the data was based on reports of mothers and patients alone. In light of the unreliable nature and potential bias of such data, the conclusions concerning father-child relationships may not be valid.
More recent studies have investigated the psychological adjustment of children with JRA utilizing stronger research designs and more objective measures. McAnarney, Pless, Satterwhite and Friedman (1974) studied the psychological adjustment of 42 children with JRA as compared to a matched control group of 42 healthy children. A comprehensive battery of tests were administered to all subjects including parent and teacher behavior checklists (Behavior Symptom Questionnaire), a screening test of intelligence, Coopersmith Self-Esteem Inventory, Children's Manifest Anxiety Scale, Draw-A-Person Test and California Test of Personality as well as parent interviews. Children with JRA were found to have significantly more psychological problems than healthy children with regard to self-esteem and parent ratings of behavior problems. The authors also investigated the relationship between severity of illness and psychological adjustment. The 42 children with JRA were classified into one of four categories (none, mild, moderate or severe disability) on the basis of the American Rheumatism Association (Steinbroker, Traeger & Balterman, 1949) ratings of degree of functional impairment. Comparisons were made between the psychological test scores of children with no disability, mild disability and moderate/severe disability. Contrary to the assumed direct, linear relationship between severity and adjustment, the authors found that on 12 of the 16 measures, the nondisabled children displayed poorer adjustment than moderately/severely disturbed children. Statistical analyses controlling for duration of illness and family disruption did not eliminate these differences. The authors speculated that perhaps parent and teachers make more allowances and have lower
expectations for more severely disabled children, whereas children with no apparent functional disability are expected to behave and perform more normally. The authors speculate that while more severely disabled children are forced to accept their limitations and develop coping strategies early on, those with very minimal overt disability are placed in a more conflictual situation in which they are not regarded by others as "sick", but are constantly reminded of their chronic illness through frequent mediations and clinic visits.

While these findings are frequently cited in the chronic illness literature, a careful examination of the data reveals that higher maladjustment scores of nondisabled children reached statistical significance on only two of the 12 measures reported (i.e. overall school adjustment rating and personal adjustment scale of the California Test of Personality). In addition, a curvilinear relationship was reported between severity of illness and self-esteem and parent ratings of behavior problems whereby nondisabled children displayed lower self-esteem and more behavior problems than moderately/severely disabled, who in turn, displayed lower self-esteem and more behavior problems than mildly disabled children.

Further complicating the relationship between severity of JRA and psychological adjustment are the findings of Ivey, Brewer and Giannini (1981). These authors compared self-esteem scores on the Piers-Harris Self-Concept Scale and level of anxiety on the Children's Manifest Anxiety Scale of two groups of children with JRA: 1) 11 with milder pauciarticular JRA and 2) 8 with more severe polyarticular or systemic JRA. No differences were found between the groups with regard to self-
esteem or anxiety. In addition, when compared to a sibling closest in age, the JRA patients were found to have significantly higher self-esteem and lower anxiety scores than the sibling. Although well-standardized instruments were utilized, in view of the small sample size of this study, the results may be spurious. It is also difficult to compare the findings of this study and McAnarney et al. (1974) since each utilized different measures of severity. Although it is likely that the two measures are highly correlated, this limits the degree to which the findings can be compared.

More recently, Billings, Moos, Miller and Gottlieb (1987) examined the relationship between severity of illness and psychological adjustment in a sample of 95 children with rheumatic diseases (primarily JRA, n=76). Patients were classified into groups on the basis of severity of illness: a mild disease group and a severe disease group. Severity was defined according to disease activity (active versus inactive), specific diagnostic group and the American Rheumatism Association four point rating of functional impairment. A comparison group of 93 healthy children and their families who were participants in a larger study, were also included and matched on occupational status, marital status and parental age and education. The child's adjustment was assessed by 1) parent ratings on the Health and Daily Living Form (taps four areas of the child's functioning: physical, psychological, behavior and total adjustment) and the Health Assessment Questionnaire (measures arthritis pain and functional impairment) and 2) child self reports on the Piers-Harris Scale and a child version of the Health and Daily Living Form. The severe disease group had more parent reported
psychological (primarily depression and anxiety) and physical problems than the mild disease group or healthy controls. No group differences were found with regard to behavior problems. These findings remained unchanged when age was controlled statistically. No group differences were found between the three groups on the two child report measures of adjustment. The findings of this study do not support McAnarney et al's (1974) report of poorer adjustment among children with minimal as compared to severe disability. However, McAnarney et al. (1974) examined nondisabled and mildly disabled subjects separately and found significant group differences between the two, whereas Billings et al. (1987) combined those with no impairment and mild impairment into a single group. Billings et al's. (1987) report of poorer parent rated adjustment in both illness groups as compared to healthy controls is consistent with McAnarney et al., (1974). Billings et al's. (1987) finding of no relationship between severity of illness and self-esteem as measured by the Piers-Harris Scale is consistent with the findings of Ivey et al. (1981). Billings et al. (1987) conclude that such variation in findings highlights the need to examine patient and family contextual factors that may modify the risk for adjustment problems irrespective of severity or diagnosis.

As part of a major investigation of a number of chronically ill adolescent groups, Kellerman, Zeltzer, Ellenberg, Dash and Rigler (1980) and Zeltzer, Kellerman, Ellenberg, Dash and Rigler (1980) examined the psychological adjustment of adolescents with JRA. Kellerman et al. (1980) administered the Rosenberg Scale of Self-Esteem, State-Trait Anxiety Inventory and Health Locus of Control Scale to 168 adolescents
with cancer, diabetes, cystic fibrosis and cardiac, renal and rheumatological (primarily JRA and lupus) disorders and to a group of 349 healthy high school students. No significant differences were found between the healthy and ill adolescents on measures of self-esteem and trait anxiety. A significant difference was found between healthy adolescents and those with cardiac, renal, oncologic and rheumatic diseases on the health locus of control measure. These groups of chronically ill adolescents were found to evidence more external locus of control than their healthy counterparts, considered by the authors to reflect an accurate perception of their diseases and treatments, rather than psychologic deviance. The 30 rheumatology patients were also found to have the most external locus of control of all groups and statistically greater than adolescents with diabetes and cystic fibrosis as well as healthy controls.

Using the same sample, Zeltzer, et al. (1980) investigated the perceived impact of illness on various aspects of the adolescents lives. An Illness Impact Questionnaire (IIQ) designed for the purpose of the study assessed the impact of illness on relationships with parents and siblings, school and peer activities, independence and autonomy, perceptions of personal, social and sexual functioning, future orientation and the effects of treatments. Healthy subjects responded to the questionnaire in terms of illnesses they had experienced such as colds, allergies, sinus problems and headaches. Although total illness impact scores across specific areas of impact did not differ significantly between the healthy and chronic illness groups as a whole, a post-hoc test of mean differences revealed that the rheumatology
patients were the only illness group to report significantly greater total impact than the healthy sample. With regard to specific areas of impact, the rheumatology group reported more treatment related disruption of body image than the healthy or other chronically ill adolescents. In addition, the rheumatology patients reported more illness related problems with parents than all other groups. This finding is particularly interesting in view of the fact that rheumatology patients reported less impact of illness on general family interactional patterns than all other groups. The authors speculated that perhaps increased physical dependency secondary to joint pain or limited mobility may create a struggle for autonomy from parental control. Although these findings are based on self-report data derived from an instrument whose psychometric properties have not yet been demonstrated, in the context of other reports of significant marital conflict and/or dysfunctional parent-child relationships in families of children with JRA (Blom & Nichols, 1954; Cleveland et al., 1965; Rimon et al., 1977; Henoch et al., 1978) they highlight the need for future research to clarify the characteristic and functioning of these families.

Several authors have examined the impact of JRA on the family. Kroll (1958) provided clinical descriptions of the problems encountered by 79 families having a child with JRA, including anxiety about the disease, financial burden, lack of adequate understanding about the illness. This author reported that approximately one-third of the mothers were "seriously affected" by the strain of caring for their JRA child and four were referred for psychotherapy. More recently, McCormick, Athreya
and Stemmler (1985) reported the findings of a study of the impact of childhood rheumatic disease on the families of 138 children, 98 of whom had JRA. Parents were interviewed by telephone surveys, utilizing a standardized questionnaire and were assigned a family impact score. The authors found a significantly greater impact of illness on unmarried mothers with lower educational levels. Degree of functional impairment (interference with activities of daily living) was highly correlated with family impact and more predictive of impact than medical diagnostic variables.

Most recently, Thompson, Varni and Hanson (1987) examined the impact of family functioning, the child's psychological adjustment and illness-related variables on the child's perception of pain in 23 children with JRA. Since this study utilized the same measures and examined many of the same variables as the present investigation, it will be considered in detail. Twenty-three aged 5-15 years (18 females, 5 males) being treated in a rheumatology clinic within a large children's hospital rated their perception of arthritis-related pain on the Varni/Thompson Pediatric Pain Questionnaire. The child's mother was asked to complete the Family Environment Scale and the Child Behavior Checklist. Severity of illness was based on physician ratings (severe, moderate, mild, quiescent or remission). First, in order to examine the child's adjustment and family functioning in comparison to norms the mean scores of the JRA sample were compared to the national norms for the CBCL and FES. The authors utilized Welch's V statistic instead of t-tests for these comparisons due to the unequal sample sizes and unequal variance which the former handles better than the latter statistic. No
significant differences were found between the JRA sample and CBCL normative sample in total behavior problems, internalizing or externalizing behavior. Comparisons between the JRA sample and normative samples were not reported with regard to social competence.

When compared to normal families on the 10 FES subscales, the JRA sample was significantly higher than normal families on three subscales: Cohesion, Moral-Religious Emphasis and Organization. The JRA sample was significantly higher than the norms for distressed families on subscales measuring Cohesion, Expressiveness, Intellectual-Cultural Orientation, Moral-Religious Emphasis and Organization and lower on the Conflict subscale. No significant differences were found between subtypes of JRA (systemic, polyarticular, pauciarticular) on any of the FES subscales.

The authors note that the pattern in the JRA sample of higher cohesion and expressiveness and lower conflict suggests an enhanced family closeness which may be related to having a sick child in the family. It is further noted that the high levels of moral-religious emphasis, organization and control together with lower levels of conflict in the JRA sample suggests that the JRA families are very controlled. The authors point out that this type of family functioning resembles what Minichun et al. (1978) considered typical of families with a psychosomatically ill child (i.e. enmeshment, overprotectiveness, rigidity and lack of conflict resolution. In order to examine the relationship between the child's psychological adjustment and perception of pain, Pearson correlations were computed. None of the correlations between child pain intensity ratings and CBCL scores (total behavior problems, internalizing, externalizing problems) were found to be
significant. Similarly, when Pearson correlations were performed to examine the relationship between child pain intensity ratings and the 10 FES subscales none of the correlations were significant.

Finally, stepwise multiple regression analyses were performed to examine the impact of the child's social competence, internalizing and externalizing behavior, severity of illness, type of JRA and a composite Family Relationship Index score from the FES (subscales of Cohesion, Expressiveness and Conflict) on the child's report of pain intensity. The results indicate that family functioning and child adjustment variables interact with illness-related variables to modulate the child's perception of pain.

Although the findings of Thompson et al. (1987) are based on a small sample of JRA children, it is the only study of this population to utilize an objective, standardized measure of family functioning and one of the few to utilize a reliable, valid, well-standardized measure of the child's adjustment. The study suggests that, when compared to normal children, those with JRA did not appear to display more behavior problems, although information about their social functioning in comparison to the normative sample was unfortunately not presented. The findings also suggest that there may be some important differences in the functioning of families of children with JRA. However, due to the small sample size and lack of information regarding the relationship between family functioning and the child's adjustment in this study, conclusions about the impact of family factors on the child's adjustment can not be made.

In summary, the literature regarding personality characteristics and
psychopathology in JRA is filled with the same types of contradictions and inconsistencies that characterizes similar research with other chronic childhood illnesses. No typical personality profile of the JRA child has been identified consistently. While some studies have reported considerable psychological maladjustment in children with JRA, including poor self-esteem and high levels of depression and anxiety (e.g. Blom & Nichols, 1954), other studies have found no differences (e.g. Kellerman et al., 1980; Thompson et al., 1987) or better adjustment (e.g. Ivey et al., 1981) in children with JRA as compared to healthy controls on various measures of self-esteem and anxiety and behavior problems. Studies of the relationship between severity of illness and adjustment have also yielded inconsistent findings which may have been due, in part, to the ways in which severity has been operationalized and measured. Although there have been numerous findings to suggest high levels of interpersonal conflict in families of children with JRA, as reflected by a high percentage of parental divorce or separation (Heisel, 1972; Rimon et al., 1977; Henoch et al., 1978), clinical impressions of dysfunctional parent-child relationships (Blom & Nichols, 1954; Rimon et al., 1977) and self-reports of significant conflict with parents (Zeltzer et al., 1980) the recent findings of lower levels of conflict in JRA families further complicates the picture. Unfortunately, only one study with a relatively small sample size has assessed family variables in this population by means of standardized, objective measures and further research is needed to clarify the significance of family factors in JRA.
Chapter III
STATEMENT OF THE PROBLEM

There is an extensive literature concerning the psychological adjustment of children and adolescents with chronic physical illness. The major approach to this problem has been to investigate the ways in which chronically ill children differ from healthy children in terms of personality characteristics, psychopathology and psychosocial functioning. Unfortunately, due to numerous conceptual and methodological problems (i.e. varying definitions of healthy or normal adjustment, different psychological constructs examined, inadequate control or comparison groups, use of unreliable, unstandardized instruments) this body of research is filled with contradictions and inconsistencies. As a result, researchers have recently argued that a more fruitful to the problem approach would be to identify variables that mediate the process of adjustment to chronic illness and which differentiate children who are well-adjusted despite their illness from those who are not.

The preceding review of the literature revealed that among the handful of studies that have examined the psychological adjustment of children with JRA most are plagued with the same problems described above. Many lack methodological rigor -- reporting data anecdotally, utilizing subjective and unstandardized instruments and lacking adequate
control groups. Among the few studies that have used stronger research designs and objective, reliable, well-standardized measures, attempts to compare children with JRA to their healthy peers on a variety of personality and adjustment measures have yielded inconclusive results. While some studies have reported greater maladjustment among children with JRA as compared to healthy controls, other studies have reported no differences or even fewer adjustment problems among the JRA children. It appears reasonable to assume that while some children are able to make an adequate adjustment to a chronic illness such as JRA, others have greater difficulty doing so. If not all children are equally at risk for psychological adjustment problems it is important to be able to identify those who are most vulnerable.

Unfortunately, there have only been three empirical investigations of variables that mediate adjustment in children with JRA. In each of these studies the variable examined was severity of illness and the findings were contradictory. As yet, there have been no systematic, multivariate studies attempting to identify variables which may increase the risk for adjustment problems in children with JRA. Therefore, the purpose of the present study was to examine the relationship between psychological adjustment and a variety of medical, child, demographic and family variables in children and adolescents with JRA.

Since prior research has demonstrated that "psychological adjustment" is a complex, multifaceted construct, certain aspects of which may be differentially impacted by particular mediating variables, the present study utilized a multitrait, multimethod approach to assess adjustment. A comprehensive assessment of adjustment requires an evaluation of the
individual's strengths as well as weaknesses or difficulties. Therefore, the present study examined several aspects of psychological adjustment including the intrapersonal domain (self-esteem), the interpersonal domain (social competence) and degree of behavioral disturbance (behavior problems). In addition, in order to obtain a broader perspective on the child's adjustment, both parent ratings and child self-report measures were utilized.

As previously mentioned, three types of variables have been most frequently investigated in previous research on factors associated with increased risk for psychological adjustment problems in chronic childhood illness. These include: 1) characteristics of the illness, 2) characteristics of the child and 3) family characteristics. With regard to illness-related variables, severity of illness, age of onset and duration of illness have been examined. The present study included these variables as well as variables related to treatment, specifically the types of medications utilized to treat JRA. Although the impact of treatment related variables has generally been neglected in studies of adjustment to chronic childhood illness, certain aspects of the treatment (e.g. pain, side effects, use of experimental drugs) could potentially be quite stressful and might impact the child's adjustment. For example, the use of steroids to treat JRA is typically accompanied by a significant weight gain which might be particularly distressing to many children and adolescents. In order to facilitate a comparison between the findings of the present study and previous research concerning the relationship between severity of illness and adjustment several indices of severity were utilized. These included: 1) total
number of joints involved at the time of assessment, 2) degree of functional impairment and 3) subtype of JRA (systemic, polyarticular, pauciarticular). The present study examined the effects of age and sex of the child and parental education, marital status and socioeconomic status on the child's adjustment. Finally, family functioning was examined both in comparison to national norms and as a set of variables mediating the child's adjustment.

Hypotheses

I. There will be a significant relationship between psychological adjustment and illness-related variables including age of disease onset, duration of illness, severity of illness and types of medication utilized.

   a. It is hypothesized that there will be significant differences in the adjustment of subjects with an onset during the first peak onset period (1-3 years) and those whose onset occurred during the second peak period (8-12 years).

   b. It is hypothesized that a longer duration of illness will be significantly correlated with better adjustment.

   c. It is further hypothesized that the relationship between severity and adjustment will vary with the measure of severity utilized.

   d. It is further hypothesized that subjects who have been treated with medications that involve dangerous or uncomfortable side effects will display poorer adjustment.
II. There will be a significant relationship between adjustment and certain child and demographic variables including child's age and sex and parental educational level, marital status and socioeconomic status.

III. There will be a significant relationship between adjustment and family functioning with better adjusted children being members of well-adjusted families. It is further hypothesized that this relationship will be stronger in the case of certain aspects of family functioning in which a relationship to adjustment has already been demonstrated in other groups of chronically ill children including conflict, organization and an active-recreational emphasis.
Chapter IV

METHODOLOGY

Subjects

The sample consisted of 45 children and adolescents with JRA being treated in the Rheumatology Clinic at Columbus Children's Hospital. Patients with other types of rheumatic diseases, other chronic medical conditions or mental retardation were excluded from the sample. Fifty patients were contacted for participation in the study. Two chose not to participate and three who had agreed to participate did not complete and return the questionnaires. The subjects ranged in age from 4 to 17 with a mean age of 10.6 years. The sample was comprised of 35 females and 10 males which is generally consistent with the overall sex distribution of JRA. Ninety-one percent of the sample was Caucasian and nine percent was Black. The average age of onset was 7.2 years and the average duration of illness was 4.3 years. Socioeconomic status was determined by Hollingshead's (1958) seven step scale of occupation. If both parents worked, the higher-status occupation was used to score SES. Occupation was chosen as the single index of SES because Hollingshead (1958) found occupation to be the single best index of his social class stratification. This method of scoring SES is also identical to the
method utilized in the development and standardization of the Child Behavior Checklist (Achenbach & Edelbrock, 1981, 1983). According to this seven-step scale, in which the two highest groups (1,2) are considered to be upper class, the middle two groups (3,4) considered middle class and the lowest three groups (5-7) considered to be lower class, no subjects were in the highest SES level. Seven percent of the sample was in level 2, 18% in level 3, 20% in level 4, 18% in level 5, 13% in level 6 and 24% in level 7.

Eighteen percent of the sample had systemic JRA, 33% had polyarticular JRA and 49% had pauciarticular JRA. This is similar to the distribution reported for the general population of JRA patients. In approximately one-quarter of the sample, the disease was inactive at the time of assessment (i.e. no joints involved). Even among those with active disease close to one-quarter had only one joint involved. Thus, close to 50% of the sample displayed only minimal joint involvement at the time of assessment. This is consistent with the distribution of ratings of functional impairment in which 53% of the sample was rated as having no impairment in activities of daily living, 36% was rated as mildly disabled, 9% was rated as moderately disabled and only 2% was rated as severely disabled. However, almost all subjects were on medication to treat JRA at the time of assessment, suggesting that perhaps the relatively large proportion of the sample with very minimal joint involvement was reflective of well-controlled illness rather than a sample bias towards milder forms of JRA.
**Instruments**

**Dependent Measures:** The psychological adjustment of children and adolescents with JRA was the dependent variable. Adjustment was assessed by means of parental ratings of social competence and frequency of behavior problems on the Child Behavior Checklist (see Appendix A) and the child's self-reported self-esteem on the Piers-Harris Self Concept Scale (see Appendix B).

**Child Behavior Checklist (CBCL)**

The Child Behavior Checklist (Achenbach & Edelbrock, 1979; 1983) is a parent report instrument designed to assess a wide variety of specific behaviors in children aged 4-16 years. The CBCL contains 118 behavior problem items rated on a three point scale and 20 social competency items rated on a three point scale. The CBCL is a factor analytically derived instrument that contains three subscales of social competency (amount and quality of activities, social relationships, school performance) and nine subscales of behavior problems. It yields scores for total social competency (as well as for each of the three subscales), a total behavior problem score and scores for each of the nine behavior problem cluster scores. The CBCL also yields two second-order factors scores concerning the child's behavior problems: an internalizing factor which includes overcontrolled, anxious, withdrawn, depressed behaviors and an externalizing factor which represents undercontrolled, aggressive, conduct problem behaviors. Separate norms are provided for males and females at each of three age levels (4-6, 6-12, 12-16 years), with t-score conversions provided. Average interparent reliability is .74 and average test-retest reliability
is .89 (Achenbach, 1978). The CBCL has been shown to discriminate effectively between clinic-referred and normal children at a significance level of p > .001 (Achenbach & Edelbrock, 1981). This instrument provides information about prevalence of behavior problems and social competence in relation to a normative sample of 1,300 children.

As noted in a recent review of child behavior assessment in pediatric settings (Eyberg, 1985), numerous studies of medical disorders in children utilizing the CBCL have demonstrated the powerful utility of this instrument in pediatric psychology research (Benjamin et al., 1982; Gordon et al., 1982; Herman, 1982; Hurtig & White, 1986; Johnson et al., 1985; Lemanek et al., 1986; McCauley et al., 1986; Morgan & Jackson, 1986; Simmons et al., 1985; Wertleib et al., 1986).

In the present study four normalized t-scores (X=50, SD=10) from the CBCL were examined in the analyses: total social competency score, total behavior problem score, internalizing score and externalizing score.

Piers-Harris Children's Self-Concept Scale:

The Piers-Harris Self-Concept Scale (Piers-Harris, 1969) is an 80 item self-report questionnaire designed to assess children's self-esteem. It assesses six areas of a child's self-concept: behavior, intelligence, school status, physical appearance, anxiety, popularity and happiness. The instrument is scored to yield an overall indication of the child's self-concept, as well as separate scores in each of the six areas. Norms, based on a national sample of 1,183 children are provided for grades 3-12. The authors also note that when administered
individually, the scale can be used below the third grade level. Reports of internal consistency range from Kuder-Richardson coefficients of .78 to .93 with test-retest reliability coefficients ranging from .71 to .77 (Piers & Harris, 1969). The validity of the scale has been demonstrated with correlations averaging .65 with other self-report measures of self-esteem and .40 with teacher and peer ratings of self-esteem (Piers, 1977).

The Piers-Harris has been used widely in research on children with chronic physical illnesses (e.g. Gordon et al., 1982; Hurtig & White, 1986; Kumar et al., 1976; Lemanek et al., 1986; Lewis & Khaw, 1982; McCauley et al., 1986; Pless & Pinkerton, 1975; Ryan & Morrow, 1986).

In the present study only the total self-concept score was examined in the analyses since this score has been shown to be the most reliable and has the best research support (Piers, 1977).

**Independent Measures**

The independent variables included family functioning as well as a variety of illness-related, individual-child and demographic variables. Family functioning was assessed by means of the Family Environment Scale (see Appendix C). Illness and demographic variables were assessed by means of the JRA Questionnaire (see Appendix D).

**Family Environment Scale (FES)**

The Family Environment Scale (Moos & Moos, 1974, 1976, 1981) is a 90 item self-report instrument designed to assess the social climate of all types of families. The FES taps three broad domains of family functioning described by 10 subscales: the "Relationship" dimension is described by Cohesion, Expressiveness and Conflict subscales. The
"Personal Growth" dimension is described by five subscales including Independence, Achievement Orientation, Intellectual-Cultural Orientation, Active-Recreational Orientation and Moral-Religious Orientation. The "System Maintenance" dimension is described by Organization and Control subscales. The FES has been standardized on 1,250 healthy and 500 distressed families. Internal consistency for the scales range from alpha coefficients of .61 (Independence) to .78 (Cohesion) and the mean 12 month test-retest reliability coefficient is .71. The scales show low to moderate intercorrelations with a mean intercorrelation of .25 (Moos & Moos, 1981). These intercorrelations suggest that the scales are measuring distinct, although somewhat related facets of the family social environment. The FES has been shown to significantly discriminate between various groups of families including psychiatrically disturbed and matched nonpatient families (Moos & Moos, 1981). The FES has been used widely in research on chronic childhood illness (e.g. Hauser et al., 1985; Johnson et al., 1985; McCubbin et al., 1983; Spaulding & Morgan, 1986; Wertleib et al., 1986).

**JRA Questionnaire**

This questionnaire was developed for the present study to obtain various types of demographic and medical history information. The demographic section includes questions about the child's age, sex, parental educational level, marital status and occupational information. This section was completed by the parent. Information regarding the child's medical history was obtained from the medical chart and consultation with pediatrician and clinic staff. Questions included in
this section concern age of onset, current number and types of joints involved and medication history. The last portion of the questionnaire consists of a rating of degree of functional impairment resulting from the child's disability. Degree of functional impairment based on the widely accepted American Rheumatism Association (Steinbroker, Traeger & Batterman, 1949) classification system was rated by the Rheumatology Clinic's physical and occupational therapists. Interrater reliability was $r=1.00$ The ARA classification is as follows:

I. Complete functional capacity to carry on all usual duties without handicaps.
II. Functional capacity adequate to perform normal activities despite handicap of discomfort or limited mobility in one or more joint.
III. Functional capacity adequate to perform only little or none of the duties or usual occupation or of self-care.
IV. Largely or wholly incapacitated with patient bedridden or confined to wheelchair permitting little or no self-care.

**Procedure**

JRA patients were asked to participate in the study while waiting for regularly scheduled medical appointments in the Rheumatology Clinic. The child and parents were given a letter to read explaining the study and its purpose (see Appendix E) and asked for their informed consent (see Appendix F). Both the child and parent were asked to sign the consent forms. Once consent was obtained the child was given the Piers-Harris Scale to complete and the child's mother was asked to complete the CBCL, FES and JRA Questionnaire (parent section). The Piers-Harris
Scale was read by the investigator to subjects in grade three and below as recommended in the manual. In the case of two subjects, the child lived only with the father as a result of parental divorce and in these two cases the father completed the parent questionnaires. The investigator remained available for questions, clarification and comments by participants during the completion of questionnaires. In a number of cases, parents were unable to complete all questionnaires while waiting for their appointment and were given a self-addressed, stamped envelope in which to return the remaining questionnaires. Among subjects who took questionnaires home, all but two completed and returned the remaining questionnaires by mail to the investigator.

At the end of each clinic day during which subjects were tested, the investigator reviewed the patients' medical charts and consulted with clinic staff to obtain ratings of functional impairment. Questionnaires were scored by the investigator, a doctoral student in clinical-child psychology. Confidentiality of subjects was maintained by the use of a code number in place of names on all questionnaires.

**Statistical Analyses**

In order to test Hypothesis I, a stepwise multiple regression analysis was performed on each of the five dependent measures (self esteem score, social competence score, total behavior problem score, internalizing score and externalizing score) to examine the relationship between adjustment and age of onset, duration of illness, number of joints involved and number of medications taken. Separate stepwise multiple regression analyses were also conducted with the addition of family functioning variables and the child’s age and parental education.
Pearson correlations were also performed to examine the relationship between adjustment and illness-related variables. In addition, to test Hypothesis Ia, analyses of variance were performed to examine differences in adjustment between subjects with an early disease onset (1-3 years) versus a late disease onset (8-12 years). To test Hypothesis Ib, analyses of variance were also performed to examine differences in adjustment in subjects with a very short duration of illness versus a very long duration of illness. Furthermore, to test Hypothesis Ic, analyses of variance were conducted to examine differences between the three subtypes of JRA and four functional classes. Finally, to test Hypothesis Id, multiple, t-tests were performed to examine differences in adjustment among subjects who have, and have not taken different types of medication.

In order to test Hypothesis II, a stepwise multiple regression analysis and Pearson correlations were performed on each of the dependent variables and the child's age and parental education. Analyses of variance were utilized to examine the effects of sex, marital status and socioeconomic status on adjustment.

Hypothesis III was tested by performing stepwise multiple regression analyses and Pearson correlations to examine the relationship between the adjustment measures and FES scores.
Chapter V
Results

Demographic and medical history data for the JRA sample is summarized in Table 1. Several initial analyses were performed to compare self-esteem, social competence, frequency of behavior problems and internalizing/externalizing symptomatology in the JRA sample to national norms for the Piers-Harris Self-Concept Scale and the Child Behavior Checklist. Welch's V statistic (Welch, 1937) was used for these comparisons instead of the t-test because it handles unequal sample sizes and unequal variance better than the t-test. Although both t-tests and Welch's V were computed for each comparison, only the results of the latter are reported as they were found to provide a more stringent test of the significance of mean differences between the JRA sample and national norms.

As can be seen in Table 2, the mean total self-concept score of the JRA sample is slightly higher than the national norms, however, this difference is not statistically significant. Average self concept scores on the Piers-Harris are considered to be between the 31st and 70th percentiles and with the exception of one subject who scored at the 71st percentile, the entire JRA sample falls within the normal range for self-esteem.

Table 3 illustrates the comparisons of means for the JRA sample and
### Table 1
Demographic and Illness Characteristics of the JRA Sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current age</td>
<td>10.62 years</td>
<td>2.96</td>
</tr>
<tr>
<td>Age of onset</td>
<td>7.27 years</td>
<td>4.13</td>
</tr>
<tr>
<td>Duration of Illness</td>
<td>51.36 months</td>
<td>45.65</td>
</tr>
<tr>
<td>Number joints involved</td>
<td>8.31</td>
<td>12.08</td>
</tr>
<tr>
<td>Number medications taken</td>
<td>3.27</td>
<td>2.10</td>
</tr>
<tr>
<td>Mother's education</td>
<td>12.25</td>
<td>1.63</td>
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<tr>
<td>Father's education</td>
<td>13.34</td>
<td>2.59</td>
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<table>
<thead>
<tr>
<th>Category</th>
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<th>%</th>
</tr>
</thead>
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<td></td>
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<tr>
<td>Female</td>
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<td>78</td>
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<tr>
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<td>22</td>
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<td>Race</td>
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<td></td>
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</tr>
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<td>Black</td>
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<td>9</td>
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<td></td>
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<tr>
<td>Unmarried</td>
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</tr>
<tr>
<td>2</td>
<td>3,8</td>
<td>7,18</td>
</tr>
<tr>
<td>3 6</td>
<td>18,13</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>24</td>
<td></td>
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<tr>
<td>Type of JRA</td>
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<tr>
<td>Systemic</td>
<td>8</td>
<td>17</td>
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<td>Polyarticular</td>
<td>15</td>
<td>33</td>
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<tr>
<td>Pauciarticular</td>
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<td>55</td>
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<tr>
<td>Functional Class</td>
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<tr>
<td>None</td>
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<td>53</td>
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<tr>
<td>Mild</td>
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<td>36</td>
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<tr>
<td>Moderate</td>
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<tr>
<td>Severe</td>
<td>1</td>
<td>2</td>
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Table 2
JRA and National Norms: Piers-Harris Self-Concept Score

<table>
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<th>Mean</th>
<th>SD</th>
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</thead>
<tbody>
<tr>
<td>JRA Sample</td>
<td>55.71a</td>
<td>10.98</td>
</tr>
<tr>
<td>National Norms</td>
<td>51.84</td>
<td>13.87</td>
</tr>
</tbody>
</table>

a Higher mean scores indicate higher self-esteem

Table 3
JRA Sample and National Norms: CBCL

<table>
<thead>
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<th></th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
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<tr>
<td>Social Competence</td>
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<td></td>
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<tr>
<td>JRA Sample</td>
<td>39.86**</td>
<td>9.16</td>
</tr>
<tr>
<td>Norms</td>
<td>50.00</td>
<td>10.00</td>
</tr>
<tr>
<td>Total Behavior Problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>JRA Sample</td>
<td>60.70**</td>
<td>12.53</td>
</tr>
<tr>
<td>Norms</td>
<td>50.00</td>
<td>10.00</td>
</tr>
<tr>
<td>Internalizing Problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>JRA Sample</td>
<td>60.00**</td>
<td>11.74</td>
</tr>
<tr>
<td>Norms</td>
<td>50.00</td>
<td>10.00</td>
</tr>
<tr>
<td>Externalizing Problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>JRA Sample</td>
<td>56.32*</td>
<td>11.62</td>
</tr>
<tr>
<td>Norms</td>
<td>50.00</td>
<td>10.00</td>
</tr>
</tbody>
</table>

* p<.05
** p<.001
national norms on the CBCL. As can be seen, on the basis of normalized t-scores the mean social competence score for the JRA sample is significantly lower than the normative mean, (p<.001). Close to half of the JRA sample (n=22) have social competence scores one or more standard deviations below the mean and 16% (n=7) are two or more standard deviations below the normative mean value. In fact, only 10% of the JRA sample scored at or above the mean for social competence.

With regard to total behavior problems, the mean score for the JRA sample is significantly higher (p<.001) than the normative mean value. Over half of the sample (55%) has a total behavior problem score one or more standard deviations above the mean and 20% scored within what is considered to be the "clinical range".

Similarly, the mean for internalizing problems is significantly higher in the JRA sample (p<.001) with over half of the sample (54%) scoring one or more standard deviations above the mean, and 36% displaying significant elevations (T >63 as defined in the CBCL manual). The mean for externalizing problems is greater than that of the national norms (p<.05). Thirty-five percent of the JRA sample scored one or more standard deviations above the mean and 20% displayed significant elevations in externalizing problems (T >63).

Prior to examining the major hypotheses, a preliminary check was made to insure that the five dependent measures were tapping distinct, yet related aspects of psychological adjustment. As can be seen in Table 4, there is a significant positive correlation between self-esteem and social competence, and significant negative correlation between self-esteem and the three behavior problem scores. There is a negative
Table 4

Correlation Coefficients Among Adjustment Measures

<table>
<thead>
<tr>
<th></th>
<th>Self-Esteem</th>
<th>Soc Comp</th>
<th>Beh Prob</th>
<th>Int</th>
<th>Ext</th>
</tr>
</thead>
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<tr>
<td>Self-Esteem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Competence</td>
<td>0.37**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Behavior</td>
<td>-0.40**</td>
<td>-0.37**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalizing</td>
<td>-0.28*</td>
<td>-0.04</td>
<td>0.80***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Externalizing</td>
<td>-0.29*</td>
<td>-0.31*</td>
<td>0.88***</td>
<td>0.69***</td>
<td></td>
</tr>
</tbody>
</table>

* p < .05
** p < .01
*** p < .0001
correlation between social competence and the behavior problem scores; however, this correlation is only significant in the case of total behavior problems and externalizing problems. There is also a strong positive correlation between the three behavior problem scores.

The Relationship Between Adjustment and Illness Characteristics

In order to examine the relationship between adjustment and illness-related variables stepwise multiple regression analyses were performed on each of the adjustment scores with age of onset, duration of illness, number of joints involved and number of medications taken for JRA as the independent variables. None of these variables were found to account for a significant amount of variance on any of the adjustment measures.

A Pearson correlation matrix was also computed including each of the adjustment measures and age of onset, duration of illness and number of joints involved. Since many variables were included in the analysis a stringent level of significance was chosen in which a result was considered significant if the probability of occurrence by chance was less than .5 percent (p<.005). There were no significant correlations between adjustment and any of the illness variables, however, a longer duration of illness was negatively correlated with self-esteem at a borderline level of significance r=-.27, p<.05. Number of joints involved was positively correlated with duration of illness at a borderline level of significance r=-.36, p<.01.

Several additional analyses were performed to further examine the relationship between adjustment and illness-related variables. In order to test Hypothesis Ia, which predicted that there would be group differences in the adjustment of subjects whose disease onset occurred
during the first peak onset period (1-3 years, n=14) and the second peak onset period (8-12 years, n=19), multivariate and univariate analyses of variance were performed. No significant group differences were found on any of the adjustment measures, suggesting that age of onset in and of itself, is not a significant determinant of adjustment in JRA. Thus, Hypothesis Ia can be rejected. Several two-way analyses of variance were performed to examine possible interaction effects with other illness-related or individual-child variables. Although no significant interaction effects were found with regard to any of the measures of severity, the influence of age of onset on self-esteem became significant when the child's developmental stage (latency versus adolescence) was taken into account. As can be seen in Table 5, latency aged subjects reported higher self-esteem than adolescents \( F(1,29)=4.96, p<.05 \). However, the impact of age of onset on self-esteem varied according to the child's developmental stage. Latency-aged children with an early disease onset reported higher self-esteem than latency children with a late disease onset. In contrast, late disease onset adolescents reported higher self-esteem than early onset adolescents.

In order to further examine Hypothesis Ib, which predicted that a longer duration of illness would be associated with better adjustment, the JRA sample was divided into thirds on the basis of duration of illness. The lowest third (< 16 months, n=15) was compared to the highest third (> 70 months duration, n=16) on each of the adjustment measures by means of multivariate and univariate analyses of variance. No significant group differences were found, which together with the nonsignificant correlation between duration of illness and adjustment
Table 5

Summary of ANOVA of Self-Esteem by Age of Onset and Agegroup

<table>
<thead>
<tr>
<th></th>
<th>df</th>
<th>SS</th>
<th>MS</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agegroup</td>
<td>1</td>
<td>440.64</td>
<td>440.64</td>
<td>4.96*</td>
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<tr>
<td>Age of Onset</td>
<td>1</td>
<td>24.10</td>
<td>24.10</td>
<td>0.27</td>
</tr>
<tr>
<td>Agegroup x AgeOnset</td>
<td>1</td>
<td>678.08</td>
<td>678.08</td>
<td>7.63**</td>
</tr>
<tr>
<td>Error</td>
<td>29</td>
<td>2578.92</td>
<td>88.93</td>
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</table>

* p < .05  
** p < .01

Means

<table>
<thead>
<tr>
<th></th>
<th>Early Onset</th>
<th>Late Onset</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latency</td>
<td>62.57</td>
<td>56.08</td>
</tr>
<tr>
<td>Adolescent</td>
<td>44.71</td>
<td>56.86</td>
</tr>
</tbody>
</table>
suggests that duration of illness in and of itself, is not a significant determinant of adjustment in JRA. Thus, Hypothesis Ib can be rejected. Several two-way analyses of variance were also performed. No significant interactions were found with any indices of severity but the impact of duration of illness on self-esteem, social competence and total behavior problems did vary with the child's developmental stage. As summarized in Table 6, although no significant main effects were found, latency-aged children with a long duration of illness reported higher self-esteem than those with a short duration of illness, whereas adolescents with a short duration of illness reported higher self-esteem than those with a long duration of illness $F(1,26)=5.43, p<.05$. This is consistent with the above findings regarding developmental stage and age of disease onset. Additionally, as can be seen in Table 7, latency-aged children with a long duration of illness also displayed greater social competence than those with a short duration of illness while adolescents with a short duration of illness had greater social competence than those with a long duration of illness $F(1,26)=4.83, p<.05$. Furthermore, latency-aged subjects with a long duration of illness also had fewer total behavior problems than those with a short duration of illness, whereas adolescents with a short duration of illness had fewer behavior problems than those with a long duration of illness $F(1,26)=5.19, p<.05$ (Table 8). Thus, all of these analyses consistently show latency-aged subjects with an early disease onset and long duration of illness to be better adjusted than late onset latency aged subjects with a short duration of illness, whereas among adolescents, those with a late disease onset and short duration of illness are better adjusted than
Table 6

Summary of ANOVA of Self-Esteem by Duration of Illness and Agegroup

<table>
<thead>
<tr>
<th>Source</th>
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<tr>
<td>Duration Illness</td>
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<td>12.98</td>
<td>0.11</td>
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<tr>
<td>Agegroup</td>
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<td>107.40</td>
<td>107.40</td>
<td>0.91</td>
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<td>643.34</td>
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<tr>
<td>Error</td>
<td>26</td>
<td>3082.98</td>
<td>118.58</td>
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* p < .05

Means

<table>
<thead>
<tr>
<th></th>
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<th>Adolescent</th>
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</thead>
<tbody>
<tr>
<td>Short Duration</td>
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<tr>
<td>Long Duration</td>
<td>60.00</td>
<td>47.56</td>
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### Table 7

**Summary of ANOVA of Social Competence by Duration Illness and Agegroup**

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<td>14.97</td>
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* p < .05

**Means**

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</thead>
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<tr>
<td>Short Duration</td>
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<td>Long Duration</td>
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Table 8

Summary of ANOVA of Total Behavior Problems by Duration and Agegroup

<table>
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<td>Agegroup</td>
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<td>167.20</td>
<td>1.20</td>
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<td>Duration x Agegroup</td>
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<td>908.70</td>
<td>6.53*</td>
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<tr>
<td>Error</td>
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<td>3618.99</td>
<td>139.19</td>
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* p < .05

Means

<table>
<thead>
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<th>Latency</th>
<th>Adolescent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Duration</td>
<td>67.11</td>
</tr>
<tr>
<td>Long Duration</td>
<td>59.43</td>
</tr>
</tbody>
</table>
those with an early disease onset and long duration of illness.

In order to test Hypothesis Ic, which predicted that the relationship between adjustment and severity of illness would vary with the way in which severity was measured, analyses of variance were performed on type of JRA and functional classification in addition to the aforementioned examination of number of joints involved by means of multiple regression and correlational analyses. Spearman correlations performed on the three indices of severity indicated that the three are highly correlated (see Table 9).

A multivariate analysis of variance showed no significant main effects for either type of JRA or functional classification. One and two way univariate analyses of variance showed no significant main effects or interaction effects with other illness and individual child-related variables on any of the adjustment measures. Since 89% of the JRA sample were classified as having none or mild functional impairment, multiple t-tests were performed to examine differences in between these two groups on each adjustment measure. Mildly impaired subjects (n=16) displayed significantly more internalizing symptoms (t=-2.72, p<.01) than nondisabled subjects (n=23). Similarly, subjects with the more severe polyarticular type of JRA (n=15) were compared with the less severe pauciarticular type of JRA (n=19). Those with polyarticular JRA displayed more externalizing symptoms than those with pauciarticular JRA (t=2.04, p<.05).

Multiple t-tests were also performed to examine whether there were differences in adjustment based on which types of joints were involved. Since many variables were included in the analyses, a stringent
Table 9

Spearman Correlation Coefficients for Severity Measures

<table>
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<tr>
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<th>Type of JRA</th>
</tr>
</thead>
<tbody>
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<td>Functional Class</td>
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<td>-.61**</td>
</tr>
<tr>
<td>Type of JRA</td>
<td>-.28*</td>
<td></td>
</tr>
</tbody>
</table>

* p < .05
** p < .0001
significance level was utilized (p<.005). No significant differences were found. However, when a Spearman correlation was computed to examine the relationship between adjustment and the number of different types of joints involved (as opposed to total number of joints), a significant positive correlation was found between internalizing symptoms and number of types of joints \( r = .38, p < .01 \). A positive correlation was also found between total behavior problems and number of joint types involved but this relationship was not as strong \( r = .28, p < .05 \).

Finally, in order to examine whether there were any differences in adjustment based on whether the child's JRA was active (n=35) or in remission (n=10), multivariate and univariate analyses of variance were performed. Although the MANOVA only approached significance \( F(1,35) = 2.36, p < .06 \) using Wilk's lambda, univariate ANOVA's showed that subjects with active disease have significantly more internalizing symptoms \( F(1,39) = 7.96, p < .01 \) (see Table 10). Those with active disease were also found to have a longer duration of illness \( (t = -3.09, p < .0001) \) and earlier age of onset \( (t = 2.73, p < .01) \).

Thus, there does appear to be some differences in the relationship between adjustment and severity of illness based on the way in which severity is operationalized and measured. Although multivariate analyses suggest that none of the measures of severity are significant determinants of adjustment, univariate analyses did reveal some relationships between severity and adjustment. However, in contrast to the prediction of variation in adjustment among different indices of severity Hypothesis in Ic, severity was consistently associated with
Table 10
Summary of MANOVA and ANOVA's of Adjustment by Disease Activity

<table>
<thead>
<tr>
<th>Source</th>
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</tr>
</thead>
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</tr>
<tr>
<td>(Wilk's lambda)</td>
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<td></td>
</tr>
<tr>
<td>ANOVA's</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>1,39</td>
<td>2.34</td>
<td>NS</td>
</tr>
<tr>
<td>Social Competence</td>
<td>1,39</td>
<td>1.34</td>
<td>NS</td>
</tr>
<tr>
<td>Total Behavior Problems</td>
<td>1,39</td>
<td>3.04</td>
<td>NS</td>
</tr>
<tr>
<td>Internalizing Problems</td>
<td>1,39</td>
<td>7.96</td>
<td>.01</td>
</tr>
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<td>Externalizing Problems</td>
<td>1,39</td>
<td>1.08</td>
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Means

<table>
<thead>
<tr>
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<th>Remission</th>
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<tr>
<td>Self-Esteem</td>
<td>60.33</td>
<td>54.09</td>
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<tr>
<td>Social Competence</td>
<td>43.00</td>
<td>38.88</td>
</tr>
<tr>
<td>Total Behavior Problems</td>
<td>55.78</td>
<td>63.53</td>
</tr>
<tr>
<td>Internalizing Problems</td>
<td>52.78</td>
<td>63.63</td>
</tr>
<tr>
<td>Externalizing Problems</td>
<td>54.11</td>
<td>58.44</td>
</tr>
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</table>
only two aspects of adjustment (frequency of total behavior problems, internalizing problems) regardless of the way in which it was measured.

Hypothesis I predicted that subjects who have taken medication for JRA that is accompanied by dangerous or uncomfortable side effects would display poorer adjustment than those who have not. This hypothesis was examined by means of multiple t-tests comparing the adjustment of subjects who have, or have not taken certain types of medication (aspirin, nonsteroidal anti-inflammatory drugs, steroids, immunosuppressive drugs). Utilizing a conservative level of significance (p<.005) no significant differences were found and none of the analyses even approached significance. Thus, Hypothesis I can be rejected.

The Relationship Between Adjustment and Child/Demographic Variables

Hypothesis II predicted that there would be a significant relationship between adjustment and the child's age, sex, parental education, marital status and socioeconomic status. In order to test this hypothesis the child's age and parental education (years) were added to the Pearson correlation matrix. No significant relationships were found between age or father's education. There was a significant positive correlation between mother's education and social competence \( r=.28, p<.05 \) as well as a significant negative correlation between mother's education and externalizing problems \( r=-.31, p<.05 \). Thus, mothers who are more well-educated have children who are more socially competent and who display fewer behavior problems, particularly undercontrolled, acting-out behaviors. The relationship between father's education and adjustment approached significance in the same
direction and on the same aspects of adjustment as mother's education (p<.10).

Secondly, multivariate analyses of variance were performed to examine the effect of the child's sex, socioeconomic status and parental marital status on the child's adjustment. No significant group differences were found for sex or socioeconomic status. However, as can be seen in Table 11, a significant group difference was found for marital status across adjustment measures F(5,28)=4.47, p<.01, using Wilk's lambda. Univariate analyses of variance showed that children of married parents (n=24) reported higher self-esteem F(1,39)=5.14, p<.05 and higher social competence F(1,39)=5.83, p<.05 than children of unmarried parents (n=14) and also displayed less externalizing problems F(1,39)=4.34, p<.05.

To further investigate the relationship between adjustment and age differences, particularly developmental influences on adjustment, latency-aged children (6-11 years, n=23) were compared to adolescents (12-17 years, n=19) on each of the adjustment measures. A multivariate analysis of variance was showed significant group differences using Wilk's lambda F(5,35)=3.28 p<.02 and univariate analyses of variance showed that latency children were seen as having more externalizing symptoms than adolescents (see Table 12). Two-way analyses of variance were performed to examine the possible presence of interaction effects with other individual-child and illness-related variables. Some of these interaction effects have already been discussed (i.e. age of onset, duration of illness). There was no significant main effects or interaction effects with sex or functional classification and no significant interaction effect with type of JRA. In the two-way ANOVA of
Table 11

Summary of MANOVA and ANOVA's of Adjustment by Marital Status

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<td>ANOVA's</td>
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<td></td>
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<tr>
<td>Self-Esteem</td>
<td>1,39</td>
<td>5.14</td>
<td>.05</td>
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<td>Social Competence</td>
<td>1,39</td>
<td>5.83</td>
<td>.05</td>
</tr>
<tr>
<td>Total Behavior Problems</td>
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<td>Externalizing Problems</td>
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<td>4.34</td>
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Means

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<tr>
<td>Social Competence</td>
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<td>35.77</td>
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<td>Total Behavior Problems</td>
<td>59.21</td>
<td>65.53</td>
</tr>
<tr>
<td>Internalizing Problems</td>
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<td>60.29</td>
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<tr>
<td>Externalizing Problems</td>
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<td>61.59</td>
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Table 12

Summary of MANOVA and ANOVA's of Adjustment by Developmental Stage

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<tr>
<td>Social Competence</td>
<td>1, 39</td>
<td>0.13</td>
<td>NS</td>
</tr>
<tr>
<td>Total Behavior Problems</td>
<td>1, 39</td>
<td>0.44</td>
<td>NS</td>
</tr>
<tr>
<td>Internalizing Problems</td>
<td>1, 39</td>
<td>0.96</td>
<td>NS</td>
</tr>
<tr>
<td>Externalizing Problems</td>
<td>1, 39</td>
<td>4.86</td>
<td>.05</td>
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</table>

Means

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<th>Adolescent</th>
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</thead>
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<td>52.84</td>
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<tr>
<td>Social Competence</td>
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<td>39.21</td>
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<tr>
<td>Total Behavior Problems</td>
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<td>60.47</td>
</tr>
<tr>
<td>Internalizing Problems</td>
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<td>59.42</td>
</tr>
<tr>
<td>Externalizing Problems</td>
<td>60.86</td>
<td>53.49</td>
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</tbody>
</table>
adjustment by developmental stage and type of JRA, a significant main effect was found for developmental stage and externalizing symptoms. Latency-aged children had a higher externalizing score $F(1,35)=4.37$, $p<.05$ (see Table 13).

In summary, Hypothesis II is supported with regard to parental marital status and education as well as the child's age when considered within the context of developmental stage. It is not supported with regard to the child's sex or socioeconomic status.

The Relationship Between Adjustment and Family Functioning

Group differences between the JRA sample and national norms on the 10 subscales of the Family Environment Scale (FES) were examined using Welch's $V$ statistic instead of $t$-tests due to unequal sample sizes and unequal variance. As can be seen in Table 14, the mean of the JRA sample was significantly higher than the mean of the normative sample in three areas of family functioning: Control ($p<.001$), Organization ($p<.001$) and Moral-Religious Emphasis ($p<.05$). Higher levels of Cohesion were also found in the JRA sample; however, this difference only approached significance ($p<.10$).

Although multivariate analyses of variance did not reveal significant group differences in FES scale scores based on type of JRA, functional classification, disease activity, age of onset, duration of illness or developmental stage, a univariate analysis of variance did show significant group differences based on developmental stage in one area of family functioning. Families of latency-aged children reported higher levels of cohesion than families of adolescents $F(1,39)=4.79$, $p<.05$. This finding is further supported by corretional analyses which
Table 13

Summary of ANOVA of Externalizing Problems by Agegroup and Type of JRA

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<th>MS</th>
<th>F</th>
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</thead>
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<td>489.32</td>
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</tr>
<tr>
<td>Type of JRA</td>
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<td>90.58</td>
<td>0.85</td>
</tr>
<tr>
<td>Agegroup x Type JRA</td>
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<td>206.05</td>
<td>1.93</td>
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<tr>
<td>Error</td>
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<td>1134.27</td>
<td>226.85</td>
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* p < .05

Means

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<th>Polya rticular</th>
<th>Pauciarticular</th>
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</thead>
<tbody>
<tr>
<td>Latency</td>
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<td>61.33</td>
<td>57.11</td>
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<tr>
<td>Adolescent</td>
<td>48.50</td>
<td>58.33</td>
<td>52.67</td>
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Table 14

<table>
<thead>
<tr>
<th></th>
<th>JRA</th>
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<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
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<tr>
<td>Cohesion</td>
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<td>Expressiveness</td>
<td>7.36</td>
<td>10.87</td>
</tr>
<tr>
<td>Conflict</td>
<td>3.25</td>
<td>1.99</td>
</tr>
<tr>
<td>Independence</td>
<td>6.59</td>
<td>1.04</td>
</tr>
<tr>
<td>Achievement Orientation</td>
<td>7.02</td>
<td>10.90</td>
</tr>
<tr>
<td>Intellectual-Cultural Orientation</td>
<td>6.18</td>
<td>6.08</td>
</tr>
<tr>
<td>Active-Recreational Orientation</td>
<td>5.23</td>
<td>2.06</td>
</tr>
<tr>
<td>Moral-Religious Emphasis</td>
<td>8.30**</td>
<td>10.78</td>
</tr>
<tr>
<td>Organization</td>
<td>6.43***</td>
<td>1.80</td>
</tr>
<tr>
<td>Control</td>
<td>5.50***</td>
<td>1.82</td>
</tr>
</tbody>
</table>

*p < .10

** p < .05

*** p < .001
revealed a strong negative correlation between age and Cohesion 
\( r = -0.39, p < 0.005 \) in which increasing age of the child was associated with less cohesiveness within the family.

In order to examine the relationship between adjustment and family functioning, stepwise multiple regression analyses were performed on each of the 10 FES subscales as independent variables. Since many variables were included in the analyses, a stringent level of significance was chosen (\( p < 0.005 \)). As can be seen in Table 15, no family functioning variables were significant predictors of the child's self-esteem, although family Organization approached significance \( F(1,39) = 5.40, p < 0.05, R^2 = 0.12 \). Three family functioning variables accounted for a significant amount of variation in the child's social competence. These included: Moral-Religious Emphasis \( F(1,42) = 26.60, p < 0.0001, R^2 = 0.39 \); Conflict \( F(1,42) = 21.15, p < 0.0001, R^2 = 0.51 \); and Intellectual-Cultural Orientation \( F(1,42) = 20.08, p < 0.0001, R^2 = 0.60 \). Two family functioning variables were significant predictors of total behavior problems. These included: Conflict \( F(1,42) = 19.53, p < 0.001, R^2 = 0.32 \) and Active-Recreational Orientation \( F(1,42) = 18.13, p < 0.0001, R^2 = 0.47 \). Two family functioning variables accounted for a significant amount of variation in the child's internalizing problems. These included: Active-Recreational Orientation \( F(1,42) = 7.84, p < 0.001, R^2 = 0.28 \) and Moral-Religious Emphasis \( F(1,42) = 7.31, p < 0.005, R^2 = 0.35 \). The degree of Conflict within the family approached significance as a predictor of internalizing symptomatology \( F(1,42) = 7.63, p < 0.01, R^2 = 0.15 \). Finally, two family functioning variables were significant predictors of the child's externalizing problems.
Table 15
Multiple Regression Analyses: FES Subscale Scores

<table>
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<tr>
<th>Variables</th>
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<th>R</th>
<th>F</th>
<th>p&lt;</th>
</tr>
</thead>
<tbody>
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<td><strong>Self-Esteem</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Organization</td>
<td>.35</td>
<td>.12</td>
<td>5.40</td>
<td>.05</td>
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<tr>
<td><strong>Social Competence</strong></td>
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<td></td>
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<tr>
<td>Moral-Religious</td>
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<td>26.60</td>
<td>.00001</td>
</tr>
<tr>
<td>Conflict</td>
<td>.71</td>
<td>.51</td>
<td>21.15</td>
<td>.00001</td>
</tr>
<tr>
<td>Intellectual-Cult.</td>
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<td>.60</td>
<td>20.28</td>
<td>.00001</td>
</tr>
<tr>
<td><strong>Total Behavior Problems</strong></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Conflict</td>
<td>.56</td>
<td>.32</td>
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</tr>
<tr>
<td>Active-Recreational</td>
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<td>.47</td>
<td>18.13</td>
<td>.00001</td>
</tr>
<tr>
<td><strong>Internalizing</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conflict</td>
<td>.39</td>
<td>.15</td>
<td>7.63</td>
<td>.01</td>
</tr>
<tr>
<td>Active-Recreational</td>
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<td>.28</td>
<td>7.84</td>
<td>.001</td>
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<tr>
<td>Moral-Religious</td>
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<td>.35</td>
<td>7.31</td>
<td>.0005</td>
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<tr>
<td><strong>Externalizing</strong></td>
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<td></td>
</tr>
<tr>
<td>Conflict</td>
<td>.49</td>
<td>.24</td>
<td>13.11</td>
<td>.001</td>
</tr>
<tr>
<td>Active-Recreational</td>
<td>.59</td>
<td>.35</td>
<td>11.17</td>
<td>.0001</td>
</tr>
</tbody>
</table>
These included: Conflict F(1,42)=13.11, p<.005, R²=.24 and Active-Recreational Emphasis F(1,42)=11.17, p<.0001, R²=.35.

To further examine the relationship between the child's adjustment and these family functioning variables, a Pearson correlation matrix was generated. As can be seen in Table 16, high levels of family conflict were strongly correlated with a high frequency of total behavior problems as well as both internalizing and externalizing problems. High levels of conflict were also negatively correlated with the child's social competence. The emphasis on social-recreational activities within the family was also strongly associated with the frequency of the child's behavior problems. The more the family engaged in social-recreational activities together the lower the rate of total behavior problems and internalizing and externalizing symptoms. A strong moral-religious orientation within the family was positively correlated with higher levels of social competence and internalizing behavior. Higher levels of social competence were also strongly associated with higher levels of family cohesion but lower levels of family organization. A strong emphasis within the family on intellectual-cultural activities was associated with higher levels of social competence and fewer externalizing behavior problems. Interestingly, for the most part, there appears to be little relationship between the child's self-esteem and family functioning as measured by the FES. It is also interesting to note that the mother's education appears to be a strong determinant of family functioning. More well-educated mothers were members of families characterized by greater Cohesion r=.29, p<.05, Expressiveness r=.29, p<.05, Intellectual-Cultural Orientation r=.42,
### Table 16

<table>
<thead>
<tr>
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<th></th>
<th></th>
<th></th>
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<tr>
<td><strong>Relationship</strong></td>
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<td>.38**</td>
<td>-.18</td>
<td>-.16</td>
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<td>Expressiveness</td>
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<td>.07</td>
<td>-.24</td>
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<tr>
<td>Conflict</td>
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<td>-.32*</td>
<td>.56****</td>
<td>.39***</td>
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<td>-.38***</td>
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<td>.62****</td>
<td>.07</td>
<td>.31*</td>
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<td>Organization</td>
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<td>-.49****</td>
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<tr>
<td>Control</td>
<td>.02</td>
<td>-.10</td>
<td>.30*</td>
<td>.14</td>
</tr>
</tbody>
</table>

* p .05  
** p .01  
*** p .005  
**** p .0001
The results of these analyses suggest that Hypothesis III can be supported. Better adjusted children (particularly as assessed by parent ratings) were more likely to be members of families with less conflict, a greater emphasis on family social-recreational activities and intellectual-cultural interests. As predicted, certain aspects of family functioning (conflict, active-recreational orientation, and to a lesser extent family organization) were more significant determinants of the child's adjustment than others.

The Relationship Between Adjustment, Family Functioning and Illness-Related Variables

Several additional analyses were performed to examine whether the impact of illness characteristics on adjustment might be mediated by family functioning. First, additional stepwise multiple regression analyses were performed on each of the adjustment measures with the 10 FES subscales, age of onset, duration of illness, number of joints involved and the child's age as independent variables. Due to the large number of variables included in the analyses a stringent level of significance was chosen (p<.001). Table 17 summarizes the results of these analyses. No variables were significant predictors of the child's self-esteem, although duration of illness approached significance $F(2,38)=5.86$, $p<.01$, $R^2=.24$. The same family functioning variables were significantly predictive of the child's social competence at the same levels of significance however, within the context of the family variables, age of onset became a significant predictor of social
<table>
<thead>
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<td>.01</td>
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<tr>
<td>Moral-Religious</td>
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competence $F(4,39)=17.69$, $p<.00001$, $R^2=.64$. Thus, the impact of age of onset on adjustment appears to be mediated by family functioning variables. As can also be seen in Table 17, the same family variables were significant predictors of the three behavior problem scores and none of the illness-related variables became significant predictors of behavior problems even when family functioning was taken into account.

Second, an additional set of multiple regression analyses were performed on each of the adjustment measures, however, in this case, the three FES composite scores were utilized instead of the 10 subscales. Previous research has demonstrated the utility of the Relationship Dimension of the FES (Cohesion, Expressiveness and Conflict) which has been termed the Family Relationship Index (FRI). This composite score has high internal consistency (Chronbach's alpha=.89) (Houlihan & Moos, 1981) and it has been utilized in previous research examining family functioning in JRA (Thompson, Varni & Hanson, 1987). The two other dimensions (Personal Growth and System Maintenance) have not yet been utilized as composite scores in previous research and therefore their inclusion in the analyses should be regarded as exploratory in nature. The results of these analyses are summarized in Table 18. No variables accounted for a significant amount of variation in the child's self-esteem. The FRI clearly accounted for the greatest amount of variation for each of the CBCL scores including social competence $F(1,42)=9.06$, $p<.0005$, $R^2=.21$; total behavior problems $F(1,42)=10.99$ $p<.005$, $R^2=.21$; internalizing problems $F(1,42)=7.61$, $p<.01$, $R^2=.15$ and externalizing problems $F(1,42)=6.05$, $p<.05$, $R^2=.12$. The Personal Growth dimension was also a significant predictor of the child's social competence, although
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accounting for less variation than the FRI $F(1,42)=11.30$, $p<.005, R^2=.21$.

None of the illness-related variables were significant predictors of adjustment in any other of these analyses.
Chapter VI
DISCUSSION

The overall purpose of the present investigation was to examine the psychological adjustment and family characteristics of children and adolescents with JRA. One aim of the study was to obtain objective information about different aspects of the adjustment of children and adolescents with JRA, utilizing reliable, valid and well-standardized instruments. A second goal was to obtain objective data concerning the functioning of families with a JRA child utilizing a reliable, valid, well-standardized instrument. However, the primary aim of the study was to examine the role that illness-related variables, individual-child variables and family functioning variables play in mediating the psychological adjustment of children and adolescents with JRA.

With regard to the overall adjustment of children with JRA, the findings suggest that some aspects of adjustment may be more disrupted by the presence of a chronic illness such as JRA than others. The data showed no significant differences between the JRA sample and national norms in overall self-esteem. In contrast, the JRA subjects were described by parents as significantly less socially competent and having a higher frequency of behavior problems, particularly of the internalizing type than the CBCL normative samples.

The finding of average or higher levels of self-esteem in the JRA
sample as compared to national norms is consistent with the findings of several other studies of chronically ill children (Hauser et al., 1985; Hurtig & White, 1986; Ivey et al., 1981; Kellerman et al., 1980; Lemanek et al., 1986; Spaulding & Morgan, 1986; Tavormina et al., 1976). Furthermore, the finding in the JRA sample of average to above average self-esteem together with well-above average frequencies of parent reported behavior problems has also been reported in other studies of chronically ill children including cystic fibrosis (Lewis & Khaw, 1982; Simmons et al., 1985) and sickle cell anemia (Lemanek et al., 1986). Such findings have frequently been interpreted as demonstrating that self-esteem is a facet of adjustment that is not affected by the presence of a chronic illness. However, as noted in the most recent manual for the Piers-Harris Scale (Piers, 1977), the self-report nature of this measure renders it vulnerable to a social desirability bias, and children, particularly young ones typically report mostly positive things about themselves. Thus, while self-concept may, in fact, be less disrupted by a chronic illness than other aspects of adjustment such as the child's social competence or behavior, such a conclusion should be viewed cautiously due to the potential social desirability bias of the self-report measures utilized in these studies.

Parent ratings of significantly lower social competence scores in the JRA sample as compared to the CBCL normative samples may be related more to the decreased activity and limited mobility of children with JRA than to actual social skill deficits or poor peer relations. Since the total social competence score is actually comprised of three
subscales (frequency and proficiency in activities and sports, school performance and social relationships) very low scores on the activities subscale could substantially reduce the total social competence score even if the social relationship and school performance subscale scores were average. This is not to suggest that children and adolescents with JRA do not display significant social relationship problems; only that it is not possible to conclude this from the present data.

With regard to frequency of behavior problems, not only did the JRA sample display significantly higher total behavior problems, as well as internalizing and externalizing problems than the normative samples, 20% of the JRA sample was reported to display a sufficiently high frequency of total behavior problems to be classified as "disturbed". This rate is higher than the 5-12% (varying by sex and agegroup) of the CBCL normative samples that scored within the "clinical range". However, this rate of disturbance is generally consistent with those reported in large population surveys of chronically ill children such as the Isle of Wight study (19%) (Rutter et al., 1970) and National Survey of Child Health and Development (25%) (Pless & Douglas, 1971). As discussed previously such comparisons are problematic; however, since inconsistencies within the psychological literature on prevalence rates for disturbance in chronically ill children are due, in part, to variability in how adjustment is operationalized across studies. Therefore, it is more useful to compare the prevalence rate for disturbance in the present study to previous studies utilizing parent behavior checklists, and the CBCL in particular. When compared to such research, the prevalence of behavior problems in the present study is
quite similar. Many of these studies report higher frequencies of behavior problems in chronic illness samples when compared to national norms for the CBCL (e.g. Hurtig & White, 1986; Lemanek et al., 1986; Lewis & Khaw, 1982; Simmons et al., 1985). Unfortunately, actual rates of behavioral disturbance (i.e. percentage of scores in the clinical range) are not reported by many authors. Among those studies which do report prevalence rates for disturbance, the present study's rate of 20% is consistent with Drotar et al.'s (1981) finding of 19% in their cystic fibrosis sample, but higher than the 6.5% reported in Simmons et al.'s (1985) cystic fibrosis sample.

Furthermore, the high percentage of subjects in the present study scoring in the "clinical range" for internalizing problems (36%) may be due, in part, to the disproportionate percentage of females in the present study. Achenbach and Edelbrock (1981, 1983) have reported significant sex differences in the wide-band factors of the CBCL, with females displaying a higher frequency of internalizing problems than males. Thus, it is possible that the high rate of significant elevations in internalizing problems in the JRA sample is confounded by the higher proportion of females with JRA in the present study, as well as in the JRA population as a whole.

Finally, although the validity of comparisons between the JRA sample and CBCL normative samples is enhanced by the availability of separate norms for males and females in three different age groups and the use of a statistical technique designed to handle unequal sample size and variance, it must be noted that comparisons to national norms are not equivalent to the inclusion of a normative control group matched for
age, sex, race and socioeconomic status. Although race and SES were found to have very minimal effects on CBCL scores in the normative samples, since these variables were not controlled in these comparisons, and there was a greater proportion of low SES subjects in the present study than in the CBCL normative samples, it is possible that there was some confounding by SES.

The first hypothesis predicted that illness-related variables, including age of onset, duration of illness, severity of illness and types of medication taken for JRA would be significantly related to the psychological adjustment of children and adolescents with JRA. For the most part, minimal relationships were found between age of onset, duration of illness, types of medication taken and any aspect of the child's adjustment. In contrast to the predictions of Hypothesis Ia and Ib, there were no differences in the adjustment of subjects whose onset occurred during the first peak onset period for JRA (1-3 years) and the second peak onset period (8-12 years). There were also no differences in the adjustment of subjects with a very short as opposed to very long duration of illness. The finding of an overall limited impact of medical variables on adjustment is consistent with prior research (Drotar et al., 1981; Gordon et al., 1982; Kellerman et al., 1980; McCauley et al., 1986; O'Malley et al., 1980; Simmons et al., 1985).

In contrast to Koocher et al.'s (1980) finding that age of onset was the best predictor of psychological adjustment in pediatric cancer patients, in the present study, age of onset only became a significant predictor of adjustment in the context of family functioning variables
and this was only evident in the case of social competence. It is difficult to determine the exact nature of the relationship between age of onset and social competence from the data available. However, this finding does suggest that certain family variables might mediate the relationship between the child's illness characteristics and adjustment, a conclusion that has been reached by previous researchers (e.g. Lewis & Khaw, 1982; Pless & Satterwhite, 1973). Additionally, the finding of a significant interaction between age of onset, developmental stage and self-esteem also lends support to the notion that the impact of age of onset on adjustment is mediated by other variables. The latter finding is also consistent with Ryan & Morrow (1986) who reported that age of onset in diabetic adolescents was only related to self-esteem when gender was taken into account.

In an effort to clarify some of the inconsistencies in previous research investigating the relationship between severity of illness and adjustment in JRA, the present study utilized several different indices of severity: type of JRA, number and types of joints involved and ratings of functional impairment. Prior research on this problem has utilized either type of JRA, functional impairment ratings or physician ratings of disease activity as indices of severity. The latter is related primarily to the presence of active joint involvement at the time of assessment. As predicted in Hypothesis Ic, the present study demonstrated differences in the relationship between severity and adjustment depending upon how severity was operationalized. No significant relationship was found between adjustment and total number or types of joints involved. However, a composite of these two
indices; number of different types of joints involved, was
significantly associated with a higher frequency of internalizing
problems, and to a lesser extent, total behavior problems. Since most
of the subjects in the present study were rated as having none or mild
functional impairment, when these two groups were compared those with
mild disability were found to display more internalizing problems than
those with no functional impairment. However, subjects with the more
severe polyarticular type of JRA displayed more externalizing problems
than those with the milder pauciarticular type of JRA. Although in
both cases greater severity was associated with more behavior problems,
the nature of these problems varied with the way in which severity was
defined. Finally, when subjects in the present study were assigned to
groups on the basis of disease activity (active or remission), those
with active disease displayed significantly more internalizing problems
than those whose disease was in remission. Although these measures of
severity are all highly correlated with one another, the present
findings suggest that both similarities and differences exist across
the various indices with regard to their relationship to adjustment.
First, regardless of how it is defined, severity does not seem to be
related to self-esteem, a finding that is consistent with previous
research on JRA (Billings et al., 1986; Ivey et al., 1981). In
contrast, there appears to be a direct, linear relationship between
severity and behavior problems, particularly the internalizing type,
across three of the four indices of severity. This is consistent with
Billings et al. (1986) who reported that subjects with severe disease
displayed more parent-reported psychological problems than those with
mild disease. Furthermore, these problems were found to be more mood-related (i.e. internalizing) than conduct-related problems. Both the findings of the present study and Billings et al. (1986) challenge McAnarney et al.'s (1974) report of a nonlinear relationship between severity of JRA and adjustment in which subjects who had no functional impairment displayed poorer adjustment than those with moderate-severe impairment. However, the validity of comparisons between the present study and McAnarney et al. (1974) may be somewhat limited by the higher proportion of subjects with none or mild functional impairment in the present study in contrast to the more equal balance between nondisabled, mildly disabled and moderate-severely subjects in McAnarney et al.'s (1974) JRA sample.

Finally, in contrast to the prediction of Hypothesis I d, that the types of medication utilized to treat JRA would be related to the child's adjustment, even the use of medications with severe or uncomfortable side effects (e.g. steroids) was not found to be significantly related to adjustment. It is possible that a more direct examination of this question (i.e. comparing the adjustment of JRA patients who have and have not experienced significant physician rated side effects from medication) would reveal differences in adjustment.

Hypothesis II predicted that there would be a significant relationship between the adjustment of children and adolescents with JRA and certain individual-child and demographic variables including the child's age and sex and parental marital status, education and socioeconomic status. The child's age, when considered within the context of developmental stage and parental education and marital
status were found to be significantly related to particular aspects of the child's adjustment. Latency-aged children displayed more externalizing problems than adolescents. Mothers with higher education were more likely to have children with greater social competence and fewer externalizing behavior problems. Children whose parents were married reported higher self-esteem and social competence but displayed more externalizing problems than children whose parents were not married. The child's sex and socioeconomic status were not found to be significantly related to any aspects of adjustment.

The finding that age, sex and socioeconomic status did not significantly effect self-esteem as measured by the Piers-Harris Scale in the JRA sample is consistent with previous research in both normal and disturbed samples (Piers, 1977). One study of a heterogeneous chronic illness sample (Zeltzer et al., 1980) did report lower self-esteem among females, as compared to males; however, this study utilized a different measure of self-esteem. The finding of no significant sex effects for total behavior problems is consistent with the CBCL normative sample (Achenbach & Edelbrock, 1983). However, sex differences were found on the wide band factors in the normative samples, with females higher on internalizing and males higher on externalizing, a difference which was not found in the present study. Consistent with the lack of effects found for race and socioeconomic status in the present study, Achenbach & Edelbrock (1983) reported no significant effects for race and socioeconomic status in their normative samples for the CBCL. The finding that mothers, and to a lesser extent fathers, with more years of education have more socially
competent children with fewer undercontrolled, acting-out behavior problems may not be unique to the present study and may reflect a more sophisticated knowledge and effective practice of child-rearing methods.

As has been previously mentioned, many authors have discussed the differential impact of chronic illness at various developmental stages from infancy through adolescence. In order to examine developmental differences in various aspects of the JRA patients' psychological adjustment and to explore whether the effect of certain variables on adjustment varies with the developmental level of the child, numerous comparisons were made between latency-aged and adolescent subjects. Too few subjects were available in the preschool group to include them in the analyses. No differences were found between the latency and adolescent groups in self-esteem, social competence, total behavior problems or internalizing problems. However, the latency group displayed a higher frequency of externalizing problems. This finding contrasts with that of Hurtig & White (1986) in their sickle cell anemia sample. These authors reported a sex by age interaction in which adolescent males with sickle cell anemia displayed a higher frequency of total behavior problems and internalizing/externalizing problems than adolescent females or the latency group as a whole. Not only did the present study not find any significant developmental stage by sex interaction effects, but adolescents in the JRA sample were found to display fewer behavior problems than the latency-aged group (particularly the externalizing type). The inconsistency of these
findings may be related to differences in the clinical characteristics of the two diseases. Several features of sickle cell anemia (i.e. growth retardation, delayed puberty) are seen as more problematic for adolescents than for younger children (Hurtig & White, 1986; Morgan & Johnson, 1986).

The results of the analyses which examined whether the impact of illness-related variables on adjustment is mediated by developmental stage revealed no interaction between developmental stage and any of the severity measures. However, there were significant interaction effects between developmental stage, duration of illness and self-esteem, social competence and total behavior problems. There was also an interaction effect found between developmental stage, age of onset and self-esteem. Consistent findings emerged regarding the role of developmental stage as a mediating variable across these various interactions. Latency-aged subjects with an early disease onset and long duration of illness were better adjusted (higher self-esteem, greater social competence and fewer behavior problems), while adolescents with a late disease onset and short duration of illness were better adjusted.

Finally, when the family functioning of latency-aged JRA subjects was compared to that of the adolescents, the only significant difference was found in the area of cohesion. Families of adolescents with JRA were less cohesive than families of latency-aged children. However, this finding may be typical of families of adolescents regardless of the presence of a chronic illness. Unfortunately, this type of normative data is not available from research utilizing the FES.
An examination of family functioning in the JRA sample in comparison to the FES normative sample revealed that JRA families are characterized by significantly higher moral-religious emphasis, organization and control, with higher levels of cohesion approaching significance. These findings can be compared to similar analyses conducted by Thompson, Varni and Hanson (1987) in their study of children and adolescents with JRA. Thompson et al.'s (1987) JRA sample also reported significantly higher moral-religious emphasis, organization and cohesion. Level of control was also higher in the JRA sample but did not quite reach significance. The striking similarities between these two studies concerning aspects of family functioning that differ significantly from normal families is even more remarkable when one considers patterns of nonsignificant differences which were almost identical. Both studies found the following JRA family functioning profile when compared to FES norms: greater cohesion, greater expressiveness, less conflict, less independence, greater achievement orientation, greater intellectual-cultural orientation, greater moral-religious emphasis, greater organization and greater control. The only difference between the two JRA samples and FES norms was in the area of active-recreational emphasis which was slightly lower than FES norms in the present study but higher in Thompson et al.'s (1987) sample.

Therefore, the findings of the present study lend support to Thompson et al.'s (1987) conclusion that, in view of significantly higher levels of moral-religious emphasis, organization and control and lower levels of conflict, JRA families appear to be very controlled. As previously noted, this type of family functioning resembles Minuchin et al.'s
description of the "psychosomatic family" characterized by enmeshment, overprotectiveness, rigidity and lack of conflict resolution.

It is also notable that among the few other studies of chronic illnesses other than JRA which have compared FES scores of the chronic illness group to the FES normative sample, no significant differences were found on any of the 10 subscales (Johnson et al., 1985; Wertleib et al., 1986). However, there were some similarities in the pattern of nonsignificant mean differences between Johnson et al.'s (1985) cystic fibrosis sample and FES norms. Similar to the present study and Thompson et al. (1987), the cystic fibrosis families were characterized by greater cohesion, less conflict, less independence, greater organization and greater moral-religious emphasis than FES norms. Although these differences were not significant, they do suggest similar trends towards enmeshment, overprotectiveness and overcontrol.

Hypothesis III predicted that family functioning would be a significant determinant of the JRA child's psychological adjustment, and that certain aspects of family functioning (conflict, organization and active-recreational emphasis) would be more powerful predictors of adjustment than others. The findings of the study support this hypothesis. The role of family functioning was clearly most powerful in the case of the four CBCL scores. Only degree of organization was significantly predictive of the child's self-esteem, with greater organization positively correlated with higher self-esteem. Degree of conflict within the family was clearly the most powerful predictor of the child's adjustment among the family and illness-related variables.
Conflict accounted for significant amounts of variation in the child's social competence, total behavior problems, internalizing problems and externalizing problems. Greater conflict was correlated with lower social competence and a higher frequency of all three indices of behavior problems. Active-recreational emphasis within the family was also a powerful predictor of the three behavior problem scores with greater active-recreational emphasis correlated with a lower frequency of total, internalizing and externalizing behavior problems. Additionally, moral-religious emphasis was significantly predictive of social competence and internalizing problems with greater moral-religious emphasis positively correlated with greater social competence and more internalizing behavior.

The finding of a strong correlation between family conflict and the child's adjustment is consistent with prior chronic illness research. Johnson et al. (1985) reported a strong positive correlation between degree of conflict as measured by the FES and a higher frequency of total behavior problems on the CBCL in their cystic fibrosis sample. Similarly, Wertleib et al. (1986) in their study of diabetic children, reported significant positive correlations between degree of conflict reported on the FES and frequency of total behavior problems, internalizing and externalizing problems on the CBCL. However, this relationship only approached significance in the acute illness comparison group. The strong association with family conflict and behavior problems reported in these chronic illness studies is consistnet with the clinical literature on the impact of family factors in child psychopathology (e.g. Broderick & Pulliam-Krager, 1979).
The present study's finding that a greater active-recreational emphasis within the family is correlated with fewer behavior problems is also consistent with data from Wertleib et al.'s (1986) diabetic sample. Greater emphasis on family activities and recreation was also positively correlated with higher perceived competence in this same sample (Hauser et al., 1985). Similarly, in both the present study's JRA sample and Wertleib et al.'s (1986) diabetic sample, moral-religious emphasis was strongly correlated with a higher frequency of internalizing symptoms. In the case of both of these aspects of family functioning, these relationships were only found in the diabetic sample and were not evident in the acute illness comparison group. This suggests that these aspects of family functioning may be particularly salient in families with a chronically ill child and support the notion of a complex interaction between family functioning, physical illness and psychological adjustment. Interestingly, the significant negative correlation between emphasis on family organization and frequency of behavior problems reported by both Johnson et al (1985) and (Wertleib et al. (1986) was not found in the present study. This may be due to an increased need for routine and scheduling in the care of children with diabetes who require daily injections and diet monitoring and children with cystic fibrosis who require daily exercises and monitoring of pulmonary functioning. However, many JRA patients require daily medication and range of motion exercise during times of flare-up of their arthritis so this explanation may not account for the lesser impact of family organization on the child's behavior problems in the JRA sample.
Unfortunately, definitive conclusions regarding the unique relationship between family functioning and the child's psychological adjustment in either homogeneous or heterogeneous chronic illness populations are not possible without data concerning the relationship between FES scores and parent ratings of behavior on the CBCL in normal samples. At the present time, such normative data is not available. However, several studies have examined the relationship between family functioning as measured by the FES and adjustment assessed by measures other than parent behavior checklists. In a sample of high school students, Forman & Forman (1981) reported correlations between FES scores and adjustment as measured by the High School Personality Questionnaire. However, comparisons are difficult due to the fact that different aspects of adjustment were assessed in this study, which did not include self-esteem or behavior problems, and instead included personality traits which are not comparable to the present study. These authors did find that no single family variable accounted for any major portion of the variance in personality traits. Rather, the authors concluded that the child's adjustment varies with the total family system functioning more than with separate aspects of family functioning.

Bell and Bell (1982) examined the relationship between FES scores and adjustment as assessed by the California Personality Inventory and Loevinger's sentence completion measure of ego development in a group of 99 15-17 year old female high school students. The authors reported that the most well-adjusted subjects were members of families who reported greater cohesion, expressiveness, and independence and less
organization and control. In contrast to the present study and related studies of other chronic illness samples, family conflict was not found to significantly differentiate well-adjusted from poorly adjusted subjects. However, the association between better adjustment and greater cohesion and less organization is consistent with the present study's finding of a significant correlation between social competence and greater cohesion/less organization. Although it is difficult to compare the results of the present study to the two described above due the fact that somewhat different aspects of adjustment were examined, and the inclusion of only adolescents in the two normal samples, the overall lack of consistency between the findings suggests that perhaps there are unique patterns of family functioning and unique relationships between family functioning and the child's adjustment in families with a chronically ill child, and a JRA child in particular.

In summary, the results of the present study support the view that the adjustment of children and adolescents with chronic illness is determined by a complex interaction between medical variables and environmental factors. The results support the relative prominence of family functioning variables over illness-related variables as determinants of the child's adjustment, which is consistent with prior research (e.g. Drotar et al., 1981; Johnson et al., 1985; Lewis & Khaw, 1982; Pless & Satterwhite, 1973). Furthermore, the finding that the child's developmental stage mediates the relationship between certain illness characteristics and adjustment highlights the need to take developmental considerations into account when examining the psychological adjustment of chronically ill children. The results of
this study, together with previous research suggests that there may well be particular patterns of family functioning characteristic of families with a JRA child. However, the relationship between these patterns and various aspects of the child's adjustment need to be placed within the context of future research that will hopefully better elaborate such relationships in normal families with healthy children and other chronic illness samples. Finally, although a significant proportion of the JRA sample in this study clearly manifests an above average number of behavior problems and below average social competence, it is not possible from the present data, to draw conclusions regarding the causal nature of the development of adjustment problems. One cannot determine whether these problems existed prior to the onset of JRA, or to what extent they developed subsequent to disease onset. Prospective, longitudinal investigations of children and adolescents with JRA are needed to clarify any causal relationship between the presence of JRA and psychological adjustment problems.

Limitations and Implications

The present study has a number of strengths as well as limitations. The use of reliable, valid, well-standardized instruments with demonstrated utility in prior pediatric psychology research is a significant improvement over most of the previous research on psychological adjustment in JRA. The use of a multitrait, multimethod approach to assessing psychological adjustment (i.e. use of both self-report and parent ratings or intrapersonal, interpersonal and behavioral adjustment) is also a strength of the present study;
however, an expansion to include other methods of assessment such as teacher ratings or direct observation would enhance the assessment of adjustment in future research. This study also improved upon much of the previous research on JRA by limiting the sample to only those subjects with a diagnosis of JRA, as opposed to the frequent practice of including subjects with other related rheumatic diseases in a "JRA" sample. Finally, conservative statistical analyses were utilized to reduce the likelihood that findings could be due to chance in analyses which included a large number of variables.

Several limitations may reduce the generalizability of the findings. First, the sample size was not large enough to permit more detailed analyses of certain aspects of adjustment such as the narrow band behavior problem factors and social competence subscales on the CBCL. Furthermore, the sample size was only marginally adequate for some of the multiple regression analyses in which a large number of independent variables were included. The use of a larger sample size in future research would permit a more extensive investigation of particular aspects of behavior problems as well as permit an examination of which aspects of social competence are most compromised in JRA children. The subscales of the Piers-Harris Self-Concept Scale or a more well-differentiated measure of self-esteem such as the Perceived Competence Scale (Harter, 1982) could be utilized if a larger sample was available.

A second limitation of the study is the lack of either a healthy control group or chronic illness comparison group matched to the JRA sample on age, sex, race and SES. As previously mentioned, the present
study's comparisons to national norms for the adjustment and family functioning measures increase the likelihood that uncontrolled variables such as SES or race might confound the findings. The inclusion of a matched healthy control and illness comparison group in future research would improve the validity of the results.

Finally, the assessment of adjustment and family functioning in the present study was limited to pencil and paper instruments. There is always a potential bias in both self-report and parent report measures. Furthermore, only mothers' perceptions of family functioning and the child's behavior were utilized. Future research could be improved by the inclusion of teacher ratings and direct observation of the child's adjustment. Furthermore, although Achenbach and Edelbrock (1983) have reported no significant differences between mothers' and fathers' ratings of their child's adjustment on the CBCL, it would be interesting to include fathers' perceptions of their child's adjustment in future research. The use of composite and discrepancy scores on the FES that combine reports of all individual family members into a single "family score" might provide a more accurate assessment of family functioning than is obtained by mothers' perceptions alone. An assessment of the quality of the parents' marital relationship which is not measured by the FES might expand our understanding about the role of family factors in the adjustment of children and adolescents with JRA.

The results of the present study suggest several clinical implications. First, in view of the finding that the impact of family
functioning on the child's adjustment is much more powerful than the impact of disease characteristics, a family-oriented approach to intervention with JRA children is more appropriate than a child-oriented model. A recognition of the importance of family factors should be integrated into both assessment and intervention strategies. Although it may not be feasible to conduct a comprehensive, formal assessment of family functioning within a medical setting, the findings of the present study point to specific aspects of family functioning that would be most critical to evaluate. The degree of conflict within the family, which has been shown to be a major determinant of the child's adjustment would be a very important area to examine. It would be important to assess the ways in which conflict is expressed and resolved in the family system and provide family-based interventions if conflict management appeared to be dysfunctional. The extent to which the family engages in social-recreational activities together has also been found to be a critical determinant of the JRA child's adjustment and this would be an important area of family functioning to evaluate. Since the results of both the present study and Thompson et al. (1987) suggest that the family environment of children with JRA tends to be overcontrolled, it would also be very important to evaluate the degree of control and rigidity within the family. The issue of overcontrol within the family system becomes even more critical when one considers the finding in the present study that JRA children and adolescents were seen as having a high frequency of internalizing (i.e. overcontrolled, inhibited) types of problems. If an assessment indicated that issues of control are problematic for the family, intervention by a mental health
professional would be appropriate.

In addition to assessing family functioning, the finding of an above-average rate of problems in the areas of social and behavioral adjustment within the JRA sample suggests a need for a brief screening evaluation of the JRA child's psychological functioning at the time of diagnosis in order to identify children who may be experiencing social and/or behavioral difficulties. If more extensive clinical interviews are not feasible, one efficient way to obtain a comprehensive picture of the child's adjustment would be to utilize an instrument such as the Child Behavior Checklist, which the parent could complete at home. The use of this type of instrument would provide a good picture of specific areas of social and/or behavior problems. If such problems were identified, referral to a mental health professional for more intensive assessment and intervention would be warranted.
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These consist of pages:

APENDICES A-C: 109-120
Appendix D

JRA QUESTIONNAIRE
JRA Questionnaire

Section A (Parents)

1. Child's age
2. Child's date of birth
3. Child's sex
4. Parents' current marital status (Check which ever apply)
   __ Married to each other       __ Divorced
   __ Single                      __ Remarried
   __ Separated                   __ Widowed
5. Highest grade/degree completed by father
6. Highest grade/degree completed by mother
7. Parents' Occupational Information
   a. What kind of work are you doing? ________________________
      (For example: engineer, stock clerk, farmer)
   b. What are your most important activities or duties? __________
      (For example: sales, filing, operating machinery)
   c. What kind of business or industry do you work in? ________________________
      (For example: insurance company, farm, TV manufacturing plant)
   d. Are you: (Check one)
      __ an employee of a private company, business or individual where you
         receive salary, wages or commissions.
      __ a government employee
      __ self-employed in your own business, farm or professional practice
      __ working without pay in family business or farm

Please answer these same questions concerning your spouse in the spaces below
   a. What kind of work is your spouse doing? ________________________
   b. What are your spouse's most important activities or duties at work?
      __________
   c. What kind of business or industry does your spouse work in?
      __________
   d. Is your spouse: (Check one)
      __ an employee of a private company, business or individual where you
         receive salary, wages or commissions
      __ a government employee
      __ self-employed in your own business, farm or professional practice
      __ working without pay in family business or farm

8. Medical insurance covers approximately what percentage of your child's medical costs? (Please circle closest percent)
   None, 25%, 50%, 75%, 100%
Section B

Age of onset of JRA ________ Duration of illness__________
Type of onset of JRA _________________
Number of joints currently involved ____________
Which joints are currently involved _________________
Number of different medications child has taken for JRA ________________
Types of medications taken for JRA _________________
Current medications prescribed for JRA _______________________

Section C

Functional Classification OT_______ PT_______
Appendix E

LETTER TO SUBJECTS
Dear Patient and Parent,

At Children's Hospital we are concerned with the psychological as well as physical well-being of our patients. We realize that coping with a chronic illness such as juvenile rheumatoid arthritis can be difficult, at times, for the patient as well as for the family. We are interested in learning more about the psychological adjustment of children with JRA and its effect on the family. This is where we ask your cooperation.

While you are at the clinic today we ask for your consent to fill out several questionnaires. Patients will be asked to fill out one questionnaire concerning what you are like as a person. This will take about 15 minutes to complete and can be worked on while waiting for your clinic appointments. Parents will be asked to fill out three questionnaires concerning your child's behavior and what your family is like. These parent questionnaires should take about an hour of your time and can be completed while waiting for your child at the clinic.

Your decision to participate in this study is voluntary and you may expect the same care at the hospital whether or not you decide to participate. You need not answer any questions that you do not feel comfortable answering. Furthermore, your responses will be kept strictly confidential, that is, all questionnaires will be given a code number to be used in place of participants' names.

Finally, for the purpose of data analysis, certain information regarding the patient's medical history is needed. This will include general information such as the age your illness began, duration of your illness, type of JRA and the types of medication you have taken for JRA. This information will be obtained from medical records and like the questionnaires, will be kept absolutely confidential.

We hope that you will decide to participate in this study. To do so, please sign the consent form and return it to Janet Meltzer. If you have any questions, please feel free to ask.

Sincerely,

John D. Mahan, M.D.  
Pediatric Rheumatology  
Children's Hospital

Thomas Linscheid, Ph.D.  
Director of Psychology  
Children's Hospital

Janet Meltzer, M.A.  
Psychology Department  
Children's Hospital
Appendix F

CONSENT FORMS
THE OHIO STATE UNIVERSITY

CONSENT FOR PARTICIPATION IN
SOCIAL AND BEHAVIORAL RESEARCH

I consent to participating in (or my child's participation in) research entitled:

Psychological Adjustment in Juvenile Rheumatoid Arthritis

Thomas Linscheid, Ph.D. or his/her authorized representative has
(Principal Investigator)
explained the purpose of the study, the procedures to be followed, and the expected
duration of my (my child's) participation. Possible benefits of the study have been described as have alternative procedures, if such procedures are applicable and available.

I acknowledge that I have had the opportunity to obtain additional information regarding the study and that any questions I have raised have been answered to my full satisfaction. Further, I understand that I am (my child is) free to withdraw consent at any time and to discontinue participation in the study without prejudice to me (my child). The information obtained from me (my child) will remain confidential unless I specifically agree otherwise by placing my initials here.

Finally, I acknowledge that I have read and fully understand the consent form. I sign it freely and voluntarily. A copy has been given to me.

Date: ____________________________

Signed: ____________________________

(Principal Investigator or his/her Authorized Representative)

Signed: ____________________________

(Foreign Authorized to Consent for Participant - If Required)

Witness: ____________________________

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