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The influence of family environment on long-term psychosocial functioning of adolescents with juvenile fibromyalgia

Soumitri Sil, PhD[1], **Anne Lynch-Jordan, PhD**[1,2], **Tracy V. Ting, MD**[2,3], **James Peugh, PhD**[1], **Jennie Noll, PhD**[1], and **Susmita Kashikar-Zuck, PhD**[1,2]

[1]Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center

[2]Department of Pediatrics, University of Cincinnati College of Medicine

[3]William S. Rowe Division of Rheumatology, Cincinnati Children's Hospital Medical Center

Abstract

Little is known about the impact of family environment on the long-term adjustment of patients with juvenile-onset fibromyalgia (JFM).

Objective—To evaluate whether family environment in early adolescence predicted later physical functioning and depressive symptoms of adolescents with JFM as they transition to early adulthood in the context of a controlled long-term follow-up study.

Method—Participants were 39 youth (M_{age} = 18.7 years) with JFM and 38 healthy matched controls who completed web-based surveys about their health status (SF-36 Health Survey) and depressive symptoms (Beck Depression Inventory II) approximately 4 years after a home-based, in-person assessment of child and family functioning. During the initial assessment, parents of participants (94% mothers) completed the Family Environment Scale, and adolescents (M_{age} = 14.8 years) completed self-report questionnaires about pain (Visual Analog Scale) and depressive symptoms (Children's Depression Inventory).

Results—Results indicated that family environment during early adolescence significantly predicted greater depressive symptoms in early adulthood for both the JFM group and healthy controls. In particular, a controlling family environment (use of rules to control the family and allowing little independence) during early adolescence was the driving factor in predicting poorer long-term emotional functioning for patients with JFM. Family environment did not significantly predict longer-term physical impairment for either group.

Conclusions—Adolescents with JFM from controlling family environments are at increased risk for poorer emotional functioning in early adulthood. Behavioral and family interventions should foster independent coping among adolescents with JFM and greater parenting flexibility to enhance successful long-term coping.

Juvenile Fibromyalgia (JFM) is a chronic pain condition characterized by widespread musculoskeletal pain and several associated symptoms that contribute to significant physical impairment and psychosocial difficulties (1, 2). Many adolescents with JFM experience symptoms that persist into early adulthood and report poorer quality of life and psychosocial functioning than their healthy matched peers (3). However, not all adolescents with JFM suffer from enduring physical and psychosocial sequelae as they transition to young adulthood indicating that some cope reasonably well over time despite their symptoms (3).

Corresponding Author: Soumitri Sil, Ph.D., Division of Behavioral Medicine and Clinical Psychology, MLC 3015, Cincinnati Children's Hospital Medical Center, Cincinnati, OH 45229, Phone: (513) 636-3438, Fax: (513) 636-0602, Soumitri.Sil@cchmc.org.

Early identification of factors that may place adolescents with JFM at risk for adjustment difficulties as they make the transition to young adulthood is of great importance to help them effectively navigate the challenges of this crucial developmental phase.

The transition to early adulthood is a critical period comprised of numerous challenges, including developing increased independence and self-sufficiency as well as exploring identity issues related to personal and vocational goals (4). In fact, the numerous changes and vital decisions that occur during early adulthood can have long-lasting implications for individuals' adult life course (4). For many youth with JFM, these challenges can be increasingly difficult as they transition to adulthood whilst still dealing with ongoing JFM symptoms and difficulties with daily functioning. A successful transition through early adulthood is likely influenced by family environment and relationships (5) but little is known about how family environment affects long term outcomes in youth with JFM.

The family environment during childhood and adolescence can shape the psychosocial adjustment and health outcomes in adolescents and young adults both with and without chronic illness (6–8). In typically developing children, negative family environments (e.g., high in conflict) have been associated with poorer physical, health, and psychosocial functioning in adulthood (6). The presence of a chronic condition, such as JFM, could conceivably increase the impact of family relationships given the family's daily involvement in caregiving and managing symptoms (9), and the family environment can have a reciprocal influence on both pain and disability (10). Thus, it is likely that family factors play an important role in predicting long-term functioning of patients with JFM, but the consequences of different family environments on outcomes in early adulthood are as yet unknown.

In a cross-sectional study of JFM, children who perceived their family environment as highly controlled reported higher pain intensity and their rheumatologists rated them as having poorer health status (7). Furthermore, in families that are controlling or engage in protective parenting, children with chronic pain reported higher levels of disability (11, 12) and more depressive symptoms (11). In our prior study of psychosocial and family functioning of adolescents with JFM, families of patients with JFM reported significantly poorer family functioning and more conflicted family relationships than healthy controls (1). It remains unclear whether or not these early family factors have any predictive impact on adolescents' functioning or whether this long-term impact persists beyond adolescence into young adulthood.

As part of our ongoing research program examining long-term outcomes of individuals with JFM, we conducted follow-up assessments of the same cohort of adolescents enrolled in our prior study (1) approximately 4 years after their initial assessment and found that the majority of them continued to suffer from pain and other JFM symptoms, along with poorer physical and emotional functioning (3). The objective of the current study was to evaluate whether family environment characteristics (conflicted, controlling, and supportive) in adolescence predicted physical functioning and depressive symptoms for JFM and healthy controls when they were in their late adolescent-early adult years at follow-up. We hypothesized that negative (conflicted and/or controlling) family environments would significantly predict poorer long-term physical functioning and greater depressive symptoms for youth with JFM compared to healthy controls.

Materials and Method

Participants

Participants eligible for this study included 47 adolescent patients (ages 13–17) who were diagnosed with JFM (using Yunus and Masi criteria (2)) and initially recruited from a pediatric rheumatology clinic. The 46 contemporaneous healthy control peers were selected from the classrooms of patients with JFM and matched based on closest birth date, sex, age, and having no chronic illness (1). At the follow-up assessment (ranging from 12–79 months), all participants in the original study (JFM and controls) were contacted to complete an online follow-up survey as part of a larger longitudinal study of patients with JFM (3).

Procedure and Measures

Initial Assessment—At initial assessment, data were collected in person at the family's home between 2006 and 2008. Both parents' participation was encouraged, however, in the vast majority of cases, mothers (94%) were the primary informant. Informed consent and assent were obtained from parents and adolescents. As part of a larger assessment protocol (see (1) for a detailed description), the following measures were used to assess adolescent's pain intensity, depressive symptoms, and family functioning.

Average Pain Intensity Rating over the past week was measured using a 0–10 cm Visual Analog Scale which is included as part of the Modified Fibromyalgia Impact Scale for Children (MFIQ) (7).

The Children's Depression Inventory (CDI), a well-validated 27-item self-report questionnaire, was used to measure the severity of depressive symptoms reported by the adolescents over the past 2 weeks (13). Participants select one of three statements for each item, and total scores range from 0 to 54 with a clinical cut-off score of 12. In this study, the total raw score was used as an overall indicator of severity of depressive symptoms, where higher scores represent a greater level of depressive symptoms.

The Family Environment Scale (FES) was used to assess parental perception of the family climate (14). The FES is comprised of 10 subscales, including items assessing family cohesion, expressiveness, conflict, independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious orientation, organization, and control. Scores on these subscales can be combined into higher order factor scales (Supportive, Conflicted, and Controlling) which demonstrate strong psychometric properties (15). A supportive family environment represents the family's mutual interest, concern, and support whereas a conflicted environment characterizes increased family conflict within a system that lacks organization and support. Lastly, a controlling family environment uses rules to control the family and fosters little independence. For the purposes of this study, we were specifically interested in the predictive value of the three broad band family characteristics of support, control and conflict. Higher scores represented a greater level of family support, control, and conflict.

Follow-up Assessment—At follow-up (assessments conducted between 2008–2011), patients with JFM and controls (or their parents if <18 years old) were contacted by phone to obtain consent for participation in a web-based follow-up study. Written informed consent (with parental permission and written assent for youth <18 years of age) was obtained by mail. Participants then received a unique login name and password to access a secure website to complete study questionnaires. The web-based survey included the following measures to assess physical functioning and depressive symptoms, which were the primary

outcomes of interest as they are commonly assessed and considered important by clinicians and recommended for use in treatment studies as indicators of functioning (16–18).

Short Form-36 (SF-36) Health Survey – Version 2 is a self-report questionnaire with strong psychometric properties designed to measure an individual's perception of his/her overall health status in the past 4 weeks (19) across 8 health domains: physical functioning, physical role limitations, social functioning, bodily pain, mental health, emotional role limitations, vitality, and general health. The physical functioning domain was of primary interest for this study, and yields norm-based T-scores. A T-score of 50 represents average functioning and higher scores represent better functioning.

The Beck Depression Inventory II, a well-validated 21-item self-report questionnaire for older adolescents (≥ 13 years old) and adults, was used to assess the severity of depressive symptoms in the past 2 weeks (20). Participants select one of four statements for each item. Total scores range from 0 to 63 with a clinical cut-off score of 17. The total raw score was used as an indicator of depressive symptom severity, such that higher scores represent greater levels of depressive symptoms.

Detailed methodology of the home-based study (1) and the follow-up study of physical and psychosocial functioning in JFM (3) are described elsewhere. Both projects were approved by the IRB and conducted in accordance with current ethical standards for human subject research.

Statistical Analyses

Baseline characteristics of participants who completed both initial assessment and follow-up assessment versus those who completed the initial assessment but did not complete the follow-up survey were compared to ensure that there was no systematic source of bias due to selective attrition. Pearson-product moment correlations on all predictive and outcome variables were computed. Hierarchical regressions were conducted in 4 steps. In step 1, group (JFM vs. healthy controls) was entered; in step 2, initial pain intensity ratings and depressive symptoms (child factors) were entered. Conflicted, controlling, and supportive family environment scores (family factors) were entered in step 3, and group by family environment interactions were entered in step 4. Adolescent physical functioning and depressive symptoms at follow-up were the primary outcomes.

Results

Sample Characteristics

The sample consisted of 40 patients with JFM (85.1% of the original JFM cohort) and 38 controls (82.6%) who completed both the initial and follow-up assessments. Of these, 1 participant (JFM) had incomplete data at follow-up. The final study sample of $n = 77$ (JFM $n = 39$, Control $n = 38$) was compared to the participants who completed the initial home-based study but did not complete the follow-up web-survey ($n = 15$) to examine baseline characteristics. No significant differences were found in demographics (adolescent age, race, socioeconomic status) or functioning during early adolescence, including functional disability ($t = -0.48$, $p = .63$), pain intensity ($t = -0.83$, $p = .41$), depressive symptoms ($t = 0.70$, $p = .49$), or overall family functioning ($t = 1.48$, $p = .14$) between the groups. The majority of adolescents in the final sample were female (91%) and Caucasian (86%) with a mean age of 14.8 ($SD = 1.76$) at initial assessment and 18.7 years ($SD = 2.34$, Range 14–23) at follow-up. The average length of follow-up (in months) was 44.16 ($SD = 18.0$). There were no significant differences between JFM and healthy controls with regard to their demographic characteristics at follow-up (e.g., living situation, work status, etc.) (see Table 1).

Correlational analyses indicated that higher levels of family conflict were significantly associated with lower scores on the supportive dimension in both the JFM group and healthy controls. For patients with JFM, more depressive symptoms and a controlling family environment at initial assessment were associated with greater depressive symptoms at follow-up (Table 2). In healthy controls, higher pain intensity during adolescence was associated with greater depressive symptoms at initial assessment and poorer physical functioning at follow-up (Table 3). Participant age at baseline and the amount of time elapsed since baseline (in months) were not significantly associated with physical or emotional functioning at follow-up for healthy controls or JFM patients.

Factors Predictive of Longer-Term Functioning

As expected, patients with JFM had significantly poorer physical functioning at follow-up compared to healthy controls. However, there was a non-significant overall predictive model for physical functioning, such that none of the family environment subtypes significantly predicted long-term physical impairment in either JFM or healthy controls (Table 4). On the other hand, results from the hierarchical regression revealed that patients with JFM had significantly greater depressive symptoms at follow-up compared to healthy controls, in which group membership accounted for 15.5% of the variance in long-term depressive symptoms. Additionally, depressive symptoms during early adolescence (CDI) were significantly associated with depressive symptoms at follow-up (BDI). After accounting for baseline child factors, a controlling family environment significantly explained an additional 9.4% of the variance in depressive symptoms at follow-up (Table 5).

Discussion

To our knowledge, this is the first study to examine the longitudinal impact of family environment during adolescence on physical and psychosocial functioning in patients with JFM as they transition to early adulthood. As reported in a previous study (1), families of adolescent patients with JFM demonstrated significantly higher levels of conflict and poorer overall family functioning than families of adolescents without a chronic illness. In this long-term follow up of the same cohort of JFM patients and controls, we found that the initial levels of conflicted relationships did not appear to have any short- or long-term negative impact on physical or emotional functioning. On the other hand, after taking into account initial pain intensity and depressive symptoms, a *controlling* family environment during adolescence predicted significantly higher levels of depressive symptoms at follow-up in patients with JFM compared to healthy controls. Interestingly, at the initial assessment, families of adolescents with JFM and controls did not significantly differ on the "controlling" dimension (1). This suggests that a controlling family environment, when it occurs in children with a chronic condition such as JFM, might increase youth's vulnerability for future psychosocial sequelae even if the environment is not *more* controlling than is typical in healthy control families.

A controlling family environment likely contributes to poorer long-term functioning in several ways. Within such an environment, parents typically implement many rules in planning and managing family life that are often rigid and unadaptable to change (15). In fact, a controlling family environment may be an adaptation among families caring for a child with chronic illness due to the considerable physical, psychological, and social demands placed on families related to medical management (21). In the context of JFM, the utilization of control to maintain the family system may be motivated by parents' excessive concern for their child's well-being and a degree of protective parenting behavior, which might stem from an underlying component of parental anxiety (11, 22). Thus, a controlling family environment may be adaptive in the short term because it helps parents manage anxiety about their child's health and regulate their own exposure to stress by maintaining

predictability in the family system, but it may be maladaptive for teens in the long run as it unintentionally hinders development of the adolescents' independence in illness self-management. Consequently, parental control may eventually contribute to the development of long-term internalizing problems (23).

Because protective parenting behavior can undermine adolescents' level of independent functioning by limiting their activities and responsibilities (24–27), these patients likely have underdeveloped independent skills needed to successfully manage their transition to young adulthood. Instead, adolescents may use pain as a vehicle to express their emotional needs and dependence on others due to reinforcement by the family system in their early years (28). By early adulthood, subtle differences in independent behaviors begin to emerge in patients with JFM compared to their healthy counterparts, with a greater proportion of patients with JFM relying on others for support (e.g., living with parents, married), not working, and not attending college or vocational school. As such, when provided with opportunities during young adulthood of decision-making about personal, health, and vocational roles and working towards independence and self-sufficiency, these patients may not be primed with the skills needed to navigate these transitional goals.

Family environmental factors were not predictive of physical functioning, which suggests that family functioning as measured in this study may not have a direct impact on this domain. Rather, the complexity of family functioning in JFM may be influenced by other parental factors not captured by the FES measure. For example, the parents' own pain history or parents' psychological distress are additional factors that have been implicated in other studies as being related to child physical functioning (7, 29). Additional research is warranted in this area to examine the role of parental factors, the impact of parental factors on the family environment, and how the interaction of parent and family factors may influence long-term functioning.

The small sample size in this study limited our ability to examine multiple parent and family factors; thus, additional studies are needed to continue identifying potential early risk factors. Additionally, the lack of a follow-up assessment of the family environment limits our evaluation of how family relationships may have changed over time. Lastly, in the healthy control group, baseline pain intensity negatively affected their physical functioning at follow-up. Although participants with a chronic medical or pain condition were excluded from recruitment for the healthy control cohort, it is likely that some healthy control participants had some undiagnosed medical or pain concerns that continued to be problematic at follow-up.

In summary, the study findings enhance our understanding of the long-term impact of the family environment in patients with JFM. Specifically, although families of adolescents with JFM may have initially reported higher levels of conflict, it did not seem to have much bearing on the long-term adjustment of youth with JFM as they transitioned to young adulthood. It was the adolescents who were exposed to more rigid and tightly controlled family environments that were at greater risk for increased depressive symptoms in early adulthood. Therefore, health professionals working with patients with JFM should be aware that parent-child relationships and environments which appear rigid, rule-bound, and provide few opportunities for independent behaviors may make an adolescent patient with JFM vulnerable for poorer emotional functioning in the future. Such families might present as compliant with medical recommendations and require less time and attention compared to those families who present with high levels of conflict. In fact, families that engage in protective parenting have been found to make more health care visits to manage pain symptoms (30). Thus, families that are overprotective or controlling may in fact have a greater need for intervention than families that present with conflicted relationships who

may benefit from information and support to help them with the short-term process of adjusting to a new diagnosis and illness management challenges. Early identification of family characteristics that place adolescents at greater risk for long-term distress may help in planning for family-based interventions to encourage parents to increase opportunities for independent behavior and decision-making for adolescents with JFM. Targeting these skills early during adolescence can help improve pain management skills, prepare patients with the independent skills needed to promote a smoother transition to young adulthood, and lead to improved emotional adjustment and illness management in adulthood.

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Significance and Innovations

- This study examined the longitudinal impact of family environment on physical and psychosocial functioning in patients with JFM relative to healthy controls
- A controlling family environment during adolescence predicted greater depressive symptoms in early adulthood for patients with JFM
- Family environment did not predict long-term physical functioning in JFM patients or healthy controls
- Early identification of family characteristics that place adolescents at greater risk for long-term distress may help target interventions

Table 1

Demographic characteristics at follow-up for healthy controls and JFM participants.

	Healthy Control (n = 38)	JFM (n = 39)
	n (%)	n (%)
Marital Status		
Single	37 (97.4)	34 (87.2)
Married	1 (2.6)	5 (12.8)
Living Situation		
With Parents	25 (65.8)	28 (71.8)
With Spouse	1 (2.6)	4 (10.3)
With Other (roommate, partner, dorm)	11 (28.9)	5 (13.1)
Alone	1 (2.6)	1 (2.6)
Missing	0 (0.0)	1 (2.6)
Attending College/Vocational School	23 (60.5)	17 (43.6)
Work Status		
Full Time	8 (21.1)	9 (23.1)
Part Time	19 (50.0)	15 (38.5)
Not Working	11 (28.9)	15 (38.5)
Source of Income		
Parents	21 (55.3)	15 (38.5)
Job	12 (31.6)	11 (28.2)
Spouse	0 (0.0)	4 (10.3)
Scholarship	0 (0.0)	1 (2.6)
Student loans	2 (5.3)	1 (2.6)
Other	0 (0.0)	1 (2.6)
Missing	3 (7.9)	6 (15.4)

Table 2

Correlations among age, depressive symptoms, pain, and family environment at initial assessment and depressive symptoms and physical functioning at follow-up for JFM group.

	Initial Assessment						Follow-up		
	Age	**CDI**	**Average Pain**	**FES Conflict**	**FES Control**	**FES Support**	**Time since Baseline**	**BDI**	**Physical Function**
Age	--								
CDI	.104	--							
Average Pain	−.094	.147	--						
FES Conflict	−.092	.213	.028	--					
FES Control	−.055	.102	.183	−.050	--				
FES Support	.094	−.025	.061	−.632**	−.021	--			
Time since Baseline	−.009	−.332*	.005	.038	.062	.139	--		
BDI	.048	.411**	.130	.102	.379*	.148	.024	--	
Physical Function	−.060	.247	.084	.225	.209	−.112	.194	.043	--

CDI = Children's Depression Inventory; FES = Family Environment Scale; BDI = Beck Depression Inventory

* $p < .05$;

** $p < .01$

Table 3

Correlations among age, depressive symptoms, pain, and family environment at initial assessment and depressive symptoms and physical functioning at follow-up for Healthy Control group.

	Initial Assessment						Follow-up		
	Age	**CDI**	**Average Pain**	**FES Conflict**	**FES Control**	**FES Support**	**Time since Baseline**	**BDI**	**Physical Function**
Age	--								
CDI	.221	--							
Average Pain	.279	.562**	--						
FES Conflict	−.081	−.009	.056	--					
FES Control	−.152	−.277	.164	.017	--				
FES Support	−.108	−.074	.047	−.390*	−.154	--			
Time since Baseline	.065	−.081	.012	.019	−.052	.113			
BDI	−.033	.436**	.263	.224	.102	−.193	−.058	--	
Physical Function	−.193	−.316	−.348*	.071	.151	.155	.098	.009	--

CDI = Children's Depression Inventory; FES = Family Environment Scale; BDI = Beck Depression Inventory

* $p < .05$;

** $p < .01$

Table 4

Hierarchical regression analysis on family environments predictive of long-term physical functioning (SF-36 Physical Function Scale).

Variable Name	β	*p*	R^2	R^2 change
Step 1				
Group (JFM, Control)	−7.844	<.001	.164	.164***
Step 2				
Pain intensity	−.584	.184		
CDI	.050	.634	.184	.020
Step 3				
FES Conflicted	.465	.058		
FES Controlling	.420	.083		
FES Supportive	.273	.219	.252	.068
Step 4				
Group × Conflicted	.021	.968		
Group × Controlling	.235	.638		
Group × Supportive	−.360	.432	.266	.013

CDI = Children's Depression Inventory; FES = Family Environment Scale; SF-36 = Short Form-36 Health Survey (primary outcome)

***$p < .001$

Table 5

Hierarchical regression analysis on family environments predictive of long-term depressive symptoms (BDI).

Variable Name	β	*p*	R^2	R^2 change
Step 1				
Group (JFM, Control)	7.982	<.001	.155	.155***
Step 2				
Pain intensity	.154	.715		
CDI	.357	.001	.304	.149***
Step 3				
FES Conflicted	.343	.134		
FES Controlling	.675	.004		
FES Supportive	.296	.158	.399	.094**
Step 4				
Group × Conflicted	.021	.966		
Group × Controlling	.564	.223		
Group × Supportive	.628	.139	.432	.034

CDI = Children's Depression Inventory; FES = Family Environment Scale; BDI = Beck Depression Inventory (primary outcome)

** $p < .01$;

*** $p < .001$