



Introduction

Fragile X syndrome (FXS) is a lifelong disability that presents multiple challenges for families. Given the centrality of the family in maintaining the quality of life of persons with FXS, there is a need for research on how the family environment influences the course of FXS. In this analysis we focus on how both positive and negative aspects of the family's emotional climate are related to the behaviors and symptoms of the adolescent or young adult with FXS.

In a search to identify characteristics of the family environment that may influence the course of a child's disability, researchers have paid considerable attention to the phenomenon of expressed emotion. *Expressed emotion* is conceptualized as a measure of the emotional valence of the household and has come to be defined as high levels of criticism and/or marked emotional over-involvement (EOI) as expressed by the primary caregiver about the person with a disability. Criticism taps feelings of negativity expressed about the individual with a disability. EOI provides an index of extreme over-protectiveness or self-sacrifice by the family member. High levels of criticism and/or EOI are predictive of increased symptom levels across a broad range of health conditions including schizophrenia, Alzheimer's disease, asthma, diabetes, and Parkinson's disease.

More recently, attention has focused on positive aspects of the family environment to promote more optimal outcomes for children with a disability (Smith et al., 2008). In the present study, we examine linkages between positive and negative aspects of the family environment and behavior and symptomatology in adolescents and young adults with FXS, and investigate whether the impact of the family environment on the individual with FXS is similar or different from its impact on individuals with ASD.

Major Aims

1. To describe the family social climate in families with an adolescent or young adult child with FXS in comparison to the family social climate in families with an adolescent or young adult child with autism spectrum disorders (ASD).
2. To examine whether adolescents or young adults with FXS and their same-age peers with ASD are similarly affected by characteristics of the family's social climate.

Study Design and Methods

The data came from two parallel studies of mothers of adolescent and young adult children with developmental disabilities. The FXS study is an ongoing longitudinal national study of 147 mothers and their adolescent or adult children with the full mutation of FXS. Mothers completed an in-depth telephone interview and a self-administered questionnaire. The data are from the first wave of the three-wave study.

The ASD study is an ongoing longitudinal study of 406 families of adolescents and adults with ASD in Massachusetts and Wisconsin. Mothers participate in an in-home interview and completed a set of self-administered questionnaires. This study is based on the seventh wave of data collection, which is closest in proximity to the first wave of the FXS study.

This analysis focuses on the 130 mothers co-residing with their adolescent or adult child with FXS and 90 mothers co-residing with their adolescent or adult child with ASD. Table 1 provides descriptive information on the two samples.

Table 1. Demographic characteristics of FXS and ASD samples

	FXS (n=130)	ASD (n=90)
Maternal Characteristics		
High school grad (N, [%])	110 (84.6%)	74 (82.2%)
Family Income (mean)	\$78,000	\$68,000
Currently married (N [%])	106 (81.5%)	71 (78.9%)
Child characteristics		
Male (N, [%])	109 (83.8%)	65 (72.2%) *
Age (mean [SD])	19.6 (6.4)	26.9 (7.3)***
Intellectual disability (N [%])	105 (80.8%)	53 (58.9%)***
Other diagnoses (N [%])		
Autism Spectrum Disorder	32 (24.6%)	-
Depression	3 (2.3%)	21 (23.3%)***
OCD	9 (6.9%)	17 (19.1%)**
ADHD	60 (46.2%)	33 (36.7%)

* p<.05; **p<.01; ***p<.001. <OCD = Obsessive-Compulsive Disorder; ADHD = Attention-Deficit/Hyperactivity Disorder

Measures

Family social climate. The five items from the *Positive Affect Index* reflecting the mother's feelings toward her adolescent or adult child were included as a measure of the affective quality of the mother/child relationship.

In addition, the *Five Minute Speech Sample (FMSS)* was used to measure four dimensions of the family's social climate: criticism, emotional overinvolvement (EOI), warmth and praise. Below are examples of families high on these four coded dimensions.

Warmth

"He was in his fifth grade musical last year. It was a big deal because he goes to regular public school. And he did great. He actually ad-libbed a few lines during the performances that were right on and made people laugh and I remember sitting in the play behind another family that didn't know we were behind them. Their older teenage son said something like 'Wow, that kid Jack was like the best kid in the whole play.' And I think Jack just has that impact on people. Like when you first meet him you might think 'Oh. He's kind of quirky. He talks to himself.....' but kind of once you can kind of get through his quirks and his talking to himself, like he's so sweet. He's so kind."

Praise

"As soon as I hear Alex's name, a big smile comes on my face. Alex is just awesome. He's such a joy most of the time. He's funny. He's real silly. He loves to tease people... He's very caring about everyone at work, family, friends, neighbors. He's very thoughtful. If he hears anything about anyone, he just keeps asking, 'How are you feeling?'"

Criticism

"Steve is my third son and most affected Fragile X child. He is 18 right now. He is non-verbal. He has OCD which drives his father and me crazy with things that have to be done. The rituals he has... He's definitely a trial. It's like having an 18 month old child in an 18 year old body... He's a good kid. I wouldn't know what to do without him... He's just a demanding child."

Emotional Overinvolvement

"I have an uncanny ability to kind of understand where he's coming from and how he sees the world. I've kind of tried to spend the last twenty years providing a safety net so that he could be successful and kind of going ahead of him each step of the way to figure out what he needs and how he can be successful. Some people see that as enabling... He doesn't have a whole lot of responsibilities at home because he works so hard at work, and home is just a safe down time for him."

Symptoms and Behavior Problems. Two measures were used to assess symptoms and behavior problems, the Child Behavior Checklist/ Adult Behavior Checklist (CBCL/ABCL) and the SIB-R (Scales of Independent Behavior – Revised). From the CBCL/ABCL, we derived a total symptoms score as well as *internalizing and externalizing* subscale scores. From the SIB-R, we derived the total score and three subscale scores representing *internalizing, externalizing, and asocial* behaviors.

Results

Family Social Climate: FXS vs. ASD

Table 2 below compares the family climate in families of adolescents and young adults with FXS versus families of adolescents and young adults with ASD. Mothers of individuals with FXS expressed higher levels of praise and warmth, and more positive affect toward the child than mothers of individuals with ASD. Further, although there was a general pattern for families of adolescents and young adults with FXS to be less critical, the differences were not statistically significant. For both groups, levels of EOI (e.g., self-sacrificing and/or overprotectiveness) were low.

Table 2. Family Social Climate: FXS vs. ASD

Measures of Family Social Climate	FXS (n=130)	ASD (n=90)
Criticism		
High	19%	23%
Borderline	29%	26%
Low	52%	41%
EOI		
High	6%	6%
Borderline	12%	12%
Low	82%	82%
Praise		
<5 positive remarks	59%	83%
5+ positive remarks	41%	17%
Mean (sd)	4.2 (3.2)	2.8 (2.4) ***
Warmth		
No warmth	0%	1%
Very little warmth	5%	10%
Some warmth	12%	16%
Moderate warmth	32%	36%
Moderately high	33%	22%
High Warmth	18%	16%
Mean (sd)	3.5 (1.1)	3.1 (1.2)*
Relationship Quality		
Mean (sd)	25.7 (2.8)	24.4 (3.7)**

* p<.05; **p<.01; ***p<.001.

The Effect of the Family Climate on Symptoms and Behavior Problems

As shown in Table 3, criticism had a similar association with behavior problems and symptoms irrespective of the child's diagnosis. For both groups, higher levels of maternal criticism were related to more behavior problems and symptoms in the son or daughter. Consistent with our prior research (see Greenberg et al., 2006), EOI had no association with the adolescent or young adult child's symptoms or behavior problems.

For individuals with FXS and ASD, higher levels of warmth and praise and having a positive mother/child relationship were related to fewer behavior problems and symptoms. Although higher levels of warmth were associated with fewer behavior problems in adolescents and adults with FXS, maternal warmth had a more consistent and stronger effect with respect to symptoms and behavior problems among those with ASD. Having a positive affective relationship appeared particularly important among individuals with FXS with respect to internalizing CBCL/ABCL symptoms (e.g., anxiety/depression) and total CBCL/ABCL symptoms and behaviors.

Table 3. Correlations of Family Social Climate with Child Symptoms and Behaviors: FXS vs. ASD

Child Behavior Problems/Symptoms	Maternal Criticism		Maternal EOI		Maternal Warmth		Maternal Praise		Positive Affect Relationship	
	FXS	ASD	FXS	ASD	FXS	ASD	FXS	ASD	FXS	ASD
CBCL Internalizing	.03	.21+	-.08	.09	-.10	-.21*	-.18*	-.27*	-.40***	-.30**
CBCL Externalizing	.26**	.30**	.01	-.10	-.18*a	-.42***a	-.22*	-.21*	-.41***	-.38***
CBCL Total	.22*	.28**	-.03	-.01	-.19*a	-.38***a	-.24**	-.31**	-.47***	-.33**
SIB-R Internalizing	.19*	.18+	.10	.15	-.31***	-.19+	-.25**	-.24*	-.25**	-.14
SIB-R Asocial	.22**	.29**	-.02	.05	-.08a	-.32***a	-.22**	-.22*	-.22*	-.32**
SIB-R Externalizing	.29**	.27*	.12	-.04	-.25**	-.33**	-.18*	-.24*	-.18*	-.29**
SIB-R Total	.30**	.29**	.08	.06	-.28**	-.34***	-.26**	-.28**	-.26**	-.31**

Analysis controls for child's gender, child's age, and Intellectual disability status of child; + p<.10; * p<.05; ** p<.01; ***p<.001; "a" indicates that coefficients are significantly different between FXS and ASD at p<.10 level

Discussion

Our findings suggest that the social climate in families of adolescents and young adults with FXS is highly nurturing, characterized by high levels of warmth, praise and positive relationships with their children. The majority of families had low levels of criticism and emotional overinvolvement.

As hypothesized, the family's social climate was associated with the behavior of the adolescent and young adult with FXS. High levels of warmth, praise, and positive relationships, and low levels of criticism were associated with fewer behavior problems and symptoms.

There was little evidence that the family's social climate had a differential effect depending on whether the adolescent or young adult child had FXS or ASD. This is consistent with the broader literature suggesting across a range of physical and mental health conditions, high levels of expressed emotion have similar effects irrespective of the specific nature of the disability.

Family psychoeducation has been shown to improve the emotional climate in families of persons with mental health disorders. A similar program might be developed for families of adolescents and young adults with FXS and targeted for those families with high levels of criticism and/or low levels of warmth and praise.

References

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