

JUVENILE RHEUMATOID ARTHRITIC (JRA) CHILDREN
AND THEIR MOTHERS: A MULTI-METHOD COMPARISON
WITH A HEALTHY POPULATION

by

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ABSTRACT

The main purpose of the present study was to assess the psychological impact of juvenile rheumatoid arthritis (JRA) upon JRA children and their mothers by comparing them to a group of physically healthy children and their mothers in four domains: maternal and child behaviors, maternal perceptions of child adjustment, and maternal personal adjustment. The second purpose was to evaluate the relative strength of each domain to differentiate between the JRA and healthy comparison groups. Lastly, the interrelationships among various measures within the JRA sample were investigated.

Eighteen mother-child pairs with a JRA child were compared to eighteen mother-child pairs with a healthy child. The two groups were balanced on a variety of demographic variables. Mothers completed questionnaires which assessed their perceptions of their child's behavior. Self-perception questionnaires were also administered to measure maternal levels of depression, anxiety and marital satisfaction. Then each mother-child pair participated in a series of home observations in which trained observers coded behaviors from the mother-child interaction.

Results from the behavioral observations indicated that mothers of JRA children gave less positive attention to their children and that JRA children were less compliant to maternal commands. Mothers of JRA children perceived their children to be more "internalizing" in their behavior (e.g., more depressed, anxious, withdrawn, dependent). Mothers of JRA children also perceived themselves to be experiencing more

personal distress than mothers of healthy children. Analyses revealed that, in order of magnitude, maternal depression, maternal positive attention, and maternal perceptions of children's internalizing behaviors were the best discriminators between the two groups. Within the JRA sample, severely ill children were perceived to have more general behavior problems, more internalizing behaviors, and were observed to have higher levels of inappropriate behavior than their less ill peers. Additional analyses indicated that mothers who gave less positive attention tended to have children who were less compliant. Measures of maternal adjustment were not related to any of the other measures within the JRA sample.

Results suggested that the psychological adjustment of JRA children and their mothers was similar to the healthy comparison group in many respects, however they did differ in some important ways. These included an increase in internalizing behaviors and less compliance to maternal commands on the part of the child and increased feelings of personal distress and decreased positive attention towards the JRA child on the part of the mother. Measures related to mothers' behaviors, perceptions and personal adjustment were the strongest discriminators between the two groups, suggesting that maternal rather than child variables are what most separated the JRA from the healthy comparison group. Within the JRA sample, the psychological adjustment of JRA children seemed to be affected by the severity of their illness, but maternal behaviors and personal adjustment were not related to this or any other measures. This suggested the overall strength and ability of mothers to cope with raising their JRA children, even though they may be experiencing increased personal distress as a result.

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Pediatricians who work with chronically ill children are acutely aware of the psychological stress and emotional burden placed on these children and their families. Anecdotal reports by pediatricians have hypothesized that many chronically ill children will develop some secondary emotional/behavior problems (e.g., overdependency, rebelliousness, anxiety, depression) (Mattson, 1972). Many parents of chronically ill children have also been observed to experience some psychological adjustment problems (e.g., anxiety, depression, guilt, marital discord) and it has been hypothesized that these result from having chronically ill children in their families (Pless & Pinkerton, 1975). Anecdotal reports further suggest that the enduring nature of the illness and the care and attention demanded by chronically ill children put extreme pressure on their families' ability to function (Korn, Chess, & Fernandez, 1978).

Many hypotheses about the psychological adjustment of chronically ill children and the effect of their illness on parental personal adjustment and family functioning are based solely on the clinical impressions and observations of pediatricians. They have yet to be empirically verified with more experimental methods. However, in recent years, researchers have begun to take a more experimental approach to studying the psychological factors involved with chronically ill children and their families. Recent studies have examined such chronic illnesses as cystic fibrosis (Kucia, Drotar, Doershuk, Stern, Boat, & Matthews, 1979), congenital heart disease (Garson, Benson, Juler, & Patton, 1978), sickle-cell anemia and diabetes (Glanville, 1978), and juvenile rheumatoid arthritis (McAnarney, Pless, Satterwhite, & Friedman, 1974).

Juvenile rheumatoid arthritis (JRA) is the major chronic rheumatic disorder of childhood, a disease of unknown cause and with no known cure (Calabro, Holgerson, Sonpal, & Khoury, 1976; Petty, 1982). The primary characteristic of JRA is persistent arthritis (i.e., swelling of a joint or limitation of motion with heat, pain or tenderness) of one or more joints for at least 6 weeks (Brewer, Bass, Baum, Cassidy, Fink, Jacobs, Hanson, Levinson, Schaller, & Stillman, 1977). Calabro et al. describe JRA as "a capricious disease . . . whose variable modes of onset and patterns of disease are accompanied by a myriad of diverse signs, symptoms and manifestations" (1976, p. 257).

The American Rheumatism Association (ARA) criteria for the diagnosis of JRA is based on the clinical features of the disease in the first 6 months. JRA is classified into three categories according to onset type: pauciarticular, polyarticular, and systemic onset (Brewer et al., 1977). Pauciarticular onset JRA is the mildest form of the disease, with arthritis occurring in four or fewer joints during the first 6 months (Brewer et al., 1977). About half of all children with JRA have the pauciarticular form. It mainly affects girls, with the peak age of onset being 1-3 years (Petty, 1982). Iridocyclitis (inflammation of the iris and ciliary body) occurs in about 20% of children with pauciarticular JRA and, if this condition goes undetected, can result in impaired vision and eventual blindness (Calabro et al., 1976; Petty, 1982).

Polyarticular onset JRA is diagnosed when arthritis occurs in five or more joints in the first 6 months of the disease (Brewer et al., 1977). The polyarticular onset group make up about 35% of the total JRA

population. It mainly affects girls, with peaks in the age of onset at 1-3 years and 6-10 years (Petty, 1982). Significant functional impairment and joint deformity occur in over half of the children with polyarticular JRA (Petty, 1982).

Systemic onset JRA is the most severe form of the disease and makes up 20% of the total JRA population (Petty, 1982). Systemic onset JRA is characterized by persistent intermittent fever with or without rheumatoid rash or other organ involvement (Brewer et al., 1977). Many children have enlarged livers, spleens or lymph nodes and systemic JRA can also affect the heart, lungs and other body organs causing serious complications (Petty, 1982).

In addition to the diagnosis of JRA according to onset type, a differential diagnosis must be made to distinguish JRA from other closely related rheumatic diseases. These diseases, (e.g., polymyositis, dermatomyositis, and ankylosing spondylitis) have similar signs, symptoms and characteristics to JRA and must be ruled out in the diagnosis.

The incidence of JRA is estimated at 3.5 to 9.2 cases per year per 100,000 children under 15 years of age and the prevalence of JRA has been estimated at about 65 per 100,000 children under 16 years of age (Petty, 1982). Petty suggests that there are between 2,500-4,000 children with JRA in Canada.

Most children with JRA outgrow the disease by the time they reach adolescence and emerge with a minimum of joint damage and disability (Calabro et al., 1976), but prognosis varies with the onset diagnosis. For pauciarticular onset JRA, 70% of the children will remit, although

there may be some minimal residual joint damage. Sixty percent of the polyarticular onset JRA children are in remission after 15 years of follow-up (Calabro et al., 1976). The prognosis for systemic onset children is less promising. Only 43% of systemics have no (or only slight) handicap and there is a 13.8% death rate with this group (Stoeber, 1981). The mortality rate for JRA is only about 1% in North American children, although it is between 4% and 7% in European children (Baum & Gutowska, 1977; Stoeber, 1981).

JRA may have a sudden or insidious onset followed by periods of partial remission (Brewer, 1970). The episodic nature of this disease makes it highly unpredictable, so that the child may be in remission for many months and then suddenly experience a severe and painful relapse (Coley, 1972). The JRA child may also experience varying levels of pain, stiffness, immobility, fever and skin rashes from day to day and may suffer from growth disturbances as a result of the arthritis and/or the medication used to treat the arthritis (Brewer et al., 1977).

JRA has no known cure so treatment is aimed at minimizing pain, preventing disability and restoring functioning (Petty, 1982). Most JRA patients' pain and joint inflammation can be controlled by corticosteroid (Schaller, 1977) or nonsteroid (Brewer, 1977) analgesic and anti-inflammatory medications. Aspirin is the first drug of choice in most cases (Petty, 1982). Joint crippling and immobility are treated with a variety of methods including splinting, physical measures such as massage, heat and ultrasound, and physiotherapy such as isometric and active-assisted exercises (Donovan, 1977). Table 1 presents a summary of the clinical characteristics of JRA.

Table 1
Clinical Characteristics of JRA by Onset Type

	<u>Pauciarticular</u>	<u>Polyarticular</u>	<u>Systemic</u>
Proportion of all JRA a	45%	35%	20%
Sex ratio (girls: boys) a	4:1	3:1	1:1
Peak age at onset (in years) a	1 - 3	1 - 3, 6 - 10	none
Number of joints affected in the first six months a	> 5	< 4	any number
Fever b	low or none	low	high
Iridocyclitis a	20% of cases	10% of cases	∅
Remission	70% b	60% b	43% c
Functional impairment a	12.5%	50%	30-50%
Death rate c	∅	1%	13.8%

a Petty, 1982.

b Calabro et al., 1976.

c Stoeber, 1981.

The symptoms and course of JRA combine to make it a highly stressful condition for children and their families. Pediatricians report that many of their JRA patients are troubled by emotional/behavior problems and that the parents of JRA children experience stress, anxiety and depression in trying to cope with the illness (Blom & Nicholls, 1954; Brewer, Giannini, & Person, 1982; Cleveland, Reitman, & Brewer, 1965; Coley, 1972; Travis, 1976; Williams, 1981). However, these data are based almost exclusively on pediatric case reports. The question of whether the frequency of psychological adjustment problems in JRA children and their families is significantly greater than in a healthy population has not been clearly demonstrated.

Researchers who have explored the psychological implications of JRA and other chronic illnesses of childhood have focused on two main issues: the psychological effect of the illness on the children, and the impact on their parents, especially the mothers. Researchers have tended to focus on the psychological adjustment of the mother because she is viewed as the primary care-giver, the one who spends the most time with the child, and the one who is most affected by the child's illness (see Patterson, 1980). A few researchers (Cummings, 1976; Gayton, Friedman, Tavormina, & Tucker, 1977; Korn et al., 1978; McAndrew, 1976) have also examined the effects on fathers and siblings.

In the following literature review, the chronic illness research will be examined to outline findings on the psychosocial effects of chronic illness on the children themselves. Special attention will be given to research with JRA children. Research which examines the

effects of chronically ill children on parents' personal adjustment and behavior also will be reviewed. Finally, the purpose and experimental hypotheses of the current investigation will be outlined.

Psychosocial Effects of Chronic Illness on the Child

The psychosocial adjustment of chronically ill children has been measured in three ways: children's self-report; parents' perceptions of their children's behavior/emotional state as assessed by interview, survey, or questionnaire; and the use of direct observation of children's behavior by independent observers. As noted earlier, the chronic illness literature is characterized by a paucity of empirical research and a reliance on survey studies and on pediatrician or parent report of children's psychological states. The questionable reliability and validity of self-report measures with young children have led many researchers to rely on parent perception measures instead.

One way that parental perceptions have been gathered is through unstructured interviews, in which parents are asked to describe any emotional and behavioral difficulties they observed in their chronically ill children. One example of such an interview study was done by McAndrew (1976), who surveyed 116 mothers whose children had spina bifida, cerebral palsy or a limb deficiency. Her survey found that one-third of the mothers interviewed reported their children to have emotional/behavior problems, including severe temper tantrums, head banging, depression, lack of confidence and other forms of insecurity.

More systematic and empirically-based research on chronic illness was conducted by Pless and Roghmann (1971). They compared chronically ill children, ranging in age from 6 to 16 years, with samples of physically healthy children, using data collected from three epidemiological surveys conducted in Britain and the United States. The chronic illnesses studied included asthma, cystic fibrosis, allergic disorders, epilepsy, cerebral palsy, and congenital and musculoskeletal disorders. Data were collected using a variety of measures including educational evaluations, parent and teacher ratings, and rates of psychiatric disorders. One survey revealed that chronically ill children were more frequently truant, more often troublesome in school, and more often socially isolated than their healthy peers. Another survey showed that 25% of chronically ill children had two or more abnormal behavior symptoms at age 15, compared with only 17% in the healthy comparison group. This is a statistically significant difference. In the third survey, parents and teachers rated chronically ill children almost twice as behaviorally deviant as their healthy peers. They also found the rate of psychiatric disorders to be 17% in the chronically ill sample, versus only 7% in the physically healthy sample.

In an extension of their 1971 study, Pless, Roghmann, and Haggerty (1972) further investigated the psychological variables associated with chronically ill children. They compared a group of chronically ill children (with a variety of disorders), aged 6 to 11, to a physically healthy sample matched on age, sex, socioeconomic status, and family size. Both groups were further divided into low- and high-functioning

families according to a family functioning index. This index was derived from family interviews and parent ratings of marital satisfaction, number of conflicts, and time spent together as a family. The chronically ill and healthy groups were compared on self-esteem, behavior symptoms and overall adjustment, using self, parent, and teacher ratings. This study revealed that chronically ill children were more poorly adjusted on all psychological measures than their healthy peers (i.e., lower self-esteem, more behavior symptoms, lower overall adjustment rating). More importantly, maladjustment was found to increase if chronically ill children were from low-functioning families. These findings suggest the importance of good family functioning in chronically ill children's ability to cope with their illness.

A recent study by Lewis and Khaw (1981) also investigated the role of family functioning as a mediating variable in the psychological adjustment of chronically ill children. The study compared three groups of children: 31 children with cystic fibrosis, 26 children with chronic asthma and 27 physically healthy children. The three groups were between the ages of 7 - 12, and similar in age, gender, educational and occupational levels of the parents and percentage who came from single parent families. On a self-report measure of self-concept, the three groups were not significantly different. However, based on a parent perception of child behavior questionnaire, both the cystic fibrosis and asthma groups had more reported behavior problems than healthy children. Parent report measures of family functioning revealed no significant differences among the groups, but an increased number of

behavior problems proved to be the best predictor of poor family functioning. Also, when the level of family functioning was controlled for, no significant differences were found between the cystic fibrosis and healthy groups on the number of behavior problems. The researchers concluded that the relationship between extreme family functioning and behavior problems in children was much more significant than the relationship between chronic illness and behavior problems.

Other recent research (e.g., Cernelc, Hafner, Koss, & Cenlec, 1977; Drotar, Doershuk, Stern, Boat, Boyer & Matthews, 1981; Gayton et al., 1977; Glanville, 1978; Tavormina, Kastner, Slater, & Watt, 1976) on a variety of chronic illnesses suggests that the psychological adjustment of chronically ill children may not be significantly different from that of physically healthy children. Glanville (1978) compared the self and parent ratings of children (aged 6 to 12 years) with sickle-cell anemia or diabetes to a physically healthy comparison group. Data revealed that both groups of chronically ill children had a significantly lower self-concept and a lower sense of physical well-being than the healthy children. However, the sickle-cell anemic and diabetic children did not differ from their peers on any other measures of emotional and behavioral adjustment.

Tavormina et al. (1976) compared the test scores of 144 chronically ill children (diabetic, asthmatic, cystic fibrotic and hearing-impaired) ranging in age from 5 to 19, to standardized norms for child-completed personality questionnaires, and self-esteem and locus-of-control measures. This study reported that most of the chronically ill children did not differ significantly from the standardized norms. Although the

researchers emphasized the normalcy of the chronically ill population, several sub-groups did show signs of psychological maladjustment on some measures. Hearing-impaired children had a lower self-concept and more pronounced instability and neuroticism than other chronically ill children. Children with cystic fibrosis were more immature and dependent than the norm, and diabetics appeared more alienated and rebellious on some of the measures. Tavormina et al. (1976) concluded that no clearcut profile of psychological maladjustment appears present in chronically ill children. However, the data also seem to suggest that individual patterns of maladjustment may be present, depending on the particular chronic illness under investigation.

Using 105 physically healthy children as a comparison group, Cernelc et al. (1977) compared the performance of 287 asthmatic, 19 diabetic, and 27 rheumatic children on IQ tests. Data were also collected from parent/child interviews conducted by a psychologist or a social worker. They found no significant differences in the IQ of the child, the overprotectiveness of the parent, or the socioeconomic status of the family. Across all groups, they found a low incidence of disturbed family life and a high rate of self-confidence in the child as well as no significant differences in school adjustment. The significant differences found among the groups were that diabetics and asthmatics were identified as more hyper-irritable, and diabetics had the "neurotic trait" of nail-biting more frequently than other groups.

A study by Gayton et al. (1977) revealed no significant differences in emotional adjustment between a cystic fibrosis (CF) population and healthy children. In their study, 143 CF children (aged 5 to 18 years)

showed no sign of emotional disturbance on several child-completed measures of self-concept and psychological adjustment. The CF children did not differ significantly from standardized norms or from their physically healthy siblings.

Drotar et al. (1981) compared parent and teacher ratings of four groups of children aged 3 - 13. The groups included 91 children with CF, 47 children with other chronic illnesses (e.g., asthma, pulmonary diseases, asthmatic bronchitis), 71 physically healthy siblings of CF children and 61 physically healthy children from the general population. The researchers concluded that the adjustment of CF children, as rated by parents and teachers, was not consistently different from that of the comparison groups. On some subscales of the parent perception measure the CF and chronically ill children had significantly higher scores (the scales labelled infantile aggression, hyperactivity, social withdrawal, fear and sensitivity), but the researchers suggested that these differences reflected the excellent adaptation of physically healthy children rather than the deviancy of the chronic illness groups. They reported that rates of disturbance in the CF (19%) and the chronic illness (18%) groups are consistent with estimates in the normal population.

Only two studies (Kogan & Tyler, 1973; Kucia et al., 1979) have employed direct behavioral observations of chronically ill children. Kogan and Tyler observed the unstructured play of 31 mother-child pairs in their laboratory. The study compared three groups of children and their mothers: physically handicapped, mentally retarded and physically healthy. The children ranged in age from 1 to 7 years. Results showed

that the involvement ratings (extent to which one person's attention is focused toward the other) for physically handicapped children were significantly lower than those of the physically healthy children. Kogan and Tyler interpreted this finding to indicate a greater tendency for physically handicapped children to play the role of passive participants in mother-child interactions. Other results indicated that physically handicapped children displayed more strongly assertive and controlling behaviors than the retarded children.

Kucia et al.'s (1979) study of families with CF children (age 6 to 17) compared families of psychologically well-adjusted CF children to those with maladjusted children (as rated by their physicians) on behavioral home observations collected during a structured family game. This study showed that well-adjusted CF children had lower success scores and lower communication scores than maladjusted CF children. Although these findings seem contrary to what might be expected, Kucia et al. suggest that high success and communication scores indicate the poorly adjusted children's increased maladaptive assertiveness and their inability to accept family routines and discipline.

The use of behavioral observation data in both these studies is a great methodological improvement over other chronic illness research, but their findings do not specify particular child behaviors, but take a more molar view of behavior. Both studies suggested that some increase in either controlling/assertive behaviors or passive behaviors is a part of chronically ill children's response to their illness.

Anecdotal reports by pediatric rheumatologists (e.g., Brewer et al., 1982) on the psychosocial adjustment of JRA children suggest that a

variety of personality and behavior changes occur with the JRA child. These include depression, anger, denial, withdrawal, frustration, anorexia, uncontrolled eating and obesity, uncooperative behavior, passive-aggressiveness, and insecurity.

Research on the psychosocial effects of JRA upon children also suggests that JRA does have a negative impact on their emotional and behavioral adjustment. Early work in JRA by Blom and Nicholls (1954) found that JRA children were greatly affected by emotional factors. On the basis of unstructured clinical interviews with 28 JRA children, aged 2 to 16 years, and their mothers, Blom and Nicholls reported that these children had depressive reactions, feeding problems, and uncooperative behavior. It was also their clinical impression that extreme mother-child interdependency existed, along with marked mood disturbances in the children and an inability to express their feelings.

Another early study, by Cleveland et al. (1965), compared a group of JRA children to asthmatic children, employing Rorschach responses and mothers' perceptions of their children's activity level. Data revealed no significant differences between the JRA and asthmatic children on Rorschach responses, except in one area. JRA children had higher barrier and penetration scores on the Rorschach. Cleveland et al. interpreted this finding as a reflection of JRA children's feelings of physical vulnerability. JRA children also received higher scores on the Performance subtests of the WISC than on the Verbal subtests, whereas asthmatic children were consistent across subtests. Cleveland et al. interpreted this finding as supporting their hypothesis that JRA children are unusually expressive in motor actions. In addition,

two-thirds of the JRA mothers reported that their child was more active than the average child before the onset of JRA, adding further support to the researchers' hypothesis that JRA children are unusually expressive in motor actions. This study and that of Blom and Nicholls (1954) provided the starting point for JRA research in this area by providing an initial conceptualization of how psychological factors might be associated with JRA. However, the results of these studies were inconclusive because of the lack of comparisons with physically healthy control groups and other chronically ill comparison groups.

Rimon, Belmaker, and Ebstein (1977) reported on data collected from interviews of 54 hospitalized JRA children and their families. On the basis of clinical judgements and ratings by a psychiatrist, psychologist and nurse, 39% of the JRA sample had suffered from some previous emotional disturbance (81% of these from depressive reactions, 9% from hyperactivity) and 31% were currently experiencing depressive symptoms, anxiety or psychomotor disturbances. According to the clinical judgement of the psychiatrist, 58% of the JRA sample showed a similiar personality profile with characterisitcs including shyness, unresponsiveness, passivity, submissiveness, aloofness, feelings of inferiority, inability to express emotions or to establish contact with peers. Results of this study are difficult to interpret because of the lack of a comparison group, the subjective and unstandardized measures used, and the fact that few statistical procedures were specified.

Singsen, Johnson, and Bernstein (1979) critiqued the previously mentioned studies on the psychological adjustment of JRA children. The shortcomings which they identified were that the studies were anecdotal

in whole or part, nonlongitudinal, poorly controlled, and paid inadequate attention to the multiplicity of variables. They also stressed that the evidence did not suggest the existence of a premorbid rheumatoid personality in JRA children, but rather some commonly observed personality characteristics that are the consequence of the disease process.

A generally well-designed investigation on the psychological aspects of JRA was conducted by McAnarney et al. (1974). Using a well-matched comparison group of physically healthy children, they studied 42 JRA children (aged 6 to 17 years) and their families. On the basis of a self-concept questionnaire, a personality inventory and projective measures, they reported that JRA children made a significantly higher number of negative self-comments than their healthy peers. JRA children also viewed themselves as different, inferior and less worthy than the comparison group. School adjustment ratings based on teacher ratings and academic performance revealed that 33% of JRA children obtained low adjustment ratings compared to only 5 of the healthy children. Parent report measures indicated that parents of JRA children perceived their children as displaying abnormal behavior problems significantly more often than did parents of physically healthy children. As well, parents judged the child's emotional health to be poor for 64% of the JRA children and 40% for comparison children. This was a statistically significant difference. The JRA group was further divided into three categories: severely-moderately disabled, mildly disabled, and non-disabled. On the basis of teacher and self-reports, the non-disabled group was viewed as more behaviorally deviant than

their more disabled peers. McAnarney et al.'s research suggests that the level of disability is an important variable to consider when investigating the psychological adjustment of JRA children.

Recent research by Ivey, Brewer, & Giannini (1981; cited in Brewer et al., 1982)) investigated the relationship between onset diagnosis and JRA children's perceptions of themselves. A group of JRA children were divided according to their onset diagnosis into pauciarticular ($n=11$, mean age = 9.9) and polyarticular or systemic ($n=8$, mean age = 10.9). This division represented a classification of less severe arthritis versus more severe arthritis. The two groups were compared on two self-report measures of anxiety and self-concept. Results indicated that the two groups did not differ with regard to their level of anxiety or self-concept. In fact, when their scores were compared to those of their siblings, the JRA children had lower anxiety levels and higher self-concepts than the siblings to whom they were closest in age.

Interpretation of these results must be tentative since the methodological and statistical procedures were not reported. However, these results suggest that children with different levels of disease severity (i.e., pauci- versus polyarticular or systemic JRA) do not perceive themselves to have differing self-concepts or levels of anxiety. They are also more well adjusted than their healthy siblings in these two areas. This is in contradiction to the McAnarney et al. (1974) results indicating that less disabled JRA children had more psychological adjustment problems and that JRA children were overall more behaviorally deviant than their healthy peers.

The evidence for psychosocial disturbance in chronically ill children as a group, and of JRA children in particular, is in dispute, in light of conflicting research in this area. Some studies (e.g., Glanville, 1978; Tavormina et al., 1976) suggest that the patterns of maladjustment may be different for each chronic illness. Chronically ill children cannot continue to be grouped together as a single entity because of the great diversity within this population. A more fruitful path for future research to follow would be a more fine-grained analysis of specific chronic illnesses, to learn the adjustment patterns of each. For example, the McAnarney et al. (1974) study pointed toward a relationship between psychological adjustment and the level of physical impairment of the JRA child.

One shortcoming in much of the research on the psychosocial adjustment of chronically ill children is the reliance on parental perceptions as the sole indicator of the children's adjustment. Recent research with children referred for treatment of behavior problems (e.g., Griest, Forehand, Wells, & McMahon, 1980; Griest, Wells, & Forehand, 1979; Lobitz and Johnson, 1975) has challenged the accuracy of parent perception measures. Lobitz and Johnson (1975) found that mothers of clinic-referred children (referred for behavior problems) perceived their children to be more deviant than non-clinic-referred children even though observational data of child behavior by independent observers showed no significant differences between the two groups. Griest et al. (1979) found that the more depressed a mother was, the more maladjusted she perceived her clinic-referred child to be. The Griest et al. (1980) study suggested that for non-clinic-referred

children, children's behavior (as measured with behavioral observation by independent observers) was the best predictor of maternal perception. However, in the case of clinic-referred children, a combination of maternal personal adjustment measures (depression and anxiety levels) and actual child behavior best predicted maternal perceptions of their children's maladjustment.

These studies suggest that the accuracy of parental perceptions of child behavior cannot be assumed. Parental perceptions must be evaluated along with the factors that influence them, such as parental personal adjustment. This research also points to the use of behavioral observation data as an alternative measure of child behavior. Both parental perception and behavioral observation measures provide unique data on children, and tap into a different dimension of children's behavior. As noted earlier, only two studies (Kogan & Tyler, 1973; Kucia et al., 1979) in the chronic illness literature have utilized behavioral observation as a method of data collection.

Effects of the Child's Chronic Illness on Parental Personal Adjustment

The chronic illness literature has consistently reported psychological maladjustment in parents of chronically ill children (Blom & Nichols, 1954; Cleveland et al., 1965; Cummings, Bayley, & Rie, 1966; Gayton et al., 1977; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981). The clinical impressions of several pediatricians (e.g., Mattson, 1972; Yancy, 1972) suggest that the most common maternal reactions to having a chronically ill child are depression, anxiety, and overprotectiveness.

Case studies and anecdotal reports by McAndrew (1976) and Lonsdale (1978) also identify stress reactions and adjustment problems in parents of handicapped and chronically ill children. McAndrew's (1976) survey of 116 mothers with physically handicapped children reported that 56% of them complained of poor physical health (primarily headaches and chronic back pain) and 17% sought psychiatric treatment. Lonsdale's (1978) survey of 76 families with handicapped children obtained similar findings. One-third of the mothers reported physical illnesses they perceived to be directly related to caring for their handicapped child (the most common problems were back pain and psychiatric concerns). Depression and back pain were common complaints for 10% of the fathers surveyed. According to their self-report, 55% of parents surveyed felt that their marital relationship had been strained by having a handicapped child.

Several more empirically-based studies have investigated the hypothesis that having a chronically ill child will affect parental adjustment. Gayton et al. (1977) collected psychological tests from parents in 43 families with CF children. Analysis of MMPI profiles revealed that 32% of fathers and 22% of mothers obtained scores in the range suggestive of emotional disturbance. Mothers tended to score highest on the Depression scale. CF fathers seemed less adjusted overall on a variety of scales. Gayton et al. also compared parents of CF children with parents of two other groups of children. One group was categorized as low on child adjustment because the child had been referred to a mental health clinic for emotional/behavior problems. The other group was deemed high on child adjustment because these children

received the highest ratings in social and emotional adjustment from their teachers. When family adjustment, satisfaction and congruence scores from a Family Q Sort test were compared, mean scores for the parents of CF children fell between those parents of low and high adjusted children on all three measures.

Boll, Dimino, and Mattison (1978) compared 20 mothers of children with congenital heart defects (aged 3 - 6) to a well-matched comparison group of 20 mothers of physically healthy children on a maternal personality inventory and a measure of parenting attitudes. There were no significant differences between the two groups on maternal adjustment or parenting attitudes. Next, data from the two groups were pooled and redivided according to scores on the Neuroticism and Extraversion subscales of the personality inventory. Results indicated that the group with higher Extraversion scores and lower Neuroticism scores perceived themselves to be more psychologically stable and socially outgoing, less prone to psychological or physical discomfort and more comfortable on all aspects of parenting. The researchers concluded that attitudes towards parenting are more a function of personality style and psychological adjustment rather than whether or not mothers have a child who is chronically ill.

Cummings et al. (1966) compared mothers of chronically ill children (rheumatic heart disease, diabetes, cystic fibrosis) to mothers with physically healthy, mentally retarded or clinically neurotic children. Their results indicated that the psychological adjustment of mothers of chronically ill children was somewhat worse than those with physically healthy children. However, it was better than that of mothers with

mentally retarded or clinically neurotic children. The authors pointed out that mothers in the chronic illness group were much more similar to mothers in the physically healthy group than those in either the mentally retarded or the neurotic group.

In an extension of his 1966 study, Cummings (1976) investigated the fathers of chronically ill, physically healthy, and mentally retarded children. Results showed that fathers of chronically ill children expressed significantly more depression, a decreased sense of competence and more negative evaluations of their children than fathers of physically healthy children. However, they were not as emotionally distressed as fathers of mentally retarded children who, Cummings (1976) suggests, experience a far greater negative impact. The study also showed that fathers of chronically ill children had more indicators of psychological stress than mothers. Cummings (1976) interpreted these findings to suggest that fathers seemed to acknowledge their psychic pain and distress more readily than mothers.

Tavormina et al. (1981) reported on a variety of psychological adjustment measures taken from 133 mothers and 93 fathers in the sample of families with chronically ill children (asthmatic, diabetic, CF, and hearing-impaired) used in their 1976 study. On a scale of parenting attitudes, both mothers and fathers scored lower than the established norms on parental confidence, understanding and acceptance of their child. Fathers had somewhat lower attitudinal scores than mothers. On a personality inventory, parents showed a significantly higher number of socially desirable responses than the norm. These parents also appeared more neurotic and introverted than the standardized norm, and mothers were more neurotic and introverted than fathers.

Mothers reported more behavior problems in their child and voiced more overall concerns (demands on time, tense home atmosphere, family problems) with raising their chronically ill child than fathers, although fathers also voiced significant levels of concern in these areas. Both parents saw more behavior problems in their chronically ill boys than girls. Parental ratings for behavior problems in their chronically ill boys fell between the scale norms reported for physically healthy, "normal" boys and for clinic-referred behavior problem boys.

When parental measures were compared for all chronic illnesses, parents of hearing-impaired youngsters had the most problematic scoring patterns, followed by those with diabetic, cystic fibrotic, and asthmatic children. Parents of hearing-impaired children reported more behavioral management-type problems, while parents of CF children were significantly more concerned with overwhelming caretaking demands.

Tavormina et al. (1981) made a series of conclusions that generally summarize the findings of the other researchers in this area. They suggested that parents of chronically ill children are an essentially normal population with special stresses and unique adjustment problems. On measures of psychological adjustment they tend to fall midway between parents with "normal", healthy children and parents whose children are emotionally disturbed or have behavior problems. They further concluded that mothers are more negatively affected by having a chronically ill child than fathers, and that parental adjustment problems vary depending on the particular chronic illness in question.

Anecdotal reports (Brewer et al., 1982; Williams, 1981) describe a

number of personal adjustment problems exhibited by parents who are trying to cope with raising a JRA child. They range from stunned disbelief at the diagnosis, guilt, self-blame, denial and bitterness to depression, anxiety, frustration and anger (Williams, 1981). However, the general consensus from the anecdotal evidence seems to be that most parents learn to cope with chronic childhood illness exceedingly well (Williams, 1981). "It is remarkable to the authors how well most children and parents do adapt to great adversity and manage to lead surprisingly normal lives" (Brewer et al., 1982, p. 112).

Almost no research in the JRA literature addresses the issue of parental adjustment to JRA. Blom and Nichols (1954) and Cleveland et al. (1965) allude to the presence of maternal maladjustment and feelings of guilt, anger, hostility, and frustration in trying to raise JRA children. Cleveland et al. reported that at least 50% of the mothers they interviewed were mildly to severely depressed, on the basis of maternal self-report and the clinical judgement of the interviewer. Unfortunately, no recent and more methodologically sound research in JRA has investigated parental adjustment.

Effects of the Child's Chronic Illness on Parental Behavior, Family Interactions, and Family Functioning

Little research exists that clarifies the role of parental behavior in children's adjustment to their chronic illness or in the ways in which chronically ill children influence their parents' behaviors. Some clinicians have discussed the coping behaviors of parents with

chronically ill children. For example, Mattson (1972) suggested that some parents tend to overprotect or pamper their sick children and to restrict their activities with other children. He also reports that parents engage in denial, rationalization, and intellectualization of their emotions to help them through crisis times. Although Mattson thoughtfully described the behaviors and emotional reactions of parents with chronically ill children, it is clearly a subjective analysis of their situation from his viewpoint.

A few studies have looked at family interactions or family functioning, thereby looking at parent behaviors in somewhat global terms. For example, Pless et al.'s (1972) study emphasized the importance of good family functioning in facilitating the psychological adjustment of chronically ill children. As noted above, when the chronically ill children came from high-functioning families, their emotional and behavioral adjustment resembled that of physically healthy children. Chronically ill children from low-functioning families had poorer psychological adjustment than the rest of the chronically ill population. This study suggests that family functioning and the psychological adjustment of chronically ill children are interrelated. Similar conclusions were drawn from a study by Lewis and Khaw (1982), described in detail in the section on child adjustment. In their study, maternal reports of family functioning did not differ between a group of CF, asthmatic and physically healthy children, and the relationship between extreme family functioning and children's behavior problems was much stronger than the relationship between chronic illness and children's behavior problems.

Kucia et al. (1979) investigated families of cystic fibrosis children (aged 6 to 17), using home observations of a structured family game. The cystic fibrosis (CF) population consisted of two groups: families with maladjusted CF children and families with well-adjusted CF children (as rated by their physicians). Results showed that families with well-adjusted children were more creative but not as successful in their problem-solving as families of maladjusted children. The maladjusted group tended to be more rigid in following the rules, and this made them more successful at the structured task. Kucia et al. interpreted this as a detriment, since families with maladjusted children were viewed as more inflexible and less able to cope with the demands and complex needs of their CF children. In terms of particular parent behaviors, fathers of well-adjusted children showed more creativity and positive support than fathers in the maladjusted group. Mothers of adjusted children were significantly less creative than those of maladjusted children. The authors believe that these results support the hypothesis that CF children's coping can be enhanced by the consistent and routine involvement of mothers, balanced with paternal support.

Kogan and Tyler's (1973) study, mentioned previously in the section on child behavior, also employed behavioral observations to study maternal behavior in an unstructured play situation. The study compared mothers of physically handicapped, mentally retarded, and physically healthy children between the ages of 1 and 7. Observers coded categories such as: exerting or accepting control, positive affect, exhibiting expertise, displaying assertiveness, following orders, and

asking for help. Mothers of handicapped children were rated as more controlling (giving orders, instructing, assisting, restraining) and showing higher levels of positive affect (warm tone of voice, praise, physical affection) than mothers of physically healthy children. This study is unique in several ways. First, it assessed a fairly narrow age range of children, and second, it applied a structured behavioral coding system to the study of parental behaviors. Although the behavioral categories are somewhat vague and subjective, this investigation is the only one to examine specific maternal behaviors toward their chronically ill children.

In the JRA literature, almost no research exists that deals with parental behavior specifically. Anecdotal reports (Brewer et al., 1982; Williams, 1981) suggest that some parents of JRA children display excessively possessive behavior towards the child, being inappropriately solicitous, overprotective and extremely controlling in their interactions with their JRA child. Rimon et al. (1977) described 33% of their JRA sample as having problematic mother-child relationships and 48% as having problematic father-child relationships. The researchers evaluated these relationships in very general and subjective terms (e.g., parent was viewed as too overprotective, child was overdependent on the parent, parent was aloof, cool, superficial or displayed an isolated and rigid personality structure). In the Ivey et al. (1981) study of pauciarticular, polyarticular, and systemic JRA children, parents completed questionnaires on family relations and child rearing practices. They were asked to state how they solved specific problems in dealing with their children. The researchers reported that there

were no significant differences between the two groups in child rearing practises or in their acceptance of or ability to manage their JRA child.

One area of family functioning that has received some attention in the JRA research is the influence of stressful family events upon the onset and exacerbation of JRA. Heisel (1972) compared 34 JRA children to a matched comparison group of 68 children randomly selected from a normal population. Parents in the two groups completed a questionnaire of a list of life events that had happened to their child during the year preceding the onset of the disease. Life Change Units (LCU) were calculated for all subjects. Results suggested that the JRA group had significantly higher LCU scores (indicating more stressful life events) than their normal peers. The JRA sample also had significantly higher LCU scores than the standardized norms for the Life Events questionnaire. JRA children experienced some similiar stressful events in their lives in the year preceding the onset of JRA. These included their own hospitalization (for other than JRA-related causes), marital separation of parents, hospitalization of a parent, birth of a sibling and moving to a new school district. Heisel (1972) 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.

Rimon et al. (1977) conducted a similiar investigation of stressful life events that preceded the onset of JRA. Their measure of life and familial stress was based on psychiatrists' judgements of a significant psychodynamic conflict where the child experienced an emotional trauma. It should be noted that this study did not employ the use of a

physically healthy comparison group. Their results revealed that, for 37% of their sample, the onset of JRA was correlated with an emotionally important conflict (e.g., divorce or marital separation of parents, hospitalization of a parent, death of a grandparent). For 63% of the JRA children, onset was not correlated with a psychodynamic conflict, but these children did have a higher incidence of rheumatoid relatives. The conclusion which Rimon et al. (1977) drew from these results was that JRA patients may be classified into two groups: those who have a hereditary predisposition and are less influenced by environmental changes; and patients with less hereditary predisposition in whom the onset of the disease is associated with psychodynamic conflict situations.

Henoch, Batson, and Baum (1978) also investigated the role of family functioning in the onset and exacerbation of JRA. Eighty-eight JRA children were compared with a random pediatric population from the same geographic area. Results indicated that a traumatic family event such as divorce, separation, or death of a parent occurred near the date of onset of JRA in 51% of the children. In the JRA population, 28.9% of parents were unmarried as a result of divorce, separation, or death of a spouse, compared with only 10.6% in the comparison group. In addition, adoption occurred three times more often in the JRA population (Henoch et al., 1978). These findings suggest that family crises (and the resulting stress and upset to family functioning) may be linked to the onset of JRA in children. However, this relationship is still ambiguous. Henoch et al. suggested a three-part model, where family stress, family breakdown, and JRA are interrelated.

Singsen et al. (1979) have criticized the research evidence linking stressful life and family events with the onset of JRA. They point out that both Heisel's (1972) and Henoch et al.'s (1978) research was based on retrospective parent report. Also, the date of onset of JRA is difficult to establish and long periods of insidious and slowly progressive symptoms may occur before the diagnosis of JRA is made. Both these problems introduce potential sources of bias and error in the measurement of stressful life events over a particular time period. Singsen et al. (1979) criticized the Rimon et al. (1977) research for not using a comparison group and for not discussing the complex literature regarding the definition of hereditary predisposition. In conclusion, Singsen et al. (1979) caution the use of the premise of life stresses/emotionally charged events as etiologic factors in JRA, and suggest that a study of emotional factors should focus on how they are related to the manner in which patients cope with the severity and chronicity of JRA.

Clearly, the chronic illness literature is just beginning to study family interactions, family functioning, and specific parental behaviors. What is needed now are objective observational data of parent and child behaviors collected in naturalistic family settings. The observational system used should clearly define and quantify parent and child behaviors so that objective comparisons can be made between groups. The present investigation employed both naturalistic home observations and a structured behavioral coding system in an attempt to study parent and child behaviors.

Purpose and Hypotheses

The purpose and hypotheses of the present study focused on three areas. First, an assessment of a JRA and healthy comparison group was conducted in four domains: maternal behavior, child behavior, maternal perception of child adjustment and maternal personal adjustment. Next, the differences between the two groups were studied to determine the relative strength of each of the domains in terms of their ability to differentiate the JRA and healthy comparison groups. Finally interrelationships among various measures within the JRA sample were examined.

The study of between group differences had three goals: to investigate the psychological effect of JRA upon children's behavior and mothers' perceptions of their children's behavior; to measure the impact of JRA upon maternal personal adjustment; and to study its effect upon maternal behavior in mother-child interactions. This investigation compared mother-child pairs in which the child had JRA to a physically healthy group of children and their mothers.

The psychological effect of JRA upon the children's behavior was measured in two ways: by maternal perceptions of the child's behavior and emotional state, and by data recorded during home observations by independent observers. These measures are an improvement over past research, which has relied on data from pediatric case reports, clinical judgments, and unstructured interviews. Child self-report measures were not used in this study because of the young age of the children (3 to 8 years). Although the research literature is divided as to the negative

psychological impact of chronic illness upon children, the few studies with JRA children (e.g., Blom & Nicholls, 1954; Cleveland et al., 1965; McAnarney et al., 1974) suggested that they were more emotionally and behaviorally maladjusted than their healthy peers. In keeping with these findings in the JRA literature, it was hypothesized that JRA children in the present investigation would be perceived by their mothers to be more behaviorally deviant than children in a physically healthy comparison group. In addition, it was hypothesized that the behavioral data would show JRA children to be less compliant with maternal commands and to engage in a higher percentage of inappropriate behavior than the children in a physically healthy comparison group.

Children in this study ranged in age from 3 to 8 years. This age range of JRA children was chosen because it is during these years that the onset of JRA most commonly occurs (Petty, 1982). This is also the age when most children begin to develop behavior problems severe enough to have them referred to mental health clinics for help (Patterson, 1980). In addition, by selecting a relatively narrow age range, extreme developmental differences between children will be considerably reduced. The use of a narrow age range of young children is an improvement over much of the prior research, which has tended to include children anywhere between the ages of 2 and 17 years.

Mothers, rather than fathers, were chosen as the focus of the study for several reasons. First, they are usually the primary care-givers for young children, so they spend the most time with the child and have the most influence over him or her (Patterson, 1980). This is even more the case with respect to JRA, where mothers conduct most of the in-home

treatment programs (e.g., physiotherapy exercises, dispensing medication) (Wright, Schaefer, & Solomon, 1979; Petty, Note 2).

The psychological adjustment of mothers with a JRA child was assessed using standardized measures of depression, anxiety, and marital adjustment. The chronic illness research suggests that these three areas are of major concern to parents of chronically ill children. Past research has tended to assess these variables globally (e.g., clinical judgments, projective techniques, or broader measures like the MMPI). The measures in the present study focused specifically on each variable and thus provided more accurate and empirically valid measures. It was hypothesized that mothers of JRA children would show lower levels of personal adjustment than mothers of physically healthy children. More specifically, it was expected that they would be more depressed, more anxious, and less satisfied with their marriages than mothers in the healthy comparison group.

Finally, maternal behaviors were studied by naturalistic home observations. It has been hypothesized by Patterson (1980) that, because mothers bear the day-to-day burden of caring for their handicapped, chronically ill, or behavior problem children, they tend to develop a negative set in responding to their children. His research suggested that these mothers issue more commands and criticisms, and less positive attention and rewarding behavior as a result (Patterson, 1980). Similar maternal behavior was expected to occur with mothers of JRA children. It was hypothesized that mothers of JRA children would emit higher rates of beta commands (vague or ambiguous commands) and have lower rates of positive parent behaviors (i.e., a lower rate of

rewards plus attends, and a lower percentage of contingent attention) than mothers of physically healthy children.

A second area of investigation focused on determining the relative strength of each of the domains (i.e. maternal and child behavior, maternal perceptions of child adjustment, and maternal personal adjustment) to differentiate the JRA and healthy comparison groups. This aspect of the investigation was exploratory in nature, since prior research does not suggest specific hypotheses concerning which domain of variables would be the most powerful discriminator between the two groups.

The investigation of interrelationships among variables within the JRA sample was also exploratory. This aspect of the investigation had two goals: to examine the relationship among levels of illness severity and other dependent measures; and to consider which dependent measures would be the best predictors of maternal and child behaviors, maternal perceptions of children's adjustment, maternal personal adjustment, and length of illness within the JRA sample.

In the McAnarney et al. (1974) study, JRA children were subdivided according to their level of disability and the non-disabled group was found to be more behaviorally deviant than their more disabled peers. In the Ivey et al. (1981) study, JRA children were subdivided according to their onset diagnosis (pauci- versus polyarticular and systemic onset) and the two groups did not differ with respect to their self-concept or their level of anxiety. In the present study, all of the JRA children would be classified in the non- or mildly disabled range (according to criteria used by McAnarney et al., 1974) and the

majority of them (12) were diagnosed as having a pauciarticular onset, so they were subdivided instead by the severity of their illness (divided into mild, moderate and severe levels of illness severity). This rating, made by the physician and nurse at the Arthritis Centre, was not based on functional impairment or onset-diagnosis, but rather by the severity of arthritic signs and symptoms (e.g. joint inflammation, pain, fever) for each child. It was hypothesized that children with the most severe illness would have the most difficulty coping with their JRA and would therefore be the most psychologically maladjusted. They were hypothesized to show higher levels of inappropriate behavior and less compliance to maternal commands, and be perceived by their mothers to have more behavior/adjustment problems. It was also hypothesized that mothers of children with more severe illness would experience lower levels of personal adjustment than mothers of more mildly affected children.

Method

Subjects

The sample consisted of 36 mother-child pairs residing in the Lower Mainland. Half of the subjects were in the juvenile rheumatoid arthritic (JRA) group and the other half were in the healthy comparison group. The JRA group contained 18 children between 3 and 8 years of age, who were diagnosed with JRA or a related arthritic disease according to the diagnostic criteria specified by Brewer et al. (1977). JRA families were solicited through the Arthritis Centre in Vancouver, which has contact with all JRA children in British Columbia through its children's treatment programme. The social worker in the children's programme contacted families in the Lower Mainland whose children fit the research criteria. She briefly explained the research to them and asked if the experimenter could phone the family to provide more information and solicit their participation in the study.

Of the 18 children in the JRA group, there were 15 girls and 3 boys. Twelve children were diagnosed with pauciarticular JRA; three had polyarticular JRA; two were diagnosed with juvenile dermatomyocitis; and one child had infantile polymyocitis. The three children with diagnoses other than JRA were included in the sample because they had related diseases which, like JRA, are chronic inflammatory diseases of the musculoskeletal system. They are related to JRA in that these connective tissue diseases are accompanied by widespread inflammation, pain, fatigue and often arthritis. At the time of their participation in the study, 15 of the children were in an active stage of their

disease and 3 were in remission (i.e., they had no signs or symptoms of inflammation and had normal laboratory test results). All three of the children in remission had pauciarticular JRA; they all had had active disease within the previous 2 years; and one child had some residual disease (i.e., joint damage that is irreparable). A physician and nurse from the Arthritis Centre's children's programme rated the illness severity to be mild for eight children; moderate for six children; and severe for four children. The age at onset of the disease ranged from under 2 years to 5 years of age, with the majority of the children (11) experiencing the onset of JRA at 2 years of age or earlier. The length of time that children had the disease ranged from under 2 years to 6 years, with the majority of children (15) having JRA for 2 years or longer.

Twenty-nine families in the Lower Mainland had JRA children who fit the research criteria. All of these families were contacted by the Arthritis Centre social worker and of these 29, 18 families completed the study. Of the eleven families who did not participate, eight families refused to participate during the initial telephone contact with the social worker. Their reasons for not participating included being too busy, the husband not allowing participation, a mother having surgery, and a family adopting a new baby and not wanting to further upset the family. Three families were discontinued from the study after some contact with the experimenter. One mother was unable to arrange a time for the first home visit, one husband vetoed participation after initial questionnaire data were collected, and one mother did not understand English well enough to complete the questionnaires or

participate in the home observations.

The healthy comparison group consisted of 18 mother-child pairs from the general population in the Lower Mainland. Children in this group had no previous referrals for child behavior problems and were free of any chronic physical illness. Families were solicited through advertisements in local newspapers in the Lower Mainland and through posters in several Vancouver community centres (see Appendix A). These notices requested volunteers for a university research project involving the study of mother-child interactions. The comparison group was balanced with the JRA group with respect to age and sex of the child, number of children in the family, marital status of the mother, ethnic background and socioeconomic status (SES). The SES of each family was derived by assigning the appropriate index number to the occupation of the head of the household according to the SES index developed by Blishen and McRoberts (1976). This index is based on a ranking of all the occupations categorized in Statistics Canada's Canadian Classification and Dictionary of Occupations (1971). All of the 18 families met the research criteria, agreed to participate during the initial telephone contact and completed the study.

A Hotelling's T^2 analysis was conducted to compare the JRA and healthy comparison groups on two demographic variables: age of the child and number of children in the family. This analysis revealed no significant differences between the groups, $F(2,33)=0.706$, $p > .5$. SES was not included in the Hotelling's T^2 analysis because of missing data. Two single mothers (one in each group) were the heads of the household but could not be assigned an SES index number because they

were both homemakers and the index did not have a classification for them. A Student's t analysis, comparing the two groups on SES indicated that there was no significant difference, $t(32) = -.71, p > .480$. The means and standard deviations for these demographic variables are presented in Table 2.

No significant differences were found between the two groups on the sex of the child ($\chi^2(1) = .177, p > .70$), mothers' employment status ($\chi^2(1) = 1.00, p > .30$) or mothers' educational level ($\chi^2(1) = 1.00, p > .30$). The frequency data for these variables are presented in Table 3. The racial composition of the two groups was balanced as well. There were 15 Caucasian and 3 Indo-Asian families in each group. The JRA group had one East Indian, one Fijian and one Phillipino family while the comparison group had two East Indian families and one Chinese family. The two groups were balanced with regard to marital status, with each group having 17 married couples and one divorced single mother. One mother in each group was in her second marriage. None of the children in the study were in daycare, except one child in the JRA group.

Observers and Training

Seven undergraduate psychology majors served as home observers for the study. They were naive as to the purpose of the study and were unaware that subjects were in different groups. Two clinical psychology graduate students and the two most experienced undergraduate observers served as calibrating home observers. All observers underwent extensive

Table 2
Means and Standard Deviations of Demographic Variables
for JRA and Healthy Comparison Groups

Variable	JRA		Healthy Comparison	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Age of child (in months) a	70.39	19.38	74.39	20.93
Number of children in the family a	2.22	0.88	2.56	0.78
Socioeconomic status b,c	44.47	14.52	48.59	18.82

a n = 18 per group.

b n = 17 per group.

c Based on Blishen and McRoberts (1976) index. Scores range from 18 to 76, with higher scores indicating higher socioeconomic status.

Table 3
Frequency Data of Demographic Variables for
JRA and Healthy Comparison Groups

Variable	JRA	Healthy Comparison
Mother's Employment Status		
Employed	10	7
Not Employed	8	11
Mother's Educational Level		
High School or Less	11	8
Some Post Secondary	7	10
Sex of the Child		
Female	15	14
Male	3	4

Note. n = 18 for each group.

training in the use of the behavioral coding system prior to formal data collection. Observer training involved at least 40 hours of systematic practice with the coding system. Before conducting the home observations, observers were required to achieve an 80% level of agreement with a prescored 10-minute videotape of a mother-child interaction. This videotape contained all the components of the coding system. Throughout the period of data collection, observers attended weekly training session to maintain a high level of reliability and guard against observer drift (Kent & Foster, 1977).

Behavioral Observation System

Each mother-child pair participated in a series of four 40-minute home observations, in which trained observers used a coding system developed by Forehand, Peed, Roberts, McMahon, Griest, and Humphreys (Note 1) to record mother-child interactions. Sequential chains of mother and child behaviors occurring in 30-second intervals were recorded in this system. Also, a 30-second time-sampling measure of child inappropriate behavior (excluding noncompliance) was recorded. The following parent and child behaviors were recorded with this coding system:

Parent behaviors: (a) rewards: praise, approval, or positive physical attention that refers to the child or to the child's activity; verbal rewards including both specific (labelled) and non-specific (unlabelled) reference to "praise-worthy" behavior.

(b) attends: descriptive phrases that follow and refer to the

child's ongoing behavior, objects directly related to his or her play, spatial position(e.g., "You're standing in the middle of the room"), or appearance.

(c) questions: interrogatives to which the only appropriate response is verbal.

(d) commands: (i) alpha commands - an order, rule, suggestion, or question to which a motor response is appropriate and feasible; (ii) beta commands - commands to which the child has no opportunity to demonstrate compliance. Beta commands include parental commands that are so vague that proper action for compliance cannot be determined, and those that are interrupted by further parental verbiage before enough time (5 seconds) has elapsed for the child to comply. A beta command is also scored if the parent restricts the child's mobility in such a way as to preclude a compliance opportunity.

(e) warnings: statements that describe aversive consequences to be delivered by the parent if the child fails to comply with a parental command.

Child behaviors: (a) child compliance - an appropriate motor response initiated within 5 seconds following a parental alpha command.

(b) child noncompliance: failure to initiate a motor response within 5 seconds following a parental alpha command.

(c) child inappropriate or deviant behavior: behaviors that include (i) whine-cry-yell-tantrum; (ii) aggressive behaviors (e.g., biting, kicking, hitting,slapping) in which the child damages or destroys an object or attempts or threatens to damage an object or injure a person; (iii) deviant talk such as repetitive requests for attention, stated

refusals to comply, disrespectful statements, profanity, and commands to parents that threaten aversive consequences.

The reliability and validity of the behavioral coding system have been demonstrated in several studies. It has adequate test-retest reliability and an average inter-observer agreement of 75% (Forehand & Peed, 1979). Repeated observations of parent-child interactions in families not involved in treatment are stable over time and parent-child interactions observed in the clinic are similar and consistent with those observed at home (Peed, Roberts, & Forehand, 1977). Griest et al. (1980) reported that the coding system showed significant differences in compliance between children referred to a mental health clinic for behavior problems and non-clinic-referred children. The coding system is also sensitive to pre- versus post-treatment parent and child behavior change in families who participate in a parent training programme (see McMahon & Forehand, in press, for a review).

Dependent Measures

Dependent measures for this study fell into three categories: observational data of mother and child behavior collected during home observations, maternal perceptions of the child's emotional/behavioral adjustment, and maternal personal adjustment measures.

Home observation data. The behavioral coding system (Forehand et al., Note 1) allowed for individual mother and child behaviors to be studied as well as several mother and child behavior chains. Parent behavior was expressed as rates per minute of attends plus rewards and

beta commands. Also, the percentage of parental contingent attention (a reward or attend emitted within 5 seconds of child compliance) was analyzed.

Child behaviors were expressed in terms of percentage of intervals of child inappropriate behavior, percentage of child compliance with alpha commands, and percentage of child compliance with total commands.

Maternal perception of child adjustment. Three self-report measures, the Parent Attitudes Test (PAT) (Cowen, Huser, Beach, & Rappaport, 1970), a modified version of the Becker Bipolar Adjective Checklist (Patterson & Fagot, 1967), and the Child Behavior Checklist (CBCL) (Achenbach, 1978) were used to assess mothers' perceptions of their children's emotional and behavioral adjustment.

The PAT (Cowen et al., 1970) consists of three scales. The Home Attitudes Scale consists of seven items that reflect the parent's perception of the child's adjustment at home. The Behavior Rating Scale consists of 23 items, each of which refers to a behavior problem. The Adjective Checklist consists of 33 adjectives, each describing a child behavior or personality characteristic. Cowen et al. (1970) have presented evidence supporting the test-retest reliability and the criterion-related and discriminative validity of this measure. Forehand, King, Peed, and Yoder (1975) and Griest et al. (1980) reported that each of the PAT scales was able to differentiate between parents whose children had been referred to mental health clinics for behavior problems and parents of non-clinic-referred children. The sum of the three PAT scales was used in the data analysis.

The modified version of the Becker Bipolar Adjective Checklist

(Patterson & Fagot, 1967) consists of 47 adjective pairs. Three factors were employed as dependent measures: less withdrawn and hostile, more aggressive, and more conduct problems. Several researchers (Becker, 1960; Patterson & Fagot, 1967; Lobitz & Johnson, 1975) have demonstrated the validity and reliability of this measure. The sum of the three factors was used in the data analysis.

The CBCL (Achenbach, 1978) is divided into two parts: the Social Competency scale and the Behavior Problem scale. This measure has separate standardized norms for boys and girls in the age ranges of 4-5, 6-11, and 12-16 years. The standardized norms were established from a large sample of behavior problem and non-clinic-referred children (Achenbach, 1978, 1979; Achenbach & Edelbrock, 1979, 1981). No norms are available on the CBCL for 3-year-olds, an age group that was included in this study. There were four 3-year-olds in the JRA group and three in the healthy comparison group, and all seven subjects were over 3 1/2 years old. The norms for the 4-5 year age range were used for the 3-year-olds in this study.

For the purposes of this study, only data from the Behavior Problem scale were used. A total behavior problem score and subscores on two behavior problem factors (Internalizing and Externalizing) can be obtained from the Behavior Problem scale. The Internalizing factor is described as a measure of problems primarily within the self and includes characteristics such as being inhibited, shy, anxious and having personality problems, while the Externalizing factor is described as a measure of problems of conflict with the outside world and includes characteristics such as being aggressive, acting-out, and having conduct

problems (Achenbach, 1979; Edelbrock & Achenbach, 1980).

The test-retest reliability of the CBCL has been repeatedly demonstrated (Achenbach, 1978,1979; Achenbach & Edelbrock, 1979, 1981). The discriminative validity of the CBCL has also been demonstrated in its ability to differentiate clinic-referred behavior problem children from non-clinic-referred children of the same age and sex (i.e., significantly lower scores on all social competence scales and higher scores on all behavior problem scales) (Achenbach, 1978). For the purposes of this study, data were analyzed using the T score from the total score of the Behavior Problem scale and the T scores for the Internalizing and Externalizing factors of the Behavior Problem scale.

Maternal personal adjustment measures. Three questionnaires were administered to mothers to assess their self-reported level of depression, anxiety, and marital adjustment. These measures were the Beck Depression Inventory (Beck, 1970), the Spielberger State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, & Lushene, 1970), and the Dyadic Adjustment Scale (Spanier, 1976).

The Beck Depression Inventory (Beck, 1970) consists of 21 items that sample the cognitive, affective and behavioral dimensions of depression. The clinical utility of this instrument to delineate levels of depression has been demonstrated by Metcalfe and Goldman (1965). They found that scores on the Beck Depression Inventory correlated highly with clinical judgements of depression. Scores on the Beck Depression Inventory also correlated highly with objective behavioral measures of depression (Williams, Barlow, & Agras, 1972). Griest et al. (1980) demonstrated the inventory's ability to distinguish between

mothers whose children were referred to clinics for behavior problems and mothers of non-clinic-referred children. The mothers of clinic-referred children were significantly more depressed (Griest et al., 1980). Data were analyzed using total scores from this measure.

The trait form of the STAI (Spielberger et al., 1970) was administered to obtain a measure of the mothers' current anxiety level. The trait form is described as a measure tapping the general tendency to be anxious rather than anxiety resulting from situational factors (Spielberger et al., 1970). The inventory consists of 20 statements that ask the subject to rate how he or she generally feels along these dimensions. Researchers (Manuck, Hinrichsen, & Ross, 1975; Spielberger et al., 1970) have demonstrated the reliability and validity of this measure. Manuck et al. also demonstrated a significant correlation between high levels of anxiety on both the trait and state measures and increasing levels of life stress. Data were analyzed using the total score on the STAI.

The DAS (Spanier, 1976) served as a measure of marital adjustment. The scale consists of 32 items which have been factor-analyzed into four subscales: dyadic consensus, dyadic satisfaction, dyadic cohesion, and affectional expression. High scores on the DAS indicate good marital adjustment. Spanier has demonstrated high internal consistency as well as content, construct and criterion-related validity. The DAS has successfully differentiated married and divorced couples on all of the subscales and the total scale score (Spanier, 1976). Data were analyzed using the total scale score.

Procedure

Initial telephone contact. Volunteer families, either solicited through the Arthritis Centre or by local newspaper advertisements and community centre notices, were telephoned by the experimenter to collect demographic data and to arrange for the first home visit. Over the telephone, the experimenter described the study as research concerning mother-child interactions and mothers' perceptions of themselves and their children. Participants were told that the study would be conducted in their own homes, that they would be requested to complete some questionnaires and that an observer would schedule four 40-minute sessions to observe the mother and her child together. Volunteers were informed that they would receive a \$15 stipend for their participation in the study and individual feedback regarding their responses to the questionnaires and results of the home observations.

In the case of the JRA group, only families who met the selection criteria for the study (i.e., child aged 3-8 years, diagnosed with JRA or related disease) were referred to the experimenter, so the purpose of the initial telephone contact was to encourage their participation and schedule an initial home visit. For the healthy comparison group, pertinent demographic information (i.e., age, sex of the child, no previous referrals for child behavior problems) was collected before explanation of the study. This insured that the child met the selection criteria before a home visit was arranged.

Initial home visit. After the telephone contact, the experimenter visited each mother at her home. These visits averaged about 1 hour in

length. The purpose of this home visit was to have the mother sign the consent form and complete the maternal perception questionnaires. A copy of the consent form is presented in Appendix B. Before the mother signed the consent form, the experimenter reviewed the purpose of the study and the participant's involvement in it.

After the consent form was signed, the experimenter administered the questionnaires to each mother. The questionnaires were arranged so that each mother first completed the three child perception questionnaires followed by the three self perception questionnaires. The experimenter instructed the mother not to consult with her spouse or others about the questionnaires. While the mother completed the questionnaires, the experimenter either visited with other family members or read. In the case of two East Indian mothers (one in each group), who were able to speak English but not read it, the experimenter read the questionnaires to them.

When the questionnaires were completed, the experimenter reviewed them to check that no items had been missed. Before leaving, the experimenter explained the basic format and rules of the home observations, provided the mother with a written handout describing these guidelines (see Appendix C) and answered any relevant questions. The mother was encouraged to schedule the four home observation sessions as closely as possible.

Collection of home observation data. Four 40-minute observations were conducted in the homes of each of the 36 families in the study. Only one observation occurred per day and observations occurred at various times throughout the day. Data were collected on consecutive

weekdays or in as short a period as possible. An average of 11.1 days (Range: 4-29 days) elapsed between the first and last observation for the JRA group and 9.6 days (Range: 4-21 days) for the healthy comparison group. The two groups did not differ with respect to the number of days required to complete each family's home observations, $t(34) = 0.77$, $p = .45$.

During each observation, the mother and the target child remained in a two-room area, within sight and hearing range of the observer at all times. Other family members were asked not to participate in interactions during observation sessions. Mothers were instructed to behave as they normally would, except for the following restrictions: They were to refrain from watching T.V. and playing board games with the child, and they were to avoid taking telephone calls.

Observers carried a small cassette tapeplayer which cued 30-second interval changes through an earplug. They also carried a clipboard with data scoring sheets attached. Observers were instructed to be as unobtrusive as possible and to refrain from interacting with the family during the observation session.

At the end of the fourth home observation, the observer gave the mother her \$15 stipend, had her sign a receipt and thanked her for her participation in the study.

Collection of reliability data from home observations. Reliability data were obtained on 24% of the home observations by having a calibrating observer record a 40-minute observation session along with the primary observer. A split-earplug device was used to synchronize recording intervals for the two observers.

A reliability index was determined from the session scores for each of the behavioral dependent measures coded by the primary observer and the calibrating observer. The reliability index chosen was an intraclass correlation coefficient (ICC) (Hartmann, 1977; Mitchell, 1979). Both Hartmann and Mitchell recommend the use of the intraclass correlation coefficient as a more stringent estimate of reliability than other reliability indexes such as the percentage agreement statistic.

To determine the ICC, a separate analysis of variance (ANOVA) was conducted on each of the coded behaviors. The model for the ANOVA and the subsequent formula for the ICC were chosen according to the criteria outlined by Shrout and Fleiss (1979). The following formula was used to calculate each individual ICC (Shrout & Fleiss, 1979):

$$r = \frac{BMS - EMS}{BMS + (k - 1)EMS}$$

where k = the number of observers rating each subject,

BMS = mean square between subjects,

and EMS = residual mean square; error.

Table 4 presents the reliability coefficients obtained for each coded behaviors.

Debriefing. All mothers who participated in the study were contacted by telephone after their data had been collected and given individual feedback regarding their responses on the questionnaires and their own and their children's behavior during home observations.

Mothers were also informed of the general design of the study and its purpose. A brief description of the results of the study was mailed to all participants.

Table 4
Reliability Coefficients Obtained for Each Dependent Measure
from the Behavioral Coding System

Variable	<u>r</u>
Parent Behaviors	
rewards plus attends	.81
contingent attention	.81
beta commands	.93
Child Behaviors	
compliance to alpha/total commands	.84
child inappropriate behavior	.92

Results

The analyses were divided into three main groups: analyses of between group differences, a discriminant analysis of the JRA and healthy comparison groups, and a series of exploratory analyses within the JRA sample.

Between Group Differences

Behavioral observation measures. The means and standard deviations for the three maternal behaviors (rate of rewards plus attends, rate of beta commands, and percentage of contingent attention) are presented in Table 5. Two of the maternal behavior measures, rate of rewards plus attends and rate of beta commands, were analyzed using a Hotelling's T^2 analysis. The results indicated that mothers of JRA children engaged in less appropriate parenting behavior than mothers of healthy children, $F(1, 34) = 3.78, p < .033$. In order to determine whether these differences existed for both maternal behaviors, subsequent multiple comparison procedures were conducted. A Bonferroni procedure was chosen to guard against an escalating Type I error rate and yet maintain reasonable power (Ramsey, 1980). The experimentwise error rate was set at $\alpha = .05$ and the critical value for each individual t-test was computed to be $.05/2 = .025$. Results suggested that mothers in the JRA group gave significantly fewer rewards plus attends to their children during observations than did mothers in the healthy comparison group, $t(34) = -2.77, p < .009$. There were no significant differences between the groups on the rate of beta commands, $t(34) = -0.63, p > .534$.

Table 5
Means and Standard Deviations of Maternal Behaviors from
Behavioral Observations for JRA and Healthy Comparison Groups

Variable	JRA		Healthy Comparison	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Rate per minute of rewards plus attends	.40	.23	.60	.22
Rate per minute of beta commands	.70	.29	.77	.38
Percentage of contingent attention	7.55	4.73	7.81	5.39

Note. n = 18 for each group.

A third maternal behavior, percentage of contingent attention, was not included in the Hotelling's T^2 analysis because it was not independent of the rewards plus attends measure. A separate Student's t analysis revealed no significant difference between the groups of mothers with respect to the percentage of contingent attention shown to their children, $t(34) = -0.16$, $p > .877$.

Means and standard deviations for the three child behaviors (percentage of inappropriate behavior, percentage of compliance to total commands, and percentage of compliance to alpha commands) are presented in Table 6. A Hotelling's T^2 analysis was computed on two of the child behavior measures, percentage of inappropriate behavior and percentage of compliance to total commands. There were no significant differences between the two groups on these observational measures of child behavior, $F(1,34) = 2.22$, $p > .125$. A third child behavior, percentage of compliance to alpha commands, was not included in the Hotelling's T^2 analysis because it was not independent of the measure of percentage of compliance to total commands. A separate Student's t analysis was computed for the percentage of compliance to alpha commands. Results indicated that children in the JRA group were significantly less compliant to alpha commands than were children in the healthy comparison group, $t(34) = -2.07$, $p < .05$.

Maternal perception of child adjustment measures. The maternal perception of child adjustment measures included: the summed score of the three scales of the PAT (Home Attitude Scale, Behavior Rating Scale, Adjective Checklist); the T scores for three parts of the Behavior

Table 6
Means and Standard Deviations of Child Behaviors from
Behavioral Observations for JRA and Healthy Comparison Groups

Variable	JRA		Healthy Comparison	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Percentage of inappropriate behavior	8.25	8.78	4.46	3.69
Percentage compliance to total commands	34.19	8.93	38.08	7.56
Percentage compliance to alpha commands	82.60	17.99	91.81	5.68

Note. n = 18 for each group.

Problem scale of the Child Behavior Checklist (CBCL): the total scale score, and the Internalizing and Externalizing factor scores; and the summed score for three factors of the Becker Bipolar Adjective Checklist (less withdrawn and hostile, more aggressive, more conduct problems). Data from the less withdrawn and hostile factor were transformed before the factors were summed so that higher scores on all three scales would indicate more deviant behavior problems (i.e., the directions and labels on this factor were reversed so that high scores on it would indicate increasing deviancy). Means and standard deviations for the maternal perception of child adjustment measures for both groups are presented in Table 7.

The JRA and comparison groups were compared on three of the maternal perception of child adjustment measures (PAT, total score of the Behavior Problem scale of the CBCL, Becker Bipolar Adjective Checklist) using a Hotelling's T^2 analysis. The results indicated no significant differences between the JRA and healthy comparison groups, $F(3,32) = 2.49$, $p > .078$.

Separate Student's t analyses were conducted on the T scores of the Internalizing and Externalizing factors of the CBCL. Results indicated no significant differences between the groups on the Externalizing factor, $t(34) = 1.90$, $p > .066$. The two groups were significantly different on the Internalizing factor, $t(34) = 2.64$, $p < .012$. This result indicates that mothers in the JRA group perceived their children as engaging in significantly more of the behaviors characterized by the Internalizing factor of the CBCL than mothers of healthy children.

Table 7

Means and Standard Deviations of Maternal Perception of Child
Adjustment Measures for JRA and Healthy Comparison Groups

Variable	JRA		Healthy Comparison	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Parent Attitudes Test	47.94	20.42	42.22	18.01
Child Behavior Checklist				
Total Behavior Problem Scale	59.33	9.92	52.44	7.99
Internalizing Factor	61.44	11.17	52.72	8.44
Externalizing Factor	59.06	11.80	52.17	9.85
Becker Bipolar Adjective Checklist	-21.94	16.36	-26.22	14.56

Note. n = 18 for each group. Higher scores indicate higher maladjustment.

Maternal personal adjustment measures. The means and standard deviations for the three personal adjustment measures are presented in Table 8. Results of a Hotelling's T^2 analysis of the maternal personal adjustment measures of depression (Beck Depression Inventory), anxiety (STAI) and marital satisfaction (DAS) indicated that mothers in the JRA group perceived themselves as having significantly more personal adjustment problems than mothers in the healthy comparison group, $F(3,30) = 3.29$, $p < .034$. These findings are based on a sample size of 34 for each variable since there were missing data from the DAS (i.e., one single mother in each group did not complete the DAS).

To insure that the significant effect occurred when data from the complete sample ($N = 36$) were included in the analysis, a separate Hotelling's T^2 analysis was conducted on the measures of depression and anxiety. Results indicated that JRA mothers still perceived themselves as having significantly more personal adjustment problems than mothers in the healthy comparison group, $F(2,33) = 4.37$, $p < .021$. Subsequent multiple comparisons were conducted using a Bonferroni procedure. The experimentwise error rate was set at $\alpha = .05$ and the critical value for each individual t-test was computed to be $.05/2 = .025$. Mothers in the JRA group perceived themselves to be more depressed, $t(25.09) = 3.00$, $p < .006$, but not more anxious, $t(34) = 1.76$, $p > .087$, than mothers in the healthy comparison group.

Results of a separate Student's t analysis on the marital satisfaction measure revealed no significant differences between the groups on mothers' perceptions of marital satisfaction, $t(32) = -1.92$, $p > .064$.

Table 8
Means and Standard Deviations for Maternal Personal Adjustment
Measures for JRA and Healthy Comparison Groups

Variable	JRA		Healthy Comparison	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Beck Depression Inventory a	8.06	5.76	3.50	2.90
Spielberger State-Trait Anxiety Inventory a	38.56	10.29	32.89	8.94
Dyadic Adjustment Scale b	109.06	12.17	117.12	12.29

a n = 18 for each group. Higher scores indicate higher levels of distress.

b n = 17 for each group. Higher scores indicate higher marital adjustment.

Discriminant Analysis of JRA and Healthy Comparison Groups

The previous analyses demonstrated that the JRA and healthy comparison group were significantly different from one another on one variable from each of the four sets of dependent measures:

- a) Parent behaviors: rate of rewards plus attends.
- b) Child behaviors: percentage of compliance to alpha commands.
- c) Maternal perception of child adjustment: Internalizing factor of the CBCL.
- d) Maternal personal adjustment: Beck Depression Inventory.

A stepwise discriminant analysis was performed to determine which of the four variables , singly and in combination, were the most powerful discriminators between the JRA and healthy comparison groups.

Results of the analysis indicated that the Beck Depression Inventory was the best discriminative variable between the JRA and the healthy comparison groups, $F(1,34) = 9.00$, $p < .005$. The rate of rewards plus attends was the next variable chosen by the stepwise analysis as significantly contributing to discriminative ability, $F(2, 33) = 8.37$, $p < .001$. The third variable to be included in the stepwise analysis was the Internalizing factor of the CBCL. This variable also increased the discriminative power, $F(3, 32) = 7.88$, $p < .0004$. The percentage of compliance to alpha commands was discarded as a discriminative variable during the stepwise analysis since it did not contribute further discriminative ability to that already gained by the combination of the first three variables. This combination of three variables (the Beck Depression Inventory, the rate of rewards plus attends, and the Internalizing factor on the CBCL) resulted in the

correct classification of 30 of the 36 cases (83.33%).

Within Group Analyses of the JRA Sample

A series of exploratory analyses were conducted within the JRA sample to investigate a variety of hypotheses concerning the relationships among the dependent variables in this group.

Illness severity and its relationship to other dependent measures.

The JRA sample were divided into three levels of illness severity, mild ($n=8$), moderate ($n=6$) and severe ($n=4$). Separate one way ANOVA's were conducted for each dependent variable, with illness severity serving as the independent variable. The use of a harmonic mean for all groups in the multiple comparison analyses was employed to guard against spurious results due to unequal n 's (Hull & Nie, 1981). Results indicated that the three levels of illness severity did not differ with respect to any of the maternal behavior measures (i.e., rate of rewards plus attends, percentage of contingent attention, and rate of beta commands). One of the three child behavior measures, percentage of child inappropriate behavior, was significantly different across the three levels of illness severity ($F(2,15)= 5.04$, $p < .02$). Multiple comparisons using a Scheffe procedure indicated that children in the severe group ($M= 18.28$) had significantly higher levels of inappropriate behavior than both the mild ($M= 4.73$) and moderate ($M= 6.25$) groups. There were no significant differences among the groups on the other two measures of child behavior.

Two of the five measures of maternal perception of child adjustment revealed significant differences among the three levels of illness severity: the total score on the PAT ($F(2,15)= 7.04$, $p < .007$) and the

Internalizing factor of the CBCL ($F(2,15) = 4.09, p < .04$). Multiple comparisons using a Scheffe procedure revealed that children in the severe group ($M = 73.75$) had significantly higher scores on the PAT than either the mild ($M = 39.88$) or the moderate ($M = 41.50$) groups. Thus, mothers who had a JRA child in the severe group perceived them to have more behavior/adjustment problems overall than mothers with JRA children in the mild or moderate groups. Multiple comparisons were also conducted on the three levels of illness severity for the Internalizing factor of the CBCL. Scheffe procedures indicated that children in the severe group ($M = 72.50$) had significantly higher scores on this measure than children in the mild group ($M = 55.75$), suggesting that mothers of children in the severe group perceived them to be more maladjusted with respect to depressive, anxious, withdrawn, and shy behaviors than did mothers of children in the mild group. The other measures of maternal perception of child adjustment revealed no significant differences among the three levels of illness severity.

None of the maternal personal adjustment measures revealed any significant differences among the three levels of illness severity.

Predictors of maternal and child behavior, maternal perception of child adjustment, and maternal personal adjustment. A series of stepwise multiple regression analyses were conducted to explore the relationships among the dependent variables in the JRA sample. Criterion variables for the analyses were chosen according to a number of research questions. First, all of the variables which demonstrated significant differences in the between groups analyses were chosen as

criterion variables in order to explore their relationship to other dependent variables within the JRA sample. Since these variables proved to differentiate the JRA group from the healthy comparison group, the research question was concerned with which variables within the JRA sample would be the best predictors of these variables. Rate of maternal rewards plus attends, percentage of child compliance to alpha commands, T score on the Internalizing factor of the CBCL, and the total score on the Beck Depression Inventory were criterion variables in the first series of stepwise multiple regression analyses.

Predictor variables for these and subsequent analyses were chosen in the same manner. One variable was chosen from each of the four sets of dependent measures (i.e., maternal behaviors, child behaviors, maternal perception of child adjustment and maternal personal adjustment). Within each set, the variable most highly correlated on an individual basis with the criterion variable was selected. Illness severity and length of illness were also included as predictor variables in all the analyses.

A stepwise multiple regression analysis was conducted with the rate of maternal rewards plus attends as the criterion variable and six dependent measures (chosen as previously described) as predictor variables. Only one of the six, percentage of child compliance to alpha commands, proved to be a significant predictor of rate of maternal rewards plus attends ($F(1,16) = 7.62, p < .01$). This variable accounted for 32% of the variance in predicting the rate of rewards plus attends.

Percentage of child compliance to alpha commands served as the criterion variable in a stepwise multiple regression analysis with seven

predictor variables. At step one of the analysis, percentage of child inappropriate behavior was chosen as the most powerful predictor of compliance to alpha commands ($F(1,16) = 9.49, p < .007$). This variable, on its own, accounted for 37% of the variance in predicting child compliance to alpha commands. At step two of the analysis, rate of maternal rewards plus attends was chosen as the next best predictor of child compliance to alpha commands ($F(2,15) = 11.40, p < .001$). This variable accounted for an additional 23% of the variance and in conjunction with percentage of child inappropriate behavior accounted for 60% of the variance in predicting child compliance to alpha commands. The other five variables were never entered into the regression equation because they did not meet the statistical criteria set by the stepwise procedure.

When the Internalizing factor of the CBCL served as a criterion variable in a stepwise multiple regression analysis, illness severity was the only significant predictor ($F(1,16) = 8.32, p < .01$). This variable accounted for 34% of the variance in predicting scores on the Internalizing factor of the CBCL.

Results of the stepwise multiple regression analysis conducted with the Beck Depression Inventory as the criterion variable indicated that none of the six variables was entered into the analysis because they did not meet the statistical requirements set by the stepwise procedure.

The second research question of interest was in regard to discovering the best predictors of maternal perceptions of child adjustment. As noted in the introduction, past research has questioned the accuracy of maternal perceptions of child behavior and found that

the level of maternal personal adjustment influenced maternal perceptions (Griest et al., 1979, 1980). A second series of stepwise multiple regression analyses were conducted with each of the maternal perception of child adjustment measures (excluding the Internalizing factor of the CBCL, which had already been done) serving as criterion variables. This included the total scores on the PAT, Becker Bipolar Adjective Checklist, and Behavior Problem Scale of the CBCL; and the score on the Externalizing factor of the CBCL. Results indicated that in all four of these analyses, percentage of child inappropriate behavior was the only significant predictor of maternal perception of child adjustment. A summary of these findings is presented in Table 9.

Finally, length of illness was chosen as a criterion variable in a stepwise multiple regression analysis to test the hypothesis that the length of children's illness might play a role in mothers' and children's behavior and adjustment to the illness, and that one of the six predictor variables might be a significant predictor of the length of illness. Results indicated that none of the variables was highly correlated enough to length of illness to pass the limits set by the stepwise procedure and enter into the analysis.

Table 9

Summary Table of Results of Stepwise Multiple Regression Analyses
for Maternal Perception of Child Adjustment Measures

	Predictor Variable: Percentage of Child Inappropriate Behavior		
	<u>F</u>	<u>p</u>	<u>r</u> ²
Total score on the Parent Attitude Test	16.36	.0009	.51
Total score on the Becker Bipolar Adjective Checklist	6.81	.02	.30
Behavior Problem Scale of the Child Behavior Checklist	6.36	.02	.28
Externalizing Factor of the Child Behavior Checklist	4.62	.05	.22
	Predictor Variable: Illness Severity		
	<u>F</u>	<u>p</u>	<u>r</u> ²
Internalizing Factor of the Child Behavior Checklist	8.32	.01	.34

Discussion

The current study had three main purposes. First, differences between the JRA and healthy comparison groups were investigated in four domains: maternal behavior, child behavior, maternal perceptions of child adjustment, and maternal personal adjustment. The next purpose was to evaluate the relative ability of each domain to differentiate between the two groups. This evaluation was exploratory in nature. The third purpose focused on exploring interrelationships among dependent variables within the JRA sample.

When differences between the JRA and healthy comparison groups were investigated in the domain of maternal behaviors, the findings partially confirmed the hypothesis that mothers of JRA children would show some deficits in their parenting behaviors. Results from the multivariate analysis indicated that mothers of JRA children engaged in less appropriate parenting behaviors than did mothers in the healthy comparison group. Subsequent analyses of specific behaviors revealed that mothers of JRA children gave their JRA children significantly less positive attention, overall, than mothers of healthy children. Mothers of JRA children did not exhibit significantly different rates of poor commands and contingent attention (i.e. positive attention given after child compliance) from that shown by mothers of physically healthy children.

Previous research with chronically ill children has not studied maternal behaviors along these dimensions and no research with JRA children has used behavioral observation measures. However, the

decreased level of positive attention shown by mothers towards their JRA children is compatible with Patterson's (1980) hypothesis that the burden of caring for a chronically ill child increases the probability of mothers developing a negative set in responding to their children.

With respect to the measures of child behavior, JRA children were significantly less compliant to maternal alpha commands than were children in the healthy comparison group. There were no differences in compliance to total commands or in levels of inappropriate behavior between the two groups. It was hypothesized that JRA children would be more behaviorally deviant than healthy children in all child behavior measures. Findings from the present study demonstrated that JRA children did not display higher levels of inappropriate behavior (e.g., tantrums, whining, smart talk, aggression, attention seeking) nor were they less compliant to total maternal commands than healthy children. However, they were less compliant in those situations where the opportunity for compliance was maximized by the mother issuing a good, clear command. In terms of observational measures of child behavior, the JRA children were not as behaviorally deviant as originally hypothesized.

Children's behavior and psychological adjustment was also evaluated by maternal perception of child adjustment measures. No significant differences were found between the JRA and healthy comparison groups on four measures of maternal perceptions of general behavior problems (PAT, Becker Bipolar Adjective Checklist, Behavior Problem Scale of the CBCL, and the Externalizing factor of the CBCL). The maternal perception measure which revealed differences between the two groups was the

Internalizing factor of the CBCL. Mothers of JRA children perceived their children as having significantly more "internalizing" behaviors than mothers of healthy children.

It was hypothesized that mothers of JRA children would perceive their children to be more behaviorally deviant than healthy children, but much of the evidence from the present study does not support this hypothesis. In four of the five maternal perception measures, mothers of JRA children did not perceive their children's behavior or psychological adjustment to be any different from that of healthy children. One important exception to these findings was on the measure of internalizing behaviors, where JRA children were perceived to be behaviorally different from healthy children. They were viewed as more shy, depressed, anxious, withdrawn, sullen, dependent and immature than their healthy peers.

The behaviors encompassed by the Internalizing factor are similar to adjectives used by pediatricians (e.g., Brewer et al., 1982) and psychiatrists (e.g., Rimon et al., 1977) to describe the adjustment problems of JRA children, suggesting congruence in maternal and pediatric perceptions of JRA children. This finding also suggests a particular pattern of maladjustment as a reaction to having JRA; i.e., a tendency to show more "internalizing" behaviors. Previous research by McAnarney et al. (1974), comparing JRA children to healthy children with self-report measures of personality and self-concept, reported that more children with arthritis viewed themselves as "different", "inferior", or "less worthy" than their healthy peers. Parents of JRA children, besides rating them as displaying more abnormal behavioral symptoms,

also judged their emotional health to be poorer than that of the healthy comparison group. These results suggest that JRA children and their parents perceive them to have some "internalizing" behaviors. Although Ivey et al. (1981) hypothesized that the main problem with the JRA child is usually low self-esteem and high anxiety (both internalizing behaviors), the results of their investigation did not substantiate their hypothesis. JRA children did not perceive themselves to be more anxious or to have lower self-esteem. In fact, they reported lower levels of anxiety and higher self-concepts than did their healthy siblings. The main difference between the present study and the Ivey et al. (1981) study is that they used no parental perception of child adjustment measures to assess children's behavior.

Previous research with other chronic illnesses has also indicated particular patterns of maladjustment, depending on the disease in question. For example, children with cystic fibrosis (CF) were reported to be more immature and dependent (Tavormina et al., 1976) and perceived by their parents as more hyperactive, fearful, sensitive and socially withdrawn (Drotar et al., 1981), while diabetics were reported to be more alienated, rebellious (Tavormina et al., 1976) and hyper-irritable (Cernelc et al., 1977). The adjectives used to describe CF children are more "internalizing" in nature whereas the diabetic children were described in more "externalizing" terms. Further investigation is required to determine if the parental perception of children as more "internalizing" in their behaviors is a common perception among all parents of chronically ill children or whether it is only specific to JRA children.

Evidence presented so far suggests that children with JRA are similar to healthy children along many psychological dimensions. However, they do differ from their healthy peers in two important ways. They are less compliant to maternal directions and they are perceived by their mothers to display more "internalizing" behaviors than healthy children. As a group these children were certainly not as maladjusted as clinic-referred behavior problem children. For example, on all measures of child behavior and maternal perceptions of child adjustment, behavior problem children are consistently more deviant than a normal comparison group (e.g., Griest et al., 1980), whereas JRA children only differed from the healthy comparison group on a few of the measures. In terms of their behavioral and psychological adjustment, JRA children appear to fall somewhere between normal, healthy children and those referred to clinics for behavior problems.

Even though JRA children, as a group, were not perceived to have major behavior problems, some JRA children in the sample were perceived to have significant behavior problems and would be classified as behaviorally deviant for their age and sex, according to norms from the CBCL. On the Behavior Problem Scale and the Externalizing factors of the CBCL, 4 of the 18 JRA children received scores placing them at the 98th percentile or above for behavior problems (two standard deviations from the mean for their age and sex). On the Internalizing factor of the CBCL, 3 of these same children and 1 other JRA child received scores in the 98th percentile or above. Only one child in the healthy comparison group received a score of this magnitude (a percentile ranking of 98 on the Externalizing factor).

Most of the child behaviors described by the maternal perception measures are similar in nature to the child behaviors measured by the behavioral observations, in that they tend to be "acting-out" or "externalizing" behaviors. The only exception to this is the Internalizing factor of the CBCL which has no representative counterpart in the behavioral observation measures. It is not surprising then that the psychological maladjustment of JRA children could be suggested by high scores on the Internalizing factor of the CBCL and yet these same children might not be observed to display more inappropriate behaviors than healthy children. It is interesting to note that while mothers generally did not perceive the behaviors and psychological adjustment of their JRA children to be different from that of healthy children, their perceptions were not completely consistent with the behavioral data, since behavioral measures showed JRA children to be less compliant to maternal commands. This discrepancy between maternal perceptions and observed behavior is an important area for future research to address.

Results from the current investigation indicated that mothers of JRA children were experiencing higher levels of personal distress and maladjustment than mothers of healthy children. This finding is supported by results from the multivariate analysis and subsequent comparisons on individual measures. Maternal depression scores were significantly higher for mothers of JRA children. Measures of anxiety and marital satisfaction revealed no significant differences between the groups, but both measures approached statistical significance, suggesting that they made a contribution to the overall level of maternal distress. These results confirm the hypothesis that mothers of

JRA children would show lower levels of personal adjustment, and also suggest that they experience more feelings of depression than mothers of healthy children. These findings support anecdotal reports and past research on maternal adjustment in the JRA literature (Blom & Nichols, 1954; Cleveland et al., 1965; Williams, 1981) and also are consistent with findings from studies on the psychological adjustment of mothers of other chronically ill children (e.g. Cummings et al., 1966, Gayton et al., 1977; Tavormina et al., 1981).

Although mothers of JRA children were significantly more depressed than mothers in the healthy comparison group, the mean depression score for the JRA group was not in the clinically depressed range, based on normative data from the Beck Depression Inventory (Beck, 1967). This indicates that, while as a group, mothers of JRA children are experiencing more personal distress than mothers of healthy children, this distress is not of clinical severity. However, six mothers in the JRA sample had scores on the Beck Depression Inventory which placed them in the borderline to moderate ranges of clinical depression. Only one mother in the healthy comparison group had a depression score in the clinically depressed range and it was at the bottom end of the range for borderline depression. It appears that a subsample of mothers with JRA children were indeed experiencing clinical levels of depression.

Also, based on normative data from the STAI (Sielberger et al., 1970), there were four mothers of JRA children whose perceived level of anxiety was so high as to place them one standard deviation or more above the mean. This is in contrast to only one mother in the comparison group, whose perceived level of anxiety was high enough to

place her two standard deviations from the mean.

The findings from the maternal personal adjustment measures suggest that mothers of JRA children perceive themselves to be experiencing noticeably more personal distress than mothers of healthy children. Raising a healthy child is stressful enough, but the additional burden of dealing with the needs of a chronically ill child appears to be having a negative effect on mothers' perceptions of themselves. Although they could not be described as extremely maladjusted, they do appear to experience increased difficulties in coping with their situation.

In order of the magnitude of their contribution, the Beck Depression Inventory, the rate of maternal positive attention, and the Internalizing factor of the CBCL, proved to be the variables which best discriminated between the JRA and healthy comparison groups. A child behavior measure, compliance to alpha commands, did not make a significant contribution to discriminative ability. All three of the discriminative variables related to mothers in some way: first, to their level of personal distress; next, to their behavior; and finally, to their perception of the psychological adjustment of their child. These findings suggest that what most strongly differentiated the JRA and healthy comparison groups was not the behavior of JRA children, but rather a combination of maternal variables. These results focus attention on the mothers of JRA children and suggest that their personal adjustment, parenting behaviors and perceptions of their child should be taken into account when assessing the strengths and coping abilities of the family and the normalcy of life provided for the JRA child.

Interrelationships among variables in each of the domains were explored within the JRA sample. Two additional variables, the length of illness and the level of illness severity were examined along with the other measures. These two variables were included in the investigation because they were thought to be important variables which might interact with the psychological adjustment of JRA children and their mothers. The within JRA group findings must be considered as more tentative and exploratory, but they do contribute a more fine-grained analysis of the relationships among various measures.

None of the maternal behavior measures were related to either of the two JRA variables, length of illness or level of illness severity. This suggests that mothers are behaving in similar ways with their JRA children (i.e., the same amount of positive attention, contingent attention, and rate of poor commands) regardless of the length of time the children have had JRA or the level of severity with which the children experience their disease. Within the JRA sample, a correlational relationship existed between maternal positive attention and child compliance to maternal commands. This relationship indicated that the mothers who gave less positive attention to their JRA children in turn tended to have children who were less compliant to their commands. Further implications of this finding will be discussed later.

When JRA children's behaviors was explored in relation to levels of illness severity, the children with severe illness demonstrated much higher levels of inappropriate behavior than children with mild and moderate levels of illness. There were no differences among the levels of illness severity in relation to the two measures of child

compliance. These findings partially confirm the hypothesis that the more severe their illness, the more inappropriate the behavior of JRA children will be. Also, none of the child behavior measures was related to the length of the illness.

Child compliance to maternal commands was most strongly related to child inappropriate behavior and next, to maternal positive attention. This finding suggests that JRA children who were less compliant also tended to demonstrate higher rates of inappropriate behavior and had mothers who gave them lower rates of positive attention. The relationship between decreased child compliance and increased child inappropriate behavior is to be expected, since they are both in the domain of conduct disorder behaviors (as described by Patterson, 1980). However, the relationship between child compliance and maternal positive attention is more difficult to interpret. These behaviors are strong predictors of one another within this JRA sample. This suggests that these maternal and child behaviors may be interacting to reduce the possibility of positive interactions and increase the probability of aversive events. Patterson (1980) hypothesized that families with chronically ill children would engage in fewer positive interactions and have higher levels of aversive events, but he did not describe specific mechanisms by which this occurs. Further investigation of the relationship between child compliance and maternal positive attention would provide more information about the behavioral mechanisms which increase negative interactions with chronically ill children.

When the two JRA variables were considered in relation to maternal perceptions of child adjustment, the length of illness was not related

to any of these measures. However, the level of illness severity interacted with two measures of maternal perceptions of child adjustment. Children with the most severe illness were perceived by their mothers to be more behaviorally deviant than their less ill peers on a general measure of child behavior problems (the total score on the PAT). Children were also perceived to have more internalizing behaviors (Internalizing factor of the CBCL) if they had a severe level of illness. These findings partially confirm the hypothesis that JRA children with severe illness will be perceived by their mothers to have more behavior/adjustment problems, especially in the area of increased "internalizing" behaviors.

The findings that children experiencing severe illness show greater levels of inappropriate behavior, and are perceived to have more general behavior problems and more internalizing behaviors, seems incompatible with the findings of McAnarney et al. (1974). They reported that moderately and severely disabled children had fewer behavioral and adjustment problems. However, as noted earlier, the present sample of JRA children is similar to McAnarney et al.'s non-disabled group. The findings of the present study suggest that within a non-disabled group of JRA children, there is a subsample of severely ill children who are also experiencing more behavior and adjustment problems.

Another research question in the domain of maternal perception of child adjustment measures concerned what would be the best predictors of maternal perceptions. Griest et al. (1980) reported that for mothers of non-clinic referred children, the child's behavior, as measured by behavioral observation, was the best predictor of maternal perceptions

of the child. For mothers of clinic-referred behavior problem children, a combination of maternal personal adjustment measures and actual child behavior proved to be the best predictor of maternal perceptions. The results of the current investigation suggest that mothers' perceptions of the behavior of JRA children are more similar to mothers' perceptions of the behavior of non-clinic referred children in that the only predictor of maternal perceptions on four of the five measures was the behavioral observation measure of child inappropriate behavior. The only exception to this was on the Internalizing factor of the CBCL, where the level of illness severity was the best predictor of this measure. As noted earlier, there were no behavioral measures of such internalizing behaviors. Maternal personal adjustment measures were not in any way predictive of maternal perceptions, suggesting that maternal personal adjustment is not interacting with mothers' perceptions of their JRA children in the way it has been shown to interact with mothers' perceptions of clinic-referred behavior problem children.

In regard to the domain of maternal personal adjustment measures within the JRA sample, much of the evidence has already been discussed. In summary, maternal personal adjustment was not related to the level of illness severity or the length of illness in JRA children. Neither were maternal depression levels related to any of the other domains of variables (i.e., maternal behaviors, maternal perceptions of child adjustment or child behaviors). Mothers of JRA children are experiencing higher levels of personal distress than mothers of healthy children but it does not seem to be directly related to any of the variables measured in the present study. The fact that neither maternal

behaviors or maternal personal adjustment were related to the length of the illness or the level of illness severity points to the overall strength and ability of mothers with JRA children to cope with a stressful and demanding situation. Although they may be experiencing considerable amounts of personal distress, they are not allowing it to spill over into their interactions with or perceptions of their JRA children. However, results of the study suggest that special attention should be paid to the psychological well-being of mothers with JRA children, since they appear to experience increased distress and maladjustment as a result of having a JRA child.

This study provided a comprehensive view of JRA children and their mothers from a psychological perspective. It was the first study with JRA children to employ several different methods of evaluating childrens' and mothers' behavioral and psychological adjustment. Through multi-method comparison, interrelationships among various domains of psychological variables could be examined, both between groups and within the JRA sample. No other study to date has assessed this population in such a comprehensive manner.

One methodological shortcoming of the study was the small sample size, which precluded a more powerful and conclusive investigation of the JRA population. Also, the design of the study was quasi-experimental, so that only correlational relationships could be discussed. The investigation could not suggest causative relationships between the variables, but did provide descriptive and comparative data which other researchers can use as a springboard to more experimental research with JRA children. One other shortcoming to acknowledge was

the fact that the behavioral observations were not conducted under completely naturalistic conditions and therefore may have been subject to bias. The possibility of a differential reactive effect for families with JRA children versus those with healthy children cannot be ruled out. No research has investigated sources of bias in behavioral observations of a JRA population, however the possibility should be considered and would be an good question for future research.

One of the most important findings of the study is the extent to which the mothers of JRA children are psychologically and behaviorally affected by their children's disease. This is not to minimize the findings of behavioral and psychological adjustment problems with JRA children, but to point out that mothers seem to be the unacknowledged victims (a phrase borrowed from Patterson, 1980) of the situation, experiencing increased distress and maladjustment as a result of caring for their JRA child. From a clinical perspective, this suggests that more emphasis should be placed on assessing the psychological well-being of mothers, and supporting them in their efforts to raise their JRA children. In some cases, the provision of child management skills training or personal counselling may be indicated.

Many avenues of research were not explored in the present study and several ideas for future research projects arise from the findings of this study. Since evidence of psychological maladjustment was found in JRA children and their mothers, other family members (i.e., fathers and siblings) should also be evaluated to determine what effect having a JRA child in the family is having on their own behavior and adjustment. Investigations along theses lines would develop a more comprehensive

picture of the role of family functioning and family interactions in the ability of JRA children and their families to cope with the disease.

Some specific research questions in this regard are: do mothers give significantly less positive attention to all their children or just to the child with JRA? Are fathers and siblings of JRA children as affected as mothers seem to be by having a JRA child in the family? What factors could account for increased levels of depression and personal distress in mothers of JRA children?

This study focused on a fairly narrow age range of young JRA children. Further research is needed to investigate the behavior and psychological adjustment of JRA children at different ages. For instance, as JRA children grow older do their psychological adjustment problems change and in what ways? Another developmental/longitudinal investigation might look at the special concerns of the JRA child and his or her family at each stage of the illness.

Finally, if psychological interventions are carried out with JRA children and their families, then these interventions should be evaluated in terms of their ability to alleviate psychological distress, to equip families with coping strategies to deal effectively with the disease, and to make the day-to-day lives of JRA children and their families as normal as possible.

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APPENDIX A

NEWSPAPER ADVERTISEMENT

APPENDIX B

PARENT CONSENT FORM

CONSENT FORM

DATE _____

I, _____, voluntarily give my consent for myself and _____ to be participants in a research project involving an assessment of parental perceptions and parent-child interactions. This study will be conducted during the period of November 1981 to August 1982 with Robert J. McMahon, Ph.D., as principal investigator and Donna Schmirler as project manager. The procedures to be followed and their purpose have been explained to me, and I understand them. They are as follows:

1. I will complete a series of questionnaires designed to measure my attitudes and perceptions toward my child and my perceptions about myself.
2. A series of four 40-minute observations will occur in my home where a trained observer will visit my home and observe my interactions with my child.

I understand that my participation in this study will involve a time commitment of approximately 4½ hours. I also understand that I will receive individual feedback regarding my interactions with my child at the conclusion of the study. I will receive \$15.00 for my participation.

All information collected about myself and my family shall be kept strictly confidential, and published results of the study will report group findings only. I understand that this consent may be withdrawn at any time without prejudice and that refusal to participate or withdrawal from the study will not jeopardize treatment of my child. My questions concerning this project have been answered to my satisfaction. I have read and understood the foregoing.

Witness_____
Parent

APPENDIX C

GUIDELINES FOR HOME OBSERVATIONS

PARENTS' GUIDELINES FOR HOME OBSERVATIONS

When the observer arrives, you will see that he or she has a tape recorder and earphone. The observer is not recording the observation. He or she is listening to a tape which is cueing him or her when to code information. If you'd like, the observer can let you hear a portion of the tape.

Occasionally, two observers will come to your home. The second observer is there to check the recording accuracy of the first observer, not to evaluate your performance.

Concerning each observation: Please try to interact normally with your child. Don't feel compelled to do anything you wouldn't ordinarily be doing at this time. Ignore the observer - he or she will try to be as unobtrusive as possible. During the observation, the observer will not be able to interact with you or your child.

It is very important that you follow these guidelines as closely as possible for each home observation. They are designed to help the observer hear and see as much of the observation as he or she can.

1. Remain in a two-room area with your child in view and hearing range of the observer. If your child leaves the observation area, please bring him or her back.
2. You may bring any work materials or toys desired into the observation area with the exception of commercial board games (for example, Candyland, Monopoly, etc.) or playing cards. It is a good idea to do this before the observation starts. Also, we have found it helpful if you check on your child's bathroom needs prior to the beginning of the observation.
3. Do not watch TV.
4. Please don't read to your child.

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5. We would also prefer that other children, your husband, or other members of your family not be present in the room or two rooms where the observation is taking place.
 6. If the telephone rings, talk as briefly as possible, or ask if you may return the call later.
 7. If you have any questions regarding the observations or your participation in the project, please do not ask the observers. If you will call us at the University, we will try to answer your concerns.
- Don't be surprised if you feel a bit awkward at first - everyone does. However, if you just pretend the observer is not there, then you will be more comfortable and will act more naturally. Thank you for your cooperation.