

# Brief Report: Adjustment to Juvenile Rheumatoid Arthritis: A Family Systems Perspective

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**Objective** To examine the relations of the family environment to adjustment to juvenile rheumatoid arthritis (JRA), and to examine how those relations are influenced by child sex and age. **Method** Ninety-four children with JRA completed a questionnaire on family environment and adjustment. **Results** Family cohesion was related to good adjustment, whereas family conflict was related to poor adjustment. Some relations of family cohesion to adjustment were stronger for younger than for older children. The relations of child autonomy to adjustment depended on child sex and age. **Conclusion** The relations of the family environment to adjustment to JRA are dependent on child sex and age.

**Key words** juvenile rheumatoid arthritis, childhood chronic illness, adjustment, family system theory.

Juvenile rheumatoid arthritis (JRA) is an idiopathic, chronic autoimmune disease that is diagnosed in children under the age of 15 years. In the United States, it is one of the most frequent childhood chronic illnesses, with an estimated prevalence between 30,000 and 50,000. The most common presentation of JRA includes persistent inflammation of multiple joints with concomitant pain, stiffness, and fatigue. The usual course of the disease is a cycle of flares and remissions. Although some children may experience one or two brief active periods and then never exhibit further symptoms, other children experience unremitting discomfort ranging from mild to severe. Girls are twice as likely as boys to develop JRA.

Most forms of JRA are not life-threatening, but the disease can have a marked impact on psychosocial functioning. Symptoms of JRA can interfere with daily activities such as schoolwork and social life. The disease process and accompanying medications can alter physical appearance (e.g., limit growth), which may affect self-image. Children might feel embarrassed by awkward movements, limping, or the necessity to wear splints or braces. Despite the many ways in which JRA might affect children's psychosocial functioning, little research has addressed the is-

sue. The studies that do exist suggest that relationships are important and that family support influences adjustment (Timko, Stovel, Baumgartner, & Moos, 1995; Timko, Stovel, Moos, & Miller, 1992; Varni, Wilcox, & Hanson, 1988).

Family cohesion reflects family support, affection, and nurturance. Numerous studies have linked family cohesion or support to disease adjustment and adherence among children with chronic illnesses (Hanson, 1992; Holmes, Yu, & Frentz, 1999; Soliday, Kool, & Lande, 2000; Thompson et al., 1999), including JRA (Kygäs, 2000; Varni et al., 1988). Lack of such cohesion reflects the family's expression of anger, hostility, criticism, and conflict. Family conflict also has been linked to adjustment difficulties and poor health behavior among children with a chronic illness (Miller-Johnson et al., 1994; Thompson et al., 1999). There is some evidence that family cohesion and family conflict are more strongly related to health outcomes for girls than for boys (Dumont et al., 1995; Hops, Davis, & Lewin, 1999; Wilson & Ampey-Thornhill, 2001).

The relation of family cohesion and family conflict to health outcomes also may depend on the child's age.

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Younger children rely more heavily on the family, while older adolescents turn to peers for support. Older adolescents with a chronic illness receive less family support than younger adolescents (Skinner & Hampson, 1998). In one study, family cohesion was associated with better adjustment to diabetes among preadolescents but not adolescents (Safyer et al., 1993). As peers take on increasing significance, family support and conflict may play a less important role in adolescents' adjustment to chronic illness.

A final dimension of the family environment that may be relevant to child and adolescent adjustment to chronic illness is the family's encouragement of child autonomy. Studies of children and adolescents with diabetes show that family emphasis on independence is associated with adolescent competence, psychosocial adjustment, and good metabolic control (Anderson, Miller, Auslander, & Santiago, 1981; Hauser, Jacobson, Wertlieb, Brink, & Wentworth, 1985). The relationship of child autonomy within the family to adjustment to JRA likely depends on both the child's sex and his/her age. We predict that older children will receive the most benefit from autonomy because of their emerging developmental need for independence. As autonomy has traditionally been defined as a feature of the male gender role (Spence & Helmreich, 1978), we also predict that autonomy will have its greatest impact on outcomes for older boys.

The first goal of this study was to investigate the role of the family environment in adjustment to JRA. We predicted that family cohesion would be adaptive and family conflict would be maladaptive. The second goal of this study was to systematically examine age and gender as moderators of these relations. We predicted that the relations of family cohesion and conflict would be stronger for girls than for boys and for younger than for older children. We also hypothesized that child autonomy would be more adaptive for boys than for girls and for older than for younger children.

## Participants

Ninety-four children and adolescents (61 female, 32 male, 1 unreported) diagnosed with JRA and their parents participated in this study. Because one child did not specify sex, this person was removed from the analyses. Participants ranged in age from 7 to 20 years ( $M = 12.63$ ;  $SD = 3.23$ ) and lived with their parents. Duration of JRA ranged from 1 to 18 years ( $M = 7$ ;  $SD = 3.91$ ). Parents reported that 9% of participants had pauciarticular JRA (i.e.,  $\leq 4$  joints affected), 22% polyarticular (i.e.,  $\geq 5$  joints affected), and 6% systemic (i.e., multiple organ systems affected). A majority of parents (63%) did not specify the kind of JRA.

Education was measured on a 5-point scale. As mother's and father's education were strongly correlated ( $r = .55$ ,  $p < .001$ ), the two were averaged to form an education index, with mean level of parental education being equivalent to "some college."

## Procedure

The research was approved by the institutional review board of the University of Michigan. Families were contacted via one of two separate mailings. The first mailing was sent through the Arthritis Foundation newsletter to families in the state of Michigan. Enclosed with the survey was a letter that explained the study along with an informed consent form. Families' names were entered into a drawing for 1 of 3 gift certificates. Thirty-seven families participated. Families also were contacted through the Pediatric Rheumatology Clinic at the University of Michigan Medical Center. Families on the clinic's mailing list were sent a copy of the survey, a consent form, and a cover letter from their rheumatologist explaining the study. Respondents participated on a voluntary basis ( $n = 56$ ). There was no incentive for this group. Response rates for the two samples could not be determined because the Arthritis Foundation and the University of Michigan Medical Center could not confirm either the total number of sent mailings or how many people with valid addresses on their mailing lists had active JRA. The two samples did not differ significantly on predictor or outcome variables.

The survey consisted of two sections. First, parents provided demographic information. Next, their children completed measures of the family environment, adjustment to JRA, and self-esteem. Parents returned completed surveys by mail.

## Instruments

### Disease Severity

We developed a measure of disease severity by consulting two pediatric rheumatologists from different university medical centers. We provided them with a list of all medications that parents indicated children were currently taking for JRA. The physicians developed a 3-tiered classification system, wherein higher numbers indicated medications that were most commonly prescribed for severe JRA, and placed each of the medications into one of these three categories. Nonsteroidal anti-inflammatory medications (e.g., aspirin, acetaminophen) were given a score of 1. Corticosteroids, such as prednisone, received a score of 2. Slow-acting disease-modifying medications (e.g.,

methotrexate, gold compounds) were assigned a score of 3. One of the authors applied this classification system to each participant's current medication(s). When more than one medication was indicated, we based our classification on the most severe medication being taken. This measure of disease severity was correlated (.36,  $p < .01$ ) with parents' reports of number of joints affected, which provides some evidence of construct validity.

### **Family Environment**

We assessed three dimensions of family environment: cohesion, conflict, and child autonomy. We assessed cohesion and conflict using two subscales from the Family Relationship Scale, a validated self-report measure of family functioning (FRS; Barbarin, 1988). The nine-item cohesion scale measures the child's experience of affection, understanding, acceptance, and support from other family members. The alpha was .79. The 6-item conflict scale assesses the presence and expression of hostility among family members, specifically openly expressed anger, aggression, and conflict. We added two items: "In family discussions we interrupt one another" and "My family has problems and secrets." We dropped one item from the scale because it detracted from the internal consistency. The alpha was .76.

We assessed child autonomy within the family using a scale that was adapted from Steinberg's measures of parenting style (Lamborn, Mounts, Steinberg, & Dornbusch, 1991; Steinberg, Elmen, & Mounts, 1989). The scale measures the child's perception of autonomy in regard to daily decisions. Each of 16 items (e.g., time spent on homework, staying overnight at a friend's house) was framed by the question stem "Who decides. . ." Responses ranged from 1 ("just me") to 5 ("just my parent"). Responses were recoded so that higher numbers indicated more child autonomy within the family. The internal consistency was .84.

### **Adjustment to JRA**

Our 12-item measure of adjustment to JRA was developed specifically for this study, and it concerned sources of worry for a child. Participants indicated how often they worry about each item on a 5-point scale that ranged from *never* to *most of the time*. Because we met the 5-participants-per-item criterion (Stevens, 2002), we examined the scale for multiple dimensions with principal components analysis followed by varimax rotation. Two factors had eigenvalues greater than 1.0. The first factor concerned illness worries and consisted of 6 items. Four of these items clearly indicated worry about illness, whereas 2 did not and cross-loaded heavily on the second factor. Thus, the second

factor was created to be a general worry factor and consisted of 8 items that referred to concerns about physical appearance and basic self-image. The internal consistencies for the illness and appearance worry scales were .71 and .82, respectively. They were correlated .36,  $p < .001$ .

### **Self-Esteem**

We used the general competence or "self-worth" subscale from Harter's Perceived Social Competence Scale (Harter, 1982). The scale was simplified from a 4-point to a 2-point scale to make the questions easier for the child to understand. The internal consistency was .71.

### **Results**

Because girls were significantly older than boys [ $t(91) = 2.11$ ,  $p < .05$ ], we conducted analyses of covariance with age as the covariate. Girls rated their families as more cohesive ( $M = 3.75$ ) than did boys ( $M = 3.55$ ),  $F(1, 89) = 5.35$ ,  $p < .05$ . There were no sex differences in family conflict or child autonomy. Age was associated with less cohesion ( $r = -.26$ ,  $p < .05$ ), more conflict ( $r = .21$ ,  $p < .05$ ), and more autonomy ( $r = .67$ ,  $p < .001$ ). Child sex was not associated with study outcomes but age was associated with greater appearance worries ( $r = .42$ ,  $p < .001$ ).

We examined the independent relations of the family environment variables to outcomes, controlling for child age, sex, disease severity, and parent education. We did not control for JRA duration, because it was not independently related to predictor or outcome variables. Family cohesion was correlated with less illness worry ( $r = -.42$ ,  $p < .001$ ), less appearance worry ( $r = -.22$ ,  $p < .05$ ), and higher self-esteem ( $r = .39$ ,  $p < .001$ ). Family conflict was related to greater illness worry ( $r = .27$ ,  $p < .05$ ), greater appearance worry ( $r = .24$ ,  $p < .05$ ), and lower self-esteem ( $r = -.34$ ,  $p < .001$ ). Child autonomy was not associated with outcomes.

There was some empirical overlap among the three family environment variables. Cohesion was negatively related to conflict ( $r = -.56$ ,  $p < .001$ ) and child autonomy ( $r = -.24$ ,  $p < .05$ ). Child autonomy and family conflict were unrelated. Thus, we examined which aspects of the family environment independently predicted adjustment with hierarchical regression analysis. We also explored whether the relations of the family environment to outcomes were affected by the child's age and sex by computing interaction terms between sex, age, and the three family environment variables. We centered the predictor variables before computing the interaction terms to reduce multicollinearity (Aiken & West, 1991). We also tested whether multicollinearity was a significant

**Table I.** Multiple Regression Analyses: Predicting Adjustment and Adherence

	Illness Worry		Appearance Worry		Self-Esteem	
	beta	$\Delta R^2$	beta	$\Delta R^2$	beta	$\Delta R^2$
Step 1						
Sex	.32*		.10		.14	
Age	-.70		1.53*		-1.08†	
Education	-.25*		-.02		.12	
Severity	.22*	.05†	-.06	.01	.08	.01
Step 2						
Conflict	.13		.74		-.34	
Cohesion	-.38		.40		.50	
Autonomy	.19	.18**	-.37	.25***	1.22*	.23**
Step 3						
Sex × Age	.63		-1.16*		1.04†	
Sex × Conflict	-.05		-.64		.18	
Sex × Cohesion	-.15		-.65		-.14	
Sex × Autonomy	-.19		.21		-1.08*	
Age × Conflict	.47		.06		-.21	
Age × Cohesion	.59		.27†		-.32*	
Age × Autonomy	1.73**	.08**	.07	.08**	.00	.12***
Step 4						
Sex × Age × Conflict	-.62		—		—	
Sex × Age × Cohesion	-.66		—		—	
Sex × Age × Autonomy	-1.63**	.08***	—		—	
Total $R^2$		.39		.34		.36
Multiple $R$		.63		.58		.60

† $p < .10$ .\* $p < .05$ .\*\* $p < .01$ .\*\*\* $p < .001$ .

problem by examining variance inflation factors (Myers, 1990). Using this criterion, multicollinearity was not a significant problem.

On the first step of the analysis, we entered the control variables: child age, child sex, disease severity, and parent education. On the second step, we entered the three family environment variables. On the third step, we entered interaction terms of sex and age with each of the three family environment variables. We also included an interaction term for sex by age on this step. Finally, on the last step, we entered the three 3-way interaction terms involving sex, age, and each of the family environment variables. The standardized betas for all variables in the final regression equations are shown in Table I. The change in  $R^2$  is shown for each step of the analysis. The overall  $R^2$  and the multiple  $R$  for each equation are displayed.

Three of the four demographic variables were significant predictors of illness worry: Being female, lower parent education, and more severe JRA predicted more illness worry. There were no main effects of family environment variables, but there was a significant Age × Autonomy in-

teraction that was qualified by a 3-way Sex × Age × Autonomy interaction. The nature of this interaction (as well as all others) was examined using the procedures outlined by Aiken and West (1991). The worry scores of children who scored  $\pm 1$  standard deviation from the mean on the autonomy scale were plotted for younger and older girls and boys. Younger and older groups were defined as  $\pm 1$  standard deviation from the mean age of the sample. Greater autonomy predicted increased illness worry among older boys but decreased worry among younger boys. By contrast, autonomy was unrelated to illness worry for younger or older girls.

One demographic variable predicted appearance worry: Older children worried more about appearance. This main effect was qualified by an interaction with sex: The relation of illness worry to age was stronger among boys. Family environment variables did not predict appearance worries but there was a marginal Age × Cohesion interaction, suggesting that cohesion was associated with less appearance worry among younger children. Three-way interactions were not significant.

None of the demographic variables significantly predicted self-esteem. Child autonomy predicted higher levels of self-esteem. This main effect was qualified by an interaction with sex, such that more autonomy was associated with higher self-esteem only among boys. There also was a significant Age  $\times$  Cohesion interaction, suggesting that the positive relation of family cohesion to self-esteem holds only for younger children. The pattern of this interaction is the same as for appearance worry. Three-way interactions were not significant.

## Discussion

We examined the relation of three aspects of the family environment to children's adjustment to JRA: family cohesion, family conflict, and child autonomy within the family. Conflict was associated with greater adjustment difficulties, whereas cohesion was associated with fewer adjustment difficulties. When all three aspects of the family environment were examined simultaneously, conflict did not predict adjustment independent of cohesion. Cohesion was associated with less appearance worry and greater self-esteem, but these relations depended on child age. As predicted, the relations were stronger for younger than for older children.

The relationship of child autonomy to adjustment depended on sex and age. As predicted, autonomy was more relevant for boys than for girls. Among girls, autonomy was unrelated to either self-esteem or illness worry. By contrast, autonomy was associated with higher self-esteem for boys and with more illness worry among older boys. The relationship with self-esteem fits with the idea that boys, more so than girls, derive their self-esteem from separating or individuating from others (Josephs, Markus, & Tafarodi, 1992). The association with illness worry may reflect adolescent boys' ambivalence toward being given more responsibility for their own self-care. The decision latitude promised by increased autonomy may provide boys with a healthy sense of self-reliance and contribute to self-esteem, but the burden of being accountable for making correct decisions may lead to illness worry, particularly if boys feel insecure in their ability to manage their disease on their own.

Other predictions we made about the impact of child sex on the findings were not confirmed. There was no evidence that family cohesion or conflict was more strongly related to outcomes for girls than for boys. Girls, however, did report more cohesive families compared with boys. This is consistent with other research showing that girls have more support available than do boys (Belle, 1987). We expected girls to be more worried about their

appearance than boys. This was true for younger children but not for older. Among older children, boys worried more about their appearance than did girls. One explanation for this sex difference may be that JRA tends to have detrimental effects on aspects of appearance that are consistent with conventional masculine ideals (e.g., agility, strength). Insofar as adolescent boys may feel more pressure to attain these ideals, boys with JRA may demonstrate more appearance worry.

Before concluding, we must acknowledge several limitations of this study. First, many of the measures used in this study were either developed or adapted specifically for this study. Thus, psychometric data on these measures are limited. However, the strong correlation between cohesion and conflict and the lack of their relation to autonomy provide evidence for construct and discriminant validity. Second, the outcome variables were all based on children's self-report. Third, although our analyses were hypothesis driven, we conducted a large number of analyses that inflated Type I error. We also had limited power to detect interaction effects. Yet, our interactions accounted for significant amounts of variance in outcomes. Finally, the cross-sectional nature of the study limited our ability to make causal claims. The child's psychological and physical state is just as likely to affect the family environment as the family environment is likely to affect the child's disease adjustment. These limitations underscore the importance of replicating the present findings, especially with respect to sex and age as moderators of the relation of family variables to child adjustment to chronic illness. Future research should explore the role of family structure in adjustment to JRA.

In conclusion, these findings suggest that the family is an important social context with respect to JRA. The connections between the family environment and adjustment that we drew notably depended on both child sex and age. Age is a critical factor in the study of children's adjustment to disease because developmental needs for independence and attachment to peers may interfere with the behaviors required to effectively manage the disease. With increasing age, needs for autonomy emerge. Autonomy entails both freedom and responsibility. For a child who faces an illness such as JRA, which imposes restrictions on behavior, the challenge is to achieve autonomy yet maintain connection to support sources so that health is not compromised.

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