

Quality of Life among Adolescents with Juvenile Rheumatoid Arthritis

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Honors Project

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Abstract

Parenting and autonomy were examined as psychosocial predictors of quality of life among adolescents with juvenile rheumatoid arthritis (JRA). Twenty-four adolescents diagnosed with JRA and their parents participated in the study. Adolescents and parents were interviewed separately to assess the child's general and JRA-related autonomy, parenting style of parent(s), and the child's general and JRA-specific quality of life. Significant correlations were found between general autonomy and worse general quality of life and general autonomy and better JRA quality of life among older adolescents (13 to 16 years). Authoritative and authoritarian parenting styles were associated with better general and JRA quality of life among younger adolescents (10 to 12 years). Parent-child relationship and parental care were also significantly related to better general quality of life. Thus, parenting appears to be especially important to the quality of life for younger adolescents and autonomy appears to be especially important to the quality of life for older adolescents.

Quality of life among adolescents with juvenile rheumatoid arthritis

Juvenile rheumatoid arthritis (JRA), an autoimmune disease, is one of the most common rheumatic disorders of childhood. JRA is loosely defined as "arthritis beginning before the age of 16 years." As the most prevalent form of arthritis in children, it affects about 71,000 - 100,000 children in the United States alone (Arthritis Foundation, 1999). The disease is characterized by inflammation of and around the joints. Such inflammation can cause mild to severe swelling, heat, and pain, resulting in weakness, decreased motor activity, and reduced coordination. JRA can also lead to altered growth in the localized areas of affliction as well as in overall physical development.

Three types of JRA have been identified and characterized as distinct from other rheumatic diseases: polyarticular, pauciarticular, and systemic (Cassidy & Petty, 2001). The number and type of joints affected as well as the presence or absence of high spiking fever within the first six months of illness onset distinguish among the three. Polyarticular onset JRA affects about 30 percent of the diseased population and is defined by the presence of five or more affected joints. Most often the smaller joints, such as those of the fingers and hands, are affected by polyarticular JRA, but weight-bearing joints (i.e., knees, hips, ankles, feet, neck and jaw) also can be affected. Girls are three times as likely as boys to be affected by polyarticular JRA. Pauciarticular or oligoarticular JRA, the most prevalent form of JRA accounting for about half of the cases, affects four or fewer joints and is accompanied by low-grade inflammation. This type of JRA affects girls five times as often as boys. Systemic onset, the most severe and rare form of JRA, is characterized not only by arthritis, but also by a high spiking fever (39° C or higher) that occurs once or twice daily during onset and then less frequently

throughout childhood. Effects of systemic JRA are not limited to arthritic symptoms; it may include chills and often a rash. In contrast to poly- and pauciarticular JRA, systemic onset JRA equally affects girls and boys. While JRA often improves or remits at puberty, there is no cure for any type of the disease. Therefore, treatment plans focus on alleviation of symptoms.

The treatments for JRA often have considerable side effects. For example, methotrexate can cause ulcers throughout the gastrointestinal tract. Steroids may cause fluid retention resulting in weight gain. Fortunately, there are ways to reduce or alleviate some of the physical side effects from medications used to treat JRA. However, there are more subtle psychosocial impacts of this disease that medical regimens do not address. For example, social development may be impaired due to the inability of some children afflicted with the disease to participate in sports activities. Appreciation of the impact of this disease on children and adolescents should include not only an examination of the physical hardships, but also the psychosocial consequences of JRA and its treatment.

The physical and psychological effects of JRA may be difficult at any age, but they present even more significant challenges for adolescents. Adolescence is a particularly critical time to study JRA because the needs of adolescents to establish a sense of independence may conflict with taking care of a chronic illness. The rigor of the JRA treatment regimen may place an extra burden on adolescents who are trying to become more independent from their parents in their social relationships, activities, and in the responsibility they take for their illness. There are also significant psychosocial concerns associated with having to deal with a chronic illness at a young age. JRA may pose physical limitations, be associated with pain, and affect body image, all of which

may impact on adolescents' physical, emotional, social, and academic functioning—in other words, their *quality of life*.

Past research in the area of quality of life among children with JRA is limited in at least three important ways. First, medical investigators typically focus on disease-related predictors (e.g., severity) rather than psychosocial predictors of quality of life. Disease severity is not always related to quality of life. For example, in one study no significant differences in social, emotional, or behavioral functioning were discovered between children evaluated to have moderate to severe disease versus mild disease according to a pediatric rheumatologist (Noll, Kozlowski, Gerhardt, Vannatta, Taylor, & Passo, 2000). The finding that greater emotional distress of the child and family is related to higher reported pain also supports the notion that psychosocial predictors of quality of life ought to be evaluated (Ross, Lavigne, Hayford, Berry, Sinacore, & Pachman, 1993). It is not clear whether disease severity or psychosocial factors are the cause of pain reports. It is important to understand the predictors of pain because parent-child pain reports are often used as a measure of disease severity. An assessment of quality of life, independent of clinically defined disease severity, may yield a more accurate representation of the adolescent's social, emotional, and physical functioning.

Second, psychosocial research on quality of life among children with JRA has often spanned a broad age range, 7 to 15 years in one study (Schanberg et al., 2000) and 6 to 17 years in another (Berry, Hayford, Ross, Pachman, & Lavigne, 1992). There are several methodological concerns that arise when employing participants of such an expansive age range. One methodological limitation of these studies is that parents report on behalf of younger children and older children report on behalf of themselves. The

data are combined and the source of the data (parent vs. child) is not given any consideration. This approach can be problematic due to the finding that adults often rate children's behavioral and emotional problems as more severe than do children themselves (Handwerk, Larzelere, Soper, & Friman, 1999). Assessment over such a broad age range is also problematic because psychosocial variables that are relevant for one age group may not be relevant for another age group. For example, family cohesion is more predictive of health outcomes among younger than older adolescents (Burroughs, Harris, Ponious, & Santiago, 1997). Furthermore, young children and adolescents differ in the conceptions they have of their JRA and may therefore understand questions concerning their illness differently (Berry et al., 1993). Therefore, age may influence factors that predict health behaviors and quality of life.

Finally, the majority of studies examine parents' rather than children's views of children's quality of life. For quality of life, in particular, it is important to know how children view the impact of the illness on their own functioning.

The goal of this research is to examine psychosocial predictors of quality of life among adolescents with JRA. We address many of the concerns raised by previous studies. We examine a group of adolescents who span a more narrow age range and obtain reports from adolescents as well as parents. We believe that two factors are important predictors of quality of life among adolescents with JRA: parenting style and child autonomy. Parenting style may be a significant predictor of social and emotional functioning by directly and/or indirectly affecting the child's social skills, sense of self, and sense of being cared for. Parent-child relationship quality and parent involvement are significantly related to peer relations and self-concept among adolescents aged 12 to

18 years (Delovic & Meeus, 1997). Autonomy is an especially important factor in adolescent development. Due to the physical challenges that adolescents with JRA face, autonomy may be restricted by dependence upon parents for daily treatment responsibilities (i.e., taking medications, performing range of motion exercises).

Therefore, I will briefly review the literature on parenting style and autonomy and make predictions about how these variables will affect the quality of life of adolescents with JRA.

Parenting Style

The psychological literature has distinguished among three parenting styles: authoritative, authoritarian, and permissive (Bukatko & Daehler, 1998). An authoritative style is characterized by reasonable expectations, warmth demonstrated by love and affection, and explanations for demands. An authoritative parent typically encourages open communication with a child and interacts in a warm manner. By contrast, an authoritarian style is characterized by parental usage of restriction and control as well as a lack of warmth. While permissive parents offer warmth, they are typically identified by their lack of limits and demands. The authoritative style is generally accepted as the optimal type of parenting (Henricson & Roker, 2000).

Parenting styles have rarely been examined in the context of children with a chronic illness, including JRA. However, there is some literature outlining the impact of different parenting styles on general health behaviors and social development. For example, Schmitz, Lytle, Phillips, Murray, Birnbaum, and Kubik (2002) found that 11- to 15-year-old girls who reported their mothers had an authoritative parenting style also reported higher physical activity and lower sedentary leisure habits. Authoritarian and

permissive parenting styles have been associated with a greater risk for problematic behaviors such as drug and alcohol abuse, delinquency, and sexual promiscuity, (Henricson & Roker, 2000; Maccoby & Martin, 1983).

One limitation of previous research on parenting style is that the style is reported by either the parent *or* the child, but not both. One strength of this proposal is that we examine parenting styles from both the parent's and the child's perspective. We will be able to examine the extent to which children and parents agree as to the parenting style used in the home, and we will be able to determine whose response is more predictive of outcomes.

Autonomy

A central developmental challenge of adolescence is to achieve an identity and develop a sense of autonomy (Collins, Gleason, & Sesma, 1997). Managing a chronic illness may conflict with these developmental needs. Autonomy in adolescence has been associated with engagement in positive health behaviors such as refraining from sexual intercourse and avoidance of negative health behaviors such as fighting and use of substances (Turner, Irwin, Tschann, Millstein, 1993). In addition, less autonomy or conflict over autonomy has been related to negative emotional functioning among adolescent girls (Frank, Schettini, Lower, 2002). We will examine two domains of autonomy—autonomy for non JRA-related tasks (e.g., completing homework, participating in social activities) as well as JRA-related tasks (e.g., taking medication, completing daily exercises).

Hypotheses

We predict that an authoritative style of parenting will be associated with an enhanced quality of life, whereas permissive and authoritarian styles of parenting will be associated with a lower quality of life. In general, we predict that features of parenting (i.e., parenting style, parent-child relationship quality, parental bonding) will be more predictive of quality of life among younger adolescents than older adolescents because younger children are more dependent upon parents for advice and direction of behavior. For example, permissive parenting may be less negative for older adolescents than younger adolescents due to older adolescents' greater desire for more independence from parents. By contrast, an authoritarian parenting style may have a less negative, or even positive, implication for younger adolescents because they need structure to carry out daily activities and treatment regimens.

We hypothesize that autonomy will be associated with a higher quality of life, especially for older adolescents. Older adolescents are at a critical period in development; they are gaining independence from parents and becoming more self-reliant, which are essential to well-being. We expect that autonomy for non-JRA-related tasks will be more critical than autonomy for JRA-related tasks to a good quality of life because non-JRA tasks are more critical to social development. JRA-tasks are often independent of social interactions (i.e., taking medications) and may not be viewed as barriers to autonomy. Non-JRA tasks, such as participation in social clubs and spending time with friends, may provide adolescents with a sense of self and independence. Therefore, it is likely that these activities will be more strongly related to well-being.

Method

Participants

Participants in this study were 24 adolescents (2 male, 22 female) diagnosed with JRA, including 22 mothers and 2 fathers. Adolescents ranged in age from 10 to 16 years of age with an average age of 12.8 years. Adolescents ranged in grade level from 4th grade to 11th grade: 4th grade (4.2 %); 5th grade (8.3 %); 6th grade (25 %); 7th grade (29.2 %); 8th grade (12.5 %); 9th grade (4.2 %); 10th grade (12.5 %); 11th grade (4.2 %).

Procedure

Participants were recruited from the Rheumatology Clinic of The Children's Hospital of Pittsburgh, Pennsylvania. A total of 97 families were sent a letter describing the research and a postcard that asked if they would like to be contacted by phone to learn more about the study. We had time to send forty-three of the families a second letter if the postcard was not returned after two weeks. Of the 97 families contacted, 47 returned postcards indicating that they would like to learn more about the study. All were contacted by phone and 30 (64%) agreed to participate. These families were sent two copies of a consent form (one to be signed and returned, and one to be kept for their records). The consent form explained the purpose of the study, what the study required, informed the participants of the right to discontinue the interview at any time, and that all information would be kept confidential. A set of seven response scales was also mailed to the participants to be used for the interview.

Once a signed copy of the consent form was received, a 45-minute structured phone interview was conducted. The adolescent and the parent were interviewed separately: the adolescent for 30 minutes and the parent for 15 minutes. Participants were told to use the response scales throughout the interview to answer the questions. The adolescent interview assessed autonomy, parenting style, parent-child relationship

quality, parental bonding, general quality of life, JRA-specific quality of life, and body satisfaction. The parent interview assessed autonomy, parenting style, general quality of life, and JRA-specific quality of life. For this study, we examined the adolescent's sense of autonomy, and both parent and child perceptions of parenting style and quality of life.

Instruments

Autonomy. Autonomy was assessed for JRA-specific tasks (e.g., taking medications, doing range of motion exercises) and non-JRA tasks (e.g., participating in extracurricular activities, time spent with friends) by both child and parent reports. In addition, we assessed conflict over how JRA tasks were divided in the family.

We assessed child general 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 1 "just me" to 5 "just my parent" for the adolescent or 5 "just my child" for the parent. Therefore, higher scores on the child report indicated that the parent made the decision whereas higher scores on the parent report indicated that the child made the decision. This scale showed an internal consistency of .79 for adolescents and .73 for parents.

The JRA-specific tasks were adapted from the Diabetes Family Responsibility Questionnaire to assess the distribution of arthritis-related responsibilities between children and their parents (Anderson, Auslander, Jung, Miller, & Santiago, 1990). We used items that were relevant to JRA and developed other items specific to JRA. The 12-

item scale included: "Who remembers doctor appointments?" and "Who remembers to take medications?" Respondents indicated who took responsibility for each task on a 4-point scale: (1) My parents take responsibility almost all of the time; (2) My parents and I share the responsibility about equally; (3) I take responsibility almost all of the time; (4) No one takes responsibility. Response categories for the parent were parallel with higher numbers meaning the child takes more responsibility. The scale had an internal consistency of .57 for adolescents and .60 for parents.

Conflict over JRA tasks was assessed by asking "How much do you argue about this?" following each of the 12 JRA tasks. Both child and parent response categories were none, a little, or a lot. We took the average of these items to reflect the amount of conflict. Because conflict in one domain was not related to conflict in another domain, we could not calculate an internal consistency.

Parenting. Three dimensions of parenting were assessed: parenting style, parent-child relationship quality, and parental bonding. Parenting style was assessed from both parent and child reports while parent-child relationship quality and parental bonding were assessed by child reports only.

Parenting style was evaluated using a subset of items from the Parental Authority Questionnaire - Revised developed by Reitman, Rhode, Hupp, and Altobello, (2002). Each of the parenting styles - permissive, authoritative, authoritarian – were measured with 5 items. Sample items for the adolescents included: "My parents believe that I should have my own way as often as they do" for the permissive parenting style, "My parents explain to me why they want me to do things" for the authoritative style, and "My parents get upset with me if I disagree with them" for the authoritarian style. The

same items were used in the parent scale, but modified to obtain the parent's perspective. After one item was deleted from the permissive subscale because it detracted from the reliability, the internal consistency was .54 for children and .64 for parents. The internal consistency of the authoritative subscale was .60 for children and .81 for parents. The internal consistency for the authoritarian subscale after 2 items were removed because they detracted from the reliability was .68 for children and .60 for parents.

Parent-child relationship quality was assessed using 8 items from the Orebro Parenting Measure (Kerr & Stattin, 2000; Kerr, Stattin, & Trost; Stattin & Kerr, 2000, 1999). The instrument was administered only to the adolescents. Respondents were asked to state how often each item occurred on a 5-point scale: 1 = never, 2 = once in a while, 3 = sometimes, 4 = often, 5 = always. Sample items are: "How often do you and your parents quarrel and fight with each other?" (reverse-scored) and "How often do you think that you and your parents understand each other?" The internal consistency of this scale was .82.

Parental bonding, assessed with the Parental Bonding Instrument was used to examine three dimensions of bonding: care (6-items), over-protection (4-items), and behavioral freedom (4-items); (Murphy, Brewin, and Silka, 1997; Parker, Tupling, & Brown, 1979). We used an abbreviated version of the scale by selecting items that had the highest loadings following a factor analysis. The scale was administered only to the child. Respondents were asked to state how often each item was true according to a 5-point scale: 1 = never, 2 = once in a while, 3 = sometimes, 4 = often, 5 = always. Sample items included: "How often are your parents affectionate towards you?" for the care dimension, "How often do your parents baby you?" for the over-protective dimension,

and "How often do your parents give you as much freedom as you want?" for the behavioral freedom dimension. The internal consistencies for each of the scales were good: .79 (care), .79 (over-protection), and .83 (behavioral freedom).

Quality of life. Two domains of quality of life were assessed from both the child and parent perspective: general and JRA-specific.

General quality of life was assessed using the PedsQL developed by Dr. James W. Varni (Varni, Seid, & Rode, 1999; Varni, Seid, & Kurtin, 2001). It assesses physical, emotional, social, and academic functioning. The physical functioning subscale consisted of nine items, and assessed the child's ability to perform physical tasks and whether physical tasks were taxing for the child. The internal consistency of this scale was .89 for children and .90 for parents. Emotional functioning was assessed using a six-item subscale, which evaluated the frequency with which the child experienced several emotions (e.g., happy, scared, angry). The internal consistency of this scale was .89 for children and .86 for parents. The social functioning subscale consisted of six items that assessed how well the child got along with other children and performed in social settings. The internal consistency of this scale was .69 for children and .65 for parents. Academic functioning was assessed using a six-item subscale that evaluated the child's performance in and attendance to school. The internal consistency of this scale was .78 for children and .80 for parents. Higher numbers on these subscales indicated poorer quality of life.

JRA-specific quality of life was assessed with the PedsQL instrument developed by Dr. James W. Varni, which evaluated pain, daily activity, treatment, worry, and communication (Varni, Seid, & Rode, 1999; Varni, Seid, & Kurtin, 2001). JRA

quality of life also was determined from both parent and child reports. The pain dimension was evaluated with four items and evaluated the extent which the child experienced arthritis-related pain. The internal consistency of this scale was .86 for children and .88 for parents. Daily activity was based on five items and evaluated the ease or difficulty with which the child was able to perform daily tasks (e.g., writing with a pen or pencil, turning door handles). The internal consistency of this subscale was .57 for children and .75 for parents. The treatment dimension was measured with a seven-item subscale examining the impact of the child's medications and arthritis related care. The internal consistency was .82 for children and .78 for parents. Worry about arthritis was assessed using a three-item scale. The internal consistency of the scale was .93 for children and .91 for parents. The communication dimension also was assessed with a three-item scale. This dimension assessed the ease or difficulty with which the child could talk with doctors, nurses, and other people about arthritis. The internal consistency of the scale was .76 for children and .81 for parents. Higher numbers on these subscales indicated poorer JRA-specific quality of life.

Results

Correspondence between Parent and Child Reports

Autonomy. We predicted that, in accordance with previous findings, there would be discrepancies between parent and child reports of autonomy. We found this to be true for general autonomy but not JRA-specific autonomy. Although the correlation between parent and child reports for general autonomy was significant, $r = .43$, $p < .05$, there was a significant difference between child and parent reports, $t(23) = 52.12$, $p < .001$. Not surprisingly, children reported more autonomy ($M = 2.88$) than parents ($M = -2.77$). JRA

autonomy reports from parent and child were not significantly correlated and there was also no difference in the mean response levels. Parent and child reports of conflict over JRA autonomy were positively correlated, $r = .44$, $p < .05$, and there was no difference in the mean levels of parent and child reports.

Parenting. Parent and child reports of all three parenting styles were unrelated, (r 's ranged from .14 to .25). There was a significant difference between parent and child reports of permissive parenting, $t(23) = 2.39$, $p < .05$, such that parents reported themselves as more permissive ($M = 3.41$) than children did ($M = 2.93$). There was no difference between parent and child reports of authoritarian and authoritative parenting.

Quality of Life. We examined four dimensions of general quality of life: physical, emotional, social, and academic. Parent and child reports were significantly correlated for each dimension: physical functioning, $r = .81$, $p < .001$; emotional functioning, $r = .72$, $p < .001$; social functioning, $r = .44$, $p < .05$; academic functioning, $r = .80$, $p < .001$. JRA-specific quality of life was measured in terms of five domains: pain, daily activity, treatment, communication, and worry. Parent and child reports were positively correlated for all five dimensions: pain, $r = .76$, $p < .001$; daily activity, $r = .66$, $p < .001$; treatment, $r = .55$, $p = .01$; communication, $r = .61$, $p < .001$; and worry, $r = .60$, $p < .001$.

Relation of Child Autonomy to Quality of Life

Child general autonomy. We predicted that children with a greater sense of autonomy would have a higher quality of life. General autonomy was associated with social functioning, but opposite of predictions. More child autonomy was related to worse social functioning, $r = .43$, $p < .05$. General autonomy was unrelated to physical,

emotional, and academic functioning. General autonomy also was not related to any of the JRA-specific quality of life domains.

Child JRA autonomy. We predicted that children with a greater sense of autonomy over tasks related to JRA would have a higher quality of life. Greater child autonomy was significantly correlated with better academic functioning, $r = -.44$, $p < .05$. JRA autonomy was not related to the other three general quality of life domains. Among the domains of JRA quality of life, JRA autonomy was significantly correlated with less worry, $r = -.41$, $p = .05$, and better communication $r = -.53$, $p = .01$. JRA autonomy was not associated with pain, daily activity, or treatment.

Child conflict over JRA autonomy. Child reports of conflict over JRA-tasks were examined in relation to their reports of both general quality of life and JRA-specific quality of life. There were no significant relations between conflict and any of the general quality of life domains. This indicates that conflict over JRA-task autonomy is unrelated to physical, emotional, social, and academic functioning. In contrast, child reports of conflict over JRA tasks were correlated with three of the five domains of JRA quality of life. More conflict was related to more problems with treatment, $r = .55$, $p = .01$, more worry, $r = .52$, $p = .01$, and worse communication, $r = .61$, $p < .001$. There was no relation of conflict to pain and daily activity.

Parent reports of child autonomy. Parent reports of child general autonomy were unrelated to parent reports of children's general quality of life and JRA quality of life. Parent reports of JRA autonomy also were unrelated to general and JRA quality of life. There was, however, a significant correlation between parent reports of conflict over

autonomy and only one JRA quality of life domain: treatment, $r = .57$, $p < .001$. More conflict was associated with more treatment problems.

Relation of Parenting to Quality of Life

Child parental bonding. Parental bonding was assessed in three domains: behavioral freedom, over-protection, and care. There was no relation between behavioral freedom and any of the general or JRA quality of life measures. In contrast, the over-protection aspect of parental bonding was significantly correlated with two general quality of life domains and one JRA-specific domain. Greater over-protection was related to poorer physical functioning, $r = .62$, $p < .001$, worse emotional functioning, $r = .63$, $p < .001$, and greater pain, $r = .49$, $p < .05$. Care was associated with one general quality of life domain. Care was associated with better social functioning, $r = -.53$, $p = .01$. There were no significant correlations between the care dimension of parental bonding and JRA-specific quality of life.

Parent-child relationship quality. Parental relationship quality was assessed to determine its relation to general and JRA quality of life. A better parent relationship was associated with better emotional functioning, $r = -.47$, $p < .05$, and social functioning, $r = -.52$, $p = .01$. Parent-child relationship quality was not related to any of the JRA quality of life domains.

Child reports of parenting style. Each of the three parenting styles, permissive, authoritative, and authoritarian, were evaluated for their relation to general and JRA quality of life as reported by children. We predicted that permissive and authoritarian parenting styles would be associated with poorer quality of life, and that the authoritative parenting style would be associated with better quality of life. There were no significant

correlations between any of the parenting styles and general quality of life. There also were no significant correlations between any of the parenting styles and JRA quality of life.

Parent reports of parenting style. Parents' reports of each of the three parenting styles, permissive, authoritative, and authoritarian, were evaluated for their relation to general and JRA quality of life. We made the same predictions as stated in the previous section. Again, there were no significant correlations between any of the parenting styles and general or JRA-specific quality of life.

Age as a Moderator of Autonomy/Quality of Life Relation

We were surprised that child autonomy revealed so few relations to quality of life. We had predicted that autonomy would be related to an enhanced quality of life and that these relations would be stronger for older children. Thus, we examined the relations of child autonomy to quality of life for younger and older children separately. We performed a median split on the age variable such that children 12 years of age and younger were placed in the young group ($n = 11$) and children 13 and older were placed in the old group ($n = 13$). As shown in Table 1, a consistent pattern of relations between autonomy and quality of life emerged for the older group but no relations were significant for the younger group. General autonomy seems to be related to a *worse* quality of life among older adolescents. In contrast, JRA-specific autonomy is related to a better quality of life for older children. Conflict shows few relations to quality of life for younger or older children.

Age as a Moderator of the Parent-Child Relationship/Quality of Life Relation.

Again, we were surprised that features of the parent-child relationship revealed so

few relations to quality of life. We had predicted that parenting would be more predictive of quality of life for younger children than older children. Thus, we examined the relations of parent relationship quality to quality of life for young and older children. As shown in Table 2, younger adolescent's rating of their relationship with parents was significantly related to all four general quality of life domains and two of the JRA quality of life domains. Also, consistent with our prediction, parent relationship quality was not associated with any of the general or JRA quality of life domains for older adolescents.

As shown in Table 2, one of the parental bonding dimensions, care, revealed stronger relations to quality of life among younger than older adolescents, consistent with our prediction. Care was marginally related to two and significantly related to one of the four general quality of life domains for younger children but none of the general quality of life domains for older children. There is a clear trend that younger children with more parental care rate quality of life better than older children.

Age as a Moderator of the Parenting Styles/Quality of Life Relation.

We also investigated whether the relation of parenting styles to quality of life would differ for older and younger children. There were no relations of the permissive parenting style to quality of life for older or younger children. However, as shown in Table 3, the relations of the authoritarian and authoritative styles of parenting to quality of life differed for younger and older children. Both the authoritative and authoritarian parenting styles were more strongly associated with quality of life for younger than older children. The relations of the authoritarian style to quality of life are consistent with predictions, whereas the relations of the authoritative style to quality of life are contrary

to prediction. Both authoritative and authoritarian styles are related to good quality of life for younger children.

Discussion

Autonomy

We predicted that more autonomy would be associated with a better of quality of life for both younger and older adolescents, but especially the older group. This was found to be the case for JRA autonomy, but not for general autonomy. Contrary to our predictions, we found that less general autonomy was significantly related to better social functioning for adolescents with JRA. This finding was further confirmed when the relation of general autonomy to quality of life was examined by age. While there were no relations between general autonomy and quality of life among younger adolescents, older adolescents with less autonomy had better physical and academic functioning and marginally better emotional and social functioning. General autonomy also was related to more pain, problems with daily activity, and worse communication (marginal) among the older group of children. These results confirm our hypothesis that general autonomy is a more important factor in the quality of life of older than younger adolescents, but in a direction opposite of what was expected. One explanation for these results is that high autonomy among older children implies less parental involvement. However, we found no evidence in our data that older children who reported more autonomy perceived less parental support, as assessed by the parent care or parent quality of life scales. Although previous literature has reported more autonomy to be related to positive health outcomes among older adolescents, it is possible that the burdens of having a chronic illness complicate the association.

Examination of JRA-specific autonomy revealed associations with quality of life that were consistent with predictions. JRA autonomy was associated with better quality of life on a few dimensions for the entire sample, but more compelling evidence was found upon examination of the data by age. More JRA autonomy was associated with better academic functioning, less pain, better daily activity, better communication and marginally better emotional functioning among older adolescents. These data further support the notion that autonomy is a vital component of adolescents' quality of life. Among children with JRA, it appears that the critical kind of autonomy is JRA-specific rather than general. This is contrary to our hypothesis that non-JRA autonomy would be more strongly correlated with a better quality of life than JRA autonomy. We may have identified an important link between having control over JRA and better quality of life. It is possible that control over a chronic illness helps shape self-esteem and functioning in a manner as to improve or hinder quality of life. This finding certainly warrants further examination with a larger sample.

Conflict over JRA autonomy revealed no significant correlations to general quality of life but was related to more problems on our measure of JRA quality of life. While conflict over JRA autonomy appeared to be more strongly related to JRA quality of life than JRA autonomy for the entire sample, examination by age showed there to be no significant relations. More relations might have been found if there had been more variability in conflict reports. The mean level of conflict reported was low by both parent report ($M = 1.13$) and child report ($M = 1.14$). The instrument also had only a 1 to 3 scale which may have hindered the amount of conflict reporting by both parties.

Parenting

We predicted that an authoritative parenting style would lead to higher quality of life. This hypothesis was not supported. There were no significant correlations between authoritative parenting and quality of life before the data were examined by age. When younger and older groups were examined separately, however, authoritative parenting was associated with good quality of life for younger adolescents but not older adolescents. Authoritative parenting is generally considered to be the style of parenting most strongly related to good health among children. In our data, this was confirmed for younger children. The fact that there was not a significant relation among the older adolescents suggests that parenting is not as critical for the quality of life of older adolescents.

We predicted that an authoritarian parenting style would be negatively associated with quality of life but that this relation would be less negative or even positive for younger adolescents. Across the entire sample, authoritarian parenting was unrelated to quality of life. Again, when we examined the data by age, we found that the authoritarian parenting style corresponded to better social and academic functioning, improved treatment, better communication, and less worry for younger children. There were no relations between the authoritarian parenting style and quality of life for older adolescents. The relations of the authoritarian parenting style among younger adolescents is partly in the direction our hypothesis predicted. The authoritarian style may be associated with positive outcomes among younger children because they need structure, especially when coping with a chronic illness. While the parenting style may lack warmth, it is characterized by rules and restrictions. These rules and restrictions may provide the necessary structure to impact quality of life positively for younger

children. The fact that there were no relations of the authoritarian parenting style to older adolescents' quality of life suggests that parenting is not an integral factor in their quality of life.

We predicted that permissive parenting would be negatively related to quality of life for older and younger adolescents, but less so for older children. We found no significant relations between permissive parenting and quality of life for these adolescents, even when we examined the sample by age. There may have been a problem with the measure employed to assess the parenting style. There was relatively low internal consistency for the scale, especially among children. Also, this subscale of the parenting measure was the only one to reveal a significant difference between parent and child reports. These limitations may have contributed to the failure to find relations of the permissive parenting style to quality of life.

We predicted that a good parent-child relationship would be associated with better quality of life and that these relations would be stronger for younger adolescents. While behavioral freedom was not related to quality of life, the over-protection and care dimensions of the parental bonding instrument did reveal significant associations. Over-protection was related to poorer physical functioning, worse emotional functioning, and greater pain among the entire sample

We also predicted that aspects of the parent-child relationship would be more strongly related to quality of life among younger adolescents. We found this to be true on two dimensions of parenting: parent-relationship quality and parental bonding. Care of the parental bonding measure was associated with better social functioning for the entire sample but upon examination by age, it was only significant for younger

adolescents. In addition to the significant relation of care to enhanced social functioning, there were marginal associations of care to physical and emotional functioning for younger adolescents. Care may be especially important for younger adolescents' general quality of life because the parent is providing the support necessary to form a strong social network, and encouraging participation in physical activities that are helpful in treating the symptoms of JRA. The overall quality of the parent-child relationship was also more strongly related to quality of life for younger than older adolescents. This construct was significantly related to better emotional and social functioning for the entire sample. However, upon examination by age, all of the general quality of life domains and two of the JRA quality of life domains were significant among younger adolescents. None of the correlations were significant among older adolescents. Again, this is consistent with our prediction that parenting is a significant variable in the quality of life of younger adolescents with JRA.

There were several limitations of this research. First, the rather small sample size led to a lack of power to detect significant relations. Second, several of the instruments we employed had low internal consistencies, which also may have contributed to fewer relations being detected. Finally, the study was cross-sectional in nature, limiting our ability to draw causal conclusions. We are not able to determine whether a positive relation of JRA autonomy to quality of life means that autonomy enhances quality of life or a good quality of life leads parents to allow more autonomy.

In sum, autonomy and parenting have revealed several associations with quality of life that may have important implications for future research and treatment of JRA. Autonomy appears to have significant relations to quality for life of older adolescents (13

to 16 years), whereas parenting was found to be significantly correlated with quality of life for younger adolescents (10 to 16 years). Future research should continue to examine the implications of parenting and autonomy for the quality of life of children with JRA. The age of the child also is an important consideration.

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Table 1
Relation of Child Autonomy and Conflict
Over Autonomy to Child Quality of Life by Age

	Child – General		Child – JRA		Child – Conflict	
	Autonomy		Autonomy		Over JRA	
	Young	Old	Young	Old	Young	Old
General Quality of Life						
Physical	.09	.74**	-.01	-.41	.21	-.04
Emotional	.38	.50+	-.14	-.53+	.31	.46
Social	.42	.55+	-.33	-.31	.26	.23
Academic	.12	.67**	-.59+	-.56*	.58+	.27
JRA Quality of Life						
Pain	.06	.76**	-.39	-.62*	.34	.20
Daily Activity	-.14	.61*	-.18	-.69**	.17	.05
Treatment	-.01	.28	-.03	-.37	.48	.65*
Communication	-.08	.54+	-.25	-.81**	.63*	.62*
Worry	.10	.51+	-.11	-.73**	.53	.55

Note: *** p < .001, **p < .01, *p < .05, +p < .10

Table 2
Relation of Parent Relationship Quality and
Parental Bonding Care to Quality of Life By Age

	Parent Relationship Quality		Parental Bonding Care	
	Young	Old	Young	Old
	General Quality of Life			
Physical	-.63*	-.08	-.54+	.04
Emotional	-.79**	-.18	-.55+	-.04
Social	-.78**	-.23	-.87**	-.03
Academic	-.66*	.12	-.45	.37
JRA Quality of Life				
Pain	-.65*	-.01	-.50	.06
Daily Activity	-.62*	.27	-.27	-.05
Treatment	-.39	-.14	-.31	.07
Communication	-.52	-.05	-.37	-.04
Worry	-.36	-.13	-.28	-.28

Note: *** p < .001, **p < .01, *p < .05, +p < .10

Table 3
Relation of Authoritative and Authoritarian
Parenting Styles to Child Quality of Life by Age

	Authoritative		Authoritarian	
	Young	Old	Young	Old
General Quality of Life				
Physical	-.52+	.31	-.34	.16
Emotional	-.84**	.51+	-.45	.01
Social	-.74**	.25	-.61*	.34
Academic	-.67*	.32	-.76**	.29
JRA Quality of Life				
	Young	Old	Young	Old
Pain	-.59+	.35	-.59	.21
Daily Activity	-.58+	.18	-.25	.16
Treatment	-.46	.41	-.65*	.11
Communication	-.54+	.45	-.36*	.09
Worry	-.44	.21	-.77**	-.14

Note: *** p < .001, **p < .01, *p < .05, +p < .10

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