

School Support and Functioning for Children with Juvenile Rheumatic Diseases

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Published online: 10 February 2007

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Abstract Information about ways to support children with Juvenile Rheumatic Diseases (JRDs) in school will help maximize their involvement in this setting. For this study, children with JRDs provided their views about the support they need from school nurses, teachers, classmates, friends and leaders of after school activities. Parents provided information about their child's disease and about family functioning. Results indicated that positive family functioning was related to lower needs for support from school nurses, teachers, and classmates. Family functioning was not related to the support children needed from good friends. Receiving help during after school activities and school nurse availability were areas of concern for some children. Future studies should continue to assess needs for school support for adolescents, who may need more support at school due to a decreased reliance on family support.

Keywords School support · Arthritis

Rheumatic diseases and other multisystem diseases that involve inflammation of the blood vessels, musculoskeletal system, and skin are common causes of disability among children (Rapoff, McGrath, & Lindsey, 2003). Juvenile Idiopathic Arthritis (JIA) is the most common rheumatic disease, and it is one of the most common chronic illnesses for children in the United States. Other JRDs include systemic lupus erythematosus (SLE), juvenile dermatomyositis (JDMA), and juvenile ankylosing spondylitis (JAS). These disorders affect about 300,000 children in the United States. The most common characteristic of JRDs is recurrent, unpredictable phases of pain flare-ups during which children can experience exacerbation of pain symptoms, limitation of movement, joint swelling, and fatigue (Sandstrom &

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Schanberg, 2004; Schanberg, Gil, Anthony, Yow, & Rochon, 2005). Children with JRDs often face physical limitations (e.g., decreased mobility due to joint deterioration) and medical problems (e.g., vision problems and growth retardation) that make involvement in classroom and after school activities difficult (Wagner et al., 2003).

Due to physical problems and pain related to their JRDs, children may need assistance and support to participate fully in school activities (LeBovidge, Lavigne, & Miller, 2005; Schanberg et al., 2005). These children may have difficulty doing things like climbing stairs, opening doors, carrying books, arriving at class on time, completing writing assignments, waiting in lines, and participating in physical education classes (Lineker, Bradley, & Dalby, 1996). They also may be underserved, in terms of receiving needed assistance to manage pain related to their JRD at school (Lovell et al., 1990; Taylor, Passo, & Champion, 1987). Varni, Thompson, and Hanson surveyed parents of children with JIA and found that 20% of their sample reported that having pain had a negative impact on the quality of the children's schoolwork. Some children with JRDs may not get the assistance they need to do well in school. Whitehouse, Shope, Sullivan, and Kulik (1989) reported that only 15% of the children with JRDs in their sample had educational planning to provide support at school, whereas 46% had experienced school-related problems. The physical limitations may be especially problematic during physical education classes. Whitehouse et al. found that only 52% of the children participated fully in physical education classes.

Von Weiss et al. (2002) found that children with JIA who reported having high levels of support from classmates and parents were better adjusted than those who reported lower levels of support. In addition, they found that support from parents and classmates were more important to children than support from teachers and good friends. This study examined children's satisfaction with school support from nurses, teachers, classmates and good friends for children with JRDs. Children provided information about the pain and fatigue they experienced at school and their ideas for ways to improve their support during school. In addition, children rated their support from after school leaders and provided information about their involvement in after school activities. Participating in sports may be particularly difficult for children with JRDs (Varni, Thompson, & Hanson, 1987), and learning about children's perceptions of after school sports was of particular interest. The children provided information about the aforementioned topics on the *How is School Survey*, which was developed by 3 children with JRDs and their parents during a series of focus groups. Bostock and Freeman (2003) used a similar participatory approach to examine adolescents' perceptions of the support they need, and how sources of support can be improved, to utilize healthcare services.

Parents completed a short survey providing demographic data and information about their child's disease history. They provided information about family functioning using the *General Functioning Scale (GFS)* of the *McMaster Family Assessment Device* (Epstein, Baldwin, & Bishop, 1983). This scale assesses the general nature of family functioning in terms of being positive or healthy versus negative or unhealthy. Regression analyses were conducted to examine the relationship between parent ratings of family functioning and children's ratings of needs for support at school. Reisine (1995) reviewed the literature on family functioning and concluded that higher family support was related to better outcomes (e.g., better school achievement and fewer psychosocial problems) for children with JRDs. Others have found that more positive family functioning is related to better adjustment for children with JRDs (Helgeson, Janicki, Lerner, & Barbarin, 2003) and having more friends (Timko, Stovel, Moos, & Miller, 1992). To our knowledge, the relationship between family functioning and support needed at school has not been assessed, and the current study adds to the literature in this area.

Method

Participants

Fifty girls and 32 boys participated. They ranged in age from 6 to 18 years ($M = 12$ years, 4 months, $SD = 3$ years, 2 months). Seventy-five percent of the children had Juvenile Idiopathic Arthritis and the other 25% had related disorders.¹ Children were diagnosed with these disorders between the ages of 7 months and 15 years ($M = 6$ years, 2 months; $SD = 3$ years, 10 months). Data on ethnic group were not recorded at the request of a reviewer from the Arthritis Foundation. Parents attending events sponsored by the Arthritis Foundation were recruited for this study. Parents ranged in age from 20 to 50 years, with a mean age of 37 years and 6 months ($SD = 6$ years, 2 months). Seventy were married and 11 were single, widowed or divorced (1 parent did not provide this information). Parents provided consent and children provided assent to participate. A university-based institutional review board and reviewers at the National Arthritis Foundation office approved this study.

Measures

*How is School Scale.*² This survey consisted of questions assessing how much support children needed from nurses, teachers, classmates and friends. It also included questions assessing their experience of pain and fatigue related to their disease and the number of days they experienced these symptoms at school. Other questions examined the types of support children needed from nurses, teachers, classmates, and friends. Additional questions allowed children to rate the amount of support they needed from adults after school as well as the types of support they needed during after school activities. A 10-point scale was used for questions requiring ratings and other questions utilized a multiple choice or open-ended format.

Parent Information Form. Parents provided background information about their child's disease (number of hospitalizations related to the child's JRD) and about themselves (e.g., marital status, age) on this brief survey, which was developed for this study.

General Functioning Scale (GFS; Epstein et al., 1983). This scale was designed to measure the general health of family functioning. It consists of 12 items about family functioning that are answered on 4-point Likert scales ranging from "strongly disagree" to "strongly agree." Questions on this scale assess perceptions in several areas, such as family activities, ability to communicate feelings with each other, and acceptance. For the standardization sample, the mean *GFS* score was 2.2 ($SD = .58$; Epstein et al., 1983). The internal consistency estimate for this scale (Cronbach's alpha) was .92. Test-retest reliability for this scale was .71 over a 1-week retest interval. Byles, Byrne, Boyle, and Offord (1988) used the *GFS* to evaluate global family functioning for over 2,000 children and their results supported the construct validity of this subscale as a measure of family functioning.

¹The name for the illness was provided by the children. Most of the children (22%) with related disorders knew the name of their chronic illness. These included dermatomyositis ($n = 6$), fibromyalgia ($n = 2$), familia mediterranean ($n = 2$), HLA-B27 ($n = 1$), lupus ($n = 1$), ankylosing spondylitis ($n = 3$), psoriatic arthritis ($n = 2$), and uveitis ($n = 1$). For the children with JIA, several did not specify the type ($n = 18$), most others had polyarticular JIA ($n = 28$), followed by pauciarticular ($n = 8$) and monoarticular ($n = 1$). Nine children reported that they did not know the name for their disease.

²The *How is School Survey* is available from the first author.

Procedure

Parents learned about this study in one of two ways. For the first method, parents were invited to participate through a letter developed by Dr. Nabors and staff at a Midwestern branch of the Arthritis Foundation. Some of these parents returned surveys by mail and others returned surveys at a foundation event for children with JRDs and their families. For the second method, handouts describing the study and study measures were distributed in conference packets to parents attending a conference sponsored by the Arthritis Foundation. These parents returned the questionnaires via mail. Due to maintaining confidentiality of names and addresses of parents and children on lists at the Arthritis Foundation, it was not possible to track how many parents were invited to participate. Instructions in the packets requested that parents complete the *Parent Information Form* and the *GFS* and children complete the *How is School Survey*. Some parents did note that they provided some help to their children in filling out the *How is School Survey* when they returned information. Two research assistants coded qualitative data on the *How is School Survey* using a grounded theory (Henwood & Pidgeon, 2002; Strauss & Corbin, 1990) approach to search for common themes in the children's responses. Disagreements in their perceptions about themes emerging from the data were resolved by consensus.

Results

Children were absent for an average of 4 days of school in the past year ($SD = 9.53$ days, range from 0 to 60 days). Three percent of the children reported missing no days of school. Thirty-nine percent had been in the hospital due to their arthritis and 75% reported experiencing pain from their arthritis or related disease. Most of the children stated that their pain began in the morning (65%), while 22% said their pain began at school. When responding to a question about when "pain usually begins," the children reported that their pain began because they were inactive or overactive (52%), they woke up after sleeping and were in pain (22%), or that the pain was related to a weather change (13%). Seventy percent had trouble concentrating when experiencing pain at school.

More children reported needing help from good friends (73%) at school, compared to needing help from classmates (53%), teachers (57%), and nurses (46%). Children's mean ratings of support needed from teachers ($M = 2.98$, $SD = 3.39$), nurses ($M = 2.32$, $SD = 3.28$), and classmates ($M = 2.54$, $SD = 3.25$) were lower than support needed from good friends ($M = 4.30$, $SD = 3.92$).

Ten of the children reported that there was not a nurse at their school and 22 had a part-time nurse available. Twenty-four of the children reported they had a full time nurse. Twenty-seven percent of the children had medication available at school. However, the majority of the children (77%) did not take medication at school. Children provided comments about their reasons for not wanting to take medication at school. Reasons involved either convenience ("the nurse isn't always available; because I have a lot of them and it takes a while [to take the medications]") or not wanting to be different from other children.

Sixty-seven of the children were enrolled in after school activities—46 played sports and 27 were in a club. The mean number of after school activities was 2.22 ($SD = 1.59$; range 0 to 6). Having a JRD made participation more difficult for 50%. Thirty-five percent indicated that adult leaders were not available to help them if they were experiencing pain. Thirty-two mentioned that adults were not making all of the changes they needed to fully participate in after school activities. Changes they endorsed included: time to rest or take breaks, being

able to slow down or participate in sports at a slower pace, or modification of activities when having a pain flare-up. However, some of the children ($n = 8$) did not want any modifications; one child described it this way, “Nothing (no changes should be made during after school activities) because I play by the rules.”

Regression Analyses. Four regression analyses were conducted using children’s ratings of the amount of support needed from nurses, teachers, classmates and good friends as the dependent variables. Predictor variables included children’s reports of feeling tired at school, number of days experiencing pain in school each week, and *GFS* scores. Preliminary regression analyses were conducted to examine the relationship between demographic factors, disease factors, and the dependent variables. Findings from these preliminary analyses indicated that age and sex of the children, diagnosis (type of JRD), age at which the diagnosis occurred, and number of times children were hospitalized were not related to children’s ratings of need for support from nurses, teachers, classmates, or friends. Table 1 presents the Beta, t , and p values and standard errors for the final regression models for the aforementioned dependent variables. Interaction terms were not significant and were not included in the final models.

The regression model for the amount of support that children needed from teachers was significant, $F(3, 67) = 4.81, p < .01$, and predicted 18% of the variance. Significant predictors were mean *GFS* scores and being tired at school (see Table 1). Children with poorer family functioning and those who were tired at school needed more support from their teachers.

Family functioning (mean *GFS* scores) and taking medicine at school were related to how much help children needed from the school nurse, $F(2, 69) = 6.20, p < .01$ (see Table 1). These factors predicted 15% of the variance in the dependent variable. Needing to take medicine at school was related to support needed from the nurse, and there was a trend for higher family functioning to be related to lower ratings of support needed from nurses.

The final model for support needed from classmates was significant, $F(2, 64) = 6.95, p < .01$. Mean *GFS* scores and the number of days per week that the children experienced pain predicted 17.8% of the variance in the dependent variable. Children with poorer family

Table 1 Regression models for support children needed from teachers, nurses, classmates and good friends

Support variables	Predictors	Beta	SE	t	p
Teacher	<i>GFS</i> scores	-.725	2.77	-2.03	.05
	Tired	-1.95	6.66	-2.00	.05
Nurse	<i>GFS</i> scores	-.215	.85	-1.92	.06
	Medicine	-.300	.93	-2.69	.01
Classmate	<i>GFS</i> scores	-.302	.84	-2.59	.05
	Days in Pain	.234	.14	2.01	.05
Good Friend	<i>GFS</i> scores	-.189	1.03	-1.64	.105
	Tired	-.333	.90	-2.89	.01

Note. The dependent or outcome variables were how much help children needed from nurses, teachers, classmates, and friends.

functioning and who experienced pain more days per week reported needing more support from classmates (see Table 1).

Mean *GFS* scores and feeling tired at school were predictors in the final model for how much support children needed from good friends at school, $F(2, 68) = 7.77, p < .001$, predicting 19% of the variance. Feeling tired at school was a statistically significant predictor, but mean *GFS* scores were not significant (see Table 1). Children who were tired at school were more likely to report needing support from good friends.

Qualitative Analyses. The research assistants identified several themes summarizing the children's ideas about the support they needed at school. Children needed emotional support from teachers and nurses, especially when they were dealing with a pain flare-up. A few of the children reported that nurses could help by explaining the nature of a JRD to teachers and classmates (e.g., "Make others understand; she's [the nurse] the smartest one in the school about JRA [Juvenile Idiopathic Arthritis]"). Teachers could help by explaining pain flare-ups to physical education (PE) teachers when the child had a flare-up at school and needed to rest or not participate in PE class. In addition, children reported that teachers could offer support by being more understanding of the pain and limitations they face, "Have more patience. They (teachers) don't understand pain they can't always see." The children needed assistance from nurses when they took medication at school or needed a place to rest, whereas they reported that teachers could provide assistance by making modifications to assignments when they experienced pain or were tired.

Classmates and good friends could be supportive by carrying books, taking notes, and walking children to the nurse if necessary. They also could work to understand the impact of the illness, "Know that if I'm sitting out of PE it's because I hurt." Research assistants reported that the scope of supportive behaviors was broader for good friends than for classmates. For example, a good friend could help with distracting the child so that he or she could forget about the illness or help with pain management ("If I hurt, talk me through it") as well as help with disease management ("keep me from overdoing it"). These types of emotionally supportive actions were not mentioned as frequently for classmates.

Discussion

Study results indicated that parents' ratings of positive family functioning were related to children's reports of needing less support from teachers, classmates, and nurses. These findings are consistent with literature showing that family support and positive family functioning is related to positive outcomes for children with JRDs (Hegelson et al., 2003; Reisine, 1995; Timko et al., 1992). In contrast, parent ratings of family functioning were unrelated to children's ratings of the support they needed from good friends at school. It may be that support from a friend is a key ingredient to adjustment at school for children with JRDs, whereas support from teachers, classmates and nurses becomes more important when family functioning is less positive. Similar to findings from other research, children needed teachers and nurses to be supportive of their health needs, both emotionally and by helping to make modifications to the physical environment and classroom assignments (Lineker et al., 1996; Whitehouse et al., 1989).

Interestingly, children provided their highest ratings (near the midpoint of the scale) for needs for support from good friends. It appeared that children with JRDs benefited from emotional support from good friends irrespective of the level of support from their family. In addition to emotional support, children's comments indicated that they would be more accepting of help with disease and pain management from good friends. La Greca and her

colleagues have developed measures of support from family and friends that are valuable tools for assessing the needs of children who have diabetes. Developing similar measures for children with JRDs or modifying La Greca's measures for use with children with JRDs is recommended to have a measure available to assess this important construct (Bearman & La Greca, 2002; La Greca & Bearman, 2002; La Greca et al., 1995).

Children's responses on the *How is School Scale* also indicated several areas of concern. Fifty percent of the children reported that their disease made participation in after school activities more difficult and 35% indicated that adult leaders were not able to help them if they were experiencing pain related to their disease. Support during after school activities emerged as an area where children with JRDs may require more support from adults. Some of the children's comments also demonstrated that participation in physical education classes can be a source of stress, and that teachers can help by communicating with physical education teachers if the child is having a "hard" day, like those including a pain flare-up at school. Ten of the 82 children reported that there was not a nurse on duty at their school and 22 reported that a nurse was available only on a part-time basis. Children with JRDs may experience pain flare-ups during the school day and it remains important for school nurses to be available and have permission to dispense pain medication. If nursing staff is not available, alternate plans for dispensing medication during pain flare-ups need to be included in care plans for school. These plans need to be sensitive to the fact that children may wish to manage their illness in subtle ways that minimize differences between them and their peers.

Several of the variables that were examined in exploratory models were not related to support children needed from others at school. It may be that some of these factors, such as age at diagnosis and gender, would be significantly related to other variables indicative of school adjustment, such as grades or perceptions of the child by his or her classmates. Age was not related to the amount of support the children needed from others. However, the children who participated in this study were fairly young and support from others may be more important for high school-age adolescents who are more independent, in terms of managing their illness. Surprisingly, the number of days that the child experienced pain at school was only related to needs for support from classmates. Children experiencing more pain at school may rely on their classmates for emotional support to help them get through "hard" days. Information from our qualitative analyses appeared consistent with this conclusion. The children's written comments suggested that individual differences might exist, both in terms of children's illness perceptions and perceptions of the amount of support needed from others. Frank and colleagues (1998) reported that adaptation for children with JRDs follows individualized trajectories (i.e., different trajectories for individual children). Thus, it remains critical to ask individual children how having a JRD impacts school adjustment and achievement and to design care plans for school that are customized to each child's needs.

Several shortcomings limited generalizability of study results. For example, the children's perceptions of family functioning and parents' attitudes about school support were not assessed. It is important to examine the perspectives of both, as children's opinions may differ from those of their parents. Data were collected using two different procedures and this may have introduced some bias, if two different samples were recruited. This study did not have an objective measure of disease severity, which may be related to support needed at school. Questions on the survey did not address children's needs for support during other neighborhood and community activities. Given the young age of this sample, these would be critical settings for examination. Because the children were relatively young, examining their reports about support needed from parents at school may have provided interesting findings (von Weiss et al., 2002). Also, children's ratings about the amount of support they

needed at school were relatively low; this may have occurred because children in our sample were “high functioning” in terms of managing their illness. Data supporting the reliability and validity of the *How is School Scale* are lacking, as it was developed by youth with JIA and their parents for this study. On the other hand, use of a participatory approach may lead to good quality research that affects change (Kirby, 2002), and this was our purpose in conducting this study.

Study results suggested that children with JRDs who are experiencing less family support or with families facing stress may require more support from school staff. Identifying ways to meet school needs for children with chronic illnesses, who do not have family support, remains an area for research. Irrespective of family functioning, children with JRDs will continue to need support from adults at school and during after school activities. Developing written care plans, with advice from the child’s medical team, parents and the child, will assist school staff in supporting children with JRDs. It will be critical to examine needs for school support for older youth and youth who report having difficulty managing their illness at school. Adolescents with JRDs, who rely less on family support (Hegelson et al., 2003) and face multiple demands at school (e.g., needs to switch classrooms quickly and carry many books), may benefit support from teachers and good friends to manage their disease and participate to the fullest extent possible in school activities.

Acknowledgement The authors would like to thank the Arthritis Foundation, Department of Psychology at the University of Cincinnati, and the Ohio Department of Mental Health for supporting this research. Moreover, the authors would like to thank Tiffany Nash, Heather Lehmkuhl, and Mark Petre for their help with data entry as well as their assistance with coding the children’s comments. Finally, the authors would like to thank the children and their families for completing study measures and would like to extend our warmest regards to the children and parents who helped us to develop this study.

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