Association between perceived treatment adherence and health-related quality of life in children with juvenile idiopathic arthritis: perspectives of both parents and children

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Objective: The aim of the study was to examine the relationship between perceived treatment adherence and health-related quality of life (HRQOL) in children with arthritis, from both parent and child perspectives.

Methods: Patients and their parents, who attended the juvenile idiopathic arthritis (JIA) clinic at the Montreal Children's Hospital, completed the Juvenile Arthritis Quality of Life Questionnaire (JAQQ), and either the Child Adherence Report Questionnaire (CARQ) or the Parent Adherence Report Questionnaire (PARQ). Linear regression models examined the associations between perceived treatment adherence and HRQOL while adjusting for age, severity, duration of the disease, and complexity of the medical regimen.

Results: Perceived adherence to medications was associated with a better HRQOL total score from the children's perspective ($\beta = -0.02$, 95% confidence interval [CI] $= -0.03$, -0.004), particularly with respect to gross motor ($\beta = -0.03$, 95% CI $= -0.05$, -0.01) and psychosocial functions ($\beta = -0.03$, 95% CI $= -0.04$, -0.01). According to parents, perceived adherence to exercises was associated with fewer symptoms ($\beta = -0.01$, 95% CI $= -0.03$, 0.000) and better psychosocial functioning ($\beta = -0.01$, 95% CI $= -0.03$, -0.002).

Conclusion: Perceived adherence to medications is associated with an improved HRQOL according to children. According to parents, adherence to exercises may be associated with an improved HRQOL.

Keywords: treatment adherence, juvenile idiopathic arthritis, health-related quality of life

Introduction

Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in childhood and a leading cause of childhood disability (Woo and Wedderburn 1998; Petty et al 2004; Petty and Cassidy 2005). The management of JIA requires a multi-disciplinary treatment approach often involving several types of nonsteroidal antiinflammatory drugs (NSAIDs), corticosteroids, and/or disease-modifying antirheumatic drugs (DMARDs) such as methotrexate or tumor necrosis factor-α inhibitors (TNFα-inhibitors) together with an exercise program that might include the application of a physical therapy regimen and the wearing of splints (Petty and Cassidy 2005).

An important outcome often used in JIA is health-related quality of life (HRQOL). In general, HRQOL is defined as "a multidimensional functional effect of an illness or a medical condition and its consequence upon the child or adolescent as perceived by the child, adolescent and family" (Ronen et al 2001). It has often been used to evaluate the effectiveness of treatment (Duffy et al 2000; Ronen et al 2001). Both disease symptoms and time-consuming treatments may alter quality of life of children with

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JIA by affecting numerous activities of daily living such as fine and gross motor activities as well as psychological and social functioning. In children with JIA, adherence is often measured by asking the parents, who act as proxy reporters for their children, since objective adherence is difficult to measure. This is especially true for some treatments such as exercises. Even if self-reported adherence can overestimate actual adherence, it can be useful in determining the frequency at which patients follow their treatment (Rapoff 2006). Moreover, perceived adherence may be important to measure in order to understand the parents' and children's motivation to change their behavior concerning treatment regimens. This is especially important for adolescents, who are at a crucial stage for developing self-management behaviours but for whom adherence to treatment is often not optimal (Tebbi et al 1986; Kyngas 1999; McQuaid et al 2003).

According to Feldman and colleagues (2006), adherence to treatments in JIA may be associated with better outcomes. However, this study looked only at the parents' perceptions of their child's adherence and HRQOL. Previous results obtained from the current study population showed that some aspects of quality of life and adherence are not perceived the same way by parents and children (Toupin April et al 2006a, 2006b). Furthermore, the association between adherence and HRQOL may differ between parents and children, indicating that different aspects of the treatments are seen as associated with different outcomes depending on the respondent.

There are a few studies that looked at the link between adherence to treatment and quality of life in other populations. Some of them found that better adherence to treatment was associated with higher HRQOL or better disease outcomes (De Smet et al 2006; Oette et al 2006). However, one study found that while good adherence to corticosteroids resulted in better outcomes for severe asthma, this was not the case for mild to moderate asthma, supporting the idea that severity of the disease plays an important role in explaining outcomes of adherence (Greaves et al 2005). A negative association between adherence to treatment and quality of life was reported in sickle cell disease (Barakat et al 2005). This could be explained by the fact that high adherence to treatment can interfere with the patients' daily activities and therefore reduce perceived quality of life.

Other factors may be associated with HRQOL. Severity of disease is known to be negatively associated with quality of life (Ruperto et al 2004). Also, patients with severe disease may be more adherent to medication (Rapoff et al 2005; De Smet et al 2006). Disease duration is usually not related to quality of life in adult rheumatoid arthritis (Bekkelund

et al 1995). However, longer disease duration seems to be associated with lower adherence to treatment in children with JIA (Litt and Cuskey 1981). Age may be associated with adherence to treatment, since older children are usually less adherent (Tebbi et al 1986; Kyngas 1999; McQuaid et al 2003). Also, older children may have a lower quality of life because of their growing need for autonomy and of difficulties in social functioning, particularly during adolescence. Finally, complexity of the regimen may be associated with reduced adherence and a lower HRQOL (Greene et al 1982).

The objectives of this study were to examine the association between perceived adherence to treatment (medications and exercises) and HRQOL in children with arthritis from both the children's and parents' viewpoints. We also wanted to examine these relationships while taking into account age, severity and duration of the disease and number of prescribed arthritis medications (as a proxy for complexity of the regimen).

We hypothesized that HRQOL would be positively associated with perceived adherence to treatment.

Methods
Population
The study population consisted of all eligible patients with JIA, 9 to 18 years of age, and their parents, who attended the JIA clinic at the Montreal Children's Hospital in Montreal, Canada between March 2003 and February 2004. Children younger than 9 years old were not included in the study because of the attention span and accuracy required to respond to the questionnaires. Parents and their children were approached to participate if they understood either English or French and if the children were currently undergoing treatment with medications or an exercise program for JIA. Parents and children signed informed consent and assent forms, respectively. Both parents and children were asked to respond to a HRQOL questionnaire and an adherence questionnaire on a single occasion. Fathers or mothers accompanying their child to the arthritis clinic were asked to respond to the questionnaires; if both parents were present at the clinic, they could either answer the questionnaires in tandem, or could decide that one would respond. Family members were included in the study only if they were living with the child who had arthritis. The study was approved by the Research Ethics Board of the Montreal Children's Hospital.

Measures
Health-related quality of life was measured using the Juvenile Arthritis Quality of Life Questionnaire (JAQQ), a validated

disease specific questionnaire (Duffy et al 1993, 1995, 1997, 2000). The JAQQ evaluates physical and psychological functioning and incorporates specific data from patients to measure HRQOL. The JAQQ has 4 domains: gross motor function, fine motor function, psychosocial function, general symptoms, and a section assessing pain. The questions on the four domains are phrased as follows: "How often have you/ your child, over the past two weeks, had difficulties with the following activities as a result of arthritis or its treatment?" Items include physical activities such as walking up or down a flight of ten stairs, participating in physical education class, fine motor activities such as cutting paper with scissors and tying shoe laces, psychosocial items such as getting teased a lot and feeling frustrated, and symptoms like stiffness and joint swelling. Each of the four domains is scored on a Likert-type scale from 1 to 7; lower scores indicate less difficulty doing activities. Pain is scored on a 100 mm visual analog scale (VAS). The mean score of a domain is calculated using the 5 highest scores (which indicate lower quality of life) while the total score of the JAQQ is derived by further calculating the mean of the four mean scores. The JAQQ has good psychometric properties: a good construct validity when compared with pain scored on a VAS (correlation coefficient = 0.72) and a responsiveness to change of 0.71 (Duffy et al 1993, 1995, 1997). This instrument has been validated in French and English for children 9 years of age and older (Duffy et al 2000).

The Parent Adherence Report Questionnaire (PARQ) (De Civita et al 2005), which has been validated in both English and French, was used to assess adherence from the point of view of the parents. Four questions are repeated for each treatment component including medication, exercises and splints, and specifically address adherence to treatment, difficulties in following treatment, frequency of negative reactions associated with following treatment, and the degree of perceived helpfulness of treatment. There is also a question assessing who is responsible for making sure that the child follows each of the treatments. Questions are scored separately on a 100 mm visual analog scale for each type of treatment as follows: "For each treatment prescribed to your child, please place a single vertical mark on the lines below at the level which best describes how often your child follows treatment recommendations as prescribed by the healthcare provider in the past three months". We also adapted the PARQ so that it could be administered to the children and called this questionnaire the Child Adherence Report Questionnaire (CARQ). The adaptation of the PARQ was minor; it involved addressing the questions to the child instead of the parent and simplifying some of the wording (eg, how hard you found it to follow your treatment" instead of "your child's general level of difficulty in following treatment"). The CARQ used the same visual analog scale as the PARQ and can be used with children who are nine years and older (McGrath 1986; Varni et al 1987). We pre-tested the CARQ in both English and French.

Data collection

While attending a clinic visit, parents completed the quality of life and adherence questionnaires (JAQQ and PARQ) in the waiting room while children answered equivalent questionnaires (JAQQ and CARQ) guided by an interviewer in a separate room. The same interviewer conducted all the child interviews. General demographic information and clinical data obtained from the charts included: age, gender, diagnosis (type of JIA), date of diagnosis, age at onset, sum of joint severity score (measure of disease severity) and number of prescribed arthritis medications. Sum of joint severity score (SJSS) is the sum of individual joint scores for effusion, tenderness and limitation in range of motion. Higher scores indicate higher severity (PRCSG 1982). We used the number of prescribed arthritis medications as a proxy for the complexity of the treatment regimen. Data concerning the number, frequency and types of prescribed exercises were not available. Exercise programs could vary from one child to the next because the physical therapist had tailored them to the specific needs of each child.

Analysis

Pearson correlation coefficients were used to analyze the association between perceived adherence to treatment and HRQOL. Linear regression models explored the associations, taking into account age of the children, severity and duration of the disease and number of prescribed arthritis medications. Because age, severity and duration did not follow a normal distribution, we dichotomized these variables at the median score. Age was classified as 8 to 12 years old and 13 to 18 years old, duration was classified as 0 to 5 years and 6 to 16 years, and severity of the disease measured by the SJSS was classified as 0 to 1 and 2 to 40. SJSS categories indicate the quasi absence vs. the presence of joint activity. Interactions between some factors (disease severity, disease duration and age) and adherence were also tested, since severity, duration and age may modify the association between adherence and quality of life. A linear regression also explored the associations between adherence to treatment and pain while taking into account the same cofactors (age, severity, duration of

the disease, and number of prescribed arthritis medications). We performed these analyses separately for both parents and children.

Results

There were 17 persons (23.6%) who declined to participate in this parent-child dyad study. Another five started to complete the questionnaires but did not have time to finish because of their appointment with the rheumatologist, leaving a total of 50 pairs who completed the questionnaires in their entirety. The children who refused to participate in the study were similar to the children included in the study with respect to age (12.94 vs. 12.67, p = 0.7), disease severity (SJSS: 4.00 vs. 4.76, p = 0.7) and number of prescribed medications (mean: 1.65 vs. 1.49, p = 0.6). Seventy one percent of nonparticipants were girls and 59% were French-speaking nonparticipants, which was also similar to participants' characteristics (p = 0.3 and p = 0.4, respectively). Mean age of participating children was 12.67 years (SD = 2.68) and mean disease duration was 6.13 years (SD = 4.00). Most of the children were girls (81.8%), 75.5% of the parent respondents were mothers, and 48.1% were French-speaking (Toupin April et al 2006a, 2006b). Concerning the types of arthritis, 23.6% of children had oligoarthritis, 34.5% polyarthritis, 10.9% systemic arthritis, 14.5% enthesitis-related arthritis, 7.3% psoriatic arthritis, and 9.1% had another type of arthritis. A description of the demographic and disease-related characteristics of the cohort is summarized in Table 1.

Table 2 describes mean perceived treatment adherence, HRQOL, and pain from both the children's and parents' perspectives as determined by our previous work using the same study population (Toupin April et al 2006a, 2006b). Paired t-tests indicated no significant differences between parents' and children's assessments of these constructs. However, our previous work indicated that the agreements between parents and children for adherence to medications and the fine motor function subscore of HRQOL were low (ICC = 0.32, 95% CI = 0.04, 0.56 and ICC = 0.35, 95% CI = 0.08, 0.57, respectively). Moreover, agreement for adherence to exercises between adolescents and their parents was lower than for younger children (Toupin April et al 2006b).

In the current study, better perceived adherence to medications was associated with a better HRQOL according to the children (Pearson r = −0.43, (p < 0.01). However, this association was not significant according to the parents' point of view (Pearson r = −0.28, p = 0.08). Perceived adherence to exercises was not associated with HRQOL from the

Table 1 Demographic, disease-related, and treatment-related characteristics of the sample of children with juvenile idiopathic arthritis (n = 50)

	Mean (SD)	Range	n (%)
Age (years)	12.67 (2.68)	8–18	
Age at onset (years)	6.55 (4.48)	Birth–14	
Disease duration (years)	6.13 (4.00)	0–16	
Active joint count (AJC)	1.07 (1.76)	0–10	
Sum of joint severity score (SJSS)	4.76 (7.25)	0–40	
Use of medications			43 (82.7)
Use of NSAID			33 (60)
Use of corticosteroids			6 (10.9)
Use of TNFα-inhibitors			7 (12.7)
Use of other DMARDs			33 (60)
Use of subcutaneous drugs			23 (41.8)
Number of prescribed arthritis medications	1.54 (1.06)	0–4	
Side effects			13 (31.7)
Use of exercises			27 (51.9)

Abbreviations: DMARDs, disease-modifying antirheumatic drugs; NSAID, nonsteroidal anti-inflammatory drugs.

children's (Pearson r = −0.08, p = 0.64) or the parents' points of view (Pearson r = −0.17, p = 0.31).

We used multiple linear regression to adjust for age, severity, duration of disease and number of prescribed arthritis medications (see Table 3). Better perceived adherence to medications remained associated with a better HRQOL from the children's perspective. However, better perceived adherence to exercises was associated with a better HRQOL from the parents' perspective. Other factors associated with HRQOL were disease severity and number of prescribed medications. Higher disease severity was strongly associated with a lower HRQOL from both parents' and children's perspectives while number of prescribed medications was negatively associated with HRQOL from the children's point of view. Age and disease duration showed no association with HRQOL. Neither the interaction between severity and adherence, that between duration and adherence nor that between age and adherence were significantly associated with HRQOL from the parents' or children's perspectives.

Further analyses showed that perceived adherence to medication according to children was associated with three of the four domains of the HRQOL (see Table 4). Higher adherence to medication was associated with better fine motor function, gross motor function and psychosocial function. However, adherence to medication was not significantly associated with symptoms. Higher disease severity was associated with lower gross motor function while higher

Table 2 Mean perceived adherence and health-related quality of life (HRQOL) of children with juvenile idiopathic arthritis according to parents and children (n = 50)

	Mean (SD) According to children	Mean (SD) According to parents	P* value for the comparison between parents and children
Treatment adherence[1]:			
To medications	84.45 (17.63)	83.07 (21.12)	0.59
To exercises	61.60 (28.85)	54.88 (31.15)	0.24
HRQOL[2]:			
Gross motor	2.53 (1.40)	2.80 (1.93)	0.14
Fine motor	1.52 (0.83)	1.61 (0.84)	0.54
Psychosocial	2.16 (1.08)	2.22 (1.20)	0.82
Symptoms	2.41 (1.06)	2.44 (1.20)	0.78
Total score	2.15 (0.86)	2.27 (0.93)	0.27
Pain[3]:	20.70 (21.28)	17.99 (22.10)	0.27

Notes: [1]On a visual analog scale from 0 to 100, 100 being a better adherence; [2]On a scale from 1 to 7, 7 being a worse HRQOL; [3]On a visual analog scale from 0 to 100, 100 being worse pain; *Paired t-test.

number of prescribed medications was associated with lower fine motor function.

Also, according to parents, perceived adherence to exercises was associated with only two of the four domains of HRQOL. Adherence to exercises was associated with less symptoms and better psychosocial functioning (see Table 5). However, adherence to exercises was not associated with other domains of HRQOL. Higher disease severity was associated with lower gross motor function, lower psychosocial functioning and more symptoms while number of prescribed medications did not seem to have an impact on HRQOL according to parents.

Both adherence to medication and exercises were not associated with pain from the children's points of view ($\beta = -0.08$, 95% CI = -0.48, 0.32 and $\beta = -0.15$, 95% CI = -0.39, 0.09, respectively) or from the parents' points of view ($\beta = 0.07$, 95% CI = -0.25, 0.39 and $\beta = -0.03$, 95% CI = -0.27, 0.21, respectively).

Discussion

Our results indicate that parents and children perceive treatment adherence to be associated with better HRQOL. However, parents and children have different opinions on which treatment is associated with improved HRQOL.

Perceived adherence to medications in JIA was associated with HRQOL from the child's perspective. More specifically, it was associated with higher fine motor function, gross motor function and psychosocial functioning. These are all aspects which are important for children and adolescent participation in daily activities and peer interactions. This association was in accordance with our hypotheses. Perhaps children feel that taking their medications really improves their quality of life. Also, children who have a better HRQOL may be more motivated to take their medications, especially if they believe it improved their health. This is consistent with previous findings which showed that children with JIA perceived medications as being helpful and are more adherent

Table 3 Regression models of factors associated with health-related quality of life (total score)

Factors	β (95% CI) (according to children)	β (95% CI) (according to parents)
Adherence to medications	−0.02 (−0.04, -0.01)*	−0.006 (−0.02, 0.005)
Disease severity (SJSS)	0.53 (0.04, 1.02)*	1.04 (0.54, 1.53)*
Disease duration	−0.01 (−0.44, 0.46)	0.13 (−0.36, 0.62)
Age	0.36 (−0.07, 0.79)	0.32 (−0.14, 0.79)
Number of prescribed medications	0.31 (0.07, 0.55)*	−0.05 (−0.31, 0.21)
R²	0.48	0.49
Adherence to exercises	−0.002 (−0.01, 0.01)	−0.008 (−0.02, 0.000)*
Disease severity (SJSS)	0.73 (0.19, 1.27)*	1.25 (0.74, 1.76)*
Disease duration	−0.04 (−0.55, 0.46)	0.07 (−0.39, 0.53)
Age	0.28 (−0.23, 0.79)	0.04 (−0.46, 0.55)
Number of prescribed medications	0.23 (0.004, 0.46)*	0.02 (−0.21, 0.25)
R²	0.35	0.53

Notes: *p < 0.05.

Table 4 Regression models of factors associated with health-related quality of life domains from the children's point of view

Adherence to treatments	Fine motor function β (95%CI)	Gross motor function β (95%CI)	Psychosocial function β (95%CI)	Symptoms β (95%CI)
Adherence to medications	−0.01 (−0.03, -0.001)*	−0.03 (−0.05, −0.01)*	−0.03 (−0.05, −0.01)*	−0.02 (−0.03, 0.003)
Disease severity (SJSS)	0.30 (−0.24, 0.83)	0.96 (0.20, 1.73)*	0.28 (−0.42, 0.97)	0.59 (−0.09, 1.28)
Disease duration	0.03 (−0.52, 0.46)	−0.06 (−0.76, 0.65)	−0.07 (−0.70, 0.57)	0.18 (−0.45, 0.80)
Age	−0.06 (−0.41, 0.54)	0.64 (−0.04, 1.31)	0.31 (−0.30, 0.92)	0.42 (−0.18, 1.02)
Number of prescribed medications	0.48 (0.22, 0.74)*	0.30 (−0.07, 0.68)	0.18 (−0.16, 0.52)	0.26 (−0.07, 0.59)
R²	0.38	0.46	0.29	0.31
Adherence to exercises	0.003 (−0.01, 0.01)	0.002 (−0.01, 0.02)	−0.01 (−0.02, 0.01)	−0.004 (−0.02, 0.01)
Disease severity (SJSS)	0.51 (−0.08, 1.11)	1.24 (0.44, 2.05)*	0.31 (−0.50, 1.11)	0.89 (0.17, 1.61)*
Disease duration	−0.16 (−0.71, 0.40)	−0.22 (−0.98, 0.53)	0.20 (−0.55, 0.95)	−0.03 (−0.70, 0.65)
Age	0.04 (−0.52, 0.59)	0.65 (−0.11, 1.40)	0.09 (−0.67, 0.84)	0.37 (−0.30, 1.04)
Number of prescribed medications	0.39 (0.14, 0.64)*	0.15 (−0.19, 0.48)	0.19 (−0.15, 0.53)	0.18 (−0.13, 0.49)
R²	0.31	0.36	0.12	0.30

Notes: *p < 0.05.

to medications than exercises (Toupin April et al 2006b). On the other hand, exercises are time and energy consuming, and may interfere with social aspects of their life much more than medication. This is especially true for adolescents, for whom social activities are often given a larger priority and who experience many difficulties with respect to HRQOL (Shaw et al 2006). Adolescents are also more responsible for their own treatment than younger children, which is indicated by the difference in percentage of children responsible for following their treatments between adolescents and younger children in our sample (34.8% and 28% for medications and 73.9% and 45% for exercises, respectively). Children may have difficulty performing exercises properly and therefore fail to feel the benefits on HRQOL. These difficulties may also be exacerbated by the fact that parents are less responsible (either partially or fully) for ensuring adherence to exercises than medications (44.2% vs. 86.4%) (Toupin April et al 2006b).

Perceived adherence to exercises was associated with HRQOL total score according to parents, which corroborates our hypotheses. When looking closer at the domains of HRQOL, it was associated with fewer symptoms and better psychosocial functioning. This may indicate that good adherence to exercises reduces the manifestation of the disease and improves the psychosocial functioning of their child. This could explain why, in a previous study with the same study population, we found that 80% of parents perceived exercises as being helpful (Toupin April et al 2006b). Another plausible explanation is that children with fewer symptoms and better psychosocial function have an easier time doing their exercises and tend to adhere more to this aspect of treatment as compared with those with more symptoms and psychosocial problems. Parents may favor exercises because they are worried about possible side effects of medications.

Discrepancies between parents and children may reveal different views of treatment helpfulness, adherence and its

Table 5 Regression models of factors associated with health-related quality of life domains from the parents' point of view

Adherence to treatments	Fine motor function β (95%CI)	Gross motor function β (95%CI)	Psychosocial function β (95%CI)	Symptoms β (95%CI)
Adherence to medications	−0.001 (−0.01, 0.01)	−0.02 (−0.04, 0.01)	−0.001 (−0.02, 0.02)	−0.01 (−0.02, 0.01)
Disease severity (SJSS)	0.26 (−0.32, 0.84)	1.93 (0.83, 3.03)*	0.64 (-0.08, 1.35)	1.32 (0.55, 2.09)*
Disease duration	0.28 (−0.29, 0.85)	0.06 (−1.03, 1.15)	0.20 (−0.50, 0.90)	−0.03 (−0.80, 0.73)
Age	0.38 (−0.16, 0.93)	0.68 (−0.35, 1.72)	−0.09(−0.76, 0.58)	0.31 (−0.42, 1.03)
Number of prescribed medications	0.14 (−0.16, 0.44)	v0.19 (−0.77, 0.38)	−0.20 (−0.57, 0.18)	0.04 (−0.36, 0.45)
R²	0.16	0.43	0.15	0.34
Adherence to exercises	0.01 (−0.01, 0.02)	−0.01 (−0.03, 0.01)	−0.01 (−0.03, −0.002)*	−0.01 (−0.03, 0.001)*
Disease severity (SJSS)	0.14 (−0.50, 0.77)	2.21 (0.96, 3.45)*	0.99 (0.25, 1.74)*	1.66 (0.91, 2.42)*
Disease duration	0.30 (−0.27, 0.88)	0.18 (−0.95, 1.30)	0.10 (−0.57, 0.77)	−0.30 (−0.98, 0.38)
Age	0.55 (−0.08, 1.18)	0.29 (−0.94, 1.52)	−0.51 (−1.24, 0.23)	−0.16 (−0.91, 0.58)
Number of prescribed medications	0.14 (−0.14, 0.43)	−0.13 (−0.68, 0.42)	−0.04 (−0.37, 0.29)	0.11 (−0.22, 0.44)
R²	0.20	0.39	0.27	0.44

Notes: *p < 0.05.

importance in the lives of parents and children, which is consistent with previous findings (Toupin April et al 2006b). It may be problematic, especially for adolescents since they are at risk of nonadherence and are at a crucial stage for developing self-management behaviors.

Disease severity was associated with HRQOL. Those with higher disease severity had a lower perceived HRQOL, which has been shown by others (Ruperto et al 2004). Although the main effect was significant, there was no interaction between severity and adherence which is not consistent with the findings of Greaves and colleagues (2005) in asthma. However, most of the children in our study did not have severe disease. Also, disease duration was not associated with perceived HRQOL which is consistent with the findings of Bekkelund and colleagues (1995). However, age was not significantly associated with perceived HRQOL, which is not perfectly in tune with Shaw and colleague's (2006) finding that adolescents experience many difficulties with respect to HRQOL. The interaction between age and adherence to treatment was also nonsignificant, which may reveal that adolescents and younger children have approximately the same views of the association between treatment adherence and their HRQOL.

Following a more complex treatment regimen (having a higher number of prescribed arthritis medications) was associated with lower HRQOL according to children. This may reflect that children who were prescribed more medications have a more severe disease and a lower HRQOL. However, the regression model controlled for disease severity. Perhaps following a more complex medical regimen may have a negative impact on HRQOL because of the time involved in following treatments or possible resultant side effects. Moreover, higher number of prescribed medications was associated with lower fine motor function, which could be explained by the fact that children who take more medication may have more severe disease and take subcutaneous medications which involve a high burden of care. Children may be reluctant to undergo an additional time and energy consuming treatment such as exercises, which may result in stiffness of the upper extremities and decreased fine motor function. Those who take more medication may also have more polyarticular involvement (often involving joints in the fingers and hands) leading to lower fine motor function.

Perceived adherence to exercises in JIA was not associated with HRQOL from the children's perspective and perceived adherence to medications was not associated with HRQOL according to the parents. Although these results did not support our initial hypotheses, they were similar to those of Hays and colleagues (1994). There may be factors influencing adherence that contribute to the complexity of the relationship between adherence and HRQOL. For example, disease severity and perceived effectiveness of the particular treatment appear to influence adherence (De Smet et al 2006; Feldman et al 2007). The next step would be to build a model that examines factors predicting adherence in order to better understand this important concept and its association with HRQOL.

Study limitations

Parents who accepted to participate in this study may be different than nonparticipants, leading to a possible selection bias. Participants may be more motivated, want to learn more about their child's state and be more communicative. Their children may be more adherent to treatment than those who refused to participate. Also, these children may have a better HRQOL since their parents want to share their experiences with the researchers. These characteristics of the responders could reinforce our hypothesis of a positive association between adherence to treatment and HRQOL. Nevertheless, we found different results for parents and children regarding the association between adherence and HRQOL. Social desirability bias may have occurred because children answered the questionnaires with an interviewer, possibly overestimating their adherence and HRQOL.

In the linear regression models, age, severity, duration of disease, and number of prescribed arthritis medications were included but other factors may have been important to consider, eg, comorbidities and socioeconomic status. Also, the number of prescribed medications is an imperfect proxy for the complexity of the regimen given that children often have to do exercises simultaneously. Unfortunately, we did not have information on the exact exercise regimen. Treatment adherence was assessed in a subjective fashion; we wished to evaluate the perceived impact of the treatments and therefore understand the motivations of both parents and children in following treatment regimens.

Finally, we cannot conclude that there is a causal association between perceived adherence and HRQOL since the study design was cross-sectional. It is possible that higher perceived adherence has a positive effect on HRQOL or that better HRQOL has an impact on perceived adherence. Longitudinal studies could help elucidate this relationship.

Conclusion

Perceived adherence to treatment was associated with certain aspects of HRQOL which may indicate that medications

and exercises decrease the effects of disease and result in improved HRQOL. However, other variables such as complexity of the medical regimen seem to be negatively associated with outcomes according to children's point of view. Our results indicate that parents and children perceive adherence to treatment to be associated with different outcomes. Understanding perceptions and motivations of both informants regarding treatment is crucial since children learn how to comply with their treatment regimen with the help from their parents. More communication between parents, children and their health care providers may lead to a better understanding of each other's goals in treatment, better treatment adherence and ultimately better outcomes.

Acknowledgments

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